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Influence of a Palliative Care Protocol on Nurses' Perceived Barriers to Palliative Care and Moral Distress

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THE INFLUENCE OF A PALLIATIVE CARE PROTOCOL ON NURSES' PERCEIVED BARRIERS TO PALLIATIVE CARE AND MORAL DISTRESS

by

CHRISTINA CAVINDER

EVIDENCE-BASED PRACTICE PROJECT REPORT

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DEDICATION

This project is dedicated to my husband, Timothy Cavinder, and my children, Leo and Sarah, who have been supportive throughout the entire project by providing encouragement, forgiveness, and enduring love.

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ABSTRACT

The World Health Organization (2013) states palliative care for children should begin at diagnosis which may even occur prenatally. Neonatal palliative care is variable due to the high technological, curative environment in the newborn intensive care unit, and the uncertain prognoses of infants born at the edge of viability. The purpose of this EBP project was to determine the influence of establishing a neonatal palliative care protocol on nurses' perceived barriers to palliative care and moral distress. Corley's Moral Distress theory and Stetler's Model were used as guides for the framework of the project. The protocol, based on guidelines supported by the American Academy of Pediatrics and the National Association of Neonatal Nurses, included forming a care team for the infant and family and educational sessions for the nurse based on the End of Life Nursing Education Curriculum. Pre-invention and post-invention surveys were administered which measured perceived barriers and moral distress. The pre-intervention and the post-intervention groups differed by gender ($X^2(1) = 4.483$, $p<0.05$) and formal education ($X^2(2) = 6.357$, $p<0.05$). A significant decrease in perceived barriers were found in (a) medical staff support palliative care ($t\ (42) = 2.031$, $p<0.05$), (b) physical environment for palliative care ($t\ (43) = 3.216$, $p<0.01$), (c) policies/guidelines are present for palliative care ($t\ (41) = 2.634$, $p<0.05$), (d) palliative care options are given to families ($t\ (42) = 2.075$, $p<0.05$), and (e) team member express opinions, values, and beliefs ($t\ (43) = 2.951$, $p<0.01$). A significant decrease in moral distress was noted in the concepts of witnessing providers giving false hope to families ($t\ (43) = 2.321$, $p<0.05$) and working with unsafe providers ($t\ (41) = 2.300$, $p<0.05$). A significant increase was noted, though, in the concept of working with incompetent providers ($t\ (41) = -2.152$, $\mathrm{p}<0.05$). The neonatal palliative care protocol has been adopted by the clinical agency.

CHAPTER 1

INTRODUCTION

The World Health Organization (WHO) states children's palliative care is an option for families and children with a life-threatening condition to receive prevention and relieve from suffering due to pain and other problems through physical, psychological, and spiritual support (WHO, 2013). This organization stresses palliative care for children should begin at diagnosis which may even occur prenatally. Each year in the United States, 29,000 infants die under the age of 1, and 66% of these deaths occur in the neonatal period (Xu, Kochanek, & Tejada-Vera, 2009). Quality palliative care must continue whether treatment for disease or comfort care is received. Palliative care in adults has been well established, but palliative care for children especially for infants is inconsistent at best. The main reason for lack of neonatal palliative care is the uncertainty of prognosis (Bhatia, 2006). Certain prognoses such as trisomy 13 and 18 are life-limiting conditions, but these infants' lengths of survival are variable. Infants born at the edge of viability have uncertain outcomes. The neonatal intensive care unit (NICU) is a highly technological environment geared at saving all lives. Attempting to save infants with uncertain prognoses causes ethical situations. At times, nurses must manage families' desire to provide futile treatments for their infants. Palliative care in the NICU is also variable. Decisions to transition from curative care to palliative care are based on families' desires not infants' physiological status (Caitlin, 2011). Nurses may perceive parental desires for futile treatments as a barrier to palliative care. Other perceived barriers may exist which prevent these infants from receiving palliative care such as lack of an optimal environment for palliative care and lack of palliative care education (Kain, 2011). Establishing a palliative care protocol which creates more uniformity to this type of care is not a top priority for NICUs, but units which do not have protocols may place nurses at increased risk of developing moral distress (Epstein, 2008). Moral distress occurs when people must perform against their beliefs due to constraints (Corley, 2002). Nurses who experience moral distress may leave their current nursing positions or leave nursing all together (Cavaliere, Daly, Dowling, & Montgomery, 2010).

Background

Infant mortality has declined over the past 70 years from 55.7 per 1000 in 1935 to 6.8 per 1000 in 2006 in the United States (Singh & van Dyck, 2010). Leading causes of death for infants are congenital anomalies, short gestation, low birth weight, sudden infant death syndrome, maternal complications of pregnancy, unintentional injuries, cord and placental complications, and respiratory distress syndrome. The gestation of viability for infants is blurry. Even birth weight is no longer the predictor of survival as in the past. Due to this unclear definition of survival, providing prognostic information to parents prior to birth is done in percentages, not definite outcomes (Bhatia, 2006). Health care technology also continues to change and advance. More treatments are available for newborns with complex conditions. Health care providers may feel pressure from society to treat these infants despite the likelihood of poor outcomes.

Families also pressure health care providers to administer futile treatments. They may hear through news or social media of infants with similar conditions surviving and having acceptable outcomes. Families also may desire futile treatments due to denial, hope for medical miracles, feelings of helplessness, belief in incorrect diagnosis, faulty reasoning, attitude of not giving up on infant, trust in God or higher power, and belief in entitlement (Romesberg, 2003). With this increased desire by society and families to attempt to save these high risk infants, more ethical dilemmas may arise for health care providers especially nurses. Ethical dilemmas occur when two or more ethically justifiable but opposable actions can be taken, but each action has a negative consequence (Epstein & Delgado, 2010). Nurses are advocates for the infants and the families. They understand the interventions used to treat these infants and how these interventions affect the infants. Nurses understand providing these treatments may cause the infants harm, and the outcomes may not be beneficial. Ethical dilemmas may occur when the family legally choses to continue futile treatments for the infant, but the nurse, who has no input in the decision-making for the infant, must carry out the futile care.

Other barriers to palliative care may exist in the NICU which cause moral distress. Physicians provide families with prognostic information regarding their infants. Nurses are not typically involved in these discussions regarding prognosis. Due to the nature of the curative NICU environment, palliative care may not be offered to families (Ahern, 2013). Nurses may believe this type of care is more beneficial to the infant and the family, but are in conflict with the medical opinion. This process causes poor collaboration between nursing and medicine which produces a strained environment. Nurses also may lack education in palliative care, so they do not understand care options for these infants. They may try to avoid dying patients because they lack coping mechanisms (Kain, 2006). They may try to control the death process or withdraw from the process which causes increased moral distress. By lacking a set protocol with clear criteria for infants requiring palliative care, having decreased interdisciplinary collaboration, and lacking education regarding palliative care, nurses are at risk of developing moral distress.

Perceived Barriers to Neonatal Palliative Care and Moral Distress of Neonatal Nurses

Literature support. According to the March of Dimes (2013) the infant mortality rate for the United States was 6.4% in 2009. In the same year, the infant mortality rate for Indiana was 7.8%. The leading causes of infant death in Indiana are birth defects, prematurity or low birth weight, sudden infant death syndrome, respiratory distress syndrome, maternal complications of pregnancy, and neural tube defects. Five of these classifications are causes for a newborn to be admitted to the NICU for care. Prematurity and its complications account for 25% of neonatal deaths. Of all neonatal deaths in the NICU 74% to 83% are preceded by withdrawal of medical treatment (Lewis, 2012). A palliative care and bereavement protocol is essential to provide quality care for these infants.

In 2000, the American Academy of Pediatrics (AAP) established a model for palliative care for infants and children. This model is directed at physicians and presents recommendations for medical care. The AAP acknowledges that the majority of children who die have not received the benefits of palliative care. A minimum standard of care identified in this model is the provision of consistency in caregivers and the availability of an interdisciplinary care team to address the physical, psychological, emotional, and spiritual needs of the child and the family. This team should be comprised of a physician, a nurse, a social worker, a spiritual advisor, and a child life therapist. The AAP also recommends that nurses, physicians, clergy, and social workers should have education regarding childhood life-threatening conditions and pediatric palliative care. The National Association of Neonatal Nurses (NANN) (2010b) also supports quality palliative care for infants. Use of a care team which works with the family to support their decisions in the infant's care is also a recommendation in the NANN model.

Nurses working in the NICU for any extended period of time have experience with palliative care or end-of-life care either directly or indirectly. Gallager, Cass, Black, and Norridge (2012) performed a needs assessment of neonatal and pediatric nurses working in intensive care regarding their knowledge about palliative care. They found nurses felt they were not educationally prepared for palliative care despite their experience with the process. The areas nurses felt most uncomfortable included legal aspects of end-of-life care, organ donation, and discussing care planning with family. In particular to care planning, the nurses were not comfortable with discussing prognoses with the family regarding palliative care. Nurses do not typically receive training or education in these areas, and do not deal with this situation frequently to instill confidence and competence.

Providing aggressive care which nurses perceive as futile also leaves nurses dealing with emotional responses. They may question their own values, become complacent regarding the futile care, express their opinions to other care providers, or seek outside assistance such as taking issues to the ethics committee (Caitlin et al., 2008). NANN (2010a) recommends a collaborative approach in decision-making for infants who require aggressive care, but may benefit from palliative care. Providing the infant with an initial assessment, warmth, and comfort is the first part of the plan. Parents are then given appropriate and understandable information about the infant's condition and potential outcomes including the technological support required and the consequences of this support. The parents weigh their options and decide on a treatment plan based on the information and their values in collaboration with the health care providers. The care plan should be regularly evaluated to determine if the plan is working and optimum care is being provided to the infant. Nurses, though, may perceive the information parents receive as inaccurate or the parents may not be able to make rational decisions due to emotional distress. This dichotomy of opinions regarding the infant's care may cause nurses to develop moral distress since they are legally obligated to provide care, but ethically believe they are causing harm.

Lack of confidence in palliative care or inability to provide palliative care may cause the nurses to develop moral distress. Moral distress occurs when a person performs against his or her moral values due to constraints placed by an organization or another person (Corley, Minick, Elswick, & Jacobs, 2005). This phenomenon has been presented extensively in the literature. Jameton (1998) was one of the first people to explore moral distress. He believed moral distress needed to be addressed before further consequences developed such as nurses leaving the profession. Corley, Minick, Elswick, and Jacobs (2005) conducted a study which demonstrated moral distress lingers even after the initial incident. Their data demonstrated moral distress is occurring frequently in hospitals, especially in units with a large proportion of ethical situations. Due to high technological advances used for life saving treatments, and the blurring line of viability for premature infants, the NICU is such an environment.

Another reason for this increase in moral distress in nursing is the lack of or limited communication between nurses and physicians regarding the care of a patient. Not all nurses recognize moral distress. They may experience anger and frustration during an ethical situation, and not realize the consequences this experience has on their health and career. These emotions may threaten nurses' moral integrity which can cause them to feel belittled, unimportant, or unintelligent (Epstein & Delgado, 2010). Nurses typically do not share these feelings which can cause further issues if unaddressed. Epstein and Delgado describe how these emotions become moral residue. This phenomenon is long-lasting and powerful. It affects how nurses view themselves. If nurses continue to have situations which cause moral distress, moral residue continues to develop, and the effects are destructive. Gutierrez (2005) showed how moral residue affects nurses. Nurses who experience moral distress may leave the unit where they work, experience burnout, or leave the nursing profession. When nurses experience burnout, patient care may suffer because the nurses are not responsive to the situation and may not advocate for their patients (Epstein & Delgado, 2010). The authors recommend evidence-based strategies for reducing nurses' moral distress which include participating in moral distress education, working in interdisciplinary groups to solve problems, developing policies with interdisciplinary collaboration, and developing workshops that work on identifying barriers for change and creating a plan of action.

Since the phenomenon of moral distress is based on human emotions and experiences, the level of moral distress is different for different people. Janvier, Nadeau, Deschenes, Conture, and Barrington (2006) examined the frequency of moral distress and the factors which affect moral distress. They found nurses who predicted poorer outcomes for premature infants tended to have more ethical dilemmas in their work and experienced more moral distress. Physicians who predicted poorer outcomes actually had less moral distress as compared to physicians who predicted better outcomes. Study results demonstrated that nurses tend to have more moral distress than physicians. Nurses having less autonomy in decision making as compared to physicians was presented as an explanation for this finding.

Nurses may also experience moral distress if they are unable to provide the care they believe their patients need (Corley, 2002). Corley discussed this issue in her theory on moral distress. This tenet was supported by Davies et al. (2008). In their study examining barriers to palliative care, nurses stated the most frequent barriers to palliative care were uncertain prognosis, family's inability to acknowledge the child's incurable condition, language, and time constraints. Nurses also identified incongruent treatment goals between physicians and families, but physicians did not identify this barrier. Furthermore, nurses felt disconnected from the decision-making for the child causing them to feel dissatisfied which may lead to moral distress.

Since the NICU is a setting with frequent ethical situations due to the high level of technology and the uncertain outcomes of the patients, this area is at risk for high levels of moral distress. Nurses may perceive barriers to palliative care which causes them moral distress. Palliative care can be stressful for nurses, but is a necessity for infants with life-limiting conditions. The provision of quality palliative care for infants, while protecting nurses from the consequences of moral distress, is imperative for the modern NICU. By discovering the nurses' perceived barriers to palliative care, and what interventions decrease moral distress, palliative care can be provided without high cost to nurses and infants. By providing palliative care, infants receive quality comfort care and families receive support through a difficult time (Peng et al., 2013).

Clinical agency data. The clinical agency for the EBP project was located in Northern Indiana. The NICU at the clinical agency is a regional center for neonatal care. This unit is a level IIIB NICU which is defined by the Committee on Fetus and Newborn of the AAP (2004) as an NICU which has continuous personnel and equipment available for life supporting treatment as long as needed and provides treatment to newborns with gestations of term to less than 28 weeks and newborns with birth weights less than 1000 grams and greater. This level NICU is able to provide some surgical procedures such a patent ductus arteriosus ligation and inguinal hernia repair. Advanced respiratory support is also offered including high frequency ventilation and nitric oxide inhalation therapy. Since this type of care is offered to a high risk population, an increased incidence of neonatal death is expected.

In 2012 the NICU had a total of 445 admissions. From this population, 18 infants died while in the NICU. A total of 14 infants were born with a gestation of 24 weeks or less, and five of these infants died while hospitalized. The causes of death listed included complex cardiac disease, respiratory failure, genetic disease, and sepsis. The families of the infants who died lived within four surrounding counties of the hospital.

The clinical agency is a regional center for mother and child care. The hospital has a children's hospital which accepts referrals for high risk obstetrics, newborns, pediatrics, and pediatric intensive care. The children's hospital is expanding to include more high risk obstetricians, neonatologists, pediatric hospitalists, pediatric specialists, and pediatric intensivists. This expansion will bring more opportunity for life saving treatments and interventions, but this expansion will also increase admissions of infants with life-limiting conditions.

Previous to the implementation of this EBP project, the NICU had a palliative and bereavement care guideline and protocol. This protocol outlined three phases which included (a) before death, (b) during death, and (c) after death. The after death phase was further divided into four distinct periods. These periods were (a) within 24-hours after death, (b) two weeks after death, (c) three months after death, and (d) one year after death. This protocol addressed providing comfort care to the family and the infant. It did not address when this care should begin, and who was responsible for the care. Typically palliative care was discussed between the physician and the family. If a care conference was arranged, the social worker, nurse practitioner, and primary nurses also attended. No formal palliative care team was available. Nurses did not have access to the family's or physician's written care directives.

Purpose of Evidence-Based Project

Compelling clinical question. The compelling clinical question for this evidence-based project was to determine if establishing a palliative care protocol which includes nursing education regarding palliative care and the establishment of a palliative care team would decrease nurses' perceived barriers to palliative care and nurses' moral distress experiences in the NICU at the clinical agency. The PICOT question for this evidence-based project was "In neonatal nurses working in the neonatal intensive care unit, how does establishing a palliative care protocol including nursing education regarding palliative care and a patient care team as compared to the present palliative care protocol affect nurses' perceived barriers to palliative care and moral distress within three months?"

Significance of Evidence-Based Project

Knowledge obtained from this evidence-based project is applicable not only to the NICU at the clinical agency, but also other NICUs which provide palliative care to newborns. This project determined if nursing education and a team approach to palliative care affected nurses' perceived barriers to palliative and moral distress. If nurses believed barriers to palliative care were not present, then the infants were able to receive the quality care they needed for end-of-life care. The information obtained in this project could help the NICU at the clinical agency to refine the protocol based on available evidence on palliative care and the perceived barriers of the nurses. Not only will the nurses benefit from the care team and the established protocol, the infants and families will benefit from receiving quality palliative care supported by evidence.

CHAPTER 2

THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

This EBP project examining the influence of establishing a palliative care protocol in a NICU on nurses' perceived barriers to neonatal palliative care and nurses' moral distress utilized Corley's moral distress theory and the Stetler model as frameworks for the project. Corley's theory was chosen due to the tenets of prevention for nurses developing moral distress such as nurses' autonomy, education, and collaboration with peers. The Stetler model was used to guide the project's design, implementation, and evaluation. The systematic literature search used to find and collect evidence required for the project will be explained. This collected evidence will be presented, critiqued then synthesized into a protocol for quality palliative care which is designed to minimize nurses' perceived barriers to palliative care for neonates and moral distress. An explanation of the best practice recommendations addressing the compelling clinical question regarding how a palliative care protocol for neonates influenced nurses' perceived barriers to palliative care and moral distress will be provided.

Theoretical Framework

Corley's moral distress theory is based on the original work by Jameton who first wrote about moral distress in nursing (Corley, 2002). Jameton (1993) believed nurses experience physical and psychological symptoms when they cannot carry out what they believe to be a moral action because barriers prevent them from completing this process. The barriers to performing these moral actions include lack of time, decreased supervisory or organizational support, lack of support from physicians, unrealistic family preferences, and legal boundaries. Jameton defined two different distresses. The first distress is initial distress which arises when nurses experience frustration, anger, and anxiety when faced with a situation which conflicts with their values. The second distress is reactive distress which occurs when nurses experience initial distress, but do not react to the situation. This type of distress can cause long term problems (Corley, 2002).

Corley believes that nursing is inherently a moral endeavor in which nurses cannot avoid moral situations. Nurses are ethically obligated to promote beneficence, protect clients from harm, and provide a psychologically stable environment for clients (American Nurses Association [ANA], 2001; Corley, 2002). When a nurse is unable to provide these inherent ethical tenets of nursing, they experience moral distress. Wilkinson (1989) was one of the first researchers of the effects of moral distress on nurses. The author's descriptive account of nurses' experiences illustrated how some nurses develop coping strategies to deal with moral distress. At times these coping strategies are not successful. If nurses continue to experience moral distress without effective coping strategies, their professional relationships suffer, and they may lose their self-esteem. Nurses express feelings of powerlessness and being overwhelmed which they believe affects the quality of patient care they provide. A study by Hamric and Blackhall (2007) showed nurses who experience high levels of moral distress are more likely to leave, or consider leaving the nursing position than nurses who experience lower levels of moral distress. These nurses with increased moral distress also experienced less satisfaction with the quality of patient care they provided. They perceived less collaboration with physicians which the authors speculated caused these nurses to experience more frustration with implementing patient care since they did not participate in the planning.

Corley (2002) cites several sources of moral distress in her theory which are supported by research. Janvier et al. (2006) demonstrated one of these sources; providing futile care in accordance with families' desires, caused nurses to experience moral distress. The authors examined ethical confrontations in the NICU among nurses and residents. The nurses experienced moral distress when families wanted futile care to continue, but the NICU staff did not feel the care was valuable or beneficial to the infant. This emotional cause of moral distress was also demonstrated by Meltzer and Huckabay (2004). Critical care nurses in this study experienced moral distress when nurses provided care they perceived as futile. Some nurses perceive relationships with physicians as the cause of moral distress. Elpern, Covert, and Kleinpell (2005) demonstrated nurses who experience high levels of moral distress believe their patients are receiving aggressive treatments from physicians which are not beneficial to the patients. Nurses felt they were unable to express their concerns to physicians due to a lack of collaboration in the treatment plan or fear of retribution as demonstrated by Gutierrez (2005). This study showed some nurses perceived physicians as disregarding patients' wishes or simply not following up on the patients' care. These nurses did not feel they were supported by nursing management or the organization. Inadequate staffing, cost constraints, and lack of patient care policies and protocols were identified as organizational factors that place nurses at risk for moral distress (Corley, 2002).

Corley (2002) examined the effects of moral distress on key stakeholders. One of the stakeholders examined was the health care organization. Many hospitals continue to promote a culture of nurse-patient relationships where nurses do not become psychologically attached to patients. These organizations promote rote task by nurses' performance which decreases their independent decision-making. Nurses are viewed as skill providers for patients by carrying out the physicians' orders, not members of the patients' care decision-making team. Corley maintained that in organizations which do not provide policies to deal with ethically complex patient care and do not include nurses in decision-making, nurses will develop moral distress. Organizations which do not deal with nurse-physician conflicts are at risk of having nurses who develop moral distress also. This distress may cause nurses to leave the organizations. Nursing turnover creates increased costs to organizations due to training replacement nurses. Replacement nurses may not be as experienced as the previous nurses which may affect the quality of patient care. These organizations may have trouble recruiting qualified nurses if the culture supporting the moral distress remains intact.

Conversely positive outcomes may result from nurses undergoing moral distress (Corley, 2002). The phenomenon may cause nurses to believe they are providing better patient care. They feel more connected with the patients, hence becoming an advocate for patients. Rushton (1992) showed moral distress enhances professional development and coping skills in nurses which are beneficial when providing more compassionate care during ethical situations. Corley (2002) hypothesized these benefits occur only in less stressful patient situations. Highly stressful ethical patient situations may cause a more detrimental moral distress which may not have a beneficial outcome. This effect is demonstrated in a study by McClendon and Buckner (2007). Nurses in this study who experienced high levels of moral distress lost focus during patient care and felt ineffective. They were less satisfied with the care they provided, and believed the cause of the poorer quality of care was due to stressful ethical situations.

The theory states nurses develop psychological and physical symptoms due to the development of moral distress. According to Corley (2002) these symptoms include anger, guilt, depression, nightmares, anxiety, pain, and dread. The phenomenon of moral distress taxes nurses' coping skills. If repeat cases of moral distress occur, the nurse may not be able to function at a level of care appropriate for the patient load. The nurse may begin to create a distance from the situation or avoid the work altogether. Corley developed a model which demonstrates ways to prevent moral distress from escalating, affecting the nurse's physical and emotional health, patient outcomes, and organizational culture.

In Corley's model, moral sensitivity is defined as the ability of a person to recognize moral conflict, understand the patient's viewpoint in the moral situation, and understand the consequences of the conflict. Nurses who witness role modeling of moral commitment to patients will have increased moral sensitivity. Moral commitment includes engaging with patients in moral situations, remaining loyal to the nurse's personal values, and having a willingness to take risks as a patient advocate. Education regarding ethics also increases moral sensitivity. Nurses who have higher moral commitment and moral sensitivity may experience moral outrage and moral courage, but rarely experience moral distress. During moral outrage, a nurse may experience anger and shock, but is able to act on this anger in a positive way. A nurse who exhibits moral courage is willing to take a stand for the patient and challenge the organization. Nurses who are able to function autonomously for their patients, experience less moral distress.

According to Corley (2002) for nurses to have lower levels of moral distress, they must have a high work satisfaction with regard to ethical situations. These nurses must have good relationships with peers such as physicians, managers, administrators, and patients. They must also have strong collaborative relationships with physicians. If nurses have more influence in the working environment, they also experience less moral distress. Organizations that do not provide clear policies to guide practice in ethically complex cases place nurses at risk of experiencing more moral distress. If nurses' autonomy is supported, these nurses experience less moral distress. Corley states nursing education and autonomy are vital to lessen the effects of moral distress. Figure 2.1 demonstrates the effects of collaboration with peers, autonomy, and education on moral distress.

Application of Corley's moral distress theory to the EBP project. Corley (2002) identified three methods to lessen nurses' moral distress in ethical situations. These methods include providing nursing education regarding ethical situations, increasing collaboration with peers, and promoting nursing autonomy in ethical dilemmas. She also stated organizations which do not have established protocols for ethically challenging patient care situations cause nurses to experience more moral distress. This EBP project established a protocol for palliative care in the NICU creating an environment which addressed all these issues. The protocol guided nurses caring for these infants in difficult situations.

Nurses received education regarding palliative care of newborns to increase their comfort with the protocol. A palliative care team was established as part of the protocol which included nurses to increase collaboration among healthcare providers thus increasing nurses'

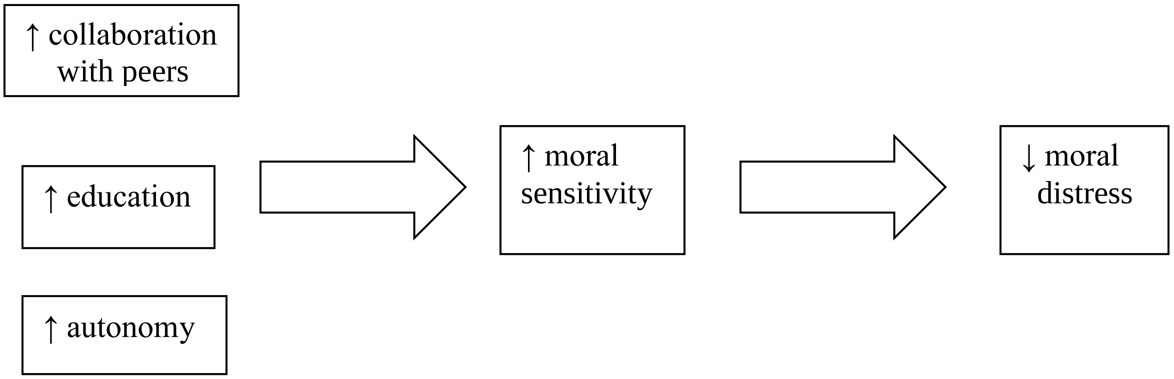

Figure 2.1. Corley Moral Distress Theory. Adapted from “Nurse Moral Distress: A Proposed Theory and Research Agenda,” by M. C. Corley, 2002, *Nursing Ethics, 9,* pp.636-650.

autonomy in decision-making regarding the newborns' palliative care. By providing methods to address these issues, nurses' moral sensitivity would be increased thereby decreasing their moral distress.

Also by increasing nursing's involvement with palliative care decisions, they may perceive fewer barriers to palliative care. Corley (2002) stated nurses may perceive barriers to their moral values preventing provision of the care they believe the patient should receive which increases their moral distress. Wright, Prasun, and Hilgenberg (2011) identified lack of education regarding palliative care, decreased support from other healthcare team members, and lack of palliative care policies or guidelines as nurses' perceived barriers to palliative care. These barriers to palliative care were assessed before and after implementing the protocol to determine if education and use of the palliative care protocol would decrease nurses' perceived barriers to moral distress.

Strengths and limitations of utilizing Corley's moral distress theory. One limitation of Corley's moral distress theory is the assumption nurses act upon their moral values and the inability to act on these values creates distress. Nurses may not have issues with performing against their moral values if they believe the patient or family's desires are followed. Pask (2003) illustrates this concept by defining compassion in nursing. Compassion is recognizing the feelings a nurse experiences may not be the feelings the patient experiences. Despite this difference, the nurse shows compassion by understanding and is not distressed due to the difference. Compassion in this form is expressed as empathy for the patient.

Zuzelo (2007) used the moral distress theory in a study among nurses in a large healthcare organization. One of the limitations of the theory identified was the influence of organizational constraint on moral distress. The scale used to measure moral distress may not have identified all of the factors influencing moral distress since the major focus was organizational barriers. Issues with nurses' coping strategies were not addressed. Corley, Minick, Elswick, and Jacobs (2005) further demonstrate this limitation by examining moral distress and the nurses' work environment. According to the theory development of moral distress is only affected by external elements affecting the nurse rather than internal elements. Since a variance is noted in the level of moral distress in nurses who experience the same ethical situations, internal elements may be influential in the expression of moral distress which is not included in the theory.

Another limitation of the theory is the lack of application to settings other than critical care facilities. Critical care environments utilize increased technological advances with frequent ethical situations. The majority of evidence examines moral distress in these environments with minimal evidence directed at other environments. This limitation is illustrated by the study performed by Rice, Rady, Hamrick, Verheijde, and Perdergast (2006) who examined moral distress in the medical-surgical area of an acute care hospital. This study showed nurses working in this area also experience moral distress at variable levels dependent on the work situation. Nurses perceiving organizational constraints to quality care or providing futile care were more likely to develop moral distress. Another area with limited examination is academia (Ganske, 2010). Nurses in academia may experience moral distress from dishonesty of students, grade inflation, and incivility. The moral distress theory may not be applicable in all healthcare settings since it is based on the critical care area.

A major strength of the theory is the evidence supporting the phenomenon of moral distress and the detrimental effects it has on nurses, patients, and the healthcare organizations. The theory has been shown to support key interventions which may decrease moral distress. Since moral distress may have different effects on people, it may be difficult to express or measure. The theory includes definitions for the different expressions of moral distress which facilitates measuring and comparing results of the phenomenon. This measurement is illustrated by the development of scales for moral distress including the Moral Distress Scale (Corley, Elswick, Gorman, & Clor, 2001) and Moral Distress Thermometer (Wocial & Weaver, 2012). The use of these tools allows outcomes to be compared among studies.

Evidence Based Practice Model

The Stetler model of EBP was used to guide this project. This model is based on critical thinking and using findings by the individual practitioner (Ciliska et al., 2011). Stetler describes two types of evidence, external and internal. External evidence is obtained systematically through research or guidelines (Stetler & Caramanica, 2007). Internal evidence is obtained from the local setting of healthcare or consensus opinions. Internal evidence may include patient preferences and experiences, data from quality initiatives, implementation projects, or project evaluations. This type of evidence should be obtained systematically which includes obtaining the data in a replicable, observable, credible, verifiable, or supportable manner. Internal evidence is used to support external evidence (Ciliska et al., 2011). Stetler has developed five phases for evidence-based utilization.

The first phase is the preparation phase (Ciliska et al., 2011). During this phase the problem is recognized in a healthcare setting. The problem is prioritized by how important the issue is to patient care. Clarity of the problem includes evaluating environmental factors which can influence implementation, and personal factors which can diminish objectivity regarding the problem and the solution (Stetler, 2001). If more than one practitioner is involved, the work is organized among the team members. Searching for relevant evidence is initiated during this phase, especially external evidence which is typically research. Internal evidence is also collected from the clinical setting where the problem exists (Ciliska et al., 2011). Freeman, Lara, Courts, Wanzer, and Garmon (2009) used the Stetler model's first phase to identify the cause of hazards of inadequate disinfection of noncritical equipment in the operating department. They wanted to determine if the decontamination policy was ineffective or application of the policy was ineffective. By using the first phase, they obtained internal and external evidence to support the policy change if needed.

Validation is the second phase of the Stetler model. During this phase the obtained evidence is critiqued regarding relevance to the established problem (Stetler, 2001). The critique is not just to determine the quality of the evidence, but the ability to utilize the evidence for the particular problem. The obtained information is then summarized depending upon the quality of the evidence, and the applicability of the evidence to the problem. An evidence table format is useful especially for a team of practitioners to review. The strength of the evidence is listed including the ability to use this particular evidence for the clinical problem.

Comparative evaluation and decision making is the third phase (Stetler, 2001). During this phase a determination of the collected evidence to utilize for the problem is based on established criteria. These criteria are fit of setting, feasibility, substantiating evidence, and current practice. Multiple sources of internal and external evidence are reviewed. The evidence is divided into groups of evidence to use, consider using, or not to use, based on criteria and the users. The judgment of the evidence is based on the strength and applicability of the evidence. The evidence is used to make a recommended, detailed plan, guideline, policy, or procedure during the translation and application phase.

This translation and application phase consists of refining evidence to be used or not used. Application of the evidence includes confirming the type, level, and method of application (Ciliska, 2011). Translation may be required for evidence which is not clearly understood by potential users. A guideline, procedure, policy, or plan or action may be required to clarify the application (Stetler, 2001). This clarification may be supplemented with a consensus, theoretical information, or expert judgment. Levels of evidence should be presented in the plan so users understand the source of the evidence. A plan of dissemination should be developed which includes any organizational changes which may be required. The plan is then put into action based on the established operational details (Ciliska, 2011).

The last phase is the evaluation phase when the plan is evaluated for its effectiveness with assisting the problem (Stetler, 2001). The evaluation includes feasibility, monitoring for desired and undesired effects, and revisions to the plan. A pilot test of the application can be done to determine if the plan is feasible on a smaller scale. Revisions and evaluating the process of change may be done before being implemented in larger settings, or the plan may be rejected all together. Formal use of the plan may then be integrated into routine practice. If organizational change is required, more formal evaluation may be needed. Internal evidence will continue to be collected and evaluated for further refinement of the plan. This refinement is illustrated by Mathers (2011). Original evidence was collected regarding use of heparin in central venous access devices, but during the development of the project, the facility changed its practice to remove the use of heparin. The evidence collected was re-examined for different outcomes such as education of nurses regarding the method of flushing these devices without heparin since the facility policy had changed.

Application of Stetler's model in the EBP project. The first phase of the model is preparation which in this project included identifying the problem and searching for internal and external evidence. The incidence of moral distress in the neonatal intensive care unit was discovered by nurses expressing concern for the inconsistency of palliative care in the NICU. These nurses were dissatisfied with the care some infants received at the end-of-life, and the families' care decisions based on misleading information given by physicians. Nurses were not involved in the decision-making of infants who required palliative care, but had to carry out this care without input. The lack of an established palliative care protocol based on evidence led to inconsistency in patient care which also added to the distress of nurses.

Internal evidence was obtained from nurses working with dying babies and their need to provide palliative care without experiencing moral distress. Nurses expressed concern over particular cases of infants dying without an established protocol which they believed would provide quality comfort care. They believed the families expected unrealistic outcomes based on the information they received from health care providers. Decision-making meetings with families were between physicians and family members, and no documentation typically existed for other providers to know the exchange of information which took place. The current palliative care protocol was reviewed for content. No supporting evidence for the interventions was given for the protocol. The unit director and the medical director were interviewed for expert opinions regarding the palliative care protocol.

External evidence was collected by searching the literature for research on neonatal palliative care, nurses' perceived barriers to palliative care, and moral distress. Also written expert opinions, established evidence-based guidelines, and guidelines from professional websites were reviewed for applicability. The validation phase included critiquing the evidence and summarizing the usefulness to the problem. Exclusion criteria were developed so only evidence which was pertinent to the problem of neonatal palliative care was used for development of a plan. The evidence was put into a table which summarized findings, type of evidence, and level of evidence. The evidence was critiqued to determine applicability to the problem and usefulness for the nurses.

The comparative evaluation and decision-making phase included determining what evidence would be used to establish a protocol for the NICU which minimized perceived barriers and moral distress for nurses. A protocol was developed which was utilized in the application phase. For evaluation of the protocol, nurses' perceived barriers to palliative care and moral distress were measured prior to the application of the protocol using the Moral Distress Scale (MDS) and the Neonatal Palliative Care Attitude Scale (NiPCAS). Education of the protocol was accomplished so all stakeholders using the protocol would have the required knowledge to implement it properly. After implementation of the protocol began, evaluation included reassessing nurses' perceived barriers to palliative care and moral distress using the MDS and the NiPCAS. Team care conferences were part of the protocol for communication regarding any changes which needed to occur during implementation and utilization.

Strengths and limitations of utilizing Stetler's model. A limitation of the Stetler model during this project was the lack of guidance for adoption of the protocol in the application phase. Users of the protocols may accept them differently. Some users might accept a protocol without issues, while others may have negative attitudes regarding a protocol. Adams and McCarthy (2005) discussed this limitation regarding school nursing. They stated the rate of adoption is influenced by the protocol itself and how the protocol is presented. School nurses have more autonomy and empowerment than nurses in other environments, so they may accept evidence more readily. These nurses do have barriers to adoption of evidence such as lack of time or decreased interest in evidence. The Stetler model does not specifically address how to deal with different users' adoption rates.

The major strength of the Stetler model is the process of critical-thinking steps designed to decrease barriers to objective and effective utilization of evidence designed to fit a particular clinical setting (Freeman, Lara, Courts, Wanzer, & Bibb, 2009). Freeman et al. used the Stetler model to produce a protocol based on evidence to clean noncritical equipment in an acute care setting. They developed the protocol using external and internal evidence which was useful for their particular clinical setting. Since each clinical setting is different regarding needs and resources, both internal and external evidence is vital for success of the protocol. Including stakeholder's opinions and experiences in this project shaped the protocol to an optimal fit for the specific NICU.

Fluidity among the model's phases and how the feedback of one phase effects other phases are strengths of the model (Mathers, 2011). Mathers required changing the goal of the policy since the problem had changed. The organization changed its policy regarding flushing central venous access devices which was the problem identified by the author. Since this problem was no longer an issue, the evidence collected was easily used for a different issue of nurses' education regarding flushing these devices. Feedback from the application phase allowed the researcher to alter the validation phase to meet the needs of the organization.

Literature Search

External evidence was obtained regarding the issue of how establishing a neonatal palliative care protocol in the NICU would affect nurses' perceived barriers to palliative care and moral distress. A literature search was done to obtain this evidence. Key words and multiple databases were utilized during the search for evidence.

Sources of relevant evidence. The sources of evidence relevant to palliative care in the neonatal intensive care unit, nurses' moral distress, and nurses' perceived barriers to palliative care were searched in multiple databases using a variety of search terms. Only evidence located in scholarly, peer-reviewed sources published over the past 10 years was reviewed for the project. The key search terms used in CINAHL, PubMed, and MEDLINE were *palliative care, end-of-life*, *moral distress, barrier, nurse*, *newborn nurse*, and *neonatal nurse.*

Joanna Briggs Institute was searched first for systematic reviews. Two reviews were obtained regarding palliative care and moral distress. These reviews were examined, but not kept since the population included children and adults, and the data were combined. The National Guideline Clearinghouse was searched for palliative care and moral distress. Twenty-seven guidelines were found. Twenty-five of these guidelines were directed at specially adults. Two of the guidelines which included children were reviewed for applicability to the EBP. Both guidelines were not kept for the project since they included adults in the population as well as children, and the data were not segregated. The Cochrane Library was searched for systematic reviews regarding palliative care and moral distress. Eleven reviews were obtained, but all were rejected since data obtained from the children population were not separated from the adult data.

The next database searched was CINAHL. Since most evidence did not include both perceived barriers and moral distress, these search terms were not combined. When the search terms of *palliative care* or *end-of-life* were combined with *moral distress* and *newborn nurse* or *neonatal nurse,* no articles were found. The term *newborn nurse* or *neonatal nurse* was changed to *nurse,* and eight articles were obtained. The term *moral distress* was changed to *barrier,* and two articles were obtained. These articles were reviewed and four of the articles were found to be relevant to the issue. One article contained data from physicians and nurses, so this article was not used since only combined data were reported.

MEDLINE via EBSCO was searched next using the same combination of search terms. Moral distress articles were searched first and 20 articles were obtained. The search for barriers yielded 2 articles. Duplicate articles from CINAHL totaled 6 articles which left 16 articles for review. Eight of these articles were reviewed after applying the exclusion criteria. These articles were not used due to lack of applicability to project. Articles containing guidelines or expert opinions were evaluated on the basis of expertise of authors and level of evidence supporting these opinions and guidelines.

The following database searched was PubMed using the same key search terms used for CINAHL and MEDLINE. The first search was for moral distress articles which yielded 19 articles. Six of these articles were duplicates from previous searches, but nine articles met all inclusion criteria and were reviewed. Seven articles were kept for analysis. PubMed was then searched for barriers to palliative care and yielded 21 articles. Of these articles eight were duplicates, but seven were reviewed since they met inclusion criteria. Two of these articles were kept for future analysis. MEDLINE via PubMed yielded the same results as PubMed.

ProQuest Nursing & Allied Health Source was the next database searched using the same key terms as used in CINAHL and PubMed. Moral distress was searched first which yielded 166 articles. The term *nurse* was modified to *neonatal nurse,* and the number of articles was 43. Of these articles 20 were duplicates and 8 met criteria for inclusion, but none of the articles were relevant to the EBP project. Next barriers were searched using the same limiters and the new term *neonatal nurse.* This search yielded 39 articles. Of these articles, 12 were duplicated and 4 met inclusion criteria, but none were relevant to the EBP project.

Hand searches were done in the following journals since the many articles found in the databases were published in these journals: Maternal Child Nursing, Advances in Neonatal Care, and Neonatal Network. This search did not yield any further evidence. Reference lists of the reviewed articles were scanned for further evidence not found in the database searches. Five articles were reviewed for potential analysis, but they did not meet inclusion criteria. Profession websites of Oncology Nursing Society, Royal College of Nursing, AWHONN, National Association of Neonatal Nurse Practitioners, American Academy of Pediatrics, and the Council of International Neonatal Nurses were scanned for guidelines specific to newborn palliative care. No new guidelines were found. Data of the evidence search are presented in Table 2.1. Final inclusion and exclusion criteria are exhibited in Table 2.2.

Levels of evidence. Melynk and Fineout-Overholt's (2011) levels of evidence were used to rate this project's evidence. The highest level is evidence from systematic reviews and meta-analysis of relevant randomized controlled trials (RCTs). Included in this level are evidence-based clinical practice guidelines if they have been developed by a rigorous process. The following levels of evidence listed from highest level of evidence to lowest level of evidence are well-designed RCTs, well-designed controlled trials without randomization, well-designed quasi-experimental studies, systematic reviews of descriptive or qualitative studies, descriptive or qualitative studies, and expert opinions. These levels are listed in Table 2.3 along with the number of articles at each level used for the project.

Appraisal of evidence. Due to the nature of the phenomenon of perceived barriers to palliative care and moral distress in nurses caring for dying infants, randomized controlled trials are more difficult to perform and thus none were available. The available evidence was reviewed using three different systems. The clinical practice guideline was evaluated with the AGREE II instrument. Case-control and cross-sectional studies were evaluated with the CASP system for analysis. Qualitative studies and expert opinion pieces were evaluated with Melnyk

Table 2.1

Evidence Search Table

Database Searched	Articles Found	Duplicate Articles	Articles Reviewed	Articles Analyzed for Project
JBI	5	0	2	0
National Guideline Clearinghouse	27	0	2	0
Cochrane	11	0	1	0
CINAHL	8	0	8	4
MEDLINE (EBSCO)	22	6	8	0
PubMed	40	14	15	9
ProQuest	82	32	12	0
Hand Search	0	0	0	0
Reference Lists	5	0	5	0
Professional Websites	0	0	0	0

Note. Databases are listed in order of search. ProQuest is ProQuest Nursing & Allied Health Source.

Table 2.2

Criteria Table for Evidence

Inclusion Criteria	Exclusion Criteria
Subjects are nurses; nurses’ data are available	Subjects are physicians or other healthcare providers other than nurses
Printed in English	Printed in language other than English
Published in the last 10 years	Published over 10 years ago
Setting in the NICU	Setting other than NICU
Addresses moral distress or perceived barriers to palliative care	Does not address moral distress or perceived barriers to palliative care

Table 2.3

Levels of Evidence

Level	Used in Project
I	1
II	0
III	0
IV	2
V	0
VI	6
VII	4

Note. Adapted from “Rating System for the Hierarchy of Evidence for Intervention/Treatment Questions” by B. M. Melynk and E. Fineout-Overholt, 2011, *Evidence-Based Practice,* p. 12. Copyright 2011 by Lippincott Williams & Wilkins.

Table 2.4

Appraisal of Evidence

Citation	Design/Rating	Sample/Setting	Major Variables/ Measurement	Findings/ Recommendations	Appraisal
Cavaliere, Daly, Dowling, & Montgomery, 2010, Moral Distress in Neonatal Intensive Care Unit RNs	Descriptive Correlational/ Level VI	94 RNs/NICU	Nurses' moral distress in the NICU/ Moral Distress Scale Neonatal-Pediatric Version	Situations in the NICU which caused the most moral distress among RNs were futile and aggressive care without perceived benefits, causing pain and suffering to patients, unnecessary treatments, inadequate staffing, and working with perceived incompetent colleagues.	Response rate was 48%, and subjects had similar demographics. No moral turmoil may have been present at time of survey. Overall strong study since researchers used quantitative measure to determine moral distress in this particular setting.
De Lisle-Porter & Podruchny, 2009, The Dying Neonate: Family-Centered End-of-Life Care	EBP Guideline/ Level VII	NICU	Guideline of palliative care for a neonatal intensive care unit based on literature review of authors.	Recommendations include creating memories for families during the three stages of dying: pre-death, active dying, and	Methods of searching the evidence to include in guideline are not provided. Guideline is not constructed after rigorous review

				after death. Barriers to end-of-life care are nurse attitudes and beliefs, nursing education, and nursing experience. Involve parents in end-of-life decisions for their infants.	of literature. Protocol based on guideline is listed including newborn criteria for inclusion to palliative care. Experiences of actual use of guideline are not included. Weak guideline due to the lack of rigorous methods of obtaining evidence to support recommendations.
Epstein, 2008, End-of-Life Experiences of Nurses and Physicians in the Newborn Intensive Care Unit	Qualitative/ Level VI	33 health care providers (21 RNs)/ NICU	Nurses' and physicians' experiences with end-of-life care in the NICU (data were segregated)/ Interviews following death of newborn regarding creating best possible experience for parents.	The issues with end-of-life care in the NICU identified were building relationships with families, preparing the families for infants' dying, creating memories for families, moral distress, and obtaining consents for autopsies.	Subjects were interviewed only once by researcher. Data was reviewed by a peer, but the peer's qualifications were not identified. Strong qualitative study where results can be used to construct further research.
Gale & Brooks, 2006, Implementing a Palliative Care Program in a Newborn Intensive	EBP Guideline/ Level VII	NICU	Guideline for palliative care in the NICU based on the authors' literature review and expert opinions.	Recommendations include a palliative care protocol based on 7 phases of care and palliative care education for the	Evidence used in compiling guideline is identified, but limited. Provided detailed protocol with phases of

Care Unit				staff of the NICU. The protocol includes a care team for the infant and the infant's family.	palliative care. Authors provide their experiences with actual use of the protocol. Guideline was strong due to rigorous evaluation of descriptive evidence.
Hamric, Borchers, & Epstein, 2012, Development and Testing of an Instrument to Measure Moral Distress in Healthcare Professionals	Descriptive Survey/ Level VI	206 health care providers (169 RNs)/ Adult and pediatric settings	Health care providers moral distress (setting and population data were segregated)/Moral Distress Scale-adult and pediatric and Olson's Hospital Ethical Climate Scale	Nurses with more nursing experience had more moral distress. Physicians had less moral distress than nurses. Providers working in areas with less ethical situations had less moral distress. Providers contemplating leaving profession had higher moral distress.	Used survey in one clinical facility. Physician group was much smaller than nurses group. Reliability was supported with Cronbach's alpha of 0.88 for all participants. Construct validity was supported in all four hypotheses examined. Content validity was evaluated by an expert panel. Inter-rated agreement was 88%.
Kain, 2011, Exploring the Barriers to Palliative Care Practice in	Qualitative/ Level VI	24 RNs/ NICU	Nurses' perceived barriers to neonatal palliative care/ Focus group interviews with researcher	Barriers identified were inadequate staffing, inconducive environment, technological and	Used group interviews with 6 to 8 subjects which may affect subjects' responses. No demographics were

Neonatal Nursing: A Focus Group Study					parental expectations.	collected which makes comparisons difficult. Useful to determine barriers for further quantified study. Weak descriptive study due to construction of interview techniques.
Kain, 2007, Moral Distress and Providing Care to Dying Babies in Neonatal Nursing	Narrative Review/ Level VII	NICU		Describes causes of moral distress in neonatal nursing based on literature review.	Causes of moral distress were providing palliative care in a curative care setting, nurses going against own ethical beliefs, interpersonal conflicts, and organizational constraints.	Used a systematic search but no rigorous appraisal method. Terms used for literature search were limited. Identified causes of moral distress in neonatal nursing which can be studied further. Weak review due to lack of rigorous appraisal.
National Association of Neonatal Nurses (NANN), 2010, Palliative Care for Newborns and Infants	EBP Guideline/ Level I	NICU		Gives recommendations for palliative care for newborns based on integrative review.	Major recommendations of guideline include written materials regarding palliative care should be given to the families, parents should be part of decision-making,	Does not list the criteria used for inclusion or exclusion of available evidence. Gives specific guidelines for different aspects of neonatal palliative care based on

				support services should be provided to families, focus of palliative care should be infants' comfort and pain management, create memories for families, and bereavement support should be given to families after infants' deaths. Also recommends continuing education regarding palliative care for nurses.	evidence including RCTs. Weak guideline based on integrative review due to lack of inclusion and exclusion criteria
Okah, Wolff, Boos, Haney, & Oshodi, 2012, Perceptions of a Strategy to Prevent and Relieve Care Provider Distress in the Neonatal Intensive Care Unit	Descriptive/ Level VI	116 health care providers (47 RNs)/ NICU	Moral distress, communication barriers, and consensus building 3 years after implementing multidisciplinary health care team meetings (data were segregated)/ Anonymous survey developed by researchers.	Staff believed the meetings occurred too late to improve communication among staff members.	Response rate was low at 31%. Sample separated by type of provider which showed responses per group. Survey used was not tested for validity and reliability. Weak study due to survey was not tested and poor response rate.
Rogers, Babgi, & Gomez,	Quasi-experimental/	82 RNs/ NICU	Effects of educational program on neonatal	Higher levels of comfort and	Six modules were given over 6

2008, Educational Interventions in End-of-Life Care: Part I	Level IV		nurses' comfort with end-of-life care/ Comfort in Caring for Dying Infant (CLCDI)	knowledge in ethical, legal, and symptom management after the intervention. Communication was lower after the intervention.	different occasions. Information from the modules was not identified in the study report. Unknown if intervention affected the actual care of the infants. Measurement tool had been previously tested. Variable number of subjects attended each session (n = 7 to 27). Weak interventional study due to variable number of subjects and unclear intervention regarding education of nurses.
Romesburg, 2007, Building a Case for Neonatal Palliative Care	Expert Opinion/ Level VII	NICU	Describes components of neonatal palliative care. Identifies challenges of implementing palliative care.	Components of palliative care include comfort care, end-of-life decision making, bereavement support. Challenges of implementing palliative care include financial support, logistics,	Does not provide how evidence was obtained, analyzed, or complied. List areas of need for further research. Opinion is strong due to the expertise of the author.

				language and cultural differences, and lack of training of providers regarding palliative care.	
Wright, Prasun, & Hilgenberg, 2011, Why Is End-of-Life Care Delivery Sporadic?	Descriptive/ Level VI	50 RNs/ NICU	Perceived barriers and facilitators for palliative care/ Neonatal Palliative Care Attitude Scale (NiPCAS).	Barriers identified by using the NiPCAS were RNs' inability to express opinions, less than ideal environment, lack of education, technological imperatives, and parental demands.	Greater than half of the sample had not been exposed to neonatal deaths. Majority (86%) had some experience with palliative care. Barriers were clearly identified using measuring tool. Strong descriptive study of barriers and facilitators of palliative care.
Zhang & Lane, 2013, Promoting Neonatal Staff Nurses' Comfort and Involvement in End of Life and Bereavement Care	Case Control/Quasi-Experimental/ Level IV	63 RNs/ NICU	Nurses' comfort with palliative care before and after a seminar on palliative care; control group did not attend seminar/ Bereavement/End of Life Attitudes about Care of Neonatal Nurses Scale	Nurses who attended seminar were more comfortable with palliative care with the newborns.	Case group and control group were not equal in size or demographics. Only 14 RNs attended the seminar. Limited demographics were given. Purpose of the seminar was to decrease staff's moral distress, but a moral distress tool was not utilized. Weak study due to

limited comparability between groups.

and Fineout-Overholt's (2011) critical appraisal checklists. Appraisal of the evidence is presented in Table 2.4.

The evidence obtained from qualitative studies was helpful in determining the areas to quantify for further research to study barriers to palliative care and moral distress. Kain (2011) used group interviews which may be prone to group think which could alter the findings. During group think, the group becomes more important than the individual. An individual's thought may transform due to the influence of the group (Ellers, 2012). Kain (2011) stated the findings would be used in future research on perceived barriers to palliative care for newborns. This study did not take place after an actual death of an infant as compared to Epstein's study (2008) which may affect staff's perceptions of barriers or development of moral distress. Limited demographics were collected which makes comparison with project subjects difficult (Kain, 2011). Actual statements from the subjects were included in the report which helps with understanding the subjects' perceptions. The number of subjects in both the Kain study and the Epstein (2008) study were adequate. Epstein included other experiences with end-of-life situations, but only moral distress data was used in the project.

An expert opinion by Romesberg (2007) was included in the analysis. This expert bases her opinion on evidence and gives clear strategies for implementing palliative care in the neonatal intensive care unit. The author did not discuss how the evidence used was analyzed or compiled. Romesberg included possible strategies for overcoming barriers to palliative care including organizational barriers which was pertinent to the project. The different stages of palliative care were clearly outlined. Kain's (2007a) narrative review addresses moral distress in the neonatal intensive care unit related to palliative care based on evidence. This review described a systematic search used to find evidence, but did not include description of analysis used to determine applicability of evidence to moral distress. Kain identified causes of moral distress present in the neonatal intensive care unit which may be helpful to establish the effects of these causes on other phenomenon using a quantitative method.

A descriptive correlational study by Cavaliere, Day, Dowling, and Montgomery (2010) identified characteristics of nurses associated with moral distress. The response rate was 48%, but the Moral Distress Scale Neonatal-Pediatric version was not tested for reliability at the time of the study. Study findings reflected a wide variation of the frequency and intensity of moral distress, but the study may not have been conducted at a time of ethical turmoil in the neonatal intensive care unit. Another descriptive study by Wright, Prasun, and Hilgenburg (2011) had a better response rate and NiPCAS had been tested for reliability. The researchers examined the barriers to palliative care, but included limited nurses' demographics which made comparisons difficult. Zhang and Lane (2013) used a pretest and posttest design to evaluate the effectiveness of a nursing education intervention. A control group was used, but the control group was much larger than the intervention group, and matching was not performed. Nurses' attitudes were examined, but moral distress was not considered. Rogers, Babgi, and Gomez (2008) examined an educational intervention to determine if nurses' attitudes changed regarding palliative care. A large number of participants and a reliable tool, CLCDI, were used. Nurses' attitudes differed regarding areas of information about palliative care. Nurses were more comfortable with ethical, legal, and symptom management issues, but less comfortable with communication with patient families after the education intervention. Okah, Wolff, Boos, Haney, and Oshodi (2012) studied how a care team would affect moral distress. This study had a poor response rate at 31%, and the researchers' developed survey was not tested for reliability. Researchers identified early use of a care team is beneficial.

Three guidelines were found regarding neonatal palliative care. The first guideline by De Lisle-Porter and Podruchny (2009) was based on evidence, but no description on how the evidence was collected or analyzed was included. This guideline outlined three different phases of palliative care which were pre-death, active dying, and after death. Specific nursing responsibilities during each of these phases were included. This guideline had a poor rating on the AGREE II in the Rigour of Development domain since the criteria for selecting evidence was not documented; strengths and limitations of evidence were not described (AGREE Next Steps Consortium, 2009). In 2010 the National Association of Neonatal Nurses (NANN) also developed a guideline. The method of obtaining the evidence for this guideline was not identified. The guideline provided specific information complete with citation of evidence supporting information, but does not distinguish the different phases of palliative care. Several of the interventions listed in the guideline were supported by RCTs. This guideline had strong ratings in all six domains of the AGREE II. The final guideline (Gale & Brooks, 2006) not only used research as evidence, but included expert opinions. This guideline offered a complete protocol for implementation and divided palliative care into seven phases complete with the care team's responsibilities during each phase. The guideline was actually implemented at a facility and the authors discussed items they learned during the process. The guideline was strong in all domains of the AGREE II except the Rigour of Development domain due to the lack of description of how evidence was obtained and its strength and weaknesses (AGREE Next Steps Consortium, 2009).

Construct EBP

Synthesis of literature to support EBP. The EBP project examined the influence of establishing a palliative care protocol in the NICU on nurses' perceived barriers to neonatal palliative care and moral distress. The first area of investigation was the nurses' perceived barriers to palliative care. Nurses were not able to provide quality palliative care to newborns if they perceived barriers were preventing this process from occurring (Kain, 2011). Barriers to palliative care were inadequate staffing, logistics, technological imperatives, parental expectations, financial support, language and cultural differences between providers and families, lack of palliative care education for providers, nurses' attitudes and believes, nursing experience, and their inability to express opinions regarding patient care (De Lisle-Porter & Podruchny, 2009; Kain, 2011; Romesberg, 2007; Wright et al., 2011). Some of the barriers to palliative care such as inadequate staffing, technological imperatives, parental expectations, and nurses' inability to express opinions may cause nurses to develop moral distress along with nurses' inability to provide quality palliative care (Kain, 2007a). In order to address barriers to palliative care, they first must be measured. The tool selected to measure barriers for the EBP project was the NiPCAS (Kain, 2009). This tool was selected due to its ability to quantify barriers in the NICU specifically, and its established reliability. Barriers along with facilitators for neonatal palliative care can be measured with this tool

Identified facilitators to neonatal palliative care in the evidence were parental involvement in decision-making, supportive medical team, supportive nursing staff, adequate time spent with dying baby, policies and guidelines supporting palliative care, available counseling for staff, palliative care education, debriefing after infant's death, multidisciplinary care teams, constructive communication and collaboration with physicians (De Lisle-Porter & Podruchny, 2009; Kain, 2011; NANN, 2010; Okah et al., 2012; Rogers et al., 2008; Wright et al., 2011; Zhang & Lane, 2013). Facilitators were identified for revising protocols to improve implementation for the stakeholders. These stakeholders would be more likely to use the revised evidence-based protocols as opposed to traditional methods which would improve outcomes.

Barriers to palliative care which should be addressed in a palliative care protocol were the lack of nursing education regarding neonatal palliative care and nurses' inability to express their opinions (Kain, 2011; Gale & Brooks, 2006). The protocol needs to provide a framework for nurses to have a clear understanding of the palliative care process, and provide specific evidence-based interventions based on the condition of the infant. A protocol divided into phases of palliative care had been shown to provide nurses with clear expectations regarding care of the infants (De Lisle-Porter & Podruchny; 2009; Gale & Brooks, 2006; NANN, 2010) Prior to the initiation of a new protocol, an education session for the nurses regarding neonatal palliative care should be implemented (Kain, 2011; Rogers et al., 2008; Zhang & Lane, 2013). The education of the nurses should not only include information about the new protocol, but also pain management, communication with families, spirituality, anxiety, prevention of moral distress, and ethical and legal aspects of neonatal palliative care. Since nurses' undergraduate education and continuing education were known to be lacking in these areas, addressing these areas filled knowledge gaps which can lead to perceived barriers to palliative care (Rogers et al., 2008).

A care team should be formed prior to the initiation of palliative care for an infant which consists of family members, physicians, nurses, social worker, chaplain, parent care coordinator, and lactation consultants. This team provides an interdisciplinary view to address the plan of care for the infant (Gale & Brooks, 2006; NANN, 2010; Okah et al., 2011; Wright et al., 2011). By including parents in decision-making, they are better able to understand the infant's condition and make choices in the best interest for the family. Since parents may have unrealistic expectations due to multiple providers giving conflicting information or the infant's fluctuating condition (Epstein, 2008), a written transcript from the care team will allow the family to be involved and to reflect on the information given (Gale & Brooks, 2006). Providing palliative care early in the infant' hospital stay decreases the costs of care along with providing quality comfort care (Romesberg, 2007). Expensive futile treatments may be prevented, and resources may be more appropriately used to provide quality care. By providing quality comfort care, nurse experience less moral distress (Zhang & Lane, 2013).

By providing nurses the opportunity to express their opinions in the care team meetings regarding infants' palliative care, nurses' moral distress may be reduced (Gale & Brooks, 2006; Kain, 2007a; Rogers et al., 2008; Okah et al., 2011) Moral distress may lead to nurses leaving their current nursing positions (Cavaliere et al., 2010). The measurement of moral distress in this EBP was completed using the Moral Distress Scale-pediatric version (Hamric, 2013). In order for moral distress to be quantified, certain assumptions were made: (a) nurses bring their values to work, (b) nurses can identify ethical problems in the NICU, and (c) nurses can evaluate how much these ethical problems cause moral distress (Kain, 2007a).

Best practice model recommendation. The practice model for this project was based on the evidence supporting development of a neonatal palliative care protocol including nursing education regarding neonatal palliative care and the formation of a care team for infants requiring palliative care. Internal and external evidence were reviewed regarding the protocol to ensure the likelihood of success with the protocol's adoption by the unit. Interviews with the nurses, the nursing unit director, and the medical director provided internal evidence. The present palliative care protocol in the neonatal intensive care unit was updated and more specific information was added. Prior to starting the new protocol a two hour education session for nurses and other participants in the protocol was provided. A care team including nurses, nurse practitioners, physicians, chaplain, social worker, lactation consultant, and hospice representative if needed will be implemented at the onset of palliative care.

Guideline. The palliative care protocol was separated into 6 distinct phases. Each phase corresponded to a stage of palliative care. Infants begin palliative care at different phases and progress at different rates to other phases. A care team is formed when any health care provider believes an infant meets criteria for palliative care. Criteria qualifying infants for initiation of the palliative care guideline are listed in Table 2.5. Attending physicians and primary nurses are encouraged to attend all care team meetings. Written materials or recordings are offered to the family members to reinforce the plan of care for the infant. Nurses receive a communication tool completed by the physician in attendance at the care team meeting which states the plan of care. A guideline for palliative care is listed in Appendix A. The protocol in the unit's format is listed in Appendix B. The tool used to communicate the care team's decisions regarding the plan of care is listed in Appendix C. This tool is not part the infant's medical record and is used only for communication between nurses and the care team.

Staff education included a presentation which was viewed in person or by video. The education session lasted two hours and contained information on the palliative care protocol, pain management, communication with families, spirituality, anxiety, prevention of moral distress, and ethical and legal aspects of neonatal palliative care. Nurses were able to access the Employee Assistance Program any time prior to the initiation, during the initiation, or after implementation of the palliative care protocol if they develop any moral distress.

Practice model recommendation and the clinical question. The establishment of the new palliative care protocol including nursing education regarding palliative care and development of a care team was used to answer the clinical question about the influence of this protocol on nurses' perceived barriers to palliative care and moral distress. Based on Corley's moral distress theory (Corley, 2002), nurses need to be included in decision-making, have autonomy, and collaborate with peers to prevent moral distress. This evidence-based protocol includes these tenets of prevention.

Table 2.5

Qualifying Infants for Palliative Care Guideline

Newborns at the threshold of viability
    (23 to 24 weeks gestation or birth weight of </= 500 grams)

Newborns with congenital anomalies incompatible with prolonged life

Newborns with genetic conditions incompatible with prolonged life

Newborns with renal failure

Newborns with central nervous system abnormalities

Newborns with complex heart anomalies

Newborns with complex structural anomalies

Newborns not responding to intensive care therapies

Note. Adapted from Gale and Brooks, 2006, p. 53.e1

CHAPTER 3

IMPLEMENTATION OF PRACTICE CHANGE

Participants and Setting

The setting of the EBP project was in the NICU at the clinical agency. The clinical agency is a 526 bed acute care hospital located in Northern Indiana. The hospital has a children's hospital located within the acute care hospital which consists of high risk obstetrics, labor and delivery, postpartum, NICU, pediatrics, pediatric intensive care, and pediatric hematology-oncology. The NICU is a 36 bed level III unit. The unit has 77 registered nurses and 4 clinical associates performing patient care. All registered nurses working in the NICU are required to obtain their certification in neonatal intensive care nursing. These nurses are required to be proficient in care of all types of infants in the NICU within two years of employment.

The participants for the EBP project examining the influence of establishing an evidence-based palliative care protocol were registered nurses working in a NICU. Nurses were asked to participate in the project if they have at least six months experience working in an NICU. For nurses to have experience with palliative care, they must have experience with caring for a patient who has died or have assisted with a dying patient. Since some nurses in this agency work in several units based on staffing needs, nurses eligible to participate in the EBP project must have worked the majority of their hours in the NICU. Other staff in the unit such as patient care extenders, physicians, and respiratory therapists was not included. Nurses working in other units which deal with infants' deaths such as pediatric unit, pediatric intensive care unit, and child birth unit were not included in the project. The vast majority of the nurses are female. Most of the nurses have worked in this particular unit for greater than 15 years.

Outcomes

The outcomes measured were the nurses' perceived barriers to neonatal palliative care and nurses' moral distress. Data regarding these two phenomena were collected prior to and after implementation of a neonatal palliative care protocol including palliative care education. The pre-intervention scores and the post-intervention scores were compared to determine if the invention had an influence on nurses' perceived barriers to neonatal palliative care and nurses' moral distress.

Intervention

The intervention for the EBP project had three parts. The first part was the education of nurses regarding palliative care. The education was based on the End of Life Nursing Education Consortium (ELNEC) and NANN's guidelines on palliative care. ELNEC's education is based on palliative care evidence collected and compiled for nurses. This education is provided by a certified trainer in the ELNEC core curriculum (City of Hope & American Association of College of Nursing [COH & AACN], 2007). Education addressing the new palliative care protocol was included, so nurses were familiar with the guideline. Topics also included in the education were pain management, communication with families, spirituality, anxiety, and ethical-legal aspects of palliative care. Education on these topics had been demonstrated to have a positive effect on nurses' comfort with palliative care (Rogers et al., 2008). Since one goal of the palliative care protocol was to potentially decrease nurses' moral distress, this topic was also included. The education session took two hours. The presentation was recorded so nurses who were unable to attend were able to view the presentation at a later date. The recording was placed on a digital video disc (DVD). The NICU has portable video players and charting computers which play the DVDs which provided a convenient setting for nurses to view the education.

The second part of the intervention was the implementation of the new evidence-based protocol on neonatal palliative care in the NICU. This protocol was based on the evidence collected and synthesized for the EBP project. The protocol was divided into six distinct phases complete with infant criteria for the protocol in each phase. Additionally, nurses' responsibilities for providing care to the infants and families were articulated for each phase. The unit director and medical director reviewed, edited, and approved the protocol prior to implementation.

The third part of the intervention involved implementing a palliative care team. This team consisted of nurses, physicians, families, social worker, chaplain, and lactation consultant. The nurses included were the infant's primary and associate nurses along with other nurses who wish to be part of the decision-making team. Physicians included in the team were the infant's attending physician and other physicians who had assisted with caring for the infant if they desired to be a part of the care team. The family included parents and any other members of the family the parents wished to participate. Only parents have legal authority to direct decision-making, but the parents may desire other family members to attend the care team sessions for support or advice. The social worker is always involved with the families while their infants are hospitalized to provide support and resources. The social worker is invaluable if the family requires assistance with visitation of the infant for extended periods of time or financial assistance with hospitalization. The chaplain provides spiritual support to the family including baptism or other religious ceremonies. The chaplain also has resources regarding bereavement care. The lactation consultant is supportive of mothers who are nursing. The consultant may provide creative ways which allow mothers to nurse infants who have congenital anomalies which makes nursing difficult. The consultant also may counsel the mother in breast milk donation or suppression after an infant's death.

Planning

The plan for implementation of the clinical change included assessing for barriers to implementation in the clinical setting and working with key stakeholders to address these barriers, implement the intervention, and evaluate the intervention for possible future changes (Hockenberry, Brown, & Melynk, 2011). The staff in the clinical setting had limited experience with the process of EBP which was a potential barrier. Providing the evidence supporting the palliative care protocol to key stakeholders was essential in the staff's adoption of the protocol. The EBP project director met with key stakeholders to review the palliative care protocol to determine if the stakeholders desired any changes. Inclusion of the stakeholders in decision-making facilitated the implementation of the protocol by providing stakeholders' impetus for change.

The first key stakeholder was the unit director. The unit director represented the nursing staff and the support staff. Since the protocol was nursing directed, the unit director had input regarding the resources available to the nurses such as staffing ratios and availability of unit space for privacy of family members. The protocol also addressed providing supplies to the families such as pictures and small mementos to build memories. The unit director was able to provide insight into the funds available for these types of supplies and the storage of the supplies. The unit director was able to provide information about possible nursing barriers based on past history of implementing change in the unit.

A meeting with the medical director was included since he represented the attending physicians who were vital to the success of the palliative care protocol. A possible barrier regarding physicians was the resistance to a protocol which includes an emphasis on nurses' decision-making. The medical director had insight into implementing a successful collaborative atmosphere among nurses, physicians, and families. Other key stakeholders such as the lactation consultant, the chaplain, and the social worker were consulted for any input regarding the palliative care protocol's implementation. The parent care coordinator represented the families in the planning of the protocol. The families' point of view was important to the success of the protocol since patient's preference is part of evidence-based practice.

Once key stakeholders gave input for the palliative care protocol, the protocol was presented to all stakeholders for final approval prior to implementation. The nursing staff was provided education regarding palliative care prior to implementation of the protocol. Education included pain management, communication with families, spirituality, anxiety, prevention of moral distress, and ethical-legal aspects of neonatal palliative care. Education was based on the ELNEC curriculum, but also included information on moral distress and the protocol. After the education portion of the intervention was complete, the protocol went into effect.

Recruiting Participants

Information regarding the education session and implementation of the neonatal palliative care protocol was provided at the unit meeting closest to these events. Nurses not attending the unit meeting received minutes of the meeting per email which is standard procedure in the NICU. This information was reiterated per the weekly email newsletters the two weeks prior to implementation for a total of two more emails. Prior to implementation, the MDS and NiPCAS surveys were coded for identification, combined with encoded envelopes, and placed in the staff's mailboxes. Nurses chose to participate by completing the surveys and returning them in a marked box for the EBP project director to collect for analysis. Only nurses who completed the first surveys were given the second surveys after the intervention.

Data

Measures, reliability, and validity. The Moral Distress Scale-Pediatric Nurse version was used to measure moral distress in the neonatal nurses. This tool was first developed by Corley, Elswick, Gorman, and Clor (2001). The original Moral Distress Scale had 32 items using a Likert 7 point scale. The survey also included demographic questions regarding gender, age, education, experience, and type of hospital in which the respondent was employed. Reliability and validity testing were conducted using Cronbach's alpha reliability coefficient. Three factors were reflected in the tool for moral distress which included (a) individual responsibility, (b) not in the patient's best interest, and (c) deception. Analysis gave Cronbach's alphas of 0.97, 0.82, and 0.84 respectively for each factor for internal consistency demonstrating reliability.

Since the original Moral Distress Scale was directed at adult critical care nurses, Hamric, Borchers, and Epstein (2012) developed different scales for nurses and physicians and also divided the scales into adult and pediatric patient populations. The original scale was shortened and updated to reflect present day situations. Each scale has 21 items, but the items are written for the specific subjects' environment and profession. The authors replaced the Likert 7 point scale with a Likert 5 point scale. Each item is scored on a scale for frequency of the situation arising and intensity of the level of disturbance to the subject. The scores may be separated for analysis or multiplied together for a new score, frequency times intensity (fxi) which represents moral distress for each concept. Reliability and validity of the new instrument were determined for the scales regarding nurses (Cronbach's alpha of 0.89), but the physician scales were modestly reliable due to the small sample size during testing (Cronbach's alpha of 0.67). The combined reliability coefficient was 0.88. Content validity was evaluated by four experts who included Hamric, Borchers, and Epstein. The fourth expert was a doctorally prepared director of a nursing ethics program. An 88% inter-rater agreement was achieved.

Perceived barriers to neonatal palliative care were measured using the Neonatal Palliative Care Attitude Scale (NiPCAS). This instrument was developed by Kain, Gardner, and Yates (2009). The scale has 8 demographic questions and 24 attitude questions which are scored using a 5 point Likert scale. The items in the scale were factor analyzed, and three factors of barriers and facilitators emerged. These factors were used for subscales within the instrument. These subscales were organization, clinician, and resources (Wright et al., 2011). The organizational subscale measures the degree the facility creates barriers and facilitators to provide neonatal palliative care. The clinician subscale measures the moral related issues of the nurse. The resources subscale measures other variables besides the organization and the nurse which cause barriers or facilitators to neonatal palliative care. Content validity was evaluated by a panel of five experts who had 100% agreement of validity (Kain, 2007b). Reliability was evaluated with factor analysis for subscales of organization, resources, and clinician (Kain, Gardner, & Yates, 2009). The Cronbach's alphas were 0.73, 0.65, and 0.63 respectively.

Collection. The collection of data was completed in the clinical setting. Instruments were marked with codes which were matched with nurses. The list of codes for the nurses was only available to the project director. The first two instruments were placed in the nurses mailboxes including envelopes so the nurses could seal their results. The nurses had two weeks to complete the instruments. A box labeled with the project name was available in the unit for the nurses to deposit their completed instruments sealed in the envelopes. After the nursing education session was complete and the new protocol had been established for two weeks, the nurses received a second set of the instruments to complete, seal, and deposit in the unit box. Again the nurses had two weeks to complete these instruments. Only data from nurses completing all four instruments was used for analysis for the PICOT question. All data was kept for possible analysis of other secondary associations.

Management and analysis. Completed instruments remained sealed and stored in a locked cabinet which only the project director had access. Each envelope had the nurses' codes. Only envelopes which had matching codes for all four instruments were opened and used for analysis for the PICOT questions. Other instruments which did not have matching codes were opened and kept for possible secondary analysis. After the surveys had been collected, the list of nurses with matching codes was destroyed. Instruments were compared between pre-intervention and post-intervention using a repeated-measure *t*-test. Secondary analyses included comparison of demographic variables with levels of moral distress and intention to leave with moral distress.

Protection of Human Subjects

A list was constructed of the nurses eligible to participate with matching identification codes. This list was locked in a cabinet with only access available to the project director. The codes were listed on envelopes and the instruments. Once the nurses completed the instruments, they sealed them in the coded envelopes and left them in a secure location which was clearly labeled with the project name in the unit. The envelopes were collected after two weeks and stored in the same locked cabinet as the code list. This same process was repeated after the nursing education session and the implementation of the new neonatal palliative care protocol. The sealed envelopes containing the instruments were again stored in the locked cabinet. Once all instruments were collected, the nurse-code list was destroyed. Only aggregate data was reported to protect identities of participants. Nurses were instructed prior to data collection that they may freely participate or not participate in the project. They could also cease participation at any time during the project without retribution.

CHAPTER 4

FINDINGS

After completion of the implementation stage of the EBP project which examined the influence of establishing a neonatal palliative care protocol on nurses' perceived barriers to palliative care and their moral distress, the data were analyzed for significance. Demographic information regarding the pre-intervention group and the post-intervention group were compared for differences between the two groups. Secondary outcomes of the correlation between nurses' experience and level of moral distress and also nurses' intent to leave their current position and level of moral distress were also analyzed.

Participants

Size. In the clinical agency for the EBP project, 77 RNs were employed and met inclusion criteria for the project. The first surveys, NiPCAS and MDS, were distributed on September 9, 2013 to all eligible nurses. The surveys were coded to ensure future surveys were matched to the same nurses to allow comparison between pre-intervention and post-intervention data. An email was sent to all nurses regarding the project and the purpose of the surveys. Each survey was placed in the nurses' mailboxes at the clinical agency. An envelope which was also coded was distributed with each individual survey. The nurses received an instruction sheet which gave directions on how to fill out the surveys, insert them in the envelopes provided, and place the filled envelopes in a labeled box in the staff lounge. Four education sessions regarding the neonatal palliative care were provided during the month of October. The first education session was video recorded for nurses who were unable to attend the education sessions. The palliative care protocol was also approved and added to the unit's protocols located in the hospital intranet. Pre-intervention surveys completed totaled 54. The post-intervention surveys were distributed in the same fashion to the nurses who completed the pre-intervention surveys on November 6, 2013. The completed post-intervention surveys totaled 44.

Characteristics. The majority of the nurses in the pre-intervention group were female (98.1%) which is consistent with the nursing staff of the unit (98.7%). Most of these nurses were 41 years old or older (63%) with more than 15 years of NICU experience (64.8%). The participants were mainly full-time employees at the hospital (70.4%). Approximately three fourths of the nurses had not received any formal education or training in NICU nursing (74.1%), and 70.4% of the nurses had bachelor or associate degrees. The majority of nurses in the project provided direct patient care (87%). The nurses were asked if they had left or considered leaving a position due to moral distress. A small percentage, 7.4%, had left a position due to moral distress. The majority had not considered leaving (74.1%), but 14.8% had considered leaving. Only a small percentage, 3.7%, had considered leaving their current positions.

The post-intervention group was all female which was significantly different than the pre-intervention group which included one male ($X^2(1) = 4.483$, $p<0.05$). The only other significant difference between pre- and post-intervention groups was regarding the category of formal education in NICU nursing. In the post group, 77.3% had no formal education in NICU nursing as compared to 74.1% of the pre group ($X^2(2) = 6.357$, $p<0.05$). No other statistical differences between the groups were found in the remaining categories of demographics. Two participants did not complete the information in the categories of leaving position in the past due to moral distress and considered leaving current position due to moral distress as represented in Table 4.1.

Changes in Outcomes

Statistical testing. The PICOT question for this EBP project was, “For neonatal nurses working in the neonatal intensive care unit, how does establishing a palliative care protocol including nursing education regarding palliative care and a patient care team as compared to the present palliative care protocol affect nurses’ perceived barriers to palliative care and moral distress within three months?” Two surveys were utilized to measure barriers to neonatal palliative care and moral distress in NICU nurses. The NiPCAS had 24 statements regarding

Table 4.1

Demographics of Participants

Demographic	Pre n (%)	Post n (%)	X^2	*df*	*p*value
Number of Participants from Eligible Nurses	54 (70.1)	44 (57.1)			
Sex					
Female	53 (98.1)	44 (100)	4.483*	1	0.034
Male	1 (1.9)	0 (0)			
Age					
20-30 years	8 (14.8)	5 (11.4)	5.354	3	0.148
31-40 years	12 (22.2)	11 (25)			
41-50 years	16 (29.6)	15 (34.1)			
51+ years	18 (33.4)	13 (29.5)			
NICU experience					
< 1 year	3 (5.6)	3 (6.8)	1.676	4	0.795
1-5 years	7 (13.0)	5 (11.4)			
6-10 years	3 (5.6)	2 (4.5)			
11-15 years	6 (11.1)	4 (9.1)			
>15 years	35 (64.8)	30 (68.2)			
Employment status					
Full-time	38 (70.4)	31 (70.5)	0.001	1	0.977
Part-time	16 (29.6)	13 (29.5)			
Formal education in neonatal intensive care					
None	40 (74.1)	34 (77.3)	6.357*	2	0.042
Certified in NICU nursing	9 (16.7)	8 (18.2)			

Postgraduate education	0 (0)	0 (0)			
Currently undertaking	5 (9.3)	2 (4.5)			
Highest nursing degree					
Diploma nurse	14 (25.9)	11 (25)	0.533	2	0.766
Undergraduate degree	38 (70.4)	31 (70.5)			
Postgraduate certificate	0 (0)	0 (0)			
Masters degree	2 (3.7)	2 (4.5)			
PhD/Doctoral degree	0 (0)	0 (0)			
Majority of working time					
Direct patient care	47 (87.0)	39 (88.6)	1.170	2	0.557
Nursing management	6 (11.1)	4 (9.1)			
Nursing education	1 (1.9)	1 (2.3)			
Nursing research	0 (0)	0 (0)			
Leaving position in past					
Consider leaving due to moral distress	8 (14.8)	33 (78.6)	2.749	2	0.253
Never considered leaving	40 (74.1)	7 (16.6)			
Has left in the past due to moral distress	4 (7.4)	2 (4.8)			
Consider leaving now					
Has considered leaving	2 (3.7)	2 (4.8)	.495	1	0.482
	50 (92.6)	40 (95.2)			

Not considered leaving	

*$p<0.05$

nurses' perceived barriers. The participants indicated their agreement with the statement on a five point Likert scale from strongly agree (5), agree (4), unsure (3), disagree (2) to strongly disagree (1). The higher the score, the more disagreement was noted. Statement scores before and after the intervention were compared using t tests. The MDS had 21 statements about experiences which could cause moral distress. Each statement had a frequency score, an intensity score, and a moral distress score which is the product of frequency and intensity. The participants' responses were indicated on a five point Likert scale with scores ranging from zero to four. For the frequency scale, zero is defined as never and four is defined as very frequently; no other descriptors are provided for scores of one through three. For the intensity scale, zero represents none, and four represents great extent; no other descriptors are provided for scores one through three. Paired t tests were also used to compare pre- and post-intervention scores regarding frequency, intensity, and moral distress.

Barriers. Using the NiPCAS, 24 concepts regarding barriers to neonatal palliative care were evaluated among the NICU nurses as shown in Table 4.2. Higher scores on the Likert scale were consistent with more disagreement with the statements. A score of one was used if the participant was unsure of his or her agreement with the statement. The three concepts with the highest means pre-intervention were ideal physical environment for neonatal palliative care, (M = 4.2727); infrequent nurses' exposure to neonatal death, (M = 3.5581); and team members ability to express opinions, values, and beliefs about providing neonatal palliative care, (M = 3.1818). After the intervention was completed, nurses were asked to complete the surveys for a second time. Significant differences were noted regarding five concepts (a) medical staff support palliative care, (b) physical environment is ideal for palliative care, (c) policies/guidelines are present to assist with palliative care, (d) palliative care options are given to families when a baby has a poor prognosis, and (e) team expresses opinions, values, and beliefs about providing palliative care. For the concept of medical staff support palliative care, the mean of

Table 4.2

Barriers to Palliative Care

NiPCAS item	Mean Pre SD (n)	Mean Post SD (n)	*t*	*df*	*p*value
Palliative care is as important as curative care	2.0455 0.21071 (44)	2.1591 0.52576 (44)	-1.530	43	0.133
Experience with providing palliative care in NICU	2.5227 0.82091 (44)	2.6364 1.05854 (44)	-1.000	43	0.323
Sense of personal failure when a baby dies	2.8864 0.96968 (44)	3.0682 0.97403 (44)	-1.091	43	0.281
Societal support for neonatal palliative care	2.8864 0.99337 (44)	2.7727 0.80301 (44)	0.670	43	0.506
Unit’s medical staff support palliative care	2.53349 0.63053 (43)	2.3023 0.46470 (43)	2.031*	42	0.049
Physical environment is ideal for palliative care	4.2727 0.89867 (44)	3.9091 0.96009 (44)	3.216**	43	0.002
Unit is adequately staffed to provide palliative care	2.8636 0.73424 (44)	2.7273 0.65994 (44)	1.289	43	0.204
Parents are involved in neonatal palliative care decision making	2.5455 0.66313 (44)	2.2955 0.66750 (44)	1.977	43	0.054
Previous experience with neonatal palliative care was rewarding	2.8293 0.80319 (41)	2.8780 0.89986 (41)	-0.361	40	0.720
Providing pain relief during palliative care is important	2.1136 0.38675 (44)	2.1364 0.40868 (44)	-0.255	43	0.800
Often exposed to death in	3.5581	3.5581			

NICU	0.90770 (43)	0.85363 (43)	0.000	42	1.000
Palliative care is necessary in neonatal nursing education	2.0909 0.29080 (44)	2.0455 0.29080 (44)	1.000	43	0.323
Sufficient time to spend with family after baby's death	2.8140 0.98212 (43)	2.6279 0.95177 (43)	1.481	42	0.146
Policies/guidelines present to assist with palliative care	2.9048 1.20587 (42)	2.3571 0.65598 (42)	2.634*	41	0.012
Palliative care options are given to families when a baby has a poor prognosis	2.8837 1.05129 (43)	2.5116 0.93534 (43)	2.075*	42	0.044
Team expresses opinions, values, and beliefs about providing palliative care	3.1818 0.78571 (44)	2.7955 0.70148 (44)	2.951**	43	0.005

*$p<0.05$, **$p<0.01$

the pretest was 2.53 (SD = 0.63), and the mean on the posttest was 2.30 (SD = 0.46). A significant decrease from pretest to final was found (*t* (42) = 2.031, *p*<0.05). Regarding an ideal physical environment for palliative care, the mean of the pretest was 4.27 (*SD* = 0.90), and the mean on the posttest was 3.91 (*SD* = 0.96). A significant decrease from pretest to final was found (*t* (43) = 3.216, *p*<0.01). Available polices or guidelines for neonatal palliative care had a pretest mean of 2.90 (*SD* = 1.20), and the mean of the posttest was 2.36 (*SD* = 0.66). A significant decrease from pretest to final was found (*t* (41) = 2.634, *p*<0.05). For the concept of giving options to families regarding care for dying infants, the mean of the pretest was 2.88 (*SD* = 1.05), and mean on the posttest was 2.51 (*SD* = 0.94). A significant decrease from pretest to final was found (*t* (42) = 2.075, *p*<0.05). And the final concept of the team expresses opinions, values, and beliefs, the mean of the pretest was 3.18 (*SD* = 0.79), and mean on the posttest was 2.80 (*SD* = 0.71). A significant decrease from pretest to final was found (*t* (43) = 2.951, *p*<0.01).

Moral distress. For each concept in the MDS, three scores were obtained (a) frequency, (b) intensity, and (c) moral distress, a product of frequency and intensity. Three concepts had significant changes in frequency after the intervention (a) witnessing providers giving false hope to families (b) working with incompetent providers and (c) working with unsafe nurses or other providers as shown in Table 4.3. For the concept of witnessing providers giving false hope to families, the mean on the pretest was 2.02 (*SD* = 0.90), and the mean on the posttest was 1.70 (*SD* = 0.85). A significant decrease from pretest to final was found (*t* (43) = 2.321, *p*<0.05). Working with incompetent providers concept had a pretest mean of 0.76 (*SD* = 0.69), and the mean of the posttest was 1.10 (*SD* = 0.96). A significant increase from pretest to final was found (*t* (41) = -2.152, *p*<0.05). The concept of working with unsafe nurses or providers had a pretest mean of 1.21 (*sd* = 1.05), and a the mean of the posttest was 0.93 (*SD* = 1.00). A significant decrease from pretest to final was found (*t* (41) = 2.300, *p*<0.05).

Table 4.3

Moral Distress Frequency

Moral Distress Frequency Item	Mean Pre SD (n)	Mean Post SD (n)	*t*	*df*	*p*value
Less than optimal care given due to pressures from administrators to reduce costs	0.8636 1.11211 (44)	0.8409 0.98697 (44)	0.136	43	0.893
Witness providers giving false hope to families	2.0227 0.90190 (44)	1.7045 0.85125 (44)	2.321*	43	0.025
Follow family's wishes to continue life support for child despite the child's best interests	2.4091 0.92304 (44)	2.1136 0.99337 (44)	1.956	43	0.057
Initiate extensive life-saving actions to only prolong death	2.1364 0.90453 (44)	1.9091 0.96009 (44)	1.495	43	0.142
Follow family's request to discuss child's death with child	0.1316 0.52869 (38)	0.3158 1.49061 (38)	-0.755	37	0.455
Carry out physicians orders for unnecessary tests and treatments	1.4419 0.98325 (43)	1.4651 0.95988 (43)	-0.144	42	0.886
Continue care for ventilated child due to no one deciding to withdraw support	1.7561 1.13535 (41)	1.5854 0.89375 (41)	1.022	40	0.313
Avoid taking action against physician or nurse colleagues' medication errors when they did not report the errors	0.1628 0.43261 (43)	0.2093 0.46589 (43)	-0.530	42	0.599
Assist physician who is providing incompetent care	0.2258 0.53865 (43)	0.3953 0.76031 (43)	-1.138	42	0.262
Required to care for patient when not qualified to provide this care	0.6977 0.74113 (43)	0.6744 0.64442 (43)	0.274	42	0.785

Medical students providing painful procedures just to increase skills	0.2857 0.67302 (42)	0.3333 0.75439 (42)	-0.305	41	0.762
Providing care which does not relieve pain due to physician's fears increase pain medication dose will cause death	0.4524 0.73923 (42)	0.5238 0.59420 (42)	-0.650	41	0.519
Follow physician's request to not discuss child's prognosis with parents	1.0500 1.28002 (40)	0.8500 1.12204 (40)	1.243	39	0.221
Increase dose of sedatives/opiates for unconscious child which could hasten death	0.2143 0.51965 (42)	0.3333 0.61154 (42)	-1.220	41	0.230
Staff member or person of authority request not to take action about an observed ethical issue	0.1190 0.39524 (42)	0.0952 0.29710 (42)	0.443	41	0.660
Follow family's wishes due to fears of a lawsuit despite not agreeing with family	0.5714 0.85946 (42)	0.5714 0.96633 (42)	0.000	41	1.000
Work with incompetent providers	0.7619 0.69175 (42)	1.0952 0.95788 (42)	-2.152*	41	0.037
Witness diminished patient care due to poor team communication	0.7619 0.69175 (42)	0.9048 0.90553 (42)	-0.973	41	0.336
Ignore situations of family not receiving adequate information to insure informed consent	0.6429 0.95818 (42)	0.5714 0.85946 (42)	0.443	41	0.667
Patient care suffers due to provider continuity	1.1429 1.13849 (42)	1.1429 0.97709 (42)	0.000	41	1.000
Work with unsafe nurses or other providers	1.2143 1.04848 (42)	0.9286 0.99738 (42)	2.300*	41	0.027

*p<0.05

None of the scores in the intensity category for moral distress had a significant change from pretest to posttest as shown in Table 4.4. The three concepts which caused the most moral distress prior to the intervention were (a) follow family's wishes to continue life support for child despite the child'sbest interests (*M* = 6.73, *SD* = 3.88), (b) witness providers giving false hope to families (*M* = 6.45, *SD* = 3.94), and (c) initiate extensive life-saving actions to only prolong death (*M* = 6.32; *SD* = 4.14) as shown in Table 4.5. The only concept which had a significant change in pretest and posttest scores after the intervention was working with unsafe nurses or other providers. The mean on the pretest was 4.33 (*SD* = 3.78), and the mean on the posttest was 3.25 (*SD* = 3.55). A significant decrease from pretest to final was found ($t(39) = 2.393$, $p<0.05$).

Secondary outcomes. Secondary analyses of specific demographic variables and moral distress were conducted. The statistical test of Kendall Tau b was performed to examine the relationship between nursing experience and moral distress. Significant positive correlations existed in the concepts (a) witnessing provider giving false hope ($\tau b(51) = 0.315$, $p<0.01$), and (b) assisting a physician who is providing incompetent care ($\tau b(46) = 0.260$, $p<0.05$) as shown in Table 4.6. This correlation indicates that as nurses' experience levels increase, their perception of providers giving false hope to families, and nurses assisting incompetent providers increase. The second outcome analyzed was the correlation between intention of leaving and moral distress. Kendall Tau b was performed and a significant positive correlation existed in the concepts of (a) following family's wishes to continue life support despite care is not in best interest of the child ($\tau b(49) = -0.33$, $p<0.05$), (b) providing care to a ventilated hopelessly ill child, and no one will make a decision to withdraw support ($\tau b(47) = -0.26$, $p<0.05$), and (c) follow physician's request not to discuss child's prognosis with parents ($\tau b(48) = -0.30$, $p<0.05$) as shown in Table 4.7. This correlation indicates that as nurses' intention to leave increases, their moral distress increases caused by providing life support to a

Table 4.4

Moral Distress Intensity

Moral Distress Frequency Item	Mean Pre SD (n)	Mean Post SD (n)	*t*	*df*	*p*value
Less than optimal care given due to pressures from administrators to reduce costs	2.8837 1.25754 (43)	2.9070 1.41108 (43)	-0.92	42	0.927
Witness providers giving false hope to families	2.9524 0.88214 (42)	2.9048 0.84995 (42)	0.274	41	0.785
Follow family's wishes to continue life support for child despite the child's best interests	2.7500 0.91816 (44)	2.5227 1.15111 (44)	1.702	43	0.096
Initiate extensive life-saving actions to only prolong death	2.7955 0.97836 (44)	2.7273 1.08614 (44)	0.476	43	0.636
Follow family's request to discuss child's death with child	2.4615 1.18868 (39)	2.3590 1.42325 (39)	0.408	38	0.685
Carry out physicians orders for unnecessary tests and treatments	2.4651 1.00827 (43)	2.5814 0.82325 (43)	-0.797	42	0.430
Continue care for ventilated child due to no one deciding to withdraw support	2.8250 0.93060 (40)	2.8000 0.75786 (40)	0.172	39	0.864
Avoid taking action against physician or nurse colleagues' medication errors when they did not report the errors	3.1750 1.19588 (40)	2.8750 1.26466 (40)	1.260	39	0.215
Assist physician who is providing incompetent care	3.2250 1.12061 (40)	2.9500 1.25983 (40)	0.976	39	0.335
Required to care for patient when not qualified to	3.1500 1.02657	2.9750 1.20868	0.943	39	0.352

provide this care	(40)	(40)			
Medical students providing painful procedures just to increase skills	3.0000 1.28784 (42)	2.8095 1.38349 (42)	0.739	41	0.464
Providing care which does not relieve pain due to physician's fears increase pain medication dose will cause death	3.0244 1.12889 (41)	2.9268 1.25280 (41)	0.417	40	0.679
Follow physician's request to not discuss child's prognosis with parents	2.8780 1.20820 (41)	2.8293 1.15979 (41)	0.230	40	0.819
Increase dose of sedatives/opiates for unconscious child which could hasten death	2.4390 1.16294 (41)	2.2927 1.12347 (41)	0.642	40	0.524
Staff member or person of authority request not to take action about an observed ethical issue	3.1750 1.12973 (40)	2.9500 1.28002 (40)	0.893	39	0.377
Follow family's wishes due to fears of a lawsuit despite not agreeing with family	2.7500 1.03155 (40)	2.4250 1.17424 (40)	1.674	39	0.102
Work with incompetent providers	3.1250 1.01748 (40)	2.9250 0.97106 (40)	1.135	39	0.263
Witness diminished patient care due to poor team communication	3.1250 0.85297 (40)	2.9750 1.07387 (40)	0.845	39	0.403
Ignore situations of family not receiving adequate information to insure informed consent	3.0500 0.95943 (40)	3.0250 1.07387 (40)	0.116	39	0.909
Patient care suffers due to provider continuity	3.0000 0.84732 (40)	2.8500 1.05125 (40)	0.845	39	0.403
Work with unsafe nurses or other providers	3.3000 0.85335 (40)	3.0500 1.15359 (40)	1.325	39	0.193

Table 4.5

Moral Distress Product Scores

Moral Distress Frequency Item	Mean Pre SD (n)	Mean Post SD (n)	*t*	*df*	*p*value
Less than optimal care given due to pressures from administrators to reduce costs	2.7442 3.92242 (43)	2.7907 3.44728 (43)	-0.76	42	0.940
Witness providers giving false hope to families	6.4524 3.93981 (42)	5.4048 3.21627 (42)	1.625	41	0.112
Follow family's wishes to continue life support for child despite the child's best interests	6.7273 3.88416 (44)	5.7273 3.84807 (44)	1.961	43	0.056
Initiate extensive life-saving actions to only prolong death	6.3182 4.14152 (44)	5.2955 3.66999 (44)	1.953	43	0.057
Follow family's request to discuss child's death with child	0.5676 2.11530 (37)	0.2973 1.12706 (37)	1.137	36	0.263
Carry out physicians orders for unnecessary tests and treatments	3.7619 3.37718 (42)	4.0238 3.26465 (42)	-0.489	41	0.627
Continue care for ventilated child due to no one deciding to withdraw support	5.2250 4.11680 (40)	4.7000 3.23602 (40)	0.924	39	0.361
Avoid taking action against physician or nurse colleagues' medication errors when they did not report the errors	0.6250 1.67466 (40)	0.6000 1.39229 (40)	0.076	39	0.940
Assist physician who is providing incompetent care	0.9744 1.97999 (39)	1.2564 2.48911 (39)	-0.623	38	0.537
Required to care for patient when not qualified to	2.3590 2.73849	2.3590 2.19434	0.000	38	1.000

provide this care	(39)	(39)			
Medical students providing painful procedures just to increase skills	1.0244 2.19645 (41)	1.0976 2.62493 (41)	-0.133	40	0.894
Providing care which does not relieve pain due to physician's fears increase pain medication dose will cause death	1.5366 2.52089 (41)	1.6829 2.03026 (41)	-0.440	40	0.662
Follow physician's request to not discuss child's prognosis with parents	3.1795 4.34603 (39)	2.0513 2.96425 (39)	1.915	38	0.063
Increase dose of sedatives/opiates for unconscious child which could hasten death	0.4390 1.16294 (41)	0.7561 1.26057 (41)	-1.766	40	0.085
Staff member or person of authority request not to take action about an observed ethical issue	0.4000 1.27702 (40)	0.3500 1.07537 (40)	0.269	39	0.789
Follow family's wishes due to fears of a lawsuit despite not agreeing with family	1.7750 2.79640 (40)	1.8250 3.53653 (40)	-0.116	39	0.909
Work with incompetent providers	3.9487 3.79715 (39)	3.7692 3.35968 (39)	0.321	38	0.750
Witness diminished patient care due to poor team communication	2.3500 2.15490 (40)	3.1250 3.36031 (40)	-1.451	39	0.155
Ignore situations of family not receiving adequate information to insure informed consent	1.7750 2.61639 (40)	1.9250 3.12465 (40)	-0.314	39	0.755
Patient care suffers due to provider continuity	3.7500 3.94026 (40)	3.7000 3.29101 (40)	0.093	39	0.926

Work with unsafe nurses or other providers	4.3250 3.77840 (40)	3.2500 3.55001 (40)	2.393*	39	0.022

*$p<0.05$

Table 4.6

Moral Distress and NICU Experience

Moral Distress Concept	Correlation Coefficient (τ_b)	*df*	*p*value
Less than optimal care given due to pressures from administrators to reduce costs	-0.013	50	0.912
Witness providers giving false hope to families	0.315**	51	0.005
Follow family's wishes to continue life support for child despite the child's best interests	-0.033	51	0.776
Initiate extensive life-saving actions to only prolong death	-0.032	51	0.778
Follow family's request to discuss child's death with child	-0.112	47	0.400
Carry out physicians orders for unnecessary tests and treatments	0.162	47	0.175
Continue care for ventilated child due to no one deciding to withdraw support	-0.016	48	0.892
Avoid taking action against physician or nurse colleagues' medication errors when they did not report the errors	-0.008	48	0.952
Assist physician who is providing	0.260*	46	0.048

incompetent care			
Required to care for patient when not qualified to provide this care	-0.089	46	0.472
Medical students providing painful procedures just to increase skills	-0.063	47	0.630
Providing care which does not relieve pain due to physician's fears increase pain medication dose will cause death	0.189	47	0.142
Follow physician's request to not discuss child's prognosis with parents	0.124	46	0.325
Increase dose of sedatives/opiates for unconscious child which could hasten death	-0.143	48	0.276
Staff member or person of authority request not to take action about an observed ethical issue	0.053	48	0.687
Follow family's wishes due to fears of a lawsuit despite not agreeing with family	-0.135	48	0.282
Work with incompetent providers	-0.041	49	0.730
Witness diminished patient care due to	-0.033	49	0.781

poor team communication			
Ignore situations of family not receiving adequate information to insure informed consent	0.015	48	0.908
Patient care suffers due to provider continuity	0.038	49	0.750
Work with unsafe nurses or other providers	0.007	49	0.953

*$p<0.05$, **$p<0.01$

Table 4.7

Moral Distress and Intention to Leave Position

Moral Distress Concept	Correlation Coefficient (τ_b)	*df*	*p*value
Less than optimal care given due to pressures from administrators to reduce costs	-0.074	50	0.570
Witness providers giving false hope to families	-0.132	49	0.282
Follow family's wishes to continue life support for child despite the child's best interests	-0.333*	49	0.042
Initiate extensive life-saving actions to only prolong death	-0.169	49	0.169
Follow family's request to discuss child's death with child	0.070	46	0.627
Carry out physicians orders for unnecessary tests and treatments	-0.197	47	0.127
Continue care for ventilated child due to no one deciding to withdraw support	-0.255	47	0.041
Avoid taking action against physician or nurse colleagues' medication errors when they did not report the errors	0.088	47	0.530
Assist physician who is providing	0.117	46	0.408

incompetent care			
Required to care for patient when not qualified to provide this care	-0.058	44	0.669
Medical students providing painful procedures just to increase skills	0.108	46	0.440
Providing care which does not relieve pain due to physician's fears increase pain medication dose will cause death	0.397**	47	0.004
Follow physician's request to not discuss child's prognosis with parents	-0.298*	46	0.026
Increase dose of sedatives/opiates for unconscious child which could hasten death	0.093	48	0.505
Staff member or person of authority request not to take action about an observed ethical issue	0.067	50	0.634
Follow family's wishes due to fears of a lawsuit despite not agreeing with family	-0.106	48	0.426
Work with incompetent providers	0.059	49	0.635
Witness diminished patient care due to	-0.174	49	0.174

poor team communication			
Ignore situations of family not receiving adequate information to insure informed consent	-0.100	50	0.458
Patient care suffers due to provider continuity	-0.057	49	0.650
Work with unsafe nurses or other providers	-0.028	49	0.824

**p*<0.05, ***p*<0.01

child despite the best interest of the child due to family wishes, providing care to ventilated hopelessly ill child while no one will make the decision to withdrawal support, and following physician's request not to discuss child's prognosis with a family. A significant positive correlation existed in the concept of providing care which does not relieve child's suffering because physician fears increasing dose of pain medication will cause death ($\tau b(47) = 0.40$, $p<0.01$). This correlation indicates that as nurses' levels of experience increase, their perceptions of physicians not increasing pain medication dosages to relieve children's sufferings due to physicians' fear of causing death increase.

Reliability and validity. Reliability was analyzed using the Cronbach alpha statistical test. For NiPCAS, the reliability coefficient was 0.710. Cronbach alpha tests were also performed on all three areas of the MDS, intensity, frequency, and moral distress scores. The reliability coefficients were 0.938, 0.867, and 0.888 respectively. No established criteria are available for validity testing. Face and content validity were previously performed using an expert panel which gave a100% validity for all statements on the NiPCAS. Experts were also utilized for content validity on the MDS.

CHAPTER 5

DISCUSSION

This EBP project examines the influence of establishing a neonatal palliative care protocol on nurses' perceived barriers to palliative care and moral distress in a NICU. The protocol consisted of six stages of palliative care including infants' criteria for initiation into the different stages. The protocol also included the formation of a care team for each infant who met criteria for palliative care. Nurses received an educational session prior to the beginning of the protocol which was based on the ELNEC curriculum. Nurses' perceived barriers and moral distress were measured prior to and after the implementation of the protocol. Several significant findings were found regarding barriers and moral distress. Each of these findings will be evaluated along with the EBP project itself.

Explanation of Findings

Demographics. The attrition of nurse participants in the project was 18.5% (pre-intervention group n = 54; post-intervention group n = 44). During the time of the project, the unit's census had increased, and major holidays were taking place. Some nurses were working overtime at different intervals which may have decreased their interest in the project. Due to the holiday season, other nurses may have taken time off from work which would have decreased their opportunities to complete surveys. One nurse who participated was pregnant before the initiation of the protocol and delivered the baby before the end of the project, so did not complete the second set of surveys. Due to the time constraints of the project, the surveys were distributed in September and November. The short interval of time between the two surveys may have place excessive burden on some nurses causing them not to participate in the second survey. Having the short time interval may have been a reason why the attrition rate was low since all of the nurses participating in the pre-intervention survey were still employed for the post-intervention survey. Also measuring the perceived barriers and moral distress only twice decreased the tedium of repeated measures for participants.

The participants were mainly female (98.1%) and 41 years old or older (63%) which was consistent with the demographics of the entire nursing force on the unit. Most nurses were employed full-time (70.4%) and had 15 years NICU experience or more (64.8%). These nurses with increased experience worked in the clinical agency for the majority of their career. The formal training nurses may receive in NICU nursing consists of obtaining certification in this area. The unit recently instituted a policy stating all nurses must be NICU certified by the end of 2014, so nurses were working on obtaining this education. During the project 74.1% of the nurses had not yet completed certification. The vast majority (87%) of the nurses performed direct patient care. Regarding moral distress, 7.4% had left positions due to moral distress, 14.8% had considered leaving positions in the past due to moral distress, and 3.7% had considered leaving their current positions due to moral distress. The effects of nurses experiencing moral distress has caused burnout and leaving positions (Gutierrez, 2005). Since the majority of the nurses in the unit have extensive NICU experience, the loss of these nurses poses a significant challenge for the clinical agency both in quality care and monetary expense.

A significant difference in gender was found between the pre-intervention and post-intervention groups. The only male participant did not complete the second set of surveys. The post-intervention group therefore consisted of all females which was significantly different than the pre-intervention group. Another significant difference between the pre-intervention group and the post-intervention groups was formal education. A larger percentage of nurses with formal NICU education was noted in the post-intervention group. One reason for this increase was due to the certification mandate for all nurses in the clinical agency; some of the participants became certified during the implementation phase of the project.

Barriers. The three barriers to neonatal palliative care which had the highest means in both pre- and post-intervention groups indicating increased agreement regarding the clinical agency's NICU were (a) less than ideal physical environment for palliative care, (b) infrequent exposure to neonatal death, and (c) inability of team members to express opinions, values, and beliefs about providing neonatal palliative care. One reason for the less than ideal physical environment is the design of the unit. The unit is separated into three large rooms. Each room has 12 bed spaces for patients without any dividers for privacy. Each space is approximately four to six feet wide which limits room for family members and equipment. A new unit with a projection date of 2016 is in the process of being designed which has private rooms. Since the nurses are aware of the new larger spaces with more privacy, they may perceive the current unit to be unfit for quality palliative care. Carter (2004) explains quality palliative care must provide privacy for families to create memories. This concept of privacy is supported by NANN (2010). Wright et al. (2011) also found nurses who believe the NICU design does not provide privacy and is not an ideal location for neonatal palliative care. Kain (2011) further explored this issue with NICU nurses. These nurses described the NICU as having no designated space for palliative care, and frequently other spaces such as storage areas are used for this care. Parents may at times feel abandoned in these rooms, and that their experiences are unimportant to the staff. The nurses state the traditional NICU design is based on the needs of multiple bed spaces, human traffic, and machinery, not the needs of the families.

Nurses also perceive they are exposed to infrequent neonatal death. In 2012 the clinical agency had 4% of the infants admitted die while hospitalized which demonstrates the low exposure to death the nurses' experience. Nurses working less than full-time (29.6%) would have less opportunity to be exposed to neonatal death due to decreased time in the clinical agency. Additionally, nurses working less than five years (18.6%) may not have experienced neonatal death since they are not assigned to critical babies until they have been evaluated by a preceptor to be competent for caring for these infants. This exposure to neonatal death varies among units since the patient population varies. Infants with cardiac disease have the highest incidence of neonatal death (Carter, Howenstein, Gilmer, Throop, France, & Whitlock, 2004).

These infants are usually treated in level IV NICUs at large tertiary centers. The clinical agency's unit does not treat these infants.

The third area frequently identified by nurses was team members not being able to express their feelings about palliative care. Lack of nurse participation in care planning for the infants may have impacted this outcome. Nurses may express themselves in patient rounds which occur on Mondays and Thursdays. Nurses may not feel comfortable in this setting due to the large number of people present: family members, physicians, nurse practitioners, social worker, parent coordinator, chaplain, nurse educator, unit director, unit manager, other nurses, and other ancillary professionals. Since these rounds occur in the middle of the day, nurses may not be available to attend. Additionally palliative care is not typically discussed during these occasions. Family conferences are scheduled by the physicians at times when nurses could attend, but again may not be able to attend or feel comfortable expressing themselves. The structure of these meetings typically is geared at answering families' questions, not eliciting input from nurses. Corley (2002) discusses how organizational culture typically supports nurses' lack of involvement in decision-making regarding patient care which causes moral distress. The structure and function of the organization does not take into account the psychological needs of the nurses. Wright et al. (2011) found this barrier to be the most frequently occurring phenomenon in a NICU.

Significant increases in occurrence were noted for five different concepts regarding nurses' perceived barriers to palliative care after the intervention which were (a) medical staff supports palliative care, (b) physical environment is ideal for palliative care, (c) policies or guidelines are present to assist with palliative care, (d) palliative care options are given to families when a baby has a poor prognosis, and (e) care team members are able to express opinions, values, and beliefs about providing palliative care. Palliative care in the clinical agency has been historically offered to families by medical providers when an infant's condition deteriorated to the point of eminent death. Physicians were the only care team members who initiated conversations with families regarding palliative care. With the new protocol for palliative care, a care team is formed when infants meet established criteria, so all members of the team are aware of the initiation of meetings with families. During the translation and application phase of the project, physicians were given the protocol for review. Physicians agreed to formation of the care team and the infants' criteria for inclusion for palliative care. Nurses may perceive this agreement as increased support for palliative care.

The physical environment of NICUs has been shown to be an issue in providing quality neonatal palliative care. Kain's (2011) qualitative descriptive study showed neonatal nurses perceive the layout of a NICU as unconducive to providing neonatal palliative care. As stated previously, the physical environment of the clinical agency has been an issue for nurses regarding privacy and space constraints for families. Previous to the implementation of the new palliative care protocol, discussion with families regarding the infant's plan of care took place at the bedside or during care conferences off the unit in a private room. The unit has three large rooms with 12 bed spaces in each room. The physical environment did not change during the implementation phase; the nurses' perception of the environment changed. With care team meetings taking place in a private area instead of at the bedside, the physical environment is no longer perceived as a barrier to palliative care. Also by initiating palliative care sooner, the family has time to bring in other family members and support people in stages instead of at the same time which makes the environment more ideal for visitation.

Nurses' perceptions of the presence of a guideline or policy to assist with palliative care also showed an increase. Prior to the EBP project, the clinical agency had a bereavement policy which dealt with dying infants and post-mortem care. In contrast, the new protocol included all phases of palliative care and especially addressed when to begin discussions with families about palliative care, and when to initiate palliative care and bereavement care. The new protocol was more detailed than the previous policy and addressed the different phases of palliative care. This type of protocol has been shown to decrease moral distress also (Gale &

Brooks, 2006). A protocol which increases communication, collaboration, and more formalized stages for palliative care allows nurses to deal with and reduce moral distress.

The new palliative care protocol also decreased perceived barriers of providing palliative care options to families when a baby had a poor prognosis. Previous to the implementation phase, the clinical agency relied on physicians to determine when an infant qualified for palliative care and when to approach the family regarding their options. With the new palliative care protocol, any team members including nurses are aware of when an infant meets criteria for palliative care since the new protocol is clear on inclusion criteria. They may initiate team meetings to discuss options with families. These options given to families and the decisions of the care team are documented for the nurses on the communication tool so they are clear of the families' desires for care.

The last perceived barrier which decreased after implementation of the protocol was the ability of the team members to express opinions, values, and beliefs about providing palliative care. Since discussions with families are now implemented as a team instead of solely between physicians and families, the nurses perceive they are able to express themselves regarding the palliative care. Lawrence (2011) showed a positive correlation between expression and work engagement. When nurses are allowed to express themselves, an increase in work engagement occurred and this in turn decreased moral distress. Epstein and Hamric (2009) found similar results. The researchers identified lack of assertiveness, self-doubt, socialization to follow orders, and perceived powerlessness as barriers to nursing care which could lead to moral distress. Nurses who are unable to express themselves and advocate for their patients may develop internal barriers which could lead to moral distress.

Moral distress. Moral distress was measured using the MDS pediatric version. The Moral Distress Scale measures 21 concepts of potential situations which may contribute to providers' moral distress. The scale first assesses frequency of concepts occurring in the clinical setting on a Likert scale of 0 (not occurring) to 4 (frequently occurring). The scale then assesses the intensity level of distress each concept causes the nurses on the same Likert scale. By multiplying the frequency by intensity a third score is obtained which measures moral distress.

The three concepts with the highest pre- and post-intervention moral distress mean scores were (a) following family's wishes to continue life support for child despite the child's best interest, (b) witnessing providers giving false hope, and (c) initiating extensive life-saving actions to only prolong death. These three concepts not only had increased frequency of occurrence, but also had increased distress intensity for the nurses. All three concepts focus on obstacles to the initiation of palliative care. The first area of following parents' wishes despite the child's best interest can be linked to the second area of providing too much hope to parents. The decision to initiate palliative can be very difficult for families. They may be in denial which is their coping mechanism (Baergen, 2006). Providers must provide information to the families which is supportive and inclusive of the families' feelings (Hinds & Kelly, 2010). Since many prognoses of infants in the NICU are not definitive, the families will cling to any possible hope. If families have hope for their infant, they will want extensive life-saving actions to only prolong death which is the third area of highest moral distress. When the decision to initiate palliative care is postponed until parental agreement is obtained regarding the imminent death of the infant instead of when the infant becomes critically ill, quality palliative care may be delayed or prevented (Catlin, 2011).

The frequency measurements had three concepts which had a significant change between the pre-intervention scores and the post-intervention scores. The first concept was witnessing providers giving false hope to families. This concept had a significant decrease in frequency after the intervention. Before the new protocol was implemented, the nurses were rarely included in discussions regarding initiating palliative care. They may have been present for the interaction between the provider and the families, but their input was infrequently included. With the new protocol development, the nurses are included in the care team and are able to view all information given to the families, and also give their input which may decrease the incidence of false hope provided to the families.

The second concept which has a significant change of occurrence was working with incompetent physicians. A significant increase in frequency of this concept was noted after the intervention. The physicians remained unchanged before and after the intervention. Nurses perceived physicians' competence changing possibly due to their increased involvement with discussions of palliative care. Since nurses are now included in the decision making process, they may perceive physicians differently. Historically physicians made the decisions regarding patient care. Physicians have realized the importance of collaborative decision-making with families and patients, but on the project unit nurses may be excluded in this process. Since this protocol now includes nurses in the decision-making process, and they are educated on the palliative care process, they may be judging physicians more harshly because they have more input and knowledge.

Working with unsafe nurses or providers was the third concept which had a significant decrease in occurrence after the intervention was done. Nurses may be able to better understand the reasoning of the nurses or providers in the care team meetings. Previous to the implementation of the palliative care protocol, the nurses and physicians did not formally meet to discuss decision-making regarding palliative care. According to research by Epstein (2010) on obligations of nurses and physicians regarding end-of-life care, physicians' focus of care was on decision-making, and nurses' focus was the actual end-of-life care. Therefore, nurses may not have understood the rationale for the initiation of a particular care plan. By being part of the care team, the nurses now are part of the decision-making and are able to understand how a decision was developed. Therefore the nurses do not perceive the care as unsafe because of their involvement in the decision-making.

One concept measured on the MDS, working with unsafe nurses and other providers, exhibited a significant change from pre-intervention to post-intervention score. Since a significant change was found in the frequency of this concept, the moral distress score, which is a product of intensity and frequency, also showed a significant difference. Since nurses are part of the decision-making team, they better understand the rationale of the other providers when suggesting different aspects of palliative care.

Secondary findings. Nurses' years of work experience and moral distress scores were analyzed for relationship between variables. Two significant correlations were identified. The first finding was nurses with more NICU work experience had higher scores of moral distress when witnessing providers giving false hope. This relationship has been supported in previous work by Bellini and Damato (2009). They found nurses with more nursing work experience were less supportive of initiating aggressive care in the NICU. The authors found a lack of consensus regarding nurses' role in decision-making for end-of-life care. These nurses perceived physicians as the provider of information to the families instead of utilization of a care team approach. They believed the options given to the families were expensive and unlikely to have any benefit for the infants. Nurses also witnessed conflict between physicians and families regarding the type of care critically ill infants were provided due to the information provided to the families.

Nurses with more NICU work experience also had more moral distress when assisting physicians who are providing incompetent care. These nurses have more experience working with different providers, so they may perceive different types of care as competent and incompetent when in reality the care is just different. The nurse on the other hand may have more opportunity to actually experience incompetent care since they have more opportunity to work with different providers. Nurses with more experience have been socialized to follow physician orders despite believing the orders are unsafe which would cause moral distress (Epstein & Hamric, 2009). They may also believe they cannot express their opinions, so they continue to work with these incompetent providers causing moral distress.

Significant correlations between nurses' intention to leave their current position and moral distress items on the MDS were also identified. Three potential causes of moral distress showed a significant positive correlation with nurses' intention to leave. The areas were (a) following family's wishes to continue life support despite care is not in the best interest of the child, (b) providing care to a ventilated, hopelessly ill child, and no one will make a decision to withdraw support, and (c) follow physician's request not to discuss child's prognosis with parents. Nurses who had intentions of leaving their current positions had significantly higher moral distress scores in these three areas. In the study by Cavaliere, Daly, Dowling, and Montgomery (2010) two nurse characteristics which had significant positive correlations to moral distress were the desire to leave a current position, and considering but not leaving a previous job because of moral distress.

Applicability of Theoretical Model

Corley's moral distress theory. In her moral distress theory, Corley (2002) states that nurses experience moral distress if they are unable to provide ethical care which includes promoting beneficence, protecting clients from harm, and providing a psychologically stable environment for clients. Nurses who experience moral distress may develop psychological or physical symptoms. These symptoms may be so distressing that nurses may avoid certain ethical clinical situations or leave the nursing profession. If nurses develop moral sensitivity, which is the ability to recognize moral conflict, they may be able to cope with moral distress in less destructive ways. Corley (2002) believes nurses who experience more collaboration with providers, have more influence in their working environment, and have clear practice guidelines experience less moral distress. This framework was used to guide the intervention development. The intervention included developing a care team which included the nurses to support collaboration with other providers, providing more nurses autonomy by including nurses in the care team to increase their influence on decision-making regarding care of dying infants, and providing a clear palliative care protocol for nurses to utilize in providing palliative care.

Strengths and weaknesses. The project included examining barriers to palliative care since these barriers may prevent the implementation of quality palliative care which may cause nurses' moral distress. Corley's theory (2002) does not directly address barriers to care as a potential cause to moral distress, although it does provide facilitators for prevention of moral distress. Promotion of beneficence, protection from harm, and provision of a psychological stable environment for clients are nursing imperatives for ethical care. According to Corley when nurses are unable to furnish this type of care which may be due to established barriers, they may experience moral distress.

Another weakness of Corley's theory is the assumption that nurses become distressed by ethical situations in the clinical setting in which they have minimal or no control. Nurses, though, experience these situations in different ways and to different degrees. This was evident in this EBP project by the wide variety of responses on the MDS. A study by Cavaliere, Daly, Dowling, and Montgomery (2010) measured moral distress using the MDS in a NICU. The individual scores in this study also demonstrated a wide variation in responses to ethical aspects of moral distress. The participants in this study did not overall show a high level of distress in this particular unit. Some participants in this EBP project experience more distress than other participants which may make interventions to prevent moral distress difficult due to the wide variety of experiences.

The theory focuses more on the prevention of moral distress which was a strength for the EBP project. The three areas examined in this EBP project which have the potential to prevent moral distress were providing a clear practice guideline, increasing collaboration with medicine, and providing education to nurses. The palliative care practice guidelines historically are very long and cumbersome, and nurses do not utilize these documents (Gale et al., 2006). Organizing the protocol into distinct palliative care phases provides the nurses with a clear practice guideline which is designed to ease its use and decrease moral distress. The education for staff has historically had variable effects on nurses' comfort with palliative care which may affect moral distress. The most effective way to create collaboration with physicians in decision-making is using a team approach (Okah et al., 2012). By implementing a care team, which not only has the goal of establishing a care plan, but also of providing a forum for providers to discuss feelings, opinions, and values provider distress decreases. Regarding education, Rogers, Babgi, and Gomez (2008) demonstrated how nurses' comfort for caring for dying infants was correlated to education sessions on different palliative care aspects. Nurses were more comfortable with pain management, spirituality, and prevention of compassion fatigue, but were less comfortable with communication and culture of families. Nurses in this EBP project had different perceptions of their co-workers after receiving education about palliative care. They perceived decreased false hope being provided to families, and their co-workers were provided safer patient care. On the other hand, they perceived their co-workers to be more incompetent after the education.

Applicability of EBP Model

Stetler's model. Stetler's model was the EBP model utilized in this project. This model recognizes two types of evidence, internal and external (Stetler & Caramanica, 2007). Internal evidence used in this EBP project was the previous bereavement protocol utilized in the clinical agency, opinions from leaders within the clinical agency, and input from users of the new protocol, the nurses. External evidence collected was obtained from the systematic literature search. The Stetler model has five phases for development of a plan to find a solution to a clinical issue. The first phase is the preparation phase. During this phase input was obtained from the unit director, medical director, and charge nurses of the unit. Additional aspects for palliative care desired by the leaders included in the protocol. The protocol was presented to the nurses and physicians, and adaptations were implemented. The next phase is validation. During this phase the available internal and external evidence was critique and summarized in a table. The third phase is comparative evaluation and decision-making. The evidence was sorted and ranked for applicability in the clinical agency. In the fourth phase, translation and application phase, the evidence is refined into a plan which is then disseminated to potential users. The final palliative care protocol was written in the style of the clinical agency's format and disseminated using the protocol website of the clinical agency. The last phase is evaluation phase. Analysis was done using data from the surveys to determine if the protocol effected nurses' perceived barriers and moral distress levels.

Strengths and weaknesses. One of the strengths of the Stetler model was the use of internal and external evidence to support the EBP protocol for the project. External evidence not only included previous research and expert opinions, but also guidelines from a professional group of neonatal providers which was supported with rigorous analysis of evidence. The internal evidence included the preexisting clinical agency's protocol which was reviewed to determine if aspects had a history of quality outcomes. Other internal evidence included the perspectives of the clinical team on goodness of fit of the protocol to the clinical agency and its feasibility. Some opinions were not supported by evidence, but the users of the protocol believe these changes were necessary for implementation.

During the translation and application phase of the Stetler model, another strength was the dissemination of the evidence to potential users. Several education sessions were offered to the nursing staff of the clinical agency regarding the protocol. These sessions allowed clinical staff to provide input on the protocol and ask questions regarding its implementation. If nurses were unable to attend these educational sessions, the information was video recorded and placed on all charting computers for them to view during down time. They could provide input via email or phone messages. The protocol was also placed on the intranet policy website so nurses could access it easily and quickly. This phase facilitated implementation of the new protocol by clinical providers, and the transition to the new practice was smooth.

A weakness of the Stetler model was the adoption phase. Adoption of a new practice may not occur with all providers. Nurses may adopt the new protocol at different rates, or they may not adopt it at all. Adoption of the protocol is effected by when the protocol is used, what the clinical situation is surrounding the patient, personalities of the nurses, past experiences, and communication within the team (Gale et al., 2006). With so many variables influencing the adoption of the protocol, this phase may be ongoing or never fully completed. This phase was difficult to measure since the protocol was not utilized during the project implementation.

Strengths, Weaknesses, and Modifications of the EBP Project

During the preparation phase of the project, several guidelines were located in the literature. Two guidelines were utilized after analysis of the literature. Several of the guidelines were found unsupported by evidence, so they were not used. The previous established protocol of the clinical agency was reviewed. No documented evidence was provided on this protocol to support it, but members of the clinical agency were interviewed to determine if any aspects of the previous protocol had positive outcomes and therefore should be considered for the new protocol. Internal evidence from the members was purely anecdotal since no documentation or plan of evaluation was in place for palliative care previously provided.

A weakness of the project was the available evidence for the development of protocol. Due to the nature of neonatal palliative, the majority of evidence was limited to lower levels. Guidelines discovered were mainly based on expert opinions or specific case studies. Ethically sound RCTs are difficult to design due to the nature of the issue of palliative care. Guidelines and systematic reviews can be rigorously constructed, but the available evidence is limited to quasi-experimental, qualitative, or expert opinions. Internal evidence is also valuable to development of the protocol, but data from the clinical agency regarding evaluation of the previous protocol was limited. Even though internal evidence was collected, a needs assessment of the clinical providers was not done to determine what aspects of palliative care were lacking in the clinical agency.

During the translation and application phase, the protocol was altered in a few ways. One medical provider had reservations regarding documentation of the care team meetings due to possible inconsistencies among providers. Another concern was the method of documentation for the families of the care team proceedings. The original plan was to have the physician document in laymen's terms the information which was provided to the family. After discussion among the care team members, the decision was made to allow the family to record the proceedings on their cell phone if this option is available, or to provide the written copy of the proceedings with any member of the care team documenting the plan. One member of the care team suggested using pastel colored paper for the documentation to decrease families' distress over the information provided. No evidence supported this decision, but this suggestion was added to the protocol as internal evidence.

During the intervention phase of the project, educational sessions were provided to the nurses regarding the protocol and different aspects of palliative care including pain management, communication with families, spirituality, anxiety, prevention of moral distress, ethical and legal aspects of neonatal palliative care. The sessions lasted 2 hours due to time and money constraints. Nurses were not willing to attend sessions without pay. The unit director approved 2 hours of pay for nurses to attend which limited the length of time spent instructing in each aspect. Longer educational sessions may have had a larger impact on nurses' perceived barriers and moral distress.

Another modification was the inclusion of a hospice representative in care team meetings if this option is viable. Typically hospice is not designed to care for small infants at their homes. The unit director of the clinical agency received information from a former mother in our unit who worked for hospice. This mother began the process of educating hospice staff on infant care and possible services for infants in their homes. The hospice representative will only be included in the care team meetings if the option is viable for the infant to be discharge to home with this service.

If this EBP project was repeated, modifications would include a longer implementation phase and measuring other outcomes. The implementation phase of this project lasted 3 months. Due to the small number of infants which meet criteria for palliative care in the clinical agency, no infants received palliative care during the implementation phase. If the protocol was actually utilized during this timeframe, the outcomes of the project may have been different. If multiple uses of the protocol were accomplished, then the outcomes may have been different and the protocol may have changed after the evaluation phase of the project. Patient outcomes including pain management and sedation could have been measured. Family outcomes such as satisfaction and support systems could have also been analyzed with possible future alterations in the protocol. Koppelman (2006) states communication between families and providers may conflict during end-of-life decisions. Providers have different views on stopping life support, whereas families may hang on to hope that the child will live therefore not consenting to withdrawal of support. This communication issue may cause increasing conflict between providers and families. By implementing the care team with the family's input, this project could be modified to measure congruence of decision-making between families and providers.

Another possible modification could be to alter data collection to determine which part of the protocol had the most effect on the outcomes being measured. The protocol incorporated several new aspects for the clinical agency which included formation of a care team, a communication tool between the care team and nurses providing care, and education sessions for the nursing staff. Tools and analysis could be altered to measure which of the aspects of the protocol had the most effect on nurses' perceived barriers and moral distress.

Four weaknesses were noted during the data collection phase of the project. The tools used were the NiPCAS and the MDS. The NiPCAS was developed to use with NICU nurses, but the MDS is the pediatric version which may be used in any unit with children. Some of the questions in the MDS were not related to the NICU which may have confused participants or decreased their desire to participate which could have increased the attrition rate. The tools combined where lengthy which could have caused participants to fatigue. Some participants did not answer all the questions and some did not complete the second surveys. Another weakness which may have contributed to participant fatigue was the short duration between pre-intervention surveys and post-intervention surveys. Due to the constraints of the EBP project timeframe, the implementation and data collection phases lasted only three months which caused participants to complete all the surveys in a short time. This short period also may have contributed to attrition. Also due to the short timeframe, no infants met criteria for palliative care, so the new protocol was not utilized. Since the protocol's utilization was lacking, nurses may not have completed post-intervention surveys because implementing the protocol alone without utilization would not have changed their perceived barriers to palliative care or moral distress. This reasoning may also be the cause no significant changes were noted in intensity of moral distress among the participants.

On the other hand, the short duration of implementation and data collection phase may also have been a strength attributing to the low attrition. The participation rate was high at 70%, and the attrition rate was low at 18.5%. These rates may be a reflection of participants understanding the importance of quality palliative care, and desiring to decrease the distress they may be experiencing in the NICU. All nurses participating in the project either attended the educational sessions in person or viewed the video without reminders which demonstrated how important neonatal palliative care was to them. This perfect attendance for the educational sessions also demonstrated another strength of the project which was the use of video recording of the educational sessions. Nurses were able to receive pay for viewing the educational session either by attending the sessions or using downtime during work hours to view on charting computers. Providing the educational sessions for nurses at times convenient to them enabled higher participation in the project and lower attrition.

Implications for the Future

Practice. The APN as a leader in clinical practice must continue to ensure protocols are based on evidence and agency's culture. This EBP project used previously established evidence to build a protocol for clinical practice which was not only supported in the literature, but also designed to fit in the clinical agency's culture. As a clinician, the APN recognizes the need for quality clinical practice which is supported by evidence. As a leader, the APN develops protocols for the clinical setting to ensure clinical practice has been examined for the desired effects. The APN leads the evaluation process to determine goodness of fit for the clinical agency, and if desired outcomes of clinical practice are being achieved.

The APN has the unique vantage point of using quality evidence-based clinical practice and designing it. The APN leader is able to search, collect, critique, and analyze available evidence for a clinical problem; design an evidence-based practice; translate this practice to other providers; and evaluate the practice to determine outcomes related to the clinical problem. This dual position allows the APN to be valued and trusted by other stakeholders and organizations. Continuing life-long learning and leadership, the APN is ensured to provide the best quality of clinical practice to clients.

Theory. Several environmental factors influence theory regarding moral distress in nursing. In the NICU setting, these influences include culture, economics, ethics, law, politics, society, and technology. Changes in practice occur frequently in the NICU environment due to changes which allow newborns to survive at early gestations. Ethical situations such as when a fetus is viable, when a life is worth saving, and how a small premature infant experiences care in the NICU, affect theory. Economics is a key factor since this high technological care is expensive, and the cost to the infant is unclear. Society continues to desire this high technological care due to the desire to save all infants, but financing this care has not been addressed. Evidence obtained by similar projects and rigorous research, may assist in determining the costs of caring for these infants, and the effects on NICU health care providers. Through expansion of theory to include more definitive causes and prevention measures of moral distress, higher levels of research can be designed to guide practice. The APN role of researcher and leader can be instrumental in guiding this theory development and change in practice.

Research. The clinical area of neonatal palliative care can be controversial due to the age of the patient population and ethical situations such as quality of life, use of resources, and undefined criteria for viability. In older patients, their desires for end-of-life care can be documented in advance directives. Newborns cannot give their permission for care. Newborns also express pain and discomfort differently than adults (O'Brien, Duffy, & O'Shea, 2010). Small premature infants often lie still when in pain which families and providers mistakenly interpret as sleeping. Families also may not be mentally prepared for end-of-life decisions, so medically futile but expensive treatments may be provided which are not in the best interest of the child.

Research on neonatal palliative care is limited due to the nature of the situation. Ethical dilemmas could arise from performing randomization on dying infants. The majority of guidelines available are based on adult palliative care which may not be transferrable to infants' care. Several studies have looked at the needs of the families, but research on needs of the infant as part of the family is lacking. Research in this area is mainly qualitative to determine factors affecting neonatal palliative care. The research needs to move to higher levels by developing quantitative tools to measure the different factors identified in qualitative studies. This EBP project used tools which measured two aspects of neonatal palliative care, nurses' perceived barriers to palliative care and moral distress. The tools used, NiPCAS and MDS, were able to quantify these two phenomena. By quantifying these aspects, interventions for neonatal palliative care can be studied for applicability to infant care.

Education. Palliative care is slowly being implemented into nursing curricula. Historically education in end-of-life care was limited to the stages of dying the client endures. In neonatal care, we cannot determine if the patient goes through these stages—our focus is on the family. Nurses are not educated in the requirements of neonatal palliative care in undergraduate curricula, but may learn the basic needs of a dying patient (Gallagher et al., 2012). The APN is instrumental in teaching nurses about the needs of the dying newborn and the family. Quality evidence-based neonatal palliative care needs to be included in NICU orientation, continued learning opportunities, or certification for all nurses who care for these critical infants. This education is not complete without the rigorous research which supports it.

Conclusion

In neonatal nurses working in the neonatal intensive care unit, establishing a palliative care protocol which included nursing education regarding palliative care and establishing a patient care team compared to the previous palliative care protocol decreased nurses' perceived barriers to palliative care and moral distress within three months in certain ethical situations. The perceived barriers which were reduced were lack of support from medicine, unconducive physical environment of the NICU, lack on established palliative care guideline, lack of palliative care options for families, and inability of team members to expresses themselves. Ethical causes of moral distress which were reduced in frequency included witnessing false hope given to families and working with unsafe nurses and physicians which was decreased in overall moral distress also. Due to the large variety of previously identified barriers to palliative care and causes of nurses' moral distress, further work is required to facilitate solutions to provide quality clinical practice. By decreasing perceived barriers to neonatal palliative care and nurses' moral distress, nurses' needs are not overlooked in the stressful practice of caring for dying infants and their families.

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BIOGRAPHICAL MATERIAL

Ms. Cavinder graduated from Indiana University with a BS in cellular biology in 1988. Following her degree completion, she worked as a laboratory technician in a genetic research lab at Indiana University's Biology Department. After obtaining her ASN from Indiana University in 1991, she worked in the neonatal intensive care unit as a nurse which included transporting patients from referral hospitals. In 1999 she completed her MSN in pediatric nursing from Indiana University and became a pediatric nurse practitioner certified by PNCB. She continued to work in the neonatal intensive care unit as a nurse practitioner while also working at a low income pediatric health clinic for Elkhart County's health department. She is currently credentialed to practice at Memorial Hospital of South Bend, Elkhart General, and St. Anthony Hospital in Michigan City and is also the coordinator for neonatal resuscitation at one facility. Ms. Cavinder has teaching experience at both the undergraduate and graduate levels. She has taught pediatric nursing to undergraduate students at Bethel College prior to becoming a Clinical Assistant Professor at Valparaiso University. Currently she teaches undergraduate students in obstetrics and pediatrics in simulation and clinical settings, family nurse practitioner students, and health care leadership students. Christina is member of ANA, ISNA, IPN, GSNA and NAPNAP serving on their palliative care committee. She is a member of Sigma Theta Tau International-Zeta Epsilon chapter. Christina became interested in neonatal palliative care and nurses' moral distress when two infants' hospitalization in a neonatal intensive care unit caused her to suffer from moral distress. She believed even though each infant's course was different, they and their families would have benefited from a more structured palliative care protocol.

ACRONYM LIST

AACN: American Association of College of Nursing

ANA: American Nurses Association

AWHONN: Association of Women's Health, Obstetric and Neonatal Nurses

APA: American Psychological Association

APN: advanced practice nurse

APP: American Academy of Pediatrics

COH: City of Hope

DVD: digital video disc

EBP: Evidence-based practice

ELNEC: End-of-Life Nursing Education Consortium

IOPO: Indian Organ Procurement Organization

JBI: Joanna Briggs Institute

MDS: Moral Distress Scale

NICU: neonatal intensive care unit

NiPCAS: Neonatal Palliative Care Attitude Scale

RCTs: randomized controlled trials

WHO: World Health Organization

APPENDICES

Appendix A

Guideline for Palliative Care Protocol

Phases	Infant Activity	Responsibilities	Goal
1 Pre-resolution Phase	Infant has fluctuating or uncertain medical status with use of life-sustaining treatment.	Care team is formed including, but not limited to, the attending physician, primary nurse, nurses caring for infant, social worker, chaplain, lactation consultant, parent support coordinator, and unit director. Any staff member may attend care team meetings at any time. After care team is formed, a family meeting with team is arranged as soon as family is available.	The care team will discuss possible outcomes and plans for infant with the family. Written plan is developed as a resource for all caretakers. Needs assessment for family is completed to ensure all aspects of infant's care are addressed. Needs of the family are assigned to corresponding care team members. Family given contact information if needs arise after meeting with care team. Medical and nursing treatments are performed in accordance with the consensus of the care team' plan.
2 Introduction of Palliative Care	Infant's condition is incompatible with life or is life-limiting.	Care team meets with family to determine exact treatment and support provided to infant.	Exact treatment and support for infant is documented for all caretakers. Meetings with family may occur at any time family or care

			takers desire. Care is directed at comfort for infant including, but not limited to pain control. Attending physician will write orders regarding resuscitation as directed by the family. Family is reassured they are not abandoned by the care takers. Enteral feedings and parental fluids will be adjusted per family request. Infant and family are moved to a private location if possible per family desires. Visitation is adjusted to allow per family request. Memories are created for families such as bathing infant, pictures, and holding. Avoid terms such as "withdrawing support."
3 Initiation of Palliative Care	Infant is receiving comfort care.	Care team continues to meet with family to assess infant's needs.	Medical and nursing treatments are provided per family's requests. Indiana Organ

			Procurement Organization (IOPO) is contacted if appropriate. Discuss with family possible infant outcomes. Continue supportive care of infant per family request. Document infant's care plan for all care takers. Continue goals from phase 2.
4 Dying Process	Infant condition is deteriorating despite medical treatments.	All care takers provide support to the infant and the family. Care team meeting with family to assess infant's needs.	Needs assessment completed on family. Visitation rules are assessed and changed per family desire. Medical and nursing treatments are given per family request. Comfort care including, but not limited to pain control is given. Organ donation is performed if prearranged and applicable. Private facilities are offered to the family. Spiritual support is given if family desires. Remove monitors and other sources of noxious stimuli if

			applicable. Ensure family care takers are always available. Continue to make memories for family including hand/feet prints and pictures.
5 Death	Infant does not possess a heart rate.	Caretakers provide family with supportive care.	Family is allowed to be with infant for extended time. Spiritual support is provided per family request. Physician to pronounce time of death.
6 Bereavement	After infant's death has occurred.	Care team meeting to debrief after death. Care takers meet with Employee Assistance Program if needed.	Provide family with mementos such as pictures, clothing, disposable care items, and blankets. Arrange pictures from "Now I Lay Me Down to Sleep." Parent Support Coordinator to call family 1 week after death. Obituary information provided to all care takers.

Note. Adapted from "Implementing a Palliative Care Program in a Newborn Intensive Care Unit," by G. Gale and A. Brooks, 2006, *Advances in Neonatal Care, 6,* p. 46-49.

Appendix B

SUBJECT: Palliative Care & Bereavement Guidelines & Protocol	REFERENCE # 4-2
DEPARTMENT: NICU	PAGES 5
Last Revision: 5/16/2006	EFFECTIVE: 7/1989
APPROVED BY: NICU Medical Director & Unit Director	REVISED: REVIEWED:

PURPOSE:

- To provide guidelines for nurses providing palliative and bereavement care to families and their infant.

PROTOCOL:

- **Dealing with an infant dying is difficult for both staff and families. Staff members need to keep an open mind when dealing with families and their religious and cultural beliefs. Remember each individual, religion, and culture deals with death differently, and staff should be sensitive to differences. Always ask the family what they would like to have done for their infant. Suggestions can be offered, but always respect the families wishes.**

- Palliative care and bereavement care are divided into 6 different phases. Each phase has different responsibilities for staff.

- A care team is formed during the first phase which will assist the family during the palliative care and bereavement process. This care team is comprised of the attending physician, primary nurse, social worker, parent support coordinator, chaplain, lactation consultant, and other staff members who would like to be involved in the palliative care process.

- The care team will meet with the family during the first phase and continue to be involved with the family throughout the palliative care and bereavement process. A written communication tool of the meeting filled out by the physician will be on the infant's clipboard to assist other staff on the care team's decisions in order to provide consistent care to the infant and the family.

PHASE 1 (PRE-RESOLUTION PHASE):

- This phase is defined as the time when an infant's status is uncertain and may not improve with life-sustaining treatments.

- A care team is formed and a meeting is scheduled with the family as soon as the infant's condition is determined to be unstable. Any staff member may initiate the meeting of a care team.

- A translator is invited to attend the care team/family meeting if the parents require one to understand the proceedings.

- Parents may choose anyone they wish to attend the meeting. These extra people may help the family make decisions or understand situations.

- Possible treatments and interventions will be discussed with the family. Possible outcomes of the infant will be addressed with the family including providing written materials to aid in the family's understanding if available.

- Families are encouraged to voice record the care team meeting. If they are unable to record the meeting, a written recording of the meeting will be offered to them.

- Psychological support will be provided to the family.

- Family's wishes will be supported. Family is informed they may have another meeting with the care team at any time. Family is encouraged to spend as much time as possible with the infant including providing infant care.

- Documentation of the proceedings of the care team/family meeting will be placed on the infant's clipboard as soon as possible.

- Emphasize "specialness" of infant, referring by name and gently handling.

PHASE 2 (INTRODUCTION TO PALLIATIVE CARE):

- This phase is defined as the time when an infant's condition is life-limiting.

- The care team will meet with the family when an infant has met the definition of this phase or the family has expressed a desire to discuss palliative care. Any staff member may attend the meeting. Family may have any persons they desire to attend the meeting. A translator to the meeting will attend if applicable.

- Assure family they will not be abandoned during this process. Do not use terms such as "withdrawal of treatment" or "withdrawal of care." Use lay term when talking with family.

- Assure family they may change their desires at any time and may request another meeting with care team at any time.

- Parents will voice record or receive a written copy of proceedings of care team meeting to reinforce choices after the meeting.

- Medications will be ordered and provided for the infant for comfort and pain.

- Infant's treatments and interventions will be guided by family's desires after meeting with the care team. Interventions included in the discussion will include, but are not limited to, respiratory support, parental support, enteral feeding, and medications. These desires will be documented in the infant's clipboard.

- Physician will write orders to reflect parents' desire as applicable.

- Lactation consultant with talk with mother about continuing to provide breast milk, suppressing breast milk production, or donating breast milk.

- Provide family with contact information if they have questions after the meeting has concluded.

- Allow parents to continue to provide infant care if possible. Assist in making memories by taking photos during care or while holding infant.

PHASE 3 (INITIATION OF PALLIATIVE CARE):

- This phase is defined when the infant has a life-limiting condition and the family has chosen palliative care.

- Infant's care is focused on comfort and supportive care. Pain medication is given as needed. Invasive and non-beneficial treatments and interventions are reduced or eliminated.

- Infant's care is directed by parental desires. Parents may choose to change care at any time.

- Infant is moved to a private location if parents desire. Provide privacy screens if parents do not wish to move their infant. Remind them the infant can be moved at any time they wish. Visitation rules are flexible to allow for family and family's support people may visit when desired by the family.

- Discuss family's beliefs, expectations and fears. Provide support to family during this difficult time.

- Continue to allow parents to provide infant care if possible. Assist in making memories for the family by taking pictures during care and providing mementos to the family.

- Care team may meet with family if they have any questions or the infant's condition changes. Care team members will continue to remain in contact with family.

- Staff is updated in any changes in plan of care for infant by the communication tool.

PHASE 4 (DYING PROCESS):

- This phase is defined as the time when the infant's condition is deteriorating.

- Infant's care is directed at comfort and pain management. Invasive and painful treatments and interventions cease. Noxious alarms are silenced or turned off if applicable. Comfort measures include:

    - Privacy
    - Dim lighting
    - Warmth
    - Holding
    - Private room per parent's choice
    - Minimal vital signs
    - Attentive nursing care (nurse has lighter assignment)
    - Quiet environment
    - Pain medications

- Family is encouraged to spend time with infant and provide care if possible in a private area. Visitors are allowed to remain at bedside if family desires. Encourage holding by parents for as much as possible.

- Psychological support is provided to the family by the staff including the social worker, parent support coordinator, and the chaplain. Offer baptism to family if they desire and this event has not occurred yet. If a chaplain or clergy is not available and the infant's death is eminent, a staff member may perform baptism. Supplies including a script are available in the bereavement cabinet.

- Be respectful and supportive of the family's culture and rituals.

- Remove supportive technology per family's desires. Explain rationale for removal versus continuation of supportive technology.

- Remove tape from face with adhesive remover assistance when oral tubes are removed so family can view infant's face.

- Notify IOPO regarding impending death of infant.

- Charge nurse will make staff members aware of grieving family by placing a "rose" card on back door to NICU, the front door, the front counter by the ward clerk, and on the assignment board.

- Maintain family's privacy. Intercept phone calls at unit desk. Screen all visitors in the unit or entering the unit. Minimize entrance to NICU whenever possible.

- Charge nurse will notify primary nurses if infant's death is eminent.

- Staff should be respectful to the family by providing privacy, refraining from loud talking and laughing.

PHASE 5 (DEATH AND FINAL CARE):

- This phase is defined when the infant no longer has a heart rate and the physician has pronounced death.

- Care team members remain in contact with family for any needs they may require.

- Allow family to participant in bathing or dressing the infant's body.

- Provide family with pictures, CD of pictures, clothing, and other mementos. Place mementos in a memory box. Include hair wisp, hand prints, feet prints, measurement care, shell with holy water, and bracelets per parents' requests. Bereavement supplies are in the cabinet marked "Bereavement" in the charge nurse office.

- Physician will approach family regarding autopsy.

- Allow family to be with infant's body for their desired length of time.

- Make molds of the infant's hands or feet. If family leaves before molds or other mementos are complete, keep items together and label with infant's name. Give items to parent support coordinator to deliver to the family.

- Provide family with list of funeral homes if they desire.

- Provide support to NICU staff by allowing time with infant, quiet area to complete charting or paperwork, assist with patient assignment, and peer support.

PHASE 6 (BEREAVEMENT):

- Provide funeral arrangement notification to the staff. Unit management makes arrangement for coverage in unit to allow involved staff to attend funeral.

- Parent support coordinator calls family within 2 weeks after death to provide support to the family.

- Parent support information is provided to the family.

- Care team meets without family after death to debrief.

- Care team will offer meeting with family if they desire to debrief after death and again at 3 months after infant's death. Family may bring anyone to the meeting per their desires.

- Staff members who require more support after infant's death are referred to the Employee Assistance Program.

- Allow staff to hold memorial service for infant to share thoughts and memories. Family is invited to attend memorial service.

- One year after infant's death the parent support coordinator will send a card to the family to let them know the staff members are still thinking about them.

Appendix C

Infant Care Team Plan

Date:

Team members present:

Full code:________ Individualized care:____________

Respiratory:

Cardiac:

Medications:

Pain Management:

Parental Support:

Enteral Feedings/IV Fluids:

Visitation Guidelines:

Special Needs:

Consults: