Endicott College

A QUALITATIVE DESCRIPTIVE STUDY OF NOVICE AND ADVANCED BEGINNER NURSE'S EXPERIENCES CARING FOR PATIENTS AND THEIR FAMILIES AT THE END-OF-LIFE

A Dissertation in Nursing

By

Bethany A. Nasser

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

April 13, 2018

Endicott College

A QUALITATIVE DESCRIPTIVE STUDY OF NOVICE AND ADVANCED BEGINNER NURSE'S EXPERIENCES CARING FOR PATIENTS AND THEIR FAMILIES AT THE END-OF-LIFE

A Dissertation in Nursing Presented

By
Bethany A. Nasser

Approved as to style and content by:

Chairperson

Committee Member

Committee Member

Vice President/Dean, Van Loan at Endicott College

Associate Dean of Graduate Education Programs

Bethany A. Nasser

Date: April 13, 2018

ACKNOWLEDGEMENT

I would like to thank my wonderful husband, Paul, and our three amazing children for encouraging me to take this step and supporting me on my journey to pursue my Ph.D. in Nursing. I am deeply grateful to all of them for their love, support, encouragement and all the time they dedicated to proofreading many of my papers. I also want to thank my beloved mom and dad who always supported and encouraged me to follow my dreams. It was from their guidance and example to make a difference in the world that I am the person I am today. I also have an enormous thank you to my siblings and friends who were always there to guide and reassure me every step of the way. Another thank you is to the faculty, staff, and students at Endicott College for their assistance with my research, especially to Elizabeth Roland for her help with my literature research. I could not have done this without the support of my professors and classmates at Endicott College; it is from their guidance and mentorship that I am a better nurse, leader, and educator today. This research would not be possible without the personal interviews of the new nurses who shared their heartwarming and courageous experiences caring for patients and their families at the end-of-life. Their experiences and quotes helped form this research. Thank you also to everyone who has touched my life and career especially my patients and their families who have allowed me to share their personal experiences as they transition from life to death.

I also wish to recognize the outstanding mentorship, encouragement, and expertise of my dissertation chair, Dr. Kelly Fisher and my committee Dr. Richard Ochberg and Jeanne Earle. Their guidance and insight have been instrumental to my success.

ABSTRACT

Nurses are the primary healthcare professionals that spend the most time caring for seriously ill patients. Nurses have a responsibility to care for patients at the end of their lives, to relieve pain, and promote dignity so that patients can experience a peaceful death. As our elderly population grows and chronic health problems increase, there is a need to teach nurses and nursing students End-of-Life Care (EOLC). New nurses must be properly prepared to provide sensitive, quality care to dying patients and their families. Nursing students do not have opportunities during clinical training to care for patients that are dying, and undergraduate education does not cover critical components of EOLC. These components may include how to talk to the dying patient and the family, pain control, and postmortem care. Therefore, further research is necessary to determine how to appropriately bridge this gap.

A qualitative, descriptive phenomenological study assessed Novice and Advanced Beginner nurses' experiences caring for patients and their families at the End of Life (EOL) and determined if and how their nursing program prepared them to speak with and care for dying patients and their families. The study provides a phenomenological approach using one-on-one interviews with each subject to identify common themes. The subjects in this study represented a convenient sample of seventeen graduate Registered Nurses who have been practicing nursing for one year or less. Based on the results of the study, the following four themes of EOLC evolved from the interviews: 1) caring for the patient, 2) caring for the family, 3) caring for the nurse, and 4) being prepared. New nurses may encounter dying patients and their families working in any area of nursing, so it is essential they be prepared to provide quality EOLC to these patients. Regardless of the lack of experience or formal instruction in ELOC during

nursing school, the majority of new nurses from this study still aimed to care for dying patients and their families with compassion and dignity. Dying patients deserve to receive the best quality care at the end of life and deserve to die with dignity surrounded by family and friends. EOLC education in nursing school curriculum can help nurses achieve this healthcare goal.

TABLE OF CONTENTS

CHAPTER IV

Chapter I

Introduction

Death and dying is something many people do not want to talk about let alone research but none of us are going to live forever, and one day each of us will confront the reality of death and dying. Nurses play a crucial role in caring for seriously ill and dying patients and have a primary responsibility to relieve pain and suffering so patients can experience a peaceful and dignified death. Studies report that nurses are the primary health professionals that spend the most time with patients during the end of the patient's life (American Association of Colleges of Nursing (AACN), 2016; Johnson & Bott, 2016; Lippe & Becker, 2015). An essential part of nursing is providing excellent care to patients near the end of life (EOL), when curative means are no longer possible or no longer desired by the patient (Ferrell, Malloy, & Virani, 2015). Many nurses perceive themselves as being incompetent when providing End-of-Life Care (EOLC) to patients and that the primary reason may be due to lack of sufficient education and preparation during nursing school (Grant et al., 2013; Ladd, Grimley, Hickman, & Touhy, 2013; Peterson, Johnson, & Scherr, 2013; Todaro-Franceschi, 2014; White & Coyne, 2011). Studies reveal most professional nurses indicate that their nursing schools did not teach EOLC skills such as pain assessment, pain management, symptom management, psychological support for patients, attention to spiritual needs and bereavement support (Todaro-Franceschi, 2011; Todaro-Franceschi & Lobelo, 2014; White & Coyne, 2011;

Grant et al., 2013). Nurses who lack these skills find caring for dying patients challenging and have increased the risk of compassion fatigue and burnout (Melvin, 2012; Todaro-Franceschi & Lobelo 2014).

It is necessary that nurses understand the needs of patients and their families at the EOL and that the nurse can feel confident when facilitating care during the dying process. Death is a critical moment in a person's life, and it is essential that nurses are confident in delivering quality care to these patients. There is a need to educate nurses on EOLC. This qualitative research study hopes to explore, describe and understand the lived experiences of new graduate nurses (Novice and Advanced Beginner nurses) caring for dying patients and their families. This new information hopes to increase nursing knowledge of how to better teach new nurses on how to care for patients at the EOL. This can help nurse educators to incorporate education methods into nursing curriculum, which will help to increase nurse's knowledge of EOLC. Inevitability the goal of this study is that nurses feel knowledgeable, confident and comfortable caring for patients at the EOL so patients can be given quality care and die pain-free and with dignity.

Background

As the elderly population expands, there needs to be an improvement in our healthcare system to provide better care for patients during the last stages of life (Jeffers, 2014). EOLC is not only crucial for the elderly, as care for the dying takes place across the lifespan and in an assortment of practice settings (Fabro, Schaffer & Scharton, 2014). EOLC is an essential part of nursing care, yet it is not perceived as an area of priority in the healthcare industry that predominately focuses on healing and health promotion. To

help provide optimal EOLC, adequate education is necessary and should be a top priority in nurse education (Jeffers, 2014; Moreland, Lemieux, & Meyers, 2012, Wessel & Rutledge, 2005). Present-day EOLC education in undergraduate nursing programs is minimal and does not adequately prepare Novice and Advanced Beginner nurses to provide high-quality palliative care. Currently, there are gaps in undergraduate nursing education curriculum for EOLC which primarily focuses on knowledge, technology and wellness (Ferrell, Malloy, & Virani, 2015; Jeffes, 2014; Todaro-Franceschi & Lobelo, 2014; White & Coyne, 2011).

According to a study conducted by Beck (1997), nurse educators have been searching for effective ways to prepare nursing students to care for dying patients since the 1960s (Beck, 1997). A review of the literature reveals countless publication relating to nursing student's experiences caring for dying patients and the need for nursing programs to teach EOLC in nursing school. Several studies have identified that nursing students and even some experienced nurses feel anxious and nervous caring for dying patients and that undergraduate education on EOLC is inadequate (Fabro, Schaffer, & Scharton, 2014; Peterson, Johnson, & Scherr, 2013; Watts, 2014). It is necessary to provide nursing students with the knowledge required to provide quality EOLC for it will increase the nurse's confidence to provide compassionate and competent care to dying patients and their families. The best ways to offer EOLC education is either in nursing school or training services to practicing nurses (Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012; Parry, 2011).

A gap in the literature exists concerning new graduate nurse's experiences caring for dying patients and their families. There is a need to educate nurses on EOLC, and this qualitative research hopes to, examine, describe and understand the lived experiences of Novice and Advanced Beginner nurses caring for dying patients and their families. Exploring this group of Novice and Advanced Beginner nurses this researcher would like to examine if they are prepared to care for dying patients and their families after they have experienced the death of a patient while a new graduate nurse. Likewise, the researcher would like to ascertain the presence of post-graduate EOLC training, which may be provided during job orientation, or they have training on the spot while experiencing the death of a patient. This study is needed to gain new knowledge of how new nurses feel caring for dying patients and their families to learn new ways to prepare Novice and Advanced Beginner nurses to care for these types of patients when they enter practice.

Problem Statement

Nurses have an important role; in improving the experience for their patients and their families at the end of life (AACN, 2016; Johnson & Bott, 2016; Lippe & Becker, 2015). Many nurses report they have received little education on EOLC or palliative care in their undergraduate nursing programs or continuing education classes. Numerous nurses also, report feeling ill prepared to care for dying patients and their families (Todaro-Franceschi, 2011; White & Coyne, 2011; Grant et al., 2013). Novice and Advanced Beginner nurses are entering the nursing practice unprepared to care for dying patients and their families. The American Association of Colleges of Nursing (AACN**)**

identifies that most nursing education programs lack EOLC content in their curriculum. Resulting in nurses entering practice not receiving the education and training to prepare them to care for dying patients and their families (AACN, 2016). Nurses who lack these EOLC skills find caring for dying patients challenging and have increased risk for compassion fatigue and burnout (Todaro-Franceschi & Lobelo 2014). Nursing faculty has identified that traditionally nursing curricula have deficits in the area of EOL content. The literature recognizes that there is a gap or a lack of focus on curriculum pertaining to EOLC. Nurse educators have identified that nursing education needs to provide comprehensive and holistic EOLC to nursing students in a variety of healthcare settings (Ferrell et al., 2015; Ferrell et al., 2016).

Purpose of the Study

The purpose of this descriptive qualitative phenomenological study is to explore, describe and understand the lived experiences of Novice and Advanced Beginner Registered Nurse's (RN) caring for dying patients and their families as they begin their nursing practice. Through a qualitative approach using semi-structured interviews, the researcher hopes to gain insight about Novice and Advanced Beginner nurse's thoughts, feelings, emotions and reactions as they enter practice caring for dying patients and their families. In addition, this research hopes to reveal how Novice and Advanced Beginner nurses feel their nursing program prepared them to care for patients and their families at the end of life. Inevitably, the goal of this study is that nurses think knowledgeable, confident and comfortable caring for patients at then EOL so patients can be given quality care and die pain-free and with dignity.

Research Questions

1. What are the experiences of Novice and Advanced Beginner registered nurses as they care for dying patients and their families?

2. What are the thoughts, feelings, emotions, and reactions that Novice and Advanced Beginner nurses experience while caring for dying patients and their families?

3. Do Novice and Advanced Beginner nurses feel that their registered nursing program prepared them to care for dying patients and their families?

Theoretical Framework for the Study

Two theoretical frameworks guided this study, Patricia Benner's (1984) theory of Skills Acquisition in Nursing and Ruland and Moore's (1998) Peaceful End-of-Life Theory. Together these theories provide a structural framework that directed and guided the research of Novice and Advanced Beginner nurses' experiences caring for patients at the end of life. Benner's theory (1984) influenced by Dreyfus and Dreyfus (1986) skills acquisition theory proposes that nurses go through five stages of clinical competence. These stages are Novice, Advanced Beginner, Competent, Proficient, and Expert. Benner's theory demonstrates the differences between practical and theoretical knowledge and claims that clinical knowledge builds over time and through nurse's experiences, relationships, and situations (Benner, 1984). The theory exemplifies that nurse's gain clinical knowledge from personal and professional experiences and that this

knowledge is different from the theoretical knowledge student nurses are taught in nursing school. A nurse's experiences and knowledge about caring for dying patients and their families can significantly affect the care that nurses give to their patients at the EOL.

The other complementary framework for this research is Cornelia Ruland and Shirley Moore; Peaceful End-of-Life Theory developed in 1998. The Peaceful End-of-Life Theory is comprised of several theoretical frameworks and constructed of standards of care. The theory based primarily on the Donabedian's model of the structure, process, and outcomes, which are part of the general, systems theory (Alligood, 2014; Ruthland & Moore, 1998). Ruland and Moore's approach focuses on meeting all the needs of dying patients, which include physical, emotional, social, psychological and financial needs (Ruland & Moore, 1998).

The Peaceful End-of-Life Theory proposes that by easing fears and anxiety for the patient and family, a nurse can create a more Peaceful End-of-Life. The theory has five outcome criteria, which are key components to EOLC. The theory is designed to promote these five outcomes: "(1) not being in pain, (2) the experience of comfort, (3) the experience of dignity and respect, (4) being at peace, and (5) closeness to significant others or other caring persons " (Ruland & Moore, 1998, p. 172). These outcome criteria help to form a framework for understanding what a peaceful end-of-life should consist of and examine the knowledge of Novice and Advanced Beginner nurses and how they express their lived experiences caring for patients at the end of life.

Nature of the Study

This study used a qualitative descriptive phenomenological design to explore, describe, elicit and understand the lived experiences of Novice and Advanced Beginner nurses caring for dying patients and their families. The study had the participants reflect on their nursing education and how their nursing program prepared or did not prepare them to care for patients at the EOL. Additionally, the research gathered findings that may be helpful to nurse educators and future Novice and Advanced Beginner nurses regarding the topic of caring for patients at the EOL. Data were collected through individual semi-structured interviews, and then data was analyzed for common themes and concepts, as well as link similarities (Glesne, 2006).

Definitions of Key Terminology

For the purpose of this research study, the following terms require theoretical definitions:

End of life care is "care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support" (National Council for Palliative Care 2006, p. 2).

Palliative care is "an approach that improves quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by, means of early identification and implacable assessment and

treatment of problems, including, physical, psychosocial, and spiritual" (World Health Organization, 2017, p. 1).

Hospice is "delivering quality, compassionate care for people facing a life-limiting illness or injury. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so" (National Hospice and Palliative Care Organization, 2017, p. 1).

Comfort Measures Only (CMO) refers to the medical treatment of a dying person where the natural dying process is permitted to occur while assuring maximum comfort. It includes attention to the psychological and spiritual needs of the patient and support for both the dying patient and the patient's family (Manual for Joint Commission, 2015).

Novice Nurse is a "beginner nurse having no experience of the situation in which they are expected to perform" (Benner, p.20). Everyone, regardless of years of experience, begins as a novice when transitioning into a new role or position and their practice is guided by rules. For this study, Novice nurses have been practicing nursing for less than six months (Marble, 2009).

Advanced Beginner Nurse: is a "nurse who can demonstrate marginally acceptable performance, ones who have coped with enough real situations to note (or to point out to them by a mentor) the recurring meaningful situational components that are termed

aspects of the situation" (Benner, 1984, p. 22). This nurse has been practicing nursing for six to twelve months (Marble, 2009).

Competent Nurse: "A nurse, who has been at the same job in the same or similar situation for two to three years, develops when the nurse begins to see his or her actions in terms of long-range goals or plans of which he or she is consciously aware" (Benner, 1984, p. 25). "The competent nurse lacks the speed and flexibility of the proficient nurse but does have a feeling of mastery and ability to cope with the management and many contingencies of clinical nursing" (Benner, 1984, p. 27). This nurse has been practicing nursing for one to two years in the same setting (Benner, 2005; Marble, 2009).

Proficient Nurse: A proficient nurse "perceives situations as wholes rather than in terms of aspects, and performance is guided by maxims. Perception is a key word here. The perceptive is not thought out but presents itself based on experience and recent events. Proficient nurses understand a situation as a whole because they perceive its meaning in terms of long-term goals" (Benner, 1984, p. 27). They have been practicing in the same nursing specialty for two to four years (Marble, 2009).

Expert nurse: "An expert nurse has an enormous background of experience, now has an intuitive grasp of each situation and zeros in on the accurate region of the problem without wasteful consideration of a large range of unfruitful, alternative diagnoses and solutions" (Benner, 1984, p. 32). They have been practicing in the same nursing specialty for four or more years (Marble, 2009).

Not being in pain: Free of suffering or symptom distress is the central part of many patient's end-of-life experiences. Pain, considered an unpleasant sensory or emotional

experience associated with actual or potential tissue damage (Lenz, Suppe, Gift, Pugh, & Milligan, 1995).

Experience of Comfort: Comfort, defined as inclusively, using Kolcaba and Kolaba's (1991) work as "relief from discomfort, the state of ease and peaceful contentment, and whatever makes life easy or pleasurable" (Ruland & Moore, 1998, p. 172).

Experience of Dignity and Respect: Each terminally ill patient is "respected and valued as a human being" (Ruland & Moore, 1998, p. 172).

Being at Peace: Peace is a "feeling of calmness, harmony, and contentment, (free of) anxiety, restlessness, worries, and fear (Ruland & Moore, 1998, p. 172). Physically, psychologically and spiritually at peace.

Closeness to Significant Others: Closeness is "the feeling of connectedness to other human beings who care" (Ruland & Moore, 1998, p. 172).

Assumptions

It is assumed that all the participants fully understand the definitions and concepts related to EOLC. It is also assumed all participants will honestly answer the questions during the interview and are willing to discuss their personal experiences caring for dying patients and their families.

Scope and Delimitations

This study used semi-structured interviews to explore, describe and understand the experiences of Novice and Advanced Beginner RNs caring for dying patients and their families after they begin their nursing practice. This study is limited to registered Novice and Advanced Beginner nurses with one year of nursing practice and experience

caring for a dying patient and their family. It includes nurses who speak English and were willing to share personal and maybe even emotional experiences caring for dying patients. This study includes Associate and Bachelors prepared nurses.

Limitations

No study is without constraints, qualitative research using interviews does have drawbacks associated with the process, the generalizability of the results and the reliability of personal experiences being accurate (Glesne, 2006). Another limitation to this study is that this researcher used a convenience sample and snowball sampling for recruitment. Snowball sampling "(also known as chain or network sampling) is a non-random method to sample the population" (Glesne, 2006, p. 35). The researcher also knew several of the new nurses interviewed which may influence their retelling of their experience. It is also the researcher's first time conducting qualitative research, so the researcher may lack unbiased influence and proper interviewing technique. A common limitation of qualitative research relates to validity and reliability since qualitative research occurs in the natural setting it is difficult to replicate studies. In addition, the data relied on self-reports of the nurses, and they may not recall all the details (Glesne, 2006).

Significance to Nursing Practice

EOLC knowledge and confidence are important to the nursing practice because most nurses at some point in their career will be required to care for dying patients and their families. Nurses who have not had proper EOLC education may feel anxious and are less comfortable providing nursing care for patients at the end of their life (Ek et al.,

2014; Fabro et al., 2014; Watts, 2014). Increased knowledge in EOLC will help Novice and Advanced Beginner nurses feel more confident caring for dying patients, which will improve communication and develop better nurse-patient relationships. More nurse knowledge about caring for dying patients is necessary to facilitate patients dying peacefully. A peaceful death will include dying with dignity, free of pain and other uncomfortable symptoms surrounded by loved ones and a supportive holistic healthcare approach (Blinderman & Billings, 2015; Ferrell et al., 2015)

Summary

Death is an inevitable part of life and nurses are patient advocates who help coordinate and guide patient care through the lifespan. Nurses need to feel confident in providing patients and families with compassion, attentiveness, and patient-centered care at the EOL. Nurses care for dying patients and their families' whether is to educate, manage symptoms, or do the little things like hold their hand. It is the caring actions of nursing that assist the patient and family during these times. If nurses are anxious or not confident in caring for patients at the end-of-life, patients will not receive quality EOLC. Therefore, it is important that Novice and Advanced Beginner nurses receive the proper education and are prepared to provide dying patients with quality and compassionate EOLC. It can be accomplished by providing comprehensive education to Novice and Advanced Beginner nurses so they can give dying patients and their families the best physical, psychological and spiritual care to meet their needs at the EOL. The goal of this research is to learn more about Novice and Advanced Beginner nurse's experiences caring for patients at the EOL and better understand their education and training on this

subject. The ultimate goal of this research is to improve the nursing knowledge and confidence on caring for patients at the EOL so that nurses can provide compassionate and competent care to dying patients and their families.

Chapter II

Review of the Literature

Literature Search Strategy

A literature review was conducted over the past four years to assess nursing education on EOLC. The study covered topics such as nurse's attitudes about caring for dying patients, improving nurse's attitudes about EOLC, the nursing shortage and new nurses entering practice in more advanced positions, and solutions to advance nursing student's education on EOLC. An online search was performed at the Endicott Library using the online database CINAHL, Google Scholar, EBSCO, and PubMed. Using various combinations of key words or phrases including; anxiety about death and dying, Benner's Novice to Expert Theory, EOLC, ELNEC project, death, dying, hospice care, new graduate nurses, nursing education, nursing shortage, Peaceful- End-of-Life Theory, palliative care, phenomenology studies, qualitative interviews, student nurses and nursing, qualitative studies on EOLC. Croxon, Deravin & Anderson, 2018 recently published a qualitative study on new graduate nurse experiences dealing with EOL. The primary research read this article during the time of interviewing Novice or Advanced Beginner nurses for her research. References in relevant articles led to further searches. Many books were borrowed from the Endicott library, and many books were purchased.

End of Life Care (EOLC)

Nurses have an important role, which is to improve the experience for their patients and their families at the EOL (AACN, 2016; Johnson & Bott, 2016; Lippe & Becker, 2015). Many nurses report they have received little education on EOLC or palliative care in their undergraduate nursing programs or continuing education classes. Numerous nurses report they do not feel prepared to care for dying patients and their families (Grant et al., 2013; King & Thomas, 2013; Mani, 2016; Todaro-Franceschi, 2011; White & Coyne, 2011). New nurses are entering the nursing practice unprepared to care for dying patients and their families. The AACN recognizes that most nursing education lacks EOLC content in their curriculum, resulting in nurses not receiving the education and training to prepare them to care for dying patients and their families when they enter practice (AACN, 2016). Nurses who lack these EOLC skills find caring for dying patients challenging and have increased risk for compassion fatigue and burnout (Melvin, 2012; Todaro-Franceschi & Lobelo 2014).

Medical advances continue to allow people to live longer and it is predicted by the year 2030, twenty percent of the United States population will be over the age of sixty-five and the majority of all deaths will be related to chronic illnesses (Center for Disease Control and Prevention, 2004; Jeffers, 2014; Ortman & Velkoff, 2014). As the elderly population expands, there needs to be an improvement in our healthcare system to provide better care for our patients during the last stages of life. EOLC is concerned with averting and easing pain experienced by people facing death (Allen & Watts, 2012).

EOLC is not only for the elderly, care for the dying takes place across the lifespan and in a variety of practice settings (Fabro, Schaffer & Scharton, 2014). The healthcare industry focuses on healing and health promotion rather than EOLC even though it is an essential aspect of nursing. EOLC is not perceived as an area of priority in both the healthcare industry and nursing undergraduate curriculums. To help provide optimal EOLC, adequate education is necessary and should be a top priority in nursing school (Jeffers, 2014; Moreland, Lemieux, & Meyers, 2012).

Nurses are the primary healthcare providers who deliver care and support to patients and their families at the EOL and thus have a need to provide EOLC. Nurses have a primary responsibility to relieve pain and suffering as to promote dignity so patients can experience a peaceful and dignified death (AACN, 2016 Johnson & Bott, 2016; Lippe & Becker, 2015). Many nurses report that caring for dying patients and their families is one of the most challenging and most feared experience. They also perceive themselves as being incompetent when providing EOLC to patients and that the primary factor is due to lack of adequate education and preparation during nursing school (Ladd, Grimley, Hickman, & Touhy, 2013). A study on professional nurses in New Zealand reported that these nurse's first experiences with dying patients left negative lasting impressions on them as caregivers because they were not prepared to care for these types of patients (Kent, Anderson & Owens, 2012).

Studies reveal most professional nurses indicated that their nursing schools did not teach EOL skills such as pain assessment, pain management, symptom management, psychological support for patients, attention to spiritual needs and bereavement support

(Todaro-Franceschi, 2011; White & Coyne, 2011; Grant et al., 2013). In addition to feeling unprepared to care for these patients, nursing students rarely experience caring for patients at the EOL in the clinical setting, and most nursing curricula have limited content on EOLC. New nurses enter the nursing practice unprepared to care for patients at the EOL and inevitably, patients are not dying with dignity, pain-free or experiencing a peaceful death.

Theoretical Framework

Two theoretical frameworks, Patricia Benner's (1984) Model of Skills Acquisition Theory and Ruland, and Moore's (1998) Peaceful End of Life Theory guided this study. Together, these frameworks provided a foundation to base the experiences of new nurses caring for patients and their families at the end of life.

Benner's Model of Skills Acquisition Theory

This study based on the theoretical framework outlined by Patricia Benner. The middle range theory explained in Benner's 1984 book *From Novice to Expert Excellence and Power in Clinical Nursing Practice.* The framework discusses how nurses develop skills and understanding of patient care over time through education and experiences. The theory does not focus on how to be a nurse but on how nurses gain knowledge and how nurses know what they know (Benner, 1984). Benner stated that "knowledge development in a practice discipline consists of extending practical knowledge (know-how) through theory-based scientific investigations and through charting of the existent "know-how" developed through clinical experience in the practice of that discipline"

(Benner, 1984, p. 3). Benner (1984) distinguishes between "theoretical knowledge, knowing that and practical knowledge, knowing how by stating that knowledge development in a practice discipline comes from the scientific investigation based on theory" (Benner, 1984, p. 2). The distinction of the theory is the difference between theory and practice.

Benner's theory originates from the Dreyfus Model of Skills Acquisition, created by Stuart and Hubert Dreyfus (1980) based their observations on chess player's and airline pilots. The theory suggests that learning is through experiences and the progression through five distinct stages of learning from novice to expert (Benner, 1984). Benner adapted and modified the Dreyfus Model of Skill Acquisition (Dreyfus & Dreyfus, 1980) to explain how nurses develop expertise in clinical practice and to provide a more objective way for evaluating the progress of nursing skills (Benner, 1984; Benner, 2004).

According to Benner, "a nurse passes through five levels of proficiency in their acquisition and development of a skill" (Benner, 1984, p.13). The five stages are Novice, Advanced Beginner, Competent, Proficient, and Expert (Benner, 1984) (Figure 1.1). Nurses move from one level to the next by using abstract principles from experiences, assessing changes in situational perception of conditions then transitioning from a passive observer to an involved performer engaged in the situation. A nurse acquires clinical knowledge through experiential learning characterized in these five stages of development within the clinical practice (Benner, 1984; Benner, 2004). The following are Benner's five levels of skills acquisition theory:

The novice is the first stage of the theory; a novice nurse has little or no previous experience in the nursing environment. Their nursing care focuses on tasks, rules, policies, and procedures. They have limited knowledge and experience and are unable to recognize which functions are most important to accomplish first since they have no experience to draw from. A novice nurse can collect objective data but require guidance and assistance from an experienced nurse to mentor to guide them with theoretical knowledge in clinical situations (Benner, 1984; Benner, 2004; Benner, Tanner, & Chesla, 2009; Haag-Heitman, 1999). Benner (1984) initially suggests that a novice is a graduate nurse, not a student nurse. Later Benner (2004) identifies the novice as a student nurse. For this study, a novice nurse defined as a new nurse who has recently graduated from an RN program and has been practicing nursing for less than six months with limited experience caring for dying patients. In EOLC, a novice nurse may have been taught theoretical concepts about death and dying in the classroom but has rarely cared for a dying patient in the clinical setting. They feel anxious caring for and communicating with the dying patient and their family since there are no concrete rules to regulate task performance in real-life situations (Benner, 1982; Benner, 1984).

The next level is the advanced beginner nurse who exhibits satisfactory nursing skills as they have experienced some real-world clinical nursing situations (Benner, 1984). They have been practicing nursing six months to one year (Benner, 2004; Marble, 2009). They still make their decisions based on theoretical knowledge because they lack many experiences to guide judgments. An advanced beginner nurse is more comfortable with institutional guidelines and uses prior situations to guide their practice. Even though

they have some clinical knowledge, they still focus on the rules, policies, and procedures and can become overwhelmed with deciphering complex situations. They still require guidance, mentoring and support in the clinical area to set priorities and ensure safe patient care (Benner, 1982; Benner, 1984; Haag-Heitman, 1999; Marble, 2009). In EOLC, the advanced beginner has limited experience assisting another nurse in the care of a dying patient but still needs mentoring with the communication aspect of EOLC and with their family.

A competent nurse typically has been at the same job in the same or similar situation for one to two years (Benner, 2005; Marble, 2005). They are able to prioritize tasks, set goals, plan and organize by using past-experiences to guide their practice. They have acquired more skills to care for complex patients and begin to see how nursing actions affect others including patients and coworkers and have developed an awareness of long-term goals. They are able to work in an efficient and organized manner but prefer the status quo (Benner, 1982; Benner, 1984, Benner, 2005). The competent nurse has increased the ability to recognize patterns and to interpret clinical situations. They become leaders and a resource for the novice and advanced beginner nurse (Benner, 1984). In EOLC, a competent nurse knows how to accurately care for a dying patient and their family but lacks multitasking and flexibility skills in complicated situations that are out of the norm (Benner, 1982; Benner, 1984; Benner 2005; Marble, 2009).

A proficient nurse begins to acclimate to the altering patient care setting and begins to use past experiences to understand a situation in a broad way (Benner, 1984). They have been practicing in the same area of nursing for two to four years (Marble,

2005). They still consult with other nurses but can integrate theoretical knowledge and their experience to think critically to reach a complex solution. This nurse has been practicing nursing in the same setting for three to five years (Benner, 1984, Benner, 2005; Marble, 2009). In EOLC a "proficient nurse remains engaged with the patient and family yet still struggles with moral and ethical dilemmas" (Haag-Heitman, 1999, p. 57). This could be about aggressively treating terminal or frail elderly patients or families that do not want their family member to comfort measures only (CMO) or a do not resuscitate (DNR).

An expert nurse uses a broad clinical experience and their intuition to focus in on a problem and look at situations as a holistically. They have been in the same field of nursing for four or more years. They have extensive knowledge of circumstances, and intuitively and confidently respond to complex changing conditions without relying on rules to connect their understanding (Marble, 2005). The expert nurse describes a deep understanding of complex situations as a gut feeling, or they sensed something was not right with their patient. Expert clinicians help to coordinate the healthcare team and are consultants for other nurses (Benner, 1984). An expert nurse caring for a patient at EOL can "separate personal feeling from moral/ethical dilemmas" (Haag-Heitman, 1999, p.57). Expert nurses who perform EOLC use experience and intuitively awareness of the clinical situation and will immediately and accurately diagnose and prioritize problems by instinctively responding to the patient's condition while giving the family support and guidance (Benner, 1984; Marble, 2005).

Benner developed this theory to explain how nurses progress in their nursing career and advance to the level of an expert nurse. The *Novice to Expert* book is based on conversations with nurses using descriptive research to identify the five levels of competencies in nursing practice. The five levels are described in nursing exemplars that were obtained by individual or group interviews with a variety of different nurses and in different settings. The five levels of competencies were accompanied by changes in three skill performances (Benner, 1984; Benner2005).

> The first is a change from reliance on rules and abstract principles to the application of concrete previous experiences to help with decision-making. The second is a change in the learner's awareness to see situations as a whole or the "big picture." The third is a change from observer to the active performer (Benner, 1984, p. 13).

"The central concepts of Benner's model are skills acquisition, experience, clinical knowledge, and practical knowledge" (Benner, 1984, p. 46.). These concepts are identified in seven domains of nursing practice, which are the "helping role, teaching-coaching function, diagnostic-patient monitoring functioning, effective management of rapidly changing situations, administration and monitoring of therapeutic interventions and regimes, monitoring and ensuring the quality of healthcare practices, and organizational and work role competencies" (Benner, 1984, p. 46). Benner's model shows the importance of retaining and rewarding nurses as they progress in their clinical practice

Benner and Wrubel expanded on the Novice to Expert theory by including the concepts of caring, nursing, person, health, coping, situation and stress in nursing practice (Benner & Wrubel, 1989). "Caring is a word for being connected and having things matter works well because it fuses thought, feelings, and action (Benner & Wrubel, 1989, p. 1). "Nursing is viewed as a caring practice whose science is guided by the moral art and ethics of care and responsibility" (Benner & Wrubel, 1989, p. xi). Benner describes, "A person as a self- interpreting being that is, the person does not come into the world predefined, but becomes defined throughout one's life. A person also has an effortless and non-reflective understanding of self in the world" (Benner & Wrubel, 1989, p. 41). The concept of health focuses "on the lived experience of being healthy and being ill" (Benner & Wrubel, 1989, p. 7). Benner does not use the word environment. Instead, the term situation is used to convey a social environment and how the person interacts with the environment (Benner & Wrubel, 1989). Coping is how one deals with stress. Benner and Wrubel give numerous examples of how one can cope with different situations (Benner & Wrubel, 1989). Stress is the experience of the distribution of meanings, understanding, and smooth functioning (Benner & Wrubel, 1989, p. 62). These concepts help to broaden and strengthen the theory.

Benner's theory known worldwide and is translated into many languages around the world. The theory has provided an understanding of how knowledge and skills are applied in nursing practice, education, research, management and administration (Fennimore & Wolfe, 2011). The model has been used in mentorship programs, preceptorship workshops and specialty training courses in healthcare organizations

(Nedd, Galindo-Ciocon, & Belgrave, 2006). Many nursing schools have applied Benner's theory to their curricula to assist nurse educators with guidelines in critical practice skills and recently simulation learning (Bambini, 2009; Carlson, Crawford, & Contrades, 1989; Dale et al., 2013; Derbyshire, 1994 & Thomas, 2015). Numerous hospitals use Benner's theory to develop career promotion ladders and as a guide to career escalation. It is also used to acknowledge and reward expert practitioners with the aim of facilitating nursing excellence. Benner's theory is constructive to nurse educators to develop a framework to assist students and nurses to achieve the goal of becoming an expert nurse (Alligood, 2014; Butts & Rich, 2011; Marble, 200; Larew, Lessans, Spunt, Foster, & Covington, 2006).

Marble (2009) applied Benner's (1984) theory to the field of oncology and identified how the oncology nurse develops through each level. Marble (2009) modified Benner's (1984) framework by illustrating a pyramid that depicted the growth and development of oncology nurses in layers through education, motivation, and experience (Marble, 2009). Brown (2017) used Benner's (1984) Novice to Expert theory and applied it to qualitative research about virtual clinical education (VCE) to undergraduate students. The study described the benefits in relating how theoretically learning of a new activity can enhance clinical performance and level of skill acquisition of nursing students. The results of the study exhibited the participants perceived themselves to be advanced beginners because of the VCE experiences (Brown, 2017).

Evidence also references Benner model when defining leadership roles among nurses in clinical settings as based on nursing research on subjects such as clinical

wisdom among proficient nurses (Uhrenfeldt & Hall, 2007) and difference in how advanced beginners, competent and expert nurses prioritize and reprioritize patient care (Burger et al., 2007). Titzer, Shirey, and Hauk (2014) describe Benner's theory as "an effective framework for leadership development and competency measurement, mentoring programs and advanced nursing practice skill acquisition, and professional advancement ladders" (Tizer, Shirey, & Hauck, 2014, p.38). Benner's theory parallels with the role of advanced practice nursing curriculums to help prepare nurses with health promotion, assessment, diagnosis, and management of patients' problems and theories about intuition (Karns, 2015; Reville & Foxwell, 2017).

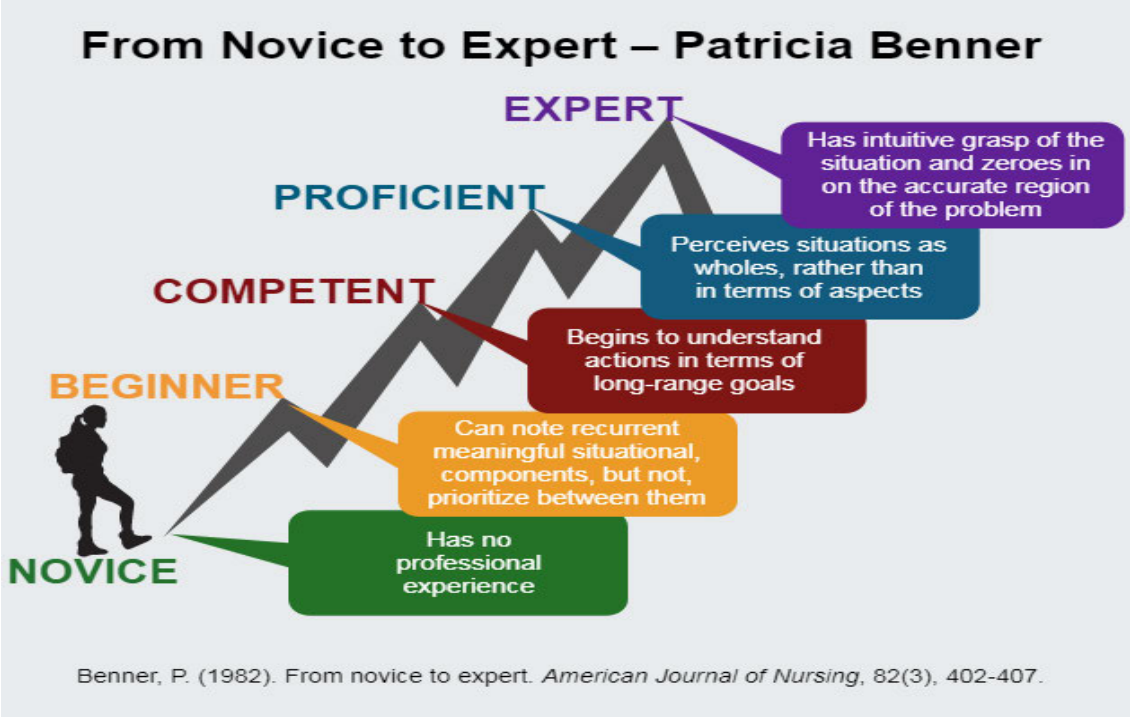
Benner claimed that textbooks and theoretical knowledge are not enough to explain nursing practice and that nurses also need experience. The theory allows for a unique perspective into why a nurse practices the way they do, based on their knowledge level and experience of the nursing practice. Her theory has universal characteristics, as the theory is not confined to a nurses' age or the practice setting (Benner, 1984). Despite the popularity of Benner's theory, it does have limitations. Altmann (2007) evaluated Benner's theory to surmise that it is a more of a philosophy and not a theory. Altmann (2007) validates that Benner's work is valuable and widely used in nursing practice, research, education, and administration but its lack of social structure, difficulty in testing and that it too simple to account for the complexity of the phenomena associated with expert intuition in nursing (Altmann, 2007). The theory does not explain what measurable change occurs to transition a nurse from one stage to another (Altmann, 2007).

Benner's theory has also been criticized for not being quantitative for her research uses a qualitative approach. Her research came from actual practice situations from nurses in a variety of nursing settings such as general medicine, critical care, community health, advanced practice, and education. Benner's research is rooted in a Heideggerian phenomenological approach using interviews with nurses in clinical practice where nurses were observed at the different levels of the novice to expert scale. Benner tested her theory based on interviews with graduate nurses, senior nursing students and experienced nursing clinicians (Benner, 1984). The theory identifies that learning and clinical knowledge are achieved through personal and professional experiences. Therefore, the experience is necessary to achieve expertise (Benner, 1984). This view has since gained support from the research community as qualitative research has become more respected.

Benner's theory is primarily based on nurse's experiences and their perception of what is happening to them. This, however, is a limitation of the theory, as the framework is dependent on clinical situations (Alligood, 2014). The theory claims that as new nurses acquire more skills and experience, they will become more confident and will move up the skills acquisition steps. As the nurse acquires more skills and experience, they can connect with their patients and give better quality care (Benner 2005). A key part of the theory is that the movement from novice nurse to an expert nurse depends on the situations and experiences experienced by the nurse. This is an important concept for my EOLC research. A new nurse may have a lot of experience caring for dying patients compared to a seasoned nurse who has had little experience caring for dying patients.

The new nurse might be more of an expert than the seasoned nurse might. Benner's theory helps give insight into the complex issues surrounding nurses performing EOLC. This study will focus on new nurses in the Novice and Advanced Beginner of Benner's theory and hopes to assess how they perceive caring for dying patients and their families and how they have learned these skills.

Figure 1.1 Benner's Model of Novice to Expert (Benner, 1984).



Cornelia Ruland and Shirley Moore (1998)

Peaceful End-of-Life Theory developed (1998) is the second theoretical Framework chosen for this research. Not only is it essential that nurses provide EOLC, but it is also necessary that nurses know how to provide a Peaceful End-of-Life. A Peaceful End-of-Life includes assisting the patient to be free from suffering, providing emotional support to the patient and significant others to assist with treatment with empathy and respect (Ruland & Moore, 1998). EOLC has become a primary concern for nurses today, and it is important for nurses to strengthen their knowledge on this type of nursing care. The Peaceful End-of-Life Theory is a middle range theory that was developed by a student (Shirley Moore) and a faculty member (Cornelia Ruland). They were in a doctoral theory course together and formed the theory during the class (Alligood, 2014). The Peaceful End-of-Life Theory is comprised of several theoretical frameworks and constructed of standards of care. It is based primarily on the Donabedian's model of the structure, process, and outcomes, which are part of the general systems theory (Alligood, 2014; Ruthland & Moore, 1998). The Peaceful End-of-Life Theory was developed because there was a lack of clear direction for quality nursing care for terminally ill patients and their family. Ruland and Moore stated, "The primary focus for standard development is not on the final instance of dying itself, but on contributing to peaceful and meaningful living in the time that remained for the patients and their significant others" (Ruland & Moore, 1998, p. 171). Ruland and Moore's theory focuses on meeting all the needs of dying patients, which includes physical, emotional, social, psychological and financial needs (Ruland & Moore, 1998).

The Peaceful End-of-Life theory proposes that by easing fears and anxiety for the patient and family, a nurse can create a more peaceful end of life. The theory has five outcome criteria, which are key components to EOLC. The theory is designed to promote these five outcomes: "(1) not being in pain, (2) the experience of comfort, (3) the experience of dignity and respect, (4) being at peace, and (5) closeness to significant others or other caring persons" (Ruland & Moore, 1998, p. 172). Ruland and Moore (1998) determined the definitions of the five outcome indicators:

> The experience of comfort is standardized as the patient not experiencing nausea, thirst, experience a pleasant environment and experiences optimal comfort. Experience of dignity/respect is that the patient and family members participate in decision making, and be treated with dignity and respect by hospital personnel. Being at peace is a standard where the patient and significant others Maintain hope and meaningfulness, the patient does not die alone, and the patient is at peace. Lastly, closeness of patients with their significant other or family and friends who care are participating in the care of the dying patient, can say farewell in compliance with their religious or cultural beliefs, and informed about funeral procedures and possibilities. (Ruland and Moore, p. 173).

The theory not only pertains to the patient but to their significant others to assist them with all care needs including, physical, emotional and spiritual. Nursing care at the end of life should include assessing for pain and other stressful symptoms, providing

interventions to improve them, provide comfort and quality of life. Nurses must work with family members throughout the dying process and after the patient's death, to provide support and counseling if needed. The theory can be in any setting and focus is on care and not cure. The goal is to support "the five concepts of no pain, comfort, dignity, and respect, peace, and closeness with the patient and their significant others" (Ruland & Moore, 1998, p. 173). This model provides a framework that reminds nurses of the importance of caring for their patient and their significant others even at the end of life (Ruland & Moore, 1998).

The Peaceful-End-of Life Theory has been integrated into nursing curricula and in nursing courses on EOLC and palliative care. The theory has gained international recognition for its vital five concepts of a peaceful death. There has been limited use of The Peaceful-End-of Life Theory in the research the theory and its key terms have been cited in research articles about the palliative care and EOLC. Beckstrand & Callister, (2006) reference Ruland and Moore (1998) in their quantitative research of eight hundred and sixty-one critical care nurses on improving EOLC. Most critical care nurses suggested they want to provide a "good death" which include dying with dignity and peacefully but many nurses concluded this is difficult to achieve in the critical care setting (Beckstrand et al., 2006). The Peaceful-End-of Life Theory was used to develop a model by Wilkie, Johnson, Mack, Labotka, & Molokie, (2010) research on palliative care for individuals and families across the lifespan (Wilkie et al., 2010). Lee et al., (2009) cited Ruland and Moore's (1998) five components to good EOLC (comfort, the absence of pain, dignity, and respect; closeness to significant family members and other

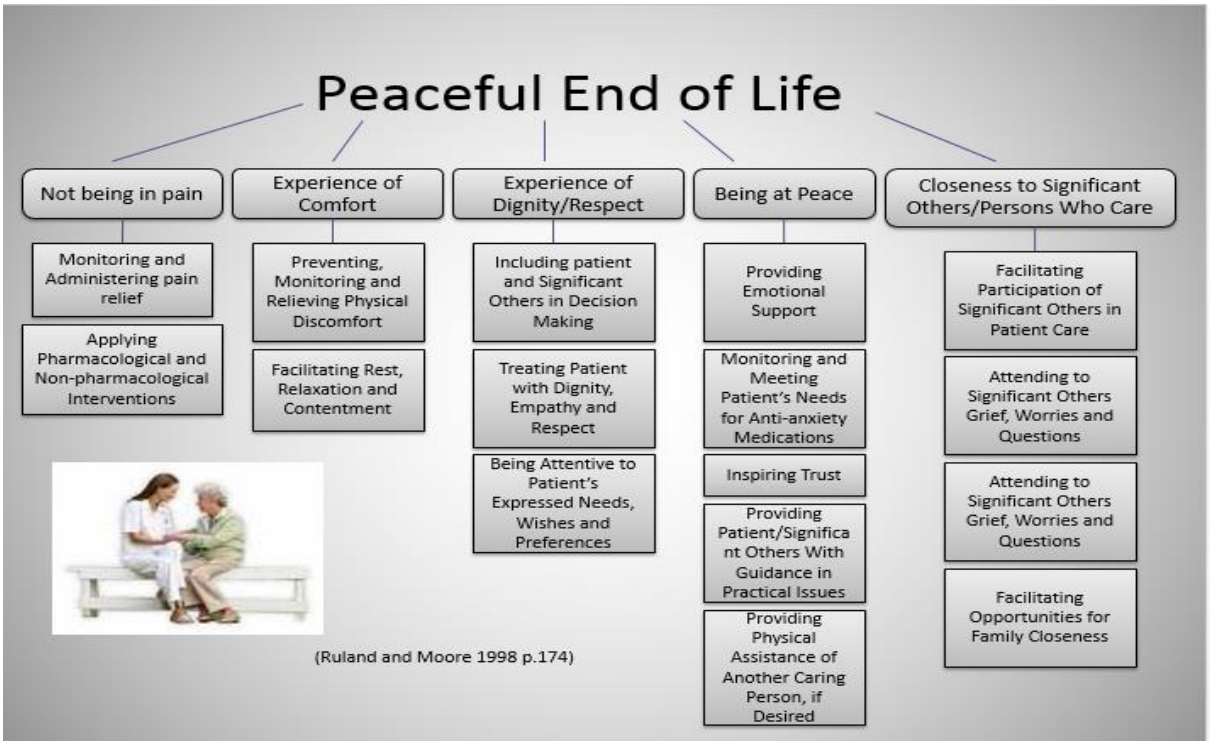
caring persons and peace). These are the most frequently considered part of a good death (Lee et al., 2009; Ruland & Moore, 1998).

The theory was evaluated in an article called "An Analysis and Assessment of the Peaceful End of Life Theory According to Fawcett's Criteria" by Zacara, A. A.L., Costa, S.F.G., Nobrega, M.M.L, Franca, J.R.F.S., Morais, G.S.N, Fernandes, M.A. (2017). The study evaluated the Peaceful End-of-Life Theory from Fawcett's point of view, and it concluded that the theory is significant because of its well-defined definitions of the concepts of the metaparadigm and consistency from its structural consistency of concept definitions (Zacara; et al., 2017).

The Peaceful-End-of Life Theory helps to advance nursing practice because it offers guidelines and principles to educate nurses on the concepts of EOLC. It also helps to further research to improve hospitals policies and budgets on EOLC. The Peaceful-End-of-Life Theory, although limited in its use in research thus far, can be integrated into this study framework as it focuses on the care of the patient and family (Alligood, 2014). EOL education is an essential part of nursing care; nurses need to know how to provide comfort to both the dying patient and the family to improve and develop quality care at the end of life. The Peaceful End-of-Life theory establishes a framework to identify the major components of a good death, and it teaches nurses the crucial aspects of nursing care at the end of life. The theory is applicable in any setting and focuses on the "five concepts: no pain, comfort, dignity, respect, peace and closeness with significant others" (Ruland & Moore, p. 173). The Peaceful End-of-Life Theory concepts are important in this study and give the research theoretical meaning. The five outcome indicators are the

focus of a nurse providing EOLC. It is inclusive of all the aspects essential to a dying patient and allows the family to be a part of the experience.

Figure 1.2



Research on Death and Dying

Nursing Education with EOLC

The role of EOLC had expanded in recent years to include advance directives, do-not-resuscitate (DNR) and palliative care decisions. The 2016 NCLEX contains many questions that focus on the nurse's role in advance directives/self-determination/ life planning and organ donation (Butts & Rich, 2013; RN_Test_Plan_2016_Final.pdf, 2016; Treas & Wilkinson, 2014). Many students report that they do not experience death and loss of a patient while in school because opportunities do not arise during traditional

clinical nursing rotations (Ek, Westin, Prahl, Osterlind, Strang, Bergh, Hammarlund, 2014). Therefore, it is imperative that future nurses be prepared with knowledge and skills to provide care to seriously ill patients.

The AACN recognizes that most nursing education lacks EOLC content in their curriculum, resulting in nurses not being prepared to care for dying patients when they enter practice (AACN, 2016). Numerous studies in the literature reveal that nursing students and nurses' report feeling uncertain, anxious and unprepared to be with patients who are dying because they do not have classes teaching them EOLC (Ek et al., 2014; Fabro et al., 2014; Peterson et al., 2013; Watts, 2014). Being confronted with human suffering and death is challenging and can be disturbing especially to young, inexperienced nurses. As a result, new nurses entering their practices are unprepared to give adequate EOLC. Research on nursing students' experiences with the death of a dying patient in the clinical setting is limited and not well documented (Gerow, L., Conejo, P., Alonzo, A., Davis, N., Rogers, S., & Domian, E. W., 2010; Gilpin & Heise, 2013). EOL education in undergraduate nursing programs is minimal and does not adequately prepare new nurses to provide high-quality palliative care

Traditionally, nursing education has not focused courses on death and dying and instead, its primary focus has been on wellness. Undergraduate nursing education is the foundation to teach the whole health continuum, and nurse educators are responsible for assisting students towards becoming proficient, competent professional nurses. There are major deficits in nursing curriculum and textbooks; in 2004 a review of nursing textbooks revealed only 1.4% of the chapters relate to EOLC (AACN, 2016; Ferrell, Mallloy,

Mazanec, & Virani, 2016). A later study reviewed the top ten undergraduate nursing textbooks published between 2013 and 2015 and there as an increase in content pertaining to EOLC up to 19% was reported yet most of the material was inaccurate and outdated (AACN, 2016; Ferrell et al., 2016). A 2015 survey of seventy-one nursing faculty from various colleges and universities across the United States reported that nursing faculty felt that nursing students were not well prepared to deliver EOLC (AACN, 2016; Ferrell et al., 2016). Other studies of nurses revealed that key components of EOLC, such as how to talk to a dying patient and their family, pain control management, and general interventions to promote comfort are not covered in their undergraduate education (Hebert, Moore, & Rooney, 2011; Jeffers, 2014; Peterson, Johnson, & Scherr, 2013). The lack of focus on this topic could be attributed to the already overcrowded curricula that focus on knowledge and technology and the lack of qualified teachers to teach death and dying for fear of the topic of death (Todaro-Franceschi & Lobelo, 2014).

Nurses' Attitudes about EOLC

Though many nurses state they are not personally and professionally prepared to care for terminally ill patients, the number of patients with terminal illness is increasing. Lack of education in the healthcare staff leads to lack of communication between nurses and family members, causing significant difficulties in EOLC. Taking care of dying patients can be a stressful, emotional and painful experience for nurses (Gama, Barbosa, & Vieira, 2012; Peters et al., 2013). Nurses' attitudes about death and dying significantly affect the care they administer to dying patients and their families. Nurses who have

intense anxiety about death report that they find it difficult to deliver the support and attention to the patient and family as they go through the process. Many nurses report that it is difficult to provide a "good death" for their patients (Marchessault, Legault, & Martinez, 2012). Research reveals that nurses who cared for a higher rate of terminally ill patients had more positive attitudes toward caring for dying patients than, nurses who cared for a lesser percentage of dying patients. In addition, nurses with more education on EOLC have increased positive attitudes caring for dying patients and their families (Gama, Barbosa, & Vieira, 2012; White & Coyne, 2011).

Improving Nurses' Attitudes about EOLC

The best way to improve EOLC and nurses' attitudes about death is to improve education on the subject. Nurses who have been educated on EOLC have increased confidence in how to manage symptoms, control pain and how to talk to dying patients, and their families (White & Coyne, 2011). Research indicates that education about death, dying, and bereavement can change attitudes about death, which affect how healthcare workers care for dying patients and their families (King & Thomas, 2013; Mateo & Foreman, 2014; White & Coyne, 2011). Education for End-of-Life Care (EOLC) is extremely important in today's health industry, and many nurses are often called upon to perform it. Most feel unprepared to assist their dying patients and families.

EOLC is the time in which the patient's prognosis is poor, or death is near. During this period, the nurse can provide comfort and care to the patient and their family utilizing effective communication and compassion skills. Other terms similar to EOLC that overlap in the literature include the terms, palliative care, and hospice care. These

terms are used interchangeable in the literature and are utilized any time a patient requires care necessary to promote quality of life, pain relief, and support (De Souza & Pettifer, 2013).

Many groups across the United States have been working to improve care administered at the EOL. In 1997, the AACN recommended guidelines in nursing curriculum to include goals regarding grief and loss because many student nurses do not experience death and loss of patient life while in school but still today most nursing curriculum lack EOLC education. In addition, it is not always possible for nurse educators to provide opportunities during traditional clinical nursing rotations to care for patients that are dying (Ferrell, 2007). Nursing education is continuously evolving, yet it has not kept up with the requirements and needed to teach student nurses quality EOLC. The research suggests that there are persistent shortcomings of health professionals and educators to meet the needs of the dying (Ferrell et al., 2015; King & Thomas, 2013; Loerzel & Conner, 2016; Mani, 2016).

In 1997, the AACN, supported by Robert Wood Johnson Foundation (RWJF) gathered nurses and other health-care professionals to discuss how to better care for patients at the EOL. They developed the End-of-Life Educational Competency Statements, called A Peaceful Death, which addressed the gaps in undergraduate nursing curriculum and provided recommendations and guidelines to educated registered nursing students and improves EOLC content areas. Even with the identification of the need for increased undergraduate nursing education on EOLC, little has been done over the years. Only 3% of nursing programs in the United States reported having a course dedicated to

end-of life-issues in 2002. Forty percent felt a need to increase this content in their curricula. Most respondents (78%) said that their faculty colleagues had an intermediate (some comfort) level of expertise regarding teaching End-of-Life content (Ferrell et al., 2015). Lack of EOLC education still exists in nursing education, and this has been identified as a major barrier to providing quality EOLC to patients. Recent studies on nurses in intensive care units and pediatric settings reveal that nurses lack knowledge and education on EOLC. These studies report that there are many challenges to providing EOLC and that there is a great need for more education, support and resources to the nurses in these settings (Mani, 2016; King & Thomas, 2013; and Curcio, 2017).

End-of-Life Care

There is an urgent need to improve nursing education about EOLC to help improve the care of patients that are dying. The End of Life Education Consortium (ELNEC) program offers many different tools that can help educate nurses on how to give competent and compassionate care to the dying patients and their families. The ELNEC is a national education program designed to improve nursing education on EOLC. It is a collaborative organization funded by the Robert Wood Johnson Foundation (RWJF) and the AACN with principal investor Geraldine Bednash Ph.D., FAAN and the City of Hope with principal investor Betty Ferrell, Ph.D., FAAN AACN, 2016). It began in 2000 and has educated thousands of health professionals about the unique needs of dying patients and the dying process itself (Ferrell, Malloy, & Virani, 2015; Paice, Ferrell, Coyle, Coyle, & Callaway, 2008).

> ELNEC's goal is to educate undergraduate and graduate nursing faculty, students and practicing nurses on EOLC in train-the-trainer sessions. The ELNEC program's foundation is the belief that the dying process can be addressed through hospice and palliative care, with a goal to improve quality of life for both the patient and family. Once an ELNEC course is completed, the participants return to their communities and train other nurses and healthcare providers, thereby extending the curriculums reach exponentially to the larger healthcare community (Ferrell, Malloy, & Virani, 2015, p. 63).

Over the years since its inception, seven separate EOLC curricula have been developed and spread throughout the United States and on six continents. "Over 19,500 nurses, physicians, social workers, chaplains, pharmacists, and other healthcare professionals have attended one of the 160 national/international ELNEC courses" (Ferrell et al., 2015, p. 61). The ELNEC has developed eight modules that teach educators the skills of EOLC. They include:

> 1) Pain management, 2) Symptoms management,
> 3) Ethical/legal issues, 4) Cultural considerations in EOLC,
> 5) Communication, 6) Grief and loss, 7) Bereavement and
> 8) Preparation and Care at the Time of Death
> (American Association of Colleges in Nursing: ELNEC, 2016, p. 2).

The curriculum is updated regularly based on new advances in the field. The AACN has identified a list of competencies that every undergraduate nursing student

should know. This list works in conjunction with the eight modules from the ELNEC to produce a comprehensive framework to help nursing curriculum with teaching EOLC. Many colleges think that this will overcrowd their already full nursing curriculum, but these competencies are essential to all nurses because unlike teaching maternity, which only pertains to less than fifty percent of the population, everyone will die. The AACN competencies can be incorporated into other existing courses such as fundamentals, health assessment, community health, pediatrics, maternity and care of the adult. The ELNEC program is not just for nursing students it is available for nurses who are currently practicing, as continuing education classes. ELNEC has trained thousands of nurses across the United States, and the curriculum has been translated into many languages and is taught in places such as Japan and Africa (Mateo & Foreman, 2014)

Other methods to increase EOLC education into nursing curriculum include having nursing students spend clinical hours at hospice centers and with a hospice visiting nurse. These sites can be part of their community health clinical or a senior internship rotation. A tailored EOL education will provide student nurses with a foundation that will prepare them to provide ethical, holistic, and meaningful EOLC. Another educational tool allows nursing students to be a part of a Palliative Care Companion program; this type of program can promote volunteer programs for undergraduate nursing students to spend time with patients that have a restricted amount of time to live. This program offers an innovative learning experience to help improve students' knowledge, skills, and attitudes caring for palliative care patients and at the same time, it provides these patients with companionship.

After students or new nurses experience the death of a patient, they need follow-up education from the clinical instructor or nurse educator to discuss their feelings and emotions. It has been studied that debriefing and reflection can assist with learning from the experience to help further the student's education about EOLC the nurse educators can assign journaling that allows the new nurse time to reflect on their thoughts and feelings about the experience. Nurse educators play an important role in providing follow-up debriefing sessions to assist the new nurse time to reflect and ask questions about the end of life experience (Heise & Gilpin, 2016)

Novice and Advanced Beginner Nurses

This study involved Novice and Advanced Beginner nurses who have newly graduated from a Registered Nursing (RN) program and have been practicing nursing for one year or less. Novice and Advanced Beginner nurses are now the largest sources of RNs available for recruitment for jobs in the United States. This is due to the retirement of baby boomer nurses. These factors have forced hospitals to rely more on Novice and Advanced Beginner nurses to staff their hospitals (Trepanier, Early, Ulrich, & Cherry, 2012). The need for qualified nurses is necessary. Novice and Advanced Beginner nurses are needed to replace the expert nurses that have acute care, critical care, emergency room, and specialty positions. Novice and Advanced Beginner nurses need to be prepared to work and take care of patients in higher acuity nursing environments than in previous years. This is why it is so essential that Novice and Advanced Beginner nurses are prepared to care for all types of patients including those at the End-of-Life

(Silvestre, Ulrich, Johnson, Spector, & Blegen, 2017; Zinn, Guglielmi, Davis, & Moses, 2012).

Summary and Conclusion

The literature informs us of gaps in EOLC education in undergraduate nursing programs, which primarily focuses on knowledge, technology and wellness (Ferrell, Malloy, & Virani, 2015; Jeffes, 2014; Todaro-Franceschi & Lobelo, 2014; White & Coyne, 2011). Currently, nursing programs do not adequately prepare new nurses to provide high-quality EOLC, and there are gaps in the undergraduate nursing education curriculum. Undergraduate nursing education is the foundation to teach the whole health continuum. It is the responsibility of nurse educators to assist nursing students to become competent professional nurses. Student nurses need to be taught how to administer a wide range of care to patients in all the different life stages, including when they are dying. EOLC knowledge and confidence are important to the nursing practice because most nurses at some point in their career will be required to care for dying patients and their families. Nurses who have not had proper EOLC education may feel anxious and are less comfortable providing nursing care for patients at the end of their life (Ek et al., 2014; Fabro, Schaffer, & Scharton, 2014; Peterson, Johnson, & Scherr, 2013; Watts, 2014). Nurses need to be the leaders in creating a "good death" for patients across the lifespan. Increased knowledge in EOLC will help Novice and Advanced Beginner nurses feel more confident caring for dying patients, increase communication and develop better nurse-patient relationships. More nurse knowledge about caring for dying patients is necessary to facilitate a "good death" for patients. A "good death" should be pain-free

with symptom control, effective communication, information, support and coordination of services to the complete healthcare team (Ruland & Moore, 1998).

Nurses are the care coordinators and patient advocates who help to guide patient care. Therefore, it is the professional role of nurses to recognize the importance of preparing student nurses to care for dying patients to ensure that new graduate nurses can provide the best care to patients at the end of life. There is a gap in the literature about Novice and Advanced Beginner nurses caring for dying patients and their families. This qualitative study hopes to find new knowledge from Novice and Advanced Beginner nurses about their experiences caring for patients at the EOL and explore how the felt their undergraduate nursing program prepared them.

Chapter III

Methodology

Aim of the Study

This research used a qualitative descriptive phenomenology research design to study the lived experiences of Novice and Advanced Beginner nurses caring for dying patients and their families in a variety of settings (hospitals, rehabilitation, and long-term-care facilities). The methodology of van Manen (1990) was applied in this study to explore the phenomenon of Novice and Advanced Beginner nurse's experiences caring for patients at the EOL. The study participants reflected on their experiences caring for dying patients and described how prepared they felt their nursing programs had equipped them to care for patients at the EOL. This study aimed to gather information to enhance nursing education and to assist future nurses when developing courses, and to educate future nurses when they are caring for patients at the EOL.

Qualitative Research Approach

Based on van Manen (1990), this study incorporated a qualitative semi-structured, descriptive phenomenology research design. This methodology provided a framework to study Novice and Advanced Beginner nurses as they explained their experiences while caring for dying patients and their families. Data was collected via semi-structured individual interviews to seek common themes and concepts, and to link similarities.

According to Sandelowski (2000; 2010), the goal of qualitative descriptive studies is a comprehensive summary of events in the everyday terms of those events. Qualitative research is a form of social analysis that focuses on the way people interpret and make sense of their experiences and it "combines the science and art of nursing to enhance the understanding of human health experience" (LoBiondo-Wood & Haber, 2014, p. 110). Qualitative research is the ideal method to gain knowledge about Novice and Advanced Beginner nurse's experiences caring for dying patients for it uses a humanistic descriptive multidimensional approach.

According to van Manen (1990), phenomenological research approach is to establish a reconnection to the memory of the original experience and give the individual the opportunity to look at the world and re-examine the meaning of the event (Van Manen, 1990). Phenomenological research is directed toward discovering the meanings surrounding a specific concept of interest by studying the transactions between the individual and the situation (Gerow et al., 2010, p. 123). It is a humanistic study of phenomena intended to explore an experience as it is lived by the study participants and interpreted by the researcher. The researcher collects the participants lived experiences through semi-structured individual interviews. The researcher's experiences, reflections, and explanations affect the data obtained from the participants. This method can also capture new concepts or ideas that may not be considered in other ways of data collection (Pope, Zieblan, & Mays, 2006; van Manen, 1990).

There are six steps to van Manen's research method of phenomenology. The first two steps are to identify a phenomenon of interest and then investigate the phenomenon

by interviewing the participants and allow them to describe their experience from their perspective. The third step is to reflect on the themes that describe the phenomenon by listening to interviews and allowing the phenomenon to be revealed. The fourth step is to code the themes, and that describes the phenomenon followed by the fifth step, which is to show a relationship to the phenomenon and the research process. The final step is to evaluate the whole context and see how the parts contribute to the whole (Curcio, 2017; van Manen, 1990). This methodology provided a framework to study new nurses as they explained their experiences caring for dying patients and their families. Data was collected via individual face-to-face and telephone interviews and found common themes and concepts, and to link similarities (Van Manen, 1990; Weiss, 1994).

Phenomenology research was the appropriate method for this study to understand the subjective dimension of the phenomena of Novice and Advanced Beginner nurse's experiences caring for patients at the end of life. For this study, Novice and Advanced Beginner nurses were asked open-ended questions and to describe their experience caring for a dying patient and their family. This descriptive study used interviews to collect qualitative data, and descriptive themes emerged (Van Manen, 1990; Weiss, 1994). As a result, this will expand the knowledge base of how prepared Novice and Advanced Beginner nurses are in caring for dying patients when they enter practice. This study has the potential to help facilitate better EOLC education at the college level.

The researcher acted as the data collection instrument and looked to answer questions about how or why a particular phenomenon occurs. "Qualitative research uses an interpretive methodological approach that generalizes about social phenomena, creates

predictions about the phenomena and proves causal explanations" (Glesne, 2006, p. 4). There is a lack of research about Novice, Advanced Beginner nurses, and their experiences caring for patients at the EOL as well as how prepared they feel performing this type of care. This study gained new knowledge to add to the literature about this phenomenon.

Semi-structured individual interviews were conducted for this study as EOLC is complex and sensitive, and face-to-face interviews can address these issues (Payne, 2007). The purpose of this semi-structured interview was to examine the participant's perception of caring for patients at the EOL. Semi-structured interviews ensured that each interview included the same questions and gave the interviews a liberated structure with open-ended questions to explore experiences and attitudes (Payne, 2007). In addition, it helped the researcher to develop a rapport with the informants (Pope, Zieblan, & Mays, 2006). The interview schedule was flexible.

Participants

Participants for this study were a convenient purposive sample of seventeen Novice and Advanced Beginner RNs until saturation of themes. The definition of a new RN is a nurse who has graduated from an Associates or Baccalaureate-Nursing program and has been practicing nursing for six months to two years. The Novice and Advanced Beginner nurses were recruited through snowball sampling. Flyers were placed in the lobbies of hospitals, rehabilitation, long-term- care facilities and a hospice center. The flyers were also distributed by email to Nurse Educators at these facilities (Please See

Appendix D). The flyers included the purpose of the study and stated that participation is voluntary and that subjects would be recorded during a private semi-structured interview. Another way participants were recruited was word of mouth called the snowball sampling. After the interview, many participants told their friends and colleagues about the study who then contacted the researcher. Participants in this study were not excluded based on race, age, or gender.

The nurses were selected from a variety of nursing programs and work in a variety of nursing settings including hospitals, rehabilitation, long-term-care facilities and a hospice center. For this study, the study group was a convenient sample of nurses who the researcher received their name as being a Novice and Advanced Beginner nurse and was eager to help with a nursing study.

Inclusion Criteria

Participants eligible to be in the study met the following inclusion criteria. (1) they must have self-identified as a Novice or Advanced Beginner RN who has been a nurse for up to a year, (2) they must have taken care of a patient at the end of life, and (3) they must be able to speak and read English at a high school level.

Exclusion Criteria

Excluded from the study were RNs who have been practicing for more than one year, as they were deemed to be proficient nurses and to have more skills and knowledge on EOLC. Also excluded from the study were Licensed Practical Nurses, and nurses who

have not taken care of a patient at the EOL, and nurses who do not speak or read English at a high school level.

Demographic Variables

A demographic questionnaire designed for this study was given to all participants and included the following: age, previous work experience as a nurse's aide**,** previous academic degree and years of formal college study, and the number patients they have cared for at the EOL (see Appendix A).

S**ample size**

The participants chosen for the study were seventeen RNs who had been practicing nursing for one year or less.

Setting

All interviews for this study were performed in a predetermined private, comfortable location chosen by the participant. A phenomenological study encourages the researcher to hold the interview where the participant is most comfortable. The interviews took place at the researcher's home, the participant's home or in a private room in a hospital. Each nurse had a chair, table, ample space and sat across the table from the interviewer or spoke on the telephone. A voice-recording device was used to record the interviews with the permission of the participant (Glesne, 2006).

Data Collection Tools

An original interview set of questions (Appendix B) was utilized to gather the descriptive information about the Novice and New Beginner Nurse's experiences caring

for dying patients and their families and educational preparation. The interview began with warm-up questions that addressed educational background, the type of unit they work at now as an RN, experience in the medical field before becoming a nurse, and any EOL education. A Demographic Datasheet (Appendix A) was utilized to gather information before the interview process with informed consent. A demographic form includes information such as age gender, ethnicity, religious affiliation, the highest level of education, nursing specialty, employment setting, College/University attended for nursing education, prior EOLC education, experience caring for dying patients and support system (see Appendix A). This demographic information helped to provide a better understanding of the nurses' experiences based on prior education and experience with EOLC and possibly gender, age, or religious differential.

Procedures

In keeping with van Manen's methodology, the phenomenon of EOLC was identified to be investigated by interviewing the participants and allowing them to describe their experiences from their perspective about EOLC and education preparation. The researcher conducted individual one-on-one interviews, and the interviews were anonymous to all except the primary interviewer. Before conducting the semi-structured interview, an informed consent (see Appendix C) was obtained from each of the participants and permission to audio-record the interviews. Each participant was assigned a study number for de-identifying each interview. The interviews were recorded with a portable voice-recording device and lasted approximately 30-60 minutes. The Interviewer utilized a semi-structured interview guide to keep the participant focused and

to implement consistency while questioning the Participants. The questions were aimed at maintaining an open dialogue on the experiences of the participants as it applies to EOLC and education preparation.

Data Analysis

According to van Manen's third step the researcher reflected on the themes that describe the phenomenon by listening and re-listening to the interviews and allowing the phenomenon to be revealed. Van Manen's fourth step was followed, and data was collected via interviews, and the interviews were transcribed verbatim into text format, selected quotes were placed into clusters and organized into themes (van Manen, 1990). To check for accuracy, the transcribed interviews were emailed to each participant and each verified that their transcription was accurate. The researcher and dissertation team thoroughly read and reread the transcribed interviews to gain a sense of the data and to acquire a sense of each and his or her experiences. From the transcripts, the researcher and dissertation team identified significant statements, which pertained directly to the proposed phenomenon. The researcher developed interpretive meanings of each of the significant statements and interpretive meanings were arranged into clusters, which allowed themes to emerge. The researcher avoided repetitive themes and noted any discrepancies during the process. The themes were generated into an exhaustive description, and according to Van Manen's fifth step, a relationship to the phenomenon and the research process was revealed. Finally, an exhaustive description of the most commonly shared themes was written. The final step was to evaluate the whole context

and see how the parts contribute to the whole (van Manen, 1990). Descriptive statistics were used to analyze the Demographic Data on each variable.

Ethical Considerations

Prior to conducting the study, approval was obtained from the Institutional Review Board at Endicott College (see Appendix E). Participation in this study was voluntary, confidential, and anonymous to all but the researcher. Subjects in the study were provided with a written and verbal explanation describing the purpose of the study as well as implications for nursing practice, nursing education, and nursing research. Each participant was assigned a study number for de-identifying each interview. Their initials and the number of their interview in the chronological order generated study identification numbers. The key that identifies the participant and their identification number and all research materials are stored in a fireproof, locked box and kept in a secure location. Participants received a twenty-dollar Amazon gift card for their involvement. None of the participants experienced distress due to the nature of the questions. All were informed that they could withdraw from the study at any time and could receive counseling by contacting the Endicott counseling center or the supervisor for this project, Dr. Kelly Fisher from the Endicott College School of Nursing. A disclosure form was included with the survey, which specifies the participant's right to withdraw or refuse to answer any questions in the survey (see Appendix C). The disclosure form was included an email address to contact the protocol director researcher with any questions or concerns about the study.

A professional transcriptionist who has experience with medical terminology transcribed the audio recordings. The Researcher and the professional transcriptionist were the only individuals to listen to the tapes and handle the hard copies of the interviews. All research materials are stored in a fireproof, locked box and kept in a secure location on a computer with a protected password. Research data will be kept for five years after the completion of the study and will then be destroyed.

Trustworthiness

In qualitative research, reliability and validity are often substituted with data trustworthiness. Trustworthiness consists of the following components: (a) credibility, (b) dependability, (c) confirmability, (d) transferability, and (e) authenticity (Glesne, 2006; Lincoln & Guba, 1985). Credibility is how confident the qualitative researcher is in the truth of the research study's findings. To obtain credibility in-depth interviews and descriptive analysis occurred over a three-month period. Credibility was also increased by triangulation by a having regular debriefing with the dissertation committee who further analyzed the data. Dependability was achieved by a solid audit trail that determines how decisions were being made during the analysis. The audit trail consisted of electronically recorded interviews, verbatim interview transcriptions and the reading and rereading of the written narratives, which allowed the descriptions of the themes to emerge (Glesne, 2006; Lincoln & Guba, 1985). The researcher and dissertation team analyzed the themes. The researcher reflected on any personal values that could have affected data collection and analysis by keeping a reflective journal to stay in contact with her own experiences.

Confirmability, which supports objectivity, was accomplished by maintaining the raw data as supportive evidence of the findings with a reflective journal, and the audit trail mentioned previously. Authenticity was supported by recording the interview and verbatim transcription. This validated the authenticity and prevented bias from handwritten notetaking. The researcher followed up with each participant and allowed each participant to review his or her transcript to verify that what was recorded is accurate. Transferability is how the qualitative researcher demonstrates that the research study's findings apply to other contexts. The taking careful field notes, writing in a precise, concise, meaningful, and descriptive way (Lincoln & Guba, 1985), supported transferability.

Potential Research Bias

Bias can seldom be entirely avoided; however, the researcher tried to reduce or eliminate bias to the most significant possibility. The researcher attempted to minimize bias in the qualitative study by asking quality questions at the right time, and by remaining acutely aware of potential sources of bias. By doing so, researchers enabled the most accurate respondent perspectives and ensured that the resulting research lives up to the highest qualitative standards.

Limitations

There are several potential limitations in this study. This is a convenient sample, which the researcher received participant's names from responding to a flyer (Appendix D). They are Novice and Advanced Beginner nurse eager to help with a nursing study.

The researcher personally knew some of the nurses interviewed. This is the first time the researcher is conducting qualitative research so the researcher may have lacked unbiased influence and proper interviewing technique. Limitations about validity and reliability are often noted in qualitative research because qualitative research occurs in the natural setting it is difficult to replicate in subsequent studies. In addition, the data relied on self-reports of the nurses who may not recall all the details of their experiences.

Timeline for Research

The study took place over a seven -month period, one of which was used to obtain IRB approval (see Appendix E). Participant recruitment and interviews took place over two months, and an additional two months were utilized for data interpretation. The remaining one months was dedicated to prepare the research results and to disseminate the findings.

Budget

The budget included funds for a transcriptionist to listen to the recordings and transcribed them for the primary investigator. The principal investigator collected all data. The participants were given a $20 Amazon gift card for their participation.

Summary

Death is an inevitable part of life and nurses are patient advocates who help coordinate and guide patient care through the lifespan. Nurses need to feel confident in providing patients and families with compassion, attentiveness, and patient-centered care

at the EOL. Nurses care for dying patients every day with simple nursing activities that can range from teaching patients and families about advance directives, managing patients' symptoms, or just holding a patient's hand. It is these caring actions of nursing that assist the patient and family during these times. If nurses are anxious or not confident in caring for patients at the end-of-life, patients will not receive quality EOLC. Therefore, it is important that Novice and Advanced Beginner nurses receive the proper education and are prepared to provide dying patients with quality and compassionate EOLC. This can be accomplished by providing comprehensive education to Novice and Advanced Beginner nurses so they can give dying patients and their families the best physical, psychological and spiritual care to meet their needs at the EOL. The goal of this research is to learn more about Novice and Advanced Beginner nurse's experiences caring for patients at the EOL and better understand their nursing education on this subject. The ultimate goal of this research is to improve the nursing knowledge and confidence on caring for patients at the EOL so that nurses can enhance the experience by providing compassionate and competent care to dying patients and their families.

Chapter IV

Results

Introduction

This phenomenological study explored how Novice and Advanced Beginner RNs understand and experience caring for a dying patient and their families as they begin their nursing practice in a variety of settings (hospitals, rehabilitation, and long-term- care facilities). A gap in previous research about this phenomenon compelled the researcher's interest to investigate the new nurse's perception regarding caring for dying patients and their families. Studying the underpinnings of the experiences of Novice and Advanced Beginner nurses revealed the importance that these nurses place on interactions with dying patients, their families and the importance of learning EOLC in nursing school. This study used a qualitative framework with semi-structured interviews, which is a standard method in phenomenological research that helped to guide the data collection and analysis.

The results are a culmination of the new nurse's expressions and share an in-depth perspective on their lived experiences. One aim of this research was to describe how these new nurses perceive and reflect on caring for dying patients and their families in the practice setting and to have them explain and look back at their experiences caring for patients and their families at the EOL. To study the Novice and Advanced Beginner nurse's experiences and understand their thoughts, feelings, emotions and reactions as

they enter practice caring for EOL patients and their families and how prepared they felt their nursing program prepared them to care for patients and their families at the end of life, the researcher established a framework based on three primary questions.

Research Questions

1. What are the experiences of Novice and Advanced Beginner registered nurses as they care for dying patients and their families?

2. What are the thoughts, feelings, emotions, and reactions that Novice and Advanced Beginner nurses experience while caring for dying patients and their families?

3. Do Novice and Advanced Beginner nurses feel that their registered nursing program prepared them to care for dying patients and their families?

Participant Characteristics

Chapter IV presents findings that evolved from the data collected through interviews of the total sample of (N=17) Novice and Advanced Beginner RNs fifteen females and two males. Each member of the sample has a Bachelor's of Science in Nursing (BSN). They work in a variety specialty settings; Subacute Rehabilitation, Long Term Care, Medical Intensive Care Unit (MICU), Burn Units, Bone Marrow Transplant Unit, Intensive Care Unit (ICU), Cardiac Care Unit (CCU), Ortho-Neuro Unit, Cardio-Thoracic Unit, Surgical-Trauma Intensive Care Unit and Emergency Department (ED). The sample included RNs that are employed in Massachusetts, North Carolina, New

Hampshire, Pennsylvania and Texas. They attended nursing schools at a variety of colleges located in Massachusetts, New Hampshire, Ohio, Pennsylvania, and Virginia. The graduate nurses have been working as RNs for 3-13 months. Sixteen of the participants are the age of 21-27 years old, and one participant was 32 years old. Fifteen of the participants identified as racially as white, one defined as Asian and the remaining participant identified as Filipino. Eight stated they had little to no EOLC education in nursing school or at work.

Table 1. **Study Participant Characteristics**

Initial	Gender	Age	Ethnicity	Degree	EOL Ed.	Prev.EOL Exp.	Working Specialty	# Deaths	Month RN
CT	F	22-27	White	BSN	NO 20 Min. PP	YES	LTC	1-5	7
AK	F	22-27	White	BSN	NO	YES	LTC/ED	1-5	9
AG	F	22-27	White	BSN	NO	NO	LTC	1-5	8
GB	F	22-27	White	BSN	YES	YES	Gen. Med	1-5	4
MB	F	22-27	White	BSN	NO	YES	Rehab/LTC	1-5	3
SK	F	22-27	White	BSN	NO	NO	Rehab/LTC	6-10	10
KJ	F	22-27	White	BSN	YES	YES	Rehab/LTC	11-20	5
MS	F	22-27	Pilipino	BSN	YES	YES	MICU	1-5	4
NB	F	22-27	White	BSN	YES	YES	Burn Unit	11-20	3
LS	F	22-27	White	BSN	2 Clinical Oncology	YES	BM Transplant	1-5	6
EC	F	22-27	Asian	BSN	YES	YES	ICU	1-5	3
AC	F	22-27	White	BSN	Capstone	NO	Cardiac-Medical ICU	1-5	5
KH	F	22-27	White	BSN	NO	YES	Ortho-neuro	1-5	5
AGU	F	22-27	White	BSN	YES	YES	Medical ICU	1-5	3
AM	F	22-27	White	BSN	NO	YES	Cardio-thoracic ICU	1-5	4
CG	M	22-27	White	BSN	YES	YES	Surgical-Trauma ICU	6-10	6
DL	M	32	White	BSN	NO	YES	ED	11-20	13

Data Analysis

The interview analysis was accomplished with a holistic approach using van Manen's (1997) methodology. This provided a venue for a comprehensive depiction of Novice and Advanced Beginner nurses' experiences caring for dying patients and their families and how prepared they felt their nursing school prepared them for these types of patients. The primary researcher analyzed the audio-recorded interviews by listening to the tapes over-and-over. A professional transcriptionist transcribed the audiotapes verbatim, and these transcribed interviews were sent individually to each participant to confirm validity. The primary researcher and research team (KF, JE, and RO) read and reviewed the transcribed interviews to identify trends and recurring patterns that reflected the participant's expression of their experiences caring for dying patients and their families (van Manen, 1990).

The research team each highlighted the coded clustered patterns and named each theme depending on its subject matter. Each researcher discussed the themes identified from the interviews, and the team generated common themes. The data was organized into four primary themes based on a review of the data and the research questions. According to van Manen (1997), structures of the experiences were described as the experiential structures that make the experience, which is then summarized into themes. Four themes emerged from the interviews of the (N = 17) participants and the analysis of the research team.

One aim of this research was to provide a depiction of how Novice and Advanced Beginner nurses describe their first or most memorable experience caring for a dying patient and their family as a new graduate nurse. To answer this question, the participants were asked to express in their own words this experience. A central theme that appeared from the data is that the participants revealed that the client is both the patient and the patient's family. EOLC is a sensitive subject and caring for dying patient can be emotional. Another theme that was revealed was that nurses that have not had previous clinical or professional experience caring for a patient at the EOL experience an assortment of emotions such as feeling upset, fear, sad, uncomfortable and scared. Therefore, nurses need to care for themselves. The last theme identified is that these nurses did not feel well prepared to meet the challenges caring for dying patients.

Regarding the theme of caring for the patient the participants described giving everyday comfort to dying patients and stated "it is the little things" that the nurse does that are the most important to ensure patients die with dignity. Dying with dignity is a sub-theme that Novice and Advanced Beginners nurses desire for their patients to have. To die a good death meaning free of pain, comfortable and surrounded by loved ones. The majority of Novice and Advanced Beginner nurses expressed feeling conflict when administering EOL medication such as Morphine and Ativan. They showed that they felt ethical that they were contributing to the death of the patient while simultaneously wanting to provide comfort to the dying patient. Another sub-theme revealed was how it could be difficult communicating with dying patients and the difference between caring for a conscious and unconscious patient.

The theme caring for the family, the participants, discussed that they thought the family was also the client and wanted to provide family-centered care. They described their interactions giving the family comfort and support as well as communicating with the family. Another theme identified is the issue of caring for patients that are elderly and frail or terminal, but the family wants aggressive treatment to save the patient. Most participants revealed that caring for dying patients and their families is emotional and they expressed an array of emotions caring for dying patient. Those with little to no EOL education in nursing school were more scared, uncomfortable and fearful about caring for a dying patient. Nurses that had previous EOLC education and EOLC experiences felt more comfortable caring for and talking to dying patients and their families. Several nurses felt that support from a nurse leader, mentor, preceptor, peers or a nurse educator helped reassure them when faced with EOLC situations. Novice and Advanced beginner nurses that had little support, guidance, or mentorship expressed feeling discouraged and upset during their EOLC experiences. Two of the seventeen participants expressed that they did not sign up for this and as a result, they left their jobs because they felt they were not prepared or supported to care for EOL patients. EOLC is stressful, and nurses need time to debrief and talk about their feelings. Many participants spoke about having a good role model or mentor to help show them how to care for dying patients and their families. It is important to have proper education, emotional support and experiences to feel more comfortable caring for EOL patients.

Four major themes identified from the analysis of the interviews with sub-themes.

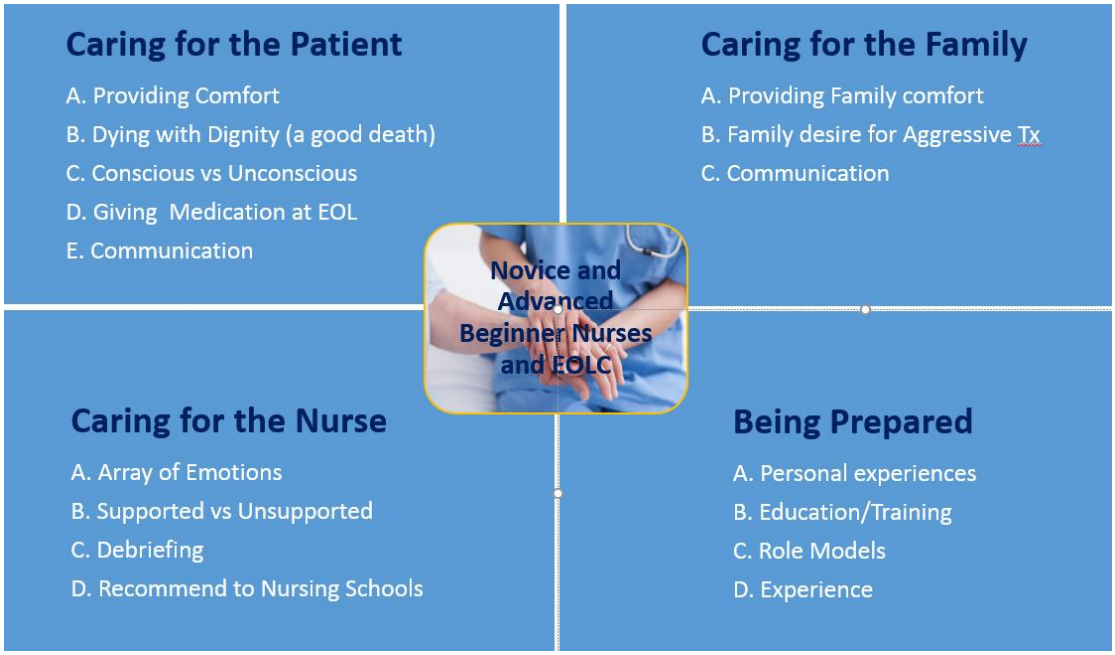


Table 2. **Theme #1 Novice and Advanced Beginner Nurses Caring for the Patient**

Major Theme #1	Sub-Theme	Added theme
Caring for the Patient	A. Everyday comfort	a. It is the little things b. Patient comfort
	B. Dying with Dignity	
	C. Conscious vs. Unconscious	
	D. Giving Medication at EOL	
	E. Communication	

The present study produced four themes and subthemes. Theme #1 Caring for the Patient had five sub-themes: A) Providing Comfort, B) Dying with Dignity "A Good Death," C) Conscious vs. Unconscious, D) Giving Medications at EOL, E) Communication. Theme #2 Caring for the Family had three sub-themes: A) Providing Family Comfort, B) Family desire for aggressive treatment C) Communication. Theme #3 Caring for the Nurse had four sub-themes A) Array of Emotions, B) Supported vs. Unsupported, C) Debriefing, D) Recommendations to Nursing School. Theme #4 Being Prepared had four subthemes A) Personal Experiences, B) Education/Training, C) Role Models, D) Experience.

Theme #1 Novice and Advanced Beginner Nurses Caring for the Patient

When patients are dying, they experience a range of symptoms physical, psychological and spiritual. It is recognizing that working with dying patients and their families is an opportunity to provide care and comfort to the patient by doing simple basic everyday care. The participants expressed wanting to give dying patients everyday care and comfort. A common theme stated is that" it is the little things" you do for a dying patient that are the most important such as holding their hand, playing music, bushing or braiding their hair, talking to them, keeping them warm, clean and comfortable. Giving the patient comfort included personalized patient-centered care, compassion, and care for the patient's primary needs.

A. Sub-Theme: Giving Everyday Comfort:

a. "It is the little things."

AGU: After I cleaned her up, he came back and said, "Look at my bride she is all clean and pretty," that kind of got me; it is never the big things. It is amazing what cleaning a patient up does for a patient's emotional health. Just washing a patient's face makes them feel ten times better.

MB: She was a 50 year of women dying from breast cancer that had spread everywhere. She was losing a lot of hair, so I helped braid it back in a ponytail, and she was so happy saying it felt pretty and it was like a spa day. It is the littlest things you do for a patient that makes them so happy, being clean and feeling like a human, not a disease.

LS: Her husband played their favorite song, and we would sing that sometimes, which was fun and just doing little things to make someone's end of life as nice as possible if that can happen.

MB: It is so important to keep them comfortable. I try to do everything I can; whether it is bathing them every day or making sure, they are getting the right medicine to keep them comfortable. It is the little things you do on a human level. I take care of the patient in a way I would want to be

cared for, to paint their nails, brush their teeth, little things, to make them feel clean and human.

KH: I think it is the little things we do as nurses. I know she loved when I sprayed the perfume and when I stayed and held her hand. I think people sometimes forget that it is the little things that matter.

b. Making the Patient comfortable

Novice and Advanced Beginner nurses discussed that at the EOL they found ways to make the patient comfortable not just with pain medication but with holistic techniques such as playing music, spraying perfume, brushing the patient's hair, praying with them, talking to them and giving reassurance.

GB: He was a 28 year old with HIV, he was on hospice, and he was going to pass very quickly. He was on a Morphine drip; I just held his hand, talked to him and played some nice music and made him comfortable. Which made me less scared. I talked to him a lot when I was going through the music stations, and I brushed his hair and cleaned his fingernails. I knew I wanted to make him comfortable and to be in the room for him and talk to him even though he could not respond. All the compassion, the sort of non-medical parts of nursing.

KH: The grandson brought in her perfume that she gets every year at Christmas. So the rest of the day I would go in her room and ask, "Do you want me to spray some of your perfume on your pillow"? She would nod her head, so I would spray a little perfume every time I went in there. The grandson told me that she is super religious so I gave her, her rosaries and placed them in her hand for her to hold. I asked her if she wanted some music on the TV because she was just lying in there with nothing on and the family was not visiting, and she nodded her head. So, I put some music on for her.

KH: At the end of my shift, I was leaving late but I went back to her room before I left and stayed with her for another ten minutes. I could have left, I held her hand, the other nurse came in with her Ativan, and I stayed there with her for a little longer.

CT: I think it was the first time I ever really identified myself as a nurse. It is an important part of nursing; we need to be there at that important moment when someone dies to make him or her comfortable. Who else gets to do that at work? You get to sit there and hold someone's hand while they die and make him or her comfortable. I think it is special.

B. Sub-Theme: Dying with Dignity: "A Good Death"

A theme that many of the participants pointed out is that they wanted their patient to die with dignity and to have a quality of life, even during death. This refers back to the framework of Ruland and Moore, A Peaceful End-of-Life Theory (1984). Taking care of the dying patient's physical, emotional and spiritual needs and treating them with respect by attending to their needs and wishes is an integral part of EOLC. Dying is something everyone will one-day experience and helping patients die with dignity and preserve their quality of life to the end by treating them with compassion and dignity and telling them they are not alone is crucial.

AM: I feel it is at a certain point, what is this person's quality of life and how can we make this the best situation that it can be? Obviously, it is not a good situation to start with, but how can we make this the best for the patient as well as the family?

SK: This is a date. This day is going to stick with them. This day that you were involved in, and I think you need to make your involvement positive. You need to make sure that how you are involved in this event in their life is a positive thing. So, definitely holding hands and therapeutic communication.

AK: I think it is very important to help these patients make the transition from being with us to passing on. I am happy if they do not have a painful death or that I help them not have one.

EC: When someone decides to withdraw care, it is hard to imagine, but the thing is we need to think about the quality of life. Because you do not know if by extending their life, you're just decreasing their quality of life, and I'd hate to do that to her.

DL: It is important to give these people a more respectful and honorable death, on their own terms.

Sub-Theme: Conscious vs. Unconscious Patient

Novice and Advanced Beginner nurses described feeling a conflict caring for conscious and unconscious patients. They stated that it is easier to assess for pain in a conscious patient but more difficult to talk to them about the dying process. Caring for the unconscious, dying patient is more difficult to assess but easier emotionally.

SK: I have not really had anyone that was dying that was cognitively aware enough that they knew they were dying. I think that would be an interesting thing to have a patient that was aware of it. I think that would be a completely

different struggle. It is one thing to have to explain it to a family but to explain to the patient what they are going to go through, that this is okay and that it is part of their life. That is hard when you are talking about that person's life.

AGU: The hardest part is, with someone who is unconscious, is you cannot say, "Are you having any pain? Are you in any distress?" You have to visually count the respirations and listen to how they are breathing and look at them. In addition, we do not do vital signs on our comfort measures patients unless the family asks, you kind of cannot go off that, and it is a completely new world.

MS: It was early in my orientation in the MICU and, we had an alert 40 year who decided to withdraw care. Typically, when we had done this it was on a comatose patient but this patient was awake, and his wife and kids were there, it was very emotional. I personally did not feel comfortable in this situation and feared I might say the wrong thing or not knowing what to share or do in that time. I was not sure of what we do in terms of comfort care and all that.

C. **Sub-Theme: Giving Medication at the EOL**

Novice and Advanced Beginner nurses expressed having ethical issues in administering EOL medications. Those that had not been taught how to

administer EOL medications expressed feeling conflicted that they were ending the patient's life. Most of the participants shared their feeling of uncertainty giving medication to their dying patients. They wanted a peaceful, comfortable death but did not want to be responsible ending or speeding up the death.

> AK: I learned early on working in rehab, that if someone was on Roxanol, (Morphine) they were going to pass away. I did not want to give them Roxanol, because I did not want to kill them. I did not want to be responsible. The advantage of giving Roxanol was I knew it was going to help him pass away and not be in pain. However, the disadvantage was I felt morally wrong by doing it in the process. I knew it was going to speed up his death. I use to ask other nurses to push it on my patients. Then it was the nightshift, and I was alone with another new graduate. My patient was dying, his respirations were eight, and then down to six. He was due for his Roxanol, and I really did not know what to do. I would sit there with him and hold his hand every time I gave him Roxanol because I knew it was going to happen. I just did not know when.

> AG: The family was on their way, but the patient was moaning in pain, and I had the Morphine order. Should I give it, what if I do and kill him? This would kill me if I were in the kids' shoes, and I am trying to see my family member, and then the nurse is about to give Morphine. What if they want to say good-bye, and they are not able to, because I give this

Morphine? I know this patient's in so much pain, but should I wait? Should I let the kids say their goodbyes, and then comfortably let the patient pass? I ended up giving only 1mg not the whole 2mgs. He stopped moaning. His breathing declined even more. Then he passed away, right there, and the family still was not there. I got emotional. I thought this is not my fault. I cannot believe that the family is not able to say good-bye. I got terribly upset.

GB: I wanted him to pass away, but I did not want him to pass away because I pushed Morphine. I guess I was cowardly, but I did not want to be the one to do it.

KJ: I have to give Morphine a lot and some of the patients, I feel as if I am just killing them. Other patients you feel, they are suffering, and they need it.

AC: I was so nervous. When you are giving alert patient narcotics, you are looking at their respiratory drive and not wanting to overdose them. Then you see this order for every one hour IV Morphine and yeah. I kept thinking in the back of my head, is this the dose to end her life? Then I would think, she is dying and that is why she is here and why we are doing

this. I spoke to my resource nurse about this, and she reassured me that that this medication was for the best and this is what your here to do, to make your patient comfortable.

AGU: I have had many patients that are comfort measures. It was scary for me because while I am a firm believer in comfort measures, and I think it is an amazing thing, being that person that has to decide, do they need the Morphine? Do they need the Ativan? Is very scary. Because you realize that, this could be the last thing that you give them. It was hard for me to make the decision. Many of the nurses on my floor say, "You need to realize they're dying. It is not going to be the 4 mg of Morphine that kills them." I know they are dying, but I did not want this dose to be the dose to stop everything.

D. Sub-Theme: Communication: Talking to Dying Patients

Novice and Advanced beginners expressed that sometimes they are unsure what to say to a dying patient. Most stated they still spoke with the dying patients even when they were unconscious. Talking to them, treating them with compassion and dignity and telling them they are not alone conveys empathy.

LS: At first, I felt I did not have anything to give her, because who am I? I am just a new nurse who is still trying to learn everything I can. Then, I

realized, just being there for her and talking to her and talking to her husband and her kids.

LS: I walked into the room, and my patient just said, “I don't know if you’ve heard, but I actually just signed onto hospice. I’m not doing well, and the plan is for me to hopefully go home soon.” I did not really know how to respond, because it shocked me. This was my first patient that that happened to and I did not expect her to be so honest. Once I got over the shock, I talked to her about why she chose hospice and how that’s good, because she’s going to get to spend some time with her family at home instead of being here in the hospital.

EC: I did talk to my patient about her decision to withdraw care. She was not sad or upset at all. She was very calm and saying, “You know dear, enough is enough.” “I just don’t want anything done, and I want to go home.” I wish that I had attacked the harder topic and asked her if there were any better ways that we could support her. I just listened to her talk about how she lived a great life and was married for over 40 years. I did not bring it up again. I think, it probably was that I thought it was kind of taboo to say, “Oh you know, you’re being discharged to go home to die” I did not want to bring it up.

SK: Whatever state a patient's in I talk to them, I tell them what I am doing. I tell them I am here and that they are safe. I would always want to be treated like that. The hearing is one of the last things to go. I want them to know they are not someone I am turning very quick and given them Morphine. No, I am here with you. I want to make you comfortable. I am going to put this blanket on you. I think that is good nursing practice. It is also cathartic in some way to talk to them. I want you to feel like I am here for you. I want you to know.

KH: She was asleep most of the time I was in there, but I would still talk to her every time I went in there. I would say I got your medicine; do you want me to swab your mouth for you? Do you want some lip moisturizer? I would still talk to her every time I went in there. I kept telling her that we know and it is okay, and we are going to make you comfortable and do not worry.

Table 3. **Theme # 2 Novice and Advanced Beginner Nurses Caring for the Family**

Theme #2	Sub-Theme	Added Theme
Caring for the Family	A. Family Comfort	a. Family not present at the death b. Family at the bedside
	B. Family Desire for Aggressive Treatment	
	C. Communication	

Theme# 2 Novice and Advanced Beginner Nurses Caring for the Family

Providing family-centered care is an essential role of the nurse. Novice and Advanced Beginner RNs acknowledged that their role as nurses included caring for the whole family and significant others, which is an essential part of the caring process. To give holistic and family-centered care the nurse needs to provide information and support to both the patient and the family to minimize the family's anxiety and achieve the best outcome. The Novice and Advanced Beginner nurse identified caring for family is an vital part EOLC, the family is also the client. Themes identified are caring for the family that is not present for the death, helping to explain the situation and circumstances, caring for the family that is present at the bedside, and teaching them how to care for their loved one at EOL. Another theme identified is the family's desire for aggressive treatment especially with terminal or frail elderly patients with not much chance for improved quality of life.

A. Sub-theme: Giving Family Comfort

a. *Family is Not Present at the death*

CT: I felt grateful to be able to be there he died. I felt honored that I could be there and hold his hand. Previously he had been homeless, he had a guardian, and we called the family, but he did not have any family that came in.

AK: When my patient died, I had to call the family. When the family came in, they were upset and asked how did this happen? Why did this happen? We do not understand. What did you do for him? It is one of the hardest things to tell the family this is a natural part of dying. We said it was not a traumatic event; he was laying in his bed, very comfortable. I told the family he did not die alone the CNA and I were next to him. We held his hands; we comforted him, told him we were there, it is okay. It made the family feel better, and they were thankful that we did that for him. It makes you feel better as a nurse.

AG: I felt so uncomfortable calling the family, I had to explain that their father had taken a turn for the worse and that they needed to come in to sign the DNR because their family member was dying, and I have never had to deal with this before, it was terrifying.

A. Sub-theme Giving Family Comfort

b. *The Family is at the bedside:*

SK: Sometimes families are nervous to touch the patient. Many times when I go into rooms and families are all sitting around the patient; I show them. I will hold the patient's hand and talk to the patient. I will say, "I'm here. I'm going to reposition you." Then I will brush the patient's hair back, and many times, it is funny, families will jump right in after

that, and they are holding the patient's hand. They need to know that their loved one is not this fragile thing, that they can touch them. I show them that it is okay if you do this, giving them little things to do makes them feel involved.

SK: The family was in every day, sitting with him. They were inquisitive. I tried to tell them every part of what I was doing. I think that really helps to make them feel involved and make them understand a little bit of the process of what is happening to their loved one. I try to explain to the family not to think about him actually passing. I try to give them a time frame for the next step. I reassure them that I will be back in an hour to check on him and I am going to check his temperature at that point, and I am going to give him some more Morphine. If you need anything before then, I will be back. That helps them knowing I will be back.

MB: Whenever I would go in the room, I would let the family know what was happening and what I was doing. They are very friendly and very understanding of what was going on. I feel it is important to help keep the patient comfortable in any way we can and to take care of the family and make sure the family is okay because taking care of the family is huge.

AGU: It is hard to see the family in that moment kind of lose everything. I found it a weird experience to say, I just met you. What can I do? Because their whole world is crashing and all you can do is make them a cup of coffee. I set up a bed in the room for one of them so that they could stay the night.

SK: At the time of death, I listen for the heartbeat, and after I make the pronouncement to the family, I always go in for a hug, and I think sometimes they might feel awkward, but I think I just want to - - "I'm here for you." They need to know that. I am here to say I am sorry and if there is anything you need at all, and I always say please, take your time. Call anyone that you want to call. I say, when you are ready, we will call the funeral home, but there is absolutely no rush. If I can get you anything to drink. I always bring in tissues. Then I will go back, check on them in half an hour, and just peek my head in.

SB: I think it is important to give the family time to say goodbye and do not rush them. Do not make them feel like they are alone and check on them. I might tell them a little story about the patient, I might say, "your mom or dad was hysterical and we loved them". Hearing little stories about the patient. They could have been the most stupid or most pointless stories, but this is an event.

AG: I think it is important to let the families know that you are there for them and you did care about their mom or dad. This also is not just a patient to you. This is not just a patient you are coming in and turning. You also want to make the family feel cared for and a part of this experience. I ask the family; do you have any questions? Is there anything I can do for you?

B. Sub-Theme: Family Desire for Aggressive Treatment

Prolonging care when the patient is frail, elderly or terminal can be frustrating for Novice and Advanced Beginner nurses. They expressed that it is frustrating and emotionally exhausting to treat terminal or frail elderly patients with aggressive treatments and felt patients were in pain and suffering. This theme surprised the primary researcher as it was not a question asked in the interview, and a majority of the interviewed participants brought up this subject. They expressed that they struggled with aggressive treatment (futile care) and expressed frustration with these situations and the desire to have their patients die with dignity. Many discussed that doing things to prolong someone's life may not be in the best interest of the patient and discussed families needing to make decisions about DNR and CMO so patients could die with dignity.

GB: There is an 81-year-old woman who has been on our floor for a month now, and she had an anoxic brain injury a year ago. She has ten children who do not agree. She is unconscious, edematous, has bedsores,

and is a full code. It is just so upsetting. We struggle a lot to with DNR status of the elderly patients.

NB: I had a 92-year-old dementia patient with a stage four infected ulcer on her sacrum that was a full code. The daughter wanted her mother to live and think the hospital could fix everything. However, what is the point, she was in the fetal position, not eating and in pain. The patient had written that she did not want anything done, but the daughter was the health care proxy and wanted everything done, which is so selfish and awful. I tried to explain to the daughter about DNR and hospice. I do not think people are educated enough about hospice. It is such a happy place to be. This patient should have been. However, she died a horrible death.

LS: She was a very tiny, frail, older woman who was not a DNR and her vital signs were deteriorating rapidly. I got so overwhelmed and nervous thinking about having to do CPR on her. I called the rapid response team and the family, and they just said, "You have to do whatever you can to save her." The family saw us coding her and then signed the DNR order and then she passed away. It was horrible that she did not pass peacefully. I do not think families understand what a DNR order is.

AC: I have a patient on my unit right now who is ninety-one or ninety-two, and he is not doing well. His family is having a hard time with it. The patient is not with it, so the family is making all the decisions and want to do everything including hemodialysis (HD). The patient clearly does not want HD, and he pulled out the line. The wife wants us to tie him down, put mitts on him, and just keep doing the HD. It is frustrating. It is hard to take care of him. Emotionally it is very exhausting.

AGU: The 90+-year-old patient came into the EW, he was a full code in CHF, grunting and struggling to breathe. He was dying, and the family stayed in the room and said, "Oh, you're not giving him fluids. You're killing him by dehydrating him," I told them; we cannot give him fluids because his lungs are filled with fluid. The family says you are killing him. You're killing him." Then they ask, "What is your recommendation?" I said, "Honestly comfort measure. They finally decided on comfort measures, and we recommended that the rest of the family come in and they were all there when the patient died peacefully.

CG: One thing that bothers me is when someone is essentially dying, and they are really suffering, but we are keeping them alive for the family to get there, and the family is not being diligent about getting there. That is

hard because we are making that person suffer and they do not need to be. There are people that go through a lot more than they probably should. They are essentially living a pointless life. They have no cognitive function, and they cannot even breathe for themselves. They will never be themselves. That is tough, but that is not my decision, that is theirs.

DL: In the ED, we had a family member that wants me to continue to resuscitate a ninety-eight-year-old woman who has a history of cancer. She is a full code. Her life is literally living in a bed, and you are like, do you know what you are doing to this person? You want us to continue to resuscitate someone that wants to go out. Let their death be an honorable death. This is the hardest thing, and it drives me crazy. Death should be an honorable thing regardless if they have been sick and fighting for a while. It is supposed to be that time when they finally get to have rest. They get to be at peace.

C. Sub-Theme: Communication with the Family:

Learning how to talk to a dying patient and family is an important skill to learn. Novice and Advanced Beginner nurses expressed that one of the hardest things in nursing is knowing how and what to say to a dying patient and family. Difficulty is having the conversations about withdrawing care, DNR status or giving bad news. It takes practice and experience to feel comfortable talking to patients about the topic of death. Some participants recommend a good way to

learn is by watching and listening to expert nurses as they do this skill and allow student and new nurses to practice in the clinical setting.

AGU: I personally think it is a real humbling experience caring for a patient that is dying, especially actively dying. You only have eight or twelve hours to build this bond. How you talk to the family and what you say builds that trust with the family, because I find you are not only treating the patient, but you are treating the family as well.

MB: It was scary. First, I had to care for an EOL patient. I was especially nervous to give care with the family in the room because I was not sure how they would react. The first times I just went in the room I did not talk to them, and just gave the meds. They were quite, but once I started a general conversation with them, they were very nice and actually were supportive of me. Each time I went in to give the patient care, it got easier. I asked if they were okay and if they thought he was comfortable.

MS: I was mostly afraid as a new nurse because family is obviously part of the patient experience and I had heard some previous nurses say that families can be of overbearing. I see death and dying every day, but they do not. I was a little afraid not knowing how to talk about the dying process, and they were a big family. But, as we got everybody situated, I think coming in with a good attitude was helpful and going above and

beyond for your patient is really, what makes the dying process a little bit better in the hospital.

AGU: The family said, “Well, didn’t you just give her Morphine?” I told the family, “This is what comfort measures are. If she is not getting better, you try to keep them comfortable by giving them more pain medication. I explained that I did not want her to be struggling to breathe and it is upsetting for you guys as well,” This helped make sense to the family.

NB: I took extra time and talked with the patient’s daughter, and she ended up really liking me. She did not get along so well with the staff, but I think she knew I really liked her mom. It is important to make a connection and build trust; it helps in this EOL situation.

KH: I had to be the one reassuring the family and helping the doctor with this CMO order. I think the hardest - - what to say to the family. It was hard to do. What is okay to say to the family?

DL How do you sit down and talk a patient and family and say, this is not going well? This is something that is lacking in nursing school, how truly

to talk to people, to give them good news versus give them bad news and lead to better understanding.

Table 4. **Theme # 3 Novice and Advanced Beginner Nurses Caring for the Nurse**

Theme #3	Sub-Theme	Added Theme
Caring for the Nurse	A. Array of Emotion	a. Not know what to do b. Scared & uncomfortable c. Sadness & Upsetting
	B. Supported vs. Unsupported	a. Supported b. Unsupported
	C. Debriefing	
	D. Recommend to Nursing School	a. Hospice Education b. More EOLC Education c. Advice to New Nurses d. Simulation Lab not Helpful

Theme # 3 Novice and Advanced Beginner Nurses Caring for the Nurse

A. Sub-Theme: Array of Emotions (scared, uncomfortable, sad, and upset)

Nurses are only human, and they experience a lot of sadness working with critically ill and dying patients. The majority of the participants interviewed express an assortment of emotions (scared, uncomfortable, sadness and upset) caring for a dying patient and their families. They described that these emotions are mostly because they have never cared for a dying patient before and lack experience. Due to inexperience, they expressed that they do

not know what to do and lack confidence caring for dying patients. Some nurses felt sadness when patients terminate care, and some expressed that they felt upset and a sense of loss. Dealing with sadness, emotions and loss are hard to cope with as a new nurse.

a. ***Not knowing what to do***

CT: When I walked into the room, I felt I did not know what to do. His heartbeat was irregular, and he would stop breathing for 30 seconds at a time. I knew his death was coming soon, that made me uncomfortable. I do not want someone to die while I am there and feel I did not do enough. I did not know what to do because I had never seen anyone die before.

LS: I was really upset and taken aback when I realized that she was dying, and just emotionally, that was tough as a new nurse. I had never cared for a person that died; I did not even know the policies and procedures. I wish I had been more confident.

AG: I had never seen a patient die before, and I honestly did not know what to do. I had not been trained on it. I was like, "Oh my gosh. This patient is dying. I need to get myself together." My first death will,

unfortunately, stay with me forever, because of how I felt, and how emotional it was for me.

b. ***Scared & Uncomfortable***

CT: I knew his death was coming soon, that made me really uncomfortable. What makes me nervous is I do not know much about EOLC, and that is what really scares me.

GB: I just was very on edge all night and very worried that he would die alone. I went into his room every ten minutes because I was so nervous. I was scared all night that he was going start looking uncomfortable and that I was going have to start making those hard decisions.

AC: Caring for a dying patient as a new nurse, in the beginning, is uncomfortable, the first time for sure. I spent a lot of the day navigating just kind of what medications to be giving her and stuff like that.

DL: My experience where I work in the emergency room you usually cure people. However, an EOL patient you are watching a person that you know is going to pass, and it is tough. It is also challenging and unsettling because you are watching.

c. ***Sadness & Upsetting***

AG: I had never seen a dead body before, let alone prepare one for the morgue and it freaked me out. He was bleeding and the smell, I do not think I will ever unsmell the smell; it was awful and so sad.

AK: If you grow some kind of attachment and your patient dies, it is so upsetting. You just do not know what to do about it. You just want to go home and cry.

EC: I had a patient that had decided to withdraw treatment. I was definitely tearful. I remember needing to step away, because I obviously could not be tearful while taking care of her. It was definitely really upsetting, but I had to try to respect her choice.

AM: I think caring for dying patients can be sad. It reminds you that you never really know what is going to happen in life. It is almost scary being in healthcare, knowing that all these things can really happen to somebody. Sometimes I question why I wanted to be in healthcare. It can just be so much at one time, and it is just so sad to withdraw care.

AC: Caring for my first dying patient it was a huge Vietnamese family and only a few spoke English. It was overwhelming. Just the sheer number of people that were in there and some people were hysterically crying, and then I was crying. I did not really expect to. I was surprised that I reacted that way and it set me off completely.

B. Sub-Theme: Supported vs. Not supported

Death is not something to fear or avoid in the healthcare profession. Caring for dying patients can be overwhelming to new nurses, and it is helpful for experienced nurses to be there as support to share experience and to help the new nurse reflect. Novice and Advanced Beginner nurses expressed that they felt confident when they have the support of nursing staff on a unit or the chaplain or social worker.

a. ***Supported***

MS: When my patient was dying, it was so traumatic, and I was upset, but my preceptor was great. At that moment, she made sure I was okay. Having her with me as we went through it was very helpful. It was a good first exposure as a nurse to deal with death and dying.

NB: We have a lot of support on the burn unit. The social worker we have on our floor is amazing. If your patient dies, she will come find you and

say, “Let’s go for a walk. Let’s go talk”. No one cares if you leave the floor. They will cover the patients for you, and you will just go for a walk and talk about how you are doing and if how this is affecting you and what do you need. It is awesome.

LS: When I was off orientation and on my own during the nightshift, I had a dying patient. I did not know what to do, but I did have the support of the nightshift nurses who really helped me through it. The best resource I have had helping me to navigate the whole EOLC is the other nurses and having them there to support me through it, so I do not feel alone. The hospital also has a Chaplain, and they do counseling services, but I have not utilized them.

AC: The day I had to care for a dying patient the resource nurse was the nurse who trained me, and we have a good relationship. She was helpful because I had no clue about giving CMO medications or how to dry up the patient’s secretions and make her comfortable. I was comfortable to bounce stuff off her, and she helped me with my questions and all my emotions. She told me to go and take a minute for myself, and she helped me with all the questions from the family about going to the morgue and the funeral home.

AM: We have a good palliative care team, and we have many family meetings to make a team plan with families. Our nurse manager is good about talking to everyone, especially if something as an unexpected death happened and she was there, she probably would have brought the nurse who was taking care of that patient at the time into her office and ask, "Are you okay?" Our staff is good about never really leaving anybody alone, so I think that is almost comforting, knowing that I am never really truly alone.

KH: I did not feel alone because I had a good charge nurse on that day and all the other nurses were; if you need anything let me know. They kept saying that throughout the day. I felt very much supported. They would be, well let me know next time you need to waste the Morphine because I was going in the med room so often and needed another nurse to witness my waste. Then, the charge nurse said -- okay, so if she dies on your shift, this is what we are going to do. It is okay. We will make it through. She was good about it.

MB: I had the other nurse and supervisor there to instruct me and run down with everything. What we fill out, because I had never seen any of the paperwork sides of any of this, so I was not sure what we did as

nurses. Therefore, we filled out the death certificate, called the morgue to let them know when the family was leaving and that they were gone, and it would be okay.

CT: The most helpful thing for me that day was the nurse's aide because she had been there for 20 years and she had been there for many deaths. She came in and said, "Oh, it's going to be soon". I was like – what is soon? I did not really know when it was going to happen. Then apnea started being longer, and the nurse's aide was in there with me, and she said – "let us just hold his hand because it's going to be coming soon." She knew more than I did.

a. Unsupported:

Novice and Advanced Beginner nurses that do not feel supported caring for EOL patients expressed that they did not sign up for this and leave a nursing position and change jobs. Supporting, debriefing and checking in with a Novice and Advanced Beginner nurse is crucial not only to ensure they are learning how to care for EOL patients properly but also to allow them to express their feelings.

AG: I had six patients total, one that is actively dying but still receiving treatments, and a DNR that has set in place, but not actually signed. I had to care for the five other patients who were very sick, also, and by

the time I had a second to address "Is this DNR in place or not?" the patient –was passing away. It was so scary. I thought, "Oh, my gosh, this is my fault. I should have addressed this like way sooner. Why isn't anyone helping me?" I had a nursing supervisor that was in the building, but she was on the other side of the building, she had kept saying, "I'll be there in a second. I'll be there in a second."

JK: I have had 13 patients die, and I have only been here five months, I did not sign up for this. No one has trained me, and no one is supporting me. I have 20 patients to do a medication pass on. I am lucky to only see the dying patient when I pass the meds. I feel anxious, and when I do, I check with my charge nurse and it never fails that the superior nurses are never around when there is something happening. In addition, you are, well, what do I do and then you do it and then, well, did I do the right thing? I signed up for a rehab not hospice.

AG**:** The next day at work after my patient had died; it was as if nothing had even happened. I feel like I should have had some educational piece with the clinical educator to review what happened but nobody addressed it, they just ignored it. I am still somewhat upset about it, as you can see. I still get emotional about it, but I feel it would have been better if my supervisor, my clinical educator, or even my director of nursing asked,

"How do you feel about this?" I was still a new graduate and just finished orientation, and nobody even addressed it at all. Soon after the unsupported death, I left that job and now work in a better-supported environment. Honestly, it is the reason why I left that place.

KH: I was upset about my patient dying, and I got emotional when I saw the grandson crying. I wanted to cry too, but I did not cry. I was afraid to talk to anyone about - - because I was afraid, I was going to get upset, and I did not want not to be professional. I was nervous and afraid to talk to the other nurses about my emotions or even ask for help about my emotions.

Theme #3 Novice and Advanced Beginner Nurse Caring for the Nurse

C. Sub-Theme: Debriefing

The participants discussed talking about their experiences caring for dying patients with fellow nurses or support systems at work is helpful but a resource not always used. A healthcare facility is a busy place, and nurses rarely care for themselves. It is important for new nurses to learn that before they can care for others, they must first care for themselves and debriefing after a death is so important.

AGU: The nurses on my unit really help each other out especially with family that are not coping well with a dying family member. We have a good team, where we will do a debriefing if it has been a hard case like a code goes wrong. We will all sit down, and everyone can talk about how they feel. After one tough death, we all went out to breakfast, because we were so flustered and needed that support.

AGU: My new graduate classes, we have debriefing; they call it a reality check, where we talk for about an hour and share experiences if something is not going that well. It is good to have that kind of outlet, especially with other new graduates.

MB: My clinical instructor was supportive. I feel like you can prepare as much as you can, but until you are put in the position and work with EOL patients, you will never really know how you are going to feel. But, even having someone there to talk to and work with, who have experienced it, and to be able to talk to them about it afterward and talk about how you feel is important.

DL: Debriefing is always important. As an EMT, it was mandatory to debrief anytime you worked a code. I think it is a great opportunity to talk to people. Where I work now, there is a formal structure of debriefing.

AC: We have had a lot of deaths recently on our floor, and our boss bought us lunch and had someone from the Spiritual Care come and do a debriefing for all of us. It was very timely with all that has been going on all these deaths have been rough on a lot of us.

D Sub-Theme: Recommendations to future new nurses caring for patients at the EOL

Novice and Advanced Beginner nurses were asked if there was anything in particular that would have been helpful to learn in nursing school about EOLC that you did not learn in school. The participants mainly recommended EOLC education in each nursing course, hospice experience and more practice communicating and medicating dying patients. They advised the reality that patients are going to die and that it is not the nurse's fault.

a. Recommend Hospice Education

AG: My recommendation for nursing school is that everyone should go to a hospice center for two weeks, and see a couple of deaths and follow an expert nurse and see how it is done.

NB: Nursing school should have more classes about end-of-life care. I had an entire clinical at a hospice center, but my classmates only had one day, and that was not enough. We spend an entire semester birthing

babies, which is wonderful, but what is the other end of that? People die everywhere. It is a good life skill to have.

DL: Taking care of a dying patient should have been a requirement especially for community health. Leaning to talk to a dying patient and family is just as important as taking blood pressure. We should have gone to a hospice center to see the role of that nurse.

AK: I think it would be great to have a hospice guest speaker or for nursing students to go for a few weeks to a hospice house, to be exposed to it. I think it would have made a difference in the world, knowing. Everyone does die.

SK: In nursing school, have hospice facility come in and lecture. I think having somebody come from hospice would be helpful. A big part of nursing school is curing diseases; it makes sense to have a part of the education about end of life.

b. Recommend More Education on EOLC

CT: I think if someone could have taught and shown me what uncomfortable looks like and I do not know what is too invasive to treat a dying patient that would have helped.

EC: I wish that we did more education on EOLC. Not just concept, but concrete, role-playing for a patient in the EOL. How to talk to patients and answer common questions. Professors or actors can play a dying patient's role and you being their care provider. What do you say? What is okay, what is not okay.

CG: The best way to learn EOLC in school is to start by talking about it in lecture and learn the theory then doing it in clinical. Just doing it, over and over again. I would say the most I have learned is an experience just doing it.

AK: I wish in nursing school they had exposed us to people that needed EOLC or at least told us and reassured us of the fact that this is going to happen. Something to prepare a new nurse to deal with such a huge and traumatic even.

AG: It would have been nice to have a class on EOLC. If I could have run through these scenarios, I would not have second-guessed myself so much. The phone call to the family could have been practiced in nursing school. What do you say to the family? How to be calm when giving them bad news? How to talk to families? The ethics of giving Morphine.

Advice to Nurses Students or New Nurses

AC: My advice to new nurses is to the acceptance piece of that people die, and sometimes it is just the end of their time.

CG: My advice to student nurses is that it should not be a sad thing. Everyone dies, and it is a natural thing. If they are dead, they either had everything done to them because they were a full code, and we coded them, and we tried our hardest, or they are dying because that is what they wanted.

DL: My advice for the nurses on EOLC is they have to understand that it is not a failure of our efforts when people pass away. It often is a patient's wish or nothing else could be done. We as nurses need to play a role in helping them die how they want to versus doing everything possible to stop it. We are not taught in nursing school that it is perfectly okay to die

and that the ultimate cure is actually death. It is great if we can cure things but also everything that we are doing will only work for a period.

SK: After a patient has died, you are not going to be able to cope with all those feelings in those five minutes, but you need a moment to de-escalate and calm yourself down. If your eyes are teary, you cannot run into someone else's room and start doing blood pressures and start giving meds - - give yourself five minutes to go outside, take some deep breaths. You need to realize, to be the best nurse to those patients, those five minutes are important for your health so you can go back in and be focused again.

d. ***The Recommendation that Simulation Lab not Helpful***

CG: You cannot learn about end of life care and postmortem care on a dummy. It is not the same because it is emotion evoking. If people are going to have a negative reaction to EOLC, they are going to have it in person, not when they are doing it to a dummy. Maybe if it was an actor, but I think the best way to learn EOLC is just doing it with your preceptor or clinical instructor.

CT: I think it is hard to do an EOLC Simulation Lab right. Because you have a person that is dying and all the emotions.

AG: I do not think a simulation of a dying patient can prepare you for what is going to happen when you are standing there. The patient's respirations are four, and the family is screaming. I think it is just hard to play on that emotion. I did wish that they had stressed that you are going to be giving meds and you are going to be uncomfortable doing it, but you need to do it. That was something that is very important.

Table 5 **Theme #4 Novice and Advanced Beginner Nurse Being Prepared:**

Theme #4	Sub-Theme	Added Theme
Being Prepared	A. Personal Experiences	a. Relating Dying Patient to Own Family b. Relating Family to the Patient
	B. Education or Training	a. No EOLC Education in School b. Some EOLC Education in School c. Instructors
	C. Missed Opportunities	
	D. Role Models	
	E. Experience	a. Novice b. Advanced Beginner

Theme #4 Novice and Advanced Beginner Nurse Being Prepared:

A. Sub-Theme: Personal Experiences

Participants were asked to discuss if they had any personal experiences with a family member or friend who had passed away and if this personal experience influenced the care, they give to patients. Some had personal experience with a family member who had died and felt a connection to the family and patients. Some reflected that they felt a connection to their patient because they reminded them of their family member, which influenced their emotions, and nursing care.

a. Relating the dying patient to own family

LS: She was about 55 years old, that is my mom's age, and she was similar to my mom, and that was hard for me, I related her a lot to my mom. I was really upset and taken aback when I realized that she was dying, and emotionally, that was tough as a new nurse.

MS: His wife was there, she was sweet. The kids were probably 10 and 12 years old, old enough to know what is happening. That was a very hard situation for me. I still have both of my parents. I could not imagine my mom or dad dying at age 40.

MB: She was in her 50s with breast cancer. It spread everywhere. She was super frail and very sick. She had two young daughters and her husband they were all in the room. Seeing them was definitely the hardest and saddest patient I have worked with. I put myself in her daughter's shoes. It was like seeing my own mom in that tough position and knowing what she was going through.

Relating to the patient to personal loss

SK: I cared for an EOL patient right after my grandmother had passed. It gave me a new perspective on taking care of a dying patient. I now could see the family side of it. You wanted this person to be with you forever and realizing that they are not going to be, and this is still what is best for them. It is a hard thing to come to terms with. I remember that hitting home with me.

NB: My grandmother passed away, and I learned a lot from being a family member. Therefore, whenever I have a dementia patient, it reminds me of my grandmother and I feel a little connection. It makes me more attached because I would want someone to take extra good care of my grandmother for me. I just want to take the best care of someone else's grandmother.

AGU: My grandparents played a huge role in me as a nurse. When I care for an elderly patient I think, if this was my grandma, if this was my grandpa what would I want to be done. I put in that extra effort. I think they have really inspired me to take care of patients in a different way.

AK: My grandfather recently died, and he wanted his a beer and not for us to be sad. That makes a difference. I think of that when I take care of dying patients what I would want a nurse to do for my family member, knowing that they are going to pass away. So I sit there, hold my patient's hand, and say it is okay, I am here with you. It is okay to go.

KH: I got upset when he said that he always bought his grandma perfume for Christmas and handed me the bottle because I am picturing the one thing I give my Nana every year for Christmas.

AGU: My best friend's mom was at the hospice house, it is a great facility, and they do such amazing things there. I feel comfortable telling families about the wonderful care at the hospice house.

B. **Sub-Theme: Education or Training**

Participants expressed that they had little to no EOLC education in nursing school and no experience in the clinical setting to practice this vital

nursing skill. They stated that their nursing school focused on basic nursing skills. They did not learn how to assess or care for a dying patient and how to handle this unique type of nursing situation. Therefore, when they had to care for a dying patient as a graduate nurse, it caused them to feel uncomfortable and unsure of what to do.

No EOLC Education in Nursing School

CT: The disadvantage of the accelerated nursing program is every class is so rushed and so much information. You learn about what is normal, and you do not really learn about the abnormal. We had one twenty-minute power point on palliative care and EOL combined. They just breezed through things. I had no clinical experiences with a dying patient.

AK: We had no EOLC education; we learned about the developmental stages of a baby and what their growth rate should be. Nothing if the mother passes away or the baby passes away, what to do, what to say. We were never exposed to how to talk to a family, how to call the morgue, how to talk to the organ donors none of this was discussed in nursing school.

KJ: I did not have any education on EOLC in nursing school. We had to read a book and do a paper on about a person that had ALS and how he

ends up dying. However, there was not a class discussion or a lecture on it.

LS: In nursing school, we had only one class on palliative/hospice care. It was more about the benefits of hospice. The class was not about how the nurse cares for a dying patient or what to do when they die. For example, when a patient dies, their body is going to stiffen in whatever position you leave them in." I never learned that kind of stuff.

EC: I did not have any training on EOLC in nursing school or during my hospital orientation. The most we had was a guest lecturer who talked about the difference between hospice and palliative care. There was never a lecture about how to have a conversation with your patient about EOLC.

DL: I got zero education on EOLC in nursing school. Only in my ethics class did, we talked about the moral aspects of death and dying. We never really discussed the role of the nurse. I never had an EOL patient in clinical we only took care of patients with different illnesses. I was not prepared at all about end-of-life care.

a. Some EOLC Education in Nursing School

Novice and Advanced Beginner nurses who had some classroom or clinical experience with EOLC stated they felt more prepared caring for EOL patients as a new nurse. They were taught the changes in the dying patient's vital signs and physical appearance and shown how to make the dying patient comfortable and how to support the family. Novice and Advanced Beginner nurses that had education and experience caring for dying patients felt more prepared and better equipped to care for a dying patient. One participant said it so well, "EOLC is so important to learn in nursing school because you can learn about the heart and lungs another time. They are not going anywhere. You can learn about them next week." NB.

GB: I had one class in nursing school on EOLC. We watched a couple of videos and discussed how people do not talk about EOL wishes. We talked about things that we would want people to do for our loved ones the end of our life such as play music, make us comfortable and not be alone or afraid. The class helped me feel prepared.

MS: My critical care course we were required to take an end-of-life course. It was a typical formal course on the medications you give, how

death and dying works, how families typically grieve. It also went over grief that healthcare professionals experience.

NB: We did end of life classes, in every single semester, medical-surgical even pediatrics and maternity. They mix it into everything. In maternity, we were taught about the fetal demise and the experience of the mother. I did a research paper on anxiety after perinatal loss. I had a clinical rotation two days a week in hospice and hospice VNA. It was people at all different stages of dying. Because of this hospice rotation, I think I am more comfortable talking to dying patients. I love taking care of patients at the end of life. I also took an online summer elective on EOLC. We learned about different faiths and how they perceive death, the different stages of coping for people who are told they are going to die and we did a project. I also did my CH rotation in a hospice VNA. It was the best clinical I ever had because now I can talk to families about this. I know what death and dying looks like and how different people see it and I was the only one in my class that has to do that clinical.

LS: My acute care clinical rotation I was on an oncology floor and then again for my leadership clinical we have to pick a specialty and, I picked that same oncology unity that I had been on for acute care. I was precepted by one nurse, and I learned so much.

AC: The spring semester of my senior year, I had a capstone course that focused on EOLC. It was a one hour weekly. We had to read the book, *Being Mortal* by Atul Gawande and most of the class was discussing the book and the ethics of making the decisions at the end-of-life such as comfort measures versus doing extensive treatment. We had to watch a different video for homework every week made by the faculty that dramatized different EOL situations.

AGU: Our nursing program threaded EOLC content all through the curriculum. Every course explained that the patient might die. We had a class on pediatric emergencies, and if a pediatric patient dies then in maternity, we discussed fetal death. The best things I had in nursing school that helped me care for patients at the EOL was an eight-week online summer EOL elective course called "Understanding Suffering." We went over caring for a dying patient, signs, and symptoms and learned about theories. We wrote papers on our own experiences and did a video project where we talked about our experiences.

b. Instructors:

Many times clinical instructors or other nurse's do not think teaching EOLC is a priority skill to learn. While students and new graduate nurses are in clinical or orientation instructors, need to seek out EOL patients to teach them this important skill. Four of the participants discussed that they thought that their instructors did not seek dying patients to care for because the instructor themselves were not comfortable with death and dying.

AK: I feel that ½ the instructors do not talk about death because they do not even know how to talk about it themselves. Someone needs to teach the instructors so they can teach the students. They never gave us clinical experiences either. Just patients with diseases that could be cured. No one ever died in clinical. Everyone was a perfect patient.

CG: I do not think my instructors in college sought out EOLC patients when I was in school and maybe they should.

DL: One of the biggest limitations to nursing school is the instructors always want you to learn tasks to do a skill well. They want you to give meds or do a bed bath. Which are all important nursing skills, but I think

some of the most important nursing skills that you never really get a chance to develop is your self-identity as a nurse as well as how this plays into their outcome. How do you sit down and talk to them and say, this isn't going well? It's lacks on how truly to talk to people, to give them good news versus give them bad news and lead to better understanding.

SK: I do find nursing professors as great as they are they have not had experience with EOLC. They were an ICU nurse, or they were in labor and delivery, or they only had one experience, the code experience with death. Instructors need more education and experience too.

C. Sub-Theme: Missed Opportunities

Many times clinical instructors or other nurse's do not think that teaching EOLC is a priority for a new graduate nurse. While students and new graduates nurse are in clinical or orientation, instructors, need to seek out EOL patients to teach them this important skill. Four of the participants discussed that when they were in clinical or in an orientation that there were situations that they could have cared for a dying patient but their instructor or preceptor missed the opportunity.

CT: My first day of orientation somebody was dying. My preceptor was giving a lot of Morphine, like Morphine, Morphine, Morphine. I really had no idea what was going on, and no one explained it to me. I did not even go in

the room with the nurse. It would have been helpful to watch how do you give the Morphine and how do you know the patient is uncomfortable? How do you approach the patient? How do you approach the family? How do you talk to the patient?

AG: When I was in clinical in the CCU a patient extubated himself, and he was actively dying, and he did die, but my preceptor did not think it was necessary for me to go in the room. I think it was a missed opportunity.

KJ: It was my first day of clinical internship, and my patient died. I just observed the CNA's, do post-mortem care. They did most of the work, and I just stood back and watched, no one explained anything to me. It would have been a great learning experience looking back now I needed more education on caring EOLC.

LS: I was in orientation, and my preceptor and I were caring for a dying patient. My preceptor did not talk to me about how I felt, and I was upset. My preceptor was a male nurse, and he did not respond well to the whole situation. I could have learned more about how to talk to the patient and family and how to get help for myself to debrief.

LS: I think as a new nurse the more experienced nurses try to keep you away from EOLC experiences which I don't think this does you too much of a favor, because you're going to have to encounter it at some point. During my orientation, they had me care for more of the tasks of nursing such as the bone marrow transplant patients and not focus on the EOL patients. When I was off orientation and on my own during the nightshift, I had a dying patient. I did not know what to do.

D. Sub-Theme: Role Models

Role models play an essential part of the learning process, and the participants stated that they felt more comfortable caring for dying patients when they had a role model showing them how to talk and care for a dying patient

NB: The most important thing I learned by just observing the hospice nurse is how to talk to patients. Before that, I felt uncomfortable talking to patients and families in general. Just by observing this nurse and watching how she talked to the families, I feel if I had to talk about dying I would be okay doing it.

KH: A staff nurse in clinical taught me the importance of how care changes from curative to palliative. She explained how to treat not only the patient by giving Morphine but how it's just as important to be in that room and show

the family that you are there and making sure they are supported as well. I went with the nurse when she drew up the Morphine every hour, and I listened to her talk to the family and showed respect to their needs. We showed the family how to swab the patient's mouth, to put cream on their hands and to hold the patient's hands. It helped them to feel involved. We also called the kitchen to get a bereavement cart so they could have food and drinks and not leave the room. Watching this nurse was helpful when I had my first CMO.

MS: My preceptor pretty much did all the essentials that I did not feel comfortable doing. She just ensured that the patient was comfortable and that we are doing everything, you know, we will not provide any aggressive treatment. Just giving the patient comfort. I learned a lot of what to say and how to say it when I asked my preceptor, which is something they do not teach you in school. It gets better when I personally observe or get to say or do something. We have guidelines on comfort care and things. So to see how she handled – to me the biggest part of interactions and knowing which medications to give in the situation and what not to give.

SK: When I was in orientation, I had a preceptor who was a great role model and showed me how to care for a dying patient. I learned how to give mouth care and to look for signs like mottling and apnea and how to do post-mortem care. However, what I remember most was how she talked to the family and

told them systematically what she was going to do and involved them in the care by showing them it is ok to talk to them or hold their hand. She also hugged the family when the patient died and said, "We are so sorry, is there anything we can do? She even told me it is ok to cry with families or share stories.

E. Sub-Theme: Experiences (Novice/Advanced Beginner)

The primary researcher described Benner's *Novice to Expert Theory* (1982) and asked each participant what stage of Benner's theory the participant thought they were in right now in regards to EOLC. It was about even, half of the participant thought they were still a novice and the other half felt they were moving toward being an Advanced Beginner. Many spoke about experience being the key factor to help them advance to the next stage of Benner's theory.

a. Novice Nurse:

AG: I think for EOLC, I am a novice; I have only had one EOL experience. Next time I have a CMO patient, I will be okay because of the first experience. You get more comfortable in practice when you are a participant, and you practice it again and again. Being exposed to a dying patient even just one time then the next time will not be so traumatic.

SK: I am absolutely a novice. I am a beginner, and I am so eager to learn. I learn from watching other people and doing things with a patient makes it stick.

GB: I am a novice even though I had experience before as a nurse's aide with EOLC someone else was responsible. The biggest difference now is I am the one that can push the drug that could end their life. I need more experience.

MB: I am a novice on the cusp of Advanced Beginner. I feel I am getting more comfortable with what I was doing. Thinking like a nurse, and trying to figure out, okay, this is happening. What do I need to do? I am feeling more comfortable.

LS: I am still relying heavily on the nurses around me to navigate exactly what to do, especially with EOLC. However, with some other things, I feel I am more experienced and able to make my own nursing decisions. However, with EOLC I am still learning, I need more experience and do it more often.

KH: I feel more confident and will want to help another nurse do EOLC when it comes up again on my unit. Just one-day experience made me feel more comfortable.

EC: I feel I need to have actually a patient die on me before I feel experienced, not just help them when they are dying. I need more real experience with the actual dying part.

b. Advanced Beginners Nurse:

LS: I have had quite a few deaths now, and it is a little easier because now it is not as hard on me because I now know what to look for when someone is dying. I sometimes almost feel a little bad about that, that I am not as upset when a person is dying. I can look at the big picture more, and not be as affected. I am better able to cope, and I am more comfortable talking to the other nurses about it and taking care of myself surrounding the whole situation.

AC: I think I am moving to more of an Advanced Beginner. I am less task-oriented and now knowing the routine. I am at the point where I am starting to not see things for the first time, I know what aspect of an

assessment changes, and I know what to expect because I have seen it before.

CG: Caring for dying patients I think I am an Advanced Beginner. I have been in an ICU as an aid or student for two and a half years. I have only been an RN for six months, but I have been in the ICU setting for a while. You get a little bit of numbness to death and dying. It is just part of the gig. I am in a setting where the highest mortality setting in the hospital, acute care, it just happens, patients die. Also, you just take care of them until they die and you take care of them after they are dead.

DL: I think because of my background as an EMT I am confident talking to patients and their families about DNR and CMO. I would say the Advanced Beginner. It is experience that makes you prepared caring for patients. You can talk all you want in a class about different scenarios and learn theory. However, until you, actually, see and touch those patients that you gain experience. You can look at a patient in those situations, and their numbers might look good but it is just something about their affect or something in their face that you know, this is not going to go well.

CT: I do not think I am advanced anything really. But I do think in terms of him dying, I may be an Advanced Beginner. I am not afraid of dying patients, and I am gaining confidence.

Chapter V

Discussion

Introduction

The purpose of this qualitative descriptive research using a phenomenological approach was to provide a deeper understanding of the lived experiences of Novice and Advance Beginner nurses caring for dying patients and their families as they begin their nursing practice. In addition, this research wanted to gain new insight about Novice and Advanced Beginner nurse's thoughts, feelings, emotions and reactions as they enter practice caring for dying patients and their families to reveal how these nurses feel their nursing program prepared them to care for patients and their families at the end of life.

Nurse scholars have explored the lived experiences of student nurses and specialty nurses caring for dying patients and produced a significant amount of literature related to this topic. Yet there is a gap in the literature pertaining to new graduate nurses and their experiences caring for patients at the EOL. The findings in Chapter 4 address the gap, expand the understanding of how Novice and Advanced Beginner nurses perceive caring for dying patients and their families and address how nursing education prepared or did not prepare these nurses to care for patients at the EOL.

This Chapter 5 is a summary of the research findings and addresses each of the three research questions. The findings of this study are related to the literature on nurses caring for dying patients and their families. Additionally, implications and limitations of this current research are discussed as well as recommendations for future research, education, and nursing practice.

Summary of Research Findings

What are the experiences of Novice and Advanced Beginner registered nurses as they care for dying patients and their families?

What are the thoughts, feelings, emotions, and reactions that Novice and Advanced Beginner nurses experience while caring for dying patients and their families?

A theme that threaded through the study was the theme of caring; caring for the patient, caring for the family and caring for the nurse. Caring is an intricate part of nursing. According to Watson (2012),

> Nursing is a human caring science, and human caring is always threatened and fragile. Because human care and caring require a personal, social, moral, and spiritual engagement of the nurse and a commitment to one's self and other humans, nursing offers the promise of human preservation in society (Watson, 2012, pg. 38).

Benner, Tanner, and Chelsa (2009), and Benner and Wrubel (1989) have proposed that caring is a requisite for the development of critical thinking. According to Watson (2012) "Nursing has always held a human care and caring stance with respect to people and their health-illness-healing concerns" (Watson, 2012, p. 43). For Novice and Advanced Beginners nurses to be able to give care to dying patients and their families they must be prepared with proper education and experiences caring for dying patients and their families.

The present study produced four themes with subthemes. Theme #1 Caring for the Patient had five sub-themes: A) Providing Comfort, B) Dying with Dignity "A Good Death", C) Conscious vs. Unconscious, D) Giving Medications at EOL, and E) Communication. Theme #2 Caring for the Family had three sub-themes: A) Providing Family Comfort, B) Family Desire for Aggressive Treatment and C) Communication. Theme #3 Caring for the Nurse had four sub-themes A) Array of Emotions, B) Supported vs. Unsupported, C) Debriefing, and D) Recommendations to Nursing School. Theme #4 Being Prepared had four subthemes A) Personal Experiences, B) Education/Training, C) Role Models, and D) Experience.

Interpretation of the Findings

The results of this study show that Novice and Advanced Beginner Registered nurses that care for dying patients and their families have a variety of thoughts, feelings, and emotions. A significant area identified is caring, caring for the patient, caring for the family and caring for the nurse.

Caring for the Patient

A finding from this study is Novice, and Advanced Beginner nurses describe caring for the dying patient and providing everyday comfort as significant, and many stated "it is the little things" that are most important. The little things they describe, as keeping a patient is clean and comfortable by providing simple physical, emotional and spiritual care. They expressed that it is the little things you do for a dying patient, which the most important when are giving EOLC. This finding confirms with Williams, Kinnear & Victor (2015) study of healthcare professions that the little things are what count to patients and the staff at the end of life. The study concludes it is by administering to the basic needs of the dying patient the nurses felt they helped their patients die with dignity (Williams, Kinnear & Victor, 2015). Novice and Advanced Beginner nurses also expressed wanting patients to die with dignity and be free of pain. This finding is consistent with a study on dying with dignity (Kennedy, 2015) which stressed the importance of a patient's right to die with dignity at the end of life and how it is important for healthcare professionals to use an open approach to assess each patient's needs and aim to meet these needs for each patient (Kennedy, 2015).

Many participants in the study expressed quality of life and helping patients to die with dignity and have a good death. The finding of nurses wanting patients to died with dignity is consistent with Ruland & Moore's A Peaceful End-of-Life Theory (1984) which describes assisting the patient to be free from suffering, providing emotional support to the patient and significant others and to assist with treatment with empathy and respect (Ruland & Moore, 1998). The participants in this study confirm with the findings

that EOLC is a primary concern for nurses today and it is important for nurses to strengthen their knowledge on this type of nursing care (Ruland & Moore, 1998).

The majority of Novice and Advanced Beginner nurses expressed concern, guilt, and conflict when administering Morphine and Ativan at the EOL. Many felt ethical that they were ending the patient's life, but simultaneously they wanted to provide comfort to dying patients. This finding is consistent with the research of Wilson, E., Morbey, H., Brown, J., Payne, S., Seale, C., Seymour, J. (2016) study on nurses administering medication at the EOL examined nurses concerns administering medications to dying patients. It confirmed that nurses want their patients to be comfortable and have relief from symptoms of having a painful death. Nurses take a leading role in administering medications at the EOL and some experience emotional burden with this role (Wilson et al., 2016). Ruland & Moore's theory also discussed the importance of administering pharmacological and non-pharmacological interventions to relieve pain and help EOL patients die peacefully (Ruland & Moore, 1998).

Communication on the subject of EOLC has been identified in the literature as a challenge (Blackhall, Erickson, Brashers, Owen, & Thomas, 2014; Wittenberg, Goldsmith, & Neiman, 2015). This research indicates that communication with dying patients is difficult for Novice and Advanced Beginner nurses as they avoid talking to patients about their prognosis and are surprised when patients candidly bring up the topic of stopping treatment or terminating care. Communication is an important component of providing EOLC. Many healthcare professionals are uncomfortable discussing death and dying with patients. Good communication with patients enables the patient to express

their EOL wishes and provides the opportunity for the nurse to explore any anxieties and concerns. This can reassure the patient and family and reduce anxiety and distress (Wittenberg, Ferrell, Goldsmith, Buller & Neiman, 2016).

The participants in this study discussed that they were taught therapeutic communication and how to cure patients in nursing school, but they were not taught how to communicate when a cure cannot happen. Some discussed not bringing up the topic of death with their patients and considered the topic to be taboo or that the conversation made the nurse feel uncomfortable. This finding is supported by previous literature that reports nurses and student nurses have difficulty communicating with dying patients and families (Curcio, 2017; Ek et al., 2014; Wittenberg, Ferrell, Goldsmith, Buller & Neiman, 2016). To improve communication in EOLC situations, role-playing scenarios should be taught in the classroom to enhance this content area.

Another aspect of care that some participants expressed was the difference between caring for a conscious and unconscious patient. They expressed feeling upset and sad terminating care with a terminal conscious patient. Not knowing what to say to terminal conscious patients was a concern. Many did not know how to bring up the topic of hospice or EOLC with conscious dying patients. They wished they knew more about having these conversations with their patients and their patient's families. Other participants expressed that it is difficult to assess pain and communicate with the unconscious patient, as they cannot ask the unconscious patient how they are feeling or if they are experiencing pain. Nurses with less experience with EOLC find it difficult to communicate with dying patients because they are still trying to refine basic nursing

skills (Benner, 1984; Barrere & Durkin, 2014). However, the literature lacks an examination of the difference between care given to conscious and unconscious dying patients.

Caring for the Family

The Novice and Advanced Beginner nurses described providing family-centered care as an important role of the nurse. They also view the family and significant others to be the client. The participants identified caring for the family as an important part of the caring process but that it can be intimidating for a new nurse to feel confident talking to family members as they lack experience and may feel insecure with the sensitive topic of EOLC. This is consistent with the literature that supports providing holistic and family-centered care the nurse needs to provide information and support to both the patient and the family to minimize the family's anxiety and achieve the best outcome. They described their interactions with the family include giving the family comfort, emotional support and involving them in caring of the patient (Benner, Kyriakidis, & Stannard, 2013; Pennbrant, Tomaszewska & Penttila, 2014). Tending to the family's emotional needs and providing physical and emotional comfort before during and after the death is an important part of the nursing care that nurses do not feel comfortable providing (Jeffers, 2014; Moreland, Lemieux, & Meyers, 2012, Wessel & Rutledge, 2005).

Another area this study revealed was that participants identified the situation of when the family is not present at the death of a family member and how to communicate during those circumstances. Some patients have no family at all, or the family did not

arrive to be with the patient at the time of the death. Participants discussed how they wanted to make sure the patients did not die alone and that they wanted to be present at the time of death. One nurse said it was an honor to be with the patient and it was the first time she identified as being a nurse. They also discussed dealing with families that are at the bedside during the EOL process. They specified how to communicate with the families in each situation. Effective communication is accomplished using active listening to the patient and family and then conveying their feelings and needs with the rest of the healthcare team (Herbert, Moore & Rooney 2011).

An interesting finding of this research is that all of the participants expressed frustration regarding aggressively caring for terminal or frail elderly patients. This was not an interview question, but each participant spoke about similar experiences caring for patients aggressively when it appeared the patient would not recover or have a quality of life. All participants discussed frustration with families that want everything done at the EOL and do not allow patients to die a peaceful and dignified death. Novice and Advanced Beginner nurses find it difficult to watch patients suffer unnecessarily and this can be a conflict to new nurses who do not have the experience to have discussions about comfort measure only (CMO) care and DNR with patients and families (Barrere & Durkin, 2014; Koesel, & Link, 2014; Ruland & Moore, 1998).

Caring for the Nurse

The Novice and Advanced Beginner nurses described that caring for dying patients and their families is an emotional experience and they conveyed an array of

emotions such as scared, uncomfortable, sad and upset. Some nurses felt sadness when patients terminate care, and some expressed that they felt emotionally attached, upset and a sense of loss. Dealing with sorrow, negative emotions and loss are hard to cope with as a new nurse. Due to inexperience, they expressed that they do not know what to do and lack confidence caring for dying patients. Novice and Advanced Beginner nurses with little to no EOL education in nursing school conveyed that they were scared and uncomfortable caring for dying patients. Nurses that had previous EOLC education and clinical experiences felt more comfortable and prepared to care and to talk to dying patients and their families as a new nurse. This finding is supported by previous studies that have identified that nursing students and nurses feel anxious and nervous caring for dying patients and that undergraduate education on EOLC is inadequate (Fabro, Schaffer, & Scharton, 2014; Peterson, Johnson, & Scherr, 2013; Watts, 2014). It is necessary to provide nursing students with the knowledge necessary to provide quality EOLC for it will increase the nurse's confidence to provide compassionate and competent care to dying patients and their families.

Several nurses felt that support from a nurse leader, mentor, preceptor, peers or a nurse educator helped reassure them when faced with EOLC situations. Novice and Advanced Beginner nurses with little support or mentorship while caring for dying patients expressed that they did not sign up for this. Two of the seventeen participants left their jobs because they felt they were not prepared or supported to care for EOL patients. The literature shows that debriefing and reflection can assist with learning from the experience to help further education about EOLC experience (Heise & Gilpin, 2016).

Nurse educators play an important role in providing follow-up debriefing sessions to assist the new nurse time to reflect and ask questions about the end of life experience (Heise & Gilpin, 2016).

Do Novice and Advanced Beginner nurses feel that their registered nursing program prepared them to care for dying patients and their families?

This study confirmed with the research that it is important to provide nurses proper education, emotional support and experiences so they can feel more comfortable caring for EOL patients. Adequate education and experiences help nurses improve the care they give to dying patients (Jeffers, 2014; Moreland, Lemieux, & Meyers, 2012, Wessel & Rutledge, 2005). The study identified that Novice and Advanced Beginner nurses feel unprepared to care for dying patients and their families due to lack of theoretical education and clinical experience in their undergraduate nursing education. EOLC is stressful, and nurses need time to debrief and talk about their feelings. As the elderly population expands, there is a need for improvements in our healthcare system to provide better care for patients during the last stages of life (Jeffers, 2014). To help provide optimal EOLC, adequate education is necessary and should be a top priority in nurse education (Jeffers, 2014; Moreland, Lemieux, & Meyers, 2012, Wessel & Rutledge, 2005).

This research reflects what previous studies reveal, which is that most professional nurses indicate that their nursing schools did not teach EOLC skills such as pain assessment, pain management, symptom management, psychological support for

patients, attention to spiritual needs and bereavement support (Kent, Anderson & Owens, 2012; Todaro-Franceschi, 2011; Todaro-Franceschi & Lobelo, 2014; White & Coyne, 2011; Grant et al., 2013). Nurses who lack these skills find caring for dying patients challenging and have increased risk of compassion-fatigue and burnout (Melvin, 2012; Todaro-Franceschi & Lobelo 2014).

This study confirmed with the research that current EOLC education in undergraduate nursing programs is minimal and does not adequately prepare Novice and Advanced Beginner nurses to provide high-quality palliative care. This study established that there is still gaps in undergraduate nursing education curriculum for EOLC which primarily focuses on knowledge, technology and wellness (Ferrell, Malloy, & Virani, 2015; Jeffes, 2014; Todaro-Franceschi & Lobelo, 2014; White & Coyne, 2011). This study findings agreed with other studies that new nurses feel anxious and nervous caring for dying patients and that undergraduate education on EOLC is inadequate (Fabro, Schaffer, & Scharton, 2014; Peterson, Johnson, & Scherr, 2013; Watts, 2014).

Previous research reveals that nursing students and nurses are seldom educated on how to deal with dying patients and due to limited EOLC education in nursing school ((Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012; Croxon, Deravin & Anderson, 2018; Gama, Barbosa, & Vieira, 2012). It is necessary to provide nursing students with the knowledge necessary to provide quality EOLC for it will increase the nurse's confidence to provide compassionate and competent care to dying patients and their families. One of the best ways to offer EOLC education is either in nursing school or training services to practicing nurses (Brazil, Brink, Kaasalainen, Kelly, & McAiney,

2012; Parry, 2011). There is a need to educate nurses on EOLC, and this qualitative research study explored, described the lived experiences of Novice and Advanced Beginner nurses caring for dying patients and their families. This study has helped to amass new knowledge of how new nurses felt caring for dying patients and their families and hoped to find new ways to prepare better Novice and Advanced Beginner nurses to care for these types of patients when they enter practice

Being Prepared

Another feeling identified by participants was compassion. Showing compassion is a trait of nursing care. Novice and Advanced Beginner nurses related to the patient and their family by putting themselves in their situation and identifying with personal experiences with a family member or friend who had passed away. Personal experience influenced the care nurses given to patients. Some had personally experienced with a family member who had died and felt a connection to the family and patients. Some reflected that they felt a connection to their patient because they reminded them of their family member, which influenced their emotions, and nursing care.

The other theme of being prepared is related to Benner's (1984) framework. Benner's Novice to Expert framework states the novice has little to no experience with the situation in which they are expected to perform. They rely on rules to guide their actions (Benner, 1984). Half of the participants in this study recognized that they were in the beginning phases of developing their nursing skills in EOLC and stated they are still a Novice nurse. These nurses had only a few experiences caring for dying patients and need to gain experience and knowledge with EOL patients. One participant stated that

> "You always remember the first time you do anything in nursing. Your first day of clinical, your fist day at a new job, your first Code, your first patient that died" CT

It is essential that these first experiences are positive experiences. As Benner's theory states, nurses, learn through experiences. If new nurses do not learn EOLC skills properly, they will avoid these types of patients and not give dying patients and their families the proper care they need to die peacefully and with dignity.

Participants that had a classroom, clinical and some real-world experience with EOLC stated that they were Advanced Beginner nurses about EOLC. The Advanced Beginner nurse exhibit satisfactory nursing skills as they have experienced some real-world clinical nursing situations are more comfortable with institutional guidelines and uses prior situations to guide their practice (Benner, 1984). Even though they have some clinical knowledge, they still focus on the rules, policies, and procedures and can become overwhelmed with deciphering complex situations. They still require guidance, mentoring and support in the clinical area to set priorities and ensure safe patient care (Benner, 1982; Benner, 1984; Haag-Heitman, 1999; Marble, 2009).

According to Benner, one of the preferred methods of learning is by observing and emulating role models. More experienced nurses can mentor Novice and Advanced Beginner nurses. When doing any new task or skill the first time having a mentor there to instruct ensures that learning takes place (Benner, 1984). When a Novice or Advanced Beginner nurse is assigned to an EOL patient, they should have an expert nurse available to ensure proper care is administered. Mentoring and debriefing from an expert nurse can

help the Novice, and Advanced Beginner nurse feel confident and learn the essential skill so medication administration, communication and the critical aspects of how to care for dying patient and their family so that the patient is given quality care and can die with dignity (Benner, 1984).

New Graduate Nurses

Another result of this study is that the participants work in a variety of settings that are not typical for new graduate nurses. Only four out of the seventeen participants had their first nursing jobs in long-term care, and only one worked in a general medical unit, which are the typical first-time positions for new graduate nurses. The other twelve participants had their first nursing jobs were in an advanced practice settings such as Medical Intensive Care Unit (MICU), Burn Units, Bone Marrow Transplant Unit, Intensive Care Unit (ICU), Cardiac Care Unit (CCU), Ortho-Neuro Unit, Cardio-Thoracic Unit, Surgical-Trauma Intensive Care Unit and Emergency Department (ED). This reflects back on the nursing shortage, and that new graduate nurses are not entering nursing practice in traditional nursing roles. New graduate nurses today face many challenges that affect their success as they transition into their first nursing roles. A study by Holler and Thomas (2016) examined the changing role of new graduate nurses today and offer solutions for their success. Mentorship programs are one suggested solution to increase new graduates to achieve competencies, confidence, and autonomy in their new position (Holler & Thomas, 2016).

Debriefing is Necessary

Another result identified is that these Novice and Advanced Beginner nurses needed to talk about their experiences caring for dying patients as a new graduate nurse. All the participants continued to speak to the primary investigator for half an hour to two hours after the interview. The principal investigator noticed that most of the new nurses expressed that the support of an expert nurse or role model to talk to about their new jobs and to reflect on their nursing school was helpful as a new nurse. The interviews were a great way for these new nurses to debrief on the feelings of being a novice nurse. This is something that these new graduate nurse's need, which is to have the support and mentorship as they, transition from a Novice to an Advanced Beginner. It is crucial that new nurses have counseling and time to debrief on their experiences as a new graduate nurse.

Limitations of the Study

One single study cannot investigate this phenomenon completely. The themes and sub-themes in this study offer opportunities for further research. Another limitation of this study is that the data is based on new nurses retelling their experiences. Some of the interviews may have exaggerated their experiences or not had the correct recall. A limitation of the qualitative research is due to validity, reliability since qualitative research occurs in the natural setting, and each study is difficult to replicate. Another limitation of this study was that only BSN nurses were utilized and that there were no Associate degree nurses.

Recommendations for Practice

Nursing education today still faces the challenge to educate and prepare new nurses to care for dying patients and their families. The Novice and Advanced Beginner nurses suggested that they would have benefited from having a course in the classroom explaining EOLC as well as a clinical experience caring for a dying patient. More research is necessary to recognize better ways to thread EOLC into the undergraduate nursing curriculum. As well as how to efficiently add both theoretical and clinical instruction on EOLC to all courses in the nursing curriculum. Both theoretical and clinical education is necessary to help better prepare nursing students to provide quality EOLC.

A recommendation for incorporating EOLC education into the nursing curriculum is by having an EOL assignment in every course starting with fundamental of nursing. Post-mortem care can be taught when teaching hygiene, and therapeutic communication discussions can include how to talk to a dying patient, deliver sad or upsetting news, how to talk about the MOLST, withdrawing care, and how to talk to an emotional patient (sad, angry or grieving). Also teaching the physical signs and symptoms of a dying patient and what is the role of the nurse caring for the patient as they transition through the stages of dying. Pharmacology courses can teach the administration of EOL medications and discuss the ethical concerns related to EOL medications. Another course can illustrate the use of alternative therapies to assist dying patients with comfort at the EOL and to die

with dignity. EOLC can be reinforced into each of the nursing courses (maternity, pediatrics, psychology, community health, and pharmacology).

In addition, adding a comprehensive online course to be taken as a prerequisite to entering fundamentals of nursing similar to taking a CPR course or Institute of Health Improvement (IHI) classes. The End-of-Life Nursing Education Consortium (ELNEC) is an online curriculum designed primarily for undergraduate nursing students to teach palliative care and EOLC. It can be taught online, in the classroom, or a hybrid of both. It consists of six one-hour modules, and the price is free for the first year to nursing schools in these grant-funded states, WA, OR, ID, and UT. The cost for students in other states is $29 per student. It is essential to add the ELNEC modules to the undergraduate nursing curriculum to teach educators and nursing students the skills of EOLC (American Association of Colleges in Nursing: ELNEC, 2016). The AACN competencies can be incorporated into other existing courses such as fundamentals, health assessment, community health, pediatrics, maternity and care of the adult. The ELNEC program is not just for nursing students it is available for nurses who are currently practicing, as continuing education classes. ELNEC has trained thousands of nurses across the United States, and the curriculum has been translated into many languages and is taught in places such as Japan and Africa (Mateo & Foreman, 2014). Nursing instructors should be trained on EOLC as well so they can adequately prepare nursing students.

Another recommendation is including caring for dying patients in the clinical setting during any of the clinical rotations. Nursing students could have a community

health clinical in a hospice center or with a hospice visiting nurse. During this experience, they can watch an expert nurse communicate, care and support a dying patient and their family. Also recommended is having guest speakers from a hospice center, organ donation center, a funeral home and hospice patients and families. This would give student nurses the opportunity to talk to these different disciplines.

More research should compare accelerated nursing programs, four-year nursing programs, and associate nursing degrees to see how these students compare in their knowledge on EOLC. More research needs to be conducted on ways to help new graduate nurses deal with anxiety and fears about death and dying. This is especially necessary today as nurses that are more new are entering advanced practice positions. Other studies should be conducted to examine EOLC clinical experiences that focus on how to communicate with dying patients and their families.

Learning how to talk to a dying patient and family is an important skill to learn. Novice and Advanced Beginner nurses express that one of the hardest things in nursing is how and what to say to a patient or family about withdrawing care, DNR status or giving bad news. It takes practice and experience to feel comfortable talking to patients about the topic of death. The literature supports simulation as an excellent experience to teach EOLC, but the participants from this study disagree (Ladd, Grimley, Hickman, & Touhy 2013; Lippe, & Becker 2015; Venkatasalu, Kelleher & Shao, 2013). An excellent way to learn is by watching and listening to expert nurses as they do this skill and allow student and new nurses to practice in the clinical setting. In addition, to have live actors act as

the patient to give a more realistic feel to the scenario. Participants did not think a simulation lab was realistic to relating to the sensitive emotions that correspond to talking to a dying patient and family.

EOLC is stressful, and nurses need time to debrief and talk about their feelings. It is important to have proper education and emotional support and to feel comfortable on a unit especially when caring for EOL patients. It is important for workplaces to offer in-service programs to discuss the needs of dying patients and their families. Discussing physical and psychological care that not only is necessary for the patient and family members but also for the nurse giving the care.

Implications for Nursing

The contribution that this study denotes is that EOLC is an essential part of nursing care. It is essential that student nurses be taught how to talk to EOL patients, and their families as well as know how to administer CMO medications to ensure patients die comfortably and with dignity. The literature supports that there is a need to continue to add EOL education to undergraduate nursing curriculum and this study reinforces these findings. A similar qualitative study recently published in January 2018 explored the perceptions of new graduate nurses in Australia and how prepared they were when faced with death and dying in the workplace and with palliative care (Croxon, Deravin & Anderson, 2018). The study had similar themes in that new graduate nurses are not prepared for palliative care and do not receive undergraduate education how to deal with death and dying in nursing school.

Implications for Further Research

There are many subjects touched upon in this research study that need further investigation. More research should be conducted on undergraduate nursing education and how to incorporate EOLC into the curriculum. In addition, the implementation of the ELNEC into nursing undergraduate programs could be researched. Many schools have accelerated BSN nursing programs, and it would be interesting to study these programs and EOLC. Exploring Novice and Advanced Beginners nurse's emotions caring for frail, terminally ill patients who are being treated aggressively and the nurse's ethical feelings administering EOL medications. Another area for future research is to do a quantitative study on Novice and Advanced Beginner nurses on EOLC.

Conclusion

New nurses today may be required to care for dying patients and their families in any area of nursing practice. It is important that they are educated and prepared to care for these types of patients. Based on the results of the study the following conclusions were drawn. Four themes and sixteen sub-themes of EOLC evolved from the interviews, which included caring for the patient, caring for the family, caring for the nurse, and being prepared. Regardless of whether the new nurses have been educated or had any experience in EOLC, the new nurses from this study still aimed to care for their dying patients and their family with compassion and dignity. Nurses need to have the proper education and skills to deliver the best care possible to their patients. Dying patients deserve to receive the best quality care at the end of life and deserve to die with dignity

surrounded by family and friends. EOLC education in nursing school curriculum may provide new nurses with the tools to face these challenges in their early careers, and help achieve this healthcare goal.

Appendix A

Demographic Data Sheet

1. What is your current age?

___ 22-27 years’ ___28-35 years

___ 36-45 year’s ___ 46-55 years

___ 56 years and older

2. What is your gender?

___ Male ___ Female

3. What is your ethnic background?

__ White/Caucasian __ Asian

__ Black/African American __ Alaska native/American Indian

__ Hispanic __ other: please specify_____

4. What is your religious affiliation? Do you practice? Yes_____ No_____

__ Orthodox ___ Jewish ___ Protestant

__ Muslim ___ Hindu ___ Presbyterian

__ Buddhist ___Agnostic ___ Catholic

__ Atheist ___ Mormon __ Other: specify

5. Highest level of education completed:

_____Associates degree _____Baccalaureate degree

___Master's degree ___Other

6. What College/University did you attend to receive your Nursing education?

_____

7. Select Current Employment Setting

__Acute care __Long-term care __Home care

__Other

8. Have you had any previous education on caring for patients at the EOL?

___ Yes ___ No

9. Prior to being a RN, have you had any previous experience in caring for dying patients and their families?

___ Yes ___ No

10. Number of patients you have provided EOLC to?

____Zero patients ____1-5 patients

____6-10 patients ____11-20 patients

____20+ patients

11. Experience as a nurse: # of months_____

APPENDIX B

Interview Questionnaire

Part I Getting Started

Introduction: I know I told you a little about this study on the phone/email, but maybe I should tell you a bit more. I have been a nurse for thirty years. I was a medical nurse for eighteen years at MGH and I have been teaching nursing for twenty-three years. Now going back for my PhD, I had to select a topic that I wanted to research. As a nurse, I worked with many patients at the end of life and it has always intrigued me that as a healthcare society, we focus so much on curing patients and as nurses, we do not know what to do when our patients are dying. I know that for me, one of the hardest things I have to do is care for patients who are dying. I knew I needed more education on the subject. It is part of the job – and I knew that going in – but it is still hard. And so I have been wondering about other nurses' experience: how do they deal with patients (and their families), what do they do that works – or doesn't work; what do they tell patients, and what do they tell themselves – just, basically, how do they cope with end of life situations? You have had experiences that, I assume.

Initial questions: First, I need to get some of the factual details straight.

Current practice:

- Where do you work now?
- What does that involve, most of the time?

- How long have you been there?

Previous work:

- Have you worked in any other settings before this?
- [brief details, and why changed location]

Experience working with end of life:

- How many patients have you worked with patients at the end of life?
- How often?

Part II: Detailed description of an incident:

If you are willing, I would like to talk with you about a few of those incidents – whichever ones stand out for you. In addition, it might be useful to start with some of your earliest experiences – when you were just starting out as a nurse.

1. Can you tell me whatever you remember of your first experience, or your most memorable experience, caring for a dying patient and their families when you were a new nurse?

    - Walk me through what happened – whatever you remember

A. Dealing with the patient:

<u>Action</u>:

- What was your role as the nurse caring for the patient?
- Anything special you did to make things easier for the patient.

Talking with patient about dying:

- Did the patient talk about dying with you?
- What did the patient say?
- What did you say?
- How was it for you – these conversations?

Problems:

- Were there any special problems that came up with the patient?
- Was the patient scared? Alone? Comfortable?
- Did you feel you knew what to do to make the patient comfortable?
- Did you feel you knew what to do to care for a dying patient and their family?

B. Dealing with the family:

- What do you remember about your interaction with the dying patient's family?
- What was your role as the nurse in dealing with family?
- Anything special you did to make things easier for the family.
- Were there any special problems that came up with the family?

Explain/retell the events of caring for dying patients and their family

- Describe your role as the nurse caring for the patient.

- Describe your interaction with the dying patient's family.

C. Personal experience: What do you remember about what you were thinking and feeling while all this was going on?

- **Feelings**: Do you remember what you felt?

-**Possible negative feelings**: Sad, confused, anxious, helpless, frustrated, and irritated

-**Possible positive feelings**: Relieved, glad no longer suffering, detached, competent.

- **Thoughts**: -You remember what you told yourself?

  -This is part of the job

  -I am helping someone get through the hardest thing they will ever do

  -I cannot stand this – tearing me apart

- **Sense of competence**: Leaving aside whatever emotional turmoil you were going through, did you feel competent – like you knew what to do and you could do it?

  -Did you feel you knew what to do to make the patient comfortable?

  -Did you feel you knew what to do to care for their family?

In retrospect: When you remember that time (and I guess it has stayed with you) how do you think about it now?

- Satisfied: Did about as well as you could?
- Wish you had done things differently? [details]
- What do you do differently now?

Part III: Training

I imagine you must have had some training in school for all of this – though I suppose nothing quite prepares you for what it is really like.

Could you tell me a bit, about whatever training you got?

Nursing school:

- Describe how your nursing school prepared -- or maybe did not prepare you to care for dying patients?
- Tell me about your nursing school classes or clinical regarding death and dying
- How were you taught in nursing school to talk to dying patients?
- Did you learn in nursing school how to create a peaceful EOL for dying patients?
- Did you have any experiences in clinical caring for a dying patient?
- What was helpful in your nursing school education about EOLC
- Did your school classes influence how you cared for a dying patient?
- Is there anything in particular that would have been helpful to learn in nursing school about EOLC that you did not learn in school?

Part IV New Nurse

- Did you learned about EOLC as a new nurse on the job
- How as a new nurse have you learned EOLC skills
- If you took care of a patient at the EOL in clinical how this experience as a new nurse was different from when you were a student.
- Tell me if you received support from experienced nurses (mentors) or medical staff while caring for a dying patient.
- Describe how you applied what you learned in nursing school to the EOL situation.
    - Describe what you did not learn in nursing school about EOLC.
    - Describe what you learn from this experience.

Part V Other Experiences with EOLC

-Did you have any other experiences you have had caring for a dying patient?

-Family, friends, patients

-In clinical in nursing school

-As a nursing assistant

7. **Describe Benner's Theory:**

If you had to relate to Benner's Novice to Expert Theory what stage of the theory do you think you are in? Describe why you are in that stage?

APPENDIX C

Informed Consent Form for Registered Nurses invited to participate in research, titled:

"Qualitative Descriptive Study of Novice and Advanced Beginner Nurse's Experiences/Perceptions of Caring for Patients and their Families at the End-of-Life".

PRINCIPLE INVESTIGATOR: Bethany A. Nasser, MSN, RN

NAME OF ORGANIZATION: Endicott College

THIS CONSENT FORM HAS TWO PARTS:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for your signature if you choose to participate)
- Participant will be given a copy of the full informed Consent Form

PART I: INFORMATION SHEET

INTRODUCTION

My name is Bethany Nasser, MSN, RN, and I am a PhD student at Endicott College in Beverly, MA. I am conducting research about new RNs (Novice and Advanced Beginner) perceptions of caring for patients and their families at the End-of-Life. You are invited to participate in a research study exploring how Novice and Advanced Beginner Nurses are learning about End-of-Life care. Prior to your participation, I am going to give you information as well as definitions regarding this concept. You do not have to decide today whether you will participate in this research. Before you decide, you can talk to anyone you feel comfortable with about the research. This consent form

may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have any questions later, you may ask them of me.

PURPOSE OF THE RESEARCH

The purpose of this study is to gain new insight about Novice and Advanced Beginner nurse's thoughts, feelings, emotions and reactions caring for patients and their families at the End-of-Life. To also gain knowledge of how comfortable Novice and Advanced Beginner nurses feel talking about death and dying with patients and if they feel their BNS nursing program prepared them to care for dying patients and their families.

TYPE OF RESEARCH INTERVENTIONS

This research will involve your participation in a one on one interview that will take about approximately 60 to 90 minutes.

PARTICIPANT SELECTION

You are being invited to take part in this research because I feel your experience as a Novice and Advanced Beginner RN can contribute much to my understanding and knowledge of nurses' perceptions of caring for patients' and their families at the End-of-Life.

VOLUNTARY PARTICIPATION

Your participation in this research is voluntary. It is your choice whether to participate or not. You may change your mind later and stop participating at any time, even if you agree earlier.

If, at any time, you wish to withdraw from the research, you are free to do so. Due to the nature of the topic and the possibility of emotional stress, if you feel the need for counseling, you can contact the Endicott counseling center. My supervisor for this project is Dr. Kelly Fisher from the Endicott College School of Nursing.

PROCEDURES

A. I am asking you to help me learn more about nurse's perceptions about caring for patients and their families at the End-of-Life. I am inviting you to take part in this research project. If you accept, you will be asked to be interviewed by myself.

B. During the interview, I will sit down with you in a private comfortable location. If it is better for you, the interview can take place in an empty college classroom or in your home. No one else but the interviewer will be present during the discussion unless you would like someone else to be there. If you do not wish to answer any questions during the interview, you may say so and I will move on to the next question. The information recorded is confidential, and no one else except the transcriptionist will access the information documented during your interview. There will also be a short individual follow-up interviews reviewing my findings and confirming the data with each participant. The entire discussion will be digitally recorded and no one will be identified on the recording. The recording will be stored in a locked area. The information is confidential, and no one else except the transcriptionist, will have access to the tapes. The tapes will be destroyed after they are transcribed.

DURATION

Your participation in this study will take place over one to two hours total including the research study introduction and an explanation of the topic. Following the interview, you will have time to ask any questions and talk about any concerns you may have. The debrief session is not recorded.

RISKS

There is a risk that you may share some personal or confidential information by chance. You may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you do not wish to do so. You do not have to give me any reason for not responding to any question or take part in the interview if you feel the questions are too personal or if talking about them makes you feel uncomfortable.

BENEFITS

There will be no direct benefit to you, but your participation is likely to help me find out more about how we can better prepare Novice and Advanced Beginner nurses to care for dying patients and their families. In addition, increase knowledge about EOLC including causes and solutions to this concept.

REIMBURSEMENT

You will receive a $20 Amazon Gift card for your participation

CO STS

There is no cost to you to participate in this research study.

CONFIDENTIALITY

The information I collect from the interview will be kept in a locked area. Any information about your interview will have a pseudonym instead of your name. Only I will know you are your pseudonym is, and that will be locked at all times. It will not be shared or given to anyone

except the transcriptionist, who will transcribe the audiotapes. They will be destroyed after transcription.

SHARING THE RESULTS

Nothing that you share with me during the interview will be shared with anyone, and nothing will be attributed to you by name. The knowledge that I get from this research will be shared with you before it is made widely available to the public. Each participant will receive a summary of the results. I will publish the results so that other interested people may learn from the results.

RIGHT TO REFUSE OR WITHDRAW

If you have read this form and have decided to participate in the research study, please understand your participation is voluntary and you have the right to with draw your consent or discontinue your participation at any time that you wish without penalty. You have the right to refuse to answer particular questions. I will give you an opportunity at

the end of the interview to review your remarks, and you can ask me to modify or remove any portion of these, if you do not agree with my notes or if I did not understand you correctly. Your individual privacy will be maintained in all published and written data resulting from the study.

CONTACT FOR INFORMATION

If you have any questions, you can ask them now or later. If you want to ask questions later, you may contact me, Bethany A. Nasser**,** at or email me at

.

The Endicott College IRB (Appendix E) has reviewed this proposal, which is a committee whose task is to make sure that research participants are protected from harm. If you have any questions, concerns or complaints about this research study, its procedures, risks or benefits, you should ask the Protocol Director, Kelly Fisher or email her at

PART II CERTIFICATE OF CONSENT

I understand that I have been invited to participate in a research study by Bethany A. Nasser, a PhD student at Endicott College. This research study will attempt to discover RN's perceptions of caring for dying patients and their families at the End-of-Life and how prepared they felt caring for them.

I agree to participate in the study; I will be interviewed for approximately 60 minutes about my thoughts and feelings caring for patients and their families at the end of life. The interview will be audiotaped and take place in a private area.

I understand every attempt will be made to minimize the risk associated with feeling uncomfortable about the topic discussed.

I realize I will receive no reimbursement for participating in the study.

I realize my participation in the study is voluntary, and I may withdraw from the study at any time I wish.

I realize that all study data will be kept confidential. However, this information may be used in nursing publications or presentations.

I realize that I may contact Dr. Kelly Fisher, Endicott College, and School of Nursing any time during the study.

I have read the above information, or it has been read to me. I have had the chance to ask questions about it. Any questions have been answered to my fulfilment. I consent voluntarily to be a participant in this study.

Print name of participant_____

Signature of participant_____

Date_____

Protocol Approval Date: _____

Statement by the researcher

I have clearly read the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the following.

1. **Participant will be interviewed by myself in a private location**
2. **The interview will be digitally recorded, with confidentiality maintained**
3. **The audiotapes will be transcribed, and then destroyed upon receipt of transcription.**

I authorize that the participant was given every opportunity to ask questions about the study, and all questions asked by the participant have been answered correctly to the best of my ability. I confirm that the individual has not been coerced to give consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print name of Researcher_____

Signature of Researcher_____

Date_____

Appendix D

Invitation to Participate in a Research Study

Are *you a RN interested in sharing your perceptions of caring for patients at the End-of- Life?*

Purpose: Explore RN's perceptions caring for patients & their families at the End-of-Life

Who may join this study?

- Registered Nurse
- Who has cared for patients and their families at the End-of-Life (EOL)?

What can you expect?

- Asked to provide personal information related to your education and professional history.
- Asked several questions about your experiences & perceptions caring for dying patients
- Information you share will remain confidential, & your name will remain anonymous.

How long & where will it take place?

- Approximately 1-2 hours
- (face to face) interviews at a location of your choosing that is private & quiet

Risks: Minimal risk study

Benefits/Compensation: A $20 Amazon Gift Card

<u>For</u> more information on the study, please contact:

Bethany Nasser, MSN, RN, PhD Student Endicott College

Appendix E

IRB Approval Endicott College

ENDICOTT COLLEGE

November 16, 2017

Institutional Review Board Decision Form

Principal Investigator:	Bethany Nasser, MSN, RN
Contact Address:	
Phone Number	
Co-Investigators:	
IRB Submission No.:	200098
Project Title:	A Qualitative Descriptive Study of Novice and Advanced Beginner Nurse's Experiences of Caring for Patients and their Families at the End-of-Life
Faculty Sponsor:	Dr. Kelly Fisher
New/Continuing Project:	
Date of Submission:	11/6/2017
Date of Resubmission (if applicable):	

For Official Use Only

IRB process:

Exempt
- ❑ Expedited Review
- ❑ Full Review

IRB Recommendation

- ✓ Approved
- ❑ Not Approved
- ❑ Revise and Resubmit

Congratulations, your research proposal was approved by the Endicott IRB.

Best wishes on your data collection. Please don't hesitate to get in touch with me if you have any questions about your review by emailing or calling

Sincerely,

Dr. Linda Robson, IRB Chair
School of Hospitality Management

References

Allen, M., & Watts, T. (2012). Promoting health and wellbeing at the end of life: The contribution of care pathways. *International Journal of Palliative Nursing, 18*(7), 348-354. http://dx.doi.org/10.12968/jpn.2012.18.7.348

Alligood, M. R. (2014). *Nursing Theory Utilization & Application* (5th ed.). St. Louis, MO: Mosby.

Altmann, T. K. (2007, May-June). An evaluation of the seminal work of Patricia Benner: theory or philosophy? *Contemporary Nurse*, *25*(1-2), 114-123. Retrieved from www.contemporarynurse.com

American Association of Colleges in Nursing: About ELNEC (2016, September). End-Of-Life-Care. 1-4. http://dx.doi.org/http://www.aacn.nche.edu/elnec/about.htm

Barrere, C., & Durkin, A., (2014). Finding the right words: The experience of new nurses after ELNEC education integration into a BSN curriculum. MEDSURG Nursing, 23(1), 35-53. https://www.highbeam.com/doc/1G1-360608987.html

Beck, C.T., (1997). Nursing students' experiences caring for dying patients. *Journal of Nursing Education*, 36(9), 408-414.

Beckstrand, R. L., Clark Callister, L., & Kirchhoff, K. T. (2006). Providing a "good death": Critical care nurses suggestions for improving end-of-life care. *American Journal of Critical- Care Nurses*, *15*(1), 38-45. https://doi.org/www.ajcconline.org

Benner, P. (1982, March). From Novice to expert. *The American Journal of Nursing*, *82*(3), 402-407. http://dx.doi.org/10.2307/3462928

Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. Menio Park, CA: Addison-Wesley Publishing Company.

Benner, P. (1994). *Interpretative phenomenology: Embodiment, caring, and ethics in health and illness*. Newbury Park, CA: Sage.

Benner, P. (2004,). Using the Dreyfus model of skill acquisition to describe and interpret skill acquisition and clinical judgement in nursing practice and education. *Bulletin of Science, Technology and Society, 24*(3), 188-199. https://doi.org/

Benner, P. (2005). Using the Dreyfus Model of Skill Acquisition to describe and interpret skill acquisition and clinical judgement in nursing practice and education. *The Bulletin of Science, Technology and Society Special Issue: Human Expertise in the Age of the Computer*, *24*(3), 188-199.

Benner, P. (2013). Clinical wisdom and interventions in acute critical care: A thinking-in-action approach (2nd ed.). New York, NY: Springer Publishing

Benner, P., Tanner, C., & Chesla, C. (2009). A transition to expertise. In *Expertise in nursing practice: Caring, clinical judgement, and ethics* (2nd ed.). New York, NY: Springer Publishing

Benner, P., & Wrubel, J. (1989). *The Primacy of caring: stress and coping in health and illness*. New York: Pearson.

Bittner, N., Ericson, K., McCarthy, M., & Jones, J. (2013, January/February). Focus on Excellence: making a difference through global initiatives. *Nursing Education Perspectives*, *34*(1).

Blackhall, L.J., Erickson, J., Brashers, V., Owen, J., & Thomas, S. (2014). Development and validation of a collaborative behaviors objective assessment tool for end-of-life communication. *Journal of Palliative Medicine,* 17(1), 68-74.

Blinderman, C. D., & Billings, J. A. (2015). Comfort care for patients dying in the hospital. *The New England Journal of Medicine, 3373*(26), 2549-2561. https://doi.org/10.1056/NEJMra1411746

Brazil, K., Brink, P., Kaasalainen, S., Kelly, M., & McAiney, C. (2012, Feb). Knowledge and perceived competence among nurses caring for the dying in long-term care homes. *International Journal of Palliative Nursing*, *18*(2), 77-88. http://dx.doi.org/10.12968/ijpn.2012.18.2.77

Burger, J. L., Parker, K., Cason, L., Hauck, S., Kaetzel, D., O'Nan, C., & White, A. (2007). Responses to work complexity: The novice to expert effect. *Western Journal of Nursing Research*, *32*(4), 497-510. https://doi.org/10.177/0193945909355149

Butts, J. B., & Rich, K. L. (2013). *Nursing ethics: Across the curriculum and into practice* (3rd ed.). Burlington, MA: Jones & Bartlett Learning.

Carlson, L., Crawford, N., & Contrades, S. (1989). Nursing student novice to expert-Benner's research applied education. *Journal of Nursing Education*, *28*(4), 188-190. https://doi.org/Retrieved from

Center for Disease Control and Prevention. (2012). Retrieved from http://www.cdc.gov/ophss/csels/despd/ ss1978/lesson6/section2.html

Center to Advance Palliative Care. (2015). Retrieved October 8, 2016, from https://www.capc.org

Croxon, L., Deravin, L., Anderson, J., (2018). Dealing with end of life-New graduated nurse experiences. *Journal of Clinical Nursing*, 27(1), 337-344. http://dx.doi.org/10.1111/jocn.13907

Curcio, D. L. (2017, January/February). The lived experiences of nurses caring for dying pediatric patients. *Pediatric Nursing*, *43*(1), 8-14. Retrieved from www.pediatricnursing.net/ce/2019/article4301814.pdf

Dale, J. C., Drews, B., Dimmitt, P., Hildebrandt, E., Hittle, K., & Tieisch-Goddard, A. (2013). Novice to expert: The evolution of an advanced practice evaluation tool. *Journal of Pediatric Health Care*, *27*(3), 195-201. https://doi.org/10.1016/i.pedhc.2011.12.004

Darbyshire, P. (*19*94, August). Skilled expert practice: is it 'all in the mind'? A response to English's critique of Benner's novice to expert model. *Journal of Advanced Nursing*, 19, 755-761.

Ek, K., Westin, L., Prahl, C., Osterlind, J., Strang, S., Bergh, I., Hammarlund, K. (2014,). Death and caring for dying patients: exploring first-year nursing students: descriptive experiences. *International Journal of Palliative Nursing*, 20(10), 509-515.

Fabro, K., Schaffer, M., & Scharton, J. (2014, January). The development, implementation, and evaluation of an end-of-life simulation experience for

baccalaureate nursing students. *Nursing Education Perception, 25*(11), 19-25. http://dx.doi.org/10.5480/11-593.1

Fennimore, L., & Wolfe, G. (2011). Nurse manager leadership development: Leveraging the evidence and system-level support. *Journal of Nursing Administration, 41*(5), 204-210. https://doi.org/10.1097/NNA.Ob13e3182171aff

Ferrell, B., Mallloy, P., Mazanec, P., & Virani, R. (2016, September/October). CARES: AACN's New competencies and recommendations for educating undergraduate nursing students to improve palliative care. *Journal of Professional Nursing, 32*(5), 327-333. https://doi.org/10.1016/profnurs.2016.07.002

Ferrell, B., Malloy, P., & Virani, R. (2015, April). The end of life nursing education nursing consortium project. *Annals of Palliative Medicine, 4*(2), 61-69. http://dx.doi.org/10.3978/j.issn.2224-5820.2015.04.05

Ferrell, B., Mazanec, P., Malloy, P., & Virani, R. (2010, February). State of undergraduate palliative nursing education. *European Journal of Oncology Nursing, 14*(1), 74-79. http://dx.doi.org/10.1016/j.ejon.2009.08.004

Ferrell, B. R., Dahlin, C., Campbell, M. L., Paice, J. A., Malloy, P., & Virani, R. (2007, July-Sept.). End-of-life nursing education consortium (ELNEC) training program: improving palliative care in critical care. *Critical Care Nursing, 30*(3), 206-212. https://doi.org/10.1097/01.CNQ.0000278920.37068.e9

Ferrell, B. R., Virani, R., Grant, M., Rhome, A., Malloy, P., Bednash, G., & Grimm, M. (2005, November 1). Evaluation of the end-of-life nursing education consortium

undergraduate faculty-training program. *Journal of Palliative Medicine, 8*(2), 107-114. http://dx.doi.org/10.1089/pm.2005.8.107

Gama, G., Barbosa, F., & Vieira, M. (2012). Factors influencing nurses' attitudes towards death. *International Journal of Palliative Nursing, 18*(6), 267-273. Retrieved from www.ijpn.co.uk/

Gerow, L., Conejo, P., Alonzo, A., Davis, N., Rogers, S., & Domain-Williams, E. (2010). Creating a curtain: Nurses' experience of grief following patient death. *Journal of Nursing Scholarship, 42*, 122-129. https://doi.org/10.1111/j.1547-5069.2010.01343.x

Gilpin, L., & Heise, B. (2013, June 17). Nursing education: The role of debriefing for nursing students' first clinical experience with death. *Brigham Young University Journal of Undergraduate Research*. http://dx.doi.org/Jur.byu-edu/?p=1034

Glesne, C. (2006). *Becoming qualitative researchers: An introduction* (3rd ed.). Boston, MA: Pearson.

Grant, M., Wiencek, C., Virani, R., Uman, G., Munevar, C., Malloy, P., & Ferrell, B. (2013). End-of-life care education in acute and critical care. *American Association of Critical-Care Nurses, 24*(2), 121-128. https://doi.org/10.1097/NC.0b013e3182832a94

Haag-Heitman, B. (1999). *Clinical practice development using novice to expert theory*. Gaitherburg, Maryland: Aspen.

Hebert, K., Moore, H., & Rooney, J. (20*11*, winter). The nurse advocate in end-of-life care. *The Ochsner Journal*, 11(4), 325-329. Retrieved from http://www.ncbi.nlm.hihgov/pubmed/22190882

Heise, B. A., & Gilpin, L. C. (2016, March/April). Nursing students' clinical experience with death: A pilot study. *National League for Nursing*, *37*(2), 104-106. http://dx.doi.org/www.neponline.net

Hofler, L., Thomas, K. (2016, March- April). Transition of new graduate nurses to the workforce: Challenges and solutions in the changing healthcare environment. *North Carolina Medical Journal*, 77 (2), 133-136. http://dx.dio. org/ 10.18043/ncm.77.2.133

Jeffers, S. (2014, March 27). Nurse faculty perceptions of end-of-life education in the clinical setting: A phenomenological perspective. *Nurse Education in Practice*, *14*, 455-460. https://doi.org/10.1016/j.nepr.2014.03.009

Johnson, S., & Bott, M. J. (2016). Communication with residents and families in nursing homes at the end of life. *Journal of Hospice and Palliative Nursing*, *18*(2), 124-130. https://doi.org/10.1097/njh.0000000000000222

Karns, L. (2015). Toward a theory of intuitive decision-making in nursing. *Nursing Science Quarterly*, *28*(3), 223-228. https://doi.org/10.117/0894318415585618

Kennedy, G. (2016). The importance of patient dignity in care at the end of life. Ulster Medical Society, 85(1), 45-48. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4847835/

Kent, B., Anderson N.E., Owens, R.G., (2012), Nurse's early experiences with patient death: The results of an on-line survey of registered nurses in New Zealand. *International Journal of Nursing Studies*, 49 1255-1256. PMI: 22572018,http://dx.doi.org/10.1016/j.ijnurstu.2012.04.005

King, P. A., & Thomas, S. P. (2013, June). Phenomenological study of ICU nurses' experiences caring for dying patients. *Western Journal of Nursing Research, 35*(10), 1292-1308. https://doi.org/10.1177/0193945913492571

Koesel, N., Link, M. (2014). Conflicts in goals of care at the end-of-life are aggressive life-prolonging interventions and a "good death" compatible. *Journal of Hospice and Palliative Nursing*, 16(6), 330-335.

Ladd, C., Grimley, K., Hickman, C., & Touhy, T. (2013, February). Teaching end-of-life nursing using simulation. *Journal of Hospice & Palliative Nursing, 15*(1), 41-51. http://dx.doi.org/10.1097/NJH.ObO13e31826251f6

Larew, C., Lessans, S., Spunt, D., Foster, D., & Covington, B. (2006). Innovations in clinical simulation: application to Benner's theory in an interactive patient care simulation. *Nurse Educator Perspectives*, *27*(1), 16-21. https://doi.org/Retrieved from

Lee, S., Hung, C., Shih, J., Weng, Y., Chang, W., Ho, Y., Lai, Y. (2009). Attaining good end-of-life in intensive care units in Taiwan- The dilemma and the strategy. *International Journal of Gerontology*, *3*(1), 26-30. https://doi.org/10.1016/S1873-9598(09)70017-1

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA

Lippe, M. P., & Becker, H. (2015, November/December). Improving attitudes and perceived competence in caring for dying patients: An end-of -life simulation. *Nursing Education Perspective*, *36*, 372-378. http://dx.doi.org/10.5480/14-1540

LoBiondo-Wood, G., & Haber, J. (2014). *Nursing research: Methods and critical appraisal for evidence-based practice* (8th ed.). St Louis, Missouri: Elevier.

Loerzel, V. W., & Conner, N. (2016,). Advances and challenge: student reflections from an online death and dying course. *American Journal of Hospice & Palliative Medicine*, *33*(1), 8-15. https://doi.org/10.177/1049909114549182

Mani, Z. A. (2016). Intensive care unit nurses experiences of providing end of life care. *Middle East Journal of Nursing*, *10*(1), 3-7. Retrieved from www.mejn.commarch2016/ICU.pdf

Manual for Joint Commission National Quality Measures (2015). Retrieved from https://manual.jointcommission.org/releases/TJC2015A/DataElem0031.html

Marble, S. G. (2009, June). Five-step model of professional excellence. *Clinical Journal of Oncology Nursing*, *13*(3), 310-315. https://doi.org/10.1188/09.CJON.310-315

Marchessault, J., Legault, A., & Martinez, A. (2012). Providing in-home palliative care within a generalist caseload: a chance for nurses to reflect on life and death. *International Journal of Palliative Nursing*, *18*(3), 135-141. Retrieved from www.ijpn.co,uk

Mateo, M. A., & Foreman, M. D. (2014). *Research for advanced practice nurses: From evidence to practice* (2nd ed.). New York, NY: Springer Publishing Company, LLC.

Melvin, C. S. (2012). Professional compassion fatigue: what is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing*, *18*(2), 606-611. https://doi.org/10.12968/jpn.2012.18.12.606

Moreland, S., Lemieux, M., & Meyers, A. (2012, June). End-of-life care and the use of simulation in a baccalaureate-nursing program. *International Journal of Nursing Education Scholarship, 3*(9), 1-16. http://dx.doi.org/10.1515/1548-923X.2405.

National Council for Palliative Care. (2006). Retrieved from http://www.ncpc.org.uk/sites/default/files/AandE.pdf

National Council of State Boards of Nursing (NCSBN). (2016). Retrieved from https://www.ncsbn.org/RN_Test_PLan_2016_Fianl.pdf

National Hospice and Palliative Care Organization (2017). Retrieved from https://www.nhpco.org/abouthospice

Nedd, N., Galindo-Ciocon, D., & Belgrave, G. (2006). Guided growth interventions: From novice to expert through a mentoring program. *Journal of Nursing Care Quality*, *21*(1), 20-23.

Ortman, J. M., & Velkoff, V. A. (2014, May). An aging nation: The older population in the United States. *U.S Department of Commerce United States Census*. http://dx.doi.org/http://www.census.gov/prod/2014pubs/p25-1140.pdf

Parry, M. (2011, September). Student nurse' experience of their death in clinical practice. *International Journal of Palliative Nursing*, *17*(9), 446-451. http://dx.doi.org/10.12968/ijpn.2011.17.9448

Payne, S. (2007). Qualitative methods of data collection and analysis, Chapter 9. In *Research Methods in Palliative Care* (pp. 139-161). Oxford: Oxford University Press.

Pennbrant, S., Tomaszewsak, M., Prentila, G. (2015). Nurse' experience of caring for palliative-stage patients in a hospital setting in Sweden. *Science Press*, 3(2), 97-108. doi: 10.5430/cns.v3n2p97

Peters, L., Cant, R., Payne, S., O'Connor, M., McDermottt, F., Hood, K., Shiminaba, K. (2013, January 24). How death anxiety impacts nurses' caring for patients at the end of life: A review of the literature. *The Open Nursing Journal*, *7*(1), 14-21. https://doi.org/10.2174/1874434601307010014

Peterson, J. L., Johnson, M. A., & Scherr, C. (2013). Is the classroom experience enough? Nurses' feelings about their death and dying education. *Journal of Communication in Healthcare*, *6*(2), 100-105. https://doi.org/10.1179/1753807612Y.0000000024

Pope, C., Zieblan, S., & Mays, N. (2006). Chapter 7. In C. Pope & N. Mays (Eds.), *Qualitative Research in Healthcare* (3rd ed.). Oxford: Blackwell Publishing.

Reville, B., & Foxwell, A. M. (2017). Competency Milestones. *Journal of Hospice & Palliative Nursing*, *19*(4), 339-342. https://doi.org/10.1097/NJH.0000000000000352

Ruland, C. M., & Moore, S. M. (1998, July/August). Theory construction based on standards of care: A proposed theory of the peaceful end of life. *Nursing Outlook*, *46*(4), 169-175. http://dx.doi.org/10.1016/S0029-6554 (98)90069-0

Sandelowski, M. (2000). Whatever happened to qualitative description?. *Research Nursing Health, 23*(4), 334-340. https://doi.org/1002/1098-240X (2000008)23:4<334: AID-NUR9>3.0.C0; 2-G

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research Nursing Health, 33*(1), 77-84. https://doi.org/10.1002/NUR.20362

Silvestre, J. H., Ulrich, B. T., Johnson, T., Spector, N., & Blegen, M. A. (2017, May/June). A multisite study on a new graduate registered nurse transition to practice program: Return on investment. *Nursing Economics$, 35*(3), 110-118. Retrieved from www.nursingeconomics.net/necfiles/2017/MJ17/10.pdf

Tizer, J. L., Shirey, M. R., & Hauck, S. (2014). A nurse manager succession-planning model with associated empirical outcomes. *Journal of Nursing Administration, 44*(1), 37-46. https://doi.org/10.1097/NNA0000000000000019

Todaro-Franceschi, V. (2011). Changing the face of death: A pedagogic intervention. *Journal of Professional Nursing, 27*(5), 315-319. http://dx.doi.org/10.1016/j.profnurs.2011.04.002

Todaro-Franceschi, V., & Lobelo, A. A. (2014). The voice of nurse educators on teaching end of life care in U.S. schools of nursing. *Journal of Nursing Education and Practice*, 4(165-171).

Treas, L. S., & Wilkinson, J. M. (2014). *Basic Nursing: concepts, skills & reasoning*. Philadelphia, PA: F.A Davis Company.

Trepanier, S., Early, S., Ulrich, B., & Cherry, B. (2012, July-August). New graduate nurse residency program: A cost-benefit analysis based on turnover and contract

labor usage. *Nursing Economic$*, *30*(4), 207-214. Retrieved from https://www.ncbi.nlm.nih.gov/pub.med/22970551

Uhrenfeldt, L., & Hall, E. O. (2007). Clinical wisdom among proficient nurses. *Nursing Ethics*, *14*(3), 387-398. https://doi.org/10.1177/096973300705886

Van Manen, M. (1990). *Researching lived experiences*. Albany, NY: State University of New York Press.

Venkatasalu, M.R., Kelleher, M., Shao, C.H. (2013). Reported clinical outcomes of high-fidelity simulation versus classroom-based end-of-life care education. *International Journal of Palliative Nursing*, 21(4), 179-186.

Watson, J., (2012). *Human caring science: A theory of nursing* (2nd ed.). Sudbury, MA: Jones & Bartlett Learning LLC.

Watts, T. (2014). Final-year nursing undergraduates' understandings of palliative care: a qualitative study in Whales, UK. *International Journal of Palliative Nursing*, 20(6), 285-293. https://doi.org/10.12968/ijpn.2014.206285

Weiss, R. S. (1994). *Learning from strangers: The art and method of qualitative interview studies*. New York, NY: The Free Press.

Wessel, E. M., & Rutledge, D. N. (2005, July/August). Home care and hospice nurse's attitudes toward death and caring for the dying: Effects of palliative care education. *Journal of Hospice and Palliative Nursing*, *7*(4), 212-218. Retrieved from www.nursingcenter.com/journalarticle?Article_ID 592758

White, K. R., & Coyne, P. J. (2011, November). Nurses' perceptions of educational gaps in delivering end-of-life care. *Oncology Nursing Forum*, *38*(6), 711-717. http://dx.doi.org/10.1188/11.ONF.711-717

WHO (2017). WHO definition of palliative care. Retrieved from www.who.int/cancer/palliative/definition/en/

Wilkie, D. J., Johnson, B., Mack, A. K., Labotka, R., & Molokie, R. E. (2010). Sickle cell disease: An opportunity for palliative care across the lifespan. *Nursing Clinics of North America*, *45*(3), 375-397. https://doi.org/10.1016/j.cnur.2010.03.003

Williams, V., Kinnear, D., & Victor, C. (2016, April). The little things count': healthcare professional's views on delivering dignified care: a qualitative study. *Journal of Nursing*, 72(4), 782-790. http://dxdio.org/10.1111/jan.12878

Wilson, E., Morbey, H., Brown, J., Payne, S., Seale, C., Seymour, J. (2016, Jan). Administering anticipatory medications in end-of-life care: A qualitative study of nursing practice in the community in nursing. *Palliative Medicine*, 29(1), 60-70. http://dxdio.org/10.1177/0269216314543042

Wittenberg, E., Ferrell, B., Goldsmith, J., Buller, H., Neiman, T. (2016, MAR). Nurse communication about goals of care. Journal of the Advanced Practitioner in Oncology, 7(2), 146-154. doi: 10.6004/jadpro.2016.7.2.2

Wittenberg, E., Goldsmith, J., & Neiman, T. (2015). Nurse-perceived communication challenges and roles on interprofessional care teams. Journal of Hospice & Palliative Nursing, 17(3), 257-262. doi:10.1097/NJH.0000000000000160

Zacara, A. A.L., Costa, S.F.G., Nobrega, M.M.L, Franca, J.R.F.S., Morais, G.S.N, Fernandes, M.A. (2017). Analysis and assessment of the peaceful end of life theory according to Fawcett's criteria. *Texto & Contexto Enfermagem*, 269(4), 1-6. http://dx.doi.org/10.1590/0104-07072017002920017

Zinn, J., Guglielmi, C., Davis, P., & Moses, C. (2012). Addressing the nursing shortage: The need for nurse residency programs. *AORN Journal*, *96*(6), 652-657. https://doi.org/10.1016/j.aorn.2012.09.011