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Development of an Evidenced-Based Bereavement Guideline in the Neonatal Intensive Care Unit: A Quality Improvement Project

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Abstract

Background: The uncertainty of how to effectively provide bereavement support to families in the neonatal intensive care unit (NICU) is a cause of stress in nurses, often leading to feelings of sadness, grief, and professional inadequacy. One way to address this need is to provide support to nurses in the form of protocols and guidelines. The use of a guideline or protocol takes the uncertainty away from the nurse and assists them in ensuring that they are providing adequate support, especially among nurses inexperienced in providing bereavement support.

Methodology: Using a pre- and post-test design, the Plan, Do, Study, and Act (PDSA) cycle was used to guide this quality improvement project. Participants were recruited via purposive sampling method. Twelve nurses were included in the study. Participants were educated on the developed NICU specific evidenced-based bereavement guideline via a one hour, online educational session. Participants were asked to fill out a demographics and professional form and a pre- and post-intervention survey, the Bereavement/End of Life Attitudes About Care of Neonatal Nurses Scale (BEACONNS) by Engler et al. (2004). The BEACONNS assesses comfort, role, and involvement in bereavement and end of life care.

Results: A paired samples t-test indicated the post-intervention mean comfort scale scores, M = 4.17, SD = 0.35, and post-intervention mean role scale scores, M = 4.23, SD = 0.41, were significantly higher than the pre-intervention mean comfort scale scores, M = 3.33, SD = 0.72, with a t-score of 3.70 and p-value of 0.003 ($p<0.05$), and pre-intervention mean role scale scores, M = 3.77, SD = 0.52, with a t-score of 5.70 and p-value of 0.0001 ($p<0.05$). A Wilcoxon signed ranks test shows that the post-intervention involvement scale median scores, Median = 5, was significantly higher than the pre-intervention involvement scale median scores, Median = 4.25, with a Z-score of 2.45 and p-value of 0.01 ($p<0.05$).

Conclusions: The positive increases in mean scores on the BEACONNS reflect that the implementation of a bereavement guideline was effective in increasing nurses' comfortableness in providing bereavement support to families in the neonatal intensive care unit. The results of the QI project reflect the need for education amongst nurses about bereavement interventions and its importance to families experiencing neonatal loss.

Keywords: bereavement support, guideline, neonatal intensive care unit (NICU), neonatal loss

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I. Introduction

Problem Identification/Background

Intensive care unit nurses care for the most critically ill patients, some of whom die despite intensive care. In this situation, nurses must provide support to the bereaved families. Despite the education in nursing school and training on the job, there is a deficiency in readiness and competencies voiced by nurses in providing bereavement support, especially among novice nurses (Arbour & Wiegand, 2014; Popejoy et al., 2009). Providing bereavement support, while lacking the confidence to provide bereavement support to families, can cause undue stress (Stayt, 2007). Studies have shown that nurses reflect on the quality of bereavement support they provided to families and question if their care has affected the families positively (Nelson et. al, 2006; Hansen et al., 2009; Popejoy et al., 2009). In general, bereavement support in the intensive care unit is a stress inducing experience for nurses, especially if they lack experience or education regarding bereavement support.

The Neonatal Intensive Care Unit (NICU) is one of the most highly specialized intensive care units caring for the sickest newborns. In 2016, in the United States, the total infant mortality rate was 5.87 deaths per 1,000 live births, with 3.88 of the deaths occurring during the neonatal period (Centers for Disease Control and Prevention [CDC], 2018; Ely et al., 2018). According to the CDC (2018), the five leading causes of neonatal death are low birthweight, congenital malformations, or maternal complications, as well as placenta, cord, and membrane complications, and bacterial sepsis. The death of a neonate demands differing bereavement support for families. Parents never got to take the neonate home and create memories with him or her outside the hospital; therefore, bereavement support for families experiencing neonatal loss differs. Neonates may come straight from the delivery room to the neonatal intensive care unit. Furthermore, due to the frailty of neonates and the necessary machines attached helping the

neonate survive, parent-neonate interactions are limited. Parents who have experienced the death of a neonate have also expressed lack of empathy and support from friends and family due to a lack of attachment to the neonate. Therefore, it is imperative for nursing staff to provide quality bereavement support to families in the neonatal intensive care unit as they cared for and have known the neonate (Gilbert, 1997).

Scope of the Problem

According to Engler et al. (2004), a majority of neonatal nurses were comfortable in many aspects of bereavement support, but it has to be noted that there was a correlation seen between increased comfort and years as a NICU nurse. Furthermore, eighty-two percent of the respondents stated that their NICU had a policy, protocol, clinical pathway, or something similar guiding them in the care of critically ill infants and/or dying infants and their families (Engler et al., 2004). Therefore, in hospitals where there is an influx of new graduate nurses, nurses new to the neonatal intensive care unit, or hospitals lacking a guideline regarding bereavement support in the NICU, nurses may not be as comfortable in providing bereavement support to families.

In a study by Moon Fai and Gordon (2009), out of 153 nurses, 84.1% believed that a clear policy for bereavement support specific to infants was important, while 83.7% of nurses deemed important the opportunity to join a training program in bereavement support. The main problem nurses encounter regarding bereavement support for families were the various and complex roles they are required to undertake (Raymond et al., 2017). Due to the highly specialized nature of the NICU, especially in terms of bereavement support services for the families, NICU nurses are subject to nurse burnout, stress, and compassion fatigue (Braithwaite, 2008; Meadors & Lamson, 2008). In a study done by Ewing and Carter (2004), some of the major contributors for development of nurse burnout in the NICU were dealing with grief, loss,

and bereavement. According to Braithwaite (2008), new nurses, who are young and highly educated, experience burnout early in their careers, specifically when starting in the NICU, with 50% of new graduate nurses leaving their positions within the first year. There is already a nursing shortage with a projected need of 11 million additional nurses (Haddad et al., 2020). Losing nurses to burnout is not an ideal situation.

Consequences and Significance of the Problem

Nurses play an important role in providing bereavement support to families experiencing a neonatal loss because the hospital may be the only place their child has known as "home" (Engler et al., 2004). Nurses providing thoughtful and patient and family centered bereavement support is crucial because the quality of the bereavement support given by the nurses may play an important part in the family's response to the infant's death (Engler et al., 2004). The experience of bereavement is known to be one of life's great stressors resulting in an increased risk for mortality and development of physical and psychological problems (Buckley et. al, 2015; Valks et al., 2005). However, the bereavement experience and its subsequent aftermath can be positively influenced by a nurse's manner and preparedness during the crucial time (Buckley et al., 2015).

When mothers and fathers experience perinatal death, compared to the general population where grief recovery takes six to 12 months, grief recovery can take as long as five to 18 years (Bonnano & Kaltman, 2001; Gravensteen et al., 2012). Furthermore, in addition to the normal grief reactions following loss of an infant or neonate, mothers may experience post-traumatic stress disorder following pregnancy (Koopmans et al., 2013). Perinatal death increases the risk for anxiety and depression, alcohol use in fathers, and decreased marital satisfaction (Badenhorst & Hughes, 2007; Vance et al., 2002). Younger siblings may also experience feeling like they are

the one to blame for the sibling's death, while older siblings may feel a severe sense of loss (Cain et al., 1964; Badenhorst & Hughes, 2007). Parent-infant attachment may also be disrupted in the subsequent child due to the trauma of losing the neonate or infant (Badenhorst & Hughes, 2007).

Needing to provide bereavement support to parents in the NICU contribute to nurses experiencing nurse burnout, stress, and compassion fatigue, which can lead to nurses developing psychological and physical ailments as well as leaving their current positions (Braithwaite, 2008; Meadors & Lamson, 2008). Having nurses with burnout leads to risks related to safe patient care (Vahey et al., 2004). Furthermore, due to the high demands of nurses in the NICU, retainment rather than recruitment of staff, is an issue when dealing with nurse burnout, and can cost organizations money (Braithwaite, 2008). Nurse burnout is also associated with high levels of absenteeism in the workplace (Eriksson et al., 2008). In addition to effects the organization may feel due to burnt out nurses, nurses' own personal and professional relationships may suffer when they are unable to cope with the symptoms of being burnt out (Braithwaite, 2008).

Proposal Solution

This DNP candidate proposed to develop a standardized guideline for bereavement support in the NICU to increase nurses' comfortableness in providing bereavement support to families affected by neonatal loss. Nurses are known to wear many hats when a person experiences a hospital stay. Nurses perform the role of educators, advocates, providers, and many more within a day's work. Being consistently considered one of the most trusted professions by the public, one can assume that patients and their families have faith that the nurses they encounter will always have their best interest at heart and are knowledgeable in the care they provide (Reinhart, 2020). However, nurses have many role responsibilities and if they

are not comfortable performing them, it can contribute to increased stress and anxiety. Increased anxiety and stress in critical care nurses can be contributed to high level of responsibility, high patient acuity, working with advanced technology, and being involved in morally distressing situations (Epp, 2012). Nurses often voice feeling inadequate when providing care and support to patients and their families due to their own personal high standard of care and expectations of themselves, which can lead to increased stress and anxiety in nurses due to the inability to meet those said expectations (Stayt, 2007).

One way to lessen the contributors to stress and anxiety in nurses is through the use of clinical protocols or guidelines because nurses will feel more comfortable having guidance in performing certain procedures than having to think about what must be done. Clinical protocols or guidelines help guide nurses in performing care or procedures. Clinical protocols or guidelines can ensure nurses that they are doing interventions within their scope of practice and helps nurses define their role and standard of care that they are able to achieve and complete (Manias & Street, 2000; Stayt, 2007). As evidenced by the Center for Disease Control and Prevention's numerous prevention guidelines, such as prevention of central line-associated bloodstream infection guideline and prevention of catheter-associated urinary tract infection guideline, which are implemented in a majority of hospitals across the country, the use of guidelines or protocols ensure consistency in quality of care and increases nurse knowledge and confidence in handling common situations they are faced with in the hospital, such as bereavement support.

There has been a positive correlation between nurses' comfortableness in providing bereavement support, and improved quality of bereavement support through the use of a standardized NICU bereavement program through clinical pathways or protocols (Hansen et al., 2009; Morgan, 2010; Van Mol et. al, 2020). The quality of the bereavement experience for

parents and families can be enhanced when nurses are more comfortable in providing bereavement support. Furthermore, the use of clinical guidelines or protocols provides nurses a form of organizational support by ensuring that evidenced based practice is being followed. A clinical guideline or protocol may increase nurses' comfortableness by clearly defining the roles and interventions known to be effective in providing bereavement support.

II. Summary of the Literature

Search Strategy

A literature review was conducted to analyze primary research studies, meta-analysis, and systematic reviews that are relevant to the clinical question: Does the use of a bereavement guideline increase nurses' comfortableness in providing bereavement support to families in the Neonatal Intensive Care Unit (NICU) as compared to nurses' comfortableness before the use of a bereavement guideline?

The two databases used to conduct the literary search were Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed through Florida International University (FIU) library system. The search terms used in the search for literature were bereavement care or bereavement support, neonatal intensive care unit, NICU, baby unit, newborn intensive care, protocol, procedure, policy, practice, guideline, and care bundle. Search limitations included studies that were published within the last ten years, written in the English language, peer reviewed, and provided the full text of the literature. Initially, the search on CINAHL yielded a total of 105 results; however, when search limitations were applied, 45 articles were retrieved. In the PubMed database using the same search terms, the search initially yielded 867 results. When search limitations were implemented, the total articles numbered 67. After carefully

analyzing the title and abstract of the results from PubMed and CINHAL, the total articles related to the proposed PICO question were 20.

Nurses' Feelings Related to Neonate Death and Bereavement Support

Despite the emphasis placed on the effects of bereavement support on patient families, importance must be placed on the nurses' feelings and confidence in providing the bereavement support because the quality of the bereavement support given depends on nurses' comfortableness. Parents have acknowledged the importance of good communication, strength in provider's technical skills, and anticipatory guidance for satisfactory bereavement support relating to perinatal death, this emphasizes the need for staff nurses to have refined skills in dealing with these situations (Baughcum et al., 2020).

When dealing with perinatal death, nurses can experience profound psychological and physical symptoms (Shorey et al., 2017). Physical and psychological symptoms of nurses mimic the symptoms parents experience when dealing with grief such as headaches, irritability, fatigue, feeling guilty, demotivated, and post traumatic disorder symptoms (Shorey et al., 2017). However, nurses are also in a position where they critically analyze their own work and whether they did a good job in providing bereavement support to the families (Shorey et al., 2017). The negative feelings associated with having to provide bereavement support to families were more common in younger nurses, lacking in experiences dealing with death, junior ranking nurses, having insufficient communication skills, those lacking in knowledge and training of bereavement support, those feeling a lack of support from colleagues and the organization, and with personal feelings of inadequacy (Shorey et al., 2017). Repeated exposures to neonatal death and having to support families affected can lead to nurse burnout and the urge to leave the profession (Shorey et al., 2017).

Bereavement Guidelines

One way to combat the feeling of guilt and the worry of whether nurses have done a sufficient job in providing bereavement support to families is through education and training (Gardiner et al., 2016; Levick et al., 2017; Ratislavová et al., 2019; Shorey et al., 2017). A standardization of the bereavement process exhibited by a protocol or guideline has been effective in educating and training staff to provide evidenced-based interventions to address the needs of parents after experiencing a neonatal or infant loss (Beltran & Hammel, 2020; Boyle et al., 2020; Hutti & Limbo, 2019; Levick et al., 2017; Salgado et al., 2021). The protocols or guidelines provide nurses with support in being able to provide bereavement support of the highest quality as evidenced by research. The use of a guideline or protocol takes the uncertainty away from the nurse because they have a checklist to rely on ensuring that they are providing adequate support, especially among the nurses who lack experience in providing bereavement support (Wool, 2013).

In a study by Lewis (2012), 56% of NICU nurses did receive end-of-life care education with 77% of the nurses deeming that the education was ineffective. The uncertainty of how to effectively provide bereavement support to families is one of the causes of major stress in nurses, often feeling sadness, grief, and professional inadequacy (Gibson et al., 2018). Due to the high levels of stress encountered in the NICU, nurses are susceptible to nurse burnout and compassion fatigue (Beltran & Hammel, 2020). In order to provide better palliative care, which encompasses bereavement support, nurses have voiced a need for concrete guidelines in the delivering of palliative care (Beltran & Hammel, 2020). According to Wool (2013), 302 healthcare providers have agreed that the development and implementation of palliative care guidelines was associated with higher confidence in providing neonatal palliative care; therefore, this DNP

candidate wants to apply a bereavement support guideline to increase nurses' comfortableness in providing bereavement support. Having higher confidence and comfortableness in providing bereavement support to families may alleviate some stress nurses experience in the NICU.

Evidenced-Based NICU Bereavement Support Interventions

Evidenced based bereavement support interventions include offering parents the ability to do memory making, ensuring support for parental caregiving, photographs, and follow-up support (Ainscough et al., 2019; Boyle et al., 2020; Coombs et al., 2017; Martel & Ives-Baine, 2018; Paize & MacWilliam, 2020; Salgado et al., 2021; Thornton et al., 2019; Wool & Catlin, 2018). In order to maximize the effectiveness of the recommended bereavement support services, a multidisciplinary and collaborative approach must be followed. However, since nurses work closely with the patients and families and are often the first provider to be there after neonatal death, nurses will often be the ones to begin and facilitate the bereavement process.

Memory Making

Memory making in the form of locks of hair, hand molds, hand prints, foot prints, keeping of the identification bracelet of the patient, and blankets is the well-studied recommendation concerning perinatal bereavement (Wool & Catlin, 2018). In a study by Paize and MacWilliam (2020), out of all the families who received a memory box, 94% of the parents found the box helpful. Memory making influences the psychosocial process of healing for parents because the memory making process provides significance of the child's brief life (Thornton et al., 2019). For memory making to be effective, guidance and parental involvement must be included. Parents must be supported and encouraged throughout the memory making process to ensure that it would be a reflective experience (Thornton et al., 2019). Parents have stated that having mementos reassured that their experience with their child was valid and their

baby was a real person worthy of being remembered and mourned (Thornton et al., 2019). The concept of their infant being a real person may be a hard concept to grasp for parents because they never got to make memories with the child outside the hospital and due to the fragility of the child, parent-child interactions might have been limited.

Parental Caregiving

When an infant or neonate dies, parents experience more than just the loss of their child, they lose their dreams and expectations of becoming parents, the plans they had for their baby, and their expectations of growing their family (Salgado et al., 2021). Furthermore, a death of a child is a concept hard to process because the current ideal situation is for children to outlive their parents. Therefore, another evidenced-based intervention is to allow parents to perform parental caregiving with their deceased child, such as holding, rocking, and cuddling the infant, and assisting in bathing, dressing, and feeding the infant (Wool & Catlin, 2018). Having the child close to the parents has shown to be a valuable and cherished experience, decreases their pain, and contributes to healthy mourning (Salgado et al., 2021).

Photography

Though taking pictures of one's deceased may not be considered "normal" practice, in bereavement support for families experiencing neonatal or infant loss, photography is one of the recommended practices to help with grief (Sieg et al., 2019; Thornton et al., 2019; Wool & Catlin, 2018). Parents who were able to have an ample number of photographs deem the experience of getting photographs a positive experience compared to parents who refused photographs and regret their decision (Thornton et al., 2019). Similar to memory making, having photographs reinforces that their child was born, and the significant grief felt is real (Thornton et al., 2019). Furthermore, a study by Martel and Ives-Baine (2018), which is one of the few studies

examining nurse feelings providing a specific bereavement intervention, found that nurses felt that being a part of bereavement photography is a positive experience as they are able to facilitate special moments between the parents and their newborns. Martel and Ives-Bain (2019) discovered that bereavement photography with nurse involvement can be considered relationship-based practice as parents and nurses are required to work collaboratively to make meaning of their experience.

Follow-Up

Support for families experiencing infant or neonatal loss does not end after the family leaves the hospital. Parents have voiced feeling abandoned and alone after leaving the hospital (Baughchum et al., 2020). Since nurses are one of the healthcare providers who have cared for the infant and witnessed their journey, parents feel a special connection and appreciate the follow-up call (Baughchum et al., 2020). In a study conducted by Levick et al. (2017), one parent stated that they appreciated when the neonatologists tried reaching out via phone, calling twice and leaving a voice message, which comforted her though she did not need to talk. In addition, a grief support program developed by Yilidz and Cimete (2017), which followed parents after the death of a newborn for 12 months, had a positive effect on grief intensity of parents in the long term. Unfortunately, some institutions lack enough resources to create a comprehensive bereavement support follow-up program; therefore, at a minimum, grief support in the community level should be provided to families (Baughchum et al., 2020).

Gaps/Recommendations for Future Studies

Several studies have been conducted focusing on bereavement support needs of the parents and how they felt different interventions helped in their mourning. However, there are only a select number of studies focused on nurses' feelings in providing bereavement support. In

regard to the PICO question proposed, there were no studies found examining the effects on nurses when a protocol or guideline is in place to help them provide and facilitate bereavement support to families experiencing neonatal loss. While there are articles detailing recommended practices to include in a bereavement protocol for the NICU, there is a gap in the research regarding experience of nurses using a bereavement guideline.

III. Goal, PICO Clinical Question, and SMART Outcomes

The primary goal of this DNP project was to develop a bereavement guideline in the NICU that will increase nurses' comfortableness in providing bereavement support to families in the NICU experiencing neonatal loss.

PICO Clinical Question: Does the use of a bereavement guideline increase nurses' comfortableness in providing bereavement support to families in the neonatal intensive care unit (NICU) as compared to nurses' comfortableness before the use of a bereavement guideline?

Population: NICU nurses providing bereavement support

Intervention: Development and implementation of a NICU specific bereavement guideline

Comparison: NICU nurses before the development and implementation of the NICU specific bereavement guideline

Outcome: Increase nurses' comfortableness in providing bereavement support to families experiencing neonatal loss

Goals and Outcomes (SMART)

In the implementation of the proposed DNP project, SMART goals were used. The goals should be specific, measurable, achievable, relevant, and time-sensitive (MacLeod, 2012). Specific

means setting goals that are well defined and ensures wording that leaves no doubt to what needs to be accomplished (MacLeod, 2012). Measurable means setting goals that are quantifiable (MacLeod, 2012). Achievable means setting goals that are reasonable to achieve considering the available time, talent, and resources (MacLeod, 2012). Relevant means setting goals that are appropriate to the organizational goal (MacLeod, 2012). Lastly, time-sensitive means setting goals with a predetermined deadline (MacLeod, 2012).

- A bereavement guideline specific to the NICU was approved by the hospital for use in a quality improvement project to increase nurses' comfortableness in providing bereavement support to families following neonatal loss in collaboration with the interdisciplinary team by July 20, 2021.
- After development of the bereavement guideline, the quality improvement project was implemented during the month of August 2021 following FIU Institutional Review Board approval.

The current strengths, weaknesses, opportunities, and threats (SWOT) identified at this clinical site are as follows along with solutions to the weakness and threats to this project:

Strength: This year there was a creation of a Palliative Care Team and there has been increased focus on palliative and bereavement support in the hospital. Practice group in the hospital is creating a project focused on palliative care and bereavement support for neonates and their families with the intention to present at the Vermont Oxford Network. This quality improvement project is intended to be a part of the project.

Weakness: Social work and child life specialists have independent protocols when bereavement support is needed, but the protocols are not published in policies and procedures of the hospital. Though there is a recommendation of keeping keepsake boxes for one year, just in case parents

initially refuse them; however, there is no space in the NICU to place bereavement support supplies. NICU nurses at the hospital where the quality improvement will take place are exposed to an average of 18 deaths a year from the years 2017-2020 according to the risk management office where the study will be conducted.

Opportunities: More emphasis has been placed on palliative care/bereavement support because of the creation of a pediatric advanced care team, which has a focus on palliative care. Due to the high turnover and increase in hiring of new staff, initial training of the new staff can include the new bereavement protocol to change current practice.

Threat: Current staff, especially those with extensive experience providing bereavement support to families experiencing neonatal loss, may be resistant in using the bereavement guideline and instead relying on one own's experience. During the training of new staff by current staff nurses, those who were not accepting of new practice may not use the bereavement guideline when providing bereavement support to families experiencing neonatal loss, losing reinforcement of the guideline.

Organizational Assessment

The quality improvement project was conducted in a Level III D 40-bed referral neonatal intensive care unit (NICU) located in a freestanding children's hospital in Miami, FL. The unit provides care for more than 800 critically ill newborns each year, admitting approximately 430 infants per year. The unit admits patients from NICUs at national and international locations, as well as patients admitted through the emergency room and outpatient clinical services within and outside the hospital's health system network. Most of the neonates admitted to this hospital were born at community hospitals after a premature or high-risk delivery. The hospital is a Magnet hospital accredited by the American Nurses Credentialing Center's Magnet Recognition Program

and its neonatology program ranks #49 in *U.S.News & World Report's* 2019-20 “Best Children's Hospitals” rankings. In between the years 2017 and 2020, the NICU has witnessed an average of 18 neonatal deaths. The table below shows the total number of infants deceased each year as well as how many infants had Allow Natural Death Orders during the years 2017 through 2020.

Table 1. Infant Deaths with “Allow Natural Death” Order (Period 2017 to 2020) in a Freestanding Children’s Hospital.

Year	“AND”	Deaths	%
2017	25	27	92.6
2018	12	19	63.2
2019	12	17	70.6
2020	6	9	66.7

Data provided by the office of Risk Management at freestanding children’s hospital.

The NICU currently employs 110 nurses with 44% direct care RNs holding specialty nursing certifications and 92% direct care RNs with BSN, MSN, or PhD degrees. Furthermore, as of 2021, in this NICU, 37% of RNs have 5 years or more experience and 15% of RNs have 1 year of experience.

IV. Definition of Terms

Bereavement: Following loss by death of a close loved one or significant other (Bartellas & Van Aerde, 2003; Lemmer et al., 1991)

Guideline: Information intended to advise people on how something should be done or what something should be (Cambridge University Press, 2021)

Neonate: Is a child under 28 days of age (World Health Organization, 2021)

Neonatal Death/Loss: Deaths among live births during the first 28 completed days of life (Guevvera, 2006)

Newborn: Recently born (Merriam-Webster, 2021)

Perinatal Bereavement: The period that follows loss of a pregnancy or loss of an infant through death (Fenstermacher & Hupcey, 2013)

V. Conceptual Underpinning and Theoretical Framework of the Project

The proposed QI project is based on Bowlby's Theory of Attachment. According to Bowlby (1979), humans are biologically inclined to seek out "attachment figures," who are likely to provide protection from physical and psychological threats, promote exploration of the environment, and encourage regulation of emotions. While this process is most important during early infancy, due to the immature abilities of infants to provide for themselves, Bowlby (1979) has claimed that attachment expands across the lifespan and manifests in times of need. With adult attachment, a physical "attachment figure" may not be necessary because mental "attachment figures" that develop through the internalization of the caring and soothing qualities of previous attachment figures can act as symbolic sense of comfort, support, and protection (Mikulincer & Shaver, 2007).

Prenatal attachment by parents to their unborn child has further been amplified through the use of medical technology, such as ultrasound and doppler (Mikulincer & Shaver, 2007). Therefore, prior to birth, the parents have been able to conceptualize the infant and anticipate how the infant will contribute to the life of the family, which, in some cases, can represent a hope for the future, a better life, or greater opportunities (Arnold & Gemma, 1994; Mikulincer & Shaver, 2007). When a perinatal loss occurs, an attachment figure (in this case, the neonate) may

be lost to the parents and can lead to unresolved grief (Mikulincer & Shaver, 2007). Therefore, bereavement support to this special population of parents experiencing neonatal loss is important.

VI. Methodology

The methodology used to guide this quality improvement project was the Plan, Do, Study, and Act (PDSA) cycle, also known as the Deming cycle (Crowfoot & Prasad, 2017). The PDSA cycle, which is highly used in the healthcare setting, consists of four phases in an effort to continually improve a process or product (Crowfoot & Prasad, 2017). The "Plan" phase consists of evaluating the current process, identifying potential areas of change, and formulating an outline of how the changes will be implemented (Crowfoot & Prasad, 2017). The "Do" phase consists of implementing the changes and observing and recording the effects of the change (Crowfoot & Prasad, 2017; Gillam & Siriwardena, 2013). The "Study" phase consists of taking the data obtained from the "Do" phase and analyzing the results to see if the change has made an improvement and how it can be further improved (Crowfoot & Prasad, 2017). Finally, in the "Act" phase, there is identification of changes to be made in the next PDSA cycle to improve the product or process (Crowfoot & Prasad, 2017).

A literature review was conducted to critically analyze systematic reviews, primary research studies, and meta-analysis that are relevant to the clinical question.
Interventions for bereavement support of families experiencing neonatal loss were identified by conducting a literature review to present the current knowledge and evidence on these topics. Since the focus of this project was to increase nurses' comfortableness in providing bereavement support to families experiencing neonatal loss, current literature focusing on NICU nurses' feelings towards providing bereavement support was identified.

In conjunction with performing the literature review, the DNP candidate performed an organizational assessment of the current practices at a level III D referral NICU. The DNP candidate found that there is currently no established guideline for nurses to follow when having to provide bereavement support to families experiencing neonatal loss. The DNP project team will collaborate and develop a NICU specific bereavement guideline.

The planning phase involves the following:

1. Study Design: This project used a pre-post design to evaluate the effectiveness of the bereavement guideline to increase nurses' comfortableness in providing bereavement support to families experiencing neonatal loss.
2. Setting: The quality improvement project was implemented at a level III D referral 40-bed NICU located in a freestanding children's hospital. The unit provides care for more than 800 critically ill newborns each year, admitting approximately 430 infants per year. The hospital is a Magnet hospital accredited by the American Nurses Credentialing Center's Magnet Recognition Program and its neonatology program ranks #49 in *U.S.News & World Report's* 2019-20 "Best Children's Hospitals" rankings. In between the years 2017 and 2020, the NICU has had an average of 18 neonatal deaths.
3. Sample and Sample Size: The NICU currently employs 110 full-time and part-time NICU nurses. This sample does not include float pool nurses and per diem nurses. The sample size for this QI project was 12 nurses.

   The inclusion criteria were full-time nursing staff who have their registered nurse (RN) license. Excluded were part time and per diem nursing staff who were not registered nurses.

4. Measurement Methods: The Bereavement/End of Life Attitudes About Care of Neonatal Nurses Scale (BEACONNS) (Engler et al., 2004) was used as the pretest and posttest survey. There are three parts to the BEACONNS scale. The first is a comfort scale identifying participants' degree of comfort with providing bereavement/end of life support. The second part is a role scale which assess participants' perception of their roles with families of critically ill and/or dying infants. The third part is an involvement scale which assesses how various factors influence participants' amount of involvement with patients' families with critically ill and/or dying infants. All three sections are on a Likert scale, with the comfort scale and the role scale ranges from very comfortable (5) to very uncomfortable (1), while the involvement scale ranges from very important (5) to very unimportant (1). The reliability of each scale was reported with a Chronbach's Alpha of 0.95, 0.85, and 0.81 for the comfort scale, roles scale, and involvement scale, respectively (Engler et al., 2004). In addition to the BEACONNS instrument, a demographic questionnaire was also given which included nursing experience with death, number of years of experience as a nurse, and nursing education.
5. Recruitment: This study utilized a purposive sampling method. In the NICU where this study was implemented, nurses can participate in councils that focus on a certain aspect of nursing (for example, there is a research council focused on conducting research or an education council focused on educating nurses on new hospital policies). This DNP candidate chose two councils, the education council and the quality council and asked the members to participate in the study in exchange for participation points for their respective councils.

6. Intervention: The DNP project team collaborated and developed a NICU specific bereavement guideline using evidenced-based practice. A PowerPoint was also developed explaining each step in the guideline. The objectives of the guideline focused on what nurses need to do when a neonatal loss occurs in order to better support the parents and consists of which disciplines need to be called first, memory making interventions, and post-mortem care and interventions.

    Once the guideline and educational PowerPoint was developed, the members in the education council and evidenced-based practice council were notified of the study and their ability to participate in exchange for participation points for their respective councils via employee email and during the monthly meetings. The potential participants notified this DNP candidate by email of their desire to participate in the study. Once the sample has been established, training dates and times was emailed out to the participants. Two sessions on day shift and two sessions on night shift were offered and times were scheduled to accommodate each shift. The training sessions were one hour. Due to COVID protocols, training sessions occurred via Microsoft Teams and surveys were completed using Qualtrics.

    Prior to the start of the training session, participants were asked to fill out the demographics and professional form and the pre-test BEACONNS survey. Each participant was assigned a code number in order to match the pre and post surveys for the paired t-test. Attendance was taken at the start of the training session for participation points. The guideline was introduced as well as the PowerPoint taking participants through each part of the guideline. After the completion of training, participants completed the post-test BEACONNS survey immediately after.

7. Data Analysis: Descriptive statistics was used to analyze demographic and professional data, as well as a samples paired t-test was used to test the difference between the results between pre- and post-intervention groups of NICU nurses regarding comfortableness in providing bereavement support.
8. Data Management and Protection of Human Subjects: Pre and post intervention surveys was confidential. Surveys did not ask for identifiable information but each participant was assigned a code number. An application for review by Florida International University (FIU) Institutional Review Board (IRB) was submitted in order to ensure research ethics and the protection of human subjects involved in this project. The clinical site accepted FIU IRB approval in order to conduct research. Adult online informed consent was given to participants stating the purpose of project, voluntary nature, right to withdraw without any negative consequences. Confidentiality of research subjects was protected through the use of code number on demographic and professional data and project instrument. All data was stored electronically in a password protected and encrypted computer in the DNP candidate's locked office. There were minimal risks with the exception of possible distress in discussion of neonatal death. The benefits associated with participation is an increase in neonatal registered nurses' comfortableness in providing bereavement support to families experiencing neonatal death.

VII. Results

Demographics

Twenty participants were recruited for this study and twelve completed the study. Participants were from a Neonatal Intensive Care Unit in a level III D referral 40-bed NICU

located in a freestanding children's hospital. Participants who completed the study predominantly identified as female. Most participants, 75%, were bachelor's prepared nurses. However, a majority of participants lacked experience in providing bereavement support and education on bereavement support in the form of continuing education or previous education in nursing school. Specifically, 50% of participants stated that they provide bereavement support in the NICU less than once a year. Eighty three percent of nurses stated that they have not received continuing education regarding bereavement support, and 66.6% of nurses stated that their nursing programs did not provide information/content regarding bereavement care.

Table 2. Demographic Characteristics of Participants

Characteristic	Frequency	Percentage
Demographics		
Gender		
Female	10	83.3
Male	1	8.3
Non-Binary/Third Gender	1	8.3
Ethnicity		
Asian	1	8.3
Black or African American	1	8.3
White	1	8.3
Hispanic	9	75.0
Professional		
Years of Nursing Experience		
<1 year	1	8.3
1-3 years	0	0.0
3-5 years	3	25.0
5-10 years	4	33.3
10-15 years	1	8.3
15-20 years	0	0.0
>20 years	3	25.0
Years in NICU		
<1 year	1	8.3
1-3 years	2	16.6
3-5 years	3	25.0
5-10 years	3	25.0
10-15 years	1	8.3
15-20 years	1	8.3
>20 years	1	8.3
Education		
Associate's	0	0.0
Bachelor's	9	75.0
Master's	3	25.0
Doctorate	0	0.0
Frequency of Providing Bereavement Support		
Never	3	25.0

Less than once a year	6	50.0
At least once every six months	2	16.6
Bereavement Care Continuing Education		
Yes	2	16.6
No	10	83.3
Nursing Program Bereavement Care Education		
Yes	4	33.3
No	8	66.6
Currently Hold Certification		
Yes	7	58.3
No	5	41.6

Pre and Post-intervention Results

A Shapiro-Wilk test was used to determine if the mean score of each participant in each part of the BEACONNS scale (Comfort Scale, Roles Scale, and Involvement Scale) followed a normal distribution pattern (see Table 3). In Shapiro-Wilk test, the closer the value W is to 1, the more likely that the sample follows a normal distribution. Furthermore, if the p-value in the Shapiro-Wilk test is greater than 0.05, we would accept the null hypothesis stating that the sample follows a normal distribution. In order to use a paired samples t-test, the distribution of the variables must follow a normal distribution, which the Comfort Scale, Role Scale, and Involvement Scale (Pre-Intervention) satisfied, see Figure 1, Figure 2, and Figure 3. A paired samples t-test measured the significant difference in the means between pre- and post-intervention. The means found in the Involvement Scale (Post-Intervention) did not follow a normal distribution pattern (see Figure 3). Due to the discrepancy of the Involvement Scale pre- and post-intervention, to analyze the scores in the Involvement Scale, a nonparametric test, which means the test does not make assumptions about the distribution of the variables and tests for significant differences in the median between pre- and post-intervention, was used.

Table 3. Shapiro-Wilk Test of Normality

Variable	W	df	Significance (p-value)
Comfort Scale - Pre intervention	0.94	12	0.52
Comfort Scale - Post Intervention	0.91	12	0.27
Role Scale - Pre Intervention	0.94	12	0.58
Role Scale - Post Intervention	0.99	12	0.99
Involvement Scale - Pre Intervention	0.92	12	0.27
Involvement Scale - Post Intervention	0.82	12	0.02

Figure 1. Distribution of Mean Comfort Scale Scores

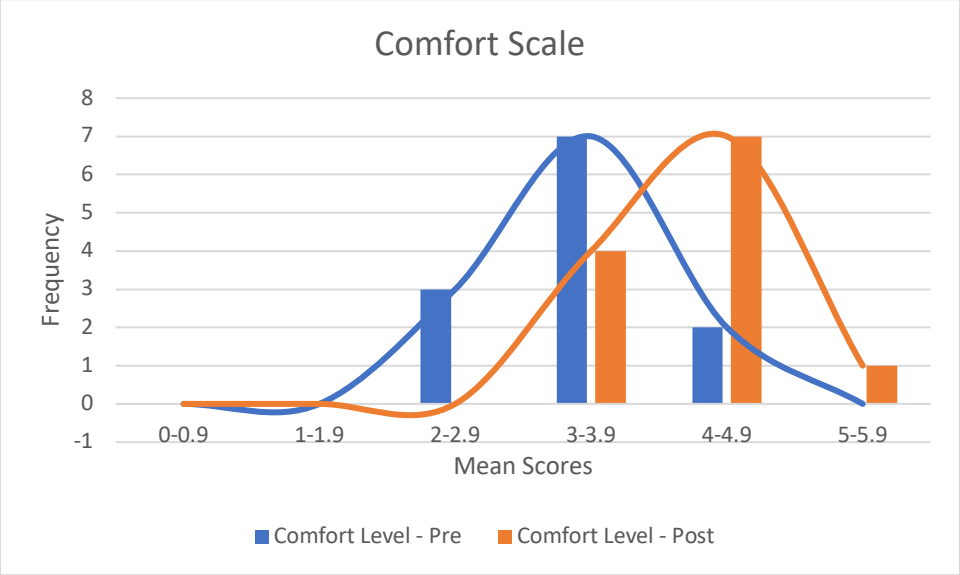


Figure 2. Distribution of Mean Role Scale Scores

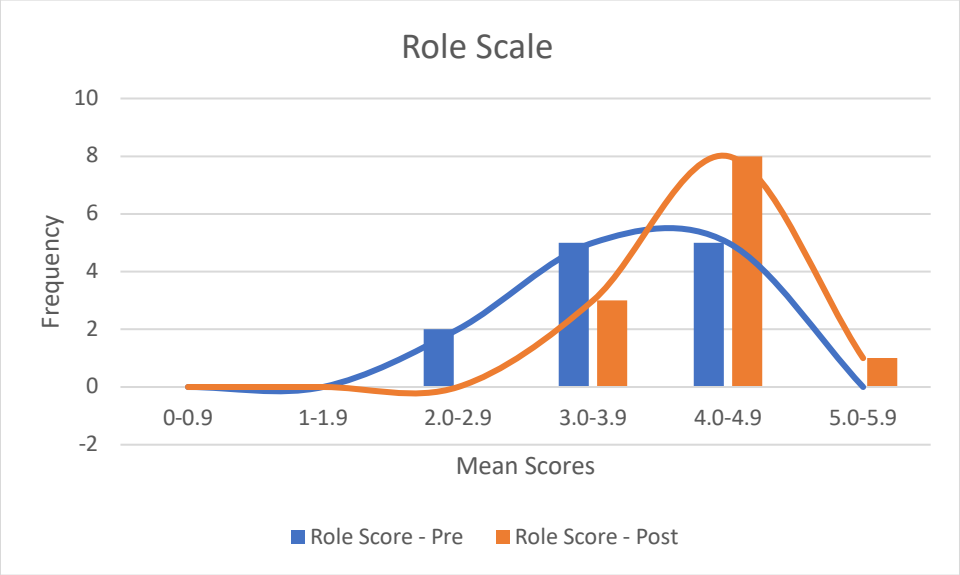
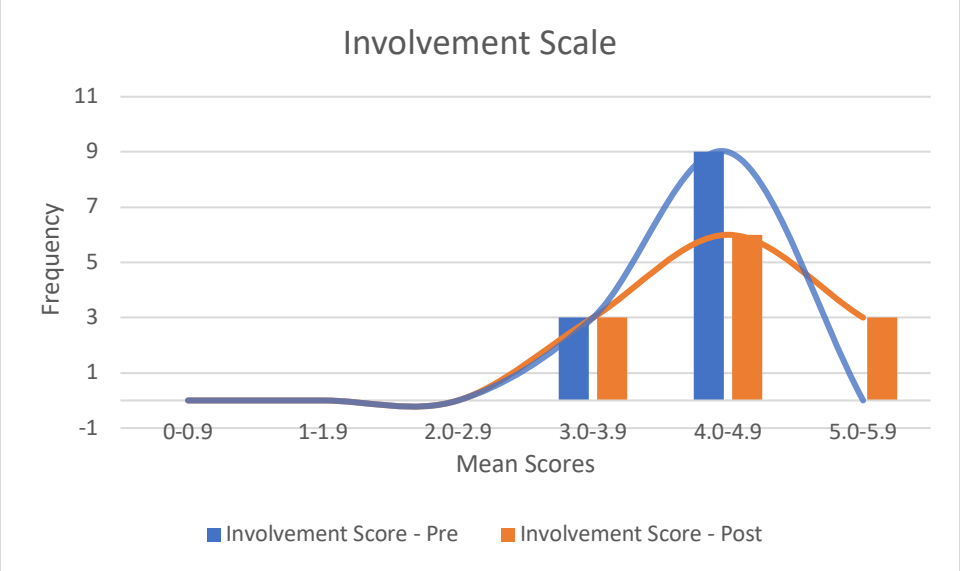
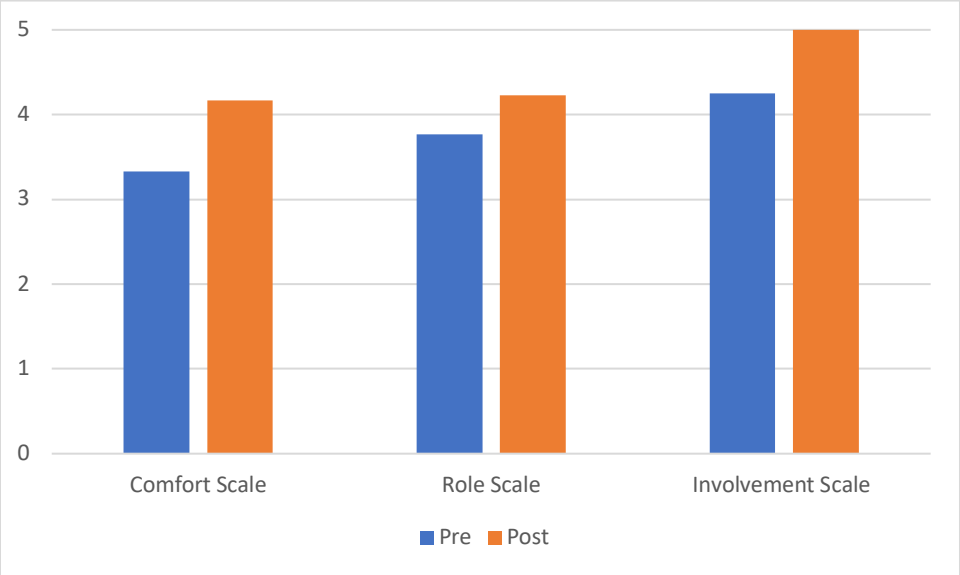


Figure 3. Distribution of Mean Involvement Scale Scores



A paired samples t-test indicated the post-intervention Comfort Scale scores, M = 4.17, SD = 0.35 was significantly higher than pre-intervention Comfort Scale scores, M = 3.33, SD = 0.72, with a t-score of 3.70 and p-value of 0.003 ($p<0.05$) (see Figure 4). A paired samples t-test indicated the post-intervention Role Scale scores, M = 4.23, SD = 0.41 was significantly higher than the pre-intervention Role Scale scores, M = 3.77, SD = 0.52, with a t-score of 5.70 and p-value of 0.0001 ($p<0.05$), see Figure 4. A Wilcoxon signed ranks test shows that the post-intervention Involvement Scale median scores, Median = 5, was significantly higher than the pre-intervention Involvement Scale median scores, Median = 4.25, with a Z-score of 2.45 and p-value of 0.01 ($p<0.05$) (see Figure 4).

Figure 4. BEACONNS Scale Scores Before and After Intervention



IX. Discussion

This QI project examined the effectiveness of implementing a bereavement guideline in increasing nurses' comfort in providing bereavement support to families experiencing neonatal

loss in the NICU. Evidenced-based interventions were researched and incorporated into the creation of the guideline and then nurses were educated via a one hour online educational session explaining in further detail each intervention in the guideline. The post-intervention BEACONNS showed an increase in levels of Comfort, Role, and Involvement regarding bereavement support to families. A paired samples t-test and Wilcoxon signed ranks test indicated that the increase in scores were statistically significant.

Findings from this study are consistent with the literature that a clinical protocol or guideline assists nurses in feeling more comfortable in delivering bereavement support (Hansen et al., 2009; Morgan, 2010; Van Mol et. al, 2020). In addition, findings from this study indicated that many nurses lacked bereavement support education which is consistent with literature findings (Arbour & Wiegand, 2014; Popejoy et al., 2009). However, this QI project did not assess if a bereavement guideline improves the quality of bereavement support given. According to Wool (2013), providing uniform guidelines for staff regarding bereavement practices enables clinicians to work confidently within their scope of practice translating to delivering seamless, comprehensive, and holistic care when it comes to bereavement interventions. A study examining the effect on quality of bereavement support when a bereavement guideline is used must be done as well as a larger study to conclude that using a bereavement guideline increases nurses' comfortableness in providing bereavement support.

X. Limitations

The limitations of this QI project are the small sample size (n=12) and the use of purposive sampling method affecting generalizability. Despite recruiting 20 people for this project, only 12 people completed the study. Participation in this study was voluntary and subjects were reluctant to commit due to personal obligations or conflicting work schedules.

Furthermore, participants who were asked to participate in the study were chosen from two hospital councils where nurses can volunteer to partake in. Subjects in the study were also given participation credit for their respective councils when they completed the study. Therefore, nurses who chose to participate in this QI project may be more willing to learn about new hospital initiatives and are more involved in hospital activities than other nurses. The sample consisted of mostly Hispanic females.

XI. Implications for Practice

Providing bereavement support to parents experiencing neonatal loss has been deemed to be difficult, demanding, and stressful with nurses often experiencing a feeling of helplessness due to the unsureness of the quality of support they are providing (Gensch & Midland, 2000; Robinson et al., 1999). The use of a clinical guideline has been shown to increase nurse comfort in performing various clinical tasks needed at the bedside, which includes providing bereavement support to families in the neonatal intensive care unit (Ahn et al., 2020; Case, 2017; Cullen & Auberry, 2016; Tierney et al., 2019). Providing nurses with evidenced-based interventions in the form of a guideline and education increases nurses' comfortableness in performing challenging tasks, such as bereavement support. Therefore, for nursing tasks that might not be done often, is considered challenging, or lacking in consistency when performed by different nurses, a guideline may benefit in increasing the nurses' comfortableness in performing the task, thus lessening the stress experienced.

The quality improvement project also identifies that there is a lack of bereavement education in the form of continuing education (83.3%) and in nursing school (66.6%), which is consistent with findings from other researchers (Arbour & Wiegand, 2014; Popejoy et al., 2009). Bereavement support education should be taught as part of the onboarding process when

transitioning to work in the Neonatal Intensive Care Unit and periodically taught to staff to retain the knowledge. Though nursing schools do a slightly better job at providing bereavement support education, nursing schools have room for improvement in incorporating bereavement education in their curriculum.

Due to the successful nature of this quality improvement project as evidenced by the statistically significant pre- and post-data, the next steps would be to educate the whole staff about the bereavement guideline in the form of an in-service. In order to sustain the change, education about the bereavement guideline will be a part of the onboarding process of new staff hired for the NICU and education about the bereavement guideline will be a part of quarterly education requirements mandated by the unit for staff to complete. The bereavement guideline will also be included in the booklet where all other guidelines and checklists are placed, and the corresponding PowerPoint presentation will be available to staff via the institution portal.

XII. Conclusion

This Quality Improvement (QI) project met the objectives of improving nurses' comfortableness in providing bereavement support to families in the neonatal intensive care unit. The results in the demographic and professional survey signified a need for bereavement education amongst nurses both already in practice and those in nursing school. The statistically significant increases in scores in the post-intervention BEACONNS compared to the pre-intervention BEACONNS reflect the efficacy of using a guideline in increasing nurses' comfortableness in providing bereavement support. This project encourages participants to use the bereavement guideline when providing bereavement support to families experiencing neonatal loss and to encourage fellow nursing staff to use the guideline.

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XV. Appendices

IRB Approval Letter

FIU | FLORIDA INTERNATIONAL UNIVERSITY

Office of Research Integrity
Research Compliance, MARC 414

MEMORANDUM

To:	Dr. Deborah Sherman
CC:	Camille-Kae Torre
From:	Elizabeth Juhasz, Ph.D., IRB Coordinator
Date:	August 26, 2021
Protocol Title:	"Development of an Evidence-based Bereavement Care Guideline in the Neonatal Intensive Care Unit: A Quality Improvement Project"

The Social and Behavioral Institutional Review Board of Florida International University has approved your study for the use of human subjects via the **Expedited Review** process. Your study was found to be in compliance with this institution's Federal Wide Assurance (00000060).

IRB Protocol Approval #:	IRB-21-0381	**IRB Approval Date:**	08/25/21
TOPAZ Reference #:	110610	**IRB Expiration Date:**	08/25/24

As a requirement of IRB Approval you are required to:

1) Submit an IRB Amendment Form for all proposed additions or changes in the procedures involving human subjects. All additions and changes must be reviewed and approved by the IRB prior to implementation.
2) Promptly submit an IRB Event Report Form for every serious or unusual or unanticipated adverse event, problems with the rights or welfare of the human subjects, and/or deviations from the approved protocol.
3) Utilize copies of the date stamped consent document(s) for obtaining consent from subjects (unless waived by the IRB). Signed consent documents must be retained for at least three years after the completion of the study.
4) **Receive annual review and re-approval of your study prior to your IRB expiration date**. Submit the IRB Renewal Form at least 30 days in advance of the study's expiration date.
5) Submit an IRB Project Completion Report Form when the study is finished or discontinued.

HIPAA Privacy Rule: **N/A**

Special Conditions: **N/A**

For further information, you may visit the IRB website at http://research.fiu.edu/irb.

Letter of Approval from Facility

7/20/21

Dear Ms. Torre and Dr. Sherman,

This letter is to confirm review and approval of your project, "Development of an Evidenced-Based Bereavement Guideline in the Neonatal Intensive Care Unit: A Quality Improvement Project". The goals of this project align with those of our organization, and we welcome the opportunity to support this project at Nicklaus Children's Hospital. This project will be supervised through your advisor at Florida International University. After review and approval as a QI project by your IRB of record, no additional IRB review or approval through Nicklaus Children's Hospital is required.

Sincerely,

Danielle Antonia Sarik, PhD, APRN-PC, RN

Danielle Sarik PhD, APRN, CPNP-PC
Research Nurse Scientist
Nicklaus Children's Hospital
(786) 624-2314

Email for Recruitment

Subject Line: Participation in NICU Specific Bereavement Guideline Study

Body:

Hello,

We need your help!

We are conducting a study to see if the implementation of an evidenced based bereavement care guideline specific to the neonatal intensive care unit will increase nurses' comfortableness in providing bereavement care to families experiencing neonatal loss.

If you agree to be in the study, we will ask you to do the following things:

- You will be asked to complete a demographic and professional form and pre-intervention survey.
- You will be educated on the new bereavement guideline.
- After the training session, you will be asked to complete a post-intervention survey.

The total duration of the study is 1 hour.

If you choose to participate, not only will you have an increased comfortableness in providing bereavement care to families experiencing neonatal loss, but your participation will also count as **participation credit** towards the council that you are in!

If you are interested in participating or have questions, please email Camille-Kae Torre (ctorr205@fiu.edu).

Thank you and we hope to hear from you!

Best,

Camille-Kae Torre, MSN, FNP-BC, CCRN, RN
ctorr205@fiu.edu
Nicole Wertheim College of Nursing Doctorate of Nursing Practice Candidate

Adult Online Informed Consent Form

/

ADULT ONLINE CONSENT TO PARTICIPATE IN A RESEARCH STUDY

DEVELOPMENT OF AN EVIDENCED-BASED BEREAVEMENT GUIDELINE IN THE NEONATAL INTENSIVE CARE UNIT: A QUALITY IMPROVEMENT PROJECT

SUMMARY INFORMATION
The study investigates if the development and implementation of an evidenced-based bereavement care guideline specific to the neonatal intensive care unit will increase nurses' comfortableness in providing bereavement support to families experiencing neonatal loss.
Things you should know about this study:

- **Purpose:** The purpose of the study is to determine if the implementation of an evidenced-based bereavement support guideline will increase nurses' comfortableness in providing bereavement support to families experiencing neonatal loss.
- **Procedures**: If you choose to participate, you will be asked to respond to a demographic and professional form and pre-intervention survey. You will then participate in a training session. After the training session, you will be asked to respond to a post-intervention survey.
- **Duration:** This will take about one hour.
- **Risks**: The main risk or discomfort from this research is possible distress with the discussion of neonatal death.
- **Benefits:** The main benefit to you from this research is increase comfortableness in providing bereavement support to families experiencing neonatal loss.
- **Alternatives:** There are no known alternatives available to you other than not taking part in this study.
- **Participation:** Taking part in this research project is voluntary.

Please carefully read the entire document before agreeing to participate.

PURPOSE OF THE STUDY

The purpose of this study is to determine if the implementation of an evidenced-based bereavement support guideline will increase nurses' comfortableness in providing bereavement support to families experiencing neonatal loss.

NUMBER OF STUDY PARTICIPANTS

If you decide to be in this study, you will be one of the fifteen people in this research study.

DURATION OF THE STUDY

Your participation will involve one hour.

PROCEDURES

If you agree to be in the study, we will ask you to do the following things:

- Read and consent to the form by clicking: "I consent to participate"
    - If you click: "I do not consent to participate", you cannot participate in the study.
- You will then be able to complete the demographic and professional form and pre-intervention survey.
- You will be educated on the new bereavement guideline.
- After the training session, you will be asked to complete a post-intervention survey.

RISKS AND/OR DISCOMFORTS

There is minimal risk associated with this study except for possible distress with the discussion of neonatal death.

BENEFITS

The study benefit to you:

- The study will benefit you by increasing your comfortableness and knowledge in providing bereavement support to families experiencing neonatal loss.

The study benefit to society:

- Increased nurses' comfortableness in providing bereavement support is correlated with better quality of bereavement support to families experiencing neonatal loss.

ALTERNATIVES

There are no known alternatives available to you other than not taking part in this study *(*Any significant new findings developed during the course of the research which may relate to your willingness to continue participation will be provided to you.

CONFIDENTIALITY

The records of this study will be kept private and will be protected to the fullest extent provided by law. In any sort of report we might publish, we will not include any information that will make it possible to identify you. Research records will be stored securely, and only the researcher team will have access to the records. However, your records may be inspected by authorized University or other agents who will also keep the information confidential.

COSTS

You will receive participation credit for research your respective council.

There are no costs to you for participating in this study.

RIGHT TO DECLINE OR WITHDRAW

Your participation in this study is voluntary. You are free to participate in the study or withdraw your consent at any time during the study. You will not lose any benefits if you decide not to participate or if you quit the study early. The investigator reserves the right to remove you without your consent at such time that he/she feels it is in the best interest.

RESEARCHER CONTACT INFORMATION

If you have any questions about the purpose, procedures, or any other issues relating to this research study you may contact Camille-Kae Torre, 954-600-3604, ctorr205@fiu.edu

IRB CONTACT INFORMATION

If you would like to talk with someone about your rights of being a subject in this research study or about ethical issues with this research study, you may contact the FIU Office of Research Integrity by phone at 305-348-2494 or by email at ori@fiu.edu.

PARTICIPANT AGREEMENT

I have read the information in this consent form and agree to participate in this study. I have had a chance to ask any questions I have about this study, and they have been answered for me. By clicking on the "consent to participate" button below I am providing my informed consent.

- ○ Yes I Consent (1)
- ○ No I do not Consent (2)

Bereavement Guideline

Bereavement Support Guideline for NICU

Before Death or Removal of Support

- Notify OA and Social Worker
    - Social Worker will find out if autopsy is requested by parents
    - Social Worker will provide information to families about resources and support
- Ask family if they would like to hold infant
    - Allow privacy for parents

After Death

- If family not at bedside, give babies quick cleaning
    - If autopsy is requested, DO NOT REMOVE SUPPORT LINES AND TUBES
- Call for bereavement tray from cafeteria
- Obtain angel gowns from supply room
    - If parents are at bedside, obtain three angel gowns and let parents choose.
- If family at bedside, ask family how they would like things to progress…
    - Would they like the chaplain?
    - Would they like to assist with bathing and dressing infant?
    - Would they like family at bedside?
    - Would they like to hold infant longer?
    - Would they like pictures taken? (**ENSURE THAT PHOTOGRAPHY IS AVAILABLE BEFORE OFFERING)
- Assist in bathing and dressing the infant (if family at bedside)
- Allow family to hold infant
    - Close door and blinds and provide privacy

Memory Making

- Obtain verbal consent from family for memory making interventions (hand and foot molds, hand and footprints). Document verbal consent as nursing note in Cerner.
- Obtain memory box from supply room
    - Memory box Ideas: (Not necessary to include EVERYTHING from list)
        - Hand and foot molds, hand and foot prints, ID band, baby blanket, lock of hair, diaper, blood pressure cuff

After Family is Gone

- Retrieve Post Mortem Body Transport Bag from supply room and obtain crib
    - Place Post Mortem Body Transport Bag on crib
- There are 3 tags that comes with the transport bag, fill out 2 tags with patient information (one will be placed on patient and the other on the bag)

- Attach ID band and tag to patient (usually on patient's legs)
- Swaddle infant in baby blanket
    - REMEMBER, IF AUTOPSY IS REQUESTED BY PARENTS, DO NOT REMOVE SUPPORT LINES AND TUBES
- Place baby in bag and zip up the bag
- Tie other tag to zipper of the Post Mortem Body Transport Bag
- Call OA to transport to morgue
- Ensure charting is complete before telling secretary to deconstruct patient chart

Pre-Intervention Demographics and Professional Survey

Demographic and Professional Information

Please circle your answer.

1. How many years of nursing experience do you have?
    a. <1 year
    b. 1-3 years
    c. 3-5 years
    d. 5-10 years
    e. 10-15 years
    f. 15-20 years
    g. >20 years

2. How many years of nursing experience specific to neonatal intensive care do you have?
    a. <1 year
    b. 1-3 years
    c. 3-5 years
    d. 5-10 years
    e. 10-15 years
    f. 15-20 years
    g. >20 years

3. What is your highest level of education in nursing?
    a. Associate's degree
    b. Bachelor's degree
    c. Master's degree
    d. Doctoral degree

4. How often do you provide bereavement support to families?
    a. Never
    b. Less than once a year
    c. At least once every six months
    d. At least once every three months
    e. At least once a month
    f. At least once a week

5. Have you had continuing education in bereavement care?
    a. Yes

b. No

6. Did the nursing program you attended offer information/content regarding bereavement care?
   a. Yes
   b. No

7. Do you currently hold a certification?
   a. Yes
   b. No
   If yes, which certification(s):_____

8. What is your gender?
   a. Female
   b. Male
   c. Non-binary/Third Gender
   d. Prefer not to say

9. How would you best describe yourself as?
   a. American Indian or Alaska Native
   b. Asian
   c. Black or African American
   d. Native Hawaiian or Other Pacific Islander
   e. White
   f. Hispanic

Pre/Post-Intervention Bereavement/End of Life Attitudes About Care of Neonatal Nurses Scale (BEACONNS)

Level of Comfort

Please circle the number that corresponds to the degree of comfort you feel with each of these aspects of bereavement/end-of-life care.

	Very Uncomfortable	Uncomfortable	Neither Comfortable Nor Uncomfortable	Comfortable	Very Comfortable
1. Allowing families to hold their dying or dead infant	1	2	3	4	5
2. Allowing families to participate in post mortem care of their infant	1	2	3	4	5
3. Appropriately touching grieving family members as a way of showing your care and concern	1	2	3	4	5
4. Assisting families in experiencing the pain of grief	1	2	3	4	5
5. Caring for the family of a dying infant	1	2	3	4	5
6. Contacting families after their infant has died in your unit	1	2	3	4	5
7. Discussing autopsy or organ donation with families of dying infants	1	2	3	4	5
8. Discussing funeral arrangements with patients' families	1	2	3	4	5
9. Discussing withdrawal of life support/therapy with patients' families	1	2	3	4	5
10. Dressing the dying/dead infant rather than leaving the infant nude or covering him or her with just a blanket	1	2	3	4	5
11. Families who cry or are otherwise verbal	1	2	3	4	5

around the time their infant is dying					
12. Getting together with other staff members who cared for a deceased infant to share food, talk about the death, and discuss your reactions to it	1	2	3	4	5
13. Helping peers learn to provide culturally sensitive and competent bereavement/end-of-life care	1	2	3	4	5
14. Participating in closure or grief conferences with families and other caregivers after the death of an infant	1	2	3	4	5
15. Providing culturally sensitive bereavement/end-of-life care for families of cultures other than your own	1	2	3	4	5
16. Providing post mortem care for your patients	1	2	3	4	5
17. Sitting with parents and listening as they express their grief	1	2	3	4	5
18. Talking to families about grief and bereavement issues	1	2	3	4	5
19. Talking to friends of the deceased infant's family about the grief process and what to expect	1	2	3	4	5

Perception of Role

Please circle the number that corresponds to the degree of comfort you feel with each of these perception of your role with families of critically ill and/or dying infants.

	Very Uncomfortable	Uncomfortable	Neither Comfortable Nor Uncomfortable	Comfortable	Very Comfortable
1. I am comfortable allowing siblings of the patient to visit outside specified visiting hours	1	2	3	4	5
2. I am comfortable discussing with patients' family members how the members are coping with having a critically ill infant	1	2	3	4	5
3. I am comfortable explaining to family members equipment or the way the infant looks	1	2	3	4	5
4. I am comfortable having patients' family members watch me do procedures	1	2	3	4	5
5. I am comfortable talking to families about their infant's progress	1	2	3	4	5
6. I have the necessary knowledge and skills required to meet the psychosocial and emotional needs of families of critically ill infants	1	2	3	4	5
7. I make sure the family knows my name when I care for their infant	1	2	3	4	5
8. I relieve other neonatal intensive care unit nurses so they can go out and talk to their patients' families	1	2	3	4	5
9. It is realistic to expect staff nurses to care for the emotional needs of families and critically ill infants	1	2	3	4	5
10. The role of the nurse is very important in providing support to	1	2	3	4	5

families of critically ill infants on a daily basis					
11. When patients' family members are in the neonatal intensive care unit, I have (no) difficulty caring for my patients	1	2	3	4	5

Factors That Influence Nurses' Involvement

Please circle the number that corresponds to how important you believe each of these are in influencing the amount of involvement with patients' families with critically ill and/or dying infants.

	Very Unimportant	Unimportant	Neither Important Nor Unimportant	Important	Very Important
1. A busy unit	1	2	3	4	5
2. A dying infant	1	2	3	4	5
3. A family being supported by others	1	2	3	4	5
4. A family whose infant just died	1	2	3	4	5
5. A receptive family	1	2	3	4	5
6. Expectations of nursing leaders in your unit and/or hospital	1	2	3	4	5
7. Expectations of your peers	1	2	3	4	5
8. When there is a language or cultural barrier between you and the family	1	2	3	4	5
9. When you are dealing with a very young parent	1	2	3	4	5
10. When you are unsure of what information the physician or advance practice nurse has given the family	1	2	3	4	5
11. When you are unsure of your nursing skills in a particular case	1	2	3	4	5
12. When you disagree with the treatment your patient is receiving	1	2	3	4	5
13. Your feeling supported by other people	1	2	3	4	5
14. Your own high stress level	1	2	3	4	5