The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care

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The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care

Yvonne L. Joy, DNP
University of Connecticut, 2015

As of 2014, nearly 6,000,000 people in the United States need palliative care. Almost 2,000,000 people with chronic, serious illnesses currently reside in long-term care facilities. Palliative care aims to relieve suffering and provide the best possible quality of life. Thus, the primary aim of this study was to evaluate the influence of an education intervention to increase nurses’ knowledge and self-efficacy in palliative care practice in long-term care settings. A secondary aim of this study was to determine if there was a significant difference in palliative care self-efficacy between registered nurses (RNs) and licensed practical nurses (LPNs). A two-group quasi-experimental design was used to compare knowledge and self-efficacy scores of an attention-control group and the palliative care education intervention group at two distinct, large long-term care facilities. Bandura’s theory of self-efficacy was used as the theoretical framework for this study. Statistical analysis using paired t-test for pre- and post-intervention knowledge and self-efficacy scores was performed within groups. Independent t-tests were performed to compare scores between groups. Analysis of covariance was used to determine if there were differences in the self-efficacy mean scores between RNs and LPNs after controlling for site, age, and years of nursing practice.
The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care

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APPROVAL PAGE

Doctor of Nursing Practice Dissertation

The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care

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University of Connecticut

2015
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My nursing career has spanned many settings and populations. Nonetheless, death was present in all of them, as death is a natural part of life. It is my belief that everyone deserves a peaceful death and it can be achieved through palliative care. This dissertation is part of my effort to educate more people, whether it is patients and families or members of the healthcare team, to become knowledgeable about palliative care. I am grateful to the following people, who, without their support, I would not have completed this dissertation:

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Chapter 1: Introduction

Palliative care is a form of health care designed to relieve distressing symptoms of chronic and terminal illness and promote quality of life. The World Health Organization (WHO) (2004) 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” (p. 14). Palliative care incorporates a holistic, multidisciplinary approach of support to the patient and family, and is consistent with good nursing practice (Becker, 2009a). Palliative care nursing is an art and a science that emphasizes quality and normality of life by simply helping people live until they die (Becker, 2009a).

The need for palliative care is evident as our population ages. People are living longer due in large part to improvements in public health, and by 2020 1 in 6 people living in the United States will be over the age of 65 (WHO, 2004). As life expectancies increase, so too will chronic and degenerative diseases that will ultimately result in end-stage illness (Braitman, Higuchi, & Murray, 2009). This growth in chronic and degenerative diseases will produce an increased demand for palliative care including symptom management.

According to the Center to Advance Palliative Care (2012), there are nearly 6,000,000 people in the United States who need palliative care, meaning they suffer from a serious illness and require relief from distressing symptoms. Over the past decade, there has been an effort to offer palliative care earlier in the disease process, to improve patients’ quality of life and the quality of end-of-life care. As a consequence the number of specialized palliative care programs
increased, with the goal of integrating these services earlier in the illness trajectory. (El-Jawahri, Greer, & Temel, 2011)

By 2030, over 3,000,000 people in the United States with chronic, serious illnesses will reside in long-term care facilities (CAPC, 2008). As more people live longer and contend with chronic illnesses, a shift in causes of death occurs and more people are dying from manifestations of serious chronic illnesses than from acute illnesses (WHO, 2004). To date approximately 20% of all deaths in the United States occur while in long-term care and this percentage is expected to climb to approximately 40% by 2020 (Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012). With this increase, there is a clear need for palliative care in the long-term care setting to benefit those with chronic and terminal illnesses (Hall, Kolliakou, Petkova, Froggatt, & Higginson, 2011). During the often-protracted period of chronic and terminal illness, patients require compassionate nurses who practice evidence-based palliative care (Brajtman et al., 2009). Nurses, therefore, must be prepared to adeptly apply palliative care knowledge in efficacious manner in order to perform this important aspect of care.

Nurses play an instrumental role in providing palliative care. According to a 2010 Institute of Medicine (IOM) report on the future of nursing, nurses are “ideal providers” of palliative care. Prevost, Rushton, Chrastek, and Kirshling (2010) further state that “palliative care is a model that is consistent with basic nursing values, which include caring for patients and their families regardless of their age, culture, socioeconomic status, or diagnoses, and engaging in caring relationships that transcend time, location, and circumstances” (p. G23). Nurses working in long-term care settings are in an optimal position to provide palliative care and meet the growing needs of patients in long-term care facilities.
Statement of the Problem

Given the aging population and increasing demand for high quality palliative care, there is a critical need to provide long-term care nurses with education that increases their knowledge and self-efficacy related to palliative care. Previous research suggests many nurses identify lack of knowledge of and self-efficacy in providing palliative care (Al Qadire, 2014; Autor, Storey, & Ziemba-Davis, 2013; Brazil et al., 2012; Iranmanesh, Razban, Tiryani & Zahra, 2013; Kassa, Murugan, Zewdu, Hailu & Woldeyohannes, 2014; Kim & Hwang, 2014; Pitman, 2013). In addition, long-term care nurses have few opportunities for continuing education (Brajtman et al., 2009; Hall et al., 2011; McIlfatrick, Mawhinney, & Gilmour, 2010; Wen et al., 2012). The deficit in knowledge, self-efficacy, and opportunities for continuing education underscores the need to promote knowledge and self-efficacy about evidence-based palliative care practice in long-term care.

Background

In this study, the setting of interest was long-term care where more patients are living longer with chronic illnesses (CAPC, 2008). Education of long-term care facility staff members, particularly nurses, should be designed to improve care for this population of chronically ill individuals. Measuring nurses’ palliative care knowledge and self-efficacy is a simple, yet effective quantification of a targeted education intervention.

Palliative Care

The history of palliative care began in 1973 in Canada, when Balfour Mount first introduced the term *palliative care*, stemming from the words *to palliate*, which means to improve the quality of something (Pastrana, Junger, Ostgathe, Eisner, & Radbruch, 2008). In
November 1978, the field of palliative care became a medical specialty in the United Kingdom and was called 'palliative medicine' (Pastrana et al., 2008).

The proliferation of palliative care organizations in the United States began with the earliest development of the National Hospice and Palliative Care Organization (NHPCO) in 1978. Through the 1980s, the Hospice and Palliative Nurses Association (HPNA), the American Academy of Hospice and Palliative Medicine (AAHPM), and the Center to Advance Palliative Care became instrumental forces in defining the scope of palliative care. The American Academy of Hospice and Palliative Medicine (AAHPM) emphasizes “palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth” (Pastrana et al., 2008, p. 224). Then in 1990, the World Health Organization’s definition of palliative care was rooted in the philosophy that ‘palliative medicine affirms life and regards dying as a normal process’ (Pastrana et al., 2008). Before the proliferation of antimicrobials and during the early stages of medicine when cures were not possible, patients were comforted and symptoms were treated (Pastrana et al., 2008). In this regard, palliative care was the standard of care.

Many patients with manifestations or exacerbations of chronic illnesses may require palliative care for an extended period of time. This is particularly true with patients in long-term care who may not qualify for hospice care, as hospice eligibility requires a prognosis of six months or less (CGS Administrators, 2014). These patients include those with Alzheimer’s disease or aggressive advanced disease; those who have a functional or cognitive decline despite receiving therapy rehabilitation; those who make repeated and frequent trips to the hospital; and those with acute, chronic, or uncontrolled pain (Dixon, 2007). Another important distinction
about palliative care, compared to hospice care, is that it can be delivered in conjunction with curative treatment.

**Palliative Care Need**

The need for palliative care is escalating due to increases in the aging population and rates of those living in long-term care and dying of a protracted illness related to chronic diseases, (Desbiens & Fillion, 2011; Ferrell, Grant, & Virani, 1999; Heals, 2008). Palliative care meets the dual needs of this vulnerable population by helping patients live as actively as possible until they die and assists their families to cope with illness and bereavement (Hall et al., 2011). Long-term care facilities providing palliative care reduce burdensome transitions to and from acute care settings (Wittenberg-Lyles, Goldsmith, Richardson, Hallett, & Clark, 2012). It is well documented that transitions between care facilities contribute to distress particularly from the trauma of the physical transfer; the confusion of an unfamiliar setting and care providers; the inability to adequately address the patient’s special needs; and the lack of communication about the goals of care (Gozalo, 2011). In 2005, the Centers for Medicaid and Medicare Services (CMS) reported the cost of potentially avoidable hospitalizations was $3.1 billion (Ouslander & Berenson, 2011).

Palliative care meets the need of the individual patient with a focus on quality of life by reducing and eliminating distressing symptoms and side effects of treatment (Adriaansen et al., 2005; Johnston & Smith, 2006). Inadequacy in pain assessment for patients living in long-term care settings is well documented (Ersek, Grant, & Kraybill, 2005), and palliative care can address this shortfall. Palliative care prevents unwanted or inappropriate life-sustaining measures during the final months of life and addresses the concerns of families regarding symptom management and emotional support (Adriaansen, & van Achterberg, 2008; Brazil et
al., 2012; Ersek et al., 2005). For patients with incurable chronic progressive disease, palliative care is widely recognized as essential to their care (WHO, 2004). One of the greatest benefits for palliative care is the opportunity for patients and their families to have meaningful dialog about their health care with health care professionals (Adriaansen et al., 2005; Adriaansen & van Achterberg, 2008).

**Palliative Care Need in the Long-Term Care Setting**

Chronic disease takes a personal toll on the quality of life for a long-term care resident. The Center to Advance Palliative Care (CAPC) (2008) reported that untreated or under-treated pain in long-term care is well documented and half of the people living in this setting suffer from untreated pain. Additionally the 2008 CAPC Report indicated that 65% of residents are functionally impaired and need help with three or more activities of daily living (ADLs). Other aspects of quality of life impacted by chronic diseases include impaired mobility, impaired performance of usual activities, anxiety, and depression (Rabin, Oemar, & Oppe, 2011).

Current barriers to palliative care in the long-term care setting are: lack of provider knowledge about the principles and practices of palliative care, provider attitudes and beliefs about death and dying, staffing levels and lack of available time for dying residents, lack of physician support, lack of privacy for residents and families, families' expectations regarding residents' care, and hospitalization of dying residents (CAPC, 2008; Wowchuk, McClement & Bond, 2007). Palliative care education is desperately needed for those working with residents in long-term care settings (Wowchuk et al., 2007); however, some of these barriers can be overcome using approaches that embrace enhanced communication, continuity of care, advance care planning, staff training, and systematic changes in clinical care practice (Goebel, 2013;
Educating nurses about communicating palliative needs to patients and families is an important step in establishing achievable goals of care (Unroe & Meier, 2011).

**Palliative Care Education Necessity**

Providing palliative care begins with educating staff, particularly nurses, who are not prepared to provide optimal palliative care (COH & AACN, 2014). Major deficiencies in education include the paucity of palliative care content in nursing texts, the nominal content in nursing curricula, and the shortage of knowledgeable nursing faculty (COH & AACN, 2014; Desbiens et al., 2011; Lange, Shea, Grossman, Wallace, & Ferrell, 2009). Access to palliative care education by nurses is also a barrier to meet the needs of patients living in long-term care (Curry, Middleton, & Brown, 2009). Additionally, licensed nursing staff members working in long-term care have lower levels of educational attainment than in other clinical settings (Ersek et al., 2005). The majority of nurses working in long-term care are licensed practical nurses (LPNs) who are eligible for licensure after completion of a twelve to eighteen month program, whereas registered nurses (RNs) must complete a minimum of two years of intensive education to be eligible for licensure (HRSA, 2013; Nurse Practice Act, 2013). Coupled with the educational barriers noted above, differences might exist between the levels of knowledge of LPNs and RNs in long-term care settings.

McIlfatrick et al. (2010) and Kim et al. (2011) identified major deficiencies in knowledge, skills, attitudes, and behaviors of staff who care for patients at the end of life. McIlfatrick et al. (2010) and Kim et al. (2011) also reported that a cultural shift in attitudes and behaviors among health care professionals through education initiatives is essential for longstanding changes in patient outcomes. Health care professionals, including nurses, also acknowledge their own lack of competency for providing palliative care (Adriaansen et al., 2005,
Brazil et al., 2012; COH & AACN, 2014; Ferrell et al., 1999; Wittenberg et al., 2012). The paucity of competent health care professionals, including nurses, results in unintentionally inadequate quality of care for patients in long-term care (Brazil et al., 2012). Moreover, evidence indicates that family members of those receiving palliative care indicate misinformation, inadequate communication, and poor collaboration with nursing staff that ultimately increases family burden (Wittenberg et al., 2012).

**Palliative Care Education Intervention**

Education is shown to improve skills in and increase knowledge of palliative care (Ersek et al., 2005), as well as overall levels of self-efficacy (Phillips, Salamonson, & Davidson, 2011). The content of the education intervention should reflect the needs of patients living in long-term care, including the chronic disease trajectory and the care culture that differs from the acute care setting (Brazil et al., 2012). The program can be brief and still effective if it focuses on specific aspects of palliative care (Adriaansen & van Achterberg, 2008). Interactive and integrated programs that mix didactical methods are known to have a positive impact on professional practice (Adriaansen & van Achterberg, 2008). When these programs are offered over a period of weeks, it allows nurses to practice what they are learning and then reflect on their experience. Programs that allow nurses to reflect on their professional practice encourage them to evaluate if their attitudes and actions meet the needs of their patients (Adriaansen et al., 2005; Curry et al., 2009). Nurses in prior studies reported increased confidence in assessment and symptom management skills after completing palliative care education programs in addition to feeling empowered to approach physicians about concerns for their patients (Dixon, 2007).

**Palliative Care Knowledge**
Palliative care knowledge is identified as the most important component of providing palliative care (Prem et al., 2012). Current research demonstrates inadequacies of palliative care knowledge, particularly related to pain management (Autor, Storey & Ziemba-Davis, 2013; Brazil et al., 2012; Goddard, 2013), opioid use and adverse drug events (Goddard, 2013; Prem et al., 2012); misconceptions about palliative care, including principles and utilization of palliative care (Autor, Storey, & Ziemba-Davis, 2013; Iranmanesh, Razban, Tirgari, & Zahra, 2013), and identifying patients most likely to benefit from palliative care (Autor, Storey, & Ziemba-Davis, 2013; Goddard, 2013; Iranmanesh, Razban, Tirgari, & Zahra, 2013). Increasing nurses’ knowledge about palliative care assessment and management will help them, and other members of the healthcare team, improve the quality of care provided (Prem et al., 2012). Evaluating palliative care knowledge is an effective measure for an education intervention.

**Palliative Care Self-Efficacy**

In addition to palliative care knowledge, self-efficacy is a relevant measure for a palliative care education intervention because it is an accurate predictor of professional and personal behavior change (Phillips et al., 2011). Self-efficacy is an individual’s belief in his or her ability to organize and carry out a course of action necessary to result in a desired behavior (Bandura, 1997; Resnick, 2003). Individual beliefs provide the foundation for human motivation, well-being, and personal accomplishment (Bandura, 1997; Resnick, 2003). This corresponds well to the goal of an education intervention, which is not only to increase declarative and procedural knowledge but also to affect competence and performance (Moore, Green, & Gallis, 2009). A nurse’s high level of self-efficacy corresponds to higher work engagement and supports clinical performance with the ultimate impact on patient outcomes and
population health (Adriaansen et al., 2005; Bandura, 1997; Salanova, Lorente, Chambel, & Martinez, 2011; Zhu, Norman, & While, 2013).

Resnick (2003) describes the four information sources for determining self-efficacy. The first source of self-efficacy is enactive attainment; the belief that performing an activity strengthens self-efficacy beliefs. Described as the most influential information source, enactive attainment greatly influences self-efficacy expectations. These expectations include the preconceived abilities, the perceived task’s difficulty, and past successes or failures. The second source of self-efficacy is vicarious experience; seeing other similar people perform successfully the same activity. The third source of self-efficacy is verbal persuasion; verbally telling that he or she has the capabilities to master the particular behavior. The fourth source of self-efficacy is physiological feedback; a person’s awareness of their physiological state to judge their abilities.

**Nursing Licensure**

Education requirements and scope of practice are the two main differences between LPN and RN licensure. Nursing education requirements for LPNs are at least twelve months of vocational instruction at an accredited institution. Nursing educational requirements for RNs are the completion of a degree, diploma, or certificate from an accredited institution. RN programs vary from an intensive one-year type to a four-year undergraduate education (National Council of State Boards of Nursing [NCSBN], 2011). Nursing licensure provides a clear distinction between these two types of nurses, whereas education length is highly variable.

Scope of practice is loosely outlined by the National Council of State Boards of Nursing (2012), but is more specifically defined by each state’s Nurse Practice Act. Connecticut’s Nurse Practice Act (2013) is one of six nationally that is essentially silent when it comes to specifying LPN delegation and supervision, particularly of unlicensed personnel (Corazzini et al., 2011);
however Connecticut’s Nursing Practice Act (2013) does explicitly state that LPNs function under the supervision and direction of RNs or APRNs.

A mix of nursing licensure is unique to the long-term care setting. Approximately two-thirds of nurses employed in long-term care are LPNs that provide direct patient care (the U.S. Bureau of Labor Statistics, 2011). LPNs provide the majority of bedside care, whereas RNs serve in a supervisory role of LPNs and nursing aides. The RNs’ level of responsibility is higher than LPNs. The national average RN hours per patient per day is 49 minutes, whereas the average LPN hours per resident per day is 50 minutes (CMS, n. d.). In Connecticut, the average RN and LPN hours per patient per day averages are 53 minutes and 45 minutes respectively. At the current study’s intervention site, the RN and LPN hours per patient day averages are 59 minutes and 47 minutes respectively. On the contrary, the control site RN and LPN hours per patient per day averages are 26 minutes and 49 minutes respectively. There may be a larger disparity in actual direct patient care RN and LPN hours as all RNs working in the long-term care facility may not provide direct patient care. These RNs may include the director of nursing, assistant director of nursing, staff development RN, infection control nurse, and minimum data set coordinator, whose positions are more administrative and supervisory, yet included in the total RN hours per resident day.

**Significance to Nursing**

The aims of this study are significant to nursing in several ways. Nurses provide the majority of direct patient care, including palliative care. In the long-term care setting, nurses are the only profession with a 24-hour presence. Nurses act as patient advocates, identify the need for palliative care, and promote action to improve symptom management and quality of life. Additionally nurses bridge the gap between the healthcare system and patient’s support systems,
especially during palliative care when patient vulnerability is significant. There are many gaps in the literature related to the effectiveness of educational interventions in long-term care. This study contributed to the growing body of knowledge related to the effectiveness of educational interventions to improve nurses’ knowledge and self-efficacy related to palliative care.

The Role

Nurses play a significant role in palliative care as the only 24-hour caregivers in the health care system (Ferrell et al., 1999). In long-term care, most of these nurses are licensed practical nurses (LPNs) who provide the majority of bedside care (Wittenberg et al., 2012). The care they deliver reflects the values and beliefs of the palliative approach, principles and practices that equates to good nursing practice (Becker, 2009a). The therapeutic relationship that nurses develop with patients and their families help nurses plan a patient’s future care, give psychological support, and coordinate care with other members of the healthcare team – this is the core of palliative nursing (Becker, 2009a).

In long-term care settings, nurses have a unique opportunity to develop longstanding relationships with patients and families. Knowing these patients and families so well, provides the nurse with a good understanding of the patient’s preferences for care and leaves the nurse acutely aware of even the slightest clinical change in the patient (Brazil et al., 2012). Nurses in long-term care are a critical link for the communication of patients’ and families’ needs and concerns to other members of the health care team (Braitman et al., 2009).

Advocacy

Nurses intrinsically advocate for the best care for their patients by using evidence-based science, interpersonal skills, and the therapeutic use of self – these are the foundation for palliative care nursing (Becker, 2009b). Nurses in long-term care recognize the vulnerability of
their patients, suffering from manifestations of the chronic illness (Becker, 2009b). Nurses also recognize that good palliative nursing care has a positive impact on patients’ quality of life (Becker, 2009c).

As patient advocates, nurses are more likely than any other healthcare professional to be present when someone dies (Becker, 2009c). They are also the ones who identify patients’ needs and institute comfort measures (Becker, 2009b) and bear the burden of care, having a pivotal impact on treatment regimens (Becker, 2009c). During palliative nursing care patients and families look to nurses for support, information, and continuity of care (Becker, 2009a). Without nurses to advocate for patients who receive palliative care, a patient’s quality of life may be disregarded (Gardner, 2012).

**Purpose of Practice Change**

The aims of this study were to evaluate the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care settings, and to determine if there was a significant difference in palliative care self-efficacy between registered nurses (RNs) and licensed practical nurses (LPNs). This study is important considering LPNs provide the majority of bedside care to patients in long-term care including those receiving palliative care. A palliative care educational program, based on the End-of-Life Nursing Education Consortium (ELNEC) Geriatric Curriculum, specifically designed for nurses working in long-term care and skilled nursing facilities, was provided. Each nurse completed a palliative care knowledge quiz and a Palliative Care Self-Efficacy Scale before and after the education intervention to determine, as suggested by Ross, McDonald, and McGuinness (1996) and Phillips et al. (2011), whether or not education interventions are effective at increasing knowledge and self-efficacy. Palliative care aims to reduce suffering and provide the best
quality of life for those who may not qualify for hospice, but suffer manifestations of chronic illnesses. Education of nurses is the first step to meeting the needs of this vulnerable population. Measuring their knowledge and self-efficacy is an effective way to evaluate their learning and ultimately impact patient outcomes.

The first aim educated nurses practicing in long-term care facilities about palliative care and then determined if nurses’ knowledge and self-efficacy increased. Nurses attended four forty-five minute sessions about palliative care. The content for these sessions was derived from the End of Life Nursing Education Consortium (ELNEC) Geriatric Curriculum (COH & AACN, 2014), a nine module curriculum that includes the following topics: principles of palliative care, pain assessment and management, non-pain symptoms, goals of care and ethical considerations, cultural and spiritual considerations, communication; loss, grief, and bereavement, ensuring quality end of life care, and preparation and care at time of death. The planned educational program used four of the ELNEC components, specifically selected to meet the individual needs of the nurses at the intervention site. These four components included principles of palliative care, pain assessment and management, non-pain symptoms, and communication. The intervention was delivered over a period of seven weeks, which allowed nurses the opportunity to reflect upon their palliative care practice as suggested by Adriaansen et al. (2005) and Curry et al. (2009).

A secondary aim of this study was to determine if there was a significant difference among RNs and LPNs in their palliative care self-efficacy. LPNs provide the majority of bedside care in long-term care; however, RNs generally have more education. One could hypothesize that since LPNs spend more time on direct patient care, develop relationships with patients and their families, and become their advocates, then they have greater self-efficacy than
supervising RNs. Conversely one could hypothesize that because RNs have more education and greater responsibilities, then they may exhibit greater self-efficacy.

**Theoretical Framework**

The Theory of Self-Efficacy provided the theoretical underpinning for this study. This theory was derived from Bandura’s social cognitive theory in the late 1970s (Resnick, 2003). Self-efficacy is a dynamic construct, affected by judgment of perceived capability to perform a specific task that changes over time as new information and experiences are acquired. Bandura (1997) asserted there are four sources of information that provide the basis for self-efficacy. These sources include enactive attainment, vicarious experience, verbal persuasion, and physiological feedback.

Enactive attainment is thought to be the most influential source of efficacy information (Resnick, 2003). Enactive attainment is the process of increasing the strength of self-efficacy through the expectation of a successful performance of a particular activity. When a person has repeated successful performances, this perpetuates the belief that the person will continue to have successful performances. This process of enactive attainment gives stability to self-efficacy, preventing occasional errors in performance from impacting self-efficacy or performance behaviors (Resnick, 2003).

Vicarious experience is a second source of self-efficacy. It is the observation and witnessing of others successfully performing a particular activity (Resnick, 2003). The greater the exposure a person has to a particular behavior, the greater the impact of the vicarious experience. The opposite is also true: with no or little experience, then vicarious experience is less affected. This translates to its impact on self-efficacy (Resnick, 2003).
Verbal persuasion is a third source of self-efficacy. It involves telling a person that he or she has the capability to perform and master a particular behavior (Resnick, 2003). This influence is well known to guide those with a high sense of self-efficacy to intensify their efforts at a particular behavior. Furthermore the greatest impact of this source of self-efficacy is outside the setting in which it is initiated (Resnick, 2003).

Physiological feedback is the fourth source of self-efficacy. The physiological response that a person feels when anticipating or performing a particular behavior will impact the actual execution of the behavior (Resnick, 2003). This varies from avoidance to decreased self-efficacy. Likewise recognition of this sensation coupled with coping mechanisms will allow the person to successfully perform the desired behavior (Resnick, 2003).

These four sources collectively impact self-efficacy. An important aspect of self-efficacy is that perception of a person’s belief of his or her own capabilities to organize and carry out a course of action determines his or her performance (Resnick, 2003). Bandura (1977) explained efficacy expectation as the “conviction that one can successfully execute the behavior required to produce the outcomes” (p. 193). The stronger the perceived self-efficacy by the individual, the greater his or her efforts will be to perform a desired task (Bandura, 1977). Therefore, self-efficacy is an appropriate measure of an education intervention in palliative care (Bandura, 2006; Phillips et al., 2011).

During this study, it was anticipated that nurses who attended all four educational sessions would experience these four sources of self-efficacy to some degree. Between education sessions, nurses might have the opportunity to practice a particular skill and doing so with repeated success will contribute to enactive attainment. When colleagues witness this performance in action, this contributes to the vicarious experience of others. Another example of
vicarious experience is when nurses share their experiences with each other during the education sessions. Verbal persuasion occurs in two ways: the trainer provides encouragement of the participants in providing palliative care and as nurses share and respond to one another during the education sessions and potentially in practice. Physiological feedback is addressed by the trainer when validating those nurses willing to share their responses. These four sources contributed to the self-efficacy of the nurses who participated.

The education sessions focused on principles of palliative care, pain assessment and management, other symptom identification and management, as well as communication. By increasing their palliative care knowledge in these specific areas, the nurse has an opportunity apply their learning to practice, reflect on their experience, collaborate with others, and encourage one another.

**Study Questions**

The research questions in this study were:

1. What is the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care?

2. Is there a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care?

**Definition of Key Terms and Variables**

**Variables of Interest**

One independent variable in this study was palliative care education. The conceptual definition of palliative care education was “a curriculum that addresses the unique needs of geriatric nurses who work in long-term care and skilled nursing facilities” (COH & AACN, 2014).
Operational definition: For the purpose of this study, palliative care education was measured by participation in four forty-five minute education sessions.

A second independent variable in this study was nursing licensure. The conceptual definition of nursing licensure was the permission granted by the state where the nurse practices, based on predetermined educational requirements and examination, to perform according to the Nurse Practice Act of that state (NCSBN, 2011).

Operational definition: For the purpose of this study, nursing licensure was measured as either RN or LPN, and indicated on the demographic form.

One dependent variable in the study was palliative care knowledge. The conceptual definition was, “information, understanding, or skill that you get from experience or education” (“Knowledge,” 2014) about “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” (WHO, 2004, p.14).

Operational definition: For the purpose of this study, palliative care knowledge was measured using the Palliative Care Quiz for Nursing (PCQN), a 20-item true, false and “I don't know” test of knowledge that is easily administered and has utility for assessing knowledge, stimulating discussion and identifying misconceptions about palliative care nursing (Ross et al., 1996).

A second dependent variable in this study was palliative care self-efficacy. The conceptual definition of palliative care self-efficacy was “a cognitive construct that refers to nurses’ judgment of their capabilities to provide quality care to patients and family experiencing a life-limiting illness or at end of life” (Desbiens & Fillion, 2011).
Operational definition: For the purpose of this study, self-efficacy was measured using the Palliative Care Self-Efficacy Scale (PCSES), a 12-item scale which focuses on perceived capabilities to manage common aspect of end-of-life care using a structured closed-ended question format (Phillips et al., 2011).

Summary

With a growing aging population, the need for palliative care cannot be overstated. Palliative care aimed at reducing suffering and promoting quality of life will meet the needs for those with incurable, chronic illnesses. This process begins with educating nurses, the bedside care providers. Measuring palliative care knowledge and self-efficacy using the PCQN and PCSES were effective methods for evaluation of education sessions.

In summary, the primary aim of this study was to evaluate the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care. Additionally the study examined whether differences exist in self-efficacy between nurses who hold LPN and RN licenses.
Chapter 2: Integrated Review of the Literature

Introduction

The primary aim of this study was to evaluate the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care. A second aim of this study was to determine if there was a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care. Over three million people in the United States will reside in long-term care settings by 2030, with an estimated 40% of them dying in long-term care facilities. Nurses need to be educated about palliative care, but it is important to measure the effectiveness of education. For the purpose of this study, the Palliative Care Quiz for Nursing (PCQN) and Palliative Care Self-Efficacy Scale (PCSES) were used to measure knowledge and self-efficacy, two effective measures of an education intervention.

This integrated review of the literature included theoretical and empirical literature related to the concepts of this study, including the theory of self-efficacy, palliative care education, palliative care knowledge, self-efficacy, and nursing licensure. Search criteria included the following key words: palliative care, nursing education, nursing licensure, long-term care, nursing home, knowledge and self-efficacy. This search excluded studies related to the pediatric population. The search was limited to English language, and research-only articles published between 2004 and 2015. Databases used were CINHAL Plus with Full Text, SCOPUS, and PubMed.

Theoretical Literature

Theory of Self-Efficacy

Bandura’s (1997) theory of self-efficacy is widely used in research pertaining to patient behavior (Resnick, 2003). Few articles, however, use the theory as a framework for research
concerning nurses’ behavior, performance, or self-efficacy. Four studies met search criteria and were retrieved for analysis.

These four studies all employed a cross sectional survey design. The sample sizes ranged from 68 (Agard & Maindal, 2009) to 186 (Hollingsworth & Ford-Gilboe, 2006). The settings for these studies included a community health center (Jimenez, Contreras, Shellman, Gonzalez, &Bernal, 2006; Vega, 2007), the intensive care unit (Agard & Maindal, 2009), general hospital (Jimenez et al., 2006; Vega, 2007), and the Emergency Department (Hollingsworth & Ford-Gilboe, 2006). The clinical conditions for these studies varied greatly and included nurse interaction with relatives (Agard & Maindal, 2009), culture (Jimenez et al., 2006), abuse of women (Hollingsworth & Ford-Gilboe, 2006), and working with HIV patients (Vega, 2007).

Findings from these studies that were relevant and significant to the current study included the belief that increased knowledge will positively affect self-efficacy (Vega, 2007), that nurses with a higher level of self-efficacy were more likely to persist at mastering a task until the new behavior is learned (Jimenez et al., 2006), and that outcome expectations of nurses corresponds with high levels of self-efficacy (Agard & Maindal, 2009; Hollingsworth & Ford-Gilboe, 2006). The theory of self-efficacy provided a sound framework for the current study due to its demonstrated versatility with nurses in multiple settings and its applicability to a variety of clinical situations.

**Concept of Self-Efficacy**

The concept of self-efficacy for clinicians is scarcely documented in the literature. Seven studies relating self-efficacy to an education intervention were retrieved for analysis. Sample sizes ranged from 22 (Engin & Cam, 2009) to 172 (Irvine et al., 2012) and four (Ammentorp & Kofoed, 2010; Doyle, Copeland, Bush, Stein & Thompson, 2011; Engin & Cam, 2009;
Kronborg, Væth, Olsen, & Harder, 2008) of these studies focused on nurses. The researchers of two studies (Irvine et al., 2012; Kronborg et al., 2008) employed a randomized controlled design, whereas the remainder utilized a single group pre-, post-test design. The education interventions varied in length from two detailed client visits (Irvine et al., 2012), to time designations of a minimum of 4 hours (Irvine et al., 2012) to 3 days (Kronborg, et al., 2008), and all were in-person training except one (Irvine et al., 2012) was computer-based training.

Self-efficacy was one measure evaluated in relation to an education intervention, on a variety of topics, including assessment of caring for parents of neonates (Ammentorp & Kofoed, 2010), how to handle difficult communication situations (Doyle et al., 2011), a self-awareness program for psychiatric nurses (Engin & Cam, 2009), an Internet mental illness training program (Irvine et al., 2012), and breastfeeding guidance (Kronborg et al., 2008). Across all studies, a statistically significant increase in self-efficacy was appreciated when measured after the intervention (Ammentorp & Kofoed, 2010; Doyle et al., 2011; Engin & Cam, 2009), and up to eight weeks later (Irvine et al., 2012; Kronborg et al., 2008). Ammentorp and Kofoed (2010) reported a significant \( p < 0.01 \) increase in self-efficacy in their pilot study of twenty nurse neonatal nurses after a 3-day coaching training. Doyle et al. (2011) reported significantly \( p < 0.001 \) higher self-efficacy scores among the intervention group of sixteen nurses who received a six-module communication course over seven hours versus the control group of seventeen nurses. Engin and Cam (2009) reported a significant \( p < 0.0001 \) increase in self-efficacy scores by the twenty-two psychiatric nurses that participated in a 72-hour education intervention over a period of twelve weeks. Irvine et al. (2012) reported a significant \( p < .001 \) increase in self-efficacy scores at post-test and at two-week follow up in their randomized control trial of 172 licensed care staff who work in long-term care. Kronberg et al. (2008) reported a significant \( p <
0.01) increase in self-efficacy scores among 52 nurses who participated in an 18-hour breastfeeding educational intervention. These significant findings further substantiate the belief that self-efficacy is a good measure of an education intervention for clinicians, including nurses.

Four additional studies were also included for analysis because the researchers examined the self-efficacy of nurses using surveys. In these studies, the sample sizes ranged from 60 (Nash, 2011) to 206 (Chapin, Froats Jr. & Hudspeth, 2013) with the researchers from the latter study employing a controlled design. Self-efficacy was correlated to other variables including listening style profile score (Chapin et al., 2013); work stress, emotional exhaustion, empowerment, and burnout (Smolen-Hetzel, 2010); years of nursing education and vicarious experience (Nash, 2011); and, years of experience in addressing patient concerns about potential pain medication addiction (Goebel et al., 2010).

Findings from these studies were relevant to the current study. Chapin et al (2013) found that the majority of nurses in their study were people-oriented listeners who had higher levels of self-efficacy to identify and assist victims of domestic abuse. Smolen-Hetzel (2010) discovered that nurses with greater self-efficacy were less likely to suffer burnout, emotional exhaustion, or report higher levels of work stress. Nash (2011) documented a positive correlation between years of nursing education and vicarious experience in relation to nurses’ self-efficacy to provide condom use training to women in Belize to reduce their HIV risk. Goebel et al. (2010) found that nurses with more experience and higher levels of self-efficacy, translated to more engagement in pain management addiction risk discussions. From these findings, one was able to glean that nurses with greater self-efficacy were able to cope with work-related stressors and were more likely to perform a desired clinical behavior. Also vicarious experience contributed positively to self-efficacy as well as level of education and years of experience.
Empiric Literature

In this section, empiric literature was evaluated for palliative care education as an intervention, specifically including ELNEC and PCQN, as well as for nursing licensure.

**Intervention: Palliative Care Education**

Five relevant studies pertaining to the evaluation of an educational intervention about palliative care were retrieved for analysis. One of the five studies was a qualitative study that used a focus group method (Curry et al., 2009). The remaining four studies were all quantitative studies of pre-test/post-test design, however Adriaansen et al. (2005) was the only controlled study. Sample sizes of the four quantitative studies ranged from 75 (Adriaansen et al., 2005) to 169 (Ersek et al., 2005). All four quantitative studies included licensed nurses and two included unlicensed personnel as well (Ersek et al., 2005; Wen et al., 2012). Adriaansen et al., (2005) were the only researchers to look at differences between RNs and LPNs.

The length of the education intervention also varied greatly, from three hours of training (Wen et al., 2012) to sixty hours (Curry et al., 2009), during as little as two sessions over two days (Kim et al., 2011) to the maximum of fifteen sessions over ten months (Curry et al., 2009). Other interventions were conducted in four sessions over two months (Adriaansen et al., 2005), four sessions over four months (Eresk, 2005), and six sessions over six months (Wen et al., 2012). Each session varied from thirty minutes (Wen et al., 2012) to eight hours (Adriaansen et al., 2005; Eresk, 2005; Kim et al., 2011) with the remaining lasting four hours (Curry et al., 2009). Adriaansen et al. (2005) provided four additional sessions lasting three hours for reflection of practice, but did not identify a specific duration of time for these sessions.

In the four quantitative studies, researchers confirmed that nurses increased their palliative care knowledge. Researchers also reported an increase in skills when evaluated by
participant self-evaluation, supervisor evaluation (Ersek et al., 2005), and a researcher-developed 8-item questionnaire (Wen et al., 2012).

Adriaansen et al. (2005) were the only researchers to evaluate self-efficacy using their own (Adriaansen & van Achterberg 2004) previously validated self-efficacy instrument for palliative care (SEP) that has a Cronbach’s alpha of 0.72 for RNs and 0.93 for LPNs. In their 2005 quasi-experimental study of the effect of a palliative care course, 38 RNs and 28 LPNs completed both pre and post-test measurements of self-efficacy. An important finding of their research, however, was that the SEP was not an effective instrument for showing differences between RNs and LPNs because both groups cared for palliative care patients and this was not statistically significant ($p > 0.20$) (Adriaansen et al., 2005).

There were many conclusions that can be drawn from these studies. One is that neither the length nor duration of the education sessions impacted outcomes. Nurses reported an increase in knowledge after attending just one 30-minute session. A second conclusion is that knowledge by itself did not translate into behavior change – behavior change or a predictor of behavior change can be measured by self-efficacy. Third the SEP was not an effective instrument for demonstrating a difference between RNs and LPNs. Last none of these studies were controlled to confirm the actual benefits of the education interventions, thus adding a control group would strengthen the results of this study.

**PCQN.** The Palliative Care Quiz for Nursing (PCQN) has been widely used in research since its inception in 1996, but few studies were performed in a long-term care or similar settings or included both RNs and LPNs. Four studies relevant to the current study were retrieved for analysis. Adriaansen, van Achterberg, and Borm (2005) were the only authors to use a quasi-experimental design with a control group, while Ronaldson, Hayes, Carey, and Aggar (2008) and
Brazil, Brink, Kaasalainen, Kelly, and McAiney, (2012) employed a cross-sectional design and Pitman (2013) used a one-group pre- and post-test design. Total sample sizes ranged from 33 (Pitman, 2013) to 97 (Ronaldson et al., 2008), but sample sizes of just nurses ranged from 4 (Pitman, 2013) to 69 (Brazil et al., 2012), as Ronaldson et al. (2008) included 61 unlicensed assistants in nursing and Pitman (2013) included 28 patient care assistants.

Adriaansen et al. (2005) evaluated the effects of an education intervention on palliative care knowledge and self-efficacy using a self-efficacy instrument for palliative care (SEP) developed by the authors and a comprehensive variant of the Palliative Care Quiz for Nursing (C-PCQN). The comprehensive variant of the PCQN is a modified version of the PCQN originally developed by Ross et al. (1996). They found that in the intervention group, the RNs, showed greater improvement on the SEP, but the LPNs tended to show greater improvement on the C-PCQN even though the difference between the first and second measurements was not statistically significant (p > 0.20) (Adriaansen et al., 2005).

Mean percentages correct scores on the PCQN were explicitly reported by the authors in two studies. Ronaldson et al. (2008) reported a mean PCQN score of 58.50%. Similarly Brazil et al. (2012) reported mean PCQN scores by each of four facilities: 62.96%, 61.67%, 63.41%, 52.50% with no significant difference found between the facilities (F=1.168, df=3, P=0.329). These scores paralleled the results of the PCQN validation study by Ross et al. (1996) where the authors calculated mean percentages correct scores of practical nurses (60%), post-RN students (65%), and RNs (75%).

In addition to measuring nurses' knowledge of palliative care, Ross et al. (1996) developed the PCQN with the intent to also identify most frequently held misconceptions about palliative care. Ronaldson et al. (2008) and Brazil et al. (2012) reported the greatest
misconception in both their studies was Item 12: The philosophy of PC is compatible with that of aggressive treatment, meaning this was the statement most often answered incorrectly. Ross et al. (1996) reported the greatest misconception as Item 14: In high doses, codeine causes more nausea and vomiting than morphine among practical nurses, post-RN students, and RNs, however they found no statistically significant concordance among the groups. Ross et al. (1996) stressed the importance of identifying misconceptions within a group and targeting education towards that misconception, even if not statistically significant, as it demonstrates a meaningful difference.

ELNEC. The education intervention for the current study was based on the End-of-Life Nursing Education Curriculum (COH & AACN, 2014). This curriculum was developed by nationally recognized palliative care experts and is based on core areas outlined in the American Association of Colleges of Nursing 1998 publication Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care. These competencies are in accordance with the International Council of Nurses’ 1997 mandate “that nurses have a unique and primary responsibility for ensuring that individuals at the end of life experience a peaceful death” (American Association of Colleges of Nursing, 1998, para. 1). The curriculum is revised on a regular basis with recent revisions reflecting the following landmark documents: the 2013 National Consensus Project’s (NCP) Clinical Practice Guidelines for Quality Palliative Care, and the 2013 Institute of Medicine (IOM) Report entitled Delivering High Quality Cancer Care: Charting a New Course for System in Crisis (AACN, 2014).

Four studies that used the ELNEC curriculum in its entirety were retrieved for analysis. Sample sizes ranged from 38 (Whitehead, 2010) to 239 (Kelley & Mazanec, 2013). Study designs included quasi-experimental (Whitehead, 2010), a survey (Malloy, Virani, Kelly &
Munevar, 2010), a one-group pretest and posttest (Kim et al., 2011), and a qualitative design (Kelley & Mazanec, 2013). The researchers from these four studies evaluated ELNEC’s impact on different factors including the nurses’ death anxiety, concerns about dying, and knowledge of the dying process (Whitehead, 2010); nurses’ identification of difficult areas of palliative care conversations (Malloy et al., 2010); nurses’ knowledge of hospice and palliative care (Kim et al., 2011); and aspects of end-of-life care that are done well, opportunities for end-of-life care improvement, and what would you change about end-of-life care (Kelley & Mazanec, 2013).

Results from these studies revealed decreased death anxiety and concerns about dying in the treatment group ($p = 0.01$) (Whitehead, 2010); the areas of difficult communications include talking to patients after they had received bad news, talking with patients and families from different cultures, and talking about religious/spiritual issues (Malloy et al., 2010); increased knowledge, particularly among nurses that were not hospice and palliative care certified ($p = 0.055$) (Kim et al., 2011); and opportunities for improvement in palliative care with communication and staff education, but that access, comfort, and support are well done, and with the prevailing desire to initiate palliative care earlier in the process (Kelley & Mazanec, 2013).

Five studies utilizing components of the ELNEC curriculum, but not its entirety, were retrieved for analysis, as this was reflective of the current study. Samples sizes ranged from 20 (Robinson, 2012) to 112 (Lange, Mager, Greiner, & Saracino, 2011), none were controlled studies, but two were pre-test post-test design (Ersek et al., 2010; Mahler, 2010). Findings from these studies included reflection and experiential learning as essential for clinical practice effectiveness (Robinson, 2012); practicing assessment and communication skills were important in palliative care (Shawler, 2011); educating nurses aided them to address the needs of older
adults near the end-of-life (Lange et al., 2011); and training nurses to assess pain and distressing symptoms improved their performance (Mahler, 2010).

Collectively the researchers in these ten studies demonstrate the use of ELNEC either partially or completely with a wide range of sample sizes, in multiple methods of study designs, varying outcome measurements, and an array of results; however, none of the researchers in these studies employed the ELNEC Geriatric curriculum specifically and none measured self-efficacy. The current study also covered assessment and management of pain and other distressing symptoms as recommended by Mahler (2010); communication skills as recommended by Malloy et al. (2010), Kelley and Mazanec (2013), and Shawler (2011); provided staff education about palliative care as recommended by Kim et al. (2011) and Kelley and Mazanec (2013); in addition to allowing integration of content into practice, as recommended by Lange et al. (2011) and Robinson (2012), by having multiple education sessions over a period of weeks that permits reflecting on practice. Similar to that of Whitehead (2010), the current study used a quasi-experimental study design.

**Nursing Licensure**

The two main components determining nursing licensure are education level and scope of practice. Educational level of nurses is sparsely examined in the literature. Malmedal, Ingebrigtsen, and Saveman (2009) investigated the educational level of 616 nurses, among other factors, affecting the likelihood of reporting inadequate care in nursing homes and found that as educational level increased so did reports of observed and committed acts of inadequate care. Al-Hussami (2009) also investigated multiple factors, including the educational level of 60 nursing home nurses, to determine their influence on organizational commitment and discovered that higher educational level corresponded with a higher level of commitment. Similarly,
Nakahira, Moyle, Creedy, and Hitomi (2009) investigated the attitudes of 675 aged care staff of dementia patients with aggression and found staff that were older, had more clinical experience, and a higher level of education in these workers indicated more positive attitudes towards these patients. A fourth study by Dilles, Stichele, Van Rompaey, Van Bortel, and Elseviers (2010) investigated educational level as the only independent variable on the pharmacotherapeutic practices of 1,412 nurses across three settings, including the nursing home. In this cross-sectional correlation survey, nurses who held Bachelor’s degrees were more likely to have identified an adverse drug reaction. Interestingly Dilles et al. (2010) also reported that nursing home nurses were generally less educated and less involved in continuing education activities.

Despite the fact that the topics of these four studies were not directly related to the current study, these studies were conducted in the setting of interest and with the target population of interest and contributed supportive information to the current study. Although Dilles et al. (2010) reported that nurses working in long-term care were generally less educated than other clinical settings, it was also recognized that education level alone does not influence reporting activity, organizational commitment, or attitudes (Al-Hussami, 2009; Malmedal et al., 2009; Nakahira et al., 2009).

The second component of nursing licensure is scope of practice. LPN scope of practice variability by state nurse practice act was described by Corazzini et al. (2011) in their observational, cross-sectional, mixed-methods designed study. They found that greater permissiveness in LPN delegation and supervision resulted in poorer performance across eight Centers for Medicare and Medicaid Services (CMS) quality measures, whereas greater restrictiveness had the opposite effect. In a related study Mueller, Anderson, McConnell, Corazzini (2012) found that the majority of 142 LPNs surveyed in their cross-sectional,
observational, descriptive survey study operated outside their scope of practice primarily due to the unavailability of RNs to help with direct care. Some of these same researchers (Corazzini et al., 2013) went a step further in a qualitative study to describe practice behaviors related to assessment, care planning, delegation, and supervision and found three factors affecting behavior, namely the quality of connections between RNs and LPNs, the degree of interchangeability between RNs and LPNs, and RN-to-LPN staffing ratios. They concluded that failure to differentiate RNs from LPNs and optimize RN-LPN collaboration results in LPNs practicing beyond their scope.

Nursing licensure also affected staff mix in long-term care. In 2009, Park and Stearns investigated the impact of state minimum staffing standards on the level of staffing and quality of nursing home care and found sixteen states that increased their staffing above the federal minimum resulted in the reduction of restraint use and the number of total deficiencies. Kim, Harrington, and Greene (2009) similarly discovered a higher RN to LPN ratio translated into a decrease of total and serious deficiencies. However Bowblis (2011) concluded that minimum direct care staffing requirements has both positive and negative effects on care practices, but were generally associated with improved resident outcomes. Castle and Anderson (2011) then performed a large, longitudinal study to confirm their hypothesis that improving staffing characteristics, specifically RN to LPN ratio, improved overall quality of care. Harrington et al. (2012) further substantiated this notion in their international study of six countries including the United States, noting that staffing standards results in higher quality nursing home care.

In specific relation to self-efficacy, nursing licensure was rarely a correlated factor for analysis. Adriaansen et al. (2005) reported improved self-efficacy scores, greater for RNs than for LPNs, in their quasi-experimental designed study analyzing the effects of a palliative care
education course, but these findings were not statistically significant ($p > 0.20$). Smolen-Hetzel (2010) evaluated three emotional labor strategies, including geriatric caregiving self-efficacy for RNs, LPNs, and human service care workers (HSCW) in a cross sectional study of work stress and emotional exhaustion, but did not find job type (RN, LPN, HSCW) to be a statistically significant and therefore did not include it in regression analysis. However, Sheffer, Barone, and Anders (2011) reported a statistically significant pre-post difference ($p < 0.01$) in self-efficacy in their study on the effect of a brief tobacco use and dependence education intervention for Advanced Practice Nurses (APNs), RNs, and LPNs. These three studies demonstrated the lack of evidence to support or refute a connection between self-efficacy and licensure status. The current study contributed to this scant body of literature.

**Summary**

This integrated literature review covered the theoretical and empirical evidence to date about the theory of self-efficacy, the concept of self-efficacy, palliative care education as an intervention, the Palliative Care Quiz for Nursing, and nursing licensure. There were several important findings from this review. First the theory of self-efficacy is a sound, versatile theory that served as the theoretical framework for the current study. Second palliative care education as an intervention increases nurses knowledge, but the best predictor of behavior change is self-efficacy. Third ELNEC is a well-established, evidence-based curriculum used as the basis for the education intervention. Fourth nursing licensure is an important factor for analysis as it encompasses educational level, scope of practice, and contributes to staff mix, an element that impacts quality of care. And last, controlled studies provide stronger evidence of scientific merit.
As a result of this literature review, the current study contributed to the existing body of literature, largely based on its design, content, and delivery. There were a few studies about nurses that employed the theory of self-efficacy as the framework, and none that utilized a controlled design. There were a small number of studies that focused on the concept of self-efficacy as a measure of an educational intervention, of which only two employed a controlled design. More specifically about palliative care education, there were no studies in the literature that utilized a controlled design, further demonstrating a need for the current study in this area. One study used a quasi-experimental design for the evaluation of the entire ELNEC curriculum, but when only components of the curriculum were incorporated, none used a controlled design.

This literature review also demonstrated that none of the studies incorporated the four specific components of the ELNEC Geriatric curriculum that were selected for the current study. The delivery of the current study was also unique, as no studies delivered the content every other week, over a seven-week period. Another unique characteristic of the current study were the selected measurements of palliative care knowledge (PCQN) and palliative care self-efficacy (PCSES). One study measured both these concepts, but did not employ these specific instruments. The current study provided evidence to a growing area of research about the influence of a palliative care education intervention, specifically in increasing knowledge and self-efficacy of nurses practicing in long-term care.
Chapter 3: Methods

Introduction

The purposes of this study were to: (1) to evaluate the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care settings, and (2) to determine if there was a significant difference between registered nurses (RNs) and licensed practical nurses (LPNs) in palliative care self-efficacy. This chapter presented a detailed outline of the methods and procedures used in the study. The research design, sample and setting, institutional approval, data collection procedure, instrumentation, data analysis, and methods to ensure rigor were addressed. The following research questions guided this study:

1. What is the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care?

2. Is there a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care?

Design

This study used a pre-test post-test quasi-experimental design to evaluate the effects of the palliative care education intervention. The decision to stratify the study groups between two long-term care facilities reflects a strategy to decrease threats to internal validity that might arise by cross-group information sharing among nurses within a single location. (Polit & Beck, 2008).

Specific Aims and Major Hypotheses

1. Determine the influence of a palliative care education intervention in increasing the knowledge and self-efficacy of nurses practicing in long-term care
Hypothesis 1a. Nurses participating in the palliative care education program will demonstrate a higher level of knowledge related to palliative care compared to control group participants.

Hypothesis 1b. Nurses participating in the palliative care education program will report a higher level of self-efficacy related to palliative care compared to control group participants.

2. Determine whether there is a significant difference between palliative care self-efficacy among RNs and LPNs practicing in long-term care

Hypothesis 2a. RN’s will score higher than LPN’s on the pre-test self-efficacy scale.

Setting

The settings for this study included two large long-term care facilities in the northeastern region of the United States. The intervention facility was a 345-bed for-profit facility, located in an urban area, serving a primarily older population (age > 65), and employing approximately 80 nurses (RNs and LPNs). The control facility was a 360-bed for-profit facility, located in an urban area, serving a primarily older population (age > 65), and employing approximately 80 nurses (RNs and LPNs).

Recruitment

Volunteer participants were recruited from two long-term care facilities. One facility served as the intervention site and the other as the control. Following informed consent, baseline data was collected about all study participants, including demographic information, such as age, gender, race, level of education, and palliative care experience. Pre-test self-efficacy scores were also obtained prior to the intervention. The education intervention occurred over a seven-week
period at the intervention facility only. At the completion of the intervention, palliative care self-efficacy scores were obtained again at both intervention and control facilities.

Nurses from both facilities were recruited by two methods. The first method was through a flyer (Appendix C) distributed with pay stubs for nurses at two points, four weeks and two weeks prior to the start of the education intervention. The flyers were also posted on the nursing units and in the break rooms of the facilities. Nurses signed up with the education department to attend an information session that included lunch.

**Sample**

The target population was nurses, RNs and LPNs, practicing in long-term care. No specific age, race, ethnicity, level of experience or palliative care knowledge was targeted. Every effort was made to recruit an ethnically diverse sample of both genders. Based on a power analysis, a convenience sample of 80 nurses (40 nurses in the intervention group and 40 nurses in the control group) was needed to test the effectiveness of the intervention. The sample size for this study was 61 nurses at the participating long-term care facilities.

The primary dependent variable in this study was the PCQN instrument at the initial and 7-week post-intervention time points. The summary estimates for the standard deviation of the PCQN (±13.5) and for the pre-training/post-training correlation coefficient (+0.35) permitted calculation of the standard deviation for changes in PCQN scores across the training period. Based on an established formula, the standard deviation of changes in PCQN scores was found to be ±15.4. This standard deviation represented the typical variation from person-to-person in the change in PCQN score that occurs with training. Additionally, it provided a basis for conducting a power analysis for the planned study. If the PCQN has a comparable standard deviation when employed in the proposed study, the sample size objective of 80 participants supported an
estimation of differences in the mean PCQN score between the intervention and control
conditions at either the post-intervention time point with standard errors that were no more than
±2.0 in magnitude that was detectable with 80% power (assuming 2-sided testing and a 5% significance level).

**Sample Access**

At the intervention facility, the Medical Director, Administrator, and Director of Nursing granted permission to the researcher for recruitment of participants, data collection, and implementation of the intervention (Appendix G), and offered cooperation and support for this study. Likewise, the Vice President of Clinical Services, Administrator, and Director of Nursing at the control facility granted permission to the researcher for recruitment of participants and data collection, attention control condition (Appendix H), and offered their support and cooperation for this study.

**Inclusion and Exclusion Criteria**

Participants included in this study were: (1) RNs and LPNs employed at the control or intervention facility, (2) practicing including full-time, part-time, or per diem, (3) nurses who provide direct patient care and (4) those willing to attend all 4 education sessions. Participants excluded from this study were those that were unable to read and write in English, were unable to attend all four education sessions, or worked at both facilities.

**Protection of Human Subjects**

Written permission from both the intervention and control site, where an IRB does not exist, was also obtained. In addition, IRB approval was also obtained from the University of Connecticut prior to recruitment of participants.
Several steps were taken in an effort to protect the participants of this study. First a risk/benefit assessment was performed to determine if the risks of participation was reasonable and acceptable given the benefits (Polit & Beck, 2008). The potential benefits to participants of this study included increasing knowledge of palliative care and having a positive effect on the self-efficacy of nurses. Potential risks for study participants included overwhelming the nurses with too much information or increasing their stress level. This study involved minimal risk, meaning that the risks anticipated were no greater than those ordinarily encountered in everyday life or during routine physical or psychological tests or during procedures (Polit & Beck, 2008).

Once potential participants signed up with the education department indicating their interest in participating in the study, the student researcher reviewed the study protocol and obtained informed consent from each potential participant, answered any questions participants may have, and invited eligible nurses to participate. Potential participants were given all the time they need to decide if they would like to take part in the study. Participants were informed that they may withdraw from the study at any time, for any reason, and without consequences. Participants were also assured that the scores on the instruments were not reported on an individual basis and will not affect their employer-based performance evaluations. Participants were informed that this study was part of a Doctor of Nursing Practice (DNP) academic requirement. Informed consent was obtained with written and oral communication to ensure participant comprehension and documented using a consent form. See Appendix A for Informed Consent Form for the intervention group and Appendix B for Informed Consent Form for the control group.

Participants were also assured of strict confidentiality. Demographic data and instrument responses were coded by each participant with his/her month of birth, mother’s maiden name,
and town of birth. Participants were instructed not to write their name on any documents during the information or education sessions. The investigator then obtained informed consent from those nurses interested in participating in the study. The researcher and all participants retained a copy of the signed consent.

A debriefing session for all study participants took place at the end of this study to allow participants to ask questions and voice concerns. A copy of study findings was provided to both long-term care facilities.

**Procedure**

**Recruitment**

Upon approval of both IRBs, the study began. Participants were recruited for the study using two methods. An information flyer was posted on each unit and in the break rooms of both the control and intervention facilities. Also flyers were distributed through payroll distribution. Participants attended one of six information sessions offered over a two-day period. At the information sessions, participants were given the opportunity to ask questions and enroll in the study.

**Palliative Care Education Intervention**

The intervention consisted of four 45-minute education sessions as requested by the intervention facility. Session content was based on the End-of-Life Nursing Education Consortium (ELNEC) Geriatric Curriculum for which the researcher is a designated *ELNEC Trainer*. “The End-of-Life Nursing Education Consortium Project is a national end-of-life educational program administered by City of Hope (COH) and the American Association of Colleges of Nursing (AACN) designed to enhance palliative care in nursing” (City of Hope (COH) & American Association of Colleges of Nursing (AACN), 2014, para. 1). This nine-
module program is designed to be administered in either a complete 2-day workshop or as customized smaller education sessions, to meet the needs of the learners or accommodate different clinical settings. The education sessions were offered twice during all three shifts for two consecutive days, every other week over a seven-week period or as preferred by the intervention facility. The sessions were a combination of didactic lecture, interactive discussions, and role-playing, supplemented by Power Point slides and handouts. Lunch was provided for participants during the education sessions.

Palliative care education session 1 (Appendix M) was held on week 1 for 45 minutes during participants’ designated lunch break. The focus of this session was on general principles of palliative care based on “Module 1: Principles of palliative care” (COH & AACN, 2014). The objectives of session 1 were to:

1. Understand the goals of palliative care
2. Identify patients that would benefit from palliative care
3. Consider spiritual, cultural, ethical, and supportive components of palliative care

Palliative care education session 2 (Appendix N) was held on week 3 for 45 minutes during participants’ designated lunch break. The focus of this session was on pain management in palliative care based on “Module 2: Pain assessment and management” (COH & AACN, 2014). The objectives of session 2 were to:

1. Determine sources, causes and descriptors of pain
2. Identify methods of pain assessment
3. Recognize methods for treating and evaluating pain, including pharmacological and non-pharmacological
Palliative care education session 3 (Appendix O) was held on week 5 for 45 minutes during participants’ designated lunch break. The focus of this session was on symptom management in palliative care based on “Module 3: Non-pain symptoms at the end of life” (COH & AACN, 2014). The objectives of session 3 were to:

1. Identify other common symptoms experienced by patients in palliative care, such as nausea, vomiting, dyspnea, fatigue, and anxiety
2. Recognize methods for assessing these symptoms
3. Discover approaches for symptom management

Palliative care education session 4 (Appendix P) was held on week 7 for 45 minutes during the participants’ designated lunch break. The focus of this session was on communication in palliative care based on “Module 6: Communication” (COH & AACN, 2014). The objectives of session 4 were to:

1. Summarize communication techniques with patients and families
2. Indicate communication methods with other healthcare providers and the larger community
3. Understand how to communicate palliative care principles and practices

Attention Control Condition

Using an attention control condition for the control group gave participants a sense of participation (Polit & Beck, 2008). In this study, participants at the control facility were invited to attend four sessions in a similar pattern to the intervention group. The four information sessions were: (1) participants received study information, enrolled in the study, completed the demographic sheet, and completed pre-test PCQN and PCSES, (2) participants received a handout about overall assessment of an older adult (Appendix K), (3) participants received a
handout about independence of activities of daily living (Appendix L), and (4) participants completed the PCQN and PCSES.

**Instruments**

**Demographics**

The demographic form (Appendix D) was completed by each participant after obtaining informed consent and before the intervention for the purposes of describing the sample and to determine the level of education and nursing licensure. Data collected included age, gender, race, ethnicity, palliative care education experience, years of nursing experience, years of long-term care experience, nursing licensure, primary language, and highest education degree.

**Palliative Care Quiz for Nursing**

The Palliative Care Quiz for Nursing (PCQN) is a validated 20-item true, false, and ‘I don’t know’ test of knowledge that takes approximately twenty minutes to complete. It is used to assess knowledge, stimulate discussion, and identify misconceptions about palliative care nursing (Ross et al., 1996). The test consists of four items about philosophy and principles, thirteen items about pain and symptom management, and three items about the psychosocial aspects of care. Ross et al. (1996) reported the item-to-total correlation coefficient was more than 0.2; internal consistency was 0.78, indicating homogeneity for the quiz; the test-retest reliability correlation coefficient was 0.56; the item discrimination index was greater than 0.50, and the item difficulty index was between 0.2 and 0.8 in their 1996 validation study (Autor, Storey & Ziembka-Davis, 2013). Possible scores on the PCQN range from 0 to 20, as answers are coded as 1 for a correct answer, and 0 for an incorrect or ‘I don’t know’ responses. A higher score corresponds with more knowledge. During the validation study of 396 participants, Ross
et al. (1996) reported scores in mean percentages by respondent type: generic students (46%),
registered practical nurses (60%), post-RN students (65%) and registered nurses (75%).

The PCQN (Appendix F) was completed by intervention group participants after
informed consent was obtained and at the completion of the fourth education session. For the
control group, the PCQN was completed after informed consent and at the fourth information
session.

Palliative Care Self-Efficacy Scale

The Palliative Care Self-Efficacy Scale (PCSES) was validated by Phillips et al. (2011)
who conducted their study on a large sample size of 405 nurses and care assistants working in
long-term care. Their multi-faceted intervention of the creation of link nurse roles, short
palliative care courses, and regular case conferencing, resulted in the validation of the PCSES.
First, the researchers determined Bartlett’s test of Sphericity was significant ($p < 0.001$), and the
Kaiser-Meyer-Olkin measure of sampling adequacy was 0.914, confirming the use of principal
component or factor analysis. Next, they calculated a cut-off of 0.4 for determining significant
factor loading. Two factors with eigenvalues greater than 1.0 were extracted, accounting for a
total variance of 65.3%. They were ‘perceived capability to answer patient’s end-of-life care
concerns’ and ‘perceived capability to patient’s end-of-life symptoms,’ accounting for 54.6%
and 10.7% of the total variance respectively. They also surmised the subject to item ratio of 10:1
which was used to determine a priori sample size with a minimum of 120 cases required for
principal component analysis. And finally, the authors calculated a Cronbach’s alpha for the
scale and subscales that ranged from 0.87 to 0.90 that demonstrates good reliability.

The PCSES has not been used in other studies to date, likely since it is a relatively newly
validated instrument. It was selected for this study due to its brevity and simplicity. The authors
also discovered that the PCSES was able to discriminate between differing workforce educational levels while being sensitive to changes overtime. Given the significant diversity of nurses and staff practicing in long-term care, the ability of this scale to make this distinction was quite relevant, as previously developed self-efficacy scales for palliative care have not been sensitive enough to make this distinction. Finally this scale measures self-efficacy, an important predictor of behavior change.

The Palliative Care Self-Efficacy Scale (PCSES) (Appendix E) was completed before the intervention began and after the intervention ended for the intervention group. For the control group, participants completed the PCSES at the first session and at the conclusion of the fourth session. The PCSES is a validated 12-item instrument designed to measure participant’s perceived self-efficacy to handle psychosocial support and symptom management of palliative care. Each item is closed-ended with the choice of four interval levels of confidence for the participant to indicate. The four choices are: (1) need further basic instruction, (2) confident to perform with close supervision/coaching, (3) confident to perform with minimal consultation, or (4) confident to perform independently. A higher score is interpreted as greater self-efficacy.

**Treatment of Data**

**Planned Data Management Tools**

Data was entered and analyzed using the Statistical Package for Social Sciences (SPSS) 21.0.0 for Windows.

**Data Management**

The researcher kept all study records (including any codes to data) locked in a secure location inside the researcher’s locked home office. Research records were labeled with a code. The code was derived from a sequential three-digit number that reflects how many people have
enrolled in the study. The master key will be destroyed after 3 years. All electronic files (e.g.,
database, spreadsheet, etc.) containing identifiable information was password protected. Any
computer hosting such files also had password protection to prevent access by unauthorized users.
Only the student researcher had access to the passwords. Data that was shared with others was
coded as described above to help protect participants’ identity. At the conclusion of this study, the
researcher may publish the study findings in aggregate form. Information will be presented in
summary format and will not identify individual participants in any publication or presentation. All
data will be destroyed after five years.

**Planned Analysis**

Descriptive statistics were used to analyze demographic data and describe the sample.
Frequencies and percentages were computed for categorical variables and means and standard
deviations were computed for continuous variables.

Research Question 1: What is the influence of a palliative care education intervention in
increasing knowledge and self-efficacy of nurses practicing in long-term care?

For research question 1, means and stand deviations were calculated for pre-test and post-
test scores of both intervention and control groups. Paired $t$ tests were used to analyze the
difference scores ($d$) of the pre-test and post-test scores within each group, with a $p < 0.05$
determining significance. Independent sample $t$ tests were then used to compare the means of
the intervention and control groups, with a $p < 0.05$ to determine significance. The $t$ test is an
appropriate test for this data set because it measures the variance within in each group, the
degree of separation between groups, and is frequently used to evaluate smaller samples (Portney
& Watkins, 2009).
Research Question 2: Is there a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care?

For research question 2, mean scores and standard deviations were calculated for RNs and LPNs within each group. Independent sample $t$ tests were used to compare pre-test means of RNs and LPNs. Analysis of covariance was used to determine if there were differences in the self-efficacy mean scores between RNs and LPNs after controlling for site, age, and years of practice. A $p < 0.05$ was considered statistically significant.

**Summary**

In this chapter, study design, methodology and analysis were discussed in detail to provide the reader with a clear understanding of the study. This two-group quasi-experimental pre-test post-test designed study consisted of intervention and control groups with 61 nurses selected from two long-term care facilities. Both groups had knowledge and self-efficacy scores measured at two points: prior to the intervention and at approximately seven weeks later. The intervention group received customized palliative care education, consisting of four 45-minute sessions. The control group received an attention control condition. Descriptive and inferential statistics were used to analyze data.
Chapter 4: Results

Introduction

This chapter presents the findings of this quasi-experimental study designed to evaluate the influence of an educational intervention on long-term care nurses’ knowledge and self-efficacy related to palliative care. The primary aim of this pre-test post-test study was to determine the influence of a palliative care education intervention on increasing knowledge and self-efficacy of nurses practicing in long-term care compared to their control group counterparts. A secondary aim was to determine if there was a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care. A demographic profile of the study participants will be presented. Results associated with the two research questions are described. Research question 1 was evaluated using paired t tests to determine group differences in knowledge and self-efficacy related to palliative care between intervention and control group participants. Research question 2 was assessed using analysis of covariance (ANCOVA) to determine if there are differences in the self-efficacy mean scores between RNs and LPNs after controlling for site, age, and years of nursing experience.

Data Collection

Data collection occurred over a four-month period from October 2014 to January 2015. The setting for the study was two long-term care facilities in Connecticut. Each facility employs approximately 80 nurses. At the intervention site, face-to-face contact was made with 65 nurses and 40 nurses agreed to participate. The most common reasons for not participating included being too busy and not interested. After informed consent was obtained, participants completed a demographic questionnaire, the Palliative Care Self-Efficacy Scale, and the Palliative Care Quiz for Nursing. At the control site, face-to-face contact was made with 60 nurses and 34
nurses agreed to participate. Similar reasons for not participating were given. Consistent with the intervention group protocol, participants at the control site completed informed consent, the demographic questionnaire, the Palliative Care Self-Efficacy Scale, and the Palliative Care Quiz for Nursing.

The intervention consisted of four palliative care education sessions, delivered every other week over a seven-week period. The control group received an attention-control condition that consisted of handouts related to geriatric care, every other week over a seven-week period. At the last session for each group, participants completed the post-test Palliative Care Self-Efficacy Scale (PCSES) and the Palliative Care Quiz for Nursing (PCQN). Figure 1 displays the flow of participants in the study.
Description of Sample

Seventy-four nurses were recruited into the study and 61 completed the study (33 in the intervention group and 28 in the attention-control group). A demographic profile of study participants is presented in Table 1. The typical participant in the intervention group was a female (85%) between the ages of 45-54 (28%) or 35-44 (28%). Most were White (42%), and reported an Associates Degree (42%) as their highest level of education. The majority were RNs (61%) with 20 or more years of nursing experience (30%). Almost all of the nurses identified previous training in palliative care; the most common sources of education were on the job training (79%) and facility in-services (70%).

The typical participant in the attention-control group was a female (85%) between the ages of 35 and 54 (61%). Most were African-American (50%) and reported an Associate’s Degree (29%) as their highest level of education. The majority were LPN’s (89%) with 8 to 11 years of nursing experience (39%). Almost all of the nurses identified previous training in palliative care; the most common sources of education were on the job training (75%) and facility in-services (75%).

To identify potential differences in intervention and control group participants, analyses were conducted to compare the groups on demographic variables. The principal difference between the groups was licensure. A significantly greater number of nurses in the intervention were RNs as compared to the control group ($p < .001$). Another difference between groups was previous palliative care education. Nurses in the control group tended to have more palliative care continuing education than their intervention group counterparts ($p = .02$).
Table 1

Demographic Characteristics of Study Participants

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<th>Control Frequency</th>
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*p < 0.05
Results

Demographic and clinical variables were summarized as mean and standard deviation for continuous variables and as count and percentage for categorical variables. Before hypothesis testing, descriptive statistics were computed for all study variables using the Statistical Package for the Social Sciences for Windows (Version 21.0; SPSS Inc., Chicago, IL) and data was examined for random and systematic missing data. No systematic missing data were found; random missing data were minimal and handled using median substitution.

Research Question Number One

Research Question 1: What is the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care?

Nurses in the intervention group demonstrated a significant increase in knowledge ($t = 5.897$, $df = 32$, $p < .001$) and self-efficacy ($t = 4.163$, $df = 32$, $p < .001$) related to palliative care following the intervention compared to control group participants. Mean score correct and standard deviation (SD) for the pre-test PCQN were 11.2 (2.83) (range 6-17) and post-test PCQN were 13.6 (2.64) (range 8-18). On the PCSES, the mean (SD) level of palliative care self-efficacy was 39.9 (6.69) on pre-test and 44.1 (4.08) on post-test.

In the control group, the mean score correct and standard deviation (SD) for the pre-test PCQN were 11.2 (2.15) (range 6-13) and post-test PCQN were 11.3 (2.59) (range 4-16). Paired t-test indicates no significant difference in participants’ pre-test and post-test PCQN scores ($t = .172$, $df = 27$, $p = .86$). On the PCSES, the mean (SD) level of palliative care self-efficacy was 41.5 (3.37) on pre-test and 40.1 (8.89) on post-test. Paired t-test indicates no significant difference in participants’ pre-test and post-test PCSES scores ($t = -.746$, $df = 27$, $p = .46$).
Independent samples $t$-test comparing pre-test and post-test means and standard deviations of the intervention and control groups indicate significance at the .05 level for palliative care knowledge ($t = 3.960, df = 59, p < .001$) and self-efficacy ($t = 2.667, df = 59, p = .01$). Table 2 displays the pre- and post-intervention scores for PCQN and PCSES in the intervention and control groups.

<table>
<thead>
<tr>
<th>Outcome Variable</th>
<th>Baseline Mean (SD)</th>
<th>Post-Intervention Mean (SD)</th>
<th>$T$-Test Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Knowledge</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention Group</td>
<td>11.2 (2.83)</td>
<td>13.6 (2.64)</td>
<td>$&lt; .001$</td>
</tr>
<tr>
<td>Control Group</td>
<td>11.2 (2.15)</td>
<td>11.3 (2.59)</td>
<td>.86</td>
</tr>
<tr>
<td>Palliative Care Self-Efficacy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intervention Group</td>
<td>39.9 (6.69)</td>
<td>44.1 (4.08)</td>
<td>$&lt; .001$</td>
</tr>
<tr>
<td>Control Group</td>
<td>41.5 (3.37)</td>
<td>40.1 (8.89)</td>
<td>.46</td>
</tr>
</tbody>
</table>

* $p < 0.05$

**Research Question Number Two**

Research Question 2: Is there a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care?

Using independent samples $t$-test analysis, there was no significant difference between RNs’ and LPNs’ palliative care self-efficacy ($t = -0.796, df = 59, p = .43$). A series of three ANCOVAs was then performed to determine if the lack of difference between RNs and LPNs might reflect confounding due to imbalances in the frequencies of sites, years of practice categories, or age groups among RNs versus LPNs. There was no significant difference in palliative care self-efficacy between RNs and LPNs when adjusting for site, $F(1,58) = 0.61, p = .81$; when adjusting for years of nursing experience, $F(1,54) = 0.331, p = .57$; or when adjusting
for age, $F(1,54) = .562, p = .46$. Palliative care self-efficacy mean scores (SD) were 39.8 (6.22) for RNs and 40.8 (5.05) for LPNs.

![Figure 2. Self-Efficacy of RNs and LPNs](image)

**Summary**

In this chapter, data collection was discussed, the sample was described, and data was evaluated using SPSS 21 for statistical analysis. The results of this quasi-experimental pre-test post-test study were presented. The sample consisted of 61 nurses (33 intervention, 28 control), who were mostly female (85%), age 45-54 (30%), white (38%), and held an Associate’s degree (36%). Twenty-three nurses (38%) were RNs and 38 nurses (62%) were LPNs. The primary aim of this study was to determine the influence of a palliative care education intervention on increasing knowledge and self-efficacy of nurses practicing in long-term care. Nurses in the intervention group demonstrated a significant increase in palliative care knowledge ($t = 5.897, df = 32, p < .001$) and self-efficacy ($t = 4.163, df = 32, p < .001$) following the intervention compared to control group participants. A secondary aim was to determine if there was a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-
term care. No significant differences were found in palliative care self-efficacy between RNs and LPNs.
Chapter 5 Discussion

Introduction

This chapter presents a summation and discussion of this quasi-experimental study designed to test the effect of a palliative care educational intervention. The primary aim of this pre-test post-test study was to determine the influence of a palliative care education intervention on increasing knowledge and self-efficacy of nurses practicing in long-term care. A secondary aim was to determine if there was a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care. In addition to findings, an evaluation of the theoretical framework, the theory of self-efficacy, is also presented. Limitations of the study are described. Conclusions and implications along with recommendations for education, practice, administration, and future research are included.

Study Summary

Sixty-one nurses participated in this quasi-experimental pre-test post-test study. Thirty-three nurses were included in the intervention group and 28 nurses made up the control group. The intervention consisted of four education sessions, with content derived from End-of-Life Nursing Education Consortium, Geriatric Curriculum (COH & AACN, 2014). Sessions were held every other week, over a seven-week period, on all three shifts, for two days each week. The control group received an attention-control condition consisting of general geriatric care education in a similar fashion to the intervention group. Nurses in the intervention group demonstrated a statistically significant increase in palliative care knowledge and self-efficacy. No significant difference in palliative care self-efficacy was found between RNs and LPNs.

Discussion of Findings
In this section, findings are discussed including the statistics about the sample, the impact of palliative care education on knowledge and self-efficacy, and the difference in self-efficacy between RNs and LPNs. The two dependent variables, scores on Palliative Care Quiz for Nursing and Palliative Care Self-Efficacy Scale, are also discussed.

Sample

The sample as a whole was largely LPNs (62%), but a statistically significant difference was noted between the licensure of the participants in the intervention and control groups ($p < .001$). Three RNs participated in the control group, whereas twenty RNs participated in the intervention group. It is unknown why more RNs from the control group facility did not participate. Another significant difference pertained to continuing education ($p = .01$). Only one nurse (3%) from the intervention group and seven nurses (25%) from the control group reported continuing education related to palliative care, where credit is earned after completion of a specified education activity. This significance is likely related to the small sample size. Since licensed nurses in Connecticut are not mandated to complete continuing education for license appointment or renewal, many nurses do not pursue continuing education activities. Both facilities require annual in-house training in many areas of care, but palliative care is not one of those areas.

Of note ten intervention group nurses categorized their race as *other*, a statistically significant difference. A few participants reported that they are from Jamaica and therefore are not African American. An unknown number of nurses also categorized their highest level of education as *other* because they did not receive any kind of degree from LPN school.

**Research Question Number One**
What is the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care?

The findings of this study support the effectiveness of an education intervention in increasing nurses’ knowledge and self-efficacy related to palliative care. Nurses participating in the intervention group demonstrated a significant increase in palliative care knowledge and self-efficacy following the intervention compared to control group participants.

**Palliative care knowledge.** Nurses’ pre-test mean score was 11.2 for both groups. This is slightly lower than a reported mean of 12.2 for the 396 nurses who participated in Ross et al.’s 1996 instrument validation study. A more comparable mean RN score of 11.7 was reported by Ronaldson et al. (2008) in their cross sectional study that did not include LPNs. Similarly, Brazil et al. (2012) reported mean scores at four different long-term care facilities of 10.5, 12.3, 12.6, and 12.7 in their survey of RNs and LPNs. Nurses participating in this study scored within the range of means from prior studies conducted in the long-term care setting. However these results highlight the need for more palliative care education, as nurses are not fully knowledgeable about palliative care.

An important finding was a significant increase in palliative care knowledge experienced by nurses in the intervention group following an education intervention. Scores improved by 2.4 points, a 12% increase by intervention group nurses. This finding is corroborated by Adriaansen et al.’s (2005) variant PCQN that found a significant increase in palliative care knowledge of the 27 intervention group nurses, who received an education intervention of four 8-hour sessions over a two-month period ($p = .03$). Kim et al. (2011) reported similar results in their one-group pre-test/post-test study of 111 Korean RNs who attended a two-day ELNEC core program. These nurses improved by 1.0 point on the PCQN, a statistically significant finding ($p < .001$).
As demonstrated in the present study and corroborated by prior research, education interventions targeting palliative care have a positive and significant impact on nurses’ knowledge.

**Palliative care self-efficacy.** Pre-test mean self-efficacy scores were 39.9 and 41.5 for intervention and control group nurses respectively. This is notably higher than for the 29 RNs who participated in Phillips et al.’s (2011) instrument validation study whom reported a self-efficacy of 34.2. It is unknown if those nurses had prior palliative care experience, but nurses in the present study reported a high rate of on-the-job training (75%) that most likely contributes to their high self-efficacy. Nonetheless a higher level of knowledge would complement this high level of self-efficacy and expectantly translate to better palliative care.

Another important finding of this study is the significant increase in palliative care self-efficacy following the intervention. Intervention group nurses self-reported an increase of 5.3 points, a 10.8% increase following the intervention. Similarly Phillips et al. (2011) reported a 6.5-point increase (13.5%) by RNs following a multi-faceted intervention with a post-test score of 38.7. This post-test score is lower than the pre-test scores of both groups in the present study. As stated by Phillips et al. (2011), “Self-efficacy is a predictor of both individual and professional behaviours, as well as influencing the effort and commitment applied to achieving a target behaviour which can be positively influenced by education” (p. 1097).

**Palliative care education.** The ELNEC Geriatric curriculum (COH & AANC, 2014) is an internationally recognized education initiative to improve palliative care. Trained faculty are permitted to tailor education sessions utilizing ELNEC materials. The researcher was able to customize four education sessions to meet the needs of the intervention facility, as similarly done by Robinson (2012), Lange et al. (2011), Ersek et al. (2010), and Mahler (2010). Topic areas were discussed with and selected by the intervention facility staff educator. Important concepts
included general principles of palliative care, as suggested by Kim et al. (2011) and Kelley and Mazanec (2013); pain assessment and management, as suggested by Mahler (2010); non-pain symptom assessment and management, as suggested by Mahler (2010); and, communication, as suggested by Malloy et al. (2010), Kelley and Mazanec (2013), and Shawler (2011). There are no other published studies that evaluate the influence of an education intervention on palliative care knowledge and self-efficacy about these four specific topics.

The spacing of the education sessions was also an important part of this study. Sessions were scheduled every other week for two days each week and offered multiple times on each shift. This allowed nurses from all shifts as well as nurses who were not full-time to participate. This flexible format permitted nurses to integrate small amounts of information into practice after each session, as recommended by Lange et al. (2011) and Robinson (2012). The importance of the spacing was influenced by nurses’ experience applying the bits of information between each session and demonstrated sources of self-efficacy.

**Research Question Number Two**

Is there a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care?

The findings of this study do not demonstrate a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care. Palliative care self-efficacy mean scores were 39.8 for RNs and 40.8 for LPNs. These scores are in contrast to findings in Phillips et al.’s (2011) instrument validation study where RNs self-reported higher self-efficacy than LPNs (34.2 and 32.3 respectively).

Self-efficacy did not correlate to knowledge in the present study. Although LPNs were more confident, they were less knowledgeable (M = 10.7) about palliative care than RNs (M =
12) and the difference was significant ($p = .05$). This is an important finding because LPNs provide the majority of patient care in the long-term care setting, whereas RNs primarily supervise. Helping LPNs and RNs become fully knowledgeable about palliative care will further enhance their self-efficacy to improve patient outcomes.

**Evaluation of Theoretical Framework**

The theory of self-efficacy (Bandura, 1997) was an appropriate guiding framework for this study. The premise of the framework is that as newly gained knowledge about palliative care is applied nurses will experience an increase in self-efficacy, which was demonstrated in this study. Participants gained new palliative care knowledge over a period of time. During that time, participants acquired new clinical experiences related to palliative care. Together new knowledge and experience was translated into an increased perceived ability, self-efficacy, to perform palliative care. Although this study did not measure the performance of palliative care, it did measure the self-efficacy to perform such care.

The four sources of self-efficacy are contributing factors to this study. Enactive attainment is when participants are able to achieve mastery of an experience. Participants shared experiences of trying out non-pharmacological interventions to provide comfort for patients, and related how easy it was to do. Vicarious experience is similar to social modeling where participants feel more confident as a result of watching another perform a task. Nurses reported they felt more confident about having difficult conversations after observing another nurse communicating with angry family members about a patient’s recent functional and cognitive decline. Verbal persuasion occurs when participants provide support to one another and this was also demonstrated in this study. One nurse reported support from another nurse when she was advocating for more pain medication from the provider. Physiological feedback is the response
that occurs during a situation. Nurses reported feeling very nervous about administering sublingual morphine in that it may cause the patient’s demise. After the education session about pain management, these nurses reported feeling more comfortable with morphine.

These are just a few examples of how the theory of self-efficacy was relevant and applicable to the present study. If a similar study is conducted, this theory is an appropriate and sound theory to utilize as a framework. Nurses were able to show an increase in self-efficacy but also reported experiences that correlated to the sources of self-efficacy.

**Limitations**

Limitations of this study included study design, sample size, and the number of education sessions. The study was a quasi-experimental design therefore it lacked randomization. Randomization was not possible in this study as nurses were employed at two distinct and separate long-term care facilities. Attempts to randomize participants would have likely caused contamination of the experimental group. The use of a convenience sample restricts the generalizability beyond the population from which the data were drawn. However this study design was purposely selected to avoid cross-contamination of participants by stratifying the study groups between two long-term care facilities.

This study also had a small sample size. Seventy-four nurses were enrolled and sixty-one completed the study. This small sample size translates to a small effect as a power analysis determined an objective sample size of 80 participants was needed to test the effectiveness of the intervention. A future study with multiple facilities will increase the sample size, allow for randomization, and increase the generalizability of study results.

Another limitation of this study was the number of education sessions. It was challenging to maintain interest and commitment after the second session. Sessions were offered
during designated break periods and food was served, however, nurses frequently reported they were too busy to participate. Nurses consistently reported a concern about punching out late if they attended the session.

**Utilization of Findings**

This study highlights the importance of palliative care in the long-term care setting. The long-term care population is expected to increase and so will their need for palliative care. As life expectancy increases, so will the number of people living with chronic, serious medical conditions that limit their ability to live independently. With the palliative care goals to relieve suffering and improve quality of life, nurses educated in palliative care will help patients with serious, life-limiting illnesses.

Findings from this study also underscore the need that nurses working in long-term care need palliative care education. Also, nurses working in long-term care lack accurate knowledge about palliative care. Nurses need to be able to identify patients that will benefit from palliative care and advocate for such care. The education intervention specifically about palliative care did increase knowledge and self-efficacy. LPNs reported higher self-efficacy than RNs, a finding worth further investigation, especially since this self-efficacy did not correlate to a high level of knowledge.

**Implications**

There are many implications pertaining to education, practice, administration, and future research.

**Implications for Nursing Education**

The findings of this study indicate that long-term care nurses have a general knowledge base of palliative care (56% correct responses), but substantial room for improvement exists in the
topic areas examined in the survey. Nurses in this study had the least knowledge on “Item 12: The philosophy of palliative care is compatible with that of aggressive treatment.” The results of this study help confirm the need to develop educational programs for nurses in palliative care, which may lead to improved quality of patient care and outcomes. In addition, findings suggest that not all nurses feel comfortable about the care needed for terminally ill patients. At each level of nursing education, specific goals and guidelines are outlined to ensure competency in palliative care prior to graduation.

- The National League for Nursing (2014) endorses a palliative care LPN competency under the program outcome “Human Flourishing”
- The American Association of Colleges of Nursing Essentials of Master’s Education in Nursing (2011) further the Baccalaureate palliative care competency as their education prepares graduates to influence the delivery of healthcare across a variety of roles, settings, and the lifespan.

Research validates this concern that students are not prepared to provide palliative care in their educational programs. Pope (2013) reported an inability to meet AACN’s Baccalaureate Essentials as evidenced by lack of palliative care knowledge among the 72 junior and senior nursing students who score an average 61% on the PCQN. Shea, Grossman, Kazer and Lange (2009) similarly reported low palliative care knowledge among 36 graduate nursing students who believed, “that the treatment they provide should have the goal of prolonging life over maintaining quality of life” (p. 187).
There is a crucial need for both students and faculty to be educated in palliative care. Nurse educators can begin by assessing the current curriculum to identify courses that have already integrated palliative materials, and courses that would benefit from the integration of palliative care materials. It would also be beneficial to determine other courses that can include palliative care content in creative ways that will encourage learning. Results of this study using an adapted ELNEC curriculum can be applied as a learning tool in several ways to address the lack of palliative care education in nursing.

- LPN educators can assimilate palliative care content into courses and clinical practicum to meet the “Human Flourishing” program outcome
- Undergraduate educators can integrate palliative care content into case studies, role playing, and lecture material in courses that have a clinical component so that material can be utilized within the patient care setting with an emphasis on understanding the philosophy of palliative care
- Graduate program educators can weave palliative care content through the fabric of a program to address advanced role development and clinical practice
- The addition of palliative care content to licensure examination

Once employed, staff development directors need to continue nurses’ palliative care education. Meier (2015) highlights the many barriers of palliative care integration into long-term care, including staff that is chronically under resourced, understaffed and experiences poor retention. In addition, the high demand for regulatory compliance, poor pay, and lack of career progression perpetuate this precarious situation. These stressors only exacerbate the problem of staff learning about and implementing palliative care. Staff development directors are...
challenged to overcome these barriers to improve patient care quality and outcomes (Meier, 2015).

- Staff development directors can host in-services, conferences, and incorporate palliative care competencies into mandated annual training.

**Implications for Nursing Practice**

It is evident from the present study that nurses are not fully knowledgeable about palliative care. The American Association of Colleges of Nursing (1998) already developed palliative competencies that can and should be incorporated into nursing care. Interdisciplinary collaboration is one of these competencies and is essential in long-term care. All members of the healthcare team play an important role in the delivery of palliative care. A few examples are (AACN, 1998, para. 6):

- “Promote the provision of comfort care to the dying as an active, desirable, and important skill, and an integral component of nursing care”
- “Collaborate with interdisciplinary team members while implementing the nursing role in end-of-life care.”
- “Assess and treat multiple dimensions, including physical, psychological, social and spiritual needs, to improve quality at the end of life.”

The National Consensus Project (2013) provides evidence-based guidelines for healthcare providers through eight domains of care. This document details vital quality measures to track and monitor outcomes. Nurses serve as the core component of the interdisciplinary team (IDT) by ensuring application of guidelines.

- Nurses ensure palliative care initial recurring assessment and documentation is completed by the IDT
• Nurses provide pain and non-pain symptom assessment and management, advocating for patient comfort
• Nurses promote patient and family coping and quality of life

Implications for Nursing Administration and Policy

In order for the provision of palliative care to reach its full potential, it must be supported by nursing administrators by allowing release time to attend sessions. Long-term care facilities need to adopt and implement a policy for palliative care, for example “comfort measure only” order set and nursing care plan (The Joint Commission, 2014) demonstrating their commitment to quality care (Agency for Healthcare Research and Quality, 2013).

• The development of policies that create a context for palliative care using the adapted ELNEC curriculum in this study
• The creation of task force and unit committees that implement palliative care initiatives
• The tracking of the delivery of palliative care in diverse patient populations

The Agency for Healthcare Research and Quality (AHRQ) (2013) tracks five quality measures related to palliative care: relief of suffering, help with emotional and spiritual needs, effective communication, and quality palliative care. Connecticut was not able to achieve the 96.5% benchmark for patients that did receive end-of-life care consistent with their wishes. Furthermore, Connecticut was unable to achieve the benchmarks for relief of suffering, including shortness of breath (68%) and moderate to severe pain (91.9%); help with emotional and spiritual needs (93.6%); and, effective communication (89%) (AHRQ, 2013). As long-term care facilities strive for their 5-Star Nursing Home Quality rating (CMS, n.d.), implementing palliative care practices then becomes the standard of care, rather than the exception.

Implications for Nursing Research
Research applications of this study are numerous and varied. They include:

- Research examining the influence of palliative care education on nurses' knowledge and self-efficacy with diverse nursing populations in several long-term care facilities
- Randomized controlled trials to confirm a causal relationship between knowledge and self-efficacy, and increase the generalizability of results to a larger population
- Multivariate studies to determine relationships among palliative care with several patient outcome indicators
- Qualitative analysis of nurses' understanding of the philosophy of palliative care, but also the meaning of palliative care to nursing practice
- Longitudinal studies of the effect of nurses' self-efficacy on quality measures

**Summary**

In this chapter, the discussion of findings was presented, including important characteristics of the sample and the research questions. Palliative Care Quiz for Nursing and palliative care self-efficacy scores were also discussed. The theory of self-efficacy was evaluated as an appropriate and helpful framework for this study. Study limitations included a nonrandomized study design, a small sample size, and the number of education sessions. Utilization of findings in long-term care was discussed. Implications for nursing education, practice, administration and research were also examined.

**Conclusion**

Six million people in the United States need palliative care today. Nearly two million people live in long-term care, where they suffer from chronic, life-limiting illnesses. The primary aim of this pre-test post-test study was to determine the influence of a palliative care education intervention on increasing knowledge and self-efficacy of nurses practicing in long-
term care. A secondary aim was to determine if there was a significant difference in palliative care self-efficacy between RNs and LPNs practicing in long-term care. A statistically significant improvement in knowledge and self-efficacy of the intervention group was noted during paired t-test ($p < .001$). A statistically significant difference was noted between groups on both measures during independent t-test ($p < .001$). When controlling for site, age, and years of nursing experience using ANCOVA, there was not a significant difference between RNs and LPNs self-efficacy ($p = .2$). This study contributes to the limited body of literature focusing on nurses practicing in long-term care. Further research is needed to address specific knowledge deficits in palliative care, and to determine if palliative care educational programs for nurses would enhance and sustain nurses’ knowledge of palliative care management.
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Appendix A: Informed consent for intervention group

Consent Form for Participation in a Research Study

Principal Investigator: Colleen Delaney RN, PhD, AHN-BC

Student Investigator: Yvonne Joy, MSN, APRN

Study Title: The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care

Introduction

You are invited to participate in a research study to determine the influence of a palliative care education intervention in increasing knowledge and self-efficacy. You are being asked to participate because you are a nurse who practices in long-term care.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and to discuss it with your family, friends and colleagues. We also encourage you to ask questions now and at any time. If
you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form.

Why is this study being done?

This study seeks to determine the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care. Study participants must be: (1) a RN or LPN that practices full-time, part-time, or per diem, (2) provides direct patient care, and (3) willing to attend all four education sessions over a seven week period.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will be asked to do the following:

- The researcher will meet with you at the beginning and end of study and ask you to complete:
  - a demographic questionnaire- at the first session (will take about 5 minutes)
  - a palliative care knowledge questionnaire – at the first and last sessions (will take about 10 minutes)
  - a palliative care self-efficacy questionnaire – at the first and last sessions (will take about 10 minutes)

- The researcher will provide palliative care education to you during lunch
  - There will be 4 sessions, 45 minutes in duration
Sessions will be offered every other week, over a 7 week period

What other options are there?

Your decision to participate in this study will not affect any employer-based performance appraisals. You may withdraw from the study at any time, for any reason, without consequences.

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the study.

What are the benefits of the study?

The potential benefits of participation in this study include increased knowledge and self-efficacy related to palliative care and potential benefits to future nurses.

How will my personal information be protected?
The following procedures will be used to protect the confidentiality of your data. The researchers will keep all study records (including any codes to your data) locked in a secure location. Research records will be labeled with a code. The code will be derived from your first and last initial followed by a sequential 3 digit number that reflects how many people have enrolled in the study. A master key that links names and codes will be maintained in a separate and secure location. The master key will be destroyed after 3 years. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

You should also know that the UConn Institutional Review Board (IRB) and the Office of Research Compliance may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

**Can I stop being in the study and what are my rights?**

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any
kind if you decide that you do not want to participate. You do not have to answer any question that you do not want to answer.

Who do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Dr. Colleen Delaney (860-486-4887). If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

Documentation of Consent:

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible hazards and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.

____________________  _________________  __________
Participant Signature:  Print Name:  Date:
<table>
<thead>
<tr>
<th>Signature of Person</th>
<th>Print Name:</th>
<th>Date:</th>
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</table>

Obtaining Consent
Appendix B: Informed Consent for control group

Consent Form for Participation in a Research Study

Principal Investigator: Colleen Delaney RN, PhD, AHN-BC

Student Researcher: Yvonne Joy, MSN, APRN

Study Title: The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care

Introduction

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This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and to discuss it with your family, friends and colleagues. We also encourage you to ask questions now and at any time. If
you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. You will be given a copy of this form.

Why is this study being done?

This study seeks to determine the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care. Study participants must be: (1) a RN or LPN that practices full-time, part-time, or per diem, (2) provides direct patient care, and (3) willing to attend all four education sessions over a seven week period.

What are the study procedures? What will I be asked to do?

If you agree to take part in this study, you will be asked to do the following:

• The researcher will meet with you at the beginning and end of study and ask you to complete:
  o a demographic questionnaire- at the first session (will take about 5 minutes)
  o a palliative care knowledge questionnaire – at the first, fourth and last sessions (will take about 10 minutes)
  o a palliative care self-efficacy questionnaire – at the first, fourth and last sessions (will take about 10 minutes)

• The researcher will provide handouts during lunch break sessions:
  o Handout about overall geriatric assessment – at the second session
• The researcher will provide palliative care education to you during lunch break:
  o There will be 4 sessions, 45 minutes in duration
  o Sessions will be offered every other week, over a 7 week period

What other options are there?

Your decision to participate in this study will not affect any employer-based performance appraisals. You may withdraw from the study at any time, for any reason, without consequences.

What are the risks or inconveniences of the study?

We believe there are no known risks associated with this research study; however, a possible inconvenience may be the time it takes to complete the study.

What are the benefits of the study?

The potential benefits of participation in this study include increased knowledge and self-efficacy related to palliative care and potential benefits to future nurses.
How will my personal information be protected?

The following procedures will be used to protect the confidentiality of your data. The researchers will keep all study records (including any codes to your data) locked in a secure location. Research records will be labeled with a code. The code will be derived from your first and last initial followed by a sequential 3 digit number that reflects how many people have enrolled in the study. A master key that links names and codes will be maintained in a separate and secure location. The master key will be destroyed after 3 years. All electronic files (e.g., database, spreadsheet, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. Data that will be shared with others will be coded as described above to help protect your identity. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

You should also know that the UConn Institutional Review Board (IRB) and the Office of Research Compliance may inspect study records as part of its auditing program, but these reviews will only focus on the researchers and not on your responses or involvement. The IRB is a group of people who review research studies to protect the rights and welfare of research participants.

Can I stop being in the study and what are my rights?
You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate. You do not have to answer any question that you do not want to answer.

Who do I contact if I have questions about the study?

Take as long as you like before you make a decision. We will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Dr. Colleen Delaney (860-486-4887). If you have any questions concerning your rights as a research subject, you may contact the University of Connecticut Institutional Review Board (IRB) at 860-486-8802.

Documentation of Consent:

I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement and possible hazards and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I have received a copy of this consent form.

____________________  ______________________  ________
Participant Signature:  Print Name:  Date:
Obtaining Consent
Appendix C: Flyer to recruit study participants

Participation in a Research Study

Volunteers Wanted for a Research Study

Study Title: The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care.

You are invited to participate in this study regarding nurses’ palliative care knowledge and self-efficacy.

The primary purpose of this study is to evaluate the influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care settings. A second purpose of this study is to determine if there is a significant difference between registered nurses (RNs) and licensed practical nurses (LPNs) in palliative care self-efficacy. Your participation in this study will take approximately 5 hours of your time.

Study participants must be:

(1) a RN or LPN, (2) practice full-time, part-time, or per diem, (3) provide direct patient care, and (4) are willing to attend all 4 education sessions.

Lunch will be provided to those that participate in the study.

This research is conducted under the direction of Dr. Colleen Delaney, School of Nursing.

To learn more about this research, contact Yvonne Joy at: Yvonne.joy@uconn.edu or Colleen Delaney PhD, RN at 860-486-4887. Sign up in the Education Department to participate in this study.
Appendix D: Demographic Collection Form

Please answer the following questions about yourself.

1. Age:
   A. □ under 25       D. □ 45-54
   B. □ 25-34         E. □ 55-64
   C. □ 35-44         F. □ 65+

2. Gender:
   A. □ Male       B. □ Female

3. What race do you consider yourself?
   A. □ White       D. □ American Indian or Alaska Native
   B. □ African American       E. □ Native Hawaiian or other Pacific Islander
   C. □ Asian       F. □ Other

4. Do you consider yourself Hispanic or Latino?
   A. □ Yes       B. □ No

5. What is your primary language?
   A. □ English       C. □ Polish
   B. □ Spanish       D. □ Other

6. What is your highest degree?
   A. □ High school diploma       D. □ Bachelor’s degree
   B. □ Certificate       E. □ Master’s degree
   C. □ Associates degree       F. □ Other

7. Have you had any palliative care education? Mark all that apply.
   A. □ A course with continuing education credit       C. □ On the job experience
   B. □ In-services by facility or other organization       D. □ None
8. Type of Nursing Professional
A. □ RN    B. □ LPN

9. Do you spend more than 50% of your workday doing direct patient care?
A. □ Yes    B. □ No

10. How many years of NURSING experience do you have?
A. □ 0-3 years    C. □ 8-11 years    E. □ 16-19 years
B. □ 4-7 years    D. □ 12-15 years    F. □ 20+ years

11. How many years have you worked in LONG-TERM care?
A. □ 0-3 years    C. □ 8-11 years    E. □ 16-19 years
B. □ 4-7 years    D. □ 12-15 years    F. □ 20+ years

12. Where do you work? Mark all that apply
A. □ Riverside Health and Rehab Center    B. □ Arden House
Appendix E: Palliative Care Self-Efficacy Scale

Please rate your degree of confidence with the following patient / family interactions and patient management topics, by ticking the relevant box below

<table>
<thead>
<tr>
<th>No</th>
<th>Patient/family interactions and clinical management</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Answering patients questions about the dying process</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Supporting the patient or family member when they become upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Informing people of the support services available</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Discussing different environmental options (eg hospital, home, family)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Discussing patient’s wishes for after their death</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Answering queries about the effects of certain medications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Reacting to reports of pain from the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Reacting to and coping with terminal delirium</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>Reacting to and coping with terminal dyspnoea (breathlessness)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Reacting to and coping with nausea / vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Reacting to and coping with reports of constipation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Reacting to and coping with limited patient decision-making capacity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Palliative Care Quiz for Nursing (PCQN)

Palliative Care Quiz for Nursing (Ross et al., 1996)

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>True</th>
<th>False</th>
<th>I don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Morphine is the standard used to compare the analgesic effect of other opioids.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>The extent of the disease determines the method of pain treatment.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Adjuvant therapies are important in managing pain.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>It is crucial for family members to remain at the bedside until death occurs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>During the last days of life, drowsiness associated with electrolyte imbalance may decrease the need for sedation.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.</td>
<td></td>
<td></td>
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<tr>
<td>8</td>
<td>Individuals who are taking opioids should also follow a bowel regime.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>The provision of palliative care requires emotional detachment.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Men generally reconcile their grief more quickly than women.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>The philosophy of palliative care is compatible with that of aggressive treatment.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>The use of placebos is appropriate in the treatment of some types of pain.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>In high doses, codeine causes more nausea and vomiting than morphine.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>Suffering and physical pain are synonymous.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>Demerol is not an effective analgesic in the control of chronic pain.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>The accumulation of losses renders burnout inevitable for those who seek work in palliative care.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Manifestations of chronic pain are different from those of acute pain.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19</td>
<td>The loss a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>The pain threshold is lowered by anxiety or fatigue.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G: Letter of approval to conduct study at intervention facility

Office of Research Compliance
The Whetton Graduate Center, Room 214
University of Connecticut
438 Whitney Road Extension, Unit-1246
Storrs, CT 06269-1246

Subject: Letter of Authorization to Conduct Research at Riverside Health and Rehabilitation Center

Dear Institutional Review Board:

This letter will serve as authorization for the University of Connecticut ("UCONN") researcher/research team, PI Colleen Delaney, PhD, RN and student researcher Yvonne Joy, to conduct the research project entitled The Influence of a Palliative Care Education Intervention in Increasing Knowledge and Self-Efficacy of Nurses Practicing in Long-Term Care at Riverside Health and Rehabilitation Center (the "Facility").

The Facility acknowledges that it has reviewed the protocol presented by the researcher, as well as the associated risks to the Facility. The Facility accepts the protocol and the associated risks to the Facility, and authorizes the research project to proceed. The research project may be implemented at the Facility upon approval from the UCONN Institutional Review Board.

If we have any concerns or require additional information, we will contact the researcher and/or the UCONN Office of Research Compliance.

Sincerely,

Karen H. Chadderton, Administrator
Printed Name and Title of Authorized Signatory

Date
6-20-2014
Appendix H: Letter of approval for control facility

Research Proposal

Mon, Aug 4, 2014 at 9:39 AM

Yody, Barbara <Barbara.Yody@genesishcc.com>

To: "Yvonne Joy (yvonne.joy@uconn.edu)" <yvonne.joy@uconn.edu>
Cc: "Costa, Michelle" <Michelle.Costa@genesishcc.com>, "Behan, Linda" <Linda.Behan@genesishcc.com>

Dear Yvonne,

The GHC Internal Research Committee and the team at Arden House have reviewed the research protocol for the study entitled “Influence of a palliative care education intervention in increasing knowledge and self-efficacy of nurses practicing in long-term care” with Principal Investigator Colleen Delaney and student researcher Yvonne Joy of the University of Connecticut.

We grant permission to collect data at our facility as outlined in application.

Our regional educators are interested in comparing the training currently in place to that in your study. Please send us a report at the completion of the study.

Barbara Benson Yody
VP Outcomes Management & Clinical Research
Genesis HealthCare
610-925-2044
Appendix I: Permission to use PSCSE

Palliative care self-efficacy scale

Jane Phillips <jphillips@stvincents.com.au>  
To: Yvonne Joy <yvonne.joy@uconn.edu>

Dear Yvonne,

You are very welcome to use the Palliative Care Self-Efficacy Scale which is in the public domain. Best wishes with your study.

Kind regards

Jane Phillips RN BN PhD MRCNA, Professor Palliative Nursing, School of Nursing | The Cunningham Centre for Palliative Care Sydney, and The University of Notre Dame, Australia Darlinghurst Campus
Sacred Heart Hospice | St Vincent's Health Network | 170 Darlinghurst St, Darlinghurst 2010 | (PO Box 944 Broadway 2007) | Tel: +61 2 04 11100 617 | Fax: +61 2 9357 7680 | Email address: jane.phillips@nd.edu.au
## Appendix J: Permission to use PCQN

**P.C. Quiz**

jjmguin <jjmguin@bell.net>  
To: yvonne.joy@uconn.edu  

Mon, Apr 21, 2014 at 5:49 PM

Hi Yvonne,
Please feel free to use the P.C. Quiz for your research.
Good luck,
Joan McGuinness
Appendix K: handout for attention control group

**Fulmer SPICES: An Overall Assessment Tool for Older Adults**

*By: Terry Fulmer, PhD, APRN, GNP, FAAN; Bouse College of Health Sciences, Northeastern University and Meredith Wallace, PhD, APRN, CS, Fairfield University School of Nursing*

**WHY:** Normal aging brings about inevitable and irreversible changes. These normal aging changes are partially responsible for the increased risk of developing health-related problems within the elderly population. Prevalent problems experienced by older adults include: sleep disorders, problems with eating or feeding, incontinence, confusion, evidence of falls, and skin breakdown. Familiarity with these commonly-occurring disorders helps the nurse prevent unnecessary iatrogenesis and promote optimal function of the aging patient. Flagging conditions for further assessment allows the nurse to implement preventative and therapeutic interventions (Fulmer, 1991; Fulmer, 1991).

**BEST TOOL:** Fulmer SPICES is an efficient and effective instrument for obtaining the information necessary to prevent health alterations in the older adult patient (Fulmer, 1991; Fulmer, 1991: Fulmer, 2001). SPICES is an acronym for the common syndromes of the elderly requiring nursing intervention:

- S is for Sleep Disorders
- P is for Problems with Eating or Feeding
- I is for Incontinence
- C is for Confusion
- E is for Evidence of Falls
- S is for Skin Breakdown

**TARGET POPULATION:** The problems assessed through SPICES occur commonly among the entire older adult population. Therefore, the instrument may be used for both healthy and frail older adults.

**VALIDITY AND RELIABILITY:** The instrument has been used extensively to assess older adults in the hospital setting, to prevent and detect the most common complications (Fulmer, 2001; Lopez et al., 2002; Paff, 2002; Turner, J. et al., 2001; NICHE). Psychometric testing has not been done.

**STRENGTHS AND LIMITATIONS:** The SPICES acronym is easily remembered and may be used to recall the common problems of the elderly population in all clinical settings. It provides a simple system for flagging areas in need of further assessment and provides a basis for standardizing quality of care around certain parameters. SPICES is an alert system and refers to only the most frequently-occurring health problems of older adults. Through this initial screen, more complete assessments are triggered. It should not be used as a replacement for a complete nursing assessment.
Fulmer SPICES: An Overall Assessment Tool for Older Adults

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>Date:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>SPICES</th>
<th>EVIDENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

- Sleep Disorders
- Problems with Eating or Feeding
- Incontinence
- Confusion
- Evidence of Falls
- Skin Breakdown


Appendix L: handout for attention control group

Katz Index of Independence in Activities of Daily Living (ADL)

By: Mary Shelley, PhD, ARNP, Virginia Mason Medical Center, and Meredith Wallace, PhD, APRN, BC, Fairfield University School of Nursing

WHY: Normal aging changes and health problems frequently show themselves as declines in the functional status of older adults. Decline may place the older adult on a spiral of intransigeant leading to further health problems. One of the best ways to evaluate the health status of older adults is through functional assessment which provides objective data that may indicate future decline or improvement in health status, allowing the nurse to plan and intervene appropriately.

BEST TOOL: The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client’s ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index checks adequacy of performance in six functions: bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored yearly for independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.

TARGET POPULATION: The instrument is most effectively used among older adults in a variety of care settings when baseline measurements, taken when the client is well, are compared to periodic or subsequent measures.

VALIDITY AND RELIABILITY: In the forty-eight years since the instrument has been developed, it has been modified and simplified and different approaches to scoring have been used. However, it has consistently demonstrated its utility in evaluating functional status in the elderly population. Although no formal reliability and validity reports could be found in the literature, the tool is used extensively as a flag signaling functional capabilities of older adults in clinical and home environments.

STRENGTHS AND LIMITATIONS: The Katz ADL Index assesses basic activities of daily living. It does not assess advanced activities of daily living. Katz developed another scale for instrumental activities of daily living such as heavy housework, shopping, managing finance and telephone. Although the Katz ADL Index is sensitive to changes in declining health status, it is limited in its ability to measure small increments of change seen in the rehabilitation of older adults. A full comprehensive geriatric assessment should follow when appropriate. The Katz ADL Index is very useful in creating a common language about patient function for all practitioners involved in overall care planning and discharge planning.

MORE ON THE TOPIC:
- Best practices information on care of older adults: [www.CommitCoreInNursing.org](http://www.CommitCoreInNursing.org)
Katz Index of Independence in Activities of Daily Living

<table>
<thead>
<tr>
<th>ACTIVITIES</th>
<th>INDEPENDENCE: (1 POINT)</th>
<th>DEPENDENCE: (6 POINTS)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>NO supervision, direction or personal assistance</td>
<td>WITH supervision, direction, personal assistance or total care</td>
</tr>
<tr>
<td>BATHING</td>
<td>(1 POINT) Bathes self completely or needs help in bathing only a single part of the body such as the back, genital area or disabled extremity.</td>
<td>(0 POINTS) Needs help with bathing more than one part of the body, getting in or out of the tub or shower. Requires total bathing.</td>
</tr>
<tr>
<td>POINTS:______</td>
<td>____</td>
<td>____</td>
</tr>
<tr>
<td>DRESSING</td>
<td>(1 POINT) Gets clothes from closet and dresses and puts on clothes and outer garments complete with fasteners. May have help tying shoes.</td>
<td>(0 POINTS) Needs help with dressing self or needs to be completely dressed.</td>
</tr>
<tr>
<td>POINTS:______</td>
<td>____</td>
<td>____</td>
</tr>
<tr>
<td>TOILETING</td>
<td>(1 POINT) Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.</td>
<td>(0 POINTS) Needs help transferring to the toilet, cleaning self or uses bedpan or commode.</td>
</tr>
<tr>
<td>POINTS:______</td>
<td>____</td>
<td>____</td>
</tr>
<tr>
<td>TRANSFERRING</td>
<td>(1 POINT) Moves in and out of bed or chair unassisted. Mechanical transferring aids are acceptable.</td>
<td>(0 POINTS) Needs help in moving from bed to chair or requires a complete transfer.</td>
</tr>
<tr>
<td>POINTS:______</td>
<td>____</td>
<td>____</td>
</tr>
<tr>
<td>CONTINENCE</td>
<td>(1 POINT) Exercises complete self control over urination and defecation.</td>
<td>(0 POINTS) Is partially or totally incontinent of bowel or bladder.</td>
</tr>
<tr>
<td>POINTS:______</td>
<td>____</td>
<td>____</td>
</tr>
<tr>
<td>FEEDING</td>
<td>(1 POINT) Gets food from plate into mouth without help. Preparation of food may be done by another person.</td>
<td>(0 POINTS) Needs partial or total help with feeding or requires parenteral feeding.</td>
</tr>
<tr>
<td>POINTS:______</td>
<td>____</td>
<td>____</td>
</tr>
</tbody>
</table>

TOTAL POINTS = ____ 6 = High (patient independent) 0 = Low (patient very dependent)


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**try this:**
Appendix M: Palliative care education session 1

**Palliative Care Education**

**Session 1: Principles of Palliative Care**

**Objectives**
- Understand the goals of palliative care
- Identify patients that would benefit from palliative care
- Consider spiritual, cultural, ethical, and supportive components of palliative care

**A Continuum of Care**

- Diagnosis
- Medicating Treatment
- Palliative Care
- Hospice Care
- Reassessment Support
- Death

**Background**
- Between 1.5 - 1.8 million people live in US nursing homes (NHS) (Kaye et al., 2005)
- By 2050, more than 3 million people are expected to spend time in a NH (Kaye et al., 2010; Vincent, 2010)
- 42% of people age 85+ die in a nursing home (NCHS, 2013)
- 67% of people with advanced dementia will die in a NH (McKee et al., 2003)
- Over half are totally dependent or need extensive assistance with bathing, dressing, toileting, and transferring (James et al., 2006)

**Place of Death Changes Over Time**

**Why End of Life (EOL) Care in Nursing Homes (NH)?**

- **Findings:**
  - Poor pain control (Teno et al., 2004; Sengupta et al., 2010)
  - Burdensome transitions (Golightly et al., 2011)
  - Lower family satisfaction with care compared to hospice care (Teno et al., 2004)
**Definition of Palliative Care**

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

*National Consensus Project, 2013
National Quality Forum, 2004*

**Opportunities for Excellent Palliative Care in NH**

- More homelike than many healthcare settings
- Long-term relationships
- Staff understanding that they are in the “EOL-care business”
- Expertise working with frail and cognitively impaired mature adults

**Dying Well**

- A natural part of life
- Opportunity for growth
- Profoundly personal experience

**A “Good Death” Defined**

- Be free of suffering
- Achieve life closure
- Receive care consistent with one’s beliefs, wishes and values

**Life Closure: A Personal Experience**

- Completion of worldly affairs
- Completion of community and personal relationships
- Meaning about one’s individual life
- Love of self
- Love of others
- Acceptance of the finality of life
- Surrender to the unknown - “Letting go”

**Hospice & Palliative Care**

- **Palliative Care**
  - Appropriate at any age and any point in a serious illness
  - Does not require a terminal prognosis

- **The Overlap**
  - Philosophy
  - Policy
  - Team
  - Best Living
  - Any Setting

- **Hospice Care**
  - A form of palliative care specializing in care at end of life
  - Patients’ expected survival by 12 weeks
  - Patients must have incurable life-limiting illness
Models for NH Palliative Care

- Hospice Care
  - Most widely studied and utilized
  - Generally associated with better resident outcomes
  - Not available to all residents
  - Hospice care not always available outside of NH

- External PC Consultant
  - Consults are requested by NHs
  - Available to all residents
  - Can be invaluable

- Internal PC Consult Team
  - NHs may have an agency that provides consults
  - No support for QI
  - Dissemination of best practices

How is palliative care different from “good health care”?
- Focus on discussing goals of care, understanding patient and family preferences
- Weighing risks and benefits of therapies in light of goals
- Open communication about difficult topics
- Comfort
- Life closure

Evidence of Deficiencies in EOL Care in Nursing Homes
- Pain assessment & management is inadequate, especially for nonwhite residents and those with cognitive impairment
- Families report less satisfaction with EOL in NHs than in hospice settings
- Only 58% of bereaved family members reported loved one experienced “a good death”

Hospice Benefits to Facility
- Interdisciplinary team to manage the hospice Plan of Care for resident and family
- Availability of professional staff 24/7 for optimal pain and symptom management
- Decreases likelihood of disruptive transfers to hospitals
- Provides in-service training to facility staff on hospice care
- Additional staff (home health aides) to assist with resident's personal care
- Grief and bereavement support

Hospice Can Enhance EOL Care in Nursing Facilities
The combined strengths of facility staff and hospice can create highest quality, most compassionate care for residents and their families.

PC Trigger Tool
- Marked decrease in functional status/ADLs in last 50 days
- More than 1 hospitalization within 30 days
- Unacceptable pain level or symptoms >24 hours
- Dementia - difficulty with speech, ambulation or aspiration
- Metastatic cancer
- Advanced cardiac disease – i.e. CHF, CAD, (LVEF<25%)
- Considering PEG tube placement
- Code status changed to DNR
- Determination of goals of care or help w/complex decisions
- Requested by patient or family

St. John's Institute of Fiorello H. LaGuardia Community College of the City of NY in collaboration with Palliative Care, 2006.
St. John Providence Health System
Palliative Care Trigger Tool

- Marked decrease in functional status/ADLs in last 60 days
- Admitted from ECF with ADL dependence or chronic care need
- More than 1 hospitalization within 30 days
- Unacceptable **pain** level or symptoms >24 hours
- Dementia- difficulty with speech, ambulation or aspiration
- Metastatic cancer
- Advanced cardiac disease – i.e. CHF, CAD, (LVEF<25%)
- Considering PEG tube placement
- Code status changed to DNR
- Determination of goals of care or help w/complex decisions
- Requested by patient or family
- No Palliative Care needs identified at this time

Source: St. John Providence Health System & Duke Institute on Care at End of Life – Collaboration for Palliative Care, 2008.
Appendix N: Palliative care education session 2

Palliative Care Education

Session 2: Geriatric Pain Assessment and Management

Objectives

- Determine sources, causes and descriptors of pain
- Identify methods of pain assessment
- Recognize methods for treating and evaluating pain, including pharmacological and non-pharmacological

General Pain Assessment

- Pain is...
  - “An unpleasant sensory and emotional experience associated with actual or potential tissue damage”
    www.aps-pain.org/terms

  - “Pain is whatever the experiencing person says it is, existing whenever he says it does.”
    Fawcett & McAlary, 1991

Pain in Older Adults

- 25 – 56% community-dwelling elders
- 45 – 85% nursing home residents
- 30 – 80% cancer patients in treat men
- 20% of hospitalized patients in their last days of life
- 20% of hospice patients
- Remember...presence of co-morbidities

Common Sources of Chronic (Persistent) Pain in Older Adults

- Musculoskeletal (ostearthritis, degenerative joint disease e.g., pain in back, hands, feet)
- Osteoporosis/compression fractures
- Peripheral vascular disease
- Neuropathies (e.g., diabetic neuropathy, post-herpetic neuralgia, post chemotherapy)
- Cancer
- Contractures
- Pressure ulcers/wounds

Goals of Pain Management

- To identify how much pain can exist without interfering with needs or desired activities
- Appropriate for all types of pain
- Goals agreed on with patient/resident to promote quality of life

Fawcett & McAlary, 2011
THE INFLUENCE OF A PALLIATIVE CARE EDUCATION

Pain Assessment in Nonverbal Older Adults
- Advanced dementia
- Progressive neurological disease
- Post CVA
- Imminently dying
- Developmentally disabled
- Delirium

The Pain Experience of Older Adults with Dementia
- Tolerance to acute pain possibly increases but pain threshold does not appear to change
- Dementia may alter response to acute pain
- Cognitive impairment may decrease the perceived analgesic effectiveness
- Pain can negatively affect cognitive function

Behavioral/Observational Cues
Obvious:
- Grimacing or winces
- Bracing
- Guarding
- Rubbing

Less Obvious:
- Changes in activity level
- Sleeplessness, restlessness
- Resistance to movement
- Withdrawal/apathy
- Increased agitation, anger, etc.
- Decreased appetite
- Vocalizations

Analgesia Trial in Nonverbal Older Adults for Pain Relief

Possible Pain Behavior

Medication Trial

Behaviors Decreased

It's probably PAIN!

When to Assess and Document
- Admission
- Regular intervals
- New pain
- Exacerbations
- Uncontrolled pain
- New therapy (new meds, increased doses)

Communicating with Physicians: Key Strategies
- Diagnosis, pre-existing pain, medication changes
- Summarize your assessment data (intensity, character, location, side effects, pattern)
- Report older adult’s/family’s concerns
- Your recommendations for changes
**Total Pain Assessment**

- Physical
  - Increase heart rate, blood pressure, respiratory rate
  - Restless, agitated, diaphoretic
- Psychological
  - Anger, sadness, hopelessness and despair may alter one’s personality, disrupt sleep, interfere with work and relationships
  - Emotional
    - Worry, anxiety, embarrassment, and the loss of the pleasures and enjoyment of life.
- Spiritual distress
  - Apathy, withdrawn, feelings of being punished
- Cultural
  - Cultural or ethnic perceptions of pain vary greatly

**Physical Pain Assessment**

- Cause if known
- Location
- Intensity
- Character/Quality/Pattern
- What makes it better or worse

**Assess Impact of Pain on Function and Quality of Life**

- Activities of daily living
- Mobility or transfers
- Mood, sleep, energy
- Participation in meals, activities
- Social activities
- Any new changes

**Pain Intensity Tools**

![Pain Intensity Scale](image)

Fink & Gates, 2013; Herr et al., 2006a

**PAINAD: Cognitively Impaired**

<table>
<thead>
<tr>
<th>Behavior</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td>Normal</td>
<td>Stridor</td>
<td>Weak</td>
<td>Breathing difficulty</td>
</tr>
<tr>
<td>Nausea/Irritability</td>
<td>None</td>
<td>Nausea</td>
<td>Irritable</td>
<td>Increased irritability</td>
</tr>
<tr>
<td>Palatal Discomfort</td>
<td>Comfortable</td>
<td>Sore, tender</td>
<td>Facial grimace</td>
<td></td>
</tr>
<tr>
<td>Body Language</td>
<td>Relax</td>
<td>Tense, distressed, pacing</td>
<td>Posture</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>Normal</td>
<td>Distorted or inaudible</td>
<td>Speech</td>
<td></td>
</tr>
<tr>
<td>Total score</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain at the End of Life**

- Existential distress
- Dimensions of QOL
  - Requires interdisciplinary approach
THE INFLUENCE OF A PALLIATIVE CARE EDUCATION

Think about it...
There are many challenges to assessing pain in older adults - nonetheless, there is no pain relief when there is no pain assessment.

Pharmacological Therapies

- Nonopioids
- Opioids
- Adjuvants

Pharmacological Approach
World Health Organization

<table>
<thead>
<tr>
<th>3 - Step Ladder</th>
<th>3 - Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphin</td>
<td>Hydromorphone</td>
</tr>
<tr>
<td>Ketamine</td>
<td>Methadone</td>
</tr>
<tr>
<td>2 - Moderate</td>
<td>A/Hydrocodone</td>
</tr>
<tr>
<td>1 - Mild</td>
<td>A/Oxycodone</td>
</tr>
<tr>
<td>ASA</td>
<td>A/Hydrocodone</td>
</tr>
<tr>
<td>Acetaminophen</td>
<td>A/Dihydrocodeine</td>
</tr>
<tr>
<td>NSAIDS</td>
<td>Tramadol</td>
</tr>
<tr>
<td>+/- Adjuvants</td>
<td>+/- Adjuvants</td>
</tr>
</tbody>
</table>

Acetaminophen: First Line

- Mild to moderate pain
- Osteoarthritis or musculoskeletal pain
- Analgesic, antpyretic (minimal anti-inflammatory)
- Maximum dose 3 grams/day
- Continuous use in liver or renal disease
- Long term should have monitoring of liver function
- Scheduled dosing works best for older adults with persistent/daily pain
- Be aware of “hidden” doses of APAP in combination products

NSAIDS

- Central and peripheral effects
- Used in inflammatory arthritis, or other situations when acetaminophen is maximized
- Complications include:
  - Gastrointestinal bleeding (PPI indicated)
  - Renal impairment – especially in patients with DM, gout, or diuretic therapy
  - Multiple drug drug interactions
- NSAID alternative – weak opioids

Analgesic Side Effects

- More common in older persons
- Anticipate, prevent & treat
- More common with hepatic or renal insufficiency
- Commonly occurs:
  - With initiation of a new analgesic
  - Following an increase in analgesic dose
  - When non-analgesic is introduced that interacts with existing analgesic
Opioids

- Effective for pain regardless of pathophysiology
- Safe for older adults when carefully initiated & titrated
- Can be delivered by all routes
- Tramadol – weak opioid
  - Inhibits norepinephrine and serotonin reuptake
  - Use in diabetic neuropathy, polyneuropathy, post-herpetic neuralgia, osteoarthritis
  - Ceiling dose 300 mg/day for elderly (50 mg Tramadol ~60 mg codeine)

Opioid Side Effects

- Sedation
- Nausea and vomiting
- Constipation – always treat
- Urinary retention
- Confusion
- Dysphoria, hallucinations
- Myoclonus (rare, on low doses)
- Respiratory depression (rare)

Nebulized/Sublingual Opioids

- Nebulized opioids provide no advantage over other routes of administration for dyspnea or pain
- Sublingual morphine – only 18% absorbed through sublingual mucosa
  - Fentanyl 51%
  - Buprenorphine 55%
  - Methadone 34%
  - Oxycodone 16%

Adjuvant Analgesics

- Anticonvulsants
- Antidepressants
- Local anesthetics
- Corticosteroids

Non-Drug Therapies

<table>
<thead>
<tr>
<th>Physical</th>
<th>Psychological</th>
</tr>
</thead>
<tbody>
<tr>
<td>Massage</td>
<td>Distraction</td>
</tr>
<tr>
<td>Cold</td>
<td>Relaxation</td>
</tr>
<tr>
<td>Heat</td>
<td>Music</td>
</tr>
<tr>
<td>Vibration</td>
<td>Comfort Foods</td>
</tr>
<tr>
<td>Positioning</td>
<td>Imagery</td>
</tr>
<tr>
<td>Exercise</td>
<td>Controlled Breathing</td>
</tr>
</tbody>
</table>

Common Myths

<table>
<thead>
<tr>
<th>Myth</th>
<th>Reality</th>
</tr>
</thead>
<tbody>
<tr>
<td>People can be distracted from their pain, the pain isn’t “real” or it’s not as bad as they are saying.</td>
<td>People can be distracted from pain because distraction is an effective nondrug therapy</td>
</tr>
<tr>
<td>Use non-drug measures instead of pain medication</td>
<td>Non-drug treatments are not an appropriate substitute for pain medication</td>
</tr>
</tbody>
</table>
**Positioning/Movement**
- Positioning eases pain by placing the body into postures that maintain or promote normal function of the muscles.
- Movement helps maintain or restore ease of function in joints, bones, nerves, and ligaments.

**Positioning/Movement Examples**
- Use of full-length body pillow.
- Pillow between knees when lying on either side.
- Pretend write the alphabet by using the feet – switch feet every 6 or 8 letters.

**Distraction**
Used to focus attention on something other than pain. By decreasing concentration on pain, it becomes more bearable.

**Distraction Examples**
- Compile a file of pictures.
- Have resident describe picture by:
  - Talking about the picture
  - Pretending they are in the picture
  - Telling a story about the picture
- Choose a new picture as soon as their interest decreases in the current one.

**Relaxation**
- Described as freedom from physical and mental tension.
- Relaxation techniques reduce stress, muscle tension, and reduce pain.

**Relaxation Examples**
- Put on headphones with a tape of calming music.
- Breathe in deeply; exhale slowly.
- Think of a calm setting or peaceful place that you’ve enjoyed visiting.
Music

Decreases pain by:
- Providing distraction
- Reducing anxiety
- Prompting recall of pleasant memories
- Interrupting the stress response

Comfort Foods

Assists in decreasing pain by:
- Providing distraction
- Evoking comforting memories
- Promoting relaxation and physical calm

Building a Toolkit
## Pain Assessment in Advanced Dementia Scale (PAINAD)

**Instructions:** Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

<table>
<thead>
<tr>
<th>Behavior</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing independent of vocalization</td>
<td>Normal</td>
<td>Occasional labored breathing</td>
<td>Noisy labored breathing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Short period of hyperventilation</td>
<td>Long period of hyperventilation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Cheyne-Stokes respirations</td>
<td></td>
</tr>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan</td>
<td>Repeated troubled calling out</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low-level speech with a negative or</td>
<td>Loud moaning or groaning</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>disapproving quality</td>
<td>Crying</td>
<td></td>
</tr>
<tr>
<td>Facial expression</td>
<td>Smiling or inexpressive</td>
<td>Sad</td>
<td>Rigid</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Frightened</td>
<td>Fists clenched</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Frown</td>
<td>Knees pulled up</td>
<td></td>
</tr>
<tr>
<td>Body language</td>
<td>Relaxed</td>
<td>Tense</td>
<td>Pulling or pushing away</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distressed pacing</td>
<td>Striking out</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fidgeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or</td>
<td>Unable to console, distract, or</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>touch</td>
<td>reassure</td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL SCORE**

(Warden et al., 2003)

**Scoring:**
The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

**Source:**
PAINAD Item Definitions
(Warden et al., 2003)

Breathing
1. Normal breathing is characterized by effortless, quiet, rhythmic (smooth) respirations.
2. Occasional labored breathing is characterized by episodic bursts of harsh, difficult, or wearing respirations.
3. Short period of hyperventilation is characterized by intervals of rapid, deep breaths lasting a short period of time.
4. Noisy labored breathing is characterized by negative-sounding respirations on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
5. Long period of hyperventilation is characterized by an excessive rate and depth of respirations lasting a considerable time.
6. Cheyne-Stokes respirations are characterized by rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization
1. None is characterized by speech or vocalization that has a neutral or pleasant quality.
2. Occasional moan or groan is characterized by mournful or murmuring sounds, wails, or laments. Groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
3. Low level speech with a negative or disapproving quality is characterized by muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic, or caustic tone.
4. Repeated troubled calling out is characterized by phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
5. Loud moaning or groaning is characterized by mournful or murmuring sounds, wails, or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
6. Crying is characterized by an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression
1. Smiling or inexpressive. Smiling is characterized by upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.
2. Sad is characterized by an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
3. Frightened is characterized by a look of fear, alarm, or heightened anxiety. Eyes appear wide open.
4. Frown is characterized by a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
5. Facial grimacing is characterized by a distorted, distressed look. The brow is more wrinkled, as is the area around the mouth. Eyes may be squeezed shut.

Body Language
1. Relaxed is characterized by a calm, restful, mellow appearance. The person seems to be taking it easy.
2. Tense is characterized by a strained, apprehensive, or worried appearance. The jaw may be clenched. (Exclude any contractures.)
3. Distressed pacing is characterized by activity that seems unsettled. There may be a fearful, worried, or disturbed element present. The rate may be faster or slower.
4. Fidgeting is characterized by restless movement. Squirming about or wiggling in the chair may occur. The person might be hitching a chair across the room. Repetitive touching, tugging, or rubbing body parts can also be observed.
5. Rigid is characterized by stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (Exclude any contractures.)
6. Fists clenched is characterized by tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
7. Knees pulled up is characterized by flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (Exclude any contractures.)
8. Pulling or pushing away is characterized by resistiveness upon approach or to care. The person is trying to escape by yanking or wrenching him- or herself free or shoving you away.
9. Striking out is characterized by hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability
1. No need to console is characterized by a sense of well-being. The person appears content.
2. Distracted or reassured by voice or touch is characterized by a disruption in the behavior when the person is spoken to or touched. The behavior stops during the period of interaction, with no indication that the person is all distressed.
3. Unable to console, distract, or reassure is characterized by the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior.
Appendix O: Palliative care education session 3

Palliative Care Education

Session 3: Non-pain symptoms at the end of life

Objectives

- Identify other common symptoms experienced by patients in palliative care, such as nausea, vomiting, dyspnea, fatigue, and anxiety
- Recognize methods for assessing these symptoms
- Discover approaches for symptom management

Common EOL Symptoms

- Respiratory
  - Dyspnea, cough
- GI
  - Anorexia, constipation, diarrhea, nausea/vomiting
- General/Systemic
  - Fatigue/weakness
- Psychological
  - Depression, anxiety, delirium/agitation/confusion

No Subjective Data? Then Look for Objective Data

- Distressing shortness of breath, air hunger, or difficulty breathing: acute or chronic
- Using the Respiratory Distress Observation Scale (RDOS) assess the following:
  - Heart rate
  - Respiratory rate
  - Restlessness
  - Breathing pattern
  - Use of accessory muscles
  - Grunting
  - Involuntary nasal flaring
  - Look of fear

Treatment of Dyspnea

- Treating symptoms or underlying cause
- Non-pharmacologic
  - Be calm and provide reassurance
  - Counseling
  - Purse lip breathing
  - Energy conservation
  - Fans, elevation, positioning
  - Other

- Pharmacologic
  - Opioids
  - Bronchodilators
  - Diuretics
  - Other

Oxygen Therapy for Dyspnea

- Effectiveness not established by research
- Worth trying especially if oxygen saturation is low
- Trial O2 2-6 L per nasal prongs; reassess 2 hours after each change in liter flow

(Clements & Klauser, 2001) (Narby et al., 2010)
(Dugan, 2010; Jacob, 2009)
(Gallagher & Roberts, 2006; Pan, 2003)
Opioids for Dyspnea

- Can be administered by oral, subcutaneous, sublingual, or intravenous routes
- Balance positive effects with the negative, especially constipation
- Significant respiratory depression is uncommon
- Nebulized opioids are no more effective than opioids given by other routes
- Studies show small, but positive effect

Cough

- Common symptom in advanced disease
- Causes pain, fatigue, insomnia
- Assess underlying cause (e.g., infection, sinusitis, reflux)
- Assess type of cough
- Assess associated symptoms
- Diagnostic tests may be needed

Dudgen, 2010

Treatment for Cough

**Pharmacologic**
- Suppressants/expectorants
- Antibiotics
- Steroids
- Anticholinergics

**Non-Pharmacologic**
- Chest PT
- Humidifier
- Positioning

Anorexia and Cachexia

- Anorexia - loss of appetite, usually with decreased intake
- Cachexia - lack of nutrition and wasting

Whishin & Kemp, 2010

Assessment of Anorexia and Cachexia

- Physical findings
- Impact on function and QOL
- Calorie counts/daily weights
- Lab tests
- Skin breakdown

Whishin & Kemp, 2010

Treatment of Anorexia and Cachexia

- Treat the cause
- Dietary consultation
- Environment
- Appetite stimulants
- Parenteral/enteral nutrition
- Counseling

Whishin & Kemp, 2010
**Constipation**
- Infrequent passage of stool
- Frequent symptom in palliative care
- Prevention is key

**Assessment of Constipation**
- Causes
  - Decreased fluid and food intake
  - Decreased physical activity
  - Medications
  - Electrolyte imbalance
  - Pain
  - Chronic illness
- Bowel history
- Abdominal assessment
- Rectal assessment
- Medication review

**Treatment of Constipation**
- Medications
- Dietary/fluids
- Other approaches

**Diarrhea**
- Frequent passage of loose, nonformed stool
- Effects (e.g., fatigue, skin breakdown)

**Assessment of Diarrhea**
- Bowel history
- Medication review
- Infectious processes

**Treatment of Diarrhea**
- Treat underlying cause
- Dietary modifications
- Hydration
- Pharmacologic agents
THE INFLUENCE OF A PALLIATIVE CARE EDUCATION

Nausea and Vomiting
- Common in advanced disease
- Assessment of etiology is important
- Acute, anticipatory or delayed

Causes:
- Physiological (GI, metabolic, CNS)
- Psychological
- Disease related
- Treatment related
- Other

King & Tancer, 2001; Mannis, 2004

Assessment of Nausea and Vomiting
- Physical exam
- History
- Lab values

Treatment of Nausea and Vomiting

Pharmacologic
- Anticholinergics
- Antihistamines
- Steroids
- Prokinetic agents
- Other

Non-Pharmacologic
- Distraction/relaxation
- Dietary
- Small/slow feeding
- Invasive therapies

Fatigue
- Subjective, multidimensional experience of exhaustion
- Commonly associated with many diseases
- Impacts all dimensions of QOL

Anderson et al., 2010

Assessment of Fatigue
- Subjective: personal interview
- Objective: VS, mobility, hydration, neuromuscular exam
- Laboratory data: O2 sats, Hgb, CBC, thyroid function

Treatment of Fatigue
- Nondrug strategies - rest, energy conservation, PT/OT
- Medical therapies: blood transfusions, corticosteroids, antidepressants

Anderson et al., 2010
Depression

- Ranges from sadness to suicidal
- Often unrecognized and undertreated
- Occurs in 25-77% of terminally ill
- Estimated to occur in 22% of older adults in nursing homes
- Distinguish normal vs. abnormal
- Should not be dismissed

Adapted EHEC1014 General Curriculum 2013

Causes of Depression

- Physical: pain, illnesses, medications, sensory deficits
- Psychological: grief, memory problems, family history
- Social: isolation, conflicted relationships
- Medications

Adapted EHEC1014 General Curriculum 2013

Assessing Depression

- Mood disturbance
- Physical signs & symptoms
- Situational factors
- Previous psychiatric history
- Standardized assessment tools

Adapted EHEC1014 General Curriculum 2013

Interventions for Depression

Pharmacologic
- Antidepressants
- Stimulants
- Nonbenzodiazepines
- Steroids

Adapted EHEC1014 General Curriculum 2013

Non-pharmacologic
- Promote autonomy
- Life review
- Psychotherapy and grief counseling
- Use cognitive strategies

Adapted EHEC1014 General Curriculum 2013

Anxiety

- Feeling of apprehension
- Muscular tension, jitters, palpitations, abdominal distress, SOB, chest pain
- Mild, moderate, severe
- Often without specific cause

Adapted EHEC1014 General Curriculum 2013

Causes of Anxiety

- Response to illness, uncertainty, dying process
- Primary anxiety disorder
- Manifestation of other disorders
- Medications

Adapted EHEC1014 General Curriculum 2013
The Influence of a Palliative Care Education

Assessing Anxiety
- Physical: ANS activation
- Behavioral: restlessness
- Emotional: worry, panic, fear
- Cognitive: obsessive thoughts, impulses
- History of anxiety
- Other possible causes

Interventions for Anxiety
- Pharmacologic
  - Antidepressants
  - Benzodiazepines
  - Neuroleptics
  - Nonbenzodiazepines
- Non-pharmacologic
  - Empathetic listening
  - Assurance and support
  - Concrete information
  - Symptom management
  - Relaxation/imagery
  - Counseling
  - Interdisciplinary care

Delirium/Agitation/Confusion
- Delirium - Acute change in cognition/awareness
- Agitation - accompanies delirium
- Confusion - disorientation, inappropriate behavior, hallucinations
- Up to 60% adults ≥ 75 yrs in nursing homes
- 80–90% imminently dying patients

Outcomes of Delirium
- Emotional distress
- Increased pain problems
- Falls
- Nursing home placement
- Increased risk of death

Assessment for Delirium
4 Important characteristics of delirium that need to be carefully monitored
- Acute onset/fluxuating
- Inattention
- Disorganized thinking
- Altered level of consciousness

Treatment of Delirium
- Pharmacologic
- Evaluate medications
- Reorientation
- Relaxation/distraction
- Hydration
- Maintain a calm, safe environment
- Avoid arguing
- Gently reorient
- Assure the patient that you will keep him or her safe
- Reduce sensory impairments
- DO NOT use restraints
<table>
<thead>
<tr>
<th>Questions</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. How knowledgeable do you feel about...?</td>
<td></td>
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<tr>
<td>2. How comfortable are you with...?</td>
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<td>3. How do you feel about...?</td>
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<td>4. How familiar are you with...?</td>
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<td>5. How satisfied are you with...?</td>
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<td>6. How involved do you feel in...?</td>
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<td>7. How supportive is the...?</td>
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<tr>
<td>8. How willing are you to...?</td>
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</tbody>
</table>

**OVER THE PAST WEEK:**

- Please note: One letter or digit per box.
Appendix P: Palliative care education session 4

Palliative Care Education

Session 4: Communication

Objectives

- Summarize communication techniques with patients and families
- Indicate communication methods with other healthcare providers and the larger community
- Understand how to communicate palliative care principles and practices

Basic Principles of Communication

- Communication is a constant two-way
- Words and actions are interpreted by the receiver
- Much communication is nonverbal
- Listening is the most important part of communication

Listening Steps

Presence

- Knowing and being comfortable with oneself
- Acknowledging vulnerability
- Knowing the other person
- Connecting
- Affirming and valuing

“Nature gave us one tongue and two ears so we could hear twice as much as we speak.”

Epictetus, 55 A.D. – 135 A.D.
**Presence**

- Using intuition
- Being empathetic
- Being in the moment
- Serenity and silence

**Factors that Influence Communication at EOL**

- Culture
- Age
- Gender
- Personal & family experiences

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**Challenges in Communicating with Dying Older Adults and Their Families**

- Societal denial of death
- Lack of direct experience with death
- Older adults’ and families’ fears and emotions
- Dementia and other conditions that make conversations about the future and other abstract ideas difficult

**Challenges continued...**

- Caregiver fears:
  - Not having “the answers”
  - Feeling helpless/Inadequate
  - Upsetting the older adult/family
  - Fear of showing emotions
  - Caregiver’s personal fear of dying

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**Basic Concepts**

- Use active listening
- Being present, rather than what you say, is most important
- Let the older adult and the family lead you — join in their journey; but emphasize that they are in charge
- Encourage reminiscing; let the older person and families tell their stories
- Let the patient know that their lives have meaning

**Important Messages to Communicate to Someone at EOL**

- Listen
- Respect
- Hopes, values, and goals
- Encourage questions
Tips for Communicating with Older Adults with Dementia

- Environment
- Treat older adult with respect
- Respond to emotions rather than words

Factors
- Losing train of thought
- Word salad
- Withdrawal
- Using curse words
- Reliance on nonverbal gestures
- Reverting to a foreign language

Behaviors When Talking with Older Adults With Dementia

- Smile
- Use humor
- Be positive
- Know the older adult
- Do not argue or confront
- YOU do most of the work in communicating!

We accept you and we will not abandon you

Messages to Give to the Dying

- I love you
- I forgive you
- Please forgive me
- Thank you
- Goodbye

Accepting and Moving Beyond Current Suffering

- Prevent and manage symptoms
- Use lightheartedness and humor skillfully
- Support older patients and families in positive self talk
- Engage the older adult in creative, joyous, aesthetic activities
- Encourage reminiscing
- Focus on past and present joys
- Share positive, hope-inspiring stories

Setting Goals and Maintaining Control

- Help the older adult/resident and family:
  - Identify, obtain, and revise goals
  - Identify resources to achieve goals
  - Maintain their sense of control
  - Identify past successes
- Provide them with accurate information
Connecting with One’s Spirituality
- Help the older adult/resident participate in religious rituals meaningful to him or her
- Assist in arranging clergy visits
- Help the older adult/resident & family find meaning in the experience

Symbolic Language: “I Want to Go Home”
- Explore with the family the possible meanings
- Don’t contradict statements
- Don’t assume delirium

Working with Families at the End of Life
- Participating
- Letting go/letting in
- Going through the stages of grief
- Achieving connection

Older Adult & Family Emotions and Responses to Impending Death
“How can families be angry with us when we haven’t done anything wrong?”

Dealing with Conflict at the EOL
- There are many points of view in every situation
- Don’t take sides
- Grief can be expressed as anger
- Anger may be directed at people who are “safe” targets (for example, staff)

When You are Communicating With Someone Who is Upset
- Treat the person with respect
- Answer the person’s questions
- Stay calm; don’t argue
- Use active listening skills
- Let the person talk
Nurse/Physician Communication

- Preparation is essential.
- Physician is dependent on information provided by the nurse.
- When the nurse and physician do not communicate well—the patient loses.

Strengthen Your Skills

- Identify your communication style/your team member’s.
- What communication styles are easy/difficult for you to deal with?
- Do you understand your role on the team and communicate it to the team?

Respect, Respect, Respect
WORDS MATTER
Communication Tools in End of Life Care

ASK-TELL-ASK
Ask
What do you understand about your illness?
What have the doctors told you about your medical condition?
Tell
Deliver information you need to. “It is a serious condition”
Ask
Sometimes I don’t communicate well. Can you tell me what you heard?
Is there something more that I can help you understand?
Can we delve deeper knowing the seriousness of your condition?

RESPOND to PATIENT EMOTION
“I WISH”
Aligning with the patient while acknowledging that bad things can happen
“I wish things were different.”
“I wish I had better news.”

N.U.R.S.E
Naming (the problem or emotion)
Understanding (where are they coming from and what are their feelings)
Respecting (show it verbally and NON VERBALLY)
Support (give them credence and express your concern)
Explore (Tell me more about… dwell more in depth on their concerns)

Explore Values and Elicit Goals
Given the severity of your illness, what is most important to you?
As you think about the future, what are your most important hopes?
What are your biggest fears?
How do you think about balancing quality of life with length of life in terms of your treatment?
What do you consider your quality of life to be like now?
What makes life most worth living for you?

Giving Bad News – S.P.I.K.E.S
Set up the interview
Assess the patient’s Perception
Obtain the Patient’s Invitation
Give the Knowledge to the patient
Address patient Emotions with Empathetic responses
Summarize and provide strategy

Phrases to Avoid
“There is nothing more we can do for you.”
“I know what this must be like.”
“Would you like us to do everything possible?”
“Stop the machines”
“Withdrawal of care”
“It is futile”

HOSPICE
Hospice care is a covered benefit under Medicare and other insurance programs for patients with a prognosis of 6 months or less. A patient can remain in hospice care beyond six months if a physician re-certifies that the patient is terminally ill.

- Hospice is a concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.
- Hospice care neither prolongs life nor hastens death.
- Hospice team members have specialized knowledge of medical care, including pain and symptom management.
- The goal of hospice care is to improve the quality of a patient’s last days by offering comfort and dignity.
- Hospice deals with the emotional, social and spiritual impact of the disease on the patient and the patient’s family and friends.
- Hospice offers a variety of bereavement and counseling services to families before and after a patient’s death.

Basic Structure for Discussing DNR
Setting
“I’d like to talk with you about possible health care decisions in the future.”

Perception
ASK-TELL-ASK

Expectation
The “Invitation” from SPIKES
What are the goals of care?
Discuss DNR
The “K” from SPIKES
Instead of giving knowledge, discuss DNR
“If you should die in spite of all of our efforts, do you want us to use heroic measures to attempt to bring you back?” Or, “How do you want things to be when you die?”
Make a recommendation
“Most people who express similar opinions have a DNR order.”

Emotions
Respond to emotions, NURSE
Establish and implement the plan
The “Summary” from SPIKES

Patients do not want CPR. They want OUTCOMES they think are likely to result from CPR. DNR order does not mean “Do Not Treat.” It is OK to use the word “die.” Don’t introduce CPR in mechanistic terms (e.g. “starting the heart” or “putting on a breathing machine”).