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Molloy College

The Barbara H. Hagan School of Nursing & Health Sciences

PhD in Nursing Program

NEONATAL NURSES' PERCEPTIONS OF PROVIDING PALLIATIVE CARE IN THE
NEONATAL INTENSIVE CARE UNIT

A dissertation

By

SUSAN DI NONNO CHIN

Submitted in partial fulfillment of the requirements

For the degree of

Doctor of Philosophy

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2020

Molloy College

MOLLOY COLLEGE

THE BARBARA H. HAGAN SCHOOL OF NURSING & HEALTH SCIENCES

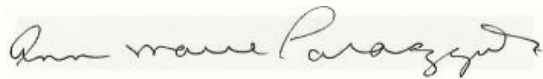
The dissertation of SUSAN DI NONNO CHIN

Entitled NEONATAL NURSES' PERCEPTIONS OF PROVIDING PALLIATIVE CARE IN
THE NEONATAL INTENSIVE CARE UNIT

In partial fulfillment of the requirement for the degree of

Doctor of Philosophy

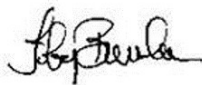
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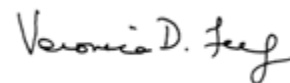
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Abstract

Background

Although advances in neonatal medicine have greatly improved infant survival rates, there remains a significant number of infants admitted to the neonatal intensive care unit who will not survive. It is estimated that 50% of the 25,000 annual hospital pediatric deaths occur in the neonatal intensive care unit (NICU) (Conway-Oriel & Edlund, 2015). Despite widely supported guidelines endorsing neonatal palliative care (NPC), implementation has been sporadic and inconsistent (Kain & Wilkinson, 2013). Lack of palliative care protocols has been associated with negative impacts on infants, their families, and multidisciplinary team members. NICU nurses are uniquely positioned to influence end-of-life care experiences for infants and their families. Although previous research has explored nurses' perceptions in specific NICU populations (Chen, Huang, Liu, Lee, Wu, Chang, & Peng, 2013; Forouzi, Banazadeh, Ahmadi, & Razban, 2017; Kain, 2008; Wright, Prasun, & Hilgenberg, 2011), the current status of PC in neonatal nursing practice throughout the United States has not been examined.

Purpose

The purpose of this study was to examine nurses' perceptions of providing palliative care (PC) in their neonatal intensive care unit (NICU). The relationship between nursing staff characteristics, unit policy, and palliative care education on the nurses' perceptions was explored to determine the influence of these factors on perceptions of barriers and facilitators encountered in practice.

Methods

The study employed a descriptive cross-sectional, correlational quantitative design with a qualitative component. Participants were recruited through two national professional nursing organizations with neonatal membership. The Neonatal Palliative Care Attitude Scale (NiPCASTM) was used to measure nurses' perceptions of palliative care in their NICU setting. Parametric statistics were conducted to explore the relationships between unit policy and NPC education, and the nurses' perceptions. A qualitative content analysis was conducted on open-ended questions to explicate the quantitative findings.

Results

An exploratory factor analysis yielded a 10-item, 3-factor model with the following subconstructs: Unit Culture, Resources, and Perceived Inappropriate Care. The barriers identified were Perceived Inappropriate Care and Societal Understanding of NPC. Unit Culture and Resource factor items were identified as facilitators to NPC. A positive correlation was noted for NiPCASTM scores and unit culture support ($r(185) = .66, n = 187, p < .01$), unit NPC policy ($r(184) = .446, n = 186, p < .01$) and NPC education ($r(185) = .373, n = 187, p < .01$). Qualitative findings demonstrated inconsistencies with parental decision-making involvement practices.

Summary and Recommendations

Nurses who work in a NICU with an NPC policy and who have received NPC education demonstrated more favorable attitudes toward NPC in their practice setting. Although policy guidelines, recommendations and educational programs have been available for the past 20 years, inconsistencies in practice continue to exist. Further research focusing on nurses'

perception of NPC at the unit level is recommended to develop strategies that will best support standardized NPC practice. Continued development of policy and NPC educational programs are important strategies to promote high-quality care for high-risk infants and their families.

Keywords: neonatal palliative care, perinatal palliative care, comfort care, end-of-life care

Dedication

“Really, the nurses run the NICU. The physicians pop in and out, but it’s the nurses who notice when something is wrong, who know when to recommend a blood transfusion, who restart babies’ hearts dozens of times each day.” -Sarah Di Gregorio (2020)

From Early: An Intimate History of Premature Birth and What it Teaches Us About Being Human.

This dissertation is dedicated to the NICU nurses who are let into the most intimate of family life events. May they bring compassion and understanding to every precious encounter.

Acknowledgments

A dissertation is a journey that requires many guides along the way to arrive at the final destination. The guides need to be acknowledged for the roles they have played in shaping this project. First, I would like to thank my dissertation committee, each providing unique talents and perspectives that have shaped this final product: Dr. Ann Marie Paraszcuk, my committee chair, for providing countless hours of support, thoughtful insights, and attention to detail; Dr. Patricia Eckardt, for her guidance and expertise on the data analysis process, and teaching me the joy of statistics; and Dr. Toby Bressler, for guiding me early in the journey to refine my thesis ideas, and for bringing her expertise on palliative care policy and recommendations to the table. Additional gratitude is extended to Bernadette Weldon, for her warm and nurturing spiritual support and to Theresa Rienzo for providing me with answers to my many library reference questions.

I would also like to acknowledge the support and love that I receive each day from my family: my husband Steve, my rock, who understood the time and space needed for my studies and listened patiently during the stressful moments; my children, Sarah and Patrick, who have taught me what it means to persevere in the face of adversity; and my parents for the lessons they instilled in me to shape the person that I am today. Without their parenting, this would not have been possible.

Lastly, I would like to acknowledge Dr. Veronica Feeg, for opening my world to ideas and possibilities that I did not know existed before I entered into the community of Molloy scholars.

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NEONATAL NURSES' PERCEPTIONS OF PROVIDING PALLIATIVE CARE IN THE
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CHAPTER 1

Statement of the Problem

Introduction

The rapid advances in medicine and technology in the 1950s paved the way for the discipline of neonatal medicine. For the first time in history, critically ill and premature newborns were able to survive. With the development of advanced treatments, a cure-oriented culture of medicine has emerged whereby, the outcome of death is seen as a failure (Craig & Mancini, 2013; Duff & Campbell, 1976). Media coverage regarding “miracle” stories of ever more fragile infants surviving against all odds has led to a society where health care professionals are often unprepared, and ill equipped to acknowledge and appropriately care for those who will die. As a result, healthcare providers may often avoid conversations related to poor prognosis or likely death and instead persist with extensive treatments that cause undue pain and suffering (Craig & Mancini, 2013). Although curative treatments are appropriate for the majority of infants in the neonatal intensive care unit (NICU), there is a need to care for those who have an uncertain or poor prognosis with a holistic approach where curative measures are not the primary focus.

Background

Prior to the technological and medical advances that arose in the 1950s, medical care for premature infants and those with life-limiting conditions centered on palliation. Infants were weighed daily, fed breast milk and provided warmth while caregivers hoped for the best (Duncan, 2018). Neonatal medicine gradually shifted its focus to that of a curative discipline as

medical advances were allowing premature and sick newborns to survive for the first time in history. As a result, between 1940 and 1970, the infant mortality rate declined by 58% in the United States (Wegman, 1971).

Although infant mortality rates were improving, by the early 1970s, physicians and families began to question medical treatments for those with life-limiting conditions and those born extremely premature (Duff & Campbell, 1973, 1976; Marc-Aurele & English, 2017). Ethical discussions surrounding poor long-term outcomes and treatments that cause pain and suffering without changing survival outcome emerged in the professional and lay literature (Duff & Campbell, 1976; Harrison, 1993; Stinson & Stinson, 1983; Whitfield et al., 1982). Out of these growing concerns, the notion of neonatal palliative care (NPC) as a treatment modality began to surface.

In 2000, the American Academy of Pediatrics published a statement on palliative care for children that included ethical principles and guidelines for practice. This statement acknowledged distinct differences between adult and childhood deaths and the need for a palliative care approach that would address issues unique to children. Pediatric palliative care is now formally recognized and supported by several professional organizations worldwide (Craig & Mancini, 2013; O'Shea et al., 2015). Approximately one third to one half of pediatric deaths occurs in the neonatal period (Younge et al., 2015), and as a result, guidelines and position statements specific to neonatal palliative care have emerged (Carter & Bhatia, 2001; Catlin & Carter, 2002; NANN Board of Directors, 2015). Despite published recommendations by professional organizations, the adoption of neonatal palliative care guidelines has been sporadic and inconsistent (Kain & Wilkinson, 2013).

Statement of the Problem

As the NICU is largely an environment aimed at saving lives, the decision to provide palliative care is often a source of emotional discomfort (Mendel, 2014). The primary notion that infants should not die causes both families and healthcare providers to often take extraordinary measures to provide life-prolonging interventions that are accompanied by pain and suffering (Thibeau & Naquin, 2012). Despite advances in technology and medical care, the fact remains that infants born at the limits of viability and those with life-limiting congenital anomalies will not survive (Marc-Aurele & English, 2017). Nurses, the most visible NICU team members at the point of care, often lack the confidence to care for these infants and to initiate conversations regarding impending death and/or palliative care options with the interdisciplinary team and family (Craig & Mancini, 2013; Wool, 2013). The stigma of neonatal death along with challenges for providing palliative care in a curative environment contributes to the difficulties in integrating palliative care practices into the NICU (Kain & Wilkinson, 2013). Without a palliative care framework, cure-oriented treatments often deprive certain infants of measures that could provide comfort and ease suffering at the end stages of life (Mendel, 2014).

Lack of a palliative care program affects parents and professional caregivers as well. Ineffective communication with parents and the NICU team regarding prognosis and end-of-life care planning has been identified as an added stressor for grieving families with long-term negative consequences (Branchett & Stretton, 2012; Currie, Christian, Hinds, Perna, Robinson, Day & Meneses, 2016; Orfali & Gordon, 2004; Penticuff & Arheart, 2005). Lack of palliative care education, NPC unit guidelines, and staff counseling support have been cited as sources of moral distress among neonatal nurses (Chen et al., 2013; Kain & Wilkinson, 2013; Lewis, 2012; Martin, 2013; Mendel, 2014; Samsel & Lechner, 2015).

NICU nurses' perceptions of the barriers to and facilitators of palliative care that they encounter in their practice have been examined throughout diverse cultural settings (Chen et al., 2013; Forouzi, Banazadeh, Ahmadi, & Razban, 2017; Kain, 2008; Killcullen & Ireland, 2017; Wright, Prasun, & Hilgenberg, 2011). Barriers to NPC that have been identified in the literature include: the organization in which the nurse practices, inadequate staffing, lack of resources to support a palliative care model, less than adequate physical environment, lack of policy guidelines, lack of educational preparation, inability to express one's opinion, the technological imperative, and parental demands.

Educational preparation and policy have become common recommendations for improving NPC practices and have resulted in the emergence of educational programs and research-driven policies over the past 20 years (Carter, 2018; Carter & Bhatia, 2001; Catlin, Brandon, Wool, & Mendes, 2015; Catlin & Carter, 2002; Kain, 2017; Mancini, Kelly, & Bluebond-Langner, 2012; Murakami et al., 2015). Subsequent research centering on education and policy have demonstrated benefits to these initiatives. Educational interventions have demonstrated increases in knowledge, attitudes, self-awareness, and performance among the interdisciplinary NICU team members and nursing students (Kain, 2017; Kirkpatrick, Cantrell, & Smeltzer, 2019; O'Shea et al., 2015). Research on unit-based NPC policy implementation have demonstrated benefits including increased use of palliative care medication, family meetings and documented redirection of care (Samsel & Lechner, 2015; Younge et al., 2015). Although these findings are important, they are limited to local practice changes and thus do not reflect NPC practice on the national level. Furthermore, the impact of these initiatives on nurses' perceptions of providing NPC has not been studied.

Purpose of the Study

The purpose of this study was to examine NICU nurses' perceptions of the barriers to and facilitators of palliative care. The relationship between nursing staff characteristics, unit policy and NPC education, and the nurses' perceptions was explored to determine the influence of these factors on nurses' report of the barriers and facilitators they encounter in providing NPC.

Research Questions

- What are neonatal nurses' perceptions regarding the barriers to and facilitators of providing palliative care?
- What are the NICU policies identified by nurses that affect the delivery of palliative care?
- What is the relationship between NICU palliative care unit policy and the nurses' perceptions of barriers to and facilitators of providing palliative care?
- What is the relationship between palliative care education and nurses' perceptions of barriers to and facilitators of providing palliative care?

Significance of the Problem

Nurses play a critical role as members of the interdisciplinary team in providing care to infants and their families. As NICU nurses maintain a consistent presence at the bedside, they interact with infants and their families more frequently than any other team member. Therefore, the nurse is positioned to substantially influence families' end-of-life experiences for their infant and subsequent grieving (van der Geest, Darlington, Streng, Michiels, & Pieters, 2014) .

Research-driven policy and education programs have been developed over the past 20 years aimed at improving NPC practice (Carter, 2018; Carter & Bhatia, 2001; Catlin et al., 2015; Catlin & Carter, 2002; Kain, 2017; Mancini et al, 2012; Murakami et al., 2015), yet there is no

research to demonstrate the impact of these recommendations on the nurses' perceptions of the barriers to NPC that they encounter in their practice.

Although unit policy and education are important initiatives that can enhance the delivery of NPC, additional unit workflow and environmental factors may influence the provision of NPC. Because nurses are at the point of care and interact with infants and their families more frequently than any other health care team member, they may understand the nuances of providing palliative care within the context of the physical environment. Regardless of policy and training initiatives, if nurses perceive that barriers to providing NPC exist, provision of desired palliative care practices may be impaired. The result may be compromised care that can negatively impact patients, families and nurses.

Increased understanding of nurses' perceptions regarding barriers and facilitators of NPC can lead to the development of strategies that will support nurses in their ability to provide palliative care in the NICU setting. Nurses' perceptions of barriers to and facilitators of NPC has been studied in Australia, Taiwan, Iran, and in one U.S. NICU hospital setting (Chen et al., 2013; Forouzi et al., 2017; Kain, 2008; Wright et al., 2011), yet no published studies exist that examine a national sample of neonatal nurses in the United States and their perceptions of palliative care in their practice setting. A nationwide study will provide insights into the current status of NICU nurses' perspectives regarding NPC and the potential influence of unit policy and education on their perspectives. These insights can be used to develop practice changes that can better support NPC.

Definition of Terms

Conceptual Definitions

Palliative Care: Numerous definitions of palliative care can be found in the literature. In its most basic form, palliate is defined as the ability “to reduce the violence of a disease; to ease symptoms without curing the underlying disease” (Merriam-Webster, 2018). The World Health Organization (2018), defines *palliative care* as “an approach, which improves the quality of life of patients and those facing life-threatening illness, through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems.”

The National Association of Neonatal Nurses position statement on palliative care (NANN Board of Directors, 2015) expands upon this definition to incorporate the often unpredictable and changing nature of illness in the NICU environment and role of parents. Within this framework, “Palliative care focuses on improving a patient’s quality of life and may be offered concurrently with curative care to treat symptoms, minimize suffering, and offer improved quality of life. Through the ongoing assessment of goals of care, families, nurses, and other providers determine the appropriateness of continuing intensive therapies and weigh the benefits of shifting the goals of care toward the provision of comfort for the infant and family” (NANN Board of Directors, 2015).

Kain and Wilkinson (2013) offer a succinct definition of *neonatal palliative care* as “providing comfort measures for both the infant and family from the time of diagnosis through death and bereavement.” From this perspective, NPC is not intended to focus solely on strategies that are to be implemented once the decision has been made to discontinue curative treatment but is a framework for ensuring that comfort measures and family support are provided from the point of admission, for all infants, regardless of diagnosis or prognosis.

Given the often prolonged and uncertain prognoses of childhood conditions, a palliative focus alongside curative therapies is an essential aspect of pediatric palliative care recommendations (National Hospice and Palliative Care Organization, 2012; NANN Board of Directors, 2015; World Health Organization, 2018). Prior to the Affordable Care Act ruling in 2010, parents in all but a few states had to forgo curative treatment in order to receive Medicaid coverage for hospice services. The “Concurrent Care for Children” section 2302 of the Affordable Care Act requires that all states provide Medicaid to cover palliative care concurrently with curative treatment, as appropriate (National Hospice and Palliative Care Organization, 2012).

End-of-life care is defined as “one aspect of palliative care that supports a peaceful, dignified death for the infant and the provision of support to the family and healthcare providers” (NANN Board of Directors, 2015).

Hospice is another term that is frequently associated with end of-life-care. As it is described, *hospice* is “a program designed to provide palliative care and emotional support to the terminally ill in a home or homelike setting so that quality of life is maintained, and family members may be active participants in care” (Merriam-Webster, 2018). Whereas palliative care is a broad model that can begin at diagnosis and includes end-of-life and hospice care, it also allows for concurrent curative treatment. End-of-life and hospice care primarily occur only after it is clear that the person is not going to survive their illness, and curative treatments are discontinued.

Perinatal palliative care is an emerging specialty that extends the palliative care approach to the fetus and family during pregnancy when a prenatally diagnosed life-limiting condition is identified (Munson & Leuthner, 2007). Perinatal palliative care addresses the importance of

providing a palliative care approach upon prenatal diagnosis so that health care providers can communicate effectively and best support families through pregnancy, birth and the neonatal period.

Curative treatment within the context of this research is defined as treatment aimed at curing the patient's disease. Although curative treatment is appropriate for most NICU patients, there remains a set of infants in the NICU with common conditions for whom palliative care, either alone or in addition to curative, is indicated (Carter, 2018; Parravicini, 2017). Despite the identification of conditions for which a palliative care approach is indicated, health care providers often persist with curative treatments beyond what has been termed "the dying point" (Docherty, Miles, & Brandon, 2007).

Perceived inappropriate care is the current terminology used to describe healthcare providers perceptions of delivering curative treatments that cause pain and suffering beyond the point when death from the underlying disease is considered inevitable (Jox, Schaidler, Marckmann, & Borasio, 2012; Nathanson & Feudtner, 2016; Singal et al., 2014). The NiPCAS™ instrument uses the term "life extending care" within this context (refer to Appendix B, Part 2, item 28). Attempts to objectively define the point at which care becomes perceived as inappropriate remains a complex ethical subject in healthcare. The religious, ethical and moral values of the nurse, other healthcare team members and the family will influence the nurse's perception of the appropriateness of treatment and need for palliative care.

Operational Definitions

End-of-life care education is defined as the nurses' self-reported in-service or educational offering. This information will be collected in the demographic data section of the survey.

Neonatal palliative care policy refers to the nurses' self-report that the NICU in which they work has a policy for palliative care in their work environment. This information will be collected in the demographic section of the survey.

Barriers to palliative care are defined as “any obstruction that may impede the uptake of a palliative care model of care in neonatal nursing” (Kain et al., 2009). The nurses' perception of barriers to providing NPC will be measured using the Neonatal Palliative Care Attitude Scale (NiPCAS)TM®.

Facilitators of palliative care are defined as conditions that support the integration of a palliative model of care in neonatal nursing. The nurses' perception of facilitators providing NPC will be measured using the Neonatal Palliative Care Attitude Scale (NiPCAS)TM®.

Research Variables

This descriptive study was intended to explore relationships and not predict outcomes. The variables of interest are end-of-life education, unit-based NPC policy, demographics/nursing staff characteristics, and the nurses' perceptions of barriers to and facilitators of palliative care as identified in the NiPCASTM® survey results. Given the changes in practice and education that have occurred since 2008, along with instrument use with a new population of nurses, an exploratory factor analysis and reliability testing was conducted to arrive at a model that would be appropriate with this population. Correlations were conducted to examine the relationships between the total NiPCASTM® scores with Unit policy and end-of-life/palliative care education demographic items. T-tests and Analysis of Variance (ANOVA) procedures were conducted with selected demographic variables to compare potential differences between the demographic item responses for the NiPCASTM® overall score. Selected variables included an open text box to capture additional qualitative details as follows:

1. Have you received education on end-of-life/palliative care?
 - a. Yes
 - b. No
 - c. Unsure

2. Please choose what best describes the type of end-of-life/palliative care education that you have received:
 - a. Certification educational program
 - b. Palliative care conference
 - i. Length of conference (half day, one day, two or more days)
 - c. Neonatal/Pediatric conference with palliative care session
 - i. Length of section on palliative care topic (one hour, two hours, three hours or more)
 - d. Poster presentation viewing
 - e. Unit-based in-service
 - f. Other (open-ended text box)
 - g. I have not received any end-of-life/palliative care education

3. Does your unit have a palliative care policy or guidelines for practice?
 - a. Yes
 - b. No
 - c. Unsure

The following demographic/nursing staff characteristics will be collected:

1. Gender
2. Age

3. Length of NICU experience
4. Current employment status
5. Neonatal intensive care nursing certification
6. Highest nursing degree obtained
7. Role in current workplace
8. Ethnicity
9. Children
10. Geographic region of practice
11. Religious identification
12. Spiritual identification
13. Visual analogue scale to identify unit culture supporting palliative care practices

The nurse's perceptions of barriers to and facilitators of palliative care will be identified with the NiPCAS™© survey results. Factor analysis of the initial instrument development resulted in a 3-factor model as follows (Kain, Gardner & Yates, 2009):

1. The organization in which the nurse practices
2. The available resources to support a palliative model of care
3. Technological imperatives and parental demands

Exploratory factor analysis was performed on the data to determine the appropriate model for this this new population of nurses. These findings were integrated with the individual NiPCAS™© item mean scores to identify the barriers to and facilitators of palliative care practice.

Conclusion

Given the unpredictable nature of prognosis and outcome in the NICU, palliative care is an important approach that should be integrated as standard practice. It requires an interdisciplinary approach that involves input from all team members to ensure that patient and family needs are met. Nurses are key team members who are continuously at the bedside monitoring patients and interacting with family members. They are uniquely situated to be the first to identify palliative care needs for the family and infant and to coordinate with the team to foster an environment that will best support these practices.

Despite published policy and educational programs, current evidence indicates that NPC is not yet a fully integrated component of NICU care. A survey to evaluate nurses' perceptions regarding NPC with a nationwide sample of NICU nurses will provide a clearer picture of current nursing practice that can be generalized to a larger population. The literature widely acknowledges the need for NPC education and policy implementation to best prepare nurses and support their practice. This study sought to evaluate the extent to which these recommendations are occurring and if they are beneficial in improving nurses' perceptions regarding NPC.

CHAPTER 2

Review of the Literature

Introduction

The notion of providing palliative care in the NICU began to emerge in the 1980s out of growing ethical concerns regarding the curative treatment approach for infants who would not likely survive. The NICU team and parents alike observed the untreated pain and suffering of these infants and began to question the appropriateness of the curative approach (Duff & Campbell, 1973, 1976; Harrison, 1993). Out of growing ethical concerns to provide compassionate care to infants with uncertain outcomes and life-limiting conditions, organizational position statements, policy development, and educational offerings have been widely published. Despite over 30 years of established recommendations, neonatal palliative care NPC remains inconsistent and sporadic (Kain & Wilkinson, 2013).

The purpose of this review is to present the literature related to caring for critically ill newborns and those with life-limiting conditions and the need for standardized neonatal palliative care. Although the literature within the neonatal specialty is the primary focus, relevant publications on pediatric and perinatal palliative care studies are included. This chapter is divided into sections as it relates to the research questions. The first section presents the theoretical framework that serves to guide the research question. The second section presents the patient population and diagnoses specific to newborns admitted to the NICU for whom a palliative care approach is warranted and the challenges that exist with integrating a standardized palliative care approach into this environment. Section three describes the research exploring the NICU family's experience. Section four examines findings related to health care team members'

experiences of caring for dying infants. Section five presents policy guidelines and educational programs that have been developed to improve the integration of palliative care in the NICU.

An initial literature search was conducted using Molloy College Library's integrated database search engine, Vu Find. The term "Neonatal Palliative Care" yielded over 8,000 related articles. The search was then limited to a time frame from 2010 through 2018 from peer-reviewed medical and nursing journals. Additional literature searches were conducted using the references from the initially selected articles. Publications from the United States, the United Kingdom, Australia, Taiwan, France, Japan, and Iran were considered for review.

Theoretical Framework

Overview of the Roy Adaptation Model

The Roy Adaptation Model (RAM) (Roy, 2009) provides the theoretical framework for this dissertation. Within this model, the nurse is understood as a holistic system in constant interaction with the environment. The perception of palliative care practice in the NICU environment is influenced by one's educational preparation and the support and resources within the practice setting. The nurses' level of adaptation to their practice environment will ultimately impact the quality of care provided to infants and their families.

Systems theory and adaptation level theory serve as the scientific foundation for RAM. Human beings as individuals and groups are viewed as holistic and adaptive systems that are in continuous interaction with their environment (Roy, 2009). Adaptation is the life process that encompasses the overall health of a person. Roy defines *health* as the process of becoming an integrated and whole human being. From this perspective, health is not limited to the absence of disease but occurs when a person functions at an optimal adaptation level in relation to their environment. The three levels of adaptation are described as integrated, compensatory, and

compromised. Integration is the optimum functioning of human systems. Compensatory adaptation occurs when an individual's integration is challenged and a person is required to make adjustments to reintegrate. Compromised adaptation refers to the use of ineffective coping mechanisms by individuals in response to environmental stimuli. Adaptation is a dynamic life process that is regulated by a person's coping processes, or subsystems.

Individuals are in a continuous process of adaptation as they respond to environmental stimuli. Coping processes are the mechanisms by which humans respond to the changing environment and play a role in a person's adaptation level. The regulator and cognator subsystems are the coping processes that work to maintain integration. The regulator subsystem pertains to a person's physiologic responses to stimuli and the cognator subsystem responds through four cognitive-emotional channels: perceptual and information processing, learning, judgment and emotion (Roy, 2009). This dissertation focuses on the nurse's cognator subsystem coping responses. Behaviors are the observable manifestations of how individuals respond to environmental input stimuli and are observed in relation to four adaptive modes: the physiologic, self-concept, role function, and interdependence mode (Roy, 2009).

Integral to the RAM is the notion of holism. Human systems are in a process of continuous, interdependent interaction with their environment. Adaptation is a dynamic and fluid process, not a static state. Although the model is categorized into adaptive modes and coping subsystems to assess human behavior, individuals can only be fully understood as irreducible wholes (Roy, 2009).

Application of RAM to NPC

The purpose of this study was to examine nurses' perceptions of the barriers to and facilitators of NPC. Within the RAM framework, nurses are human systems that are in

continuous interaction with their NICU environment. Events occurring within the nurse's work setting are the environmental stimuli to which the nurse will adaptively respond. Roy (2009) identifies three types of input stimuli: focal, contextual and residual. The focal stimulus is the most immediately pressing situation that faces an individual. Ethical conflicts surrounding the care of critically ill newborns, perceived inappropriate medical care, and instances in which the nurse carries out painful treatment that they perceive as inappropriate, are the focal environmental stimuli that the nurse encounters in the NICU.

Contextual stimuli are those that contribute to the impact of the focal stimulus. Unit policy, culture and organizational processes that support palliative care, staffing ratios, and a physical environment that allows for quiet and privacy at the end of life are the contextual stimuli that will play a role in the nurse's adaptation to their environment and their ability to provide NPC. The residual stimuli for nurses are their education; life experiences; and religious, spiritual and moral values. The contextual and residual stimuli will influence the nurses' perception (the perceptual and information processing channel of the cognator subsystem) regarding the barriers to and facilitators of palliative care in their practice settings (Roy, 2009).

Within this framework, nurses who have not received end-of-life education and who work in an environment that lacks policies to support NPC (contextual stimuli) may experience challenges to adaptation. Additional organizational barriers such as staffing ratios, physical environment and a lack of interdisciplinary support may impact adaptation. Compensatory adaptation behaviors for nurses under these conditions may include increased sick calls and avoidance of caring for critically ill or dying patients. If they continue to work in such an environment, adaptive behaviors such as seeking out end-of-life education opportunities and

involvement in unit activities to improve policy and guidelines for palliative care may result in positive adaptation.

Nurses who continue to work in an environment that does not provide guidelines, structure, resources, and support for a palliative care delivery model, may eventually go on to exhibit compromised adaptation behaviors. The link between a lack of palliative care and moral distress has been well documented in the literature. Burnout, high turnover rates, and emotional and physical illnesses are documented behaviors that are linked to moral distress and are examples of compromised adaptation behaviors (Cavaliere, Daly, Dowling, & Montgomery, 2010; Cavinder, 2014; Corley, 1995; Kain, 2007; Sannino, Gianni, Re, & Lusignani, 2015). Furthermore, these behaviors are associated with impaired nurse-patient interactions and compromised care (Cavinder, 2014; de Veer, Francke, Struijs, & Willems, 2013; Janvier, Nadeau, Deschênes, Couture, & Barrington, 2007; Kain, 2007; Rogers, Babgi, & Gomez, 2008).

When a nurses encounter a patient and family scenario that would benefit from a palliative care approach, their level of adaptation is influenced by the contextual and residual stimuli. Nurses, who receive education on palliative care and work within an environment that incorporates NPC policy and provides the resources to support their role, may be more likely to function at the integrated level of adaptation. They have the potential to best influence the NICU environment for patients and their families (Brosig, Pierucci, Kupst, & Leuthner, 2007; Cortezzo, Sanders, Brownell, & Moss, 2015; Currie et al., 2016; Penticuff & Arheart, 2005).

NICU Population, Environment and Ethical Considerations

Despite the advances in neonatal medicine that have allowed for a marked reduction in infant deaths, there remains a significant number of those born with specific conditions who will not survive. Approximately 22,000 infant deaths occur annually, with more than 50% of them

occurring in the neonatal period and in the NICU setting (Ely & Driscoll, 2019; Youngblut & Brooten, 2012). Yet despite this large number, studies indicate that less than 4% of children who meet the criteria for palliative care have documentation to demonstrate receiving palliative services (Keele, Keenan, Sheetz, & Bratton, 2013). The distinct attributes of the neonatal population and the NICU environment of care are important to explicate in order to understand the barriers that surround the provision of NPC.

Pediatric patients who would benefit from a palliative care approach have a wider age range and differing set of diagnoses when compared to the NICU population. Based on pediatric mortality rates, conditions that would benefit from palliative care are highest for malignant neoplasms (8.8%), whereas infant mortality rates are highest for life-limiting congenital malformations (20.2%) and prematurity and low birth weight (16.8%) (National Hospice and Palliative Care Organization, 2012).

Parravicini (2017) grouped the conditions for which NPC would be indicated in two broad categories: those with life-limiting conditions and those with terminal conditions. Life-limiting conditions include severe central nervous system anomalies associated with short life expectancy; lethal lung hypoplasia; complex cardiac anomalies; and genetic conditions such as trisomy 13 and 18, inoperable conjoined twins, and metabolic conditions with a short life expectancy despite treatment. Terminal conditions include extreme prematurity, newborns not responding to cardiopulmonary resuscitation, severe brain and neurologic injury, and end-of-life multi-organ failure.

Prior to the advent of neonatal medicine, infants with the above conditions would not have been expected to survive. Care would have focused on comfort measures to support a peaceful death (Duncan, 2018). With the development of medical treatments and technologies,

infant survival for decreasing ages of prematurity and many congenital conditions became possible for the first time. As a result, between 1940 and 1970, the infant mortality rate declined by 58% in the United States (Wegman, 1971).

Increased survival rates, along with changing trends in the timing of NICU death have further highlighted the need for a palliative care approach in the NICU. Dupont-Thibodeau, Langevin and Janvier (2014) conducted a retrospective chart review to examine age at death in a single center Level III NICU between 2000-2002 (cohort one) and 2007-2010 (cohort two) to compare timing, cause and mode of death in the two groups. An analysis of 204 neonatal deaths revealed that the average age of death doubled from 9.71 days in the first cohort to 18.8 days in the second cohort and the number of deaths in the first 48 hours of life fell from 52% to 29% ($p < .0001$). Although overall NICU mortality rates did not change, this study identified that infants were living for longer periods before they died in the NICU. Standardized NPC would improve the quality of care received for these infants and their families.

In addition to infants surviving for longer periods in the hospital, the majority of NICU deaths today occur after the withdrawal or withholding of life-sustaining treatment. Published studies estimate that the incidence of this occurring is between 74-82% of all NICU deaths (Abe, Catlin, & Mihara, 2001; Weiner, Sharma, Lantos, & Kilbride, 2011). Abe et al. (2001) conducted a retrospective chart review to evaluate end-of-life care practices after the withdrawal of care for 18 infants who had died in 2 urban hospital NICUs. Through an examination of the documentation that included ventilator withdrawal, medication administration, parental involvement in decision making, and support of the family, the researchers identified a lack of clarity and consistency in documented care received. Among these infants, 22% had no written orders for ventilator removal, only two-thirds were receiving pain medication in conjunction

with ventilator removal and in one case, a fentanyl drip was discontinued at the same time the ventilator was withdrawn. Moreover, although emotional support was documented as being provided by clergy (33%) and social workers (83%), and friends (11%), nurses did not document the emotional support that they provided to parents in any of the charts reviewed. Although this study involved a small sample, these findings illustrate the need for a standardized palliative care approach that would better address pain management and articulate the nurses' role in providing emotional support for parents.

Weiner et al. (2011) conducted a retrospective chart review of 414 infants who died between 1999 and 2008 in a regional referral NICU. Infants were grouped into the following categories: very preterm (<32 weeks), congenital anomaly and other. They found that 61.6% had care withdrawn and 20.8% had care withheld. Furthermore, the percentage of deaths that followed withholding treatment increased by 1% each year, primarily in the premature group.

Ethical concerns raised by nurses, physicians, and families in the 1970s over caring for newborns born extremely premature and those with life-limiting conditions (Duff & Campbell, 1973, 1976; Harrison, 1993; Stinson & Stinson, 1983) led to the development of guidelines to direct resuscitation and withholding of care decisions. The Neonatal Resuscitation Program, with its first textbook published in 1987, includes a chapter on ethics that provides guidelines for delivery room resuscitation and withholding and withdrawal of care decisions (Weiner, Zaichkin & Kattwinkel, 2016). The challenge with these guidelines is that there is no clear-cut demarcation for determining age of viability, nor a set of absolute diagnoses that warrants withholding and/or withdrawal of care. In addition, parental preferences for a treatment course vary widely based on their values and life experiences. Additional factors such as limited precision for fetal gestational age and birth weight estimates, variations in outcomes for infants

born at the thresholds of viability, and social and cultural assumptions regarding infant death all play a role in influencing care provider decision-making processes. As a result, the decision-making processes remains complex and emotionally challenging for health care providers.

Physician and nurse pre-licensure and continuing education, with its primary emphasis on treating diseases and “saving lives,” further complicates the decision-making process regarding non-initiation of care and withdrawal of curative treatment. Withholding and/or stopping curative treatment, along with a shift toward a palliative care approach, are commonly perceived as “giving up” or “doing nothing” for the patient and often result in anxiety and distress for the NICU team members. Catlin and Stevenson’s (1999) seminal study examining physicians’ experiences of delivery resuscitation for extremely low birth weight (ELBW) preterm infants illustrates these challenges. This qualitative study used descriptive, naturalistic inquiry to interview a convenience sample of 54 physicians who resuscitated ELBW infants. Despite their awareness of high morbidity and mortality rates, 96% of physicians offered resuscitation to all ELBW infants in the delivery room. The main factors cited for this action included, the role of the physician as being trained to save lives, inability to determine precise gestational age and requests from parents to “do everything.”

In addition to issues surrounding nurse and physician education, cultural assumptions regarding NPC further influence health care team members’ decision-making processes. The societal expectations of medicine to cure and save lives create the perception that death is a medical failure (Craig & Mancini, 2013). Furthermore, the very notion of end-of-life care occurring at the beginning of life can seem a contradiction of terms (Bétrémieux & Simeoni, 2011). Whereas death at the end of a long life can be understood as part of the life cycle, it is a difficult concept to understand as an event that occurs with or soon after birth. At a societal level,

conversations surrounding infant death are often viewed as unthinkable, as this is considered a life that has ended too soon (Kain, 2007; Kain & Wilkinson, 2013). The lacking social norms and customs surrounding infant death contribute to a workforce of health care providers that lack the skillset to have conversations with families surrounding palliative care (Henner & Boss, 2016). As a result, nurses and physicians often avoid conversations surrounding palliative care approaches that could lead to enhanced comfort measures for infants and families.

To better understand nurses' perceptions of palliative care in the NICU, it is important to note distinctions between practices that support a natural end of life after the withdrawal of care and those that involve active infant euthanasia. In 2005, the *New England Journal of Medicine* published an article that described a set of guidelines from the Netherlands for the deliberate ending of an infant's life. Known as the Groningen Protocol (Verhagen & Sauer, 2005), the authors outlined detailed steps to be taken when making decisions regarding infant euthanasia. This article drew significant media attention and generated much controversy in lay and professional publications.

In 2013, the American Nurses Association (ANA) published a position statement titled "Euthanasia, assisted suicide and aid in dying" whose purpose was to define these terms and to describe nurses' ethical obligations in responding to requests for euthanasia and assisted suicide. Euthanasia is defined as "the act of putting to death someone suffering from a painful and prolonged illness or injury" (ANA, 2013, p.4). Within this statement, the ANA explicitly prohibits nurses' participation in assisted suicide and euthanasia, citing that these acts are in direct violation of Code of Ethics for Nurses with Interpretive Statements (ANA, 2015). The statement goes on to state that "this does not negate the obligations of the nurse to provide compassionate, ethically justified, end of life care which includes the promotion of comfort,

alleviation of suffering, adequate pain control and at times, forgoing life sustaining treatments” (p. 4). The ANA provides clear distinctions between euthanasia, palliative care practices and the nurse’s ethical obligations regarding providing compassionate end-of-life care.

This section provides an overview of the challenges inherent in the NICU environment and patient population that contribute a lack of standardized NPC integration. Despite published guidelines that support withholding and withdrawal of care for infants with life-limiting and terminal conditions, health care providers face considerable challenges when navigating this decision-making process. The limited precision of fetal gestational age and birthweight detection, variability in outcomes for those born at the limits of viability, parental preferences, and societal and health provider assumptions regarding infant death are among the challenges that health care providers face when making treatment decisions. The next section presents the findings surrounding parents’ experiences with care received for their infant in the NICU, with attention given to palliative care, end-of-life care, decision making, and interactions with the health care team members.

The Parent Experience in the NICU

Research pertaining to parents’ experiences in the NICU focus on the following: shared decision making, palliative care, end-of-life care, and the long-term impact of these experiences on the subsequent grieving process. Common themes identified include the following barriers and facilitators to the grieving process: communication, shared decision making, continuity of care, the physical environment, and memory-making activities.

In a seminal publication by Whitfield, Siegel, Glicken, Harmon, Powers and Goldson (1982), the notion of neonatal hospice care was first introduced in the literature with a description of the program in the NICU. The authors outlined the components of their unit’s

program that included the decision-making process, a family room, involvement of the family in making decisions and hospice training for the NICU staff. Prior to the implementation of a neonatal hospice program in their unit, they identified that 33% of parents who had experienced infant loss in the NICU reported a serious family disruption such as marital difficulty or separation. The parents described feelings of isolation, lack of understanding on the part of families and friends and extended family, as well as financial difficulties related to the infant's hospitalization. Although this report did not describe the data collection methods used to arrive at their findings, it was the first publication to describe a palliative care program for the NICU and highlight the long-term negative impact that a lack of this approach can have on parental grieving.

Firsthand parent accounts of their NICU experiences began to emerge at this time as well. *The Long Dying of Baby Andrew* (Stinson & Stinson, 1983) outlined the daily experiences of parents who had a 24-week premature son that lived for 6 months. Accounts of their infant's repeated painful procedures, frequent and unpredictable changes in condition, and negative interactions with staff gave fresh insights into the emotional turmoil that NICU parents experience. The authors provided a clear picture regarding the extensive technological support required for those born at the limits of viability and raised ethical concerns regarding the appropriateness of care for these infants. Subsequent studies exploring parents' end-of-life experiences emerged, creating a body of knowledge that would drive NPC guideline development.

Orfali and Gordon (2004) conducted an ethnographic study to explore cross-cultural parent experiences of medical decision making and coping with having a critically ill baby in a NICU. The researchers conducted in-depth interviews on 75 mothers who had critically ill or

deceased infants in Level III NICUs located in France and the United States. In the French NICU, characterized by a paternalistic approach to decision making, parents expressed overall higher satisfaction with the care of their babies and were better able to cope with the loss of their child than American parents. In contrast, in the American NICU environment, where emphasis on parental autonomy in the decision making approach is more common, the aim of full parental involvement in decision-making was not always achieved, which, in many cases, resulted in parental feelings of isolation. American mothers felt that they were not given clear information and guidance to support decisions and were left largely on their own to make decisions regarding their child's treatment. Issues of physician mistrust and unclear communication were identified, most notably in relation to changes in attending coverage throughout the infant's hospitalization. This study underlines the importance of clear communication, consistent messaging and the support that parents need when making end-of-life decisions for their infants.

Munson and Leuthner (2007) conducted an exploratory study to identify factors important to parents with their infant's end-of-life care. Nineteen parents who had an infant die at less than one year of age were interviewed via telephone or in person and completed the Revised Grief Experience Inventory (RGEI), a 22-item Likert-type scale. Although parents scored significantly lower on the RGEI, when compared with normative data from a sample that had lost a close family member or friend, the qualitative item results revealed factors that were important to their end-of-life experiences. The themes identified in this study included honest communication, empowered decision-making, need for staff providing parental care, environment, faith/trust in nursing care, follow-up and bereavement groups, and keeping memories alive.

An ethnographic study conducted by Armentrout (2009) explored parents' perspectives of grief following the death of their infant in the NICU after the withdrawal of life-supporting treatment revealed similar themes. This study utilized narrative inquiry via in-person and telephone interviews with 15 parents consisting of four couples and seven mothers. The parents were recruited via a parent support group's online newsletter. This homogenous sample consisted of 13 white, 1 Hispanic and 1 African American parent, all of whom were college educated with a bachelor's degree or higher. Parents from this study identified the following facilitators for grieving: privacy and time alone with their child to hold them and say goodbye; and memory-making activities such as taking pictures, saving footprints and hair clippings. They expressed regret over not having created more of these memories and not having more parenting opportunities such as bathing and dressing their child. Regrets were also expressed for not having friends and families see their infant. When asked how health care professionals could have helped more during this time, the parents' response was to encourage them to be parents and to help them collect memories.

An inductive, qualitative study from the United Kingdom (U.K.) (Branchett & Stretton, 2012) provided rich qualitative data on personal experiences of parents who experienced the death of an infant in the NICU. Research participants were sought through an online support forum and through acquaintances of mutual support networks. The sample was comprised of 54 mothers and 3 fathers who had lost a child in the neonatal period. The parents were asked the following questions: "What did you want or need professionals to know about your experiences of losing your baby or your experience of their palliative care?" and "What was 'good' about the palliative care you and your child received and what could have been improved?" Eight themes emerged from the responses: creating memories; empathy; time and space; practical help and

understanding; sensitivity; communication with parents; accurate record keeping and communication; and support afterwards. These findings were incorporated into the evidence base that went on to support a subsequent integrated comfort care pathway for a regional newborn network in the United Kingdom.

A study examining parents' experiences of pediatric palliative care and its impact on long-term parental grief (van der Geest et al., 2014), demonstrates the positive benefits of communication and continuity of care on the grieving process for parents. Eighty-nine parents of 57 children who died of cancer participated in this retrospective cross-sectional study. Parents answered survey items using a 5-point Likert-type scale that measured grief, parents' perceptions of interactions with health care professionals and symptom management during the palliative phase. Parents highly rated communication ($M = 4.6 \pm 0.6$), continuity of care ($M = 4.3 \pm 0.6$) and parental involvement ($M = 4.6 \pm 0.7$) during the palliative phase. Higher ratings of parents on communication ($\beta = -9.08, p = .03$) and continuity of care ($\beta = -11.74, p = .01$) were associated with lower levels of long-term parental grief. These findings are consistent with the literature on NICU parents' experiences and further highlight the positive impact that communication and continuity of care have on long-term parental grief.

An exploratory cross-sectional study was conducted at a single center Level III and IV NICU to explore parent and the health care team experiences with end-of-life care (Cortezzo, Sanders, Brownell & Moss, 2015). Nine neonatologists (64.3%), 20 advanced practitioners (50%) and 75 neonatal nurses (40.8%) from the identified NICUs completed an online Likert-type scale survey with open-ended questions in 2013. Parent surveys were mailed to each of the 28 family members whose baby had died in either of the identified NICUs between July 1, 2011, and December 31, 2012; seven families (30%) completed either a paper or telephone survey.

Both health care providers and parents provided favorable responses regarding the quality of end-of-life care they perceived was provided to infants. Of the families who responded, 57.1% recounted that the health care team made sure their wishes were met and did not feel abandoned by staff, 71.4 % reported that they received adequate emotional support and 85.7% stated that they received information about bereavement services. Themes from the open-ended responses included the importance of memory making, the need for bereavement services and the appreciation for staff who provided comfort, support and clear communication. Although the sample size for the parent group was small, this study suggests that when NICU health care team members can incorporate palliative care within their practice, parents will be more satisfied with the quality of care that they and their dying infant receive.

In a recent qualitative descriptive study, Falck, Moorthy and Hussey-Gardner (2016) examined the provision of palliative care as experienced by mothers and health care providers (HCPs) of NICU patients with life-threatening illnesses. Interviews were conducted on six mothers and corresponding HCPs. The format used a 20-question open-ended interview guide that was developed from a literature review. Common themes that emerged from the data were as follows: communication, privacy, continuity of care and relationship building, maternal knowledge seeking and emotional turmoil. Mothers emphasized the importance of communicating with transparency and trust building issues that occur when the attending physician coverage changes. The emotional turmoil reported by these mothers reinforces the need for psychosocial and spiritual support that a palliative care program would address. This study highlights the importance of the nurse's role within the interdisciplinary team to provide clear communication to parents, bridge gaps that can occur with physician coverage changes, and coordinate with appropriate team members to ensure that parents' emotional needs are addressed.

Additionally, this study underlines the importance of privacy within the NICU for families during their crisis.

A descriptive qualitative study using in-depth, face-to-face interviews was conducted to explore parents' experiences related to their infants NICU hospitalization, end-of-life care, and palliative care consultation (Currie et al., 2016). The sample consisted of 10 parents whose infant had died in a large level III NICU in the southeastern United States. Six of the 10 parents received a palliative care consultation during their infants' NICU hospitalization. The primary theme that emerged from the data was "Life and Death in the NICU Environment with three categories: ups and downs of parenting, decision making challenges in the NICU and parental support." Within the category of parenting was the importance of having the opportunity to "be a parent" and participate in their child's care. Although parents expressed difficulty in making decisions regarding end-of-life care, they expressed that they wanted to be an informed partner with the health care team in the process. Barriers to parenting in the NICU involved communication conflicts that arose with parents and the health care team members as a result of inconsistent nursing staff assignments. While parents stated that most nursing staff were supportive and helpful, they also experienced some nurses as being insensitive to their needs.

The research on NICU parents' experiences and the impact of these experiences on long-term grief further emphasize the importance of the consistent delivery of a palliative care model. The published studies identified the following factors that were important to parents' NICU experiences: communication, shared decision making, continuity of care, the physical environment, memory-making activities, and follow-up support. The next section presents the literature on nurse and physician experiences in providing palliative care in the NICU.

Health Care Professionals' Experiences with Caring for Critically Ill Infants

The literature on health care professionals' experiences with caring for critically ill infants has focused on the following themes: Moral Distress; Nurses' Perceptions of Palliative Care in the NICU; Perinatal Palliative Care and the Transition from Curative to Palliative Comfort Care. This section reviews the pertinent literature as it relates to these themes.

Moral Distress

The link between moral distress and caring for critically ill infants with uncertain and/or life-limiting conditions has been well documented in the literature (Cavaliere, Daly, Dowling, & Montgomery, 2010; Hamric & Blackhall, 2007; Janvier, Nadeau, Deschênes, Couture, & Barrington, 2007). The term *moral distress* was first described by Jameton (1984) as he sought to describe the painful feelings and psychological disequilibrium that nurses experience when they are conscious of an appropriate moral action to take but are unable to do so because of external constraints (Corley, 2002). The source for moral distress has been largely attributed to nurses' experiences of what is now referred to as perceived inappropriate care (Goold, Williams, & Arnold, 2000; Hefferman & Heilig, 1999; Jox, Schaidler, Marckmann, & Borasio, 2012; Singal et al., 2014).

Publications on moral distress in critical care and NICU nurses describe the impact that providing this type of care has on nurses, and in turn on the quality of care that is provided to their patients and families. A descriptive pilot study (Hamric & Blackhall, 2007) surveyed nurses ($n = 196$) and attending physicians ($n = 29$) working in intensive care units on their perspectives of providing care to dying patients in intensive care units. Salient findings included that 45% of nurses reported having left or considered leaving a position because of moral distress. When compared with physicians, nurses experienced more moral distress, less collaboration, a negative

ethical environment and less satisfaction with the quality of care they provided. Although limited to two intensive care units, this study provides insights into how a negative ethical environment adversely affects nursing care.

A quantitative survey design study (Janvier et al., 2007) was conducted to determine the frequency with which nurses and residents experienced ethical confrontations and what factors are associated with the increased frequency of these encounters. Ethical confrontations were defined as events that go against one's moral beliefs (moral distress). The survey was distributed to nurses at a university center, a high-risk obstetric service, a maternity hospital NICU with 85% inborn patients and an outborn NICU whose preterm admissions include a majority of infants with surgical complications. Additionally, obstetric and pediatric residents from the four universities in the region received the questionnaire. A total of 297 caregivers completed the survey with 114 full-time nurse and 164 residents comprising the sample. Salient findings included a higher percentage of nurses (35%) reported experiencing ethical confrontations as compared to the residents (19%). The level of significance is not noted in the study. The threshold for the resuscitation of newborns was much higher for nurses working in the outborn NICU setting than the nurses in either the inborn NICU or the delivery room ($p < .05$). A higher proportion of nurses unwilling to resuscitate infants at 24-25 weeks reported frequent ethical confrontation ($p < .05$). Also, nurses who overestimated the prevalence of cerebral palsy reported higher thresholds for resuscitation (46%). This study provides insight into the link between moral distress and nurses' direct experience in caring for critically ill, extremely premature infants.

A descriptive, correlational study (Cavaliere et al., 2010) of registered nurses ($n = 94$) working in Level III NICUs in a large healthcare system examined moral distress and personal characteristics that were associated with their moral distress scores. The situations that received

the highest scores for moral distress were consistent with other research findings on moral distress among critical care nurses. The characteristic significantly related to moral distress included the desire to leave a current position, lack of spirituality, altered approach to patient care and considering leaving a previous job as a result of moral distress. Moral distress not only affects the emotional and physical health of nurses but also negatively influences NICU infants and their families. Burnout, turnover, and avoidance of patient assignments ultimately impact the quality of nursing care provided in the NICU.

Nurses' Perceptions of Palliative Care

Studies that center on nurse and related health care professionals' experiences with providing care to infants with uncertain and life-limiting conditions have focused on neonatal and perinatal palliative care, and end-of-life care, and the transition from curative to purely palliative treatments. The research on nurses and parents share the following common findings: communication and the physical environment on providing quality patient care. Additional findings specific to nurses' perceptions include inadequate resources, parental demands, provision of perceived inappropriate care, and a lack of educational preparation.

The Neonatal Palliative Care Attitude Scale (NiPCASTM®) (Kain et al., 2009) is a validated instrument designed to measure neonatal nurses' perceptions of barriers and facilitators of palliative care in the NICU environment. After face and content validity development, the tool was administered to a cross-section of Australian neonatal nurses working in a Level III NICU ($N = 465$). Through exploratory factor analysis and data reduction techniques, the investigators arrived at a three-factor model regarding barriers to and facilitators of palliative care in neonatal nursing: (1) inadequate staffing to support palliative care practice, (2) a physical environment that is not conducive to palliative care practice and (3) technological imperatives

and parental demands. This study established preliminary reliability using exploratory factor analysis; however, further testing on additional populations of neonatal nurses was recommended using a confirmatory factor analysis approach (Kain et al., 2009).

The NiPCASTM© has subsequently been administered to additional populations of neonatal nurses. A sample of nurses ($n = 50$) in a large Level III NICU setting in the Midwestern United States completed the NiPCASTM© (Wright et al., 2011). The authors of this study identified barriers and facilitators based on the mean scores of participants' responses for each question. They did not conduct an exploratory factor analysis to arrive at their results. The barriers identified in this study were: inability to express values and opinions, inadequate physical environment, technological demands, parental demands and lack of educational support. The eight facilitators identified in this study were supportive medical staff, support from medical team when palliative care is implemented, staffing, time spent with dying baby, policies/guidelines supporting palliative care and available counseling. This study utilized a convenience sample of nurses from a single NICU, thus limiting generalizability of results to a larger population of nurses.

Chen et al. (2013) translated The NiPCASTM© into Taiwanese to examine neonatal nurses' beliefs and attitudes toward caring for dying neonates in Taiwan. A cross-sectional sample of neonatal nurses ($n = 80$) across four medical centers in different cities in Taiwan completed the survey. In addition to the previously identified barriers noted among the Australian nurses, results from this study identified additional barriers related to the nurses' role in communication and difficulty expressing their opinions, value conflicts, educational preparation, and emotional support. The small sample size is a limitation to the strength of the

findings. Furthermore, the Taiwanese cultural context would prevent generalizing findings to Western cultures.

The most recent study to utilize the NiPCAS™© was conducted in Southeast Iran, with a sample of 70 nurses from three NICUs (Forouzi et al., 2017). Using content face validity, the tool was modified and translated into Farsi so that it would have cultural relevance for Iranian nurses. A panel of expert nurses identified the following five barriers to palliative care for the modified NiPCAS™©: insufficient resources, inappropriate use of technology, inappropriate organizational culture, inappropriate personal and social attitudes, and inadequate nursing proficiency. Statistical analysis demonstrated that overall, 42.63% of nurses agreed or strongly agreed with the proposed five barriers. Correlational analysis was performed and identified that nurses with lower levels of education (vocational versus baccalaureate-trained nurses) reported the presence of more barriers in the categories of inappropriate organizational culture and/or inadequate nursing proficiency. Although these findings are limited to Iranian culture, it raises the issue regarding the need for appropriate educational preparation of nurses that may be of relevance to other populations of neonatal nurses.

A qualitative, phenomenological study design (Kilcullen & Ireland, 2017) was used to explore neonatal nurses' perceptions of facilitators and barriers in Australian Level III NICU. Semi-structured interviews were conducted with eight neonatal nurses recruited with purposive sampling. Six themes emerged around staff factors and family support that were perceived to support the delivery of high-quality palliative care. Staff factors included leadership, clinical knowledge, and morals, values and beliefs. Family support factors involved emotional support, communication and practices within the unit. The barriers to provision of NPC included a perceived lack of staff education, lack of privacy, isolation, staff characteristics and policy and

procedure factors. Although limited to one NICU setting, these findings are consistent with the quantitative studies conducted using the NiPCAS™© instrument.

Perinatal Palliative Care

Perinatal palliative care (PPC) extends the palliative approach to the fetus and family during pregnancy when a prenatally diagnosed life-limiting condition is identified (Munson & Leuthner, 2007). The manner in which parents are approached with a life-limiting fetal condition during pregnancy impact parents' expectations for the care of their infant in the NICU and thus influence the nurse's interactions with the family.

Wool (2013) conducted a cross-sectional survey exploring physician and advanced practice nurse perceptions in providing perinatal palliative care (PPC). This quantitative study design utilized a web-based survey tool, The Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS) that was completed by a total of 66 physicians and 146 advanced practice nurses across North America. The results demonstrated that although physicians and advanced practice nurses have fundamentally similar perspectives regarding ethical principles of PPC, physicians were significantly more confident than the advanced practice nurses in initiating and facilitating PPC. This study is important, as it is the first of its kind to evaluate provider comfort and confidence with addressing palliative care needs in the perinatal period. It also highlights the need to initiate palliative care planning with parents when receiving life-limiting prenatal diagnoses.

Another study identified similar challenges among maternal fetal medicine specialists throughout France regarding barriers to referring families with lethal fetal anomalies (LFA) for PPC (Tosello et al., 2014). In total, 224 specialists from 48 multidisciplinary prenatal centers were surveyed regarding their perceptions of what would be considered a LFA diagnosis.

Inconsistencies and discrepancies of opinion concerning LFA coupled with legal and ethical aspects of caring for these pregnancies were noted. This study raises issues regarding the information that parents receive about fetal diagnoses and the availability of palliative care options. Families who do not receive accurate information regarding prognosis and palliative care options often require additional support and counseling resources when their infant is admitted to the NICU, thus putting further strain on the NICU team and the NICU nurse's role.

NICU Nurses' End-of-Life Care Experience

Qualitative studies have explored the NICU nurses' experiences surrounding care at the end of life. Using narrative inquiry, Lewis (2017) explored NICU nurses' affective responses to end-of-life care. Thirty-six nurses from the United States who were members of the National Association of Neonatal Nurses submitted written narratives about an end-of-life experience that evoked strong emotions. Demographic characteristics were collected, including end-of-life education and unit policy in their practice. The most frequently reported affective responses included an overall feeling of responsibility to deliver high-quality, compassionate care, moral distress over perceived inappropriate care, and identification of shared grieving with families. Healthy coping mechanisms reported included support from colleagues, debriefings and the practice of intentional gratitude. Unhealthy coping mechanisms included avoidance in the forms of refusing a patient assignment and calling in sick to work. These findings reiterate the negative consequences of moral distress with end-of-life care. The author also noted a significant relationship ($p = .04$) between the percentage of nurses who received end-of-life care education in their nursing programs and the percentage of these same participants who reported this education was not clinically helpful in caring for dying infants. This finding highlights the need for ongoing end-of-life education for practicing nurses within the context of their current role.

A qualitative exploratory study (Fortney & Steward, 2017) using semi-structured face-to-face interviews was conducted with 14 NICU nurses who cared for 20 infants that died at a large children's hospital in the Midwestern United States. The aim of this study was to examine nurse observations of symptoms in infants at the end-of-life in the NICU. Data analysis of the recorded and transcribed interviews revealed the following themes: uncertainty, discomfort and chaos. Issues surrounding uncertainty was related to prognosis, symptom recognition and treatment and timing of appropriate transition from curative to purely palliative treatment. The theme of discomfort was characterized by ethical issues surrounding perceived inappropriate care and inconsistencies witnessed by provider transitions and change of plan. One nurse noted the anxiety and stress that she experienced when she had conveyed the physician's plan of care with the family, only to have a new doctor take over and change the plan. Chaos was characterized by the lack of clear guidelines in caring for the dying infant and family. This study is consistent with previous findings regarding the nurses' perception regarding the lack of knowledge related to palliative care guidelines and the inconsistent integration of NPC within NICUs.

Transition from Curative to Palliative Care

Additional palliative care research has focused on neonatal and pediatric health care professionals' perceptions on the transition points from a curative focus to a palliative comfort care plan in the acute care setting. A qualitative study by Docherty, Miles and Brandon (2007), using semi-structured interviews, explored health care workers' experiences with providing care to children in pediatric, neonatal and bone marrow transplant units at a southeastern United States medical center. The participants, chosen by purposive sampling, consisted of six staff nurses, four physicians, three social workers, three advanced practice nurses and one respiratory

therapist. Three broad themes emerged from the findings of the study: palliative care as an added dimension in the illness trajectory, palliative care moving away from curative treatment, and professional issues. Concepts within these themes included the need to provide a palliative approach alongside curative treatments and the difficulties in identifying “the dying point,” whereby the shift from curative treatments to a primary palliative care focus is appropriate. This dying point is not always agreed upon by families and providers, and families often need more time to acknowledge the need to transition away from curative treatments. Professional issues identified were the lack of formal and informal preparation that the subjects received.

A quantitative descriptive study (Catlin, 2011) using a web-based survey questionnaire reported similar findings regarding the difficulties with identifying the point when care should transition from curative to a purely palliative focus. The survey was distributed to NICU physicians and nurses at selected national conferences. A total of 285 participants completed the survey: 75% were nurses and 25% were physicians. All of the participating physicians and 98% of nurses believed that palliative care was appropriate for infants with lethal conditions. The conditions identified by the subjects were consistent with those in the literature that are categorized as life-limiting and lethal conditions. Ninety-two percent of the respondents stated there were barriers to providing palliative care to infants with lethal conditions; 50% ($n=126$) named “parents,” “parental hopes” and “parental expectations” as a barrier. The respondents stated that parental agreement was the determining factor to transition away from curative treatments, and regardless of physiology, curative treatments continued until parental agreement occurred. When asked about what would improve the transition process, 67% ($n = 174$) of the respondents identified the need for more education for staff and families, 33% ($n = 84$) identified

the need for improved communication, and 17% ($n = 44$) identified adopting a palliative care protocol.

The review of the literature related to parents' and HCPs' experiences regarding uncertain and life-limiting infant conditions and end-of-life care demonstrates common themes. Themes specific to families include communication, care transitions, shared decision making, parental support in the NICU, shared memory making, and follow-up bereavement and support. Themes specific to health care providers include communication with the multidisciplinary team and family, lack of comfort in providing care to infant and family, the need for education and unit policy. The following section presents the policy and educational programs that have emerged as a result of the growing body of literature regarding HCP and parents' experiences in the NICU.

Palliative Care Policy and Education

This section presents the policy, guidelines and educational programs that have developed in order to best integrate NPC as a standard of care. In addition, interventional studies evaluating policy and educational implementation are examined. At the global level, palliative care (PC) has been identified by the World Health Organization (WHO, 2018) as a key health priority that countries need to address. WHO recommendations to address PC issues include policies to develop structure and financing for PC at all levels of care, including PC education as a core component for current and new health care professionals, as well as the public, and policy that will ensure the availability of pain-relieving medicines for effective symptom management. Policy and protocols have emerged over the past 20 years to address the WHO recommendations.

The American Academy of Pediatrics statement on palliative care for children (2000) and the Institute of Medicine's report (2003) titled *When Children Die: Improving Palliative and End-of-Life Care for Children*, identified the unique palliative care needs for children and their families and paved the way for pediatric and neonatal focused protocol development. Caitlin and Carter (2002) were the first to publish a detailed NPC protocol. Elements of their protocol include an NPC model with an option for concurrent curative treatment and a multidisciplinary team approach to address family and infant needs. The protocol outlines specific interventions that begin before birth and extend to after-death support for the family and staff. This protocol addresses prenatal discussion planning, transport issues, location for provision of PC, pain and symptom management, withdrawal of life support, discussion of organ donation and autopsy, family care and addressing cultural, spiritual, and practical family needs, follow-up care, and ongoing staff support. Together for Short Lives, a United Kingdom-based charity organization, published a similar pathway (Dickson, 2017) that expands on communication issues for parents, home-hospice options and issues related to sibling and extended care family needs.

The National Association of Neonatal Nurses position statement, *Palliative and End-of-Life Care for Newborns and Infants* (NANN Board of Directors, 2015), emphasizes the essential role of the neonatal nurse in the provision of palliative care. This statement expands upon Catlin and Carter's protocol to include additional detail on available pain assessment tools, end-of-life care order sets, and the option for nurses to specialize in NPC through current training and certification programs.

Additional guidelines and implementation plans are described in the literature and reinforce the core components of quality NPC. Gale and Brooks (2006) explained a unit-specific NPC program development and implementation experience. Specific aspects noted in this

publication is a seven-phase palliative care pathway that emphasizes concurrent curative/palliative care approach, a resource for mothers following infant death to prevent and treat breast engorgement, maternal postpartum discharge instructions specific for those with an infant death that omits the typical newborn guidelines that may further upset grieving families, and a “lessons learned” section. Reid et al. (2011) focused on providing information and guidance for NICU nurses on the care and support of newborn infants with life-limiting conditions and a short life expectancy. They address the stress and emotional challenges that nurses encounter in caring for these infants and emphasize the importance of self-care and care of colleagues.

Conway-Oriel and Edlund (2015) implemented a protocol algorithm focused on premature infants less than 28 weeks with the intention of expanding the program to include additional diagnoses after the initial rollout. The aim of their program was to provide open, consistent communication, decrease confusion for families and staff members, provide symptom management for the infant and provide psychosocial and spiritual support for the family that would begin upon admission. Kenner, Press and Ryan (2015) presented recommendations that include guidelines to address anticipated and unanticipated losses, families of multiples, differences in maternal and paternal responses, and the need for staff support.

Notable federal level policy in the US includes the 2010 Affordable Care Act with a provision to address palliative care for children. The “Concurrent Care for Children” section 2302 of the ACA requires Medicaid coverage for pediatric palliative care, concurrently with curative treatment, as appropriate (National Hospice and Palliative Care Organization, 2012). Prior to this ruling, parents in most states had to forgo curative treatment in order to receive Medicaid coverage for hospice services. Although significant barriers remain with this ruling, such as certification by a physician that a child is within the last six months of life, it is important

legislation that acknowledges the need for palliative care to begin before curative treatments are discontinued.

The Institute of Medicine report, *Dying in America* (2015), brought significant attention to the need for palliative care to be integrated across all acute care settings. Recommendations from this report include appropriate training and education for all health care professionals. End-of-life curriculum programs that are relevant to neonatal nurses include the End-of-Life Nursing Education Consortium (ELNEC, 2019) Pediatric and Perinatal Palliative Care curriculum, and Resolve Through Sharing® Bereavement Training, developed through Gundersen Lutheran Hospital (Resolve Through Sharing, 2019). A growing number of publications exploring the effectiveness of policy and educational implementation NPC have been published that suggest favorable patient care benefits.

Younge et al. (2015) evaluated two changes in end-of-life care practices following the initiation of a palliative care program in a tertiary-care academic center NICU in the United States. This quantitative research study design utilized a retrospective chart review comparing aspects of infant deaths before and after the implementation of a palliative care program. The program, developed by an interdisciplinary team, included a palliative care protocol, a modifiable electronic order set, a nursing plan of care, staff education, and medication guidelines for palliative and end-of-life care. Pre- and post-implementation groups established by time periods were compared with the exclusion of a 3-year period surrounding implementation to minimize the contamination of results. The researchers found that end-of-life family meetings and benzodiazepine use increased following the implementation of the program with a statistically significant difference noted before and after implementation. Although limited to one

NICU setting, this study demonstrates measurable benefits resulting from a standardized NPC program.

A retrospective/prospective quantitative study was conducted by Samsel and Lechner (2015) to evaluate the implementation of an NPC care initiative at a Level IV regional NICU in the Northeastern United States. Chart reviews of NICU deaths were conducted for 24 months prior, 16 months during, and 24 months post-implementation of the initiative that included provider education, the development of formal palliative care policy and communication skills training that were developed through a multidisciplinary NICU palliative care group. NICU attending physicians, fellows, residents and nurses completed the education through a series of conferences that were offered over a period of time. Exact number of staff attending the conferences was not identified in this study. A total of 106 neonates were included in the study: $n = 44$ in the pre-implementation, $n = 40$ in the during implementation phase and $n = 22$ in the post-implementation phase. Significant findings include an increase in redirection of care ($p = .012$) and palliative medication usage ($p = .022$) and a decrease in variability of end-of-life interventions for the implementation and post implementation phases of the study ($p < 0.001$). This study demonstrates the benefits of a standardized NPC program for improving medication use for symptom management and in standardizing unit practice. As with the program evaluated by Younge et al. (2015), this study is limited to one NICU. Further research is needed to determine the extent that NPC programs are developed throughout the US.

A study evaluating the effectiveness of ELNEC Pediatric Palliative Care curricula integration in pre-licensure baccalaureate nursing education was conducted by O'Shea et al. (2015). This study utilized a matched pre-posttest design in a public and private university in the northeastern US. The intervention group received the ELNEC curriculum integrated within their

maternal-child and pediatric coursework. Coursework for the intervention group was taught by ELNEC-trained professors who have been practicing in their specialty areas for over 25 years. The control group received specialty curriculum that did not include the ELNEC material. Learners were tested using the Pediatric End-of-Life Care test, a tool that was modified from the ELNEC curriculum and underwent face and content validity. A change in knowledge scores was noted to be statistically significant by time for the experimental group ($n = 40$) when compared to the control group ($n = 19$) (Wilks' Lambda = .90, $F(1, 57) = 6.70$, $p = .012$). The experimental group's knowledge scores increased from pretest ($M = 34.78$, $SD = 4.42$) to posttest ($M = 37.78$, $SD = 4.96$) while the control group scores did not change from pretest ($M = 37.42$, $SD = 4.06$) to posttest ($M = 37.00$, $SD = 3.28$). This study demonstrates the benefits of the integrated ELNEC curricula for pre-licensure baccalaureate nursing students. Studies that examine the benefits of this program for practicing nurses are needed.

Pilot testing of an online educational program to improve neonatal palliative care practice was conducted (Kain, 2017) to explore the program's impact on staff knowledge and attitudes toward neonatal palliative care delivery. This study included a convenience sample of multidisciplinary team members at a tertiary-level Australian NICU. The study design employed a randomized waitlist-controlled trial with rolling enrollment so that all participants could receive the intervention. Group A participants ($n = 25$) completed the online module upon study enrollment along with a completed a pre- and post-questionnaire that was designed to measure knowledge and attitudes of NPC, using items adapted from the NiPCASTM© tool (Kain et al., 2009). Group B participants ($n = 15$) completed the pre-questionnaire, waited a 2-week period before completing the module with no post-questionnaire assessment. All participants completed a post-module survey consisting of open-ended responses to obtain general feedback to guide

future module development and testing. A Wilcoxon signed-rank test demonstrated a statistically significant difference in knowledge and attitude in relation to neonatal palliative care ($z = 2.171, p < 0.03$) in the immediate intervention group. A Mann-Whitney U test to compare differences between the two groups revealed that the immediate intervention group had a significant increase in knowledge and attitude scores compared to the waitlist (control) group ($U = 82.00, z = -2.955, r = 0.47, p < .001$). This pilot study supports the notion that an online educational program for neonatal palliative care has the potential to improve clinician knowledge and attitudes toward NPC delivery. The limited research on end-of-life educational programs demonstrates immediate benefits of change in knowledge and attitudes, but how this translates over time into nursing practice and nurse's perception of NPC has not yet been explored.

A mixed-method study was conducted to evaluate the effectiveness of 1-day palliative care education workshops on knowledge, attitude and self-efficacy scores for team members from a regional network of NICU's in the United Kingdom (Knighting, Kirton, Silvero & Shaw, 2019). Seventy-three professionals from NICUs within a hospital network system attended the 1-day workshop that was offered three times over a two-year time frame. The majority of participants were NICU nurses ($n = 60$). Participants completed a Likert-type questionnaire to measure knowledge, attitudes and self-efficacy at the start and end of the workshop with follow-up interviews conducted with a subsample of four participants. Significant improvements were noted in knowledge, attitude and self-efficacy after the completion of the workshop. Parent stories were identified as a powerful component of the training and were noted to have a lasting impact on the participants.

Conclusion

This section provides a comprehensive review of the literature related to the NICU environment and its unique challenges in providing NPC, NICU parent and staff experiences related to critically ill infants with uncertain and life-limiting conditions, and policy and educational programs that have been developed in response to parent and staff needs. Despite established educational programs and NPC policy guidelines, studies continue to demonstrate ongoing challenges that NICU staff encounter in providing NPC. Nurses' perceptions of NPC has been studied in Australia, Taiwan, Iran, and in one U.S. NICU hospital setting (Chen et al., 2013; Forouzi et al., 2017; Kain et al., 2009; Wright et al., 2011), yet there are no published studies that include neonatal nurses throughout the United States and examine their perceptions of palliative care in their practice setting. A nationwide study will provide insights into the current status of NICU nurses' perspectives regarding NPC and the potential influence of unit policy and education on their practice. These insights can be used to develop practice changes that can better support NPC.

CHAPTER 3

Research Methods

Continuously at the bedside, registered nurses are best positioned to cultivate a palliative care model for their patients and families in the NICU. Identifying nurses' perceptions of the barriers to and facilitators of palliative care in their NICU will provide insights into current neonatal practice in a nationwide sample. This chapter describes the purpose of the study, research design, sample, variables, instruments, data analysis, data management and the protection of human subjects for this study.

Purpose of the Study

The purpose of this study was to examine NICU nurses' perceptions of the barriers to and facilitators of palliative care. The relationship between nursing staff characteristics, unit policy and NPC education on the nurses' perceptions was explored to determine the influence of these factors on nurses' perceptions of the barriers they encounter in providing NPC.

Design

This study employed a descriptive cross-sectional and correlational design with a qualitative component. The rationale for this approach was that the qualitative data will add depth to the quantitative findings and thus provide a more comprehensive understanding of barriers to and facilitators of palliative care in neonatal nursing than either approach alone (Creswell, 2014). Concurrent qualitative and quantitative data collection was conducted by incorporating open-ended questions with comment boxes into the existing NiPCAS™© instrument. The qualitative data was analyzed and then triangulated with the quantitative data. This approach allowed the researcher to further expand upon the quantitative findings with supporting qualitative data.

The quantitative section of this study used an exploratory, prospective, non-experimental and correlational design to examine nurses' perceptions of barriers to and facilitators of NPC. The relationship between nurses' perception of existing unit policy for palliative care and NPC education and the nurses' perceptions of barriers to and facilitators of palliative care was explored to determine the potential effect that these variables may have on nurses' perceptions of their practice. The variables of interest for this part of the study were end-of-life education, unit policy, and the nurses' perceptions of barriers to and facilitators of palliative care as identified in the NiPCAS™ survey results. Factor analysis of the initial instrument development resulted in a three-factor model as follows (Kain et al., 2009):

1. The organization in which the nurse practices ("Organization" subscale)
2. The available resources to support a palliative model of care ("Resources" subscale)
3. Technological imperatives and parental demands ("Clinician" subscale)

Additional data regarding nursing staff characteristics (demographics) were collected to correlate findings with the survey results. This included gender, age, length of NICU experience, current employment status, formal education in neonatal intensive care, highest nursing degree obtained, role in current workplace setting, marital status, number of children, and state of practice.

The qualitative component employed open-ended comment boxes embedded in the survey. A content analysis of the data was conducted to explore themes and patterns that emerged from the responses. Findings were triangulated with quantitative data to enrich the detail regarding perceived barriers to and facilitators of NPC.

Sample/Population

The participants for this study was a sample of registered nurses who work in the NICU recruited from the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) and the National Association of Neonatal Nurses (NANN) organizations. The intent in recruiting nurses from the AWHONN and NANN membership was to obtain a sample that would be representative of the nationwide population of NICU nurses to enhance generalizability. After receiving permission from AWHONN and NANN, NICU nurses from these organizations were contacted by email (AWHONN) and message board and e-newsletter (NANN) to participate in the study by completing the survey using the web link provided. The AWHONN email invitation distribution was limited to members who were listed as NICU nurses in their organization. Participants were limited to registered nurses working in the NICU with a minimum of one year of experience in the United States. Nurses practicing outside of the United States were excluded because the focus of the research is on neonatal practice in the United States. Nurses with less than one year of experience also were excluded as they would most likely have limited experience and exposure in providing palliative care and/or end-of-life care.

Recommendations for an adequate sample size that would result in a reliable exploratory factor analysis are noted to vary widely in the literature. Suggested methods include ratios ranging from 5-10 sample cases per variable (Beavers et al., 2013). In addition, some researchers have criticized sampling size estimates, noting that the sample size sufficiency is determined by the characteristics of the data collected and therefore cannot be fully determined until the data are analyzed (Beavers et al., 2013; Henson & Roberts, 2006). Given the lack of consensus regarding sampling estimation procedures, this researcher estimated a sample size of 200 would fall within the ranges recommended in the literature; the number of variables being 26

with a target sample size of 200 cases would allow for a ratio of 7.6 cases per variable. A Kaiser-Meyer-Olkin Measure of Sampling Adequacy and Bartlett's Test of Sphericity was conducted on the collected data to confirm the sampling adequacy of the responses.

Quantitative

Instrument

The NiPCAS™ (Kain et al., 2009) is a validated tool designed to explore neonatal nurses' perceptions regarding palliative care practices for infants who are not expected to survive due to a poor prognosis. It was initially tested on a large, nationwide sample of Australian NICU nurses ($n = 645$) (Kain et al., 2009) and in subsequent smaller samples of nurses in Taiwan ($n = 80$) (Chen et al., 2013), Iran ($n = 57$) (Forouzi et al., 2017), and the United States ($n = 50$) (Wright et al., 2011). The validity and reliability of this tool was tested and confirmed in each prior study.

The NiPCAS™© tool consists of two parts. The first section contains seven demographic questions. This section was modified for this study based on the intended sample of nurses recruited to provide more detailed and relevant data regarding nursing education and practice in the United States (see appendix B for demographic data collection details). The following nursing staff characteristics were collected: NICU acuity level, gender, age, length of NICU experience, current employment status, neonatal certification, highest level of education, role in current workplace setting, ethnicity/race, children status, geographic region of practice, and religious and spiritual identification. A visual analogue scale was used to elicit information regarding the role of unit culture in supporting palliative care. The following questions related to education and policy were included in demographic section:

Have you received education on palliative and/or or end-of-life care?

- a) Yes
 - b) No
1. Please provide details on the type/name of the nature of the palliative and/or end-of-life education you received. Check all that apply:
- a. Certification educational program
 - b. Palliative care conference
 - i. Length of conference (drop down list for days)
 - c. Neonatal/Pediatric conference with palliative care session
 - i. Length of section on palliative care topic (drop down list for hours)
 - d. Poster presentation viewing
 - e. Unit-based in-service
 - f. Other (open-ended text box)
2. Does your unit have a palliative care policy or guidelines for practice?
- a) Yes
 - b) No
 - c) Unsure

The second section of the tool contains 26 attitude questions that use a 5-point Likert-type scale to collect responses (see Appendix B, Part 2). The response scale is coded as follows: 1 = *strongly disagree*, 2 = *somewhat disagree*, 3 = *unsure (neutral)*, 4 = *somewhat agree*, 5 = *strongly agree*. On the actual instrument, the “unsure” response is situated to the far right of the scale to discourage participants from routinely picking unsure responses by making them less conspicuous. During the development of this instrument, Kain et al. (2009) used data-reduction techniques with principal component analysis, which initially extracted six factors. A further

examination of the questions within each factor and the Cronbach's α of each factor determined if factors were accepted or rejected. Only the factors with an acceptable Cronbach's α of .6 or greater were retained. This resulted in a three-factor model that identified the barriers to and facilitators of palliative care (see Appendix C for Factor Subscales) (Kain et al., 2009). The constructs identified by the factor analysis are grouped as follows:

1. The organization in which the nurse practices
2. Available resources to support a palliative model of care
3. The technological imperatives and parental demands

The author has recommended further use of this instrument in different populations of NICU nurses to perform additional reliability testing and to conduct confirmatory factor analysis.

Data Collection

The AWHONN and NANN organizations were used to contact members who are neonatal nurses via email request (AWHONN) and message board posts and a e-newsletter (NANN). AHWONN membership includes nurses who work with antepartum, intrapartum or postpartum women and their newborns, in women's health, and NICU, but the email distribution was limited to nurses who have identified through the organization as NICU nurses. The body of the email invitation included the purpose of the study, importance of participation and assurance of anonymity. Researcher contact information for questions or concerns was included in the email. A link to a website to complete the survey was included in the body of the email. The survey platform was Google Forms. The email invitation was sent with one reminder, two weeks from the original email, as per the organizations policy for survey distribution. The National Association of Neonatal Nurses (NANN) membership includes nurses working with newborns. After approval was obtained through NANN, the survey invitation was posted on the

organization's message boards and included in their e-newsletter. Members received notification of all message board posts via email. This organization was contacted for permission to post the survey to their message board and e-newsletter (see Appendix A for the email letter).

Quantitative Analysis

Appropriate descriptive and inferential statistics were used in the data analysis. The quantitative results of the survey in Google Forms were uploaded into SPSS version 25 for analysis. Exploratory Factor Analysis and Cronbach's alpha were conducted on the data in order to determine the constructs and reliability of the instrument for the new population of nurses studied. Correlations were performed with the total NiPCAS™ score and the Visual Analogue scale to evaluate the extent to which the tool measures nurses' perceptions of NPC in their NICU environment. Correlations with supportive independent *t* test analyses were performed to examine the relationship between end-of-life education with total NiPCAS™ score and for the relationship between NPC unit policy/guidelines with the total NiPCAS™ score. Additional *t* tests and ANOVAs were conducted to examine the association with selected demographics and the NiPCAS™.

Qualitative Analysis

The qualitative section presented open-ended items with comment boxes embedded in the survey to collect information regarding palliative care policy and guidelines that are implemented in the respondents' NICUs and for questions that were previously identified within the factor subscales (see Appendix C). The following identified questions were selected based on their relevance to the literature on NPC:

(23) In my NICU, the team expresses its opinions, values and beliefs about providing care to dying babies; (27) In my NICU, the staff go beyond what they feel comfortable with in using

technological life support; (28) In my NICU, staff are asked by parents to continue life-extending care beyond what they feel is right; and (31) When a baby dies in my NICU, counseling is available if I need it. An additional open-ended comment box was at the end of the survey: Please provide any additional comments regarding your experiences with providing palliative care in your practice setting.

The qualitative responses were downloaded from the Google Forms survey and uploaded into N-Vivo for analysis. A content analysis of the data was conducted to explore themes and patterns that emerged from the responses. Findings were triangulated with quantitative data to provide information regarding perceived barriers to and facilitators of NPC.

Data Management

Approval to conduct the study was obtained from the Molloy College Institutional Review Board (IRB). Since recruitment and data collection was accomplished using an anonymous survey and demographic tool, this study was exempt from a full board review. A recruitment letter explaining the study was distributed electronically and contained ethical consent components (Appendix A). Consent to participate was inferred by participants' completion of a submitted electronic survey and was stated as such in the invitation letter. Risks to participate in the research were considered to be not more than what is experienced in everyday life with the potential benefit described as contributing to scientific knowledge of the profession. Any subjects requesting study results have been de-identified from the data to ensure the anonymity of results. Data have been secured in a password-protected electronic file that was accessible only to the researcher. Data will be kept for five years. Results may be presented at professional conferences or published in a professional journal.

Conclusion

This research study examined NICU nurses' perceptions of the barriers to and facilitators of palliative care. The relationship between nursing staff characteristics, unit policy and NPC education on the nurses' perceptions were explored to determine the influence of these factors on nurses' perceptions of the barriers they encounter in providing NPC. Appropriate statistical testing was conducted on the quantitative data. Content analysis was performed on qualitative data to identify emerging themes and triangulated with the quantitative data to strengthen the research findings.

CHAPTER 4

Results and Findings

The purpose of this descriptive study was to examine NICU nurses' perceptions of the barriers to and facilitators of palliative care using the Neonatal Palliative Care Attitude Scale (NiPCAS™) (Kain et al., 2009). The relationship between nursing staff characteristics, unit policy and NPC education on the nurses' perceptions was explored to determine the influence of these factors on nurses' perceptions of the barriers they encounter in providing NPC. A qualitative content analysis was conducted through open-ended comment boxes for selected instrument items to expand upon the quantitative findings.

Study participants included a national sample of registered nurses who identified as working in a Level II, III or IV NICU, and were recruited through the Association of Women's Health, Obstetric and Neonatal Nursing (AWHONN) and The National Association of Neonatal Nurses (NANN). A total of 200 nurses consented and completed the survey.

The findings in this chapter are organized according to the research questions:

- What are neonatal nurses' perceptions regarding the barriers to and facilitators of providing palliative care?
- What are the NICU policies identified by nurses that affect the delivery of palliative care?
- What is the relationship between NICU palliative care unit policy and the nurses' perceptions of barriers to and facilitators of providing palliative care?
- What is the relationship between palliative care education and nurses' perceptions of barriers to and facilitators of providing palliative care?

Description of the Participants

Subjects were approached through two professional nursing associations with an email invitation to participate in the study. The sample enrollment period was September 18-December 14, 2019. After receiving approval from AWHONN, the email invitation was distributed to 1,800 NICU nurse members on September 18, 2019, with an additional reminder email sent on October 2, 2019. A total of 99 AWHONN members completed the survey, representing a response rate of 5.5%. After receiving approval from NANN to distribute the invitation to their membership, the invitation was posted on the following MYNANN message boards: NANN, NANNP (National Association of Neonatal Nurse Practitioners, members and the Staff Nurse SIG [Special Interest Group]). Approximately 4,000 of the 7,000 NANN members subscribe to the organization's message board service. The postings were made on November 4, 11, and 25, 2019. In addition, the invitation was included in the November 2019 e-newsletter that was sent by email to all NANN members. Total NANN message board responses were 101/4000, indicating 2.5% response rate. Given that message board postings and e-newsletter have limited visibility when compared to a direct email invitation, the response rate for this organization was considered a conservative and acceptable estimate. In total, 200 surveys were completed with minimal data missing, thus resulting in a final sample size of 200.

Data were exported from Google Forms to an Excel file, inspected for outliers and uploaded into IBM SPSS Version 25 for analyses. Due to listwise deletions in SPSS, items with missing data were automatically omitted for calculations for NiPCASTM total and individual item scores. This resulted in a sufficient final sample size for inference ($n = 187$) from analyses performed to answer the research questions (independent sample t tests, ANOVAS, and correlations) that are described in relation to the research questions. The sample size for

individual demographic frequencies is listed respectively with each item, with most respondents answering the demographic questions.

Characteristics and Demographics

The demographic detail presented in this chapter is based on the data sample of 200 participants. The demographic data obtained in the survey included the NICU level of acuity in which the nurse works (Level II/ Level III/IV), gender, age, length of NICU experience, employment status (full/part-time/per diem), certification status, level of education, work role in NICU setting, ethnicity, children, geographic location of work, religious affiliation, religiosity, and spirituality.

Personal Characteristics

Demographic data for personal characteristics are listed in Table 1. The gender analysis indicates that 97.4% ($n = 195$) were female and 2.0% ($n = 4$) were male, with 0.5% ($n = 1$) preferred not to say. These findings are consistent with maternal child-nursing specialty estimates. Although the National Council of State Boards of Nursing Workforce Study (NCSBN, 2020) reported that 9.1% of US registered nurses are men, this number is estimated to be much lower in maternal child-nursing (Cudé, 2004). In order to encourage response rate anonymity for age reporting, the survey requested information regarding age ranges, rather than an exact age number. Age groups were categorized as follows: 21-30 years of age ($n = 32$, 16%), 31-40 years of age ($n = 39$, 19.5%), 41-50 years of age ($n = 41$, 20.5%) and 51 years of age and older ($n = 88$, 44%). The distribution of age for this sample of nurses is consistent with the current nursing workforce average age of 51 (NCSBN, 2020).

The sample characteristics of race/ethnicity demonstrated a somewhat more homogenous sample in comparison with the current U.S. nursing workforce. Whereas the majority of the

participants in this sample (91%), identified as White/non-Hispanic, the U.S Department of Health and Human Services (2019) reports a racial demographic distribution of the RN workforce as follows: White/non-Hispanic, 73.3%, Black/non-Hispanic 7.8%, Asian/non-Hispanic 5.2%, and Hispanic/Latino/Spanish, 10.2%. The breakdown of geographic region of practice is noted in Table 1, with the largest group located in the South Atlantic region of the United States ($n = 58$, 28%). Seventy-four percent ($n = 148$) of the respondents reported that they have children.

Table 1
Sample Demographics: Personal Characteristics

		Frequency	Percent
Personal Characteristics			
gender	Female	195	97.5
	Male	4	2.0
	Total	199	99.5
	Missing	1	0.5
age	21-30	32	16.0
	31-40	39	19.5
	41-50	41	20.5
	51 and over	88	44.0
	Total	200	100.0
race/ethnicity	Asian	3	1.5
	Hispanic	17	8.0
	Black/African American	8	4.0
	White	182	91.0
	More than one race	5	2.5
	Total	198	99.0
region of practice	Missing	2	1.0
	New England	26	13.0
	Middle Atlantic	30	15.0
	East North Central	24	12.0
	South Atlantic	56	28.0
	East South Central	9	4.5
	West South Central	15	7.5
	West North Central	11	5.5
	Mountain	9	4.5
	Pacific	18	9.0
	Outside U.S.	2	1.0
	Total	200	100.0
children	Yes	148	74.0
	No	51	25.5
	Total	199	99.5
	Missing	1	0.5

Work Experience and Educational Characteristics

Demographic data for work experience and educational characteristics are listed in Tables 2 and 3. The majority of nurses completing the survey were noted to work in a Level III acuity NICU ($n = 178, 89\%$), have more than 15 years of NICU experience ($n = 102, 51\%$), work full-time ($n = 156, 78\%$), and work in direct patient care as an RN ($n = 103, 51\%$). The majority of respondents reported having a certification in their specialty ($n = 119, 59.5\%$). Educational degree distribution is as follows: Diploma ($n = 1, .5\%$), Associate's ($n = 6, 12\%$), Baccalaureate ($n = 101, 51.5\%$), Master's ($n = 68, 34\%$), and Doctoral ($n = 16, 8\%$). This sample size demonstrated higher educational preparation in comparison to the U.S. Department of Health and Human Services (2019) report whereby the highest level of education for nurses is listed as follows: Diploma (6.4%), Associate's (29.6%), Baccalaureate (44.6%), Master's (17.5%) and Doctoral (1.9%). Table 4 presents the reported religious and spiritual characteristics of the sample.

Table 2
Sample Demographics: Work Experience

		Frequency	Percent
NICU level	Level II	21	10.5
	Level III	178	89.0
	Total	199	99.5
	Missing	1	0.5
length of NICU experience	Less than 1 year	3	1.5
	1-5 years	44	22.0
	6-10 years	20	10.0
	11-15 years	30	15.0
	Greater than 15 years	102	51.0
	Total	199	99.5
	Missing	1	0.5
employment status	Full-time	156	78.0
	Part-Time	28	14.0
	Per Diem	12	6.0
	Total	196	98.0
	Missing	4	2.0
role	RN: Direct Patient Care	103	51.5
	Nurse Practitioner	22	11.0
	Nursing Education	40	20.0
	Nursing Management	23	11.5
	Other	11	5.5
	Total	199	99.5
	Missing	1	0.5

Table 3
Sample Demographics: Education Characteristics

Educational Characteristics			
		Frequency	Percent
Certification	NCC: Neonatal Intensive Care	76	38.0
	NCC: Neonatal Nurse Practitioner	26	13.0
	NCC: Low-Risk Neonatal Nursing	10	5.0
	AACN CCRN: Neonatal	7	3.5
	No certification	79	39.5
	Missing	2	1.0
	Total	198	99.0
Education	Diploma	1	0.5
	Associate's	12	6.0
	Baccalaureate	103	51.5
	Master's	68	34.0
	Doctoral	16	8.0
	Total	200	10.0

Table 4
Sample Demographics: Religion and Spirituality

Sample Characteristics			
		Frequency	Percent
Religious Affiliation	Christian	102	51.0
	Jewish	9	4.5
	Muslim	1	0.5
	Protestant	7	3.5
	Atheist	1	0.5
	Catholic	56	28.0
	None	18	9.0
	Hindu	0	0
	Buddhist	0	0
	Other	6	3.0
	Total	200	100.0
Religiosity	Very Religious	60	30.0
	Somewhat Religious	99	49.5
	Not at all Religious	41	20.5
	Total	200	100.0
Spirituality	Very Spiritual	105	52.5
	Somewhat Spiritual	86	43.0
	Not at all Spiritual	9	4.5
	Total	200	100.0

Analyses were conducted to evaluate if selected demographic variable responses were associated with differences in total NiPCAS^{TM©} scores. Independent-samples *t* tests were conducted to compare the Total NiPCAS^{TM©} scores for those respondents who do and do not

have children and for those who do and do not have a certification, with no statistically significant findings noted. One-way between-groups ANOVA tests were conducted to explore differences on total NiPCASTM scores within age groups, length of experience, highest educational degree attained and workplace role, with no statistically significant differences noted among the groups in each demographic item.

Exploratory Factor Analysis

The NiPCASTM is a 26 item Likert-type scale instrument that has previously established validity and reliability testing in 2008. Given the changes in practice and education that have occurred since 2008, along with this instrument being used with a new population of nurses, an exploratory factor analysis and reliability testing was conducted to arrive at a model that would be appropriate with this sample. Guidelines for instrument development reporting from Henson and Roberts (2006) and Cabrera-Nguyen (2010) were used to steer the factor analysis steps. The data were coded in SPSS analyses. The number identification for each item in the NiPCASTM instrument and Kain's (2008) rules for recoding scale items were adhered to for the data preparation. Items 10, 24, 27, 28, 29, 30, 32, and 33 were worded so that a lower score corresponded with a more positive measure. These items were reverse-coded so that higher scores represented the more positive end of the measure, so that all items responses are in the same direction of agreement.

Principal component analysis was the initial data reduction technique used to conduct the exploratory factor analysis. Factor loadings of .30 and higher were accepted. Although this method demonstrated sampling adequacy with a Kaiser-Meyer-Olkin test (KMO) of 0.752 and a Bartlett's Test of Sphericity significance level of < 0.001 , the oblimin and orthogonal rotations both resulted in a structure with cross-loading of items (see Table 5 for a comparison of factor

loadings for the initial and final model). Using a minimum eigenvalue of 1 as the criterion for factors, both rotations resulted in a nine-factor model with low subscale Cronbach values noted. Items that cross and negative loaded were removed, with subsequent analyses continuing to demonstrate the cross-loading of items and low Cronbach scores.

Given that the various iterations of PCA technique with both the oblimin and orthogonal rotations yielded models that violated the assumptions of shared space, the principal axis factor analysis (PAF) technique was then conducted. This resulted in a simple structure model with the least number of cross-loaded-negative loaded items. The KMO (.752) and Bartlett's Test ($< .001$) demonstrated sampling adequacy for PAF analysis. The analysis revealed a nine-factor structure with eigenvalues exceeding 1. See Table 6 sub-constructs for Eigen values and variance explained. A comparison of the PCA and PAF factors was conducted and items within each factor were assessed for conceptual fit. Based on the factor matrix findings of item 18 negative-loading, and item 21 cross-loading on three items in both the PCA and PAF models, the decision was made to remove these items from the scale. Items in factors 1, 2 and 3 were retained as they demonstrated conceptual cohesion and retained an acceptable Cronbach's alpha value. The remaining items contained in factors 4 through 9 were deleted as they did not demonstrate conceptual cohesion, nor did they result in acceptable Cronbach's alpha values. A final Principal Axis Factor analysis using the varimax rotation was performed on the 10 retained items (Tables 5 and 7).

Table 5

Initial and Final Factor Analysis Models

Item	Initial PCA		PAF		Final PAF	
	Score	Factor	Score	Factor	Score	Factor
8. Palliative care is as important as curative care in the neonatal environment.	.721	5	.501	5		
9. I have had experience of providing palliative care to dying babies and their families.	.716	6	.661	7		
10. I feel a sense of personal failure when a baby dies.	.705	7	.510	6		
11. There is support of neonatal palliative care in society.	**		.409	4		
12. The medical staff support palliative care for dying babies in my unit.	.737	1	.672	1	.665	1
13. The physical environment of my unit is ideal for providing palliative care to dying babies.	.709	2	.536	2	.526	2
14. My unit is adequately staffed for providing the need of dying babies requiring palliative care and their families.	.782	2	.775	2	.874	2
15. In my unit, parents are involved in decisions about their dying baby.	.656	1	.554	1	.518	1
16. My previous experiences of providing palliative care to dying babies have been rewarding.	**		.366	7		
17. When babies are dying in my unit, providing pain relief is a priority for me.	**		.383	5		
18. I am often exposed to death in the neonatal environment.	***			***		
19. Palliative care is necessary in neonatal nursing education.	.738	5	.577	5		
20. When a baby dies in my unit, I have sufficient time to spend with the family.	.724	2	.614	2	.583	2

Table 5 (Continued)

Initial and Final Factor Analysis Models

Item	Initial PCA		PAF		Final PAF	
	Score	Factor	Score	Factor	Score	Factor
21. There are policies/guidelines to assist in the delivery of palliative care in my Unit.	**		**			
22. In my unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options.	.777	1	.743	1	.772	1
23. In my unit, the team expresses its opinions, values and beliefs about providing care to dying babies.	.608	1	.555	1	.570	1
24. Caring for dying babies is traumatic for me.	.814	7	.648	6		
25. I have received in-service education that assists me to support and communicate with parents of dying babies.	**		.633	4		
26. All members of the healthcare team in my unit agree with and support palliative care when it is implemented for a dying baby.	.708	1	.629	1	.591	1
27. In my unit, the staff go beyond what they feel comfortable with in using technological life support.	.669	3	.486	3	.483	3
28. In my unit, staff are asked by parents to continue life-extending care beyond what they feel is right.	.723	3	.595	3	.667	3
29. My personal attitudes about death affects my willingness to deliver palliative care.	.710	9				
30. Palliative care is against the values of neonatal nursing.	**		.551	9		
31. When a baby dies in my unit, counseling is available if I need it.	.560	4	.432	1		
32. There is a belief in society that babies should not die, under any circumstances.	**					
33. Curative care is more important than palliative care in the neonatal intensive care environment.	.814	8	.668	8		

** Items cross- loaded. ***Items negative loaded

Table 6
Total Variance Explained- 10 items PAF

Factor	Initial Eigenvalues		
	Total	% of Variance	Cumulative %
1	3.724	37.244	37.244
2	1.336	13.359	50.603
3	1.081	10.811	61.414
4	.799	7.989	69.403
5	.692	6.922	76.325
6	.622	6.219	82.544
7	.566	5.663	88.207
8	.487	4.868	93.075
9	.356	3.560	96.635
10	.336	3.365	100.000

Extraction Method: Principal Axis Factoring.

The retained 10 items using the PAF technique resulted in a final three-factor model with identified sub-constructs. Factor One subscale items related to the unit cultural norms regarding palliative care practices and was thus labeled as the “Unit Culture” subscale. Factor Two subscale items related to the resources available to support the delivery of palliative care practices and were labeled as the “Resources” subscale. Factor Three subscale items related to the concept of “Perceived Inappropriate Care” and was likewise labeled with this name.

Internal Consistency Testing

The Cronbach’s alpha coefficient inter-item reliability for the final 10-item structure of the NiPCAS™ instrument is reported in this section. Various factors are noted to influence the Cronbach’s alpha coefficient value and acceptable scores for an instrument. Levels of .7 and above are generally considered to be acceptable with pilot testing and subscale values, whereas coefficient values of .8 or above are considered acceptable for existing instruments (Pallant, 2013). It is important to note conditions that can alter the Cronbach’s alpha value when evaluating these results. A higher number of items tend to artificially inflate the Cronbach’s

alpha value and uncorrelated items will result in a lower value (Streiner, 2003a, 2003b). Given that the accepted factor structure was obtained through principal axis factoring using the Varimax (uncorrelated) rotation, and the final instrument is limited to 10 items, the Cronbach's alpha of .77 for the total scale and subscale values of .81, .75 and .47 are considered acceptable. Table 7 presents the final 10-item model with Cronbach's, factor loadings and identified sub-constructs.

Table 7		
Final PAF with 10 Retained Items		
Unit Culture Subscale: Cronbach: $\alpha = .81$	Score	Factor Loading
12. The medical staff support palliative care for dying babies in my Unit.	.665	1
15. In my Unit, parents are involved in decisions about their dying baby.	.518	1
22. In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options.	.772	1
23. In my Unit the team expresses its opinions, values and beliefs about providing care to dying babies.	.570	1
26. All members of the healthcare team in my Unit agree with and support palliative care when it is implemented for a dying baby.	.591	1
Resources Subscale: Cronbach: $\alpha = .75$		
13. The physical environment of my Unit is ideal for providing palliative care to dying babies.	.526	2
14. My Unit is adequately staffed for providing the need of dying babies requiring palliative care and their families.	.874	2
20. When a baby dies in my Unit, I have sufficient time to spend with the family.	.583	2
Perceived Inappropriate Care Subscale Cronbach: $\alpha = .47$		
27. In my Unit, the staff go beyond what they feel comfortable with in using technological life support.	.483	3
28. In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right.	.667	3
Overall Cronbach's .77		

The survey utilized a Visual Analogue Scale (VAS) item question as an additional measure to evaluate the strength of the total NiPCAS™ score in measuring nurses' perception of palliative care practice in their NICU environment and was worded as follows: "On a scale of 1-10, please indicate how strongly you feel that the culture of your unit supports palliative care." Lower scores indicate low degree of support and higher numbers reflective higher levels of support. A Pearson's product-moment correlation was conducted to examine the relationship between the total NiPCAS™ score and the VAS. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedacity. There was a positive correlation noted between the VAS and the total NiPCAS™ score, $r(185) = .66$, $n = 187$, $p < .01$, with higher NiPCAS™ score associated indicating positive unit culture support for palliative care practice. Using Cohen's (1988, pp. 79-81) guidelines for interpreting the strength of the r value, a score of .50 to 1.0 is considered a large or strong positive correlation.

Barriers and Facilitators to NPC

This section addresses the research question: What are neonatal nurses' perceptions regarding the barriers to and facilitators of providing palliative care? Using Kain's scoring rules (2008), the mean scores for the NiPCAS™ instrument items were evaluated. The 5-point Likert scale items range from 1 (*strongly disagree*) to 5 (*strongly agree*). Items scoring above 3 indicate a positive agreement toward palliative care practice and were thus identified as facilitators of palliative care. Items scoring below 3 indicate negative agreement and thus were identified as barriers to palliative care. As previously described, retained items 27 and 28 maintained reverse-coding so that they demonstrated favorable agreement with higher scores. In addition to mean and standard error of the mean calculations, 95% Confidence Intervals were calculated to determine the final decision as to whether an item was defined as a barrier or facilitator. If the

lower and upper CI range crossed over cutoff value of 3, the item was considered neither a barrier nor a facilitator and thus removed from the analysis. See corresponding tables for Barriers (Table 8) and Facilitators (Table 9).

Table 8. Barriers to Neonatal Palliative Care

Item	<i>M</i>	<i>SEM</i>	<i>95% CI</i>
11. There is support of neonatal palliative care in society	2.84	0.08	[2.67, 3.00]
27. In my Unit, the staff go beyond what they feel comfortable with in using technological life support*	2.75	0.07	[2.60, 2.91]
28. In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right*	2.29	0.07	[2.14, 2.44]
32. There is a belief in society that babies should not die, under any circumstances*	2.5	0.08	[2.33, 2.66]

* Reverse-coded items

Table 9. Facilitators to Palliative Care

Item	<i>M</i>	<i>SEM</i>	<i>95% CI</i>
8. Palliative care is as important as curative care in the neonatal environment.	4.56	0.074	[4.41, 4.70]
9. I have had experience of providing palliative care to dying babies and their families.	4.25	0.08	[4.09, 4.40]
10. I feel a sense of personal failure when a baby dies.	3.61	0.08	[3.43, 3.78]
12. The medical staff support palliative care for dying babies in my Unit.	4.06	0.07	[3.92, 4.19]
14. My Unit is adequately staffed for providing the need of dying babies requiring palliative care and their families.	3.21	0.09	[3.01, 3.40]
15. In my Unit, parents are involved in decisions about their dying baby.	4.42	0.05	[4.31, 4.52]
16. My previous experiences of providing palliative care to dying babies have been rewarding.	3.90	0.07	[3.76, 4.03]
17. When babies are dying in my Unit, providing pain relief is a priority for me.	4.61	0.03	[4.53, 4.68]
19. Palliative care is necessary in neonatal nursing education.	4.86	0.03	[4.80, 4.91]
20. When a baby dies in my Unit, I have sufficient time to spend with the family.	3.61	0.08	[3.44, 3.77]
21. There are policies/guidelines to assist in the delivery of palliative care in my Unit.	3.31	0.09	[3.12, 3.49]
22. In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options.	3.87	0.07	[3.71, 4.02]
23. In my Unit the team expresses its opinions, values and beliefs about providing care to dying babies.	3.72	0.07	[3.57, 3.86]
24. Caring for dying babies is traumatic for me.	3.2	0.09	[3.02, 3.37]
26. All members of the healthcare team in my Unit agree with and support palliative care when it is implemented for a dying baby.	3.72	0.074	[3.57, 3.86]
29. My personal attitudes about death affects my willingness to deliver palliative care.	3.88	0.09	[3.69, 3.69]
30. Palliative care is against the values of neonatal nursing.	4.89	0.02	[4.83, 4.95]
31. When a baby dies in my Unit, counseling is available if I need it.	3.69	0.08	[3.51, 3.86]
33. Curative care is more important than palliative care in the neonatal intensive care environment.	3.79	0.08	[3.61, 3.96]

Unit Policies Identified by Nurses

Open-ended responses were used to answer the research question, “What are the NICU policies identified by nurses that impact on delivery of palliative care?” Of the 200 nurses who

completed the survey, 43 added comments in the text box provided in the survey regarding the palliative care policies/guidelines used in their NICU. Upon further examination, 9 of the 43 participants indicated they were unsure or had no policy, and 2 reported policies on caring for neonatal demise. These were removed from the analysis based on the following rationale: not knowing whether a policy exists is equivalent to practicing without guidelines, and policies on caring for a demise does not address palliative care practices that are recommended from the time of birth/diagnosis. In total, 32 respondents, which comprised 16% of the entire sample, provided information on their NPC unit policy that was included in the analysis. The data were then examined for themes and grouped into the following categories:

- Palliative care program with website identified
- Unit policy—No published guideline identified
- Unit policy—Published guideline

Among those who identified a palliative care program with a website, three were perinatal palliative care programs and two were general palliative care with no mention of a pediatric/perinatal/neonatal focus. The 23 responses grouped under “Unit policy—No published guideline identified” ranged from the simple name of policy such as “Neonatal Palliative Care Policy” to more detailed descriptions that included a palliative care team, palliative care order set, and meetings and education sessions. The published policies identified were ELNEC ($n = 2$), Catlin Candarter (2002), and a textbook on maternal child care (Lowdermilk & Perry, 2007).

Table 10
Identified Palliative Care Policies

Category	<i>n</i>
Palliative Care Program with Website Identified	5
Unit Policy—No Published Guideline Identified	23
Unit Policy—Published Guideline	4

Relationship of NiPCAS™ Results to Unit Policy

A Pearson’s product-moment correlation was conducted to examine the relationship between the total NiPCAS™ score and whether respondents reported having a unit palliative care policy/guidelines. There was a positive correlation noted between these two variables, $r(184) = .446, n = 186, p < .01$, with higher NiPCAS™ scores associated with those reporting that they have a unit policy/guidelines for palliative care. Using Cohen’s (1988, pp. 79-81) guidelines for interpreting the strength of the r value, a score of .30-.49 is considered a medium positive correlation. Independent-samples t tests were conducted to compare the total NiPCAS™ scores for those respondents who reported that their unit had a policy/guidelines for NPC with those who reported that either they had no policy or were unsure if policy guidelines existed for their unit. Given that 42 nurses reported that they were unsure if they had a unit/policy for NPC, the no/unsure responses were compressed into one category to perform the analysis. The rationale for this decision was that nurses who did not know of a policy would not provide care based on an outlined unit practice. The 87 respondents who reported having a palliative care unit policy/guideline ($M = 100.29, SD = 10.22$), compared to the 99 respondents who did not report having a policy/guideline ($M = 89.7, SD = 10.89$), demonstrated significantly higher NiPCAS™ scores $t(184) = 6.7, p < .001$.

Relationship of NiPCAS™ Results to Palliative Care/End-of-Life Education

A Pearson's product-moment correlation was conducted to examine the relationship between the total NiPCAS™ score and whether respondents received palliative care/end-of-life education. Using the final sample of 187, 127 responded yes to receiving education, with 60 responding no/unsure to receiving education. There was a positive correlation noted between these two variables, $r(185) = .373$, $n = 187$, $p < .01$, with higher NiPCAS™ score associated with palliative care education. Using Cohen's (1988, pp. 79-81) guidelines for interpreting the strength of the r value, a score of .30-.49 is considered a medium positive correlation. An independent-samples t test was conducted to compare the Total NiPCAS™ scores for those respondents who did and did not report receiving end-of-life education. The 127 respondents who reported receiving palliative care/end-of-life education ($M = 97.66$, $SD = 11.58$), compared to the 60 respondents who did not receive education ($M = 88.28$, $SD = 9.49$), demonstrated significantly higher NiPCAS™ scores $t(185) = 5.4$, $p < .001$.

Additional analysis regarding the length of palliative care education was conducted. Of those who reported receiving education on end-of-life/palliative care ($n = 127$), 2 attended a one-day conference, 14 attended a two-day conference, 20 attended a one-hour session, 9 a two hour session and 8 attended a session lasting three hours or more. There were seven responses in the open-ended comments regarding the type of educational offering reported. The responses are as follows:

- A forum on palliative care
- During orientation
- Computer modules required for unit
- Resolve Through Sharing Infant Bereavement

- RTS (Resolve Through Sharing) and hospital palliative program
- Palliative care certified neos (neonatologists) and nurses run a program/service- they train us and lecture to my graduate students
- Journal review

The Palliative care education was converted to hours to analyze whether a “dose dependent” number of palliative care education hours would result in significant differences in the total NiPCAS™ scores. Pearson’s correlations and ANOVAs were conducted with no significant findings noted between the converted number of hours reported for palliative care education and the total NiPCAS™ scores between the groups.

Table 11.

<i>Palliative Care Education in Hours</i>	<i>n</i>
None	135
One hour	20
Two hours	8
Three hours or more	8
One-day conference (8 hours)	2
Two-day conference (16 hours)	13

Qualitative Data Analysis

Selected NiPCAS™ instrument items were formatted with an additional comment box so that qualitative data could be used to explicate the quantitative findings. Using the steps as outlined in Polit and Beck (2012, pp. 558-560), content analysis was conducted and then triangulated with the quantitative findings for the corresponding instrument item. In order to ensure trustworthiness and rigor of the data interpretation (Krefting, 1990), two nurse researchers with neonatal expertise independently analyzed the written responses using the following

questions to guide the analysis: “What is this? What is going on? What does this stand for? What else is like this? What is this distinct from?” (Polit & Beck, 2012, pp. 558). The data were grouped into thematic categories based on clusters of common words and phrases that emerged from the analysis. Once the categories were identified and labeled, the data were re-read and coded according to the categories. Index cards and highlighters were used to code the words and phrases that were placed within the categories. The themes that emerged from the data were then triangulated with the quantitative findings.

Societal Understanding of Neonatal Palliative Care

Instrument item number 11: “There is support of neonatal palliative care in society,” was identified as a barrier to NPC as previously described. A total of 71 respondents provided follow-up comments regarding their impression of society’s understanding of NPC. Three themes were identified and are presented in this section.

Neonatal Palliative Care is Poorly Understood

Many of the comments addressed society’s lack of understanding or misunderstanding of neonatal palliative care. “I do not believe there is a good understanding,” “The general public does not understand what palliative care is” and “In my experience, society has no understanding of palliative care” are examples of simply stated responses. Additional comments spoke to the misperception that palliative care and hospice are synonymous:

They (society) confuse palliative care and hospice care...They hear palliative care and think immediately the baby is dying.

I don’t think it (palliative care) is utilized enough nor initiated early enough in certain cases. There is a misconception that this is hospice, which it is not. I feel the earlier that the palliative care team is involved, it helps the whole family-medical team dyad in the support of the baby whom has very serious life-threatening problems.

I have heard “babies don’t usually die; there is no need for palliative care; you only take care of happy families; end of life care is not something you need to worry about”—
Many untruths.

The Dichotomy of Giving up vs. Doing Everything

The phrases “giving up” and “doing everything” were noted throughout the comments on societal impressions of NPC. The responses spoke to the notion that curative, lifesaving treatments and palliative care are mutually exclusive care approaches whereby curative lifesaving treatments are perceived as an active process (“doing everything”) and palliative care is perceived as a passive process of “giving up” and doing nothing for the infant. The following comments illustrate this theme:

I believe when and if it is discussed, society sees it as we are quitting or giving up on this baby.

I feel society views palliative care in the neonatal setting as “giving up” or not trying.”

Social media portrays palliative care as “giving up” on babies or deeming babies not worthy of treatment.

I feel that the overwhelming majority of people think everything should be done to prevent death without considering the tremendous agony we would be putting a baby through.

I believe a lot of the population holds on to extending life, especially with the neonate, without consideration of quality of life. Many choose to “do everything” to save/keep the baby alive without looking at the pain the baby may have to endure with a poor prognosis.

The Stigma of Neonatal Palliative Care

Phrases such as “pushed under the rug,” “kept under wraps,” “stigma,” and “taboo” were used to describe the perception that society avoids the reality of infant death, thereby dismissing the need for NPC.

There is a stigma that it is only for death but not the long-term care and possible disabilities associated with prematurity.

I don't think people like to think about babies dying, so the topic is generally avoided in many areas of nursing practice/hospital policy.

It's taboo; people are afraid to bring up losses, discuss the plans for what's to come with expected losses of newborn's due to life-limiting illnesses.

One nurse's comments demonstrated the emerging incorporation of evidence based-practice guidelines that includes compassionate communication to counter the societal stigma surrounding NPC:

There is definitely a stigma. We have to introduce it lightly to parents. Our unit does a really good job of recognizing that palliative care can be for any NICU baby, not just babies that are dying. Being sensitive in the approach to families however is much more difficult. I do think that American society and our families in general don't know what it is and think that we are giving up on them. So how do we show we aren't giving up and still care?

Parental Involvement in Decision Making

Instrument item number 15: "In my unit, parents are involved in decisions about their dying baby" was identified as a facilitator to NPC, as previously described. A total of 42 respondents provided follow-up comments regarding their impression of parents' involvement in the decision-making processes for their child. While some of the comments are reflective of a standardized approach to family involvement as part of palliative care unit practice, others demonstrated an inconsistent approach that is largely physician dependent. The language used to convey the nurses' positive experiences of standardized unit practice with parental decision making also reflected a multidisciplinary approach based on current NPC practice recommendations. The following comments demonstrate positive experiences regarding parent involvement in decision making:

Our palliative care coordinator meets with the family as soon as a diagnosis is made. Together with the parents, a plan of care is developed which outlines the parent's wishes. The plan is filed on the unit and available for reference.

We have a perinatal palliative care conference utilizing an interdisciplinary team for families with an in-utero diagnosis of a life-limiting condition. Implementation of this process also includes education of all staff on key points of the approach, support and communication with these families. Care conferences are held with families every step of the way to support shared decision making.

The comments reflecting inconsistent unit practices to involve parents in decision-making illustrate a lack of standardized process. In contrast to the multidisciplinary approach, these nurses describe an independent, physician-driven practice toward parent involvement.

Providers are not always comfortable including families in care decisions.

It all depends on the attending (MD) and his willingness to allow parents to make decisions.

Doctors make most decisions without parental input. Only very involved parents make the decisions.

We have a large physician group, so this varies based on physician on service.

Technological Life Support and Parental Requests to Continue Life-Extending Care

Instrument item 27, “In my unit, the staff go beyond what they feel comfortable with in using technological life support” and 28, “In my unit, staff are asked by parents to continue life-extending care beyond what they feel is right” were identified as barriers and comprised the “Perceived Inappropriate Care” sub-construct in the factor analysis. Given the theoretical cohesion of these items, the comments were analyzed together to explicate the quantitative findings for these instrument items. A total of 37 respondents provided follow-up comments regarding their impression of their comfort level with using technological life support and 34 respondents provided follow-up comments regarding parental requests to continue life-extending care beyond what the nurse feels is right. The following themes were identified:

“Supporting the parents through the decision-making process”

Many of the comments refer to the challenges that nurses face in supporting parents during the painful decision-making process to withdraw curative treatment. Phrases such as “letting go,” “denial,” and “parents need time” were used to describe the stages that parents go through before they are ready to withdraw curative treatment. The respondents described their belief that the final decision to withdraw curative treatment lies with the parents, that the parents need to be supported through this process, and that this process takes time. Until the parents are ready to make this decision, the nurses felt it was the NICU team’s responsibility to continue curative treatments, despite the complexity of care and the possibility of pain and suffering of the infant. The following comments illustrate the concept that the decision to withdraw curative treatment is ultimately up to the parents:

It’s not up to us; it’s up to the families.

When this happens (parents asking to continue life-extending care beyond what nurse feels is appropriate), we try to be as supportive as possible to the families. Physician input is given but the parent’s right to make decisions are honored. Staff work hard to keep their feelings in check if different from parents.

Perceived Inappropriate Care

Despite respecting the parental decision-making process, the emotional challenges that nurses experience in providing care they feel is inappropriate and causes pain and suffering, was evident in the responses. Phrases such as “futile care” and “infants as guinea pigs” illustrate the moral conflict that nurses experience over care that is perceived as inappropriate. Additional comments more fully capture the essence of the nurses’ experiences:

Our unit has begun resuscitating 22 weekers at the parent’s request. We have not seen any of these infants survive to discharge since beginning this policy. Many of the staff are uncomfortable with the continuation of providing technological life support when the

outcome is futile. Especially when we feel the infant is in pain or that the quality of life of the infant before dying is unacceptable.

I am deeply disturbed for infants who appear to be suffering.

Waiting for parents to come to a decision to terminate care can also be frustrating and torturous.

The complex range of emotions and issues that nurse's encounter in providing care beyond what they feel is appropriate was most fully captured in the following response:

We are definitely taught that we have to put our beliefs, attitudes, bias, etc. aside and support the family in their decision. It should be their decision; I agree. What is really hard is when you know the outcome will end in death, and we still have to push, push, push. So what ends up happening is that millions of dollars are spent keeping these kids alive. Ultimately, they die, whether that be before the first year of life or during the first year. What we buy ourselves is time. For the parents, I'm sure they treasure that time. But the amount of suffering for the infant, the staff, and our healthcare system. The costs to our care systems are causing the entire American healthcare system to be unsustainable. We have a major problem in the country in valuing quantity of life, not quality. Our families are terrified to "give up" and "let their baby die." They feel as if they are not good parents unless they keep their babies alive until a bitter, bitter end. I am not sure what the answer is, but our system can't handle a continuation of these situations.

Conclusion

The NiPCASTM instrument was used to measure nurses' perceptions of palliative care practice in their NICU environment. A factor analysis using Principal Axis Factoring technique with varimax rotation yielded a final 10-item, 3-factor model that demonstrated theoretical cohesion of the accepted factors. The sub-constructs identified through the factor analysis were: Unit Culture, Resources, and Perceived Inappropriate Care.

A strong positive correlation was noted between the VAS Unit culture and total NiPCASTM score. Based on the strength of this relationship, the original instrument comprising 26 items was used to conduct additional analyses with selected demographics. Using mean scores and confidence intervals, the individual NiPCASTM facilitators and barriers to NPC

practice were identified. The items retained under the Unit Culture and Resources subscales were identified as facilitators to NPC, whereas the items contained in the Perceived Inappropriate Care subscale were identified as barriers to NPC practice.

This study demonstrated a positive relationship between palliative care/end-of life education and the total NiPCASTM score. Higher mean total NiPCASTM scores were noted for those who received education when compared to those who did not, although the length of the education sessions varied. There also was some variation in the information on NPC policies provided by those who responded to this open-ended question. Nevertheless, a positive relationship was noted between having unit policy/guidelines and the total NiPCASTM score with higher mean scores noted for those who reported having a unit policy in their NICU. A significant difference in the total NiPCASTM scores was also demonstrated between those who reported having a policy for NPC and those who did not.

The qualitative findings identified the nurses' perceptions that there is a lack of societal understanding of NPC, and that people avoid the topic of neonatal death, thus providing barriers in their ability to provide palliative care. The dichotomy between a curative approach that is characterized as "doing everything" in contrast to a palliative care approach that is viewed as "giving up" and a passive process was noted in the nurses' comments as well.

While the NiPCASTM results identified parental involvement in decision making as a facilitator to NPC practice, the qualitative responses demonstrated mixed experiences with parental decision making. Nurses describing a strong parental involvement in the decision-making process also identified use of evidence-based NPC practices that were characterized by a multidisciplinary team approach. Others described the inconsistent approach to parental

involvement in decision making in their NICU that is characterized by physician-dependent practice.

Lastly, the comments regarding experiences with providing care to infants beyond what is felt to be appropriate added insights into the “Perceived Inappropriate Care” sub-construct. Although noted as a barrier to providing NPC, the nurses’ conveyed an understanding that despite their personal conflicts they experience in providing care, the decision to move away from curative treatment should rest with the parents. They acknowledged that parents need to have the time and be supported during the process and for the final decision that is made.

The findings of this study suggest that a unit NPC policy and palliative care/end-of-life education will positively influence nurses’ perceptions of NPC practice in their NICU environment. The barriers identified, along with the qualitative content analysis, speak to inconsistencies in NICU NPC practices that continue to exist in the United States.

CHAPTER 5

Summary

This study examined Neonatal Intensive Care Unit (NICU) nurses' perceptions of the barriers to and facilitators of palliative care. The relationship between nursing staff characteristics, unit policy and neonatal palliative Care (NPC) education, and the nurses' perceptions was explored to determine the influence of these factors on nurses' report of the barriers and facilitators they encounter in providing NPC. Using a quantitative, descriptive cross-sectional and correlational design, concurrent qualitative data were collected with comment boxes for selected instrument items. Through content analysis, the qualitative data were examined and then triangulated with the quantitative data. This approach allowed the researcher to further expand upon the quantitative findings with supporting qualitative data. Identification of nurses' perceptions of palliative care practice in their NICU environment can inform policy and practice recommendations to best support standardization and integration of palliative care practice within the neonatal intensive care unit.

The Roy Adaptation Model (RAM) (Roy, 2009) provided the theoretical framework for this dissertation. Within this model, the nurse is understood as a holistic system in constant interaction with the environment. Events occurring within the NICU work setting are the environmental stimuli to which the nurse adaptively responds. The perception of palliative care practice in the NICU environment is influenced by one's life experiences, educational preparation, and support and resources within the practice setting. The results of this study demonstrated a positive relationship between the environmental stimuli of unit policy and palliative care/end-of-life education and the nurses' perceptions of palliative care in their NICU setting. Nurses who have more a positive perception of palliative care may be more likely to

function at the integrated level of adaptation when they are caring for infants and families for whom neonatal palliative care is appropriate. This in turn may improve the quality of the care these infants and families receive in the NICU.

Instrument Testing

An exploratory factor analysis was conducted on the NiPCASTM instrument with this population of nurses. The Principal Axis Factor method using varimax rotation resulted in a simple structure, three-factor model with 10 retained items from the original 26-item tool. Kain's (2008) original exploratory factor analysis (EFA) of this instrument used Principal Component Analysis and varimax rotation to arrive at a three-factor, 12-item model for the population of Australian NICU nurses. Although this researcher's factor analysis methods varied from the original study, the subscales and retained instrument items yielded similar findings.

The items falling into Kain's "Organization" subscale are the same for the "Unit Culture" subscale in this study. Within the theoretical framework for this dissertation, this researcher felt that "Unit Culture" more accurately described the items that fell into the factor one subscale. Although this study did not yield the same items for the "Resources" subscale that were identified in Kain's original findings, the thematic content is consistent. The third subscale identified in this study contained the same items and thematic content as the original "Clinician" subscale but was renamed "Perceived Inappropriate Care" to more accurately capture the concept using current recommended terminology. The field of medical ethics literature supports the use of this term to describe healthcare providers perceptions of delivering curative treatments beyond the point when death from the underlying disease is considered inevitable (Jox, Schaidler, Marckmann, & Borasio, 2012; Nathanson & Feudtner, 2016; Singal et al., 2014).

Given that the factor analysis for both the original research and this study yielded a model that retained a smaller number of the original scale items, there were concerns that the total NiPCAS™ scores may not accurately reflect participants' attitudes. As an example, instrument item 21: "There are policies/guidelines to assist in the delivery of palliative care in my Unit" did not load onto a factor for this study. Furthermore, those who responded *strongly agree* to this item may have a higher total score not because of their attitude but because their unit has a policy. For these reasons, this study included a Visual Analogue Scale (VAS) question on unit-culture support for NPC as an additional measure to assess the reliability of the total NiPCAS™ score to measure the respondents' perceptions of NPC in their work environment. The positive relationship between the VAS item and the overall NiPCAS™ score adds strength to the subsequent analyses conducted on unit policy/guidelines and palliative care and end-of-life education demographic items.

Perceptions of Barriers/Facilitators

Previous research using the NiPCAS™ instrument employed various methods to identify barriers and facilitators to NPC. Whereas Kain's (2007) original study utilized a mixed-method approach that focused on factor analysis, item mean scores, and qualitative findings, other studies modified the instrument and used mean scores for each item. This researcher chose to analyze barriers and facilitators by analyzing mean scores and confidence intervals using the full published instrument without any modification. The rationale for this decision is that items not included in the final factor analysis model may provide additional insights into current NPC practice. The items included in the "Unit Culture" and "Resources" subscales were identified as facilitators to palliative care, thus suggesting a favorable trend toward integration of NPC recommendations into unit practice. Items such as medical staff support, parental decision-

making involvement, staffing, pain management, and agreement with the team's ability to express opinions, scored with higher levels of agreement for this sample of nurses.

Four scale items were identified as barriers to NPC. Two of the items related to the perceived lack of societal understanding of NPC and belief that babies should not die under any circumstances. The qualitative responses provide additional detail whereby palliative care is incorrectly assumed to be the same as hospice care and that the move to palliative care is viewed as a passive process of "doing nothing" "giving up" and "not trying." These findings are not new and are consistent with prior publications concerning societal perceptions of infant death (Catlin & Stevenson, 1999; Craig & Mancini, 2013; Kain, 2007; Kain & Wilkinson, 2013).

The remaining items identified as barriers comprise the "Perceived Inappropriate Care" subscale. These items were also identified as barriers in prior studies that used the NiPCAS™ instrument (Chen et al., 2013; Forouzi et al., 2017; Kain, 2008; Wright et al., 2011). Although the NiPCAS™ item scores indicated that the care provided to the infant may not be appropriate, the qualitative analysis revealed a fuller picture whereby nurses are sensitive to the parent's role as final decision maker to discontinue curative treatments and that families need time to arrive at their choices.

Prior research by Docherty et al. (2007) and Catlin (2011) support this perception among NICU team members that parents are the final decision makers. Both studies reported that parental agreement was the determining factor to transition away from curative treatments, and regardless of physiology, curative treatments continued until parental agreement occurred. Docherty et al. (2007) describe the element of time that is required for families to acknowledge the need to transition away from curative treatments. Gale and Brooks (2006) describe their unit's palliative care program that includes a seven-phase pathway whereby the initial focus of

care is predominantly curative and then gradually shifts to a stronger palliative focus as the infants course progresses. A concurrent curative/palliative approach is important so that parents are provided with accurate information on a routine basis and are supported through the decision-making process. This approach also places an emphasis on managing infant pain and comfort needs at all phases of care.

Although prior research studies using the NiPCASTM instrument share common barrier and facilitator findings with this researcher's results, differences were noted as well. This study is the first to report favorable agreement with staffing and the nurses' ability to express opinions regarding NPC. Prior studies describe these items as barriers to palliative care (Chen et al., 2013; Fourouzi et al., 2017; Kain, 2008; Wright et. al, 2011). Among the previous publications, two were conducted in countries that have notable cultural differences from the United States, thus limiting the generalizability of those findings to the population of neonatal nurses in the United States(Chen et al., 2013; Fourouzi et al., 2017). Although the study by Wright and colleagues (2011) was conducted within the same cultural context as this study, it sampled nurses from one NICU within the United States, also limiting generalizability to the nationwide population. Furthermore, Wright et al.'s study was published in 2011 and may not be reflective of current NICU practice. Publications on NPC research, recommended guidelines, and educational programs occurring over the past decade may have contributed to this positive finding related to staffing and nurses' contributions to neonatal NPC discussions and may suggest a trend toward improved NPC practices within the United States.

Instrument item 13, "The physical environment of my unit is ideal for providing palliative care to dying babies," was not identified as either a barrier or facilitator for this study, but it is worth noting that this item had a lower mean score of 2.84 with an upper confidence

interval of 3.04 that marginally kept it from being categorized as a barrier with the scoring guidelines used in this study. Previous studies identified this item as a barrier to NPC (Chen et al., 2013; Falck et al., 2016; Kain, 2008; Wright et al., 2011). In the qualitative study conducted by Falck and colleagues (2016) on staff and parents' perceptions of NICU palliative care, parents reported negative experiences with privacy in the traditional open-bay NICU environment. Over the past decade, single bed-family room NICU designs have emerged as a recommended standard of care to reduce toxic neuro-sensory environmental stimuli for infants and promote family-centered care (Swanson, Peters & Lee, 2013; Winner-Stoltz et al., 2018). Research findings on the single-bed family NICU environment have demonstrated increased nurse and parent satisfaction regarding parental privacy (Watson et al., 2014; Winner-Stoltz et al., 2018). Although data were not collected on NICU design or room type, the improved perceptions of NICU environment in this study may be related to the trend toward the single-family room design in the United States.

The NiPCASTM scores pertaining to parental decision-making involvement demonstrated a favorable response to this item as a facilitator to palliative care. However, the qualitative analysis revealed inconsistencies that exist in NICU practice. The respondents who described a standardized approach to parental involvement also included detail consistent with recommended NPC practices such as policy, multidisciplinary team meetings and palliative care teams. Conversely, others reported inconsistent parental involvement that is largely physician dependent. Although the quantitative findings are suggestive of improved NPC practices surrounding family involvement, the qualitative results demonstrate that inconsistencies in NICU practice continue to exist across the United States.

Prior studies examining NICU parents' experiences with end-of-life care and subsequent grieving reveal the importance of clear communication and involvement in decision making. Qualitative studies have reported findings such as honest communication, empowered decision making, and shared decision making as factors identified by parents that were important to their infant's end-of-life care (Branchett & Stretton, 2012; Currie et al., 2016; Munson & Leuthner, 2007). A quantitative study examining parents' experiences of pediatric palliative care and its impact on long-term parental grief (van der Geest et al., 2014) found that higher ratings of parents on communication and continuity of care were associated with lower levels of long-term parental grief. These findings illustrate the positive impact that standardized NPC practices can have on parents long after their infant has died.

Policy-Related Findings

Open-ended responses were used to answer the research question: "What are the NICU policies identified by nurses that affect the delivery of palliative care?" Sixteen percent of the nurses responding to this survey identified palliative care policies that were part of their unit practice, with four respondents naming a published guideline. The Catlin and Carter (2002) NPC guidelines, the End-of-Life Nursing Education Consortium (ELNEC) program and an additional textbook based NPC, were the published policies named in this study. Although the number of nurses who identified a published policy is very small, those who did not name a publication provided details of their unit practice that are consistent with NPC recommendations. The ability to name a published policy is likely not as important as nurses identifying that a unit policy for NPC exists and that they can speak to their unit practices.

This study demonstrated a positive correlation between unit policy/guidelines and nurses' perception of palliative care. The nurses who identified as having a unit policy/guideline

demonstrated significantly higher NiPCAS™ scores when compared with nurses who did not have or were unsure of having a unit NPC policy. These findings are consistent with prior studies examining nurses perceptions of NPC with those reporting policy as a facilitator to NPC practice (Wright et al., 2011) and those lacking a policy as a barrier to practice (Chen et al., 2013; Forouzi et al, 2017; Kilcullen & Ireland, 2017).

It is important to note that although this study reported a positive relationship between NPC policy and nurses perceptions, 87 of the 200 respondents (43%) reported having a unit policy for NPC. Given that published recommendations for standardized NPC have existed in the literature for over two decades (American Academy of Pediatrics, 2000; Carter & Bhatia, 2001; Catlin & Carter, 2002; Gale & Brooks, 2006; NANN Board of Directors, 2015), these overall low numbers suggest that inconsistent NPC practices continue to exist throughout the United States.

Education-Related Findings

This study demonstrated a positive relationship between unit palliative care and end-of-life education and nurses' perception of palliative care. The nurses who identified as having received education demonstrated significantly higher NiPCAS™ scores when compared with nurses who did not have report receiving NPC education. Additional information collected regarding the length and type of education received raises questions as to the most effective delivery method of education and the role that extraneous factors may play in contributing to the more favorable perceptions of NPC for this group of nurses with regard to education. Of the 127 nurses who reported receiving education, 51 provided detail on the length of education received, with the majority receiving either a one-hour session ($n = 20$) or a 2-day conference ($n = 13$). The open-ended responses related to this survey item provided additional detail regarding the

nature of the NPC education that included the following: forum on palliative care, during orientation, computer modules required for unit, Resolve Through Sharing Infant Bereavement Program, a hospital-based program conducted by palliative care certified neonatologists and nurses, and journal review. Although the length and type of education responses were small, these findings suggest that nurses can benefit from a variety of educational offerings on NPC.

Previous studies evaluating the effectiveness of NPC educational offerings are consistent with this study's findings. O'Shea et al. (2015) demonstrated increased knowledge scores using integrated ELNEC curricula for pre-licensure baccalaureate nursing students. Kain (2017) reported a positive change in attitude and knowledge scores among practicing nurses completing an online NPC module. Knighting et al. (2019) demonstrated positive changes in perceived knowledge, attitudes and self-efficacy among multidisciplinary NICU team members who participated in a one-day workshop on NPC.

Previous studies on unit NPC program implementation have demonstrated benefits of a comprehensive approach that includes education and policy. Younge et al. (2015) conducted a retrospective chart review study comparing chart documentation practices before, during and after the implementation of their unit palliative care program. Positive findings included increased documentation of family meetings and benzodiazepine use for sedation after the implementation of the program. Samsel and Lechner (2015) conducted a retrospective/prospective study design to evaluate the implementation of an NPC program with an education plan that included communication skills training for the multidisciplinary team. Positive findings for this study included increased redirection of care and palliative medication use along with a decreased variability in end-of-life interventions.

Implications of Findings

Nursing Practice

The results of this study demonstrate the importance for NICUs to have a standardized NPC program that includes the articulation of the nurses' role, a multidisciplinary approach, parental involvement in decision making, and evidence-based policy and educational support. As nurses are continuously at the point of care, they interact more frequently with infants and parents than any other NICU team member. The nurse is often the first to identify changes in the infant's condition, pain and comfort status, and the first to hear parents' concerns. The manner in which the nurse interacts and provides support to parents is critical to the immediate comfort of the infant and the long-term well-being of the parents. In order for the nurse to provide appropriate NPC care, they need to work in an environment that supports their unique role. The nurse should also have policy and educational resources so that they can provide evidence-based care.

The results of this study demonstrate the importance of a multidisciplinary approach to unit practice. Published literature describes the negative impact of ethical confrontations (Janvier et al., 2007) and moral distress (Cavaliere, Daly, Dowling & Montgomery, 2010; Cavinder, 2014; Corley, 1995; Kain, 2007; Sannino, Gianni, Re, & Lusignani, 2015) on staff working in the NICU. The effect these issues can have on patient care have also been described (Cavinder, 2014; de Veer, Francke, Struijs, & Willems, 2013; Janvier et al., 2007; Kain, 2007; Rogers, Babgi, & Gomez, 2008). When all team members work together and communicate effectively, they are able to best support parents and provide consistent information. Furthermore, nurses who work within an environment that incorporates this approach are likely to have increased job satisfaction, experience less ethical and moral conflicts and a higher degree of job retention.

Current palliative care recommendations place an emphasis on early palliative care that occurs within the curative trajectory. When nurses practice within an environment that allows for concurrent treatments, they can better support parents as they undergo the overwhelming anxiety and stress inherent in a NICU experience.

This study has important implications for nurse leaders and organizations. Issues such as staffing, NICU environmental design, and education for the clinical nurses are important factors that nurses leaders need to understand and advocate for so that the nursing staff can be best supported to provide high-quality care. Furthermore, nurses in direct-care roles should have counseling services that include self-care strategies to help them manage the workplace stressors associated with caring for critically ill and dying infants. When nurses are provided with the emotional support and the skills to care for their own well-being, they are better positioned to function as engaged and effective professionals.

Policy and Education

This study demonstrated the benefits of unit-based policy and education in positively influencing nurses' perceptions of NPC. Despite established NPC policy and recommendations existing at the federal level, from professional organizations, and within the published literature, inconsistencies in NPC policy integration continue to exist throughout the United States. Although this study suggests there is movement toward improved integration, findings also indicate there is more work that needs to be done before palliative care policy is fully integrated within the NICU culture.

NPC education is an essential component of a palliative care program. ELNEC and Resolve-Through-Sharing are two nationally recognized educational programs that are both available in conference and online formats and provide comprehensive curriculums. Neonatal

textbooks and other publications that include NPC guidelines provide additional educational resources to support nursing practice. Furthermore, the qualitative findings suggest that education does not have to be extensive and that simple ongoing programs such as a unit-based journal club can impact nurses' knowledge and attitudes regarding NPC. Nursing leadership and organizational support of educational offerings will not only support nursing practice but also shape underlying unit-based cultural assumptions regarding the importance of NPC.

Limitations of the Study

Although this study demonstrated a positive relationship between policy and education and nurses' perceptions of NPC, it is important to identify limitations to this study design that will impact the generalizability of the results. This study surveyed nurses practicing in the United States and may not be reflective of nurses' perceptions from other cultural settings. The sample comprised a relatively homogenous group of nurses with a higher percentage of White nurses and disproportionately less Black, Hispanic and Asian nurses when compared to the national nursing workforce demographics. The findings may therefore not accurately represent Black, Hispanic and Asian nurses' perceptions regarding NPC.

Nurses were recruited for this study through two professional organizations with a neonatal specialty focus. It can be inferred that nurses who belong to professional organizations tend to be more engaged in their profession's evidence-based practice recommendations. Nurses in this study reported higher educational preparation with both degree attainment and specialty certification status; thus the findings may not accurately represent perceptions for those who are not certified and have less educational preparation, and do not belong to a professional organization.

The sample demographics demonstrate an older and more experienced group of nurses and the results may not be relevant to younger, less experienced groups. The nurses completing this study come from a range of roles within the NICU. Although all of the participants were registered nurses working in the NICU, their role differences may have influenced the overall findings and may not be representative of each group if studied separately. Lastly, this study was a quantitative design with a qualitative component and not a true mixed-method design. The comments were analyzed as supportive data to expand upon the quantitative results and should be considered only in relation to the quantitative findings.

Research Recommendations

The NiPCASTM instrument is a published tool to measure nurses' attitudes toward palliative care in their NICU setting. The exploratory factor analysis supports the researcher's original findings of a three-factor model with similar thematic subscales. Given that only 12 items were retained with the original study and 10 items with this study, future research aimed at tool refinement that is reflective of current literature recommendations are warranted. An improved and perhaps streamlined tool may be more effective in measuring nurses' perceptions for future studies of NPC in specific NICU environments.

Although this study did not demonstrate a difference in perceptions with regard to age and experience, the sample size of 200 may not have been sufficient to detect differences among these groups. Considering the stigma associated with infant death that was noted in this study, it can be inferred that younger, less experienced nurses may encounter additional barriers and need additional support as they become more experienced in their practice. Additional research is needed to describe perceptions among these groups of nurses. Also with NICU design changes

underway in the United States, future studies to compare the open bay versus the single-family room NICU design on staff and parents' perceptions of NPC is warranted.

This study captured a cross-section of nurses practicing throughout the United States. The findings suggest that whereas some units are successful in integrating NPC practices, others are not. Additional studies focused at the local unit and regional levels will better identify individual practice variations and barriers that continue to exist.

Policy Recommendations

The findings of this study demonstrate the need for continued federal policy development that will address the existing stigma and misperceptions associated with NPC in society. Policy advocacy that will lead to improved societal awareness as to the true nature and need for NPC will be important so that the needs of both infants and parents are better understood and supported within community of family and friends.

Although the focus of this study was limited to the NICU environment, there are situations in which infants with life-limiting conditions may benefit from being cared for in their home environment. The "Concurrent Care for Children" section of the Affordable Care Act requires states to provide Medicaid coverage for pediatric palliative care, concurrently with curative treatment (National Hospice and Palliative Care Organization, 2012) so that parents do not need to forgo curative treatment in order to receive Medicaid coverage for hospice services. Despite the improvements with access to palliative care that this policy has afforded, provisions require certification by a physician that a child is within the last six months of life in order to receive concurrent services. Given the uncertain and often prolonged course of life-limiting diagnoses, future policy revisions that would eliminate this requirement are recommended so that children can receive palliative care alongside curative treatment.

Conclusion

This study explored nurses' perception to neonatal palliative care in their NICU environment. Through a descriptive cross-sectional and correlational quantitative design with a qualitative component, this study identified barriers to and facilitators of palliative care in neonatal nursing practice. Positive relationships between unit policy and nurses' perceptions and NPC education and nurses' perceptions were demonstrated. This study was the first to identify a favorable agreement for staffing and support of nurses' opinions as facilitators to NPC. The implications of this study suggest that although policy guidelines, recommendations and educational programs have been available for the past 20 years, inconsistencies in practice continue to exist. Further research focusing on unit practice at the local level is needed in order to better identify barriers to implementing consistent NPC practices and ways to address these. Continued policy development and efforts to incorporate neonatal palliative care as a standard of care in all NICU settings are needed to promote high-quality care for the high-risk infants and their families.

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Appendix A

Email Letter to Participate in Web Survey

Dear Professional Nurse,

You are invited to participate in a research study whose purpose is to examine neonatal nurses' perceptions of palliative care in their Neonatal Intensive Care Units (NICU).

Despite successful survival outcomes in neonatal medicine, the fact remains that infants who are born with life-limiting conditions and uncertain prognoses will continue to be cared for in the NICU. Palliative care policy recommendations allow for curative treatments as appropriate, while ensuring that infant comfort and parent support needs are addressed.

Your voice is important so that we can better understand current practices regarding NICU palliative care.

This brief web-based survey that will take approximately 15 minutes to complete.

As a token of appreciation for your participation in the study, you will be eligible to enter a drawing for a \$50.00 Amazon gift card.

Please select the below link to continue with the survey:

[Take the Survey](#)

Appendix B

Google Forms Survey Instrument

The Neonatal Palliative Care Attitude Scale NiPCAS TM©

4/5/20, 8:38 AM

The Neonatal Palliative Care Attitude Scale NiPCAS TM©

Dear Professional Registered Nurse,

You are invited to participate in a survey intended to examine neonatal nurses' perceptions of palliative care in their Neonatal Intensive Care Units (NICU). Despite successful survival outcomes in neonatal medicine, the fact remains that infants who are born with life-limiting conditions and uncertain prognoses will continue to be cared for in the neonatal intensive care unit. A common misconception is that palliative care occurs only after curative treatments have been discontinued. NICU palliative care is defined as a care model that is considered from the time of prenatal diagnosis and/or birth and occurs concurrently with curative treatments to manage symptoms, minimize suffering and offer improved quality of life. Families partner with the NICU team to ensure that comfort needs and family support are addressed, while determining the appropriateness of curative treatments.

The purpose of this study is to better understand attitudes to palliative care practice in neonatal nursing. When you identify yourself as a nurse working in a NICU, you will be able to participate in this brief web based survey that will take approximately 15 minutes to complete. Results from this study will be used to inform palliative care policy and educational approaches that will best support the nurse in providing compassionate care to patients and their families.

Your participation in this research is your choice. If you decide to participate in the survey, you may change your mind and stop at any time, without penalty. Your name or email will not be associated with your survey and no information that can identify you personally is being collected to maintain anonymity. Your information may be put in controlled access data-base. This means only researchers who apply for and get permission to use the information for a specific research project will be able to access the information. There are no known risks if you decide to participate other than the inconvenience of completing the forms, but there is a possibility that questions asked in the survey may make you uncomfortable as you remember caring for critically ill infants. You may skip any questions that you do not want to answer. There is no direct benefit to you from participation in this study, however, your input can enhance our knowledge regarding nurses' perception of palliative care in the NICU and improve the ability to support neonatal nurses in providing palliative care to infants and families. The investigators can be contacted at aparaszczuk@molloy.edu with any questions you may have regarding the study. If you have questions about your rights, an unresolved question, a concern or complaint about this research, you may contact the Molloy IRB office at irb@molloy.edu, or call 516-323-3000.

Study results will be shared with you after the research is completed upon your request. As a token of appreciation for your participation in the study, you will be eligible to enter a drawing for a \$50.00 Amazon gift card. The probability of receiving the gift card is one in 30. Please following the directions at the end of the survey if you want your name to be entered for the prize drawing. By completing the survey, you have implied that you consent to participate in the study.

Area of practice

We would like to ask some questions about yourself

1. 1. Please identify your current area of practice

- NICU Level II
- NICU Level III/IV

Demographics

2. 2. Gender

- Male
- Female
- Gender variant/nonconforming
- Prefer not to say

3. 3. Age

- 21-30
- 31-40
- 41-50
- 51 and over

4. 4. How long have you worked in a neonatal intensive care unit?

- Less than 1 year
- 1-5 years
- 6-10 years
- 11-15 years
- Greater than 15 years

5. 5. Please identify your employment status in the NICU setting.

- Full time
- Part time
- Per Diem

6. 6. Please indicate your nursing certification status.

- NCC: neonatal intensive care
- NCC: Neonatal Nurse Practitioner
- NCC: Low Risk Neonatal Nursing
- AACN CCRN-Neonatal
- I do not hold a certification

7. 7. What is your highest level of completed education?

- Diploma
- Associate's degree
- Baccalaureate degree
- Master's degree
- Doctoral degree (EdD/DNP/PhD)

8. 8. Which statement best describes how you spend the majority of your time in your current practice:

- RN: Direct patient care
- Nurse Practitioner
- Nursing Education
- Nursing Management
- Other

9. 9. Are you of Hispanic, Latino or Spanish origin?

- Yes
- No

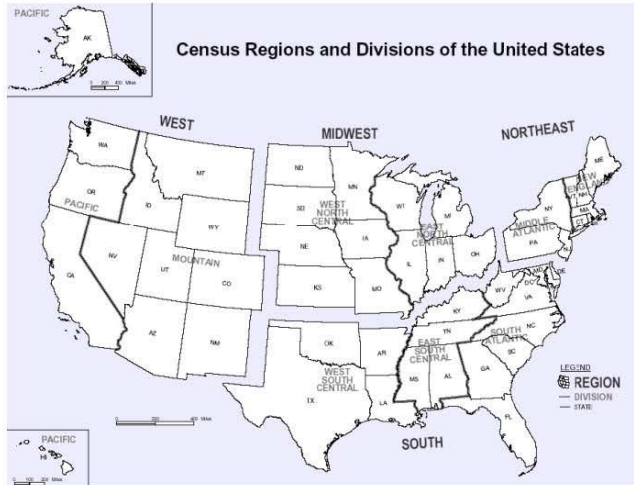
10. 10. How would you describe yourself? (Check all that apply)

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White

11. 11. Do you have children?

- Yes
- No

12. 12. Based on the diagram, please indicate the region in which you practice.



- New England
- Middle Atlantic
- East North Central
- South Atlantic
- East South Central
- West South Central
- West North Central
- Mountain
- Pacific
- Other region outside the United States

13. 13. What is your religion?

- Christian
- Jewish
- Muslim
- Protestant
- Atheist
- Catholic
- Hindu
- None
- Buddhist
- Other

14. 13A. If not listed, please indicate your religious affiliation below

15. 14. Do you consider yourself to be religious?

- I am very religious
- I am somewhat religious
- I am not at all religious

16. 15. Do you consider yourself to be spiritual?

- I am very spiritual
- I am somewhat spiritual
- I am not at all spiritual

17. 16. Does your unit have a palliative care policy or guidelines for practice?

- Yes
- No
- Unsure

Palliative Care Unit Policy

18. 16A. Please provide any information you may have regarding the name or author(s), or type of policy utilized in your Unit.

Palliative Care Education

19. 17. Have you received education on end-of-life/palliative care?

- Yes
- No
- Unsure

20. 18. Please choose one of the below that best describes the type of end-of-life/palliative care education that you have received.

- Certificate educational program
- Palliative care conference
- Neonatal/Pediatric conference with palliative care session
- Poster presentation viewing
- Unit based inservice
- Other
- I have not received any end-of-life/palliative care education

Length of palliative care conference

21. 18A. Length of palliative care conference.

- Half day
- One day
- Two or more days

Length of palliative care session at a conference

22. 18B. Please indicate the length of the session.

- One hour
- Two hours
- Three hours or more

Other education

23. 18C. Please identify the type of educational offering on palliative care that you attended

The Neonatal Palliative Care Attitude Scale NiPCAS TM®

24. 19. Palliative care is as important as curative care in the neonatal environment.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

25. 20. I have had experience of providing palliative care to dying babies and their families.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

26. 21. I feel a sense of personal failure when a baby dies.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

27. 22. There is support of neonatal palliative care in society.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

28. 22A. Please feel free to include additional information regarding your impression of society's understanding of neonatal palliative care

29. 23. The medical staff support palliative care for dying babies in my Unit.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

30. 23A. Please feel free to include any additional comments regarding the medical staff's support of palliative care in your Unit.

31. 24. The physical environment of my Unit is ideal for providing palliative care to dying babies.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

32. 25. My Unit is adequately staffed for providing the need of dying babies requiring palliative care and their families.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

33. 26. In my Unit, parents are involved in decisions about their dying baby.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

34. 26A. Please feel free to provide additional comments regarding the parent's involvement in making decisions about their child's care in your unit.

35. 27. My previous experiences of providing palliative care to dying babies have been rewarding.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

36. 28. When babies are dying in my Unit, providing pain relief is a priority for me.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

37. 29. I am often exposed to death in the neonatal environment.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

38. 30. Palliative care is necessary in neonatal nursing education.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

39. 31. When a baby dies in my Unit, I have sufficient time to spend with the family.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

40. 32. There are policies/guidelines to assist in the delivery of palliative care in my Unit.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

41. 33. In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

42. 34. In my Unit the team expresses its opinions, values and beliefs about providing care to dying babies.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

43. 35. Caring for dying babies is traumatic for me.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

44. 36. I have received in-service education that assists me to support and communicate with parents of dying babies.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

45. 37. All members of the healthcare team in my Unit agree with and support palliative care when it is implemented for a dying baby.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

46. 37A. Please feel free to provide additional comments regarding the health care team and support of palliative care implementation in your Unit.

47. 38. In my Unit, the staff go beyond what they feel comfortable with in using technological life support.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

48. 38A. Please feel free to provide additional comments regarding your comfort level with technological life support beyond what you perceive is appropriate.

49. 39. In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

50. 39A. Please feel free to provide additional comments regarding your experience with parents asking to continue life-extending care beyond what you perceive is appropriate.

51. 40. My personal attitudes about death affects my willingness to deliver palliative care.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

52. 41. Palliative care is against the values of neonatal nursing.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

53. 42. When a baby dies in my Unit, counselling is available if I need it.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

54. 42A. Please feel free to provide additional comments regarding counseling available on your unit

55. 43. There is a belief in society that babies should not die, under any circumstances.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

56. 44. Curative care is more important than palliative care in the neonatal intensive care unit.

- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Unsure

Unit Culture

57. 45. On a scale of 1-10, please indicate how strongly you feel that the culture of your unit supports palliative care.

	1	2	3	4	5	6	7	8	9	10	
My unit does not support a palliative care approach	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	My unit consistently supports palliative care

58. 46. If there is additional information regarding your experiences in providing palliative care that we have not addressed in this survey, please feel free to answer below.

59. 47. We would like to contact you as a follow up to this study to learn more about your experiences surrounding NICU palliative care. If you are in agreement, please submit your email address via the below link. Your responses to this survey will remain anonymous and will not be connected to your email address.

60. 48. Thank you for your participation in this survey. Would you like to be enrolled in the raffle to receive a \$50.00 Amazon Gift Card?

- Yes, please!
- No thank you

Raffle Entry

61. 48A. Please enter your email address below for the \$50.00 Amazon Gift Card raffle. Your responses will remain anonymous and will not be connected with your email address.

End of Survey

Thank you for your participation in this survey! Please click submit to send your responses.

This content is neither created nor endorsed by Google.



Appendix C

Factor Subscales

Organization Subscale: Cronbach $\alpha = .73$	Score	Initial Factor Loading
12. The medical staff support palliative care for dying babies in my Unit	.664	1
15. In my Unit, parents are involved in decisions about their dying baby	.610	1
22. In my Unit, when a diagnosis with a likely poor outcome is made, parents are informed of palliative care options	.671	1
23. In my Unit the team expresses its opinions, values and beliefs about providing care to dying babies	.654	1
26. All members of the healthcare team in my Unit agree with and support palliative care when it is implemented for a dying baby	.595	1
Resources Subscale: Cronbach $\alpha = .65$		
13. The physical environment of my Unit is ideal for providing palliative care to dying babies	.530	1
14. My Unit is adequately staffed for providing the need of dying babies requiring palliative care and their families	.595	1
17. When a baby dies in my Unit, I have sufficient time to spend with the family	.450	1
21. There are policies/guidelines to assist in the delivery of palliative care in my Unit	.528	1
31. When a baby dies in my Unit, counselling is available if I need it	.512	1
Clinician Subscale Cronbach $\alpha = .63$		
27. In my Unit, the staff go beyond what they feel comfortable with in using technological life support	.819	4
28. In my Unit, staff are asked by parents to continue life-extending care beyond what they feel is right	.774	4

Appendix D

Permission to Use Survey

From: Susan Chin <schin2@lions.molloy.edu>
Sent: Sunday, 28 October 2018 1:58 AM
To: Victoria Kain
Subject: Re: PhD student inquiry

Dear Dr. Kain,
I hope this email finds you well. I wanted to update you on our previous correspondence regarding my dissertation research plans.

I am in the dissertation proposal development phase and with your permission, I would greatly appreciate using your tool.

At this point, I am anticipating that I will make minor modifications to the demographic questions so that they best capture U.S nursing roles. I have also been advised that due to our college IRB requirements, I may be restricted from sharing all raw data, but that I would be able to provide you with aggregate data results. Once I have these details finalized, I will send you a formal letter requesting permission for tool use. I anticipate that I will have this request to you within the next 2 months.

In the meantime, please let me know if there is any additional information that I can provide you with.

Thank you again for your interest in my dissertation activities!

Best regards,

Susan Chin

On Nov 6, 2018, at 4:44 PM, Victoria Kain <v.kain@griffith.edu.au> wrote:

Dear Susan,

Apologies for my delayed response.

I am very pleased to hear that you are progressing with this research, and I am more than happy for you to use the NiPCASTM and to assist you in any way.

I will be running a neonatal palliative care workshop at the ANN conference in Palm Springs in 2019 - it would be wonderful if you were attending also?

All the best, and let me know what I can do,

Vicki.

Kind regards,

Dr. Victoria Kain PhD | Director of Undergraduate Nursing Programs
Convener | 3900NRS Neonatal Nursing

Griffith University | Nathan N48, Rm 1.21; Logan L05 4.62 P: +61 7 373 55221

Appointments via [Maree Dempsey](#).

School of Nursing and Midwifery, Griffith University - CRICOS Provider Number
00233E

Visiting Professor, Kyoto Tachibana University, Japan

Visiting Professor, Chang Gung University of Science and Technology, Taipei, Taiwan

Appendix E

IRB Approval Letter



Institutional Review Board

1000 Hempstead Avenue
Rockville Centre, NY 11571

www.molloy.edu

Tel. 516.323.3711

Date: August 14, 2019
To: Ms. Susan D. Chin
From: Patricia A. Eckardt, Ph.D., RN, FAAN
Chair, Molloy College Institutional Review Board

SUBJECT: **MOLLOY IRB REVIEW AND DETERMINATION OF EXPEDITED STATUS**
Study Title: **An Exploratory Study of Nurses' Perception of Palliative Care in the Neonatal Intensive Care Unit**
Approved: August 14, 2019 – August 12, 2020
Approval No: 19030309-0314

Dear Ms. Chin:

The Institutional Review Board (IRB) of Molloy College has reviewed the above-mentioned research proposal and determined that this proposal is approved by the committee.

It is considered an EXPEDITED review per the requirements of Department of Health and Human Services (DHHS) regulations for the protection of human 45 CFR 46 110 (b) (1) categories.

Please note that as Principal Investigator (PI), it is your responsibility to be CITI Certified in both the Responsible Conduct of Research and Human Subjects Research and to submit the evidence in order to conduct your research.

Remember, all consents and recruitment flyers for any research protocol need to have Molloy IRB dated stamps of approval. To obtain the official stamp, please contact Ms. Gina Nedelka (gnedelka@molloy.edu) to arrange a time to meet with her in her office in Kellenberg-Room 009. You will bring one clean consent (of each consent and/or assent) and any recruitment flyers to the meeting with Ms. Nedelka for IRB dated stamp of approval. You then make copies of stamped materials and use those copies for recruiting and consenting.

You may proceed with your research. Please submit a report to the committee at the conclusion of your project. Your project is approved for ONE YEAR.

Changes to the Research: It is the responsibility of the Principal Investigator to inform the Molloy College IRB of any changes to this research.

A change in the research may change the project from EXPEDITED status that would require communication with the IRB.

Sincerely,

Patricia A. Eckardt, Ph.D., RN, FAAN