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Nurses Engagement in End-of-Life Discussions with Dying Patients and Their Families

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This dissertation, NURSES ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES, by Frances Gomes Marthone was prepared under the direction of the candidate's dissertation committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of Nursing and Health Professions in the college of Health and Human Sciences, Georgia State University.

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ABSTRACT

NURSE ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES

by

FRANCES GOMES MARTHONE

Nurse engagement in end-of-life (EOL) conversations with terminally ill patients and their families is a crucial part of EOL care. However, research about nurses' attitudes about care of dying patients, their preparation to provide that care, and their perceived self-efficacy in engaging in EOL discussions is limited. The purpose of this descriptive correlational study was to a) assess medical-surgical nurses' self-efficacy for conducting EOL discussions and b) examine the relationships between mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations), self-efficacy, and nurse behaviors for conducting EOL discussions.

A total of 168 nurses from two hospital systems completed an online survey. Participants were primarily white/non-Hispanic (n=129; 77%) females (n=153; 91%) with a mean age of 45.1 years. These nurses averaged 11.5 years in nursing practice; half the nurses (50%) had an Associate's Degree.

The constructs of Psychological State (R^2 =20.08%; p=<.0001) and Mastery of Experiences (R^2 =13.19%; p=<.0001) made the largest contributions to Self-Efficacy, accounting for 33.27% of the variance. Self-efficacy had a significant relationship to Nurse’s Behaviors for EOL Discussions (R^2 =20.93%; p=<0.0001). The four constructs of Bandura’s model (Mastery of Experience, Vicarious Experiences, Psychological State, Social Persuasion) and Self-Efficacy significantly contributed to Behaviors for EOL Discussions (R^2 = 36.5; p=<.0001); Self-Efficacy made the largest contribution to the model (R^2 =20.93; p=.0001). Nurses with a high degree of self-efficacy reported a more positive Psychological State (AUC=0.748; p<=0.0001) and Mastery of Experiences (AUC=0.653; p=0.0339); however, Psychological State made the most significant contribution.

These findings suggest that nurses’ psychological state is the predominant factor in nurses’ engagement in EOL discussions with dying patients and their families. Also nurses’ personal attitudes about death and dying are pivotal to engaging these patients in EOL discussions. Future research is needed to test educational interventions that will better prepare nurses to conduct EOL discussions with dying patients and their families.

NURES ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES

by

FRANCES GOMES MARTHONE

A DISSERTATION

Presented in Partial Fulfillment of Requirements for the
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2016

DEDICATION

Let perseverance finish its work so that you may be mature and complete, not lacking anything. James 1:4

I start by saying prayers are answered every day, as I am reminded that GOD never gives you more than He knows you can handle. This accomplishment stands as a testimony to my Lord and Savior who put the desire for higher learning in my heart and gave me the stamina to accomplish this incredible milestone. Thank You Lord!

This dissertation is dedicated to my family and friends who stood by me during this tremendous journey especially my husband, Weiner, whose steadfast support and unwavering encouragement kept me on task, his humor gave me the strength and confidence to continue on when it seemed an impossible task. I can’t thank you enough Babe, you are the best!

In addition, I thank my three brilliant children, Madeline, Christian, and Jon Anthony who have been a tremendous support and awesome cheerleaders often lifting me up with needed encouragement. My children have taught me so much about myself, and having them in my life has enriched my existence more than I can ever express. I pray for the day that I can return the favor and can give each of you the same love and support as you pursue your Ph.Ds. GO team Marthone!

Lastly, I am extremely thankful and grateful to my late Father, Joao Damata Bento and my wonderful mother Antonia Gomes Bento who believed in me and gave me the confidence to push myself as I reached for the stars. Without your constant encouragement and words of wisdom I would never have dared to dream so big!

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Most importantly, I would like to thank all the nurses who participated in this study. Without your participation it would not have been possible to understand the role of perceived self-efficacy and the many subtleties involved in engaging patients in end-of-life conversations that otherwise would go unspoken. Your dedication to your patients and to our profession is invaluable.

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
CHD	Congenital heart disease
CHF	Congestive heart failure
CKD	Chronic kidney disease
CNO	Chief Nursing Officer
ESRD	End stage renal disease
FATCOD	The Frommelt Attitudes Toward Care of the Dying
HIV	Human immunodeficiency virus
HFHS	High fidelity-human simulation
ICU	Intensive Care Unit
ID	Identification
IPS	Internet Protocol address
NHPCO	National Hospice and Palliative Care Organization
PC	Palliative Care
PHC	Piedmont Healthcare
PICC	Peripherally inserted central catheter
PPMHS	Phoebe Putney Memorial Health System
QOC	Quality of Communication
SE	Self-Efficacy
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment

CHAPTER I

INTRODUCTION

Among the characteristics of human behavior, few are more pervasive than beliefs of personal efficacy.

-Albert Bandura & Edwin A. Locke, 2003.

Discussions around end-of-life (EOL) decisions are not easy. The practice of initiating EOL discussions is not a straightforward process. Despite patient preferences for EOL discussions, meaningful conversations between patients and their providers have not become part of routine care (Gaber, Planchant, & McGavin, 2004; Janssen, Schols, & Wouters, 2011; Leung, Udris, Uman, and Au, 2012). The reluctance of physicians to discuss EOL care with their patients has been attributed to a lack of time, lack of training, and insecurity about the content of these discussions (Knauft, Engelberg, Patrick, & Curtis, 2005; Leung, Udris, Uman, & Au, 2012). Physicians feel that these discussions might disrupt the therapeutic relationship they have with their patients (Knauft, Engelberg, Patrick, & Curtis, 2005; Leung Udris, Uman, & Au, 2012;) while nurses feel these discussions may diminish hope or compound the patient and family's suffering (Davison, 2001; Lamiani, Meyer, Leone, Vegni, Browning, Rider, Trugo, & Moja, 2011).

Timely conversations about EOL are important because of the numerous decisions to be made by the patient and their families, the time involved in making these decisions, and the emotional toll talking about EOL care raises. Communication about EOL care and decisions is a complicated yet vital process that must be endured to secure the patient's final wishes. Patient-clinician communication is needed to inform patients and families and assist them in understanding their diagnosis, treatment, prognosis, and what dying might be like (Fine, Reed, Shengelia, & Adelman, 2010). EOL discussions are also necessary to help patients, family, and clinicians understand patient preferences related to life-sustaining treatments (Fine, Reed, Shengelia, & Adelman, 2010). Discussions about EOL offer the best opportunities to ensure that EOL is in accordance with patients' wishes and values (Leung, Udris, Uman, & Au, 2012). The lack of timely EOL discussions leaves patients and their families confused and unsure of when and how to proceed with EOL decisions (Waldrop, Meeker, Kerr, Skretny, Tangeman, & Milch, 2012). It is important for family members and health care providers to know the kind of medical care the patient wants at the EOL. If decisions about EOL care have not been discussed between the patient, caregivers and the health care team in advance, caregivers may feel anxious as they struggle to understand changes in their loved one's physical condition, thus not recognizing when important care decisions should be made.

The majority of people in the United States will die from chronic illnesses, with a dying trajectory of months or years (Boot & Wilson, 2014). While some deaths are sudden and unpredictable, most people go through a period of illness in which death becomes increasingly probable. This time affords an opportunity for the patient, family members and the healthcare team to be involved in EOL discussions about their care, preferences, priorities, and final wishes.

Terminally ill patients at the end-of-life and their families report that honest communication is vitally important (Glaser & Strauss, 2009). Challenges, barriers, and opportunities for communication exist for many healthcare providers who come into contact with these patients and their families (Dunn, 2009). Findings from the SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) revealed poor communication between patients and healthcare providers as one of many deficiencies in EOL care (The SUPPORT Principal Investigators, 1995). When EOL issues are not addressed, the lack of knowledge about the person's preferences can severely compromise the quality of EOL care and the dying experience for terminally ill patient and their families (Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008). Nurses can positively impact these experiences by engaging their patients and families in EOL discussions.

Background and Significance of the Problem

Quality EOL care is increasingly recognized as an ethical obligation for healthcare providers (Glaser & Strauss, 2009). Communication among patients, families, and healthcare professionals is an important component of high quality care, yet empirical data suggest that communication about end-of-life care is often limited in frequency and in scope (Bradley, Cherlin, McCorkle, Fried, Kasl, Cicchetti, Johnson-Hurzeler, & Horwitz, 2001). Previous studies have estimated that fewer than 40% of patients with advanced cancer have EOL care discussions with physicians (Clayton, Butow, & Tattersall; Mack, Paulk, Viswanath, & Prigerson, 2010, 2005). Research findings also indicate that ineffective communication related to EOL issues is likely a result of the physicians' inability to have these discussions. In a study of medical interns caring for dying patients only 16% of the medical students reported conversations with their patients specifically about dying or the psychological issues surrounding death (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurseler, & Bradley, 2005).

Healthcare providers may experience anxious thoughts or feelings when thinking about or talking about death and/or the dying process, or when interacting with someone who is dying (Lehto, Stein, & Farchaus 2009; Mallet, Jurs, Price, & Slenker, 1991; Tomer, & Grafton, 1996). These uncomfortable thoughts or feelings may be a result of the avoidance of such discussions about death and dying in the American culture (Nyatanga & deVocht, 2006). The focus of medical care in the United States is primarily on prolonging life and avoiding death. Many nurses and physicians feel inadequately trained to provide high quality EOL care or to communicate effectively with a patient who is dying (Billings, Engelberg, Curtis, Block, & Sullivan, 2010; Schell, Green, Tulksy, & Arnold, 2013; White & Coyne, 2002).

National guidelines recommend that patients who have incurable cancer and a life expectancy of less than one year have EOL care discussions with their physicians or health care provider as soon as feasibly possible (Mack, Paulk, Viswanath, & Prigerson, 2010). Although the acceptance of “do not resuscitate” (DNR) has increased significantly over the past six years, most cancer patients or their surrogates sign directives on the day of death. The time-based relationship between the signing of the DNR order and death is a reflection of the lack of timely conversations related to end-of-life care planning (Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008). Existing literature asserts that many physicians avoid EOL care discussions until death is imminent (Mack, Paulk, Viswanath, & Prigerson, 2010). This late timing may be a manifestation of the discomfort and difficulty healthcare professionals experience when discussing this sensitive topic. Evidence shows that EOL discussions occur late in the course of illness leading to hospice referrals that occur within days of death (Earle, Neville, Landrum, Ayanian, Block, & Weeks, 2004; Mack et al., 2010).

Terminal cancer is a disease with a more predictable trajectory of decline, yet many patients and families do not receive the benefit of EOL discussions with healthcare professionals entrusted with their care (Boyd, Merkh, Rutledge, & Randall, 2011). According to data collected by the National Hospice and Palliative Care Organization (NHPCO), an estimated 1.4 million patients received services from hospice in 2011. The median length of hospice care services during that time was 19.1 days. Half of hospice patients studied received care for less than three weeks before dying (NHPCO, 2011). Because of the increased prognostic accuracy of cancer, the need for effective communication about life expectancy and final wishes is more urgent for this patient population (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurseler, & Bradley, 2005).

Studies also indicate that patients with chronic diseases such as acquired immunodeficiency syndrome (AIDS) (Curtis, Patrick, Caldwell, & Collier, 2000), congenital heart disease (CHD) (Swetz, Freeman, AbouEzzeddine, Carter, Boilson, Ottenberg, Park, & Mueller, 2011; Tobler, Greutmann, Coleman, Yantiri, Librach, & Kovacs, 2012a) and chronic obstructive pulmonary disease (COPD) (Iley, 2012; Reinke, Griffith, Wolpin, Donesky-Cuenco, Carrieri-Kohlman, & Nguyen, 2011) have the same experiences as many terminal cancer patients. EOL care discussions are not consistently happening between these patients, their families, and their healthcare providers. For example, in a study of 1,031 persons with AIDS, 68 percent knew of advanced directives, but only 11 percent had discussions with their healthcare providers about EOL care or advanced directives (Curtis, Patrick, Caldwell, & Collier, 2000).

In a study of adult patients with congenital heart disease (N=48) EOL discussions were documented in 10 percent of the patients' records with the median of 16 hospitalized days before death. Forty-one percent of documented EOL discussions occurred with family members, suggesting the patient was not able to participate. These discussions occurred generally two days before death (Tobler, Greutmann, Coleman, Yantiri, Librach, & Kovacs, 2012a). In a second study by this same team only two patients (N=200 patients) reported having EOL discussions with their medical team. In contrast 50 percent of the physicians (N=48) reported typically discussing issues including life expectancy, advance planning and resuscitation preferences with their patients (Tobler, Greutmann, Coleman, Yantiri, Librach, & Kovacs, 2012b). This study suggests a disconnect between what patients are experiencing and what physicians are reporting.

Harding and colleagues conducted a study about the information needs of congestive heart failure (CHF) patients. The evidence revealed that patients (N=20) suffering with CHF often lack knowledge about their condition and prognosis – a factor which may contribute to depression, poor drug adherence, unplanned admissions, low patient/physician congruity regarding advanced care preferences, and less decision-making involvement than occurs with cancer patients (Harding, Selman, Beynon, Hodson, Coady, Read, Walton, Gibbs, & Higginson, 2008).

Despite the progressive nature of COPD, less than 20 percent of patients (n=376) with this diagnosis had advanced directives and less than one third had EOL discussions with their healthcare provider (Reinke, Griffith, Wolpin, Donesky-Cuenco, Carrieri-Kohlman, & Nguyen, 2011). The results of this study underscore the importance of timely healthcare provider communication and EOL discussions with patients and families. Such discussions foster EOL decision making that incorporates the patients' values and preferences (Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008).

The EOL discussions and DNR directives support patient autonomy related to palliative care decisions including a peaceful, natural death. Improved doctor-patient communication about EOL care goals may lead to timelier decision-making and improved communication for the patient and family about EOL options (Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008).

The lack of EOL discussions impacts the family of the dying patients as well. Family members often play central roles in EOL treatment decisions and depend on clinicians for understandable information about their loved one's prognosis and alternative approaches to care. Several studies have reported that what matters to patients and families at the EOL is having clear understanding of the patient's illness and treatment options (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurseler, & Bradley, 2005; Earle, Neville, Landrum, Ayanian, & Block, 2004; Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008; Singer, Martin, & Kelner, 1999).

Patients and families tend to view the end-of-life with broader psychosocial and spiritual meaning, shaped by a lifetime of experiences (Steinhauser, Christakis, Clip, McNeilly, McIntyre, & Tulsky, 2000). The lack of EOL discussions denies patients and families the physical, emotional, and spiritual work processes that can lead to acceptance of the terminal prognosis (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurseler, & Bradley, 2005). Holdsworth and King (2011) found that lack of information about the dying process was upsetting to the family as they believed more information on what to expect in the final weeks, days and hours would have made coping and planning easier (Holdsworth & King, 2011).

Cherlin and associates (2005) examined physician communication with terminally ill patients and families and reported 41 percent of family caregivers (N=218) indicated that physicians waited until less than one month prior to the patient's death to tell them the patient's illness could not be cured (Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurseler, & Bradley, 2005). Without EOL discussions to guide them or a record of the loved one's final wishes, the family was left feeling unsure about the choices they had made for EOL care (Holdsworth & King, 2011). When the family members are better prepared for the death of their loved one, they are less likely to experience complicated grief during bereavement (Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008). Family members felt more prepared for their loved one's death when there was open communication with and between providers. Although it will never be an easy discussion to have with patients and family members, conversations about EOL are a vital part of the dying process (Jackson, Derderian, White, Ayotte, Fiorini, Hall, & Shay, 2012).

Evidence is clear that physicians are not engaging patients in EOL discussions in a timely and effective manner. Using this information, it is reasonable to extrapolate that other healthcare providers such as nurses are equally poor in engaging patients and families in EOL discussions. Most acute care nurses have little training and lack knowledge about palliative care practices that are appropriate for patients at EOL (Boyd, Merkh, Rutledge, & Randall, 2011). The majority of nurses participating in a study by Dunn (2009) reported that they had received previous educational training on death and dying; however, 69 percent of the sample (N=58) felt the education they had received did not adequately prepare them to deal with death and dying (Dunn, Otten, & Stephens, 2005).

Nurse-initiated discussions regarding the disease process, expectations of care, and the integration of information assist in reducing conflicts and improving decision making (Jackson, Derderian, White, Ayotte, Fiorini, Hall, & Shay, 2012). Nurses can have an integral role in facilitating EOL discussions as a function of their role as patient advocates. They can also be facilitators as they assess the patients' and families' perceptions of the prognosis and their coping skills (Jackson, Derderian, White, Ayotte, Fiorini, Hall, & Shay, 2012). The majority of nurses in a study by Dunn and team (2005) felt strongly that caring for and interacting with dying patients and their families was worthwhile and an important part their work (Dunn, Otten, & Stephens, 2005).

Nurses spend more time with patients who are dying than physicians because of the central role that nurse's play in care at the end-of-life. Research evaluating the quality of care for terminally-ill patients should focus on nursing interventions and related outcomes (Bradley, Cherlin, McCorkle, Fried, Kasl, Cicchetti, Johnson-Hurzeler, & Horwitz, 2001). Nurses are in an ideal position to assume an important role in EOL processes because of the frequency and continuity of contact that nurses have with their dying patients (Boyd, Merkh, Rutledge, & Randall, 2011).

Patients have palliative care needs, but communication about prognosis and end-of-life care is lacking. Nurses can play an important role in such communication, but their views on this topic have rarely been sought (Hjelmfors, Strömberg, Friedrichsen, Mårtensson, & Jaarsma, 2014). Awareness of the important role nurses have and want to have in EOL discussions should be raised and taken into account. Nurses have much to offer regarding EOL discussions but are often left out of the conversation (Boyd, Merkh, Rutledge, & Randall, 2011). The exact nature of the nurse's role and how nurses may contribute to timely and effective EOL discussions is not well understood (Kirby, Broom, & Good, 2014).

Purpose

The purpose of this descriptive correlational study was twofold: a) to assess the level of nurse self-efficacy for conducting EOL discussions, and b) to examine the relationships between mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for participation in EOL discussions with terminally ill patients and their families.

Specific Aims of the Study

Nurses' attitudes, behaviors and role related to discussions of EOL care issues with their patients and their families were examined. Nurses' experience with death and dying and its impact on their perceived self-efficacy with this skill set was explored. The effect of nurse education for engaging patients and families in EOL discussion, nurse barriers and resistance to engaging in timely EOL discussions with patients and family members and the reasons nurses do or do not facilitate EOL discussions were also investigated. Bandura’s Model of Self-Efficacy that includes four constructs (Mastery of Experiences, Vicarious Experiences, Psychological Status and Social Persuasion) guided the exploration of nurse engagement in EOL discussions with their patients.

The specific aims of this study were to:

- To examine the relationship of mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families.
- To examine the relationship between self-efficacy and nurse participation in EOL discussions.
- To explore the relationship of mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing

leadership expectations), nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions.

- To examine the difference in mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions between oncology nurses and medical-surgical nurses.
- To examine the difference in mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions between nurses with higher self-efficacy and those with lower self-efficacy.

For the purposes of this study EOL care discussions was defined as any discussion between the nurse and patient, the nurse, patient and family, or the nurse and family about physical and emotional changes caused by the disease, its progression, and treatment; advanced care planning and the venue for care [e.g., hospice, home, hospital, nursing home]; and the patient's preferences related to care [e.g., resuscitation, do not resuscitate (DNR), pain management, comfort measures, etc.] as verbally reported by the nurse (Mack, Paulk, Viswanath, & Prigerson, 2010).

Self-efficacy is an important competency for nurses who are advocates for their patients. Nurses with high levels of self-efficacy are successful in managing the multidimensional role of the nurse in today's practice environment. Research indicates that self-efficacy and knowledge have a positive effect on performance (Clark, Owen, & Tholcken, 2004; Ip, Tang, & Goggins, 2009; Madorin & Iwasiw, 1999; Multon, Brown, & Lent, 1991; Schunk, 1996). When nurses have greater knowledge and self-efficacy they are more available to meet their patients' needs and less likely to focus solely on the skill needed to perform; instead they focus on the patient's individual needs (Coolen, Loeffen, & Draaisma, 2010; Radwin, 1998). Bandura's Theory of Self-Efficacy (1977a) proposes that one's belief in her/his abilities to activate the motivation, cognitive resources, and courses of action needed to exercise control over one's work predicts performance. Consequently, nurses who demonstrate higher levels of perceived self-efficacy are more likely to have greater control over their work and better performance when providing nursing care, including participation in EOL discussions with their patients (Bandura, 1977a).

The concept of perceived self-efficacy has been described as a person’s beliefs in their ability to influence events that affect their lives. This core belief is the foundation of human motivation, performance accomplishments, and emotional well-being. Unless nurses believe they can produce the desired result by their actions such as engaging patients and their families in EOL discussions, they have little incentive to undertake activities or to persevere in the face of more difficult situations (Bandura, 1997a, 1986).

If nurses are competent with their skills but do not have perceived self-efficacy, they may not act as quickly and effectively to address a patient’s need. For example, a nurse may know how to perform cardiopulmonary resuscitation (CPR) but not have perceived self-efficacy due to minimal experience with conducting a code or lack of mastery with the skill. On the other hand, if nurses have sufficient self-efficacy but lack the necessary knowledge and skills, an unsafe situation could occur (Turner, Lukkassen, Bakker, Draaisma, & ten Cate, 2009). Clinicians must have knowledge, skill and self-efficacy in order to provide competent care to their patients (Tzeng & Yin, 2006). Manojlovich (2005a) explored the relationship between self-efficacy and professional practice behaviors in a sample of 266 nurses. Self-efficacy was found to be a stronger predictor of behavior than a sense of empowerment (Manojlovich, 2005a). Self-efficacy may be an important construct related to nurse engagement in EOL discussions with patients and their families yet very little research has explored this phenomenon.

Research that explores the relationship between perceived self-efficacy and nurses’ engagement in EOL discussions with their patients and families will make a valuable and needed contribution to the body of nursing knowledge. Identifying barriers to engaging in these conversations and strategies to improve perceived self-efficacy related to nurse participation in EOL discussions gives direction to interventions that will assist nurses in improving the patient and family experience with EOL care and decision-making.

Theoretical Framework

Much of the psychological research is aimed at understanding how people gain knowledge of their social and physical environment; equally important is how a person comes to know themselves and how their self-precepts affect their psycho-social functioning (Bandura, 2010). Among the different facets of self-knowledge, the most important in daily working relationships is the understanding of one's own self-efficacy and how it influences one's judgments and behaviors. Bandura (1982) affirms that self-efficacy is concerned with judgments about how well one can organize and execute a skill necessary to deal with situations encountered every day.

Self-Efficacy Theory

Bandura's Theory of Self-Efficacy was the selected theoretical framework for this study which focused on nurse's perceived self-efficacy for engaging patients and family members in EOL discussions. Bandura (1977b) presented self-efficacy as the primary base for social cognitive theory. Self-efficacy is associated with the concept of one's conviction of one's own capabilities, which directly affects an individual's presentation, conduct, performance, and motivation (Bandura, 1977b, 1982).

This social cognitive theory provides a framework for understanding how determinants of behavior operate together to explain action. Self-efficacy is defined as a self-perception of one's own ability to perform competently and effectively in a particular task or setting (Bandura 1977b, 1982). It is based on individuals' belief that they can change their behavior by having the self-efficacy to change it. Self-efficacy beliefs influence how individuals think, feel, and motivate themselves to act (Bandura, 1982).

Self-efficacy is a person’s feelings and thoughts about his/her ability of accomplishing a given task. If a person believes that a given situation exceeds his ability, he will avoid that situation. The stronger the perceived self-efficacy the more active and persistent are the efforts of the individual. Competence and knowledge are gained through sustained efforts. Bandura suggests that individuals who have a strong sense of efficacy engage their attention and effort on the demands of the situation and are spurred on to greater effort by the challenge (Bandura, 1977b, 1982).

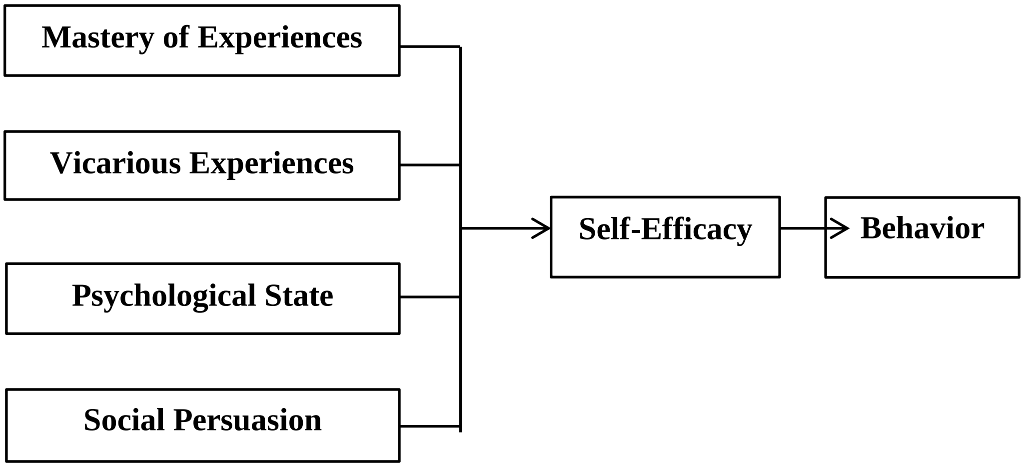
A strong sense of self-efficacy allows a person to persevere in efforts towards success. Behavior and actions are dependent on one’s efficacy beliefs, which determine which behaviors a person chooses to perform, the degree of perseverance, and the quality of the performance (Tobler, Greutmann, Coleman, Yantiri, Librach, & Kovacs, 2012).

Proponents of this theory believe the value of self-efficacy is that people who judge themselves as being capable to perform a particular task will attempt to and successfully complete it, in contrast to those who do not have this belief (Murphy & Kraft, 1993). Individuals who perform unsuccessfully are likely to do so not because they are deficient or lack the skill and knowledge, but because they have lower perceived self-efficacy to use their skills effectively (Lauder, Holland, Roxburgh, Topping, Watson, Johnson, Porter, & Behr, 2008).

Four Elements of Self-Efficacy

Bandura identified four elements of the Self-Efficacy Theory that contribute to a person's perceived self-efficacy: mastery of experiences, vicarious experiences, social persuasion, and psychological state. See Figure 1. Mastery of experiences reflects performance accomplishments or enactive attainment. Vicarious experiences are described as social modeling, while social persuasion is derived from peer and environmental cues. Finally, psychological state is measured by one's psychological response to the situation at hand (Bandura, 1977b, 1982). Bandura's theory suggests that with the mastery of the knowledge and skills attained through life experiences, examples attained from people and situations in one's environment, encouragement from others, and one's own positive response to the phenomenon of interest, an individual accrues the necessary self-efficacy to act or lacks sufficient self-efficacy to act.

Figure 1. Bandura's Self-Efficacy Model



Mastery of Experiences

Mastery of experiences, also called enactive attainment and performance accomplishments (Zulkosky, 2009) refers to a personal history of success and failures performing a particular task (Bandura, 1977b, 1982). It is a primary source of self-efficacy. A person with a strong success record will have a strong sense of self-efficacy. This high level of perceived self-efficacy based on past successes will allow the individual to persist longer at a new task until he/she succeeds in demonstrating mastery in the situation. This increased perceived self-efficacy reinforces the behavior of success with each new task. A person who does not believe they can master a task due to past failures, will have a lower sense of perceived self-efficacy. They will give up quickly and their beliefs that they do not have the skills or education needed to perform successfully in the situation will be reinforced thus sealing the belief of low self-efficacy **(**Cheraghi, Hassani, Yaghmael, & Alavi-Majed, 2009)**.**

Vicarious Experiences

A vicarious experience is the act of modeling one's behavior after a peer who has been identified as an equal in abilities, skill set and education. A vicarious experience occurs when a person observes while another individual performs activities without adverse consequences. This act of modeling generates expectations in the observer that he/she too will be successful in the observed endeavor (Cheraghi, Hassani, Yaghmael, & Alavi-Majed, 2009). Vicarious experiences positively motivate the observer to perform a task, which increases self-efficacy.

Social Persuasion

Social persuasion is the attempt to influence a person's behavior by convincing them through suggestion and encouragement that they can accomplish the task (Bandura, 1977b, 1982). Verbal or social persuasion is a form of coaching and mentoring; it provides encouragement and positive reinforcement. Social persuasion is most effective when the person giving the feedback is viewed as credible and has knowledge of other past experiences with the individual being coached (Brown & Inouye, 1978). The encouragement and positive reinforcements provided through social persuasion builds the person's self-efficacy which allows the needed behavior to occur.

Psychological State

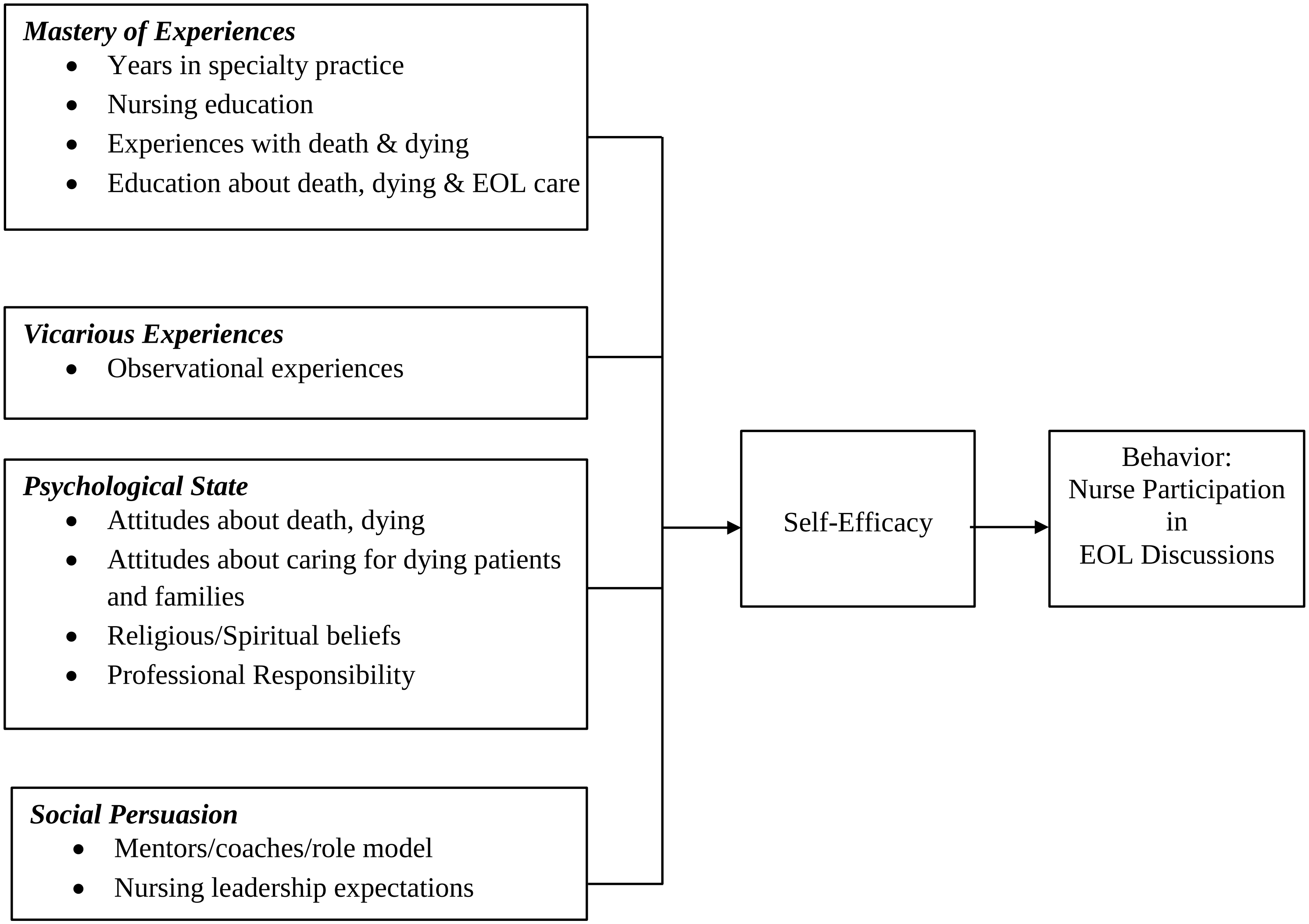
Psychological state or emotional arousal is generated from stressful and taxing situations (Bandura, 1977a, 1982). Stress, anxiety and perceived vulnerability can impact one's assessment of their ability to successfully complete the task. One's perception of his/her own capabilities also influences his thought process and emotional reaction during anticipatory and actual events making the task more formidable than it actually is (Bandura, 2010). A positive psychological state can increase self-efficacy, while a stressed or taxing psychological state could cause one to doubt their abilities and decrease perceived self-efficacy.

Self-Efficacy and Nurses' Participation in EOL Discussions

To date, nurse participation in EOL discussions has not been quantified so little is known about nurse self-efficacy in conducting these conversations. Bandura's self-efficacy refers to a self-perception of one's own ability to perform competently and effectively in a particular task or setting (Bandura, 1977a, 1982). Based on this theory, if nurses have the knowledge and skills (mastery of experiences), observe peers as they engage in EOL discussions (vicarious experiences), are encouraged by colleagues and nursing leadership (social persuasion), possess a positive attitude about death and dying and caring for dying patients and their families, and perceive that participation in EOL discussions is a professional responsibility (psychological state), they will possess a higher level of self-efficacy related to EOL engagement, and thus will initiate and participate in EOL discussions with dying patients and their families. See Figure 2.

The following sections present the application of the Bandura's theoretical concepts (mastery of experiences, vicarious experiences, psychological state, and social persuasion) to this study. The variables associated with each of these concepts are described.

Figure 2: Application of Bandura's Self-Efficacy Model



Mastery of Experiences:

For this study, the mastery of experiences was defined as the number of years the nurses have worked in their specialty practice, their highest level of nursing education, their experiences with death and dying (professional and personal), and their education related to death, dying, and EOL care. Nurse's clinical knowledge and expertise evolves from their nursing education and years of specialty practice. In addition, educational, professional and personal experiences with death enlighten the nurse's awareness of the needs of both the dying patient and their families.

Vicarious Experiences:

Vicarious experience was defined as watching peers successfully engage patients and families in EOL discussions. When a nurse who has little experience and knowledge related to EOL discussions observes a peer engaging in such discussions, she learns how to do the task and believes that she too can be successful engaging patients and families in EOL discussions.

Social Persuasion:

In this study, social persuasion was approached from two perspectives: a) the influence of mentors and coaches in EOL skill development, and b) the employer's perceived expectations that the nurse will engage in EOL discussions with dying patients and their families. Nurse mentors and coaches can be a significant influence in a nurse's skill development related to EOL care and conducting EOL discussions with dying patients and their families. These mentors/coaches teach, encourage and support nurses as they develop these important skills.

Nurses who perceive that the nursing administrative team (e.g., nurse manager, chief nursing officer (CNO), director, or supervisor) expect nurses to have EOL conversations are more likely to engage in EOL discussions. As advocates for their patients, many nurses feel that they must direct their patients' concerns, questions or problems to the appropriate people who can address these issues for the patient and family. Many nurse administrators hold the same expectation. Thus, if the patient has concerns or questions about EOL care, the nurse administrator would expect the nurse to address these issues.

Psychological State:

The psychological state of nurses was measured by assessing nurses' a) attitudes about death and dying, b) attitudes about caring for dying patients and families, c) spiritual/religious beliefs related to care of the dying, and d) professional responsibility to engage in EOL discussions. Nurses' personal attitudes toward death and dying may influence the care a patient receives. If the nurse is apprehensive or perceives the situation as stressful or taxing, EOL care may be delayed, incomplete or not provided. On the other hand, having a positive attitude towards death and dying allows the nurse to use her knowledge and skills to support the dying patient and their families. Also spiritual or religious beliefs may influence the nurse's attitudes about death and dying and caring for terminally ill patients. Finally, a nurse's sense of professional responsibility related to the care of dying patients and their families supports nurse self-efficacy to care for these patients and families including engaging in EOL conversations.

In review, the Theory of Self-Efficacy was an appropriate fit for this study. This model provided the conceptual structure to examine the factors that influence a nurse's perceived self-efficacy (mastery of experiences, vicarious experiences, psychological state, and social persuasion) and the relationship of self-efficacy and nurse engagement in EOL discussions with dying patients and their families.

In addition, Bandura's theory assisted in identifying barriers that interfere with nurses engaging in EOL discussion, examining nurse self-efficacy and engaging in EOL discussions across nurse practice settings. In essence Bandura's Theory of Self-Efficacy provided a framework for identifying gaps in engagement in EOL discussions between education and practice.

Summary

In summary there is a clear need for effective and timely EOL discussions with terminally ill patients and their families across many chronic and life threatening diagnoses. Patients and families are not receiving needed information to make final decisions, primarily due to the lack of education, training, experience and comfort levels of heath care providers engaging in EOL discussions. Evidence is lacking that indicates nurses are among those healthcare providers engaging their dying patients in these needed conversations.

Current research has identified that little is known of the nurse's role in relation to EOL care and discussions. The goal of this study was to understand and identify the issues that hinder nurses from engaging in EOL discussions with dying patients and their families. Bandura's Theory of Self-Efficacy affirms that a nurse's self-efficacy in her skills and knowledge influences how she approaches situations that may be perceived as challenging. This study will provide in depth information which can be used to create and test interventions that enhance self-efficacy such that nurses actively seek opportunities to engage dying patients and their families in EOL discussions.

CHAPTER II

REVIEW OF THE LITERATURE

Patients with serious illness generally understand their medical condition, but many do not understand their prognosis or the possible outcomes of treatment. Sometimes they overestimate the probability of a cure or long-term survival. Despite the essential role that communication plays in informed decision-making, research has demonstrated serious deficiencies in regard to patient's understanding of their condition as it relates to the end-stage progression of their disease (Gramling, Norton, Ladwig, Metzger, DeLuca, Gramling, Schatz, Epstein, Quill, & Alexander, 2012). Research confirms that physicians lack training and self-efficacy in communication skills that would enable them to engage in these important conversations (Fisher, 2006).

Although nurses spend more time with terminally ill patients than all other members of the healthcare team, evidence that addresses nurses' participation in EOL discussions is sparse. In addition, little is known about nurse self-efficacy related to discussions of EOL issues. This literature review discusses the state of the science regarding health provider communication about EOL care and issues with patients and families. The role of self-efficacy in discussing EOL issues will be highlighted and factors that support this self-efficacy will be examined.

Nurses' Participation in EOL Discussions

Participation in EOL discussions is not a regular or frequent experience for most nurses working in acute care settings. Although nurses on medical-surgical units or other specialty units such as those treating congestive heart failure (CHF) or chronic obstructive pulmonary disease (COPD) may have the occasion to address EOL issues with patients, the frequency of such discussions is likely minimal. Oncology nurses are more clearly associated with EOL care; this is evidenced by the fact that most articles related to nurses and EOL are focused on oncology nurses. Literature does not address the role of the medical-surgical nurse as it relates to EOL care or discussions. The evidence available has examined the role of the nurse and EOL care in settings such as nursing homes, hospice, and oncology units and in the intensive care units, leaving a gap in the literature concerning medical-surgical nursing units. However, the lack of evidence does not negate the responsibility of any nurse to engage in EOL care and discussions with dying patients and their family.

On a daily basis, nurses who work in oncology settings care for patients who are dealing with a potentially terminal disease. They provide expert clinical care, as well as educational and emotional support to both patient and family (Davison, Goldenberg, Gleave, & Degner, 2003). These nurses play a principal role in the care of dying individuals and their families (Wagner, Riopelle, Steckart, Lorenz, & Rosenfeld, 2010). In general, they receive education related to death and dying that includes management of the psychological aspects of living and dying with a terminal illness. Oncology nurses are also exposed to role models and mentors who exemplify ways to best manage the physical, emotional and spiritual needs of these patients. These nurses work in a supportive environment where they can learn about care of the dying from those around them. For oncology nurses, EOL discussions with dying patients are considered a professional responsibility.

Research supports some of the benefits that nurses receive from caring for those with life-threatening illnesses. In a convenience sample of 403 employed nurses, those nurses who cared for a greater percentage of terminally ill patients had more positive attitudes towards caring for dying patients than nurses with less experience. These nurses felt death was not a topic to be avoided, they considered death as neither good nor bad, and many viewed death as a deliverance from pain and suffering (Wagner, Riopelle, Steckart, Lorenz, & Rosenfeld, 2010).

With positive attitudes about death and dying and recognizing the personal satisfaction in caring for dying patients, nurses are most likely to participate in EOL discussions (Boyd, Merkh, Rutledge, & Randall, 2011). Bradley and colleagues (2001) questioned 31 oncology nurses about the initiation of EOL discussions. Descriptively, these nurses had discussed hospice care and EOL issues more often with family members (81%) than with their patients (71%). The majority of nurses (66%) reported that family members inquired about hospice and EOL care prior to any nurse-initiated discussions. These nurses (23%) engaged in EOL discussions with patients and family members more frequently than oncologists (13%). Nurses who practiced in an inpatient setting were more likely to engage in EOL discussion than those working in an outpatient setting. Increased frequency in performing end-of-life care activities was significantly associated with more years working as a nurse, having received hospice training, and being more comfortable with discussing the patient’s prognosis. The findings indicate that oncology nurses integrate palliative care practices into patient care (Bradley, Cherlin, McCorkle, Fried, Kasl, Cicchetti, Johnson-Hurzeler, & Horwitz, 2001).

EOL has been studied internationally. Studies conducted in Europe surveyed ICU nurses in respect to their involvement in EOL discussions. Findings indicated that 85% of the respondents had cared for patients at EOL in the ICU. In addition, 69% of the nurses stated they believed the EOL decisions were made too late for the patient and their families (Latour, Fulbrook, & Albarran, 2009). The study by Ho and colleagues reported that “senior” nurses were most involved with EOL discussions. This finding suggests that senior nurses have more experience and would naturally be more involved in such discussions than less experienced nurses (Ho, English, & Bell, 2005).

In a study with 73 men diagnosed with early stage prostate cancer, Davison and colleagues (2003) examined the role of the nurse as a source of information. Oncology nurses were able to provide high quality information and assist patients by interpreting information provided by other healthcare professionals. These nurses were perceived as effective and important information providers by cancer patients, especially in the provision of explanations and clarification of information previously provided by the physician (Davison, Goldenberg, Gleave, & Degner, 2003).

Oncology nurses address EOL issues as they arise while providing care for their patients. Although oncology nurses receive some training post-graduation, for many nurses EOL training is limited, informal and inconsistent in content (Brant & Wickham, 2013). Nursing programs across this country are inconsistent with providing such education to nursing students (Koutsopoulou, Papathanassoglou, Katapodi, & Patiraki, 2010). Koutsopoulou et al. concluded that most oncology nurses develop the attitudes, knowledge, and skills needed to care for dying patients on-the-job and over time. These learned skills are mainly related to providing physical and emotional support to both patients and family members (Ferrell, Grant, & Virani, 1999). Identifying strategies that help nurses be more confident in having EOL conversations may lead to structured interventions to improve perceived self-efficacy which will result in more effective and timely EOL communications. Nurses understand the concept of on-the-job training and oncology nurses are more familiar than other nurses with the need for timely and effective EOL discussions (Koutsopoulou, Papathanassoglou, Katapodi, & Patiraki, 2010). However, there should be a more formal and organized educational process related to EOL discussions for all nurses who care for terminally ill patients. This is most critical for nurses who care for chronic and terminally ill patients such as those with COPD, end stage renal disease (ESRD) and cardiac conditions as these nurses are not as exposed to caring for dying patients.

EOL Discussions and other Health Care Providers

The evidence about nurses' participation in EOL discussions is limited. Insight related to participation in EOL discussions is obtained from research studies that involve other health care providers, such as physicians.

It is a common concern among healthcare providers that communicating difficult news may diminish hope or compound the patient and family's suffering (Lamiani, Meyer, Leone, Vegni, Browning, Rider, Trugo, & Moja, 2011). In a systematic review of literature on EOL discussions Harding and colleagues present strong evidence to support the lack of discussions between healthcare professionals and terminally ill patients concerning dying, life expectancy, and final wishes (Harding, Selman, Beynon, Hodson, Coady, Read, Walton, Gibbs, & Higginson, 2008). Parker and colleagues (2007) conducted a review of the literature that examined 20 articles that involved direct observation of patient/physician discussions of EOL care. Of the 20 articles reviewed, half of the studies took place in the intensive care units; many of the patients had a terminal cancer diagnosis. The physicians focused their conversation with the patient and family on medical and technical procedures and treatments avoiding discussion of EOL care and concerns. The researchers reported many missed opportunities for physicians to address EOL issues. Sensitive topics were perceived by physicians to take too long to discuss, taking time away from their already busy schedules. Also, when physicians dominated the conversation, patients and families lost the opportunity to ask questions (Parker, Clayton, Hancock, Walder, Butow, Carrick, Currow, Ghersi, Glare, Hagerty, & Tattersal, 2007). These studies highlight the reasons that EOL conversations are not taking place, however, they do not provide data about the number of patients who actually received EOL discussions during the direct observations.

Han and colleagues (2012) examined attending physicians' (N=17) attitudes regarding the use of a prognostic model for six-month mortality in older adults with declining health and found that physicians acknowledged discomfort with death. A lack of training in communicating prognostic information was associated with a level of discomfort with talking to patients about EOL issues. This study also noted that optimal use of prognostic models in EOL care requires shared decision making between physicians and their patients (Han, Hootsmans, & Hallen, 2012).

Timing of EOL Discussions

Levin and team examined do-not-resuscitate (DNR) orders from the time the order was written to the death of the patient. A review of almost 2,000 charts of patients with an advanced cancer diagnosis revealed that 77 percent of the patients had a DNR order on their charts at the time of death but only 13 percent were written upon admission (Levin, Li, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008). Those charts with a written DNR upon admission suggested that the patient, family and physician had conversations prior to admission and had made a decision about code status. The fact that 64% of the DNRs were written on the day of death implies that no discussions or decisions regarding EOL care were made prior to the patient’s impending death. Twenty-five percent of the patients experienced CPR before death indicating that advanced directives expressing the patient’s choices for EOL care were not available. The median time from DNR order to death was 32 days. Most of the DNR orders (67%) were authorized by healthcare proxy, suggesting the patient was no longer able to authorize this choice (Gardner, 2012; The SUPPORT Principal Investigators, 1995).

Situations where patients are not active participants in the EOL conversations often reflect clinical contexts where the patient is too sick to participate (Bruera, Neumann, Mazzocato, Sala, & Stiefel, 2000). Two studies reported the median time from DNR order to death to be 21 and 30 days respectively (Earle, Neville, Landrum, Ayanian, Block, & Weeks, 2004; Parker, Clayton, Hancock, Walder, Butow, Carrick, Currow, Ghersi, Clare, Hagerty, & Tattersal, 2007) with one study finding DNR orders written on the day of death (Gardner, 2012; Levin, Weiner, Lewis, Bartell, Piercy, & Kissane, 2008). Clinicians wait for patients to be seriously ill before they feel comfortable bringing up EOL discussions (NHPCO, 2011; The SUPPORT Principal Investigators, 1995).

The issue of healthcare providers’ failure to engage in EOL discussions is not limited to this country. Palliative care (PC) physicians in Europe, South America and

Canada were surveyed about their EOL care practices. These PC specialists spent only 30 percent of their time practicing palliative care. Of the182 physician respondents, 48 (24%) had EOL discussions with their patients that were limited only to CPR status while 109 (60%) also included helping the patient understand their terminal diagnosis. These PC physicians failed to identify any discussions related to death and dying, family involvement, hospice care, or the final wishes expressed by the patient (Brown & Wissow, 2009).

EOL Discussions and Chronic/End-Stage Conditions

Advance health care planning including patient–clinician communication about EOL is not limited to a cancer diagnosis. These discussions are important for all patients and their family members, no matter the diagnosis. Patients suffering from conditions, such as chronic obstructive pulmonary disease (COPD), human immunodeficiency virus (HIV), infection and chronic kidney disease (CKD) have the same need for these discussions as cancer patients (Fine, Reed, Shengelia, & Adelman, 2010). Patients with CKD are likely to experience sudden declines or complications which could leave their surrogate decision maker unprepared for EOL conversations. The need for clinicians to have effective communication about future medical care and the trajectory of CKD is critical for these patients and their families (Agard & Maindal, 2009).

Patient-clinician communication is needed to inform patients about their diagnosis, treatment, and prognosis. It also helps prepare them for the dying experience. The EOL discussions are necessary to help patients, family members, and the clinicians understand patient preferences for life-sustaining treatments. Despite the need for EOL discussions, advance care planning and conversations about end-of-life care in current practice are limited and their quality is often poor (Fine, Reed, Shengelia, & Adelman, 2010).

Wagner and team conducted a randomized trial of 400 Veterans in the Greater Los Angeles Healthcare System of which two-thirds were cancer patients. The remaining veterans were described as having other chronic terminally-ill diagnoses. All participants had a one-year risk of mortality estimated by their primary physician. Of all enrolled participants, 70 percent reported being informed of their life-limiting condition by their primary care provider, but only 50 percent understood the one-year mortality risk and 35 percent reported no such communication from their primary care physician. Of the patients who were informed of their life-limiting condition 76 percent rated their chances of being alive in one year as “excellent” or “good”. This study suggests that healthcare professionals could do a better job explaining EOL issues in a way that provides the patient with a better understanding of the progression of their disease (Wagner, Riopelle, Steckart, Lorenz, & Rosenfeld, 2010).

A study by Reinke and team (2011) looked at EOL discussions with patients diagnosed with COPD. Using a self-report questionnaire, they characterized the content of patient-clinician communication about EOL care from the patients’ perspective and associated specific communication items that were not addressed to clinician characteristics. The clinicians included staff physicians, physician trainees, and advanced practice nurses. The patients completed the Quality of Communication (QOC) questionnaire that consisted of seven items for discussion in EOL conversations. Patients were asked if clinicians: a) involved the patient in decisions about the treatments that he would want if he would get too sick to speak for himself; b) talked to him about how long he might have to live; c) asked about his spiritual or religious beliefs; d) discussed with him about what dying might be like; e) talked with him about his feelings concerning the possibility that he may get sicker; f) discussed details concerning the possibility that he might get sicker; and g) asked about the things in life that are important to him.

The results indicated that four of the seven topics (talking about how long the patient might live; talking about what dying may be like; involving patient in future treatment discussions; and talking about spiritual/religious beliefs) were not addressed as much as 94% of the time. The lack of discussions in these areas left the patient poorly informed about expectations for the final days and denied the patient the opportunity to prepare self and family as well as making plans and choices for EOL care. Heart failure and COPD patients often have little awareness that they have a life-limiting illness, which in turn defers healthcare professionals from engaging in EOL discussions. The dying trajectory in these chronic conditions is less predictable than in terminal cancer care, leaving the healthcare professional unwilling to enter into prognostic discussions (Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011).

Impact of Delayed EOL Discussions with Families

Patients and their families do not always fully understand the implications of treatment or realize their loved one’s specific diagnosis is life-limiting and may eventually result in death. Supporting patients and their families in making choices about care and treatment is a challenging, but an essential part of EOL care (Swetz, Freeman, AbouEzzeddine, Carter, Boilson, Ottenberg, Park, & Mueller, 2011). Studies have found that ineffective communication about choices for EOL care is associated with the physician’s limited discussion of EOL issues and the family caregiver’s distress at hearing bad news (Bruera, Neumann, Mazzocato, Sala, & Stiefel, 2000; Jansen, Engelberg, Wouters, & Curtis, 2012; Mack, Cronin, Taback, Huskamp, Keating, Malin, Earle, & Weeks, 2012). Clinician barriers have been found to be more common and more strongly associated with the occurrence of EOL communication than patient and family barriers to these discussions (Bruera, Neumann, Mazzocato, Sala, & Stiefel, 2000; Jansen, Engelberg, Wouters, & Curtis, 2012; Mack, Cronin, Taback, Huskamp, Keating, Malin, Earle, & Weeks, 2012; Waldrop, Meeker, Kerr, Skretny, Tangeman, & Milch, 2012).

In a qualitative study by Waldrop et al., three concepts were used to organize their findings from the interviews which demonstrated the importance of family connectedness to the EOL care discussions. The study concluded that communication, as experienced by family caregivers, continues to be inadequate in situations surrounding end stage cancer (Waldrop, Meeker, Kerr, Skretny, Tangeman, & Milch, 2012). This poor communication left the families feeling unprepared and confused, not understanding what to expect during the final stages, or how best to support and care for their dying loved one (Earle, Neville, Landrum, Ayanian, Block, & Weeks, 2004). Poor communication among providers and family members regarding the overall plan for the patient led the family to make uninformed decisions (Holdsworth & King, 2011). Communication about prognosis is essential for shared decision-making, yet prognosis discussions tend to be infrequent in the routine care of seriously-ill patients (Bruera, Neumann, Mazzocato, Sala, & Stiefel, 2000).

Studies have also looked at factors identified as important at the EOL by patients, family members and healthcare providers (Holdsworth, & King, 2011; Jackson, Derderian, White, Ayotte, Fiorini, Hall, & Shay, 2012; Reinke, Griffith, Wolpin, Donesky-Cuenco, Carrieri-Kohlman, & Nguyen, 2011; Steinhauser, Christakis, Clip, McNeilly, McIntyre, & Tulsky, 2000). Jackson and colleagues (2012) conducted 19 interviews of family members who had lost a loved one in a long term care facility in the past 3-18 months and found all participants agreed that feeling prepared to die, believing that one's family is prepared for one's death, and knowing what to expect about one's physical condition at the time of death are important factors that need to be established before the EOL (Jackson, Derderian, White, Ayotte, Fiorini, Hall, & Shay, 2012).

In summary, the research supports the need to have effective communication between the healthcare team and the patient and family. The literature is clear about the fact that the healthcare teams are not adequately trained, skilled or comfortable with EOL discussions. Yet the patient and family members have clearly expressed the need and desire for clear and timely explanations about the dying process to ensure that the patient can make decisions about his/her care and that their final wishes are respected.

Self-Efficacy

Nurses' perceived self-efficacy for participating in EOL discussions has not been reported in the literature. Thus self-efficacy in nurses must be studied to identify which factors influence their confidence level as it pertains to EOL discussions (Canton & Klemm, 2006). Identifying these factors and understanding how they influence nurse's self-efficacy will help with training and education for future nurses and improve the final outcomes for patients and their families at the EOL.

Sixty-eight Danish ICU nurses completed a self-administered questionnaire based on Bandura's self-efficacy theory to ascertain ICU nurses' perceptions of self-efficacy related to involving family members in care elements of patients admitted to ICU (Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011). These nurses perceived their knowledge and skills of interaction with relatives to be good and reported positive expectations related to the outcomes of interacting with relatives. However, there were disparities in the nurses' agreement on involving relatives in selected caring activities or allowing them to be with the patient during CPR or acute intubation. In the final analysis, there was no significant relationship between knowledge, skills, nurses' attitude related to involving relatives in caring activities and nurses' self-efficacy (Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011).

Manojlovich (2005a) investigated the interaction between self-efficacy and behaviors of nursing empowerment, and nursing leadership. The aim of the study was to determine if self-efficacy contributed to professional nursing behaviors. A sample of 376 nurses responded to questions related to professional practice, leadership and self-efficacy. Results indicated that there was a significant relationship between empowerment ($r=0.32$, $P <.01$) and self-efficacy ($r=0.45$, $P<.01$), suggesting that nurse empowerment and perceived self-efficacy both influence professional practice behaviors (Manojlovich, 2005).

McCabe and associates (2012) explored nurses' ($N=69$) self-efficacy in assessing depression among patients in palliative care. These nurses had a high level of contact with their patients and therefore were well positioned to recognize depressive symptoms, provide pathways for treatment, and support depressed patients and their families. However, many of these nurses reported a lack of confidence or diminished self-efficacy in assessing depression, little time to discuss emotional issues with their patients and the inability to effectively recognize depression. Over half (54%) of the nurses reported low confidence in recognizing depression, knowing its signs and symptoms, and understanding its effects on the patient's overall condition. Two-thirds (64%) of the nurses attributed this diminished self-efficacy to a lack of training and knowledge of how to assess and care for patients with depressive symptoms (McCabe, Mellor, Davidson, Hallford & Goldhammer, 2012). Clearly without the proper education, these nurses could not provide quality patient care.

In a study examining self-efficacy and information seeking, Brown and colleagues (2001) hypothesized that employees with high self-efficacy would seek information to improve role clarity and work performance while employees with low self-efficacy would be distracted by negative thoughts and uncertainties about their abilities. Findings indicated that high self-efficacy was associated with higher performances in job duties. Employees with high self-efficacy demonstrated the ability to integrate and interpret information better because they were more focused and less distracted by cognitive interference and were less likely to distort information (Brown, Ganesan, & Challagalla, 2001). These results are not specific to healthcare, but they can be applied to nurses working at the bedside. Nurses with high self-efficacy would be more effective in integrating and interpreting information as it relates to their role as advocate and resource for their patients. Based on these findings, nurses with high sense of perceived self-efficacy would be more focused on patient needs and less distracted by self-doubt and negative attitudes.

Self-Efficacy in Nursing Education

Simulation has become a significant part of the education of nursing students. In these settings nursing students can be exposed to situations that would not likely happen during their clinical practice rotations. These simulation activities focus on various clinical situations but often have a significant communication component. Several of these studies addressed self-efficacy. Studies have reported varying results with videotaping nurses and nursing students while in simulation activities involving admission of patients (Kameg, Clochesy, Mitchell, & Suresky, 2010; Kruijver, Kerkstra, Bensing, & van de Wiel, 2001).

Kameg and colleagues (2010) used a quasi-experimental design to compare two teaching strategies, traditional lecture and high fidelity-human simulation (HFHS), to examine nursing students' (N=38) self-efficacy related to communication skills. Students were exposed to a "distressed patient". It was noted that these students used limited nonverbal behaviors to comfort the patient. They reported feeling anxious and unprepared, fearful of making a mistake and not knowing what to say as reasons for their inability to provide support. Researchers related the poor performance to low self-efficacy when dealing with patients in distress. Although scores in both groups increased, students in the HFHS group showed the most improvement indicating that HFHS significantly improved student self-efficacy with communication skills for dealing with distressed patients (Kameg, Clochesy, Mitchell, & Suresky, 2010).

A similar simulation study conducted by McConville and Lane (2005) used on-line video clips to evaluate student nurses' self-efficacy (N=146) to effectivity communicate with potentially difficult or delicate patient groups. Through this experience, the researchers hoped to improve the student's ability to communicate with difficult patients and families versus traditional lecture material. The results indicated that using only the video clips or the lecture material had no significant effect on the students' self-efficacy; however, a significant increase in self-efficacy occurred over time when using both modalities to teach nursing students how to effectively communicate with difficult patients and families (McConville & Lane, 2005).

Although research about nurse self-efficacy is limited, the literature does address the importance of mastery of experiences, vicarious experiences, psychological state and social persuasion as they relate to nurse performance. A discussion of these concepts and related literature follows.

Mastery of Experiences

Demonstrating care and concern for seriously ill patients and their families is an intrinsic part of nursing philosophy. Evidence of the importance of effective communication with patients and family related to EOL care is clear (Nelson, Weissefeld, Paimtollop, Danis, Deal, Levy, & Cook, 2006) suggesting that clinicians working with terminally ill patients must possess these essential skills (Dunn, Otten, & Stephens, 2005). While nurses have a key role in meeting patients' informational needs, communication around sensitive areas of end-of-life care can be challenging for even the most experienced oncology nurses (Nelson, Weissefeld, Paimtollop, Danis, Deal, Levy, & Cook, 2006). Yet, information is central for the empowerment of terminally ill patients as it allows the patient and his/her family to make informed decisions about treatment and the plan of care (Chelf, Deshler, Thiemann, Dose, Quella, & Hillman, 2002; Shannon, Long-Sutehall, & Coombs, 2011).

Nurses who care for patients with chronic illnesses and terminal diseases frequently develop long-term and trusting relationships that place them in unique positions to assist patients and families struggling with complex information and difficult decisions. EOL discussions are often challenging and require professional knowledge, skill and commitment to meet individual needs. Without adequate preparation, nurses may feel inadequate and uncomfortable facilitating such discussions or may avoid addressing patient cues that seek exploration and clarification (Briggs & Colvin, 2002). To enhance their sense of self-efficacy, nurses require communication skills such as being able to craft different conversations for diverse individuals, provide information unique to each situation, learn how to assist an individual in weighing benefits and burdens, and translate goals into specific treatment decisions (Briggs & Colvin, 2002).

The findings of Ho and colleagues (2010), with 202 nephrology nurses, revealed that the majority (89%) of these caregivers found EOL care to be an emotionally demanding part of their jobs and believed they needed special training to effectively communicate and address EOL with their patients. Ninety-five percent of these nurses voiced a need for training on how best to provide psychological support for their patients in order to comfortably discuss EOL issues with patient and their families. Interestingly, the nurses (37%) who routinely verbalized their feelings about their experiences with EOL discussions with supportive peers had a more positive attitude ($p=0.002$) towards providing care to dying patients. These findings substantiate the influence of education and social persuasion to building self-efficacy which affects behavior and performance (Ho, Barbero, Hidago, & Camps, 2010).

Mallory (2003) has suggested that providing education which included effective communication, stress management techniques, palliative care treatments and clinical management of EOL can improve the confidence and skill levels of healthcare providers and improve the quality of care provided to patients who are at the EOL. These studies imply that nurse education and mastery of skills such as effective communication, palliative care, and the clinical management of EOL enhance nurses' perceived self-efficacy and support positive nurse practice behaviors including engaging patients in discussion about EOL.

Vicarious Experiences

An emerging body of literature asserts that students are able to learn from each other's experiences. Learning from a peer's experience is known as vicarious learning. Although each student will have their own personal experiences from clinical practice, other students or nurses can benefit and use shared examples to teach and learn (Roberts, 2010).

Vicarious learning can take the form of case studies, direct observation, storytelling, dialogue and discourse. The benefit to learners of being able to observe or listen in on experts or peers as they discuss new topics or perform a specific task allows for skilled behaviors to be observed and later modeled. The observing student may identify with their peer student and the dialogue would be more student-centered, creating an instructionally uncluttered and safe environment for learning (Cox, McKendree, Tobin, Lee, & Mayes, 1999).

Storytelling has been utilized as a formal teaching tool and communication technique for some time. The use of storytelling has been employed to effectively teach such concepts as ethics, caring values and cultural norms and differences (Davidson, 2004). EOL care and discussion skills can also be learned through vicarious learning as nurses experienced with caring for terminally ill patients share their stories of successful conversations with less experienced nurses.

Nurses must be able to competently assess and provide the necessary care to meet the needs of patients, regardless of their location within the acute care setting. McFetridge and Deenycha (2004) used case studies as a teaching mechanism to help senior nursing students (N=29) prepare for clinical rotations in the ICU setting. The use of case studies based on actual real-life nursing practice can be used to generate debate and discussion giving insight to the nursing student's ability to process and critically think about their interactions with the patients. They described the case studies as a vehicle to close the gap between classroom learning and clinical practice. Ninety percent of the students either strongly agreed or agreed that the use of the case studies encouraged them to perform holistic patient assessments involving the patient more frequently, while 85% felt that they became more involved with their patient's care (McFetridge & Deenycha, 2004).

As nurses "grow up" in the practice of nursing, they encounter nurses and health care providers who "demonstrate" excellent care. On occasion nurses will observe a colleague insert a PICC line, create a better way to dress a wound, advocate for better pain management, or talk with a patient about her diagnosis of breast cancer. These expert clinicians demonstrate the best way to provide care, to talk with patients, to advocate for patients and more. The vicarious experiences in which nurses encounter these clinical experts provide nurses with opportunities for learning. These learning opportunities inspire them to enhance their own practice. They believe they can pattern the behavior and skill. They incorporate the behavior or skill into their practice.

A vicarious experience can enhance nurses' perceived self-efficacy so that they will improve their knowledge and skills related to engaging in EOL discussion with patients and families. Self-efficacy must be fostered through social persuasion (mentoring) and vicarious experiences so nurses can have a more powerful influence in EOL discussions (Manojlovich, 2005b).

Psychological State

The literature suggests several barriers to engage in EOL discussion with patients and families. Although nurses are strong advocates for their patients, many find it difficult to discuss death and dying with their patients. What are the barriers that keep nurses from entering into such discussions? Several come to the forefront—anxiety; a lack of confidence in their ability to discuss the issues; fear of saying the wrong thing; not knowing what to say; a lack of clarity related to the nurse's role in these situations; and their personal discomfort with death and dying.

Lee and King (2014) have reported that providing care to patients who are in a declining state of health increases feelings of anxiety in healthcare workers. This anxiety can be rooted in lack of confidence in their ability to discuss the issues, fear of saying the wrong thing, or not knowing what to say. These nurses may not acknowledge the cues that patients and families present, thus ignoring the signals that they want to talk about the dying experience. Without adequate preparation, nurses do not know what to say or how to say what needs to be said. Nor are they comfortable with discerning what information the patient and family are seeking (Lee & King, 2014).

Nurses may be reluctant to discuss EOL issues with their patients because they fear the patient may not be receptive to conversations about death and dying. Secondly, the patient may be in denial, which may hinder or completely block communication attempts. Lastly, some nurses fear that the patient may lose hope if such conversations occur (Davison, 2001).

Nurse's personal discomfort with death and dying can be a barrier to having EOL discussions. The fear of a patient's death or the dying process can prevent a therapeutic interaction between patients and caregivers and can hinder the delivery of quality EOL care (Deffner & Bell, 2005; Lehto, Stein, & Farchaus, 2009).

In many cases nurses and other healthcare providers have not received formal education about death, dying or the grieving process, thus they may not feel qualified or confident enough to initiate or participate in discussions about EOL preferences with patients who are in a declining state of health (Hopkins, Kott, Pirozzi, Deposits, Pond, Randolph, & Cote-Arsenault, 2001; Hopkinson, Hallett, & Luker, 2003). Although death and dying is a topic that is addressed in academic curriculums for health care providers, the lack of exposure to the dying experience (personal or professional) inhibits these providers from engaging in EOL discussions about the plan of care, the trajectory of health decline, and patient care preferences and decisions. In some cases, personal experiences with the death of a loved one can reinforce a provider's discomfort with EOL discussions (Hopkins, Kott, Pirozzi, Deposits, Pond, Randolph, & Cote-Arsenault, 2001; Hopkinson, Hallett, & Luker, 2003).

Education related to death, the dying process, and the care needs of the patient and family are important. But more is needed. Health care providers must also be guided to reflect on their perspective of death and dying, consider how they would respond or had responded to the death of a loved one, identify what they would want for dying loved ones, and recognize what they need to know or discuss with healthcare providers as the family member. The feelings of not knowing, the uncertainty of decisions not made, and unspoken questions often lead to feelings of self-doubt, guilt and anxiety for patients, families and providers (Leighton & Dubas, 2009). In other words, providers need to reflect on their own perspectives and views of the dying experience and keep in mind the needs of the patient and family they are treating.

Spiritual or religious beliefs may influence nurses' perspectives on death, dying and their role in care of the dying patient. Religiosity refers to behaviors and attitudes a person has with regards to a particular religion. It is also the study of how individuals' religious attitudes affect how they live and interact with others (Sulmasy, 2001). There are limited studies examining religious attitudes in nursing and even fewer examining the effect of nurse religiosity and attitudes towards death and dying.

A study by Christopher (2010) examined the relationship between nurses' religious beliefs and how nurses communicate with patients at the end-of-life. An on-line survey of graduate nursing students (N=104) found that nurses who scored higher on the religious belief scale were more willing to let patients take control of the conversations about EOL care. Christopher concluded that a nurse's religious beliefs can enhance the clinical experience without the nurse trying to impose his or her beliefs on the patient (Christopher, 2010).

Understanding how a nurse's religious/spiritual beliefs or lack thereof influences his/her decision to engage in EOL discussions with dying patients and their families will clarify the role of values and beliefs in seeking the patient’s final wishes during the EOL discussions.

Professional responsibility and the role of the nurse in EOL care is not clearly defined in the literature. However, several studies discussed the wide-ranging role of the nurse in care of the dying.

In one such study in northern England, McMillen (2008) interviewed eight ICU nurses. In a semi-structured interview two questions were posed; “What role do nurses play in end-of-life decision in the ICU in which you work?” and “How does their involvement affect them?” One of the themes “supporting the family” highlighted these nurses (professional) responsibility for finding out from the patient their final wishes and working with the family to understand their grasp on the situation. These nurses also discussed doing “groundwork to prepare them (the family) for bad news”. The theme “being a patient advocate” was supported by the comments of two participants who spoke of their role as patient advocate and their professional responsibility to protect the patient’s safety and to ensure the EOL decisions were honored (McMillen, 2008).

A Finnish study by Hilden, Louhiala, Honkasalo, and Palo (2004) surveyed 800 nurses regarding their experiences and views on end-of-life decision making and compared them with physician views. Almost all the nurses (89%) considered it their (professional) responsibility to talk to physicians about respecting living wills that were presented by the patient and their families. The study concluded by saying Finnish nurses have a positive attitude towards living wills. These nurses stressed and respected the patient’s role in decision making at the end-of-life and felt professionally responsible as the patient advocates to ensure the patient’s final wishes were honored.

Social Persuasion

In the context of this study, social persuasion includes the influences of mentors, coaches and role models and the nurse's perception of his/her organization's nursing leadership that nurses engage in EOL discussions with patients.

Nursing role models and mentors make a difference in nurses' professional lives. They serve as examples of the best of nursing. They demonstrate a knowledgeable, caring approach to patients, peers/colleagues, and novice nurses. Nursing role models and mentors positively influence nurses by demonstrating the knowledge, skill and expertise of direct patient care. In addition, these role models/mentors offer the nurse both guidance and encouragement that strengthens the nurse's perceived self-efficacy to improve his/her practice. Mentors have been shown to unconditionally champion mentees' careers (McCloughen, O'Brien, & Jackson, 2009). An environment that includes such role models and mentors is a valuable asset to an organization (Alberto, 2003). Nurses who have had relationships with role models and mentors experience an informal method of teaching that is critical to their success.

Nursing leadership has a direct effect on professional practice behavior (Krairiksh & Anthony, 2001; Kramer & Schmalenberg, 1993). The original magnet hospital research highlighted the importance of visible, supportive leadership to professional nursing practice. Without nursing leadership support throughout the organization, an environment conducive to professional nursing practice could not evolve (McClure, Poulin, Sovie, & Wandelt, 1982). In a heathy practice environment, nurses can understand and fully engage in the expectations of nursing leadership in their organizations. If nurses acknowledge the expectation that all nurses are supported, encouraged and expected to engage in EOL discussions and care of terminally ill patients and their families, they will do so. If nurses are unclear of this leadership expectation, the likelihood of these conversations occurring is reduced.

In summary, strong evidence in the literature suggests that many healthcare providers are lacking the skills, training and education to conduct EOL discussions with terminally ill and dying patients and their families. The need of patients and their families to understand their options at the EOL is clearly documented in the literature. End-of-life topics that are not addressed yet important to the terminally ill patient and their families should be the focus of interventions that will facilitate improvement in clinicians' communication skills and level of engagement in EOL discussions (Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011).

Gaps in the Literature

The literature to date has largely focused on physician's ineffective communication and lack of discussions surrounding EOL issues and options. In this review, several studies are cited about the ineffective transfer of vital information to patients in the final stages of disease, leaving the patient and family uninformed and unprepared for death. This lack of communication can negatively impact the family of the dying patient, leaving them distressed and anxious. Yet, the literature is void of studies that examine nurse participation in EOL discussions. Studies describing nurse's self-efficacy are also lacking in the literature. Poor and ineffective communication regarding EOL care and discussions are not limited to the care of terminal cancer patients; the lack of EOL discussions has been documented with patients with HIV, COPD and CHF. These studies focused on physician and patient/family communication and did not address nurse involvement in EOL discussions with patients who suffer from terminal or end-stage chronic illnesses and their family members.

Limitations in previous studies include the absence of nurse as study sample, lack of prospective studies, the limited focus of current studies of oncology and ICU nurses, and conflicting research findings. Few studies discussed the nurse’s role, their skills in conducting effective EOL discussions, and how they could assist patients in EOL decision-making. Many of the studies used a retrospective approach, examining EOL preparation after the patient had died. These studies neglected to inquire about how the nurse’s participation in EOL care and planning was perceived by the patient and family members during the final days of life.

Clearly, better communication of EOL issues with involvement from all members of the healthcare team is needed. Nurses are recognized as a source of information for the patients and families, are seen as trustworthy, spend more time with patients, and have the knowledge, skills, and resources to support patients and families yet their participation in EOL discussion and care planning has not been documented. This study contributes to nursing knowledge by examining the role of self-efficacy in staff nurses’ participation in EOL discussions with terminally ill patients and their family members.

CHAPTER III

METHODOLOGY

This chapter presents descriptions of study design, sample, and the sampling strategies and study procedures. In addition, the instruments used are presented and data collection and data analysis procedures are described.

Research Design

The purpose of this descriptive correlational study was twofold: a) to assess the level of nurse self-efficacy for conducting EOL discussions, and b) to examine the relationships between mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families.

A descriptive correlational research design was used to examine nurses' self-efficacy to conduct EOL discussions with terminally ill patients and their families. Nurses who regularly care for patients with end-stage chronic or terminal illnesses were asked to complete a survey that explored their perceived self-efficacy in conducting EOL discussion with these patients and their families.

Sample and Setting

The sample for this study included oncology and medical-surgical nurses working in rural and urban community hospitals in Georgia. Two hospital networks participated in this study. The first hospital network, Phoebe Putney Memorial Health System (PPMHS), has four hospitals that are located in three rural counties, while the second hospital system, Piedmont Healthcare (PHC), has six hospitals that are located in a mix of rural and urban counties. Both hospital systems have inpatient oncology and medical-surgical inpatient units.

The nurses who met the following inclusion criteria were invited to participate in this study.

Nurses participating in this study must…

- Work in an acute care hospital facility;
- Be a registered licensed nurse for at least three years;
- Have worked for current employer for at least one year;
- Be employed full-time or half-time ($\geq$ 20 hours/week);
- Provide direct patient care at the bedside at least 50% of their working hours per week;
- Provide direct care to patients with end-stage chronic or terminal illnesses (e.g., cancer, cardiovascular disease, end-stage renal disease, etc.).

Nurses were excluded from this study if they…

- Worked outside the hospital or in an outpatient department;

- Worked in intensive care, pediatric, orthopedic, or maternal child units or any unit wherein they did not care for patients with end-stage chronic or terminal illnesses (e.g., cancer, cardiovascular disease, end-stage renal disease, etc.)
- Worked in inpatient or home hospice facilities.

Settings

The hospital systems that agreed to support this study were Phoebe Putney Memorial Health System (PPMHS) and Piedmont Healthcare (PHC). Phoebe is a not-for-profit integrated healthcare delivery system comprised of more than 4,500 physicians, employees and volunteers caring for patients in 35 counties. Serving more than 500,000 residents in Southwest Georgia for more than a century, Phoebe has been recognized as a leader in delivering exceptional care. Phoebe offers a full spectrum of care for residents in Southwest Georgia, ranging from outpatient specialty services to some of the most advanced surgical, cardiac, cancer and gastrointestinal treatments. (PPMHS is a Det Norske Veritas (DNV-GL) accredited not-for-profit community health care organization and leading healthcare provider in Southwest Georgia.) Phoebe is recognized as a leader in cancer care, orthopedics, and cardiology, the winner of the 2003 Foster G. McGaw award in community service and recipient of VHA Leadership Award for Clinical Excellence (Rapid Assessment Team). Of the four hospitals approached within this health system, three chose to participate.

The second hospital system, Piedmont Healthcare, is located across greater Atlanta and north Georgia. For more than a century, Piedmont Healthcare has been a recognized leader in delivering expert care. Last year, Piedmont served nearly two million patients - performing over 44,000 surgeries, delivering 8,000 babies, providing 471,695 outpatient encounters, completing 235 organ transplants, and handling nearly 250,000 emergency room visits. All six hospitals in the health system participated in the survey process.

Contact was made with each of the two hospital systems' Chief Nursing Officers (CNO). A letter of introduction to the research project was sent to each of the participating hospitals' CNOs to request their support to survey their nursing staff for the purposes of this research. The letter described the purpose of the study, the nurse sample, and the data collection plan. A meeting with each CNO and her selected leadership staff was scheduled to provide further details about the study and answer their questions. Upon learning their interest in participation, information was requested related to the nursing staff who would meet the criteria for inclusion, how data collection could be facilitated in their institutions, and the process of attaining IRB approval in their facility.

Sample Size

The sample size was calculated using a-priori sample size calculator for a multiple regression model (Iley, 2012). The sample size was calculated with a medium effect size of R^2= 0.15; a statistical power level of 0.8 with 10 predictor variables, and the probability level of 0.05. A minimum of 130 participants were recruited for this study. Over sampling by 15% was built-in to accommodate for attrition, thus, 150 participants were required.

A total of 250 nurses attempted to take the on-line study, however, only 168 (67.2%) completed the on-line survey. Nurses from all six hospitals in the Piedmont Healthcare System participated in the survey, and nurses from three of the five hospitals in the Phoebe Putney Memorial Hospital Health System participated. Hospital representation was identified by zip codes (ZipCode Database, 2016). The hospital with the highest participation rate was the Newnan hospital with 11.15% of the eligible nurses taking the survey. The Atlanta hospital had the largest number of eligible nurses who could take the survey; however, there were only 11 (2.75%) nurses who completed the survey. Thirty-two (n=32; 19%) nurse participants did not identify their hospital zip code as requested in the survey. See Table 1.

Table 1

Hospitals' Response Rate

Hospital Location	Zip Codes	# of Eligible Nurses	# of RN Respondents	Response Rate
Covington, GA	30014; 30016; 30663	134	11	8.2%
Jasper, GA	30143; 30513	175	12	6.9%
Fayette, GA	30214; 30215; 30290	315	16	51.%
Stockbridge, GA	30216; 30253	300	20	6.6%
Newnan, GA	30263; 30265	260	29	11.15%
Atlanta, GA	30301; 30309	400	11	2.75%
Albany, GA (includes main and North campus)	31701; 31702; 31705; 31706; 31707; 31763	272	30	11%
Sylvester, GA	31791	175	7	4%

(Table 1 Continues)

(Table 1 Continued)

Hospital Location	Zip Codes	# of Eligible Nurses	# of RN Respondents	Response Rate
Missing Zip Codes	No Zip Code Noted	Unknown	32	No response rate available
Total	21	2,031	168	8.3%

Measures

This section contains a description of the independent, dependent and demographic variables, their measurement tools and reliability and validity information associated with previous research studies and this study. Instruments can be found in Appendices A through F.

Dependent Variables

Two dependent variables were appraised. Self-efficacy was examined by exploring its association with the elements of master of experiences, vicarious experiences, psychological state, and social persuasion. The behavior of nurse participation in EOL discussions was investigated by assessing the relationship of mastery of experiences, vicarious experiences, psychological state, social persuasion and self-efficacy.

Self-Efficacy

The nurse’s perceived self-efficacy was measured using the Quality of Communication Questionnaire (QOC) modified, University of Washington School of Medicine. The QOC was designed to assess patient’s perception of the skills and ability of their physician to discuss EOL issues such as how long patients might live, what dying might be like, and patient wishes related to end-of-life. Patients were asked to rate their physicians' communication with them on a scale of 0-10, with "0" indicating "the very worst I could imagine" and "10" indicating "the very best I could imagine". The patients could opt to answer "my doctor did not do this," allowing the patient to leave the item unrated when the topic was not covered in the discussion or "I don't know" if the patient was unsure of how to rate the doctor on a particular topic or skill. There are two final questions in the questionnaire. The first asks the patient to rate their physician's overall comfort with EOL discussion with "0" indicating "not at all comfortable" and "10" indicating "extremely comfortable". The second asks the patient to rate how the physician handled the EOL discussions overall with "0" indicating "the very worst I could imagine" and "10" indicating "the very best I could imagine" (Engelberg, Downey, & Curtis, 2006; Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011).

In this study, the QOC was used to assess nurses' self-perception of how good they are in discussing EOL topics with their dying patients and their families. The 19 items of the QOC questionnaire were modified to ask the nurse to describe how good he/she is in performing these end-of-life behaviors. For example, in Item 1, the patient was asked to rate the quality of the physician's communication related to "using words you can understand". For this study, Item 1 was modified such that the nurse is asked how good he/she is in "using words the patient can understand." The same 0-10 scale was used; however, the responses were changed to "0" indicating "not at all good" and "10" indicating "extremely good". See Appendix A.

The QOC score for self-efficacy is the sum total of all the responses. The range of possible scores is 0-190 with the highest scores representing higher perceived self-efficacy in discussing EOL issues with dying patients and their families (Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011).

The data from the QOC instrument were used for determining groups. Comparisons were made between nurses whose scores suggested they are “poor” to “fair” communicators of end-of-life topics and those nurses whose scores indicated they are “good” to “extremely good” communicators. As can be noted on the revised QOC in Appendix A, each item is scored from “not at all good” (0) to “extremely good” (10). For comparisons of groups, nurses who rated the items 0 to 7 were considered to have poor to fair self-efficacy on the item and those who rated themselves between 8 and 10 were designated as having good to extremely good self-efficacy on the item. These scoring designations were suggested by the originators of the instruments (Frommelt, 1991). The total QOC score was determined. Thus nurses with good to extremely good levels of self-efficacy have a total score of 152 (19 x 8) or above; those with lower levels of self-efficacy have a score equal to or less than 151 (Engelberg, Downey, & Curtis, 2006; Frommelt, 1991).

Engelberg and colleagues (2006) have evaluated the psychometric characteristics of the QOC. Analyses included principal component analyses, internal consistency analysis (reliability) and correlational and group comparisons (construct validity). Two subscales were supported: general communication skills scale (6 items) and communication about end-of-life care (7 items). Results indicated that the two scales met standards for scale measurement factor convergence [values $\geq$ 0.63]; discrimination [values different ≥ 0.25]; percent of variance explained [69.3%]; internal consistency [$\alpha \geq 0.79$]; construct validity [significant associations $p \leq 0.01$] (Engelberg et al., 2006). The Cronbach's alpha for this study was .84.

Behaviors of EOL Communication

To assess the behaviors of the nurses in performing EOL communication techniques with their dying patients, the same QOC tool was used with modifications.

The first 17 items of the 19-item questionnaire were used. The first 17 items of the QOC questionnaire describe the behaviors to be assessed while the final two questions ask for an overall rating. These final two questions (items 18 and 19) ask the nurse about his/her comfort level in talking about dying and their perception of their communications skills with dying patients, but they do not assess specific behaviors; thus items 18 and 19 were not used for the assessment of performance of behaviors.

The nurse was asked to rate the frequency with which she/he has used each behavior listed. An example–"In situations wherein end-of-life issues come up, indicate how often you use 'words that the patient can understand'". A 5-point Likert scale was used with responses ranging from never (0); rarely (1); occasionally (2); often (3); and always (4). Total scores range from 0-68 with the higher scores demonstrating consistent use of behaviors facilitating EOL discussions with dying patients and their families. The item scores are summed for the total score. See Appendix B. For more information about the psychometrics of the QOC, please see the discussion of the QOC self-efficacy scale psychometrics above and refer to Engelberg, Downey, & Curtis, 2006.

As noted above, this instrument is a modification of the original QOC that eliminates Items 18 and 19. A pilot test of this modified questionnaire with the new rating scale was conducted; a Cronbach’s alpha reliability coefficient of 0.839 was validated for this study.

Using the same instrument to measure two different variables presents issues as it is likely that some of the scores of repeated items will be strongly associated (>.80) with each other. To address this issue, those items that had a correlation equal to or greater than .80 were eliminated. The measurement of behaviors consisted of only those items with correlations equal to or less than .79. However, it was the intent to collect data on all Behavior QOC items so that the self-reported behaviors that nurses “do” and “do not do” could be described. Using the same tool will help to assess the nurse’s perception of how well he/she performed these behaviors while the second tool captures how often the nurse self-reports using these behaviors.

Following the completion of the Behaviors questionnaire, the participants were asked to answer the following two summary questions: “How did you actually learn to engage dying patients and their families in EOL discussions?” and “What would help you to become more comfortable and proficient in talking about death and dying with terminally ill patients and their families?” These items gave insight into the nurses’ actual learning experiences and the knowledge and skills needed by nurses who care for terminally ill patients and their families at the bedside.

Psychological State

Psychological state was assessed by identifying the nurse’s attitudes about death and dying, attitudes about caring for dying patients and families, religious/spiritual beliefs related to death and dying, and the nurse’s perception of his/her professional responsibility related to engaging in end-of-life discussions. The instruments for measurement of these variables are described below.

Attitudes about Caring for Dying Patients

The Frommelt Attitudes Toward Care of the Dying (FATCOD) Scale (Frommelt, 1991) is a 30-item scale designed to measure respondent's attitudes toward providing care to dying patients. See Appendix C. The FATCOD is made up of equal numbers of positively and negatively worded items. Positively worded items such as "giving nursing care to the dying person is a worthwhile learning experience" and negatively worded items such as "I would not want to be assigned to care for a dying person" are rated on a five-point Likert scale ranging from "strongly disagree" to "strongly agree" (5). Participants were asked to rate the degree that they agree or disagree with each statement. Positive items such as "giving nursing care to the dying person is a worthwhile learning experience" are scored from "strongly disagree" (1) to "strongly agree" (5). Items 1, 2, 4, 10, 12, 16, 18, 20, 21, 22, 23, 24, 25, 27, and 30 are positively worded statements. Negatively worded items (3, 5, 6, 7, 8, 9, 11, 13, 14, 15, 17, 19, 26, 28, and 29) such as "I would not want to be assigned to care for a dying person" are scored "strongly agree" (1) and "strongly disagree" (5).

The scores range from 30-150 with higher scores representing more positive attitudes toward providing care for dying patients (Frommelt, 1991). The items scores are summed for the total score. Frommelt used the test-retest procedure to assess the reliability of the FATCOD with a computed Pearson product-moment correlation co-efficient of r = 0.94. To assess validity of the FATCOD, a content validity index was computed to be 1.00 and a determination of interrater agreement was calculated yielding an interrater agreement of 0.98 (Dunn, Otten, & Stephens, 2005). A Cronbach's alpha reliability coefficient of 0.81 was validated for this study.

Nurse's Attitudes about Death and Dying

The Death Attitude Profile-Revised (DAP-R) (Wong, Reker, & Gesser, 1994) is a 32-item scale that uses a seven point Likert scale to measure respondents' attitudes toward death. See Appendix D. The DAP-R contains five subscales that determine respondents' feelings towards death and dying. The first subscale measures "fear of death" and contains 7 items [1, 27, 18, 20, 21, 32] that measure negative thoughts and feelings about death. The second subscale is "death avoidance" which includes 5 items [3, 10, 12, 19, 26] that assess attempts to avoid thoughts of death as much as possible. Next is "neutral acceptance" which contains 5 items [6, 14, 17, 24, 30] that measure death as neither welcomed nor feared. The fourth subscale is "approach acceptance" that includes 10 items [4, 8, 13, 15, 16, 22, 25, 27, 28, 31] that view death as a passageway to a happy afterlife. The last subscale is "escape acceptance" that consists of 5 items [5, 9, 11, 23, 29] that consider death as an escape from a painful existence. The mean subscale score is computed by summing the item scores ["strongly agree" (1) to "strongly disagree" (7)] on each of the individual subscales and then dividing the summed scores by the number of items included in that subscale. Participants' mean score of the death aptitude profile was determined by summing each nurse's responses on the profile and dividing that sum by 32. A higher score indicates a stronger tendency to identify with that particular subscale (Wong, Reker, & Gesser, 1994).

Wong and colleagues demonstrated the reliability of the DAP-R using alpha coefficients of internal consistency and four-week test-retest coefficients. The alpha coefficient ranged from a low of 0.65 in “neutral acceptance” to a high of 0.97 in “approach acceptance” (Dunn, Otten, & Stephens, 2005). A Cronbach’s alpha reliability coefficient of 0.81 was validated for this study. For the scale of DARP-fear of death a Cronbach’s alpha reliability coefficient of 0.92 was obtained. The Cronbach’s alpha reliability coefficient for DAPR-death avoidance scale was 0.76. The Cronbach alpha scores for the DAPR-Neutral, the DAPR-Approach and the DAPR-Escape scales were .79; .77 and .73, respectively.

Religious/Spiritual Beliefs Related to Death and Dying

Two questions from the Frommelt instrument were used to assess the influence of religious/spiritual beliefs on the nurse’s attitudes towards death and dying. See Appendix E. The first question asks if the nurse’s religious/spiritual beliefs have a “strong”, “minor” or “no” influence on his/her attitudes toward death and dying; one descriptor is selected. The second question asked if the lack of religious/spiritual beliefs on the nurse’s part has a “strong”, “minor” or “no” influence on his/her attitude toward death and dying; one response is selected. The respondent is asked to answer the question based on her/his persuasion. These two questions determine if religious/spiritual beliefs or lack thereof plays a role in the nurse’s attitudes towards death and dying.

Nurse’s Perception of Professional Responsibility to Engaging in End-of-Life Discussions

To assess the nurse’s perception of his/her professional responsibility to engage dying patients and their families in EOL discussions, the researcher developed five questions. See Appendix F. These questions asked the nurse to what degree does she/he feel that it is her/his professional responsibility to answer the patient’s questions or talk with him about issues related to death and the dying process. Response options are on a 4-point Likert scale of 0-3 [“not at all my responsibility” (0), “rarely is it my responsibility” (1), “sometimes it is my responsibility” (2), and “it is always my responsibility” (3)]. Scores on the five items are summed; the range of scores is 0-15. Higher scores indicate that nurses perceive EOL discussions with dying patients is their professional responsibility.

The pilot test discussed earlier determined the clarity of these items. Content experts determined that the content of the questions adequately measured professional responsibility to engage in dying patients and families in EOL discussions. Although the small number of questions is a limitation, a Cronbach’s alpha was calculated to assess reliability for these new questions. The Cronbach’s alpha reliability coefficient of 0.97 was validated for this study.

Social Persuasion

Social persuasion addresses two concepts: the mentors’ and coaches’ influence on nurses’ engagement in EOL discussions and nurses’ perception of nursing leadership’s expectations that nurses will engage in EOL discussions. Two measurement tools were developed by the researcher and are discussed below.

Influence of Mentors/Coaches

The influence of mentors and coaches on nurse self-efficacy to engage in EOL discussions was assessed by five questions. See Appendix G. Question 1 asks the nurse about having a mentor or coach who encouraged him/her to engage in EOL discussions; the response is Yes (2) or No (1). The second question asks the nurse to rate the effectiveness of the mentor/coach [“not at all effective” (1) to “very effective” (4)]. The higher the score for Question 2, the more influential the mentor/coach. The total score for the influence of mentor/coaches variable was determined as follows. If the participant responds “No” to Question 1, his/her score will be “0”. If the participant responds “Yes” to Question 1, his/her score for influence of mentor/coach will be the number of his response for Question 2. In using this approach, variation in the influence of a coach/mentor can be captured. The mentor or coach could have either a formal or informal role in the participants’ experience.

Question 3 asks the nurse to identify the professional background of the mentor/coach (i.e., nurse, social worker, spiritual advisor, physician or other). The participant was directed to check ‘all that apply’. The number and professional backgrounds of the mentor/coaches are reported.

Nurse experts were asked to review these questions to determine their appropriateness for this study. The questions were modified and approved. The usefulness of the questions was examined following the pilot test.

In reviewing the data, it was recognized that Question 1 which inquired if the respondent had an EOL mentor or coach was too limiting. Several nurses did not respond to Question 1 but answered Questions 2 and 3. The decision was made to eliminate Question 1 and use the responses to Questions 2 and 3 to address the influence of mentors and coaches.

Nursing Leadership Expectations

To assess nurses’ perception of nursing leadership expectations related to EOL discussions, a three-item tool was developed by the researcher. See Appendix H. As noted earlier nurse managers, chief nursing officers (CNO), directors of nursing, and nurse supervisors were included in the domain of nursing leadership. Question 1inquires about the degree to which the hospital's nursing leadership expects nurses to participate in EOL discussions. The responses for this item range from "no expectations" (1) to "high expectations" (5). Question 2 asked to what degree nursing leadership encourages nurses to participate in EOL discussions; responses range from "no encouragement" (1) to "lots of encouragement" (5). The third question asks to what degree does nursing leadership provide professional development resources related to caring for dying patients; responses range from "no resources" (1) to "lots of resources" (5). The item responses are summed; scores ranged from 1 to 15. The higher the score the higher the perceived expectation that nursing leadership expects staff nurses to engage terminally ill patients and their families in EOL discussions.

Content experts were asked to evaluate the validity of the items; the content validity score was 1.00. In addition, data from the pilot test was used to examine the clarity and usefulness of the items. The number of items is small which is likely reflected in the Cronbach's alpha reliability coefficient of 0.636.

Vicarious Experiences

Vicarious experiences are described as opportunities to observe an expert clinician or spiritual advisor talking with patients and families about EOL issues, decisions and final wishes. These experiences are most often observational. Observational experiences were assessed using three researcher-developed questions that ask the participant about observational opportunities. See Appendix L. Question 1 asks if the nurse has had an observational experience wherein she learned about discussing EOL issues; the responses are Yes (1) and No (0). If the nurse answers "yes", she/he is asked if the observational experience encouraged him/her to participate in EOL discussions with their dying patient; the responses are Yes (1) or No (0). The range of scores for Questions 1 and 2 is 0-2. Scoring for the vicarious experiences variable goes as follows. If the participant answers Question 1 with a “No”, the total score is “0”. If the participant answers “Yes” to Question 1 and responds with a “No” to Question 2, the total score will be 1; if the participant answers “Yes” to Question 1 and responds with a “Yes” to Question 2, the total score is 2.

Question 3 inquired about the professional background of the person(s) who was (were) observed (i.e., nurse, social worker, spiritual advisor, physician or other). Question 3 instructed the participant to ‘check all that apply’. Descriptive information about the numbers and types of disciplines observed are reported. Content experts were asked to evaluate the appropriateness and usefulness of the items. The content validity index was 1.0. In addition, data from the pilot test was used to examine the clarity and usefulness of the items.

Patients often help nurses to learn. Question 4 asks the respondent “Have you had the opportunity to learn how to have end-of-life discussions from your patient(s)? If so, please tell us about this experience”.

Mastery of Experiences

Mastery of experiences was assessed by considering the number of years in specialty nursing practice, nursing education, experiences with death and dying, and education about death, dying and end-of-life care. The items that measure years in specialty practice and nursing education can be found on the demographic form in Appendix K. The variables assessing education about death and dying and the previous personal and professional experiences with death and dying are measured via the FATCOD tool.

Nursing Education: Education about death and dying was measured with one item wherein the participant was asked to indicate if she/he a) took a course in death and dying, b) did not take a course but gained some information in other courses, or c) had no courses or information presented to her related to death and dying. See Appendix J.

Experiences with Dying and Death: This variable assessed both the personal and professional experiences of the nurses; it is addressed with three questions. See Appendix J. Question 1 asked the participant if she/he has cared for “many” (3), “some” (2), “rarely” (1) or “never” (0) terminally ill persons and their families. The higher the score the more experience they have with death and dying.

Question 2 inquired about their experiences with personal loss; it contains two parts. This question asked participants if they experienced a personal loss of someone within the past year. The participant can respond “I have no previous experience with the loss of someone close to me” (0), “I have lost someone close to me but not in the past year” (1) or “I have lost someone close to me in the past year” (1). The range of scores for this item is 0-2. The higher the score the more experience they have with death and dying.

The second component of Question 2 was added for descriptive purposes. If the participant responds that she has lost someone within the past year, she is requested to identify that person (i.e. immediate family member, significant other, child, or close friend).

Question 3 asks participants to indicate if they a) have a loved one who is terminally ill with life expectancy 1 year or less (1), b) are presently anticipating the loss of a loved one (1), or c) have no impending loss at the present time (0). Again, the higher the score the more experience they have with death and dying.

The scores for these questions were summed with the higher total score indicating more experience with death and dying. The range of total scores for the three questions is 0 to 7. Responses to these questions provide some indication of the breadth of the nurse's experiences with death and dying in the workplace.

Demographic Information

The demographic tool includes questions concerning: age, gender, race, marital status, initial nursing education, highest nursing/non-nursing degree, employment status, current position, and years of experience in nursing and in specialty practice. See Appendix K. This information was collected to describe the participants and to ensure balanced representation of the sample (Reinke, Griffith, Wolpin, Donesky-Cuenco, Carrieri-Kohlman, & Nguyen, 2011).

Procedure

After IRB approval, appointments were made with nurse leaders of both hospital systems to confirm the processes and procedures for nurse access and data collection. Following these meetings, the nurse researcher attended nurse leadership meetings that included the CNOs of each participating hospital to discuss the study details. The nurse leaders were given the study materials and gift cards for distribution to their staff. At the meetings, the researcher described the study, discussed the purpose and importance of the study, the inclusion criteria, informed consent, time commitment required, and incentives for participation, and provided instructions for participation which included information on how to access the survey on-line. The nurse leaders were informed that there was no difference between taking the survey on-line or on paper. The researcher answered all questions the nurse managers had regarding the study, the process and access to the on-line survey.

Online (Internet) surveys are becoming an essential research tool for a variety of research fields, including healthcare. The online survey was provided by the Georgia State Informatics Technology Services department. The survey was created using the Qualtrics tool and is housed within this department at GSU. Instructions to access the survey via a web address were included in the information packets and on the information flyers and emails.

In the case where nurses opted to complete the survey via pencil and paper, a survey packet containing an introductory letter (see Appendix O), an informed consent form (see Appendix P), and the questionnaire (see Appendix Q) was distributed during the manager meeting. Extra copies of the survey documents were left with the nurse manager in sealed envelopes with written instructions for nurse leaders who did not attend the meeting. The researcher's contact information was included in the packet should the participant or nurse leader have further questions.

Nurse leaders were informed that completion and return of the survey constituted consent to participate. No names or other nurse identification were collected. Nurses were asked to complete the survey by a specific date (two weeks was allotted from time of initial manager meeting to completion for each hospital). Posters reminding staff to complete the survey were distributed to the nurse leaders during the meetings and posted as permitted by the nurse managers. Reminders were also sent to each nurse leader via email by the nurse researcher at the end of Week 1 and mid-way through the second week to encourage participation. A locked box was provided for return of the completed paper surveys. Locked boxes were located on the unit as directed by the nurse manager. Surveys in the locked box were to be collected by the researcher. Only the researcher had access to the completed surveys. Although a paper survey option was made available, no paper surveys were submitted.

A $5.00 Starbucks card was attached to each survey information packet. Each eligible nurse received a survey information packet with the $5.00 gift card whether the nurse completed the survey or not. Each entity received no less than 20 packets with gift cards included, the larger facilities received no more than 100 information packets.

Following the nurse leader meetings, the introductory letter and information including the on-line link for completing the on-line survey and copies of the paper survey were given to the nurse leaders for distribution to all eligible nurses via email by the nurse manager. This strategy ensured that eligible nurses who were not present for the staff meeting would have the same information and opportunity to participate in the survey. The email contained the same information provided during the manager meetings and included the link to the online survey for those wishing to complete the electronic version of the survey. Nurses wishing to complete the paper survey were directed to pick up the survey packet from the nurse manager or other designated source.

The on-line survey welcome screen included the study's inclusion/exclusion criteria; participants were asked to check any of the criteria that applied to them. If no exclusion items were selected, the participant was directed to the consent form and then on to the survey. If any of the exclusion criteria were checked, participants were informed that they did not meet the criteria, were thanked for their willingness to participate and then exited from the website. The packets for the paper survey included the exclusion criteria. If any exclusion criteria were selected, the participant was informed that they did not meet the criteria and were thanked for their willingness to participate.

Data Analysis

Data from all the electronic surveys was uploaded to SAS 9.4. All survey data was inspected for completion. The uploaded data was inspected, cleaned and checked for errors. Subjects were included if they had valid answers for either Self-Efficacy or Behaviors of EOL.

The characteristics of the sample were described using frequency distributions, means and standard deviations. Histograms and frequency distribution were used to assess the properties of the distribution of scores for symmetry and normality (Tobler, Greutmann, Coleman, Yantiri, Librach, & Kovacs, 2011). Means and standard deviations were calculated for the continuous variables and frequency and percentages for categorical variables. Tables, graphs and charts further describe and explain the outcomes. Analyses for the specific aims include multiple regression, logistic regression, Pearson’s r correlation coefficient, and t-tests (Lehman, O’Rourke, Hatcher, & Stepanski, 2013).

For those surveys with data points missing, a multiple imputation strategy was employed. Rather than filling in a single value for each missing value, multiple imputation replaces each missing value with a set of plausible values that represents the uncertainty about the right values to impute (Rubin, 1976, 1987). In this study it was found that not all participants answered every question. Thus it was decided to use multiple imputations to correct for missing data. If this technique had not been used more than 50 surveys would have been lost resulting in 30%-40% of the data being discarded. Using multiple imputations has several advantages such as no assumptions are made about whether data are randomly missing (Tabachnick & Fidell, 2001). But rather, it incorporates random error because it requires random variation in the imputation process (Patrician, 2002). This method also simulates proper inferences from data and increases efficiency of the estimates (Patrician, 2002) by minimizing standard errors (Rubin, 1987). One disadvantage to using this approach is it does not produce a unique answer because randomness is preserved in the multiple imputations process, making reproducibility of exact results problematic (Patrician, 2002). Whenever using the imputations method, Tabachnick and Fidell (2001) recommend repeating analyses with and without missing data to make sure that the results do not get distorted by the imputed values. This final step was completed to ensure no distortion occurred.

Research Aims and Analyses:

The specific aims of this study were to:

- To examine the relationship of mastery of experience (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families. The selected analysis for this aim was multiple regression. Multiple regression is used when there is a measureable multiple correlation between a group of predictor variables and one dependent variable (nurse self-efficacy) (Mertler & Vannatta, 2002; Munro, 2005). Estimates of Pearson correlation, R^2, and p-values were calculated from the 100 replicates. These were then combined and the results presented in Table 11. Construct analysis using multiple regression from the 100 replicates, R^2 and p-values were calculated for each of the four constructs separately and for the combination of the 4 constructs (Full Model). These were then combined and the results presented in Table 12.

- To examine the relationship between self-efficacy and nurse participation in EOL discussions.

A bivariate correlation coefficient allows one to mathematically state the relationship that exists between two variables (Mertler & Vannatta, 2002; Munro, 2005). A scattergram was presented relating Behaviors of EOL and Self-Efficacy to Behaviors of EOL. This was done using the original dataset #1 above. Estimates of Pearson correlation, R^2, and p-values were calculated from the 100 replicates. These were then combined and the results presented. Multiple linear regression was used to determine the relationship between Self-Efficacy and Behaviors of EOL controlling for the 4 constructs (and for the full model) using the 100 replicates. Hierarchical regression was used by first relating Behaviors of EOL to each of the 4 constructs. Self-Efficacy was then added to this model. The overall R^2 and p-value for Self-efficacy controlling for the construct(s) were calculated. These were then combined and the results presented in Table 13.

- To explore the relationship of mastery of experience (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations), nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions.

A hierarchal regression was selected for this analysis as it allows for a forced entry of the variables into the equation such that the concept variables that are significantly associated with self-efficacy can be entered first, followed by self-efficacy. This is theoretically sound as the concept variables contribute to self-efficacy, all of which are expected to influence the behavior of engaging in EOL discussions with dying patients and families. (Munro, 2005). Multiple linear regression was used to determine the relationship between Behaviors of EOL, Self-Efficacy, and for the 4 constructs (and for the full model) using the 100 replicates. The overall R^2 and p-value for Self-efficacy and the construct(s) were calculated. These were then combined and the results presented in Table 14.

- To examine the difference in mastery of experience (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations), nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions between oncology nurses and medical-surgical nurses.

The most basic statistical test to measure group differences is the t-test. It was utilized to analyze significant differences between these two groups on the selected variables (Mertler & Vannatta, 2002; Munro, 2005). Due to the small sample of oncology nurses a multivariate analysis was done. Using the non-imputed data, t-test were used to compare the means from individual items of the four constructs for medical surgical nurses to that of oncology nurses. Sample sizes, means, standard deviations, and p-values are presented in Table 15.

- To examine the difference in mastery of experience (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse participation in EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions between nurses with higher self-efficacy and those with lower self-efficacy.

A t-test is designed to test the differences between two groups; therefore, it was the analysis of choice. (Munro, 2005). Using the non-imputed data, t-tests were used to compare the means from individual items of the four constructs for high self-efficacy nurses to that of low self-efficacy nurses. Sample sizes, means, standard deviations, and p-values are presented in Table 16. Logistic regression was used to investigate the relationship between high and low self-efficacy and the four constructs (and the full model). Area-Under-the-Curve (AUC) and p-values for each construct separately were calculated for each of the replicates. These were then combined and the results presented in Table 17.

Protection of Human Subjects

This research study was submitted to the Georgia University State Institutional Review Board and the Community Hospital Network Review Board for both PPMHS and PHC.

In order to protect the human rights of the participating nurses, this study was voluntary. All questionnaires were confidential by assuring that responses could not be linked back to the individual. However, to best describe the response rate and the type of units the responders work on, surveys from each data collection site were coded to reflect the hospital and the unit.

As previously discussed, the study was presented to the nurse leaders by the researcher via manager meetings at each hospital, followed by email distribution of the same information via the participating hospital systems' Community Hospital Network intranet. An introduction letter and informed consent form accompanied each survey packet which was distributed during the manager meetings. For those interested in completing a paper survey, a copy of the survey, consent form and directions for completion and return of the survey were also included. For those choosing to complete the electronic survey, a link to the on-line survey was provided.

To secure all paper surveys, a locked box was provided to each nurse manager and placed on the unit for return of the completed surveys. Surveys in the locked box were collected by the researcher. Only the researcher had access to the completed surveys. The researcher maintained the key for the lock box in a separate and secure location. There were no paper surveys returned to the lock boxes.

Data were reported in aggregate so no individual would be identified. Questionnaires were coded with an identification number to track the surveys distributed by hospital system and unit; however, no participant identifiers were collected. It was explained to the nurse leaders and participants that their consent to participate was indicated with the completion and return of the questionnaires to a locked box on the unit or with submission of the on-line survey. The participant was able to revoke consent for participation by exiting the on-line survey or not submitting the paper survey.

Three ethical principles were followed throughout the study. First, the participants were informed about the purpose and procedures related to the study as an effort to ensure they were knowledgeable. Second, study activities would cause minimal risk and psychological harm to the participants. Third, confidentiality was maintained at all levels. Only the principal investigator, the research team and the webmaster have access to the data.

Georgia State University contracts with Qualtrics, an independent secure survey company. Surveys were accessed through Qualtrics. Although the surveys were linked to the participant through the IPS email address, the confidentiality of the participant was maintained as participants were given an ID number/code. The links between the IPS address and the participants' surveys were kept separate from the database and were not accessed by the research team; thus confidentiality was maintained.

Assumptions of the Study

Four assumptions for this study follow. First, survey questions will capture the data and be measurable. Nurses will be truthful in their self-assessment when answering questions about attitudes and beliefs. The survey responses will be complete and reliable.

In summary, this chapter identified the study design, described the sample (access, inclusion and inclusion criteria, sample size, response rates), the study instruments, the procedure, the statistical analyses, and the protection of human subjects.

CHAPTER IV

RESULTS

This chapter describes the descriptive statistics, sample characteristics, results, and interpretation of the findings.

Sample

Before presenting the demographic information of the sample, it is important to note that some nurses did not respond to all of the background questions. Thus, the reader will notice some inconsistency in the total of the sample described in the demographic variables presented below. The presentations reflect the actual numbers from respondents completing these questions. See Table 2 for the demographic characteristics of the sample.

Nurses ages 50-59; 32 (32%) comprised the largest age group followed by 29 (29%) of nurses ages 40-49 years. Nine respondents (9%) identified with the 20-29 age group while six (6%) were greater than 60 years of age.

All participants were licensed registered nurses (n = 176). The number of eligible surveys was 168. The gender of the sample was similar to the general population of RNs in the United States. According to the U.S. Census Bureau (2011), 300,000 (9%) men were employed as nurses; female nurses represent 91% (n = 3.2 million) of the RN population. In this study, the female sample percentage was a bit higher than the national data base with 96.6% (n = 168) female participants; male representation in this sample was lower 3.4% (n = 8) than the national percentage (9%). This data reflects a somewhat larger female to male nurse ratio than reported by the U.S. Census Bureau's data of nursing demographics in the United States (U.S. Bureau of Labor Statistics, 2011).

The survey respondents were asked to identify their race. In this study, white, non-Hispanic nurses represented 77.9% (n = 116) of the sample followed by Black/African American nurses (16.1%; n=24). The remainder of the sample included Blacks/non-African Americans (3%; n = 3); Alaskan native or Native Americans (1.3%; n = 2); Asian, Native Hawaiian and Pacific Islanders (1.3%; n = 2); and Hispanics/Latinos (0.7%; n = 1).

Associate degree nurses comprised almost half of the sample (49.7%; n = 74). Nurses with Baccalaureate degrees in Nursing followed with 34.2% (n = 51) of participants; 3.4% (n = 5) of the nurses held a non-nursing Baccalaureate degree. Eleven nurses (7.4%) reported a Master's degree in Nursing while 2.7% (n = 4) listed a Master's in Business Administration. Four nurses (2.7%) had a Diploma.

Participants were asked how many years they had practiced nursing; only 92 respondents answered this question. Thirty-eight respondents (41.3%) were employed in nursing 0-9 years while 24 (26%) worked in nursing for 20-29 years. Sixteen (17%) were in nursing practice 10-19 years, whereas 10 (10 .8%) cared for patients for 30-39 years. Only four nurses (4.3%) practiced nursing 40 years or more.

In this sample, 51.7% (n = 77) participants were in staff nurse roles and 29.5% (n = 44) were charge nurses. The remainder identified themselves as nurse leaders (14.8%; n = 22) and nurse educators (1.3%; n = 2). Four nurses (2.7%) did not identify their roles within the organization.

The participants were also described by clinical specialty. Medical-surgical nurses comprised 75% (n = 108) of nurses. Medical-surgical designation included nurses working in the following care units: medical-surgical, orthopedics, stroke/neurology, surgical, gynecological surgery, emergency department, and transitional care units (i.e., step-down or intermediate care units). Eighteen nurses (12.5%) listed their specialty as cardiovascular nursing while 15 (10.4%) nurses provided care for oncology patients. Three nurses (2.1%) nurses did not declare a clinical specialty.

Table 2

Characteristics of Sample

Characteristic	M(SD)	*n**	Percentage
Age (N=100)	45.1 (11.8)		
20-29 years		9	9.0
30-39 years		24	24.0
40-49 years		29	29.0
50-59 years		32	32.0
60 plus year		6	6.0
Gender (N=178)			
Female		168	96.6
Male		8	3.4
Race (N=178)			
White Caucasian		116	77.9
Black/African American		24	16.1
Black non-African American		3	2.0
Hispanic/Latino		1	0.7
Asian		2	1.3
Alaskan/Native American		2	1.3
Undeclared		1	0.7

(Table 2 Continues)

(Table 2 Continued)

Characteristic	M(SD)	*n**	Percentage
Education (N-149)	11.45 (11.49)		
Diploma		4	2.7
Associate Degree		74	47.7
Bachelor of Science in Nursing		51	34.2
Bachelor of Science in Other Field		5	3.4
Master of Science in Nursing		11	7.3
Master's in Nursing Administration		4	2.5
Non-Nursing Degree (MBA)		5	2.2
Years in Nursing Practice (N=92)	16.0 (11.5)		
0-9 years		38	41.5
10-19 years		16	17.4
20-29 years		24	26.0
30-39 years		10	10.8
40 plus years		4	4.3
Current Position (N=149)			
Staff Nurse		77	51.7
Charge Nurse		44	29.5
Nurse Leader		22	14.8
Nurse Educator		2	1.3
Undeclared		4	2.7
Clinical Specialty (N=144)			
Medical/Surgical		108	75.0
Cardiovascular Disease		18	12.5
Oncology		15	10.4
Undeclared		3	2.1

*Missing data account for sample size less than 168

Variable Outcomes

This section describes the results of the analysis of the variables identified in the framework.

Psychological State: The Influence of Spiritual/Religious Beliefs on Nurses' Attitudes toward Death and Dying: This instrument is composed of two questions. Question 1 inquired about the influence that the nurse's spiritual/religious beliefs have on his/her attitude towards death and dying. The majority of the respondents (76.97%;

n = 127) stated their spiritual/religious beliefs were a strong influence on their attitudes towards toward death and dying. Thirty-one respondents (18.79%; n = 31) felt their spiritual/religious beliefs had a minor influence on their attitudes toward death and dying. Only 4.24% (n=7) believed their religious beliefs had no influence on their attitudes toward death and dying.

Question 2 asked about the influence that a lack of spiritual/religious beliefs has on the nurse's attitudes towards death and dying; 71.11% (n = 96) felt their lack of spiritual/religious beliefs had no influence on their attitudes towards death and dying while 21.48% (n=29) believed their lack of spiritual/religious beliefs had a minor influence on their attitudes towards death and dying. Only 7.41% (n = 10) stated their lack of spiritual beliefs had a strong influence on their attitude towards death and dying. See Table 3.

Nurses in this survey believe their spiritual/religious beliefs strongly influence their attitudes toward death and dying. Only a small number of respondents believe their lack of spiritual/ religious beliefs impacts their attitudes towards death and dying. Because so many respondents answered both questions it is difficult to interpret with certainty anything more than the responses to the strong influences questions.

Table 3

The Influence of Spiritual/Religious Beliefs on Nurses' Attitudes toward Death and Dying

	Responses	Percent
My spiritual/religious beliefs…		
are a strong influence on my attitudes towards death and dying	127	76.97%
are a minor influence on my attitudes towards death and dying.	31	18.79%
do not influence my attitudes toward death and dying.	7	4.24%
TOTAL	165	100%
My lack of spiritual/religious beliefs…		
has a strong influence on my attitudes towards death and dying.	10	7.41%
has a minor influence on my attitudes towards death and dying.	29	21.48%
has no influence on my attitudes towards death and dying.	96	7.11%
TOTAL	135	100%

Psychological State: Professional Responsibility to Engage in EOL Discussions with Terminally Ill Patient and Families. To address this variable, participants were questioned about their professional responsibility to address the five domains (the dying process, the patient's wishes for dying, the patient's concerns about pain, and patient's concerns about the family's acceptance of his/her approaching death) of EOL discussions when talking about end-of-life issues. See Table 4. When questioned about their responsibility to discuss these topics with patients, an overwhelming majority of the nurses agreed/strongly agreed that it was their responsibility to have discussions with patients about the dying process (93.3%; n = 155); the patient's final wishes (91.5%; n = 150); pain (97.5%; n = 159); patient's desires for no life-extending care (96.3%; n = 158); and the patient's concerns their family's acceptance of his/her approaching death (95.8%; n = 158). These nurses were very clear in their belief it was their professional responsibility to engage their dying patients in EOL discussions. The majority agreed or strongly agreed they should discuss each of the five elements of the discussion as presented in this survey with their dying patient.

Table 4

Nurses' Professional Responsibility to Engage in End-of-Life Discussions

It is my professional responsibility to answer the patients' questions or talk to them about…	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)	Mean	SD
The dying process	4 (2.4%)	6 (3.6%)	91 (55.2%)	64 (38.8%)	3.30	0.66
His/her final wishes for dying	2 (1.2%)	12 (7.3%)	69 42.1%)	81 (49.4%)	3.40	0.68
His/her concerns about pain	2 (1.2%)	2 (1.2%)	50 (30.7%)	109 (66.9%)	3.63	0.58
His/her desires for NO further treatment which could extend life or prolong death	2 (1.2%)	4 (2.5%)	65 (39.6%)	93 (56.7%)	3.52	0.61
Their concerns about the family's acceptance of his/her approaching death	2 (1.2%)	5 (3.0%)	77 (46.7%)	81 (49.1%)	3.44	0.62

Note: N = 176; Range of scores = 1-4.

Social Persuasion: Mentor/Coach Influence in EOL Skill Development. Sixty nurses (36.59%) indicated that a mentor/coach had encouraged them to have EOL discussions with patients and families. However, 104 nurses (63.41%) noted they had not received support from a mentor or coach to engage in patients in EOL discussions. When asked if they had ever received help to learn how to talk about EOL issues, 71 nurses (47.33%) reported that they did receive help on how to discuss EOL issues with patients and families but the majority of the respondents (n = 79; 52.67%) did not receive guidance in this area.

When asked how effective the mentors/coaches were in helping them improve their EOL communication skills, the large majority of the respondents felt their mentor/coach was effective/very effective (n = 52; 71.42%) in helping the nurse improve his/her EOL communication skills. The remaining respondents (n = 22; 28.58%) indicated their mentor/coach was somewhat effective/not at all effective.

Ninety-seven nurses identified the profession of their mentor/coaches. Half of the respondents (n = 49; 50.5%) reported that their mentor/coaches were nurses. Nineteen nurses (19.5%) were physicians. The remaining mentor/coaches were evenly divided between social workers (n = 13; 13.4%) and spiritual advisors (n = 13; 13.4%). The remaining three nurses (3.1%) listed their mentor/coaches as hospice volunteers (n = 2) and the mother of a dying patient (n = 1). See Table 5.

Only 36.59% of the nurses had a coach/mentor, the majority of the mentors were nurses. Of those who had a coach/mentor, 47.33% received help and were encouraged to engage in EOL discussions suggesting that nurses continue to educate and learn from other nurses. Education for nurses is needed on how to conduct EOL discussions as well as training for mentors/coaches, otherwise known as preceptors, on how to support, encourage and facilitate these important discussions.

Table 5

Professional Background of Mentors and Coaches

Profession	Responses	Percent
Nurse	49	50.5%
Social Worker	13	13.4%
Spiritual Advisor	13	13.4%
Physician	19	19.5%
Other	3*	2.2%
Total	97	100%

*Other category included 2 hospice volunteers, and the mother of a dying patient.

Social Persuasion: Nurse Leadership's Expectations for Nurses Participation in End-of-Life (EOL) Discussions. Four questions queried respondents' perceptions about nursing leadership's expectations related to nurse participation in EOL discussions with their dying patients and their families. As noted earlier, nurse leaders were identified as the nurse manager(s), CNO, director and supervisors within the organization. Nurses were asked if nursing leaders in their work place expected (Q1), encouraged (Q2), and supported (Q4) nurse participation in EOL discussions and provided nurses with resources related to caring for dying patients (Q3). The results indicated that these nurse leaders moderately expected nurses to participate (M = 3.32; SD = 1.11), support (M = 3.24; SD = 1.09), and encourage (M = 3.17; SD = 1.17) their nurses to participate in EOL discussions with dying patients and their families. Respondents also indicated that nursing leadership provided some professional development_resources (M = 2.79; SD = 1.14) related to caring for dying patients and their families. See Table 6.

Table 6

Nursing Leadership's Expectations for Nurses Participation in End-of-Life (EOL) Discussions

To what degree does nursing leadership (nurse manager, CNO, director, supervisor) in your organization… (n=151)								Mean	SD
		No (1)	Little (2)	Some (3)	Moderate (4)	High (5)			
1. Expect nurses to participate in EOL discussions with dying patients and families?	No expectations	11 (7.28%)	21 (13.91%)	51 (33.77%)	45 (29.80%)	23 (15.24%)	High expectations	3.32	1.11
2. Encourage nurses to participate in end-of-life discussions with dying patients and families?	No encouragement	15 (9.93%)	25 (16.56%)	52 (34.44%)	37 (24.50%)	22 (14.57%)	Lots of encouragement	3.17	1.17
3. Provide nurses with professional development resources related to caring for dying patients and their families?	No resources	21 (14.09%)	43 (28.86%)	41 (27.52%)	34 (22.82%)	10 (6.71%)	Lots of resources	2.79	1.14
4. Support nurse participation in end-of-life discussions with dying patients and their families?	Not supportive at all	9 (5.96%)	29 (19.21%)	49 (32.45%)	43 (28.47%)	21 (13.91%)	Very supportive	3.24	1.09

Vicarious Experiences: Participants were asked if they had ever had a vicarious experience, an unexpected observation, where they learned about discussing death and dying. Eighty-one respondents (53.64%) indicated that they had such a vicarious experience while 70 nurses (46.36%) said they had not had a vicarious experience. When asked if the observation encouraged them to participate in EOL discussions, a large majority of the respondents (92.6%; n = 75) confirmed that the vicarious experience had encouraged them to engage in EOL discussions with their dying patients. However, six nurses (7.4%) indicated that the vicarious experience did not encourage them to participate in EOL discussions. A significant number of respondents stated they did not have a vicarious experience; it was not a common phenomenon. This lack of opportunity to observe a vicarious experience suggests nursing education should include these experiences and should not wait on chance or a casual encounter but rather a planned event during onboarding of new staff.

Finally, participants were asked if they had opportunity to observe or learn from their patients or family members about EOL discussions. Sixty-eight nurses (45%) reported that they had observed/learned from their dying patients and families about EOL discussions. However, 83 nurses (55%) indicated that they had not had the experience of observing/learning about EOL discussions from their dying patients.

Nurses identified the professional background of the person(s) who they observed engaging in EOL discussions with patients. Those observed included nurses (n = 43; 37.4%); physicians (n = 27; 27.8%) spiritual advisors (n = 25; 21.7%) and social workers (n = 13; 11.3%). Two hospice volunteers (1.8%) were listed in the “other” category. Many nurses learned from their patients. Nurses should recognize the value of these experiences and how to incorporate them when educating new or less experienced staff. If nurses work in environments where people die, this should be part of their education and onboarding experience.

Mastery of Experiences: Education About and Professional and Personal Experiences with Death and Dying. Formal education prepares nurses for what they may encounter when caring for their patients. Participants were queried about their EOL education as well as professional and personal experiences with death and dying. The majority of the nurses (50.99%; n = 77) indicated that they did not take specific courses in death and dying, but did have EOL information in other courses. Forty nurses (26.46%) had taken courses on death and dying, while 34 nurses (22.55%) indicated that they had no information on dealing with death and dying patients.

Many participants were experienced in caring for terminally ill persons and their families. A large majority of the respondents (84.2%; n = 128) had provided care for some/many terminally ill patients. Only 24 nurses (15.8%) reported that they had rarely/never cared for dying patients and their families.

Personal experience with death and dying can also influence a nurse’s skill in providing EOL care. Almost all of the nurses (n = 121; 93%) had experienced the death of someone close to them; only nine nurses (7%) had never experienced the loss of someone close to them. At the time of this survey, nineteen nurses (12.84%) were anticipating the loss of a loved one. See Table 7.

Only a fourth of the respondents had courses in death and dying while others had some content in other courses, and 23% did not have any education related to death and dying. Seventy-three percent of the respondents reported insufficient amounts of education in nursing curricula or in professional development courses related to death and dying. Hospitals could take advantage of existing courses and could require such courses to ensure nurses are prepared. Organizations need to address this educational deficit for their staff who are currently taking care of patients who are dying. Nursing programs should also address this gap in current curricula. Professional experiences (47.37%) as well as personal losses (70.0%) with death and dying patients were significant in this sample. These results support the concept of “on the job learning” wherein nurses learn and gain insights about how to engage dying patients in EOL discussions yet, there is still a need for a more structured learning experiences.

Table 7

End-of-Life Education and Professional and Personal Experiences with Death and Dying

Education (N=151)	Responses	Percent
I took a course(s) in death and dying previously.	40	26.49%
I did not take a specific course on death and dying, but material on the subject was included in other courses.	77	50.99%
No information dealing with death and dying was previously presented to me.	34	22.52%
Professional Experience (N=152)		
I have cared for many terminally ill persons and their family members.	72	47.37%
I have cared for some terminally ill persons and their family members.	56	36.84%

(Table 7 Continues)

(Table 7 Continued)

Professional Experience (N=152)	Responses	Percent
I have rarely cared for terminally ill persons and their family members.	20	13.16%
I have had NO experience caring for terminally ill persons and their family members	4	2.63%
Personal Experience with Loss (N=130)		
I have lost someone close to me within the past year.	30	23.0%
I have experienced the loss of someone close to me, but not within the past year.	91	70.0%
Personal Experience with Loss (N=130)		
I have no previous experience with the loss of someone close to me.	9	7.0%
Present Experience with Dying Loved One (N=148)		
I presently have a loved one who is terminally ill (life expectancy 1 year or less).	8	5.41%
I am presently anticipating the loss of a loved one.	11	7.43%
I am not dealing with any impending loss at the present time.	129	87.16%

Psychological State. Professional Responsibility of the Nurse in Caring for Dying Patients and Families. The respondents’ perception of their professional responsibility to assess, plan and anticipate the needs of their dying patients was assessed. The large majority of the nurses agreed/strongly agreed (92.7%; n = 152) that it was their professional responsibility to assess the readiness of both the patient and family to engage in EOL discussions. Similarly, these participants (92.6%; n = 150) agreed/strongly agreed that it was their professional responsibility to plan for and anticipate the needs of the dying patient and their families. The large majority of this sample believed it was their professional responsibility to plan (agreed 56.10%/strongly agreed 36.59%) and anticipate (agree 58.02%/strongly agreed 34.57%) the needs of their dying patients and family.

Table 8

Professional Responsibility of the Nurse in Caring for Dying Patients and Families

Professional responsibility to assess, plan, and anticipate needs of dying patients.	Strongly Disagree	Disagree	Agree	Strongly Agree
It is my professional responsibility to ASSESS the readiness of dying patients and their families to engage in EOL discussions. (n=164**)**	5 (3.05%)	7 (4.27%)	92 (56.10%)	60 (36.58%)
It is my professional responsibility to PLAN for and ANTICIPATE the needs of the dying patient and their families to initiate/conduct EOL discussions**.** (n=162)	4 (2.47%)	8 (4.94%)	94 (58.02%)	56 (34.57%)

Descriptive Statistics. Table 9 contains a summary of the sample size, minimum and maximum scores, mean and standard deviation (SD) for the instruments used in this study.

Table 9

Descriptive Statistics for Instruments

Variable	N	Minimum	Maximum	Mean	S.D.
Quality of Communication Questionnaire	168	95.00	192.11	158.75	21.03
Quality of Communication Questionnaire Behaviors	151	34.00	85.00	71.63	9.03
Frommelt Attitudes Toward Care of the Dying	168	90.00	148.00	128.53	11.09
Death Attitude Profile-Revised	169	2.78	6.10	4.65	.604
Death Attitude Profile-Fear of Death	169	1.00	6.57	3.21	1.26
Death Attitude Profile-Death Avoidance	169	1.00	7.00	2.87	1.35
Death Attitude Profile-Neutral Acceptance	169	3.40	7.00	5.75	.69
Death Attitude Profile-Approach Acceptance	169	1.20	7.00	5.87	1.10
Death Attitude Profile-Escape Acceptance	169	2.20	7.00	4.89	1.39
Perception of Professional Responsibility	169	5.00	20.00	17.26	2.73
Influence of Mentors and Coaches	164	1.00	4.00	1.90	1.12
Age	145	24	89	44.88	11.81

Qualitative Data Outcomes

Three open-ended questions were included in the survey. The respondents were given the ability to free text their responses. No word or space limits were applied to the free texting option. Coding took place in multiple stages over time using direct content analysis. The initial coding process was an open process whereby the researcher closely read and annotated each comment. During this process, concepts were identified and comments were grouped by themes. A second reviewer completed this same process independently. Once agreement on themes and groupings of comments was achieved, coding was deemed complete (Munhall, 2012; van Mahen, 1997).

Question 1. How did you actually learn to engage dying patient and their families in EOL discussions? There were 134 responses to this question. Six responses were excluded as they were incomplete or the respondent did not answer this question. Six themes emerged from the responses to this question: T1: on the job training/working with patients; T2: observing members of the health care team; T3: engaging with patients and families; T4: personal experience with death; T5: education; and T6: perceptions of the dying process.

An example statement for each theme follows: T1 On the Job Training: Working on the floor with dying patients and families."; "senior nurses and on the job training": T2 Observing Colleagues: "Working and seeing how the MD and palliative care nurses handle family members and patients"; T3 Engaging with Patients: "Like I said above, it's important to gage their readiness to learn, and where they are in the grieving process. Have they accepted the news or are they still in denial? Then sit with them and talk to them like they are your own family. I try to put myself in their shoes and show empathy"; T4

Personal Experience with Death: “Through experiences in my own life and nursing at bedside for 15 years. My patients have been my greatest teachers”; T5 Education: “A hospice nurse came in to educate the nursing staff. It was a really eye opening experience”; T6 Nurse’s Perceptions of the Dying Process: “Coming with the mindset that this person is their loved one, and that whatever the patient is experiencing, the family feels the direct effect of the experience. So, coming with a compassionate perspective, and an openness to listen and give feedback when appropriate is a common course for me.” See Appendix L for more examples.

In summary, many nurses learned the art and skill of engaging dying patients and their families in EOL discussions from more experienced members of the health care team, from patients, and from personal life experiences. Their learning experiences were both active and passive as described by the respondents. The nurses expressed a sense of admiration and respect as they observed the interactions between their more seasoned colleagues and the dying patients and families.

Question 2. What would help you to become more comfortable and proficient in talking about death and dying with terminally ill patients and their families? Ninety-four (n=94) nurses responded to this question. Eleven responses were excluded as they were incomplete or the respondent did not answer this question. Six themes were identified: T1 Education; “taking classes or having an in-service”; T2 Real Time Experience/On the Job Training; “my preceptor was my best teacher”; T3 Shadowing/Observing; “watching more seasoned nurses”, watching the renal doctor having the hard talk”; T4 Relationship Building: “having a previous relationship with them (the patient)—at least having met them before and knowing a little about them before being in that situation with them.” T5

Nothing More Needed: “I have been a nurse for many years, I have enough experience: and T6 Sentiments of How Hard Death Is: “Death is never an easy subject talking about. Death is inevitable but the finality of it and not knowing what happens after you die is concerning not only to myself but to others as well.”

The thread in each theme was based on common terms used to explain a concept. For example: the education theme included words and phrases that reference additional education for nurses in general or specific to the respondent.

An example statement for each theme follows: See Appendix L for additional examples:

- T1 Education: “I believe that caregivers should be educated far more on the stages of death and dying. I feel that more guidance, more counseling, more family huddles or rounding with all physicians, caregivers and families present at one time should occur so everyone is speaking the same language, so support can be given to the patient AND their families”;
- T2 Real Time Experience/On the Job Training: “Continue interaction with dying patients and learning from others by observing their interactions with dying patients”;
- T3 Shadowing: “Continue to watch others, examine my own beliefs and faith”;
- T4 Relationship Building: “I would feel much more comfortable with the process if I could have more time. Often feel that I am not able to provide fully what the patient/family needs because of work load.”;
- T5 Nothing More Needed: “I am comfortable with these discussions”;

- T6 Death is Not Easy: “I don't think anything can make a nurse comfortable talking about death and dying with a terminally ill patient. It is a hard and uncomfortable subject for both the nurse and patient. The nurse must understand the different stages of grief a patient will go through and adjust accordingly. You don't want to take hope away because I believe in mind over matter. I believe a patient can will themselves to die or live. My mother was given 3 months to live. She lived 3 years. She wanted to see her son graduate high school and she did. She died 3 months after he graduated.”

For more examples, see Appendix L. These nurse responses indicated that the respondents desired more formal, structured education related to engaging dying patients and their families’ in EOL discussions.

Question 3. Have you had the opportunity to observe or learn about having end-of-life discussions from any of your patients? There were 37 responses to this question. The two themes that emerged from the data were “interactions between the nurse and the dying patient” and “interactions between the nurse and the families of their dying patients”. The following examples describe ‘learning from dying patients’:

- “I had a patient tell me their life story and show me how easy it was to talk about their impending death.”;
- “My patient was at peace with dying, she made it easy to talk about dying, what to expect and what she wanted”,
- “I learned so much from my first patient, he had end stage AIDS, he described the importance of listening and what that meant to him to have me there during this time.”

See Appendix L for additional examples. These nurses discussed conversations and interactions between themselves and their dying patients. They also described how they were moved, changed and inspired by using the ‘lessons learned’ from these experiences in future interactions with dying patients.

Examples of the phrases and comments that were the foundation of ‘learning from family of dying patients’ follow:

- “Watching the families interact with their loved one, having open discussions, sharing stories and having the difficult conversations really showed me how it can be done in love.”;
- Families really take on a lot when they have a loved one dying, and to take the time to include me in that process is amazing, I learned so much watching this son and mother say their good-byes.”
- I was working with a dying nun, she had so many people come to see her, she was an amazing person. Her church family and her own family all supported her, prayed with her and talked about moving on… it was so natural, so peaceful.”

See Appendix L for additional examples. Nurse comments reinforce that learning can happen whenever there is a willing participant and an attentive audience. These nurses shared their personal stories and their commitment to continue to listen, learn and discuss EOL issues with future patients as a result of these intimate moments shared with families of dying patients.

Results of Research Aims

Research Aim 1**.** To examine the relationship of mastery of experience (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families. The correlation of mastery of experiences, vicarious experiences, psychological state, and social persuasion versus self-efficacy using multiple imputation is shown in Table 10. The selected analysis for this aim was multiple regression.

The largest R^2 (16.1%; p= <0.0001) was found in the Psychological State variable ‘attitudes about death and dying’. The second largest R^2 (10.6%; p= <0.0001) was ‘experiences with death and dying’ found in the Mastery of Experiences construct. Two other variables were significant; both were positioned under the construct of Psychological State. ‘Professional responsibility’s R^2 was 5.03 (p=0.0034) and ‘attitudes about caring for dying patients and families’ R^2 was 3.48 (p=0.0154) to the model.

These findings suggest that the psychological state of the nurse is the predominant factor in how a nurse approaches interactions with dying patients and their families. The nurse’s personal attitudes about death and dying are pivotal to engaging these patients in EOL discussions. This finding suggests if the nurse has a negative attitude towards death and dying or is fearful of the dying process, it is unlikely he/she will engage in EOL discussion. Conversely, if the nurse has a positive attitude towards death and dying and does not fear the dying process, it is more likely that he/she will engage dying patients and their families in EOL discussions.

Table 10

Relationship of Mastery of Experiences, Vicarious Experiences, Psychological State and Social Persuasion with Self-Efficacy Using Multiple Imputations

	Correlation	r^2 (%)	p-value
Mastery of Experiences			
• Years in specialty practice	-0.0862	0.74	0.5087
• Nursing education	-0.0472	0.22	0.6926
• Experiences with death & dying	0.3261	10.63	<0.0001*
• Education about death, dying & EOL care	-0.1593	2.54	0.0533
Vicarious Experiences			
• Observational experiences	0.1136	1.29	0.1559
Psychological State			
• Attitudes about death, dying	0.4010	16.08	<0.0001*
• Attitudes about caring for dying patients and families	-0.1866	3.48	0.0154*
• Religious/spiritual beliefs	-0.0802	0.64	0.3117
• Q6 (Religious/Spiritual beliefs)	0.1082	1.17	0.2081
Q7 (Lack of Religious/Spiritual beliefs)			
• Professional Responsibility	0.2244	5.03	0.0034*
Social Persuasion			
• Mentors/coaches/role model	0.1179	1.39	0.1342
• Nursing leadership expectations	0.0623	0.30	0.4511

The model predicts that Mastery of Experiences ‘experiences with death and dying’ surmises that nurses with past experiences with death and dying are more likely to engage patients in EOL discussions. Past experiences dealing with death and dying likely prepare nurses to better handle future encounters with dying patients and their families.

R^2 was calculated for each construct. The results indicated that Psychological State had the largest R^2 (20.08%) followed by Mastery of Experiences R^2 (13.19%). The other two constructs, Vicarious Experiences (R^2 = 1.29%) and Social Persuasion (R^2 = 1.6%) were not significant. R^2 for all four constructs together was 28.91%.

All four constructs contributed significantly to self-efficacy. When all the variables were examined in relationship to self-efficacy, four variables (attitudes towards death; attitudes about caring for dying patients and families; experience with death and dying; and professional responsibility) contributed the most to self-efficacy. With all four constructs in the full model, two constructs contributed significantly to self-efficacy−mastery of experiences and psychological state.

Table 11

β -weight Coefficients

	Mastery of Experiences			Vicarious Experiences			Psychological State			Social Persuasion		
Variable	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*	B	SE B	*B*
Intercept	151.699	7.703	0	154.296	2.342	0	92.216	25.395	0	150.571	5.805	0
Years in specialty practice	-0.197	0.197	-0.090									
Nursing Education	-0.628	3.360	-0.015									
Education on Death and Dying	-3.810	2.363	-0.129									
Experience with Death and Dying	4.973*	1.280	0.308									
Vicarious Experience				2.389	1.676	0.112						
Frommelt Attitudes Toward Care of the Dying							0.628*	0.154	0.332			
Death Attitude Profile-Revised							-6.343*	2.649	-0.182			

(Table 11 Continues)

(Table 11 Continued)

	Mastery of Experiences			Vicarious Experiences			Psychological State			Social Persuasion		
Variable	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*	B	SE B	*B*
Religious Beliefs							-3.529	3.116	-0.089			
My lack of Religious/Spiritual Beliefs							3.014	2.534	0.090			
Perception of Professional Responsibility							0.566	0.610	0.073			
Influence of Mentors and Coaches										2.048	1.512	0.109
Nursing Leadership Expectations										0.239	0.590	0.033
R^2	13.2%			1.3%			20.1%			1.5%		
Construct P-value	0.0004			0.1556			<0.0001			0.2899		

* $p<0.05$

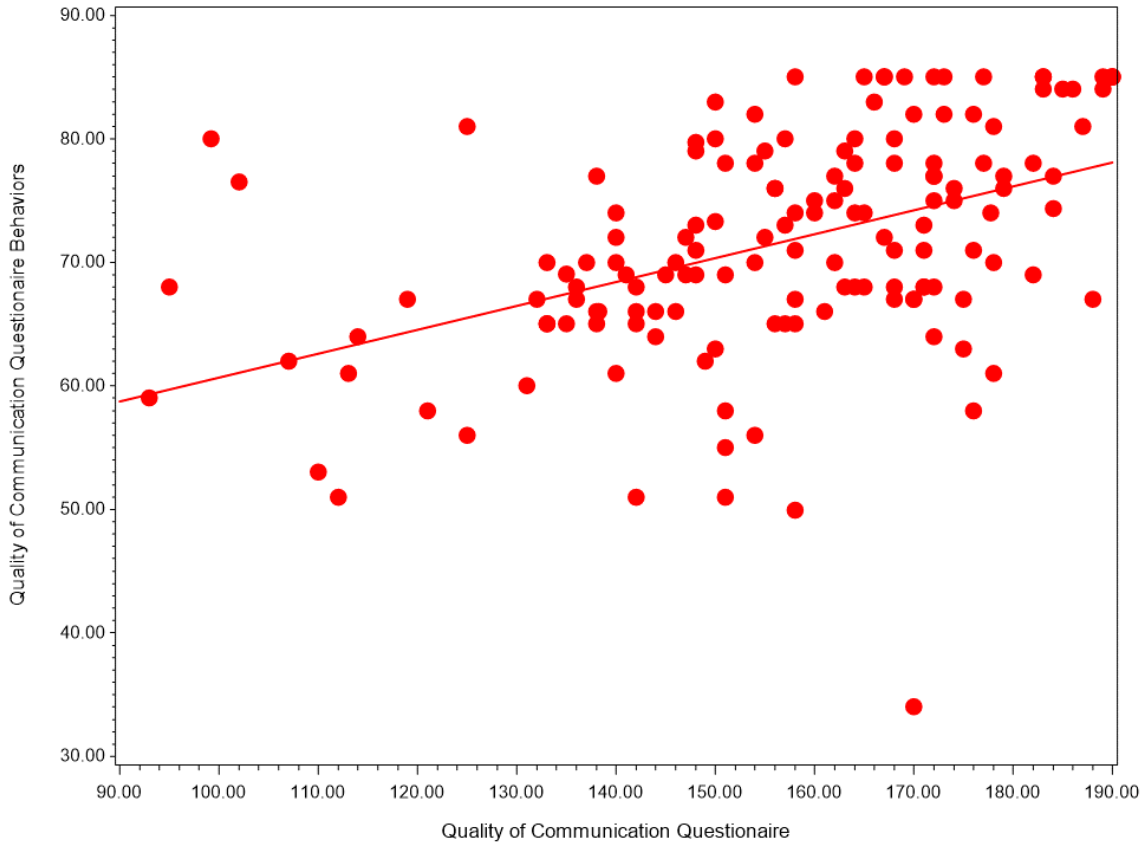
Table 12

Summary: R^2 for Models of Self-Efficacy

Model	R^2	p-value
Full	28.91	<.0001
Mastery of Experiences	13.19	0.0004
Vicarious Experiences	1.29	0.1556
Psychological State	20.08	<.0001
Social Persuasion	1.52	0.2899

Research Aim 2. To examine the relationship between self-efficacy and nurse behaviors for EOL discussions. For this computation, the relationship between nurses' responses on self-efficacy (Quality of Communication with Dying Patients Questionnaire) and the Behaviors for EOL Discussions questionnaire was examined. The Pearson correlation using multiple imputation was ($r = 0.4575$, $p = <0.0001$). This relationship is displayed in Figure 3 (R^2=20.93%). Nurses with greater self-efficacy reported more behaviors for conducting EOL discussions.

Figure 3. Correlation Between Self-efficacy and Nurse Behaviors for EOL Discussions



Multiple linear regression using multiple imputation was used to examine the relationship between self-efficacy and behaviors controlling for the four constructs. The results are shown in Table 13. Behavior was related to self-efficacy after adjusting for each construct and the combination of all four constructs ($p<0.0001$). Nurses with higher levels of self-efficacy reported more behaviors for engaging patients in EOL discussions.

For the first construct, mastery of experiences, a regression model with intercept, years in specialty practice, nursing education, education on death and dying, and experience with death and dying was constructed. Self-Efficacy was the added to the model. The resulting $R^2 = 22.7\%$. Self-Efficacy was significantly related after controlling for mastery of experiences (slope: 0.187 ± 0.034, $p<0.0001$). For the second construct, vicarious experiences, a regression model with intercept and vicarious experiences was constructed. Self-Efficacy was the added to the model. The resulting $R^2 = 22.8\%$. Self-Efficacy was significantly related after controlling for vicarious experiences (slope: 0.192 ± 0.032, $p<0.0001$). For the third construct, psychological state, a regression model with intercept, Frommelt attitudes toward care of the dying, death attitude profile-revised, religious beliefs, my lack of religious/spiritual beliefs, and perception of professional responsibility was constructed. Self-Efficacy was the added to the model. The resulting $R^2 = 27.0\%$. Self-Efficacy was significantly related after controlling for psychological state (slope: 0.170 ± 0.034, $p<0.0001$). For the final construct, social persuasion, a regression model with intercept, influence of mentors and coaches, and nursing leadership expectations was constructed. Self-Efficacy was the added to the model. The resulting $R^2 = 27.5\%$. Self-Efficacy was significantly related after controlling for mastery of experiences (slope: 0.189 ± 0.031, $p<0.0001$). A full regression model was constructed with the four constructs. Self-Efficacy was the added to the model. The resulting $R^2 = 35.7\%$. Self-Efficacy was significantly related after controlling for all four constructs (slope: 0.151 ± 0.035, $p<0.0001$).

Table 13

Coefficients for Constructs and Full Model

	Mastery of Experiences			Vicarious Experiences			Psychological State			Social Persuasion		
Variable	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*
Intercept	38.410	6.063	0	40.315	4.988	0			0			0
Years in specialty practice	0.052	0.074	0.054									
Nursing Education	0.826	1.364	0.045									
Education on Death and Dying	0.297	0.965	0.023									
Experience with Death and Dying	0.766	0.545	0.023									
Vicarious Experience				1.242	0.672	0.135						
Frommelt Attitudes Toward Care of the Dying							0.049	0.069	0.059			

(Table 13 Continues)

(Table 13 Continued)

	Mastery of Experiences			Vicarious Experiences			Psychological State			Social Persuasion		
Variable	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*
Death Attitude Profile-Revised							0.104	1.173	0.007			
Religious Beliefs							0.741	1.383	0.043			
My lack of Religious/Spiritual Beliefs							2.750*	1.267	0.189			
Perception of Professional Responsibility							0.403	0.265	0.121			
Influence of Mentors and Coaches										0.420	0.484	0.052
Nursing Leadership Expectations										0.747*	0.229	0.238
Self-Efficacy	0.187*	0.034	0.430	0.192*	0.032	0.442	0.170*	0.034	0.391	0.189	0.031	0.437
R^2	22.7%			22.8%			27.0%			27.5%		

* $p<0.05$

Table 14

R^2 and P-values: Behaviors Versus Self-Efficacy Controlling for Constructs

Model	R^2	p-value
Full	35.69	<.0001
Mastery of Experiences	22.72	<.0001
Vicarious Experiences	22.77	<.0001
Psychological State	26.99	<.0001
Social Persuasion	27.54	<.0001

* p-value for self-efficacy after adjusting for construct(s)

Research Aim 3. To explore the relationship of mastery of experience (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations), nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions.

Multiple linear regression using multiple imputation was used to examine the relationship between behavior, self-efficacy and the four constructs. For the first construct, mastery of experiences, a regression model with intercept, years in specialty practice, nursing education, education on death and dying was fit. The resulting R^2 = 6.6%. Mastery of experiences was significantly related to behaviors (p=0.0368). For the full model, the four constructs, self-efficacy, and an intercept was fit. These were significantly related to behaviors (R^2 = 35.69%, p<0.0001).

The full model that included all four constructs (Mastery of Experience; Vicarious Experience; Psychological State; Social Persuasion) and Self-Efficacy resulted in an R^2 of 35.69% (p=<.0001). From a construct perspective, Psychological State has the largest R^2 (R^2 = 14.73%; p=0.0005). However, all four constructs made a significant contribution to the model. See Table 13. These findings confirm that Mastery of Experience, Vicarious Experience, Psychological State, Social Persuasion and Self-Efficacy related to death and dying are predictors for nurse behaviors in engaging in EOL discussions with dying patients and their families.

Table 15

Coefficients for Constructs and Full Model

	Mastery of Experiences			Vicarious Experiences			Psychological State			Social Persuasion		
Variable	B	SE B	β	B	SE B	β	B	SE B	β	B	SE B	*B*
Intercept	66.720	3.392	0	69.877	1.057	0	38.764	11.906	0	62.625	2.539	0
Years in specialty practice	0.015	0.079	0.016									
Nursing Education	0.709	1.523	0.039									
Education on Death and Dying	-0.413	1.053	-0.032									
Experience with Death and Dying	1.695*	0.570	2.242									
Vicarious Experience				1.699*	0.742	0.184						
Frommelt Attitudes Toward Care of the Dying							0.155*	0.071	0.189			

(Table 15 Continues)

(Table 15 Continues)

	Mastery of Experiences			Vicarious Experiences			Psychological State			Social Persuasion		
Variable	B	SE B	*β*	B	SE B	*β*	B	SE B	*β*	B	SE B	*B*
Death Attitude Profile-Revised							-0.972	1.246	-0.064			
Religious Beliefs							0.142	1.487	0.008			
My lack of Religious/Spiritual Beliefs							3.260*	1.319	0.224			
Perception of Professional Responsibility							0.499	0.285	0.150			
Influence of Mentors and Coaches										0.087	0.647	0.999
Nursing Leadership Expectations										0.793*	0.254	0.253
R^2	6.6%			3.5%			14.7%			8.7%		
Construct P-value	0.0368			0.0229			0.0005			0.0013		

* $p<0.05$

Table 16

R^2 and P-values: Behaviors Versus Self-Efficacy Controlling for Constructs

Model	R^2	p-value
Full	35.69	<.0001
Mastery of Experiences	6.60	0.0358
Vicarious Experiences	3.46	0.0229
Psychological State	14.73	0.0005
Social Persuasion	8.71	0.0013
Self-Efficacy	20.93	<.0001

Research Aim 4. To examine the difference in mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations), nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions between oncology nurses and medical-surgical nurses.

Due to the low number of oncology nurse participants (n=18), data analysis was extremely limited. However, two variables could be examined. A comparison of years in nursing specialty indicated that medical-surgical nurses (n=129; mean =13.35 years) practiced in their specialty more years (p = .3201) than the oncology nurses (n=12; mean = 9.46 years). However, these differences were not significant (p=0.3201).

As noted above, statistical procedures were limited due to the difference in sample sizes between oncology and medical-surgical nurses. However, one significant finding was observed. Oncology nurses reported significantly more experience with death and dying than medical-surgical nurses (4.08 versus 2.95; p p-value=.0033).

Table 17

Oncology Nurses and Medical-Surgical Nurses Differences

Variable	Medical-Surgical			Oncology			p-value
	n	mean	sd	n	mean	sd	
Years in Specialty	129	13.35	9.71	12	9.46	8.12	0.3201
Education on Death and Dying	134	1.98	0.70	11	1.73	0.79	0.2596
Experiences with Death and Dying	134	2.95	1.73	12	4.08	1.16	0.0033
Vicarious Experiences	133	1.05	0.98	13	1.23	1.01	0.5336
Frommelt Attitudes Toward Care of the Dying	133	128.3	11.2	13	133.0	9.6	0.1472
Death Attitude Profile-Revise	134	4.68	0.61	13	4.45	0.51	0.2013
Religious Beliefs	134	1.27	0.54	13	1.23	0.44	0.8057

(Table 17 Continues)

(Table 17 Continued)

Variable	Medical-Surgical			Oncology			p-value
	n	mean	sd	n	mean	sd	
Q7(Lack of Religious/Spiritual Beliefs)	111	2.65	0.60	9	2.56	0.73	0.6591
Perception of Professional Responsibility	134	17.2	2.8	13	18.3	2.3	0.1585
Influences of Mentors and Coaches	134	1.94	1.15	13	2.38	1.26	0.1773
Nursing Leadership Expectations	133	9.51	2.90	13	9.31	2.95	0.8133

Research Aim 5. To examine the difference in mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying, and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families, attitudes about death and dying, religious/spiritual beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse participation in EOL discussions with terminally ill patients and their families, and nurse participation in EOL discussions between nurses with higher self-efficacy and those with lower self-efficacy.

Scores on all variables were compared for nurses with high self-efficacy and nurses with low self-efficacy. Participants' mean score of the death aptitude profile was determined by summing each nurse's responses on the profile and dividing that sum by

32. The results of the t-tests are shown in Table 18. Nurses with high self-efficacy scored significantly higher on several variables when compared to nurses with low self-efficacy. These variables were: experiences with death and dying (p = 0.0067); vicarious experiences (p = 0.0344); attitudes toward care of the dying (p < 0.0001); perception of professional responsibility (p = 0.0372); and influences of mentors and coaches (p = 0.0277). Interestingly, nurses with low self-efficacy scored higher on the death attitude profile than did nurses with high self-efficacy (p = 0.0165).

Table 18

Self-Efficacy (High vs Low)

Variable	Low Self-efficacy			High Self-efficacy			p-value
	n	mean	sd	n	mean	sd	
Years in Specialty	53	11.64	9.03	90	12.08	9.60	0.7845
Education on Death and Dying	57	2.02	.072	92	1.92	0.70	0.4332
Experiences with Death and Dying	58	2.71	1.20	92	3.29	1.31	0.0067
Vicarious Experiences	60	0.82	0.97	94	1.16	0.98	0.0344
Frommelt Attitudes Toward Care of the Dying	65	123.9	10.2	103	131.5	10.6	<0.0001
Death Attitude Profile-Revise	65	4.79	0.66	103	4.56	0.55	0.0165
Religious Beliefs	64	1.30	0.52	103	1.24	0.53	0.5215

(Table 18 Continues)

(Table 18 Continued)

Variable	Low Self-efficacy			High Self-efficacy			p-value
	n	mean	sd	n	mean	sd	
Lack of Religious/Spiritual Beliefs	56	2.52	0.69	78	2.71	0.56	0.0853
Perception of Professional Responsibility	65	16.7	2.83	103	17.61	2.63	0.0372
Influences of Mentors and Coaches	64	1.66	0.96	99	2.05	1.19	0.0277
Nursing Leadership Expectations	61	8.99	2.94	95	9.69	2.86	0.1442

Logistic regression using multiple imputations was used to determine the probability that high or low self-efficacy could be predicted by the four variables in the model. Table 16 presents the results for the logistic regression reporting ‘area under the curve” (AUC) and p-value for various models. The AUC demonstrates the sensitivity and specificity of the predictor variables in the model. The larger the AUC the greater the discriminating power.

The AUC for the full model was 0.777. The greater the AUC the better the model in predicting high or low self-efficacy. The two constructs that were significant were Psychological State (AUC=0.748, p<0.0001) and Mastery of Experiences (AUC=0.653, p=0.0339). The construct Psychological State was almost equal to the full model. Psychological State and Mastery of Experiences contribute significantly to self-efficacy for nurse participation in EOL discussions.

Table 19

Area Under the Curve and p-value of Models

Model	R^2	p-value
Full	0.777	<.0001
Mastery of Experiences	0.653	<0.0339
Vicarious Experiences	0.581	<0.0605
Psychological State	0.748	<0.0001
Social Persuasion	0.608	<0.0569

Summary

In summary, 168 nurses from two hospital systems completed this online survey. Participants were primarily white/non-Hispanic females with a mean age of 45.1 years. These nurses averaged 11.5 years in nursing practice, half of the nurses had an Associate’s Degree. Nurses responded to the open-ended questions generating several themes of how nurses learned the art and skill of engaging dying patients and their families in EOL from other professionals as well as their dying patients and their families. These nurses believe that their spiritual and religious beliefs influence their attitudes towards care of the dying patient. They also believe that it is their professional responsibility of the nurse to engage their patients in EOL discussions, even though there is little to no expectation, encouragement or resources to do so from their nurse leaders.

The constructs of Psychological State and Mastery of Experiences made the largest contributions to Self-Efficacy. Nurses with higher self-efficacy demonstrated more behaviors conducive to engaging their patients and families in EOL discussions.

Nurse with high scores related to psychological state would be described as having positive attitudes towards death and dying, and caring for dying patients, thus would be more likely to engage in EOL discussions with patients and families. Nurses with more experience with dying patients demonstrated a higher degree of self-efficacy and communication skills related to EOL discussions. Participants highlighted a need for enhanced nursing education to assist in skill development from conducting EOL discussions

CHAPTER V

DISCUSSION AND CONCLUSIONS

This chapter presents a discussion of the study findings, limitations of the study and implications for future research.

Sample

Participants were predominately White/non-Hispanic females, which closely resembles the national make up of professional nurses across the United States (HRSA, 2013). Most of the respondents (n = 53; 53%) reported ages from 30-49 years of age; national statistics indicate that 50.3% of U.S. nurses are in this age group. This sample appears to be in the middle of their work life and relatively young in their professions. Six nurses (6%) were age 60 years or older. These results were slightly lower than the aging populations of nurses (8.5%) soon to be exiting the profession (HRSA, 2013; U.S. Bureau of Labor Statistics, 2011). However, in general this sample is representative of registered nurses in the U.S.

The national data base shows 44.6% registered nurses hold a Bachelor’s degree (HRSA, 2013), while 37.6% of this sample reported Bachelor’s degrees in nursing or other fields. Half of the respondents reported Associate degrees (49.7%) whereas, HRSA (2013) indicates that 37.9% of registered nurses of have an Associate’s degree. As noted earlier, many health care facilities in rural and underserved areas rely heavily on local Associate Degree programs to supply registered nurses to fill vacancy needs (Sizemore, Hoke, Robbins, & Billings, 2007). This sample may be a better representation of the education level of nurses practicing in rural and underserved areas.

Conceptual Framework

Bandura's Self-Efficacy model provided a useful conceptual structure to examine the factors that influence a nurse's perceived self-efficacy (mastery of experiences, vicarious experiences, psychological state, and social persuasion) and the relationship of self-efficacy and nurse engagement in EOL discussions with dying patients and their families. Relationships among the variables predicted by the model were supported by the findings. As a result, knowledge about the factors that influence nurses' to initiate EOL discussions with dying patients and their families was attained.

Discussion of Findings

Psychological State: Spiritual/Religious Beliefs on Nurses' Attitudes toward Death and Dying. The majority of the respondents (76.97%) stated their spiritual/religious beliefs were a strong influence on their attitudes towards death and dying. This positive attitude could support enhanced patient care and lead to better-quality patient outcomes and improved patient satisfaction with the EOL experience (Irvine, Sidani, & Hall, 1998). However, drawing this sample from the "Bible belt" of the country may have contributed to the high number of respondents agreeing that their spiritual/religious beliefs strongly influence their attitudes towards death and dying. Future research with a broader base for sample attainment is warranted.

Psychological State: Professional Responsibility to Engage in EOL Discussions with Terminally Ill Patient and Families. An overwhelming majority (92.69%) of the nurses agreed/strongly agreed that it was their responsibility to have discussions with patients about the dying process, the patient’s final wishes, pain, patient’s desires for no life-extending care and the patient’s concerns about their family’s acceptance of his/her approaching death as a part of their role as patient advocates. During the patient’s transition from life to death, the nurse provides care, educates and advocates for patients and encourages reflection on the implications of end-of-life (Lewis, 2013). These findings also support the nurse’s role as patient advocate.

Social Persuasion: Mentor/Coach Influence in EOL Skill Development. Most respondents indicated that their mentors were nurses. This is possibly a by-product of the on-boarding process in many organizations; nurses train nurses. It is not surprising, therefore, that the majority of nurses identified their mentor/coach as a “senior/seasoned” nurse. Physicians were also identified as mentors. Understanding the healthy working relationship of many nurses and physicians, this outcome is not surprising. In many specialties, nurses work more closely with their physician partners than any other health team member. However, as the literature has shown, physicians often lack the skills, time and self-efficacy to conduct EOL discussions with their dying patients (Knauft, Engelberg, Patrick, and Curtis, 2005; Leung, Udris, Uman, & Au, 2012). Thus, these respondents’ replies may not reflect the norm in most nurse/physician relationships in regards to EOL mentors/coaches; more research is needed in this domain.

Some respondents felt their mentor/coach did assist and encourage them to engage in EOL discussions, however, the majority of respondents did not have this experience. It is unclear if the absence of this coaching experience is due to the lack of EOL coaches in the workplace or other causes. To be an effective coach, an individual must develop a collaborative relationship and be willing to share her knowledge and skills. Franklin

Covey (1989) teaches that becoming an effective coach and mentor takes time, training, and a huge investment to build lasting relationships.

Social Persuasion: Nurse Leadership's Expectations for Nurses Participation in EOL Discussions. Results indicated that nurse leaders had low to moderate expectations that their nurses would participate in EOL discussions, provided modest support for nurse participation, and offered nondescript encouragement to their nurses to participate in EOL discussions with dying patients and their families. These findings confirm there is no strong expectation or support for nurses to actively engage in EOL discussions.

Respondents did indicate that nursing leadership provided some professional development resources related to EOL care. This result alludes to the fact that resources for enhancing nurse skills to engage in EOL discussions are minimal to scarce. Yet, nurses have expressed concerns about EOL discussions such as 'the fear of removing all hope', 'making the wrong decision', 'giving up too soon', or 'starting the discussion before the patient and family are ready' (Lamiani, Meyer, Leone, Vegni, Browning, Rider, Trugo, & Moja, 2011). Unfortunately, many health care professionals feel inadequately trained to know when and how to initiate EOL discussions (Harding, Selman, Beynon, Hodson, Coady, Read, Walton, Gibbs, & Higginson, 2008). Yet, authors addressed the importance of strengthening nursing education to improve EOL care (Ferrell et al., 1999a; Ferrell, Virani, Grant, & Borneman, 1999b; Ferrell, Virani, Grant, & Rhome, 2000; Ferrell et al., 2005; Paice, Ferrell, Virani, Grant, Malloy, & Rhome, 2006).

Vicarious Experience. Of the eighty-one participants who had a vicarious experience wherein they learned about discussing death and dying, 92.6% confirmed that this experience encouraged them to participate in EOL discussions with their dying patients. Bandura (1977) noted that one can build self-efficacy by watching others do a task that either he has never done before, or has done with little success (Bandura, 1977). These findings support Bandura's statement. Educational activities should include observation and practice. Future studies to test simulation and other experimental strategies to ensure practice experiences are warranted.

Mastery of Experience: Education and Nurses' Professional and Personal Experience with Death and Dying. The majority of the participants were experienced in caring for terminally ill persons and their families (84.2%) and had lost loved ones (93%). As might be expected, professional and personal experiences with death and dying can influence a nurse's skills in providing EOL care. Sharing these experiences with colleagues who have little or no experience with death and dying could promote a mentor relationship with less experienced nurses.

Although the majority of these nurses (76%) indicated that they had received some education related to EOL care, it was clear that they had little formal education about EOL care other than classes in nursing school or an occasional professional development lecture. Clinical agencies would benefit by offering an EOL care program to their nursing staff, particularly to those nurses who frequently care for dying patients. These programs should include both education and work experiences as these have been shown to have positive effects on communication contributing to improved patient outcomes (Feudtner, Santucci, Feinstein, Snyder, Rourke, & Kang, 2007).

Psychologic State: Professional Responsibility of the Nurse to Care for Dying Patients and Families. The large majority of the nurses (92.7%) agreed/strongly agreed that it was their professional responsibility to assess the readiness of both the patient and family to engage in EOL discussions in order to plan for and anticipate the needs of dying patients and their families. Yet, most of these nurses did not have educational programs to assist them in skill development. By chance, some connected with mentors/coaches and/or had vicarious experiences in the practice environment to rely on. To achieve quality care for the terminally ill patients, educational and experiential strategies for conducting EOL discussions should be required for nurses who care for dying patients.

Qualitative Responses

Vicarious Experiences: Participants discussed vicarious experiences of watching their peers and other healthcare professionals engage dying patients in EOL discussions. It was through these observations that these nurses learned how to go about having EOL talks with their patients. Vicarious experiences can positively affect nurses' self-efficacy to conduct EOL experiences. Cheraghi and colleagues (2009) noted that nurses observed and later modeled these conversations with their own patients. However, structured "hands-on" learning experiences should be available to nurses who care for dying patients and their families. Quality of care depends on it.

Educational Preparation: Nurses in this study expressed a desire to have the educational training to become an effective communicator with dying patients regarding EOL care and issues. In general, nurses receive little training on how to engage the patient or family in EOL discussions (Curtis, Patrick, Caldwell, & Collier, 2000). Educational and clinical organizations should implement EOL care and communication programs to assure that nurses are prepared to meet the needs of dying patients and their families.

Evidence shows that EOL discussions occur late in the course of illness. A desire to protect patients and their families and to prevent ‘the loss of hope’ delays the much needed conversation about EOL that could tremendously improve the dying experience for all. (Earle, Neville, Landrum, Ayanian, Block, & Weeks, 2004; Mack, Paulk, Viswanath, & Prigerson, 2010). If nurses are prepared and are confident in their abilities to initiate EOL discussions with patients and families, they will likely initiate these conversations earlier in the trajectory of patient care. As patient advocates, they can communicate the needs of the patients and families to physicians, social workers, and other appropriate health professionals.

Research Aims

Research Aim 1. As noted previously, all four constructs (Mastery of Experiences, Vicarious Experiences, Psychological State, Social Persuasion) significantly contributed to self-efficacy. Psychological State, specifically the variables ‘attitudes about death and dying’, ‘attitudes about caring for dying patients and their families’ and ‘professional responsibility’, was the construct which contributed the most to nurse self-efficacy while Mastery of Experiences’ variable ‘experiences with death with death and dying’ also made a significant contribution. Nurses’ positive attitudes about death and dying and caring for dying patients and their families, along with a sense of professional responsibility, greatly influence their ability and willingness to have these difficult discussions.

The challenge will be how to assess nurses for their readiness to work with dying patients and provide learning opportunities to gain these skills before they are faced with this challenge. Clinical facilities and academic settings should explore ways of conducting evaluations or screenings of graduate nurses and nursing students for their “death aptitude”, provide education related to EOL care and conducting EOL discussions, and provide opportunities for clinical exposure to dying patients. Understanding how nursing students and nurses feel about these experiences would set the stage for additional education if needed. Simulation labs are becoming more effective in providing learning modalities for hands-on training, perhaps using such a model in the workplace environment would give nurses at the bedside a means to gain needed experiences before they encounter their first dying patient.

Research Aim 2. Self-efficacy was significantly associated with nurse behaviors related to EOL discussions. Nurses with high levels of self-efficacy demonstrated strong scores in communication, had positive attitudes towards death and dying and were older with more years practicing as a nurse. These aspects are EOL behaviors that were learned “over time” and “on-the-job”, which indicates that these behaviors can be taught, improved or modified and more importantly screened for as organizations assess staff for skills and behaviors needed to engage in EOL discussions. As a result, nursing schools and hospitals can use screening tools (e.g., self-efficacy, attitudes about death and dying, attitudes about caring for dying patients, professional responsibility to conduct EOL discussions with patients, etc.) to plan for the educational and experiential needs of their nurses and customize their learning for success.

Research Aim 3. All four constructs of Bandura’s Self-Efficacy Model (Mastery of Experiences, Vicarious Experiences, Psychological State, Social Persuasion) made a significant contribution to nurse Behaviors for EOL discussions with Psychological State making the largest construct contribution to the model. Self-efficacy also made a strong positive contribution to the model. This finding underscores the importance of self-efficacy in the performance of nurse behaviors related to EOL discussions and care. Assessing a nurse's self-efficacy related to EOL care can provide the way to individualized education and experiential professional development activities.

Research Aim 4**.** As noted in earlier, due to the small sample size of oncology nurses, comparisons were not possible. Future research can explore these comparisons.

Research Aim 5. The difference between nurses with higher self-efficacy and those with lower self-efficacy was examined. Nurses with low levels of self-efficacy reported higher scores on only two variables, 'attitudes about death and dying' and education related to death and dying, however, education was not significantly different. Interestingly, nurses with high levels of self-efficacy had significantly higher mean scores on experiences with death and dying, years in specialty, vicarious experiences, attitudes toward caring for the dying, the influence of mentors and coaches, and perception of professional responsibility. Higher scores related to 'attitudes about death and dying' maybe a result of living in the Bible belt and strong religious/spiritual beliefs. Education related to death and dying although not specific to the dying patient may have contributed somewhat to self-efficacy in this sample. As expected, nurses with high levels of self-efficacy demonstrated higher means in the areas related to care and attitudes towards dying patients as well as behaviors which engage dying patients. These findings among medical-surgical nurses are similar to research reports that ICU nurses' perception of their skills related to interactions with dying patients as positive (Reinke, Slatore, Uman, Udris, Moss, Engelberg, & Au, 2011). Nurses with high self-efficacy scored higher on those variables that contributed to their self-efficacy score (i.e., attitudes about death and dying; attitudes about caring for dying patients and their families; professional responsibility; experiences with death with death and dying).

It seems appropriate to focus on factors that support higher degrees of self-efficacy and higher levels of nurse behaviors related to EOL discussions and care; it may be the combination of the constructs and their variables that makes the difference. For example, results from this research study indicate that all four constructs (Mastery of Experiences, Vicarious Experiences, Psychological State, Social Persuasion) made significant contributions to Behaviors related to EOL discussions and care. Outcomes related to self-efficacy were supported by two constructs, Psychological State and Mastery of Experiences. Additional research is needed to apply these results to develop screening, educational, and experiential strategies for preparing nurses to conduct EOL discussions.

Implications for Nursing

More Americans are living longer, the proportion of the U.S. populations that is aged 65 years or older is growing rapidly (U.S. Census, 2011). Nurses will continue to care for patients across the illness trajectory and will increasingly have to deal with chronic illnesses and diseases of the aging population. This care will include care of the dying patient. The need to understand what barriers exist that keep nurses from engaging in EOL discussions, and what resources are needed to enhance this skill set, will become increasingly evident.

While the findings of this study may have limitations, it has revealed several observations that confirm the need for continued research in this venue. Nurses clearly need resources and exposure to experiences that will enhance self-efficacy with engaging terminally ill patients and their families in EOL discussions. Simulation labs have been found to be an effective and safe tool for “practicing” (Kameg, Clochesy, Mitchell, & Suresky, 2010; Kruijver, Kerkstra, Bensing, & van de Wiel, 2001). The usefulness of simulation experiences related to EOL discussions should be explored.

As noted in this study, nurse leaders do provide some level of support for nurse participation in EOL discussions with dying patients and their families, yet, not all of the respondents indicated they were comfortable having EOL discussions with dying patients and their families. Nurse leaders must make their expectations for EOL discussions clear to the staff, and once the expectation is set, as with any other competency, EOL aptitude should be evaluated. The nurse leader must ensure the staff have the resources and skills needed to participate in these crucial conversations. Education programs that provide information on EOL care and conducting EOL discussions, and offer experiential opportunities (simulation; practice), should be tested and incorporated into nursing education and professional development programs for nurses. Developing a plan to address educational experiences for nurses to build on behaviors that will increase self-efficacy to engage terminally ill patients and their families in EOL discussions would be the next step.

Although two of the constructs, and several of their associated variables made strong contributions to the statistical models, more research is needed to clarify nurses’ needs to better care for their dying patients and their families by conducting EOL discussions.

Implications for Research

This study identified Self-Efficacy, Psychological State, and Mastery of Experiences as the factors that significantly contribute to nurses engaging their dying patients and families in EOL Discussions. With this understanding, future research can focus on how to evaluate nurse's aptitude for caring for patients at the EOL, what is the role of nursing schools in training for these experiences, and finally, how does the hospital onboard and train existing staff in EOL discussions?

It is crucial that Nurse Leaders understand their role in setting the expectation for staff to engage in EOL discussion and to provide the resources and tools needed to be successful. As the leader, it is her/his responsibility to understand the needs of their patient population and to provide the competent staff to care for these needs. Nurse leaders must provide experienced, competent staff who employ the appropriate skills, knowledge and Self-Efficacy to ensure all patients feel their EOL desires are noted and honored.

The literature indicates there are very few studies examining the nurse's role in EOL discussions. Consequently, there is a need for additional studies to examine the role of the nurse in EOL discussions, how to prepare nurses for these complex and dynamic discussions and how to assess the competency for those already caring for patients at the end-of-life.

Limitations of the Study

Although the sample size was adequate for all but one of the analyses, a larger sample would have provided more data for clarification of the findings. Nurse participation was low. Over 2,000 registered nurses were invited to participate in this study; only 168 (8.3%) participated. Nurses are not always willing to engage in research studies. However, an incentive greater than a $5 gift card may have stimulated more participation.

The confusion surrounding the question on spiritual/religious beliefs causing nurses to respond to both questions limited analysis of this variable. Limiting the study to the southeast “Bible belt” could have introduced biases related to spiritual/religious beliefs that were unaccounted for in this sample.

Lessons Learned

Obtaining participants from two hospital systems with multiple sites was challenging. Coordinating schedules with the nursing teams at each hospital proved to be a bigger challenge than anticipated. More time visiting each participating unit for visibility and to answer questions may have improved participation. A better system for distribution of the gift cards for staff who participated will need to be explored.

The online link to the survey did prove to be a challenge and had to be re-distributed several times. Firewalls on some of the hospital computers prevented direct access to the link.

Overall, once all obstacles were overcome, the process was relatively smooth; communication was effective; staff and managers alike were comfortable emailing the researcher directly with questions or concerns. The Qualtrics product provided by Georgia State University proved to be easy and user friendly.

Study Summary

The purpose of this study was to examine nurse self-efficacy and engaging in EOL discussions with dying patients and their families. The contributing factors

(Psychological State; Mastery of Experiences) to self-efficacy were identified. Nurses with higher levels of self-efficacy displayed more behaviors for conducting EOL discussions with dying patients and their families. Participants indicated that it was their professional responsibility to engage in end-of-life discussions with their dying patients and families and reported positive attitudes about death and dying, caring for dying patients and their families, and engaging their patients in end-of-life discussions. Strategies for assessing nurse self-efficacy and competence in discussing EOL issues were explored. The need for end-of-life nurse education and “on the job training” was identified.

When nurses are empowered with appropriate EOL education, skills and behavioral training needed to be proficient and competent in EOL discussions, nurse self-efficacy will increase. As a result, these nurses will engage dying patients and their families in EOL discussions.

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APPENDICES

Appendix A

Communication with Dying Patients

This set of questions focus on your perception of how good you are in discussing things with dying patients and their families. Using the following scale, where "0" is "not good at all, and "10" is "extremely good", please check the number that best describes how good you feel you are in talking about the following topics with dying patients and their families.

How good are you about…	Not at all good										Extremely good
1. Using words that the patient can understand.	0	1	2	3	4	5	6	7	8	9	10
2. Looking the patient in the eye.	0	1	2	3	4	5	6	7	8	9	10
3. Including the patient's loved ones in decisions about his illness and treatment.	0	1	2	3	4	5	6	7	8	9	10
4. Answering all the patient's questions about his illness and treatment.	0	1	2	3	4	5	6	7	8	9	10
5. Listening to what the patient has to say.	0	1	2	3	4	5	6	7	8	9	10
6. Caring about the patient as a person.	0	1	2	3	4	5	6	7	8	9	10
7. Giving the patient your full attention.	0	1	2	3	4	5	6	7	8	9	10
8. Talking with the patient about his	0	1	2	3	4	5	6	7	8	9	10

How good are you about…	Not at all good										Extremely good
feelings concerning the possibility that he might get sicker.											
9. Talking to the patient about the details concerning the possibility that he might get sicker.	0	1	2	3	4	5	6	7	8	9	10
10. Talking to the patient about how long he might have to live.	0	1	2	3	4	5	6	7	8	9	10
11. Talking to the patient about what dying might be like.	0	1	2	3	4	5	6	7	8	9	10
12. Talking with the patient’s loved ones about what his dying might be like.	0	1	2	3	4	5	6	7	8	9	10
13. Involving the patient in the decisions about the treatments that he wants if he gets too sick to speak for himself.	0	1	2	3	4	5	6	7	8	9	10
14. Asking about the things in life that are important to the patient.	0	1	2	3	4	5	6	7	8	9	10
15. Respecting the things in the patient’s life that are important to him.	0	1	2	3	4	5	6	7	8	9	10
16. Asking about the patient’s spiritual or religious beliefs.	0	1	2	3	4	5	6	7	8	9	10
17. Respecting the patient’s spiritual or religious beliefs.	0	1	2	3	4	5	6	7	8	9	10

How good are you about…	Not at all good										Extremely good
The next two questions ask you to rate how comfortable you are in talking about dying and how well you communicate with your dying patients.											
	Not at all comfortable										Extremely comfortable
18. How comfortable are you in talking about dying with your terminally-ill patients?	0	1	2	3	4	5	6	7	8	9	10
	Not at all good										Extremely good
19. Overall, how would you rate your communication with dying patients?	0	1	2	3	4	5	6	7	8	9	10

Appendix B

Behaviors for EOL Discussions

In situations wherein end-of-life issues come up, indicate how often you use the following communication techniques with dying patients. Check on your response.

How frequently have you…	Never	Rarely	Occasionally	Often	Always
1. Used words that the patient can understand.					
2. Looked the patient in the eye.					
3. Included the patient’s loved ones in decisions about his illness and treatment.					
4. Answered all the patient’s questions about his illness and treatment.					
5. Listened to what the patient has to say.					
6. Cared about the patient as a person.					
7. Gave the patient your full attention.					
8. Talked with the patient about his feelings concerning the possibility that he might get sicker.					
9. Talked to the patient about the details concerning the possibility that he might get sicker.					
10. Talked to the patient about how long he might have to live.					
11. Talked to the patient about what dying might be like.					
12. Talked with the patient’s loved ones about what his dying might be like.					

How frequently have you…	Never	Rarely	Occasionally	Often	Always
13. Involved the patient in the decisions about the treatments that he wants if he gets too sick to speak for himself.					
14. Asked about the things in life that are important to the patient.					
15. Respected the things in the patient's life that are important to him.					
16. Asked about the patient's spiritual or religious beliefs.					
17. Respected the patient's spiritual or religious beliefs.					

Summary

1. How did you actually learn to engage dying patients and their families in EOL discussions?

2. What would help you to become more comfortable and proficient in talking about death and dying with terminally ill patients and their families?”

Appendix C

Attitudes Toward Caring for the Dying Scale

These items assess how nurses feel about certain situations in which they are involved with patients. All statements concern the giving care to the dying person and/or his/her family. Where there is reference to a dying patient, assume it refers to a person who is considered to be terminally ill with six months or less to live.

Please circle or check on the letter(s) following each statement which corresponds to your own personal feelings about the attitude or situation presented. Please respond to all 30 statements on the scale. The meaning of the letters is:

SD = Strongly Disagree
D = Disagree
U = Uncertain
A = Agree
SA = Strongly Agree

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
1. Giving nursing care to the dying person is a worthwhile learning experience.	SD	D	U	A	SA
2. Death is not the worst thing that can happen to a person.	SD	D	U	A	SA
3. I would be uncomfortable talking about impending death with the dying person.	SD	D	U	A	SA
4. Nursing care for the patient's family should continue throughout the period of grief and bereavement.	SD	D	U	A	SA
5. I would not want to be assigned to care for a dying person.	SD	D	U	A	SA

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
6. The nurse should not be the one to talk about death with the dying person.	SD	D	U	A	SA
7. The length of time required to give nursing care to a dying person would frustrate me.	SD	D	U	A	SA
8. I would be upset when the dying person I was caring for gave up hope of getting better.	SD	D	U	A	SA
9. It is difficult to form a close relationship with the family of the dying person.	SD	D	U	A	SA
10. There are times when death is welcomed by the dying person.	SD	D	U	A	SA
11. When a patient asks, "Nurse, am I dying?" I think it is best to change the subject to something cheerful.	SD	D	U	A	SA
12. The family should be involved in the physical care of the dying person.	SD	D	U	A	SA
13. I would hope the person I'm caring for dies when I am not present.	SD	D	U	A	SA
14. I am afraid to become friends with a dying person.	SD	D	U	A	SA
15. I would feel like running away when the person actually died.	SD	D	U	A	SA
16. Families need emotional support to accept the behavior changes of the dying person.	SD	D	U	A	SA
17. As a patient nears death, the nurse should withdraw from his/her involvement with the patient.	SD	D	U	A	SA
18. Families should be concerned about helping their dying member make the best of his/her remaining life.	SD	D	U	A	SA

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
19. The dying person should <u>not</u> be allowed to make decisions about his/her physical care.	SD	D	U	A	SA
20. Families should maintain as normal an environment as possible for their dying member.	SD	D	U	A	SA
21. It is beneficial for the dying person to verbalize his/her feelings.	SD	D	U	A	SA
22. Nursing care should extend to the family of the dying person.	SD	D	U	A	SA
23. Nurses should permit dying persons to have flexible visiting schedules.	SD	D	U	A	SA
24. The dying person and his/her family should be the in-charge decision makers.	SD	D	U	A	SA
25. Addiction to pain relieving medication should not be a concern when dealing with a dying person.	SD	D	U	A	SA
26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	SD	D	U	A	SA
27. Dying persons should be given honest answers about their condition.	SD	D	U	A	SA
28. Educating families about death and dying is not a nursing responsibility.	SD	D	U	A	SA
29. Family members who stay close to a dying person often interfere with the professional’s job with the patient.	SD	D	U	A	SA
30. It is possible for nurses to help patients prepare for death.	SD	D	U	A	SA

Appendix D

Attitudes Toward Death Profile

This questionnaire contains a number of statements related to different attitudes toward death. Read each statement carefully, and then decide the extent to which you agree or disagree. For example, an item might read: “Death is a friend.” Indicate how well you agree or disagree by circling or clicking on one of the following: SA = strongly agree; A= agree; MA= moderately agree; U= undecided; MD= moderately disagree; D=disagree; SD= strongly disagree. Note that the scales run both from strongly agree to strongly disagree and from strongly disagree to strongly agree.

If you strongly agreed with the statement, you would circle SA. If you strongly disagreed, you would circle SD. If you are undecided, circle U. However, try to use the undecided category sparingly.

It is important that you work through the statements and answer each one. Many of the statements will seem alike, but all are necessary to show slight differences in attitudes.

1. Death is no doubt a grim experience.	SD	D	MD	U	MA	A	SA
2. The prospects of my own death arouse anxiety in me.	SA	A	MA	U	MD	D	SD
3. I avoid death thoughts at all costs.	SA	A	MA	U	MD	D	SD
4. I believe that I will be in heaven after I die.	SD	D	MD	U	MA	A	SA
5. Death will bring an end to all my troubles.	SD	D	MD	U	MA	A	SA
6. Death should be viewed as a natural, undeniable, and unavoidable event.	SA	A	MA	U	MD	D	SD
7. I am disturbed by the finality of death.	SA	A	MA	U	MD	D	SD
8. Death is an entrance to a place of ultimate satisfaction.	SD	D	MD	U	MA	A	SA

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

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

Appendix E

Religious/Spiritual Beliefs

We are interested in learning if spiritual or religious beliefs influence clinical practice. Answer the question that best reflects your persuasion. Check or click on your response.

1. My spiritual/religious beliefs

   ____ are a <u>strong</u> influence on my attitude toward death and dying.
   ____ are a <u>minor</u> influence on my attitude toward death and dying.
   ____ do <u>not</u> influence my attitude toward death and dying.

2. My lack of spiritual/religious beliefs

   ____ has a <u>strong</u> influence on my attitude toward death and dying.
   ____ has a <u>minor</u> influence on my attitude toward death and dying.
   ____ has <u>no</u> influence on my attitude toward death and dying.

Appendix F

Nurse's Perception of Professional Responsibility to Engage in End-of-Life Discussions.

Please check or click on the box with your response.

It is my professional responsibility to answer the patients' questions or talk with them about…	Strongly Disagree	Disagree	Agree	Strongly Agree
1) The dying process?				
2) His/her final wishes for dying?				
3) His/her concerns about pain?				
4) His/her desires for no further treatment which could extend life or prolong death?				
5) Their concerns about the family's acceptance of his/her approaching death?				

Appendix G

Mentor/Coach Influence in EOL Skill Development

In the course of moving from novice to expert, nurses frequently become engaged with a mentor or coach (formal or informal) who teaches, supports, and encourages him/her to expand her knowledge and skills in the practice of nursing. Sometimes we have opportunities to have a mentor who teaches us about care of the dying patient and his family and encourages us to engage in end-of-life discussions with patients when the occasion arises.

1) Have you ever had a mentor(s) or coach(s) who encouraged you to engage your dying patients and family members in end-of-life discussions?

_____ Yes
_____ No

If no, go to (insert location here)

2) Overall, how effective was your mentors/coaches in improving your skills related to end-of-life care and communication?

_____ Not at all effective
_____ Somewhat effective
_____ Effective
_____ Very effective

3) What was the professional background of the mentors/coaches who encouraged you to engage in end-of-life discussions with dying patients and families? (Check all that apply)

_____ Nurse
_____ Social worker
_____ Spiritual advisor
_____ Physician
_____ Other. Please indicate: ____________________________________

Appendix H

Nursing Leadership Expectations

Please provide your perceptions of your organization's nursing leadership's expectations related to nurses' engagement in end-of-life discussions with patients and families. Check or click on the box of the number that best reflects your nursing leadership's expectations.

Note: Nursing leadership refers to all or any of the following positions: nurse manager, chief nursing officer (CNO), directors, and supervisors.

To what degree does nursing leadership (nurse manager, CNO, director, supervisor) in your organization…							
1. Expect nurses to participate in end-of-life discussions with dying patients and families?	No expectations	1	2	3	4	5	High expectations
2. Encourage nurses to participate in end-of-life discussions with dying patients and families?	No encouragement	1	2	3	4	5	Lots of encouragement
3. Provide nurses with professional development resources related to caring for dying patients and their families?	No resources	1	2	3	4	5	Lots of resources

Appendix I

Vicarious Experiences: Observations

Sometimes we have opportunities to observe an expert clinician or spiritual advisor talking with a patient and/or his family about the patient's death. This observation makes an impression on us and teaches us about discussing death and dying with patients and families.

1) Have you ever had an observation wherein you learned about discussing death and dying from clinician(s), social worker(s) or spiritual advisor(s)?

_____ Yes
_____ No

If no, go to Question (Insert # HERE)

2) Did these observations encourage you to participate in end-of-life discussions with patients and/or families?

_____ Yes
_____ No

3) What was the professional background of the person(s) you observed in end-of-life discussions with dying patients and families? (Check all that apply)

_____ Nurse
_____ Social worker
_____ Spiritual advisor
_____ Physician
_____ Other. Please indicate: ___________________________________

4) Patients often help nurses to learn. Have you had the opportunity to observe or learn about having end-of-life discussions from any of your patients?

____Yes   _____No

If yes, please briefly describe that experience. ______________________

Appendix J

Education on and Experiences with Death and Dying

Education on Death and Dying

1) Previous education on death and dying
____ I took a course in death and dying previously.
____ I did not take a specific course on death and dying, but material on the subject was included in other courses
____ No information dealing with death and dying was previously presented to me.

Experiences with Dying and Death

1) Previous experience in dealing with terminally ill persons
_____ I have cared for many terminally ill persons and their family members.
_____ I have cared for some terminally ill persons and their family members.
_____ I have rarely cared for terminally ill persons and their family members.
_____ I have had NO experience caring for terminally ill persons and their family members.

2) Previous experience with loss (Check all that apply)
_____ I have lost someone close to me within the past year.
Specify:
    ____ Immediate family (husband, wife, mother, father, sibling)
    ____ Significant other
    ____ Child
    ____ Close friend
_____ I have experienced the loss of someone close to me, but not within the past year.
_____ I have no previous experience with the loss of someone close to me.

3) Present Experience (Check all that apply)
_____ I presently have a loved one who is terminally ill (life expectancy 1 year or less).
_____ I am presently anticipating the loss of a loved one.
_____ I am not dealing with any impending loss at the present time.

Appendix K

Background Information

1. Nursing Education

______ Diploma

______ Associate Degree

______ Baccalaureate Degree in Nursing

2. Education (highest degree)

______ Diploma

______ Associate Degree

______ Baccalaureate Degree in Nursing

______ Baccalaureate Degree in other field

______ Master's Degree in Nursing

______ Master's Degree in other field

______ Doctoral Degree (PhD, EdD)

______ Doctorate in Nursing Practice (DNP)

Other. Please indicate: ________________________________

3. Race

______ African American

______ Asian

______ Black, non-African American

______ Caucasian/White

______ Hispanic

______ Other. Please indicate: ________________________________

4. Years in nursing practice _______ Years

5. Current position:

______ Staff nurse

______ Charge nurse

______ Other. Please indicate: _____________

6. Clinical practice specialty:

______ Cardiac vascular disease (e.g. congestive heart failure)

______ End-stage pulmonary disease

______ Oncology

______ End-stage renal disease

______ End-stage HIV/AIDS

______ Other. Please indicate: ________________________________

7. Years in clinical specialty practice _______ Years

8. Age: _______ years

9. Sex: ___________ Female ___________ Male

Appendix L

Qualitative (Open-ended) Questions

Q1. How did you really learn to engage dying patient and their families in EOL discussions?	
Themes	**Quotes**
On the Job Training/Working with Patients	• #15) "I worked as a Hospice Volunteer before my Nursing Degree, took care of a dying pt. who did die on my shift in nursing school and have taken care of so many dying pts who passed during my nursing career I can no longer remember the number." • #46) "Most learning has occurred through experience with patients. Some information concerning engaging families was being presented in lecture format by hospice workers while working with a prior employer." • # 86) "From my experience working in long term care and Hospice."
Observing Members of the Health Care Team	• #64) "I have learned how to engage patients and families in end-of-life discussions through my experience with palliative care physicians. • #66) "Watching experienced nurses that I worked with that have been around for years." • # 70) "I learned to engage patients and their families by observing other nurses with more experience in this area."
Engaging with Patients and Families (listening, etc.)	• #55) "I have worked as a nurse in the med/surg field for over 25 years. I have dealt with many patients and their families in EOL situations. I have learned something from each of these EOL situations I have been involved in and have used this to become very comfortable in dealing with EOL issues." • #110) "real life experience as hospice relief during nursing school. My first client was the mother of my science high school teacher. She hugged me and vented openly in a way that made me realize my 18 years of life experience

	was comforting simply because I can listen well. People respond to genuine nonjudgmental support and need time to talk. I had recently lost my father to a heart attack where I was first on scene to initiate CPR. It gave me a different perspective to realize he had the sense of impending death and made efforts to give me attention before he passed. I learned through conversation with mom and my siblings that he did the same for them. I passed that care to all my clients with impending death for themselves or loved ones.”
Personal Experience with Death	• #9) “I have had personal experiences that taught me about what to expect when dying and have cared for many actively dying patients during my nursing career. I've learned to pay close attention to body language as well as the concerns that are voiced from the patient and family members. Dying is part of living and we all must face one day.” • #16) “I took care of my husband who was diagnosed w/ liver cancer. He was given 2-3 months but survived for 11 months after diagnosis. He passed away in August 2012. I learned a lot caring for him and having our families close as well. My daughter and his two sons as well as siblings and extended family members.” • #84) “Mostly from my experience in losing my father who was well one day, diagnosed with colon cancer the next, went into the hospital for what his surgeon called uncomplicated surgery and "may not even need chemo" to dying within 30 days. My experiences as his daughter, caregiver, as being the only person in the family with any medical knowledge; all of this taught me how unfair it is to leave a family completely uneducated, unprepared for what is happening to their loved one. I learned the most by all the things that DID NOT occur in my father's situation. The physician was not open and honest about his situation and treated us and him as though his life was insignificant even though he was a productive member of society one day and dying the next. Not one professional stepped up to say, "Your father is dying," take him home and love him for the time he has left. No one gave us that opportunity, instead, they gave us all false hope until the day before he died. One person out of so very many came forward the day before he died and finally asked

	what were his wishes. One person!! Because of this, we as the family were completely unprepared. We all felt as though we had failed him. So now, I know. As a person who has lost and as a nurse, I understand that it is so important to be honest, to involve the family, to ask from the beginning what is important to that patient AND to their family AND to actually HEAR those answers. To treat each and every person like their life matters, because to someone, that sick person was everything. That patient loved and was loved. That patient laughed and cried, that person was real. My own father's death helped me to understand that sometimes death is NOT the worst thing that can happen to the patient. But, for those who remain, listening, being quiet, saying a kind word, a gentle touch, a caregiver's empathetic tear can make all the difference in the world. It helps the family to go forward, to breathe again. Every life matters because someone, somewhere loved and was loved.”
Education (nursing school, professional and personal development)	• #34) “Nursing school education regarding death and dying.” • #48) “A hospice nurse came in to educate the nursing staff. It was a really eye opening experience.” • #52) “Classes about death and dying and reading articles on End of Life.” • # 73) “We had a nursing conference last year that had an informative presentation from palliative care. It was very insightful and expanded my knowledge.”
Perceptions of the dying process	• #55) “As they have recently been given terminal diagnoses, they are often open to discussing options and planning for care.” • #90) “Coming with the mindset that this person is their loved one, and that whatever the patient is experiencing, the family feels the direct effect of the experience. So, coming with a compassionate perspective, and an openness to listen and give feedback when appropriate is a common course for me.” • #102) “Death is a part of life. No one lives forever. Sometimes people forget that any of us could be killed or die at any time. A car accident, a heart attack, etc. Having an illness is not always the worst thing. Sometimes the suffering that one might experience might be worse than actually dying. Having a life-threatening illness does however offer the opportunity to think about how one

	might want their "end-of-life" to be spent and with whom."

Q2. What would help you to become more comfortable and proficient in talking about death and dying with terminally ill patients and their families?

Themes	**Quotes**
Education **(n=27)**	• #3) "I feel that education of the nursing staff is always a plus in providing care on patients" • #20) "Hospital nurses need more education about how/when to have this discussion and what hospice care can provide the patient and family." • #33) "More exposure I think would be the most helpful. For example, a class or sessions where videos are shown and different professions are reviewed having these conversations. Seeing how different professional interact during these time would be helpful."
Real Time Experience/On The Job Training (Observation/Practice) **(n=16)**	• #16) "Working with someone more experienced, like the hospice nurse." • #40) "Continue interaction with dying patients • #50) "through experiences in my own life and nursing at the bedside for 15 years"
Shadowing/observing **(n=12)**	• #20) "I learned though watching other nurses and physicians bring up and talk with patients and families about end of life" • #33) "I have mostly learned by watching other nurses and hospice nurses engage with patients who are dying." • #40) "learning from others by observing their interactions with dying patients." • #50) "Shadowing other nurses with their dying patients." • #72) "my first preceptor was very good at discussion end of life with patients and families, I got more comfortable listening to her."
Relationship building (**n=4)**	• #36) "Having a previous relationship with them (the patient)—at least having met them before and knowing a little about them before being in that situation with them." • #68) "sit down in a chair and speak to them privately" • #74) "It is important to gage their readiness to learn, and where are they in the grieving process. Have they accepted the news or are they still in denial? Then sit with them and talk to them like they are your own family. I try to put myself in their shoes and show empathy.

NA/Nothing more needed **(n=13)**	• #26) “I have had lots of experience with death and dying, I don’t feel I need anymore.” • #60) NA • #65) “nothing”
Death is not easy **(n=11)**	• #7) “I don't think anything can make a nurse comfortable talking about death and dying with a terminally ill patient. It is a hard and uncomfortable subject for both the nurse and patient. The nurse must understand the different stages of grief a patient will go through and adjust accordingly. You don't want to take hope away because I believe in mind over matter. I believe a patient can will themselves to die or live. My mother was given 3 months to live. She lived 3 years. She wanted to see her son graduate high school and she did. She died 3 months after he graduated.” • #14) “Death is never an easy subject talking about. Death is inevitable but the finality of it and not knowing what happens after you die is concerning not only to myself but to others as well. In this past year, my ex-husband was killed in a car wreck and I had to go to the school and tell my 5-year-old daughter that her daddy had died. Death is so finite. You want to have a chance to say what you always wanted to say, tell the person how much you love them, how much they mean to you. You want to have no regrets. When caring for a patient with a terminal illness, the family and patient gets a chance, they know the end is coming. They have opportunity to make things right and have a peace of mind.”

Q3. Patients often help nurses to learn. Have you had the opportunity to observe or learn about having end-of-life discussions from any of your patients?	
Themes	**Quotes**
Learning from Dying Patient **(n=17)**	• #3) “Yes, patients can offer new aspects and ideas about care for themselves as well as other patients that the nurse may encounter in the future.” • #9) “First patient I witnessed dying was ready to go and stated she had taken care of all the arrangements needed to make sure her wishes stay in order. Also, her family respected her arrangements. This was 32 years ago in Germany. She took away the stigma/ fear of dying and the fear to speak to family member or the dying patient- as long their heart is beating they are here with us. They are to respected and treated with kindness.” • #30) “I've learned a lot from the combined experiences I've had. Mostly, you have to "read" the patients and families to know where they are in the process of understanding everything prior to initiating conversations regarding death. Sometimes you have to push them into discussions, but it is ALWAYS better when you anticipate that they are ready for discussions and approach them on their time instead of my time. I've also learned that being open and honest with patient and families is extremely important. It builds a certain level of trust that they respect if not immediately, then eventually. It's also important not to push your beliefs/attitudes on them. Each family unit responds differently to similar situations. The entire process must be individualized each time.”
Learning from family of dying patients **(n=15)**	• #12) “I had a dementia man in the ICU who was a code blue at the very beginning of my shift. We worked very hard to keep him alive and were able to stabilize him fairly quickly. He was intubated/sedated and on IV medications. When we got in touch with his wife, we were so proud to let her know how we had saved his life. His wife on the other hand was not as happy. After sitting down to talk with her more, we had found out she was a breast cancer survivor but still on oral chemotherapy medication. She stated she does not want her husband to get so bad with his dementia that he will think she was an intruder in their home and shoot her. She stated that she wanted her husband to go peacefully and after he was gone she will move down to Savannah to be with her daughter and grandchildren. This opened my eyes to realize death and dying was not always a "bad" thing and people pray for it to happen sooner than later so they can move on and live.” • #22) “I was taking care of a dying patient who just asked us to help keep him alive until his family arrived. He was not scared to die as he felt very much at peace

	with his eternal life after death. It was so sweet and wonderful to see how the family and the patient used the time they had not to be angry, but to celebrate all that they had been given. There was laughter, stories, tears, just a tremendous amount of love. There was also the hope that he shared with everyone that he would see them all someday again." • #33) "Yes, I had a patient just recently who was faced with the possibility of death after a surgical procedure. She and her four daughters decided together that she would be a DNR and if she didn't make it through surgery, she had lived a good and long life. She was at peace. Did cross word puzzles, and enjoyed her family visits prior to surgery. The loved the children showed their dying mother was encouraging and heart wrenching. I lost my mother when I was 21 from Leukemia, I understood what they were going through and it made my heart ache for them."

Appendix M
Introductory Letter

Byrdine F. Lewis School of Nursing & Health Professions
140 Decatur Street, NW
Atlanta, GA 30303

April 6, 2016

Self-efficacy and End-Of-Life Discussions Survey

Thank you for participating in this survey that will be used in my research study, NURSE ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES. Your participation is most important for the success of this research endeavor.

Evidence that supports nurses' engagement in end-of-life (EOL) discussions with dying patients and their families is lacking. Thus, the purpose of this descriptive correlational study is twofold: a) assess the level of nurse self-efficacy for conducting EOL discussions and b) to examine the relationships between mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families attitudes about death and dying, religious beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families.

In essence there are four things that you are being asked to do:

1. Complete the entire questionnaire. Please do not skip any questions.
2. Take time to consider each question, some of the questions will seem familiar, but they are being asked in a different context as you interact with your patients and their families. Some questions are asking about process and others about your practice.
3. Please take your time to answer the open-ended questions and be thoughtful about your past experiences with dealing with dying patients and their families.
4. Please click on the link below to begin. The Survey will close on May 15, 2016.

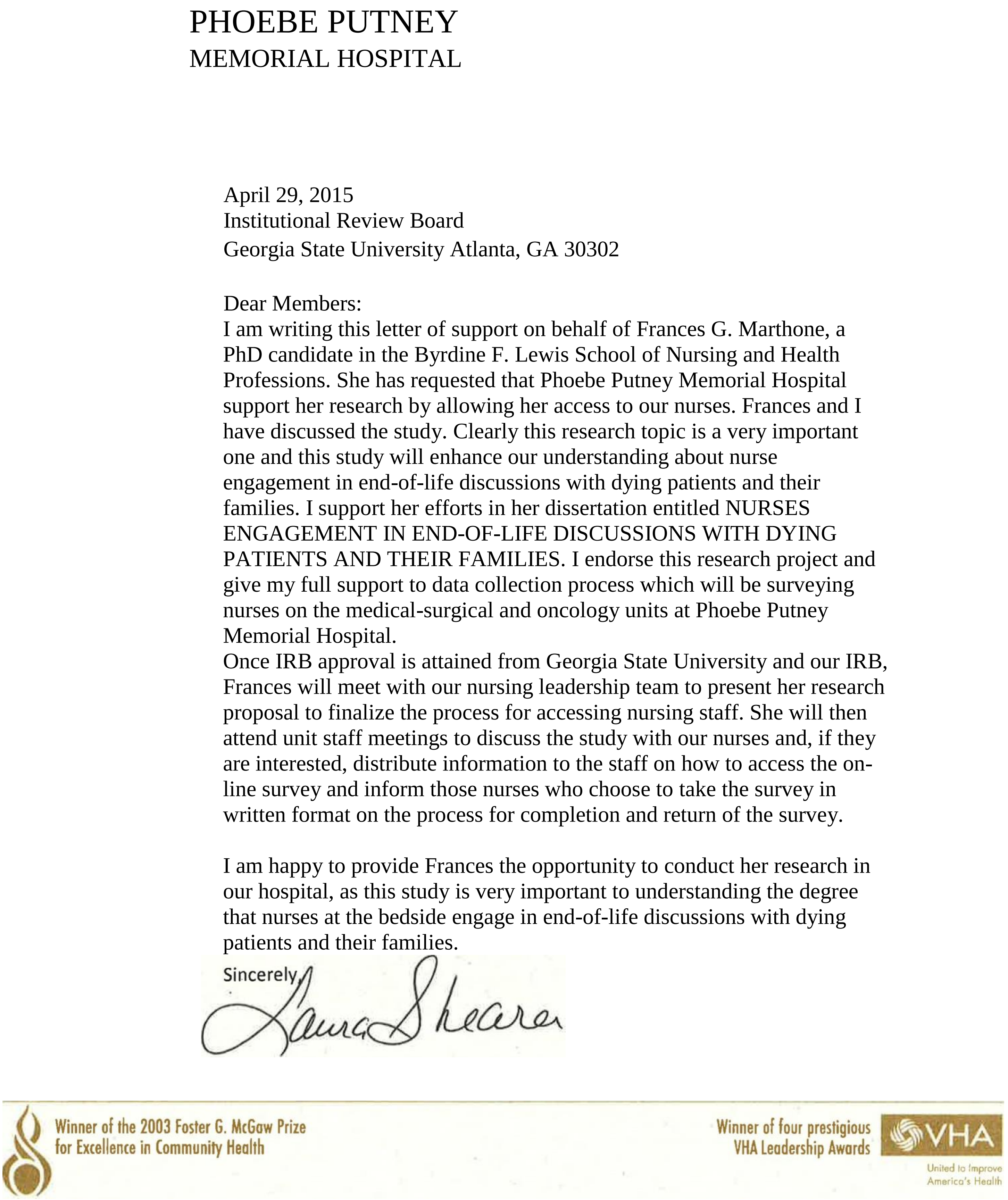
https://gsu.qualtrics.com/SE/?SID=SV_1LgqxHgnZBev8K9

If you have any questions about completion of this survey, please contact me.
francesmarthone@yahoo.com or call my cell 678-209-3996.
Again, thanks so much for your participation and commitment to serving our profession and our patients.

Respectfully,
Frances G. Marthone, RN, MSN
PhD Candidate 2016
Georgia State University

Appendix N

Letter of Support from System Chief Nursing Officers



PHOEBE PUTNEY
MEMORIAL HOSPITAL

April 29, 2015
Institutional Review Board
Georgia State University Atlanta, GA 30302

Dear Members:

I am writing this letter of support on behalf of Frances G. Marthone, a PhD candidate in the Byrdine F. Lewis School of Nursing and Health Professions. She has requested that Phoebe Putney Memorial Hospital support her research by allowing her access to our nurses. Frances and I have discussed the study. Clearly this research topic is a very important one and this study will enhance our understanding about nurse engagement in end-of-life discussions with dying patients and their families. I support her efforts in her dissertation entitled NURSES ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES. I endorse this research project and give my full support to data collection process which will be surveying nurses on the medical-surgical and oncology units at Phoebe Putney Memorial Hospital.

Once IRB approval is attained from Georgia State University and our IRB, Frances will meet with our nursing leadership team to present her research proposal to finalize the process for accessing nursing staff. She will then attend unit staff meetings to discuss the study with our nurses and, if they are interested, distribute information to the staff on how to access the on-line survey and inform those nurses who choose to take the survey in written format on the process for completion and return of the survey.

I am happy to provide Frances the opportunity to conduct her research in our hospital, as this study is very important to understanding the degree that nurses at the bedside engage in end-of-life discussions with dying patients and their families.

Sincerely,

Laura Shearer

Winner of the 2003 Foster G. McGaw Prize
for Excellence in Community Health

Winner of four prestigious
VHA Leadership Awards

VHA
United to Improve
America's Health

Laura Shearer, BSN, MSM, CENP
Sr. Vice President Patient Care Services/CNO

Piedmont
HEALTHCARE

April 27, 2015

Institutional Review Board
Georgia State University
Atlanta, Ga. 30302

Dear Members,

I am writing this letter of support on behalf of Frances G. Marthone, a PhD candidate in the Byrdine F. Lewis School of Nursing and Health Professions. She has requested that Piedmont Healthcare support her research by allowing her access to our nurses. Frances and I have discussed the study. Clearly this research topic is a very important one and this study will enhance our understanding about nurse engagement in end-of-life discussions with dying patients and their families. I support her efforts in her dissertation entitled NURSES ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES. I endorse this research project and give my full support to data collection process which will be surveying nurses on the medical-surgical and oncology units at Piedmont Healthcare.

Once IRB approval is attained from Georgia State University and our IRB, Frances will meet with our nursing leadership team to present her research proposal to finalize the process for accessing nursing staff. She will then attend unit staff meetings to discuss the study with our nurses and, if they are interested, distribute information to the staff on how to access the on-line survey and inform those nurses who choose to take the survey in written format on the process for completion and return of the survey.

I am happy to provide Frances the opportunity to conduct her research in our hospitals. As this study is very important to understanding the degree that nurses at the bedside engage in end-of-life discussions with dying patients and their families.

Respectfully,

Denise Ray

Denise Ray, RN, BSN, MBA
System Chief Nursing Executive

Appendix O
Informed Consent

Georgia State University
Department of Byrdine F. School of Nursing
Informed Consent November 6, 2015

Title: NURSE ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES.
Principal Investigator: M. Ptlene Minick, RN PhD
Co-Investigator: Cecelia Grindel RN, PhD
Student Principal Investigator: Frances Gomes Marthone RN, MSN

I. Purpose:

You are invited to participate in a research study. The purpose of this descriptive correlational study is twofold: a) assess the level of nurse self-efficacy for conducting EOL discussions and b) to examine the relationships between mastery of experiences (experiences with death and dying, nursing education, years in specialty practice, and education about death, dying and EOL care), vicarious experiences (observational experiences), psychological state (attitudes about caring for dying patients and families attitudes about death and dying, religious beliefs, professional responsibility), social persuasion (influences of mentors/coaches, nursing leadership expectations) and nurse self-efficacy for conducting EOL discussions with terminally ill patients and their families.

You are invited to participate because you work in an acute care hospital facility; Are a registered licensed nurse for at least three years; Have worked for current employer for at least one year; Have been employed full-time or half-time ($\geq$ 20 hours/week); Provide direct patient care at the bedside at least 50% of their working hours per week; Provide direct care to patients with end-stage chronic or terminal illnesses (e.g. cancer, cardiovascular disease, end-stage renal disease, etc.).

A total of 150 participants across two Georgia healthcare systems will be recruited for this study. Participation will require 25 minutes of your time over the next two weeks.

II. Procedures:

If you decide to participate, you will be asked to complete a research survey (on-line or paper survey) asking questions about NURSE ENGAGEMENT IN END-OF-LIFE DISCUSSIONS WITH DYING PATIENTS AND THEIR FAMILIES. This surveys is seeking to understand the nurse’s role in EOL discussions. If you choose to take the survey on-line, you will be provided a sealed packet with detailed instructions including a log-in and web address for the survey. If you choose to complete the paper version of the survey you will receive a sealed packet with detailed instructions including a copy of the survey and instructions of where to return your completed survey. The survey will be available for two weeks and can be competed at your convenience. The survey will take approximately 25minutes to complete. The survey is anonymous; no personal information will be required. Completed paper surveys will be dropped into a locked box located throughout your facility for your convenience. These survey will be collected by the researcher at the end of the two weeks.

III. Risks:
There is the possibility that participation in this study may cause you emotional discomfort due to the nature of questions about death and dying. If you experience any emotional discomfort and need assistance dealing with these feelings a volunteer Chaplin and councilor will be available by phone free of charge to you.

IV. Benefits:
Participation in this study may not benefit you personally. Overall, we hope to gain information about the nurse's role and comfort in EOL discussions with their dying patients and their families.

V. Compensation: You will receive a $5.00 Starbucks gift card for participating in this study.

VI. Voluntary Participation and Withdrawal:
Participation in research is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. Whatever you decide, you will not lose any benefits to which you are otherwise entitled.

VII. Confidentiality:
We will keep your records private to the extent allowed by law. Our research team, Dr. Minick and Student Investigator Frances Marthone and our data analyses will have access to the information you provide. Information may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP). We will use a hospital code and unit/floor code rather than your name on study records. The information you provide will be stored on password- and firewall-protected computers. Your name and other facts that might point to you will not appear when we present this study or publish its results. The findings will be summarized and reported in group form. You will not be identified personally.

VIII. Contact Persons:
Contact Dr. M. Ptlene Minick at pminick@gsu.edu or 404-413-1155 office or Frances Marthone at francesmarthone@yahoo.com or 678-209-3996 if you have questions, concerns, or complaints about this study. You can also call if you think you have been

harmed by the study. Call Susan Vogtner in the Georgia State University Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu if you want to talk to someone who is not part of the study team. You can talk about questions, concerns, offer input, obtain information, or suggestions about the study. You can also call Susan Vogtner if you have questions or concerns about your rights in this study.

IX. Copy of Consent Form to Participant:
We will give you a copy of this consent form to keep.

If you are willing to volunteer for this research, please sign below and complete the survey.

Participant	Date:
Principal Investigator or Researcher Obtaining Consent	Date:

Appendix P

Paper Survey

Nurse's Perceived Self-Efficacy with EOL discussions

Welcome to the Nurse's Perceived Self-Efficacy Survey! To participate in this survey, you must be.... -an RN with at least 3 years' experience -working in an acute care hospital -have worked with your current employer for at least one year -be employed full-time or part-time (working at least 20 hours/week) -provide direct patient care to patients with end-stage chronic or terminal illnesses (e.g. cancer, cardiovascular disease, end- stage renal disease, etc.) IF you answered No to any of these criteria. You are not eligible to participate. Thank you.

○ Yes (1)
○ No (2)

If Yes Is Selected, Then Skip to Communication with Dying Patients...If No Is Selected, Then Skip to End of Survey.

Q1 Communication with Dying Patients This set of questions focuses on your perception of how good you are in discussing things with dying patients and their families. Using the following scale where "0" is "Not Good at All" and "10" is "Extremely Good", please click the number that best describes how good you feel you are in talking about the following topics with dying patients and their families. How good are you about...

	NOT Good at All 0 (1)	2 (2)	3 (3)	4 (4)	5 (5)	6 (6)	7 (7)	8 (8)	9 (9)	Extremely Good 10 (10)
SE1. Using words that the patient can understand. (1)	○	○	○	○	○	○	○	○	○	○
SE2. Looking the patient in the eye. (2)	○	○	○	○	○	○	○	○	○	○
SE3. Including the patient's loved ones in decisions about his illness and treatment. (3)	○	○	○	○	○	○	○	○	○	○
SE4. Answering all the patient's questions about his/her illness and treatment. (4)	○	○	○	○	○	○	○	○	○	○
SE5. Listening to what the patient has to say. (5)	○	○	○	○	○	○	○	○	○	○
SE6. Caring about the patient as a person. (6)	○	○	○	○	○	○	○	○	○	○
SE7. Giving the patient your full attention. (7)	○	○	○	○	○	○	○	○	○	○
SE8. Talking with the patient about his/her FEELINGS	○	○	○	○	○	○	○	○	○	○

concerning the possibility that he/she might get sicker. (8)										
SE9. Talking with the patient about the DETAILS concerning the possibility that he/she might get sicker. (9)	○	○	○	○	○	○	○	○	○	○
SE10. Talking to the patient about how long he/she might have to live. (10)	○	○	○	○	○	○	○	○	○	○
SE11.Talking to the patient about what dying might be like. (11)	○	○	○	○	○	○	○	○	○	○
SE12. Talking with the patient's loved ones about what his/her dying might be like. (12)	○	○	○	○	○	○	○	○	○	○
SE13. Involving the patient in decisions about the treatments that he/she wants if he/she gets too sick to speak for themselves.	○	○	○	○	○	○	○	○	○	○

(13)										
SE14. Asking about the things in life that are important to the patient. (14)	○	○	○	○	○	○	○	○	○	○
SE15. Respecting the things in the patient's life that are important to him/her. (15)	○	○	○	○	○	○	○	○	○	○
SE16. Asking about the patient's spiritual or religious beliefs. (16)	○	○	○	○	○	○	○	○	○	○
SE17. Respecting the patient's spiritual or religious beliefs. (17)	○	○	○	○	○	○	○	○	○	○

Q2 The next two questions ask you to rate how comfortable you are in talking about death and dying and how well you communicate with your dying patients.

	Not at all Comfortable 0 (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	Extremely Comfortable 10 (11)
SE18. How comfortable are you in talking about dying with your terminally-ill patients? (1)	○	○	○	○	○	○	○	○	○	○	○

Q3 Click to write the question text

	Not at all Good 0 (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (6)	6 (7)	7 (8)	8 (9)	9 (10)	Extremely Good 10 (11)
SE19. Overall, how would you rate your communication with dying patients? (1)	○	○	○	○	○	○	○	○	○	○	○

Q4 Attitudes Toward Caring for the Dying Scale We are interested in learning how nurses feel about giving care to dying patients and their families. The dying patient refers to a person who is considered to be terminally ill and to have six months or less to live. Please circle or click on the response that best reflects your personal feelings about the statement. Please respond to all items on the scale.

	Strongly Disagree (1)	Disagree (2)	Uncertain (3)	Agree (4)	Strongly Agree (5)
AC1. Giving nursing care to a dying person is a worthwhile learning experience. (1)	○	○	○	○	○
AC2. Death is not the worst thing that can happen to a person. (2)	○	○	○	○	○
AC3. I would be uncomfortable talking about impending death with the dying person. (3)	○	○	○	○	○
AC4. Nursing care for the patient's family should continue throughout the period of grief and bereavement. (4)	○	○	○	○	○
AC5. I would not want to be assigned to care for a dying person. (5)	○	○	○	○	○
AC6.The nurse should not be the one to talk about death with the dying person. (6)	○	○	○	○	○
AC7. The length of time required to give nursing care to a dying person would frustrate me. (7)	○	○	○	○	○
AC8. I would be upset when the dying person I was caring for gave up hope of getting better. (8)	○	○	○	○	○
AC9. It is difficult to form a close relationship with the family of the dying person. (9)	○	○	○	○	○
AC10. There are times when death is welcome by the dying person. (10)	○	○	○	○	○
AC11. When a patient asks, "Nurse am I dying?", I think it is best to change the subject to something cheerful. (11)	○	○	○	○	○
AC12. The family should be involved in the physical care of the dying person. (12)	○	○	○	○	○
AC13. I would hope the person I'm caring for dies when I am not present. (13)	○	○	○	○	○
AC14. I am afraid to become friends with a dying person. (14)	○	○	○	○	○

AC15. I would feel like running away when the person actually died. (15)	○	○	○	○	○
AC16. Families need emotional support to accept the behavior changes of the dying person. (16)	○	○	○	○	○
AC17. As a patient nears death, the nurse should withdraw his/her involvement with the patient. (17)	○	○	○	○	○
AC18. Families should be concerned about helping their dying member make the best of his/her remaining life. (18)	○	○	○	○	○
AC19. The dying person should not be allowed to make decisions about his/her physical care. (19)	○	○	○	○	○
AC20. Families should maintain as normal an environment as possible for their dying member. (20)	○	○	○	○	○
AC21. It is beneficial for the dying person to verbalize his/her feelings. (21)	○	○	○	○	○
AC22. Nursing care should extend to the family of the dying patient. (22)	○	○	○	○	○
AC23. Nurses should permit dying persons to have flexible visiting schedules. (23)	○	○	○	○	○
AC24. The dying person and his/her family should be the in-charge decision makers. (24)	○	○	○	○	○
AC25. Addiction to pain relieving medication should not be a concern when dealing with a dying person. (25)	○	○	○	○	○
AC26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying. (26)	○	○	○	○	○
AC27. Dying persons should be given honest answers about their condition. (27)	○	○	○	○	○
AC28. Educating families about death and dying is not a nursing responsibility. (28)	○	○	○	○	○
AC29. Family members who stay	○	○	○	○	○

close to a dying person often interfere with the professional's job with the patient. (29)					
AC30. It is possible for nurses to help patients prepare for death. (30)	○	○	○	○	○

Q5 Attitudes Towards Death and Dying. This questionnaire contains a number of statements related to different attitudes towards death. Read each statement carefully, and then decide the extent to which you agree or disagree. For example, an item might read: "Death is a friend". Indicate how well you agree or disagree by clicking one of the following: SA=Strongly Agree; A=Agree; MA= Moderately Agree; U=Undecided; MD=Moderately Disagree; D= Disagree; SD=Strongly Disagree. If you strongly agree with the statement, you will click SA. If you strongly disagree you would click SD. If you are undecided, click U. However, try to use the undecided category sparingly. It is important that you work through the statements and answer each one. Many of the statements will seem alike, but all are necessary to show slight differences in attitudes.

	Strongly Disagree (1)	Disagree (2)	Moderately Disagree (3)	Uncertain (4)	Moderately Agree (5)	Agree (6)	Strongly Agree (7)
AD1. Death is no doubt a grim experience. (1)	○	○	○	○	○	○	○
AD2. The prospect of my own death arouses anxiety in me. (2)	○	○	○	○	○	○	○
AD3. I avoid death thoughts at all costs. (3)	○	○	○	○	○	○	○
AD4. I believe that I will be in heaven after I die. (4)	○	○	○	○	○	○	○
AD5. Death will bring an end to all my troubles. (5)	○	○	○	○	○	○	○
AD6. Death should be viewed as a natural, undeniable, and unavoidable event. (6)	○	○	○	○	○	○	○
AD7. I am disturbed by the finality of death. (7)	○	○	○	○	○	○	○
AD8. Death is an entrance to a place of ultimate satisfaction. (8)	○	○	○	○	○	○	○
AD9. Death provides an escape from this terrible world. (9)	○	○	○	○	○	○	○
AD10. Whenever the thought of death enters my mind,	○	○	○	○	○	○	○

I try to push it away. (10)							
AD11. Death is a deliverance from pain and suffering. (11)	○	○	○	○	○	○	○
AD12. I always try not to think about death. (12)	○	○	○	○	○	○	○
AD13. I believe that heaven will be a much better place than this world. (13)	○	○	○	○	○	○	○
AD14. Death is a natural aspect of life. (14)	○	○	○	○	○	○	○
AD15. Death is a union with God and eternal bliss. (15)	○	○	○	○	○	○	○
AD16. Death brings a promise of a new and glorious life. (16)	○	○	○	○	○	○	○
AD17. I would neither fear death nor welcome it. (17)	○	○	○	○	○	○	○
AD18. I have an intense fear of death. (18)	○	○	○	○	○	○	○
AD19. I avoid thinking about death altogether. (19)	○	○	○	○	○	○	○
AD20. The subject of life after death troubles me greatly. (20)	○	○	○	○	○	○	○
AD21. The fact that death will mean the end of everything as I	○	○	○	○	○	○	○

know it frightens me. (21)							
AD22. I look forward to a reunion with my loved ones after I die. (22)	○	○	○	○	○	○	○
AD23. I view death as a relief from earthly suffering. (23)	○	○	○	○	○	○	○
AD24. Death is simply a part of the process of life. (24)	○	○	○	○	○	○	○
AD25. I see death as a passage to an eternal and blessed place. (25)	○	○	○	○	○	○	○
AD26. I try to have nothing to do with the subject of death. (26)	○	○	○	○	○	○	○
AD27. Death offers a wonderful release of the soul. (27)	○	○	○	○	○	○	○
AD28. One thing that gives me comfort in facing death is my belief in the afterlife. (28)	○	○	○	○	○	○	○
AD29. I see death as a relief from the burden of this life. (29)	○	○	○	○	○	○	○
AD30. Death is neither good nor bad. (30)	○	○	○	○	○	○	○
AD31. I look forward to life	○	○	○	○	○	○	○

after death. (31)							
AD32. Uncertainty of not knowing what happens after death worries me. (32)	○	○	○	○	○	○	○

Q6 Religious Beliefs. We are interested in learning if spiritual or religious beliefs influence clinical practice. Answer the question that best reflects your persuasion. Click on your response. RB1. My religious/spiritual beliefs ....

○ are a strong influence on my attitude toward death and dying (1)
○ are a minor influence on my attitude toward death and dying (2)
○ do not influence my attitude toward death and dying (3)

Q7 RB2. My lack of Religious/Spiritual beliefs....

○ has a strong influence on my attitudes towards death and dying (1)
○ has a minor influence on my attitudes towards death and dying (2)
○ has no influence on my attitudes towards death and dying (3)

Q8 Professional Responsibility It is my professional responsibility to answer the patients' questions or talk with them about .....

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
PR1. The dying process? (1)	○	○	○	○
PR2. His/Her final wishes for dying? (2)	○	○	○	○
PR3. His/Her concerns about pain? (3)	○	○	○	○
PR4. His/Her desires for NO further treatment which could extend life or prolong death? (4)	○	○	○	○
PR5. Their concerns about the family's acceptance of his/her approaching death? (5)	○	○	○	○

Q50 Clinical Responsibility of the nurse to.....

	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
CR1. It is my clinical responsibility to ASSESS readiness of dying patients and their family members to engage in EOL Discussions. (1)	○	○	○	○
CR 2. It is my clinical responsibility to PLAN for and anticipate the need of the dying patient and their families to initiate/conduct EOL discussions. (2)	○	○	○	○

Q9 Mentors/Coaches in the course of moving from novice to expert, nurses frequently become engaged with a mentor or coach (formal or informal) who teaches, supports, and encourages her to expand her knowledge and skills in the practice of nursing. Sometimes we have opportunities to have a mentor who teaches us about care of the dying patient and his family and encourages us to engage in end-of-life discussions with patients when the occasion arises. MC1. Have you ever had a mentor(s) or coach(s) who encouraged you to engage your dying patients and family members in end-of-life discussions?

○ Yes (1)
○ No, (if no please go to question # 12) (2)

Q10 Overall Mentor/Coach Effectiveness

	Not at all Effective (1)	Somewhat Effective (2)	Effective (3)	Very Effective (4)
MC2. Overall, how effective were your mentors/coaches in improving your skills related to end-of-life care and communication? (1)	○	○	○	○

Q11 MC3. What was the professional background of the mentors/coaches who encouraged you to engage in end-of-life discussions with dying patients and families? (Check all that apply)

☐ Nurse (1)
☐ Social Worker (2)
☐ Spiritual advisor (3)
☐ Physician (4)
☐ Other, please indicate: ________________________(5)

Q12 MC4. Have you ever had someone help you learn how to talk about end-of-life issues with patients/families?

○ Yes (1)
○ No (2)

Q13 Nurse Leadership Expectations: Please provide your perceptions of your organization's nursing leadership's expectations related to nurses' engagement in end-of-life discussions with patients and families. Nursing Leadership refers to all or any of the following positions: Manager, Chief Nursing Officer (CNO), Director, or Supervisor. To what degree does nursing leadership in your organization.....

	No Expectation 1 (1)	2 (2)	3 (3)	4 (4)	High Expectation 5 (5)
NL1. Expect nurses to participate in end-of-life discussions with dying patients and families? (1)	○	○	○	○	○

Q14 To what degree does nursing leadership in your organization...

	No Encouragement 1 (1)	2 (2)	3 (3)	4 (4)	Lots of Encouragement 5 (5)
NL2. Encourage nurses to participate in end-of-life discussions with dying patients and families? (1)	○	○	○	○	○

Q15 To what degree does nursing leadership in your organization....

	No Resources 1 (1)	2 (2)	3 (3)	4 (4)	Lots of Resources 5 (5)
NL3. Provide nurse with professional development/ resources related to caring for dying patients and their families? (1)	○	○	○	○	○

Q16 To what degree does nursing leadership in your organization...

	Not at all Supportive 1 (1)	2 (2)	3 (3)	4 (4)	Very Supportive 5 (5)
NL4. Support nurse participation in end-of-life discussions with dying patients and their families? (1)	○	○	○	○	○

Q17 Vicarious Experiences Sometimes we have opportunities to observe an expert clinician or spiritual advisor talking with a patient and/or their family about the patient's death. This observation makes an impression on us and teaches us about discussing death and dying with patients and families. VE1. Have you ever had such an observation wherein you learned about discussing death and dying from a clinician or spiritual advisor?

○ Yes (1)
○ No, (if no please go to question #20) (2)

Q18 VE2. Did this observation encourage you to participate in end-of-life discussions with patients and/or families?
○ Yes (1)
○ No (2)

Q19 VE3. What was the professional background of the person(s) who you observed in end-of-life discussions with dying patients and families? (Check all that apply)
☐ Nurse (1)
☐ Social Worker (2)
☐ Spiritual Advisor (3)
☐ Physician (4)
☐ Other, please indicate_________________________(5)

Q20 VE4. Patients often help nurses to learn. Have you had the opportunity to observe or learn about having end-of-life discussions from any of your patients?
☐ Yes (1)
☐ No (2)
☐ If Yes, please briefly describe that experience (3) ____________________

Q21 Education on Death and Dying. ED1. Previous education on death and dying.
○ I took a course(s) in death and dying previously. (1)
○ I did not take a specific course on death and dying, but material on the subject was included in other courses. (2)
○ No information dealing with death and dying was previously presented to me. (3)

Q22 Experience with Dying Patients. EX1. Previous experience in dealing with terminally ill persons.
○ I have cared for MANY terminally ill persons and their family members. (1)
○ I have cared for SOME terminally ill persons and their family members. (2)
○ I have RARELY cared for terminally ill persons and their family members. (3)
○ I have had NO experience caring for terminally ill persons and their family members. (4)

Q23 Previous Experience with Loss: EX2. I have lost someone I cared for within the past year (Click all that apply)
☐ Immediate family member (husband, wife, mother, father, sibling) (1)
☐ Significant other (2)
☐ Child (3)
☐ Close friend (4)
☐ I have experience with the loss of someone close to me, but not within the past year. (5)
☐ I have no previous experience with the loss of someone close to me (6)

Q24 PE1. Present Experience with Loss:(Click all that apply)
☐ I presently have a loved one who is terminally ill (life expectancy 1 year or less) (1)
☐ I am presently anticipating the loss of a loved one. (2)
☐ I am not dealing with any impending loss at the present time (3)

Q25 Discussions with Dying Patients. In situations wherein end-of-life issues come up, indicate how often you use the following communication techniques with dying patients. How often do you.......

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)
DP1. Use words that the patient can understand. (1)	○	○	○	○	○
DP2. Look the patient in the eye. (2)	○	○	○	○	○
DP3. Include the patient's loved ones in decisions about his/her illness and treatment. (3)	○	○	○	○	○
DP4. Answered all the patient's questions about his/her illness and treatment. (4)	○	○	○	○	○
DP5. Listened to what the patient has to say. (5)	○	○	○	○	○
DP6. Care about the patient as a person. (6)	○	○	○	○	○
DP7. Give the patient your full attention. (7)	○	○	○	○	○
DP8. Talk with the patient about his/her FEELINGS concerning the possibility that he/she might get sicker. (8)	○	○	○	○	○
DP9. Talk with the patient about the DETAILS concerning the possibility that he/she might get sicker. (9)	○	○	○	○	○
DP10. Talk to the patient about how long he/she might have to live. (10)	○	○	○	○	○
DP11.Talk to the patient about what dying might be like. (11)	○	○	○	○	○
DP12. Talk with the patient’s loved ones about what his/her dying might be like. (12)	○	○	○	○	○
DP13. Involve the patient in decisions about the treatments that he/she wants if he/she gets too sick to speak for themselves. (13)	○	○	○	○	○
DP14. Ask about the things in life that are important to the patient. (14)	○	○	○	○	○
DP15. Respect the things in the patient's life that are important to him/her. (15)	○	○	○	○	○
DP16. Ask about the patient's spiritual or religious beliefs. (16)	○	○	○	○	○
DP17. Respect the patient's spiritual or religious beliefs. (17)	○	○	○	○	○

Q26 DP18. Please share how you really learned to engage patients and families in end-of-life discussions

Q27 DP19. What, if anything might help you become more comfortable in talking about death and dying with terminally ill patients and their families?

Q28 DEMOGRAPHICS What is the Highest level of Education (degree) you have completed?
○ Diploma (1)
○ Associate Degree (2)
○ Baccalaureate Degree in Nursing (3)
○ Baccalaureate Degree in other field (4)
○ Master's Degree In Nursing (5)
○ Master's Degree in other field (6)
○ Doctoral Degree (PhD, EdD) (7)
○ Doctorate in Nursing Practice (DNP) (8)
○ Other: please indicate ________________________(9)

Q29 Race:
○ White/Caucasian (1)
○ Black/African American (2)
○ Black, non-African American (3)
○ Hispanic/Latino (4)
○ Asian (5)
○ Alaskan Native or Native American (6)
○ Native Hawaiian or Pacific Islander (7)
○ Two or more races (8)
○ Other: please indicate _______________________(9)

Q30 Years in nursing practice:

Q31 Current Position:
○ Staff Nurse (1)
○ Charge Nurse (2)
○ Nurse Educator (3)
○ Nurse Leader (4)
○ Other: please indicate___ (5) ____________________

Q32 Clinical Practice Specialty:
- ○ Cardiac vascular disease (e.g. congestive heart failure) (1)
- ○ End-stage pulmonary disease (2)
- ○ Oncology (3)
- ○ Medical/Surgical (4)
- ○ End-stage renal disease (5)
- ○ End-stage HIV/AIDS (6)
- ○ Other, please indicate_____ (7) ____________________

Q33 Years in current nursing specialty:

Q34 Gender
- ○ Female (1)
- ○ Male (2)

Q35 Age

Q36 How long did it take you to complete this survey (minutes)?

Q37 Were there any directions or questions that were unclear or difficult to understand? Please explain and included the question(s) number.

Q51 Timing
- First Click (1)
- Last Click (2)
- Page Submit (3)
- Click Count (4)

Q52 What is your hospital's zip code?