

NURSING COMFORT WITH END-OF-LIFE
CARE OF PATIENTS AND FAMILIES

by

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ABSTRACT

MEGAN MASON. Nursing Comfort with End-of-Life Care of Patients and Families.
(Under the direction of DR. DONNA KAZEMI)

Background: Majority of Americans are faced with mortality in the acute care setting and require excellent care in order to maintain comfort, quality, and dignity at the end-of-life (EOL). Nurses play a large role in palliative and EOL care. Current nursing programs lack palliative education and clinical opportunities. Also, the Cone Health Palliative Medicine Team has recently expanded to Alamance Regional Medical Center. Along with the excitement of this expansion, come the challenges of educating staff on palliative medicine and EOL care. Cone Health nurses do not have yearly continuing education requirements that relate to palliative or EOL care.

Purpose: The purpose of this scholarly project was to evaluate comfort level and gaps in knowledge of bedside nurses caring for EOL patients and families. There are many skills nurses need to feel comfortable with when caring for a dying patient and family including communication and patient care delivery.

Methodology: This descriptive pilot study was implemented in a 218 bed hospital located in Burlington, North Carolina. The target population included voluntary nurses working on a medical/surgical unit or an intensive care unit. There were no exclusions regarding age, gender, ethnicity, education, length of nursing career, or length of employment at ARMC. The End-of-Life Professional Caregiver Survey (EPCS) was the measurement tool to identify a baseline nursing comfort level with aspects of EOL care. Nurses were provided a detailed palliative PowerPoint and multiple unit in-services throughout implementation. After the educational intervention, it was requested that

nurses complete the post EPCS to evaluate if there was increased comfort with EOL care. The EPCS also identified gaps in knowledge with certain EOL topics. Data was collected in Survey Monkey and analyzed in Excel and SPSS. Quantitative and qualitative methods were used to draw conclusions from the data.

Results: Recruitment emails were sent to 75 nurses. A total of 37 nurses completed the pre-survey and a total of 25 nurses completed the post survey after educational intervention. There were 7 participants that completed the post survey that did not complete the pre-survey. Eighteen (n=18) participants completed the pre and post survey for comparison. Pre comfort score was compared to post comfort score by paired t-tests that revealed statistical significance ($p=0.00021$). Three question domains also proved to be statistically significant by paired t-tests. Linear regression evaluated comfort level with demographics which did not reveal statistical significance with gender, age, ethnicity, education, length of nursing career, and length of employment at ARMC. Qualitative themes were identified from reflection questions in the post survey.

Implications: Despite many limitations identified, there are implications appropriate for further implementation of this project. Although sample size was small, data from 18 surveys was statistically significant. EOL knowledge gaps were also identified and serve as a foundation for future education on this topic. Post survey reflection questions provided valuable information too. The goal is for change to be sustained as best practice with EOL communication and patient care delivery. With future incentive for nurses on other units in the health system, increased motivation for participation may be possible. In general, there remains a knowledge gap with some EOL concepts and role of palliative medicine in healthcare. Continuous education is essential throughout the entire healthcare team.

Conclusion: Bedside nurses are at the forefront of patient care delivery when death is imminent. It is necessary for nurses to have a good understanding of primary palliative nursing and feel comfortable with the many skills involved with EOL care. In the last days and hours of a patient's life, it is essential to provide comfort, quality, and a dignified death. Nurses are given these opportunities to connect with patients and families in ways that will never be forgotten.

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DEDICATION

This doctoral scholarly project is dedicated to my husband who has been nothing short of amazing throughout this journey. Thank you for being kind, understanding, encouraging, and extremely patient. You, and the dog, never failed to bring a smile to my face on the toughest days. Also thank you to all my family and friends who have constantly loved and inspired me to continue working hard to achieve this dream.

TABLE OF CONTENTS

LIST OF TABLES	x
LIST OF FIGURES	xi
LIST OF ABBREVIATIONS	xii
CHAPTER 1: INTRODUCTION	13
1.1. Problem Statement	14
1.2. Purpose of the Project	15
1.3. Clinical Question	16
1.4. Project Objectives	16
CHAPTER 2: LITERATURE REVIEW	18
2.1. Theoretical Framework	22
2.2. Post Project Literature Review	24
CHAPTER 3: METHODOLOGY	25
3.1. Setting	25
3.2. Population	25
3.3. Measurement Tools	25
3.4. Ethical Considerations	26
3.5. Interventions	26
3.7. Data Collection and Analysis	29
3.8. Translation and Impact on Practice	31
3.9. Fiscal Impact	32
3.10. Confidentiality	32

CHAPTER 4: RESULTS	33
4.1. Quantitative Findings	33
4.2. Qualitative Findings	37
4.3. Outcomes	40
4.4. Discussion of Results	41
CHAPTER 5: DISCUSSION	44
5.1. Interpretation/Significance	44
5.2. Limitations	45
5.3. Implications	46
5.4. Recommendations	47
5.5. Summary	48
5.6. Conclusion	49
REFERENCES	50
APPENDIX A: EPCS	53
APPENDIX B: EOL POWERPOINT	55
APPENDIX C: EOL POSTER BOARD	71
APPENDIX D: PALLIATIVE RESOURCES	72

LIST OF TABLES

TABLE 1: Demographic Information	34
TABLE 2: Descriptive Statistics	35
TABLE 3: Paired T-tests	35
TABLE 4: Demographic Linear Regression	36

LIST OF FIGURES

FIGURE 1: Change Theory	23
FIGURE 2: Implementation Timeline	29
FIGURE 3: Sample Size	33
FIGURE 4: Most Valuable Qualitative Themes	38
FIGURE 5: Barrier Qualitative Themes	39
FIGURE 6: Outcome 1: Baseline Comfort	40
FIGURE 7: Outcome 2: Gaps in EOL Knowledge	40
FIGURE 8: Outcome 3: Comfort Level Comparison	41

LIST OF ABBREVIATIONS

ARMC	Alamance Regional Medical Center
ASN	Associate of Science in Nursing
BSN	Bachelor of Science in Nursing
CAPC	Center to Advance Palliative Care
CHPMT	Cone Health Palliative Medicine Team
CES	Cultural, Ethical, and Spiritual Values
ECD	Effective Care Delivery
ELNEC	End-of-Life Nursing Education Consortium
EOL	End-of-Life
EPCS	End-of-Life Professional Caregiver Survey
H0	Null Hypothesis
H1	Alternative Hypothesis
ICU	Intensive Care Unit
NC	North Carolina
PFC	Patient Family Communication
PI	Principal Investigator
SSOM	Stanford School of Medicine
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

Palliative care is a growing specialty in healthcare today. This specialized medical care is aimed at improving quality of life and relief from suffering for patients and families living with serious illnesses (WHO, 2017). Unfortunately, it has been determined that only 14% of individuals worldwide actually receive palliative care when appropriate (WHO, 2017). Palliative medicine includes a multidisciplinary team approach comprised of doctors, advanced practice providers, nurses, pharmacists, speech and physical therapists, social workers, case management, and chaplains (CAPC, 2014).

Palliative care teams can be involved at any stage of an individual's illness and also included if the goal of treatment is curative (CAPC, 2014). Examples of diagnoses that benefit from palliative medicine team consults include cancer, chronic cardiovascular, respiratory, renal or liver diseases, kidney failure, dementia, AIDS, diabetes, multiple sclerosis, amyotrophic lateral sclerosis, and Parkinson's disease (WHO, 2017). End-of-life (EOL) is eventually inevitable with chronic, progressive diseases. EOL care is defined as medical support and care provided to individuals in the final days and hours before death occurs (NIA, 2017). Majority of American mortalities occur either in the hospital or long-term care settings, with 60% occurring in hospitals and 20% occurring in long-term care facilities (SSOM, 2018).

Nurses play a large role in palliative and EOL care. The American Nurses Association along with the Hospice and Palliative Nurses Association (2017)

collaborated in the development of the *Call for Action: Nurses Lead and Transform Palliative Care* which defines the role of primary palliative nursing. Primary palliative nursing involves symptom assessment and management, patient and family education regarding disease progression, evaluation of coping and need for support, and the “respectful care” of EOL patients and survivors (ANA & HPNA, 2017). In many patient situations, nurses may be the first to identify needs, issues, or signs of distress that could benefit from palliative care (ANA & HPNA, 2017). Although not required to become palliative care experts, it is still important for nurses to feel comfortable when caring for the physical, psychological, cultural, and spiritual needs of seriously ill and dying patients (ANA & HPNA, 2017).

Problem Statement

Cultural and social barriers regarding death and dying exist along with a lack of awareness and insufficiency in training among healthcare professionals (WHO, 2017). Current nursing programs have little to no education on palliative care principles, palliative clinical opportunities, and professional mentoring by palliative specialists (ANA & HPNA, 2017). Since nursing programs lack palliative care education, it is necessary to address this gap across various healthcare settings, especially in acute care settings.

The Cone Health Palliative Medicine Team (CHPMT) has recently expanded services to Alamance Regional Medical Center (ARMC) in Burlington, NC. ARMC merged with the Cone Health system in 2013 (Cone Health, 2013). ARMC had one locum provider for palliative services in the past. The CHPMT plans to staff three

palliative clinicians at ARMC, two clinicians for inpatient and one clinician at the cancer center.

Along with the excitement of this expansion to ARMC, come the challenges of educating staff on palliative medicine and end-of-life care. The problem that exists is the lack of comfort and knowledge of bedside nurses when caring for EOL patients and families. Core health nurses do not have yearly continuing education requirements that relate to palliative or EOL care. Nurses have access to Center to Advance Palliative Care (CAPC) modules and an End-of-Life Care module on Healthstream, but rarely complete these modules because they are not required (S. Grounds, personal communication, September 5, 2017). Nurses need to be evaluated and educated in palliative and EOL patient care delivery to promote comfort and dignity in the last days and hours of a patient's life.

Purpose of the Project

The purpose of this DNP scholarly project was to evaluate comfort level and gaps in EOL knowledge of bedside nurses caring for EOL patients and family members. All patients at the EOL deserve comfort, quality, and dignity. Many individuals will spend the last days of life in a hospital setting with loved ones surrounding them. There are many skills nurses need to feel comfortable with when caring for a dying patient. These skills include recognizing and managing symptoms of distress, family communication, cultural, ethical, or spiritual concerns, grief and bereavement, and comfort with being present with a patient and family during death (Lazenby, Ercolano, Schulman-Green, & McCorkle, 2012). The End-of-Life Professional Caregiver Survey (EPCS) was utilized

to assess baseline comfort of nurses caring for patients at EOL. Post comfort level was evaluated by the same survey after an educational intervention was completed.

Clinical Question

Upon completion of a palliative care educational intervention, do acute care nurses indicate an increased comfort level when caring for patients and families at end-of-life? Nurses at Alamance Regional Medical Center (ARMC) were evaluated to determine if a palliative care educational intervention increased one's comfort level with communication, ethical and cultural values, patient care delivery, and symptom management at the EOL. The EPCS was used to measure pre and post comfort level of nurses.

Project Objectives

The primary objective of this DNP project was to evaluate baseline comfort level of nurses caring for EOL patients and increase baseline comfort level after providing nurses an educational intervention. The EPCS assessed pre and post comfort level of nurses as well as gaps in EOL nursing knowledge, educational needs, and barriers that may be in existence on the implementation units. Nurses participated in a palliative/EOL educational intervention aimed at improving comfort level when caring for EOL patients and families. It was hypothesized that upon completion of this scholarly project, nurses would identify an increased comfort with EOL communication, ethical and cultural values, and patient and family care delivery.

The investigator anticipated that nurses would express interest in this educational intervention that allowed them more comfort in caring for most of the patient population on these units. When nurses are comfortable caring for these types of patients and

families, these individuals will receive quality symptom management, communication, compassion, and empathy in the last days and hours of life.

By including reflection questions in post-survey, the investigator was able to evaluate current barriers with EOL care and EOL topics necessary for further education. Another objective was to provide nurses with resources they can personally use and also provide to family members.

CHAPTER 2: LITERATURE REVIEW

This scholarly writer conducted a literature review using CINAHL and PubMed. Journals were in English, full text articles, and peer-reviewed between 2010 and 2017. A variety of search terms were used in different combinations including palliative, nursing education, end-of-life, symptom management, acute care setting, dying patient, ELNEC, CAPC, and End-of-Life Professional Caregiver Survey. From these various search terms, 101 journal articles were saved to a folder. All of these 101 abstracts were reviewed, and the most pertinent journal articles were chosen for this literature review.

Moir, Roberts, Martz, Perry, and Tivis (2015) performed a study using the End-of-Life Professional Caregiver Survey (EPCS) to identify palliative and EOL care education needs of nursing working in a hospital in Idaho. These authors evaluated 60 nurses from a telemetry unit, oncology unit, and intensive care unit and were most interested in determining comfort level based on age, years of nursing experience, and unit of employment. In conclusion, participants with more nursing experience self-reported moderate to high comfort levels and also nurses working on the oncology unit scored highest in all categories (Moir et al., 2015). The lowest scores for all three units were in the effective care delivery domain which included questions regarding knowledge of palliative and EOL care, EOL patient situations, and resources; therefore indicating an increased need for palliative and EOL education at this hospital (Moir et al., 2015). Study participants also expressed a desire to participate in education that would enhance communication with patients and families regarding palliative and EOL care needs.

In 2013, Sinha et al. performed a pilot study at The University of Virginia to determine if EOL knowledge, comfort, and collaboration were positively affected by workshops. Students in the medical and nursing programs were participants. Investigators created a survey to measure attitudes of students pre and post intervention. The educational intervention was the HeArt of Medicine (HOM) program which included three workshops for participants. Workshops included an art museum on death and dying and group discussions with role play on managing hard conversations (Sinha et al., 2013). The workshops also included education on hospice referral, symptom management, and the collaboration between art and science at EOL (Sinha et al., 2013). In conclusion, the authors determined that the HOM program positively affected medical and nursing students' comfort, knowledge, and collaboration when providing EOL care (Sinha et al., 2013).

Coyle et al. (2015) also determined that training modules on EOL communication increased oncology nurses' confidence and comfort level when caring for dying patients. Authors of this project modified communication skills training (CST) modules from the Department of Psychiatry and Behavioral Science at Memorial Sloan Kettering Cancer Center in New York. Oncology nurses received workbooks to review before a day-long CST session which included the 'Discussing Death, Dying, and End-of-Life Goals of Care' module and role play sessions. A retrospective pre-post evaluation form was utilized to measure whether or not nurses felt increased confidence and comfort when caring for EOL patients and families. In conclusion, authors determined that the CST module increased nursing confidence in discussing death, dying, and EOL goals and felt

the intervention would benefit them in future EOL communication with patients and families (Coyle et al., 2015).

Corcoran (2016) concluded that comfort in EOL care delivery increased by 21% when healthcare professionals were provided a day-long education workshop on this topic. The investigator developed an End-of-Life Workshop that included three modules from ELNEC, which is the End-of-Life Nursing Education Consortium. Participants were provided two dates to attend the workshop. Comfort level of the 56 healthcare professional participants was measured by the End-of-Life Professional Caregiver Survey (EPCS). Not only did participants express increased comfort when caring for patients/families at EOL but also less compassion fatigue when provided self-care tools (Corcoran, 2016).

Cooper, Gambles, Mason, and McGlinchey (2014) evaluated acute care nurses caring for individuals with learning disabilities with palliative care and EOL needs. The investigators developed a questionnaire to determine participants' levels of training and confidence when providing general care to patients with learning disabilities, as well as care at the EOL. Thirty-three out of 111 surveys were completed. Only 6% of participants recognized palliative and EOL needs in patients with learning disabilities, but a majority of responses felt confident in managing symptoms at EOL (Cooper et al., 2014). Although the sample size was small, a template was developed from participant responses. The Liverpool Care Pathway template was developed to aid in facilitation of best practice measures from a hospice facility to acute care settings (Cooper et al., 2014).

Lippe and Becker (2015) developed a simulation for nursing students consisting of four sections including continuation of care, change in status, withdrawal from care,

and final debriefing. Nurses' competence was measured by the Perceived Competence in Meeting ELNEC Standards survey, Concerns About Dying scale, and The Frommelt Attitudes Toward Care of the Dying Scale. In conclusion of the three cohorts of nursing students, all three demonstrated increased competence with withdrawal from care/end-of-life simulation and two cohorts demonstrated more positive attitudes when caring for EOL patients (Lippe & Becker, 2015). Principal investigators felt that simulations would benefit experienced nurses in the acute care setting because some of the participating students were ADN to BSN students with experience and demonstrated increased competence.

A descriptive, cross-sectional study was performed by White and Coyne (2011) that evaluated oncology nursing perception of EOL care core competencies and gaps in education. All 714 participants received questionnaires via mail or email. Majority of participants shared that palliative care was involved at his or her hospital setting, but 25% answered that personal preparation level of effectively caring for EOL patients and families was fair to poor (White & Coyne, 2011). Also, a majority of nurses participating in this study had two or fewer hours of continuing education regarding EOL care in the past two years. These authors determined that EOL education programs will be more effective by first evaluating nursing perception of EOL core competencies and then developing programs based on gaps that are identified.

Lazenby et al. (2012) surveyed 369 participants between September 2008 and May 2009. Participants in this study included physicians, nurses, and social workers. The survey used for this study was the EPCS. The EPCS incorporates the eight domains of the national palliative care guidelines. The first four domains include structure and

processes of care, physical aspects of care, psychological and psychiatric aspects of care, and social aspects of care (Ferrell et al., 2007). The final four domains include spiritual religious and existential aspects of care, cultural aspects of care, care of the imminently dying patient, and ethical and legal aspects of care (Ferrell et al., 2007). Data analysis revealed mean scores that were highest among social workers, compared to nurses and physicians although social workers were the smallest representation of the sample size. Authors felt this may be due to psychosocial training opportunities that are readily available in the social work discipline. Validity and reliability of this survey was determined by Cronbach's alpha (Lazenby et al., 2012). In conclusion, the EPCS proved to be an effective tool to evaluate educational needs of healthcare professionals caring for patients at the EOL (Lazenby et al., 2012).

By reviewing the literature, it is evident that there is a gap in comfort, confidence, and knowledge of nurses caring for EOL patients and families. The reviewed studies demonstrate that various educational interventions including modules, simulations, and role play may contribute to increased comfort, confidence, and knowledge of nurses with EOL patient care delivery and communication with families. Overall, there is still a vast need for continuous palliative education across the spectrum of healthcare professionals.

Theoretical Framework

Lewin's Change Theory was the theoretical framework for this scholarly project. This theory, developed by Lewin in 1947, involves three stages, including an unfreezing stage, a moving or transitional stage, and a refreezing stage (Shirey, 2013). The unfreezing stage was an ideal way to begin this project simply because the scholarly writer identified a problem or a gap in clinical practice that was in need of change and

expressed to others this need for change. The transitional stage involves formulating a plan of action and involving peers to support the change that needs to occur (Shirey, 2013). The final stage is the refreezing stage which desires to ‘freeze’ the change into every-day practice as the new expectation of that particular topic (Shirey, 2013).

This theory was beneficial to incorporate into this scholarly project. The gap in nursing comfort level of caring for patients at EOL was identified by personal communication with members of the palliative medicine team and directors of nursing units (S.Grounds, personal communication, September 5, 2017). In the transitional stage, the scholarly writer formulated a detailed plan and intervention that was implemented in an acute care setting. The project will strive to reach the refreezing stage of Lewin’s theory involving sustainability. The goal is that this comfort level will continue with all patients and families that are cared for on these two units and other hospital units in the future.

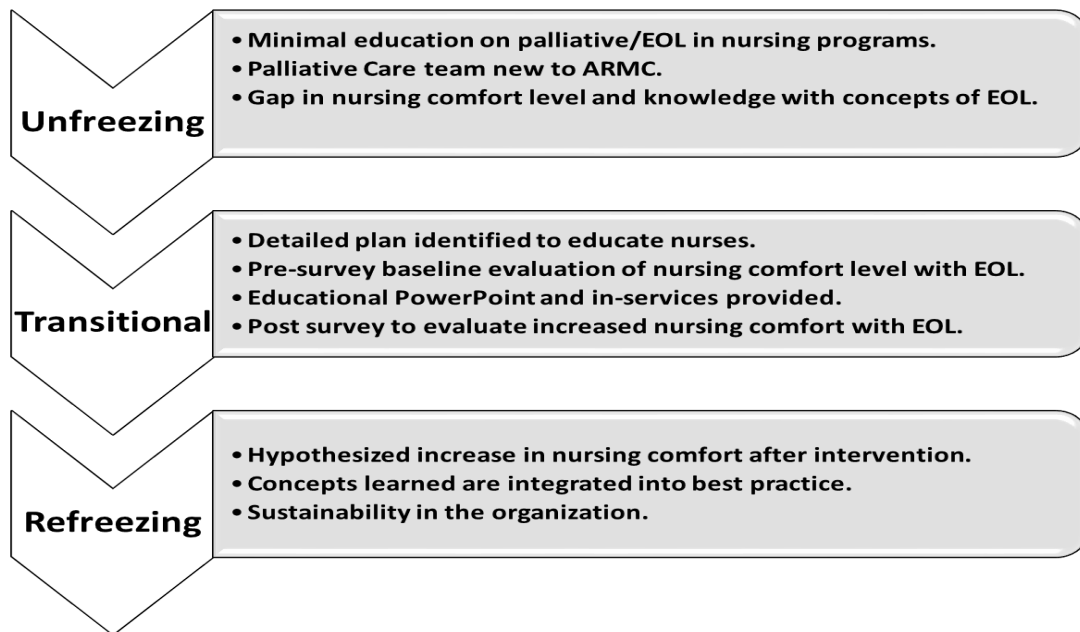


FIGURE 1: Change Theory

Post Project Literature Review

After completion of this scholarly project, another literature review was performed to evaluate newly published research on the topic of nursing comfort with EOL care of patients and families. Kisvetrova, Vevodova, and Skoloudik (2018) performed a cross-sectional, descriptive study of 907 nurses working in various hospitals or long-term care facilities in the Czech Republic. Nursing baseline comfort was evaluated by a 31 question survey with answers on a Likert scale. Questions were organized in four dimensions of comfort including physical, psychological, social, and spiritual/existential. Authors concluded that nurses performed physical comfort interventions more often than interventions related to psychological, spiritual, and social comfort with end-of-life patients (Kisvetrova et al., 2018). Authors spoke of the continued need to evaluate and support comfort nursing activities in these environments that care for many EOL patients.

The study above did not have an educational intervention to compare pre and post levels of comfort but was still similar to this scholarly project on nursing comfort with EOL patient and family care. Kisvetrova, Vevodova, and Skoloudik (2018) did conclude gaps in patient care delivery with psychological, social, and spiritual/existential concepts. Future implementation recommendations for these authors would include further evaluation on why nurses perform psychological, social, and spiritual comfort interventions less often than physical. Is there a knowledge gap or simply an existing barrier to patient care delivery in that health system? In addition, it may be beneficial to provide an educational intervention and measure post comfort level after this intervention.

CHAPTER 3: METHODOLOGY

Setting

This scholarly project was implemented at Alamance Regional Medical Center (ARMC), a hospital in the Cone Health network. ARMC is a 218 bed hospital located in Burlington, North Carolina. One implementation unit was a 32 bed medical/surgical and oncology unit. The population consists of general medical patients, oncology patients, and the majority of end-of-life patients at this hospital (S. Wineman, personal communication, September 20, 2017). The other implementation unit was a 20 bed intensive care unit (P. LeBlanc, personal communication, February 6, 2018).

Population

Voluntary nurses from an ICU and medical/surgical unit at ARMC were involved in the implementation of this scholarly project. There are 30 nurses that work on the medical/surgical unit including two nurses that are hospice and palliative care certified and two nurses that work part-time at a hospice facility. The ICU consists of 45 nurses including day and night shift. Any type of nursing degree was acceptable in this project, including licensed practical nurses, associates, and bachelors. There were no exclusions involving age, gender, race, or ethnicity. A nurse was excluded if he or she was younger than age 18 and not a nurse on the medical/surgical unit or ICU. Nurses consented to participation in this scholarly project.

Measurement Tools

The End-of-Life Professional Caregiver Survey (EPCS) (Lazenby et al., 2012) was used to measure pre and post comfort level of nurses caring for patients and their family members at EOL. The EPCS provides an evaluation of healthcare professionals

and education needs necessary for caring for palliative and EOL patients. The EPCS is a 28 question survey with answers on a 5-point Likert scale (not at all, a little bit, somewhat, quite a bit, and very much). Answers are coded 0-4 with zero indicating not at all and four indicating very much. Maximum score for the survey is 112. Higher scores indicate an increased comfort level with EOL care. Three themes evolve from the questions, including 12 questions on patient/family communication, 8 questions on cultural and ethical values, and 8 questions on effective care delivery (Lazenby et al., 2012). EPCS has demonstrated reliability with Cronbach's alpha >0.70 (Lazenby et al., 2012). Permission was granted by the Yale School of Nursing to use the EPCS in this scholarly project. Nurses were emailed a link to take the EPCS via Survey Monkey at the beginning of implementation to evaluate baseline comfort level.

Ethical Considerations

Implementation began after approval by The University of North Carolina at Charlotte Institutional Review Board and Cone Health Institutional Review Board. Nursing directors of both the medical/surgical unit and the intensive care unit had also approved for the principal investigator to implement on each unit. There were no conflicts of interest.

Intervention

To recruit participants, flyers were placed around the medical/surgical unit and the ICU. On the first day of implementation, nurses were sent a recruitment email requesting participation in the scholarly project. This email included a brief explanation of the project, consent form, link to pre-survey on Survey Monkey, and the EOL PowerPoint developed by the principal investigator. It was requested that participants

complete the pre-survey before viewing the PowerPoint. Also during the first week of implementation, the principal investigator was present during shift changes to encourage participation and explain the importance of completing pre-surveys before the in-services that were conducted in the following weeks.

The link provided in the email went to the pre-survey through Survey Monkey. Nurses initially reviewed the consent form and if agreeable, would then press OK to the next section of the survey. To protect the participants' identity, they were asked to submit a unique identifier for the project which was linked to the pre and post surveys. The unique identifier was a six digit number consisting of two digits of birth month and last four digits of cell phone number. The next section was demographic questions which included gender, ethnicity, age, the highest level of education, length of nursing career, length employed as a nurse at ARMC, and questions regarding previous EOL or palliative education. Participants then completed the 28 questions from the EPCS with answers on a Likert scale. These questions identified a baseline nursing comfort level with EOL care of patients and families.

After completing the pre-survey, nurses were encouraged to review the PowerPoint at personal convenience in the next week before in-services. Topics incorporated in the PowerPoint related to primary palliative nursing including symptom assessment and management, EOL education and communication, and effective care delivery. The PowerPoint also included ethical, cultural, and spirituals values that often play a factor in EOL care.

The principal investigator was actively educating nurses during weeks 2 and 3 of the project. Approximately 55 in-services were held on the day and night shifts as well as

weekends to target weekend option nurses. In-services were between 10 to 15 minutes in length. A poster board was used to educate on highlights from the PowerPoint. Nurses were given the opportunity to ask questions and voice concerns regarding EOL care. Nurses were provided paperwork with palliative resources for personal use and patient/family use. Pre-survey participants remained anonymous through unique identifiers; therefore all nurses on the units were educated regardless of whether or not a pre-survey was completed. After completion of each in-service, nurses were given a small piece of paper with post survey link and were again encouraged to complete.

During the beginning of week 4, the investigator provided a few more in-services to target nurses that had not yet participated in the previous two weeks. Nurses on both units were sent another email with post-survey link and appreciation for participation. The link provided in the email went to a post-survey through Survey Monkey. Nurses were asked to provide the same six-digit unique identifier to remain anonymous. The next section consisted of the same 28 questions from the EPCS with answers on a Likert scale. The final section of the survey included reflection questions on what was most valuable from the project, biggest barriers with EOL care, and suggestions for improvement with future implementation of the project. This post-survey evaluated nursing comfort level after an EOL educational intervention was provided.

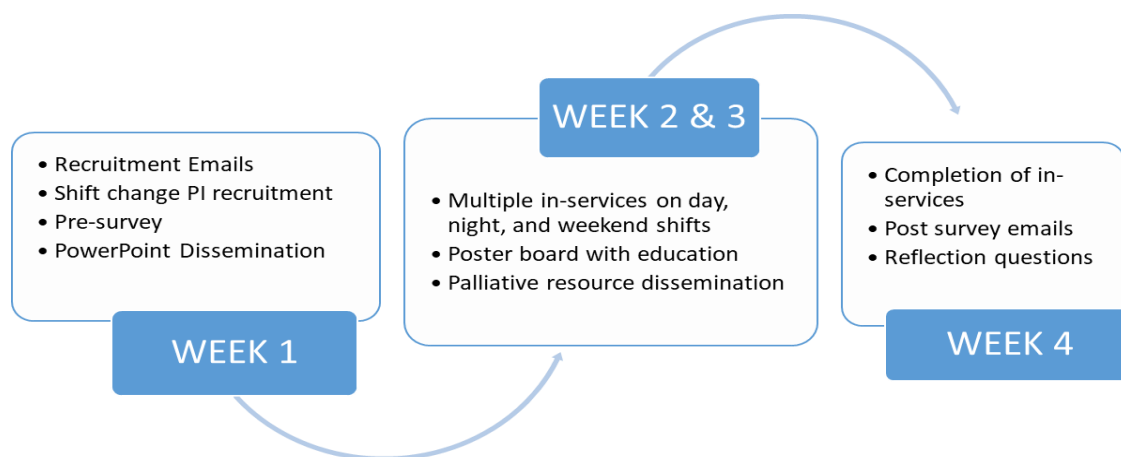


FIGURE 2: Implementation Timeline

Data Collection and Analysis

Implementation occurred over four weeks on each unit. On day one of implementation, nurses were sent a recruitment email requesting participation. Participants were encouraged to review the PowerPoint within the first week. Nurses had the opportunity to attend multiple in-services in weeks 2, 3, and 4 of the project. The principal investigator was present during day and night shifts to educate all nurses. Emails were sent by the middle of week 4 encouraging nurses to complete the post survey.

To evaluate comfort level and gaps in knowledge of nurses working in an acute care setting, data was collected by a valid measurement tool, the EPCS via Survey Monkey. The EPCS is a 28 question survey with answers on a Likert scale. Maximum

score for the survey was 112. Higher scores indicate an increased comfort level with EOL care.

Quantitative Data Collection

Data was exported from Survey Monkey and organized in spreadsheets on Microsoft Excel 2013. Excel and SPSS Statistics Software Version 24 were used for statistical analysis. The investigator used a mixed design of both quantitative and qualitative methods to analyze the data. Descriptive analysis was performed on pre-survey scores and post-survey scores. Survey questions were separated into three domains including patient/family communication (PFC), cultural/ethical/spiritual values (CES), and effective care delivery (ECD). Four paired t-tests were conducted, one comparing the total of pre and post survey results and three t-tests comparing each pre-survey domain to post-survey domain. Linear regression was used to determine whether or not demographic data contributed to pre-survey comfort level. Linear regression was also used to determine if the implementation unit (medical/surgical or ICU) influenced EOL comfort level on the post survey. Demographics were coded into dummy variables to run linear regression.

Survey Monkey provided weighted averages for all 28 questions. These averages were individually reviewed and analyzed. By doing this, the investigator was able to identify lowest scoring questions that indicated a gap in nursing knowledge of that topic. Pre-survey averages were compared to post survey averages.

Qualitative Data Collection

EOL post-survey included open-ended reflection questions. The questions encouraged participants to contemplate topics learned throughout the project and barriers

that are encountered during patient care delivery. The first question was ‘after participation in this project, do you feel more comfortable caring for EOL patients and families?’ The second question was ‘what is your biggest barrier with EOL patients and families?’ The third question was ‘what did you find most valuable in this project.’ The final open ended question was ‘please list any suggestions for improvement or additional comments.’ Statements from these questions were individually reviewed by the PI and evolved into barrier themes and most valuable themes. Topics on the EOL educational PowerPoint guided the development of the themes. Suggestions from the last question were noted for future implications.

Translation and Impact on Practice

The initial goal was to impact the medical/surgical oncology unit and ICU at ARMC. Next steps involve implementation on other ARMC units and Cone Health units that care for EOL patients. This project started in Alamance but investigator anticipates future dissemination at Moses Cone Hospital and Wesley Long Hospital in Greensboro, NC as well as Annie Penn Hospital in Reidsville, NC. From the beginning of this scholarly project, key stakeholders were interested and supportive of project implementation. After completion of this project, results will be shared with stakeholders and the nursing research counsel in hopes of approval for future implementation.

This project may not yet benefit a national level but will contribute to the body of knowledge on nursing comfort with EOL care of patients and families. By contributing to the body of knowledge of this topic, the integration of palliative care in hospitals may continue to be accepted as well as further included in nursing programs.

Fiscal Impact

Before chronic disease progression and the point of imminent death, it is important for patients to make known their EOL wishes in regards to advanced directives and code status. Nurses should have a basic understanding of concepts related to advanced directives and code status in order to educate patients and families. When EOL wishes are known, it is easier to ensure comfort and dignity at the EOL. When the focus of care is transitioned from aggressive medical treatment to comfort measures only, interventions not aimed at comfort are discontinued. When it is determined that a patient is eligible for hospice, the goal is to prevent recurrent hospitalizations as disease progresses. Although it may be minor, this scholarly project may provide a fiscal impact if unnecessary interventions, such as lab work or imaging, are discontinued. When goals of care are transitioned to comfort, appropriate hospice referrals are made in order to prevent future costs from re-hospitalization that often just put a temporary band aid on symptoms of chronic disease.

Confidentiality

Confidentiality was maintained throughout the project. Consent was obtained at the beginning of the survey. Participants provided a unique identifier to remain anonymous. Demographic data was requested during the pre-survey but the unique identifier allowed for participants to remain anonymous. Data from surveys is on a password protected computer and any paper data is stored in a locked cabinet.

CHAPTER 4: RESULTS

Quantitative Findings

Recruitment emails were sent to 75 nurses working on either a medical/surgical unit or an intensive care unit. A total of 37 nurses completed the pre-survey including demographic data, which equals a 49% response rate. A total of 25 nurses completed the post-survey after the educational intervention, which equals a 33% response rate. There were 7 participants that completed the post-survey that did not complete the pre-survey. Eighteen (n=18) participants completed the pre and post survey. Review *Figure 3* below.



FIGURE 3: Sample Size

Majority of the participants were female, younger than age 40, and Caucasian. Majority of participants had a BSN and did not have previous EOL education. Majority of nurses have worked less than 10 years. Review *Table 1* for further demographic data.

The null hypothesis (H0) states there is no difference in nursing comfort level between pre-survey and post-survey following an educational intervention. The alternative hypothesis (H1) states there is a true difference in nursing comfort level between pre survey and post survey following an educational intervention.

TABLE 1: Demographic Information

Demographic Information (n=37)		
Variables	Pre-Survey Percentage (count)	
Gender	Male	5% (2)
	Female	95% (35)
Age	18-30	35% (13)
	31-40	32% (12)
	41-50	14% (5)
	51-60	16% (6)
	>61	3% (1)
Ethnicity	Caucasian	78% (29)
	African American	11% (4)
	Native American/Indian	3% (1)
	Asian/Pacific Islander	5% (2)
	Other	3% (1)
Highest Nursing Education Level	ASN	30% (11)
	BSN	57% (21)
	MSN	8% (3)
	Other	5% (2)
Length of Career	<1 year	13% (5)
	1 to 2 years	16% (6)
	3 to 5 years	27% (10)
	6 to 10 years	22% (8)
	>10 years	11% (4)
	>20 years	11% (4)
Length of Employment at Cone	<1 year	24% (9)
	1 to 2 years	24% (9)
	3 to 5 years	27% (10)
	6 to 10 years	14% (5)
	>10 years	5% (2)
	>20 years	5% (2)
Prior EOL Education	Yes	43% (16)
	No	38% (14)
	Unsure	19% (7)

The paired t-test for pre-survey scores and post-survey scores (n=18) revealed statistical significance less than alpha ($p \leq 0.00021$). The null hypothesis is rejected and alternative accepted, revealing there is a difference in nursing comfort level between pre and post surveys following an educational intervention. Mean score increased from 77.44 on the pre-survey to 93.11 on the post-survey. The paired t-tests for the three domains (PFC, CES, ECD) also revealed statistical significance with p-values less than alpha ($p \leq 0.00067$, $p \leq 0.00012$, and $p \leq 0.00041$). All domain t-tests revealed improvement in mean pre-score to mean post-score. Refer to *Table 2* and *Table 3* for further data on descriptive statistics and paired t-tests.

TABLE 2: Descriptive Statistics

Descriptive Statistics Pre and Post Survey Scores (n=18)		
	Pre Score	Post Score
Mean	77.44	93.11
Median	75.5	94
Mode	55	112
Range	68	56
Standard Deviation	19.44	17.56
Minimum Score	43	56
Maximum Score	111	112

TABLE 3: Paired T-tests

Paired T-tests (n=18)					
	Mean Pre	Mean Post	Variance	Standard Deviation	P-value (alpha: p=0.05)
Total EPCS	77.44	93.11	377.91	19.44	0.000214
PFC Domain	34.5	40.83	62.85	7.93	0.000667

CES Domain	21.83	26.5	36.85	6.07	0.000122
ECD Domain	21.11	25.78	41.75	6.46	0.000412

For linear regression testing, the null hypothesis (H0) states there is no relationship between demographical data and an increased comfort level. The alternative hypothesis (H1) states there is a true relationship between demographical data and an increased comfort level. Despite multiple linear regression tests that were conducted and analyzed, there was only one demographic that was statistically significant. It was demonstrated with a value $p \leq 0.042$ and coefficient of 28.10, that African Americans in this project had a higher mean comfort level according to pre survey score. Gender, age, highest level of education, length of career, length of employment at ARMC, and EOL education prior to intervention did not prove to be statistically significant to baseline comfort level; therefore the null hypothesis was accepted.

A linear regression test was also conducted to compare post comfort survey score with unit of employment, the ICU or medical/surgical unit. The coefficient for the ICU as a dummy variable was -16.97 meaning mean post-survey scores were about 17 points lower than scores of participants who worked on the medical/surgical unit. Review *Table 4* for data on linear regression.

TABLE 4: Demographic Linear Regression

Table 4: Demographic Linear Regression			
Pre Survey (n=37)	Dummy Variable	Coefficients	P-value (alpha: $p=0.05$)
Age	18-30 years	-10.42	$p=0.1899$
Age	31-40 years	1.11	$p=0.8973$
Ethnicity	Caucasian	6.97	$p=0.5093$
Ethnicity	African American	28.10	$p=0.0418$

Education	BSN	-15.56	p=0.1364
Education	ASN	-16.07	p=0.1389
RN Career	3-5 years	-2.91	p=0.7312
RN Career	>10 years, >20 years	14.46	p=0.0999
ARMC Career	3-5 years	-4.39	p=0.6619
ARMC Career	<1 year, 1-2 years	-4.82	p=0.5642
Prior ELNEC	NO	4.82	p=0.5712
Prior Healthstream	YES	15.74	p=0.0962
Prior Healthstream	NO	8.58	p=0.3573
Post Survey (n=24)	Dummy Variable	Coefficients	P-value (alpha: p=0.05)
Hospital Unit	ARMC ICU	-16.97	p=0.0077

Weighted averages for all questions were analyzed via Survey Monkey. The lowest average question on pre-survey was “I feel confident addressing requests for assisted suicide” at 1.57. Other pre survey questions below an average of 2.5 were “I am comfortable starting and participating in discussions about code status”, “I am comfortable helping to resolve difficult family conflicts about end-of-life care”, “I am comfortable providing grief counseling for families and staff”, and “I am knowledgeable about cultural factors influencing end-of-life care.”

On the post survey, the weighted average on the assisted suicide question increased from 1.57 to 2.28. There was an increase to 2.8 and above on the questions regarding code status discussion, difficult family conflicts, grief counseling, and EOL cultural factors.

Qualitative Findings

Participants reflected on what was most valuable to them in the project. Four themes evolved from these responses. The first theme was Hospice Information. The

second theme was Palliative Resources which included responses such as “vast amount of resources that are available.” The third them was Educational Refresher which included responses such as “general education on a topic I was not significantly familiar with” and “refreshing of a topic that I am uncomfortable with.” The last theme was EOL Discussions which included responses such as “gave coworkers a chance to talk about EOL care” and “spreading the word on this important topic.” Review *Figure 4* below.



FIGURE 4: Most Valuable Qualitative Themes

Participants also identified barriers with EOL patient and families. Four themes evolved. The first theme was Provider Challenges which included responses such as “unrealistic expectations and negligence of physicians to have honest conversations with patients/families about prognosis” and “doctors not allowing an appropriate palliative consult due to own personal beliefs.” The second theme was Ethical Issues which

included responses such as “patient’s death prolonged for the convenience of the family” and “family not realistic of patient outcomes and patients have suffered needlessly.” The third theme was Family Communication which included responses such as “helping them understand medical indications that lead to EOL” and “starting the code status discussion.” Lastly, the fourth theme was Grieving which included responses such as “having people in multiple stages of grieving in the same room and contradicting care of EOL patient” and “getting hospital staff comfortable with the dying process.”



FIGURE 5: Barrier Qualitative Themes

Outcomes

The figures below serve as relationships between objectives and outcomes and how they are linked to the theoretical framework.

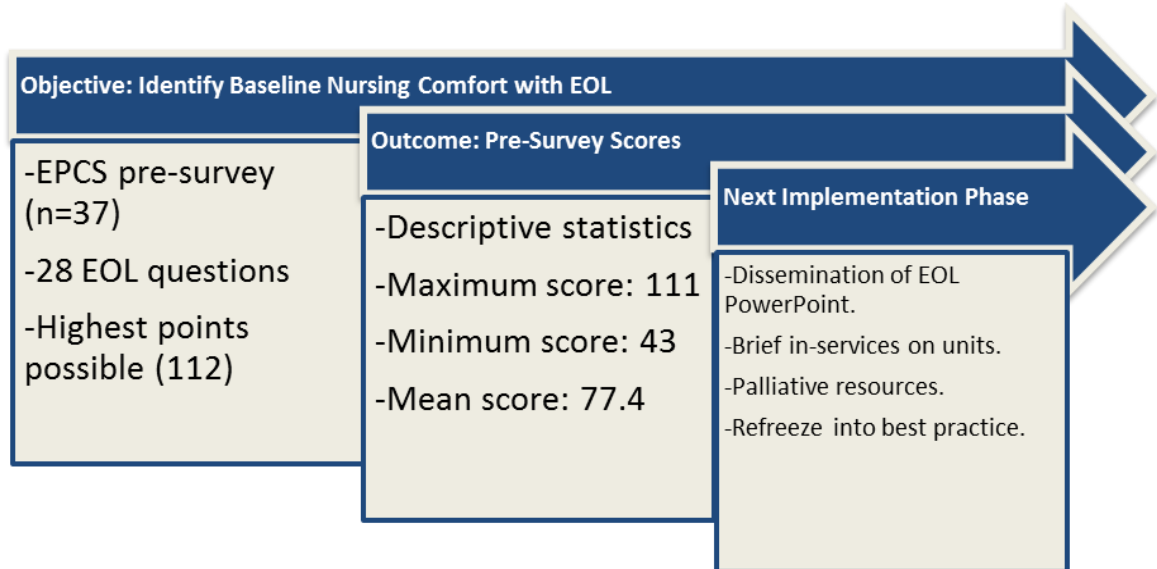


FIGURE 6: Outcome 1: Baseline Comfort

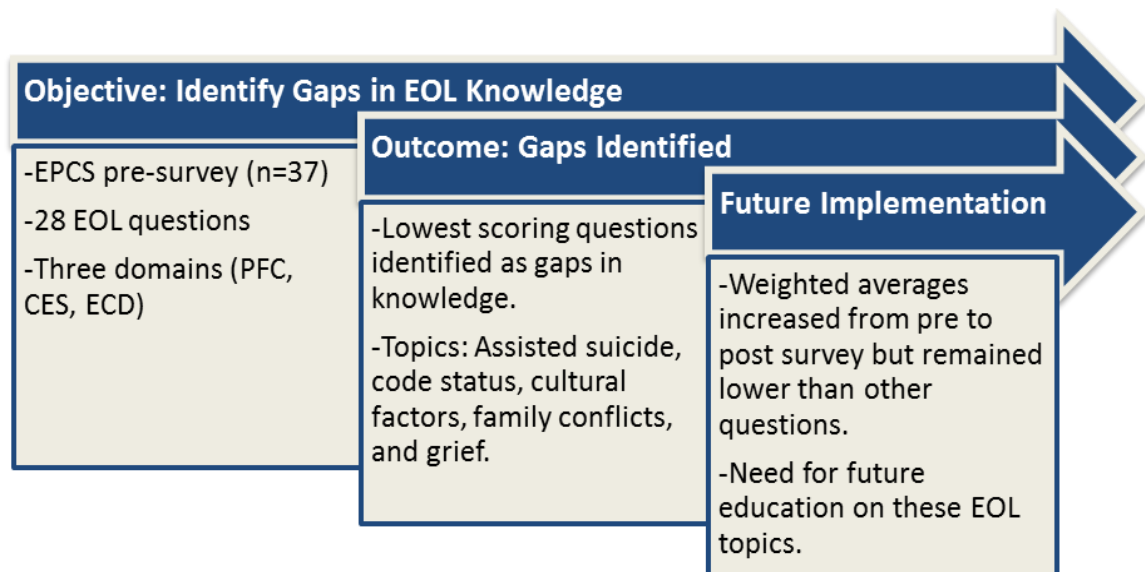


FIGURE 7: Outcome 2: Gaps in EOL Knowledge

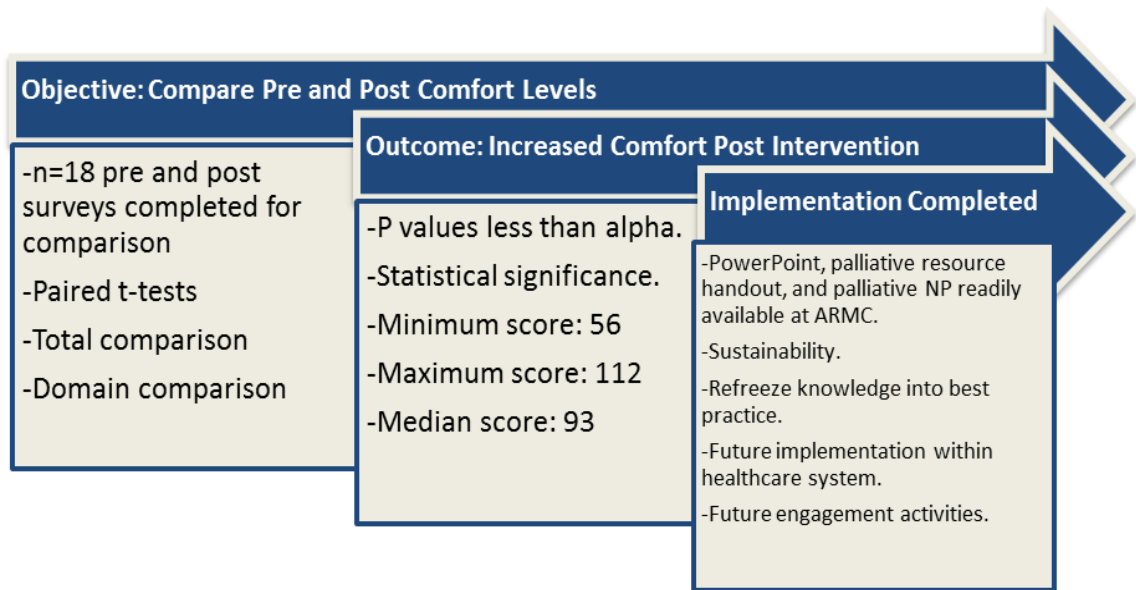


FIGURE 8: Outcome 3: Comfort Level Comparison

Discussion of Results

The Cone Health system embraced these educational opportunities for growth and was receptive to implementation from the beginning of the project. By comparing pre and post-survey results by a paired t-test, it was concluded that nursing comfort level with EOL care of patients and families increased after education was provided. All 18 participants did have an increase in post-survey score compared to pre-survey score. This significance is also evident by increased mean score (77.4 to 93.1) from pre to post-survey. There was an increased average score in each domain of the EPCS, including patient/family communication, cultural, ethical, and spiritual values, and effective patient care delivery.

Gaps in nursing knowledge with certain EOL topics were identified by analyzing weighted averages of each question on pre and post-survey. Lowest scoring questions included the topics of physician assisted death, code status discussions, difficult family

conflicts, grief counseling, and EOL cultural factors. Weighted averages for all of these questions increased from pre to post-survey.

All available nurses on the units during in-service times were educated because the pre-survey was anonymous. More than 50 nurses were educated from both the ICU and medical/surgical unit. Participants not only received a paper copy of the EOL PowerPoint, which provided detailed information on multiple aspects of a dying patient, but also a list of palliative resources to reference in the future. Multiple in-services were held on both day and night shifts and weekends to target all nursing staff. In-services are viewed as a success. Not only did participants listen and ask questions but also many participants shared concerns and fears about caring for patients at the end-of-life. Participants shared experiences about patient deaths that were peaceful and dignified as well.

The most important aspect of this scholarly project was to educate on palliative care and share knowledge on EOL aspects of care that are inevitable in all settings of healthcare. It was important to also identify barriers to communication and effective care delivery. Qualitative themes were developed from open-ended reflection questions on the post-survey.

Out of 25 participants that completed the post-survey, the most valuable information learned was on information regarding hospice and palliative resources and the opportunities for EOL discussions with colleagues. Many participants appreciated the education as a refresher. Nurses will have continued access to this education moving forward. The majority of nurses that were educated seemed receptive to information and appreciative of palliative care team playing a vital role in this healthcare system.

Knowing this information was valuable during the project will provide the PI encouragement that it will be a successful education tool for future implementation.

Barriers in EOL care were also identified from a reflection question in the post-survey. Participants felt the largest barriers in EOL care include challenges with patient providers, ethical issues, family communication, and grieving. This qualitative data serves as valuable information moving forward. Not only do these barriers serve as a foundation for future education but also topics of discussion for focus groups or debriefing sessions.

CHAPTER 5: DISCUSSION

Interpretation/Significance

Using the EPCS as a measurement tool, EOL concepts regarding symptom assessment and management, patient/family education and communication, ethical/cultural/spiritual factors, and effective care delivery were assessed. Nurses were then given detailed information on these concepts through a PowerPoint and brief in-service. It was hypothesized that the educational intervention would increase scores on the post-survey. By analyzing the data, the investigator determined increased comfort level, via survey post-scores, with EOL patient and family aspects of care. It was also hypothesized that demographical information would contribute to a higher level of baseline comfort prior to education. This was not found to be statistically significant ($p=0.19$, $p=0.51$, $p=0.14$, $p=0.73$, $p=0.66$, $p=0.57$) when demographic dummy variables were compared with pre-survey scores. This information reveals that regardless of demographic features, all participants had learning needs.

There is a degree of association between the intervention and outcomes when comparing total survey scores and three domain pre and post-scores. Although it may be a small degree due to sample size, the project had a positive impact on nurses and the healthcare system as a whole by evidence of statistical significance from paired t-tests as well as qualitative responses from post-survey reflection.

Qualitative data revealed valuable feedback for future implementation. Most valuable themes indicated topics that proved to be successful during dissemination of the PowerPoint and brief in-services. Knowing this education was valuable, provides the PI reinforcement that future use of these education tools may also serve to be valuable on other units. Barrier themes identified challenges that participants face when caring for

EOL patients. The need for future evaluation on these topics is necessary in order to decrease barriers to effective communication and patient care delivery. These barriers need to be eliminated in order to ensure quality care for all EOL patients and families.

Limitations

Several limitations were determined throughout the implementation phase. From beginning of implementation, it was anticipated from pre-survey completion (n=37) that there would be a larger sample size of comparison for data analysis. On completion of implementation, there were only 18 nurses who had completed both pre and post-surveys for comparison analysis. The maximum number of nurses emailed was 75 but a third of these nurses are per diem and only required to work three shifts in six weeks; therefore the investigator did not have the opportunity to meet and educate these per diem nurses in the short span of implementation. Time may be seen as a limitation. The principle investigator may have met per diem nurses if the implementation phase was longer.

Email played a large role in recruitment for the project, and nurses may not check work emails on a regular basis. Since participation remained anonymous throughout implementation, all nurses present for in-services received education regardless of completion of pre-survey. This is likely the reason there were 7 post surveys completed that did not link to pre-surveys. Motivation for participation was extremely challenging without incentive for nurses.

A design imprecision was determined during implementation. Two nurses contacted the investigator with concerns that the pre-survey was not able to be completed due to a glitch stating that participant had already completed a survey. This may have occurred if the participants inadvertently had the same unique identifier, which was the

first two digits of birth month and last four digits of phone number. Investigator instructed these participants to pick another six digit identifier that they would remember. These participants may not have attempted to complete the pre survey again after initial complication.

Implications

Despite many limitations identified, there are implications appropriate for further implementation of this project. Although the sample size was small, data was statistically significant with $p \leq 0.00021$, and a 15-point increase from pre score mean to post score mean. There was also statistical significance in regards to all three domains of the EPCS when pre and post surveys were compared. With future incentive for nurses on other units in the health system, increased participation may be possible.

During data analysis, each survey question was individually evaluated. Questions with lowest average scores included physician-assisted suicide, code status discussion, difficult family conflicts, grief counseling, and EOL cultural factors. These same questions in the post-survey all resulted in an increased average. This evaluation indicated gaps in nursing knowledge and provided the investigator topics that recommend future education to maintain or increase level of comfort.

Nurses who completed the post-survey provided valuable, qualitative feedback for future implementation including the need for implementation on all units in the health system, role play for nurses on EOL scenarios as well as the need for physician and advanced practice provider education. In general, there remains a knowledge gap with some EOL concepts and the role of palliative medicine in healthcare. Continuous education is essential throughout the entire healthcare team.

Moving forward with nursing, the goal is for change to be sustained as best practice with EOL communication and patient care delivery. It may be beneficial in the future to evaluate sustainability by another post-survey within the two implementation units. In addition to educational in-services, future implementation with engagement activities such as role play or integrative journal clubs may be beneficial. Focus groups and debriefing sessions would allow nurses a safe environment to express thoughts, concerns, and fears with EOL as well as barriers to effective care delivery.

During implementation, the nurses were provided multiple EOL/palliative resources. Nurses also understand the principle investigator is readily available during the week as a resource. The investigator plans to continue educating when palliative and EOL opportunities arise as well as engage and encourage the healthcare team in discussing EOL situations.

This project was piloted at one hospital in the Cone Health system. The goal is for multi-site dissemination throughout the other three hospitals in the system. Providers and other healthcare professionals will also be educated along with nurses. The CHPMT will soon have outpatient opportunities for education in two of the health system's cancer centers. The need for palliative and EOL education is essential throughout the entirety of the health system.

Recommendations

It is recommended that Cone Health integrate yearly continued education on palliative and EOL care whether that is through Healthstream or the CHPMT. It may be beneficial for the CHPMT to collaborate with the nursing education department in order to ensure sustainability on current implementation units and future implementation on

other units in the healthcare system. Knowing majority of Americans will die in the acute care setting, it is important for nurses to feel comfortable with many skills that are necessary when a patient is at the EOL. Although primary palliative nursing is lacking in nursing programs, it is feasible for these skills to become best practice in this healthcare organization.

It is also necessary for the CHPMT to educate physicians and advanced practice providers on concepts of palliative and EOL care. When EOL wishes are known and the goals of care have transitioned to a focus on comfort, appropriate symptom management and patient care delivery will be maintained. Unnecessary, costly testing will be discontinued and a patient will have comfort, quality, and dignity at the end of their life. Effective communication will ensure ethical, cultural, and spiritual needs are addressed.

Summary

The primary objective of this scholarly project was to evaluate a baseline nursing comfort level with EOL patient and family care and improve EOL comfort level by providing an educational intervention. Another objective was to identify gaps in nursing knowledge with EOL topics and provide nurses palliative resources for future use.

This project remained an opportunity to educate on an important topic that can often be uncomfortable and awkward for nurses. Palliative and EOL educational materials have been disseminated throughout the medical/surgical unit and the ICU. According to data analysis, the 18 nurses that completed both surveys did identify increased comfort with EOL care after educational intervention. Feedback from post-surveys revealed that nurses valued the education and the opportunity to discuss EOL with colleagues. Nurses who were fairly comfortable before implementation of this

project, expressed willingness to participate and refresh themselves on aspects of EOL care.

Conclusion

Sixty percent of American deaths will occur in a hospital setting (SSOM, 2018). Bedside nurses are at the forefront of patient care delivery when death is imminent. It is necessary for nurses to have a good understanding of primary palliative nursing and feel comfortable with the many skills involved in EOL care. In the last days and hours of a patient's life, it is essential to provide comfort, quality, and a dignified death. Nurses are given these opportunities to connect with patients and families in ways that will never be forgotten.

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APPENDIX A: EPCS

End-of-Life Professional Caregiver Survey

Below is a list of statements that other end-of-life professional caregivers have said are important. Please circle one number per line to indicate your response as it applies to you today.

	Not at all	A little bit	Some-what	Quite a bit	Very much
I am comfortable helping families to accept a poor prognosis	0	1	2	3	4
I am able to set goals for care with patients and families ...	0	1	2	3	4
I am comfortable talking to patients and families about personal choice and self-determination.....	0	1	2	3	4
I am comfortable starting and participating in discussions about code status.....	0	1	2	3	4
I can assist family members and others through the grieving process	0	1	2	3	4
I am able to document the needs and interventions of my patients	0	1	2	3	4
I am comfortable talking with other health care professionals about the care of dying patients	0	1	2	3	4
I am comfortable helping to resolve difficult family conflicts about end-of-life care	0	1	2	3	4
I can recognize impending death (physiologic changes)	0	1	2	3	4
I know how to use non-drug therapies in management of patients' symptoms	0	1	2	3	4
I am able to address patients' and family members' fears of getting addicted to pain medications	0	1	2	3	4
I encourage patients and families to complete advanced care planning	0	1	2	3	4
I am comfortable dealing with ethical issues related to end-of-life/hospice/palliative care.....	0	1	2	3	4
I am able to deal with my feelings related to working with dying patients.....	0	1	2	3	4

End-of-Life Professional Caregiver Survey

I am able to be present with dying patients.....	0	1	2	3	4
I can address spiritual issues with patients and their families.....	0	1	2	3	4
I am comfortable dealing with patients' and families' religious and cultural perspectives.....	0	1	2	3	4
I am comfortable providing grief counseling for families..	0	1	2	3	4
I am comfortable providing grief counseling for staff.....	0	1	2	3	4
I am knowledgeable about cultural factors influencing end-of-life care.....	0	1	2	3	4
I can recognize when patients are appropriate for referral to hospice.....	0	1	2	3	4
I am familiar with palliative care principles and national guidelines.....	0	1	2	3	4
I am effective at helping patients and families navigate the health care system.....	0	1	2	3	4
I am familiar with the services hospice provides.....	0	1	2	3	4
I am effective at helping to maintain continuity across care settings.....	0	1	2	3	4
I feel confident addressing requests for assisted suicide....	0	1	2	3	4
I have personal resources to help meet my needs when working with dying patients and families.....	0	1	2	3	4
I feel that my workplace provides resources to support staff who care for dying patients.....	0	1	2	3	4

APPENDIX B: EOL POWERPOINT

Nursing Comfort with End-of-Life Care of Patients and Families



By: Megan Mason, MSN, FNP-C
Cone Health Palliative Medicine Team
University of North Carolina at Charlotte-DNP Student

Palliate:

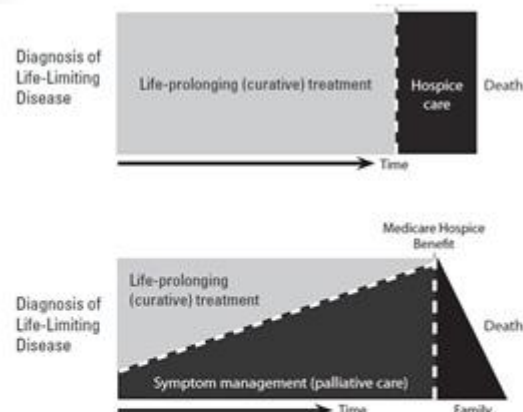
To make less severe
without eliminating
the cause.

Palliative Medicine

- Specialized medical care aimed at improving **quality of life** and **relief from suffering** for patients and families living with serious illnesses.
- Can be **involved at any stage** of a serious illness, including intent to cure.
- Multi-disciplinary, team approach to care.



Approximately 90 million individuals in the US are living with serious, life-limiting illnesses and it has been predicted that this number will double in the next two decades as the baby boomer population continues to age (CAPC, 2014).



Involve palliative care from beginning of diagnosis

Primary Palliative Nursing

- Nursing role in palliative care is immense.
- Primary palliative nursing includes:
 - **Symptom assessment and management**
 - **Preparing patients/families for expectations of disease progression**
 - **Assessment of patient/family coping, concerns, and needs**
 - **Respectful care of dying patients and compassion to survivors**
- In many patient situations, nurses are often the first to identify patient needs, concerns, or distress.
- Important for nurses to feel comfortable when caring for the physical, psychological, cultural, and spiritual needs of seriously ill and dying patients.

When caring for patients and families at the EOL, nurses should be...

ADVOCATE
PROFESSIONAL
COMPANION
EDUCATOR
CAREGIVER
SUPPORTER
EMPATHETIC
NON-JUDGEMENTAL
SENSITIVE
TRUSTWORTHY
CRITICAL THINKER

End-of-Life (EOL):

Medical support and care given to individuals in the final days and hours before death occurs.

EOL Communication

The Basics

- Develop relationships with patients and families.
 - How much does the patient want to know?
 - Who does the patient want you to share information with?
- Keep conversations centered around the patient, not disease.
- Open-ended questions.
- Simple language-avoid medical jargon
- Acknowledge non-verbal cues.
- Allow empathetic listening and silence.
- Repeat and clarify information to confirm understanding.
- Document and communicate important conversations with the healthcare team.

EOL Communication

- **Patient/family goals of care**
 - Establish goals of current care and anticipate future needs.
 - Are goals practical or beneficial?
 - Sense of meaning (purpose, value, efficacy, self-worth).
 - Acknowledge fears (dying process, abandonment, symptom burden, the unknown).
- **Understanding poor prognosis**
 - Determine patient/family understanding of prognosis.
 - Closure to relationships, showing forgiveness.
 - Closure to work or financial concerns.

EOL Communication

- **Code status/advanced directives**
 - Resuscitation originally intended for accidental deaths (such as drowning) or in cardiac arrest in a healthy individual.
 - Now CPR is a standard of care in all settings unless DNR is in place.
 - **According to Dunn (2016), approximately 17% of hospitalized, resuscitated patients will survive to be discharged but survival significantly decreases (less than 2%) when a patient has two or more serious illnesses or terminal illness and/or a resident of a long term care facility.**
 - CPR more harm than good – resulting in rib fractures, punctured lungs, brain damage, and often intubation/mechanical ventilation.
 - Likely a poor quality of life and inhibits the chance of a peaceful and dignified death.

EDUCATE AND ENCOURAGE YOUR PATIENTS!!

EOL Communication

- **Resolving patient/family conflicts**
 - Family hesitant to speak of “death” around the patient but patients often understand they are dying.
 - Keep discussions centered around the patient and focus on concerns.
 - Ask about family history and stories.
 - Detach the medical problem from personality
 - Personality: “Doctors are giving up” or family is in denial.
 - Instead focus on PROBLEM: the patient is dying, interventions are not successful or will not improve quality of life.
 - Determine if physician/advanced practice provider has made clear recommendations.
 - In every situation, we hope for the best but prepare for the worst.

Hospice Services and Eligibility

- Terminal illness, <6 months life expectancy.
- Opt for comfort approach over curative approach.
- Quality of life over length of life.
- Consider other chronic diseases even if not main hospice diagnosis.



Hospice Benefit

- Covered by Medicare and most commercial insurance if life expectancy is <6 months.
- Involved in one's home, nursing home, or residential hospice facility if death is imminent.
- Patient can revoke hospice at any time.
- Includes physicians, advanced practice providers, nurses, aides, social workers, chaplains, and even physical/occupational/speech therapists if necessary.
- Most interventions covered if intent is palliation: **medications, supplies, equipment, enteral products, and palliative chemo/radiation.**
- Bereavement care for families.
- Re-hospitalization only if symptoms cannot be managed at home or there is a delay in hospice team response.

Grief and Bereavement

Grief: emotional suffering from loss, a natural response.

Bereavement: the period of mourning caused by loss from a death.

five stages of grief - elisabeth kübler ross	
denial	cling to a false, preferable reality
anger	Why me?
bargaining	Seeking a compromise
depression	Disparaging, alienating, anti-social
acceptance	Emotionally stable and moving on

Nurses play a role in the grieving process of families:

- Preparing for death leads to improved bereavement outcomes.
- Be honest and discuss EOL expectations.
- Normalize the grieving process and acknowledge emotional pain or grief.
- **Normal responses of grief**
 - Anger/guilt
 - Sorrow
 - Denial/disbelief
 - Yearning
 - Numbness
 - Confusion
 - Loss of appetite
 - Fatigue
 - Aches and pains
 - Interrupted sleep
- **Provide support**
 - Listen and empathize
 - Offer chaplain
 - Offer bereavement services
 - Send condolence card



Patient Care Delivery

Six months to one month prior to death:

- Weakness
- Weight loss
- Dysphagia
- Drowsiness/increased sleep
- Decreased appetite
- Increased symptom management need
- Emotional withdrawal
- Physical deterioration becoming total care
- Mild hypotension and tachy or bradycardia
- Phases of grief from diagnosis of terminal illness

Patient Care Delivery

Physiologic symptoms of impending death (days to hours):

- Bedbound
- Severe dysphagia
- Tachycardia
- Hypotension
- Oliguria (<500cc/day)
- Hyper/hypothermia
- Cheyne-stokes respirations/apnea
- Lethargy/comatose
- Terminal delirium
- Terminal secretions
- Hallucinations
- Decreased pulses
- Cool mandible
- Skin mottling and cyanosis
- Nasolabial fold droop
- Hyperextension of neck
- Decreased or absent bowel sounds
- Loss of rectal tone

Patient Care Delivery

Symptom Management

- EOL is different for every patient.
- Most common symptoms at EOL (>50% of patients) include pain, dyspnea, respiratory congestion/terminal secretions, and confusion.
- Consider behavioral cues (grimacing, posturing, restlessness) and medicate as needed.
- Treat dyspnea/air hunger with prn opioid instead of escalating care with oxygen-this may prolong the dying process.
- Other symptoms that may require medication management include anxiety, constipation/diarrhea, nausea, vomiting, acid reflux, delirium, depression, cough, insomnia, dry mouth/thrush, or pruritus.
- Communicate symptom burden with physicians/advanced practice providers to initiate management.

Patient Care Delivery

Non-pharmacological Interventions

Pain/Anxiety

- Music
- Distraction
- Massage therapy
- Local heat/ice for pain
- Guided imagery
- Specialty mattress
- Prayer
- Pet therapy

Delirium

- Reorientation
- Stimulate cognition
- Hearing aids/glasses
- Remove lines if possible
- Familiar faces
- Blinds open, lights on during the day
- Safety sitters
- Calm environment

Nausea

- Small sips of clear liquids
- Small bites of bland foods

Secretions

- Repositioning
- Elevating HOB

EOL/Hospice Myths

1. Starvation and Dehydration

- Loss of appetite/thirst **normal** at EOL. Patient is **not** hungry.
- Forcing food and fluids may lead to discomfort.
- IV fluids not recommended: increase edema/anasarca, ascites, or pleural effusions.
- Let the patient eat/drink what they can and if willing.
- Frequent oral care will help with dry mouth.

2. Death Rattle

- Normal for decreased cough/gag reflex making it difficult to clear secretions.
- May be traumatizing for family.
 - Secretions are deep/unable to be suctioned.
 - Give prn meds for secretions.
 - Use the term "terminal secretions" or "respiratory congestion" instead.

3. Medications will hasten death.

- Given as needed for comfort and to manage symptoms.
- Palliative sedation only if symptoms are intractable.

EOL/Hospice Myths

4. Hospice is a place.

- Can be provided in homes and nursing facilities.

5. Hospice is only for cancer patients.

- Any individual with serious, life-limiting illness/end stage chronic diseases with <6 month life expectancy can have hospice.

6. Hospice is for old people.

- All ages facing a serious, terminal illness.

7. Hospice care is expensive.

- Limited financial burden due to Medicare hospice benefit. Minimal (if any) out-of-pocket expense.

8. Hospice means “no hope.”

- Comfort, quality, and dignity for each day that is left.
- Personal and spiritual connections that lead to a peaceful, dignified death.

Cultural, Ethical, and Spiritual Aspects at EOL

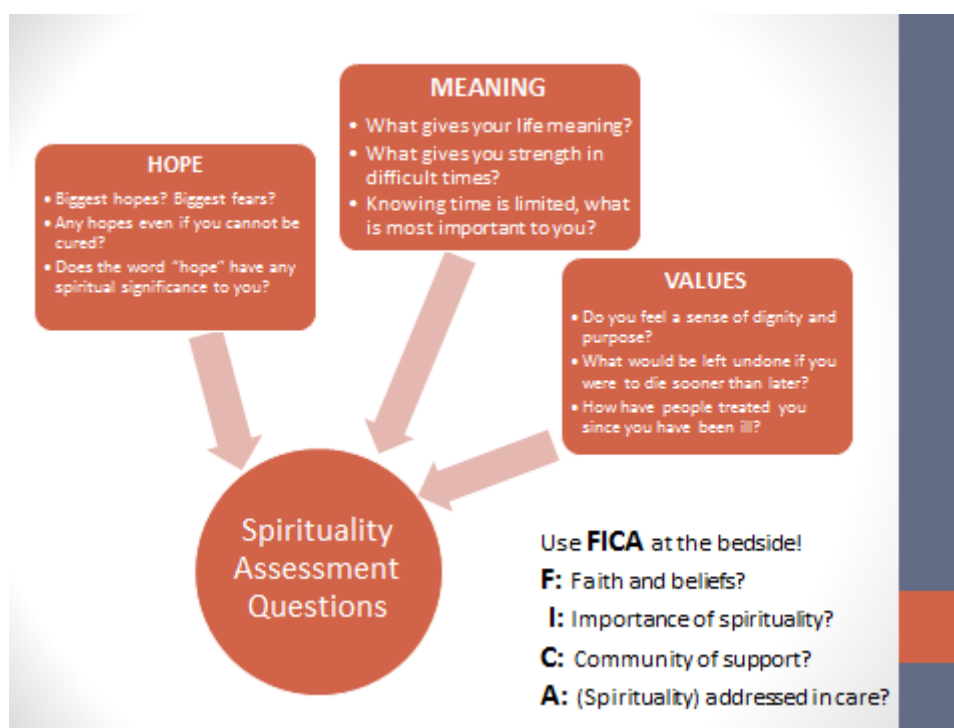
ETHICAL

- Consider ethical principles of autonomy, beneficence, nonmaleficence, and justice.
- We must honor and respect a patient’s informed decision making and continue to educate for future decisions.
- Moses (2014) explains that emotional suffering may outweigh physical suffering therefore influencing patient decision making.
- When ethical concern arises, make known to palliative physician or advanced practice provider who can further evaluate the situation and discuss with ethics team if necessary.

Cultural, Ethical, and Spiritual Aspects at EOL

SPIRITUAL

- **Spirituality:** one's search for meaning and purpose in life.
- **Religion:** shared beliefs and behaviors.
- Both can HELP or HINDER a patient in response to illness and medical interventions.
- Nurses role to identify spiritual needs or concerns.
- Provide spiritual comfort as the patient requests, whether it is by prayer, hymns, rites, or rituals.
- Respect all spiritual beliefs and religions.
- Explore emotions behind faith statements.
- Place spiritual service consults and involve chaplain if patient/family allows.



Cultural, Ethical, and Spiritual Aspects at EOL



CULTURAL

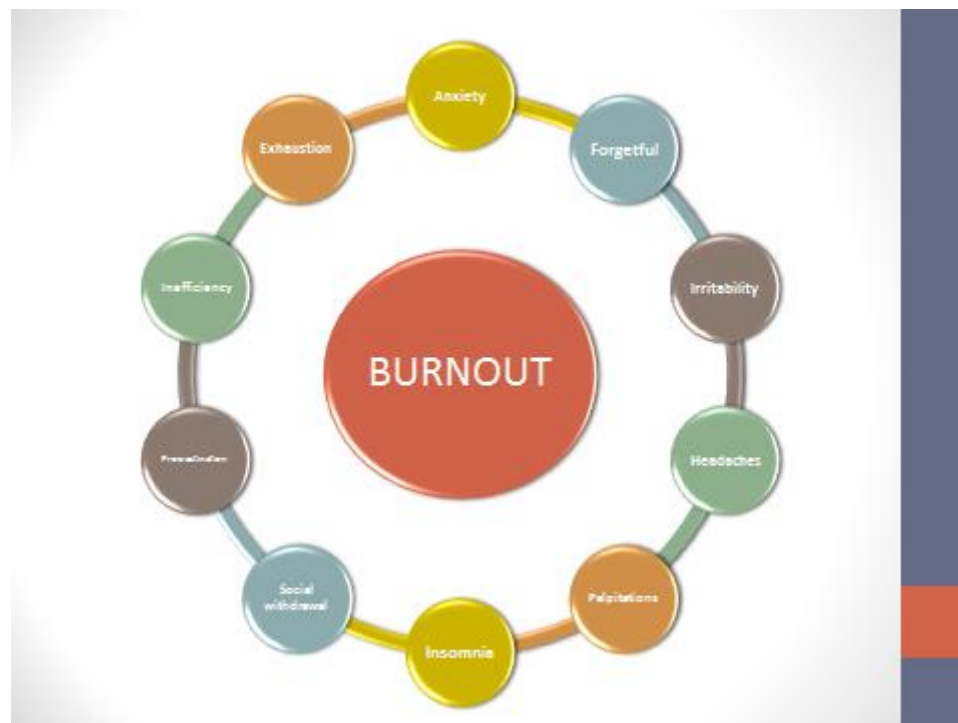
- Numerous cultural views related to pain, suffering, terminal illness, and death and dying.
- Ask patients and families if there are any cultural values the healthcare team needs to acknowledge during hospitalization or the dying process.
- Be respectful of all cultures and rituals at EOL.
- Visit *Healthcare Chaplaincy* for detailed information
 - <https://www.healthcarechaplaincy.org/userimages/doc/Cultural%20Dictionary.pdf>

Self-Assessment and Self Care

Do you feel comfortable working with dying patients?

Are you able to be with patients and families at the EOL?

- If experiencing intense feelings about a particular patient, step back and ACKNOWLEDGE THE EMOTION (anger, sadness, dislike, or frustration).
- Often times, these emotions are normal. Other times, emotions may interfere with patient care delivery.
- Discuss with close colleagues and adjust assignment if necessary.
- Identify BURNOUT: work overload, family/work life imbalance, and inadequate resources.



Self-Assessment and Self Care

- Signs of burnout can lead to self/family neglect, mental illness, substance abuse, patient insensitivity, anger, and loss of self-worth.
- **How to manage burnout?**
 - Debrief with healthcare team
 - Take time off of work
 - Spend time with family, friends, and pets
 - Meditation
 - Exercise
 - Enjoying hobbies
 - Spirituality and religion

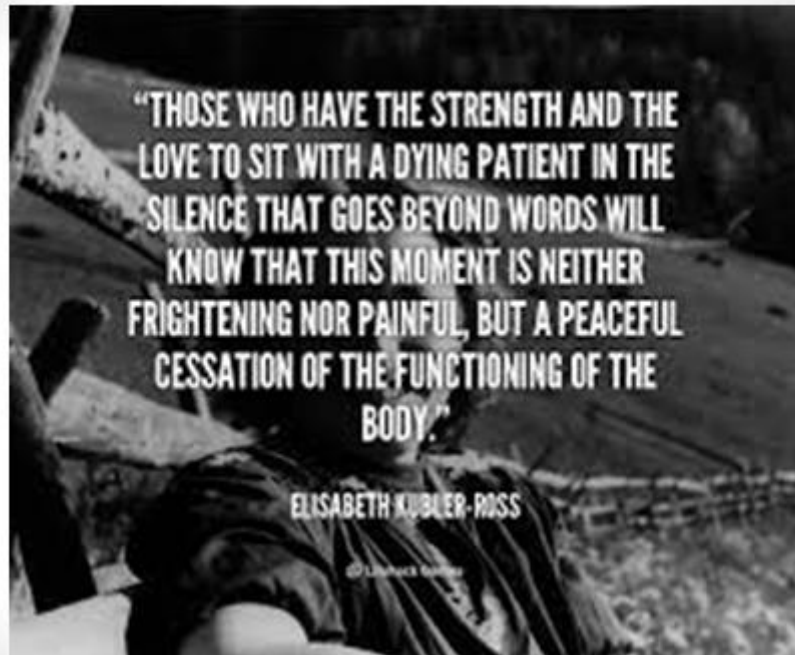


Conclusion

Nurses should have a basic understanding of primary palliative care and feel comfortable caring for patients with serious illnesses at the EOL.

EOL communication and patient care delivery are essential in order to provide patients a comfortable and dignified death.

Nurses are the forefront of patient care and often faced with EOL opportunities to connect with patients/families in ways that will never be forgotten.



APPENDIX C: EOL POSTER BOARD

EOL CARE

end-of-life

Impending death (days/weeks)

- Bleeding
- Stroke/dementia
- Hypertension
- Chronic respiratory
- Chronic renal/hepato-renal
- Cancer progression
- Fracture/osteoporosis
- Terminal infection
- Terminal pneumonia
- Metastatic disease
- Cachexia
- Depressed patient
- Care involving end organ
- Hospitalized end stage
- Hospitalized in acute rehab unit
- Loss of recent weight

Palliative Medicine

Specialized medical care aimed at improving quality of life and relief from suffering for patients and families living with serious illnesses. Can be involved at any stage of a serious illness, including end of life.

Multi-disciplinary team approach to care.

Approximately 90 million individuals in the US are living with serious, life-limiting illnesses and it has been predicted that this number will double in the next two decades as the baby boomer population continues to age (CAPC, 2014).

EOL/Hospice Myths

- Hospice is for "old people" or just cancer patients
- Hospice means "no hope"
- Hospice is expensive
- Hospice means "fast death"
- Medications will hasten death

Nonpharmacological

Secretion

- Drooling
- Excessive H2O

Pain/Anxiety

- Restlessness
- Irritability
- Agitation
- Restless legs
- Delirium
- Anxiety
- Depression
- Pain
- Sleep changes

Communication

- Patient/family goals of care
- Understanding poor prognosis
- Advanced directives
- Resolving patient/family conflicts

HOSPICE ELIGIBILITY

- Terminal illness, or death is expected
- One year or less survival
- Quality of life poor
- Consideration of patient's wishes

Primary Palliative Nursing

- Promotes autonomy and empowerment
- Promotes communication and participation in decision making
- Addresses psychosocial, spiritual, cultural, and ethical needs
- Supports care of living patients and caregivers in continuity

Communication

- Assess communication skills and needs
- Assess patient's understanding of illness and prognosis
- Assess patient's emotional and spiritual needs
- Assess patient's cultural and religious beliefs
- Assess patient's social support system
- Assess patient's ability to understand and follow directions
- Assess patient's ability to make decisions
- Assess patient's ability to express their wishes
- Assess patient's ability to cope with loss
- Assess patient's ability to accept death
- Assess patient's ability to find meaning in life
- Assess patient's ability to find purpose in life
- Assess patient's ability to find joy in life
- Assess patient's ability to find peace in life
- Assess patient's ability to find hope in life
- Assess patient's ability to find faith in life
- Assess patient's ability to find love in life
- Assess patient's ability to find compassion in life
- Assess patient's ability to find forgiveness in life
- Assess patient's ability to find reconciliation in life
- Assess patient's ability to find healing in life
- Assess patient's ability to find restoration in life
- Assess patient's ability to find redemption in life
- Assess patient's ability to find renewal in life
- Assess patient's ability to find revival in life
- Assess patient's ability to find resurrection in life
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- Assess patient's ability to find revival in life
- Assess patient's ability to find resurrection in life
- Assess patient's ability to find life in life

Continuum of illness

Do you feel comfortable working with aging patients?

Are you able to be with patients and families at the EOL?

- Acknowledge the emotion.
- These emotions are normal.
- Are they affecting patient care delivery?
- Discuss with close colleagues.
- Adjust assignment if necessary.
- Identify BURNOUT.

EOL communication and patient care delivery are essential in order to provide death.

Nurses should have a basic understanding of primary palliative care and feel comfortable caring for patients with serious illnesses at the EOL.

Nurses are the forefront of patient care and often faced with EOL opportunities to connect with patients/families in ways that will never be forgotten.

Nurses play a role in the grieving process of families

- Assessing family needs
- Providing emotional support
- Facilitating communication
- Educating families on the dying process
- Supporting families in decision making
- Providing bereavement support

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- Supporting families in decision making
- Providing bereavement support

APPENDIX D: PALLIATIVE RESOURCES

Palliative Resources

- North Carolina Palliative Care Resource Guide: <https://www.communitycarenc.org/media/related-downloads/nc-palliative-care-resource-guide.pdf>
- Palliative Care Network of Wisconsin FAST FACTS: <https://www.mypcnw.org/fast-facts>
- Get Palliative Care: <https://getpalliativecare.org/>
- Center to Advance Palliative Care (CAPC): <https://www.capc.org/>
- Hard Choices by Hank Dunn
- Gone From My Sight by Barbara Karnes

Grief and Bereavement

- Hospice and Palliative Care of Alamance Caswell <https://www.hospiceac.org/>
 - Adult support groups: Grief and Growth, Pathways, and First Tuesdays
 - Kids Path: support for kids 0-18yo who lost a loved one.