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Nurses' Attitudes Toward Death: Examining the Relationship with Background and Palliative Education and Training Variables

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Nurses' Attitudes Toward Death: Examining the Relationship with Background and Palliative
Education and Training Variables

by

Julie D. Vognsen

A dissertation submitted in partial fulfillment
of the requirement for the degree of
Doctor of Philosophy
in Curriculum and Instruction with an emphasis in
Career and Technical/Workforce Education
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Labor

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Dedication

This dissertation is dedicated to my daughters, April and Ashley. My dissertation journey has been a long one with many life changes along the way. My daughters have continually and positively supported me throughout every step I have encountered in pursuing my Ph.D.

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Abstract

The purpose of this study was to describe Registered Nurses' attitudes toward death and their perspectives on education and training related to death and end-of-life patient care. A complementary goal was to determine whether nurses' attitudes and perspectives are associated with background variables. The three attitudes toward death included anxiety, escape, and neutral attitudes. The background variables of the nurses included formal educational level, age, gender, ethnicity, years of nursing practice, state of residence, and area of nursing practice.

A survey including four sections was used for data collection. The first section of the survey utilized an established 32-item survey based on the Death Attitude Profile Revised survey developed by Wong, Reker, and Gesser in 1994. The questions asked how nurses felt about the topic of death. The second section of the survey was about the extent of palliative care education and training, while the third section was concerned with the demographics of the respondents. Part four of the survey included two open-ended questions regarding attitudes toward death and how prepared respondents felt in meeting their patients' end-of-life needs.

The survey was sent to state nurses' associations across the United States in 2015. Survey Monkey was the link for the survey and it was opened for a three-week period. The original responses totaled 248 participants. Responses with any missing values were excluded. The final dataset included 167 total responses. Data was analyzed using descriptive statistics and regression analysis to determine the association between the variables of interest.

The results of the study were most significant in relation to *anxiety* toward death. Nurses who were more experienced on the job, female, and with more formal education had lower

anxiety levels, as did nurses with a higher confidence level in dealing with death. For the *neutral* attitudes, the best predictor was the rating of the nurses' end-of-life preparation. The best predictor of the *escape* attitude was years of nursing experience. The results supported the need for college level end-of-life education and the significance role of nursing experience in relation to less anxiety towards death. The surprising result was that post-college end-of-life education actually increased the anxiety attitude toward death. More research is needed to ascertain if these results could be replicated. There is a need to determine what type of post-collegiate education would decrease death anxiety in nurses.

Chapter One: Introduction

My nursing career spans over 35 years, which includes my current position as a nurse educator. Since 2005 I have been teaching classes and conferences on death and dying to novice and expert nurses. Over the years, I have realized that for many nurses, death is a very difficult subject to talk about. Nurses can talk about the clinical aspects of dying, such as symptoms and pain management, but may not be as comfortable regarding their own feelings about death and are often reluctant to discuss their own mortality. This situation is unique for nurses, as in many cases they have to support a patient through the dying process while feeling unease regarding their own feelings about death. My concern is that if nurses are not comfortable acknowledging and discussing their own mortality, they may not be as effective when caring for their patients or as supportive of the patients' family. Luckily, I am not alone in this thinking, and an emerging movement in palliative care is calling for a shift in focus from curative care that actually presents no cure to comfort care and quality of life. The question is, what do we need to know and do to train the nursing workforce to provide improved support in end-of-life care? This question is at the core of my research interest. Thus, my research focus is to determine nurses' attitudes toward death and whether there is a relationship with extent of palliative education and training and background variables, as the basis for identifying implications for educational programs.

According to the Administration on Aging (2010), citizens 65 years of age and older will double in number from the year 2000 to 2030. By 2030, about 19% of the U.S. population will be 65 or older. As our overall population is living longer and growing older, the way we care for these aging groups will need to change, and the demand for related care will increase. Alaniz

(2000) argued that, as the baby boomer population ages, the issues of death and dying, and terminal care, will become more pressing in the healthcare sector and will bring renewed attention back to these issues in connection to terminal care.

With this increased focus on dying and mortality, a need exists for additional nursing education related to these topics. However, many healthcare professionals—and nurses specifically—are uncomfortable with end-of-life issues. According to a report published by Naropa University (2014), healthcare professionals are faced with physical, emotional, and spiritual suffering on a daily basis, yet they have little or no training to deal with such issues. The same report notes that the majority of the professionals surveyed were deeply uncomfortable dealing with the realities of dying and death.

Attitudes Toward Death and Dying

Why in this sophisticated technological age is death such a difficult subject? One explanation is that at the turn of the twentieth century, extended families lived together. Young family members witnessed the aging process of their elders and watched as older family members died. In contrast, today's modern families are often fractured and live in different areas of the country, so we rarely witness the aging process, let alone the death of family members. Our elderly population often lives alone, with a spouse, in a nursing home, or in an assisted living facility, as opposed to living with extended family members. According to Benoliel and Degner (1995), 60% of deaths today occur in a hospital or some type of medical center. As a result, many people today have minimal exposure to or experience with aging and death.

Another major issue regarding the discussion of death is that our American society emulates youth and all that goes with it. Aging is seen as a negative, as something to avoid. We witness this idea through media entertainment and the daily news. Our society searches for ways

to avoid aging because it is equated to becoming incapacitated (Peppard, n.d.). Similarly, death is also a difficult topic, which is sometimes minimized in the public view. For example, during movies, prime-time shows, and soap operas people die quickly and, at times, beautifully. The patients have makeup on, their hair is coiffed, and they usually look fairly healthy. But in real life death is not necessarily a pleasant sight for those sitting vigil.

Over the years, in teaching nurses and nursing assistants, I have found that, in general, these healthcare professionals were very uncomfortable with the topic of death. I often utilized a visualization exercise that requires nurses to imagine they are experiencing the last hour of their life. They were to think about where they would want to be, whom they would want with them, what they would want to look at, what smells they would like to smell, and so on (Hospice and Palliative Nurses Association, n.d.). Invariably, many nurses stated that this was a very difficult exercise to do because thinking of their own mortality made them uncomfortable. Yet we expect them—as nurses—to be proficient and efficient in assisting their patients with impending mortality.

For nurses, attitudes toward death are further shaped by the culture of the American healthcare system. At the turn of the century, physicians were available to give comfort to the dying patient, as there were few cures for the illnesses of that time. Patients primarily died at home of acute diseases such as the flu and pneumonia (Blodget, 2012). Today more patients die of long-term illnesses, and due to the complexities of the illnesses and treatments, patients are taken care of primarily in hospitals and nursing homes as their health declines (DeSpelder & Strickland, 2011). In this context, today's healthcare system has a curative emphasis, relying on advanced technology and viewing death as a failure. Within this culture, healthcare workers also view as a failure their inability to help patients survive their illnesses, and it is therefore common

for the workers to try everything to “cure” the patients, even if they know the treatments will not have a positive outcome. At the other end of the spectrum is the idea of withdrawing care when the patient is seen as incurable. Physicians often have to ask the patient’s family members if they want the healthcare team to perform cardiopulmonary resuscitation or to maintain comfort care and not to prolong life (U.S. National Library of Medicine NIH National Institute of Health, 2013).

In our society’s healthcare system, these two opposing viewpoints have been the two extremes in the spectrum of patient care: to do everything, or to withdraw care. In one extreme, healthcare professionals work on the patient using every kind of technology available. On the other end of the spectrum, healthcare workers are seen as withdrawing or withholding care (ELNEC, 2009). Families perceive the withdrawing of care as a lack of effort on the part of nurses and doctors to treat and care for their loved ones. This perception may prejudice families’ decision-making so that they choose the option of doing “everything” for their family member, even if they don’t understand what “everything” encompasses (ELNEC, 2009). Caught in the middle of the complex culture of the healthcare system, their own uneasy attitudes about death and dying, and the emotional circumstances of patients and their families, nurses and other healthcare professionals are often in the best position to make a difference in end-of-life care.

Shifting Perspectives on End-of-Life Care

To address the sociological issues associated with death and end-of-life care, a movement referred to as Palliative Care has emerged in recent years. Palliative Care is caring for the patient who has a life-limiting illness. Unlike Hospice Care, which is defined as caring for terminally ill patients during the last six months of their life, Palliative Care can and should be initiated as soon as a patient is diagnosed with an incurable condition, and the care could continue for weeks,

months, and even years (ELNEC Curriculum, 2009). Examples of these life-limiting diseases include illnesses such as Parkinson's disease, certain forms of terminal cancer, Multiple Sclerosis, and Chronic Obstructive Pulmonary Disease (COPD). The two main objectives of Palliative Care are quality of life and comfort care, not curative care, as there is no cure for the patient's disease. Given the fact that views on quality of life and comfort care can differ greatly across the spectrum of patients, nurses should be able to discuss the patient's death and the patient's end-of-life wishes honestly and in-depth. This discussion and assessment allows the nurse to discern what the patient's wishes and needs are for the time they have remaining. The goal is for the patient to *live* until they die. The nurse supports the patient in his or her wishes and should feel morally and ethically obligated to do so (ELNEC Curriculum, 2009). At issue is how to prepare the nursing workforce for this growing shift in approaching end-of-life care.

In support of the Palliative Care movement, several end-of-life programs are sponsored by national organizations such as the American Association of Colleges of Nursing (AACN). These programs include End-of-Life Nursing Education Consortium (ELNEC) and Hospice and Palliative Nurses Association's (HPNA) End-of-Life Program for Nursing Assistants. These programs address end-of-life issues such as pain and symptom management, ethics, and the last hours of life. The programs concentrate on nurses addressing these issues with their patients, the patient's family, and other healthcare professionals. Nurses are expected to support their patients through the dying process and to be open to their needs (ELNEC Curriculum, 2009). The question at hand is whether nurses are prepared to overcome their personal attitudes toward death to function effectively under the emerging movement of palliative care.

Problem Statement

The U.S. Census Bureau (2001), states that an estimated 7,918 people turn 60 years old every day. By the year 2050, 21% of our population will be over 65, which equals 86.7 million people over 65 years of age. Palliative Care is and will continue to be an important alternative for the aging members of our society who have an incurable illness. To assist these patients in their quest for quality of life and comfort care before they die, healthcare professionals and especially nurses must be open to and comfortable talking about the issues related to death and dying with the patient, family members, and other healthcare professionals on the patient's care team. The concern is that nurses who are not comfortable with death will do their patients a disservice; they may be scared or reluctant to discuss important topics that the patient wants and needs to address. In addition, the family may want to discuss related issues, as well, but nurses may feel more comfortable leaving such discussions to someone else, which may result in poor communication among all parties involved (Jackson et al., 2012).

Clearly there is a need for workplace educational programs that specifically address the nurses' personal feelings about death. Before nurses and other healthcare professionals can support and communicate with their patients regarding their death, they should become comfortable with their own feelings and beliefs regarding death. Only then can they truly be open to these difficult topics. Providing end-of-life education for nursing staff can prepare them for the emotions that erupt when the patient and family experience the dying process (Jackson et al., 2012). The problem is that nursing students receive minimal training in end-of-life care, and that trend continues in the workplace. According to the End-of Life Nursing Education Consortium (2009), more than 50% of the 2,300 nurses polled in a study reported they had not received adequate training in end-of-life topics. The same study noted that in a review of over 50

nursing textbooks, only 2% of the content referred to end-of-life care. This lack of training and content emphasis is problematic if patients need a caregiver who will be open and honest in discussing the patient's options of care and defining his or her quality of life.

In this context, it is imperative to understand how comfortable nurses are talking about end-of-life issues before they can adequately support and advocate for the Palliative Care patient. However, in teaching nurses and other healthcare professionals, it has become evident that even seasoned, currently practicing nurses with more than 20 years of nursing experience have difficulty thinking about, let alone discussing, the issues surrounding death. This lack of self-awareness hinders nurse-patient communication and the supportive process that should occur at the patient's end of life. Of all healthcare professionals, the nurse spends the majority of the time with the patient. Once a patient voices his or her concerns, fears, needs, and wishes, the nurse can then advocate for the patient and assist in meeting these needs and wants. If the dialogue is not opened, the patient cannot be assisted toward experiencing the highest quality of life possible. Thus, to inform end-of-life training programs, we should first learn about the nurses' own attitudes toward death and identify the implications for curriculum and instruction.

To be sure, a body of knowledge has emerged in recent years on end-of-life care topics such as lack of communication with patients, families, and coworkers; ethical issues; lack of end-of-life education; and how nurses view caring for their dying patients (ELNEC, 2009). However, virtually no emphasis has been placed on current research focusing on how nurses personally feel about death, taking the patient out of the equation. Data on nurses' attitudes toward death should prove valuable for identifying important implications for related education of the nursing workforce.

Demographics and training education in end-of-life research is not a prevalent research focus/topic. A study by Jacobs, Ferrell, Virani, and Malloy (2009) focused on pediatric end-of-life nursing education. The participants included 211 pediatric nurses. The demographics included gender, ethnicity, nursing position, and nursing environment. The pre-assessment asked about pediatric palliative care training in their respective institutions. The participants then participated in a pediatric palliative care class. After the class they were asked about the effectiveness of the palliative care course they just completed. The participants rated the overall helpfulness of the course as very helpful = 9.06 on a scale from 0 to 10, with 10 being very helpful. These results were not broken down further in regards to gender and ethnicity in relationship to the helpfulness scale.

A similar evaluation by Malloy, Ferrell, Virani, Uman, Rhome, Whitlatch, and Bednash (2006) focused on end-of-life education for continuing education and clinical staff development educators. There were 227 participants. The demographics included role in nursing, years of nursing experience, work setting, and program affiliation such as belonging to a specialty nursing organization and state nursing associations. These results were analyzed by their rating of current end-of-life curriculums and not by the participants' demographics.

Demographics in previous studies have been asked of participants. The results of these demographics have not been correlated with the responses to end-of-life education. It is important to understand these correlations, if they do exist, between varying demographics and the relationship to palliative care education and feelings towards death the nurse may have. With this understanding of the variables, palliative care education can be developed and modified to facilitate the most productive learning environment possible.

Purpose and Research Questions

The primary purpose of the study was to describe nurses' attitudes toward death and the extent of their education and training related to palliative care. A complementary goal was to determine whether nurses' attitudes are associated with background and extent of palliative education and training variables. This study targeted the national nursing workforce representing the naturally occurring distribution by years of experience, experience with caring for dying patients, age, and gender. Attitudes toward death were defined as beliefs about this construct to be documented through a 32-item survey based on the Death Attitude Profile Revised developed by Wong, Reker, and Gesser in 1994. The profile of attitudes focused on *anxiety* toward death (e.g., I avoid death thoughts at all costs), death as an *escape* to life's troubles (e.g., I believe that I will be in heaven after I die), and neutrality regarding death (e.g., death is a natural aspect of life). In turn, the extent of palliative education and training was determined through a complementary survey building upon a Palliative Care Education Needs Assessment Survey, which focused on key components of end-of-life care (Lien Centre for Palliative Care, 2014). In addition, background variables were defined as gender, ethnicity, years of nursing practice, nursing specialty, educational level, and state of residence.

To meet the purpose of the study, the following research questions were used to drive the inquiry:

1. What is the nurses' profile of attitudes toward death (anxiety, escape, neutrality)?
2. What is the extent of nurses' education and training on palliative care?
3. What background (age, gender, years of experience, nursing area, ethnicity, state of residency) and educational and training variables has impacts on nurses' attitudes toward death (anxiety, escape, neutrality)?

4. What is the best set of background and education and training variables explaining attitudes toward death (anxiety, escape, neutrality)?
5. What are the nurses' perspectives on study results regarding attitudes toward death and relationship with background and education and training variables?

Conceptual Framework

Nurses might not be ready to discuss and support their patients openly during death. To educate them in this endeavor, it was useful to understand their attitudes toward death in the context of a highly emotional role. Attitudes were defined in this research as “the way a person views something or tends to behave towards it” (Dictionary.com, 2014). To this effect, the theory of emotional labor provided a suitable framework for informing the proposed study. Emotional labor referred to work conducted under stressful or demanding circumstances that often required workers to keep their emotions and personal beliefs (i.e., attitudes) in check in order to be effective at their work. The ability to use or inhibit one’s emotions at work could contribute to emotional burnout in workers and could therefore deter them from interacting with others (e.g., patients) (Barry & Yuill, 2011).

According to Kubler-Ross (1993), patients receive support from family, friends, and their healthcare team and go through five stages of the dying process: Denial, Anger, Bargaining, Depression, and Acceptance. In Denial the person feels that the loss or potential loss is like a dream, it is surreal. The person expects things to go back to normal. In Anger the person becomes angry at what will or has been lost. They believe that this is all so unfair and may feel abandoned. Bargaining starts when the person wants to make a deal to reverse the potential or real loss. He makes promises to make the loss go away or reverse the loss. Depression sets in when the person realizes that bargaining is not going to work. He feels helpless to change the

loss and may have trouble sleeping, eating and maintaining relationships. Last, in Acceptance, the person is accepting of the loss and learns to live with it and starts to move forward with his life (Kubler-Ross, 1993). Kubler-Ross did not, however, account for the emotional toll of death on the medical caregiver. In this regard, nurses have long been taught to support not only the patient but also the patient's family, as both parties experience the stages of dying. In serving and caring for others, a nurse must be supportive, caring, and "present." Being present, means being in the current moment with that patient. If the nurse is feeling uncomfortable with the situation and then masks those feelings, the nurse is experiencing emotional labor. If the situation, such as a dying patient, makes the nurse uncomfortable, he cannot show that discomfort to the patient and the family. This false bravado or false front can lead to anxiety and stress for the nurse. The nurse is laboring to be emotionally supportive when that may be the furthest thing from how he is really feeling.

Emotional labor can lead to dissatisfaction with one's job as well as burnout. It is common practice for a nurse to care for a dying patient, experience the loss of that patient, and within an hour admit another patient to that same room, same bed. There is not time for the nurse to grieve or decompress from taking care of a dying patient. This bottling up of emotions, or emotional labor, can cause stress as well as physiological and psychological harm to the nurse (Block, 2000). Thus, understanding one's personal emotions in regard to death could help decrease the emotional labor caused by caring for these dying patients.

Based on the tenets of emotional labor theory, this study posited that older nurses with more experience and related training involved in end-of-life care would exhibit more positive attitudes toward death compared to novice nurses.

Significance of the Study

Quality end-of-life care is extremely important for those going through the dying process and also for their families and loved ones. Effectively assisting patients with reaching their end-of-life goals is dependent on whether nurses can openly communicate with patients and their family. To this end, many research studies on the subject of palliative care have focused on the nurses' views on the actual care of patients at the end of life. However, a lack of research exists on how nurses personally feel about death, and this study generated baseline data drawing from the entire nursing workforce. As such, the study findings should be valuable for informing healthcare institutions such as hospices, hospitals, nursing homes, and home health agencies about the emotional wellbeing of end-of-life care workers. Further, study findings should have direct implications for the design of curriculum and instruction associated with the self-awareness education that is typically implemented in training nurses in these emotionally charged environments. Finally, the study should generate further questions to inform subsequent research that delves deeper into the role of background and other intervening variables in work and instructional contexts.

Limitations

The data for this study was obtained through a survey. The nurses who volunteered in the study might already feel comfortable with death, hence their willingness to volunteer regarding this topic. Just knowing that the questionnaire is about death might already have discouraged some nurses from participating. Nurses who were fearful of and uncomfortable with this topic might not have participated in the study and may not have volunteered. Similarly, it is possible that some nurses might have declined to participate in the study due to their negative experiences regarding death. They may have had issues with deaths that they had witnessed or with people

they had watched suffer through a traumatic dying process. Although provisions were in place to ensure representation of all nurses, accounting for such factors was difficult.

Chapter Two: Review of Literature

The purpose of the study was to describe nurses' attitudes toward death and the extent of their education and training related to palliative care. A complementary goal was to determine whether nurses' attitudes are associated with background variables and extent of palliative education and training. Thus, the review of literature in this chapter addresses related issues organized into five sections. The first section provides background information on the extent of the aging population, death rates, and public attitudes about death. The second section focuses on the nursing workforce and nurses' attitudes toward death. In turn, the third section describes current practices on end-of-life care in intensive care units, including emerging views on palliative care. The fourth section provides an overview of the preparation of nurses for related work and how experienced nurses approach related work compared to novice nurses. The final section presents a conceptual framework for the study.

An Aging Population: Death Rates and Attitudes toward Death

An aging population. The elderly segment of our population is growing at a more rapid rate than ever before in our country's history. In 1900 the average life expectancy for males and females was 46.3 years and 48.3 years, respectively (Life Expectancy in the USA, 2013). In contrast, according to the United States Census Bureau (2012), the projected life expectancy in 2020 will be 77.1 years for males and 81.9 years for females.

In general, our society is living longer. With this increase in longevity comes an increase in our elderly population. Studies estimate that in 2008 there were 39 million people in the 65-and-older age group, or 13% of the United States population (Russakoff, 2010). In 2030, when

all of the Baby Boomers turn 65 and older, an estimated 72 million people in the 65-and-older age group will be living in the United States, totaling 20% of our population (Russakoff, 2010). Most surprising is the growth in the 85-years-and-older age group. This age group is the fastest-growing segment in the United States; it is projected to increase from 5.8 million in 2010 to 19 million in 2050 (Russakoff, 2010).

In the early 1900s, people died from infectious diseases such as tuberculosis and influenza. However, with improvements in medicine, we now die of chronic diseases such as heart disease and cancer, which take longer to develop and allow us to live longer on the average (Sharp, 2012). Research from the Centers for Disease Control confirms this trend. In 2010 our life expectancy was 78.7 years and the two leading causes of death were heart disease, with 597,689 deaths, and cancer, with 574,743 deaths (Centers for Disease Control and Prevention, 2013).

Other leading causes of death today include stroke, lower respiratory diseases, and Alzheimer's Disease (Russakoff, 2010). These are all chronic diseases, which contribute to an increasingly elderly population dealing with medical issues and healthcare such as palliative and hospice care. Further, more deaths in the United States occur in healthcare institutions versus at home. The National Center for Health Statistics reports that only 27% of U.S. deaths occurred at home. Hospital and nursing home deaths account for 50% of U.S. deaths (CBS News, 2013).

Public attitudes toward death. Gender and age can have an effect on how one views death. For example, Russac, Gatliff, Reece, and Spottswood (2007) examined death anxiety across the adult years to ascertain whether attitudes toward death changed in relation to age and gender. Using two death questionnaires—the Collett-Lester Fear of Death scale and the Thorson and Powell revision of the Templar Death Anxiety Scale, they found that both men and women

score high on death anxiety in their twenties, with women scoring significantly higher in anxiety than men. Russac et al., (2007) also found that both groups declined in death anxiety as their age increased, except for one interesting period for women who in their fifties had a spike in anxiety over death. Researchers speculate that this may be due to the fifties being the menopause years, when women are ending their reproductivity and are forced to look at their mortality. The authors also emphasize the gender difference of women in their twenties scoring higher in death anxiety than men. This could be because men are not as willing to voice their fears and confront their feelings. By their sixties both men and women had relatively lower levels of death anxiety (Russac et al., 2007).

In other research, Neimeyer, Wittkowski, and Moser (2004) looked at death attitudes by evaluating psychological studies and found that such attitudes might vary by ethnicity. In this regard, DePaola, Griffin, Young, and Neimeyer (2003) found that African Americans were more afraid of the unknown in relation to dying, being buried alive, and questioning what happens to the body after death. In turn, older Caucasians displayed more fear of the actual dying process.

Neimeyer et al. (2004) also studied life experiences in relation to death attitudes. In this regard, experiences such as the tragedy of 9/11 and experiencing interpersonal death as a young person are thought to be experiences that accumulate over a life span. These experiences can have a subtle impact on attitudes toward death and dying. For instance, Neimeyer et al. (2004) found numerous studies regarding religiosity and death anxiety. Their findings showed that people with moderate or ambivalent religious tendencies have more death anxiety than those at both extremes of the spectrum—those who are devoutly religious and those who are nonreligious. However, most of these studies looked at Christian and Jewish viewpoints, and very little is known regarding death anxiety for groups representing other religions.

Further, what happens in a culture at a specific point in time can influence the level of death anxiety in society. Terror Management Theory, for instance, states that we as humans would be frozen by fear if we were constantly aware of how fragile human life is (Greenberg et al., 1990; Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989). An example involves the attacks of 9/11. After that day, a large spike in death anxiety occurred in those who viewed the events as discovered by Pyszczynski, Solomon, & Greenberg 2003 (as cited in Neimeyer et al., 2004).

In short, as the average life expectancy continues to rise, the elderly population in the country is increasing at a rapid pace. As the population grows older, attitudes toward death may vary based on gender, age, ethnicity and the occurrence of traumatic events.

The Nursing Workforce and Attitudes toward Death

The nursing workforce. As the American society ages, nurses will be in higher demand. The American Nurses Association (ANA) states that 2.6 million nurses are employed in the United States. The average age of these nurses is 45.5 years, with 45% of the nurses being 50 and older, and with the largest group of employed Registered Nurses in the 50 to 54-age range. According to the Health Resources and Services Administration (HRSA) (2013), around one third of nurses in the workforce are older than 50. Of these nurses, 6.6% are male and 16.8% are from a racial or ethnic minority group. ANA (2011) projects that a 22% growth in nursing jobs will occur between 2008 and 2018, and projects a shortage of 260,000 nurses by the year 2025. Based on these nursing workforce trends, HRSA (2013) projects that in the next 10 to 15 years, almost one million nurses will reach retirement age, equaling about one third of the nursing workforce.

Further, the U.S. Department of Health and Human Services (2010) has reported that 5.3% of working nurses are employed in nursing homes and extended care facilities, and that 6.4% of employed nurses are practicing in the home health system. The same source reported that 0.7% of nurses employed in hospitals are working in nursing home type patient units (HHS, 2010). In terms of education, the majority of nurses, 55%, have a bachelor degree or higher (HRSA, 2013).

Nurses' attitudes toward death. In a study of healthcare professionals' attitudes toward death and the impact on patient care, Neimeyer et al. (2004) found that nursing home employees with higher death anxiety had more negative views toward the elderly and aging. In addition, it has also been found that these employees are less likely to talk about death and dying (Vickie & Cavanaugh, 1985). Along these line, Cochrane, Levy, Fryer, and Oglesby (1990) and Kvale, Berg, Groff, and Lange (1999) found that when physicians had high death anxiety they tended to have more negative attitudes toward their dying patients and were less likely to discuss a terminal diagnosis/prognosis with these patients. In turn, Schulz and Alderman (1979) found that physicians with high-death anxiety tended to keep dying patients in the hospital for longer periods of time than patients of physicians with lower death anxiety. In some cases, high-death-anxiety physicians may tend to perform more heroic measures to treat their dying patients even when these treatments may not contribute in any way to a better quality or quantity of life for their patients (Schulz and Alderman, 1978-1979).

Another issue is the lack of shared understanding about the nuances of end-of-life care. For instance, to describe how nurses view end-of-life care, a study conducted by Mahon and McAuley (2010) explored whether oncology nurses understand the difference between hospice care and palliative care. Hospice care is taking care of anyone with a life-limiting illness and

usually concentrates on the last six months of life. Palliative care is taking care of anyone with a life-limiting illness and can go on for years. The nurses in the study were interviewed, and the findings indicated that nurses in oncology did not understand the difference between hospice care and palliative care. They thought that a patient could only have palliative care if the patient was nearing the very end of life. This study showed that misunderstandings regarding palliative care exist even in the healthcare field with experienced staff.

In this context, how do nurses feel about death? Regarding patient care, while there is plenty of research focusing on nurses' feelings about death, there is very little research focusing on just the thoughts and feelings of the nurse, taking away the patient element. When the patient is included in the research question, the nurse might be thinking as a nurse tasked with patient care and not as an individual. Under these conditions, it has been reported in the literature that it is important for nurses to be self-aware of their own attitudes about death and their patients to provide better end-of-life care (Khader, Jarrah, & Alasad, 2010; Kim & Lee, 2003). With this frame of reference, it has been suggested that education for nurses regarding death should include self-exploration of issues such as grief, loss, self-care, and healing (Khader et al., 2010; Wowchuk et al., 2007).

In general, nurses have shown general discomfort talking about end-of-life issues. To wit, Murrish (2010) sought to determine the effect of written information for dying patients and their families, and questioned ICU nurses about what content they felt was important to include in a palliative care pamphlet for patients and families. In this study, Murrish (2010) found that 50% of the nurses stated they did not feel comfortable talking about death and dying with their patients. This issue of talking with patients and their families about death and dying process appears to be consistent across many cultures. For example, a reader survey conducted by the

Nursing Times in England reported that 33% of the nurses who responded stated they did not feel they were equipped to discuss end-of-life issues with their patients (Ford, 2010). In Spain, a study of nephrology nurses using the Frommelt Attitude Toward Care of the Dying Scale showed that 88.9% of the nurses surveyed depicted end-of-life care as a demanding and emotional task (Ho, Barbero, Hidalgo, & Camps, 2010). The same study also showed that 95.3% of the nurses thought that assisting in the dying process required special skills. Similarly, in New Zealand, a qualitative study of nurses' attitudes regarding their role in end-of-life decisions with their patients was completed using an immersion/crystallization method (McLennan, Celi, Gillett, Penney, & Foss, 2010). In that study, it was reported that some of the nurses thought of communication regarding death as difficult. In a question regarding whether communication was important in end-of-life care, the answer was, "Yes, rather someone else did it though."

Current Practices in End-of-Life Care

End-of-life care in the intensive care unit. Nurses in the intensive care unit—also known as the critical care unit, work with a variety of critically ill patients. These patients include trauma patients, those with serious medical conditions and those who have had complicated surgeries. ICU Nurses should be highly skilled and able to deliver very technologically complex treatments (Schoenly, n.d.).

ICU nurses' feelings about end-of-life care are well documented in the literature. These feelings focus on how nurses view the nurse-physician relationship, the interdisciplinary communication process, and aspects of these relationships that hinder end-of-life care. For example, one study noted that ICU nurses experienced moral distress when taking care of patients at the end of life (Hansen, Goodell, DeHaven, & Smith, 2009). This moral distress was due to a lack of support in the work environment because of weak communication between

patient, families, nurses, and physicians. The study also stated that the ICU nurses lacked education regarding the dying process. Further, the researchers found that the ICU unit lacked necessary written protocols for care of the dying. The study involved implementing several measures that nurses stated were lacking, and questioning the nurses before and after implementation of these measures, to see whether the moral distress of the nurses declined. The implementation measures recommended for inclusion are listed below.

1. A bereavement program for families.
2. A palliative care team to promote comfort care and palliative medicine.
3. Preprinted orders for palliative care.
4. Employment of a mental health nurse specialist.
5. Provision of end-of-life education for staff nurses.

The study conducted by Hansen et al (2009), also reported a modest improvement from the pre-questionnaire to the post-questionnaire after all of the measures noted above were implemented. The Cronbach alpha varied from 0.71 to 0.93 pre-implementation to 0.76 to 0.91 post-implementation, depending on the interventions. The main limitation of this study was that the nurses responding in the pre-questionnaire were not necessarily the same nurses who answered the post-questionnaire. This discrepancy was due to many factors, including nurse turnover in the ICUs. Results were also skewed because of a lack of a coding process, which meant researchers were not sure whether the same nurses responded during each questionnaire period.

Despite the limitation of the ICU study, a common theme is often seen in the literature regarding the need for related training and improvement in end-of-life care to enhance the quality care for patients who are going through the dying process. A survey conducted by Asch, Shea,

Jedrziwski, & Bosk (1997), supported this emerging notion on the need for end-of-life education and interventions.

Palliative care. An alternative to curative care, like the care we see in the ICU, is palliative care. Palliative care can be initiated for patients of any age and with any illness. The goals of palliative care are to control symptoms such as pain and fatigue as well as improve the patient's quality of life (American Academy of Hospice and Palliative Medicine, 2013). The focus of palliative care is the patient and family unit; their goals, hopes, and dignity are supported. Aide is given to the patient and family unit to make informed decisions and to formulate goals and support them through the process of reaching these goals (ELNEC, 2009).

Represented by a multidisciplinary healthcare group, the palliative care team includes physicians, nurses, social workers, chaplains, nutritionists, pharmacists, and others who are needed (American Academy of Hospice and Palliative Medicine, 2013). The World Health Organization defines palliative care as:

“an approach that improves the quality of life of 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 impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (2014, p. 1).

Nurses' Preparation for End-of-Life Care

Nurses' education and training on end-of-life care. Nursing curriculum has not traditionally provided a thorough background on death and dying education. Most nursing schools provide a limited overview of this topic through lectures, readings, or case studies. Hebert, Moore, & Rooney (2011), reported that when nurses were asked about their end-of-life training, 71% stated that their education regarding pain management was inadequate. Further,

overall end-of-life education was rated inadequate by 62% of respondents, and 59% stated that symptom management was not covered adequately.

To address this training issue, Frommelt (1991) developed a questionnaire that asked nurses about their attitudes toward caring for dying patients and their families. She then completed a study that presented this questionnaire to nurses before they attended an educational program regarding end-of-life care. The nurses attended the educational program and then answered the questionnaire again. The results showed an improvement in their attitudes toward the dying patient ($p < 0.01$) after the educational intervention. Frommelt believes that inserting end-of-life education into nursing curriculum can change nurses' attitudes on the topic. The study did not address the nurses' own personal issues, values, and beliefs but addressed their feelings and beliefs about death regarding their patients. A limitation of this study was that the sample size included only 34 nurses and the results were not generalizable to the general nursing population.

Experienced versus novice nurses. “What would a good nurse do?” This is a question that comes to mind in the context of emotional situations occurring in end-of-life care. The premise is that a good nurse should know how she feels about death before she can openly assist and support a patient and his or her family. And most likely, a good nurse is probably a nurse with several years of experience on the job.

Largely supporting the above premise, several research studies found that more experienced nurses had more positive attitudes toward their dying patients and the death process. One study involved 58 registered nurses who, on average, were 41 years of age (Dunn, Otten, & Stephens, 2005). This study utilized several established questionnaires that concentrated on attitudes toward death and attitudes in taking care of dying patients. The results of the study

supported the fact that nurses with more experience had more positive interactions with death than the nurses' younger counterparts under the premise that practical knowledge is acquired through experience (Benner, 1984).

Thacker (2008) worked on the same ideas as Frommelt but utilized the nurses' experience to promote advocacy for the patient. Her study divided nurses into three groups: novice, experienced, and expert. She found that the experienced and expert nurses were more comfortable acting as advocates for their dying patients. She did find that all three levels of nurses experienced fear as hindering their end-of-life care. However, this was not fear of the subject of death. This fear had to do with the patriarchal system in healthcare: that most physicians are male. These nurses were afraid to speak up when they witnessed the physician going against the patients' care wishes. Their lack of intervention on behalf of the patient was due to fear of termination or fear of discipline by their superiors. The method in which some healthcare systems are structured can be a barrier to nurses working for the good of their patients. This can be harmful to the patient, especially at the end of life, if their wishes are not supported.

Dees (2008) also found that nurses needed to work through their fears of death. In this regard, she suggested nurses must gain experience by becoming involved in caring for those who are dying or by having exposure to them. Does this mean that patients may get subpar care during their dying process because the nurse has little practical experience? To address this issue, a mechanism must be put in place to fill that knowledge void so that nurses, even novice nurses, are able to adequately communicate and care for their patients going through the dying process. The patient should not have to wait for his or her nurse to gain experience before receiving optimal end-of-life care.

Conceptual Framework: Emotional Labor

Emotional labor as defined by Hochschild (1983) deals with the emotions of caring for a patient, not just the physical set of skills that nurses must possess. As such, healthcare workers are expected to have appropriate emotional responses to what their patients are experiencing. That is, the nurse may have to hide feelings of fear, disgust, boredom, or frustration from the patient. The nurse should also be fully aware of her attitudes toward certain issues to provide appropriate care to patients experiencing those issues such as death.

Hochschild initially focused her work on airline stewardesses. In their role, stewardesses were expected to smile and be friendly to all passengers. When questioned, the stewardesses reported that they felt their emotions were no longer their own. They felt as if their emotional persona was false and they felt burned out. The stewardesses also noted that over time they used up all of their positive emotions—and realized that these emotions were not in infinite supply.

Nurses today face this same dilemma. When dealing with dying patients nurses feel that the emotional costs can lead to burnout, aggression, abuse of alcohol or drugs, and even suicidal thoughts. The problem for nurses and healthcare organizations is that emotional labor is difficult to quantify and study, as opposed to established work items such as overtime, hours worked, and patient assignments. “The negative consequences of emotional labour therefore remain unchallenged, creating further and deeper issues of well-being for health workers and health professionals” (Barry and Yuill, 2011, p. 323). For example, a practice common among healthcare workers is to place patients into good and bad categories. Good patients are those who are compliant. Bad patients are those who are harder to help, such as drug users or mental health patients. An emotional conflict then arises for the nurse, who must be compassionate and caring for a patient who is labeled and viewed as bad (Gray, 2009).

Loukidou, Ionnidi, and Kalokerinou-Anagnostopoulou (2009), stated that two factors categorize nursing as fitting into emotional labor. First, nurses are socially thought of as sympathetic, caring, and involved with their patients. In this regard, Loukidou et al. (2009) referenced Bolton's (2001, p. 97) description of nurses as "emotional jugglers." Second, nurses must suppress their true feelings when faced with distasteful nursing care, a patient's intractable pain, as well as conflicts between their ethical standards and expectations and demands of the workplace. This suppression of feelings can lead to stress, fatigue, sleeplessness, alienation, depression, moral distress, cynicism, and withdrawal from involvement with peers and patients.

Further, some practitioners hold the view that showing any fear or emotional uncertainty regarding patient care is a sign of incompetence. That is, the general view is that healthcare professionals are to be compassionate and caring even when extremely uncomfortable with the patient's situation. As such, there is limited research on the connection between individual factors and the way service employees perform emotional labor (Hochschild, 1983). If the employee is in a situation or job that is not a good emotional fit for him, then that employee may experience more job dissatisfaction and stress. Individual characteristics, strengths, and weaknesses should be taken into account when looking at the emotional labor an employee may experience. If the nurse has a negative attitude toward death, she must emotionally labor to disguise those negative views and present a positive presence to her patient.

In the context of an emotional labor environment, Louikdou et al. (2009) suggested enhancing nursing education to include an emphasis on critical thinking, decision-making skills, ethical issues, problem solving, and project management. The authors suggested utilizing role-playing, teamwork, and storytelling to enhance learning surrounding these topics. Chu (2002) reinforced the connection between emotional labor and the implications to education and training

noting that service employees must display positive emotions, which translates to a positive experience for the customer. That is, employees' emotions are public domain and can be developed and honed using training programs. Bryan (2007) further argued that taking care of dying patients could be so emotionally charged and draining that management must provide related supports to nurses, or they will emotionally detach from their patients. Thus, the healthcare teams' emotional health must be supported through education and training. Research to date suggests that emotional labor is a significant factor in the nursing workforce and affects them when caring for their patients.

As such, based on the tenets of the emotional labor theory and relevant review of literature, it was posited that nurses with more work experience and higher level of palliative education and training would exhibit more positive attitudes toward death compared to novice nurses. Likewise, it was posited that background variables such as gender, ethnicity, area of nursing work, and state of residency might also be associated with attitudes toward death and serve as factors as implied by the emotional labor theory.

Summary

The American culture is aging at a rapid rate. Our elderly population in the United States will grow to 80 million by the year 2050. We are living longer and dying of chronic diseases. According to the United States Census Bureau (2012), our life expectancy in 2020 will be 77.1 years for males and 81.9 years for females. Along with this increase in aging is the lingering need to care for those experiencing the dying process. Barriers to caring for these patients include social and cultural views. Younger people experience more death anxiety than older people. Younger women tend to rate higher in death anxiety than young males do. Ethnicity can

also affect one's view on death, whether that view considers what happens to the physical body or the actual death.

The average age of a nurse is now around 47 years and with the largest group of nurses working today in their fifties. Nurses report that their end-of-life education has been inadequate to prepare them for the challenges in caring for their patients and their patients' families.

In addition to lack of end-of-life education is the emotional labor that nurses experience. If a nurse is not comfortable with death and the dying process, he or she must still put on a "good front" for the patient and support the patient through the process. This emotional labor takes a psychological and physical toll on the nurse, due to the stress involved in "acting" in an expected way. Assisting nurses in becoming more comfortable with death may decrease the anxiety and stress they feel in caring for these patients.

Palliative care focuses on the patient and the family unit. To place patients under the guidelines of palliative care allows the patients to achieve quality of life and comfort care. To guide patients in this process, nurses must be open to discussing end-of-life wishes, concerns, and needs with the dying patient. Thus, it is essential to provide nurses with the education that supports them in self-discovery and self-awareness regarding end-of-life concerns.

Chapter Three: Methods

To recap, the primary purpose of the study was to describe nurses' attitudes toward death and the extent of their education and training related to palliative care. The study also sought to determine whether nurses' attitudes are associated with background variables and extent of palliative education and training. The target population for the study was registered nurses throughout the United States, in general, to be identified using state nursing association databases.

Research Questions

The following research questions were used to meet this study's purpose:

1. What is the nurses' profile of attitudes toward death (anxiety, escape, neutrality)?
2. What is the extent of nurses' education and training on palliative care?
3. What background (age, gender, years of experience, nursing area, ethnicity, state of residency) and educational and training variables have impacts on nurses' attitudes toward death (anxiety, escape, neutrality)?
4. What is the best set of background and education and training variables explaining attitudes toward death (anxiety, escape, neutrality)?
5. What are the nurses' perspectives on study results regarding attitudes toward death and relationship with background and education and training variables?

Attitudes toward death referred to their ratings of "comfortableness" with death on a survey featuring three scales to measure *anxiety* toward death, death as an *escape* to life troubles, and *neutrality* regarding death. In turn, preparation on palliative education and training referred

to the nurses' level of formal education, extent of palliative training, self-assessment of overall preparation on end-of-life patient care, and level of confidence carrying out related tasks.

Further, background variables included: Age, gender, ethnicity, level of education obtained, years of nursing practice, area of nursing the registered nurse practiced in, and state they lived in.

Research Design

To address the research questions, a non-experimental research approach relying on survey strategies was used to conduct the study. Survey strategies represent a common form for data collection in descriptive research, and was the primary method used in this study. Survey methods resulted in descriptive data of trends, attitudes, and perspectives on topics of interest drawing from a sample of a target population (Creswell, 2009). The survey method was less expensive to administer versus utilizing an interview and allowed for anonymity, which provided for less bias on the part of the respondent (Trochim, 2006). As such, the research approach was suited for this study involving the documentation of nurses' attitudes toward death, and the extent of related education and training. Survey data also allowed the analysis of the association between a set of independent variables (i.e., palliative education and training and background variables) and a set of dependent variables (i.e., anxiety, escape, and neutrality attitudes toward death) (Petrocelli, 2003).

The research design was complemented with a focus group to verify and gather further insights on attitudes toward death. Focus groups are often used as a complementary strategy to validate results and enrich survey findings. As such, additional perspectives drawn from focus groups are used to enhance the description and understanding of study results (Ashar & Lane, 1993).

Target Population and Sample

In previous research studies of similar focus, the subjects have been limited in number and from a very small participant pool. In this study, the target population consisted of Registered Nurses throughout the United States representing the entire nursing workforce. The Health Resources and Services Administration Bureau of Health Professions (2013) reported there are an estimated 2,824,641 registered nurses working during the years 2008-2010. The goal was to then draw a representative sample from this larger pool taking into consideration regional and background variables.

Israel (2009) stated there are three main points for determining sample size in a research study. These include the level of precision or accuracy that the researcher is aiming for, the confidence level or how true to the general population the research results are and the degree of variability of the qualities being studied in relation to the population. The recommendation, according to Israel, was to sample well over 400 registered nurses to achieve a confidence level of 95% if the population contains over 100,000 members. Since this research study was looking at registered nurses in general and the number of working nurses in the general population is over two million, the sample size was set at 400 nurses. Surveys would need to go out to over 1000 nurses to achieve close to a return rate with 400 responses. To ensure a response rate of at least 50% (or 200 respondents), comparable with other survey studies (Hawkins, 2009; Kostrzewski, 2007), additional surveys were sent out if necessary based on initial response rates. The final sample was then compared with the general population of nurses based on demographic variables and geographical location to assess overall representation.

Variables and Instrumentation

The variables of interest in the study included, attitudes toward death, extent of palliative education and training, and background characteristics including age, gender, ethnicity, nursing area, and state of residency. A survey instrument was used for data collection including four major components: Attitudes toward death, extent of palliative education and training, and background information, and open-ended input (see Appendix A).

Attitudes toward death. Attitudes toward death were determined by the *Death Attitude Profile-Revised (DAP-R)* survey (Wong, Reker and Gesser, 1994). The survey, in its entirety, featured five subsets of statements regarding death and dying, for a total of thirty-two questions. Each subset focused on specific feelings about death and dying. These included Fear of Death, Death Avoidance, Neutral Acceptance, Approach Acceptance and Escape Acceptance (Neimeyer, 1994; Wong, Reker, & Gesser, 1994). These were the specific feelings that this study focused on aligned with attitudes toward death (see Appendix A, Section I). In general, the DAP-R scales had reported to have “good” to “very good” reliability (Wong et al., 1994). The factor analysis of the DAP-R showed that the five dimensions were independent of each other. Alpha coefficients of the DAP-R range from .84 on Escape Acceptance up to .97 on Approach Acceptance (Wong et al., 1994).

For the purposes of this study, fear of death and death avoidance were collapsed into one category of attitudes to be referred to as *anxiety toward death* including a total of 12 items. Related attitudes measured anxiety levels using items such as: “The prospects of my own death arouses anxiety in me” and “I always try not to think about death”. In turn, the subsets of 15 items focused on approach and escape acceptance were treated as one category of attitudes toward death referred to as *escape acceptance*. The *escape* referred to the extent to which

individuals view death as a way to escape life's troubles. Sample items representing *escape acceptance* attitudes included: "I look forward to life after death" and "I see death as a relief from the burden of this life". In turn, the category of *neutral acceptance*, included as a subset of five items, gauged the extent to which attitudes toward death represented views that are neither anxious nor too accepting. Sample items reflecting neutrality were: "Death should be viewed as a natural, undeniable, and unavoidable event" and "Death is neither good nor bad".

The Likert scale used in the survey required a numerical answer ranging from one to seven, with one being "strongly disagree" to seven representing "strongly agree." To estimate the overall results, the scores were added from each statement and then divided by the total number of statements. Thus, the higher the final score on each category, the higher the respondents were identified with related attitudes (i.e., anxiety, escape, neutrality). For example, a composite mean score of 7 on the "anxiety" component suggested a high level of fear and avoidance thoughts about death and dying.

Extent of palliative education and training. The extent of palliative education and training was determined through a complementary survey building upon a Palliative Care Education Needs Assessment Survey, which focused on key components of end-of-life care (Lien Centre for Palliative Care, 2014). The survey for this purpose included 12 items profiling nurses' education and training background including formal education in palliative care, related training, and level of confidence performing related tasks (see Appendix A, Part II). The survey items were drawn from the Palliative Care Needs Assessment Survey, which was validated through its administration with a sample of 216 doctors, 1139 nurses, 89 psychosocial professionals, and 46 pharmacists in Singapore (Lien Centre for Palliative Care, 2014). No formal statistics were acquired from this survey.

For extent of education and training, two items featured yes/no response options with corresponding follow-up items featuring multiple choices to identify extent of related preparation. Specifically, related items were used to document extent of formal nursing education, and training in palliative care. In turn, the remaining items were used to gather data on overall self-assessment of preparation in palliative care and level of confidence performing related tasks. For the assessment of overall preparation, a 5-point Likert scale (from 1 = Not at all prepared to 5 = very much prepared) was used. For level of confidence carrying out related tasks, a set of six items featured a Likert scale moving from “I could not do this on my own at all” to “I am confident I can do this on my own.” To estimate the overall level of confidence on palliative care preparation, the scores were added together and then divided by the total number of items in the related set.

In general it was expected that nurses with a higher level of formal nursing education, extent of palliative training, self-rating of overall palliative preparation, and confidence conducting related tasks should have had results reflecting more positive attitudes toward death.

Background variables. To gather data on background characteristics, a section of the overall survey included six related items (see Appendix A, Part III). Respondents were asked about their age, gender, ethnicity, years of nursing practice, area of nursing work, formal educational level, and their state of residence. In addition to serving as demographic descriptors of the study sample, these variables had been identified as potentially important in connection to attitudes toward death based on the review of literature and conceptual framework. To wit, age was found to have a relationship with attitudes toward death as it was expected that older individuals would be more comfortable talking about it (Russac et al., 2007). Regarding gender, it had been reported a differential showing of attitudes toward death with men tending to hide

their emotions while women tended to be more open (Russac et al., 2007). In turn, attitudes toward death also appear to be different based on ethnicity in connection to cultural roots and group views about death (e.g., some groups celebrate death while others are more fearful of the afterlife) (DePaola et al., 2003). Along these lines, the geographical location (i.e., state of residence) was often associated with cultural beliefs rooted in a particular region (e.g. bible belt), which could also influence attitudes toward death (Neimeyer et al., 2007). About years of nursing practice, it was expected that more experienced nurses would be more comfortable discussing death and related issues compared to novice nurses (Dunn et al., 2005). Similarly, it was posited that the area of nursing work mattered, with nurses working in areas where they are more closely exposed to terminally ill patients most likely exhibiting more positive attitudes toward death (Dees, 2008). These questions addressing background variables had multiple-choice answers suited to their individual nature.

Open-ended questions. Finally, at the end of the overall survey there were two open-ended questions to provide respondents with the opportunity to characterize their attitudes toward death and extent of palliative care preparation. The items were stated as follows:

- “How would you describe your attitudes toward death?”
- How prepared do you feel you are in meeting patients’ end-of-life needs?

Each item was in a separate free text box and the respondents typed in their responses using their own words (see Appendix A, Part IV).

Focus group. The goal of the focus group was to complement survey data and as a means to verify and gather further insights on attitudes toward death and views on palliative care preparation. Thus, the emphasis of the focus group was on getting group reactions to results on the profile of attitudes toward death, extent of palliative education and training, and the

association between background variables including education and training and attitudes toward death. For this purpose a focus group protocol with open-ended questions around the areas noted above, was used to facilitate discussion and gather related insights (see Appendix B).

Data Collection Procedures

The United States individual states Nurses Associations were contacted to find voluntary participants. Emails requesting participation were sent to all the states nurses associations. A short research and survey description was in the email as well as the Survey Monkey link for nurses to use to participate. The goal for the number of surveys returned was at least 200 responses.

The survey was set up using Survey Monkey's website and containing four sections. The first section featured statements focusing on feelings about death featuring the *Death Attitude Profile-Revised (DAP-R)* survey (Wong et al., 1994). The second section concentrated on the extent of palliative education and training including 12 items. The third section included demographic questions to collect data on age, gender, ethnicity, years worked as a Registered Nurse, area of nursing work, and state of residence. Finally, the fourth section included two open-ended questions to provide participants with the opportunity to share in their own words any reflections they may have had about their attitudes toward death.

The overall survey including the four sections was piloted with a small convenient sample of registered nurses. The sample consisted of 10 nurses affiliated with a large hospital in an interstate regional area. Participants were recruited as volunteers for the completion of the survey with the goal to get their insights on the overall validity of the survey, issues with items, and length. The feedback collected through the pilot test of the survey was used to revise the survey as needed.

The final version of the survey was accessed through the SurveyMonkey service. A turnaround time frame of three weeks for responses was established with SurveyMonkey. This online survey method allowed for ease of response, tracking of responses, as well as anonymity.

Regarding the anticipated focus group, participants were recruited from the pool of nurses at a large regional hospital. As per related literature, the target group included six to ten nurses so the group was large enough for rich discussion but not too big to make participation cumbersome (Ashar & Lane, 1993). Request for participation was disseminated in different nursing areas advising the nature of voluntary and anonymous participation. Upon agreement to participate, the approach to selection was to ensure representation by nursing area of work, include novice and experienced nurses, and ethnic balance if feasible. The focus group was conducted at a time that was convenient for participants, with an expected duration of 60 minutes, and was facilitated by the primary researcher. The focus group was tape recorded for later analysis.

Data collection procedures were cleared with approval from the Internal Review Board (IRB) of the University of South Florida and appropriate process set by the regional hospital where the pool of nurses for focus group were recruited.

Analysis

For questions one and two, related to the profile of attitudes toward death and extent of palliative education and training; the analysis involved the use of descriptive statistics (mean, standard deviation) to summarize the data for interpretation purposes. For question one, a total composite score was computed for attitudes toward death as well as composite scores for each of the three scales. In addition, overall and scale composite scores were computed for relevant variables in the study (e.g., gender, ethnicity, years of nursing practice). For question two on

extent of palliative education and training, frequency measures were used for categorical items, while descriptive statistics (mean, standard deviation) were used for continuous items. Palliative education and training results were also be analyzed based on relevant demographic variables. In turn, the open-ended statements were sorted out and used to enrich and complement the analysis of frequency data in connection to attitudes toward death. The open responses were analyzed using Survey Monkey's tool called Text Analysis. Specified words, phrases and themes were tracked and filtered for categorization. This approach allowed for classification of responses related to different issues associated with discussing death.

For the analysis of questions three and four seeking to determine whether attitudes toward death were associated with background variables; *anxiety toward death*, *escape acceptance*, and *neutrality toward death* were used as dependent variables. For reporting purposes, the dependent variable *anxiety toward death* was further referred to as *anxiety*. Again, this variable merged 12 items from two subsets related to fear of death (items # 1, 2, 7, 18, 20, 21, 32) and death avoidance (items # 3,10,12,19, 26) in the DAP-R survey component. In turn, the dependent variable *escape acceptance* were referred to as *escape* in the results. The *escape* variable merged 15 items from two related subsets including approach acceptance (items # 4, 8, 13, 15, 16, 22, 25, 27, 28, 31) and escape acceptance (items # 5, 9, 11, 23, 29) in the DAP-R survey component. Further, the third dependent variable representing *neutrality toward death* was referred to as *neutrality* and included five items (# 6, 14, 17, 24, 30) in the DAP-R survey component.

Background profile (gender, age, ethnicity, area of nursing work, state of residency, years of work experience) and extent of palliative education and training (formal nursing education, extent of palliative training, overall self-assessment of palliative preparation, and level of

confidence conducting related tasks) were treated as independent variables. All variables were coded appropriately depending on their scale of measurement.

Cronbach's alpha internal reliability was computed for the DAP-R survey to gauge the overall consistency of that survey component. Next, simultaneous regression was used to determine the level of association between the independent variables (gender, age, ethnicity, years of experience, area of nursing work, state of residence, formal nursing education, extent of palliative training, overall self-assessment of palliative preparation, and level of confidence conducting related tasks) and each dependent variable (anxiety, escape, and neutrality). Simultaneous regression was recommended as the appropriate procedure when there is no prior evidence of causal priority and there is a lack of information about the relative contributions of the independent variables to the three dependent variables under consideration (Petrocelli, 2003).

The assumptions underlying multiple regression were checked and all computations were performed using SAS statistical software. To this end, because three simultaneous regressions were conducted using the same demographic predictor variables, a Bonferonni correction was used to ensure that each regression was based on an alpha level of .01 to test the significance of *F*. The correction was calculated by taking the standard alpha of .05, and dividing by three (Abdi, 2007). For question three seeking to determine the individual contributions of background and education and training variables to attitudes toward death, the beta weights were checked and reported. Beta weights are typically used to determine the importance of individual variables and are used as the starting point for exploring contributions to a regression equation (Nathans, Oswald, & Nimon, 2012). In turn, for question four, R-square results were checked and reported as a product measure to help identify the best explanatory set of background and palliative education variables. R-square is a measure of how well a set of independent variables explains an

outcome variable. That is, it represented the percentage of variation in the outcome variable associated with the independent variables (Nathans, Oswald, & Nimon, 2012).

Finally, focus group data was analyzed and interpreted as a complementary strategy to validate and enrich the interpretation and discussion of survey results. As such, the analysis focused on identifying consistent agreement to support or clarify survey results. In addition, the analysis of focus group data allowed the identification of specific insights through direct quotes to help illustrate key study results. Based on the purpose of the focus group, a simple descriptive narrative was deemed as appropriate to enrich survey results (Krueger & Casey, 2000).

Limitations

The limitations of the online survey were the inability to verify that the respondent was actually a Registered Nurse. In addition, the survey was only made available in English, thereby possibly limiting the diversity of respondents. Since this was an anonymous survey, there was no guarantee that the respondents were answering honestly.

Ethics

This was an anonymous survey. No names or identifying information were obtained from respondents. Confidentiality was maintained and IRB guidelines were followed throughout the survey process.

Chapter Four: Results

The purpose of this study was to describe Registered Nurses' attitudes toward death and their perspectives on education and training related to death and end-of-life patient care. A complementary goal was to determine whether nurses' attitudes and perspectives were associated with background variables. The three attitudes toward death included anxiety, escape, and neutral attitudes. The background variables of the nurses included formal educational level, age, gender, ethnicity, years of nursing practice, state of residence, and area of nursing practice. In this chapter, a summary of the survey and a description of the participants are provided along with the results addressing each of the research questions.

Survey Participation and Reliability

The Death Attitude Profile-Revised (DAP-R) survey was sent to Registered Nurses across the country utilizing states' nurses' associations. A total of 22 state nurses' associations were identified and sent an introductory email regarding the survey and purpose. Some states declined to send the survey to their members unless a fee was paid. Other states volunteered to place the research and survey information in a quarterly newsletter, which did not correspond to the collection time frame. Those states (California, Rhode Island and Tennessee) were excluded from survey consideration. Eleven other states did not respond to the invitational survey email. The final group of respondents was from nine states across the United States including New Jersey, Colorado, Minnesota, Pennsylvania, Delaware, New York, Florida, Utah, and Wyoming. The majority of participants were from New Jersey, (91%) and 9% were from the other states listed.

The original dataset included 248 surveys. However, the responses that had missing values on any item were excluded and the final dataset was reduced to 167 usable surveys. As reported in Table 1, the respondents in the final dataset were predominately female (n=154 or 92.2%) with only a small group of male participants (n=13 or 7.8%). These numbers were similar to national averages. According to the National Nursing Workforce Study (2015) the number of male registered nurses between 2013 and 2015 was 14.1% and the number of female registered nurses equaled 85.9%.

Table 1

Survey Participation by Gender and Ethnicity

		Frequency (n=167)	Percent	Cumulative Frequency	Cumulative Percent
Gender	Male	13	7.78	13	7.78
	Female	154	92.22	167	100.00
Ethnicity	Caucasian	133	79.64	133	79.64
	Other	34	20.36	167	100.00

Similarly the respondents were primarily Caucasian (79.6%), with about a fifth (20.4%) representing non-Caucasian ethnic backgrounds (see Table 1). Not surprisingly, the geographical location of respondents mirrored the representation in the initial dataset with the majority (91%) based in New Jersey. Regarding age, the range was from 20-73 years old with an average of 51 years.

Overall, survey participants represented eight areas of nursing work as follows:

1. Psychiatry (6%),

2. Maternal-Child (7.2%) including pediatrics, pediatric trauma, maternal-child, pediatric outpatient, pediatric oncology, neonatal intensive care, labor and delivery, school nursing, and obstetrics,
3. Management (9%), including management, quality, administration, case management, legal, performance improvement, and utilization management,
4. Extended care (10.2%), including long term care, extended care, geriatrics, rehabilitation, and residential facility,
5. Critical care (10.2%), including intensive care unit, emergency department, anesthesia, and cardiac catheter lab,
6. Outpatient (15%), including ambulatory care, outpatient, employee health, primary care, aging services, palliative care, hospice, public health, college health, community health, and family care,
7. Medical-Surgical (21%), including progressive care, wound care, HIV, IV clinician, medical-surgical, telemetry, neurology, oncology, urgent care, acute care, cardiology, infectious disease, and orthopedics, and
8. Education (21.6%), including education, research, and health promotion.

The Cronbach's Coefficient Alpha for the entire instrument, including 32 items, equaled .824. There were three categories in the instrument including anxiety toward death, escape acceptance toward death, and neutral acceptance toward death. The Cronbach's Coefficient Alpha for the three categories was .914 for anxiety (12 items), .931 for escape acceptance (15 items), and .463 for neutral acceptance (5 items).

General Attitudes Toward Death

The first research question was concerned with a profile of the participants' attitudes toward death focusing on three defining constructs: anxiety, escape, and neutrality. The responses on attitudes toward death were based on a 7-point scale where 1 = Strongly Disagree and 7 = Strongly Agree. In turn, the educational level was coded from 1 (Associate Degree) to 4 (Doctorate Degree), while gender was coded 1 for male and 2 for female. Whether respondents have had any training on palliative care was coded 1 for "no" and 2 for "yes." The number of courses attended on palliative care during formal education was ranked from 0 (none) to 4 (more than 3). In turn, ethnicity was coded as a 1 for Caucasian and 2 for Non-Caucasian. Further, since the majority of the respondents were from the state of New Jersey, the state locale was coded as 1 for New Jersey and 2 for non-New Jersey. Finally, the eight nursing areas represented by participants were coded as follows: 1=Extended Care, 2=Psychiatry, 3=Outpatient, 4=Critical Care, 5=Management, 6=Medical-Surgical, 7=Education, and 8=Maternal-Child.

Anxiety toward death was a measure of anxiety levels covering the fear of death and death avoidance. Answers included items such as "I always try not to think about death." In turn, the *escape attitude* referred to an individual's view of death as a way to escape one's troubles. One of the responses representing this attitude was "I see death as a relief from the burden of this life." The third attitude was a *neutral attitude* where there was neither anxiety towards death nor an acceptance of death. One response choice was "Death is neither good nor bad."

Overall, as reported in Table 2, the highest mean attitude toward death was observed for *neutral* attitude with 5.79 indicating a very high level of neutrality (i.e., neither anxious nor too accepting). In turn, the mean response for the *escape* attitude was 4.69 reflecting a slight

tendency towards acceptance of death, while *anxiety* was rated as moderately low on the average with 2.77.

Table 2

Mean Nurses' Attitudes Toward Death Based on Anxiety, Escape, and Neutral Subscales

Variable (n=167)	Mean	Standard Deviation	Minimum	Maximum
Anxiety	2.77	1.09	1.00	6.67
Escape	4.69	1.28	1.13	7.00
Neutral	5.79	0.68	3.60	7.00

These results suggest that nurses, as a group, may exhibit high neutral attitudes toward death, with just slight tendency toward escaping views, and low anxiety. This general attitude can be best summarized by one of the open comments reported on the survey in response to a question asking to describe the respondent's attitudes toward death: "It is a part of life, I do not like the loss but it is inevitable."

Regarding attitudes toward death in relation to background variables, the results for gender are reported in Table 3. In terms of gender, the results suggested a moderately low level of *anxiety* for males (3.13) and relatively similar level for females (2.74). Similarly, both males and females reported relatively equivalent high levels of *neutrality* with 5.69 and 5.79, respectively. The only slight difference was observed on the level of *escape* attitude with females tending toward the moderately high level (4.72) compared to males (4.25). In general, given the standard deviations for results, it appeared that attitudes toward death based on gender were relatively similar.

Table 3

Mean Nurses' Attitudes Toward Death Based on Participants' Gender

		Mean	Standard Deviation	Minimum	Maximum
Anxiety	Male (n=13)	3.13	1.44	1.08	5.42
	Female (n=154)	2.74	1.05	1.00	6.67
Escape	Male (n=13)	4.25	1.24	2.20	6.47
	Female (n=154)	4.72	1.28	1.13	7.00
Neutral	Male (n=13)	5.69	0.66	4.60	6.40
	Female (n=154)	5.79	0.68	3.60	7.00

Regarding formal education, the results suggested that the *anxiety* level tends to decrease as the level of education increases from an associate to a doctoral degree. As noted in Table 4, the average level of anxiety for respondents with an associate degree was 3.17, and decreased slightly with every increase in formal education to 2.5 reported for respondents with a doctoral degree. Otherwise, the results for *escape* and *neutrality* attitudes were relatively similar tending toward moderately high escape (range: 4.57 to 4.83) and high neutrality attitudes (range: 5.73 to 5.94).

Table 4

Mean Nurses' Attitudes Toward Death Based on Education

(n=167)		Mean	Standard Deviation	Minimum	Maximum
Associates	Anxiety	3.17	1.04	1.92	5.17
	Escape	4.83	1.03	3.00	6.47
	Neutral	5.94	0.56	4.60	6.80
Bachelors	Anxiety	2.82	1.26	1.08	6.42
	Escape	4.59	1.26	1.40	6.87
	Neutral	5.73	0.68	4.40	7.00
Masters	Anxiety	2.77	1.09	1.00	6.67
	Escape	4.76	1.27	2.00	7.00
	Neutral	5.75	0.75	3.60	7.00
Doctorate	Anxiety	2.5	0.75	1.00	4.33
	Escape	4.57	1.46	1.13	6.73
	Neutral	5.89	0.51	5.00	6.80

About the breakdown of attitudes based on the area of nursing work (see Table 5), the reported levels of anxiety were relatively equivalent clustering toward moderately low anxiety with a mean of 2.52 for nurses working in education and a mean of 3.26 for nurses working in maternal-child units. In turn, the results suggested neutral views on *escape* attitudes for respondents working in extended care (4.2), psychiatry (4.1), outpatient (4.5), and critical care (4.4), and attitudes tending toward moderately high escape views for respondents in management (5.5), medical-surgical (4.7), education (4.9), and maternal-child care (5.0). By comparison, the

responses on *neutrality* attitudes showed similar views representing a high level of neutrality (range: 5.6-5.9).

Table 5

Mean Nurses' Attitudes Toward Death Based on Area of Work

	Anxiety Mean	Standard Deviation	Escape Mean	Standard Deviation	Neutral Mean	Standard Deviation
Extended Care	2.55	1.39	4.22	1.52	5.80	0.86
Psychiatry	2.55	1.23	4.12	0.91	5.60	0.78
Outpatient	2.79	0.67	4.49	1.21	5.78	0.54
Critical Care	2.92	1.38	4.40	1.12	5.91	0.56
Management	2.92	1.38	5.53	0.83	5.92	0.47
Medical- Surgical	2.97	1.15	4.72	1.09	5.70	0.71
Education	2.52	0.77	4.86	1.43	5.80	0.78
Mat/Child	3.26	1.40	5.01	1.55	5.82	0.64

Finally, regarding ethnicity, the results suggested comparable views with average attitudes representing moderately low *anxiety* for Caucasian (2.8) and non-Caucasian (2.7) respondents (Table 6).

Table 6

Mean Nurses' Attitudes Toward Death Based on Ethnicity

Variables	Anxiety Mean	Standard Deviation	Escape Mean	Standard Deviation	Neutral Mean	Standard Deviation
Caucasian	2.8	1.07	4.63	1.27	5.79	0.70
Non- Caucasian	2.7	1.16	4.91	1.28	5.78	0.63

There was moderately high escape for Caucasian (4.63) and for non-Caucasian (4.91). There was also an equivalent tendency toward high level of neutral attitudes for Caucasians (5.79) and non-Caucasians (5.78).

Education and Training in Palliative Care

Palliative care education encompasses end-of-life care and knowledge about death and dying. In this regard, the second research question was used to determine the extent of nurses' education and training on palliative care and the results are presented in Table 7. To set the context for related results, the extent of nursing experience was first determined. As a whole, the respondents appeared to be normally distributed with a range of 1 to 52 years in nursing work, with an average of about 24 years in the profession.

Table 7

Mean Nurses' Education and Training on Palliative Care

Variables	Statistics			
	Mean	Standard Deviation	Minimum	Maximum
Years of experience	24.46	13.97	1.0	52
Formal courses taken on palliative care	1.28	1.38	0	4
Rating of end-of-life preparation	6.92	2.38	1	10
Confidence level	3.44	0.54	1.33	4.0

Looking at formal courses on palliative care, an example of a course offered in the nursing field is a national course titled ELNEC: End of Life Nursing Educational Consortium. In general, the goal of such courses is to educate nurses on comprehensive end-of-life topics such as pain management, symptom management, cultural competence, last hours of life and bereavement. In

this regard, less than half of the respondents (47.31%) reported that they had attended training on palliative care in the last five years, while a slight majority (52.69%) indicated they had not attended a palliative care class in that same time frame. As such, and as noted in Table 7, the number of courses taken by respondents ranged from zero to four and with an average of 1.3 formal courses.

Further, the respondents rated their end-of-life preparation on a scale of 1 to 10, with 1 equivalent to “not at all prepared” and 10 equal to “very much prepared.” In this regard, the respondents rated their preparation on palliative care relatively high with a mean of 6.9. In turn, the level of confidence in meeting palliative care needs ranged from 1 (I could not do this on my own at all) to 4 (I am confident I can do this on my own), and a mean of 3.4 reflecting a “somewhat” level of confidence requiring some supervision.

Table 8

Mean Confidence Level of Nurses in Meeting Palliative Care Needs

Palliative Care (n=167)	Level of Confidence	
	Mean	Standard Deviation
Identify grief and bereavement needs	3.35	0.70
Provide grief and bereavement support	3.30	0.78
Identify patients and families emotional and spiritual needs	3.51	0.68
Manage psycho-emotional distress	3.31	0.73
Break bad news to a patient or relative	3.44	0.72
Care for an actively dying patient	3.70	0.60
Overall confidence meeting palliative care needs	3.44	0.54

The level of confidence was based on six areas of palliative care as noted in Table 8.

On the average, the participating nurses reported they were most confident in caring for an actively dying patient, while they were least comfortable providing grief and bereavement support. Caring for the dying patient would be the more technical aspect of nursing while providing bereavement support would be more on the psycho-social end of the spectrum. These general attitudes were further reinforced with related comments reflecting some level of preparation, but seeing the need for additional training to increase the level of confidence in related work. For example, one of the respondents provided the following perspective: “[I feel] somewhat prepared, I shadowed a hospice care nurse during nursing school but would feel more comfortable with additional training and resources.”

Impact of Background and Education and Training Variables

After establishing the nurses’ profile of attitudes toward death and determining their extent of education and training on palliative care, the objective of the third research question was to gauge the contribution of each independent variable in terms of explaining attitudes toward death. In this case, the independent background variables included age, gender, years of experience, nursing area, ethnicity, and state of residency; while level of education achieved, formal end-of-life education obtained, post-graduate education and training, and confidence level in caring for end-of-life patients were the education and training variables. Regression analysis was conducted for each dependent variable identified as a defining category of attitudes toward death: anxiety, escape, and neutrality.

First, the responses to research question three regarding background and education and training were correlated to attitudes toward death. All three dependent variables, anxiety, neutral, and escape, were relatively normally distributed with skewness and kurtosis absolute values less than 0.9 and 1.2, respectively. The Pearson product-moment correlation coefficient was used to examine the correlation between any two continuous independent variables. As reported in Table

9, most variables had weak to moderate correlations to each other except age and years of experience in nursing practice ($r=0.83, p<.0001$). The correlation coefficient of $r = 0.83$ represents a strong correlation between the age of the research participant and their years of experience as a nurse. The older in age they were the more experience they had. It was a direct correlation.

The r value equaled 0.83 meaning there was a strong correlation between years of age and years of nursing experience. The value of $p<.0001$ means there is an extremely low chance that the strong correlation of age and years of experience was due to chance.

Table 9

Correlations of Background and Education/Training Variables

Variables (n=167)	Age	Years Experience	Palliative Care Courses	Preparation	Confidence
Age	1.0	0.8275	0.2521	0.3074	0.3388
Years Experience	0.8275	1.0	0.1702	0.2780	0.279
Palliative Care Courses	0.2521	0.1702	1.0	0.32	0.390
Preparation	0.3074	0.278	0.32	1.0	0.454
Confidence	0.3388	0.279	0.39	0.454	1.0

The variable age, therefore, was excluded in the analyses to avoid a multicollinearity problem. Thus, years of experience was used in analysis instead of age, as it would be practical to conclude that someone with more years of work experience was also older in physical age.

Beta weights were used to look at the individual impact of the independent variables (see Table 10). Looking at the anxiety attitude as an outcome variable, the beta weight for the number of courses taken in palliative care predictor was 0.21. This indicated that for every one standard deviation increase in the number of courses taken there was an increase of 0.21 standard deviation of the anxiety level. When looking at the preparation level predictor the beta weight was -0.32. This indicated that with every one standard deviation increase in preparation there was a 0.32 standard deviation decrease in the anxiety attitude. The area of nursing practice had a significant difference for those working in extended care and psychiatry versus those working in maternal child areas. The beta weight was -0.24 and -0.21 in relation to extended care and psychiatry, respectively. Those numbers represented the fact that a nurse working in maternal child had a higher level of anxiety in relation to death and dying than those in extended care or psychiatry.

The neutral attitude was not significant in any variable except for the how prepared the nurse felt he was in relation to topics of death and dying. The beta weight for “preparation” was 0.23 with a regression coefficient of 0.02. Those results supported the idea that the more prepared the nurse felt in caring for a dying patient, the higher the neutral attitude was.

For the escape attitude, the regression coefficient for years of experience predictor was 0.01. This means that for every one year increase in years of experience there was a 0.01 increase in the escape attitude. Beta weights for years of the experience predictor was 0.26 showing that a one standard deviation increase in years of experience would result in an increase of 0.26 standard deviation in the escape attitude. The only other variable that had an impact on the escape attitude was education. When moving from a masters prepared nurse to a doctorate prepared nurse, one standard deviation, there is a decrease of 0.32 standard deviation in the escape attitude.

Table 10

Beta Weights of Significant Variables

Dependent Variable	Independent Variable	Beta Weights	$p < 0.05$
Anxiety	Extended Care vs Maternal Child	-0.24	0.04
	Psychiatry vs Maternal Child	-0.21	0.04
	Courses	0.21	0.03
	Preparation	-0.32	0.0006
Neutral	Preparation	0.23	0.02
Escape	Years Experience	0.26	0.01
	Masters vs Doctorate	-0.32	0.03

Based on t-tests with the significant level of 0.05, the *p-values* for the number of courses and preparation ($p=0.022$ and 0.006 , respectively) were less than 0.05, which indicated sufficient evidence for predicting anxiety toward death. The difference of anxiety between participants with nursing practice in the areas of Psychiatry and participants in Maternal Child, and the difference between Extended Care and Maternal Child was statistically significant with *p-values* of 0.037 and 0.041, respectively. The other independent variables included years of experience, gender, ethnicity, state of residency, education, confidence, and training did not show any statistically significant impact on anxiety towards death.

Examining the regression coefficient parameter represents the mean change in the outcome variable for every one unit increase in the corresponding independent variable when all the other variables are fixed. The anxiety level decreased about 0.15 for every one unit increase

in college/school preparation that the participant had. A 95% confidence interval for college/school preparation was -0.23, -0.64. The results showed that the anxiety level decreased between 0.06 and 0.23 for every one unit increase in preparation. In regards to extra courses taken in palliative care, the anxiety level increased 0.17 for every additional course taken. The confidence level was 95% that the anxiety level increased between 0.02 and 0.31 for every additional one post graduation course taken. These results showed a conflicting message regarding education. With every one unit increase in participation in college courses regarding palliative care/end-of-life, there was a decrease in anxiety between 0.06 and 0.23. When looking at classes in end-of-life taken after graduation (not in academia) there was an increase in anxiety for every one course taken. Could this be due to the fact that as nurses are out in the workforce and acquire more knowledge regarding palliative care they realize how little they know about the subject? Or could it be that learning about palliative care in the workplace causes more anxiety as the nurse then knows they would have to use this knowledge in real time to take care of their patients and their families? This is a concern for nurse educators in the workplace. Palliative care nursing education should alleviate or at least decrease anxiety when taking care of end-of-life patients. The results obtained did not support this. More research is needed to ascertain why this disconnect between workplace education and alleviating anxiety occurred.

Predicting Attitudes Toward Death

Once the relative contribution of the background and education variables was estimated, research question four called for the analysis of the best set of background and education and training variables explaining attitudes toward death (anxiety, escape, neutrality). In this regard, the results of the global *F test* indicated that the model was statistically significant for predicting anxiety attitude toward death based on the group of independent variables (background variables

and education and training variables). The value of *R-square* was 0.19, which means that approximately 20% of the variation of anxiety was explained by the background and education and training variables. Approximately 95% of the sampled anxiety values fell within two standard deviations ($2s=2.064$) of the respective predicted values. The *F test* equaled 1.99 with a *p* value of 0.01 (see Table 11).

Further, the *F-test* value of 0.93 and the *p-value* of 0.54 indicated that the results were not statistically significant for predicting neutral attitude toward death based on the group of independent variables (see Table 11). The model that predicted the escape attitude toward death and the group of independent variables, background variables and education and training had an *F test* of 1.63 and *p-value* of 0.06. These results were not significant for the alpha of 0.05. The value of the *R-square* for the results was 0.1 which means that only 10% of the variation of the overall attitudes toward death were explained by the background and education and training variables. The adjusted *R-square* was -0.007.

Table 11

Attitudes Toward Death as a Function of Independent Variables

Dependent Variable	Source	DF	Sum of Squares	Mean Square	<i>F Value</i>	<i>p</i> <0.05	<i>R-square</i>
Anxiety	Model	18	38.31	2.13	1.99	0.01	0.19
	Error	148	158.19	1.07			
Escape	Model	18	44.69	2.48	1.63	0.06	0.17
	Error	148	225.74	1.53			
Neutral	Model	18	7.84	0.44	0.93	0.54	0.10
	Error	148	69.08	0.47			

The stepwise regression approach showed that the best set of predictors for anxiety toward death included the number of courses taken on palliative care during formal education and end-of-life preparation. As reported in Table 12, for the neutral attitude toward death the best and only predictor was end-of-life preparation ($p=0.02$). The significant predictor for escape toward death was years of experience ($p=0.01$).

The best set of variables to explain attitudes toward death focused heavily on the anxiety attitude. As would be expected, as the confidence level increased, the anxiety toward death decreased. There was also a negative correlation in regards to formal education regarding palliative care. The more formal training a nurse received, the lower the anxiety level. It was interesting that this did not hold true for post college education. Palliative care training after one entered the workplace actually increased anxiety towards death. The reason for this is a viable topic for future research. The best set of predictors for a neutral attitude toward death was the rating of the nurses' end-of-life preparation. The best predictor for the escape attitude toward death was years of nursing experience. The more experience a participant had in nursing, the higher the level of the escape attitude.

Table 12

Individual Predictors for Anxiety, Neutral and Escape Attitudes

Variable	Anxiety <i>p value</i>	Neutral <i>p value</i>	Escape <i>p value</i>
Years of Experience	0.47	0.43	0.02
Courses	0.03	0.64	0.42
Preparation	0.0006	0.02	0.26
Confidence	0.49	0.77	0.85

$p < 0.05$

Nurses' Perspectives on Study Results

To clarify and verify the study results, a final research question called for the use of a focus group to gather nurses' perspectives on major survey results. Thus, once the survey results were analyzed and summarized a focus group was conducted to gather related feedback. The focus group consisted of six registered nurses who worked at a Veterans Hospital in northern Florida. The nurses' years of experience ranged from 1 year to 40 years, with the average being 17.83 years. The focus group was conducted via teleconferencing and all of the participants agreed to have the session recorded with the understanding that no personal identifiers would be used in regards to their responses. The only background data acquired from the participants was years of experience in nursing and gender. The Focus Group introduction was read to the group as scripted in Appendix B.

After explaining the attitude scales: anxiety, neutrality, and escape, the first discussion question centered on the results of the general attitudes toward death. The results stated that the most prevalent attitude was neutrality, then escape and last, anxiety. The group collectively felt that these results represented their own attitudes toward death. The group responded that the results were pretty accurate. However, one participant stated that the anxiety results might possibly be higher if the nurses were asked the same questions in the real moment of having to take care of patients and families, in the actual work setting. In this regard, another participant provided additional insights regarding experience and area of work as important factors:

“The work situation and how long they’ve been in nursing maybe? If you’re talking about [providing palliative care to] children that’s a whole different ball game.”

In general, participants felt that the level of anxiety would most likely differ depending on where the nurse worked in healthcare and the type of patients they are caring for. The consensus was there would be a higher level of anxiety providing care to children as characterized by the quote above. It was also explained that the survey results showed that *neutrality* did not have any real significance in relation to demographics, that the *escape* attitude was rated higher for females, lowest for those working in psychiatry and highest in those working in management. Further, they were made aware that the *anxiety* attitude was highest for those working in maternal-child, while nurses with more formal education had reported lower anxiety. In reaction to these results, one participant agreed with the general findings by noting that, “when you were reading [about the neutral attitude] all of our heads were nodding.” In this regard, there was a general agreement that the significance of the particular attitudes toward death may all depend on the nurses’ own personal life experiences.

Further, it was reported to the focus group that survey results showed: (a) that the overall preparation in palliative care in a formal education setting was only 1.28 courses on average, and (b) that 52.69% of the survey respondents stated that they had not attended any workplace or post education palliative training in the last five years. About those results, one participant noted that professional development education may be lower in some states using knowledge of her regional area as a reference:

“Your estimates were higher than you would get in North Florida/South Georgia. I think you would have more people saying they hadn’t had education in the last five years.”

This perspective reflected the general agreement of the group that palliative care is not a detailed subject matter in school or the focus of professional development. One group member shared that exposure to formal education in palliative care could all depend on when the nurse

graduated. She stated that nurses with many years of nursing experience usually have no formal education on palliative care whereas nurses new to the profession may have experienced a curriculum that devoted a portion of the time to death and dying. To this end, using her own case as an example, she was quoted as saying that:

“I think some of the schools are lately trying to add some in but for us who have been out of school for a while haven’t had any.”

In addition, it was shared with the focus group participants that the confidence level of the survey respondents regarding conducting palliative care was a mean score of 3.4 on a scale of 1 to 4. In this regard, focus group members stated that they were surprised by these results. In general, participants felt the results appeared to be high, especially when nurses are asked to float across nursing units. One of the participants with a background of teaching ELNEC courses and nurses’ level of confidence providing palliative care reinforced the general agreement noting, “I think that seems very high. [Having the benefit of] teaching ELNEC, the result seems high.” Another participant further suggested that if a nurse floated to another nursing unit and was not familiar with the new unit’s routine, then the nurse would not be as comfortable providing palliative care as they would be in their own nursing unit. Since they would be out of their element, she offered that, “if a nurse floats over here [to another unit] they aren’t going to feel nearly confident.”

Finally, in reviewing the summary of the study results, the group was told that the *neutral* attitude did not demonstrate any strong demographic correlations, while the *escape* attitude correlated with years of experience. In turn, it was noted that the *anxiety* attitude was lowest for those with a higher confidence level and with the number of courses taken on palliative care during formal education. In reaction to the recap of major results, one participant stated that the

escape attitude might possibly be higher in association to years of experience. In her view, she suggested, “maybe that’s a sign of burnout.” That is, as nurses work longer and continue to be exposed to highly emotional work a higher level of *escape* attitude may develop. In this regard, there was general agreement that as nurses work more and more years they might experience burnout causing them to believe more in death and dying as an escape, rather than something to be anxious about. In this context, the correlations for *anxiety* were seen as “pretty accurate” by the entire focus group. The group agreed with the *anxiety* results in total regarding the relationship of anxiety to the extent of preparation in palliative care.

Chapter Five: Conclusions, Discussion and Implications

Conclusions

The number of people over 65 years of age in the United States is increasing at a rapid rate. Citizens 65 years of age and older will double in number from the year 2000 to 2030, according to The Administration on Aging (2010). This increase in the elderly population brings with it a renewed focus on end-of-life care. In this regard, nurses are in a unique position to assist those who are dying to experience a high quality of life to the end of their life. As such, nurses must be able to have the emotional insight into their own feelings about death and dying to adequately support their patients through the dying process. Overall the nurses surveyed had a high mean score in the *neutral* attitude toward death followed by the *escape* attitude, and lowest for *anxiety* attitude. To this end, the research results confirmed some assumptions regarding nurses and end-of-life attitudes. That is, nurses with more formal education on palliative care had less anxiety toward death, and female and male nurses rated relatively the same in regards to anxiety and escape attitude. Thus, one of the conclusions in the study was that nurses with more formal education had less anxiety toward death. It was also found that as the confidence level increased, the anxiety toward death decreased. Neutral attitudes were best predicted by the nurses' rating on end-of-life preparation. The escape attitude was higher in nurses with more nursing experience.

Education in the collegiate setting was conducive to decreasing anxiety, but correlations for the escape attitude were not as strong. The results showed that experienced nurses with more formal education were the most comfortable with death. Additional research needs to be done to

look at the effects of self-exploration education regarding death and dying and its impact on improving emotional stamina in regards to palliative care. The goal is to support the patient in the dying process to improve their quality of life and support their end-of-life wishes.

The results of the study were largely confirmed by nurses participating on a focus group to discuss key findings relative to each attitude toward death: anxiety, escape, and neutral. For example, when focus group participants were asked for their insights related to survey results on the role of background variables, one group member stated that “Male nurses in my opinion they don’t really like to appear at times, they don’t like to relinquish some of the control which you have to do at the end-of-life.” The participant was saying that male nurses might have rated slightly higher in the anxiety attitude on the survey, as male nurses don’t appear to like to relinquish control of their patient’s care. And, as the group member stated, in caring for someone who is dying the nurse has to relinquish control and honor the patient’s wishes.

Overall, the focus group participants agreed with the general results of the survey in relation to anxiety, neutrality, and escape. However, the high level of confidence reported by survey participants surprised the focus group participants as a whole. The group believed that the confidence score was very high and that the nurses they knew in their workplace would experience more anxiety in a palliative/end-of-life setting.

Discussion

How do the study results compare to relevant literature and prior research on nurses’ attitudes toward death? A brief discussion of results is presented below to put the relevance of key findings in the context of previous research. Further, the results are also discussed using the premises of emotional labor as a frame of reference.

Relevance to previous research. Looking back at previous research, Russac, Gatliff, Reece, & Spottswood (2007) examined death anxiety in the adult years in the general population. They found that death anxiety was higher in women than men. In this research study it was found that male nurses had about the same anxiety level as female nurses, male nurses rating just slightly higher in anxiety.

In regards to education Herbert, Moore, & Rooney (2011) reported that 62% of nurses reported their overall end-of-life education was inadequate. The results of this study mirrors similar statistics. In the survey the nurses only had a mean of 1.28 courses on palliative care during their formal education. When one considers that pursuing a bachelor's of nursing degree takes four years, 1.28 courses in end-of-life care is a very inadequate preparation in palliative care. Further, education in the workplace as professional development did not appear to decrease anxiety but actually increased it. Nurses in the survey stated that the more end-of-life education they had received post-graduate, in the workplace, the higher their anxiety level was. This is an area of concern for nurse educators. Is the curriculum reaching the needs of the nurses attending it? Post-graduate end-of-life education needs to meet the educational needs of the working nurse. The topics covered should include medical issues such as pain control, symptom management, and medication regimens. In addition, since dying is a very emotional experience, the curriculum should cover having difficult conversations, cultural beliefs in end-of-life care, bereavement support, and ethical issues that might arise with the patient and families.

Also, more research needs to look at anxiety in relation to end-of-life education. Dunn, Ottenm and Stephens (2005) found that nurses with more experience had more positive interactions with death than younger nurses. In this study nurses with more experience had a higher escape attitude than less experienced nurses. The escape attitude was seen as a way to

escape one's troubles. One of the responses on the survey was "I see death as a relief from the burden of this life." The attitude of the nurse could depend on how much death and care of the dying the nurse encountered throughout their career. A novice nurse would have much less exposure and be less comfortable with death and the dying process than a nurse working in hospice.

Palliative care as emotional labor. Communication and caring at the end-of-life can be very stressful and the nurse needs to be open and honest with patients under her or his care. If the nurse is feeling stressed when anticipating these difficult conversations, and care has to be given, then emotional labor takes over as the nurse may mask the stress and thus an increase in anxiety occurs.

Barry and Yuill (2011) found that the negative consequences of emotional labor could create well being issues for health professionals. Dealing with dying patients could lead the nurse to feeling burnout or aggressive. This idea was brought up in the focus group seeking the perspectives of nurses about the major results of the study. In this regard, after learning about the survey results suggesting that the *escape* attitude correlated with years of experience, one focus group participant stated, "maybe that's a sign of burnout," which is at the core of emotional labor resulting from work-related stress.

Hochschild (1983) stated that if an employee was in a job that was not a good emotional fit than that employee might experience more stress. To this end, one survey respondent stated, "...I started out in Critical Care, but found the constant death too much to take in my twenties...so I switched to school nursing." Amidst the stressful nature of palliative care work the nurse must remain calm in front of the patient and family, which may in itself become a

source of stress as well. According to the premises of emotional labor, the need to control one's emotions at work can be a source of burnout over time (Barry & Yuill, 2011).

A report published by Naropa University (2014) stated that healthcare professionals are faced with physical, emotional, and spiritual suffering on a daily basis, yet they have little or no training to deal with such issues. The same report noted that the majority of the professionals surveyed were deeply uncomfortable dealing with the realities of dying and death. The need for end-of-life education for nurses was supported by the Naropa survey. One would expect that more experienced workers are able to handle their emotions at work, and in this vein one would surmise that nurses with a higher level of palliative education and training would have more positive attitudes toward death.

In this case, survey results supported this idea for education received in a college setting with more educated nurses reporting decreasing levels of anxiety. Interestingly though the education received post-graduate for professional development did not relieve the stress of emotional labor and anxiety towards death. This could possibly be due to the fact that as nurses gained more experience they realized how much they did not know about healthcare and death. It could also pertain to the quality of the education they received in the workplace. This lack of perceived educational support by the staff nurse could cause emotional labor. If a nurse is not getting the education to adequately support their patients' needs, it may lead to emotional labor burnout since she has to appear to be confident but might internally feel she is lacking appropriate knowledge and skills.

The format of the workplace education available to nurses could be adding to the stress of emotional labor in relation to two attitudes toward death: Anxiety and escape. As suggested by survey results, *anxiety* increased with less experience and less education regarding end-of-life

care. Under these conditions, *anxiety* would then increase emotional labor as one would try to mask the personal anxiety from the patient. In turn, an *escape* attitude could also relate to emotional labor. If the nurse is feeling “out of place” or awkward in the patient care situation they might have an increase in their *escape* attitude toward death (e.g., “I don’t want to think about it”), but because they have to support their patient through the dying process, emotional labor increases falling into a cycle that may result in burnout.

Implications for Nursing Practice

The study presented some interesting results but it does have some limitations. The first limitation centers on the participants. Even though the survey link was emailed to numerous states nurses’ associations, the large population of respondents was from New Jersey. The participant group was also heavily female and Caucasian. The number of respondents was large but could have included even more participants if the survey had been “live” for more than three weeks.

The survey divided the attitudes into three categories: anxiety, escape, and neutral. In the original survey, the DAP-R survey included five categories of attitudes. Compressing the categories from three to five attitudes might have supported different values to results. Overall the results provided positive insight into correlations between nursing demographics and attitudes toward death. The results also brought out some areas in need of improvement in nursing practice and education. One area was education in palliative care in the collegiate setting. More education at this level decreased anxiety so why aren’t there more palliative care classes at the collegiate level? Education in the workplace setting was another area for consideration. More years of nursing experience and lower anxiety were inversely related and need to be addressed.

The study results also suggested that nurses with more years of experience and more formal education had less anxiety towards death. The question then is what education needs to be provided to newer nurses to ease their anxiety towards death? Patients should not have to wait for their nurse to gain years of experience to obtain exemplary end-of-life care. Nursing education needs to focus on providing more education in the collegiate setting to remedy this. End-of-life education after graduation needs to provide medical knowledge as well as personal knowledge on death and dying signs, symptoms and personal viewpoints. The format of any workplace education received could have an impact on the nurse as well. Is the class online or a lecture format with no chance for interaction, discussion, or role-playing? Many educational opportunities in the healthcare workplace are now self-study online tutorials. These types of end-of-life educational presentations do not support any personal interaction or support and could deter from the learning process for nurses, leading to more emotional labor.

Further, nurse educators can provide multi-disciplinary team discussions regarding end-of-life care of actual patients that are being cared for. Post conferences can also be provided for nurses and the entire care team to discuss what was learned, what was missing, and what could have been done better regarding the actual care provided. It could also decrease anxiety for registered nurses if nurse educators provided palliative care classes on a continual and annual basis for all patient care staff. In addition, providing nurses, in the workplace, with experiential education such as self-reflection exercises, role-playing scenarios regarding dying, and journaling with discussion groups could lead to less personal anxiety toward death and a decrease in emotional labor of the registered nurse. Face-to-face education versus on-line education provides discussion of issues, questions, and anxieties faced when taking care of dying patients.

The workplace setting the nurse works in can also impact their confidence and anxiety levels in dealing with the dying patient. Murrish (2010) found that 50% of the ICU nurses in a study stated they did not feel comfortable talking about death and dying with their patients. My research survey asked two open-ended questions. The second question asked “How prepared do you feel in meeting patients’ end-of-life needs?” The responses were varied from “very personal” and “somewhat prepared” to “it is a process,” and “...I shadowed a hospice nurse during nursing school but would feel more comfortable with additional training and resources.” One would expect ICU nurses to be more prepared to take care of dying patients because of the critical nature of their patients’ status but according to the responses ICU nurses also feel a need for more education and want to be more adequately prepared to take care of patients who are dying.

Implications for Further Research

Various implications for further research were identified drawing from the administration of the survey and nature of results. For example, the type of survey used in the study, additional survey questions, and the pool of participants are areas that could be further improved upon or manipulated in further research.

First, the survey was a computer-based instrument administered through a link to Survey Monkey. This type of survey might have deterred nurses who were not computer literate or those without easy Internet access. The focus group brought to light some issues in relation to surveying nurses as for many the survey was a computer exercise that could not be completed on the job site. This may have altered somewhat the nurses’ level of escape or anxiety they reported. If they were to complete a survey on the job site their responses might be quite different than if they took it at home. If taking the survey at work, they would possibly be experiencing the stress

and related emotions that arise when taking care of real life patients and families, emotional labor, and may result in more accurate report of anxiety and escape attitudes. Thus, further research using different modes for survey administration may contribute to more accurate reporting of related attitudes.

This survey also utilized the DAP-R survey but compressed the subsets of questions from five categories to three categories. This compression of categories could have altered response analysis. The neutral subset only had five questions that could have influenced the results and limited the neutral responses. Further research could either duplicate the compressed question categories to validate if the results would be the same or could administer the survey in its original form of five subsets.

In reviewing the responses to the open ended questions, changes could be made to question number one in a subsequent survey. Clarification of question one could be made to include the words “your personal attitudes toward death.” Some of the narratives focused their answers on their attitudes toward the death of their patients. They did not internalize the question for themselves and how they were feeling. Their responses were in relation to how they felt about their patient’s death.

In addition, the survey asked for years of experience but did not ask for a burnout rating. It might be possible that how a nurse viewed their job in relation to their feelings of burnout might influence their feelings toward death including anxiety, escape, and neutrality which are related to emotional labor. Also the survey did not ask for demographics related to religious and spiritual beliefs. This could be an important correlation for future surveys to include in their research. In the open-ended question section of the survey someone stated: “Your initial survey questions were in my opinion directed towards those of the Christian faith. Is there a process

where questions are vetted so that the frame of reference is more neutral?” Religious and/or spiritual beliefs could influence the attitude of the nurse regarding death.

It could also be included in future surveys to ask nurses how much control they like to have in their patient’s care. This could cover the range from one-on-one care to multi-disciplinary care, where a group of healthcare providers all have a say, along with the patient and family, in how best to manage the patient’s course of treatment and support. The dying process is about losing control of the patient, not being able to “fix” them. This could lead to an increase in anxiety or an increase in the escape attitudes.

There should also be changes in disseminating the survey. For example, I would ask additional demographic questions to include faith, religion and where the nursing education was received. The survey should be open for a longer timeframe. It should also be clear that nurses should answer the attitude questions in relation to how they personally feel about death and not in regards to their patients.

The sampling of the participants was focused more on some groups than others. As stated previously, the majority of respondents were from New Jersey. To try to alleviate a skewed sample the survey could have been left open for a much longer length of time, instead of the three weeks. A couple of the state nurses’ associations were willing to place the survey link in their newsletters but the newsletter only went out to their members on a quarterly basis. The timing of the survey did not fit the newsletter circulation timeframe. In the future, the survey should be available for at least two months with timing to coordinate with the organizations newsletter circulation.

The location of the respondents could skew their responses, a location cultural influence. For example, if a nurse lives in Washington state where assisted suicide is more positively

viewed, a nurse may have more open views about dying as the topic has been discussed in the state at length. States that are more heavily populated with elderly citizens, such as Florida or Arizona, may be states where nurses experience dying patients at a higher percentage than younger aged states. This may have an influence on nurses' attitudes toward death and dying.

Another sampling issue is that the survey went out to nurses involved in state nurses' associations. This limited the nurses who were approached about the survey. Nurses who belonged to an association paid yearly dues to belong making it a voluntary organization with possibly limited members. A broader sampling could be obtained by disseminating the survey through an official survey company. The drawback here is the cost associated with utilizing a survey company.

The survey was heavily skewed with female respondents but that is the nature of nursing, a predominately female occupation. It is possible to try to gain a sample of male nurses in proportion to male nurses in the nursing population, utilizing a survey company. The ethnicity of the respondents was questioned but not where the nurse received their nursing education. There are many nurses in the United States who were trained in the Philippines and in India. It would be interesting to see if the education received overseas would alter the nurses' perspectives on their education and attitudes toward death. Would these attitudes be different depending on what country and culture they received their nursing education from?

The research results supported some previous studies and were contradictory to other studies. From this study it was found that more research is needed to ascertain what type of post-graduate education would most support the registered nurse in the workplace and aide in decreasing the anxiety level toward death. Population statistics from The Administration on Aging (2010) states that approximately 19 percent of the United States population will be 65 or

older by the year 2030. This increasingly aging population of the United States supports the need for increasing the end-of-life care provided by registered nurses. These nurses must be knowledgeable as well as comfortable supporting their patients in their end-of-life wishes and palliative care. To provide the elderly population with a good death is the ultimate goal.

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Appendices

Appendix A

Attitudes Toward Death and Palliative Care Education Needs Assessment Survey

Thank you for taking the time to complete this survey. The purpose of the survey is to gather attitudes toward death and extent of palliative care education and training of registered nurses in the United States.

The survey includes four sections and should take approximately 15 minutes complete. Part I of the survey is about attitudes toward death, Part II is about extent of palliative education and training, Part III focuses on demographic information, and Part IV includes two open-ended questions to provide a chance for free responses on related topics.

Survey Part I Attitudes Toward Death

Indicate how you would respond to each statement. Agree or disagree by choosing one of the following:

SD= strongly disagree; D= disagree; MD= moderately disagree; N=Neutral;
MA= moderately agree; A= agree; SA= strongly agree

Please work through each question even if it seems similar to another question.

1. Death is no doubt a grim experience. SD D MD N MA A SA
2. The prospects of my own death arouses
anxiety in me. SD D MD N MA A SA
3. I avoid death thoughts at all costs. SD D MD N MA A SA
4. I believe that I will be in heaven after I die. SD D MD N MA A SA
5. Death will bring an end to all my troubles. SD D MD N MA A SA
6. Death should be viewed as a natural,
undeniable, and unavoidable event. SD D MD N MA A SA

- | | |
|--|-------------------|
| 7. I am disturbed by the finality of death. | SD D MD N MA A SA |
| 8. Death is an entrance to a place of ultimate satisfaction. | SD D MD N MA A SA |
| 9. Death provides an escape from this terrible world. | SD D MD N MA A SA |
| 10. Whenever the thought of death enters my mind, I try to push it away. | SD D MD N MA A SA |
| 11. Death is deliverance from pain and suffering. | SD D MD N MA A SA |
| 12. I always try not to think about death. | SD D MD N MA A SA |
| 13. I believe that heaven will be a much better place than this world. | SD D MD N MA A SA |
| 14. Death is a natural aspect of life. | SD D MD N MA A SA |
| 15. Death is a union with God and eternal bliss. | SD D MD N MA A SA |
| 16. Death brings a promise of a new and glorious life. | SD D MD N MA A SA |
| 17. I would neither fear death nor welcome it. | SD D MD N MA A SA |
| 18. I have an intense fear of death. | SD D MD N MA A SA |
| 19. I avoid thinking about death altogether. | SD D MD N MA A SA |
| 20. The subject of life after death troubles me greatly. | SD D MD N MA A SA |
| 21. The fact that death will mean the end of everything as I know it frightens me. | SD D MD N MA A SA |
| 22. I look forward to a reunion with my loved ones after I die. | SD D MD N MA A SA |
| 23. I view death as a relief from earthly suffering. | SD D MD N MA A SA |

- | | |
|--|-------------------|
| 24. Death is simply a part of the process of life. | SD D MD N MA A SA |
| 25. I see death as a passage to an eternal and blessed place. | SD D MD N MA A SA |
| 26. I try to have nothing to do with the subject of death. | SD D MD N MA A SA |
| 27. Death offers a wonderful release of the soul. | SD D MD N MA A SA |
| 28. One thing that gives me comfort in facing death is my belief in the afterlife. | SD D MD N MA A SA |
| 29. I see death as a relief from the burden of this life. | SD D MD N MA A SA |
| 30. Death is neither good nor bad. | SD D MD N MA A SA |
| 31. I look forward to life after death. | SD D MD N MA A SA |
| 32. The uncertainty of not knowing what happens after death worries me. | SD D MD N MA A SA |

Survey Part II
Extent of Palliative Care Education and Training

1. What formal educational certifications and/or degrees have you obtained?
1) ASN/AD 2) BSN/BS/BS 3) MS/MA/MSN 4) Ph.D./DNP 5) Other_____
2. How many courses have you taken on palliative care during your formal education certifications and/or degrees that you have obtained?
1) None 2) One 3) Two 4) Three 5) More than three
3. In the last five years have you attended or are you currently attending any training (e.g., workshops, short courses) on palliative care? (Please do not include any courses from your basic degree).
1) No 2) Yes (If yes, please go to 3A)
- 3A. If you have attended any training in palliative care, please estimate how much time you spent in total on related training.
Approximate number of hours:_____

4. Overall, on a scale of 1 to 10, with 1 equivalent to “not at all prepared” and 10 equivalent to “very much prepared,” how would you rate your end-of-life care preparation?

Not at all prepared										Very much prepared
1	2	3	4	5	6	7	8	9	10	

For the following questions, please indicate your level of confidence meeting the identified palliative care need:

5. Identify grief and bereavement needs.

- I am confident I can do this on my own.
- I am somewhat confident but I feel more comfortable with occasional supervision.
- I am not confident of doing this and need supervision most of the time.
- I could not do this on my own at all.

6. Provide grief and bereavement support.

- I am confident I can do this on my own.
- I am somewhat confident but I feel more comfortable with occasional supervision.
- I am not confident of doing this and need supervision most of the time.
- I could not do this on my own at all.

7. Identify patients and families emotional and spiritual needs.

- I am confident I can do this on my own.
- I am somewhat confident but I feel more comfortable with occasional supervision.
- I am not confident of doing this and need supervision most of the time.
- I could not do this on my own at all.

8. Manage psycho-emotional distress.

- I am confident I can do this on my own.
- I am somewhat confident but I feel more comfortable with occasional supervision.
- I am not confident of doing this and need supervision most of the time.
- I could not do this on my own at all.

9. Break bad news to a patient or relative.

- I am confident I can do this on my own.
- I am somewhat confident but I feel more comfortable with occasional supervision.
- I am not confident of doing this and need supervision most of the time.
- I could not do this on my own at all.

10. Care for an actively dying patient.

- I am confident I can do this on my own.
- I am somewhat confident but I feel more comfortable with occasional supervision.
- I am not confident of doing this and need supervision most of the time.
- I could not do this on my own at all.

Survey Part III Demographics

1. What is your age?
1) 19-28 years 2) 29-38 3) 39-48 4) 48 and over
2. What is your gender?
1) Male 2) Female
3. What is your ethnicity?
1) Hispanic 2) African American 3) Caucasian 4) Asian 5) Other
4. How many years do you have in Nursing Practice (after receiving nursing degree)?
1) less than one year 2) 1-5 years 3) 6-10 years 4) 11-20 years 5) over 20 years
5. What state do you live in? _____
6. What is the area of nursing practice you currently work in?
1) Medical/Surgical 2) Intensive Care 3) Emergency/Trauma 4) Maternal/Child
5) Education 6) Management 7) Home Health 8) Hospice 9) Rehabilitation
10) Outpatient 11) Nursing Home/Extended Care

Survey Part IV Open-ended Questions

Finally, help us understand how you feel in your own words, about death and working with terminally ill patients. Your candid insights will be appreciated, so please elaborate as much as you can.

1. How would you describe your attitudes toward death?
2. How prepared do you feel you are in meeting patients' end-of-life needs?

Appendix B

Focus Group Protocol

Introduce the Focus Group

Thank you for agreeing to serve on this focus group. The goal of the focus group is to verify and gather further insights on the results of a survey about attitudes toward death and views on palliative care preparation.

Clarify and Provide Assurances for Participation

Your participation is voluntary and you may stop participating in the focus group at any time without any penalty. To make sure I capture all of your insights and for accurate documentation, I would like to record the focus group. In this regard, be assured that your insights will remain anonymous and won't be shared with anyone. For reporting purposes, all focus group insights will be tagged in the aggregate as group perspectives to verify and enrich survey data. That is, your responses will not be attributed to any specific participant in the focus group. So, do I have your permission to tape-record the focus group?

Questions About Attitudes Toward Death¹

General attitudes. The goal of the survey was to determine nurses' attitudes toward death. In general, the results of the survey indicated that: Summarize and show the results here for overall attitudes toward death.

Based on these results:

- How representative are the results of your own attitudes toward death?
-

- In general, do you think the results are accurately representing nurses' attitudes toward death?

Attitude scales. Attitudes toward death have been characterized as having three dimensions referred to as avoidance, escape, and neutrality. *Avoidance* is essentially related to anxiety toward death and represented by attitudes such as: "The prospects of my own death arouses anxiety in me" and "I always try not to think about death". In turn, *escape* refers to the extent to which individuals view death as a way to escape life's troubles and represented by attitudes such as: "I look forward to life after death" and "I see death as a relief from the burden of this life". Finally, *neutrality* refers to the extent to which attitudes toward death represent views that are neither anxious nor too accepting such as "Death should be viewed as a natural, undeniable, and unavoidable event" and "Death is neither good nor bad".

In this regard, the survey resulted in the following profile of avoidance, escape, and neutrality attitudes: Summarize and show profile.

Based on these results:

- How representative is the overall profile compared to your own attitudes toward death associated with avoidance, escape, and neutrality?
- In general, do you think the profile of attitudes toward death is accurately representing the nurses' profile of attitudes?

Questions About Palliative Education and Training

Self-assessment of overall preparation. Another goal of the survey was to determine the extent of preparation on Palliative education and training. In general, the results of the survey indicated that: Summarize and show the results here for self-assessment of overall Palliative care preparation.

Based on these results:

- How representative are the results of your own preparation in Palliative care?
- In general, do you think the results are accurately representing the nurses' preparation on Palliative care?

Level of confidence conducting palliative care. Another indicator of preparation on Palliative care is the level of confidence conducting related tasks. In general, the results of the survey indicated that: Summarize and show the results here for level of confidence conducting Palliative care tasks.

Based on these results:

- How representative are the results of your own level of confidence conducting related tasks?
- In general, do you think the results are accurately representing the nurses' level of preparation conducting related Palliative care tasks?

Questions About Explanatory Variables

Finally, the study results suggested that (summarize the interpretation of the best set of explanatory variables) are associated with more positive attitudes toward death.

Based on these results:

- Based on your nursing experience and attitudes toward death, how accurate is this characterization?
- How do you explain the importance of the reported characteristics found to be more closely associated with attitudes toward death?

Wrap-Up

Thank you for your participation in this focus group.

- Is there anything else you would like to add to the discussion?