Early Program Evaluation of the Impact of ELNEC Communication Education on Registered Nurse Death Anxiety and Communication Apprehension Scores

Carol Fitzgerald Robinson MS, RN

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EARLY PROGRAM EVALUATION OF THE IMPACT OF ELNEC COMMUNICATION EDUCATION ON REGISTERED NURSE DEATH ANXIETY AND COMMUNICATION APPREHENSION SCORES

Carol Fitzgerald Robinson MS, RN

A Dissertation Submitted to the Graduate Faculty of GRAND VALLEY STATE UNIVERSITY

In Partial Fulfillment of the Requirements For the Degree of Doctor of Nursing Practice

Kirkhof College of Nursing

December 2012
Dedication

My passion for end of life care stems from the privilege of caring for those with chronic, life-limiting illness. I remain in awe of their courage, resilience, and faith as we walked together to the end of their earthly journeys.

I am especially indebted to my dad, Gordon E. Fitzgerald. He was my strongest source of encouragement, and allowed me the privilege of caring for him in his final days. Dad, to answer your question: “Don’t you want to be a doctor? You’re smart enough.” The answer is: “Yes, but I want to be a Doctor of Nursing Practice!”

To my mother, Tamsen R. Vanderwier: you taught me resilience and persistence in the face of adversity, as well as the concept of unconditional love. Your charitable heart models Christ’s love to others. I love you.

To my husband, Douglas R. Robinson: Thank you for living with and supporting me through yet another academic degree. I am thankful for your love and kindness.

To my children; Andrew, Becky, Greg, and Grace; and my grandchildren; Andrea, Haylee, James, and “R4”. Education is a journey, not a destination. Remain curious, seek to understand, find good mentors, and remember you are never too old to learn new things!

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“Without counsel plans fail, but with many advisors, they succeed.” Proverbs 15:22

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Abstract

Nurse expertise with end-of-life (EOL) conversation skills can facilitate the assessment of the patient’s sociocultural and spiritual beliefs about quality of life issues, yet nurse death anxiety may act as a barrier to needed conversations. Nurses are the most consistent healthcare provider at the inpatient bedside and as such they play an important role in EOL conversations.

The purpose of this practice dissertation project was to evaluate the impact of a nurse-facilitator led quality improvement initiative in one acute care hospital using the End of Life Nursing Education Consortium (ELNEC) communication Module 6. Specifically, nurse attitudes regarding death anxiety (using the Revised Death Anxiety Scale [DAS-R]) and communication apprehension (using the Communication Apprehension with Dying [CA-Dying] scale) were evaluated pre and post education. A multi-faceted evaluation approach was utilized, the Promoting Action on Research Implementation in Health Services (PARiHS) framework for assessment of organizational readiness for change, and the Donabedian Quality Model to evaluate efficacy of the ELNEC Module 6 education on nurse death anxiety and communication apprehension.

Preliminary evaluation of the ELNEC Module 6 intervention indicated that, controlling for the DAS-R pre-score, nurses with an ADN or Diploma degree had a significantly lower post-test death anxiety score than nurses with a BSN or MSN degree. Nurses who cared for more dying patients per year, controlling for the CA-Dying pre-score, had a statistically significant lower CA-Dying score. Experiential learning and reflection are central to creating a culture of innovation, improvement and effectiveness.
The ELNEC curriculum promotes personal reflection about death. By embedding nurses skilled in advanced communication techniques at the frontline, a sustainable model for peer consultation and support regarding difficult conversations is possible. Providing effective palliative care across an organization is a complex endeavor. A doctorally prepared nurse can have an integral role in transforming EOL care.
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CHAPTER 1

INTRODUCTION

This project will engage professional nurses in a select international educational module to enhance their communication skills with terminally ill patients and explore barriers to communication engagement. By providing education and an evaluation process this site-specific project will enhance palliative care efforts. Facilitating better care by eliciting patient choice may result in lower costs to the institution and the patient by avoiding unnecessary care. Just as important, improving a patient’s well-being until the end-of-life (EOL) with coordinated symptom support is an important aim of this project.

Multiple initiatives now exist to support the pressing efforts in healthcare to reform care of the dying patient. Nurses in multiple settings are in ideal positions to augment critical decision-making at end of life (EOL) that is truly patient-directed and supportive of patient’s rights to self-determination.

In guiding patients through end-of-life (EOL) conversations, nurse expertise facilitates the assessment of the patient’s sociocultural and spiritual beliefs about quality of life issues. By facilitating the communication, nurses assist the patient to make an informed decision about his or her own healthcare (American Association of Colleges of Nursing [AACN], 2004). However, in the case of EOL issues, a nurse’s death anxiety may act as a barrier to nurse-patient communication (Brisley & Wood, 2004; Mallory, 2003; Martin, 2011). Death anxiety is described as the feelings one has regarding death.
Death anxiety includes the fear towards the dying process, personal fears, the meaning of
death, and coping with the finality of death (Jones, 1993; Thorson & Powell, 1988).

When asked to speak with patients at EOL, some nurses may experience
communication apprehension. Communication apprehension is defined as a level of fear
or anxiety associated with real or anticipated communication about death (Hayslip, 1986-
87). Whether the nurse experiences death anxiety, communication apprehension, or both,
the result can be a failure of communication between the nurse and patient about choices
available to patients for EOL care (Berman, 2012).

An absence of EOL communication is an unacceptable outcome for patients as
they have a moral and legal right to make decisions about their own healthcare (AACN,
2004; Berman, 2012). Patients who do not participate in EOL communication are denied
the opportunity to complete an advance directive (AD), the legal document which could
delineate the patient’s choices for EOL care (Fischer, Sauaia, Sung-Joon, & Kutner,
2012; Sabatino, 2010). Because of the presence of nurses across all healthcare settings,
their potential to have a distinct role in facilitating the process of informed decision-
making at the EOL is significant (AACN, 2004).

Background and Significance

In 1991, the United States Federal Government enacted the Patient Self
Determination Act (PSDA) (Omnibus Budget Reconciliation Act of 1990). The intent of
the PSDA was to ensure U.S. citizens of their right to make prescriptive decisions
regarding their medical care and course of treatment should become incapacitated or
incompetent in the future (Jezewski, Meeker, Sessanna, & Finnell, 2007; Kelley, Lipson,
Daly, & Douglas, 2006; Office of Inspector General, 1993). The PSDA was proposed
and passed after a series of well publicized cases in which persons deemed to be in a persistent vegetative state were not allowed to die a natural death and instead underwent aggressive and futile care. The PSDA was a legislative attempt to provide the patient with self-determination rights for EOL care (Hader, 2005; Sabatino, 2010).

While the intent of the PSDA had patient self-determination at its core, the PSDA was remiss in not requiring conversation about the contents of the AD. Thus, the PSDA did not require the healthcare provider to honor an AD, if present (Hader, 2005; Sabatino, 2010). As a result, the overall completion rate of ADs in practice remains low, at 18-36% of adults, including those with chronic or life-limiting illness. This is in comparison to 20% of adults in 1990, when the PSDA was enacted (Fischer et al., 2012; Sabatino, 2010).

In chronically ill populations, advance care planning (ACP) is especially important, because these individuals are more likely to face repeated hospitalizations as they approach the end of life. Currently 68% of U.S. Medicare costs are related to chronic illness, representing 90 million people. By 2020, people with chronic illness will number 157 million (Center to Advance Palliative Care [CAPC], 2011a) and the financial implications will be staggering for an already challenged healthcare system. As an example, Medicaid patients in one New York hospital who received palliative care in lieu of more aggressive measures were less likely to die in the intensive care unit than those who received ultimately futile care. In this study, this represented a savings of $4,098 in hospital costs per living discharge, and $7,563 for patients who died in the hospital. Projected to all Medicaid patients in New York State alone, the annual savings would have amounted to $84 million to $252 million (Morrison et al., 2011).
The most important reason for effective palliative care and ADs is that patients deserve the right to choose how they will spend their last months, weeks and days (Berman, 2012). Yet, there are inherent challenges to helping patients make their wishes known. Nurses often lack clarity in their role as facilitator of ADs and lack a consistent skill level when speaking about EOL preferences (Kelley et al., 2006).

Nurses are the most consistent healthcare provider at the inpatient bedside and as such they play an important role in ACP conversations (Kennard et al., 1996). The registered nurses’ (RN) role in patient advocacy and patient self-determination is clearly supported by the American Nurses Association (ANA) (ANA, 2010; 2001), the AACN (2004), the American College of Healthcare Executives (ACHE) (2011), and the Hospice and Palliative Nurses Association (HPNA) (2011). Skilled communication leads to true collaboration of the healthcare team in the care of the patient. The team must be able to discuss and resolve issues related to goals of treatment and the benefit/burden of the choices in order to ensure patient advocacy and safety (AACN, 2004). Ultimately, improved nursing skill in EOL communication and implementation of patient-determined wishes has the potential to ensure that individuals have a greater likelihood of a peaceful death congruent with their values (AACN, 2004). However, for the EOL communication to occur, practicing bedside nurses need continuing education aimed at effective communication skills as well as strategies to provide compassionate and comprehensive EOL care (ANA, 2010).

There is an increased momentum in the U.S. to improve nurses' expertise in EOL issues via the End of Life Nursing Education Consortium (ELNEC) standardized curriculum. The ELNEC program was developed by nurse researchers at the City of
Hope National Medical Center in collaboration with the AACN to provide recommended competencies and curricular guidelines for evidence-based EOL nursing care (AACN, 2004; ELNEC, 2012b; Virani & Sofer, 2003). The intention of the international program is to provide EOL education in order to enhance palliative care and care of the dying. Topics include pain and symptom management; ethical/legal issues; cultural considerations at EOL; communication; loss, grief and bereavement; and preparation for care at the time of death (AACN, 2004; ELNEC, 2012b). Currently over 13,250 nurses and other healthcare professionals in all U.S. states have received ELNEC curriculum training (ELNEC, 2012b).

Use of the ELNEC curriculum by practicing nurses within the hospital environment can help nurses improve important communication skills with patients. Pedagogical techniques using ELNEC Module 6: Communication standardized curriculum ([ELNEC Module 6], ELNEC, 2012a) to develop nurse communication skills for EOL care are covered in depth by Matzo, Sherman, Sheehan, Ferrell and Penn (2003). Key messages of the module include the critical nature of skillful communication; the importance of strong interprofessional collaboration as a prerequisite to communication; the importance of verbal and nonverbal communication; and the importance of offering presence while actively listening to the patient and family. Of critical importance, Matzo et al. emphasizes that nurses’ willingness to bear witness to the patient’s suffering by offering their presence is often perceived by the patient and family as the most important of all interventions.
Purpose

The purpose of this evidence-based project was to address two questions:

1. Does use of the ELNEC Module 6 curriculum with acute care RNs affect RN death anxiety scores?
2. What is the impact of the ELNEC Module 6 curriculum on RN communication apprehension scores?

Intervention

A site-specific quality improvement evaluation was designed to examine the impact of ELNEC Module 6 on acute care RNs’ death anxiety and communication apprehension. Two reliable, valid survey tools were used: the Revised Death Anxiety Scale (DAS-R) (Neimeyer, 1994) and the Communication Apprehension with the Dying scale (CA-Dying) (Hayslip, 1986-87). Both scales had established reliability and validity. A demographic survey was also used to gather relevant variables (see Attachment 1).

Specifically, the DAS-R (see Attachment 2) measures feelings regarding death, including the dying process, personal fears, the meaning of death, and coping with the finality of death. Communication apprehension with the dying was measured utilizing the CA-Dying Scale tool (see Attachment 3). Hayslip’s (1986-87) original research compared hospice volunteers’ communication apprehension at-large with dying patients. Specifically, Hayslip examined the volunteers’ interpersonal, cognitive, and affective components of communicating with dying patients.

Summary

This project was developed to examine the effectiveness of an international EOL communication module by comparing pre and post-test scores of participants on the nurse
death anxiety (DAS-R) and the communication apprehension (CA-Dying) scales. The evaluation was intended to inform the institution regarding how RNs approach EOL communication, identify barriers to communication, and lastly describe whether RNs felt differently about their communication comfort level after receiving ELNEC education. The legalistic approach of mandating healthcare institutions to record the presence of advance directives has not been successful in facilitating EOL communication or increasing advance directive completion rates. Yet, patients are entitled to thoughtful, respectful conversation to determine their feelings about their disease process, obtain information to aid decision-making, and incorporate personal control, meaning and hope in their lives (ELNEC, 2012a). Skilled nurse communication is essential in the assessment of quality of care, regardless of what treatment is ultimately chosen (ANA, 2010).
CHAPTER 2

LITERATURE REVIEW

The purpose of this chapter was to review pertinent literature exploring nurse death anxiety, communication avoidance or apprehension, and communication education efforts for inpatient nurses caring for terminally ill patients. Additionally, background information on past legislative issues to support patient self-determination and advocacy was reviewed. Medline, PsyInfo, PubMed, Institute for Healthcare Improvement and the Agency for Healthcare Quality and Research databases were reviewed from 1998 to 2011 using the key terms end-of-life, communication, nurses, hospitalized, palliative care, advance care planning, advance directives, death anxiety and communication avoidance. The search update features of the databases were utilized when available to feed additional items of interest automatically as they were published. Lastly, to assure comprehensiveness, the reference lists of studies were reviewed for additional relevant literature. For clarity, this review was organized according to common variables in existing literature. Important variables in this review include the legislative impact of advance directives, expert communication skills, nursing profession and death anxiety, death anxiety and communication apprehension, relationships as a factor in advance directives, professional organization support for nursing scope of practice, and nurse education and educational initiatives.

Legislative Impact of Advance Directives

Patient values and beliefs, as recorded in a living will, can be incorporated by the RN into the interdisciplinary patient plan of care (POC). When the POC is followed, the
patient and family may be assured that their desires for EOL care will be respected, whether that means dying at home in hospice care with loved ones in attendance, or dying in the hospital with all life support measures. The key to an effective ACP is clarity of intentions and incorporation of patient preferences into a POC (Sabatino, 2010).

Briggs and Colvin (2002) describe the current culture of ADs as one of compliance with the letter of the PSDA law, rather than with the spirit of the law. As a result, there is rarely a discussion about the contents or intent of the AD and little to no incorporation of the AD into the POC. As they exist, patients who have completed an AD and have discussed it with their physician are more likely to have care at EOL that is consistent with their previously defined preferences (Fischer et al., 2012). Briggs and Colvin further found that, when nurses are given the appropriate communication education to enact their roles as patient advocate and a supportive organizational environment to fulfill their role as a patient advocate in EOL decision-making, positive patient and family outcomes occur. In this study, RN education included a competency statement regarding ACP and EOL decision-making with ten associated criteria for competency. Learning options varied from computer-based training to observing and working with a preceptor to practice EOL discussion skills.

Summarily, despite enactment of the PSDA legislation, the overall completion rate of ADs in practice remains low at 18-36% of adults including those with chronic or life-limiting illness. This compares to 20% of adults in 1990, when the PSDA was enacted (Fischer et al., 2012; Sabatino, 2010). According to Hiltunen (1995), a legal transactional approach to ADs has neither empowered nor motivated patients to a great extent in completing ADs. Moreover, it has not compelled nursing professionals to
further their patient advocate role by increasing their participation in procurement of ADs. Hiltunen further postulated that improved patient self-determination for EOL care will not occur until organizational cultures support the patient advocate role of nurses and provide nursing educational competencies for expert communication skills.

**Expert Communication Skills**

Several investigators report the emergence of an alternative approach to AD completion that focuses on the patient/provider relationship and the development of expert communication skills (Beresford et al., 2002; Black & Emmet, 2006; Dugan, 2009; Finnerty & Gregory, 2010; Jezewski et al., 2007; Whitehead, Anderson, Redican, & Stratton, 2010). This approach focuses on the added value gained from building relationships to ascertain patients’ goals and wishes for care. In order to be “present” with a patient and have the sometimes difficult EOL discussion, nurses and other healthcare providers may need to overcome personal issues and beliefs regarding death, such as personal difficulty with a frank discussion of a poor prognosis and need for advanced care planning.

Increasing evidence suggests that assuring EOL preferences are obtained and documented is a key role for nursing to support patient autonomy and self-determination (ACHE, 2011; ANA, 2001; Black, 2006; Briggs & Colvin, 2002; Matzo et al., 2003). Unfortunately, several authors describe gaps in nursing education and institution-based continuing education regarding death and dying. These educational gaps contribute to a lack of knowledge and comfort with crucial conversations, potentially contributing to nurse death anxiety (Beresford et al., 2002; Black & Emmet, 2006; Dugan, 2009; Finnerty & Gregory, 2010; Jezewski et al., 2007; Whitehead et al., 2010). In turn, a high
level of nurse death anxiety has been associated with a low willingness to engage in EOL or critical ACP conversations (Betcher, 2010; Brisley & Wood, 2004; Dugan, 2009; Kelley et al., 2006; Mallory, 2003; Martin, 2011).

**Nursing Profession and Death Anxiety**

While nurses are supported in their scope of practice to increase involvement with the ACP process (American College of Healthcare Executives [ACHE], 2011; ANA, 2001; ANA, 2010; HPNA, 2011; Tilden et al., 2011) effective communication with the patient, family and interdisciplinary team may be hampered by nurses’ personal experiences and expectations about illness and death (Moore, 2005). Unresolved personal grief issues, lack of personal experience with death and fear of one’s own mortality may inhibit the nurse’s ability to address EOL issues (Matzo et al., 2003).

According to Thorson and Powell (1994), the fear of death is universal and not necessarily unusual. In fact, these authors found that the fear of death has many dimensions, based on cultural, religious, age and personal factors. In an earlier study, Thorson and Powell (1988), believing death avoidance was central to human existence, probed for meanings of death among a heterogeneous sample of age sensitive adults. They tested the hypotheses that women would have higher death anxiety than men and that older persons would have lower death anxiety than younger people. Their methodology used a modified instrument developed from the works of Nehrke, Templer, and Boyar that identified four principal factors associated with death anxiety including: (a) fear of isolation and immobility, (b) fear of pain, (c) fear of the finality of death, and (d) fear of decomposition.
Factor analysis supported the hypotheses that women have higher death anxiety than men, and that older persons have lower death anxiety than younger people. Importantly, the factor analysis also supported the multidimensionality of death as a construct. Personal constructs of death were reported as highly individual, yet they varied with age. Specifically, older persons were found to engage in life review and ponder more existential questions, and they had fewer death anxieties than young people. Older people did, however, have concerns about whether there is an afterlife, what the next world will be like, and the fear of the loss of personal control. In contrast, younger people had a higher overall death anxiety score than older persons and were more concerned with fear of pain, decomposition, immobility, of not being (not thinking, feeling, missing out on things), isolation, helplessness, and uncertainty about what happens after death (Thorson & Powell, 1988).

Jones (1993) described death anxiety as a “response to fear, arising out of an awareness of death” (p. 148). He theorized that if a nurse could have the opportunity to prepare for the death of a patient, there may be an opportunity to integrate the anxiety associated with death rather than avoid it. He posed that through integration, nurses may grow as human beings. Jones’ work on nurse death anxiety lacked a traditional empiric base. Rather, he used a case study of a nurse who experienced extreme death anxiety triggered by a combination of clinical and personal milestone events, which ultimately caused her to leave her employment caring for dying patients. Thus his theory was not generalizable to the nursing profession as a whole.

Boyle and Carter (1998) found there was a paucity of evidence regarding the concept of nurse death anxiety and coping measures to provide dying patients with
effective palliative care. Boyle and Carter identified the presence of complex emotional responses as potential barriers to care. Their literature review revealed the significance of death anxiety among healthcare professionals as a barrier to addressing the concept of death with patients. The hesitancy to address death was based on the belief that healthcare professionals may inadvertently pass on ineffective and uncaring attitudes towards the dying patient and the family. Those ineffective and uncaring attitudes may allow the healthcare professionals to remove themselves from their own fear or anxiety surrounding death. Clinical mentors who have not worked through death anxiety may in turn subconsciously mentor a student nurse to have a more negative attitude toward a dying patient and their family.

In an early study by Madfes, as cited by Boyle and Carter (1998), the author identified four main dimensions of death anxiety including death avoidance, death fear, death denial, and reluctance to interact with the dying. In this study, death anxiety was found to be overt, or unconscious: either distorting or denying death and its related issues. Because death anxiety can exist on a subconscious level, it becomes even harder to measure.

An early study by Eakes (1985) reported that nurses with a high level of death anxiety had a more negative attitude towards elderly patients than those with low death anxiety. She examined the relationship between death anxiety and attitudes toward the elderly among nursing home staff using Templer’s Death Anxiety Scale (DAS) and Palmore’s Facts on Aging quiz. Demographics included the nurse’s sex, age, and race; years of nursing experience; specific years of practice in a nursing home; previous experience attending a death; and formal death education. While she found no difference
in the demographic variables between participants, Eakes did report that nurses with high death anxiety showed a more negative attitude toward the elderly than those with low death anxiety. She postulated that increased supportive and educational efforts sanctioned by nursing administration may reduce death anxiety and improve attitudes towards the elderly.

One of the most frequently used tools in the early study of death anxiety was the Death Anxiety Scale (DAS) developed by Donald Templer in 1970 (Neimeyer, 1994; Templer, 1970). Templer theorized that those who deny fear of death may suffer from higher levels of death anxiety. His development of the DAS was originally thought to measure only a single general death anxiety construct, although over the years it was shown to have a more diverse factor structure. Different psychological researchers have attempted to modify the DAS to make it more comprehensive. The tool underwent continuous revision and validity testing until it solidified into its current version, the Revised Death Anxiety Scale (DAS-R) created by Thorson and Powell (as cited in Neimeyer, 1994).

The DAS-R is an instrument that measures feelings regarding death, including the death process, personal fears, the meaning of death, and coping with the finality of death. Through factor analysis, the instrument supports concern with death as a multidimensional construct. The seven factors include (a) anxiety over what happens after one’s death; (b) fear of pain; (c) body concern and anxiety over decomposition; (d) fear of dependency and being a burden; (e) afterlife; (f) anxiety over coffins; and, (g) leaving careful instructions.
Several examples of the DAS-R have been used with a specific nursing population. Nurse educators in Australia modified Templer’s original DAS for use with new graduate nurses in an attempt to explore new graduate death anxiety and coping skills. In this study, Brisley and Wood (2004) did not report the modifications made to their DAS tool. Their premise was that new graduate nurses who received additional education in care of the dying would experience lower death anxiety when caring for terminally ill patients. Additionally, they posed that new graduates would have a greater ability to gain self-support, and be able to give support more readily to colleagues.

Although they did not provide statistical evidence for their conclusions, Brisley and Wood (2004) reported that nurses in the study group and control group all had a decrease in death anxiety. Interestingly, the nurses in the study group actually had a significantly higher death anxiety score than the control group. The authors surmised that death had become more meaningful for these nurses as they had greater reflection on death issues. In contrast, the control group nurses had learned a certain level of professional detachment in response to not being as well prepared to handle patient death. Despite an increase in death anxiety within the study group, the authors reported a belief that the post-study interviews supported their conclusion that participants in the subject groups had minimized professional detachment, which has the potential to translate to improved EOL care.

Nurse Death Anxiety and Communication Apprehension

While nurses’ comfort with speaking to patients about EOL issues has been identified as an important issue in EOL Care, there is little research exploring the relationship between death anxiety in nurses and how this equates to their comfort level
when speaking to the acutely ill hospitalized patient about EOL choices. Deffner and Bell (2005) attempted to demonstrate a relationship between death anxiety and comfort level of nurses when communicating about death with patients and families. The investigators posed that nurses exposed to continuing education in effective communication skills could decrease their death anxiety and, at the same time, have a positive impact on comfort levels when speaking to patients about death. The investigators theorized that death was seen as a failure, and undue significant emphasis was being placed on death avoidance.

Deffner and Bell (2005) utilized multiple regression analysis to estimate the relationship between the possible predictors of gender, age, education, experience, exposure to communication education, and working location to selected death anxiety items from Templar’s (1970) death anxiety scale. The authors also used multiple regression analysis to estimate each variable’s relationship to nurse EOL communication comfort level. To measure association of how one variable contributes to explaining changes in a second, the authors utilized a simple cross-tabulation (bivariate analysis) using a measure called “Gamma” (p. 21).

Deffner and Bell’s (2005) findings included a statistically significant inverse relationship between a nurse’s death anxiety level and the nurse’s communication comfort level with patients and families regarding death ($p = .000$). The authors also found that nurses who had past communication education (74% of sample) reported feeling more comfortable talking with patients and families regarding death (Gamma value = - 0.303 with a $p < .012$).
The limitations of Deffner and Bell’s (2005) study included a convenience sample and a lack of statistical significance between some of the DAS and comfort level variables. The authors concluded that death anxiety may adversely affect patient care. Additionally, the authors recommended further studies examining particular types of educational exposure nurses have had and the DAS. The findings may inform educators about the types of communication education most helpful for staff education.

In contrast, Kennard et al. (1996) explored the effectiveness of communication as perceived by patients. Among the 1,427 patients surveyed, over 50% stated conversations with nurses were very helpful in making healthcare decisions, while only 10% of the nurses thought their communication was influential. The authors proposed nurse involvement in the decision-making process as a means to preserve patient autonomy, improve quality of care, and increase patient satisfaction.

Hayslip (1986-87) was one of the first researchers to consider the underlying communication difficulties that hospital and nursing home staff may experience when caring for the terminally ill. Hayslip’s original study administered the CA-Dying scale to potential hospice volunteers to establish reliability and validity of the tool. Hayslip demonstrated that the CA-Dying scale possessed more than adequate reliability (r = 0.78, p < .01) and internal consistency (α = 0.86). Hayslip concluded that the CA-Dying scale was a useful index of difficulties caregivers may have when communicating with patients at EOL.

Servaty, Krejci and Hayslip (1996) utilized the CA-Dying scale to explore possible relationships between death anxiety, communication apprehension with the dying, and empathy of those considering careers in nursing and medicine. The
participants in this study were students of nursing and medical school in various stages of education. The medical students had received no formal death and dying training, while the nursing students participated in informal discussions about death in their current undergraduate program. None of the students in this study received formal education on death and dying. All students were asked to complete three separate instruments: the Mehrabian and Epstein Empathy Scale, the original Death Anxiety Scale, and the CA-Dying scale (Hayslip, 1986-87).

The Pearson correlation revealed significant positive correlations between death anxiety and communication apprehension with the dying (0.12, \( p < .01 \)), as well as death anxiety and empathy (0.20, \( p < .05 \)). Univariate analysis indicated a significant difference in communication apprehension with the dying scores between freshman and senior students, with seniors scoring lower than freshmen in apprehension (\( F_{1, 121} = 11.24, p < .001 \)). The results suggested that communication apprehension is less common in those with lower anxiety about death-related events.

While communication apprehension scores may decline with a decrease in death anxiety, in some instances anxiety was found to actually increase with death education. According to several researchers, exposure to death education for new nurse graduates transitioning to the workplace is a meritorious idea given that the majority of undergraduate programs do not present formal education in caring for the dying patient (Brisley & Wood, 2004; Leighton & Dubas, 2009; Sperlazza, 2009). However, for some nurses, not being exposed to death education allowed them to professionally detach from death until they were faced with the actual situation.
In contrast, new graduate nurses attending a twelve month transition program that included death education experienced an increase in their pre-post death anxiety scores using a modified Death Anxiety Scale (Brisley & Wood, 2004). While the program was meant to ease transition to the “real world” of nursing, the new graduates in this study discovered that they had received little preparation for patient death in their undergraduate education. Thus, thinking about caring for dying patients forced the new nurses to deal with their own death issues. The authors concluded that the new graduate transition program was helpful in providing new nurses with a common support group and the opportunity to discuss various coping strategies.

Few studies have specifically examined nurses’ comfort in addressing EOL communication, suggesting that healthcare professionals with high death anxiety may be reticent to engage in communication with people at EOL. Conclusions from the literature support the importance of nurse communication with the patient for ACP from a professional organizational standpoint, and from the patient perspective (ACHE, 2011; ANA, 2001; ANA, 2010; HPNA, 2011; Kennard et al., 1996; Tilden et al., 2011).

**Relationships as a Factor in AD**

In an early survey evaluating the effectiveness of U.S. EOL care, survey results described every U.S. state as “mediocre or worse in the care of people who are dying” (Thompson, 2005). At the same time, the public has been exposed to more information about advance directives, the availability of hospice and palliative care, the inappropriate use of technological resources, and personal choice as a factor in quality of life more than ever before (AACN, 2004).
As the focus of healthcare shifts to include patient-centered care relationships, it is natural that the public would consider nurses as one source of information and a potential source of expertise as they provide care across settings. Longitudinal care includes symptom management, patient-centered education, care coordination, and provision of emotional support (Moore, 2005). The nurse skilled in EOL communication can be integral to the ACP process. When nurses are able to shift the focus of ACP from information-giving to a relational, patient-centered model, the nurse opens the door for the patient to gain an understanding of their clinical situation. This includes how much authority the patient would like their healthcare surrogate decision-maker to have. Use of this type of model could additionally provide a framework between the surrogate-and the healthcare team about when and how to use that authority. Moore (2005) concluded that respectful, reflective listening as an intervention encouraged patient self-determination and advocacy as it gave the patient “permission” to talk about subjects that may have been considered off-limits within the family unit. Further, reflective listening provided an opportunity for the healthcare team to give the patient specific risk/burden information that may facilitate further ACP decisions (Briggs, 2004).

Professional Organization Support for Nursing Scope of Practice

Deffner and Bell (2005) found that a synthesized POC reflecting the patient’s values and beliefs for EOL care requires that nurses are adept in crucial conversation skills, yet nurses in this study did not necessarily see themselves as important communicators with patients. The authors suggested that this perception is not borne out by the public at-large. In fact, a 2011 Gallup poll of Americans over the age of 18 rated nurses as having the highest degree of honesty and integrity from a selection of twenty
different professions suggesting that the public values nurses as credible healthcare professionals (Jones & Saad, 2011).

The scope of practice for the professional RN includes patient advocacy for the delivery of dignified and humane EOL care. Patient advocacy cannot be optimized without excellent communication skills to gain insight into the patient’s values and goals (ANA, 2001; ANA, 2010; Briggs & Colvin, 2002; Briggs, 2004; Moore, 2005). According to the ANA (2010), effective advocacy in turn supports patient self-determination. Self-determination, or autonomy as it is also known, forms the basis for informed consent in healthcare. Patients have the moral and legal right to make decisions about their own healthcare (the premise of PSDA), and nurses have a professional responsibility to facilitate the process of informed healthcare decision-making for patients.

In fact, in 2004 the AACN recommended competencies and curricular guidelines for EOL care. The competencies explicitly state that nurses need education to recognize personal feelings, values, and expectations in order to communicate effectively and compassionately with the patient, family, and healthcare team members about EOL issues. The ANA Code of Ethics reinforces the nurse’s obligation to assure patients have the information and the comprehension of the information they need in order to make decisions about their healthcare. If the patient is not able to make decisions, the ANA (2001) encourages the nurse to engage in consultation with the surrogate decision-maker to ensure that the patient’s healthcare preferences are consistently provided, including the decision not to engage in ACP.
Experts from other healthcare organizations have shown considerable interest in ACP. Tilden and colleagues (2011) describe support for a greater involvement by nurses in ACP by several national organizations in a recent study of urgent EOL public health concerns. The ACHE (2011) policy statement on decisions near EOL supports the professional nursing advocacy role by developing a culture that supports further education for nurses on EOL decision-making and patient care. In addition, the American Academy of Nursing’s (AAN) Task Force on EOL Care has also issued an official comment, urging training and education to enhance the knowledge, skills, and attitudes that nurses bring to the bedside of patients with life-limiting conditions (AAN, 2010; Tilden et al., 2011). The AAN membership further believes content on ACP and interprofessional conversational education exercises should be an expectation to enhance skill in eliciting patient preferences and values, aid treatment decisions, and engage surrogate decision-makers (Tilden et al., 2011).

The ACHE leaders acknowledge that moral distress can occur among nurses who participate in EOL decision-making conversations. Moral distress was defined by Jameton (1984) as painful feelings and/or psychological disequilibrium caused by a situation in which a person knows an ethical action to take but cannot do so due to either institutional obstacles, lack of supervisory support, medical power, institutional policy or legal limits. The ACHE has advocated for the establishment and use of effective support programs (e.g. ethics committees and employee assistance) for the nurse who engages in EOL decision-making discussions with patients in order to address the ethical conflicts and moral distress nurses face. The ultimate goal is to create institutions that foster reasoned, compassionate decision-making that considers the rights and values of patients.
and nurses, respecting the dignity and inherent worth of every person (ACHE, 2011; Tilden et al., 2011).

The HPNA (2011) policy statement on the nurse’s role in advance care planning acknowledges that nurses are uniquely positioned to discuss a patient’s values, beliefs, and goals about future healthcare interventions. Nurse involvement with the patient’s ACP promotes patient advocacy, supports patient self-determination, and develops a synthesis of the patient’s preferences into the plan of care. Educating nurses in the process of ACP, including necessary communication skills for difficult conversations, is essential to provide a practice environment conducive to quality outcomes in advanced illness and EOL care.

**Nurse Education and Educational Initiatives**

When asked about their first experience with a patient death, practicing nurses may speak of confusion, lack of preparedness, anxiety, and even guilt about how the event was handled, during and after the death. In fact, many nurses felt they were not adequately prepared for their first, or subsequent, EOL experiences (Leighton & Dubas, 2009; Sperlazza, 2009). Practicing nurses identified communication techniques regarding how to talk to patients and families about dying as one of the major missing components in their undergraduate education (Matzo et al., 2003). This suggests that nurses may benefit from a specific, skill-based education to provide effective and compassionate EOL care to patients.

Currently there is a paucity of literature describing post licensure, patient-centered outcomes in EOL care, as well as outcomes in relation to the EOL nurse education to decreased death anxiety. Since death anxiety is multifactorial and universal,
facilitating learning has remained a challenge. In fact, the clinical experiential learning of many undergraduate nurses was filled with the tasks of caring for the living. Schlairet (2009) reported that student nurses are rarely given the opportunity to care for someone who is actively dying. Undergraduate students who do have exposure to the terminally ill during clinical rotations and are not adequately prepared, often feel undo stress and even a desire to disengage or avoid the patient (Brisley & Wood, 2004; Mutto, Cantoni, Rabhansl, & Villar, 2012).

Use of the ELNEC curriculum within the acute care setting can help nurses improve more directed communication skills with patients. Betcher (2010) used a combination of pedagogies to train volunteer nurses on an inpatient palliative care unit using videotaped simulations with patient actors. The nurse’s confidence in personal ability to convey a caring attitude was then measured via the Caring Efficacy Scale by Coates (1996). In Betcher’s study, the average score of the nurse volunteers increased 11% post-intervention, suggesting an increased confidence in the nurses’ ability to portray a caring attitude. Limitations to this study included selection bias, a lack of generalizability due to the small size of the subject pool (8 nurses), and the cost of the actors and videotaping. Interestingly, physicians who were aware of the project professed an interest in participating in any future simulations.

Matzo et al. (2003) provided a thematic overview of the ELNEC Module 6, presenting pedagogical techniques to improve communication skills for EOL care. Key themes of the module include the critical nature of skillful communication; the importance of strong interprofessional collaboration as a prerequisite to communication;
the importance of verbal and nonverbal communication; and the need for listening and presence in order to enhance effective palliative nursing care.

In this module, Matzo et al. highlighted an adapted version of the Six-Step Protocol for Breaking Bad News by Buckman (1998). These steps include: (a) getting the physical context right, (b) finding out how much the patient knows or suspects, (c) finding out how much the patient wants to know, (d) sharing medical information, (e) responding to the patient’s feelings, and (f) planning and summarizing.

In addition to Buckman’s Six-Step Protocol, Matzo et al. included additional diverse factors that may influence the ensuing discussion. Those factors included family systems issues, financial, educational and physical concerns, and the patient/family’s stage in the coping and grief process. Several strategies were used for teaching communication skills including videotaped role-playing and group conversations. In the videotaped session, learners had the opportunity to become aware of their behaviors and communication styles. In groups of three (nurse, patient, observer), the learners participated in a goal-directed conversation. Participants discussed a list of questions provided to elicit the patient’s goals and incorporated them into the interdisciplinary plan of care.

Finally, students were shown film clips from a video, “In the Gloaming” (Zollo, 1997), with a set of questions to consider as they watched the clips. Discussion then ensued regarding nonverbal communication of the actors, intervention by the nurse to improve family communication skills, and the observance of and response to family dynamics issues. Of critical importance, Matzo et al. reinforced that the willingness of
nurses to bear witness to the suffering of the patient and offering their presence was often perceived by the patient and family as the most important of all interventions.

As it exists, ELNEC appears to increase nurse knowledge about the provision of palliative and EOL care. Kurz and Hayes (2006) attempted to measure the impact of ELNEC education on RN death anxiety, death attitudes and knowledge over time. Using a quasi-experimental longitudinal design, the investigators examined nurses who took an ELNEC course versus RNs who volunteered to participate in the study who had not taken ELNEC.

At the time of the pre-test the intervention group included 26 nurses. The post-class intervention groups numbered 15 at the first post-class evaluation (timeframe 1[T1], immediately after the class), 11 at the second post-test (T2), and 12 at the third post-test (T3). The control group included 34 nurses who completed the T1 test, 15 who completed the post-test at T2, and 15 who completed the post-test at T3. General Systems Theory provided the foundation for the study. Metrics included the Death DAS-R, the Death Attitude Profile-Revised (DAP-R), and a Visual Analog Scale (VAS), measuring knowledge related to EOL care.

While the investigators did find that there was an increase in knowledge regarding EOL care post-ELNEC, they also found death anxiety scores increased immediately after the class. Yet, on retest after six months the death anxiety scores had decreased. In contrast, the control group had increased death anxiety scores that remained consistent over time. An increase in post class death anxiety scores could be attributed to increased exposure to death and dying and possible enhanced self-awareness of mortality. Kurz and Hayes (2006) postulated that the ELNEC curriculum might encourage self-
exploration about death. Therefore, death anxiety may increase until the person has time to reflect on their own personal concept of death.

Limitations of the study included high subject attrition, lack of a non-random sampling design, and a potential environmental bias due to the recent start of the Iraq war (high terror alerts). Recommendations from this study included a retiming of evaluations after participants have had time for reflection, and planning "booster programs" to sustain effects. According to the authors, future studies should include larger samples, incentives, and research method triangulation (Kurz & Hayes, 2006).

In a second study to explore the value of ELNEC training to improve EOL care by nurses, Whitehead et al. (2010) attempted to substantiate the hypothesis that providing ELNEC training to nurses as a singular intervention could result in decreased death anxiety, reduce concerns about dying, and increased knowledge of the dying process. Whitehead et al. attempted to support this hypothesis using a quasi-experimental, longitudinal design in the hospital setting. They used the DAS-R to measure death anxiety, the Concerns About Dying instrument (CAD) to measure death attitudes or concerns about dying, and evaluation tools provided by ELNEC (knowledge of death and dying, or KDS) to evaluate the perceived knowledge of participants at the end of each of the six modules.

Five hundred nurses were contacted to participate in a matched pair analysis. Twenty-seven were in the treatment group and 118 were in the control group. Measurements took place pretest, post-test (within two weeks after training), 6 months, and 12 months post ELNEC education. Due to attrition, a total of 11 nurses in the intervention group and 27 in the control group completed all four phases of testing.
Whitehead et al. did note that while not statistically significant \((p = .09)\), those nurses with less nursing experience tended to have higher attrition rates as compared with more experienced nurses.

The nurses were matched primarily on the number of years worked as a nurse and secondarily on age, ethnicity, and whether the participant had previous EOL education. For the matched pair analysis of KDS, there was a significant difference between groups at post-test \((p = .01)\) and again at the 12 month test \((p = .013)\). Interestingly, there was no statistically significant difference between the groups for either DAS-R or the CAD at any of the time periods. Thus, the hypothesis that providing ELNEC training to nurses as a singular intervention could result in decreased death anxiety and reduced concerns about dying was not supported.

The limitations of this study included the small sample size, which may have been inadequate to measure subtle changes between the groups. Additionally, the tools may not have been sensitive enough to measure subtle changes in a small sample size. Despite the results regarding death anxiety and concern about dying, the authors stressed that organization and cultural modifications of the care environment are crucial to truly improve palliative care.

Lynn et al. (2000) questioned the original intervention of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments – SUPPORT (SUPPORT Principal Investigators, 1995) to change communication, decision making, and treatment patterns with patients. Lynn et al. examined organizational culture of the healthcare environment and the relationship with improved patient decision-making. While improved communication has value with patients, the authors suggested that
practice patterns and social expectations may strongly influence a patient’s course of care. Efforts to improve system function may offer additional methods for reform of EOL care (e.g. quality improvements, changing financial incentives).

Minimal studies have been published to gauge the effect of the ELNEC Module 6 education on nurse death anxiety. The few studies that have been published have provided some groundwork for future study design, but to date have not supported the assumption that ELNEC education consistently decreases nurse death anxiety over time. Further, there has been minimal use of a communication apprehension tool to determine whether use of the ELNEC communication education module increases nurse comfort in speaking to patients and families about EOL issues.

Conflicting results with ELNEC Module 6 education and its effect on nurse death anxiety may be due to minimal, underpowered, and/or poorly designed studies. Communication apprehension, when measured, does demonstrate a positive relationship between death anxiety and communication apprehension. Those with less death anxiety tend to report lower communication apprehension with dying patients (Servaty et al., 1996). The dual use of the DAS-R and Communication Apprehension with Dying (CA-Dying) scales are intriguing as an impact measure for the ELNEC communication module. Death anxiety results have varied in previous studies, and is worthy of further examination. Perhaps the real issue is whether after participating in ELNEC communication education a nurse is more willing to enter a patient’s room and engage in difficult conversations.
Summary

In summary, although nurses are trusted by patients to deliver holistic care, encompassing body, mind, and spirit, there is an absence of studies that document the important role of the bedside nurse to engage in EOL conversations. Nurses are in a unique position to make a difference in patient self-determination and be “present” with patients throughout their EOL process. By providing evidence-based EOL education and a framework to support nurses as patient advocates, nurses will have the opportunity to explore personal feelings related to death and dying. Nurses must be empowered to minimize needless suffering of patients while honoring EOL wishes and supporting the family. Families will always remember the last moment of a loved one’s life.
CHAPTER 3

CONCEPTUAL FRAMEWORK

The purpose of this chapter is to provide an overview of two conceptual models for this project: ELNEC education adoption and implementation at the organizational level of care, and innovation implementation measures at the individual staff nurse level of care. The organizing framework, Promoting Action on Research Implementation in Health Services (PARiHS) (Hutchinson, Wilkinson, Kent, & Harrison, 2012; Rycroft-Malone, 2004, 2010), guided the implementation of the ELNEC curriculum into the organizational setting. Donabedian’s Quality Design (2003) framework was used to evaluate implementation of the ELNEC Module 6 intervention at the staff nurse level.

**Effectiveness of Evidence Based Care**

Implementation science focuses on improving the quality and effectiveness of health services, including influences on healthcare professionals and organizational behavior (Eccles, 2008). Effectiveness evaluation reflects on the population perspective (macro-level view) and the clinical perspective (micro-level view) of healthcare. Both views are necessary for clinical improvement or health benefits to patients, as well as for the socioeconomic health of the population (Aday, Begley, Lairson, & Balkrishnan, 2004). When considering the effectiveness approach to EOL care, patient “clinical improvement” may seem counterintuitive. However, one of the goals of quality evidence-based palliative care is to relieve suffering and improve quality of life for those patients and families who are burdened by life-threatening illness. This is done through skilled symptom management and communication to determine care goals of the patient.
and family, which are then communicated via an interdisciplinary POC. Well managed palliative care improves the quality of life, and in some cases can even prolong survival of patients with advanced illness (Morrison et al., 2011).

Evidence-based care consists of using the best and most relevant evidence to answer a clinical question, meshing clinician expertise with the preferences and values of the patient (Melnyk & Fineout-Overholt, 2005; Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). In his quality model, Donabedian (2003) focuses on whether the right thing is being done for the patient, and whether it is done well. Interaction between the patient and clinician is paramount to this model, as meaningful conversation elicits the values and beliefs about a patient’s care.

A clinical problem presents when meaningful conversations are not occurring on a regular basis due to poor clinician communication skills regarding EOL. This in turn results in the lack of a meaningful ACP to guide the patient’s care. Too often, this culminates in a high percentage of older adults dying in hospital intensive care units with life support therapies for futile conditions rather than dying in familiar surroundings such as in their homes with hospice services (Morrison & Meier, 2004; Morrison et al., 2011).

Enhanced clinician competence in the initiation and advocacy for a patient’s individualized, interdisciplinary ACP improves effectiveness of palliative and EOL care. Early initiation of palliative care services has proven to be especially effective in improving patient quality of life and increased life span (Temel et al., 2010). Additionally, early and effective palliative care may decrease healthcare costs to the patient and family by decreasing utilization of intensive care services (Kass-Bartelmes & Hughes, 2003).
Knowledge Translation

The PARiHS framework was used as the overarching design for this project. PARiHS is a multidimensional model that was developed to represent the function of the relationships between evidence, context, and facilitation (Kitson et al., 2008; Rycroft-Malone, 2004; 2010). Evidence is defined as “different sources of knowledge and information needed to be combined and used in clinical decision making at the bedside with the patient” (Rycroft-Malone, 2004, p. 298). Evidence in the PARiHS framework includes empiric research, clinician expertise, patient preferences and experiences, and local information (Kitson et al., 2008; Rycroft-Malone, 2004).

Clinical experience is an important, related sub-element of evidence. Described by Stetler (2011) as a tacit and often intuitive form of knowledge, clinical experience is derived from the experience of others as well as personal practical knowledge. The stakeholders own experience can influence the targeted innovation and related values, beliefs, and motivation for the change.

The context of PARiHS includes the environment or setting in which people receive healthcare services, or the setting in which the proposed change is to be implemented (Rycroft-Malone, 2004). Key ingredients for change in the context include the presence of transformational leaders, a continuous learning organizational culture, and appropriate, evaluative monitoring mechanisms (Kitson et al., 2008; Rycroft-Malone & Bucknall, 2011).

Facilitation within the PARiHS framework is defined as “a technique by which one person makes things easier for others” (Kitson et al., 2008, p. 9). The facilitation continuum ranges from a practical and task driven role to enabling and empowering
others, guiding the staff to control their own learning and change processes (Kitson, 2008). Skilled facilitators improve the likelihood of success in implementing the evidence into practice. Thus, facilitation can be seen as an intervention, a concept that is central in the PARiHS framework.

The purpose of the facilitator is to guide and support the implementation of an evidence-based intervention (Stetler, 2011). The role expectation of the facilitator is to directly or indirectly influence individual and process change, thereby enhancing overall implementation of the targeted change (Stetler, 2011). The role and skill of the facilitator enables others to analyze, reflect, and change their own attitudes, behaviors, and ways of working (Kitson et al., 2008). Facilitators can serve in an internal, external, or combined capacity (Stetler, 2011).

The supposition of the PARiHS framework is that if there is well-conceived and designed evidence (rated “high” in the model), a contextual culture that promotes learning with appropriate resources and expectations (again, rated “high” in the model) and skilled facilitation, then successful implementation of the evidence is more likely (Rycroft-Malone, 2004) (see Figure 3.1). The standardized ELNEC Module 6 (ELNEC, 2012a) curriculum served as the evidence for change for this project. The environmental context was an acute care setting with transformational nursing leadership support. The facilitator of the project was the Doctor of Nursing Practice (DNP) student, acting as an expert mentor to the organization’s new ELNEC trainers (co-facilitators).

There was no hierarchy or linear effect in the PARiHS model. Rather, the multilevel context included the hospital environment, management involvement in
quality of care issues related to ACP, and nurse involvement in EOL discussions and the educational environment.

Figure 3.1 The PARiHS Diagnostic and Evaluative Grid

\[\text{Figure 3.1 The PARiHS Diagnostic and Evaluative Grid}\]


**Donabedian Quality Design**

Although the intent of the PSDA was to effect meaningful change in ACP, that often does not occur in actual practice (Halpern et al., 2011; Tilden et al., 2011). The gap between the time it takes for evidence-based interventions to become a routine part of practice is a knowledge-to-action cycle (Kitson, 2009). The use of quality indicators are one method of assessing gaps.
Donabedian’s quality model of structure, process, and outcome served as the conceptual framework for the project at the micro-level. Donabedian (1993) focuses on the healthcare system and its associated science and technology, and also on the patient-clinician interaction, or ways in which the science and technology are applied in practice. The model examines whether the right thing is done for the patient and whether that thing is done well (Aday et al., 2004).

The Donabedian framework places the interaction of patient and practitioner at the center of the healthcare environment. Through the patient-clinician interaction, the process of care itself can be assessed, rather than outcomes alone (Donabedian, 2005). Donabedian states, “It is there that the processes and decisions most critical to quality take place” (p. 33). If true quality means doing the right thing for the patient at the right time, surely meaningful conversation and nurse understanding of a patient’s wishes will influence the quality of care.

Donabedian’s model for this project is illustrated in Figure 3.2. The structural factor of the model includes elements of care that are associated with receipt of services (Aday et al., 2004). In an institutional environment, factors could include the healthcare system/institutional resources as well as clinical and patient factors. For this project, structural factors included the hospital policy for EOL educational offerings (e.g., ELNEC participation was elective versus mandatory), historical absence of a formalized ELNEC program, presence of an established Palliative Care service, and willingness of leadership to offer ELNEC education to staff as a paid benefit.
The process component of the Donabedian model under evaluation for effectiveness is the intervention. In this case, the intervention was the ELNEC Module 6 class.

The outcome measure may bear a relationship to the structure and process. In this project, differences in RN death anxiety scores and comfort in speaking with patients (communication apprehension behaviors) regarding EOL choices were measured and reported pre and post ELNEC education. In addition, the findings of the death anxiety and communication apprehension scores were analyzed in comparison to the demographic variables to determine any trends related to the clinical (RN) and system/institution factors.
Summary of Models

Implementation science provides a scientific method to promote systematic uptake of evidence-based practices into routine practice (Eccles, 2008). The PARiHS framework was a useful reference tool to plan and implement the ELNEC curriculum within the organization. The structured guide to inform the PARiHS context was the organizational assessment. The organization-wide implementation of the ELNEC
curriculum served as the evidence component of PARiHS. The internal and external facilitators of the ELNEC Module 6 curriculum served as the PARiHS intervention.

Donabedian’s Quality Model informed the innovation implementation at a more granular level. The clinical (RN factors) and the system/institution factors informed the structural assessment of the project. In this case, the structure addressed factors that may or may not have a relationship to effective implementation of the ELNEC curriculum innovation, or process. A change in nurse death anxiety and communication apprehension scores served as the outcome of the innovation implementation.
This chapter describes the methods used to develop an evaluation strategy to answer the question as to what effect the ELNEC Module 6 education had on nurse death anxiety and communication apprehension with the dying. This chapter will include a discussion of design, setting, participants, definitions, instruments, and intervention, followed by the project procedure and implementation.

Because discussing EOL issues can be an emotional experience, it is important to attend to the concerns of the RN regarding personal perceptions and beliefs about death (Beresford et al., 2002; Black & Emmet, 2006; Finnerty & Gregory, 2010; Jezewski et al., 2007; Whitehead et al., 2010). This approach was chosen to best address previous conclusions from the literature suggesting that care providers need to acknowledge personal issues regarding death in order to practice presence with their patients. Weiner and Cole (2004) recommended education programs designed to improve EOL communication attend to emotional distress of the clinician during discussions with dying patients, use cognitive principles to revise counterproductive beliefs, and provide experiential training regarding shared decision making as well as patient-centered communication. In particular, the ELNEC curriculum is focused on nursing and examines personal barriers to communication while educating nurses in appropriate communication techniques. Thus, the evaluative question for this quality initiative was: “Among registered nurses caring for hospitalized patients, what is the impact of the
ELNEC Module 6: Communication education on nurse death anxiety and communication apprehension scores?"

**Project Design**

This project used a descriptive approach with a pre-posttest measure to report and compare changes in death anxiety and communication apprehension as measured by the DAS-R and CA-Dying scales. A descriptive approach was selected because little research has been centered on the role of the professional nurse relative to advocacy communication for patient choice in the acute care setting. Because discussing EOL issues could be an emotional process, it was deemed important to examine concerns of professional nurses regarding personal attitudes regarding death, communication with the dying, and the influence of the ELNEC module on these factors. The ELNEC communication education module was selected as an evidence-based intervention for voluntary RN participants. A minimum of 25 participants was desired for this quality improvement initiative.

**Definitions**

For the purpose of this project, “death anxiety” was referred to as the nurse’s response to the anxiety of the anticipation of death, ranging from a low personal fear of death to a high fear of death (Thorson & Powell, 1994). Communication apprehension with the dying (CA-Dying) was described as the degree of fear or anxiety the nurse associated with communication specifically with dying persons (Hayslip, 1986-87).

**Setting**

Located in the Midwest, the hospital site for this scholarly project is a member of a national, faith-based, health partnership consisting of ten other hospitals within the state.
(Trinity Health [TH], 2012b). The organization is an urban academic referral hospital, serving a metro population of 189,815 and a county-wide population of 608,453 (U.S. Census Bureau, 2012). The hospital also provides specialty care to adjacent counties. The hospital has 324 licensed and staffed acute care beds (Trinity acute care facilities, 2010). The nursing staff within this organization consists of 965 full-time equivalents (FTEs) or 1,260 staff members. There are eight separate divisions directly reporting to the Senior Vice President (SVP)/Chief Nursing Officer (CNO). Moreover, two community health centers, case management, occupational health, associated clinics and ancillary services report directly to the CNO.

**Leadership Engagement**

In order to ascertain the institution’s potential to engage in the project, an in-depth organizational assessment was planned and conducted. The importance of institutional support is consistent with successful knowledge translation of evidence to the bedside. The CNO directly promoted and supported participation in the ELNEC classes.

The directors, managers, clinical nurse specialists (CNS), professional development specialists (PDS), nursing research council and clinical nurse leaders (CNL) were given a brief presentation by the DNP student on the background of the scholarly problem issue, content of the ELNEC class and possible outcomes. Managers also received personnel benefit information for class and scholarly project participation (e.g., Clinical Advancement System [CAS] points, contact hours, and pay).

To engage the organizational leaders in a climate for innovation, interdisciplinary team members with strong communication skills were involved in the class planning. The DNP student met with the medical director of the Palliative Care team and directors
of the Pastoral Care and Social Work departments to explain the content and garner project support. The directors were amenable to acting as resources for staff who may grapple with personal loss issues potentially triggered by the class content.

**Participants**

A convenience sample of RNs employed by the hospital comprised the sample population. Twenty RNs enrolled in the ELNEC classes. Eligibility to participate included RNs employed by the facility in the adult acute care and maternal/child setting. Nurses working on adult and maternal/child care units and nursing leadership staff received in-service and email announcements presenting the purpose of the scholarly project, objectives, and an invitation to participate in the study. No remuneration was provided for participation in this project, although participants did receive their usual hourly wage for attending the education session, contact hours, and clinical advancement system (CAS) points.

**Intervention**

The intervention for this project was the ELNEC Module 6: Communication standardized core curriculum (ELNEC, 2012a). ELNEC education provides an evidence-based approach to teaching palliative care to nurses caring for patients with acute and chronic life-limiting illness. The ELNEC curriculum was developed by nationally known palliative care experts, and is regularly revised based on participant recommendations and new advances in the palliative care field (ELNEC, 2012b). The curriculum covers EOL core competencies recommended in the AACN’s (2004) peaceful death document. The ELNEC trainer is permitted to reproduce all handouts. When participants complete all eight modules of the curriculum they are eligible to become trainers as well. Thus the
initial investment of training for five individuals may be multiplied throughout the organization.

**Project Facilitation**

The ELNEC trainers served as the primary facilitators of the evidence-based ELNEC Module 6. Their clinical expertise included geriatrics, critical care, emergency nursing, and previous hospice care. Only one trainer had previous experience as a nurse educator. The years of experience as a RN ranged from 5 to 30 plus years.

The ELNEC trainers divided the teaching duties of the ELNEC curriculum between the eight ELNEC modules. Module 2: Pain Management was taught first, as it was a familiar topic to the trainers and staff. ELNEC Module 6 classes were scheduled 15 days apart with three trainers.

In general, the trainers were still somewhat new to teaching and the use of audiovisual aids. All five trainers participated in the ELNEC-provided role-play scenarios at the beginning of the class. At the culmination of the session, trainers were rated individually on the organization’s continuing education evaluation form.

The ELNEC Module 6 addresses the unique needs of patients and their families during difficult discussions about EOL decisions. Concerns regarding family fears, emotions and the patient/family societal values are common. The nurse may also have to deal with patients compromised by dementia and other comorbidities that make complex EOL discussions more of a challenge.

**Measurement**

Measures in this quality improvement project were nurse death anxiety (measured by DAS-R) and comfort when speaking with patients (measured by CA-Dying) regarding
EOL choices and ACPs. This project had two quality improvement evaluation questions. The first question was, “Does use of the ELNEC Module 6: Communication curriculum with acute care RNs affect RN death anxiety scores?” The second question was “What is the impact of the ELNEC Module 6: Communication curriculum on RN communication apprehension scores?”

Within-subjects, pre-posttest comparison evaluation was used to examine the effectiveness of the educational intervention. Demographic data were used to provide descriptive detail. Range and average, including standard deviations, were reported.

The level of measurement for the ELNEC curriculum and certain demographic variables were nominal (e.g., experience working on palliative care unit/service, experienced personal loss, formal EOL education), while the level of measurement for death anxiety scores and communication apprehension with patients regarding EOL choices and ACP were both interval in nature. ANCOVA and $t$-tests were used to detect any difference in means between the DAS-R and CA-Dying scores pre and post intervention.

**Instruments**

**Death Anxiety Scale-Revised (DAS-R)**

Operationally, the DAS-R (Appendix B) is a 25-item self-report questionnaire using a 5-point Likert format. Items were scored with the value of “1” given for least anxiety and “5” for highest death anxiety. Seventeen of the items were phrased positively and eight negatively to minimize response bias. Respondents were asked to agree or disagree with the statements on the Likert scale. Responses to negatively-
phrased items were reversed in the scoring process. The range of possible scores was 5 to 125, with higher scores denoting higher death anxiety.

The DAS-R has been used in numerous studies over the past two decades and possesses established reliability and validity. The Cronbach alpha reliability of the DAS-R was 0.8037, with a seven-factor structure accounting for 58.5% of the variance (Neimeyer, 1994; Thorson & Powell, 1988; Thorson, 1992). Factor loadings of 0.30 or greater included anxiety over what happens after one’s death; fear of pain; body concern and anxiety over decomposition; fear of dependency and being a burden; afterlife; anxiety over coffins; and leaving careful instructions.

In the DAS-R, Pearson product-moment correlation coefficients were calculated for scale score by sex ($r = 0.090$, $p < .02$) and by age ($r = 0.352$, $p < .0001$), indicating a weak relationship of higher anxiety for females, and a slightly stronger correlation for age, with younger respondents having a higher death anxiety. While this instrument has had limited use, conclusions from this study were that those in older age groups (especially over 66 years of age) had a lower DAS-R score. When the overall DAS-R scores were correlated for sex and age, women expressed greater anxiety on subscales relating to fear of pain and bodily decomposition. The elderly were more concerned with whether there is an afterlife, what the world would be like, or a fear of loss of personal control (Thorson & Powell, 1988). Thorson cautions that while the DAS-R may measure death anxiety, personal constructs of death are highly individual, and the DAS-R should not be used as a clinical tool in counseling the user.
Communication Apprehension with the Dying (CA-Dying) Scale

The second measure utilized was the communication apprehension with the dying (CA-Dying) scale (Hayslip, 1986-87). Operationally, the CA-Dying scale (Appendix C) contains 30 statements on a five-point scale ranging from strongly agrees to strongly disagree. The items include statements such as, “I feel comfortable in developing an intimate conversation with a dying person,” “I would avoid talking with a dying person if possible,” and “I would hesitate in revealing my true feelings in talking with a dying patient.” Items were scored with the value of “1” given for least communication apprehension and “5” for highest communication apprehension. The CA-Dying scale demonstrated more than adequate test-retest reliability ($r = 0.78$, $p < .01$) and internal consistency ($\alpha = 0.86$) (Hayslip, 1986-87). In this instrument, higher scores equate to higher communication apprehension.

Demographic Data

A demographic data tool was utilized to determine intervening variables. Variables included previous experience with caring for dying patients, previous experience working on a dedicated palliative care unit or service, previous experience with death and dying on a personal level, and previous formal EOL education. Additional data included the number of dying patients cared for in the past year; highest level of nursing education preparation; years of practice as a RN; and years worked on the palliative care unit or service.

Procedure

Participants were informed of the project through the institution’s electronic mail nurse list serve, as a screensaver, postings on bulletin boards in staff lounges and shared
governance structure. The staff notification included information on the project purpose and objectives. Recipients of the information were assured of the confidentiality and anonymity of their responses if they chose to participate.

Prior to initiation of the class the participants received a verbal explanation of the project and were given the opportunity to ask questions. Paper questionnaires, including the demographic questionnaire, the DAS-R (Neimeyer, 1994; Thorson & Powell, 1994), and the CA-Dying scale (Hayslip, 1986-87) were left on the table at every seat. Participants had the opportunity to either fill out the questionnaires or leave them blank and then place them in a confidential, non-marked envelope.

The intervention of ELNEC Module 6 curriculum was delivered in a two hour face-to-face class format. The module consisted of a didactic component with slides, lecture notes and associated video clips. Participants received a copy of the slides, ELNEC handouts containing helpful phrases to use with dying patients, and a copy of the organization’s advance directive form that is given to patients upon request. The class was facilitated by certified ELNEC trainers who conducted ELNEC-provided scripted scenario role-play at the beginning of the class, and again at the end of the class with volunteer participants. The scenarios provided the participants time and risk-free space to practice methods they had observed in the educational intervention material.

Following the education intervention, participants had the opportunity to either fill out the DAS-R and the CA-Dying questionnaires or leave them blank and then place them in a second confidential, non-marked envelope. The sealed envelopes were placed in a cardboard box and taken by the investigator to the investigator’s workspace in the secured Administration office. Immediately following the class, the participants’ de-
identified survey responses were entered into a confidential database and assigned a
coded participant number. After data entry the original questionnaires were locked in a
cabinet in the investigator’s administration workspace. The investigator was the only
person with a key to the locked file.

**Human Subjects Considerations**

Exempt Human Research Review Committee approval was obtained from Grand
Valley State University (GVSU). The healthcare institution’s Institutional Review Board
(IRB) approved the project with expedited review status. Neither GVSU nor the
healthcare institution’s IRB required a signed informed consent. Rather, the participants
received the project information sheet both in an email format and again in hardcopy
format at the class.

All RN questionnaires were void of specific identifying data, such as age and
assigned workplace unit. The questionnaires were pre-coded to protect confidentiality of
the participants. The completed questionnaires were secured in a locked file located in
the investigator’s office. The investigator’s office was located in the secured
Administration office, which was not readily accessible to employees of the institution.
The questionnaire responses were entered into a codebook which was saved to a secure
hospital drive. The codebook was then encrypted and uploaded from the institution site
to the secured access, password protected Grand Valley State University L drive. The L
drive secured access allowed for data analysis without the use of portable devices (e.g.,
USB drive) which are vulnerable to loss or theft.
Summary

The project design employed a convenience sample in one Midwestern, urban, acute care, referral hospital. The knowledge generated did not extend beyond the scope or purpose of the quality improvement initiative for this institution. However, because ELNEC is a nationally recognized versus individual site program, this project could serve as a useful model for further ELNEC knowledge translation. Replication of the model could contribute to ELNEC’s knowledge base regarding program efficacy.
CHAPTER 5

RESULTS

This chapter will describe results of this quality improvement project effort aimed at the implementation of an international communication module in an acute care setting. Specifically, this chapter will support the impact of ELNEC Module 6 on nurse death anxiety and communication apprehension as measured by the DAS-R and CA-Dying scales. The results will include a description of the utilization of an overarching knowledge translation model and a more focused quality improvement conceptual model. For this project, the PARiHS framework guided the implementation of knowledge translation, while the Donabedian Quality Model served to guide the evaluation of the ELNEC Module 6 intervention.

PARiHS Framework

PARiHS is a multidimensional model that was developed to represent functional relationships between evidence, context and facilitation (Kitson et al., 2008; Rycroft-Malone, 2004). The most successful implementation of evidence occurs when the three elements of PARiHS (evidence, facilitation, context) exist together at a high level (Hutchinson, 2012). The specific sub-elements of evidence, context, and facilitation enable successful evidence implementation and are the subject of the following organizational assessment.

Context

Context includes the environment or setting in which people receive healthcare services, or the setting in which the proposed change is to be implemented (Rycroft-
Malone, 2004). Key ingredients for change in the context include the presence of transformational leaders; continuous learning organizational culture; appropriate, evaluative monitoring; and feedback mechanisms (Kitson et al., 2008). Evaluation of the context in this project is consistent with the goals of implementation science, that is, improved quality and effectiveness of health services with influences on healthcare professional and organizational behavior (Eccles & Mittman, 2008).

**Organizational Assessment**

At the meso level, the organizational goal is to be transformational in the areas of services and operations, exceeding national performance benchmarks. The overall organization is committed to providing high quality care within an affordable cost structure. Accordingly, the foundational priorities of the nursing division at the meso level include a commitment to the Magnet® framework, shared leadership, evidence-based nursing, and caring models (e.g., Relationship-Based Care, the Jean Watson/Joanne Duffy model and the Kristin Swanson model) (Trinity Health, 2012a).

**Transformational Leadership**

Porter-O’Grady and Malloch (2007) describe transformational leaders as individuals who “create a new and improved system that allows individuals to contribute to their fullest potential to deliver the most effective healthcare possible” (p. 313). Transformation to evidence-based EOL care cannot occur without transformational leadership (Melnyk, Fineout-Overholt, Gallagher-Ford and Kaplan, 2012). In particular, Kerfoot’s (2012) work in transformational leadership within the palliative care environment is congruent with the CNO’s vision for palliative care within the organization of interest.
The CNO’s focus on providing evidence-based EOL education to nurses provides best care to patients and families by creating an environment conducive to a respectful, peaceful death versus dying alone or with unbearable symptoms. Next, the transformational leader must also reflect commitment to best care for the staff caring for patients at EOL. Ensuring that nurses have support and advocacy for their work optimizes the patient’s EOL experience (Kerfoot, 2012). The CNO has been a steadfast advocate for improving EOL care, committing resources and encouraging interdisciplinary collaboration for targeted change. Likewise, embedding palliative care nurse champions on every unit provides a mechanism of support for nurses as they care for patients.

**Continuous Learning Organizational Culture**

The development of staff is a key strategy at this organization. The organization offers several options for RNs to obtain the BSN degree, thus achieving the Institute of Medicine’s (IOM) recommendation to increase the proportion of nurses with a Bachelor of Science of Nursing (BSN) degree to 80% by 2020 (IOM, 2011). The CNO in this project demonstrated transformational leadership qualities by providing full funding for five nurses to receive ELNEC training at an out-of-state national conference. This organization is one of the first at the meso level of the organization to provide on-site ELNEC-Core education for all staff, helping fulfill a meso level 2013 goal of improved palliative care. The role of “nurses as teachers” is the focus of Force #11 of Magnet® (ANCC, 2008). The ELNEC curriculum is designed as a “train-the-trainer” program (ELNEC, 2012b).
Implementation Climate

The implementation climate should not be confused with the organizational climate, culture or context as it does not describe the general state of affairs in an organization (Weiner, Belden, Bergmire, & Johnston, 2011). For this scholarly project, the implementation climate to promote ELNEC education included strong leadership support in all areas of the institution. Evidence of this was found in the payment of staff nurses to attend the ELNEC 6 class and funding five nurses to attend the national ELNEC-Core Training.

The innovation climate relies heavily on positive leadership perceptions and attitudes towards the utility of the intervention (Weiner et al., 2011). In this case, the attitudes and perceptions of frontline leadership and staff regarding the intervention and its timing were not directly measured. While there may have been a perception throughout the frontline management that the class was important, the attitude of the frontline leadership may not have been strong. The class was offered twice. The first class had only 6 participants, none of whom were aware they would receive pay for the class. In the second class of 14 participants at least 30% were not aware they were being paid. The positive aspect of this knowledge gap was that the nurses obviously wanted to attend the class. The downside was that despite various modes of communication the nurses were not receiving the message about pay. While pay is not the driving force for all nurses to pursue further EOL education, the low class registration numbers suggests staff may not have understood the innovation intent or the frontline leadership was not actively engaged in the innovation intent.
Finally, a barrier to implementation of the classes was a delay in the announcement of the project and actual class dates. The advance notice for the class shortened to just 10-14 days. The delay was problematic as nurses’ schedules were already published, and staff had three separate mandatory education initiatives occurring within the same timeframe.

**Evaluative monitoring mechanisms**

Evaluation of the sub elements of the PARiHS framework post-implementation assists frontline leadership to understand strengths and weaknesses of their organizational structure (Kitson et al., 2008). For this scholarly project the more granular examination of nurse attitudinal changes following the education intervention are represented through the Donabedian Quality model. From an implementation science perspective, the PARiHS framework has future potential to act as an organizational methodology for long-term evaluation of changes in this organization and within the national enterprise.

Within the institutional context, the transformational leadership style of the CNO provided support for ELNEC education through financial and professional support of the staff and trainers. Multiple communication mechanisms were utilized to promote the project. Additionally, multidisciplinary leadership engagement was obtained to promote the ELNEC curriculum. Finally, the core staff of ELNEC trainers will contribute to the sustainability of the ELNEC curriculum throughout the organization, and may support potential for innovation spread to partner hospitals.

**Facilitation**

Within the PARiHS framework, the facilitation of evidence into practice is viewed as an intervention (Kitson, 2008). In this project, the clinical experience,
teaching expertise and leadership of facilitators took on additional importance. As a recognized expert in EOL care, The DNP student served as the expert advisor to the ELNEC trainers. The program evaluation provided two evaluative statements directed at facilitator effectiveness. The statements were, “demonstrated expertise in subject matter, content met objectives, used effective teaching strategies”, rated as strongly agree, agree, disagree, or strongly disagree [emphasis added] (Joseph Mercy Health System, 2012). For all objectives, 100% of participants strongly agreed or agreed that the course objectives had been met.

**Evidence and Intervention**

In this project, the evidence-based ELNEC Module 6 intervention was combined with nurse clinical experience and the acknowledged need for patient self-determination. In clinical practice, experience is “verified through critical reflection, critique, and debate with a wider community of practice to be considered at the high end of the continuum” (Rycroft-Malone & Bucknall, 2011, p. 202). The ELNEC Module 6 was delivered consistent with the curriculum provided by the AACN (ELNEC, 2012a).

**Donabedian Quality Model**

Donabedian’s (2005) Quality Model of structure, process and outcome served as the conceptual framework for this project at the micro level of the actual ELNEC Module 6 intervention. Donabedian’s ultimate focus rests on the patient-clinician interaction and evaluation of the care process. The use of the ELNEC Module 6 as the process served to determine if an educational intervention could indeed result in changed nurse attitudes about communication, leading to improved EOL care at the bedside.
Structure

The structural factor of the Donabedian Quality Model includes elements of care that are associated with receipt of services (Aday, Begley, Lairson, & Balkrishnan, 2004). In an institutional environment, factors could include healthcare system/institutional resources as well as clinical and patient factors. For this project, structural factors included the absence of a mandatory hospital policy for EOL educational offerings, historical lack of a formalized ELNEC program, presence of an established palliative care service, and willingness of leadership to offer ELNEC education to staff as a paid benefit with CAS points and contact hours.

Process

The ELNEC classes served as the process component for effectiveness evaluation in the Donabedian model. The ELNEC curriculum (ELNEC, 2012a) was presented via a standardized format, including slide decks, handouts, scripted role-play, and lecture notes. Additionally, a video clip from the movie, “Little Miss Sunshine” (Big Beach Films, 2006) was shown, depicting how not to break bad news to a family. Particular goals for the sessions were consistent with the ELNEC Curriculum. The first goal was to “understand the importance of good communication in life limiting diseases and EOL care.” The second goal was to “discuss the complexities of communicating with patients and families at this critical time” (ELNEC, 2012a).

Following the two class sessions the organization’s usual evaluation form was distributed (Joseph Mercy Health System, 2012). A total of 31 participants returned the program evaluations, 20 RNs and 11 undergraduate BSN students. The 11 BSN students were an unanticipated addition to the second course. While the students were not
recruited for the project, their instructor was an employee of the institution and felt the
class was important to their clinical education. The instructor asked the students to fill
out the course evaluation. Because program evaluations were anonymous, there were no means to delineate which evaluations belonged to the student nurses versus the
RN participants. The BSN students were not engaged as participants in the project and
did not receive the pre-posttest surveys. However, their class evaluations were included
in the process evaluation.

Participants then rated their level of attainment on four educational objectives on
the evaluation form. When asked about the importance of preserving ongoing
communication with the interdisciplinary team, patient and family throughout the EOL
process, most participants (87%, \( n = 27 \)) strongly agreed or agreed (13%, \( n = 4 \)) that they
were successful. Likewise, when asked about their ability to identify three factors that
influence communication in palliative care, 71%, \( n = 22 \) strongly agree or agreed (13%,
\( n = 9 \)).

Next, when asked to describe their perceived ability to describe important factors
in communicating bad news, only 29 participants rated the statement. Of those who
answered, seventy-nine percent \( (n = 23) \) strongly agreed, while twenty-one percent \( (n = 6) \)
gave a neutral response.

Finally, the participants were asked to state whether the curriculum content
enabled them to better identify characteristics that patient/families expect of healthcare
professionals. Most (68%, \( n = 19 \)) strongly agreed, while 32% \( (n = 9) \) agreed to the
objective statement. Of interest, one participant did not mark any of the boxes and
instead wrote in “silence” and “open-ness.” No space was allocated on the questionnaire
for narrative comments. However, one participant commented, “Just want to state that this affects oncology nurses and we don’t have all the information and we struggle too” (Anonymous, October 17, 2012).

The total time of completion for the demographic survey, DAS-R, and CA-Dying scales was approximately 15 minutes. During the posttest phase the participants also completed the program evaluation, increasing the posttest time to approximately 18 minutes.

Outcome

The interaction between the patient and practitioner is at the center of the Donabedian framework. The patient-clinician interaction is assessed as a process of care, rather than simply outcomes alone (Donabedian, 2005). Donabedian recognized that the processes and decisions most critical to quality care take place at the patient care level.

In this scholarly project, doing the right thing for the patient translates into nurses becoming skilled in the art of meaningful conversation, eliciting and discerning a patient’s wishes to influence the direction of care. As a result, the outcomes of the intervention focused on potentially decreasing nurse death anxiety and communication apprehension. Both outcome measures (DAS-R and CA-Dying scores) were focused on the potential influence of the demographic variables via the ELNEC Module 6.

Data Analysis

Descriptive statistics (means and percentages) were computed to report the demographic variables of participants. Significance tests (paired t-tests, analysis of covariance [ANCOVA], multiple regression) were computed to examine the relationship between the-DAS-R and CA-Dying scores with the demographic variables (nurse
education level, years of experience, number of dying patients cared for in the past year, personal experience with death, and formalized EOL education). All analyses were conducted using both SAS version 9.3 (SAS, 2012) and SPSS version 18 (IBM Solutions, 2012) to assure the integrity of results, using a $p < .05$ as the level of statistical significance.

**Sample Size**

A total of 20 RNs were recruited and completed the ELNEC Module 6 course. All 20 of the RNs participated in both phases of the program evaluation. Three RNs had missing information regarding number of dying patients cared for on the demographic survey. Additionally, two participants returned incomplete DAS-R or CA-Dying scale surveys. Therefore, only 18 RN participant surveys were used in the final analysis for DAS-R and CA-Dying for all variables except the variable of dying patients cared for ($n = 15$).

**Demographics**

Overall, 60% ($n = 12$) of RNs held a BSN degree. Ten percent ($n = 2$) of participants held a master of science in nursing (MSN) degree. Twenty-five percent of participants ($n = 5$) held either a diploma or associate of nursing (ADN) degree. Five percent of participants ($n = 1$) held a bachelor degree in a non-nursing major. Based on 18 valid demographic surveys, experience in clinical practice ranged from 1 to 36 years (mean = 17.9 years). None of the participants reported previous work experience on a designated palliative care unit or service. Ninety-five percent ($n = 19$) of the RNs reported previous personal experience with the death of someone close to them. Forty-three percent ($n = 6$ of 14) of nurses reported some type of previous EOL education,
primarily delivered via a workplace inservice. Only one respondent had attended a
formal two day EOL class (non-ELNEC curriculum) in another state. Based on 15 valid
demographic surveys for the number of dying patients cared for in the past year, results
ranged from 0 to 30, with an average of 3.71 (SD = 5.23) patients.

**Death Anxiety Scale-Revised (DAS-R) Survey**

The first question in this quality improvement project was: “does use of the
ELNEC Module 6 curriculum with acute care RNs affect RN DAS-R scores?” The
mean score for the DAS-R prior to class was 83.26 (SD = 14.37), compared to 82.26 (SD
= 14.30) at post-class measurement. There was no statistical evidence that death anxiety
decreased after the ELNEC education. A two-tailed paired *t* test was not statistically
significant for difference between the pre and posttest DAS-R scores (*t* = -.413, df = 17, *p*
= .684).

Next, to determine the influence of select variables, participants were grouped by
demographic variables of interest into two subgroups; education level and previous EOL
education. The highest degree of education was collapsed into two groups, using the BSN
degree as the point of reference. Thus, the two groups were those nurses with an ADN or
diploma degree (*n* = 5), and those with a BSN or MSN degree (*n* = 13).

Using this approach, a 2 sample *t*-test was statistically significant for difference
between the pre and posttest DAS-R scores of the two groups of nurses based on highest
level of education. The mean score for the DAS-R posttest in the ADN/Diploma group
was 70.4 (SD = 13.74), compared to 86.5 (SD = 12.31) in the BSN/MSN group. That is,
those nurses with an ADN or Diploma had a significantly lower post-test DAS score than
those who held a BSN or MSN (*t* = -2.44, *p* = .026, *df* = 17). With 95% confidence,
nurses with less than 4 years of education will have, on average, a posttest DAS-R score of at least 4.6 points less than those with 4 or more years of education.

Next, multiple regression models were used to estimate the effects of years of experience as a RN or by the number of dying patients cared for in the previous year. In both models, the pretest score was used as a covariate. There was no evidence of a relationship between the number of dying patients cared for in the past year and the post DAS-R score. Likewise, no relationship was found for previous RN EOL education and the post DAS-R score.

Finally, question four regarding personal experience of the death of someone close to the participant was not analyzed due to insufficient data, as 15 of the 16 participants had previous experience with a personal loss. For accuracy, statistical models require more than one participant in a group in order to estimate the standard deviation (Polit & Beck, 2010).
Table 1

*Revised Death Anxiety Scale (DAS-R) with Pre-Score as a Covariate*

<table>
<thead>
<tr>
<th>Groups</th>
<th>TEST</th>
<th>df</th>
<th>F</th>
<th>n</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest level of education</td>
<td>ANCOVA Type III SS</td>
<td>1</td>
<td>0.32</td>
<td>18</td>
<td>.5792</td>
</tr>
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<td>Years as RN</td>
<td>Multiple regression-Type III SS</td>
<td>1</td>
<td>0.07</td>
<td>18</td>
<td>.7918</td>
</tr>
<tr>
<td>Experience on Palliative Care Unit</td>
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<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>Number dying patients care for in past year</td>
<td>Multiple regression-Type III SS</td>
<td>1</td>
<td>0.17</td>
<td>15</td>
<td>.6883</td>
</tr>
<tr>
<td>Number dying patients care for in past year</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>3 missing information</td>
<td></td>
</tr>
<tr>
<td>Personal experience death of someone close</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>15</td>
<td>NA</td>
</tr>
<tr>
<td>Previous EOL education</td>
<td>ANCOVA- Type III SS</td>
<td>1</td>
<td>1.98</td>
<td>18</td>
<td>.1796</td>
</tr>
</tbody>
</table>

*Note.* In the model accounting for the pre-score covariate, Type III SS (sums of squares) represents the p value for the inclusion of the defined variable. *p < .05.

**Communication Apprehension with the Dying Scale (CA-Dying) Survey**

The second question posed in this scholarly project was: “what is the impact of the ELNEC Module 6 curriculum on RN communication apprehension scores?” The mean pre-score for the CA-Dying survey prior to class was 107.68 (SD = 13.97), and the post-score was 110.79 (SD = 11.84). A two-tailed paired t test was not statistically significant between the pre and posttest CA-Dying scores (t = 1.006, df = 17, p = .328). Results of the CA-Dying posttest scores are shown in Table 2.

The highest degree of nursing education was again collapsed into two groups for comparison, similar to the DAS-R analysis. The BSN was used as the point of reference.
Thus, the two groups were those nurses with an ADN or Diploma degree \( (n = 5) \), and those with a BSN or master degree \( (n = 13) \).

TABLE 2

*Communication Apprehension with the Dying (CA-Dying) with Pre-Score as a Covariate*

<table>
<thead>
<tr>
<th>Groups</th>
<th>TEST</th>
<th>df</th>
<th>F</th>
<th>n</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Highest level of education</td>
<td>ANCOVA- Type III SS</td>
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<td>0.42</td>
<td>18</td>
<td>.5272</td>
</tr>
<tr>
<td>Years as RN</td>
<td>Multiple regression- Type III SS</td>
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<td>.8855</td>
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<tr>
<td>Experience on Palliative Care Unit</td>
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<tr>
<td>Number dying patients care for in past year</td>
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<td>15</td>
<td>.0392*</td>
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<td>Personal experience death of someone close</td>
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<td>NA</td>
<td>NA</td>
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<tr>
<td>Previous EOL education</td>
<td>ANCOVA- Type III SS</td>
<td>1</td>
<td>0.48</td>
<td>18</td>
<td>.4992</td>
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</table>

*Note.* In the model accounting for the pre-score covariate, Type III SS (sums of squares) represents the \( p \) value for the inclusion of the defined variable. 

\*\( p < .05 \).

Of the four models tested, using the CA-Dying pre-test score as a covariate, only the number of dying patients cared for in the past year was statistically significant \( (df = 1, F = 5.35, n = 15, p = .039) \). This result suggests that RNs caring for larger numbers of dying patients per year have a lower communication apprehension post-score. Therefore, for two participants with the same pre-score, a RN with a greater number of dying patients will, on average, have a lower post-score.

In summary, nurses with ADN/Diploma degrees who participated in this ELNEC Module 6 class had statistically significant lower posttest death anxiety (DAS-R) scores than RNs with a BSN/MSN degree. Nurses who cared for more dying patients per year,
controlling for the pre-score, had a statistically significant lower communication apprehension (CA-Dying) score.

**Questions/Comments from Participants**

In addition to didactic content provided by ELNEC, additional time was provided for participant questions and concerns due to the complexity and sensitive nature of EOL care. Three additional themes surfaced, warranting further discussion between participants and the DNP facilitator. The themes identified were moral distress, concerns about death anxiety, participant advance directives, and ACP documentation issues.

**Summary**

The intervention was conducted as planned, using 20 RN participants. The results revealed that the ELNEC Module 6 class may cause an increase in nurse death anxiety scores, with nurses holding a BSN or advanced degree experiencing a higher post-test score. When controlling for the CA-Dying pre-score, nurses who cared for more dying patients per year may experience significantly less communication apprehension than nurses who cared for fewer dying patients per year.

The 11 BSN students were an unplanned but welcome addition to the class. Gaps in undergraduate and institution-based continuing EOL care have been noted in the literature (Beresford et al., 2002; Black & Emmet, 2006; Dugan, 2009; Finnerty & Gregory, 2010; Jezewski et al., 2007; Whitehead et al., 2010). Undergraduate participation in the ELNEC 6 class provided beginning communication skill-building for the students, and was in alignment with the AACN’s (2004) recommended competencies for EOL care.
CHAPTER 6
DISCUSSION

This chapter will discuss the results of this scholarly project. Attention will be
given to nurse attitudes regarding death and communication at EOL as well as evidence-
based knowledge translation in the acute care practice setting. The purpose of this
project was to effectively implement the ELNEC standardized curriculum into a hospital
environment and evaluate potential nurse-perceived barriers to meaningful EOL
discussions with patients and families. The project was intentionally developed in phases
including a readiness evaluation of the organization, timed implementation of the ELNEC
curriculum, and pre-post measures of RN attitudes towards death anxiety and
communication apprehension. The outcomes of this project implementation have
culminated in an awareness of RN perceptions of barriers to meaningful EOL
conversation and organizational structures supportive of RNs providing EOL care.

PARiHS Framework and Outcomes

The PARiHS framework served as the overarching evaluative mechanism for
knowledge translation of the ELNEC curriculum. Palliative care is complex in nature,
and acknowledges the need for incorporation of psychosocial, spiritual, and cultural
needs of the patient and family with physical care. In order to provide this level of
comprehensive care, staff must first identify personal psychosocial, spiritual, and cultural
barriers which may encroach on their caregiving capacities. At the same time, the ANA
competencies and curricular guidelines for EOL nursing care (ANA, 2004) reinforce the
need for skilled, compassionate and effective communication, applying attained
knowledge from palliative care research and EOL education. Interdisciplinary
collaboration is then a key component for the healthcare team members when implementing the professional nursing role, and requires support from the organization to foster best practices.

**Context**

**Transformational Leadership**

The CNO of the organization was supportive of palliative care in general and in particular, the implementation of the standardized ELNEC curriculum. The CNO’s transformational leadership style was reflected in her support of nursing staff to learn new ways of providing palliative care. Advancing the principles and practices of palliative care via nursing education programs is consistent with the recommendations of the Center to Advance Palliative Care (2011b) and is recognized as a performance improvement measure to attain palliative care certification from The Joint Commission (2012). Her transformational leadership style also aligns with the Triple Aim endorsed by the Institute of Medicine and strives for improving the experience of care, improving the health of specific populations, and reducing per capita costs of healthcare (Berwick, Nolan, & Whittington, 2008).

As an engaged leader, the CNO supported all acute care RNs who indicated interest in attending the ELNEC Module 6 class. This included payment for class attendance, contact hours, and CAS points. No limitation was placed on the number of participants in the class. Likewise, there were no qualifying requirements for attendance. Further, the support garnered from various interdisciplinary partners, including Pastoral Care, Social Work, Ethics Committee members, and the Medical Director of the
Palliative Care Team provided a strong and supportive environmental context for ELNEC curriculum delivery.

The development of an internal structure to provide sustainability for this project was a key strategy of the DNP student and was wholly supported by the CNO. By sending five nurses to the national ELNEC training conference, the CNO demonstrated commitment to the role of nurses as teachers. This action supported incorporation of the ELNEC curriculum and at the same time supported important criteria for Force #11 of Magnet®, nurses as teachers (ANCC, 2008). The organization’s intent to continue providing ELNEC Core Curriculum classes to staff utilizing the embedded ELNEC trainers will promote continuous learning of evidence-based EOL care.

**Implementation Climate**

The implementation climate of the acute care setting was multifactorial, adding complexity to the education of nurses in EOL care. The reach, or proportion of staff who ultimately attended the class, was small. Only twenty nurses attended the course, even though it was offered to all inpatient nurses. Not all nurses who attended the class were aware that conference attendance would be a paid benefit. It did raise the question as to whether class participation was receiving support from frontline management.

In this project there were potential barriers to participant engagement that may have impaired class registration. The compressed school schedule of the DNP student, unexpected IRB delays, short notice to staff for the classes, and competing mandatory education during the month of the class may have impacted class registration. Additionally, it is possible the nurses were not using class communication efforts available to them (e.g., email, unit-based postings, CNS/CNL direct communication).
is also possible there was an overall lack of interest by the staff in EOL communication education.

Evidence

ELNEC Module 6 (ELNEC, 2012a) of the standardized curriculum served as the evidence-based intervention for this scholarly project. While the ELNEC modules have not been empirically tested for actual change in patient outcomes, the curriculum is in wide use throughout the U.S. and the world (ELNEC, 2012b). The high rate of strong agreement (90%) with the purpose statement of the class as defined by ELNEC demonstrated that the participants had an understanding of the importance and complex nature of communication with patients and families during the dying process. The participant who shared the perception that “oncology nurses do not have all the answers” spoke to the need to be inclusive when teaching and implementing evidence-based practices.

Facilitation

Peer facilitators brought frontline credibility to the implementation process. They adapted the ELNEC content to include the organization’s Guiding Behaviors and organizational priorities. They understood the reality of their organization’s clinical practice environment and were able to provide real-life examples of communication issues.

The nurses chosen by the CNO for ELNEC facilitator training were selected with intention to make the greatest impact. None of the ELNEC trainers worked on the oncology unit. This decision was not an intentional slight of the oncology staff. Rather, the choice was an acknowledgement that palliative and hospice care is common in
oncology and now increasingly used by patients and families with a noncancerous
diagnosis (Caffrey et al., 2011). However, the small participant sample size did pose the
question as to whether the lack of inclusion of palliative care or oncology nurses as
trainers could have been a barrier to participation by other nurses. There was no
mechanism to test that question. What is known is that unit-based palliative care
champions who provide evidence-based content and support are required in all acute care
areas, not just oncology (Kerfoot, 2012).

While the majority of ELNEC trainers did not yet have formal education
expertise, unique to EOL care or otherwise, they did possess clinical expertise within
their chosen specialty. Additionally, the ELNEC trainers appeared to be growing in their
self-confidence, possessing enthusiasm for the ELNEC content. They were willing and
eager to consult with colleagues facing challenging communication scenarios with
patients and families.

The frontline leadership was underrepresented in the ELNEC classes; however,
their supportive role of the curriculum could not be discounted. The frontline leaders
have the ability to support the ELNEC content long-term, and their support speaks to
sustainability within the institution. The frontline manager instills the perception that
ELNEC is important to the organization by ensuring future ELNEC scheduling,
reinforcing participation as an expectation for excellence in clinical care, and providing
contact hours. By meshing these factors, ELNEC then becomes a sustainable expectation
versus a one-time scholarly project.

Finally, the ELNEC project received considerable support from the CNO. Her
active verbalization of the importance of excellence in palliative and EOL care served as
an important perceptual factor for staff and frontline leadership. This support was seen as a direct and powerful form of facilitation.

**Donabedian Quality Model and Outcomes**

The Donabedian Quality Model provided a more granular evaluation structure for the incorporation of the ELNEC Module 6 (ELNEC, 2012a) as an intervention. The structural factors presented are those which may have had a direct impact on the effectiveness of the intervention. In this case, the ELNEC curriculum delivery evaluation served as the process component. The outcome is reflected by the actual scores of the DAS-R and CA-Dying scales and whether there was any significant relationship to the structure components.

**Structure**

The literature synthesis completed relative to the evaluation of the ELNEC Module 6 curriculum revealed few models examining death anxiety and communication apprehension in acute care nurses. The most influential evaluations for this project from a structural perspective included the work by Deffner and Bell (2005) and Whitehead et al. (2010). While Deffner and Bell did not examine the ELNEC Module 6 curriculum specifically, their questions informed this project design. The authors did not conduct pre-post evaluation with their convenience sample mailing to RNs, but did inquire as to death anxiety and a Likert-form question as to whether the nurses felt comfortable talking with patients and families about death. Their second question on communication comfort informed the DNP’s search for a quantifiable tool to measure communication apprehension, leading to the discovery of Hayslip’s work with communication apprehension and dying patients (1986-87).
The original studies to validate the DAS-R and CA-Dying scales included items such as the participant’s age as a factor in scores (Hayslip, 1986-87; Thorson & Powell, 1988). The original structural evaluation plan in this project included demographics such as identification of a nurse’s age, the unit usually worked, and full-time work status. However, neither the university nor the organization’s IRB supported collection of these variables due to expectation of a small sample size. Having such specific information could unintentionally identify class participants. Therefore, the demographic information was limited to the nurses highest level of education, years in practice as an RN, previous experience with personal loss, prior formal EOL education, previous or current practice on a designated palliative care unit or service, and number of patients cared for in the past year (see Appendix A). The additional pertinent structural factors in the institution included the presence of a long-established and experienced Palliative Care service, elective offering of the new ELNEC curriculum and payment for the ELNEC Module 6 education.

Process

The ELNEC Module 6 Communication curriculum (ELNEC, 2012a) served as the intervention dose. The DNP garnered support from interdisciplinary colleagues for the scholarly project (e.g. Pastoral Care, Social Work, Palliative Care); however, the class audience consisted only of RNs and BSN students. Participants were given professional, confidential support information prior to the beginning of the class for unexpected emotional reactions to the course content. This ongoing support is offered at no charge to participants desiring the service.
Participants indicated that although they could speak to the importance of ongoing communication with their interdisciplinary team members, they perceived a need for further self-confidence in the communication skills taught in ELNEC Module 6. Specifically, the ELNEC module included the art of breaking bad news, factors that influence effective communication, and characteristics that patients and families find important in healthcare professionals. These findings suggest that further interdisciplinary communication education and role-play may be of benefit to nursing staff.

**Outcome**

In quality improvement initiatives random sampling is not necessarily the most beneficial or desired strategy. In this project, the subject matter expert (DNP student) utilized the dissertation committee to help guide sample selection and segments of the process improvement most important to understand. In consultation with her dissertation committee, the DNP student chose to exclude the emergency department (ED) from the eligible participants, as they are officially deemed an outpatient department. While they encounter patient deaths on a regular basis, the ED scenarios usually vary significantly from the inpatient setting.

Both Hayslip (1986-87) and Thorson and Powell (1988) found significant inverse differences in their scale scores according to age. Whitehead et al. (2010) did not find significant differences between nurse age, level of education, or years as a RN. While age has been found to be important in some studies reviewed in this project (Hayslip, 1986-87; Thorson & Powell, 1988), this project’s evaluation design did not allow for richness of information according to age of the nurse or area of practice.
Death Anxiety According to Educational Preparation

The percentage of BSN-prepared nurses attending the class closely aligned with the overall percentage of nurses in the organization (67%). While the original two-tailed t-test for significant difference in pre and posttest DAS-R scores was not significant, the subsequent finding that the DAS-R posttest was statistically significant in the group of nurses based on highest level of education is intriguing. Specifically, the nurses with a BSN or MSN had a higher post-test DAS-R. Neither Deffner and Bell (2005) nor Whitehead et al. (2010) found a statistical difference based on educational preparation.

Conventional wisdom posits that nurses’ experience is more important than their educational levels (Aiken et al., 2003). However, when the effect of education preparation on patient mortality was examined, the authors suggested that improved patient outcomes were associated with higher levels of BSNs in hospitals, independent of nurses’ mean years of experience. While nurses with ADN or Diploma degrees are prepared to provide direct patient care in various healthcare settings, the BSN degree prepares RNs with additional skills focused on leadership, knowledge translation, population health, and practice across all healthcare settings (IOM, 2011). The IOM concluded that the BSN is thus equipped to help manage patients with chronic illness in order to improve the quality and effectiveness of care (IOM, 2011).

The care of patients with life-limiting illness is complex, and the healthcare systems required to support them carry an additional layer of complexity. One of Kitson’s (2009) five propositions regarding successful translation of new knowledge into any complex healthcare system includes the involvement of key stakeholders at the individual, team and unit level. Further, experiential learning and reflection are central to
creating a culture of innovation, improvement and effectiveness. The ELNEC Module 6 provides didactic and role-play opportunities, promoting personal reflection about death. The nurses who voluntarily participated in the class were predominantly BSN or MSN prepared. They knew the topic of the class before enrolling. Process surveys suggested the participants need more communication education. It is possible that the immediate post-test of their DAS-R score serves as an indicator of reflective behavior based on exposure to new knowledge and their realized need for improved self-confidence in EOL communication.

**Communication Apprehension and Nurse Experience with Death**

With the CA-Dying pre-test score as a covariate, the second significant outcome noted was the number of dying patients cared for in the past year with the CA-Dying score. That is, nurses who cared for more dying patients per year had a significantly lower communication apprehension score. Again, the nurses participating in the class were volunteers, and knew the course topic in advance. Perhaps reflective behaviors and a desire for self-efficacy may also serve as motivation to seek additional knowledge in providing high quality EOL care to patients.

**Additional Observations**

Four themes emerged from the participants that warrant consideration and recommendations for further inquiry at the organization. The themes include nurse moral distress, nurse death anxiety versus acuity level of terminal patients, participant advance directives and advance care plan documentation.
Moral Distress

In the first session, midway through the presentation, a RN shared her frustration with situations in which the family and patient have had a plan in place of how to receive bad news and the plan is not followed by the physician. She expressed a sense of lack of control and not honoring the patient’s wishes. As a result the patient and family were upset, the RN was upset, and the patient/family required additional nursing time to process the bad news. At this point the trainers were not sure how to respond. The DNP student stepped in and defined the nurse’s expressed concerns as consistent with the definition of moral distress. Moral distress is defined by Jameton (1984) as painful feelings and/or psychological disequilibrium caused by a situation in which one believes one knows the ethical action to take, but cannot carry out the action due to institutional obstacles, supervisory support, medical power, institutional policy, or legal limits.

Increasing evidence of moral distress is evident in the literature, including deft handling of difficult conversations with physician colleagues. The DNP student provided examples of how to approach a physician in a private and collegial manner to explain what happened with a patient after the physician delivered the bad news and left the room. Perhaps the physician was not aware that the patient wanted family present to receive bad news, or that the patient did not feel the discussion went well. The DNP student presented information on lack of communication skill-building in medical school curricula (Boucher et al., 2010) and presented the scenario of talking with the physician as an opportunity to build interdisciplinary relationships and communication skills for both nurses and physicians.
Death Anxiety versus Patient Acuity Level

At the end of the second class a nurse asked, “Do you think we don’t go in a patient’s room as often after a do not resuscitate order (DNR) is written because of death anxiety or because once the DNR is written we change the patient’s acuity level (changed to a lower level of care)?”

The answer to this question consisted of more questions. Patients who are dying do not necessarily require “less care.” Rather, it is a different type of care. Questions posed back to the nurse included, “Knowing what you know now, what would you do differently? Would you make more use of your interdisciplinary colleagues (MSW, Pastoral Care)?”

Participant Advance Directives

Sample advance directive forms from the organization were distributed with the class handouts at the beginning of class. The participants were asked if they already had their own directive completed. Only three people acknowledged having an AD. At the end of the class, one participant stated, “We (the organization) should make it mandatory that all staff fill out an AD. We ask our patients to do it and we don’t even know what is in it.” Lively discussion ensued. While it was not agreed that nurses should be forced to complete an AD, the group agreed that perhaps the AD should go to the unit-based councils for review and discussion.

Advance Care Plan Documentation

Participants raised the question of how to best document a patient’s ACP in the electronic medical record. In a group discussion, the trainers and participants acknowledged there are a variety of areas where pertinent ACP information may be
recorded. Further, participants had various opinions as to where the most accurate place was to chart, acknowledging that not all disciplines chart in the same area. Thus, discussions that are documented are difficult to find and incorporate into the plan of care. Participants recommended this issue receive further attention in collaboration with the unit-based councils, nursing leadership, the Palliative Care team, and Information Technology Services.

Limitations and Challenges

First and foremost, this project was a quality improvement initiative in an acute care, academic, referral setting. It was designed to serve as an initial baseline measure of nursing comfort when speaking with patients and families about EOL issues. The results and limitations are pertinent only to this particular site. Further, the setting was limited to one Midwestern, urban, location. The location is characterized as a conservative area of the U.S. with strong Judeo-Christian principles. Other areas of the U.S. with greater diversity (culturally, religiously and socioeconomically) of both patients and nurses may obtain different results.

No attempt was made to randomize the participants in this early-stage improvement project. While randomization is the gold standard for research, this was a quality improvement initiative, and as such a convenience sample was utilized. Thus, the project design was descriptive using within-subjects, pre-posttest measures.

The sample size was small (N = 20) which may have hampered outcome measures. A greater number of participants may have resulted in different scores relative to the other variables. However, the ELNEC education intervention was provided to voluntary subjects who may have already held an interest in EOL care. The institution
has not offered ELNEC education in the past. The institution’s established palliative care service has contributed to an organizational culture sensitive to the needs of patients and their families at EOL, which could influence the type of hiring that occurs on the units (e.g., nurses already comfortable with EOL issues). Additionally, the surveys were completed immediately after the intervention, limiting time for reflection on the ELNEC content.

The ELNEC Module 6 course was offered twice, which may have exposed the second group to advanced knowledge of the survey questions. Thus the Hawthorne effect may have been a factor in the evaluation of the course regarding personal death anxiety and communication apprehension. The Hawthorne effect (or reactivity) can occur when subjects of research change their behavior due to the process of being studied versus reacting to the intervention (Vogt & Johnson, 2011).

There was no assessment of the nurses’ assigned unit. Thus it was not possible to compare the DAS-R and CA-Dying scores with areas that may see higher numbers of dying patients (e.g., intensive care, adult specialty care, and oncology). Further, the DAS-R and CA-Dying post-scores were obtained immediately after the class, which may have impacted outcomes. The participants were given the option of taking up to two weeks to complete the posttest, but the time to complete the posttest survey would only be reimbursed during the designated class time. In retrospect, either affording an additional paid fifteen to thirty minutes for reflection time for RNs regarding the ELNEC content, or not paying at all for the post-test time may have changed the DAS-R and CA-Dying scores. The risk in not paying for the post-test time could result in lack of survey returns.
The strength of this project included use of validated DAS-R and CA-Dying scales that could be self-administered, eliminating interviewer bias. The design of this project would have been enhanced if there had been an ability to track the changes in the DAS-R and CA-Dying scores over time. Reflection on content, discussion with mentors, and further opportunities to test new knowledge may have resulted in a decreased death anxiety score and improved communication apprehension score over time.

**Implications of Results for the Organization**

The purpose of this quality improvement initiative was to determine the impact of the specific ELNEC communication education module at a specific institution, with a focus on RN death anxiety and communication apprehension with dying patients and/or their families. A secondary goal was to help nurses uncover personal barriers to participation in EOL conversations, thereby promoting patient self-determination for quality of life choices. As the project evolved, it appeared that even when organizational systems are in place to support nurses in further education, nurses do not always avail themselves to educational opportunities. Personal concerns of the nurse may hamper knowledge translation of evidence-based practice. In fact, Lynn et al. (2000) postulated that improved, sustained system changes (e.g. pain management, educating patients and families on benefit/burden ratio of resuscitation efforts in some situations) is an essential component of lasting quality improvement, while reliance on better education may be insufficient to support patient decision-making.

The nurse evaluations of the ELNEC class reflected the need and concern for communication education, including skill-building in interdisciplinary communication. Furthermore, it was suggested that education needs exist across all areas of the acute care
environment, including those who traditionally care for more dying patients (e.g. oncology). The narrative comments of participants and the raised issue of moral distress and ACPs must be addressed, not only for the patient and family’s well-being, but also because it is a major source of burnout in nurses (Pendry, 2007).

In the setting of this scholarly project, the CNO provided a supportive environment for nurses to care for patients with life-limiting illness. Her vision is in agreement with national quality criteria posed by The Joint Commission (TJC) palliative care certification program (2012), which includes specialized nurse palliative care education as a marker of excellence. The ELNEC curriculum is ideally suited to meet this need.

Ultimately the provision of the entire ELNEC curriculum in this particular institution is planned. Interdisciplinary support exists for the ELNEC curriculum from the institution’s Palliative Care, Social Work and Pastoral Care departments, with the potential for interprofessional education opportunities in the future. Further evaluation should be focused on the efficacy of the ELNEC Communication module to decrease nurse death anxiety and communication apprehension. This may inform nurse professional development specialists in methods useful for other evidence-based programs and staff support initiatives. In addition, use of the ELNEC curriculum with pre-licensure and new graduate students may provide improved preparation for entry into practice as a registered nurse.

Finally, embedding support for ELNEC trained nurses to act as consultants to colleagues may improve the quality of EOL conversations. The availability of skilled
nurses on all shifts and weekends will allow for conversations to occur at a time convenient to the patient and family.

Sustainability

The CNO’s vision for improved EOL care, coupled with the organization’s goal of achieving Joint Commission certification in palliative care served as a strong impetus for introduction of the ELNEC curriculum. While the original financial expenditure for staff training was significant, the ELNEC program entails a “train-the-trainer” format (ELNEC, 2012b). Therefore, as more nurses attend the training there will be a greater number of embedded ELNEC trainers in all areas of the hospital, offsetting the original cost of ELNEC training. Furthermore, the ELNEC trainers may be of assistance at the meso organizational level as ELNEC is implemented at partner hospitals.

The Doctor of Nursing Practice Role

The benefits of doctoral education for advanced nursing practice (AACN, 2006) include the development of advanced competencies for complex practice issues, grounded in advanced scientific knowledge and leadership skills. The DNP must be adept at identifying and applying an appropriate implementation science framework to translate evidence-based practices into the workplace.

In the nursing leadership role, the understanding of systems thinking and quality improvement principles guided this scholarly project. Interdisciplinary communication and collaboration is vital to provide effective palliative care, thus the original groundwork with the CNO, nursing directors and managers, Pastoral Care, Social Services and the Palliative Care team was essential.
As an advanced practice nurse and mentor, the DNP student supported the ELNEC trainers to hone their educator role provided not only for sustainability of the program, but also self-efficacy of the trainers themselves. Barriers to effective documentation were uncovered during the course, and will require collaboration with specialists in information systems technology to develop a more streamlined method of ACP documentation. The scientific underpinnings of nursing practice were inherent in this project as nurses gained new ways of thinking to assess and treat a patient’s human response to illness. New practice patterns in communication between nurses and colleagues may improve the practice environment and patient outcomes.

Advocacy for effective palliative care was most important to the DNP student in this scholarly project. Having cared for patients with chronic, life-limiting illness for many years there was ample opportunity to promote patient self-determination and develop an ACP suited to the patient’s desires. Implications for further education include incorporation of EOL curriculum into undergraduate BSN and new graduate orientation programs. Further, regularly scheduled ELNEC courses at the organizational level will enhance the palliative care skills of practicing nurses. Finally, future research examining nurse death anxiety and communication apprehension in relationship to patient care outcomes over time may further inform protocols for EOL care.

**Summary**

In conclusion, providing effective palliative care across an organization is a complex endeavor. Effective systems must be in place to support nurses in providing high quality patient care, consistent with the Triple Aim: improving the experience of care, improving the health of specific populations, and reducing per capita costs of
healthcare (Berwick, Nolan, & Whittington, 2008). The U.S. is facing a looming increase in the chronically ill patient population, requiring adept nursing skills in interdisciplinary collaborative practice. Nurses at the frontline of care will require an increased skill set in communication, both with patients and their interdisciplinary team members.

A solid organizational foundation to provide the appropriate context and facilitation of best evidence will be required for transformational change in palliative care. Donabedian (2005) reminds the clinician that true quality means doing the right thing for the patient at the right time. Surely meaningful conversation and nurse advocacy to promote a patient’s EOL wishes will influence quality of care outcomes.
APPENDICES
APPENDIX A
Demographic Survey

ID number __ __ __

Instructions:
Check the appropriate box for each answer. Legibly enter any additional comments.

1. What is the highest level of education you have completed? If currently enrolled, mark the previous highest degree received.
   - 2-year college degree (ADN)
   - 3-year degree - Diploma
   - 4-year college degree – Nursing
   - 4 – year college degree - other ____________________________
   - Master’s degree – Nursing
   - Master’s degree – other ____________________________
   - Doctoral Degree – Type (PhD, DNP, EdD, other) ______________

2. Years of experience as Registered Nurse ______ (report in rounded years. If less than one year report in months).

3. Do you have any experience working on a designated palliative care unit?
   - Yes: Amount of time (report in rounded years. If less than one year report in months). ________
   - No

4. Number of dying patients you have personally cared for in the past year _______

5. Do you have personal experience with the death of someone close to you?
   - Yes
   - No

6. Have you had any type of formal End of Life Education?
   - Yes (please indicate where/when) ____________________________
   - No

Thank you for your participation!
# Death Anxiety Scale-Revised (DAS-R)  

ID number ___

Circle the number that best represents your opinion on items 1 through 25

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Uncertain</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
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<tr>
<td>I fear dying a painful death</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Not knowing what the next world is like troubles me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The idea of never thinking again after I die frightens me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not at all anxious about what happens to the body after burial</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Coffins make me anxious</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I hate to think about losing control over my affairs after I am gone</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Being totally immobile after death bothers me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I dread to think about having an operation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The subject of life after death troubles me greatly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not afraid of a long, slow dying</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I do not mind the idea of being shut into a coffin when I die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I hate the idea that I will be helpless after I die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not at all concerned over whether or not there is an afterlife</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Never feeling anything again after I die upsets me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The pain involved in dying frightens me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am looking forward to a new life after I die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not worried about ever being helpless</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am troubled by the thought that my body will decompose in the grave</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The feeling that I will be missing out on so much after I die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>distubs me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am worried about what happens to us after we die</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not at all concerned with being in control of things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The total isolation of death is frightening to me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I am not particularly afraid of getting cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I will leave careful instructions about how things should be done</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<tr>
<td>after I am gone.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What happens to my body after I die does not bother me</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>


Thank you for your participation!
### Communication Apprehension-Dying (CA-Dying) Scale

Circle the number that best represents your opinion on items 1 through 30 (see back of sheet)

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. I would feel awkward starting a conversation with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I would feel strained or unnatural in talking with a person who was dying.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I would look forward to visiting a dying patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I would feel uneasy if I found out that a patient of mine was dying</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. I would guard what I say to a terminal patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. I would feel comfortable in developing an intimate conversation with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. I would not hesitate to criticize a dying patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. My thoughts would become confused when discussing important issues with a dying patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. I would hesitate in revealing my true feelings in talking with a dying patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. I would hesitate to touch someone who was dying</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. I would avoid controversial topics in talking with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. I would prefer to talk over the telephone with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. I would prefer to talk face to face with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. I would have difficulty in talking with the family of a dying patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. I would have more difficulty in talking if the dying person was a child</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16. I would have more difficulty in talking if the dying person was elderly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17. I would have more difficulty in talking if the dying person was about my age</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18. My hands would tremble when I was talking to a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19. I would be hesitant in developing a &quot;deep&quot; conversation with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20. I would avoid talking about myself when speaking with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>21. I would have more difficulty in talking if the dying person was the same sex as I</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>22. I would have difficulty in maintaining eye contact with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>23. I would be a better listener than a talker in dealing with a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>24. I would avoid talking with a dying person if possible.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>25. I would avoid talking about death and dying with a person who was terminally ill</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>26. Dying persons are difficult to talk with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27. I would hesitate to discuss my own feelings about death and dying with a person who was terminally ill</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28. I would have little difficulty in expressing my true feelings to a dying person</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29. I would have more difficulty in talking with a person who was dying if I knew him/her personally</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30. I would have more difficulty in talking with a person who was dying if I did not know him/her personally</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Used with permission from Bert Hayslip, Jr., Ph.D.

Thank you for your participation!
APPENDIX D
Information for RN volunteers to participate in ELNEC

Communication education evaluation

You are being asked to participate because you provide acute inpatient nursing care to adults at Saint Mary’s Health Care. Nurses are the most consistent healthcare provider at the bedside, and play an important role in conversations by acting as a patient advocate for self-determination of care

Objective

The End of Life Nursing Education Consortium (ELNEC) education evaluation will explore the impact of a SHMC quality improvement initiative to improve end of life (EOL) care, specifically communication between nurses and patients with life-limiting illness. Questions include:
1. The impact the ELNEC Module 6: Communication on RN responses on Death Anxiety (DAS-R) scores
2. The impact the ELNEC Module 6: Communication on RN responses on Communication Apprehension (CAS-Dying) Scores

Materials

If you agree to voluntarily participate in the evaluation, you will be asked to complete the following surveys before and after the ELNEC Module 6 Communication class:
1. Demographic survey (take before class only)
2. Death Anxiety Scale-Revised (DAS-R)
3. Communication Apprehension Scale with the Dying (CAS-Dying)

Procedure

1. Watch your email and unit communication areas for the ELNEC Communication class flyer and sign up.
2. If you would like to participate in the evaluation, arrive early to the class to ask any questions, receive the evaluation instructions and your confidential survey packets. Evaluation participation is not mandatory to take the class.

Risks & Benefits

1. While we do not think there is any risk to you from participating in this project, the surveys will ask you about your feelings and emotions when caring for people with a terminal or life-limiting diagnosis.
2. An inconvenience associated with participation would be the time that it takes to fill out the surveys.
3. Continuing education credit

Questions?

Contact the Project Manager Carol Robinson MS, RN at email: robicaro@mail.gvsu.edu or cell phone: 616-745-6248. This project is being conducted for the partial fulfillment of the requirements for the degree of Doctor of Nursing Practice (DNP) at the Kirkhof College of Nursing, Grand Valley State University.

This EXEMPT research protocol has been approved by the Human Research Review Committee at Grand Valley State University (File No. 13-004-H).

If you have any questions about your rights as a research participant, you may contact:

200 Jefferson Ave. SE- Grand Rapids, MI 49503
Telephone: 616-685-6198
DATE: July 31, 2012

TO: Carol Robinson, MS, RN
FROM: Grand Valley State University Human Research Review Committee
STUDY TITLE: [346201-1] A Quality Improvement Initiative to Evaluate the Impact of ELNEC Communication Education on Registered Nurse Death Anxiety and Communication Apprehension Scores
REFERENCE #: 13-004-H
SUBMISSION TYPE: New Project

ACTION: APPROVED
EFFECTIVE DATE: July 31, 2012
REVIEW TYPE: Exempt Review

Thank you for your submission of materials for this research study. The Human Research Review Committee has reviewed your submission and approved your research plan application under Exempt Review. This approval is based on no greater than minimal risk to research participants. All research must be conducted in accordance with this approved submission.

This study compares nurses' death anxiety and comfort with communication after taking a class on communication at the end of life. A short demographic survey with no identifiers, and 2 scales (pre and post test). No identifiers and not sensitive.

1. The researcher requests expedited review as a quality assurance study. But no patient data is collected, only a pre/post test, so exempt category 1-2.
2. The sample is "25" or how ever many are recruited via posters. Nurses are paid for the class so long as they are "on duty." The hospital apparently plans to offer this class in the future - this is a preliminary evaluation of the class.

ADVISORY comments not affecting approvability:

1. Changing death anxiety in a 2 hour class might not be possible. In addition, such a small sample size may not show significant results, thereby undermining your efforts to give justification for the benefits of this class. If there are no differences pre and post test, will it hurt your chances of getting this important information out to the staff?
2. Why only full time RN's? If your sample was enlarged to include part time, float, etc. you could separate out the results by the FTE data. Unless you think there is reason to include only FT RNs.
3. Since this is exempt it does not require a consent document so long as the survey is described as research.

There are several problems with the consent document written the way it is.

- Eliminate the evaluation questions from the description of the study. Subjects likely don't know what ELNEC is.
• Eliminate citations to sources.
• Under risks: there are no foreseeable risks to the subjects. However, some questions might bring up uncomfortable emotions related to their experiences with death and dying. That is all you need to say.
• There are no direct benefits to the participants from the research, so state that.
• How will you give the nurses information about the results as you describe?

Please insert the following sentence into your information/consent documents as appropriate. All project materials produced for participants or the public must contain this information.

_This EXEMPT research protocol has been approved by the Human Research Review Committee at Grand Valley State University. File No. 13-004-H._

Exempt protocols do not require formal renewal. However, we do confirm on an annual basis that the research continues to meet the criteria for exemption and that there have been no significant changes in activity or key personnel. By July 31, 2013, please complete the brief Continuing Review Application Form, available in your IRBNet Project Designer, or from our website, [www.qpu.edu/hrcc](http://www.qpu.edu/hrcc), and submit this form via IRBNet.

Once study enrollment and data analysis have been concluded, please complete the Closed Protocol Reporting Form on our website, and upload a saved copy to IRBNet.

This project remains subject to the research ethics standards of HRCC policies and procedures pertaining to exempt studies.

Please note the following in order to comply with federal regulations and HRCC policy:

1. Any revision to previously approved materials must be approved by this office prior to initiation. Please use the Change in Protocol forms for this procedure. This includes, but is not limited to, changes in key personnel, study location, participant selection process, etc.
2. All UNEXPECTED PROBLEMS and SERIOUS ADVERSE EVENTS to participants or other parties affected by the research must be reported to this office within two days of the event occurrence. Please use the UP/SAE Report form.
3. All instances of non-compliance or complaints regarding this study must be reported to this office in a timely manner. There are no specific forms for this report type.

If you have any questions, please contact the HRCC Office, Monday through Thursday, at (616) 331-3197 or hrcc@qpu.edu. The office observes all university holidays, and does not process applications during exam week or between academic terms. Please include your study title and reference number in all correspondence with this office.

cc:
NOTICE OF EXPEDITED NEW IRB APPROVAL

SAINT MARY'S
HEALTH CARE

200 Jefferson Ave. SE – Grand Rapids, MI 49503
P: 616.685.6198

To: Carol Robinson, MS, RN
   5367 Abbey Mill Blvd., SE
   Ada, MI 49301-7743

Re: IRB# SM12-0824-02
   Early Program Evaluation of the Impact of ELNEC Communication Education on Registered Nurse Death Anxiety and Communication Apprehension Scores

Date: September 12, 2012

This is to inform you that Saint Mary's Health Care IRB has approved the above research study by expedited review. This includes approval for:

- Protocol, Version Date June 18, 2012
- Waiver of Informed Consent
- Information for RN volunteers to participate in ELNEC Communication education valuation (not dated). This will preface the survey and also be used for recruitment purposes.
- Demographic Survey (not dated)
- Communication Apprehension-Dying questionnaire (not dated)
- Death Anxiety Scale-Revised questionnaire (not dated)

The approval period is from September 12, 2012 to September 11, 2013. Your study number is SM12-0824-02. Please be sure to reference this number and/or your study title in any correspondence with the IRB.

Your responsibilities to the IRB do not end with this approval. You will be required to submit a continuing review report by the date indicated below or a notification of study closure form with a report of the study's findings upon completion of the study.

Continued approval is conditional upon your compliance with the following requirements:

- All protocol amendments and changes to approved research must be submitted to the IRB and not be implemented until approved by the IRB except where necessary to eliminate apparent immediate hazards to the study subjects.

- Significant changes to the study site and significant deviations from the research protocol and all unanticipated problems that may involve risks or affect the safety or welfare of subjects or others, or that may affect the integrity of the research must be promptly reported to the IRB.
NOTICE OF EXPEDITED NEW IRB APPROVAL

- All forms of advertising (including but not limited to: television, radio, internet, flyers, brochures, posters) must be submitted to the IRB and must not be implemented until approved by the IRB.

- Unanticipated problems/events and adverse events, whether related to the study article or not, must be reported to the IRB. Contact the IRB office for the appropriate form.

- Please complete and submit reports to the IRB as follows:
  
  Renewal of the study - complete and return the Continuing Review Report/Request for Renewal by August 1, 2013. The study cannot continue after September 11, 2013 until re-approved by the IRB.

  Closure of the study – complete and return the Notification of Study Closure form.

Please call me if you have any questions about the terms of this approval.

Brinda Hoffman
IRB Chairperson

Copy: File
APPENDIX G
DEATH ANXIETY HANDBOOK: Research, Instrumentation, and Application

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REF 309.1 Ne31 1993
155.9 37-—dc20

ISBN 0-8027-782-9
ISBN 0-8735-3510

93 38598 CIP
APPENDIX 2-1: Scoring the Revised Death Anxiety Scale (RDAS)

The RDAS is a scale with 25 statements, 17 phrased positively and eight negatively (see Table 2-2). Respondents are asked to agree or disagree with the statements on a five-point Likert format. Items are scored with the value 0 given for least anxiety and 4 for highest anxiety; responses to negatively- phrased items are reversed in the scoring process. Thus, the possible range of an individual respondent’s total score is from 0 (lowest) to 100 (highest possible score). Note that some earlier articles using these items had a true-false format; we now recommend using the Likert response format with the RDAS.

Simply score the following values for the responses indicated on the positively phrased items (Numbers 1, 2, 3, 5, 6, 7, 8, 9, 12, 14, 15, 16, 18, 19, 20, 22, and 24): strongly agree = 4; agree = 3; neutral = 2; disagree = 1; strongly disagree = 0. And score the following values for the items that are phrased negatively (Numbers 4, 10, 11, 13, 17, 19, 21, 23): strongly disagree = 4; disagree = 3; neutral = 2; agree = 1; strongly agree = 0.
REVISED DEATH ANXIETY SCALE

13, 17, 21, 23, and 25: strongly agree = 0; agree = 1; neutral = 2; disagree = 3; strongly disagree = 4. Count any items left blank as neutrals (score = 2). Then, just add up the assigned item scores to get a respondent's total score.

Other researchers may use the RDAS, provided they cite this text as the source.

Respondents were also asked to give their sex and their age.
APPENDIX H
Carol Robinson <robicaro@mail.gvsu.edu>

DNP study using communication apprehension
3 messages

Carol Robinson <robicaro@mail.gvsu.edu> Fri, Mar 9, 2012 at 1:20 PM
To: hayslipb@unt.edu

Hello Dr. Hayslip,

I am a doctor of nursing practice (DNP) student, completing my final year of education at Grand Valley State University in Grand Rapids, Michigan. My professional career includes a long history of caring for people with life-limiting chronic illness. My scholarly project is centered on improving nurse communication skill using the End of Life Nursing Education Curriculum (ELNEC). I plan on using two measures pre and post nurse education. One is the Revised Death Anxiety Scale by Thorson and Powell. I am also interested in knowing whether there is an outcome more related to what nurses do once they have the theoretical knowledge and are aware of their anxiety.

In searching for outcomes that may relate more to how we interact with patients I discovered your work with the Communication Apprehension Scale in the Journal of Death and Dying in 1986-87. I subsequently found two articles modifying the scale, one for physicians and one used with hospice nurses (though no instrumentation or statistical analysis was provided).

I am writing to inquire as to your knowledge of any further studies using your instrument, and the conditions for use in my project. Short of actually studying nurse behavior for several years as they continue to grow in knowledge and experience, your instrument may provide a view of whether the nurse feels he or she can actually change communication behavior with terminally ill patients.

Please let me know if you would be willing to provide a copy of your instrument, your cost and any other pertinent information.

Most sincerely,
Carol Robinson

--
Carol F. Robinson MS, RN, RRT
DNP student, Nursing Administration and Health Care Systems
GVSU, Kirkhof College of Nursing
robicaro@mail.gvsu.edu
cell: 616-745-6248

Hayslip, Bert <H.B.Hayslip@unt.edu> Fri, Mar 9, 2012 at 2:38 PM
To: Carol Robinson <robicaro@mail.gvsu.edu>

Ms. Robinson- I'm not aware of any recent research using the original scale, though we have modified it for physicians and have been using that for that purpose for some time. The paper's senior author is Levetown, and it appeared in Omega around 2001 or so - you do have my permission to use the original scale as well as the version for physicians. Good luck with your work!

Bert Hayslip

https://mail.google.com/mail/u/0/?ui=2&ik=7839e0505e&view=pt&q=hayslipb%40unt.ed... 12/3/2012
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