

Studying the Effects of the End-of-Life Nursing Education Consortium

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(ABSTRACT)

The purpose of this quasi-experimental study was to assess the ongoing impact of the End-of-Life Nursing Education Consortium (ELNEC) training program on registered nurses' death anxiety, concerns about dying, and knowledge of the dying process utilizing the principles of The Comfort Theory and Practice by Kolcaba (2003) at the institutional level. The research hypothesis was upon completion of the ELNEC training, registered nurses would have decreased death anxiety, less concerns about dying, and increased knowledge of the dying process. The Revised Death Anxiety Scale (RDAS) was used to measure death anxiety which is a 25 item self-report questionnaire. The Concerns about Dying Instrument (CAD) was used to measure death attitude or concerns about dying which includes three distinct but related areas for providers: general concern about death, spirituality, and concerns about working with dying patients. Participant's perceived knowledge of dying was measured using a self report 5-point Likert format with "0" indicating no level of knowledge to "4" reflecting complete knowledge of death and dying.

Pre-tests of all dependent variables were administered to both a treatment and control group. Post-tests were administered two weeks after the two day ELNEC training, at 6 months, and finally at 12 months to both groups in order to study its lasting efficiency upon participants at one primary care medical center. Thirty eight participants completed all four questionnaires with 27 participants in the control group and 11 participants in the experimental group. Matched pair analysis with 11 participants in each group was conducted with statistical significance found for perceived knowledge about dying at post two weeks and 12 months ($p= 0.01$) for the intervention group. Death anxiety and concerns about dying were not found to be statistically significant at any testing interval, but mean scores of the treatment group revealed less death anxiety and concerns about dying.

Recommendations included offering the ELNEC training on a routine basis to all registered nurses who care for dying patients. Additionally, clinicians and administrators were encouraged to seek out additional funding opportunities to plan more robust studies with larger samples, incentives, and research method triangulation addressing the qualitative aspects of palliative care.

Dedication

Dedicated to my loving husband, son, and mother, without your continual support and encouragement, this would not have been possible.

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Chapter I: Introduction

Dying is an inevitable life event, but in the United States there has been an unrealistic sense that death can be avoided or conquered (Hammel, Sullivan, Block, & Twycross, 2007; Wass, 2003). The focus of healthcare has been on life-sustaining technologies resulting in a delinquency of proper end of life (EOL) care. There is a sense that death is simply one more disease to overcome (Hammel et al.). The healthcare industry along with society is now confronting the need to improve EOL care (Ferrell, 1999). The Project on Death in America was established in 1994 to promote a better understanding of the experience of dying and bereavement in order to transform the culture surrounding death (Soros, 1999). According to the Project, dying is viewed as a failure here in the states. Sadly, the emphasis at EOL is on treating or defeating a disease instead of viewing this life event as a natural and normal process with the emphasis of providing care and support for the patient and family.

Improvements in health care have gradually changed the nature of dying here in the United States. Death is no longer predominately likely to be the sudden result of infection or injury but is now more likely to occur slowly, in old age, and at the end of a period of life limiting or chronic illness (National Institute of Health, 2004). As a result, a demographic shift is beginning to occur that will include an increase in the number of seriously ill and dying people at the same time that the relative number of caregivers decreases (National Institute of Health).

Statement of Problem

Unfortunately, dying in the United States continues to be associated with needless suffering with particular focus on “doing everything” with the maximal utilization of technology (Hammel et al., 2007; Paice, Ferrell, Coyle, Coyne, & Callaway, 2007; Paice et al., 2006). Over the last twenty years, research has illustrated that there are major insufficiencies in palliative care education.

Without appropriate EOL education, it is impossible for nurses to provide adequate EOL care. Additionally, it is vital to balance education with attention to personal understanding and attitudes towards death and dying in order to allow students opportunities to become knowledgeable about death and grief, to deal with their own feelings, and to develop empathy (Wass, 2004). Registered nurses play an integral role in caring for patients facing fatal illnesses (Ferrell, 1998; Kurz & Hayes, 2006; Matzo, Sherman, Penn, & Ferrell, 2003; Sherman, Matzo, Panke, Grant, & Rhome, 2003; Sherman, Matzo, Pitorak, Ferrell, Malloy, & 2005; Sherman, Matzo, Rogers, McLaughlin, & Virani, 2002; White, Coyne, & Patel, 2001).

Hence, a crucial strategy is the expansion of educational materials and curricula development in palliative care (Paice et al., 2006). To rectify these educational scarcities the American Association of Colleges of Nursing joined forces with the City of Hope National Medical Center to initiate a national educational program, entitled the “End of Life Nursing Education Consortium”

(ELNEC). Despite the dissemination of the ELNEC program, it has not been evaluated for its long term effectiveness at the institutional level. In 2006 Kurz and Hayes studied the influence of ELNEC using the General Systems Theory. They concluded that additional research was needed with consistent ongoing ELNEC sessions (Kurz & Hayes). Barrere, Durkin, and LaCoursiere (2008) construed that little research existed on the effects of the ELNEC curriculum on students' attitudes. Furthermore, standardized instruments that measure death attitudes ranging from anxiety to acceptance should be used to determine effective death education (Wass, 2004).

Purpose of Study

The purpose of this study was to assess the ongoing impact of the ELNEC training program on registered nurses' death anxiety, concerns about dying, and knowledge of the dying process utilizing the principles of The Comfort Theory and Practice by Kolcaba (2003) at the institutional level. The Revised Death Anxiety Scale (RDAS) was used to measure death anxiety. The Concerns about Dying Instrument (CAD) was used to measure death attitude or concerns about dying. Participant's perceived knowledge of dying was measured using a self report 5-point Likert format with "0" indicating no level of knowledge to "4" reflecting complete knowledge of death and dying.

Research Question and Hypothesis

What was the impact of ELNEC training program on registered nurses' death anxiety, concerns about dying, and perceived knowledge of the dying process? The research hypothesis was upon completion of the ELNEC training, registered nurses will have decreased death anxiety, less concern about dying, and increased perceived knowledge of the dying process.

Limitations

There were several limitations faced in this study. Subject selection may have been an issue but attempts were made to have equivalent groups but without random selection and assignment this was a potential threat. Attrition was a concern with conducting a longitudinal study over a 12 month period. In addition, contamination was possible since participants from the treatment and control groups worked together and could have shared information from the training materials. Finally, generalizations were limited to registered nurses not to licensed practical nurses or other disciplines.

Definitions

Certain terms needed to be clarified to ensure comprehensive understanding of this research.

1. End of Life Care: This pertained to the care of a dying patient.
2. Palliative Care: This was another term for end of life care and was used interchangeably throughout this dissertation for end of life care.

The World Health Organization defined "palliative care as an approach

that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

3. End of Life Nursing Education Consortium (ELNEC): This was the end of life nursing educational program designed to improve the care of the dying patient and his/her family.
4. Comfort Theory and Practice (CTP): This provided the theoretical framework for this study. This conceptual framework defines comfort as “the immediate state of being strengthened through having the human needs for relief, ease, and transcendence met in four contexts of experience (physical, psychospiritual, sociocultural, and environmental)” as defined by Kolcaba (2003).
5. Death Anxiety: This was the discomfort experienced when caring for patients and/or loved ones who were dying as measured by the Revised Death Anxiety Scale (RDAS).
6. Concerns about Dying: These were the trepidations associated with the care of the dying patient as measured by the Concerns about Dying (CAD) instrument.

7. Perceived Death Knowledge: This was the perceived understanding by the registered nurse on how to care for the dying patient and his/her family as measured by the Perceived Knowledge about Dying tool.

Chapter II: Review of Related Literature

Introduction

The focus of this chapter is the review of the current literature related to end of life care. In 2004, there were an estimated 1,627,900 deaths due to cardiovascular disease including coronary heart disease, myocardial infarction, and stroke which combined is the number one cause of death in the United States (American Heart Association, 2008). In 2007 almost ten million Americans had cancer with 559,650 of these individuals dying of the disease (American Cancer Society, 2008; Coyne et al., 2007). Other studies suggest that one in five Americans will die in an intensive care unit (ICU) in the last three days of life (Ferrell et al., 2007). Furthermore, nearly half of dying patients in hospitals endure moderate to severe pain, and nearly half spend their last 10 days in the ICU (Wass, 2004).

There are approximately 2.4 million deaths in the U.S. and more than 50 million deaths internationally each year (Paice et al., 2007; Von Gunten, 2005). About 10% of these deaths are sudden in nature, and the remaining 90% are from chronic disease (Von Gunten). EOL symptoms commonly reported include fatigue, anorexia, dyspnea, xerostomia, cough, pain, depression, constipation, nausea, insomnia, and vomiting (Centers for Disease Control and Prevention, 2007; Von Gunten). The data indicate that as many as 50% of dying persons with cancer or other chronic illnesses experience unrelieved symptoms during their

final days despite standardization of care and advancements in medical technology (National Institute of Health, 2004). Additionally, the number of patients experiencing these symptoms consistently grows due to the failure of modern medicine and the escalating aging population (Von Gunten).

During the 20th century, with advances in medical treatment, there has been a 30-year increase in life expectancy (United States Government Accountability Office, 2007). The average life expectancy in the United States has increased for women from 49 to 81 years and for men from 46 to 76 years (Center for Disease Control, 2008; Röcke & Cherry, 2002; Soros, 1999). As people are living longer, their expectations about quality of life at EOL are increasing. Unfortunately, death itself is ultimately not preventable, and most people will die as a result of chronic disease. Death and dying in the United States is associated with a substantial burden of suffering among dying individuals and also has health and financial consequences that extend to family members and society. Furthermore, recent studies demonstrate an increased likelihood of depressive symptoms and mortality among caregivers of terminally ill patients (National Institute of Health, 2004).

Nearly 40 million Americans will be 65 or older by 2010 and by 2030, 20% of the United States population will be over the age of 65 (Robinson, 2004). It is projected that by mid-century, 40% or more of all deaths in the United States will occur in long term care facilities (Kelly, Ersek, Virani, Malloy, & Ferrell, 2008). Ninety-three percent of Americans believe improving EOL care is key, and 60%

give a rating of fair or poor to the current care being provided (Robinson). Moreover, in 2007 the Center for Gerontology and Health Care Research at Brown University reported that dying in nursing homes was far from a “good death” (Kelly et al.).

The State of Dying

Over the last 100 years, noteworthy changes have occurred with regard to the societal view of death and dying. As late as the 1940's, the majority of people died at home cared for by their family and loved ones, but today patients die in facilities (Röcke & Cherry, 2002; Soros, 1999; Wass, 2004). The dying process has been lengthened due to the changes in causes of death from acute infections to complications related to chronic illnesses. Changes in medical technology have influenced the process of dealing with dying and death. With the improvement in medical care and life-sustaining techniques, health care has become extremely complicated resulting in ethical dilemmas at EOL and specifically delusions of providers, patients, and caregivers that the inevitable can be delayed, potentially indefinitely (Röcke & Cherry; Soros; Wass). These advances in medical and biological sciences, such as genetics, genomics, proteomics, and in new technologies, such as nanotechnology and regeneration technology, have raised expectations to extend human life and unrealistic hopes for physical immortality bolstered by a flourishing anti-aging industry (Wass).

Today less people have direct personal experience with death. Death is characterized by individualism, fragmentation, and disparity (Strange, 2000). For instance, funeral homes take care of many of the details for loved ones who have experienced a death fostering a separation between the deceased person and relatives potentially creating denial of the loss. In addition, the majority of those dying today are eighty or older, and more than half of those over 65 die in institutions such as hospitals even though most Americans, approximately 70%, prefer to die in their own homes (Malloy, Virani, Kelly, Jacobs, & Ferrell, 2008).

Hospitals are not the ideal places to die since they are designed to care for patients with acute illnesses rather than the normal process of dying. Unfortunately, these patients often die with unrelieved symptoms and without their goals or wishes addressed (Paice et al., 2007). The medical team continues to work to prolong life instead of preparing the patient for death resulting in a state of limbo between living and dying (Wass, 2004). Finally, as a society, it is no longer acceptable to have extended mourning or grief rituals resulting in a general sense of cultural denial of death and dying (Röcke & Cherry, 2002).

This lack of experience with dying has led to a fear of death. Röcke and Cherry (2002) discussed four categories of dying including the fear of death as the end of life, death as a fate, death as a release from pain, and death as a terrible event associated with fear. Patients also fear that providers will abandon them and their families will lose all their savings paying for life-sustaining

technology and treatments (Malloy et al., 2008). Physical pain is what patients fear the most about dying (Soros, 1999). Families fear a bad dying experience more than death itself and stress the importance of professionals acting in their dying loved ones' best interest (Andershed, 2006).

Family involvement is a crucial facet that must be considered when caring for the dying. Relatives often experience fatigue, anxiety, agony, fear, anorexia, depression, difficulty sleeping, feeling overwhelmed, loneliness, loss of control, difficulty understanding, feelings of helplessness, uncertainty, conflicts within the family, financial burdens, and loss of future goals (Andershed, 2006). Families may lack vital knowledge about the disease progression and symptom management resulting in inadequate patient care because of their fear of addiction or hastening death (Andershed).

Another approach to examining EOL care is the utilization of the Medicare Hospice Benefit. By the late 1990's, only 25% of Medicare beneficiaries and 5% of nursing home residents received hospice before death (Dy, Wolff, & Frick, 2007). During this same timeframe, the proportion of beneficiaries receiving intensive care unit services, chemotherapy or undergoing intensive procedures increased (Dy et al.). Between the years of 1989 and 1999, Medicare utilization over the last year of life did not substantially change despite a growth in hospice care (Dy et al.).

Additionally, in 1998 the Dartmouth Atlas of Health Care proclaimed that "geography is destiny..." The Atlas reported that dying in the hospital varied significantly by region of the United States and that the availability of services in a region (and not patient preferences) predicted whether persons died in an acute care setting (Brown Atlas, 2005). These results highlight the difficulties of changing the way EOL care is provided within the current health care system and the need for dramatic reform. Accurate and timely descriptions about dying in America are key in order to improve the dying experience.

According to Lynn and Adamson (2003), a more useful way to think about "near death" conditions is to focus on fragility rather than time to death. From this point of view, people living with serious illness at the end of life can be identified not from certainty of timing of death, but from "living on thin ice" - suffering long periods of illness or disability, diminished functioning, and potential exacerbation of symptoms, any of which could prove fatal. Patients could keep "living on thin ice" for some years, or die in a week allowing palliative care support throughout the latter stages of their illnesses (Lynn & Adamson). This philosophy of care promotes the normalization of the dying process as simply the final stage of life and reduces fear affiliated with death.

Palliative Care and Hospice

To meet this challenge, the best evidence that health care can offer must be applied to guarantee the quality of care provided to the dying individual and

their surviving loved ones (National Institute of Health, 2004). EOL care is an essential and expanding aspect of health care. The World Health Organization regards palliative care as affirming life and that dying and death should be regarded as normal processes (Matzo et al., 2002). The World Health Organization (1998) defines “palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

It is noteworthy to discuss the contributions of Dame Cicely Saunders who founded St. Christopher’s Hospice in Britain and is credited with the modern hospice movement. Amazingly, she was a nurse, social worker, and physician. Dame Saunders believed that EOL care should include a combination of good physical, psychological, social, and spiritual care. Additionally, she proclaimed appropriate palliative care involved caring for the living until they happened to die. The focus of care should always be the patient and family. Palliative care embodies a unique combination of love and logic, heart and mind, and affect and cognition. Furthermore, Cicely Saunders believed searching for meaning in the face of death must be emphasized and that it involves both a psychological and a spiritual experience (Parkes, 2007).

In 1997 the Institute of Medicine asserted via its report, *Approaching Death: Improving Care at End of Life*, that patients with potentially terminal

diseases are entitled to receive competent and skilled care (Paice et al., 2006). The report further asserts that when the EOL makes its inevitable appearance, patients should be able to expect reliable, humane, and effective caregiving. Yet too many dying people suffer unnecessarily. While an "overtreated" dying is feared, untreated pain or emotional abandonment are equally frightening (Institute of Medicine).

Approaching Death reflects a wide-ranging effort to understand what health care providers know about care at the end of life, what is yet to be learned, and what is known but is not adequately applied. The report emphasizes the importance of determining diagnosis and prognosis, communicating these to patient and family, establishing clinical and personal goals, and matching physical, psychological, spiritual, and practical care strategies to the patient's values and circumstances. Moreover, it emphasizes the importance of initiating changes in educational programs for providers to ensure that practitioners have relevant attitudes, knowledge and skills to care well for dying patients (Institute of Medicine, 1997).

Because of the current deficient dying experiences in hospital settings, radical reform must occur. This transformation comprises EOL quality measurement and improvement, implementation of evidence-based palliative care practice guidelines, open and honest discussions of futile treatments resulting in extraordinary costs, and ethical/legal issues such as assisted suicide. Furthermore, health professionals must become better prepared to provide care

for those who are dying and to understand that these are not patients for whom "nothing else can be done" (Institute of Medicine, 2007; Paice et al., 2007).

One approach to improve communication between patients, families and professionals is the promotion of The *Five Wishes*. *Five Wishes* is a document that guides patients in expressing how they want to be treated when they are seriously ill and unable to speak for themselves. It is unique among all other living wills and health agent forms because it looks to all of a person's needs: medical, personal, emotional and spiritual. *Five Wishes* encourages discussions of these wishes with families and physicians to promote better EOL decision making and ultimately improved patient care (*Five Wishes*, 2007).

The National Quality Forum (NQF), whose mission is to improve the American health care system, has acknowledged the importance of palliative care by making it a national priority area for health care quality improvement. The NQF identified preferred practices for palliative and hospice care including the need to provide continuing education to all healthcare professionals on the domains of EOL care as well as adequate training and clinical support to assure that health care providers are competent. Additionally, the NQF provided recommendations for research in order to create a system of quality improvement for EOL care (National Quality Forum, 2006).

In 2000 only 14% of U.S. hospitals had palliative care programs and only 23% had hospice programs (Robinson, 2004). Unfortunately, few health care

professionals receive formal EOL education resulting in inadequate training especially in regards to controlling pain and other symptoms (Malloy et al., 2006; Malloy et al., 2008; Paice et al., 2007). Research has shown that medical and nursing students felt hesitant and uncomfortable when caring for dying patients. After receiving palliative care education and the opportunity to reflect upon issues related to death and dying as well as their own personal losses, students report an increase level of comfort when caring for dying patients. Other studies have shown that after EOL education students express an appreciation for the privilege of being with patients at the time of death (Barrere et al., 2008).

Education

This lack of EOL education becomes apparent when one examines the deficiencies of EOL care in the United States as disclosed by the 1995 SUPPORT study which involved over 9000 patients in five major medical centers. This study revealed that aggressive medical interventions persisted until EOL, patients experienced moderate to severe pain, there existed a lack of communication between patients and physicians about EOL preferences resulting in the majority of physicians not knowing their patients' EOL wishes, and of those who knew, only 15% actually talked with their patients about these issues (Jennings, 2005; Sherman, Matzo, Panke, Grant, & Rhome, 2003; SUPPORT; Wass, 2004;). Moreover, additional research is needed to explain why efforts to improve physician-patient-relative communication did not change EOL care as it relates to ICU treatment, pain management, and do not

resuscitate orders (Röcke & Cherry, 2002). As proclaimed by the SUPPORT report, success will involve a re-evaluation of health care's commitment to reshaping EOL care and forceful attempts at changing the prevailing belief that death can somehow be avoided or conquered (SUPPORT').

Historically, EOL issues have not held a pivotal place in medical schools' or nursing curricula here in the United States (Dickinson, 2006; Hammel et al., 2007). In the mid-1990's, the expected amount of palliative care training was one lecture during four years of medical school (Dickinson, 2002, 2006). In general, medical students are inadequately prepared to address EOL issues resulting in poor and possibly horrible patient outcomes (Dickinson). There is considerable evidence that current training is inadequate especially in clinical years (Hammel et al.). One of the most therapeutic skills, physicians can acquire is simply talking to their dying patients and assuring them that they will not be abandoned (Dickinson). The most problematic issues in current medicine are discomfort with communication, inability to truthfully answer EOL questions, incapacity to shift from curative to palliative care, failure to accurately prognosticate, and incompetent pain and symptom management (Dickinson). Therefore, medical and nursing students report feeling unprepared to provide proper palliative care (Hammel et al.).

Additionally, there are several factors that contribute to these inadequacies. First, medicine focuses on cure of diseases and the prevention of death and in fact is dedicated to preserving life at all costs (Dickinson, 2002,

2006). Secondly, given the limited training in learning effective communication and interpersonal skills as well as the lack of integration of palliative care into medical schools, it is not surprising that physicians have difficulty with EOL care. One of the top sources of EOL education is trial and error and watching someone else. Unfortunately, the problem is “the someone else” that providers are watching also learned by trial and error (Von Gunten, 2005). Another interesting point is that although providers develop confidence in providing palliative care, unfortunately, their knowledge and competencies do not improve over time (Von Gunten). Because healthcare professionals have inadequate training, they do not apply existing evidence-based care at EOL (Von Gunten).

The care of the dying is an art and if done well will empower patients and families to navigate the technologically complicated medical environment that occurs at EOL (Dickinson, 2002, 2006). In 1997 Ira Byock recognized the omission of medicine in recognizing the significance of establishing EOL patient goals of care that shift the emphasis from cure to care (Dickinson). As in many cases, it is the nurse who must advocate for her dying patient and assist the medical staff in recognizing the importance of palliative care. Nursing represents the largest segment of the nation’s health care workforce and plays a significant role in EOL care (Ferrell & Winn, 2006). Because nurses spend the most time with patients and their loved ones, it is the nurse who has the greatest potential to change the way palliative care is provided especially when she partners with other disciplines including social work and medicine (Paice et al., 2007).

Over the last twenty years, research has illustrated that there are major insufficiencies in palliative care education including absence of EOL care in nursing curricula with only 3% of nursing programs reporting a palliative care course, lack of EOL care inclusion in leading nursing textbooks (only 2%) with only 1.4% of the chapters related to EOL care, and a shortage of knowledgeable nursing faculty (Ferrell, Virani, & Malloy, 2006; Kelly et al., 2008; Kurz & Hayes, 2006; Mallory, 2003; Malloy et al., 2006; Malloy, Ferrell, Virani, Wilson, & Uman, 2006; Malloy, Summer, Virani, & Ferrell, 2007; Paice et al., 2007; Robinson, 2004). Full course offerings of palliative care are only available in 15% of nursing schools resulting in less than a fifth of students being offered a full course on palliative care and only a fourth of the students actually taking the course (Wass, 2004). This lack of content dissatisfies both faculty and students resulting in ill-prepared nurses (Wass).

When queried about future plans, only half of the nursing schools surveyed planned to offer or expand death and dying education (Wass, 2004). Forty percent of the nursing programs felt the need to increase palliative care in their curricula (Robinson, 2004). Time constraints, lack of need, and limited faculty were cited as reasons why EOL education was not added to the curricula (Wass). The National Council Licensure Examination for Registered Nurses (NCLEX-RN) includes EOL care as one aspect of psychosocial integrity (National Council of State Boards of Nursing [NSCBN], 2006). Studies illustrate that only 0.41% of nurses are certified in palliative care with 89.5% nurses stating that

EOL content is important for basic nursing education and 62% rating their undergraduate preparation as inadequate (Robinson).

The American Association of Colleges of Nursing (AACN) has identified eleven competencies for appropriate EOL care for undergraduate nursing students which include: population dynamics and service delivery, communication skills, understanding one's own values, cultural diversity, respecting the wishes of patients, collaboration, symptom management, complementary therapies, psychosocial care, the grief process, and legal and ethical issues (Barrere et al., 2008; Robinson, 2004). Upon further review of 14 critical care nursing textbooks, none of them included material on all of the EOL content areas identified by the AACN. Most of the textbooks did not include palliative care pharmacology with three textbooks not including any EOL content (Barrere et al.). Despite an already crowded nursing curriculum, it is imperative to integrate these core competencies into nursing undergraduate and graduate programs (Ferrell et al., 1999).

In 1998 AACN created "Peaceful Death: Recommended Competencies and Curricular Guidelines for EOL Nursing Care" to outline specific aspects of professional nursing care considered requisite for each graduate in order to assist nursing schools in incorporating the above competencies into existing courses such as health assessment and/or pharmacology. Other organizations are also encouraging the inclusion of EOL education including the Institute of Medicine, the National Hospice and Palliative Care Organization, the American

Association of Critical Care Nurses, the National League for Nursing, and the National Council of State Boards of Nursing. In addition, the City of Hope National Medical Center has worked to increase the quality and quantity of EOL content in nursing textbooks (Robinson, 2004).

Last Acts, the nation's largest coalition working to improve EOL care, published a report in 2002 entitled, "Means to a Better End" which detailed the deficits in EOL care and education as well as advocating for improvements. Now archived *Last Acts* provided a series of web-based articles that addressed the deficits in palliative care. Topics included cardiopulmonary resuscitation, nutrition and hydration, EOL decision making, African-American EOL care, children dying, spirituality, pain and symptom management, and caregiver support (*Last Acts*).

In addition, between the years 2000-2003 clinical guidelines have been developed by the Froedtert Medical College in partnership with the End of Life Palliative Education Resource Center (EPERC). These clinical recommendations augment hospital policies in support of best palliative care practices, serve as educational vehicles for physician, nursing and other hospital staff, and provide benchmarks for quality improvement activities. The suggestions were all developed as consensus documents among various hospital committees and relevant departments. The clinical proposals include analgesic recommendations, do not resuscitate orders, managing conflict, feeding tubes, use of pentobarbital, and protocol for ventilator withdrawal (EPERC).

In 2007 the Oncology Nursing Society Board of Directors asserted via its position paper on palliative and EOL care that skilled palliative care should be integrated into a comprehensive interdisciplinary plan of care for oncology patients. Aggressive pain and symptom management is imperative in order to provide skilled EOL care. Health care providers should receive adequate training in palliative care at the undergraduate and graduate levels as well as required continuing education programs (Oncology Nursing Society). Additionally, it is essential to provide hospital-based nurse educators with evidence based curricula in order to educate practicing nurses.

Without appropriate EOL education, it is impossible for nurses to provide adequate EOL care. Additionally, it is vital to balance education with attention to personal understanding and attitudes towards death and dying in order to allow students opportunities to become knowledgeable about death and grief, to deal with their own feelings, and to develop empathy (Wass, 2004). Advances in medical technology, changes in social support systems, and an unlimited array of healthcare options have created a complex health care system which necessitates the importance of a heightened understanding of palliative care (Matzo, Sherman, Nelson-Marten, Rhome, & Grant, 2004). Through education, nurses will gain the knowledge, attitude, and competencies to improve the care of terminally ill patients and meet their ethical obligation as defined by the Nurses' Code of Ethics to alleviate pain and suffering while providing supportive care of the dying (American Nurses Association, 2002).

Other key factors affecting nursing practice include a deficit of willing and available family and/or caregivers; an inability to define medical futility; an increase fear of litigation among providers; an aging population; a lack of knowledge about appropriate treatment at EOL; confusion associated with assisted suicide; limited access to hospice and palliative care; legal and bureaucratic barriers to EOL care; and poor reimbursement (Matzo et al., 2004). Despite thirty years of proven effective hospice care in the United States, traditional medicine still continues to reject palliative care principles and practices in the acute care setting (Wass, 2004).

Registered nurses play an integral role in caring for patients facing fatal illnesses (Kurz & Hayes, 2006; Matzo et al., 2003; Sherman et al., 2002; Sherman et al., 2003; Sherman et al., 2005; White et al., 2001). Nurses spend more time with dying patients and families than any other professional, work closer with members of the interdisciplinary team, and are pivotal in implementing institutional and governmental EOL care changes (Paice et al., 2007; Sherman et al.). Caring for terminally ill patients is filled with personal meaning for providers. It is inevitable for caregivers to link images of the patient with her own inner experience and feelings about death (Hainsworth, 1996).

According to Hainsworth (1996), the extent to which providers have come to terms with their personal conception of death has ramifications for how they relate to the dying. Attitudes are believed to be the most significant predictor of behavioral changes (Hainsworth). Additionally, high levels of discomfort were

predictors of personal fear of death, suggesting that providers with high death anxiety are vulnerable to experiencing negative patient outcomes (Wass, 2004). Inadequate EOL education invariably produces limited knowledge but also results in little or no attention being paid to the student's personal dimension. It is self-reflection that encourages students to confront, clarify, and share personal understandings and attitudes about death (Wass). Studies show that nurses' attitudes are significantly improved with EOL education (Barrere et al., 2008). Palliative care education prepares registered nurses to provide holistic care during one of the most intimate healing moments between a nurse and her patient.

Possessing excellent communication skills including active listening is essential in order to assess a patient's physical, psychological, social, and spiritual dimensions at EOL (Malloy et al., 2008). In addition, registered nurses have identified palliative care issues as one of the most problematic concerns that they face clinically (Kurz & Hayes, 2006). Literature confirms that there are many EOL ethical dilemmas encountered by registered nurses including clashes about pain medication administration, EOL conversations with patients and families, and withdrawal of life-sustaining treatments (Ferrell et al., 2005). Unfortunately, registered nurses are ill prepared to care for dying patients and their families because they lack vital EOL care knowledge.

According to the National League of Nursing, there are ten trends impacting nursing education today, one of which is palliative care. Technological

advancements in the treatment of illness and disease have created new modalities that extend life while challenging traditional ethical and societal values regarding death and dying. The report goes on to state that greater recognition of the need to ensure comfort and promote dignity is reflected in the now nearly universal promotion of advanced directives, organ donation, and palliative care for the terminally ill. Additionally, new settings for care, such as inpatient and home-based hospice, and new forms of care, including pain management, spiritual practices, and support groups and bereavement counseling, should be part of well-developed health care systems. Unfortunately, a significant gap in the body of scientific knowledge and clinical education with regard to palliative and EOL care remains, and nursing education must prepare graduates for a significant role in these areas (Heller, Oros, & Durney-Crowley, 2007).

Goals of palliative care education should encompass the utilization of evidence-based, culturally sensitive symptom management as well as basic learning principles (Krasuska, Stanislawek, & Mazurkiewicz, 2002). It is imperative to increase professional and public knowledge related to symptom management in order to improve EOL care. Nurses must be empowered and recognized for their contributions including their role in translating research into nursing practice, creating evidence-based practice guidelines, and impacting regulatory practices and policies to improve EOL care (Krasuska et al.).

Adult Education Principles

Adult learners have unique characteristics which must be addressed when designing educational opportunities. Health care providers learn best through active processes of participation in problem solving activities that are directly pertinent to their needs (Meier & Beresford, 2006). Usually, adults enroll into learning experiences to create change in skills, behavior, knowledge or attitude (Russell, 2006). There are major differences in adult learners including degree of motivation, amount of previous experience, level of engagement in the learning process, and how the learning is applied (Russell). Learners need to be respected as individuals and provided with timely feedback, and it is important to make the learner feel safe and engaged (Collins, 2004). The recognition that learning is an internal and emotional process is crucial (Trapp, 2005).

Adults should be encouraged to create their own personal, goal-based learning objectives that will guide them in setting goals (Collins, 2004; Ferrell, Grant, Borneman, Juarez, & Virani, 2002). This self-initiated or participative learning is the most lasting and pervasive (Collins; Ferrell et al.). Assessing learning styles and planning instruction based on an understanding of different learning theories enhances information retention and active learning (Dobbin, 2001; Horii, 2007). Adult learning is best facilitated when teaching strategies combine visual, auditory, and kinesthetic approaches (Russell, 2006). Comprehending these principles of adult education will improve the learning experience and make teachers better facilitators of knowledge acquisition (Collins).

Additionally, it is important to understand learning theories which include behavioral, cognitive, andragogy, and phenomenology. Behavioral learning theory is based upon the assumption that behavior is determined by its consequences and that positive reinforcement motivates learners (Dobbin, 2001). With cognitive learning theory, the learner is an active and accountable participant in learning new knowledge and gaining new skills with real-world application being highly valued (Dobbin). The art and science of helping adults learn is termed andragogy and is most successful when actively solving real problems with new information (Collins, 2004; Dobbin). The use of narrative reflection to assess and understand clinical reasoning is phenomenology (Dobbin). When educational programs combine different aspects of these learning theories, the learning experience is optimized.

Adults learn best when they can participate actively in the planning, implementation, and evaluation of their own learning. Problem-based learning entails active participation of the learners to solve a real problem or analyze a situation in need of improvement (Dobbin, 2001; Lujan & DiCarlo, 2006; Trapp, 2005). It is this active processing of information via effective utilization of case studies and narrative, not passive reception of information that facilitates learning (Dobbin; Lujan & DiCarlo). Adult learners need to conceptualize new knowledge and skills in order to relate it to previously learned information and experiences (Trapp).

A recent additional challenge to adult learning is the explosion of the internet and its impact upon the availability and accuracy of information as well as the learning experience. When contemplating teaching strategies, educators must address student characteristics including generational differences.

Teachers are now confronted with a new type of student, the Net Generation or Millennials. The Net Generation members are assertive, self-reliant, independent, innovative, value immediacy, curious, and net savvy (Skiba & Barton, 2006). The Millennials prefer to work in teams, participate in peer interactions, and have little tolerance of delays (Skiba & Barton). By understanding how learners of all generations process information, educators will facilitate learning more efficiently by integrating multiple media technologies into the curricula (Mohanna, Chambers, & Wall, 2007).

The basic principles of effective teaching involve setting clear goals and expected outcomes, providing adequate supervision and meaningful feedback, and showing concern for students' progress (Mohanna et al., 2007). Ultimately by consistently applying the new knowledge in practice, patients' outcomes will improve (Khan & Coomarasamy, 2006). Overall, the evidence suggests that educational interventions can improve both professional practice and patient outcomes (Khan & Coomarasamy). Educational activities with an interactive format is crucial in altering behavior and/or attitudes (Khan & Coomarasamy).

With EOL education, it is imperative to provide the fundamental principles of palliative care while fostering an environment that encourages the learner to

gain knowledge and skills in the core domains of palliative care. The best educational programs incorporate both didactic and experiential teaching strategies (Hainsworth, 1996; Wass, 2004). Research demonstrates that learners show significant improvement in attitudes and comfort levels in caring for dying patients when they participate in death and dying education (Dickinson, 2002; Hainsworth). Educators should utilize existing curricula to offer evidence based didactic content while incorporating audio and video, patient scenarios, role-play, and reflective exercises (Meier & Beresford, 2006).

Ultimately, the test of a quality educational program lies in the effectiveness of the care and specifically improved patient outcomes at EOL (Wass, 2004). Current methods of palliative care instruction and evaluation often show disappointing outcomes in terms of achieving meaningful and lasting change among clinicians (Sullivan, Lakoma, Billings, Peters, & Block, 2006). Many continuing education programs have limitations in scope of practice, only address narrowly defined clinical content, and integrate non-interactive teaching strategies which do not to equate to change in attitude and behavior (Sullivan et al.). The real merit of an effective educational program lies with its ability to have lasting impact upon its learners in terms of changes in clinical practice and improved patient outcomes. Thus, continuing education must include interactive, learner-centered designs, assessment of learning needs, multifaceted activities, and longitudinal and sequenced training of at least 2 or more days (Sullivan et al.).

End of Life Nursing Education Consortium

Hence, a crucial strategy is the expansion of educational materials and curricula development in palliative care (Paice et al., 2006). To rectify these educational scarcities the American Association of Colleges of Nursing joined forces with the City of Hope National Medical Center to initiate a national educational program, entitled the “End of Life Nursing Education Consortium” (ELNEC). Funded for approximately three million dollars from the Robert Wood Johnson Foundation, ELNEC was launched in February 2000 as a consortium of many organizations, represented through the ELNEC Advisory Board, to ensure a collective professional approach to improve EOL care.

Developed through the work of project consultants and with extensive input from the Advisory Board and expert reviewers, the ELNEC curriculum is a “train-the-trainers” course. The expectation is that those trained in the ELNEC curriculum will be critical to the dissemination of knowledge related to EOL care (American Association of Colleges of Nursing, 2007). Nursing faculty and clinical nurses must apply for acceptance, and if selected, will receive extensive written materials and a CD-ROM to prepare them to teach the ELNEC content to students or fellow nurses (Barrere et al., 2008).

As of February 2009, 750 undergraduate nursing faculty and 800 continuing education providers and clinical staff development educators have been prepared as ELNEC trainers and more than 37,500 nursing students have

received ELNEC education (AACN, 2009). As of February 2009, over 5250 nurses, representing all 50 states have received ELNEC training through these national courses and are sharing this new expertise in educational and clinical settings (AACN, 2009). Initially the focus of ELNEC was in the United States, but ELNEC has spread internationally including six of the seven continents, representing 53 countries (AACN).

ELNEC training involves a didactic and experiential learning experience in EOL care for registered nurses. Over a two or three day training program, nine modules related to EOL care are presented. The one thousand page ELNEC curriculum provides educators with power-point slides, “talking points” for each slide, case studies, teaching strategies, and numerous key references for each of the nine modules. The instruction includes the following topics:

- ***Nursing Care at EOL:*** Overview of death and dying in America, principles and goals of hospice and palliative care, dimensions of and barriers to quality care at EOL, concepts of suffering and healing, and the nurse’s role in EOL care.
- ***Pain Management:*** Definitions of pain, current status of and barriers to pain relief, components of pain assessment, specific pharmacological, and non-pharmacological therapies including concerns for special populations.

- ***Symptom Management:*** Detailed overview of symptoms commonly experienced at EOL, and for each, the cause, impact on quality of life, assessment, and pharmacological/non-pharmacological management.
- ***Ethical/Legal Issues:*** Recognizing and responding to ethical dilemmas in EOL care including issues of comfort, consent, prolonging life, withholding treatment; euthanasia, and allocation of resources; and legal issues including advance care planning, advance directives, and decision making at EOL.
- ***Cultural Considerations in EOL Care:*** Multiple aspects of culture and belief systems, components of cultural assessment with emphasis on patient/family beliefs about roles, death and dying, afterlife, and bereavement.
- ***Communication:*** Essentials of communication at EOL, attentive listening, barriers to communication, breaking bad news, and interdisciplinary collaboration.
- ***Grief, Loss, Bereavement:*** Stages and types of grief, grief assessment and intervention, and the nurse's experience with loss/grief and need for support.
- ***Achieving Quality Care at End of Life:*** Challenges for nursing in EOL care, availability and cost of EOL care, the nurse's role in

improving care systems, opportunities for growth at EOL, concepts of peaceful or "good death", "dying well", and dignity.

- ***Preparation and Care for the Time of Death:*** Nursing care at the time of death including physical, psychological, and spiritual care of the patient, support of family members, the death vigil, recognizing death, and care after death.

(American Association of Colleges of Nursing, 2007; Malloy et al., 2006).

ELNEC provides evidence based knowledge and addresses personal characteristics and experiences of nurses in order to overcome discomfort associated with death and dying (Andershed, 2006). EOL education is the intervention that must occur to alleviate the fear and avoidance associated with death. Only with increased knowledge of the dying process will providers begin to view death and dying as a normal part of the life cycle, not some terrible event to be feared. Additionally, the need for information and communication is especially essential in palliative care. The more comprehensive the understanding of what to expect, the better the dying experience will be for the patient (Andershed). It is the nurse's responsibility to develop trusting relationships with both the patient and the family in order to have open, honest, and positive interactions with the purpose of optimizing care at EOL. Extensive education of health care providers as well as the general public must occur in order to improve EOL care.

ELNEC incorporates essential adult learning principles including both didactic and experiential learning opportunities, the AACN's recommendations for competencies and curricular guidelines for EOL nursing care as well as the principles of CTP. ELNEC is a nationally and internationally known, evidence-based educational program that is highly regarded for its positive impact upon improving EOL care. Data have been collected from multiple training courses developed to enhance expertise in nursing faculty teaching in undergraduate and continuing education programs in regards to the ELNEC training. Numerous faculty members representing 460 different nursing programs from all 50 states, the District of Columbia, Virgin Islands, and Puerto Rico received ELNEC training and shared this new knowledge with students and colleagues in a variety of educational settings (AACN, 2005). In addition, ELNEC-trained faculty used this curriculum to teach outside of their own nursing program (49%); attended other conferences on palliative care (46%); and began subscribing personally to EOL publications and journals (43%) (AACN, 2005).

But despite the dissemination of the ELNEC program, it has not been evaluated for its long term effectiveness at the institutional level. In 2006 Kurz and Hayes studied the influence of ELNEC using the General Systems Theory. They concluded that additional research was needed with consistent ongoing ELNEC sessions (Kurz & Hayes, 2006). Barrere et al. (2008) construed that little research existed on the effects of the ELNEC curriculum on students' attitudes. Furthermore, standardized instruments that measure death attitudes ranging

from anxiety to acceptance should be used to determine effective death education (Wass, 2004). In spite of successful implementation of this educational initiative, additional research is needed using multidimensional measures of death anxiety, concerns about dying, and perceived knowledge of dying which will lead providers to a more comprehensive approach to EOL care.

Theoretical Framework

Comfort Theory and Practice (CTP) provides the theoretical framework for this study. The construct of comfort is the very essence of nursing (Novak, Kolcaba, Steiner, & Dowd, 2001). This conceptual framework defines comfort as “the immediate state of being strengthened through having the human needs for relief, ease, and transcendence met in four contexts of experience (physical, psychospiritual, sociocultural, and environmental)” (Kolcaba, 2003; Kolcaba & Wilson, 2002).

It is important to understand the meaning of comfort as defined by Kolcaba including its application in acquiring new knowledge and skills in caring for dying patients and their families (Wilson & Kolcaba, 2004). There are three states of comfort. The first is relief, which is defined as the state of having a severe discomfort mitigated or alleviated. Secondly, ease is the absence of specific discomforts. And finally, transcendence is the ability to “rise above” discomforts when they cannot be avoided or eradicated (Kolcaba, 2003; Kolcaba & DiMarco, 2005; Kolcaba & Wilson, 2002).

Using this conceptualization, it is important to note that comfort is more than the absence of physical pain but includes emotional and spiritual suffering. Enhanced comfort also incorporates the principles of hope and confidence. Nurses ultimately strive to provide quality care for their patients to improve patient outcomes; but what happens when patients cannot get better. Intellectually, emotionally, and spiritually what process occurs in order to reconcile this discrepancy in one's nursing training to cure. CTP provides the framework for nurses working with patients and families to use the time before death not only to affirm life and to maximize the quality of life but to prepare for the moment of dying and death as a very inimitable spiritual experience not only for the patient and family but for the nurse (Krasuska et al., 2002). CTP principles foster this ideal therapeutic relationship between patients and nurses by empowering nurses to envision the possibility of transcendence.

In addition, nurses need to foster open and honest communication with other health care providers, patients, and family members. This requires the nurse to sort through a time of uncertainty and find meaning in living, as well as in dying (Krasuska et al., 2002). Transcendence is a thought provoking awareness that heightens one's creativeness and wisdom at EOL. Caring for a dying patient can actually be an extremely beautiful experience and privilege. These efforts ultimately guide the nurse in achieving the goal of complete "transcendence" to a place of hope,

confidence and self-awareness which are indispensable when providing palliative care.

Studies have documented that nurses themselves have identified caring for dying patients as particularly difficult (Rogers, Babgi, & Gomez, 2008). Nurses must wrestle with personal, ethical, legal, spiritual, social, and cultural issues at EOL without proper training and support (Rogers et al.). High level of work-related stress results in burn-out, feelings of anxiety, inadequacy, self-doubt, low self-esteem, irritability, depression, and poor health (Rogers et al.). With basic palliative care education, these frustrations and distresses can be reduced, allowing nursing to achieve the fundamental principles of CTP, relief and ease. With ongoing educational opportunities and support, nurses can optimally embrace transcendence and begin to view death and dying as a normal life process that must be addressed in an open and honest fashion not avoided or seen as something that can be conquered.

CTP provides a strong foundation for this study. Understandably relief and ease occur more quickly than transcendence with EOL education. Whereas, transcendence involves accepting discomfort as part of a patient's fate and then coming to terms with how best to assist one's patients in adapting to this discomfort, in this case, the act of dying. "Rising above" is the realization that one's patient has a life threatening illness and involves an extremely individualized and multifarious process for both the nurse and her patient. This is

an emotional and spiritual journey for the nurse as she partners with her patient during his last phase of life. It is unrealistic to expect the nurse to accomplish this transcendence without a comprehensive knowledge of the dying process.

Additionally, nurses must professionally and personally achieve levels of psychosocial and spiritual wellbeing prior to caring for dying patients. This can only be accomplished by providing nurses with ample EOL education and resources. CTP provides a clear structure for nurses to embrace the psychospiritual and sociocultural aspects of dealing with their anxieties associated with death and dying, to become comfortable interacting with people in crisis and to develop empathy. Nurses need a conceptual model to guide them as they explore their feelings such as anxiety and fear, attitudes, and concerns in regards to personal issues associated with death and dying (relief and ease) so professionally they can provide expert care for the terminally ill and their families (transcendence).

Integration of these attributes will make nursing a humane and compassionate profession (Wass, 2004). CTP recognizes the importance of addressing the physical, psychospiritual, sociocultural, and environmental needs of nurses in order to provide the highest quality of care (Kolcaba, 2003). Thus, CTP is truly holistic, easy to understand and implement, and is congruent with established principles of EOL nursing care (Kolcaba & Wilson, 2002) (see Figure 1).

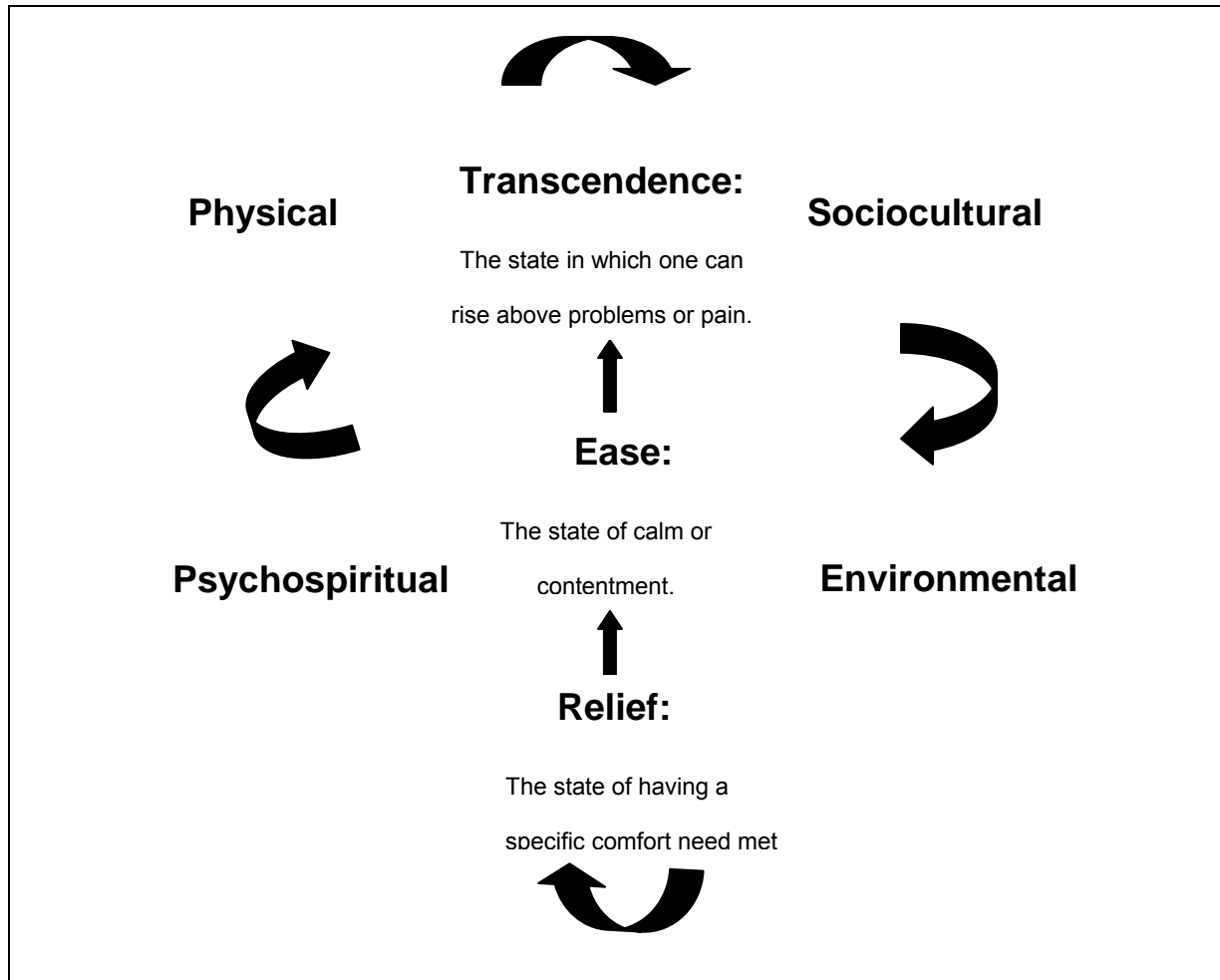


Figure 1. Comfort Theory and Practice by Katharine Kolcaba (2003) as visualized by Phyllis Whitehead, 2009.

Chapter III: Methodology

The basis of this chapter is to discuss the methodology and procedures that are used to answer the research question. The purpose of this research is to study the impact of ELNEC training upon registered nurses' death anxiety, concerns about dying, and perceived knowledge about the care of the dying patient at the institutional level.

Research Question and Hypothesis

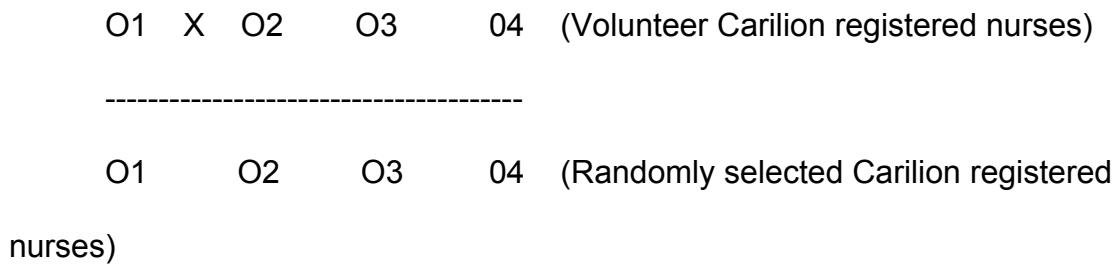
Specifically, this study assessed the ongoing impact of the ELNEC training program on registered nurses' death anxiety, concerns about dying, and perceived knowledge of the dying process from the perspective of Kolcaba's Comfort Theory and Practice (2003) at the institutional level. The null hypothesis was that there would be no difference in registered nurses' death anxiety, concerns about dying, and perceived knowledge of the dying process as a result of receiving the ELNEC training. The research hypothesis was upon completion of the ELNEC training, registered nurses would have decreased death anxiety, less concern about dying, and increased perceived knowledge of the dying process and whether improvements were maintained at six and twelve months after baseline.

The independent variable was the ELNEC training program. The dependent variables were death anxiety, concerns about dying, and perceived knowledge of the dying process. Three covariates were studied including years of experience as a registered nurse, experience with death and dying both

personally and professionally, and previous EOL education.

Research Design

This was a quasi-experimental, longitudinal study. The research design was:



Participants

Participation in the study was completely voluntary and confidential. It was anticipated approximately 50 to 60 nurses from adult units at Carilion Roanoke Memorial Hospital would be recruited into two study conditions. The treatment group would be 25-30 registered nurses who volunteered to take the ELNEC training program and would be solicited via the routine methods of Carilion educational offerings. The control group would be 25-30 registered nurses who did not receive the ELNEC training and who worked in one of the adult units at Carilion Roanoke Memorial Hospital. The control group would be randomly selected from a list of eligible nurses who do not receive the ELNEC training. Both groups would be sent an email inviting them to participate in the study.

Measures

Revised Death Anxiety Scale (RDAS). The Revised Death Anxiety Scale

(RDAS) was used to measure death anxiety. It is a 25 item self-report questionnaire that uses a 5-point Likert format with items scored with the value of “0” given for least anxiety and “4” for highest death anxiety. Responses to negatively-phrased items are reversed in the scoring process. Thus, the possible range of a respondent’s total score is from “0” (lowest) to “100” (highest) level of death anxiety (Kurz & Hayes, 2006; Neimeyer, 1994). The RDAS has been shown to be reliable (Cronbach $\alpha = .804$) to discriminate death anxiety differences and similarities between and within groups, is age-sensitive, and demonstrates differences in the elements that comprise the construct of death anxiety (Neimeyer).

Concerns about Dying Instrument (CAD). The Concerns about Dying Instrument (CAD) was used to measure death attitude or concerns about dying. The CAD includes three distinct but related areas: general concern about death, spirituality, and concerns about working with dying patients. The CAD consists of 10 descriptive statements intended to elicit concerns and beliefs from health care practitioners about death and dying with the intent to create a succinct measure that directly assesses providers’ comfort levels in caring for patients who are dying, as well as general concerns about death. Each item is followed by response options: disagree completely, disagree somewhat, neutral, agree somewhat, and agree completely. Greater agreement to the descriptive statements equates to greater concerns about death and dying (Mazor & Schwartz, 2004; Schwartz et al., 2005; Schwartz, Mazor, Rogers, Ma, & Reed,

2003). The CAD was developed explicitly for use with healthcare providers, for use with curriculum evaluation efforts, and in descriptive studies of provider-level correlation of end of life care and has demonstrated internal consistency (i.e., $\alpha = .83$; Mazor, Schwartz, & Rogers, 2004).

Perceived Knowledge about Dying (KDS). Participant's perceived knowledge of dying was measured using a self report 5-point Likert format with "0" indicating no level of knowledge to "4" reflecting complete knowledge of death and dying (KDS). Each ELNEC module was evaluated to determine perceived knowledge as measured by eight questions. The questions address overall perceived knowledge of nursing care at EOL, pain management, symptom control, ethical and legal issues, cultural considerations, bereavement care, challenges in providing quality EOL care, and nursing care at the time of death. The higher the score likens to greater perceived knowledge of EOL care. As supported by the current ELNEC literature (Ferrell et al., 2007; Hammel et al., 2007; Paice et al., 2007; Rogers et al., 2008; Sullivan et al., 2005), perceived knowledge about dying is routinely measured using a Likert format with questions based upon participants' perception of knowledge obtained from each module of the ELNEC training.

Procedure

Pre and Post Tests. Participant demographic characteristics were measured at pre-test. This included age, gender, ethnicity, years worked as a nurse, educational level, position, previous formal EOL education, and number of

dying patients cared for over the last year. Age, years worked as a nurse, and number of dying patients cared for over the last year were continuous variables. Gender, ethnicity, educational level, position, and previous formal EOL education were categorical variables. Prior to performing the primary analysis, the study groups were compared with respect to demographic variables in order to evaluate baseline comparability.

Pre-tests of the three outcome variables were administered to both the treatment and control groups. Post-tests were administered to both groups within two weeks after the two day ELNEC training, 6 months after baseline, and finally at 12 months to both groups. The Carilion Institutional Review Board (IRB) and the Virginia Tech IRB both granted exempt approval of this study. Due to institutional policy, random assignment of participants via a control waiting design for the ELNEC training program was not feasible. The treatment group registered nurses who volunteered to take the ELNEC program and the control group registered nurses who did not receive the ELNEC training were sent an email inviting them to participate in the study. The email included a link to the Qualtrics web-based survey comprised of the demographic questions, RDAS, CAD, and KDS. This introductory email included basic instructions and intentions of the survey which included measuring their perceived knowledge on dying, death anxiety, and concerns about dying. Furthermore, potential participants were assured that the data would only be used for research purposes to improve how nurses are provided nursing education regarding end of life care. Additionally, the

participants were informed that they would receive the questionnaire again in a few weeks, six months, and one year as well as the time commitment needed to complete the questionnaire. The introductory email included a link to the Qualtrics web-based survey. Upon navigating to the web-based survey, participants again were given basic instructions and intentions of the study and informed that completion of the survey was consent to participation in the study.

A follow-up email was sent to both treatment and control participants approximately two weeks, six months, and one year after the ELNEC training. This follow-up email included the basic instructions and intentions of the study as well as the link to the Qualtrics web-based survey. The web-based survey included the RDAS, CAD, and KDS each time and reiterated to participants that completion of the survey was consent to participate in the study.

ELNEC Intervention

ELNEC incorporates essential adult learning principles including both didactic and experiential learning opportunities, the AACN's recommendations for competencies and curricular guidelines for EOL nursing care as well as the principles of CTP. ELNEC is a nationally and internationally known, evidence-based educational program that is highly regarded for its positive impact upon improving EOL care.

The ELNEC training was offered and promoted as an educational program via Carilion Corporate University in October 2008. Numerous speakers presented the nine modules of the ELNEC training using the provided PowerPoint

presentations along with other ELNEC interactive activities. The control group was solicited from a list of registered nurses provided by the Carilion human resources department who had not registered for the ELNEC training. Identifying information was minimized to ensure confidentiality. A random number generator was used to select approximately four hundred email addresses to send the Qualtrics solicitation email letter.

Control Condition

Registered nurses in the control group were randomly selected from a list of registered nurses who care for adult patients at the designated medical center and were invited to participate and complete study assessments as described above. The no treatment control group received the same email invitation with no additional incentives for participation in the study.

Data Analysis

All assessment data was imported from Qualtrics into Microsoft Excel 2003® where it was audited for accuracy. The data were then exported into SAS 9.1 for Windows® for analysis. The instruments included a unique identifier (subject identification number) for each participant and were matched with that same identifier to enable repeat testing at post two weeks, six months, and one year.

The following analyses were performed. First, analysis of matched data for participants who completed all four surveys of the study was done to address the issue of non-randomization of the research design. Nurses were matched

primarily on the number of years the participant had worked as a nurse and secondarily on age, ethnicity, and whether the participant had previous EOL training. Both rank-transformed and untransformed (original) data were considered the primary analysis. Next, analysis of unmatched data for participants who completed all four visits of the study was completed. Again both rank-transformed and untransformed (original) data were analyzed. These analyses were considered as sensitivity analyses testing the robustness of the primary analysis. Finally, analysis of matched data for participants at each visit, regardless of whether they completed all four visits of the study was completed. This analysis was done only for untransformed data. It, too, was considered a sensitivity analysis.

Prior to the analysis, the two groups were compared with respect to demographic and baseline characteristics. For the matched pairs analysis no differences were detected (see Table 1). For the unmatched analysis differences were detected in age ($p= 0.0547$) and race/ethnicity ($p= 0.0648$) (refer to Table 2). Although not statistically significant, the control group participants tended to have more formal nursing education, specifically more bachelors, masters, and doctorate degrees.

Table 1

Summary of Demographic and Baseline Characteristics of Nurses in the Matched Analysis

Characteristic	Category	Experimental ^a	Control ^a	Fisher's exact test ¹
				2-sample <i>t</i> -test ²
				<i>p</i> -value
Age ²	Mean	50.9 ^b	45.9 ^b	0.2066
	Standard deviation	8.3 ^b	9.6 ^b	
Gender ¹	Male	1(10%)	0(0%)	0.4762
	Female	9(90%)	11(100%)	
Race/Ethnicity ¹	Caucasian	8(72.7%)	10(90.9%)	0.5865
	Hispanic/Latino	1(9.1%)	0(0%)	
	Other	2(18.2%)	1(9.1%)	
Education ¹	Diploma	0(0%)	2(18.2%)	0.1456
	Associate	7(63.6%)	2(18.2%)	
	Bachelors	2(18.2%)	4(36.4%)	
	Masters	2(18.2%)	3(27.3%)	
Position ¹	Staff	7(63.6%)	8(72.7%)	0.3270
	APN ^c	1(9.1%)	3(27.3%)	
	Manager	1(9.1%)	0(0%)	
	Other	2(18.2%)	0(0%)	
EOL ed ^{1d}	Yes	4(36.4%)	2(18.2%)	0.6351
	No	7(63.6%)	9(81.8%)	
RN years ^{2e}	Mean	23.1 ^b	22.6 ^b	0.8634
	Standard deviation	10.9 ^b	11.5 ^b	

Note. ^an = 11 for each group. ^byears. APN^c is an advanced practice nurse. EOL ed^d is previous formal EOL training. RN years^e is years worked as a nurse.

Table 2

Age Versus Years Worked as a Nurse in Unmatched Analysis

Variable	<u>Intervention group (n = 11)</u>	<u>Control group (n = 27)</u>	2-sample <i>t</i> - test <i>p</i> -value
Age (years)			0.0547
Mean	50.9	44.5	
Range	45.3 – 56.5	40.9 – 48.2	
Standard deviation	8.3	9.24	
Median	51	47	
Years worked			0.3703
Mean	23.1	19.5	
Range	15.3 – 30.8	15.3 – 23.8	
Standard deviation	11.5	10.7	
Median	25	20	

Since the sample size was less than 51, the Shapiro-Wilk statistic was used to test for normality. The test was statistically significant for a considerable number of the dependent variables. This indicated that for these variables the data were non-normal. The non-normality tended to be more associated with skewness than with kurtosis. As a precaution, the primary analysis and most importantly sensitivity analysis were performed on both rank-transformed and untransformed data. The rank-transformation creates a distribution free test. That is, the tests do not depend on the assumption of normality.

The statistical methodology used was the analysis of covariance (ANCOVA), adjusting for pre-test score which addressed the non-randomization of the research design. In each analysis the dependent variable was the changed score via the adjusted mean difference for each outcome variable. There were four pre-specified covariates - baseline total score, years worked as a nurse, previous formal end-of-life education (yes/no), and the number of dying patients cared for over last year. However, the responses given for the number of dying patients cared for over last year were a qualitative response for many of participants such as very few, several, multiple, and many which could not be quantified, so this covariate could not be used in the final model. The covariate, years worked as a nurse, had some responses such as <1 year, > 25 years, 9+ years. In this case the attached sign was dropped and only the number was recorded. The three outcome variables were considered independent from each

other and thus, no correction for multiplicity was made. All comparisons were made at the 0.05 level of significance.

Baseline total score was a significant factor in all three analyses. For the other two covariates statistical significance was only detected in one analysis. When the analyses were done with and without these two covariates, the results did not change appreciably. Therefore, the final model excluded terms for both years worked as a nurse and whether each nurse had previous formal end-of-life education.

Analyses were performed for two different participant groups using the analysis of covariance addressing the non-randomization of the research design. The first analysis consisted of matched pairs of participants; in deference to the non-randomized design each nurse completing the experimental treatment was paired with a nurse in the control to achieve the highest possible equivalence between the groups. Nurses were matched primarily on the number of years the participant had worked as a nurse and secondarily on age, ethnicity, and whether the participant had previous end-of-life training. Only participants who completed all four of the questionnaires were included in the analysis to create as equivalent groups as possible.

Design Limitations

Since random assignment was not feasible for this study, threats to internal validity exist to the extent the resulting study groups were not equivalent.

History could have been a threat to this study depending on events that occurred during the study and were differentially experienced by the study groups. These threats were expected to be minimal as the samples of nurses were drawn from the same population suggesting similar historical experiences. Sensitivity to instrumentation was controlled by using identical automated data collection procedures at each assessment point on the same schedule across groups. Subject selection was an issue as volunteers for an educational program on end of life issues may differ on important characteristics from volunteers to complete a series of assessments. Attempts were made to have equivalent groups, and differences between groups were controlled as much as possible in the analyses both by matching and by using the analysis of covariance. Attrition was a concern with conducting a longitudinal study over a 12 month period, but efforts were made to maximize participation across both study groups with follow-up and thank-you emails. Contamination was possible since participants from the treatment and control groups work together and could share information from the training. Generalizations will be limited to registered nurses not to licensed practical nurses or other disciplines.

Chapter IV: Results

Participants

Over 500 registered nurses were contacted to participate in this quasi-experimental study with 145 nurses completing the pre-test, 27 in the treatment group and 118 in the control group (refer to Table 3). A total of 38 nurses completed all four phases (pre-test, post-test, six months, and twelve months) of the research resulting in 11 participants in the intervention group and 27 in the control group, see Table 4 which summarizes the participant characteristics.

Matching of participants occurred at the end of the study to ensure that all matched pairs completed all four tests. The second analysis, referred to as the “unmatched” analysis, consisted of all participants who completed the four set of surveys (pre-test, post-test, six month, and twelve month). The total sample size for the matched pairs analysis was 22, 11 per group, whereas for the unmatched analysis the sample size was 38, 27 in the control group and 11 in the intervention group (see Tables 1 and 4).

Findings

The primary analysis was the matched pair analysis on rank-transformed differences between the test and pre-test data with baseline total score as the only covariate. For the matched pair analysis of perceived KDS, significant differences between the experimental and control groups were detected at the post-test ($p= 0.01$) and again at the twelve month test ($p= 0.013$) (Table 5).

Table 3

Participant Accountability

	<u>Intervention group</u>	<u>Control group</u>	<u>Total</u>
<hr/>			
Number of participants			
<hr/>			
Contacted	53	459	512
Started	27	118	145
Completed all 4 surveys	11	27	38
<hr/>			
Number of matched pairs			14
Number of matched pairs completing all 4 surveys			11
<hr/>			

Table 4

Demographic Characteristics of Nurses Completing All Four Surveys (Unmatched Analysis)

Variable					Fisher's exact test
	Intervention group		Control group		<i>p</i> -value
	n	%	n	%	
Gender					
Female	9	90	25	93	1.0
Male	1	10	2	7	
Ethnicity					
Caucasian	8	73	26	96	0.0648
Hispanic	1	9	0	0	
Other	2	18	1	4	
Educational level					
Diploma	0	0	2	7	0.3235
Associate	7	63	9	33	
Bachelors	2	18	12	44	
Masters	0	0	3	11	
Doctorate	0	0	1	4	
Work position					
Staff nurse	7	64	21	78	0.3730
APN ^a	1	9	4	15	
Manager	1	9	1	4	
Other	2	18	1	4	
EOL^b education					
Yes	4	36	6	22	0.4318
No	7	64	21	78	

Note. ^aAPN refers to Advanced Practice Nurses. ^bEOL is end of life.

No significant difference ($p= 0.07$) was detected at the six month test (Table 5). There were no statistically significant differences detected between the treatment and control groups for either the RDAS or the CAD at any of the time periods. Interestingly, the treatment group had less death anxiety and concerns about dying at each studied interval when the raw mean scores were compared (Table 6).

For the unmatched analysis, the KDS results were very similar to those seen in the matched analysis. There were statistically significant differences between the two groups at the post-test ($p= 0.004$), and at 12 months ($p= 0.006$). The groups were also borderline significant ($p= 0.06$) at the 6-month test. No statistically significant differences were detected between groups for either RDAS or the CAD factors (see Table 7). Noteworthy, once again when comparing adjusted mean differences for the RDAS, the treatment group had less death anxiety as compared to the control group at each interval. The adjusted mean differences for the CAD revealed less concerns about dying for the treatment group at post and six months but not at twelve months (Table 7). The similarity of treatment effects across both the matched and unmatched analyses suggest that age and ethnicity, the variables on which the unmatched groups differed, did not contribute substantially to the effects of the ELNEC treatment.

As a sensitivity analysis, each analysis was repeated using the original, untransformed data (see Tables 2 and 3). For the *unmatched* data analysis these analyses produced the same conclusion and were equally as sensitive as the rank-transformed data (Table 7). However, for the matched data the transformed analysis were more sensitive. Although the treatment effects tended to be in the same direction, the non-transformed data analysis yielded a significant difference only at post-test ($p= 0.04$). At six months and twelve months the differences did not reach significance ($p= 0.17$ and $p= 0.10$, respectively).

Table 5

Analysis of Matched Pair Data Comparing Experimental and Control Groups at Baseline, Post, 6 Months, 12 Months for Nurses Completing All Four Surveys

Variable		Pre-test	Adjusted	Adjusted	<u>Experimental vs control group</u>		
Group ^a	Test	mean	mean difference	mean rank difference ^b	Standard error	F (df = 1)	<i>p-value</i>
KDS							
Experimental							
	Post	18.73	3.64	14.75	1.60	8.16	0.0101
	6 mo	18.73	2.59	13.90	1.73	3.80	0.0661
	12 mo	18.73	3.46	14.18	1.36	7.61	0.0125
Control							
	Post	20.36	-0.09	8.25	1.60		
	6 mo	20.36	-0.69	9.10	1.73		
	12 mo	20.36	0.99	8.82	1.36		
RDAS							
Experimental							
	Post	37.09	-3.35	11.57	1.97	0.00	0.9592
	6 mo	37.09	-4.75	10.57	1.79	0.53	0.4738
	12 mo	37.09	-4.67	10.63	1.85	0.44	0.5152
Control							
	Post	39.91	-2.56	11.43	1.97		
	6 mo	39.91	-0.93	12.43	1.79		
	12 mo	39.91	-0.87	12.37	1.85		

<u>Experimental vs control group</u>							
Variable	Pre-test	Adjusted	Adjusted	Standard			
Group ^a	Test	mean	mean	rank	error	F (df = 1)	<i>p-value</i>
		difference	rank	difference ^b			
CAD							
Experimental							
	Post	23.36	-0.48	10.05	2.01	1.02	0.3258
	6 mo	23.36	-0.43	10.81	2.03	0.22	0.6414
	12 mo	23.36	0.96	10.97	2.05	0.13	0.7240
Control							
	Post	24.73	-2.56	12.95	2.01		
	6 mo	24.73	-0.93	12.19	2.03		
	12 mo	24.73	-0.87	12.03	2.05		

Note. KDS =, RDAS =, CAD = ^an = 11 for each group. ^banalysis performed on adjusted mean rank differences.

Table 6

Raw Mean Scores of Matched Pair Data Comparing Experimental and Control Groups from Baseline for Post, 6 Months, 12 Months

Variable		Standard	Range	Range		
Group	Test	Mean	deviation	minimum	maximum	Median
KDS						
Experimental						
	Baseline	18.7	6.3	8.0	28.0	20.0
	Post	22.6	6.0	8.0	29.0	24.0
	6 mo	21.7	5.6	8.0	29.0	24.0
	12 mo	22.7	3.4	16.0	29.0	24.0
Control						
	Baseline	20.4	5.5	8.0	24.0	23.0
	Post	20.0	5.0	8.0	24.0	22.0
	6 mo	19.3	6.3	9.0	24.0	23.0
	12 mo	20.8	4.1	11.0	24.0	22.0
RDAS						
Experimental						
	Baseline	37.1	12.4	8.0	56.0	38.0
	Post	34.0	13.4	1.0	51.0	37.0
	6 mo	32.8	10.1	19.0	44.0	30.0
	12 mo	32.7	11.3	9.0	46.0	34.0

Variable		Standard	Range	Range		
Group	Test	Mean	deviation	minimum	maximum	Median
Control						
	Baseline	39.9	14.1	19.0	71.0	39.0
	Post	37.1	12.4	18.0	61.0	34.0
	6 mo	40.4	14.4	19.0	70.0	37.0
	12 mo	38.7	16.5	12.0	71.0	40.0
CAD						
Experimental						
	Baseline	23.4	3.3	17.0	27.0	24.0
	Post	23.0	4.3	15.0	31.0	23.0
	6 mo	22.9	4.8	16.0	30.0	24.0
	12 mo	24.4	4.9	16.0	32.0	25.0
Control						
	Baseline	24.7	5.2	16.0	34.0	27.0
	Post	25.1	4.4	16.0	30.0	27.0
	6 mo	25.3	5.7	15.0	32.0	26.0
	12 mo	25.5	5.8	14.0	36.0	25.0

Note. KDS = RDAS = CAD = n = 1 for each group.

Table 7

*Analysis of Unmatched Pair Data Comparing Experimental and Control Groups at
Baseline, Post, 6 Months, 12 Months*

Variable		Pre-test	Adjusted	Adjusted	<u>Experimental vs control group</u>		
Group	Test	mean	mean difference	mean rank difference ^c	Standard error	F (df = 1)	<i>p-value</i>
KDS							
Experimental ^a							
	Post	18.73	3.79	27.15	2.93	9.58	0.0039
	6 mo	18.73	2.72	24.05	2.74	3.88	0.0569
	12 mo	18.73	3.75	25.77	2.54	8.53	0.0061
Control ^b							
	Post	19.59	-0.77	16.39	1.86		
	6 mo	19.59	-0.55	17.64	1.74		
	12 mo	19.59	0.66	16.95	1.62		
RDAS							
Experimental ^a							
	Post	37.09	-3.63	19.04	3.47	0.02	0.8776
	6 mo	37.09	-5.75	16.33	2.02	1.34	0.2544
	12 mo	37.09	-5.68	18.14	3.24	0.24	0.6251
Control ^b							
	Post	47.04	-2.56	19.69	2.18		
	6 mo	47.04	-0.10	20.79	2.02		
	12 mo	47.04	-2.57	20.05	2.04		

Variable		Pre-test	Adjusted	Adjusted	<u>Experimental vs control group</u>		
Group	Test	mean	mean difference	mean rank difference ^c	Standard error	F (df = 1)	<i>p-value</i>
CAD							
Experimental ^a							
	Post	23.36	-0.43	18.29	2.24	0.15	0.7051
	6 mo	23.36	-0.67	18.17	2.24	0.18	0.6775
	12 mo	23.36	0.80	19.89	3.54	0.09	0.7716
Control ^b							
	Post	27.70	-0.23	19.99	3.65		
	6 mo	27.70	0.31	20.04	2.24		
	12 mo	27.70	-0.07	18.62	2.22		

Note. KDS =, RDAS =, CAD = ^an = 11 for experimental group, ^bn = 27 for control group. ^canalysis performed on adjusted mean rank differences.

To further address the issue of attrition and to examine the robustness of the primary matched pairs analysis, additional sensitivity analyses were undertaken using the different matched pairs comparing the experimental and control groups from baseline to post, six months, and twelve months. Again, the KDS results were very similar to those seen in the previous analyses. There were statistically significant increases in KDS between the treatment and control groups at the post-test ($p= 0.004$) and at 12 months ($p= 0.04$). The groups were not statistically significant ($p= 0.11$) at the 6 month test. Additionally, the treatment group made larger increases in knowledge of death than the control group at each time point. No differences were detected between groups for either the RDAS or the CAD factors except for a six month outlier for the CAD ($p= 0.04$) (see Table 8). Of note, participants with less nursing experience tended to have higher attrition rates as compared to more experienced nurses ($p= 0.09$) which is consistent with other research findings (Barrere et al., 2008).

Table 8

Sensitivity Analysis of All Available Data Using Matched Pairs Comparing Experimental and Control Groups from Baseline for Post, 6 Months, 12 Months

Variable		Pre-test	Adjusted	Standard	<u>Experimental vs control group</u>	
Group ^a	Test	mean	mean difference	error	F (df = 1)	<i>p-value</i>
KDS						
Experimental						
	Post ^a	18.47	4.03	0.94	9.91	0.0036
	6 mo ^b	19.63	2.55	1.20	2.70	0.1114
	12 mo ^c	18.23	4.24	0.88	4.99	0.0354
Control						
	Post ^a	18.94	-0.15	0.94		
	6 mo ^b	19.19	-0.23	1.20		
	12 mo ^c	19.69	1.45	0.88		
RDAS						
Experimental						
	Post ^a	37.35	-4.76	1.83	1.05	0.3142
	6 mo ^b	37.63	-3.01	2.09	2.58	0.1191
	12 mo ^c	38.31	-4.74	2.64	0.87	0.3620
Control						
	Post ^a	44.24	-2.06	1.83		
	6 mo ^b	41.69	1.76	2.09		
	12 mo ^c	39.85	-1.26	2.64		

<u>Experimental vs control group</u>						
Variable		Pre-test	Adjusted	Standard		
Group ^a	Test	mean	mean	error	F (df = 1)	<i>p-value</i>
			difference			
CAD						
Experimental						
	Post ^a	24.18	-0.51	0.70	0.61	0.4406
	6 mo ^b	24.38	-0.62	0.64	4.51	0.0423
	12 mo ^c	24.08	0.50	1.05	0.03	0.8737
Control						
	Post ^a	27.12	0.28	0.47		
	6 mo ^b	25.25	1.30	0.64		
	12 mo ^c	25.15	0.27	1.05		

Note. KDS = RDAS = CAD = ^an = 17; ^bn = 16; ^cn = 13 for each group.

Chapter V: Discussion

Review

The purpose of this study was to assess the ongoing impact of the ELNEC training program on registered nurses' death anxiety, concerns about dying, and knowledge of the dying process utilizing the principles of The Comfort Theory and Practice by Kolcaba (2003) at the institutional level. Registered nurses play an integral role in caring for patients facing fatal illnesses and must have proper EOL education in order to provide evidence based palliative care (Ferrell, 1998; Kurz & Hayes, 2006; Matzo et al., 2003; Sherman et al., 2003; Sherman, Matzo et al., & 2005; Sherman et al., 2002; White et al., 2001).

Demographic and experiential characteristics of the experimental and control groups were controlled via matched analysis to address the issue of nonrandom selection and assignment (Kurz & Hayes, 2006). Nurses who received the ELNEC training, showed improvement ($p= 0.01$) relative to matched no-treatment control nurses in their perceived knowledge about the dying process immediately after the ELNEC training which was sustained at twelve months ($p = 0.01$). Nurses receiving the ELNEC training and matched-control nurses did not differ statistically significantly in their post-training death anxiety or concerns about dying which was contrary to other studies that showed nurses' attitudes were significantly improved with EOL education (Barrere et al., 2008). But when the raw mean scores of the RDAS and the CAD were compared, the

treatment group showed less death anxiety and less concerns about dying at each studied interval as compared to the control group. These findings suggest that an educational program on EOL care can provide long-term benefits to registered nurses supporting the merit of offering the ELNEC training to registered nurses who care for dying patients.

Confounding Factors and Limitations

Power analysis projected a desired sample size of 30 in each group. Since this sample size was not achieved, power was diminished and the risk of a Type II error increased. The ELNEC training was expected, for example, to result in improvements in the participants' death anxiety and concerns about dying as supported by Mallory (2003), Malloy, Paice, et al. (2008), and Malloy, Virani, et al. (2008). Additionally Ferrell et al. (2005) and Rogers, Babgi, & Gomez (2008) found a significant change in nurses' comfort level as result of EOL education when studying an intervention group without comparison to a control group. The failure to demonstrate enhancement in death anxiety and concerns most likely reflects the effects of a small sample size experienced in previous research (Hainsworth 1996; Kurz & Hayes, 2006; Mallory, 2003) and billows the positive influence of ELNEC training on these variables.

Additionally research demonstrated that attitudes were one of the most significant predictors of behavioral changes (Hainsworth). Furthermore, high levels of discomfort were predictors of personal fear of death, suggesting that providers with high death anxiety are vulnerable to experiencing negative patient

outcomes (Wass, 2004). According to Hainsworth (1996), the extent to which providers have come to terms with their personal conception of death has ramifications for how they relate to the dying. Although this study did not find statistically significant improvements in death anxiety and concerns about dying, the treatment group did experience less death anxiety and concerns about dying as illustrated by smaller mean scores as compared to the control group, validating the merits of EOL education and supporting the need for additional research with larger sample sizes.

In addition to being under-powered, the research questionnaires used in the current study, although validated may not have been sensitive enough to measure subtle changes due to small sample size, thus necessitating additional quantitative and qualitative inquiry to develop better means and methods of assessing death attitudes, anxiety, and knowledge (Lange, Shea, Grossman, Wallace, & Ferrell, 2009; Wass, 2004). Replicating this research with larger sample size with more selective questionnaires would be helpful. Ideally true random selection and assignment would be most desirable. Unfortunately, the realities of studying working nurses in a hospital setting make this option unlikely (Hainsworth, 1996).

Finally, the non-equivalent groups design includes a potential for self selection bias. Participants volunteered to participate in both the intervention and control groups suggesting that they were highly motivated and/or interested in EOL care. Generalizability of study findings is questionable because of the small

sample size (Lange, Thom, & Kline, 2008; Rogers et al., 2008). High subject attrition, lack of data depth, environmental bias, nonrandom sampling, and lack of male representation are limitations. Additionally, lack of financial incentives may have influenced participation at multiple time points.

Recommendations

Education can make a difference in improving EOL care but achieving change in behavior in clinical practice and measuring that change may require additional revised strategies. Other research has suggested nurses may have under-rated their death anxiety or concerns about dying (Lange, Thom, & Kline, 2008; Paice et al., 2006). Moreover, nurses may not have fully examined their own mortality as addressed by the CTP principles of relief and ease which may explain the lack of transcendence or recognition of death anxiety and concerns about dying.

Clinicians should not expect long term improvements as a result of a single training but should integrate repeated interventions. Providing ongoing reinforcement is imperative in sustaining desired EOL care behaviors, such as additional EOL educational opportunities, incorporation of a palliative care philosophy into hospital orientation programs, periodic debriefing after patient deaths including group and/or individual support sessions (Kurz & Hayes, 2006; Rogers et al., 2008). Qualitative research is necessary to focus on triangulation of data collection methods, specifically the use of interviews and/or observation to enhance the depth of the questionnaires by providing an opportunity to expand

upon participants' thoughts or concerns (Kurz and Hayes, 2006). Both qualitative and quantitative inquiries are needed to assess if patient care is significantly improved as the result of the ELNEC training (Rogers et al., 2008).

The foundation for improvement is providing nurses with proper palliative care instruction, but education alone is not enough. Organizational and cultural modifications must occur to truly improve EOL care. Linking theory to nursing practice is crucial to ensuring abiding evidence based EOL practices. Specifically, organizational and macro-system theories must be applied to successfully achieve essential work environment modifications. These activities include supporting nurses as they experience death anxiety, cumulative loss, and grief (Malloy, Sumner, Virani, & Ferrell, 2007). Additionally, altering and advancing EOL care within hospital systems, the health care industry, commercial and governmental payer systems, and the American culture is imperative to truly improving how EOL care is viewed and delivered (Malloy et al., 2007). As the debate over national health care reform continues, EOL care must be discussed and elevated as a legitimate specialty worthy of inclusion in any national health care plan.

Furthermore, financial, workforce challenges, and cultural bias regarding disclosure of terminal diagnoses and proper symptom management must be tackled (Paice, Ferrell, Coyle, Coyne, & Callaway, 2007). Foundation monies and grants may be a source of support for expanding EOL nursing training and research as well as organizational advancements in palliative care (Virani,

Malloy, Ferrell, & Kelly, 2008). Clinicians and administrators should be encouraged to seek out such funding opportunities to plan more robust studies that reduce limitations including longitudinal research that address qualitative aspects of palliative care.

Quality care throughout the continuum of life is promoted in hospital and other health delivery settings, but nurses can only provide this quality care if they are educated in EOL practice standards. Palliative care education is key to unlocking the mystery of why patients are dying in pain and with poor symptom management (Virani, Malloy, Ferrell, & Kelly, 2008). Families will always remember those last moments of their loved one's life so it is essential that nurses be empowered to minimize needless suffering while honoring their patient's EOL wishes and supporting family members through this journey (Virani et al., 2008).

Conclusions

The ELNEC project has been a tremendously successful educational enterprise in improving nursing knowledge at EOL over the last nine years. Nurses are receptive to palliative care education and are industrious in implementing the content of the training into their clinical practice. EOL education yields nurses with higher levels of hope and confidence creating more competent clinicians and improving patient outcomes at EOL. Results from this study and others reinforce the importance of providing ongoing EOL education to nurses. Nurses spend more time at the bedside with dying patients than any other health

care provider and must be educated in EOL care in order to facilitate appropriate medical decision making for patients and their families at EOL. Education on the dying process can benefit all clinicians but especially nurses who have more opportunities for personal engagements with patients and families.

Most Americans believe they can avoid death and medicine can cure any disease or illness. Furthermore, death is viewed as a failure of the health care system rather than a natural life occurrence. This misconception must change as death is unavoidable and needless suffering ensues with this dangerous perspective. With the privilege of caring for dying patients comes the responsibility to be well educated in order to provide quality care including relieving pointless physical, emotional and spiritual suffering of patients and their families. The ELNEC training provides nurses with the knowledge and skills to improve how EOL care is delivered and continue to alter how the American culture views death and dying.

The purpose of this study was to assess the ongoing impact of the End-of-Life Nursing Education Consortium (ELNEC) training program on registered nurses' death anxiety, concerns about dying, and knowledge of the dying process utilizing the principles of The Comfort Theory and Practice by Kolcaba (2003) at the institutional level. The findings of this research support the importance of providing EOL education in improving death and dying knowledge. Additionally, it identifies challenges to alleviating death anxiety and concerns about dying including the development of more sensitive questionnaires and

other strategies to ensure meaningful and sustainable long term changes to how Americans view death and dying, Without modifications to the American culture including health care organizations, government, and the insurance industry, dying patients and their families will continue to suffer senselessly.

Summary

The purpose of this study was to assess the ongoing impact of the End-of-Life Nursing Education Consortium (ELNEC) training program on registered nurses' death anxiety, concerns about dying, and perceived knowledge of the dying process utilizing the principles of The Comfort Theory and Practice by Kolcaba (2003). Despite the dissemination of the ELNEC program, it had not evaluated for its long term effectiveness at the institutional level. This quasi-experimental, longitudinal study's goal was to measure the impact of the ELNEC training upon registered nurses at the same medical center who completed the workshop with anticipation of decreasing death anxiety and concerns about dying while increasing the perceived knowledge of the dying process. The Revised Death Anxiety Scale (RDAS) was used to measure death anxiety via a 25 item self-report questionnaire that uses a 5-point Likert format with items scored with the value of "0" given for least anxiety and "4" for highest death anxiety. The Concerns about Dying Instrument (CAD) was used to measure death attitude or concerns about dying and includes three distinct but related areas: general concern about death, spirituality, and concerns about working with dying patients. Participant's knowledge of dying was measured using a self report 5-point Likert

format with “0” indicating no level of knowledge to “4” reflecting complete knowledge of death and dying. Therefore, pre-tests of all dependent variables were administered to both the intervention and control groups. Post-tests were administered two weeks after the two day ELNEC training, at 6 months, and finally at 12 months to both groups in order to study its lasting efficiency upon participants at one primary care medical center. Thirty eight participants completed all four questionnaires with 27 participants in the control group and 11 participants in the experimental group. Matched pair analysis with 11 participants in each group was conducted with statistical significance found for perceived knowledge about dying at post two weeks and 12 months ($p = 0.01$) for the intervention group. Death anxiety and concerns about dying were not found to be statistically significant at any testing interval ($p > 0.05$) but mean scores of the treatment group revealed less death anxiety and concerns about dying as compared to the control group. Recommendations included offering the ELNEC training on a routine basis to all registered nurses who care for dying patients. Additionally, clinicians and administrators were encouraged to seek out additional funding opportunities to plan more robust studies with larger samples, incentives, and research method triangulation addressing the qualitative aspects of palliative care.

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Appendix A

Revised Death Anxiety Scale

1. I fear dying a painful death.
(strongly agree; agree; neutral; disagree; strongly disagree)
2. Not knowing what the next world is like troubles me.
(strongly agree; agree; neutral; disagree; strongly disagree)
3. The idea of never thinking again after I die frightens me.
(strongly agree; agree; neutral; disagree; strongly disagree)
4. I am not at all anxious about what happens to the body after burial.
(strongly agree; agree; neutral; disagree; strongly disagree)
5. Coffins make me anxious.
(strongly agree; agree; neutral; disagree; strongly disagree)
6. I hate to think about losing control over my affairs after I am gone.
(strongly agree; agree; neutral; disagree; strongly disagree)
7. Being totally immobile after death bothers me.
(strongly agree; agree; neutral; disagree; strongly disagree)
8. I dread to think about having an operation.
(strongly agree; agree; neutral; disagree; strongly disagree)
9. The subject of life after death troubles me greatly.
(strongly agree; agree; neutral; disagree; strongly disagree)
10. I am not afraid of a long, slow dying.
(strongly agree; agree; neutral; disagree; strongly disagree)
11. I do not mind the idea of being shut into a coffin when I die.
(strongly agree; agree; neutral; disagree; strongly disagree)
12. I hate the idea that I will be helpless after I die.
(strongly agree; agree; neutral; disagree; strongly disagree)
13. I am not at all concerned over whether or not there is an afterlife.
(strongly agree; agree; neutral; disagree; strongly disagree)
14. Never feeling anything again after I die upsets me.

- (strongly agree; agree; neutral; disagree; strongly disagree)
15. The pain involved in dying frightens me.
(strongly agree; agree; neutral; disagree; strongly disagree)
16. I am looking forward to new life after I die.
(strongly agree; agree; neutral; disagree; strongly disagree)
17. I am not worried about ever being helpless.
(strongly agree; agree; neutral; disagree; strongly disagree)
18. I am troubled by the thought that my body will decompose in the grave.
(strongly agree; agree; neutral; disagree; strongly disagree)
19. The feeling that I will be missing out on so much after I die disturbs me.
(strongly agree; agree; neutral; disagree; strongly disagree)
20. I am worried about what happens to us after we die
(strongly agree; agree; neutral; disagree; strongly disagree)
21. I am not at all concerned with being in control of things.
(strongly agree; agree; neutral; disagree; strongly disagree)
22. The total isolation of death is frightening to me.
(strongly agree; agree; neutral; disagree; strongly disagree)
23. I am not particularly afraid of getting cancer.
(strongly agree; agree; neutral; disagree; strongly disagree)
24. I will leave careful instructions about how things should be done after I am gone.
(strongly agree; agree; neutral; disagree; strongly disagree)
25. What happens to my body after I die does not bother me.
(strongly agree; agree; neutral; disagree; strongly disagree)

Scoring Information:

(Numbers 1, 2, 3, 5, 6, 7, 8, 9, 12, 14, 15, 16, 18, 19, 20, 22, 24)

strongly agree = 4; agree = 3; neutral = 2; disagree = 1; strongly disagree = 0

(Numbers 4, 10, 11, 13, 17, 21, 23, 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.

0 (lowest score) - 100 (highest score). 0 = least and 4 = highest death anxiety.

Appendix B

The Concerns About Dying Instrument (CAD)

Kathleen Mazor

1. I get anxious or uncomfortable when I think about my own death.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
2. I sometimes worry that I will die young.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
3. I get anxious or uncomfortable when I think about someone I care about dying.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
4. I am worried that my own death may be painful.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
5. I think that when its time for me to die, I will be able to let go.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
6. I believe that my soul or spirit will continue after death.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
7. My religious and/or spiritual beliefs and practices help me think about death.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
8. I am worried about how I will react emotionally to dying patients.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
9. I think that I will feel powerless with dying patients.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)
10. I think I will find it hard to work with dying patients.
(disagree completely; disagree somewhat; neutral; agree somewhat; agree)

Scoring Information:

(Number 1, 2, 3, 4, 6, 8, 9, 10)

disagree completely = 1 ; disagree somewhat = 2; neutral = 3; agree somewhat = 4; agree completely = 5

(Numbers 5 and 7)

disagree completely = 5; disagree somewhat = 4; neutral = 3; agree somewhat = 2; agree completely = 1

Item scoring was done such that greater agreement reflected greater anxiety or concern about death or dying.

Appendix C

Perceived Knowledge of Dying Survey

Please rate the following statements “0” indicating no knowledge to “4” reflecting complete knowledge.

(0-No Knowledge;1-A Little Knowledge;2-Neutral;3-Moderate Knowledge;4-Complete Knowledge)

1. How would you rate your overall knowledge of nursing care at end-of-life?
0 1 2 3 4
2. How would you rate your knowledge of how to manage pain at end-of-life?
0 1 2 3 4
3. How would you rate your knowledge of how to manage symptoms at end-of-life?
0 1 2 3 4
4. How would you rate your knowledge of the ethical and legal issues surrounding end-of-life care?
0 1 2 3 4
5. How would you rate your knowledge of the cultural considerations at end-of-life?
0 1 2 3 4
6. How would you rate your knowledge of the bereavement needs of patients and families at end-of-life?
0 1 2 3 4
7. How would you rate your knowledge of the challenges in providing quality care at end-of-life?
0 1 2 3 4
8. How would you rate your knowledge of providing nursing care at the time of death?
0 1 2 3 4

Appendix D

Sample Email Invitation/Solicitation

Dear Fellow Nurse,

I am writing to invite you to participate in an important study to improve end of life education.

You have been identified as an individual who may have an interest in end of life care.

You are being asked to complete the following questionnaire regarding your knowledge on dying, death anxiety, and concerns about dying. The data will only be used for research to improve how we provide nursing education regarding end of life care. You will receive the questionnaire again in a few weeks, six months and one year. It will only take approximately 15-20 minutes to complete each time. The completion of the questionnaire is considered your consent to participate in the study. Please complete the questionnaire within a week of receiving the notice if possible.

Your participation is completely voluntary but it is very important to enhance how we care for our patients and their families.

If you have any questions, please email me at pwhitehead@carilion.com or call me at 540-981-8126.

Click here for the link to complete the web-based questionnaire:

http://carilion.qualtrics.com/SE?SID=SV_9Ks3oyvEp2ivfla&SVID=Prod

Thank you for your help and time!

Phyllis Whitehead

Appendix E

Sample Thank You Email

Thank you for taking the time to complete the end-of-life web-based questionnaires! Your responses have been very helpful in studying the effects of our new educational program (End of Life Nursing Education Consortium).

If you have not had an opportunity to complete this final questionnaire, you still have time.

Click here for the link to complete the web-based questionnaire:

http://carilion.qualtrics.com/SE?SID=SV_9Ks3oyvEp2ivfla&SVID=Prod

If you have any questions, please email me at pwhitehead@carilion.com or call me at 540-981-8126.

Once again, thank you for your participation and support.

Phyllis Whitehead