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“Improving End-of-Life Care on Navajo Through Education”

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Improving End-of-Life Care on Navajo Through Education

by

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Abstract

End-of-life care (EOLC) is an essential component of comprehensive healthcare and has been shown to improve the quality of life of patients and their families by preventing and relieving pain caused by physical, psychosocial, and spiritual complications. Many rural communities lack access to EOLC, specifically certified palliative and hospice services. The lack of this specialty in rural areas directly affects the experience of healthcare staff. The absence of education for rural healthcare staff and the importance of culturally sensitive care among indigenous people are key concepts in this study.

The purpose of this study was to measure the knowledge, confidence, and comfort level of staff in a rural setting on the Navajo Nation related to palliative and EOLC, including Navajo cultural beliefs about EOLC. A 2-day training—the End-of-Life Nursing Education Consortium (ELNEC) Core Course—was led by two certified ELNEC trainers and one traditional Navajo healer for healthcare providers in the rural area. The impacts the training had on participants were evaluated through a survey, and quantitative data were collected at three points in time and analyzed using the two-paired *t*-test. This study compared the mean scores from the survey and analyzed the data from Time 1 to Time 2 and from Time 1 to Time 3.

Dedication

It is with utmost respect and admiration that I dedicate this Doctor of Nursing Practice Scholarly Project to my children: Amanda Eve, Garrison Matthew, Kayla Jo, and John William. I thank each one of them for their unwavering support and patience, and for the time that this work took away from time with them. We have all experienced losses during the time this work was being done, but they continued to offer their support and love. For this I will forever be thankful.

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List of Acronyms

ANA	American Nurses Association
AI/AN	American Indian/Alaska Native
CSU	Chinle Service Unit
ELNEC	End-of-Life Nursing Education Consortium
EOLC	End-of-life care
EPCS	End-of-Life Professional Caregiver Survey
IOM	Institute of Medicine
IHS	Indian Health Service
NN	Navajo Nation
PC	Palliative care
REDCap	Research Electronic Data Capture

CHAPTER 1: INTRODUCTION AND BACKGROUND

Palliative care (PC) is an essential component of comprehensive healthcare. Nationally, the need for improved comprehensive healthcare is evident. One goal of Healthy People 2020 is to improve access to comprehensive, quality healthcare, which has been shown to improve health outcomes, including quality of life and overall physical, social, and mental health status (Office of Disease Prevention and Health Promotion, 2014). This includes access to care across the lifespan, from birth until death. Palliative and hospice care are both essential to improving the quality of life for individuals who are at the end of their lives, as well as that of their families.

PC improves the quality of life of patients and their families through the prevention of and relief from pain and other physical, psychosocial and spiritual complications. The goal of PC is to provide relief from pain and acceptance that the dying process is a part of life. PC does not slow or stop the dying process. It incorporates both psychological and spiritual aspects of care and provides support to the family during the illness and after the death of their family member. One primary aim of PC is to allow the patient to live as actively as possible until death (World Health Organization, 2018). Those who are experiencing terminal and/or chronic illnesses are challenged with various difficulties, and without proper access to care, these challenges can seem insurmountable and overwhelming. Often these challenges last for weeks, months, or even years, depending on the type of illness and the type of care required during this time (Institute of Medicine [IOM], 2015).

In 2017, approximately 13% of the total U.S. population comprised people aged 65 and older, with an anticipated increase to 1 in every 5 people, or approximately 72

million, by the year 2030 (IOM, 2015; Miller & Brown, 2017). As the proportion of those aged 65 and over continues to rise, end-of-life care (EOLC) is an essential component of comprehensive healthcare. PC and EOLC have been shown to improve the quality of life not only for individuals diagnosed with a terminal or chronic illness, but also for their families (Bharadwaj et al., 2016). Currently, there are no palliative or hospice services in many rural U.S. communities, and often there are too few resources for EOLC.

Professional ethical considerations for nurses are in accordance with the American Nurses Association Code of Ethics. Provision One of this code states that nurses are professionally responsible for providing dignified, respectful, and empathetic care to the patient and family unit (American Nurses Association, 2015). This includes advocating for such care in all geographic settings, including rural America.

Problem Statement

The Navajo Nation (NN) spans over 27,000 square miles, with a population of over 250,000 (Navajo Nation Department of Information Technology, 2011), and has no recognized hospice or PC centers. This results in many individuals with serious illnesses dying without access to this care, care that is the right of all people. Healthcare on the NN is primarily provided by the Indian Health Service (IHS), with six acute care hospitals spread across the nation. There are no certified hospice or PC clinicians or services available on NN.

The primary issue is not only the lack of PC and EOLC services, but also the lack of education and/or training to those providing care to patients who are at the end of their life. Although the IOM (2015) identified some key accomplishments related to education and training of healthcare staff, there continues to be a gap in the transfer of this

knowledge. This gap occurs both within educational institutions and healthcare facilities that provide EOLC. The IOM (2015) identified basic PC competencies that all healthcare staff who provide care should possess. Four domains of competencies included in basic PC are: scientific knowledge and skill, interpersonal skills, ethical and professional principles, and organizational skills.

Fink, Oman, Youngwerth, and Bryant (2013) identified barriers within rural hospitals relating to PC. These include patients and families not wishing to discuss death and dying, lack of policies related to PC, and lack of knowledge related to PC and EOLC among healthcare personnel. These barriers also exist within the IHS, in which some hospitals have an active user population of over 35,000 and which provide both inpatient and outpatient acute care services to many communities within the NN.

Study Purpose

The intended purpose of the study was to measure the knowledge, confidence and comfort level of healthcare staff in relation to PC and EOLC, as well as the possible impacts on providing care to patients who require these services. The study participants were staff who currently provided care or were responsible for care provided to patients on the adult medical/surgical unit in one hospital on the NN. This study included knowledge of the Navajo cultural perspective on death and dying and how it relates to those responsible for providing healthcare services. In general, the Navajo fear the dead and do not openly discuss death (Navajo Code Talkers Administration, 2014). The staff in healthcare organizations on the NN currently do not have any standard or structured training or education related to PC or EOLC. Although they do provide these services, the services are very limited.

Research Question

The study sought to answer the clinical research question: do structured PC and EOLC education and training, including components of Navajo culture and traditions around death and dying, for healthcare staff improve their confidence, comfort, and ability to provide care to patients who are at the end of their lives?

Study Aims and Objectives

The aim of the study was to assess the current knowledge of PC and EOLC among healthcare staff on the adult medical/surgical unit before and after training regarding basic PC and EOLC.

The study objectives were to:

- Assess the healthcare staff's knowledge of PC and EOLC
- Assess the comfort and confidence level of the staff in providing PC and EOLC
- Obtain baseline data related to staff knowledge, comfort level, and confidence in providing PC and EOLC
- Assess staff's knowledge of Navajo culture around death and dying
- Make recommendations to improve the confidence, comfort level, and basic knowledge of PC and EOLC among healthcare staff who are not considered specialists in this field
- Empower the staff, so they are more confident in providing culturally sensitive Navajo PC and EOLC to patients and families

Scope of the Study

The study included a 2-day education session and assessment of the knowledge, comfort level, and confidence of healthcare staff in a rural hospital related to PC and

EOLC. The limitations of this study were geographic isolation, time, and sample size. It was limited to one small hospital on the NN and to the small number of healthcare staff in this hospital. Due to the time limitations, a more thorough study could not be completed.

The study was completed over a 1-month period and was conducted in one hospital on the NN. This study utilized a quantitative approach, using a Likert scale questionnaire to assess the domains listed above prior to, immediately after, and 1 month after the education and training.

Assumptions

Assumptions regarding this study included:

- 1) The participants fully comprehend the questions asked in the survey.
- 2) The participants answer honestly survey questions related to their knowledge, comfort level, and confidence in providing culturally sensitive PC and EOLC at all survey points.
- 3) The PC and EOLC training—the End-of-Life Nursing Education Consortium (ELNEC) Core Course—is presented by ELNEC-certified trainers to staff over a 2-day period.
- 4) A Navajo cultural component about death and dying is presented by a Navajo Native Medicine practitioner on the first day of the ELNEC training course.
- 5) Staff who work in a rural hospital on the NN attend the training and participate in the training and the survey, including all staff who work on the adult medical/surgical unit.

Significance of the Study

This study further validates the need for PC and EOLC training and education for staff who provide care in rural acute care settings and in areas where there is no access to certified PC and EOLC. This study demonstrates the positive impact that basic training in PC and EOLC has on the confidence and comfort levels of healthcare staff in providing PC and EOLC. Such training improves the culturally sensitive EOLC provided, and thus improves the experience for the patients who are at the end of their lives and their family members.

This study further establishes the need for advocacy for these services in rural areas like the NN among policy makers and organizational leaders. The current lack of services on the NN results in patients at the end of their lives receiving poor or limited pain and symptom management, limited emotional and spiritual counseling, lack of care coordination in relation to their terminal or chronic illness, readmission to the hospital for various reasons, and increased use of the emergency room. Altogether, this results in a poor quality of life for the patient and their caretakers.

Lastly, this study opens very sensitive and difficult dialogue with key stakeholders. It sets the foundation for a feasible alternative for providing timely, culturally sensitive PC and EOLC within the boundaries of the NN. This study prompts the NN government and IHS leadership to address this deficiency in access to this specialty care on the NN.

CHAPTER 2: REVIEW OF LITERATURE

EOLC is a primary component of comprehensive, family-centered healthcare and should be afforded to all people and their families. EOLC includes both hospice and PC and extends past the death of an individual, providing quality spiritual, physical, and emotional healthcare to those at the end of their lives and their families (Hospice Action Network, 2017).

Focus and Methods of Review

The focus of this review is the importance of education related to PC and EOLC in the adult population. This review supports the positive impacts that EOLC has on patient and family outcomes, and it focuses on rural areas, and specifically Native people, in describing the important impact that traditional and cultural beliefs have on PC and EOLC.

The CINAHL and PubMed search engines were used to query the following search terms in various combinations: staff education, staff training, rural, remote, “small-town,” indigenous, quality of care, “Native American,” “First Nation,” “palliative care,” “end-of-life care,” quality of life, (hospice*), and (local*). Initial filters for the searches included English language and peer reviewed articles. Results varied from none to more than 200 by combining search terms, using OR to expand the search, and using AND to limit the search. Additional filters were used based on the number of results obtained, including publication dates between 2002 to 2018.

This literature review considered both qualitative and quantitative research. From a total of 37 articles, 12 were deemed eligible to include. Selection was based on each study’s focus on the impact that education and training for healthcare staff have on PC or

EOLC, the impact that PC has on health outcomes, EOLC in Native American and/or Indigenous communities, and how cultural and traditional customs or beliefs are viewed within Indigenous communities, specifically related to death and dying. Three of the 12 eligible articles are outside of the 5-year literature span, due to sparse numbers of studies focused on American Indian EOLC or EOLC provided by the IHS.

After reviewing the abstracts of the selected articles, a more thorough review and analysis of themes took place. Four key themes were identified for this review: 1) education and training related to PC, 2) PC in rural settings, 3) healthcare outcomes related to PC, and 4) PC among Native Americans or Indigenous communities. These themes structured this review and analysis of the literature.

Education and Training

Education, training, and knowledge of healthcare staff impact the quality of EOLC provided to patients and their families and have a direct correlation to staff's comfort and confidence levels in providing care (IOM, 2015; Shulman, Hudson, Kennedy, Brophy, & Stone, 2018). By empowering healthcare staff with the knowledge of basic EOLC, organizations support an environment of quality care. Such environments are marked by improved quality of life for patients and families, improved communication among healthcare teams and patients, improved care coordination, improved decision making by the healthcare team, and improved symptom management (IOM, 2015; Mayrhofer et al., 2016; Thomas, Tanner, & Wilson, 2016; Shulman et al., 2018; Wilson, Tariman, & Graf, 2018).

Shulman et al. (2018) demonstrated an improvement in the areas of confidence, knowledge, and openness between pre- and post-EOLC training and education. A

decrease in stress by staff was also noted in this study. In the qualitative study by Holms, Milligan, and Kidd (2014), similar results were reached.

Acute care settings without specialty palliative or EOLC services often do not provide basic palliative or EOLC training to staff (Holms et al., 2014). Staff who work in areas where EOLC is not a specialty, such as acute care hospitals, expressed that lack of training and education has negative impacts on patient care (Holms et al., 2014; Wilson et al., 2018). These negative effects impact overall quality and effectiveness of the care provided. Staff expressed that this lack of knowledge has a direct influence on decision making, quality of postmortem care, communication, stress levels of staff, and overall quality of care provided (Holms et al., 2014; Shulman et al., 2018; Wilson et al., 2018).

Providing basic palliative and EOLC training and education has been shown to improve staff's ability to provide care in a more confident manner, which then improves the overall care provided to the patient and their family members (Shulman et al., 2018). Incorporating basic palliative and EOLC training for healthcare staff in any setting is important and empowers staff to provide EOLC in a more confident manner. It also improves communication and, most notably, the quality of care provided to patients (Holms et al., 2014; IOM, 2015; Shulman et al., 2018; Wilson et al., 2018).

Palliative Care in Rural America

The increasing number of elderly adults and those with chronic illness continues to rise, and this holds true in all areas of the country, including rural communities such as the NN. PC and EOLC services are more available in urban areas of the country (Fink et al., 2013). This care is considered a specialty in healthcare, indicating that no education

in PC or EOLC is required in most physician, nursing, and advanced nursing programs across the country (IOM, 2015).

Despite the increasing number of patients who require EOLC and the cost of care for chronically ill patients, a lack of care continues to exist in meeting the needs of those at the end of their lives. This lack is increased for those who live in rural areas (Fink et al., 2013). Medicare reported that the number of individuals who used hospice services are twofold in urban areas compared to rural areas of the country (Rural Health Information Hub, 2019).

Rural areas have increased challenges in implementing PC services. Fink et al. (2013) identified lack of support from administrators in implementing PC, inadequate training and education of staff in rural areas, lack of mentorship of healthcare staff in rural areas, and lack of resources related to PC for healthcare staff working in rural settings. Fink et al.'s study emphasized the need for forming relationships, or establishing partners, with those who have expertise in PC and EOLC. Fink et al. also stressed the need to improve the knowledge of staff who work in rural care settings through alternative methods, such as online training programs.

Campbell, Merwin, and Yan (2009) identified decreasing numbers of available hospice services in rural areas. They also noted that rural areas have decreased numbers of physicians in general, and many rural areas are without any certified hospice-licensed physicians. Even more alarming, only 23% availability of hospice services exists in rural zip codes, as compared to 98.7% availability in urban areas. Additionally, Campbell et al. (2009) found rural areas have increased health disparities, and the lack of availability of EOLC was most common among those who also had higher levels of poverty and higher

numbers of minorities. Forty percent of American Indians and Alaska Natives (AI/AN) live in rural areas and have higher rates of chronic disease, including diabetes, liver disease, and cancer, yet they account for only 0.2% of the users of hospice care in the United States (Colclough & Brown, 2014; Gebauer et al., 2016).

Healthcare Outcomes

Sidebottom, Jorgenson, Richards, Kirven, and Sillah (2015) discussed the improvements in symptom burden, depression symptoms, and quality of life for those in which a PC model was implemented into the plan of care. Their study involved adult patients diagnosed with heart failure admitted to an inpatient setting and used a randomized trial method among eligible candidates. The intervention consisted of standard PC implementation by the identified PC team within the hospital. Data were drawn from three questionnaires that assessed quality of life, depression, and symptom burden. Data were collected at baseline and 1 month and 3 months after enrollment. Overall results demonstrated improvement in all three outcomes in the intervention group at 1 month and 3 months, contributing to evidence within current literature that PC can improve symptom burden, depression symptoms, and quality of life.

PC supports aspects of care that improve overall outcomes. Managing symptoms at the end of life, promoting the independence of the patient through the progression of disease, and focusing on the needs of the caregiver are all aims of PC (Swami & Case, 2018). Keeping patients comfortable and decreasing the suffering patients often experience is a priority. Swami and Case note that overall outcomes and quality of life are improved when PC or EOLC is a component of care for those who have terminal or advanced illness. This study highlights that PC contributes to fewer hospital admissions

and often prolongs the life of patients, thus decreasing the stress and burden on patients and their families.

Native American or Indigenous Communities

A qualitative study performed by Kelly et al. (2009) identified the cultural differences among First Nations people versus traditional western hospital-based care at the end of life. Data were gathered through phenomenological, semi-structured, in-depth interviews with 10 grieving Cree and Ojibway aboriginal family members. The interviews were conducted in English, but also had a mixture of the Ojibway-Cree language. Findings from this study identified three key themes: communication, caregiving, and environment.

The interviews cited communication as the most discussed topic. This was analyzed as communication between the family members, physicians, and interpreters. Findings indicated that communication by physicians could be more direct, factual, and not misleading regarding the prognosis of the patient. Family members voiced that it was at times difficult to communicate due to cultural views regarding death. Some identified limitations regarding communication from a family unit, as opposed to communicating with one individual, which in turn had an impact on advanced care planning. Lastly, communication issues with interpreters were identified, noting that interpreters were not always available and their importance in the communication needs of the patient. The lack of interpreter training related to PC was evident.

Caregiving was also a theme identified in this study. Overall care was a positive experience for the families, specifically the management of symptoms. Spiritual aspects of care, including prayer, singing, and the availability of clergy, were acknowledged as

important by the family members. Lastly, the importance for the family to have time with the deceased was recognized as an important element.

Environment was the final theme noted in this study, in particular the amount of space available for family members during EOLC. The First Nations people indicated that within their culture, family consists of extended family and the community and is a vital part of their cultural beliefs. Study participants conveyed appreciation of the hospital staff's cultural awareness and the importance of offering tea during to those experiencing the end of a family member's life. Lastly, the overall environment was discussed in terms of the participation and knowledge of the entire hospital staff and their roles in providing EOLC. The authors emphasized the importance of education for all staff involved with EOLC. The overall study findings, in which family members identified communication as a primary component of EOLC, revealed the importance of a culturally spiritual component in care, the need for adequate space for multiple family and community members to visit the patient, and the need for education for all hospital staff in both PC and EOLC.

Kitzes and Berger (2004) found that EOLC and PC issues within the IHS Albuquerque Area are directly related to chronic disease, which is the leading cause of death among AI/AN. They also noted an increasing life expectancy among AI/AN. This study employed both quantitative and qualitative approaches, using retrospective, randomized chart reviews and semi-structured interviews with hospital staff and cultural advisors regarding EOLC policy and procedures within selected IHS sites. The researchers noted that EOLC issues were documented only occasionally among the AI/AN participants. Forty-five percent of the medical records reviewed documented

discussion by the physician regarding diagnosis, but only 5% described what was discussed with the family. Twenty-seven percent of the records documented do-not-resuscitate orders, of which 97% were documented only when it was apparent that death was imminent, suggesting there was insufficient preparation for EOLC. The records reviews also revealed a lack of symptom management, including lack of use of assessment scales for pain or any other symptoms, despite a patient's prognosis. None of the records noted documentation offering hospice or home care for the patients and/or family members.

The interviews with staff indicated the facilities had no financial planning or strategies in place to support EOLC, nor policies, procedures, or protocols for any type of PC service. The interviews demonstrated support from all facilities for the use of traditional ceremony by designating a special place for these ceremonies to take place in. All facilities were open to traditional healers to be a part of patient care, supported medical and nursing staff in encouraging the use of traditional practices, and allowed autonomy to the family regarding the care of the body after death. Lastly, the interviews with cultural advisors highlighted that EOLC should be individualized and avoid any stereotyping, particularly if one is a member of a specific tribe.

Cultural considerations in EOLC among AI/AN are a vital component in implementation of EOLC services. Discussing or planning for death is forbidden in most AI/AN tribes, as it is viewed as a means of luring bad or evil spirits (Colclough & Brown, 2014). Ensuring education related to cultural customs and practices is an essential part of basic PC and EOLC training for healthcare staff.

AI/AN consider family the foundation and essence of life and self-identity.

Family includes extended family members, community members, and relations through clanship. Family is a vital component in making life-changing decisions (Colclough & Brown, 2014). Colclough and Brown found that AI, both patient and family, have different concepts and views of death and the dying process, and are inclined to use traditional healing practices as a means of remaining connected to nature and their environment through the advancing illness until death. Their study discussed the concept of complex adaptive systems and how such systems exist in AI tribes and their cultural beliefs. The researchers highlighted the need for continued education within AI communities to allow them access to EOLC with the goal of improving end-of-life experiences.

Summary

This literature review highlights: 1) the positive impacts that EOLC has on managing symptoms and decreasing suffering at the end of life; 2) the lack of PC or EOLC education in rural areas and acute care settings, along with the results of these gaps in education; 3) the scant availability of EOLC in rural areas; 4) the importance of culturally sensitive care among Indigenous people; and 5) the lack of standard practices related to EOLC within IHS.

Sidebottom et al. (2015), although studying heart failure patients, demonstrated the positive effects that PC has on symptom management and quality of life. In their study, symptoms related to pain, tiredness, nausea, depression, anxiety, shortness of breath, appetite, and well-being were assessed and seen to improve with PC. Kelly et al. (2009) demonstrated the importance and challenge of integrating cultural values into the

care of those at the end of life. The need for space large enough to accommodate family, the understanding of cultural traditions, and the importance of communication and respect were all identified in Kelly et al.'s study.

This review identified the impacts EOLC has on patients and family members who are experiencing a terminal or advanced illness. The reviewed literature emphasized the importance of cultural traditions and beliefs among Indigenous people in the care they receive. Lack of PC or EOLC increases the risk for poor quality of life and poor health outcomes for those at the end of their lives. Individuals who live in rural locations have decreased or no access to PC or EOLC, even while AI/AN have increased rates of chronic illnesses (Isaacson & Lynch, 2018).

CHAPTER 3: THEORETICAL MODEL AND METHODOLOGY

Theoretical Model

Kolb's Experiential Learning Model

The primary theoretical foundation that guided this project was David Kolb's (2015) Experiential Learning Model. This model is based on constructivist ideology, has six principles, and is a cyclical learning theory. The emphasis of this theory is on the experience of the individual and how experiences impact and build on the learning process that is unique to each person. Experiential learning is a continuous process that interconnects an individual's education, work, and experiences. Building knowledge and learning through experience allows individuals to master their own growth and is a never-ending process. This theory appreciates the uniqueness of all people and that each person learns and comprehends differently.

The six principles of Kolb's Experiential Learning theory are principles of adult learning and are founded on the concept that experience lays the central foundation in human learning and development. These principles are shaped on the concept that humans are adaptive to their experiences. The six principles are: 1) Learning is a process; 2) Learning is re-learning; 3) Emotional reflection; 4) Holistic learning; 5) Environmental learning; and 6) Constructivism (Kolb & Kolb, 2005).

Collaborative work between David Kolb (2015) and James Zull espouses the belief that experiential learning has a neurological foundation and that this type of learning is built on each person's neuronal structure. This concept explains the brain's function and response to learning experiences and explores the split-brain effect in one's course of learning. The split-brain notion describes how the left and right hemispheres of

the brain work together to grasp, retain, and build concepts of learning. Figure 1 shows which areas of the brain relate to each aspect of Kolb's theory. Kolb's theory also supports dual knowledge theory as it relates to experiential learning (Kolb, 2015). The emphasis of dual knowledge theory is that left and right hemispheres of the brain have unique functions that impact experiential learning. While the left hemisphere is abstract and analytical and rationalizes input, the right hemisphere is spatial, concrete, analogical, and intuitive.

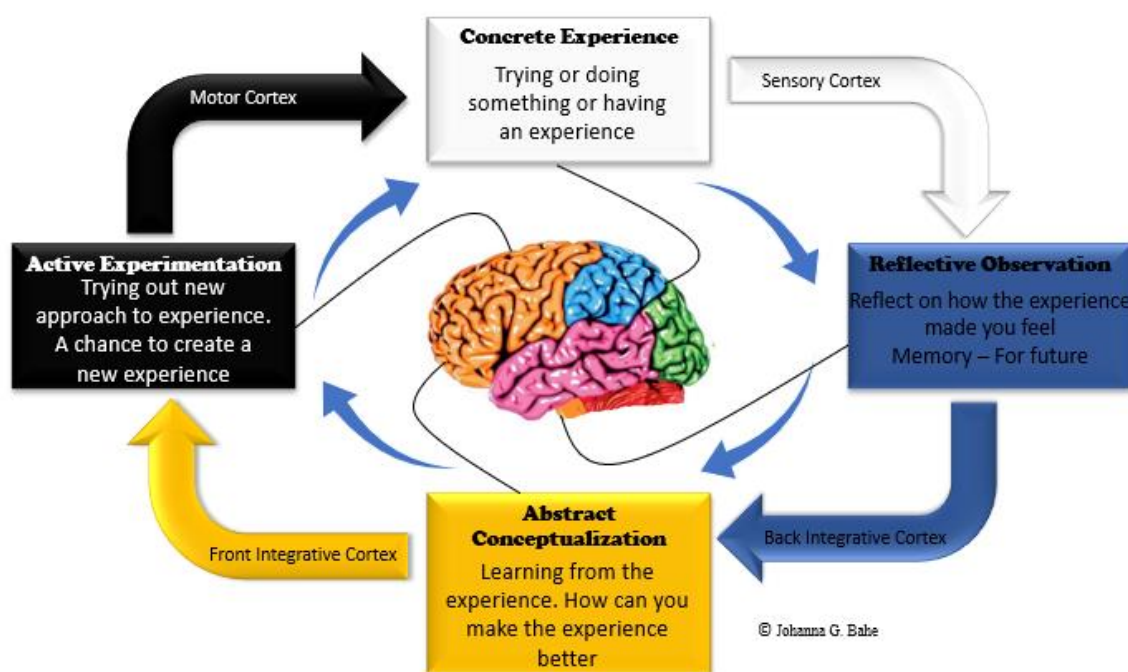


Figure 1. Kolb's Experiential Learning Theory and the brain.

The use of both hemispheres of the brain further explains how experiential learning is built on the brain's neuronal structure. Interestingly, over time the brain physically changes, and these changes are dependent on one's experiences (Kolb, 2015). The sensory cortex receives message and information in the form of senses, and this in turn creates emotions. In Kolb's Experiential Learning theory, this process is based on concrete experiences and occurs when an individual has an experience through their

senses. Reflective observation is an experience that induces memory, and these memories create emotions—a process that occurs in the rear integrative cortex of the brain. The front integral cortex is an area where judgement is achieved, short-term memories are housed, and problem solving takes place. This area is vital in making decisions in a learning environment, especially deciding how to improve upon a previous experience. Finally, the motor cortex is where actions are created. Actions can be based on previous experience or can arise directly from receiving messages or impulses from the sensory cortex (Kolb, 2015). Kolb's theory uses these physical processes to explain how both sides of the brain impact and improve the learning experience.

This study focuses on the impacts that training and education have on healthcare staff's comfort level and knowledge of palliative and EOLC. This study incorporated Kolb's process of learning and implemented each aspect of the cycle. The healthcare staff participants learned through lecture and discussion, and this allowed them to discuss their concrete experiences and follow up with reflection. Reflection allowed them to express the experiences they each had with EOLC. Reflection included sharing stories of being the caregiver for family members or loved ones who had chronic or terminal conditions and were at the end of their lives, as well as sharing their feelings in caring for patients at the end of their lives without having had the education of this 2-day training session. Some participants shared their experiences caring for Navajo individuals at the end of their lives and how those experiences impacted them personally and as healthcare providers.

Chinle Service Unit Improvement Cycle

This quality project also utilized the Chinle Service Unit (CSU) Improvement Cycle (Figure 2). This framework was established by the CSU Bluebirds, the improvement team comprised of senior leaders within the organization. This model is grounded in the Plan-Do-Study-Act cycle (PDSA; Institute for Healthcare Improvement, 2020), which allows for assessments of change to be carried out after planning a process, testing it, reflecting on the actions taken, and revising the process for improvement. Here the PDSA cycle has been modified to incorporate Navajo traditions and beliefs and follows the pathway of the sun, moving in a clockwise direction. This model was combined with Kolb's Learning theory for this project.

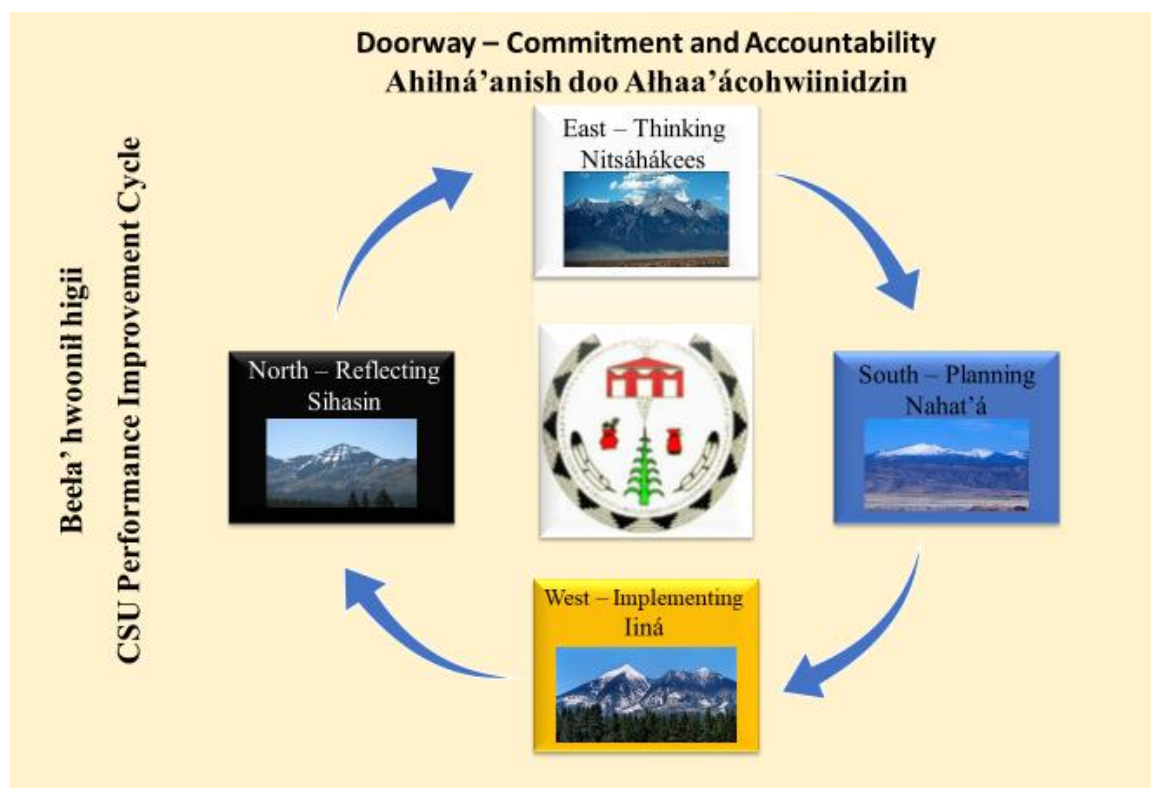


Figure 2. Chinle Service Unit Performance Improvement Cycle.

The CSU Improvement Cycle incorporates the Navajo model of wellness, in that it moves in a clockwise motion and never counterclockwise. Moving in the pathway of sun signifies a harmonious balance. All the improvement work at CSU moves in the clockwise direction, meaning as each phase is achieved, the cycle continues to the next phase until a full circle is complete. Once the cycle is complete, next steps are identified, and the cycle continues. Counterclockwise motion depicts an imbalance. Any time there is an imbalance, immediate intervention is essential to regain balance and a state of harmony.

This project moved through this path or cycle, and like Kolb's theory, it is a continuous cycle, building on and learning from each previous cycle. It was important to include a familiar and meaningful process for staff who were part of this project. All healthcare staff at CSU participate in and use this cycle to perform improvement work at the hospital. The Kolb Experiential Learning theory and the CSU Improvement Cycle continue through time and can result in the birth of new improvement cycles and ideas or improve current processes and ideas.

In Navajo tradition, the East direction is where thinking (Nitsáhákees) takes place and where an issue or problem is identified. The East mountain is Mount Blanca and is physically located in Alamos, Colorado. It is believed that the Holy People of the Dine' dressed this mountain in a perfect white shell for positive thoughts and thinking (U. Knoki-Wilson, personal communication, April 27, 2019).

In healthcare on Navajo, this Thinking phase involves assessing the current state of healthcare. This evaluation brings up many healthcare issues on the NN, such as lack of access to specialty services. The East direction includes the how—how to improve

care to rural communities like those on the NN. Many specialty services, including PC and EOLC, are not provided on the NN. This has impacted the quality of care that patients receive and has impacted patient care outcomes negatively. Through this Thinking phase or East direction, this project's focus was established.

The South direction is where planning (Nahat'á) begins. The southerly sacred mountain is Mt. Taylor located in Grants, New Mexico. It was decorated with the turquoise stone for health, positive learning, and clarity of life goals. It represents planning and development and gives voice to direction for making difficult decisions and solving issues (U. Knoki-Wilson, personal communication, April 27, 2019).

For this project, the South direction and Planning phase included thought and research as to how to format and build the concepts of the project, with the aim of improving patient care on the NN. Planning this project involved various components to ensure its successful completion. Writing a proposal was the backbone of the planning for this project and entailed working collaboratively with the University of New Mexico College of Nursing faculty, the faculty of the ELNEC group and trainers, and the staff of the CSU.

The West mountain is the San Francisco Peaks located in Flagstaff, Arizona. The Holy People of the Navajo decorated this mountain with abalone shell to create appreciation of life. This is where process occurs and where action takes place and implementation (Iiná) of ideas and concepts is initiated (U. Knoki-Wilson, personal communication, April 27, 2019). The Implementation phase of this project consisted of holding the 2-day ELNEC training program at CSU, then applying the knowledge gained into the healthcare staff's practice.

The North mountain is located northeast of Mancos, Colorado. This mountain is adorned with the beautiful black jet stone for positive awareness and protection (U. Knoki-Wilson, personal communication, April 27, 2019). This direction represents intellectual thinking (Sihasin) and allows reflecting on what was learned from this project. The Reflecting phase of this project included analysis of the data obtained and determining next steps in moving forward. Sihasin allowed study of the results and interventions, which resulted in improvements in training or changing the approach to providing knowledge to the healthcare staff, with an overall goal of improving patient care.

Methodology

The quantitative aspect of this study utilized a Likert survey process. The survey was given to the participants before the training session, after the training, and 1 month after training. The End-Of-Life Professional Caregiver Survey (EPCS; Appendix A) was provided to all participants at each of the three points in time. Three additional questions were added to this tool and related to Navajo cultural concepts of death and dying (questions 29, 30, and 31 on the survey). The Research Electronic Data Capture (REDCap) was used to collect survey data at all points. Use of the REDCap software allowed data to be collected and managed in a confidential and standard method for all participants who completed the survey. The surveys were automatically generated by the REDCap system at each timepoint in the study.

Ethical Issues and Human Subject Protection

This study did not present any specific ethical concerns. Confidentiality was protected for all participants, who were provided the survey through the REDCap survey

collection process. To ensure that Navajo traditional customs were practiced, a protection prayer in the Navajo language was performed each day to reduce or eliminate the fear of taboos when discussing death and dying.

Setting and Resources

This study took place in a hospital on the Navajo Nation. Physical resources utilized were the building where the training took place, technical equipment and support, and educational supplies. Staff resources utilized were those of the hospital and the certified ELNEC trainers.

Study Population

The study population was healthcare staff who provide care or are responsible for care provided to patients in the adult medical/surgical unit of a rural hospital on the NN. The staff included nurses, nursing assistants, Native Medicine practitioners, medical assistants, and other healthcare staff who provide care to patients on this unit. The Native Medicine practitioners, discharge planner, and behavioral health staff are active members of the interdisciplinary team managing patients on this unit.

This population was selected based on location. The location was chosen for the care the hospital provides and because it is in a rural geographical area. This hospital provides care to patients at the end of their lives and who also require comfort care, but there are no standard palliative or hospice services at this hospital or within the community. The lack of access to palliative and hospice services at this hospital contributes to the lack of healthcare staff specializing in palliative or EOLC. As in many rural settings, a deficiency exists here in clinician education related to PC practices (Taylor, Dionne-Odom, Currie, Stockdill, & Bakitas, 2019). This deficiency is also

evident at the hospital, which does not require or provide training related to PC or EOLC to any healthcare staff in the organization.

Research Design

Sources of data. All data sources were directly retrieved from the EPCS that was completed by the healthcare staff. These data were collected using the REDCap program at three points in time.

Data collection process and tool. Data were collected from staff attending the 2-day ELNEC Core Course. This course covered nine modules (Appendix B). Eight of the modules were directly from the ELNEC program, and one module was added. The added module was developed and taught by a Navajo Native Medicine practitioner from the CSU. The other eight ELNEC modules were taught by two certified ELNEC trainers, who traveled to the NN to teach the course.

The ELNEC project is a collaborative effort between the American Association of Colleges of Nursing and the national cancer research center City of Hope to improve palliative care throughout the nation by improving the education and knowledge of healthcare staff. Since 2000, this program has reached approximately 25,000 healthcare staff in the United States and provided training in over 100 countries (American Association of Colleges of Nursing, 2020). Since this initiative's inception, it continues to grow and reach healthcare staff, faculty, and students.

Because discussing death is viewed by Navajo as taboo and is very sensitive in nature (G. Begay, personal communication, August 2018), each day of the training in Chinle began with a prayer performed in the Navajo language, and each day ended the same way. Beginning and ending each day with positive thoughts through prayer is

practiced by the Navajo people, especially in settings that involve discussing death and dying, since talking of death in any sense is considered wrong and is thought to possibly produce negative circumstances in one's daily life.

Data were collected using the EPCS tool. Demographic data were collected on the initial survey. Three additional questions gauged the healthcare staff's comfort level, confidence, and knowledge related to Navajo beliefs about death and dying. The EPCS is a validated instrument used to assess the knowledge of healthcare professionals in relation to palliative and EOLC.

The EPCS is a 28-question, 5-point Likert scale survey, with the lowest rating represented by a score of 0 and the highest rating represented by a score of 4. The scale range is from *not at all* (0) to *very much* (4). The survey questions relate to comfort level, knowledge, and confidence in providing palliative and EOLC. Lazenby, Ercolano, Shulman-Green, and McCorkle (2012) found internal reliability to be a strength of the EPCS. Reliability for this study was determined using Cronbach's α . Lazenby et al. (2012) determined > 0.70 to evidence adequate reliability, and the results of their study showed an α of 0.96 for all 28 items in the EPSC. Their findings also allude to the EPCS's comprehensive coverage of all subjects contained in the end-of-life core curriculum. The EPCS is considered a valid scale to evaluate the educational needs and familiarity of healthcare professionals concerning EOLC.

Data collection plan. Data were collected at three time points in this study. The initial time point (Time 1) occurred 2 weeks before the ELNEC Core Course training. Time 2 occurred the first week after the training was complete. Time 3 occurred 1 month after the training.

All data were gathered using the REDCap software. Participants received an email invitation at each time point notifying them that the survey was available to complete. The email invitations were autogenerated using the REDCap software program and included instructions with a link to the survey.

The extracted, de-identified data were recorded into the EPCS Excel spreadsheet electronic file by the investigator, which was housed on an encrypted computer in a locked office in a locked drawer accessible only to the investigator.

Timeline

The timeline for this study included:

1. Planning – June 2017 to April 2019
2. Proposal defense – April 08, 2019
3. UNM Institutional Review Board approval – August 27, 2019
4. Training on PC and EOLC – September 13–14 2019
5. Data collection and analysis – September 2019 to December 2019
6. Defense of Doctor of Nursing Practice Scholarly Project – May 7, 2020

Statistical Analysis

Descriptive statistics of frequency, central tendency, and variation were used to analyze data collected at the three time points, as well as demographic data (gender, race, occupation, and highest level of education). The two-paired *t*-test compared the mean scores obtained from the survey for the same participants at each time point. Power analysis for effect size was determined using Cohen's *d* testing. Cohen's *d* was used to determine difference between groups where the *t*-test was used. The following values were used: 0.2 = small effect, 0.5 = medium effect, and 0.8 = large effect (Pallant, 2016).

The null hypothesis was that the mean scores would be equal or not change at each time point. The alternative hypothesis was that the mean scores would not be the same at each time point, and at Times 2 and 3 the mean score for each question would be higher than the mean scores at Time 1.

Budget

The budget for this project was \$6000. The major portion of the expense comprised the fees to bring two certified ELNEC trainers to complete the 2-day course in Chinle, Arizona—an all-inclusive rate of \$5500. One trainer traveled from Oregon and the other traveled from Phoenix, Arizona. Refreshments were provided to participants and instructors at a cost of \$250 for both days, paid by the researcher. Supplies and material cost approximately \$250. The costs of supplies, materials, and trainers were paid by the organization using funds allocated for staff education.

Additional expenses included the time each staff member spent attending the training, the time staff members spent preparing for the training, having additional staff cover the adult medical/surgical unit so all regular staff from this unit could attend the training, and set-up and clean up time before and after each training session. Some of these costs were compensated in the form of overtime pay to staff.

CHAPTER 4: RESULTS AND DISCUSSION

Results and Outcomes

A total of 42 healthcare staff participated in the 2-day ELNEC Core Course. All attendees worked and provided care to patients in the CSU. Twenty-six registered nurses, seven nursing assistants, five medical clerks, and four other healthcare staff attended the training sessions (Figure 3). While the training was open to a total of 40 participants, the actual attendance exceeded this number, as some individuals did not pre-register, arrived for the training, and were allowed to attend.

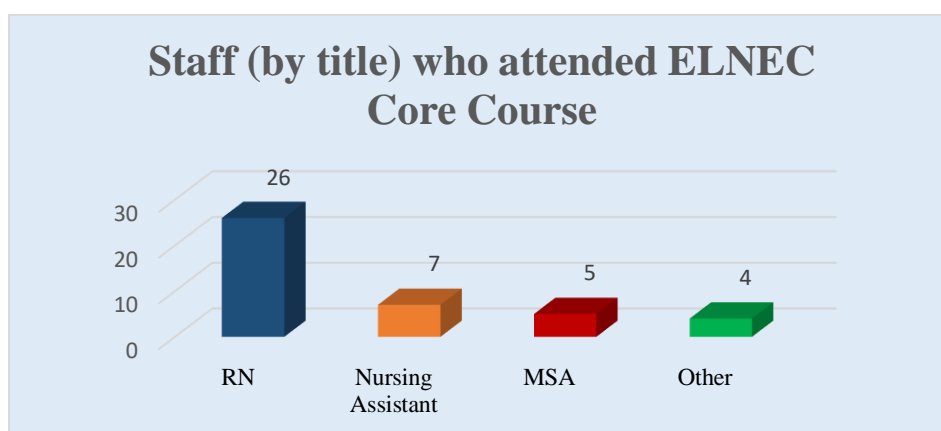


Figure 3. Staff participants by title.

The EPCS tool was distributed via REDCap software to 37 of the 42 participants. Of the 42 who attended the training, five individuals did not pre-register for the course and so did not receive the initial survey invitation. The initial survey is identified as Time 1 in this study. This study compared the results from Time 1 to Time 2 and from Time 1 to Time 3. Hence those who did not complete the initial survey were considered ineligible to complete the survey at Times 2 and 3.

Thirty-three (89.2%) of the 37 individuals who received an invitation for the initial survey participated in the survey at Time 1. Of the 33 individuals who completed

the initial survey, 28 (84.8%) completed the EPCS at Time 2, and 27 (81.8%) completed the survey at Time 3. At each time point, at least one participant did not answer all the questions; thus, their answers were excluded from the analysis of data.

Table 1 presents demographic distribution totals and percentages, including gender, race, and occupation for those who participated in the initial survey ($N = 33$). Ages ranged from 24 to 65 years. The mean age of the participants was 43.8 years ($SD = 12.3$). A majority of participants, $n = 20$, (61%), listed AI/AN as their race. Seven (21%) selected Asian, one (3%) selected Black or African American, three (9%) selected White, one (3%) selected More than One Race, and one (3%) chose not to answer. A vast majority, $n = 32$ (97%), were female, and 3% ($n = 1$) were male. Seventy percent ($n = 23$) were registered nurses, two (6%) were health technicians/medical assistants, one (3%) was a licensed practical nurse, five (15%) were nursing assistants, and two (6%) listed Other as their occupation.

Table 1

Demographics—Gender, Race, and Occupation

	American Indian/Alaska Native	Asian	Black or African American	More Than One Race	Unknown / Not Reported	White	Grand Total $N = 33$
Female	20 (61%)	7 (21%)	1 (3%)	1 (3%)	1 (3%)	2 (6%)	32 (97%)
Health Technician - Medical Assistant	2 (10%)						2 (6%)
Licensed Practical Nurse	1 (5%)						1 (3%)
Nursing Assistant	5 (25%)						5 (16%)
Other	2 (10%)						2 (6%)
Registered Nurse	10 (50%)	7 (100%)	1 (100%)	1 (100%)	1 (100%)	2 (100%)	22 (69%)
Male						1 (3%)	1 (3%)
Registered Nurse						1 (100%)	1 (100%)
Grand Total	20 (61%)	7 (21%)	1 (3%)	1 (3%)	1 (3%)	3 (9%)	33

Table 2 presents the level of education of participants who participated in the initial survey. The highest level of education varied between some college/no degree to

doctoral-level education. A majority of participants, $n = 16$ (49%), had bachelor-level education. $n = 6$ (18%) listed Certificate Program as their highest level, $n = 3$ (9%) had an associate's degree, $n = 4$ (12%) had a master's degree, $n = 1$ (3%) had doctoral-level education, $n = 2$ (6%) had some college but no degree, and $n = 1$ (3%) did not answer.

Table 2

Level of Education

Highest Education Level	Grand Total $N = 33$
Associate Degree (e.g. AA or AS)	3 (9%)
Bachelor's Degree (e.g. BA or BS)	16 (49%)
Certificate Program	6 (18%)
Doctorate Degree (e.g. PhD or EdD)	1 (3%)
Master's Degree (e.g. MA/MS/MeD/MLS/MSN)	4 (12%)
Some College (No Degree)	2 (6%)
(blank)	1 (3%)
Grand Total	33

Results from the 31-question Likert scale EPCS (Appendix A) were subdivided into four domains. These domains are: Patient/Family Centered Communication (the first 12 questions of the survey), Cultural Ethical Values (the next 8 questions), Effective Care Delivery (the following 8 questions), and Cultural Competence (the last 3 questions). Survey questions focused on participants' knowledge, comfort level, and confidence in each of these domains.

Table 3 presents the mean (M) scores and standard deviation (SD) in each of the four domains at the three time points. The t -value and Cohen's d values are presented for Times 2 and 3 to express whether any significant difference in scores existed before training and after training, as well as to indicate the effect size of the significance. The mean scores before the training ranged from a low of 1.85 ($SD = 0.80$) in the Effective

Care Delivery domain to a high of 2.38 ($SD = 0.76$) in the Patient/Family Centered Communication domain. Immediately after the training, mean scores ranged from 2.90 ($SD = 0.84$) in the Effective Care Delivery domain to 3.17 ($SD = 0.77$) in the area of Cultural Competence.

Table 3

Comparison of Outcomes at Times 1, 2, and 3

	<i>M</i>	<i>SD</i>	<i>T</i>	<i>d</i>
Patient/Family Centered Communication				
1: Pre-training ^a	2.38	0.76		
2: Post-training	3.06	0.82	6.38***	0.87
3: 1-month follow-up	2.89	0.72	4.76***	0.81
Cultural Ethical Values				
1: Pre-training ^b	2.09	0.87		
2: Post-training	2.98	0.81	7.90***	1.05
3: 1-month follow-up	2.72	0.78	4.40***	0.85
Effective Care Delivery				
1: Pre-training ^c	1.85	0.80		
2: Post-training	2.90	0.84	6.63***	1.28
3: 1-month follow-up	2.58	0.76	4.94***	1.02
Cultural Competence				
1: Pre-training ^d	2.03	1.21		
2: Post-training	3.17	0.77	6.02***	1.06
3: 1-month follow-up	3.03	0.93	5.16***	0.91

^a $n = 26$, $M = 2.29$, $SD = 0.78$ for comparison to Time 3

^b $n = 26$, $M = 2.00$, $SD = 0.90$ for comparison to Time 3

^c $n = 26$, $M = 1.78$, $SD = 0.80$ for comparison to Time 3

^d $n = 25$, $M = 1.97$, $SD = 1.28$ for comparison to Time 3

*** $p \leq .001$

Significance, measured by the two-way t -test, existed at all comparison time points. The t -value ranges for all four domains showed significant difference in mean scores before and immediately after training ($p \leq .001$). They also revealed a significant difference in mean scores before training and at 1 month post-training ($p \leq .001$).

Cohen's d values ranging from 0.81 to 1.28 revealed large effect sizes in all four domains at all time points. The largest effect size yielded a Cohen's d value of 1.28 and

was observed between the pre-training and immediately post-training mean scores in the domain of Effective Care Delivery. A Cohen's d value of 1.06 was observed in the area of Cultural Competence from pre-training to immediately post-training.

Interpretation of Findings

The findings indicate that providing basic EOLC education, such as the ELNEC Core Course, to healthcare staff improves their confidence, knowledge, and comfort level regarding EOLC. All domains of this study, most notably Effective Care Delivery and Cultural Competence, demonstrated this outcome. The evidence in this study allowed the null hypothesis to be rejected and the alternative hypothesis to be accepted, as all mean scores in all areas improved at both comparison times. These results support the need to provide education and training to staff in rural and frontier geographic areas who have limited or no access to palliative and EOLC.

The area of greatest improvement in mean scores was Cultural Competence. This domain consisted of questions related to staff's knowledge, comfort level, and confidence regarding Navajo traditional beliefs on death and dying. For this study, a ninth module was added to the 8-module ELNEC Core Course and covered various aspects of traditional Navajo beliefs concerning death and dying. The content of this module proved to be effective in increasing the knowledge of the participants, thus improving their confidence in providing EOLC and understanding the Navajo concepts of death and dying. Incorporating cultural values and beliefs into the care provided at the end of life is an important component for healthcare providers, as it helps them recognize the importance of family and other values (Kelly et al., 2009) when working in culturally rich communities.

Sixty-one percent of the participants selected AI/AN as their race, and the other 39% varied among Asian, White, African American/Black, and Other. Although AI/AN were the largest number of participants in this study, the Cultural Competence domain had a pre-training mean score of 2.03—the second lowest mean score in all four domains. The mean score difference in this domain from pre-training to immediately post-training was the single biggest difference in mean scores. This is of interest in that most of the AI/AN participants were from the NN, indicating that cultural competence is imperative in all settings, no matter the background of the healthcare staff.

Discussion

Implications for Practice

The implications of this study for practice in rural areas, specifically on the NN, support improving EOLC by educating healthcare staff. This can be accomplished by providing evidenced-based education, such as the ELNEC Core Course, on site in rural area hospitals, which allows more staff to attend at one time in one place and facilitates the discussion of challenges experienced by that specific institution. Many challenges are common among healthcare institutions, but many are unique to rural settings (Taylor et al., 2019).

Improving quality of life and patient outcomes through EOLC education and training for those with chronic or life-limiting illnesses (Takenouchi et al., 2017) should be considered for all healthcare staff who provide care for this population. These staff include primary care providers, home health providers, and those who work in hospital settings where an absence of specialized PC or EOLC exists. Cultural aspects of

palliative and EOLC are a vital component in assuring patients are provided with appropriate, culturally sensitive care (Fink et al., 2013; Takenouchi et al., 2017).

In training staff, especially in rural or frontier geographic areas, more innovative methods should be considered, along with a goal of sustainability. Methods to consider may include: virtual tele-education sessions by certified trainers; educational symposiums held in rural areas; online programs; and train-the-trainer initiatives with identified staff, who would receive necessary training and then provide on-site training for rural staff.

Lastly, fostering relationships with urban palliative and hospice care centers should be a priority for rural communities. Doing so helps to meet the IOM's (2015) overarching goal of assuring all patients and their families have access to palliative care. Collaborative efforts can not only close the gap of lacking EOLC education for rural healthcare staff but also improve resources and access to care for patients who require it.

Patient-centered approach. Education related to EOLC is imperative for healthcare staff, as it demonstrates the importance of integrating the goals of patient and family care into overall healthcare goals. For many Indigenous people, dying within their communities is important and valued (Taylor et al., 2019), and this should be considered by healthcare providers offering care within the boundaries of Indigenous communities. Indigenous patients consider extended and clanship relations an important component in their decision making, including their healthcare decisions (Colclough & Brown, 2014). The module on Navajo beliefs on death and dying in this study included the importance of family in EOLC. Comprehending the overarching goals of PC and EOLC is imperative for healthcare providers so they understand that patient-centered care is a vital component

of overall care and so they allow a patient-centered approach to drive EOLC when coordinating care for patients with chronic or life-limiting illnesses (Dahlin, 2019).

Limitations for Health Policy

Health policy—in general regarding access to EOLC and specifically in rural areas like the NN—is limited regarding the importance of education and training. Navajo beliefs around death and dying impact policy and advocacy related to palliative and EOLC. Advocacy for EOLC begins with education of tribal policy makers and key community-level stakeholders.

Currently no policy related to EOLC exists on the NN, although there are national and state policies. The NN is recognized as a sovereign nation, which in itself can be considered an obstacle, as any federal, state, or national policy or legislation might not be adopted by the NN government. While the state of Arizona does have legislation regarding EOLC for terminally ill individuals (Compassion and Choices Arizona, 2013), it is vague and the payer source is not well defined. It includes limitations, such as a 6-month life expectancy to be eligible for Medicare services, and does not address or offer any waived options for those who reside in rural or frontier geographic locations.

Strengths and Limitations of the Study

A strength of this study was that it verified the necessity for EOLC education and training in rural settings, such as the NN. This study utilized an evidenced-based intervention, the ELNEC Core Course, which proved to be an effective training program. Education and training specifically related to Navajo traditional cultural competence was a component of the training and was shown to improve the knowledge and confidence of the healthcare staff in this area.

The limitations of this study were that the number of participants was a small sample ($N=27$), limiting the study's generalizability, and the study was only performed at one rural hospital on the NN. A further limitation of this study was that the participants were primarily nurses ($n = 23$; 70%); however, palliative and EOLC utilize a multidisciplinary approach to be most effective in benefiting patients (Dahlin, 2019).

Suggestions for Further Research

This study not only focused on the need for training and education to improve the knowledge and confidence of healthcare staff in one rural hospital, but also brings to light the absence of palliative care in rural settings, such as the NN. Given that this study was limited to one hospital with a small number of participants, this study should be repeated in a larger number of hospitals on the NN and with a larger number of participants from multiple disciplines. A further suggestion for future research is geared toward improving patient and family outcomes for those with chronic or life-limiting illnesses on the NN by researching the effects of culturally appropriate EOLC and how this care impacts patient care outcomes.

Concluding Remarks

Improving the quality of life until one dies encompasses the ability to provide competent healthcare across the healthcare continuum. This involves ensuring patients receive competent care when facing chronic or terminal illnesses. The benefits of training and education for healthcare staff are directly related to their confidence and comfort level in providing competent EOLC to patients, which improves quality of care and patient care outcomes (Malloy & Davis, 2019). In today's complex healthcare, all people

deserve the right to equal and equitable healthcare from birth until death. This includes dignified, respectful, and competent care at all phases of the life cycle.

The continued need for health policy regarding palliative and EOLC is evident, especially for rural areas, where poverty levels are high and access to care is inadequate and does not keep up with the need for specialty care services. Recognizing access to palliative care as a basic human right enforces the need for improved health policy regarding payment and access to services.

The NN has all the challenges of other rural communities, like poorer health outcomes, transportation issues, and higher unemployment rates, as discussed by Kaasalainen et al. (2014), but it also has an additional challenge related to beliefs and customs around death and dying. Because Navajo people do not openly discuss death, the importance of educating key stakeholders within the healthcare arena, as well as political leaders within communities, cannot be overemphasized. Openly discussing EOLC issues that affect the quality of care patients receive must find support and acceptance on the NN for outcomes to be improved. Educating the community, healthcare executives, health board members, and political entities within the NN is an essential component of building a sustainable palliative and EOLC education requirement for healthcare providers. Advocating the implementation of EOLC on the NN is an ethical responsibility of all healthcare professionals.

References

- American Association of Colleges of Nursing. (2020). *End-of-life care*. Retrieved from About ELNEC: www.aacnnursing.org/ELNEC/About
- American Nurses Association. (2015). *Code of ethics for nurses with interpretive statements*. Retrieved from American Nurses Association: <https://www.nursingworld.org/coe-view-only>
- Bharadwaj, P., Helfen, K. M., Deleon, L. J., Thompson, D. M., Ward, J. R., Patterson, J., . . . Bleznak, A. D. (2016). Making the case for palliative care at the system level: Outcomes data. *Journal of Palliative Medicine*, 19(3), 255–258.
doi:10.1089/jpm.2015.0234
- Campbell, C. L., Merwin, E., & Yan, G. (2009). Factors that influence the presence of a hospice in a rural community. *Journal of Nursing Scholarship*, 41(4), 420–428.
doi:10.1111/j.1547.5069.2009.01310.x
- Colclough, Y. Y., & Brown, G. M. (2014, October). American Indians' experiences of life-threatening illness and end of life. *Journal of Hospice & Palliative Nursing*, 16(7), 404–413. doi:10.1097/NJH.0000000000000086
- Compassion and Choices Arizona. (2013). *Choices and care at the end of life*. Retrieved from SB 1304 - palliative care (2013): <http://www.choicesarizona.org/SB1304.htm>
- Dahlin, C. M. (2019). National consensus project for quality palliative care: Assuring quality palliative care through Clinical Practice Guidelines. In B. R. Ferrell, & J. A. Paice (Eds.), *Oxford textbook of palliative nursing* (5th ed., pp. 5–12). New York: Oxford University Press.

- Fink, R. M., Oman, K. S., Youngwerth, J., & Bryant, L. L. (2013). A palliative care needs assessment of rural hospitals. *Journal of Palliative Medicine*, 16(6), 638–644. doi:10.1089/jpm.2012.0574
- Gebauer, S., Morley, S. K., Haozous, E. A., Finlay, E., Camarata, C., Fahy, B., . . . Marr, L. (2016). Palliative care for American Indians and Alaska Natives: A review of literature. *Journal of Palliative Medicine*, 19(12), 1331–1340. doi:10.1089/jpm.2016.0201
- Holms, N., Milligan, S., & Kydd, A. (2014). A study of the lived experiences of registered nurses who have provided end-of-life care within the intensive care unit. *International Journal of Palliative Nursing*, 20(11), 549–556.
- Hospice Action Network. (2017). *What is hospice?* Retrieved from Hospice Action Network: <http://hospiceactionnetwork.org/get-informed/what-is-hospice/>
- Institute for Healthcare Improvement. (2020). *How to improve*. Retrieved from: <http://www.ihl.org/resources/Pages/HowtoImprove/ScienceofImprovementTestingChanges.aspx>
- Institute of Medicine. (2015). *Dying in America: Improving quality and honoring individuals preferences near the end of life*. Washington: National Academic Press. doi:10.17226/18748
- Isaacson, M. J., & Lynch, A. R. (2018). Culturally relevant palliative and end-of-life care for U.S. Indigenous populations: An integrative review. *Journal of Transcultural Nursing*, 29(1), 180–191. doi:10.1177/1043659617720980
- Kaasalainen, S., Brazil, K., Williams, A., Wilson, D., Willison, K., Marshall, D., . . . Phillips, C. (2014, June 25). *Nurses' experiences providing palliative care to*

individuals living in rural communities: Aspects of the physical residential settings. Retrieved from Rural and Remote Health:

<http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=2728>

Kelly, L., Linkewich, B., Cromarty, H., St. Pierre-Hansen, N., Antone, I., & Gilles, C.

(2009). Palliative care of First Nations people; A qualitative study of bereaved family members. *Canadian Family Physician*, 55, 394–395.e1-7.

Kitzes, J., & Berger, L. (2004). End-of-Life issues for American Indians/Alaska Natives:

Insights from one Indian Health Service area. *Journal of Palliative Medicine*, 7, 830–838.

Kolb, A. Y., & Kolb, D. A. (2005). Learning styles and learning spaces: Enhancing

experiential learning in higher education. *Academy of Management Learning &*

Education, 4(2), 193–212. Retrieved from <http://www.jstor.org/stable/40214287>

Kolb, D. A. (2015). *Experiential learning: Experience as the source of learning and*

development (2nd ed.). Upper Saddle River, New Jersey: Pearson.

Lazenby, M., Ercolano, E., Shulman-Green, D., & McCorkle, R. (2012). Validity of the

End-of-Life Professional Caregiver Survey to assess for multidisciplinary

educational needs. *Journal of Palliative Medicine*, 15(4), 427–431.

doi:10.1089/jpm.2011.0246

Malloy, P., & Davis, A. (2019). Nursing Education. In B. R. Ferrell, & J. A. Paice (Eds.),

Oxford textbook of palliative nursing (5th ed.). New York: Oxford University

Press.

Mayrhofer, A., Goodman, C., Smeeton, N., Handley, M., Smador, S., & Davies, S.

(2016). The feasibility of a train-the-trainer approach to end of life care training in

care homes: An evaluation. *BMC Palliative Care*, 15(11), 1–8.

doi:10.1186/s12904-016-0081-z

Miller, W., & Brown, P. R. (2017). Motivators, facilitators, and barriers to physical activity in older adults. *Holistic Nursing Practice*, 31(4), 216–224.

doi:10.1097/HNP.0000000000000218

Navajo Code Talkers Administration. (2014). *Navajo Death Rituals*. Retrieved from NavajoCodeTalkers Sharing the Story of the Soldiers that Ended the War: <http://navajocodetalkers.org/navajo-death-rituals/>

Navajo Nation Department of Information Technology. (2011). *Navajo Nation government history*. Retrieved from Navajo Nation Government: <http://www.navajo-nsn.gov/history.htm>

Office of Disease Prevention and Health Promotion. (2014). *2020 topics and objectives—objectives A-Z*. Retrieved from HealthyPeople.gov: <https://www.healthypeople.gov/2020/topics-objectives>

Pallant, J. (2016). *SPSS survival manual* (6th ed.). New York: McGraw-Hill Education.

Rural Health Information Hub. (2019). *Rural hospice and palliative care*. Retrieved from Rural Health Information Hub: <https://www.ruralhealthinfo.org/topics/hospice-and-palliative-care>

Shulman, C., Hudson, B. F., Kennedy, P., Brophy, N., & Stone, P. (2018). Evaluation of training on palliative care for staff working within a homeless hostel. *Nurse Education Today*, 135–144. doi:<https://doi.org/10.1016/j.nedt.2018.09.022>

- Sidebottom, A. C., Jorgenson, A., Richards, H., Kirven, J., & Sillah, A. (2015). Inpatient palliative care for patients with acute heart failure: Outcomes from a randomized trial. *Journal of Palliative Medicine*, 18(2), 134–142. doi:10.1089/jpm.2014.0192
- Swami, M., & Case, A. A. (2018, April). Effective palliative care: What is involved? *The Oncology Journal*, 180–184.
- Takenouchi, S., Sasahara, T., Miyashita, M., Kawa, M., Umeda, M., Kuwata, M., . . . Tamura, K. (2017). Empowering nurses through translating the end-of-life nursing education consortium. *Journal of Hospice & Palliative Nursing*, 19(6), 539–549. doi:10.1097/NJH.0000000000000385
- Taylor, R. A., Dionne-Odom, J. N., Currie, E. R., Stockdill, M., & Bakitas, M. A. (2019). Rural palliative care. In B. R. Ferrell, & J. A. Paice (Eds.), *Oxford textbook of palliative nursing* (5th ed., pp. 670–681). New York: Oxford University Press.
- Thomas, K., Tanner, T., & Wilson, J. A. (2016). End of life care: Doing it better. *Practical Nurse*, 46(11), 34–40.
- Wilson, C. K., Tariman, J. D., & Graf, R. (2018). Online palliative care education in the skilled nursing facility. *Journal of Nursing Practice Applications & Review of Research*, 8(2), 21–34. doi:https://doi.org/10.13178/jnparr.2018.0802.0805
- World Health Organization. (2018). *Cancer: WHO definition of palliative care*. Retrieved from World Health Organization:
<https://www.who.int/cancer/palliative/definition/en/>

Appendix A

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
I am able to be present with dying patients.....	0	1	2	3	4

	Not at all	A little bit	Some-what	Quite a bit	Very much
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
** I am knowledgeable about Navajo cultural beliefs about death and dying.....	0	1	2	3	4
**I am comfortable providing end-of-life care that respects Navajo beliefs of death and dying	0	1	2	3	4
**I am confident in providing end-of-life care that respects Navajo beliefs of death and dying.....	0	1	2	3	4

**Added question for purpose of study

Appendix B



Module	Description
Palliative Care Nursing	Introduction to Palliative Care Nursing, this module provides an overview of palliative care and the important role nurses play when providing care to those with terminal or chronic illnesses. This module covers the lack of appropriate specialized care for those at the end of their life, this include for both the patient and their family. This module reminds the healthcare provider of the importance of effective collaboration among various disciplines in healthcare to honor patient's goals of care and to provide palliative care across the continuum. Palliative Care combines compassionate caring, concise communication, up-to-date, evidence-based knowledge and practice, and is "being with" the patient and their families and not just "doing for" (Relias Academy, 2020).
Symptom Management	This module provides an overview of symptoms common in patients, necessitating palliative care, and emphasizes the importance in managing them. This module divides the symptoms by systems (gastrointestinal, respiratory, etc.), discussing the fact that many life-threatening illnesses most likely present with multiple symptoms. Stresses the importance of evidence-based symptom management and identifying ideal treatments. This module covers the critical role that healthcare providers have in recognizing, assessing, and managing symptoms. The importance of symptom management is to relieve the suffering for patient who is at the end of life (Relias Academy, 2020).
Communication	This module emphasizes that communication is a critical component and is the foundation of palliative care. It covers the difficulties that healthcare providers face with communicating with patients who are at the end of life, but also remind healthcare staff of the unique opportunity to contribute to the compassionate care. Discusses the various types of communication and how to be attuned to the non-verbal cues from those who require palliative or hospice care (Relias Academy, 2020).
Loss, Grief, Bereavement	By doing this important work, we witness grief in our patients and their family members every day. As healthcare professionals, we experience a tremendous amount of loss as we think of the many patients we have cared for. These memories and losses can accumulate over time and can cause healthcare staff to experience compassion fatigue and burn-out. This module will support ways to provide exceptional bereavement care to family members after the patient has died. It also stresses the importance of practicing good self-care for the healthcare providers (Relias Academy, 2020).
Pain Management	This module builds on the concepts presented in Module 1, Introduction to Palliative Care Nursing and will outline the general care management strategies related to pain assessment and management, stressing the importance of the nursing assessment. Pain

	must be treated using a multimodal approach (e.g. pharmacologic/non-pharmacologic therapies, mental health professionals, rehabilitation therapists, spiritual guides, chaplains, etc.) (Relias Academy, 2020).
Final Hours of Living	This is a very important, as it emphasizes the preparation necessary to ensure the best care at this critical event in the trajectory of illness and provides education in how to better provide care in the final days, hours, and minutes of a patient's life. It takes preparation, proactive planning, and good communication skills with the entire team. Family members will always remember the final moments of their loved ones' life. Emphasizes that the care at this time demands attention to the physical, psychological, social, and spiritual needs of patients and the special needs of their families (Relias Academy, 2020).
Culture/Ethics	In this module, common ethical issues in palliative care as well as how to address these issues is discussed. Ethical issues and dilemmas are inherent in care provided to patients and their families in palliative care. This module examines the most important and privileged roles healthcare professional have. One is that healthcare provides individually and collectively serve as advocates for patients and their families by supporting communication about the patient's healthcare decisions (Relias Academy, 2020).
Leadership	Leadership is vital in advocating for palliative care in the continuum of care for those at the with terminal and/or chronic illnesses. Understanding the evidence will allow leaders to find ways to ensure all patients have access to this care, while understanding it has on the quality of life for the patient and their families, but also on the overall healthcare cost.
Navajo Cultural Belief	This module covered the Navajo cultural beliefs on death and dying. This module was taught by a Navajo Native Medicine practitioner. An overview and history of the traditions and beliefs for those who are dying and what the Navajo beliefs are once one has died. Discussions on the "taboo" of death and how to respectfully approach these beliefs as healthcare providers.
Blessing of the Hands	This was not a module, but a ceremony performed after the completion of each ELNEC course

Appendix C

**Human Research Protections Program**

August 27, 2019

Christine Delucas
 ADelucas@salud.unm.edu

Dear Christine Delucas:

On 8/27/2019, the HRRC reviewed the following submission:

Type of Review: Modification
 Title of Study: Improving End-Of-Life Care on Navajo
 Investigator: Christine Delucas
 Study ID: 19-194
 Submission ID: MOD00010185
 IND, IDE, or HDE: None

Submission Summary: Modification #1 for Study 19-194 to update study record with Navajo IRB approval letter.

Documents Approved: • NNHRRB approval letter.pdf

Review Category: EXEMPTION: Categories (2)(i) Tests, surveys, interviews, or observation (non-identifiable)

Determinations/Waivers: Provisions for Consent are adequate.
 HIPAA Authorization Addendum Not Applicable.
 Re-consent is not required.

Submission Approval Date: 8/27/2019
 Approval End Date: None
 Effective Date: 8/27/2019

The HRRC approved the study from 8/27/2019 to inclusive. If modifications were required to secure approval, the effective date will be later than the approval date. The "Effective Date" 8/27/2019 is the date the HRRC approved your modifications and, in all cases, represents the date study activities may begin.

Because it has been granted exemption, this research is not subject to continuing review.

Please use the consent documents that were approved by the HRRC. The approved consents are available for your retrieval in the "Documents" tab of the parent study.

If the study meets the definition of an NIH Clinical Trial, the study must be registered in the ClinicalTrials.gov database. Additionally, the approved consent document(s) must be uploaded to the ClinicalTrials.gov database.



As a reminder, it is the responsibility of the principal investigator or delegated study team member, to re-consent former and/or current participants as directed in the "Determinations/Waivers" section of this letter.

This determination applies only to the activities described in this submission and does not apply should you make any changes to these documents. If changes are being considered these must be submitted for review in a study modification to the HRRC for a determination prior to implementation. If there are questions about whether HRRC review is needed, contact the HRPO before implementing changes without approval. A change in the research may disqualify this research from the current review category. You can create a modification by clicking Create Modification / CR within the study.

If your submission indicates you will translate materials post-approval of English materials, you may not recruit or enroll participants in another language, until all translated materials are reviewed and approved.

In conducting this study, you are required to follow the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library.

Sincerely,

A handwritten signature in black ink, appearing to read 'Thomas F. Byrd'.

Thomas F. Byrd, MD
HRRC Executive Chair

Abbreviated Investigator Responsibilities

NOTE: For a full unabridged version of the Investigator Manual please visit the HRPO Website at <https://hsc.unm.edu/research/hrpo/>

What will happen after HRRC review?

The HRPO will provide you with a written decision indicating that the HRRC has approved the Human Research, requires modifications to secure approval, or has disapproved the Human Research.

- **If the HRRC has approved the Human Research:** The Human Research may commence once all other organizational approvals have been met. HRRC approval is usually good for a limited period of time which is noted in the approval letter.
- **If the HRRC requires modifications to secure approval and you accept the modifications:** Make the requested modifications and submit them to the HRRC. If all requested modifications are made, the

Appendix D

THE NAVAJO NATION

JONATHAN NEZ | PRESIDENT MYRON LIZER | VICE PRESIDENT



Auagust 20, 2019

Dr. Christine Delucas, DNP, MPH, RN, NEA-BC
UNM College of Nursing
PO. Box 1143
Chinle, Arizona 86503

Dear Dr. Delucas,

This is to advise you that the **Study #NNR-19.352T: "Improving End-of-Life Care on Navajos"** has been presented to the Navajo Nation Human Research Review Board (NNHRRB) on August 20, 2019, and the following action taken subject to the conditions and explanation provided below.

Reasons:	New Application
Description:	Request Review and Acceptance of New Protocol
NNHRRB Action:	<u>Accepted and Approved – August 20, 2019 – August 20, 2020</u>
Conditions:	With All Standard Conditions

The Navajo Nation Human Research Review Board has added a very important additional contingency regarding failure to comply with NNHRRB rules, regulations, and submittal of reports which could result in sanctions being placed against your project. This could also affect your funding source and the principal investigator. Under Part Five: Certification, please note paragraph five wherein it states: *"I agree not to proceed in the research until the problems have been resolved or the Navajo Nation Human Research Review Board has reviewed and approved the changes."* Therefore, it is very important to submit quarterly and annual reports on time and if continuation is warranted submit a letter of request sixty (60) days prior to the expiration date.


The following are requirements that apply to all research studies:

1. The Navajo Nation retains ownership of all data obtained within its territorial boundaries. The Principal Investigator shall submit to the NNHRRB a plan and timeline on how and when the data/statistics will be turned over to the Navajo Nation;
2. Only the approved informed consent document(s) will be used in the study;
3. Any proposed future changes to the protocol or the consent form(s) must again be submitted to the Board for review and approval prior to implementation of the proposed change;
4. If the results of the study will be published or used for oral presentations at professional conferences, the proposed publication, abstract and/or presentation materials must be submitted to the Navajo Research Program for Board review and prior approval;
5. Upon Board approval, three (3) copies of the final publication must be submitted to the Navajo Research Program;
6. All manuscripts must be submitted to the Navajo Research Program for Board Review and prior approval;
7. The Principal Investigator must submit a dissemination plan on how the results of the study and how these results will be reported back to the Navajo Nation;

8. The Principal Investigator must share specifically how these results will generally benefit or improve the health of the Navajo people. This can be completed by:
 - a. Conducting an educational in-service for the community people and health care providers on the Navajo Nation and present the findings. Provide documentation of these in-services presented.
 - b. Developing educational materials for use by the health care providers and the community people and providing the training on how to use the materials; and
 - c. Presenting and sharing the results of the study at a research conference sponsored by the Navajo Nation for its health care providers and the Navajo people.
9. The Principal investigator is expected to submit documentation on 8a, b, & c;
10. The Principal investigator must submit quarterly and annual reports as scheduled.

Please begin using your **Study Protocol Number NNR-19.352** on all correspondences. If you have any questions on this subject, please call the Navajo Research Program at (928) 871-6929.

Sincerely Yours,


Beverly Becenti-Pigman, Chairperson
Navajo Nation Human Research Review Board

Cc: #NNR-19.352 file

Appendix E



CANYON DE CHELLY COMPREHENSIVE HEALTH SERVICES, INC.

CDCCHS.071119.JBahe

RESOLUTION OF THE BOARD OF DIRECTORS

RECOMMENDING AND SUPPORTING JOHANNA G. BAHE TO CONDUCT HER DOCTORATE SCHOLARLY QUALITY IMPROVEMENT PROJECT TITLED “IMPROVING END-OF-LIFE CARE ON NAVAJO.”

WHEREAS:

1. The Canyon De Chelly Comprehensive Health Services, Inc. (CDCCHS) is certified by the Navajo Nation Business Regulatory Authority as a non-profit tribal corporation since July 1997 and;
2. The Canyon De Chelly Comprehensive Health Services advocates for the provision of high quality, cost effective, responsive and culturally appropriate health care services in the 16 Navajo Nation Chapters and;
3. The CDCCHS has the authority, pursuant to resolution CMY-46-80 of the Navajo Tribal Council, to review health care matters affecting the people served by the Navajo Area Indian Health Service, Chinle Service Unit and to advocate for and assist the Indian Health Service's (IHS) mission to elevate the health status of the Navajo and other American Indians to the highest level and;
4. Johanna G. Bahe, MSN, RN, a Doctor of Nursing Practice – Nurse Executive Organizational Leadership student at the University of New Mexico College of Nursing, is seeking resolution from Canyon De Chelly Comprehensive Health Services, Inc. to support her Doctoral Scholarly Quality Improvement Project at the Chinle Service Unit, which comprised of three (3) health care facilities, they are: Chinle Comprehensive Health Care Facility, Tsaile Health Center, and Pinon Health Center; and
5. Because the proposed Quality Improvement Project involves obtaining pre and post survey information from Chinle Service Unit health care staff, the Navajo Nation Human Research Review Board will grant their approval to conduct the Doctoral Scholarly Quality Improvement Project. The Board is in receipt of all the documentation to support the proposed doctoral scholarly project and finds this doctoral scholarly project will benefit the Navajo Nation; and
6. The purpose of this Doctoral Scholarly Quality Improvement Project is to assess the current knowledge, comfort level, and confidence of End-of-Life care of health care staff who attend the End-of-Life Nursing Education Consortium (ELNEC) Core Course training. The assessment will occur before and after training using an anonymous survey tool; and

P.O. Box 3469 Chinle, AZ 86503

Telephone: (928) 674-7802

Fax: (928) 674-7372



CANYON DE CHELLY COMPREHENSIVE HEALTH SERVICES, INC.

CDCCHS.071119.JBahe

7. This Doctoral Scholarly Quality Improvement Project will include making recommendations to the Chinle Service Unit, to improve the basic knowledge of palliative and End-of-Life Care to health care staff who will improve their skill and confidence in this field; and
8. The objective of this Quality Improvement Project is to improve the knowledge and comfort level of health care staff and their confidence to provide End-of-Life Care. This will be accomplished through standardized education of health care staff at the Chinle Service Unit, including an educational component of the Navajo views on End-of-Life presented by a Navajo practitioner; and
9. The implications for future care on the Navajo Nation is by improving the knowledge and comfort level of health care staff, it will in turn improve the care provided to those patients who require End-of-Life Care.

NOW THEREFORE BE IT RESOLVED THAT:

The Canyon De Chelly Health Services, Inc. Board hereby respectfully recommends and supports Navajo Nation Human Research Review Board grant their approval for Johanna G. Bahe to conduct her Doctorate Scholarly Quality Improvement Project titled, "Improving End-of-Life Care on Navajo."

CERTIFICATION

I, the undersigned, do hereby certify that the foregoing resolution was duly considered by the Canyon De Chelly Health Services, Inc. Board of Directors at a duly meeting in Chinle, Navajo Nation (Arizona) at which a quorum was present and that the same was passed by a vote of 4 in favor, 0 opposed, and 3 abstained on this 11th day of July 2019.

Rex Lee Jim
President, CDCCHS, Inc.

Motion: Kevin Rand, MD

Second: Patrick Lynch, MPH

Appendix F



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service, IHS
Chinle Comprehensive Health Care Facility

MEMORANDUM

Date: April 10, 2019

To: Johanna Bahe, Chief Nurse Executive

From: CCHCF: Administration ~ Office of the CEO

Subject: SUEC Presentation

Thank you for your proposal to SUEC in April 2019. The following has been approved as requested:

Description of Request
<p><i>Approval Requested for:</i></p> <ul style="list-style-type: none"> • <i>Permission to utilize the CSU Improvement Cycle model in the Doctorate of Nursing Practice (DNP) Scholarly Project;</i> • <i>Permission to use the employee (healthcare staff) survey data for analysis for the DNP Scholarly Project. This data includes survey data pre and post training and is an overview of staff knowledge and comfort level related to end of life care;</i> • <i>For current enrolled student, Johanna Bahe, in the Doctorate of Nursing Practice program with the University of New Mexico.</i>

Thank you for your interest and efforts in improving Nursing Services, Chinle Service Unit.

Darlene Chee, Administrative Officer
Acting Chief Executive Officer

cc:

file

Appendix G

**RESOLUTION OF THE CHINLE AGENCY COUNCIL
NAVAJO NATION
Resolution No: CAC-07/19-07**

**RECOMMENDING AND SUPPORTING JOHANNNA G. BAHE TO CONDUCT HER
DOCTORATE SCHOLARLY QUALITY IMPROVEMENT PROJECT TITLED
"IMPROVING END-OF-LIFE CARE ON NAVAJO"**

WHEREAS:

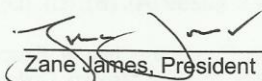
1. The Chinle Agency Council is comprised of sixteen (16) chapters of Central Agency: Black Mesa, Blue Gap/Tachee, Chinle, Forest Lake, Hardrock, Lukachukai, Many Farms, Nazlini, Pinon, Rough Rock, Round Rock, Tsaile/Wheatfields, Tselani/Cottonwood and Whippoorwill; and
2. The Navajo Nation Human Research Review Board is the Institutional Review Board of the Navajo Nation and requires all researchers to follow the "IRB Research Protocol Application Guidelines", [13 N.N.C §3259 (A), (B), (C), (D), (E), (F), (G) and §3260 (A), (B), (C), (D), (E), (F)] ; and
3. Johanna G. Bahe, MSN, RN a Doctor of Nursing Practice – Nurse Executive Organizational Leadership student at the University of New Mexico College of Nursing, and is seeking resolution from Chinle Agency Council to support her doctoral scholarly quality improvement project at the Chinle Service Unit, which comprised of three (3) health care facilities, they are: Chinle Comprehensive Health Care Facility, Tsaile Health Center, and Pinon Health Center; and
4. Because the proposed doctoral scholarly quality improvement project involves obtaining pre and post survey information from Chinle Service Unit healthcare staff, the Navajo Nation Human Research Review Board will grant their approval to conduct the doctoral scholarly quality improvement project. The Board is in receipt of all the documentation to support the proposed doctoral scholarly project and finds this doctoral scholarly project is in the best interest of the Navajo Nation; and
5. The purpose of this doctoral scholarly quality improvement project is to assess the current knowledge, comfort level, and confidence of End-of-Life care of healthcare staff who attend the End-of-Life Nursing Education Consortium (ELNEC) Core Course training. The assessment will occur before and after training using an anonymous survey tool; and
6. This doctoral scholarly quality improvement project will include making recommendations to the Chinle Service Unit, to improve the basic knowledge of palliative and end of life care to healthcare staff who are not considered specialists in this field; and
7. The objective of this quality improvement project is to improve the knowledge and comfort level of healthcare staff and their confidence to provide end of life care. This will be accomplished through standardized education of healthcare staff at the Chinle Service Unit, including an educational component of the Navajo views on death and dying presented by a Navajo practitioner.

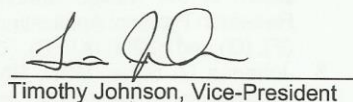
NOW, THEREFORE BE IT RESOLVED THAT:


1. The Chinle Agency Council hereby recommends and supports Navajo Nation Human Research Review Board grant their approval for Johanna G. Bahe to conduct her scholarly quality improvement project titled "Improving End-of-Life Care on Navajo".

CERTIFICATION

I hereby certify that the foregoing resolution was considered at a duly called Chinle Agency Council meeting at the Chinle Chapter House, Chinle, Navajo Nation, Arizona at which a quorum was present and the same time passed by a vote of 31 in favor 0 opposed and 2 abstained on this 13th Day of July, 2019.


Zane James, President


Timothy Johnson, Vice-President


Valencia Edgewater, Secretary