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Exploring Neonatal Intensive Care Nurses' Affective Responses to Providing End-of-Life Care

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I am submitting herewith a dissertation written by Stephanie Lynn Lewis entitled "Exploring Neonatal Intensive Care Nurses' Affective Responses to Providing End-of-Life Care." I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

Mary E. Gunther, Major Professor

We have read this dissertation and recommend its acceptance:

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(Original signatures are on file with official student records.)

Exploring Neonatal Intensive Care Nurses' Affective Responses to Providing End-of-Life Care

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Stephanie Lynn Lewis
December 2013

Dedication

“A person’s a person, no matter how small.” –Dr. Seuss

This study and its findings are dedicated to all neonatal nurses who care for dying infants as if they were their own, guide parents and families through one of the worst times of their lives, strive to meet the needs of all, and cry with them at the end. It’s the hardest, most rewarding job and infants and families are blessed by your work.

Acknowledgments

I would like to express my deepest gratitude for the unwavering support, guidance, and expertise of my dissertation committee. Dr. Mary Gunther, my chair, was a source of stability and great knowledge during this journey. Dr. Joanne Hall served as my methodology expert and contributed significantly to this study's data collection, analysis, and rigor. Dr. Sandra Mixer, my first advisor, lent her expert end-of-life knowledge to this study and most of all, served as my constant champion during this endeavor. Dr. Mary Zeigler provided an interdisciplinary perspective that contributed to a well-rounded study. I thank you all for helping me!

I would also like to acknowledge the National Association for Neonatal Nursing for their enthusiasm and help in providing me access to their membership for this study. Their guidance and involvement with this project demonstrates their ongoing commitment to neonatal nursing, the development of new knowledge, and the improvement of patient and family outcomes.

Finally, but most importantly, I must acknowledge the absolute and unending support and love I received from my family while undertaking this challenge. Steve, your support and unconditional love astounds and amazes me. Emma, Nick, and Sam, thank you for sharing your momma and her time with this endeavor. I hope you see that nothing is impossible in this world. I love you all. Dr. and Mrs. William Lacefield, your love for me is unwavering and unconditional and because of that, I am blessed. Shannon Lacefield, my sister, thank you for being at the end of my frantic texts and phone calls. Reverend and Mrs. Phillip Lewis and Dr. Ellen Lewis, thank you for your support and enthusiasm for this adventure of mine!

Abstract

Significance. The Joint Commission established standards to evaluate comprehensive end-of-life infant care and the positive outcomes of such care are well documented. However, findings from multiple studies conducted over the last decade indicate that end-of-life care in the neonatal intensive care unit is not provided consistently or holistically to all dying infants. Because nurses are the healthcare professionals most often responsible for providing this care, anything that detracts from their ability to provide it, including their own affective responses, needs to be addressed.

***Aim*.** The purpose of this study was to explore—through lived and told stories—the affective, interactional, and meaning-related responses that NICU nurses have while caring for dying infants and their families.

Sample, Design, and Methods. Neonatal intensive care nurses were recruited through the online membership discussion boards of the National Association of Neonatal Nurses. Participants were asked to access an online survey link and provide a written narrative describing an end-of-life care situation in which they experienced strong emotions. Demographic data also were collected.

Findings. Narrative analysis revealed many affective responses, but three were the most frequent: responsibility, moral distress, and identification. Feelings of responsibility included (a) a commitment to deliver the best end-of-life care possible, (b) professional inadequacy, (c) disbelief, and d) advocacy. Feelings associated with moral distress were quite common and often related to conflicts between nurses, physicians, and families. Nurses reported feelings of identification with families of dying infants through (a) sharing their grief, (b) forming excess attachments, and (c) experiencing survivor-like guilt.

Implications. Nurse educators are encouraged to discuss more extensively and perhaps through the use of simulation, the positive and negative emotions that may be experienced by nurses who are involved in end-of-life care situations. Nurse leaders are encouraged to promote supportive environments in NICUs and ensure debriefing opportunities for nurses who have recently cared for a dying infant. Significant associations, such as NICU nurses not perceiving their EOLC education as being helpful in providing that care clinically and the percentage of NICU nurses reporting the presence of an end-of-life care policy in their units of employment, also merit further examination.

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List of Abbreviations

AACN	American Association of Colleges of Nursing
AAP	American Academy of Pediatrics
ANP	adult nurse practitioner
BLS	basic life support
CLAS	National Standards for Culturally and Linguistically Appropriate Services
CT	Comfort Theory by Kolcaba
DNR	do not resuscitate
ELNEC	End of Life Nursing Consortium
ELNEC-PPC	End-of-Life Nursing Care Consortium–Pediatric Palliative Care
EFA	exploratory factor analysis
ENA	Emergency Nurses Association
EOL	end-of-life
EOLC	end-of-life care
IOM	Institute of Medicine
IRB	Institutional Review Board
MSN	Masters of Science in Nursing
NANN	National Association of Neonatal Nurses
NICU	neonatal intensive care unit
NIH	National Institutes of Health
NiPCAS	Neonatal Palliative Care Attitude Scale
NNP	neonatal nurse practitioners
NRP	Neonatal Resuscitation Program
PEAS	Professional End-of-Life Attitude Scale
PICU	pediatric intensive care unit
RWJF	Robert Wood Johnson Foundation
WHO	World Health Organization

Chapter One: Introduction

Many sick infants, who might have died 20 years ago, are able to recover and live normal lives today because of technological advances in medical interventions. The sickest infants are generally cared for in neonatal intensive care units (NICU), which provide life-sustaining, monitored care around the clock (American Academy of Pediatrics [AAP], 2004). While in the NICU, patients have access to the most advanced equipment available including mechanical ventilators, vital sign monitors, and intravenous medication delivery pumps. Nevertheless, some infants reach a point when both healthcare professionals and families recognize survival is not possible. According to Catlin (2011), this threshold point involves changing the patient goal from recovery to peaceful death. NICU nurses shift their attention from curative to end-of-life care (EOLC). Often, this shift involves withholding or withdrawing life sustaining treatment and focusing on the family's needs and wishes for peaceful death for their infant. Ideally, provision of EOLC care starts when a consensual decision is made by parents, physicians, and nurses to discontinue curative care and continues after the infant's death and into the bereavement period (Catlin, 2011). In other instances, when an infant's health declines rapidly, parents and healthcare professionals are forced to address EOLC needs and wishes without much notice.

The pediatric nursing discipline, which includes neonatal care, is steeped in the philosophy of family-centered care, which promotes family involvement in patient care and decision-making, and gives attention to parent preferences related to spiritual and cultural considerations (Harrison, 2010; Malusky, 2005). The application of this philosophy spans the entire spectrum of pediatric care including normal newborn care, curative care, EOLC, and bereavement care. The National Association of Neonatal Nurses (NANN) (2010) recognizes the importance of family involvement in neonatal care and therefore defines EOLC as care that "… supports a peaceful, dignified death for the infant and loving support to the family and healthcare providers" (p. 287).

In 2008, 48,073 children—from infanthood to age 19—died, with 26,531 of these deaths being newborns and infants. In 2009, the five leading causes of infant death were congenital malformations, deformations, and chromosomal abnormalities; disorders related to short gestation and low birth weight; Sudden Infant Death Syndrome; newborns affected by maternal pregnancy complications; and accidents. The complex chronic conditions that contribute to the most deaths in the first year of life are cardiovascular diseases, respiratory disorders, and congenital/genetic disorders (Kochanek, Kirmeyer, Martin, Strobino, & Guyer, 2012).

More than four million infants are born in the United States each year. Approximately 280,000 of all live births are admitted to a NICU (Osterman, Martin, Mathews, & Hamilton, 2011). Findings from one study indicated that the vast majority of infant deaths occur in a hospital setting (Brandon, Docherty, & Thorpe, 2007). Until the first NICU was opened in 1960 at Yale-New Haven Hospital, sick and premature infants often were cared for in pediatric units (National Institutes of Health [NIH], 1992). The creation of NICUs brought about new dilemmas, such as the ethical concerns of discontinuing support versus not initiating it in the first place (Munson, 2007). Ethicists began discussing different methods of life-sustaining and life-limiting decision-making for infants sick enough to be in the NICU (Mackler, 1989).

Although the rates of pre-term and low birth weight deliveries increased markedly over the last several decades, they have remained essentially constant since 2009. Researchers attribute the earlier increases to rises in multiple births, increased maternal age, and the use of infertility therapies (Kochanek et al., 2012). From 2008 to 2009, births for women aged 40–44 increased by three percent. The Centers for Disease Control and Prevention (2012) reported a 100% increase in the use of artificial reproductive technology from 2000 to 2010. Between 1980 and 2005, twin birth rates increased by 76% and higher-order multiple birth rates have increased almost 46% since 1990. While the twin birth rate has remained flat since 2005, the rate of higher-order multiple births has risen 4% since 2008. These statistics are of special interest to NICU providers of EOLC since infants from multiple gestation births are eight times more likely than singletons to die within the first month of life (Kochanek et al., 2012).

A review of recent statistical data clearly indicates that significant numbers of infants still die in the NICU setting every year. Consequently, NICU nurses are regularly confronted with the challenges of delivering EOLC. Frequently, EOLC in the NICU is associated with withholding and/or withdrawing life-sustaining treatment, such as ventilator support, which may allow nurses more time to plan EOLC. This extra time, according to the literature, may contribute to improved patient and family outcomes. A review of the nursing literature published over the past eleven years revealed that, despite existing standards of care, some aspects of EOLC are not delivered consistently. While studies have been conducted to identify facilitators and barriers to providing effective EOLC, little is known about how NICU nurses' individual experiences affect the provision of holistic EOLC. The purpose of this study was to explore—through lived and told stories—the affective, interactional, and meaning-related responses NICU nurses have while caring for dying infants and their families in the hope of improving EOLC delivery in the NICU.

Background

This section will provide an overview of the different types of care associated with end-of-life, with special attention given to the distinctions between them. Precise definitions of palliative care, hospice care, and EOLC are extremely important as the interchangeable use of these terms can lead to professional and public confusion (Lewis, 2013). Additional definitions are provided before exploring the research problem, purpose of the study, research questions, and study assumptions.

Palliative Care

Palliative care—which begins with the diagnosis of a life-threatening, often terminal, illness and is delivered in conjunction with curative care—seeks to maintain or improve a patient’s quality of life through the prevention of suffering until the time of death. This team-delivered care attends to a patient’s pain and physical symptoms as well as psychological, spiritual, and family support needs. Palliative care concludes with EOLC (World Health Organization [WHO], 2012). Palliative care for children is similar to that of adults but with a greater emphasis on family needs. Providing palliative care for an infant or child involves unique considerations of physical, psychological, and social distress (AAP, 2000; WHO, 2012).

Hospice Care

Hospice care, a concept developed by Dame Cicely Saunders in London in 1948, has similar goals to palliative care, but does not include curative care. Hospice care begins when a patient and family decide to choose such care and a healthcare provider determines that a patient has a six month or less prognosis. This specialized care was first introduced in the United States in 1963 when Saunders visited Yale University. Hospice care became a priority in the United States throughout the 1970s and 1980s. During this time, Medicare developed standards and funding for hospice care, which is commonly provided in patients' homes or inpatient facilities. In 2010, the AAP affirmed the National Hospice and Palliative Care Organization's (2012) *Standards of Practice for Pediatric Palliative Care and Hospice*.

End-of-Life Care

The WHO (1998), as cited by O'Connor (2008) defined EOLC as "… the active total care of patients whose disease is not responsive to curative treatment … [and the goal of EOLC is to]… attain maximal quality of life through control of the myriad physical, psychological, social, and spiritual distress of the patient and family" (p. 7). End-of-life care is defined by the International Association for Hospice and Palliative Care (2009) as "… [care] that combines the broad set of health and community services that care for the population at the end of their life" (para. 1). However, O'Connor (2008) noted that the NIH (2004) stated that it was impossible to define end-of-life (EOL) or EOLC or establish a timeframe for such care without sufficient research data to support it. The NIH, however, did state two conditions that indicate a patient is in the EOL period: the underlying disease process is irreversible, and management of that disease process requires professional or volunteer caregiving until the time of death. The National Consensus Project for Quality Palliative Care (2009) published outcome domains for quality EOLC that include addressing physical symptoms, psychological symptoms, social relationships, spiritual or philosophical beliefs, hopes, expectations and meaning, satisfaction, economic considerations, and caregiver and family experiences. The concept that unites these domains is the desire to provide the highest possible quality of life for dying patients.

In 1998, the American Association of Colleges of Nursing (AACN) published *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Care* that outlined the importance of quality palliative and EOLC and provided an overview of the essential knowledge nurses and physicians need to provide such care (AACN, 1998). In response to this publication, the Robert Wood Johnson Foundation (RWJF) funded the End of Life Nursing Consortium (ELNEC), a partnership between the AACN and City of Hope, Los Angeles, California in 2000 to address the need for EOLC education for nurses. Since 2000, ELNEC has educated over 16,000 nurses and health care providers from all 50 states and 77 countries about quality palliative care and created nursing courses in oncology, geriatrics, and pediatrics (AACN, 2013a).

Many professional organizations have designated quality EOLC a priority through position statements, white papers, and funding aimed at improving both access to and the quality of such care. The WHO (2012) recommended that families of actively dying patients receive social, emotional, and spiritual support. The NANN (2010) recommended that, in addition to physical care of the dying neonate, nurses should provide emotional, spiritual, and sibling support during EOLC. The End-of-Life Nursing Care Consortium-Pediatric Palliative Care (ELNEC-PPC) curriculum—whose development was funded through the AACN and the RWJF—detailed the importance of nurses addressing the physical, psychological, social, cultural, and spiritual needs of the child and the family at the EOL (Malloy, Sumner, Virani, & Ferrell, 2007). Acknowledging the primary role of the nurse as patient and family advocate, the authors stated, “The nurse is the conduit for assessing the needs of the child/family and implementing the goals of a family-centered plan and treatment” (p. 302).

The Joint Commission, the regulating body of hospital accreditation, established standards to evaluate EOLC delivered in U.S. hospitals. In a 2010 publication, the Joint Commission provided a guide for patient-provider communication, cultural competence, and family-centered care during EOLC. These standards developed over a nine-year period that began with a gap analysis comparing Joint Commission standards to those of the Office of Minority Health’s National Standards for Culturally and Linguistically Appropriate Services (CLAS).

Definitions of Terms

A ***NICU*** is defined as a unit designed to care for normal newborns, ill newborns who are predicted to recovery quickly without complication, and extremely ill and complex newborns who require continuously available healthcare professionals who are capable of providing continuous life support and comprehensive care, including pediatric surgical expertise (AAP, 2004; Barfield, 2012). NICUs are classified as level I, II, III, or IV. As the level of the NICU increases, so does the infant’s level of acuity and need for intensive care.

NICU nurses are defined as registered nurses who work primarily in one of the four levels of NICUs described above. Most NICU nurses have received training to care for newborns on a spectrum from healthy infants to those who are extremely fragile. Most NICU nurses possess a current nursing license and basic life support (BLS) and Neonatal Resuscitation Program (NRP) certifications.

End-of-life care is defined as preparing a patient for his or her anticipated death (e.g., discussing in advance the use of life-support technologies in case of cardiac arrest or other crises) and managing the end stage of a fatal medical condition (Institute of Medicine [IOM], 2003, p. 2). NICU nurses’ EOLC responsibilities include addressing the physical, psychosocial, cultural, and spiritual needs of the dying infant and his or her family. Additionally, societal needs are addressed through the discussion of organ donation when it is a viable option.

An ***EOL policy or guideline*** is defined as a policy that guides nurses in the delivery of holistic EOLC and addresses the physical, psychosocial, cultural, and spiritual needs of the dying infant and its family.

End-of-life education refers to any EOL content received in a program of study and/or post-degree continuing EOL education such as that provided by ELNEC.

Research Problem

Seminal studies have been conducted to determine the multiple, vital, and complex dimensions of neonatal end-of-life nursing care. Such studies detailed the importance of the neonatal EOLC programs and policies providing certain vital services:

- addressing pain and symptom management and comfort care for the infant (Carter & Bhatia, 2001; Carter & Guthrie, 2007; Catlin & Carter, 2002; Gale & Brooks, 2006; Leuthner & Pierucci, 2001);
- managing the process of ventilator withdrawal (Carter & Bhatia, 2001; Carter & Guthrie, 2007; Catlin & Carter, 2002; Gale & Brooks, 2006; Leuthner & Pierucci, 2001);
- communicating with parents and families, including decision-making and preparation for end-of-life (Carter & Bhatia, 2001; Carter & Guthrie, 2007; Catlin & Carter, 2002; Gale & Brooks, 2006; Leuthner & Pierucci, 2001) ;
- optimizing the physical environment (Carter & Bhatia, 2001; Carter & Guthrie, 2007; Catlin & Carter, 2002; Gale & Brooks, 2006; Leuthner & Pierucci, 2001);
- identifying psychosocial, cultural, and spiritual needs of parents, siblings, and extended family and coordinating care delivery that meets those needs (Catlin & Carter, 2002; Carter & Guthrie, 2007; Gale & Brooks, 2006; Leuthner & Pierucci, 2001);

- continuing physical care coordination for the mother including lactation management (Gale & Brooks, 2006);
- creating memories and other aspects of bereavement care (Carter & Bhatia, 2001; Carter & Guthrie, 2007; Gale & Brooks 2006; Leuthner & Pierucci, 2001); and
- discussing organ donation and autopsy (Carter & Bhatia, 2001; Carter & Guthrie, 2007; Catlin & Carter, 2002; Gale & Brooks, 2006).

Study findings indicated, however, that NICU nurses are less likely to deliver care that addresses the spiritual, cultural, and psychosocial needs of parents and families (Carter & Guthrie, 2007; Engler et al., 2004; Yam, Rossiter, & Cheung, 2001). The lack of documentation of EOLC interventions also appears to be a problem in a profession where many nurses and administrators say,"if it was not charted, it was not done" is a guiding value (Abe, Catlin, & Mihara, 2001; Brandon et al., 2007; Carter & Guthrie, 2007). Two studies highlighted the importance of addressing parents' cultural and spiritual wishes. Moseley et al. (2004) examined the cultural differences in decision-making of parents of infants (n=38) in the NICU when faced with physician recommendations to withhold or withdraw life-sustaining medical treatment. Caucasian families agreed to these recommendations at a rate of 80% (n=16) compared to African-American families who agreed only 62% of the time (n=22). A study by Kodadek and Feeg (2002) used vignettes, similar to case studies, to explore the EOL decision-making processes of volunteers who were willing to play the role of a patient's family member. The different vignettes varied the patient's age, the volunteer's relationship to the patient, and the patient's medical condition. The findings showed that volunteers making decisions for infants were twice as likely to use religious or spiritual criteria as were volunteers making decisions for older patients.

Rates of EOLC Delivery in the NICU

Brandon et al. (2007) found that only one of 37 NICU infants who died during the period examined received EOLC interventions. In one study, as many as 76.5% (n=39) of infants in a NICU who eventually died were not referred to the hospital's palliative care team (Leuthner & Pierucci, 2001). Other studies and publications confirmed Leuthner and Pierucci's findings that only a small percentage of infants and their families who had reached the juncture between curative and EOLC actually received EOLC care (Carter & Guthrie, 2007; Leuthner & Pierucci, 2001; Maginnes, 2002). Additionally, the IOM (2003) noted that healthcare professionals intend to provide consistent and reliable EOLC but "that goal is too often not met" (p. 20). Such omissions in care delivery are contrary to EOLC guidelines and the position statements of leading professional nursing organizations (Malloy et al., 2007; NANN, 2010; The Joint Commission, 2010; WHO, 2012). End-of-life care in the NICU, which is complex and multi-dimensional, is not being delivered to all or even a majority of dying infants and their families.

Barriers and Facilitators

Research findings identified some barriers and facilitators to EOLC in the NICU. One common barrier was a lack of EOL education for healthcare professionals (Botwinski, 2010; Engler et al., 2004; Lewis, 2012a; Rogers, Babgi, & Gomez, 2008; Wright, Prasun, & Hilgenberg, 2011). Another barrier is NICU nurses' discomfort in delivering this specialized care (De Lilse-Porter & Podruchny, 2008; Engler et al., 2004; Ferrell, 2006; Feudtner et al., 2007; Jacobs, Ferrell, Virani, & Malloy, 2009; Novak, Kolcaba, Steiner, & Dowd, 2001; Roberts & Boyle, 2005; Rogers et al., 2008; Brown-Whitehead, Anderson, Redican, & Stratton, 2010; Yam et al., 2001). Kain, Gardner, and Yates (2009) developed a tool to elicit the identification of facilitators and barriers to EOLC in the NICU: The Neonatal Palliative Care Attitude Scale (NiPCAS). Two additional studies since 2009 validated these findings and the NiPCAS tool's efficacy (Kain, 2011; Wright et al., 2011).

To date, only one intervention study has addressed the facilitators of and barriers to EOLC in the NICU. Rogers et al. (2008) assessed whether NICU nurse knowledge and comfort was improved by an educational intervention that was modeled from ELNEC-PPC, provided by a hospice expert, and organized by the hospital ethics committee. Overall nurse comfort scores increased significantly after the intervention, specifically in the areas of ethical/legal issues and symptom management. Interestingly, comfort with communication and culture decreased after the intervention.

Knowledge of the barriers to and facilitators of care is vital to the process of improving EOLC. However, the barriers and facilitators emerging from published research focus on external factors such as the physical and psychosocial environment and EOLC resources. One understudied area is the specific affective responses NICU nurses experience during EOLC. If NICU nurses are experiencing frequent distressing emotional responses during EOLC situations, it may very well affect their care. This knowledge, coupled with information about the external influences present during EOLC, NICU nurses' methods of coping with these emotions, and the outcome of EOLC experiences could aid in the creation of interventions to improve care delivery.

Purpose

The purpose of this study was to explore—through lived and told stories—the affective, interactional, and meaning-related responses that NICU nurses have while caring for dying infants and their families.

Research Question

RQ1: What are NICU nurses' affective responses while caring for dying infants and their families?

- How do NICU nurses cope with these affective responses?
- How do NICU nurses interpret these responses and situations that give rise to them?
- What are the outcomes for NICU nurses from the ongoing accumulation of EOLC experiences, affective responses, and their interpretation?

Assumptions

1. The delivery of EOLC to all populations is a moral imperative of all healthcare professionals who provide direct care to patients and their families.
2. The topic and experience of death and dying evokes strong feelings in most human beings, including nurses.
3. Because of the contrast of emotional responses elicited during the birth and impending death of an infant, the affective responses in this context are more pronounced and complex.
4. Nurses from the National Association of Neonatal Nursing will complete an online survey about their stories about caring for dying infants.
5. Memory of EOLC incidents, as related in the stories, are accurate enough to explore the subjective feelings of the nurses.

Significance

Many NICU deaths are preceded by one or more of the following components: a decision to withhold or withdraw life-sustaining support, the actual withdrawing of the support, and allowing the patient to die naturally. In one study, 51.4–67.6% of NICU infant deaths were preceded by the decision to withhold or withdraw support (Brandon et al., 2007). Another study conducted over a 10-year period found that almost 72% of infant deaths (n=380) resulted from withholding or withdrawing care (Barton & Hodgman, 2005). Once such a decision is made, death may not happen right away. There may be a considerable interval between the decision to withdraw support and the actual discontinuation of that support (Barton & Hodgman, 2005; Gale & Brooks, 2006; Munson, 2007). Additionally, not every newborn dies immediately following support withdrawal (Catlin & Carter, 2002). Given these findings, it is apparent that NICU nurses care for dying infants and their families during many periods, some of them prolonged, periods of EOL.

Unfortunately, there has been a lack of outcomes studies about neonatal nursing EOLC (Lewis, 2012a). It is known, however, that infants who receive planned, holistic EOLC experience fewer invasive and unnecessary treatments such as painful procedures, curative medication, mechanical ventilation, and cardiopulmonary resuscitation (Pierucci, Kirby, & Leuthner, 2001). It is well-documented in the literature that when the specific needs of parents and families of dying infants are met by nurses providing EOLC, positive family outcomes resulted (Branchett & Stretton, 2012; Brosig, Pierucci, Kupst, & Leuthner, 2007; Widger & Picot, 2008). Grief scores were lower and adaptation scores higher for parents and families who received holistic EOLC (Brosig et al., 2007). Specifically, parents who experienced the death of their infant said they were helped during EOLC when nurses

- allowed them time and space to work through difficult adjustments and decision making,
- communicated with them effectively and frequently,
- provided practical help when needed, such as making phone calls to coordinate funeral home arrival and ensuring newly postnatal mothers received necessary care,
- facilitated memory-making activities, and
- provided support during the bereavement period (Branchett & Stretton, 2012).

Additionally, research indicated that spiritual, psychosocial, and cultural considerations played a significant role in parent decision-making during an infant's EOL period (Kodadek & Feeg, 2002; Moseley et al., 2004).

Seeking answers to this study's research question uncovered new information from the perspective of NICU nurses delivering EOLC. This information may aid in the development of innovative interventions to address, alleviate, or provide appropriate coping mechanisms to combat the most prevalent negative affective responses NICU nurses experience during EOLC. Ideally, such interventions—continually refined through subsequent NICU nurse responses—will lead to more effective and consistent delivery of holistic EOLC for infants and their families. Additionally, the emotions closely related to nurse burnout and attrition found from the analysis of this data will add to the existing body of knowledge so that eventually, plan targeted interventions to help reduce or resolve such emotions and thereby decrease nurse turnover and boost nurse satisfaction.

Delimitations

The inclusion criteria for the sample were NICU nurses who (a) had varying degrees of experience, (b) were current members of the NANN, and (c) had the ability to read and write in

English in order to comprehend and respond to survey questions. However, the study invitation did not exclude nurses who had English as a second language. Initially, purposive sampling was part of this study design. However, the sample group (n=36) was small enough that all responses were analyzed. Variables such as years of NICU nursing experience, age, gender, race, and the presence of an EOL policy in the unit of employment were compiled and analyzed in order to more accurately consider the application of these findings to a majority of similarly situated neonatal nurses as they provide EOLC. However, transferability of findings to nurses who deliver EOLC to other patient populations might be imprudent until a similarly designed study is carried out with more diverse patient populations.

Chapter Summary

Regardless of technological advancements in medical care, infants will continue to die in newborn intensive care units. Consequently, NICU nurses must be prepared to provide EOLC to these infants and their families. Outcome studies indicated that EOLC results in positive outcomes for patients and families and yet, recent research findings revealed that this care is not being delivered consistently. Influential organizations in healthcare have published statements and other literature indicating the importance of EOLC for infants and their families. Guidelines and policies have been established to guide NICU nurses in delivering care. Joint Commission Care Standards have been created to evaluate EOLC. Yet, the psychosocial, spiritual, and cultural components of EOLC are not delivered at the same rate as pain management and physical comfort care for the infant. Evidence suggests that these care aspects contribute to parental decision-making and satisfaction with the EOLC process. Specific facilitators and barriers to this care have been identified. However, most of the facilitators and barriers are cognitive and environmental in nature. There is a gap in the literature: very few studies have explored the less tangible aspects of EOLC. Perhaps these findings should not be surprising. For example, it is known that spiritual self-awareness—a component of Carper’s (1978) personal knowing for nurses, the “therapeutic use of self”—is the most difficult state for nurses to achieve. However, this type of personal knowledge is essential for nurses if they are to meet infants and families at the EOL and address their psychosocial, spiritual, and cultural care needs (Benner, Sutphen, Leonard, & Day, 2010; Brien, Legault, & Tremblay, 2008; Sperlazza & Cangelosi, 2009). Therefore, this study’s deeper exploration of the affective responses experienced by NICU nurses providing EOLC is vitally important if, as a profession, we are to continue to improve care so that patient and family outcomes can be improved, as well.

Chapter Two: Literature Review

This chapter begins with a detailed description of the search methods used to locate current knowledge and research studies related to the affective responses of NICU nurses who provide EOLC. Within the review of literature, selected research studies are discussed, analyzed, and critiqued to assess the body of knowledge related to this phenomenon and determine their applicability and generalizability to this study. After laying a foundation of knowledge, a summary is provided of current knowledge and gaps that need to be addressed through further research.

Literature Search Methods

The CINAHL, PubMed, and PsycInfo electronic databases were used to conduct the literature search. The key words searched were neonatal intensive care, nursing, nurses, end-of-life care, palliative care, barriers, obstacles, facilitators, supports, affective responses, feelings, attitudes, perceptions, education, coping, and emotions. These words were searched in several combinations to locate as many relevant research studies as possible to provide a comprehensive illustration of the studied phenomenon. Palliative care was used as a search term due to the common practice of interchanging this term with EOLC. Articles examining true palliative care, as defined in the conceptual definition of terms, were excluded. All NICU-related research findings that used the key words were included in the literature review. An overview of findings from other populations is included to provide a comprehensive illustration of general EOLC phenomenon. Several associated key words were not considered for this study after their definitions were explored, including advanced care planning, challenges, problems, behaviors, beliefs, and values. Additionally, articles describing nurses' emotional responses related to the transition from curative to EOLC were not included. The inclusion criteria were English-written studies published after 2002. From this search, 66 articles were identified and organized into the following categories: EOLC facilitators and barriers to include EOLC education, affective responses of nurses who provide EOLC, and—as a sub-topic of affective responses—moral distress. The concepts of nurse coping and changes in practice as a response to EOLC experiences in the literature were also examined. This study's underlying goal was improving patient care by exploring—through lived and told stories—the affective, interactional, and meaning-related responses that NICU nurses have while caring for dying infants and their families. Examining EOLC facilitators and barriers was a logical place to begin exploring the existing body of knowledge, especially considering the possibility that some researchers might identify specific affective attributes as EOLC facilitators or barriers.

EOLC Facilitators and Barriers

In a response to the increasing importance professional organizations are placing on the provision of quality EOLC, much research has examined the facilitators and barriers to providing EOLC for both adult and pediatric, including neonatal, populations. This body of research and its findings was evaluated and studies that provided an accurate account of what is already known are discussed. In order to gain a more thorough understanding of these facilitators and barriers, and because only a few studies examine NICU nurse populations, research findings related to nurses who care for adult and pediatric populations were explored, as well. Many similarities and differences exist across nurse populations.

Five studies conducted with nurses who care for adults in critical care, emergency, pediatric, and oncology units were evaluated and critiqued for inclusion in this literature review. Renea Beckstrand and her research teams (2005, 2006, 2008, 2009, 2010) have conducted considerable research examining the facilitators and barriers—defined as obstacles and supports—to providing EOLC for diverse patient populations. What stands out in these findings is that each population of nurses identifies a slightly different set of EOLC obstacles and supports and rates their magnitudes and frequencies differently. These facts lend credence to the thought that the NICU environment is distinctive, as well. Only the studies with nurse populations similar to that of the NICU are discussed here. For consistency, the top three obstacles and supports, in magnitude and frequency, are reported for each of the studies, if provided.

The first of these studies, conducted in 2005, used the National Survey of Critical Care-Nurses Regarding End-of-Life Care questionnaire that was originally developed in 1997 to measure the magnitude of EOLC obstacles and supports. The study surveyed 864 members of the American Association of Critical-Care Nurses. Beckstrand and Kirchhoff (2005) adapted a previously used questionnaire to gauge the frequencies of these occurrences. The Cronbach's alpha for the frequency and magnitude of the 72 obstacles and supports was 0.81–0.89, indicating internal consistency. The obstacles to providing EOLC, reported in order of magnitude, were

1. the patient's friends and family calling frequently for updates instead of getting updates from a designated family member,
2. family confusion about the meaning and properties of the term *life-saving measures*, and
3. multiple physicians' disagreement about patient care goals.

The frequency of the obstacles differed slightly with the nurses becoming aware of poor prognosis before the family appearing among the top three. The supports to providing EOLC, reported in order of magnitude, were

1. allowing family to spend adequate time with patient after death,

2. providing a peaceful bedside during EOL, and
3. educating families about how to act around a dying patient.

The supports' frequencies were identical to their perceived magnitude.

In a similar study, Beckstrand, Callister, and Kirchhoff (2006) sought suggestions from more than 1,400 members of the American Association of Critical Care Nurses on how to improve EOLC care through an open-ended question along with a questionnaire related to care facilitators and barriers. The study's researchers did not state whether the 72-item survey of EOLC perceptions was the same as the one used in the 2005 study or if it was created for the 2006 study. The questionnaire's findings were evaluated by seven experienced critical care nurses and he researchers' analysis noted a 0.92 interrater reliability. The responses offered an overarching theme: the desire to provide patients and families with a good death. The sub-theme was the desire to have more time to care for dying patients. The facilitators included nurses manipulating the environment to encourage death with dignity, managing pain and discomfort, and knowing and following patients' EOLC wishes. The barriers included poor staffing patterns restricting the time nurses could spend with dying patients and their families, communication difficulties that included physicians not fully disclosing a patient's status and realistic prognosis, and physicians' inability to view patient death as anything other than a professional failure. The nurses surveyed also cited lack of EOLC education as a barrier.

An oncology nurse population identified different obstacles and supports. Beckstrand, Moore, Callister, and Bond (2009) explored the same research question using an adapted survey instrument with members of the Oncology Nursing Society. Responses from 375 of the 1,000 participants indicated that the EOLC obstacles for this population were interacting with angry family members, dealing with families unable to accept a loved one's poor prognosis, and being called away from the patient’s bedside to help with admissions or other nurses’ workloads. Supportive EOLC actions included allowing family members adequate time alone with patients after death, providing a peaceful bedside environment after patients die, and having a social worker or palliative care professional on the oncology EOLC team. The random sample increased the study’s rigor and added to the generalizability of findings to all oncology nurses.

Other researchers also have conducted studies to explore EOLC facilitators and barriers. Crump, Schaffer, and Schulte (2010) explored this topic by conducting a study based on Beckstrand and Kirchhoff’s 2005 study. Using the same questionnaire, the National Survey of Critical Care Nurses Regarding End-of-Life, along with the Perceptions of Knowledge Needed for Providing End-of-Life Care Survey, these authors obtained data from 56 critical care nurses from multiple units in the same Midwestern trauma center. The sample ranked topics in the order of their perceived need for additional education: cultural aspects, ethical issues, and communication with families. The reported obstacles to care included family and friends calling the nurse for updates rather than a designated family member, family members not comprehending what lifesaving measures entail, and poorly designed units that lack privacy. Support behaviors included designating one family member as the communication link between the patient and other family and friends, having family members who accept that the patient is dying, and creating a peaceful bedside for family once the patient has died.

Most of the research conducted on EOLC facilitators and barriers have examined nurses’ perceptions. Friedenberg, Levy, Ross, and Evans (2012) examined perceptions of professionals from the medical and nursing disciplines who practiced in an intensive care unit. The study sample included 125 medical residents, 20 fellows, 13 attending physicians, and 60 nurses. The researchers administered a survey developed by the Robert Woods Johnson Foundation (RWJF)

Critical Care Peer Workgroup’s *Promoting Excellence in EOL Care Project* that explored barriers to quality EOLC. This survey evaluated three domains: patient and family factors, institutional factors, and clinician factors. The researchers added a fourth domain to evaluate the degree to which lack of education and training was perceived as a barrier to quality EOLC.

Generally, all disciplines perceived that patient and family factors were more significant than institutional and clinician factors. Specifically, the most significant barriers were reported in two situations: when patients could not participate in EOL discussions and decisions, or when they lacked advanced directives. The study findings revealed differences in perception among the disciplines. Participants in the medical discipline viewed the lack of an advanced directive as a much greater EOLC barrier than did the nurse participants. The nurses viewed barriers related to religion, language, and cultural beliefs much more significant than did the medical personnel. In addition, differences among disciplines were revealed in the perception of EOLC barriers in the institutional and clinician domains related to inadequate communication, the lack of continuity of care, and unrealistic clinician expectations.

The study also addressed perceived inadequacies in EOLC education. The most significant item in this area was the residents’ lack of education about communicating during EOL. The residents did not perceive this deficit as much as the attending physicians and nurses did. This finding suggests that EOLC education is more highly valued among more experienced practitioners. The study’s major limitation was its sample composition, which contained nearly three times as many residents and physicians as nurses. Since this study is concerned with the nursing discipline, a sample with at least an equal number of nurses and physicians would shed more rigorous light on differences in perception related to EOLC.

Pediatric EOLC Facilitators and Barriers

Two studies explored EOLC barriers and facilitators in the pediatric population. Beckstrand, Rawle, Callister, and Mandleco (2009) administered a survey to a large (n=474) sample of pediatric intensive care nurses who also were members of the American Association of Critical-Care Nurses. As with other Beckstrand studies, previous questionnaires were combined and adapted for the pediatric nurse sample. The researchers improved the study's rigor by consulting with experts to increase the validity of the items on the adapted questionnaire. Additionally, the questionnaire was pilot tested in a smaller pediatric nurse sample (n=27) and questions were further revised based on the comments gathered. It is noteworthy that the findings in this population of nurses were dramatically different from those of nurses caring for adult populations. The highest rated obstacles to EOLC were language barriers, parental discomfort about withdrawing or withholding mechanical ventilation, and poor interdisciplinary team communication resulting in discontinuity of care. The supportive behaviors more closely mirror those of adult EOLC. The highest rated supportive behaviors were allowing family adequate time with the child after death, allowing parents to hold the child as mechanical ventilation is withdrawn, and creating a peaceful bedside environment after the death has occurred.

Another study of EOLC barriers in the pediatric population also explored differences in perceptions of these barriers among physicians and nurses and between intensive care and non-intensive care staff. Davies et al. (2008) conducted a survey study using a sample of 240 pediatric caregivers from a west coast children's hospital. Nurses composed 83% (n=117) of the sample, physicians accounted for 34% (n=81), and 3% (n=42) were from other disciplines. All participants provided direct care to pediatric patients during at least 50% of their shifts. The researchers created the study's data-gathering tool, which was based on tools from published literature and the researchers' clinical experiences. Expert consultation bolstered the study's content validity. The instrument also was pilot tested with a small sample (n=8) and further refined before being used with the larger sample. The barriers most frequently encountered by the sample, without regard to discipline, were uncertain prognoses, families not ready to acknowledge an incurable condition, and language barriers. The time constraint barrier also was reported as occurring frequently or almost always. When discipline was used as a variable, two differences in barrier perceptions were identified. Physicians identified cultural differences and conflicts between family and staff members more often than did nurses. Additionally, nurses identified the lack of availability of an ethics committee more often than did physicians.

EOLC Facilitators and Barriers in the NICU Setting

Catlin and Carter (2002) were perhaps the first researchers to examine barriers to the provision of EOLC in the NICU. In their report detailing the development of an end-of-life protocol for neonates, they specifically addressed the need to provide ongoing educational and emotional support to care providers. The researchers noted three factors that contributed to the difficulties healthcare professionals had in transitioning NICU patients from curative to palliative care: a lack of formal palliative care education in nursing programs, difficulty acknowledging an infant's terminal prognosis, and problems coping with their personal feelings about death.

Catlin and Carter (2002) used Delphi Methodology to construct the study's protocol. This methodology seeks multiple perspectives from subject experts to reach a consensus on a solution to a problem (Burns & Grove, 2001). The study was conducted via e-mail with a 101-member panel and included four sequential questionnaires administered over an 18-month period. Additionally, 16 published and unpublished end-of-life protocols were synthesized and integrated into the report's recommended protocol. Responses were analyzed after each round of e-mails, with the investigators distilling the vast amounts of information into concepts generally agreed upon by the expert panel. Part of the protocol developed by this method concerned providing ongoing support for staff members who facilitated EOLC. Recommendations for this support included the use of critical incident debriefings. During these sessions, nurses and physicians would examine and discuss previous care situations to help formulate strategies that could improve care.

In 2009, Kain, Gardner, and Yates developed, piloted, and used a new instrument to identify and understand more fully the facilitators and barriers to end-of-life care delivery in the neonatal nursing. The Neonatal Palliative Care Attitude Scale (NiPCAS) was analyzed for face and content validity, which were achieved through expert panel review. Exploratory factor analysis (EFA) and Cronbach's alpha also were used to verify the instrument's reliability. EFA showed that the NiPCAS's most reliable sub-scale constructs related to the organization, available resources, and clinicians themselves. Cronbach's alpha for each of these constructs was 0.63–0.73.

The NiPCAS was then pilot tested with a sample of 645 NICU nurses in Australia. Such a large sample size contributes to the study's generalizability. The analysis identified five facilitators: (a) healthcare team support for a neonatal palliative model of care, (b) a healthcare team that feels free to express values, opinions, and beliefs, (c) counseling support for caregivers, (d) at least some clinical guidelines to support practice, and (e) parent support of the healthcare team. The NiPCAS identified four barriers: (a) inadequate staffing, (b) a physical environment not ideal for palliative care, (c) technological imperatives, and (d) parental demands. The last barrier describes a common conflict in intensive care settings between parental demands that all available advanced technology be used to save the infant's life, and the inevitability of death for some infants despite the use of such technology. This conflict often results in moral distress in NICU nurses, a phenomenon discussed in more detail later in this chapter. This initial test of the NiPCAS paved the way for other researchers to use it to explore further EOLC facilitators and barriers in the NICU.

Kain (2011) designed and implemented a follow up study that used focus groups of NICU nurses to further explore and validate the findings of the original 2009 study. Focus groups were conducted in three Australian NICUs to discuss the barriers previously identified in the Kain et al. (2009) research. A purposive sample of 24 NICU nurses with at least two years NICU experience was recruited. Each focus group was comprised of six to eight nurses. Group sessions were recorded and transcribed before analysis. Findings from the previous study were identified as *a priori* knowledge. As such, the three barriers of (a) inadequate staffing, (b) un-conducive environment, and (c) technological implications and parental expectations were used as a framework for the focus group discussions. While useful for further validation of the NiPCAS, the predetermined barriers limited the study's findings.

The barrier of technological implications and parental expectations was the root of the moral distress identified as a common EOLC manifestation. One participant said, "We had three newborns die last year, and their lives were shockingly unpleasant due to treatment, drugs, machines …" (p. 12). Another noted, "If another ventilator is sitting there, or the oscillator, or whatever, it's just so tempting for the doctors to say well let's just try another machine just because it is there, just in case … it's annoying, frustration, but you need follow orders, I guess" (p. 12).

To continue testing Kain's instrument, Wright et al. (2011) also conducted a study using the NiPCAS. A convenience sample of 50 NICU nurses from a level III Midwestern NICU participated in the study. Identified barriers included (a) nurses' inability to express opinions, values, and beliefs regarding palliative care, (b) less than ideal physical environments, (c) technological imperatives and parental demands, and (d) lack of education. Identified facilitators included (a) supportive medical staff, (b) support from the medical team when palliative care is implemented, (c) adequate staffing, (d) adequate time to spend with dying infant, (e) policies/guidelines supporting EOLC, and f) available counseling. All (100%) of the nurses who completed the questionnaire strongly or somewhat agreed that end-of-life education is necessary in neonatal nursing education. However, only 46% of the nurses reported that they had received any such education. While the study's convenience sample was a limitation, Wright et al.'s data supported and/or confirmed much of the more rigorous findings (Kain et al., 2009).

Education as an EOLC Facilitator

Nurses indicate that education, a possible facilitator of EOLC, is important to the quality of care they deliver. Ten studies reported on the body of knowledge related to EOLC education. White and Coyne (2011) surveyed members of the Oncology Nursing Society from four different states about their perceptions of gaps in EOLC education. These researchers had conducted a similar study in 1999 using a questionnaire they developed. This tool, which had no reported reliability or validity, was developed in two phases with a convenience sample of registered nurses and expert consultants. The newer study's questionnaire incorporated the National Consensus Project for Quality Palliative Care's 12 core competencies. Using this updated instrument, researchers collected 714 (30%) nurse responses over a six-month period. Interestingly, the percentage of participants who reported receiving recent EOL education decreased to 63% in the 2011 study from 74% in the 1999 study. The authors attributed this decrease to the economic constraints of hospitals and other healthcare facilities and their reduced ability to offer continuing education. Twenty-five percent of respondents reported not feeling adequately prepared to deliver EOLC. Another prominent finding was that 57% of participants ranked three of the twelve core competencies most important: (1) symptom management, (2) how to talk to patients and families about dying, and (3) the meaning of palliative care. Of significance to this literature review was the participants' fifth most important competency: dealing with their feelings during end-of-life care. The study's limitations included the homogenous sample of oncology nurses and the researcher-created measurement tool that had no reported reliability and validity.

The gold standard for EOLC education is the End-of Life Nursing Education Consortium (ELNEC) course series. Funded by the Robert Wood Johnson Foundation (RWJF), created by the City of Hope, and promoted through the AACN, this series of continuing education courses has expanded since its inception in 2000 to include EOLC for specialty areas such as pediatrics, oncology, geriatrics, and critical care. To date, more than 15,000 nurse educators and bedside nurses have completed one or more of these courses (AACN, 2013a). Undergraduate and graduate nursing programs also are heeding the call for EOLC education to facilitate this specialized care. The AACN, in conjunction with the ELNEC series, has developed curricular competencies and guidelines for nursing programs (AACN, 1998). One of the fifteen published competencies addresses the importance of nurses exploring and identifying their attitudes and feelings related to EOLC delivery (AACN, 2013a). In chapter one, it was noted that The Joint Commission has developed standards for EOLC by which facilities are evaluated during accreditation visits. The effects of both ELNEC education and nursing program education on EOLC are discussed below.

The Impact of ELNEC on EOLC Education

In 2006, Malloy, Ferrell, Virani, Wilson, and Uman published the findings of a pretest/posttest survey study that evaluated the influence that ELNEC-PPC had on subsequent staff and student education. Nurses in various educational roles—such as staff educators, faculty leaders, and unit managers—were asked to estimate the number of EOLC educational offerings they provided before and after taking the ELNEC-PPC course. The researchers also measured the number of students participating in these programs, as well as educator perceptions and attitudes towards EOLC before and after completing the ELNEC-PPC program. The study's findings included significant increases in both the number of pediatric EOLC continuing and curricular education sessions offered and the number of nurses and nursing students receiving ELNEC-PPC education. The posttest findings also highlighted important changes in nurse educators' perceptions, including increases in their belief in the importance of, and their effectiveness in teaching, pediatric palliative care, as well as their practicing nurses' increased effectiveness in caring for dying children and their families.

In 2006, Paice et al. published a study describing a survey of 382 graduate nursing programs that examined the current state of their EOLC curricula as a foundation for developing an ELNEC graduate program. In summary, the importance of EOLC content was rated high and, while the majority of programs incorporated parts of EOLC into their curricula, self-perceived adequacy and content effectiveness were low.

Another study designed to evaluate ELNEC programs outcomes was conducted by Brown-Whitehead, Anderson, Redican, and Stratton (2010). Framed by Kolcaba's Comfort Theory (CT), the study attempted to test the institutional integrity part of the theory. The purpose of the study was to assess the ELNEC program's impact on nurses' death anxiety, concerns about dying, and knowledge of the dying process. Brown-Whitehead et al. proposed that basic palliative care education would reduce the frustration and distress experienced by nurses delivering EOLC and that nurses would become more comfortable with the idea of transcendence, the ability to rise above problems and pain. The authors hypothesized that this transformation would ultimately lead to a higher quality of care delivered by nurses, higher patient and family satisfaction scores, and improved institutional integrity.

This quasi-experimental, longitudinal study included an experimental group of 11 registered nurses and a control group of 27 registered nurses who consented to participate. The treatment or independent variable was completion of an ELNEC program. Dependent outcome measures (or dependent variables) included death anxiety, concerns about dying, and perceived knowledge about the dying process. The study's outcome measures are not consistent with Kolcaba's CT framework (2003). Outcome measures consistent with CT would include (a) rest, (b) ease, and (c) transcendence. In fact, a comfort scale was not used, bringing the study's rigor into serious question. Additionally, there was seemingly no measure of change in institutional integrity within the report. The small sample size was a significant limitation in discerning differences between the experimental and control groups and raised the risk of a Type II error.

Significant differences in knowledge about the dying process were found between the groups at the immediate posttest measurement and again at the 12-month posttest when the groups were matched. While there were no significant differences between groups for the measures of death anxiety and concerns about dying, the treatment group alone showed decreasing scores on both scales at each testing interval. Based on the significant differences in the levels of knowledge about the dying process, interventions to increase nurses' EOLC knowledge should be repeated at intervals over time.

In addition to formal education, years of nursing experience is thought to facilitate EOLC. One study examined the relationship between years nursing experience, hours of palliative care education, and comfort while delivering end-of life care (Feudtner et al., 2007). Three predictors—greater number of years in nursing practice, more hours of palliative care education, and higher scores on the Hope Scale—were associated with three outcomes: higher levels of comfort working with dying children and their families, lower levels of difficulty talking about death and dying, and higher total palliative care competency scores. The study's researchers created instruments to measure participants' comfort and decreased difficulties. The use of a comfort-measuring instrument with previously established reliability and validity would have lent more rigor to the study design. The predictor of palliative care education accounted for most of the explanations of the outcomes. One limitation was that the sample was composed of only 8.1% (n=33) nurses from the NICU. However, since the sample came from a children's hospital, it was homogenous and adds to the body of literature that links EOLC education and the level of comfort nurses feel while delivering that type of care.

One group of researchers conducted an interventional study with PICU nurses. Haut, Michael, and Moloney-Harmon (2012) used a one-group, quasi-experimental, pretest/intervention/posttest study design to evaluate changes in knowledge and attitudes towards end-of-life care in PICU nurses. The attitudes measured were more closely associated with nurses' EOLC values rather than their affective responses to the care. The intervention was the ELNEC-PPC program, which was modified with permission and placed online as a learning opportunity for the nurses. The authors converted the original questionnaire from an open-ended format to a Likert-scale response format. Twenty-three PICU and pediatric nurses completed all portions of the study, including a demographics questionnaire. A major limitation of the study was that nurses who failed to complete the intervention were still allowed to take the posttest, thus drawing the findings into question. Content validity for the revised questionnaire was 0.94. A correlation measured a positive relationship between certification and knowledge scores. Overall, scores for knowledge and attitude increased significantly after the intervention.

Implementing EOLC Education in Undergraduate Programs

Many researchers have designed and conducted studies to determine the effects of EOLC education. In addition, many nursing programs are beginning to incorporate ELNEC modules into curricula in the hopes of improving student knowledge and emotional readiness for EOLC. One such study used a mixed-methods approach to evaluate student knowledge prior to the integration of the ELNEC content into the curriculum (Wallace et al., 2009). The study sample received the AACN Essentials for Nursing Education Programs EOLC competencies through their curriculum at the time of data collection. The course content began in the first semester of the sophomore year and continued throughout the senior year. An open-ended, 50-item questionnaire was administered to 111 students (61 sophomores and 50 seniors) to gauge their EOLC knowledge. There was a significant difference ($p<.001$) between sophomore-level knowledge (60.98%) and senior-level knowledge (83.26%). While the researchers noted this improvement in students’ EOLC knowledge over time, they decided that an ELNEC-influenced curriculum could possibly boost student knowledge even more than the current curriculum. The study was limited by the self-selected nature of the sample and the fact that no Institutional Review Board (IRB) approval was sought because the study was a component of the organization’s program review.

Sperlazza and Cangelosi (2009) described the creation and use of simulation scenarios to teach EOLC more effectively. In their anecdotal report of the findings, the researchers noted that, while student knowledge increased after the simulation, the simulation's greatest impact appeared to be on student's heightened awareness of the emotions and relational work involved in such care. This finding reflects a similar goal that Benner et al. (2010) described as a much needed, radical transformation in nursing education. More rigorous study designs are necessary to determine specific effects that educational simulation has on EOLC.

Twigg and Lynn (2012) also conducted a study examining the effectiveness of simulation to teach EOLC. The single-group, pretest/posttest pilot study design sought to measure an EOLC simulation scenario's effect on students' EOLC knowledge and emotional readiness to care for dying patients. Sixteen baccalaureate-level nursing students from one university were recruited for the study and compensated with a gift card after completion. Their knowledge was measured by standardized test questions and their emotional readiness was measured by the Concerns about Dying (CAD) tool, which has sub-measures for general concerns about death, spiritual beliefs, and anxiety related to providing care to a dying patient and family members. The intervention consisted of an EOLC scenario using a human patient simulator along with faculty and students who portrayed family members and healthcare professionals. The scenario involved a conflict between the patient's daughter, who was in denial about her father's condition, and her mother. The students who played interdisciplinary team members had to address these issues and were present at the bedside when the simulated patient died.

The findings revealed that students actually had higher rates of stress and anxiety after the intervention. The researchers hypothesized that the student sample, previously uneducated about EOLC situations, recognized for the first time —through the simulation experience—the inherent stress and anxiety of such situations. A gender difference also was noted, with males consistently reporting lower stress and anxiety in providing EOLC, both pre- and post-intervention.

EOLC Education in the NICU

Only one published study reported the effects of an EOLC educational intervention in the NICU. Rogers et al. (2008) designed and implemented an intervention aimed at decreasing moral distress levels in NICU nurses. The study's review and discussion is included with the other studies related to moral distress.

Summary of Facilitators and Barriers to EOLC in the NICU

This body of literature has added much knowledge to what we know about nurses' perceptions of the obstacles and facilitators to providing EOLC. Synthesis of the findings from the adult nurse population reveals slight differences between specialties. Many obstacles reported by nurses caring for adults on oncology, critical care, and emergency units center upon lack of adequate time to spend with a dying patient and the family, a poor understanding by families about the effects of life-saving measures, and communication issues. Perceptions of EOLC facilitators were consistent across nurse samples. Allowing the family adequate time to spend with their deceased loved one at a peaceful bedside appeared in almost all the samples. EOLC education is perceived as a facilitator. ELNEC programs have demonstrated effectiveness in raising awareness about the importance of EOLC and equipping nurse educators with the tools to educate students and staff.

Studies of pediatric nurse populations revealed much different EOLC obstacles than those reported by nursing caring for adult populations. Language barriers and families' inability to accept a poor prognosis were consistently identified as barriers to care among pediatric nurses. These differences in perception continue in research designed to elicit NICU nurses reported

EOLC barriers and facilitators. Environmental and administrative issues affecting EOLC also surfaced in the literature, in the form of staffing levels and physical space requirements that would aid in the delivery of the holistic care that NICU nurses desire to give. NICU nurses consistently reported the conflict between available technology and parental expectations, a probable basis for moral distress in such an environment. Distress of any type involves complex emotions. The concept of moral distress, discussed later in this chapter, is likely to emerge in any study that explores the affective responses of nurses who deliver EOLC.

Affective Responses of Nurses Who Provide EOLC

Merriam-Webster (2012) defines the word affective as, "relating to, arising from, or influencing feelings or emotions." Twenty-two studies examining nurses' perceptions, experiences, perspectives, perceptions, feelings, attitudes, and emotions were critiqued for inclusion in this literature review. In addition to identifying the affective responses uncovered by these studies, differences between specialties were examined, as well. While many studies examined these feelings in nurses who care for adult and even pediatric populations, few have examined these feelings in the neonatal nurse population.

Affective Responses of Nurses Who Provide EOLC to Adult Populations

Qualitative inquiries often yield rich data about emotions. Calvin, Kite-Powell, and Hickey (2007) conducted semi-structured interviews with 12 neuroscience intensive care nurses to explore their perceptions about EOLC. One of the three themes to emerge was "… feeling the emotions of patients and families" (p. 143). Nurses reported feeling confused and helpless in response to unpredictable patient progress. One nurse noted the emotional turmoil involved with the decision to transition from curative to EOLC. The nurses expressed their feelings of frustration after it became clear to them that the patient would not survive and yet family members were reluctant or opposed to withholding or withdrawing care. Sadness was reported by nurses as they considered their own mortality and other death experiences. The nurses also described emotional pain in many gut-wrenching, heart-breaking responses. Others mentioned powerlessness and the feeling of resignation when faced with a dying patient who cannot be helped to live. However, the nurses did report feeling worthy, gratified, and privileged while delivering EOLC.

A set of two studies were designed and conducted to examine apprehension in caregivers working with dying patients. The first study, by Weigel, Parker, Fanning, Reyna, and Gasbarra (2007), examined apprehension among nurses (n=151) in a Midwestern hospital. This quantitative, cross-sectional survey study used the Professional End-of-Life Attitude Scale (PEAS) to examine apprehension and its association with other characteristics such as experience, education level, gender, unit of employment, and end-of-life education. The PEAS measures personal impact, professional impact, and a total communication apprehension score. Overall, total apprehension levels were extremely high, with the highest being found in the hospital’s rehabilitation unit. Males were more apprehensive about EOLC than females, and no significant difference in apprehension levels was identified when education level and end-of-life education were considered. Interestingly, nurses with less clinical experience had higher personal impact scores indicating that they are able to mask their emotions in professional situations, while playing influential roles in their personal lives.

The second study, by Parker, Fanning, and Ye (2009), sought to examine the differences in apprehension levels between nurses who care for the dying in the U.S. (n=183) and in China (n=151). The study is unique in its attention to cultural differences among nurses and the impact the differences have on EOLC delivery. Using the PEAS again, the study measured differences in EOLC education and experience between the samples. The findings showed no significant difference in apprehension levels between nurses in the two countries, thus suggesting that apprehension is a universally experienced emotion among nurses who care for the dying.

Affective responses also have emerged from studies examining stressors experienced by nurses delivering EOLC. Gelinas, Fillion, Robitaille, and Truchon (2012) conducted a qualitative, descriptive study that used focus groups to elicit stressors experienced during EOLC. The sample was composed of 42 intensive care nurses from Quebec, Canada. Three categories emerged, one of which was emotional stressors. All nurses reported being uncomfortable when unnecessary or futile care was ordered for dying patients. There also seemed to be a conflict with the nurses' personal values (moral distress) in these situations. Nurses reported frustration with the inequity in attention and time spent on EOLC when compared with that spent on curative care. Time constraints also were described as a factor in nurses' dissatisfaction with the EOLC they provided. Participants report a lack of emotional support outside of the workplace, which may be associated with poor coping skills and suffering. Frequently, a nurse is the caregiver who performs the actual discontinuation of mechanical ventilation for a dying patient. The nurses described this task as incredibly stressful and difficult.

Emotional responses typically surface when nurses who provide EOLC are asked to describe their experiences or perceptions. A mixed-methods study, conducted in New Zealand, used a researcher-developed survey to evaluate staff perceptions of EOLC to gather data to help create an integrated care pathway. These pathways often are developed to improve patient outcomes through a sequential map of a certain type of care. The study also included open-ended questions and the researchers gathered written comments from a sample of 195 nurses in a long-term care facility (Marshall, Clark, Sheward, & Allen, 2011). While the quantitative survey data indicated high levels of confidence among caregivers, the narrative responses to the open-ended questions contradicted these data. Written narratives revealed several emotions including fear, lack of confidence, avoidance of EOL situations, helplessness, lack of control, vulnerability, and stress.

One phenomenological study sought to explore the EOLC experiences of intensive care nurses. Espinosa, Young, Symes, Haile, and Walsh (2010) conducted semi-structured interviews with 18 registered nurses. While none of the study’s three major themes were related to a specific emotion, descriptions of emotional responses were found throughout the transcripts. The themes present in the interviews were barriers to optimal care, internal conflict, and coping. Nurses expressed frustration at the differences in care goals between nursing and medical care models. One nurse described her anger at a physicians’ practice of offering false hope to families by reporting a single, sometimes barely improved, test result. The nurses also reported having internal conflict. Feelings of relief often came with the decision to discontinue curative care. Conversely, nurses also expressed feelings of abandonment and powerlessness when they discontinued mechanical ventilation. Interestingly, the powerlessness described by nurses was similar to physicians’ feelings of powerlessness when failing to save a life as reported in other cited studies.

A recent study concluded that nurses who care for dying patients progress through predictable stages of emotional development (Bailey, Murphy, & Porock, 2011). This qualitative ethnographic study included 900 hours of observation and naturalistic interviews with a sample of 23 participants. Participants included nurses, physicians, a student nurse, assistants, patients, and their families from an emergency department in the United Kingdom. Interpretation of these observations and interviews led the researchers to conclude that caregivers in EOL situations typically progress through defined developmental stages until they reach emotional intelligence. Bailey et al. (2011) cite and adopt Goleman's (2001) description of emotional intelligence for the purposes of this study, which includes self-awareness, self-management, social awareness, and relationship management. Novice caregivers function in stage one which involves investing the therapeutic self in the nurse-patient relationship. Participant words such as *intimate, therapeutic self*, and the *value of touch* developed this stage. The next stage involved managing the emotional labor that resulted from the first stage. Emotional labor is defined as the manipulation of personal and outward feelings in order to provide patients a sense of safety and caring. The researchers noted that nurses who were not able to master the work of emotional labor chose instead to distance themselves from patients and families as a coping mechanism. This labor is associated with caring for patients who are near the EOL, have experienced loss, and are transitioning from curative to EOLC. The last stage was the development of emotional intelligence.

Finally, a mixed methods study conducted to explore adult population nurses' self-perception of capability and comfort in caring for dying patients adds valuable knowledge about this phenomenon (Powazki, et al., 2013). A research-team created questionnaire was developed to collect demographic characteristics, data about nurses' comfort and capability in caring for actively dying patients, based on the National Consensus Project's nine domains, and finally qualitative data regarding the nurses' self-perception of what they found most distressful were collected. The measurement tool was validated through pilot testing with two different nurse groups. Statistical analysis revealed that age and years of clinical experience were positively correlated with self-perceived feelings of comfort and capability in most of the nine domains. However, nurses with continuing education in end-of-life care reported greater comfort and capability related to ethics, culture, religion, and bereavement. The open-ended question revealed three dominant themes related to subjects that caused the sample the most distress: 1) bioethics, 2) communication, and 3) grief. In reference to the grief experienced by the participants, Powazki et al., write, “Nurses grieved when they absorbed sadness and witnessed suffering” (p. 4). Recommendations for future practice that stemmed from this study included continuing education, the use of formal debriefing, and preceptor support for less experienced nurses.

Affective Responses of Nurses Who Provide EOLC to Pediatric Populations

Two studies examining pediatric nurses’ emotional responses to EOLC. Lee and Dupree (2008) designed and conducted a qualitative, descriptive study that examined staff experiences, through interviews (n=32), with EOLC in a pediatric intensive care unit. Participants included nurses, physicians, and psychosocial support professionals. Using content analysis methodology, researchers found that two major themes emerged from the data: ambiguity about the use of technology and sadness. One physician participant described a feeling of panic and failure when the withdrawal of life support was discussed. Sadness was experienced when caregivers witnessed families’ grief. Nurses actually expressed gratitude for this feeling, as it was evidence that they had not lost all sense of empathy and humanity. Interestingly, while physicians also identified sadness as a prevalent feeling, they also described feeling helpless and frustrated because they were unable to save lives. One physician described an order written to escalate treatment that was ultimately withdrawn because, “my head took over from my heart” (p. 988) indicating that physicians’ instinctual drive is toward curative care.

During the development of a pediatric palliative care program, Contro, Larson, Scofield, Sourkes, and Cohen (2004) conducted a mixed-methods study examining the comfort and expertise of 446 staff members and physicians related to EOLC delivery. Family members of deceased children (n=68) were interviewed about their experiences with their child’s EOLC. Staff expressed feeling inadequacy and distress, specifically related to their communication with patients and families and their ability to manage patients’ pain, during the EOL period. The inability to contact the family after a death resulted in feelings of disappointment. Staff reported feelings of anguish and helplessness at watching children suffer.

Affective Responses Nurses Who Provide EOLC to NICU Patients

Only five studies examined the emotions, outside of moral distress, NICU nurses experience while delivering EOLC. Lindsay, Cross, and Ives-Baine (2012) described their interpretive narrative analysis to explore NICU nurses’ experiences with EOLC. Using Newman’s *Research as Praxis* process, the researchers worked with a convenience sample of 17 female ‘co-participants.’ Through two small-group dialogue sessions and the sharing of EOLC stories, the researchers examined emerging patterns of experience. Pertinent findings included a call-to-presence that requires an “…intimate relationship…” (p. 246) between the nurse and the infant near the EOL. Intimacy implies emotional connection. The pattern of knowing/unknowing—referring to a NICU nurse’s knowledge that certain therapeutic interventions caused infant suffering—was found in the data, which is another element of moral distress. Finally, the pattern of exploring experience to transform practice was discovered. The participant group pointed out that they often listen to each other’s EOLC experiences, thus co-constructing nursing EOLC knowledge. While the study did not directly examine affective responses, some developed spontaneously, indicating their powerful presence in EOLC situations. A notable limitation was the study’s lack of male NICU nurse participants. A study with a more diverse sample might reveal significant gender differences.

A similar study that sought to examine NICU nurses' experiences also uncovered affective themes and patterns. Archibald (2005) conducted a phenomenological study to examine nurses' experiences caring for neonates "… at the edge of life" (p. 53). During the data collection phase, participants reported feeling many emotions while caring for neonates. However, one emotion was directly associated with neonatal death: fear of dealing with patient death. At least two of the eight female participants noted their fear of an infant dying during their shift and stated they felt unprepared to care for the dying infant and the struggling parents. An undertone of personal responsibility to keep an infant alive during their shift was present, as well. Again, the lack of male nurses in the participant group is a limitation to fully understanding the NICU nurse experience.

Another instance of affective responses spontaneously arising during studies whose aim is to examine experiences of NICU nurses who provide EOLC is Yam et al.'s (2001) exploratory study of NICU nurses' experiences in Hong Kong. The researchers interviewed a 10-nurse convenience sample using semi-structured, open-ended questions. Data analysis consisted of a content analysis of the transcribed interviews. The data revealed many emotions as well as moral distress. This analysis revealed eight categories: (a) disbelieving, (b) feeling ambivalent and helpless, (c) protecting the emotional self, (d) providing optimal physical care to the infant, (e) providing emotional support to the parents, (f) expressing empathy, (g) lack of knowledge and counseling skills, and (h) conflicting care values. These conflicting values of care referred to the nurses' inability to provide emotional support to parents of dying infants because of inadequate staffing and the lack of importance administration and physicians gave to family-centered emotional support during EOL. The small convenience sample is a limitation. However, the cultural differences in the study sample make the findings extremely important since there are many similarities with other U.S. studies' findings.

One study sought to examine a particular affective response. Engler, et al. (2004) explored how comfortable neonatal nurses are with end-of-life and bereavement issues. These researchers conducted a cross sectional, descriptive, correlational study to examine neonatal staff and advanced practice nurses' (n=190) perceptions of end-of-life care of dying infants and determine any differences in perception between the two groups. The authors used the Bereavement End-of-Life Attitudes about Care: Neonatal Nurses Scale. The tool was revised based on content testing with a convenience sample of 24 NICU nurses. The final survey contained four sections: A comfort scale, a roles scale, an involvement scale, and demographics. Two hundred forty hospitals across the nation were randomly selected from eight different regions and two questionnaires were sent to each. They achieved a 52% response rate, which equated to 190 completed surveys from NICU registered nurses (RNs) and adult nurse practitioners (ANP). The comfort scale, which was a Likert tool with a possible range of responses of one (very uncomfortable) to five (very comfortable) revealed that participants reported feeling comfortable (4.13) with many parts of EOLC. A correlation was revealed between comfort level and the number of years of NICU experience. However, a significant number of participants reported feeling less comfortable discussing organ donation and autopsy with families of dying infants. A significant finding was that NICU RNs and ANPs reported significantly higher comfort in providing bereavement or EOLC when their units had palliative care policies.

Huang et al. (2012) examined Taiwanese neonatologists' (n=25) and neonatal nurses' (n=84) attitudes toward do not resuscitate (DNR) orders for dying infants in a cross-sectional, survey study. The questionnaire was developed by the researchers and its content validity was evaluated through expert review. Content validity was high (0.86) and additional reliability measures were implemented after the questionnaire was translated into Chinese. Findings showed that most of the participants (86.5%) agreed that DNR orders should be discussed with parents of dying infants. However, a majority of participants (76.9%) concurred that talking to patients' parents about DNR orders is difficult for them. The study did not discuss why such discussions are difficult and reported no additional findings about emotions this sample experienced.

NICU nurses might respond differently to providing EOLC than nurses working with other populations. Since earlier cited studies found that NICU nurses are less likely to deliver spiritual care to families of dying infants, additional exploration of nurses' responses is needed. A recent comparative study by Ronaldson, Hayes, Aggar, Green, and Carey (2012) found that spiritual self-awareness was higher in nurses who practiced EOLC exclusively versus acute care nurses concerned mainly with curative care. Spiritual self-awareness, according to Ronaldson et al. (2012), is a part of Carper's (1978) personal knowing, and the most difficult awareness for nurses to master. Personal knowing is essential for the interpersonal process that is foundational to the nursing discipline and has been found to contribute to improved patient outcomes. In the case of spiritual care, nurses must provide a "therapeutic use of self" (Carper, 1978, p. 19) to form a personal relationship with patients and family. Additionally, Ferrell, Otis-Green, and Economou (2013) noted that oncology nurses are often not prepared to give spiritual care to their patients and as a result, that critical aspect of EOLC can be omitted. Ferrell et al. state that spiritual care education and skills can contribute to better care in this essential area.

NICU nurses may be involved with ethical dilemmas not faced by other caregivers, such as delivery room resuscitation. Often, NICU transport teams are called to be present for high-risk deliveries, where they engage in EOL decision-making and care in a less familiar environment. These instances may contribute to lapses in EOLC simply due to time constraints and the healthcare professional's lack of preparation. Lastly, NICU nurses may feel differently than other nurses since their patients are newly born and not elderly as is the case in other specialties.

Moral Distress

Moral distress in nursing, especially in the context of EOLC, is a relatively new focus of research. Russell (2012) conducted a concept analysis of moral distress in neuroscience nursing. Moral distress in nursing was defined as a situation in which nurses can identify and want to carry out the morally correct choice, but are prevented from doing so by institutional constraints or conflicts between the nurse's personal values and the institution's values (Corley, 2002; Jameton, 1993). Russell (2012) also identified four attributes of moral distress in the context of neuroscience nursing: negative feelings, powerlessness, conflicting loyalties, and uncertainty. Negative feelings included anger, frustration, guilt, anxiety, depression, hopelessness, worthlessness, sadness, and helplessness. Medical futility or futile care, which is often described by nurses as part of the EOLC experience, was identified as an antecedent to moral distress. Consequences of moral distress in nurses were identified as physical symptoms such as headaches, fatigue, and insomnia; loss of self-worth; changes in religious and health related behaviors; and personality changes. Other less personal consequences of moral distress related to the work environment were increased absenteeism, increased staff turnover rates, and low morale, which can lead to a decreased quality of patient care and increased healthcare costs.

In her theory of moral distress, Corley (2002) asserted that nurses also feel moral distress when patients experience pain and suffering that nurses believe is preventable. Moral distress evokes frustration, anger, and guilt that can cause a nurse to avoid a patient. Avoidance both increases patient suffering and negatively affects the nurse's psychosocial well-being (Corley, 2002; De Villers & DeVon, 2012). Moral distress associated with EOLC in the NICU is believed to occur when the infant is given "… prolonged, aggressive treatment that was perceived [by physicians and NICU nurses] as futile" (Epstein, 2008, p. 775). Similar definitions of moral distress, in the NICU and other populations, have been offered by other researchers (Catlin et al., 2008; Hefferman & Heilig, 1999; Lawrence, 2011; Mobley, Rady, Verheijde, Patel, & Larson, 2007; Rogers et al., 2008; Yam et al., 2001).

Studies have examined moral distress in nursing, and EOLC situations are frequently cited as contributing to moral distress. However, for the purposes of this review, only studies that explored this concept in the context of EOLC or futile care were included. Piers et al.'s (2012) study explored the frequency, intensity, and characteristics of moral distress present in a group of geriatric nurses (n=222) who frequently provide EOLC. Using the Moral Distress Scale, researchers discovered that while the frequency of moral distress was relatively low (1.1/4.0), when it did occur, the intensity was significant (2.3/4.0). Additionally, the nurses identified situations that triggered feelings of moral distress: unjustified life support, unnecessary tests and treatment, and incompetent colleagues. Another salient finding was that higher moral distress scores were reported by nurses who intended to or were in the process of leaving their nursing jobs. Two of the three situations identified by the study, unjustified life support and unnecessary tests and treatment, can be classified as futile care. Medical futility is using of technology to sustain individuals’ lives well beyond the point of reasonable hope for recovery. Meaningful quality of life often is considered when deciding whether care is futile (Ferrell, 2006).

Ferrell (2006) analyzed written narratives about moral distress and futility from 108 nurses at an ELNEC conference. The survey asked the nurses to describe a distressing clinical experience that included futile care and how that experience affected them professionally. An overwhelming number of narratives described aggressive curative care that denied the patient EOL or palliative care. Emotional responses included feeling demoralized, powerless, helpless, hopeless, frustrated, angry, distressed, or guilty. A few nurses reported a positive experience that helped them grow professionally. Nine nurses reported making a career change to become a hospice or palliative care nurse.

Mobley et al. (2007) examined the situations that caused moral distress in a critical care unit and how often caregivers reported such situations. A sample of 44 critical care nurses completed the Corley Moral Distress Scale, which has been proven reliable and valid in the critical care environment. The findings revealed that futile care was experienced as a precursor to moral distress in 66–89% of the nurses and the frequency of their encounters with futile care increased with the nurses’ age and years of critical care and nursing experience. To explain this result, researchers hypothesized that the duration of the nurses’ career exposed them to more instances of futile care or that their experience enabled them to recognize futile care more easily. More than 50% of the participants also reported feeling moral distress when discussing organ donation with families when it was clear the patient would not survive.

Lawrence (2011) conducted an interesting study that explored the relationship among moral distress, education level, critical reflective practice, and work engagement in a diverse sample of ICU nurses who cared for dying patients and families. Lawrence (2011) noted that work engagement can be described as a mental perspective that results in a positive, energetic and dedicated focus on one's job. According to this definition, work engagement is the opposite of the avoidance behaviors other studies found in some nurses who delivered EOLC (Corley, 2002; Espinosa et al., 2010; Marshall et al., 2011). NICU nurses were one subset of the study sample. Five instruments, four with published reliability and validity data, were used to measure the concepts. The instrument that measured critical reflective practice was a combination of an established measure, the reflection-rumination questionnaire, and a researcher-created tool, the critical reflective practice questionnaire. Twenty-eight percent (n=8) of the 28 ICU nurse sample was composed of NICU nurses.

Findings derived from various quantitative analytic processes revealed a positive direct relationship between critical reflective practice and work engagement and a negative direct relationship between moral distress and work engagement. For these NICU nurses, a direct positive relationship existed between education level and critical reflective practice, as well as an indication that education level had a negative relationship to moral distress levels. At the end of each instrument, an open-ended question encouraged more qualitative data collection. Analysis of the responses indicated that the ICU nurses learned about EOLC through practice-based, relationship-based, and academic-based methods. Moral issues included death and suffering or futile care, dealing with family when they are holding out hope when no hope is perceived by the nurse, medical versus nursing values, and orders/interventions that are identified as not in the patient's best interest. These findings are highly significant to the topic of NICU nurse affective responses during EOLC. A similar study in the future using a NICU sample would be a valuable complement to this work.

Moral Distress and EOLC in the NICU

The root of moral distress experienced by NICU nurses often is related to the provision of futile care (Kain, 2007). Futile care involves aggressive interventions that are not expected to cure dying infants and that nurses feel cause needless pain and suffering. The word “torture” is often associated with futile care and nurse moral distress (Catlin et al., 2008; Ferrell, 2006; Hefferman & Heilig, 1999). Moral distress results when nurses are compelled to act against what they believe is the right thing to do in response to external influences such as physicians’ orders or parents’ wishes to continue care. Other feelings nurses report when faced with futile care include helplessness, powerlessness, anger, frustration, and sadness (Catlin et al., 2008). The data from three studies—two in NICU nurses, and one in pediatric caregivers—revealed moral signs of moral distress in those who care for dying infants and children.

Epstein (2008) conducted a study using semi-structured questions to explore nurses’ (n=21) and physicians’ (n=11) EOLC experiences in the NICU. While the interview data was analyzed for themes, a process consistent with phenomenological methodology, quantitative statistics were also discussed with the themes, producing a more mixed methodology. Most themes were discussed with interview excerpts provided as supporting data. The overarching theme identified by both nurses and physicians was that of creating the best possible experience for the parents. Sub-themes included building relationships, preparing for EOL, and creating memories. Three additional themes, less directly related to patient and parent care, also developed: moral distress, parental readiness, and consent for autopsy. Moral distress was linked consistently with futile care, which was defined as prolonged and aggressive interventions that had little hope of success. When relating an experience providing futile care, one physician said, “…this is wrong. This is so wrong.” (p. 775).

The nurses reported that false hope was related to futile care and that allowing parents to continue hoping for their terminally ill infants' survival was directly responsible to the rate of futile care provided. Nurses noted feelings of frustration when describing incidences of healthcare providers being dishonest with parents about an infant's prognosis. Nurses also reported that discontinuity of care was an antecedent of futile care. High physician and nurse turnover resulted in the lack of one primary care provider who was aware of an infant's entire history. The theme of parental readiness described the feeling of bewilderment that a majority of nurses expressed at how parents concluded that "…now's the time ..."[to discontinue life support]" (p. 775).

Rogers et al. (2008) designed and conducted the only interventional study related to the phenomenon of moral distress of NICU nurses (n=82) who provide EOLC. Prompted by a specific case in which the NICU nursing staff requested assistance from a hospital ethics committee, the study's aim was to examine the effects of an educational intervention on NICU nurses' levels of comfort when caring for dying infants. Although the literature review discussed moral distress, the research question examined the concept of comfort. A researcher-created comfort measurement instrument was used in the pretest/intervention/posttest study. The researchers noted the logical extension that relieving moral distress relief in caregivers would lead to increased caregiver comfort, which, in turn, would help promote improved EOLC delivery. The intervention consisted of six, one-hour EOL education sessions delivered over a six-month period. The session topics included pain management, symptom management, ethical and legal issues, communication and culture, spiritual and anxiety issues, and prevention of compassion fatigue.

A noteworthy study limitation was that the instrument created to measure comfort, the Comfort in Caring for Dying Infants tool, was discovered to lack reliability and have poor validity statistics (Babgi, Rogers, Gomez, & McMahon, 2008). Even though the findings from such an instrument must be called into question, the results are discussed here because this is the only interventional study related to this phenomenon. Nurse overall comfort scores increased significantly after the intervention, specifically in the areas of ethical/legal issues, prevention of compassion fatigue, and symptom management. Changes in comfort related to pain management, spirituality/anxiety, and prevention of compassion fatigue approached significance. Comfort with communication and culture decreased after the intervention.

Solomon et al. (2005) conducted a large-scale study with a sample of 781 pediatric physicians and nurses from three different children's hospitals and four general hospitals in the eastern, southeastern, and southern United States. The researchers administered the Decisions near the End of Life Institutional Profile to uncover concerns of conscience and other variables. Findings included occasions of acting against their conscience when writing care orders (63% of house officers and attending physicians) or carrying them out (47% of nurses). Other items that received high rates of agreement from physicians and nurses included "sometimes I feel we are saving children who should not be saved" and "sometimes I feel the treatments I offer children are overly burdensome" (p. 875).

Neonatal researchers have recognized moral distress and its most frequent causes and have identified some solutions, including the idea of nurse conscientious objection. Concept analyses are often helpful in fleshing out a particular phenomenon. Catlin et al. (2008) provided an in-depth analysis of conscientious objection as a possible action nurses could take in response to futile care orders to avoid resultant moral distress. Using the *Hybrid Method of Concept*

Development, Catlin and colleagues explored prior nursing articles describing instances of conscientious objection, as well as the history of the concept related to military action, the discipline more traditionally associated with it. Several attributes emerged, including moral distress, as well as its antecedents, and consequences, allowing the following definition to be composed:

> For the nurse, conscientious objection may occur when the nurse interprets that the care that has been assigned for a patient is harmful or will cause suffering. The nurse does not wish to provide this form of care and feels sincerely, and has for some time, that this decision is a question of conscience. The nurse objects to the nature of the care orders, is willing to assist in other forms of care, and does not wish to abandon the patient (pp. 104–105).

As part of the Hybrid Method, the researchers then applied the concept in the clinical area to obtain feedback about the practicality of the concept definition. Catlin et al. administered an open-ended questionnaire to 66 NICU and PICU nurses who cared for critically ill infants. Barriers to the use of conscientious objection in the case of orders for futile care included physician’s orders (44%), administrative policies and legal consequences (42%), and job loss and sanction (19%).

Summary of Affective Responses of Nurses Who Provide EOLC

Research clearly indicates that nurses experience strong emotions when providing EOLC, independent of age or type of patient population. The majority of emotions are negative, although one study documented the positive emotions of worthiness, gratification, and feelings of privilege. Much more is known about the emotions of nurses who care for adult patient populations than those in pediatric and neonatal care environments. Frustration, powerlessness, helplessness, fear, apprehension, and anguish are the most consistently reported emotions across all nurse specialty areas. Gender differences related to this phenomenon need to be explored more fully as the available literature is contradictory about which sex experiences the most emotional stress when providing EOLC. Moral distress, a concept composed of many of the negative emotions reported in the literature, seems generally to be a by-product of futile care efforts at the EOL.

Overwhelming citations of negative emotions experienced by nurses who provide EOLC support the need for additional research into this area. Before comprehensive and consistent EOLC can be delivered to all patients who require it, some questions must be answered, including those surrounding the roots of nurses' negative emotions and their effect on patient care and nurse well-being. Earlier in this chapter, the differences between identified facilitators and barriers among nurse specialties were noted. Since the literature about pediatric nurse and NICU nurse populations is lacking, and because it is logical that bedside nurses' emotions could serve as EOLC barriers or facilitators, it is imperative to expand the body of knowledge about the affective responses of NICU nurses who provide EOLC.

Nurse Coping Strategies Related to End-of-Life Care

Self-care, stress, and burnout are not new concepts in the nursing profession. There is a multitude of causes of nursing stress, but delivering end-of-life care can be particularly taxing. Because research into NICU nurses' coping methods is lacking, the following is a critical discussion of a select group of studies from other nurse populations.

Badger (2005) explored the coping strategies used by ICU nurses during EOLC using brief observations and focus group interviews. The researcher categorizes these methods as cognitive, affective, and behavioral. Cognitive strategies included "putting up with it" as a way to recognize that care will not prevent death, visualizing to facilitate empathy, reminiscing as a way to assign value to past patients who have died in their care, learning from experience, and putting things into perspective by intentionally not taking the emotions that surround EOLC home. Affective strategies included laughter, externalizing feelings through informal debriefing with colleagues, and emotionally compartmentalizing by not discussing EOLC situations outside of the unit. The participants also shared behavioral coping strategies, including retreating, avoiding, and distancing-type behaviors. These behaviors all describe the ICU nurses' need to step back from the EOLC situation because of strong emotions, personal frustration, or distress of some kind. Finally, less prevalent coping strategies included faith, existential support, and colleague support. The most common situations that caused nurse distress were providing futile care and nurse perceptions of torturing the patient.

Peterson et al., (2010) used grounded theory methodology to explore nurses' coping mechanisms during EOLC. The researchers collected interview and open-ended survey data to examine the participants' experiences in providing EOLC. Before providing qualitative data, the fifteen participants provided demographic information and completed the fear of death measurement instrument and the Frommelt Attitudes Towards Nursing Care of the Dying scale. The findings categorized nursing coping behaviors as stemming either from internal and/or external sources. Internal sources included reflecting on the death and using professional boundaries. External sources included peer and colleague support, religious beliefs, and using patients and families as a source of comfort. Although the small sample size may be viewed as a study limitation, the diversity in education and nursing experience may add to the transferability.

Melvin (2012) explored the relationships among professional compassion fatigue, coping strategies, and nurses who care for dying patients. In the study, professional compassion fatigue was defined as "… the cumulative physical and emotional effects of providing care over extended periods of time" (p. 606). Although this was a pilot study with a relatively small purposive sample of six hospice and palliative care nurses, interesting data were revealed about coping strategies nurses used to avoid professional compassion fatigue. Setting professional boundaries, talking with colleagues, reflection, and physical exercise were identified as effective coping methods that allowed participants to continue caring for dying patients.

Espinosa et al. (2010) identified coping strategies of ICU nurses when exploring their experiences delivering EOLC. Through qualitative, semi-structured interviews, the major coping themes identified were building trust with the family, crying, humor, talking with others about terminal care, and finally, avoidance.

A study conducted with pediatric nurses is perhaps the most relevant to the population of interest for this study. Cook et al., (2012) examined the coping strategies used by 22 pediatric nurses who cared regularly for dying children. A senior investigator led focus group discussions, 45–60 minutes in duration, to collect data. The study's findings were generated through a content analysis of the focus group transcripts. Four coping categories were found. Listed in order of use by the novice and then by the expert pediatric nurses, these coping strategies were boundaries, memories, disconnecting, and labeling.

Notably, the use of professional boundaries was described as both a facilitator of coping and a hindrance to the type of care the nurses desired to give. The nurses discussed extending these boundaries as a way to convey caring in this special patient population. Similar to the reminiscing strategy described by Badger (2005), the study's memories category detailed how pediatric nurses use memories of healthier patient times and bedside pictures of the patients as a reminder of the life the patient had before the EOL period.

Participants also described distancing, both physically and emotionally, as a coping mechanism. As the pediatric nurses gained experience, they clearly recognized the need for this type of self-preservation behavior. The strategy of compartmentalization or forgetting a highly emotional situation was applied to the home environment and nurses shared that colleagues understand more than families about their EOLC experiences. Frequently, the participants noted how colleagues provided the most support because of their intimate knowledge of the situation versus family and non-nurse friends who did not understand. Finally, experienced pediatric nurses used labeling to protect family and friends from the realities of their work. The nurses used phrases such as, “I had a bad day” and “I had a busy day” so as not to put the burden of EOLC on their families. Such language also was a way of avoiding in-depth discussions at home. Participants also noted contextual resources of colleagues and institutional support.

Summary of Coping Strategies

Coping strategies, revealed throughout the research, can be categorized as internal or external, or as cognitive, affective, and behavioral. The strategies also can be discussed in terms of healthy and less healthy approaches, although these labels might be too generalized and not take into account individual nurse differences and needs. Using professional boundaries, distancing, and avoidance were common ways of coping with EOLC situations and were implemented to protect the nurses’ emotional health. Reminiscing and using memories with long-term patients were common for remembering what patients were like when they were healthier. Finally, avoidance for protection was reported, especially in response to the delivery of futile care.

Changes in Practice from EOLC Experiences

What do NICU nurses ‘do’ with their EOLC experiences? Very little research has attempted to answer that question directly, but studies examining the concept of critical reflection relate both indirectly and directly to strategies for improving EOLC. Chinn and Kramer (2011) stated that the process of reflection, as it relates to professional growth, is similar to emancipatory knowing. In both the reflection and emancipatory knowing processes, reflection and action are required for change to result from prior experience. In the reflection process, individuals examine their actions and rationales in a way that allows them to implement practice improvements.

Researchers have revealed that EOLC practice experiences contribute to NICU nurse learning, often through the process of critical reflection (Lawrence, 2011; Lewis, 2012b). Vittner (2009) defined general reflective practice in the NICU as “… creating meaning from interpreting experiences through purposeful thought that guides decision making for taking the next step of action” (p.43). Lawrence (2011) defined critical reflective practice in ICU nursing as “… being mindful of self within or after professional practice situations, i.e., processing the cognitive, behavioral, moral … socio-political and affective components of professional practice situations, so as to continually grow … and develop…” (p. 258). Lewis (2012b) examined critical reflective practice as a possible facilitator of quality end-of-life care through a concept clarification process. Related to this dissertation study’s specific context, Lewis defined critical reflective practice as, “... a structured, formal, and routine process that allows healthcare professionals the opportunity to critically examine their experiences ... discuss those experiences ... construct new meaning, and identify creative interventions to improve care ... in the future” (p. 410).

Changes in Practice in Adult Care Settings

No published research examines changes in practice from EOLC situations. However, a few researchers have designed and implemented studies to examine the effect that critical reflection has on EOLC and even EOLC in the pediatric setting. In a study described earlier related to moral distress, Lawrence (2011) examined critical reflective practice as it relates to other concepts such as work engagement, moral distress, and education level with a sample of ICU nurses. A segment of the study sample was NICU nurses. Lawrence found a positive relationship in NICU nurses between education level and critical reflective practice.

Bailey and Graham (2007) implemented a structured reflective practice with a group of eight palliative care nurses in Ireland. Over the course of a year, facilitators guided eight sessions (each lasting two and a half hours) for the nurses. Participants were required to attend and participate in each reflective practice session. Additionally, they were encouraged to keep a reflection diary and apply their new skills in reflective practice in order to grow professionally. At the conclusion of the yearlong study, participants were asked to complete a questionnaire asking open-ended questions such as “Where do you see this process taking you?” and “How will this change and guide future practice?” Researchers used thematic content analysis to analyze the responses. Four themes emerged: understanding the process of reflective practice, the importance of keeping a reflective diary, guided group reflections, and moving forward. Akin to formal debriefing, the group reflective practice sessions were highly valued by participants and were noted to be supportive, inspiring, a non-judgmental environment, a positive experience, and a vital element to the process. Most participants indicated that they hoped to continue the process on their own or integrate it into their workplaces.

Other studies have evaluated the effects of formal guided reflective practice sessions on specific outcomes. Halm, Evans, Wittenberg, and Wilgus (2012) implemented a pre-test, intervention, post-test pilot study design to examine the effects of a two-stage intervention—consisting of cultural EOLC practices and reflective practices—on EOLC professionals' ability and comfort in providing EOLC to patients who hold culturally different beliefs. The intervention's reflective practice segment was composed of case studies that encouraged reflection about cultural conflict sources at EOL, reflection about healthcare professionals feelings related to these conflicts, what actions would be helpful to resolve such conflicts, and how a patient and his/her family might react to those actions.

The research team worked with a sample of 24 healthcare professionals from oncology units and used a variety of measurement tools: the Intercultural Development Inventory, the Frommelt Attitudes Toward Caring of the Dying, a knowledge of cultural beliefs/traditions measure, and self-perceived comfort in providing culturally competent EOLC scale. The researchers developed the knowledge of cultural beliefs, satisfaction with the intervention, and comfort tools. The majority of the final sample was RNs (71%). While there were no appreciable differences between the majority of pre-test and post-test measures, a small increase in self-perceived level of developmental orientation was noted and significant increases were present in the samples' perception of knowledge, skills, and comfort levels. Other significant associations included sample characteristics that related directly to higher levels of knowledge, skills, and beliefs related to cultural differences at EOL: discipline, highest degree, EOLC and cultural competence education, self-perceived knowledge and skills, and self-perceived comfort in providing culturally sensitive EOLC.

Action research is a methodology in which critical reflection is a central component of identifying practice issues, and creating and implementing potential solutions. Taylor et al. (2008) published a study in which eight palliative care RNs completed the action research process and, through group reflective activities, pinpointed and examined the need to “get it right under pressure.” After sharing their experiences, the group composed an action plan to improve care. Overall, the participants’ reported the process as being helpful and satisfying.

In a similar study, Rowley and Taylor (2011) implemented action research methodology to help a sample of 14 EOL caregivers improve their practice. Using guided reflective practice, writing, and group sharing, the participants identified the need to increase knowledge and improve pain management practice. The group worked together to create a plan of action to accomplish these goals. In the final step, the group reflected on the plan’s effectiveness. Findings indicated that the action research process, which included the concept of critical reflection, improved practice at the facility.

Changes in Practice in Pediatric Care Settings

To date, no research has examined the changes nurses undergo because of their EOLC experiences. However, researchers have developed models for reflection in pediatric palliative care and neonatal care (Lewis, 2012b; McNeilly, Price, & McCloskey, 2006). Similar in many ways to Taylor’s action research studies, these models focused specifically on end-of-life care. Commonalities between the methodology and models were the need for self-awareness, sharing practice experiences in a group setting, identifying and deconstructing areas that need improvement, and a post-reflective phase to encourage professional growth and evaluate learning.

Summary

Research on the cumulative effects that EOLC experience has on nurses is sorely lacking. Researchers need to ask what nurses should do with their experiences. Critical reflection often is used in nursing and other disciplines to process individual experiences and apply the lessons learned to future practice. The literature related to EOLC practice changes is just emerging. So far, this literature indicates that reflective practice is a valuable activity that may promote increased nurse expertise and improve future patient outcomes.

Chapter Three: Methods

This chapter describes the methodology used to explore the affective responses of NICU nurses caring for dying infants and their families, including the study's philosophical foundations, sample, participant questions, data collection, data analysis, and limitations.

Philosophical Foundation

This study was viewed and designed through the lens of constructivism. This paradigm originated as a rejection of the positivist assertion that there is only one reality to be experienced by all humans. In the early 20th century, philosophers—such as Vico, von Glaserfeld, Dewey, and Vygotsky—asserted that the positivist view was limited and did not take into account personal experiences or varying contextual situations in which experiences occurred (McLeod, 2007). Constructivists state that knowledge is merely what one person has assimilated based on his or her personal interactions with and experiences in the world. Further, because individuals create contextual meaning through their interactions with each other and their environments, no two people can have identical experiences.

Asserting a relativist ontology, constructivists contend that, in addition to the immediate distinctiveness of an experience, a person's memory of an experience changes over time due to interactions with the world and the comprehension of additional contextual concepts (Polkinghorne, 2007; Riessman, 2008). Therefore, constructivist researchers acknowledge the subjectivity and contextual variability of any gathered data. Additionally, such researchers recognize that data co-construction occurs as the researcher-participant relationship unfolds, providing yet another influence on the participant's experience and memory. Another point of subjectivity within this philosophical view is the interpretative nature of analytic methods.

Studies designed with constructivist underpinnings often use purposive sampling and inductive data analysis to reveal the most natural and diverse findings within a given population's experience with a particular phenomenon, and illustrate patterns within that phenomenon (Appleton & King, 1997; Riessman, 2008).

Constructivism is especially relevant to nurses' experiences as well as the health-related experiences of all persons since both types of experiences include interactional dynamics between two or more people (Hall, 2011; Riessman, 2008). This study is grounded in the belief that each NICU nurse's past and present personal beliefs, experiences, and social/professional interactions contribute to the feelings she experiences while providing EOLC to dying infants and their families. No two NICU nurses' perspectives of such care experiences are identical; however, as a population, many encounter similar EOLC scenarios.

Research Design

Using narratives as a data collection method is supported by a constructivist researcher's perspective and commonly used in qualitative research (Creswell, 2013). As much as possible, researchers using qualitative methodologies aligned with a constructivist philosophy base their research findings on participants' experiences of a particular phenomenon (Creswell, 2013; Meleis, 2012). Personal narratives—individuals' experiences as communicated through their stories—arise from all aspects of life as individuals attempt to make meaning of their lives (Riessman, 2008). Riessman (1993) emphasized that, even when asked straightforward questions, most participants will answer in the form of a story when "… there has been a breach between the ideal and real, self and society" (p. 3). Riessman (2008) wrote of the individual's need to "… narratively reconstruct discontinuities in an imagined biography" (p. 55) in order to relate past events to current circumstances. Narratives can be presented in oral, written, recorded, and visual (photographic, drawn images, and photographic) forms.

Narratives are particularly common and useful in healthcare, as professionals commonly use them to add to the already established knowledge base (Hall, 2011). When referring to using narrative methodology to explore illness, Riessman (2008) noted that stories serve as a means of cognitive restructuring, frequently undertaken in order to make meaning or sense of a situation. Ringham (2012) discussed the use of narratives in the NICU environment as a method to help nurses understand their experiences, access "… embodied knowing … and … come to terms with traumatic events" (p. 16). Indeed, narratives often serve as a form of experiential learning for novice and experienced nurses alike. Individual narratives even can contribute to action taken within social groups (Polkinghorne, 2010; Riessman, 2008).

Rashotte (2005) referred to pediatric critical care nurses' narratives about grief over patient deaths as "stories that haunt them." This study strongly resonated with the researcher's own nursing experiences. Virtually all nurses have "war stories" that have remained vivid and made lasting impressions on them as human beings and as professionals. Rashotte makes the case that these frequently remembered and told stories allow nurses to gain higher levels of understanding while resolving grief. Another notable idea is that these death stories serve as benchmarks against which all other death experiences are compared.

Ringham (2012) explored using narratives in the NICU to cultivating nurses' *embodied knowing*, which is a compilation of Carper's (1978) empirical, ethical, aesthetic, socio-political, and personal knowing. Ringham (2012) used the concept of embodied knowing and narratives to explore a NICU nurse's moral distress while resuscitating an infant born pre-viability. Because narrative aligns with the philosophical perspective of constructivism, and because virtually all nurses have meaningful stories to tell, the use of narratives is an appropriate way to answer this study's research question: what are the affective responses of NICU nurses caring for dying infants and their families? Additionally, and to a lesser degree, this study design seeks to explore how NICU nurses cope with these affective responses, interpret these responses and situations that give rise to them, and the outcomes for NICU nurses from the ongoing accumulation of EOLC experiences, affective responses, and their interpretation.

Sample

This study's design included a plan to use purposive sampling to align with its constructivist perspective and analysis methodology. Purposive sampling allows the researcher to put together a richly diverse sample, or a maximum variation type of sample, in order to examine differences according to participant characteristics (Creswell, 2013). Such sampling also gives credence to the constructivist tenets of the emerging and inductive nature of data collection and analysis, and facilitates researcher immersion in rich and varied data related to the studied phenomenon in order to best interpret meaning (Appleton & King, 1997; Riessman, 2008).

The sample was recruited through the NANN's membership database, which lists more than 7,500 nurses from across the United States. The inclusion criteria required that each participants have access to a computer and Internet connection and be a NICU registered nurse, a current NANN member, and able to read and write in English. Nurses who did not have English as their first language were not excluded from the study. Neonatal nurses who lacked computer access or were not NANN members were excluded from the study. Length of experience as a NICU nurses was not an exclusion criterion because the relationship between affective responses and years of experience was of interest in this study.

Because NANN’s membership is so large, the number of completed surveys expected was greater than the actual response received. Thus, the target sample size of 50 participants was not reached. As a result, the researcher was unable to implement a purposive sample that was diverse in age, gender, NICU experience, spirituality/religion, and race.

Ethical Considerations

Approval to conduct this study was obtained from the IRB at the University of Tennessee, Knoxville. A support letter was obtained from the NANN Board of Directors’ liaison to the Research Committee after the submission of a summary of the study design and other required documentation. All potential participants were informed of the study purpose and its risks via the participant information and informed consent (Appendix E). Participation was voluntary, with no consequences to nurses who declined participation or withdrew from the study during data collection, and subjects were informed as such both in the recruitment link and on the consent form. All questions contained a non-response option to facilitate participant autonomy. The back button was available to participants throughout the survey, which allowed them to re-access and edit their responses, if desired.

Participant Risks

Participant risks were minimal; however, safeguards were built into this design to protect against potential risks. This study did not use experimental treatments or require any participant expense.

Emotional distress. One risk was that participation might bring back memories of stressful emotional experiences. The survey’s back button gave participants constant access to counseling support resources. These resources—including contact information for a board certified psychiatric nurse practitioner—were listed on the consent form and again at the end of the survey.

Participants who reported being troubled by upsetting memories would have been directed to contact the primary investigator via a private mobile phone number. Those without free long-distance telephone service could contact the primary investigator via e-mail. Participants who experienced increasing or prolonged distress related to study participation would have been encouraged to contact the health care provider of their choice. Participants reporting extreme emotional distress, who not wish to contact the provided resources, would have been instructed to terminate their participation immediately and seek counseling locally. None of the participants contacted the primary investigator or the psychiatric nurse practitioner during data collection.

Loss of privacy. While the researcher used many strategies maintain the privacy of all participant responses, anonymity of participants in an online survey cannot be guaranteed. While the researcher did not collect participant IP addresses, the online survey site did. Online survey data collection poses many risks to participant informed consent, anonymity, and privacy (Flicker, Haans, & Skinner, 2004; Heilferty, 2011; Holmes, 2009; University of Tennessee Office of Research Compliance, 2013). Specific study design elements were implemented to mitigate these risks so that they remained similar to those of face-to-face data collection.

Survey Questions

Since the range of affective responses of nurses in providing EOLC in NICUs has not been adequately explored, as noted in the literature review, the following questions were piloted with a small, representative sample and yielded responses of moderate length:

- Narrative Question: Please share a story that stands out in your mind that describes a time in the past in which you provided EOLC that evoked strong feelings in you. Please include as many details of the situation as possible. There is no character limit on your response. Please consider addressing or including in your response some or all of the following:
    - Situation specifics and how they made you feel
    - Any personal beliefs that may have guided the care you provided in the described situation
    - A description of your response (physical, emotional, etc.) after the described situation occurred
    - Specific coping mechanisms used
    - Changes in feelings or practice as a result of this experience
- Please complete the demographic data sheet included here (Appendix A).

After evaluating the initial survey responses, the narrative question was revised slightly, and after IRB approval for the change was received, it was edited to appear as:

> The purpose of this study is to understand NICU nurses' experiences as they care for dying neonates and their families. The way that this information is best uncovered is through the stories, the accounts that practicing nurses give about providing this care, and how it affects the nurse personally and emotionally. Collecting such narratives is the main goal of this research. Share your story as follows:
>
> *Think of an instance that evoked strong feelings when you were in the situation of providing neonatal end-of-life care. It may be recent or some time ago. What happened? What stood out for you in the experience? Please include as many details as possible*

concerning time frames, interactions with others, decisions you made, your responses to this episode (immediate or later), and how you managed feelings that emerged in the process.

Data Collection

The study's data consisted of written narratives and demographic information collected via an online survey. A link to the survey was posted on the National Association for Neonatal Nurses' (NANN) membership page for 30 days. Participants who chose to access the survey were taken to a page soliciting participant information and informed consent. Participants then had the choice of leaving the survey link, consenting to participate in the current study only, or consenting to participate in the current study and have their responses available for further research in this area. After indicating consent, a *continue* button directed participants to the narrative portion of the study, then to the demographics data section.

Data were collected via Qualtrics Research Suite (Qualtrics, 2012), a secure, web-based survey program. Participants had the ability to save their responses and return later to complete the survey. After 24 hours, the survey was closed. To maximize the receipt of timely and complete participant responses, the survey had no timeout during the 24-hour period and the size of the narrative was virtually unlimited (100,000 characters maximum). The written narratives were collected through Qualtrics and downloaded into Microsoft Word documents.

The demographic data were downloaded into an Excel spreadsheet. An online tool (randomizer.org, published by the Social Psychology Network) generated and assigned random identification numbers that maintained the association between a participant's narrative and demographic data during data analysis. Qualtrics was then used for demographic data management and analysis. Its functionality includes basic descriptive statistics as well as comparative statistics used to detect relationships between responses. Several demographic characteristics were analyzed for statistically significant associations.

The data collected may be re-analyzed in the next three years for other purposes, such as theory construction. Approval from NANN's Research Committee and the IRB of any university or facility related to it will be sought for any additional studies using this data. After three years, all data associated with this study will be destroyed.

Maintaining Confidentiality

Listed below are the strategies used to keep study data confidential.

- The informed consent form included a statement reminding participants to omit the names of their hospitals and cities.
- Participant responses were collected on a secure survey site with password-controlled access.
- Participant names were never collected.
- Word documents containing the written narratives were stored on the researcher's personal, password-protected computer.
- Narrative hard copies were printed offline and stored in a locked file cabinet in the researcher's Lucerne, Switzerland office where they will be kept for three years.
- Additional data copies were stored securely in a password-protected computer and a locked cabinet in the UT College of Nursing office of Dr. Mary Gunther.
- Any identifying information discovered during narrative data analysis was removed.
- No identifying data were included in the findings or narrative excerpts.

Qualtrics contains a collaborative function that allowed the researcher to grant access to the surveys and demographic data to the University of Tennessee's IRB committee members, and the dissertation committee, led by Dr. Mary Gunther. Everyone given access to the data had previously signed confidentiality agreements.

Data Analysis

The narratives were evaluated using thematic analysis. In contrast to other forms of narrative analysis that examine structural and temporal dimensions, thematic analysis is concerned only with content. The ultimate goal of such analysis is to provide an increased understanding of a particular phenomenon by performing an inductive, subjective interpretation of narrative text to uncover common concepts and themes within and between participant stories (Riessman, 2008). Examining the NICU nurses' narratives about EOLC care delivery to discover and interpret their specific affective responses—through definitions, descriptions, comparisons and contrasts—allowed the richer meaning of those feelings to emerge.

For this study, narrative was defined as the written account of an EOLC episode that was significant to an individual NICU nurse, as well as the nurse's evaluative statements about and responses to the episode as described in the context of the story. In contrast to other methodologies that examine interviews line by line, the goal of narrative analysis is to keep the story intact and examine it as a whole (Riessman, 2008). Consequently, the unit of analysis was the written narrative in its entirety.

The study's analysis followed Riessman's (2008) methodology of thematic narrative analysis. Hall's (2011) description of a narrative study of trauma recovery served as an exemplar of Riessman's method and provided the steps for analysis. Riessman's method—with its goal of facilitating the emergence of concepts as well as definitions, patterns, and relationships among the concepts—is well-suited to explore the thematic properties of narratives related to healthcare (Hall, 2011, Riessman, 2008).

The analysis process specifically developed for this study, aligned with Riessman's method, was as follows:

Data Analysis (For each, individual narrative):

1. Remove any identifiers and assign a random number linking demographics with narrative: http://www.randomizer.org/form.htm
2. Read narrative as a whole to gain essence of the story being told
3. Identification of the underlying affective concept or assumption present in narrative
4. Begin forming tentative definitions of these concepts in the NICU context
5. Isolate any metaphors or individual narratives that illustrate best a given affective response and explore their function in the narrative text
6. Complete the summary narrative assessment

Data Analysis (for narratives as a group of data):

1. Implement purposive sampling to best illustrate the meaning, range, and degree of affective responses of NICU nurses.
2. Continually add to list of affective concepts or assumptions present in narratives to date
3. Begin observation for most prevalent affective responses that have emerged from the narratives
4. Continually revise definitions of the affective concepts, within the NICU context, as additional data emerges from the narratives

5. Begin observing for correlations, via summary narrative assessments, between years of experience, affective responses, EOLC education, etc.
6. Maintain audit trail
7. Weekly or bi-weekly phone calls with committee members to debrief and confer about findings to date (to improve researcher coping/decrease compassion fatigue and increase validity of findings by ensuring presuppositions have been set aside and continue to be set aside during data analysis)
8. Confer with committee members about point at which data saturation has been reached.
9. Send preliminary findings to group of expert NICU nurses to increase validity.
10. Descriptive statistical analysis will be performed on the demographic data

The first step of analysis was to read each narrative as a whole to determine the essence of the story. The process of data reduction began during the reading the first transcript with the tentative identification of affective concepts/assumptions and provisional definitions of these concepts. These concepts and definitions then were revised and refined during the ongoing data analysis. Hall (2011) created a template to facilitate data reduction, compare data and concepts across the narratives, and maintain focus on the research question(s). This process is akin to Riessman’s reference to outlining the narrative to include salient concepts and the story’s turning points. The researcher created a similar process specific to the affective responses of NICU nurses that included a summary narrative assessment template (Appendix G). J. Hall (personal communication, November 12, 2012) noted that, while such a template can be tentatively constructed to reflect general concepts before analysis begins, the template likely would evolve after analysis is underway.

Data saturation was achieved when written narrative data revealed similarities among participants' affective responses and no new affective responses were present. After this occurred, a comprehensive list of affective concepts and definitions was compiled, the concepts were examined in context and in different combinations to identify and compare/contrast patterns, similarities, and differences. Riessman (2008) refers frequently to the constant movement that takes place during this part of the interpretative analysis between specific concepts and the broader contexts within which they occur. When participants used metaphors, they were examined to determine their influence and significance within the narrative. Narratives or narrative excerpts that illustrated certain concepts and patterns were chosen as exemplars and included in the study's findings. The entire process was documented to create an audit trail to ensure the researcher performed a logical and rigorous analysis and achieved internal design consistency (Creswell, 2013). This validation method was created and maintained in a Word document and updated as needed. It served as a diary of sorts and was provided to members of the committee as documentation of the analysis process.

Descriptive Statistical Analysis

Descriptive statistical analysis was used to examine the demographic data. Frequencies and mean averages were calculated for the sample characteristics. To preserve maximum data for analysis, any omissions from the demographic instrument were noted in the findings instead of eliminating the entire case.

In addition to questions about age, gender, and nursing experience (both general and NICU), participants were asked the following questions to explicate further the findings from previous research, as described in Chapter Two:

- What is your highest level of education? (diploma, associate’s degree, baccalaureate degree, master’s degree, doctor of nursing practice, or doctor of philosophy)
- Did you receive education in end-of-life care during your nursing program?
- If yes, do you feel it adequately prepared you to deliver end-of-life care to dying infants and their families?
- Have you completed any additional end-of-life education since your undergraduate or graduate program?
- If yes, what additional education did you receive?
- What level (I, II, III, or IV) NICU do you primarily work in?

Rigor and Validity

Qualitative researchers generally measure study rigor differently than quantitative researchers. Polkinghorne (2007) and Riessman (2008) first addressed validity, or trustworthiness, in narrative analysis. Trustworthiness is the traditional standard by which qualitative studies are evaluated to determine their validity and authenticity (Creswell, 2013). A study’s findings are trustworthy when “…researchers employ accepted strategies to document the ‘accuracy’ of their studies” (Creswell, 2013, p. 250). Riessman (2008) noted that every narrative analysis should address two dimensions: the validity of the story (narrative coherence) and the validity of the researcher’s analysis or interpretation of the story (interpretive validity). Descriptions of these validity dimensions are described below along with the application of the analysis results.

Narrative coherence. Coherence is a term often associated with the trustworthiness of participants’ stories. Evaluation of narratives for coherence includes assessing consistency within the narrative. Agar and Hobbs (1982) posited that each narrative should contain three dimensions of coherence: global, local, and themal (thematic). In other words, does the narrative ring true when contextually compared with the larger scope of the phenomenon (global), with the phenomenon in the examined setting (local), and on its own (thematic)? Narrative interpretation is more trustworthy if the narrative itself has been evaluated and deemed coherent. However, Riessman (2008) notes that trauma victims' narratives may be very disconnected, bringing the story's coherence into question. Thus, in the case of trauma, the coherence criterion may not be as useful.

The researcher evaluated narrative coherence in the first reading of each narrative. Narratives displaying a high degree of plausibility were included in the sample. Plausibility was evaluated by this researcher, who holds a long history of NICU bedside practice. Narrative findings also were shared with a group of expert NICU nurses to obtain their feedback about whether the findings were consistent with their personal experiences. As analysis progressed, narratives were assessed for global, local, and thematic consistency.

Interpretive validity. The researcher extended interpretive validity through persuasive argument construction, a meticulously documented audit trail, and expert consultation. Riessman (2008) and Polkinghorne (2007) asserted that researchers must construct a persuasive argument in order to use their findings as general knowledge within a phenomenon. Polkinghorne (2007) described Perelman's steps for constructing such an argument. While not promoting a predetermined argument structure, Perelman asserts that the researcher must lead the reader through the data and findings, present alternative interpretations, and defend why the other interpretations are not correct. Riessman (2008) noted that constructing an audit trail aids in this endeavor.

Coherence of the findings, described by Creswell (2011) using the term *peer review*, was used as a validation method, as described in Chapter Four. This process involved asking the dissertation committee and selected highly experienced NICU nurses (non-participants with more than 20 years' experience in level III NICUs in the northern United States) to read a summary of the findings, including selected participant quotations, and comment on whether they felt the findings reflected the true affective range of responses NICU nurses experience during EOLC. Feedback from the peer review was considered and integrated into the analysis. Expert consultation also included frequent checkpoints during the analysis stage in which a committee member used the audit trail to either confirm the findings to that point or question the analysis. Additionally, the constant comparative method as described by Riessman's back and forth method, helped the researcher focus on examining each narrative as a whole and examining the group of narratives for patterns, similarities, and differences. To limit researcher bias, the researcher submitted a written reflexivity narrative to the dissertation committee before the data collection period began. The researcher also received feedback and guidance to help mentally "set aside" her own narrative and objectively interpret participants' narratives.

Application of results. The ultimate determinate of a study's validity is other scholars using the findings in their own work. Although some researchers debate the relevance, usefulness, and generalizability of qualitative, interpretive study findings, Flyvbjerg (2006) gave five reasons such findings can contribute to a body of knowledge:

- context-dependent case examinations are vital to an individual's discipline development;
- critically chosen cases have served as the foundation for knowledge advancement;
- examining extreme, outlying cases is vital to a rich understanding of a phenomenon;

- cases contribute depth to the knowledge about a phenomenon and can refute previously held beliefs about it, and;
- case examinations reveal multiple and diverse factors from which new knowledge can be gained.

Of course, this type of validity cannot be determined until after study findings have been published. However, the methods outlined above used to ensure interpretive coherence contribute to the future usability of this study's findings.

Limitations

There are inherent limitations in the use and analysis of narratives to represent, in a rigorous manner, human experience (Polkinghorne, 2007; Riessman, 2008). Personal narratives often are limited by the storyteller's concern for presenting their experience in a socially acceptable manner and their ability to accurately remember the experience and communicate its complexity and depth. Obtaining data through electronic written narratives eliminated the ability to gain additional meaning through body language and other linguistic properties, both of which are important tools in face-to-face narrative collection. Additionally, there was no opportunity to ask participants follow-up, clarifying questions, which might have increased the data's richness and depth. Sample diversity limitations are explained in Chapter Four.

Lastly, researcher bias also was a limitation. Given the researcher's nursing background in level III NICUs and her EOLC experiences with dying infants and their families, there was a risk that her personal feelings about this phenomenon could permeate the data analysis. Therefore, the personal written reflexivity narrative, described in the prior section, was conducted to decrease bias during data collection and analysis. Acknowledging that researcher beliefs are ever-present during the study process allows the researcher to adopt additional measures to ensure validity of the findings. The process of continuous reflexivity also was conducted during data analysis. Pyett (2003) recommends constantly reflecting on how personal knowledge and beliefs about the phenomenon of interest might be shaping the analysis. Another strategy, sharing the personal narrative with the committee and allowing them to challenge potential biases during data analysis, helped increase the rigor of the findings.

There also was the risk that researcher compassion fatigue could affect the study's rigor. According to Coetzee and Klopper (2010), compassion fatigue is the end of a process that begins with compassion discomfort and stress and is "… caused by prolonged, continuous, and intense contact with patients, the use of self, and exposure to stress" (p. 239). The debate over addressing researcher emotions is ongoing. While quantitative researchers assert there is no place for emotions in research, some qualitative constructivist researchers believe researcher emotion is necessary for the meaning-making process. For this study, it was imperative that the researcher possess the ability to recognize truthful emotional responses or the plausibility of the narratives, within the NICU context. There are ways, however, to moderate the potential emotional stressors that a researcher might experience during the study process. According to Rager (2005), simply recognizing the emotional work that qualitative research requires is a huge first step towards protecting the researcher and study rigor. Additionally, Rager recommended journaling, peer debriefing, and seeking support from social networks. Debriefing, through phone calls and emails with committee members, was used to moderate compassion stress. This allowed the researcher to discuss her feelings and moderate stress. Because working with the narratives for more than two hours at a session was stressful and fatigue-inducing, the researcher chose to work in shorter intervals.

The next chapter details the NICU-specific affective responses that emerged from the collected narratives, the contextual definitions, and the relationships observed between them. The demographic data from the participant group also is discussed, analyzed for descriptive and comparative statistics as well as, observed associations with the affective responses.

Chapter Four: Findings

In this chapter, participant characteristics are reviewed by first analyzing the demographic data using descriptive statistics. Then the data regarding participant education, EOLC education, nursing experience, and employment unit are presented. Comparative statistics used to examine relationships among the demographic data and education, nursing experience, and unit characteristics are reported. Next, the affective responses are identified, defined, and explained within the NICU context, and supported by selected participant quotations. Finally, associations discovered among the affective responses are presented and discussed.

Participant Demographic Characteristics

Thirty-six NICU nurses consented to participate and submitted written narratives and responses to the other survey items. One participant submitted her gender, age, ethnicity, and the narrative, but chose not to answer the questions about education or her unit. She may have chosen to leave some questions blank to maintain her anonymity. This participant's narrative expressed particularly strong emotions therefore her responses were included in these findings. However, since she chose not to answer any education or unit questions, a sample size of 35 was used to calculate the education and unit questions.

The participants came from 20 different states representing all regions of the country. The states with most respondents were Pennsylvania (n=5 or 14%), Michigan (n=5 or 14%), California (n=3 or 8%), Georgia (n=3 or 8%) and Texas (n=3 or 8%). The mean age of the study participants was 49.7 years, with an age range of 28–64 years. The mean years of nursing experience was 26.9 and the mean years of NICU nursing experience was 23.3 years. All participants (n=36) were white females.

The majority of respondents (n=15 or 43%) reported a master’s degree in nursing (MSN) as their highest education. Eleven respondents (31%) held a bachelor’s degree (BSN). Five participants (14%) were licensed neonatal nurse practitioners (NNP) in addition to their MSNs. Two (6%) participants completed doctorates in nursing. One (3%) respondent reported having a diploma degree and one (3%) reported having an associate’s degree in nursing (ADN).

Of the 36 participants, 20 (56%) received EOLC education in their nursing program. Of these twenty, (22%) found the education helpful in the clinical area when caring for dying infants and their families, while 77% found it not helpful. There is a significant relationship (p = 0.04) between the percentage of the sample that received EOLC education (56%) and the percentage of those participants who perceived that education as not helpful (77%).

Twenty-two participants (63% of the sample) had received EOLC education outside of their nursing program curricula, with unit- and hospital-based continuing education the most frequently reported. The Resolve to Share program and the ELNEC also were listed as additional sources of EOLC education. There was a statistically significant relationship between NICU nurses holding an advanced practice degree and completing additional EOLC education outside of their formal nursing programs (p=0.03).

Ninety-four percent (n=33) of the sample worked in level III or level IV NICUs, with only two participants working in level II NICUs. None of the participants worked in level I NICUs or newborn nurseries. Sixty-three percent (n=22) of respondents indicated that their units had EOLC policies. There was no statistically significant relationship between the nurses’ level of education and whether they had received EOLC education in their nursing programs.

Affective Responses

Many distinct emotions were found in the NICU nurse participants' stories. The researcher initially discerned the nurses' affective responses by working with each narrative individually. When the narratives were examined as a whole, these emotions naturally sorted into broader feelings (Figures 1 and 2). Definitions of these emotions, included below, evolved from the same process. In many cases, one narrative contained multiple affective responses. During analysis, prominent and less prominent emotions were noted on the Summary Narrative Assessment Template (Appendix G), revealing some interesting patterns. For instance, participants reported feelings of responsibility more than any other emotion. However, in stories describing conflicting feelings and multiple emotions, the most prominent emotions described were anger, guilt, powerlessness, and hopelessness. These patterns are discussed in more detail under each affective response. When the narratives were considered as a group, several associations, worthy of further consideration, were found between emotions and demographic data.

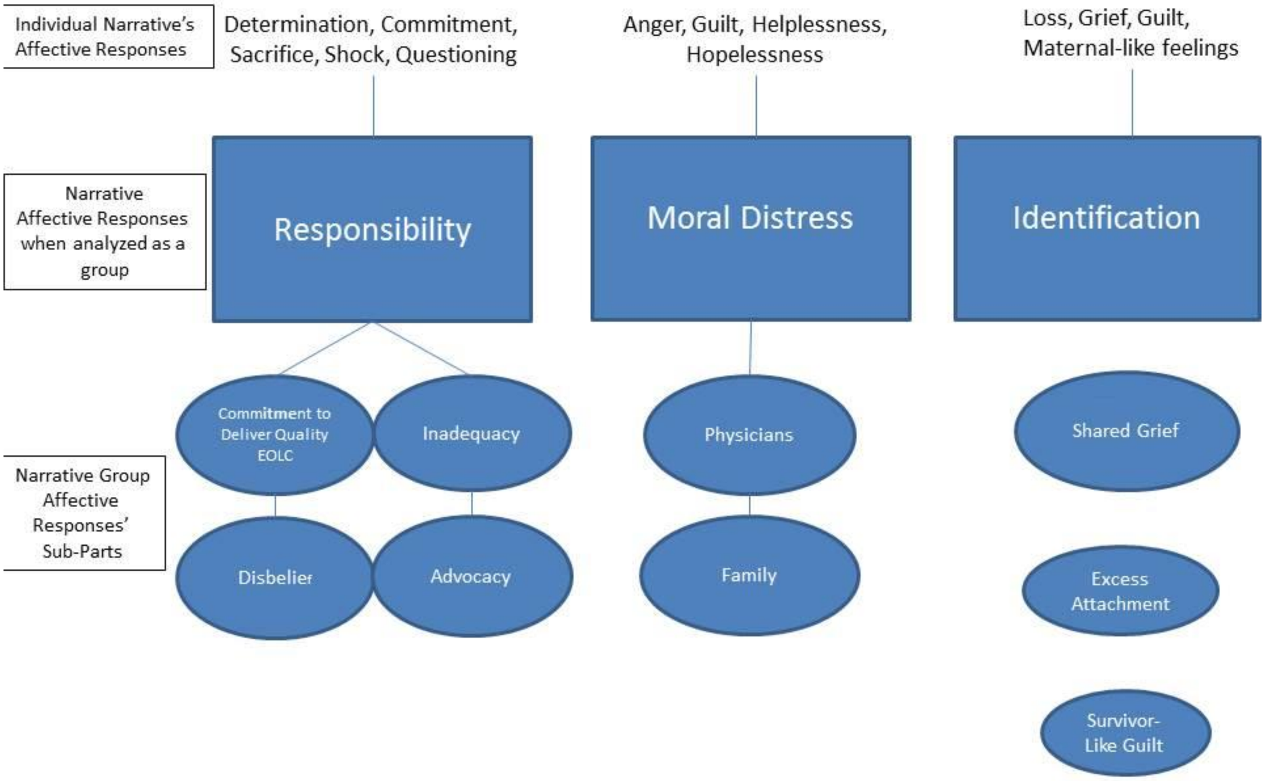

Figure 1. Predominant Affective Responses and Sub-Categories

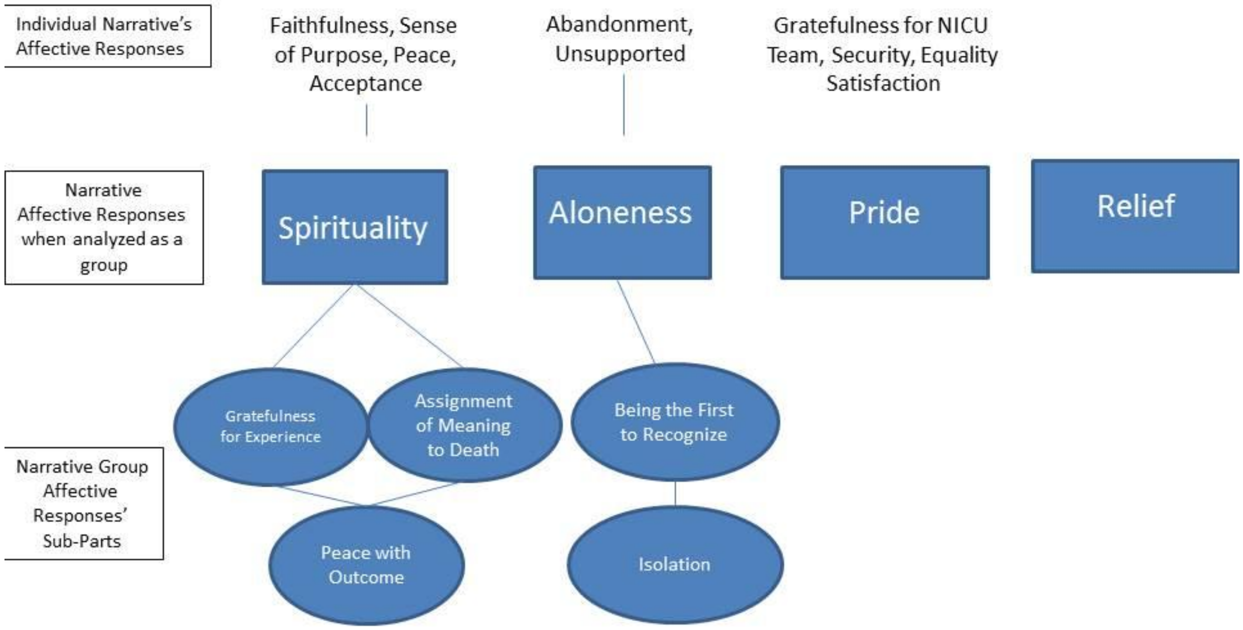

Figure 2. Less Dominant Affective Responses and Sub-Categories

Responsibility

The most frequently reported affective response was a general feeling of responsibility. In the NICU context, participants described experiencing an overwhelming sense of responsibility for the needs of the dying infant, the family, and the EOLC process. This feeling most often was expressed in one of the following four ways:

- a strong *commitment* to provide the best EOL experience possible for the infant and the family,
- frequent feelings of *inadequacy* related to the NICU nurses' inability to provide successful curative care,
- *disbelief* that a previously stable infant was dying, and
- the need to *advocate* for the infant's and family's needs.

Almost all of the NICU nurse participants reported having feelings of responsibility, along with the other emotions that tended to accompany these feelings. These four responses are described below.

Commitment

Many participants expressed a strong commitment to delivering the best EOL experience possible to dying infants and their families. This commitment was broad and included providing EOLC interventions, from the seemingly minor to the extraordinarily extensive.

P96: *"Through the night, I put together a memory box for the family."*

P18: *"…I have never liked the idea of translating via the telephone because there is no way to know if anything is being 'lost in translation' [describing having to use a translator to tell parents their infant is dying].Mom had come unprepared [to remove her infant from life support]* *so we needed to ask [for the] OB's assistance with providing her with emergency scripts."*

Several participants described performing extraordinary actions. These descriptions contributed to the researcher's identification of responsibility as a primary affective response in the NICU.

P18: *"We bagged the baby for several hours (to allow time for the parents to get to the hospital, the conversation about her condition and poor prognosis to be translated, the chaplain's baptism 'ceremony', and her mother to hold her for the first time)."*

P1: *"One of our staff held the infant at all times until she passed away which was over 24 hours."*

Participants also reported a compelling desire to plan and implement individualized EOLC whenever possible. Sometimes, this was achieved through offering parents opportunities to create memories that they might not otherwise have thought to request.

P96: *"Our plan for end of life care included a private room for the family next to our NICU, where our MD decided we would bring the baby, still on life support, which of course included ventilation but also dopamine/epi drips, we would place the infant in the Mom's arms, remove all support, and leave the family alone with their dying infant. It was all very quiet. I remember communicating with the RT [Respiratory Therapist]and MD non-verbally."*

P8: *"I knew she would die and I wanted to parents to hold her while she was alive. I had to get permission to move her off the warmer and into mom's arms … creating memories is critical for these families … giving parents choices— do you want to bathe your baby, dress the baby in a special outfit, hold and have other family members involved? … working with families experiencing a neonatal death is empowering the family to make this experience 'their' experience."*

Nurses described feeling a great deal of responsibility when facilitating parental decision-making about the withdrawal of life support. These nurses also felt responsible for delivering excellent EOLC even before the parents realized that the infant would not survive. A discussion of the feeling of aloneness a NICU nurse has when she realizes that an infant will not survive before the physicians and parents do is included later in this chapter.

P95: *"I helped the family to see how neurologically devastating this meningitis was for him … I could help the family in the process to make something awful in their lives a little more tolerable by creating positive memories and by sharing in their grief."*

P20: *"… the parents were undecided on their wishes for continuing care of the infant. After 21 days I assumed care of the infant and learned that the parents had not yet held their infant … I placed the infant in kangaroo care with the mother."*

Thus, through these narratives, it seems extremely important to NICU nurses to be able to make a horrible experience for parents just a little better through their interventions and EOLC experience.

Inadequacy

The nurses described feeling professionally inadequate and frustrated at their inability to "cure" some infants. Feelings of professional questioning, guilt, and powerlessness—most common during acute EOLC situations—were grouped together under professional inadequacy. When an infant does not survive, a NICU nurse experiences feelings of failure, which stem from their overall sense of professional responsibility. Some of these feelings also are present in moral distress, discussed in detail in the next section, but stem from different roots. It is interesting to note that NICU nurses experience the urge to cure all infants. NICU nurses often review an infant's course of care and wonder if their clinical judgment and treatment was sound.

P27: *"… that baby looking up at me … like he was asking for help and I felt like I let him down."*

P64: *"By the end of this event ... I [doubted the] care I provided as a RN and as a patient advocate."*

P13: *"It just seemed that no matter what we did, he just didn't improve."*

Most feelings of inadequacy were associated with the NICU nurses' frustration at not being able to cure the infant during a decline in health. However, one participant questioned the decision to remove an infant from life support and described feelings of professional inadequacy related to that decision's outcome:

P4: "Everything was according to the mother's plan and request. And yet, she just completely lost her mind when her baby died … crying, literally screaming … rocking the chair so violently that I seriously [thought] that she would flip it over. The worst is that an hour after the mother went home she called back to the unit asking how her son was doing. I questioned if we had done the right thing taking him off."

Disbelief

Based on narrative analysis, the affective response of disbelief stems from instances where a previously stable infant progressing towards discharge suddenly experiences a life-threatening event that culminates with the NICU nurse's realization that the infant will die. Such instances generally involve a full- or near-term infant. While such disbelief seems akin to shock, it is usually more closely related to the nurses' realization that their skills and interventions have failed an infant that would usually benefit greatly from them. This disbelief is professional in origin and is another component of responsibility.

P69: *"I was very shocked that this occurred so quickly with limited symptoms, etc."*

P27: *"… how baffled we all were on why this happened." "… there are no guarantees even when we are taking care of that easy 'feeder and grower.'"*

P74: *"He was going to get better after all and go home [in reference to a 10 day old, 35-week gestation infant, who became septic]… we just couldn't fathom that anything like that was happening. Really happening, and so fast."*

Advocacy

Often, NICU nurses are called upon to act as objective representatives of the infant and family and as a liaison between family and physicians.

P94: *"I am an NP, and I questioned what he* [the neonatologist] *was thinking, reminding him of the birthday plan/death plan … no intervention, and look what we were doing* [providing curative care]*."*

P90: *"…not to be afraid to speak up. To read between the lines. That our parents want input from the nurses that care for ther [sic] babies. Good or bad."*

The concept of advocacy reflects the NICU nurse's overall feeling of responsibility. NICU nurses' feelings of advocacy are strong and can contribute to moral distress when nurses feel unable to speak for infants and families in their care.

Moral Distress: Anger, Guilt, Powerlessness, Helplessness

A comprehensive body of published literature indicates that moral distress, which is a compilation of feelings of anger, guilt, powerlessness, and helplessness, is often present during EOLC and can be experienced as a result of futile care (Catlin et al., 2008; Corley, 2002; Epstein, 2008; Hefferman & Heilig, 1999; Jameton, 1993; Lawrence, 2011; Mobley, Rady, Verheijde, Patel, & Larson, 2007; Rogers et al., 2008; Russell, 2012; Yam et al., 2001). The study narratives supported this idea, as these feelings were present in the majority of the narratives. In the narratives that contained moral distress, it was the predominant, pervasive feeling in the story. In other words, when a participant described feelings of moral distress, these emotions seemed to overpower other emotional responses.

The data showed that, most often, NICU nurses feel anger, guilt, powerlessness, and helplessness in response to decisions and actions made by physicians and family members. It is worth noting again that participants chose the story they wanted to share. Many of the chosen stories contained negative feelings and responses to instances of futile care. Often a nurse is compelled to provide ineffectual curative care that is causing her infant patient to suffer unnecessarily. Such situations create a great deal of inner moral distress.

Physicians: Neonatologists

Participants described conflict with neonatologists' decisions and care orders. NICU nurses often viewed orders, written with the hope of providing curative care, as futile care that caused patient suffering. Other narratives described similar feelings related to inaction by neonatologists that often prolonged futile care. For various and largely unknown reasons, participants did not tell of any actions they took to change the situation or specify why they were unable to effect change. In addition, most of the narratives did not specify whether the story described had happened the day before or decades before, preventing analysis of the feelings with regard to the number of years' NICU nursing experience.

P87: *"It began to feel like we were torturing this fragile little human; their [the neonatologists] focus was on the tasks at hand and the continued focus on 'cure at all costs.'"*

P77: *"... no one was willing to sit the parents down and be honest with them ... they danced around the issue [that the infant would not survive]."*

P89: *"Our nursing care clearly caused the infant pain. The situation caused feelings of helplessness and hopelessness and anger."*

P60: *"Due to conflicting medical opinion in treatment strategies of attendings, this infant and family continued suffering throughout a weekend with eventual discontinuation [of life support]. I felt that we collaboratively let this family down … They trusted us to guide them to do what was right."*

P60: *"With continued advocacy for the infant, I felt it fell on deaf ears because of power struggle of the egos."*

P66: *"…politics prevent me as a staff nurse from changing the practice at the time."*

All but one of the moral distress narratives described futile care in some fashion. Powerlessness, anger, helplessness, and guilt were prevalent in these stories as nurses described situations in which they believed curative care was continued too long and as a result, caused great suffering for the infants. One distinctive narrative described withdrawal of what the nurse felt was necessary care.

P1: *"The SiPAP[Synchronous Inspiratory Positive Airway Pressure] and IV fluids were stopped [as methods of discontinuing life support] and the family left, leaving the message to call them when the baby had passed away … I had a very difficult time with this as I did not agree that the family had the right to stop the IV fluids. If they wanted to stop the respiratory support and go with some nasal cannula oxygen I would have been fine with that. This baby essentially died of dehydration and we, as hospital staff, assisted in killing her. This incident caused a lot of ethical debate in the unit and among the staff. When do the parents have the right to decide to withhold life support? What is my role when the decision is made? How do I justify what was to my mind an assisted killing of an innocent child? I personally was unable to care for this infant because I* *could not condone the actions of the Neonatologist for allowing it or the family for making this decision … This caused many sleepless nights as well as other issues."*

When this nurse said she could no longer care for this infant, she made a connection between moral distress and avoidance, another affective response found in the narratives. Avoidance, as a response to and coping mechanism for providing EOLC, is discussed later in this chapter.

Family

Nurses also described feeling conflicted about parents' decisions, especially when they felt powerless to change the course of events that often led to futile care. They also were greatly affected by the seemingly unfeeling decisions made by some infants' family members.

P33: *"Dad did not want to come in while we withdrew [life support], this created a lot of feelings among nurses in the unit."*

P77: *"The nursing staff were getting angry with the family because we felt the infant was suffering and in pain. Most wanted to find a bed in a private room for the parents to hold their baby and let her die."*

P74: *"It was difficult after he died because the Mom refused to see or hold him. I felt like she should have closure and I believe that parents should at least see their baby to accept that the baby died."*

Aloneness

Feelings of aloneness were found in descriptions of physical and emotional isolation in the NICU. Emotional aloneness seems to have the highest potential for producing moral distress and may even be a precursor to moral distress in these participants. When NICU nurses get to the junction between curative and futile care, they are typically the first to recognize the infant's suffering, which creates feelings of emotional isolation as physicians and parents, who are still optimistic for the infant's survival, continue to advocate for curative care orders.

Being the First to Recognize

Emotional aloneness often occurred when nurses described the phenomenon of being the first person in the care situation to recognize that the withdrawal of support should occur to avoid futile care. There seems to be a significant time period between the nurse "knowing" and the time it takes for the physician and parents to "know." It may be that, the shorter that period is, the less moral distress the NICU nurse experiences. Conversely, extended periods between these two realizations may result in a greater risk for moral distress for the nurse.

P27: *"Often it is nursing who comes to the place of letting go before physicians do and have to wait for others to while watching infants 'suffer' if their [sic] discomfort or pain."*

P32: *"As an NNP, one of the most difficult issues in caring for dying infants and families revolves around conflict between bedside nurses' thoughts/emotions and family thoughts/emotions when the staff have 'decided' that removal of support would be in the best interest of the infant but the family is not in agreement. Our personal experiences and knowledge can limit the ability to be supportive to family as they begin to realize the gravity of the situation. I find it often takes families several days longer to come to the understanding that their infant is very unlikely to survive in the long term."*

Isolation

Physical isolation and subsequent lack of caring by colleagues, as described in two narratives, had negative consequences for NICU nurses. The dynamics that allow physical and emotional isolation of NICU staff seems to be the opposite of those that precede the pride and teamwork described in the next section.

P87: *"I recall the more experienced members of the medical team not able to engage in any conversation with me as a new nurse with regards to my feelings of futility and concern."*

P17: *"One of the most challenging and unique end of life situations for me was when I was asked to hold someone's baby after they left until their funeral home personnel arrived … little did I know, it would take several hours for their funeral home to arrive, and I would be sitting in a private room by myself holding a deceased infant … I wish I had more support from my fellow staff instead of being alone most of that time. I don't think I will ever offer to do something like that again."*

Identification

NICU nurses expressed feelings of grief, loss, sadness, guilt, and strong emotional attachment in EOLC situations. This stands in contrast to narratives in which disagreement with some parents' decision let to avoidance, described above. When the narratives were examined as a group, responses indicated that some NICU nurses identified with the patients' parents. In addition to representing the affective response of identification, the excerpt below gives an example of a nurse sharing similar feelings with the grieving parents of her patient.

P87: *"… we were so focused on his survival. This was a first baby for this family and his young parents, only a little older than me, had so many hopes and dreams for their son. They would … share this with me … I found myself sharing in their hope as well."*

Shared Grief

NICU nurses sometimes experienced the same strong emotions as the parents of dying infants. Because infants often have extremely long stays in the NICU, nurses often develop maternal-like feelings during the long hours of care they provide. Overall, participants described this feeling in a positive light and as a way of demonstrating to parents how much they cared and that their infant had touched them.

P46: *"While the tube was removed, I remember crying as much as the family."*

P13: *"…every death takes a little part of me with them."*

P96: *"Of course, I came home and cried. And cried. And cried. The baby was a big, beefy beautiful boy, their first. I would describe how I felt as 'being dropped in to someone else's nightmare.'"*

While these are various examples of grief identification, the nurses' responses in the situation ranged from positive hope to nightmarish experiences.

Excess Attachment to the Infant

While the shared grief expressed by NICU nurses can contribute to a positive EOLC situation, some NICU nurses described feelings of excessive attachment to infants who died while in their care. One participant perceived herself as having crossed a professional boundary. It is interesting to note that the same stories of positive shared grief mentioned above can be seen here. However, the same emotions are experienced much more intensely, affect the nurses more deeply, and are reported in a more negative way.

P66: *"… I felt like the only one who cared, besides the parents."*

P88: *"I was grieving along with the parents and came in often, even when not on my shift, to be with them. I realize now that I had crossed some professional boundaries, but at the time felt compelled to be there for the parents and myself."*

P57: *"As a nurse in this situation, it was hard because this patient was older (about six months) and the family was very attached to the hospital staff … many of us as staff cried with the family. The next several days were difficult for me as well. Many times unexpectedly I would think about* *the baby, family, and fellow coworkers. Several daily tasks seemed somewhat harder. The grief process of the nurse is very different from that of the family; yet, it is very real."*

Feelings of identification among NICU nurses might be placed on a spectrum ranging from therapeutic shared grief to less therapeutic excess attachment to the infant. The next theme that emerged, survivor guilt, might be placed between the other two more extreme feelings.

Survivor Guilt

Feelings of guilt were described in many of the narratives. Most often, these feelings were related to the delivery of futile care, infant suffering, or the inability to help an infant survive. However, a different type of guilt related to the nurses' feelings about having healthy children or less tragedy in their own lives also emerged: survivor guilt. The NICU nurses identified with the parents' feelings of grief and loss and experienced survivor guilt because their own fetuses or children were healthy. These responses were mostly positive and sometimes contributed to the nurses' intentional gratefulness for the good in their lives.

P96: *"[I was] sad, but guilty too, cause you know my life is good."*

P44: *"I was very pregnant at the time and the memory of doing chest compressions on this big baby while carrying my own baby will never leave me ... I kept thinking about how lucking [sic] I was to have this healthy term baby growing inside of me. I ached for his parents."*

P83: *"So I held that baby as she died. Now what is most eventful here is that I myself was 24 weeks pregnant [same gestation as the dying infant]. I so vividly recall holding this baby as she died and feeling my own baby move within my womb. I remember how tiny and fragile she was and recalling how quickly life can change from happy, healthy baby to grief and loss."*

However, some participants described various influences that helped them in narratives that took a positive turn.

Spirituality

Feelings of spirituality were woven throughout some of the narratives. Spiritual feelings of acceptance, faith, peace, and a sense of purpose, emerged from the narratives as nurses described caring for a dying infant. In other stories, nurses used spirituality to support parents as they made decisions about continuing life support or after their infant's death.

P94: *"… we nurses prayed with them [the family]."*

P20: *"… the mother asked me what I would do if the infant were my child. I told her being a mother, I would pray about it and take time to discuss with the infant's father and other trusted family members before making a decision."*

Gratitude

Some of the narratives included feelings of gratitude. Most of the nurses recognized that providing EOLC is difficult, but also an honor. These excerpts expressed NICU nurses' positive responses to being able to provide this care and it serving a purpose in their lives.

P13: *"I think that helping a patient and their family at the end of their life is one of the most important things a nurse can do."*

P96: *"Something beautiful came to me when I returned to work 12 hours later. The baby (I have difficulty saying remains or dead baby, it sounds so cold), was just being picked up by the mortuary … but I really felt like my job there had been completed that morning. It wasn't. One of the post-partum nurses came in to the NICU and called me by name and said 'The baby's Mom is out there in the hallway all alone.' I went to see her, and we just wrapped our arms around each other and I said some words of comfort. She never said a word. She just cried. I cried … I don't regret having been a part of the process—in fact, I feel like I was meant to help people in* *just that way … to share my love and kindness, and I somehow feel fulfilled at being given this gift of providing care in some else's nightmare."*

P87: *"I feel humbled and blessed when I have opportunity to walk alongside these families."*

Assigning Meaning to Death

Some narratives revealed NICU nurses' spiritual feelings as they purposefully assigned meaning to an infant's short or difficult life. Such responses, that emerged from the stories, are both indications of participants' expressions of faith and a coping method.

P27: *"…what I came to believe, and still believe, over time is that some children are born to die, that they have no lessons to learn and therefore are not required to stay and life [sic] life here on earth. There [sic] 'life' and death is about us and what we learn and how we handle it and what we take away from it. That is their purpose and their gift to us. For me this is what works with my faith and my connectedness to the universe."*

P72: *"I made 'friends' with death. I see death as part of life and believe that life, no matter how short or long, has purpose. Death is as human as is birth. This believe [sic] allows me to give myself to the patient and the family and it protects me from the emotional pain."*

P27: *"That is their [infants who die in the NICU] purpose and their gift to us … I have his picture on my bulletin board in my home office, to remind me that there aren't answers to all the questions, some things just have to be accepted on faith."*

Pride

Feelings of pride most often were related to a NICU staff's ability to work together as a team to deliver compassionate, quality EOLC to a dying infant and his or her family. In one narrative, this pride is described through the notion that her team values the infants' quality of life above all else and every member of the team can voice his or her opinion when faced with a dying infant. Feelings of self-worth and of doing something important shine through these excerpts.

P87: *"I observed the caring and compassion with which the team cared for this family …"*

P96: *"I felt, at that moment, and through much of the next 24 hours, extremely grateful to be part of a team of such kind and gentle caregivers."*

P8: *"What stood out for me with this episode was how the team pulled together. I never felt abandoned by my fellow nurses, the NNP, or physician."*

P27: *"I am grateful that I have worked in units where the quality of life has been as important as the life itself and that nursing staff and respiratory therapists have had as much input as physicians when life and death are discussed—especially when talking about withdrawal of support."*

Thus, the work environment and the institutional commitment to quality care were influential in enhancing nurses' positive affective responses.

Relief

Participants occasionally reported feeling relief and peace when a terminally ill infant died. In the context of the NICU, this relief came from the cessation of suffering for an infant who had no hope for a good quality of life.

P2: *"After his death, I think I felt peace because I didn't think he would have had much quality of life had he survived."*

P13: *"I felt very sad at his death, yet a little relieved that his suffering was over."*

P27: *"There are some deaths in the NICU that are blessings, the lethal anomalies or the infants that have reached the end of medical capability."*

P57: *"I think I mostly felt relief (though there was a sense [sic] of loss)."*

Coping

In their narratives, most NICU nurses discussed how they coped with delivering EOLC during and after an infant's death. Some of the seemingly healthier coping strategies were colleague support, debriefing, and intentional gratefulness. Less positive coping involved avoidance and compartmentalization. Collegial support, going through debriefing after the death, and intentional gratefulness seemed to have positive effects:

Colleague Support

Colleague support was the most frequently reported helpful coping strategy. Participants shared how seemingly minor acts affected them greatly during and after providing EOLC.

P20: *"Another nurse agreed to stay with the family for a few minutes while I took a break. I had to run to the restroom because I felt so nauseous, and I did cry."*

P66: *"I am grateful for the chaplains who make rounds and support the staff ... They understood and supported me."*

P57: *"... great support from my coworkers. My nurse manager even sent me a card thanking me for serving as a patient advocate. That support from schedule changes to attend the funeral and cards/kind words really helped me cope with the sadness of being so involved with death."*

Debriefing

Conversing with co-workers was a common and helpful coping method after the death of an infant. Participants shared that these debriefing sessions allowed them to discuss their feelings with others who understood the situation.

P76: *"We had a debrifing [sic] after the incident to discuss our feelings."*

P27: *"We did all the 'hospital' things post the event— we met and looked at the event and we met and talked about the event—but some of the best discussions happened spontaneously outside the facility over lunch or dinner weeks later."*

One participant noted that her family does not really understand when she tries to talk about EOLC experiences at home:

P74: *"Talking with other staff members involved in the care of this baby was helpful. Getting the feelings out and having someone listen to me about the situation helped to justify my feelings. My family knows to let me have space when I get home after a situation where the baby dies. They [my family] hear me but don't really understand. My coworkers are my support."*

Although most NICU nurses found debriefing an effective means of coping, one participant felt rushed into the process:

P37: *"... [I] felt frustration with having to 'debrief' immediately after the event when some emotional decompression needed to occur."*

Intentional Gratefulness

Many NICU nurses shared that they respond to infant deaths and the accompanying feelings by being actively grateful for their own blessings, usually their children.

P1: *"My coping mechanism was to go home and hug my healthy daughter and tell her how much I loved her."*

P8: *"... yes, I felt sad, I cried, I went home and hugged my infant and I thanked my luck that I had a health[y] child."*

When avoidance and compartmentalization of emotions occurred, these were characteristic of less effective coping.

Avoidance

Several participants related reaching a point where, emotionally, they could no longer care for a particular infant. Feelings of moral distress were present in half of the narratives that mentioned avoidance as coping method.

P13: *"It finally came to a point when I just couldn't care for him anymore; I had to have a break. It was very stressful to come in and see him every night and feel that we were doing things to him and not for him … I never really talked to anyone. I just kept everything to myself other than asking not to care for him again."*

P1: *"I personally was unable to care for this infant because I could not condone the actions of the neonatologist for allowing it or the family for making this decision. I also had a difficult time with a family that made this decision and then walked away as if the child did not matter."*

P66: *"…and [I] mostly kept quiet about it [the EOLC situation shared]."*

Compartmentalization

Several participants purposefully avoided processing feelings related to EOLC in order to cope with infant deaths. These statements were interpreted and grouped together under compartmentalization, which was defined in a NICU context as purposefully ignoring personal feelings in order to meet the needs of the dying infant and its family. While this strategy might help a NICU nurse deliver high quality EOLC in the short-term, in the long-term it may deter her from reflecting on the death, growing from it, and finding ways to give even better care the next time around.

P29: *"I put away my feelings and step up to theirs."*

P28: *"…I had intended to come back up from the morgue and slowly take apart the pieces of her short life, clean them up, and store them (as well as my feelings) away."*

Changes in Practice

Growth

Participants consistently reported that learning and growth helped them initiate practice changes in response to a particularly negative and emotional EOLC situation. Some of the changes related to nurses' advocacy practices:

P1: *"I am more aware of what is happening in the unit now than I used to be and talk more directly with the families than I used to."*

P20: *"…in retrospect, I would have advocated for the infant to have less invasive intervention. Since this experience I have cared for two infants in end of life situations and I have felt more comfortable in counseling parents and advocating for humane infant care."*

While sharing stories of practice changes, some participants expressed gratitude for the experiences and the new knowledge they gained from them.

P90: *"I grew and learned so much from this."*

P11: *"This experience taught me that I couldn't have made a difference without having done things differently. Change is sometimes radical. There can be more than one way to look at things. 'Sometimes you break glass; sometimes you bend it; sometimes you leave it the way it is and look through it.'"*

P27: *"There, [in the NICU] "life" and death is about us and what we learn and how we handle it and what we take away from it … That day and its emotions, and watching those parents in their faith, gave me so much to take forward and think about … I told them that day I would never forget their son, that I would carry him with me and he would impact the care that I provided to every other infant and family that I came in contact with. And it has."*

P33: *"Moving forward I think I grew in my process of dealing with end of life care, and have helped parents process through this difficult time."*

While the growth in practice typically happened on either a personal or an individual professional level, some NICU nurses shared that they used the situation as an opportunity to teach other staff members.

P42: *"We had articles regarding this practice in this particular culture. I shared this with our [flight] team, who rounded in our unit, for I felt that they may see this as they would respond to an emergency of someone else with this culture and religious background."*

P28: *"I do, however, repeat this story from time to time when discussing loss and bereavement."*

Associations among Affective Responses and Demographics

Analyzing the narratives as a data set and constructing a comparative matrix uncovered associations among the affective responses and participant characteristics. Themes were cross tabbed analytically to determine and raise questions about patterns in associations. These findings are identified and examined below. They also are discussed as future research opportunities in Chapter Five.

Many narratives that described moral distress also included feelings of responsibility. Considering the possible underlying causes for this association generates an important question: Are NICU nurses' feelings of responsibility *triggered by conflict* or do they experience feelings of conflict because they *already feel responsible*? One possible explanation for this difference is that when forces outside the NICU nurses' control, such as physician or family decisions, prevent them from delivering the highest quality EOLC and/or contribute to feelings of inadequacy, they are more likely to experience the anger, guilt, and powerlessness associated with moral distress.

A noteworthy exception to this association between feelings of moral distress and identification occurred in only one narrative. That participant described being a part of an end-of-life situation in which she disagreed with the process of discontinuing life sustaining support. She described feelings of anger and guilt related to her perception that the removal of life support was too aggressive. Does this mean that feelings of moral distress contribute to NICU nurses' not sharing their feelings of identification with parents and family members? This is an important question because such sharing fosters empathy, which is essential to the nurse-patient-family therapeutic relationship.

A tentative association between moral distress and avoidance was illustrated in two narratives. It is possible that when NICU nurses experience the helplessness and powerlessness associated with moral distress, they cope by disengaging from the situation. Additionally, most of the narratives that expressed feelings of relief after a suffering infant died also contained feelings of moral distress. This is a plausible relationship since the situation that caused moral distress, futile care, ended when the infant died.

Half of the narratives that expressed feelings of spirituality also indicated that the NICU nurse had grown from the shared EOLC situation. It is also noteworthy that participants over the age of 50 (slightly higher than the mean age of the participant group) wrote the majority of the narratives that mentioned feelings of spirituality. It is possible that NICU nurses who infuse spirituality into their EOLC will reflect more frequently. The practice of intentional gratefulness was found in some of the narratives that described feelings of survivor-like guilt. Possibly these participants reacted to their guilt with gratefulness in order to remind themselves of their blessings and confirm that there can be at least one positive outcome from a sad situation.

Feelings of isolation and aloneness were more common among participants with advanced degrees. This finding is not surprising when considering that NNPs or doctorally prepared NICU nurses generally have more responsibility and autonomy in clinical practice than do less educated nurses. Advanced practice nurses may also have more access to extensive education in ethics. There was no association between education level and the feelings of responsibility for the participant group. Thus, it appears that feelings of responsibility are very common among NICU nurses, without regard to role or scope of practice.

All the participants who described feelings of pride had more than 25 years of NICU experience, suggesting that the ability to focus on the positive aspects of EOLC comes with more experience and/or increased age. These feelings of pride also could come from the high quality of EOLC that NICU teams with a great many years of experience are able to deliver.

Summary

The data collected and analyzed from the written narratives revealed many strong and pervasive affective responses that NICU nurses experience when delivering EOLC.

While the participant group was extremely homogenous (a fact discussed in Chapter Five), this study sample and the study findings might be applied in a general manner to other NICU nurse groups. Age and nursing experience are associated with some of the more positive affective responses, such as pride and spirituality. Nurses with increased autonomy and responsibility during EOLC, including NNPs, MSNs, and doctorally prepared nurses, may have increased feelings of isolation. Perhaps the most significant finding from the demographic data was the number of participants reporting that the EOL content in their nursing program curricula was not particularly helpful nor did it prepare them for providing EOLC in the NICU setting.

The main affective responses reported were responsibility and moral distress. In addition to being the most commonly reported emotions, they also appeared to be related. Moral distress, also strongly associated with other affective responses, may precipitate NICU nurse avoidance and feelings of relief after infant death. Additionally, moral distress may be inversely related to feelings of identification, as noted in the one narrative that described moral distress related to aggressive discontinuation of life support, as opposed to the more frequently noted futile care.

Participants widely reported feelings of identification. The data indicated that controlled feelings of shared grief could positively affect EOLC, while experiencing these feelings too strongly can lead to negative effects for nurses. Other affective responses that were selectively prominent throughout the narratives were spirituality, aloneness, pride, and relief.

The data revealed a mix of healthy and less healthy coping strategies. Colleague debriefing and intentional gratefulness appear to be the healthier strategies, while avoidance and compartmentalization appear to be less healthy strategies with negative implications for NICU nurses. Growth in EOLC practice was the overwhelming change that resulted from the shared experiences of the NICU nurses. The participants clearly communicated how these emotion-filled experiences served as ongoing EOLC education. In addition to promoting practice changes, the nurses’ memorable experiences facilitated shared learning. However, there was no association between growth in EOLC practice and colleague debriefing. Thus, the data indicate a range of affective responses that occurred in particular circumstances, with some associations between themes being almost universal in the narratives.

Chapter Five: Discussion

To integrate the new knowledge about NICU nurses' affective responses during EOLC from this study into existing knowledge, the information needs to be discussed in the context of the previously published research summarized in Chapter Two. Such a discussion may help future research questions and studies evolve in a logical manner so that rigorous interventions to address some of the more negative emotions may be developed. Furthermore, this same discussion might generate research questions that examine the positive affective responses revealed, such as pride, acceptance, and peace, with the goal of facilitating or growing such emotions. This chapter includes a critical discussion of the study's sample, findings, and implications for nursing education, practice, and research. Finally, the direction of future research into the phenomenon is discussed.

Sample Characteristics

Even with a small study sample, it was still important to examine the demographics and to cross-relate themes for patterns and associations in an effort to add to the body of knowledge about EOLC in the NICU. While 110 NICU nurses entered the survey link, seven completed just the demographics section, and 36 completed the demographics section and the written narrative. There are several possible explanations for this data distribution. Potential participants might not have understood that a written narrative was requested or were not prepared to write one. Some might have planned to return to the survey once they had chosen an experience to describe. Perhaps some participants who did this can be considered part of the sample. Potential participants—especially the seven who only provided demographic data—might have become overwhelmed at the thought of sharing an emotional EOLC experience and exited the survey.

Avoidance of this task could be considered a coping strategy as discussed in Chapter Four and later in this chapter.

During the creation of the study design, the researcher desired a study sample diverse in geography, race and gender. The sample’s geographic diversity facilitates the application of the findings to more general NICU nurse populations and helps offset the sample’s more homogenous attributes. It was hoped that a diverse gender and race sample would allow for the examination of differences in affective responses since previous research has revealed contradictory findings (Twigg & Lynn, 2012; Weigel et al., 2007). Unfortunately, there was no diversity in participants’ race or gender. While the entire sample was composed of white females, it is a close representation of the gender characteristics of NANN’s membership, which is 98% female (C. Gremer, personal communication, July 8, 2013). NANN does not keep records about their members’ ethnicity.

Although greater sample diversity was desired, the sample’s homogeneity is in itself a noteworthy finding that invites a question meriting further examination: Do differences in affective responses to EOLC exist between males and females and likewise among ethnicities? Previous research indicates that nurses with diverse ethnic and cultural backgrounds share the same feelings of apprehension about EOLC (Parker, et al., 2009). While this study raises the possibility that such demographics do not affect nurses’ affective responses as a whole, its sample is not representative of the U.S. RN population. In 2008, the U.S. Department of Health and Human Services reported that 93% of the registered nurses in the U.S. were female and 83% were white. A study sample not obtained from a professional organization might have been more diverse.

The study participants’ mean age of 49.7 years was slightly higher than the mean age of 47 years reported for all U.S. nurses in 2008 (U.S. Department of Health & Human Services, 2010). The national projected average age for nurses in 2012 was 44.5 years (AACN, 2012). Only two participants (6%) were under the age of 40. These age demographics can be explained by the fact that the typical professional nursing organization, such as NANN, has a mean member age of 48 years (C. Gremer, personal communication, July 8, 2013). These demographics also may indicate that this segment of the NICU nurse population feels strongly enough about their EOLC experiences to enroll in a study about them.

The mean years of nursing and NICU experience were very high, at 26.9 and 23.3 years respectively. NANN’s membership has an average NICU nursing experience of only 18 years (C. Gremer, personal communication, July 8, 2013). The fact that study participants had more NICU experience than the general NANN membership could indicate an association between a nurse’s cumulative years of NICU nursing experience, her experience with a higher number of emotionally provocative EOLC situations, and her recognition of the challenges in providing EOLC. This finding aligns with previous research that found an association between a nurse’s years of experience, her comfort levels providing EOLC, ability to mask personal emotions, and willingness to discuss death and dying (Engler et al., 2004; Feudtner et al., 2007; Powazki, et al., 2013; Weigel et al., 2007). Findings from Bailey et al.’s (2011) study indicate that examining nurses’ progress through the stages of emotional development while providing EOLC is more easily examined in a study with participants who have more diversity in years of experience.

The majority of the study participants (63%) had an MSN, NNP license, and/or doctoral degree. The education level of this study sample is not representative of the general U.S. nursing population where just 13.2% of nurses held an MSN or doctoral degree (AACN, 2013b). It is also not representative of NANN membership where 45% of the NICU nurses hold masters or doctoral degrees and 43% report a bachelor’s degree as their highest education (C. Gremer, personal communication, July 8, 2013). This statistic might reflect the degree to which NICU nurses with advanced practice degrees value participating in nursing research. In a NICU, advanced practice nurses generally have more responsibility than do ADN- or BSN-prepared nurses. Nurses with more responsibility may have stronger feelings about EOLC situations, a finding discussed later in this chapter.

The participants’ NICU characteristics were unsurprising. The majority of respondents worked in level III and IV NICUs, where the infant population is more acutely and critically ill and more infant deaths occur. Eighty percent of the NANN membership reports employment in a level III or IV NICU, therefore this demographic variable seems well represented by the study sample (C. Gremer, personal communication, July 8, 2013). There was no significant relationship between NICU level and the presence of a written EOLC policy. There was no overt association between participants who noted an EOLC policy in their employment unit and any of the affective emotions revealed in the narratives. This finding was inconsistent with previous studies that found an association between increased comfort delivering EOLC and the presence of a unit policy (Engler et al., 2004; Wright et al., 2011). There was also no association between NICU level and participants’ completion of additional EOLC education. There was, however, a significant positive relationship between holding an advanced practice degree and completing additional EOLC education. Only one participant with an advance practice degree reported completing ELNEC’s program as additional EOLC education. That particular NICU nurse shared a narrative with a predominant emotion of conflict over futile care that was accompanied by feelings of responsibility to deliver the best EOLC possible.

There was a significant relationship (p = 0.04) between the percentage of the sample that received EOLC education in their nursing programs (56%) and the percentage of those same participants who felt the education was not clinically helpful (77%) in caring for dying infants and their families. This might raise the possibility that, while earlier studies support EOLC education as an effective intervention for increasing nurse knowledge, practicing nurses may not perceive it as particularly helpful, especially when dealing with emotionally charged EOLC situations (Beckstrand et al., 2006; Feudtner et al., 2007; Haut, Michael, & Maloney-Harmon, 2012; Malloy et al., 2006; White & Coyne, 2011;Wright et al., 2011). Perhaps a crucial element is missing; documenting the affective responses NICU nurses experience while delivering EOLC care and designing interventions to resolve the negative responses and employ strategies to optimize the positive ones. It is important to note, however, that undergraduate programs generally focus on adult patient populations while the NICU setting is certainly considered a specialty area and thus, perhaps not specifically addressed in EOLC content. This study's data do align with Weigel et al.'s 2007 findings that education level and EOLC education were not associated with decreased apprehension levels in nurses. The utilization of simulation to teach EOLC in undergraduate education has been shown to be effective in exposing nursing students to the many emotionally charged dimensions of EOLC and could be an intervention to explore more thoroughly through research (Sperlazza & Cangelosi, 2009; Twigg & Lynn, 2012). Powazki et al (2013) reported that nurses with greater continuing education felt greater comfort and capability in engaging in issues related to ethics, culture, religion, and bereavement. Perhaps, the differences in outcomes between undergraduate EOLC education and post-graduate EOLC education should be examined.

One last significant finding that must be addressed is that just 63% of the study's participants indicated that their units possessed EOLC policies. If this finding is accurate, it indicates a prime opportunity to provide more NICU nurses with the tools they need to care for dying infants and their families. Another possible explanation for this finding might be that the respondents did not fully understand the survey question. Regardless, it merits further exploration.

Affective Responses, Coping, and Changes in Practice

While several findings align with previous research about EOLC in the NICU, other findings revealed new information, not previously published, that raised several novel questions. The three most frequently shared affective responses will be reviewed in detail, critically examined, and followed by a holistic overview of their relationship to one another. With the exception of moral distress, which might be a universal response of nurses caring for the dying, this study revealed other affective responses that seem to be exclusive to the NICU environment (Table 1). These less frequently reported emotions will be examined and followed by a discussion of NICU nurses' coping strategies and EOLC practice changes.

Table 1: Comparison of Affective Responses among Nurses Who Serve Different Patient Populations

NICU Nurses' Affective Responses	Present in Other Nurse Populations	Present in Other ICU Nurse Populations	Unique to NICU Nurses
Responsibility		X	
Commitment to the best EOLC	X		
Professional Inadequacy		X	
Disbelief		X	
Advocacy	X		
Moral Distress	X		
Identification			
Shared Grief	X		
Excess Attachment			X
Survivor-Like Guilt			X
Spirituality			
Aloneness			
Being the First to Recognize		X	
Pride			
Relief		X	
Avoidance	X		

Responsibility

The most frequently shared emotion was a constant underlying feeling of responsibility for patients. Under the affective umbrella of responsibility, the strong desire to deliver the highest quality EOLC was pervasive. This finding is consistent with Epstein's (2008) study with the same population. She stated that the NICU nurses and physicians who sought to provide the best care experienced similar feelings. This finding was also present in a pediatric nurse population (Beckstrand et al., 2010). Responsibility and commitment to deliver the best EOLC possible were also present in Bailey et al.'s (2011) second stage of emotional development, called *emotional labor*. Although Bailey et al.'s theory of emotional development was derived from a study of emergency department (ED) nurses, the similarities between ED and NICU nurses made the Bailey theory helpful for a holistic examination of responsibility in EOLC. While the data revealed that feelings of responsibility are universal among the different nurse roles in a NICU, there were no associations noted about education level.

Deep-seated feelings of responsibility are a desirable trait in any nurse, but to what degree? When experienced in excess, can such feelings lead to other less desirable responses, such as professional inadequacy, moral distress, and survivor-like guilt? These more negative emotions may lead to less healthy coping mechanisms, as well. Is there a point at which feelings of responsibility are optimal for the provision of quality EOLC? Is there a way to gauge the level of these feelings in nurses? The narrated experiences also pointed to an association between feelings of responsibility, identification, and moral distress, which are discussed later in this chapter. No previously published research studies have examined this association.

While feeling responsible for keeping a patient alive is more closely associated with physicians than nurses, these participants reported feelings of professional inadequacy related to their inability to cure patients. Professional inadequacy has been discussed in previously published literature, but not at length (Archibald, 2005; Lee & Dupree, 2008). The nurse's feelings of guilt, powerlessness, and professional questioning stemmed from a deep sense of professional failure and inadequacy in these studies. These feelings also were revealed in a sample of neuroscience intensive care nurses (Calvin et al., 2007). It is noteworthy that these feelings are present in nurses who care for adults and infants, with the common element being the intensive care environment. In contrast to less intensive settings, does the intensive care setting and its technologies engender in nurses a more intense need or desire to cure all patients?

In this study, feeling disbelief was closely related to NICU nurses' overall feelings of responsibility. This finding is consistent with an early study about NICU nurses' EOLC experiences (Yam et al., 2001). While also present in Calvin et al.'s (2007) study, feelings of disbelief have not be reported in any other study of the affective responses of nurses providing EOLC in adult populations. It is possible that feeling disbelief is much more common in NICU nurses and, therefore, should be examined more closely for its long-term effects on nurses and EOLC outcomes.

Feelings and expressions of advocacy for dying infants are exclusive to this study's findings. This concept has not been revealed in other studies of NICU nurses who provide EOLC. It is possible that the intimacy of the, often long-term, NICU nurse-infant-family relationship naturally produces more intense feelings of responsibility that compel a NICU nurse to advocate for her patient.

Moral Distress

Long thought to be one of the prevailing issues of EOLC, moral distress is a compilation of anger, guilt, powerlessness, and helplessness. The narratives lend additional support to previous research findings linking moral distress and futile nursing care (Contro et al., 2004; Crump et al., 2010; Epstein, 2008; Ferrell, 2006; Gelinas et al., 2012; Kain, 2007; Mobley et al., 2007; Piers et al., 2012; Russell, 2012; Solomon et al., 2005). These findings, combined with those of previously published studies, seem to indicate that, while its frequency among nurses providing EOLC is not terribly high, when moral distress does occur, its intensity is significant (Piers et al., 2012). After objecting to futile care orders, NICU nurses often are placed in the troubling and frustrating position of being compelled to provide the very care they believe will do nothing but prolong a dying infant's suffering. A study by Espinosa et al. (2010) described this phenomenon as internal conflict. While the long-term consequences of moral distress, including nurse burnout and higher attrition rates, have been studied closely (Corley, 2002), a new question has arisen: How do NICU nurses' feelings of moral distress affect the therapeutic feelings that they need to deliver quality EOLC? This study revealed a relationship between feelings of moral distress, responsibility, and identification, discussed later in this chapter.

These findings also linked moral distress to physician orders and differences between nursing and medical care models. These findings add weight to previous research indicating that inadequate communication between nurses and physicians is a perceived barrier to delivering EOLC (Beckstrand et al., 2009; Friedenberg et al., 2012; Yam et al., 2001). Previous research has shown that an open environment—where NICU nurses felt comfortable sharing personal values, opinions, and beliefs—was highly valued by nurses and necessary to positive EOLC outcomes (Kain et al., 2009; Wright et al., 2011). These findings raise a question about the timing of this poor communication barrier: is it a precursor to or a result of moral distress? While other cause(s) of poor communication between physicians and nurses may be unknown, the communication issues resulting from moral distress may be tied to NICU nurses using avoidance behaviors as coping mechanisms. Two narratives described avoidance behaviors, a concept included in Corley's (2002) theory of moral distress and a more recent study that examined differences in moral distress and avoidance behaviors in ICU and non-ICU nurses (De Villers & DeVon, 2012). It is possible that avoidance behaviors among NICU nurses experiencing moral distress are more common than this data indicates.

The one contrasting narrative—in which a nurse described feeling moral distress when support (intravenous fluids) was withdrawn from an infant in her care—demonstrated that NICU nurses experience moral distress in situations that don't involve futile care, although less frequently. If this narrative is representative of other EOLC situations that cause moral distress in NICU nurses, it is logical to assume that the root of moral distress is the nurse's *inability to voice dissenting opinions about EOLC* (Corley, 2002). Instead of feeling empowered to speak up, this nurse used avoidance to cope and offer her opinion about this infant's EOLC in a passive way.

Identification

Participants expressed identifying with families through shared grief, excess attachment to the infant, and survivor-like guilt. Feelings of shared grief include sadness, distress that often included crying, and the desire to attend deceased infants' memorial and funeral services. Previous studies have reported these feelings in nurses who care for adult or neonatal populations (Calvin et al., 2007; Contro et al., 2004; Lee & Dupree, 2008; Yam et al., 2001).

Feelings of excess attachment to a dying infant and family were expressed with regularity in the data. One nurse even recognized crossing a professional boundary. Lindsay et al.'s (2012) narrative analysis of NICU nurses experiences while giving EOLC revealed that NICU nurses often feel a need to be present for or form an intimate relationship with the infant. Bailey et al. (2011) identified emotional development stages of nurses providing EOLC. The first stage involved the nurse investing her therapeutic self in the nurse-patient relationship (Bailey et al., 2011). Most nurses know that intimacy, a hallmark of the first stage, is foundational to a therapeutic nurse-patient-family relationship. Nevertheless, what effect does this intimacy have on the nurse? For a nurse to provide effective, compassionate EOLC while protecting her emotional well-being, she must maintain a delicate balance between gaining enough intimacy, but not too much. Malloy, Thrane, Winston, Virani, and Kelly (2013) recently conducted a study to explore self-care strategies among nurses (n=605) who work in palliative or EOL settings. The most frequently reported self-care activity was taking at least one week of vacation each year. Fostering meaningful relationships outside of work and the ability to “celebrate life despite [witnessing] suffering and death …” (p.102) also were reported with high frequencies. It is noteworthy that, although they accounted for less than 18% of the study sample, the pediatric nurse population reported using self-care activities at a higher rate than the adult nurse populations.

The feelings of survivor-like guilt reported in the narratives are unique among published literature about NICU nurses providing EOLC. Several participants vividly remembered being involved in EOLC situations while they were pregnant, such as performing compressions or holding a dying infant while a healthy fetus kicked in their wombs. When ‘survivor guilt’ and ‘nurses’ were used as search words, there were no results in multiple nursing databases. Very little research has examined the concept of survivor guilt among nurses.

Relationship between Moral Distress, Responsibility, and Identification

An association among feelings of moral distress, responsibility, and identification was revealed during data analysis. Participants who expressed feelings of moral distress almost always expressed feelings of responsibility. Unfortunately, the data did not reveal the sequence of these feelings, so it is unknown whether moral distress increased feelings of responsibility among NICU nurses or vice versa. Likewise, participants who shared feelings of identifying with the dying infant and family frequently expressed feelings of responsibility. This seems logical when the components of identification are considered, including shared grief, excess attachment, and survivor-like guilt. Because feelings of moral distress and identification were never shared in the same narrative, a negative relationship between these two responses must be considered. This is an important question because such identification is a main component of empathy, which is which is a trait of emotional intelligence, an advanced state of development, which supports previous research (Akerjordet & Severinsson, 2010; Bailey, et al., 2011). Situations that produce feelings of moral distress in NICU nurses may eliminate or severely reduce the empathetic feelings that contribute to positive outcomes.

Spirituality

Non-interpretative studies of nurses’ affective responses to providing EOLC often focus on negative emotions. In contrast, qualitative, interpretive study designs—such as the one used in this study—often uncover conflicting emotions. These participants expressed feeling negative emotions and spirituality simultaneously. These findings reflected previously published findings (Calvin et al., 2007; Lee & Dupree, 2008) in which participants described EOLC experiences that involved feelings of identification and professional inadequacy along with gratitude, faithfulness, a sense of purpose, peace, acceptance, and privilege.

NICU nurses’ self-awareness of personal spirituality has not been explored in previously published literature. It is unknown if a high degree of spiritual awareness is associated with more positive affective responses and coping mechanisms during EOLC situations. Nurses’ awareness of their personal spiritual beliefs, which is a component of personal knowing (Carper, 1978; Chinn & Kramer, 2011) and the therapeutic use of self, has been associated with more positive patient outcomes (Ronaldson et al., 2012). In fact, Chinn and Kramer (2011) purport that spirituality, as a component of personal knowing, is “…a complex combination of values, attitudes, and hopes…” (p. 113). This spirituality is developed through experiences with existential issues including life and death and despair and suffering.

A finding exclusive to this study was that about half of the participants who expressed feelings of spirituality also felt they had experienced growth in their EOLC practices. This finding raises a question that merits further study: is there an association between personal spirituality, reflection, and professional growth? Additionally, the mean age of NICU nurses who reported a spiritual affective response was slightly higher than the mean age of the participant group as a whole and even higher than the mean age of NANN members and U.S. RNs. Does this finding mean that there is a link between age and spiritual affective responses in NICU nurses? This data also indicated that intentional gratefulness is generally a reaction to feelings of survivor-like guilt, a relationship that also should be explored further.

Aloneness

Most NICU nurses are intensely aware of a specific period in EOLC care: the time between the nurse’s realization (“knowing”) that an infant will not survive and the doctors’ and parents’ realization of the same fact. When this period lasted too long, the participants described this “knowing” as a precursor to feelings of isolation and aloneness. This finding may be closely related to the pattern of knowing/unknowing—referring to a NICU nurse's knowledge that certain therapeutic interventions caused infant suffering—described in recent similar studies (Beckstrand & Kirchhoff, 2005; Lindsay et al., 2012). It may be that the shorter the period of "knowing" before others, the less moral distress NICU nurses experience. Conversely, the longer the period, the greater possible risk for nurses to experience moral distress as this extended time facilitates futile care.

Study participants also reported feeling physical isolation and emotional abandonment, responses also described by Espinosa et al., (2010). This study, however, found a distinctive connection: these feelings were more common among participants with advanced degrees. This finding is not surprising given the level of responsibility NNPs holds in NICU practice settings. While participants described these emotions in a negative way, NICU leadership might help alleviate these feelings by acknowledging the most common responses to distressing NICU situations and fostering a caring unit environment.

Pride

This study uncovered feelings of pride among nurses providing EOLC, an affective response not addressed in any published literature. Every participant who expressed these feelings had more than 25 years NICU experience. This data adds supports to the recommendation to having seasoned EOLC mentors in the NICU, which is discussed later in this chapter. Another interesting association noted in this study, which merits closer examination, is that participants who expressed pride in their NICU team's EOLC very rarely expressed feelings of isolation and aloneness.

Relief

While not overwhelmingly present in the narratives, some NICU nurses expressed feeling relief when support was withdrawn from dying patients. These feelings of relief were most often associated with discontinuing futile care, ending infant suffering, and questioning the quality of the infant's life. The ICU nurses who participated in Espinosa et al.'s (2010) study expressed similar feelings with identical associations.

Coping Strategies

The participants' coping strategies can be categorized as either positive/healthy strategies or negative/less healthy strategies. Other researchers classify nurse coping behaviors as internal/external or cognitive, affective, and behavioral (Badger, 2005; Peterson et al., 2010). Specifically, this study's participants identified three positive ways they coped with stressful EOLC situations: seeking collegial support, undergoing debriefing (formal and informal), and cultivating intentional gratefulness. Avoidance was discussed as a less healthy method of coping that was often used in morally distressing situations.

Colleague and Family Support

Two of the participants noted that, while valued, support from the nurse's family is not terribly helpful because their knowledge of the dynamics of EOLC in the NICU is limited. Both these participants felt that coping through colleague support and informal debriefing were more helpful than family support. Many other studies had similar findings (Badger, 2005; Melvin, 2012; Peterson et al., 2010). In contrast, Gelinas et al.'s (2012) study's found that lack of family support not only was associated with poorer coping skills in nurses caring for patients at the EOL, but also actually caused nurse suffering. Clearly, creating a supportive NICU work environment is beneficial in many ways, but might be extremely helpful in EOLC practice settings.

Debriefing

Finally, the pattern of debriefing was discovered as a coping mechanism (Lewis, 2012b; Lindsay et al., 2012). The participant group stated that they often listened to each other's EOLC experiences, which served to manage strong feelings and co-construct nursing EOLC knowledge. Debriefings, both formal and informal, were identified in this study and others as helpful coping and support strategies for NICU nurses (Badger, 2005; Catlin & Carter, 2002). Debriefing is closely associated with critical reflection strategies, which are discussed later in this chapter in relation to nurse-actuated practice changes.

Avoidance

These participants described using avoidance, in the form of refusing to care for a particular infant/family or taking off mental health days from work, as a reaction to difficult emotional responses to EOLC. The concept of avoidance is closely related to moral distress and is often identified as one of its consequences (Corley, 2002; Russell, 2012). Specific to the NICU environment, Yam et al. (2001) identified this coping strategy as a way to protect the emotional self. Other researchers also have identified avoidance or retreating as a coping mechanism (Badger, 2005; Cook et al., 2012; Espinosa et al., 2010; Marshall et al., 2011). One study in particular highlighted the possibility that while nurses verbally communicate their confidence in providing and coping with EOLC, their actions —such as avoiding a stress-inducing situation—suggest something entirely different (Marshall et al., 2011). Avoidance also has been identified as a coping strategy of nurses who have not have successfully navigated the emotional developmental stages necessary to care for dying patients (Bailey et al., 2011).

Interestingly, the literature on nurse coping during EOLC brought the concept of reflection into the discussion of coping strategies (Badger, 2005; Peterson et al., 2010; Melvin, 2012). Critical reflection can help EOLC experiences produce positive outcomes through improved bedside practice (Lawrence, 2011; Lewis, 2012b; Lindsay et al., 2012). While reflection certainly was documented in this study, it was more closely associated with participant discussions about changes in practice resulting from EOLC experiences in the NICU.

Changes in Practice

There is no literature exploring what nurses “do” with their EOLC experiences. However, a great many published findings explore reflective practice in the nursing discipline as a method of professional growth, or what could be considered changes in practice in response to experiences. End-of-life care literature also addresses the need for nurses to use this strategy to adapt and grow in their practice.

Growth through Reflection

Previous research findings have described the concepts of personal knowing, emancipatory knowing, reflective practice, and professional growth (Carper, 1978; Chinn & Kramer, 2011; Schon, 1983). This study’s participants frequently noted experiencing practice growth as an outcome of previous EOLC experiences. While some of the lessons were emotionally difficult, all participants who addressed practice growth used positive tones and words to describe the lessons as something valuable that came from their experiences. Lindsay et al. (2012) reported a pattern among a NICU nurse sample of “… exploring experience for transformation of practice” (p. 246). In Ferrell’s (2006) study, some nurses reported a positive experience that helped them grow professionally. Lewis (2012b) defines this process as an opportunity to “… construct new meaning and identify creative interventions to improve care delivery in the future” (p. 410). Such findings align closely with this study’s findings that NICU nurses used EOLC experiences to improve their practice.

Study Implications

This study revealed new knowledge and several ideas and associations that could be implemented to improve EOLC through nursing education, practice, and research. These findings can be applied in each area of the nursing profession in order to prepare, educate, and support nursing students, nurse leaders, and bedside NICU nurses who are frequently faced with the emotionally charged EOL situations when providing care.

Nursing Education

Applying new nursing science knowledge to nursing education is a logical place to begin to effect positive changes in nursing knowledge, skills, and behaviors. Nursing science has demonstrated that EOLC education, specifically through the ELNEC organization, improves EOL knowledge among nurses and recommends incorporating ELNEC fundamentals into nursing education (Feudtner et al., 2007; Malloy et al., 2006; Paice et al., 2006; White & Coyne, 2011). To meet these evidence-based recommendations, nursing programs are encouraged to continue to integrate ELNEC-driven modules into their curriculum. This provides a solid foundation of knowledge for nursing students about EOL, which can then lead to deeper discussions related to common affective responses. Nurse educators responsible for this curricular content would benefit from becoming ELNEC-educated and having a hospice experience background, in order to help illustrate important concepts for students. Educators who teach high-risk newborn care might consider implementing a smaller NICU-specific EOL module since this study’s data have revealed several affective responses unique to NICU nurses who provide this care. While increasing nursing students’ EOLC knowledge is an important endeavor, these findings clearly demonstrated that such knowledge does not help NICU nurses handle the strong emotions that come with providing this specialized and highly demanding care.

Thus, curricular development to include some of the less tangible aspects of this specialized care might prove valuable in order to better prepare future nurses for EOLC challenges.

Nursing program faculties are encouraged, based on this study's findings, to seek ways to introduce student nurses to the negative and positive affective responses they may experience during EOLC situations. Future nurses could be involved in seminar-like discussions and/or role-play about moral distress, excess attachment to patients and family, and feelings of inadequacy after a patient dies so that these responses can be recognized when they occur. The topic of moral distress, its attributes, common causes, and effective ways to resolve it would be extremely helpful additions to curricula. The awareness of these common negative and often unhealthy emotions leading to less than optimal EOLC in the NICU might reduce the severity of them as well as encourage nurses to implement resolution strategies. It is also recommended that educators encourage and mentor nurses to maintain professional EOLC boundaries in all patient populations, recognize and acknowledge their feelings, and refocus on the patient and family as a protective coping mechanism that also facilitates higher quality EOLC (Badger, 2005; Cook et al., 2012; Melvin, 2012; Peterson et al., 2010). From this study's findings and others, these appear to be self-care and self-protective strategies for nurses when giving EOLC.

Reflective practice is a potentially valuable tool to thread throughout nursing curricula and encouraged as a method to improve not only EOLC practice, but also all nursing practice. Research findings have supported the necessity and effectiveness of this strategy in improving practice (Bailey & Graham, 2007; Chinn & Kramer, 2011; Halm et al., 2012; Lawrence, 2011; Lewis, 2012b; Lindsay et al., 2012; Taylor et al., 2008; Rowley & Taylor, 2011). Fortunately, most nursing programs already use reflective practice in the form of post-clinical conferences. These sessions encourage clinical practice refinement through a combination of debriefing and reflective practice. This learning strategy could be integrated more deeply throughout nursing curricula to also include EOLC content.

Nursing Practice

EOLC practice changes ideally start with newly hired NICU nurses. All healthcare facilities that have not integrated ELNEC's principles into NICU nurse orientation might be restructured to include them in order to educate nurses who did not receive EOL education content in their undergraduate programs. Introducing the less tangible aspects of EOLC, such as moral distress, will help novice NICU nurses recognize and address any potentially negative responses. Since past research and this study's findings suggest that NICU nursing experience facilitates healthier affective responses to EOLC, NICUs would benefit from pairing new NICU nurses with more experienced nurses to handle EOLC situations (Bailey et al., 2011; Engler et al., 2004; Feudtner et al., 2007; Powazki, et al., 2013; Weigel et al., 2007).

During EOLC situations in NICUs, research data suggest that charge nurses and nurse managers who are more aware of professional dynamics are able to be a source of support to bedside nurses. Fostering active support of colleagues who are directly involved in EOL situations will help to moderate the stress of any one bedside nurse by limiting the perception of isolation, both emotional and physical (Badger, 2005; Melvin, 2012; Peterson et al., 2010). Additionally, it is recommended that NICU nurse leaders converse with staff nurses periodically to gauge their moral distress and, when possible, offer suggestions for relieving feelings of powerlessness, helplessness, anger, or frustration. Nurse leaders can encourage the creation of a safe environment where staff nurses feel comfortable sharing their honest thoughts and opinions without fear of reprisals. This strategy could help counteract nurse-cited barriers to conscientious objection found in Catlin et al.'s (2008) study.

The benefits of reflective practice encouraged formally and informally in the nursing discipline are supported throughout the literature, especially related to EOLC providers (Bailey & Graham, 2007; Chinn & Kramer, 2011; Halm et al., 2012; Lawrence, 2011; Lewis, 2012b; Lindsay et al., 2012; Taylor et al., 2008; Rowley & Taylor, 2011). This can be accomplished through facilitating colleague discussions about a specific EOLC event or EOLC in general. As this study and other recent research suggest, this nurse population appreciates informal debriefing and finds it more helpful than formal sessions (Badger, 2005; Catlin & Carter, 2002; Lewis, 2012; Lindsay et al., 2012; McNeilly et al., 2006). However, one recently published study recommends formal, organized debriefing (Powazki, et al., 2013). Thus, NICU managers and educators who are aware of this can exercise sensitivity as they plan formal debriefing sessions. EOLC journal clubs and structured action research that implements reflective practice might be suggested as methods that are time efficient and most helpful. Facilitating several, less formal, debriefing sessions in the days or weeks after an infant death would allow NICU nurses to decide when they are ready to discuss the events and which session best fits their schedules.

Healthcare facilities might offer periodic NICU professional in-services that identify and encourage healthy coping strategies, such as maintaining professional boundaries, seeking colleague support, and attending debriefing sessions. Common, less-healthy coping mechanisms, such as avoidance, could also be identified and discussed along with alternative strategies. Self-care strategies might also be useful tools for NICU nurses to acquire.

Future Research and Theoretical Development

To expand upon the solid foundation of knowledge about EOLC in the NICU, nurse scientists are encouraged to consider theory development, correlational study designs, and interventional research. Theory construction about NICU nurses' engagement and affective responses during EOLC would be a valuable addition to the literature. Grounded theory research would be particularly well suited to the qualitative nature of this phenomenon as interviews with NICU nurses would shed more light on the experience of providing EOLC. Other potential studies might explore and build upon Bailey et al.'s (2011) theory of emotional development in nurses delivering EOLC. Further knowledge about the role emotional intelligence plays among this nurse population could potentially assist with intervention construction.

While this study's research question exploring affective responses, nurse coping, and outcomes of EOLC experiences was best answered by a qualitative method, several reliable and valid instruments that will aid in advancing knowledge related to this phenomenon are available for use in correlational and pre-test, intervention, post-test study designs. Instruments such as the moral distress scale, the NiPCAS, the PEAS, the Frommelt scale, and fear of death and dying have been used in past studies to explore NICU nurse experiences with EOLC (Corley, 2002; Engler et al., 2004; Kain et al., 2009; Lawrence, 2011; Peirs et al., 2012; Peterson et al., 2010; Weigel et al., 2007).

Future studies designed to examine the concepts common to NICU nurses have great potential to improve the quality and comprehensiveness of EOLC. Studies from this phenomenon could yield information to help meet NICU nurses' needs and resolve common problems that prevent infants and families from receiving the best care. Several affective responses identified in this study seem to be unique to NICU nurses: excess attachment, advocacy, and survivor-like guilt. These concepts lend themselves to foundational exploration through concept analyses and clarifications specific to the NICU environment. Additionally, further examination of the benefits of employing nurses with extensive NICU and EOLC experience is merited to determine how to leverage this resource to train and mentor younger, less experienced nurses. Studies with a more diverse NICU nurse sample would be valuable, as well, to examine how gender and ethnicity differences affect responses, if at all.

Like most new knowledge, this study's findings are compelling simply as knowledge gained. However, improving nursing care and patient and family outcomes should remain the ultimate goal of this study and all nursing research. It is logical to assume that nurses who have the negative affective responses and less healthy coping mechanisms are more likely to provide less than optimal care, which is more likely to result in less favorable outcomes. Conversely, NICU nurses who experience more positive emotional responses and utilize healthier coping mechanisms might be more likely to provide more holistic EOLC that favors positive outcomes. Therefore, future research should further explore these strong emotions and seek to create interventions to mitigate them among nurses providing EOLC, particularly in NICU settings.

Moral distress remains a prominent concept in EOLC nursing care, regardless of the age of the patient population. Since this phenomenon has been associated with many negative consequences such as avoidance behaviors, burnout, and nurse attrition, moral distress experienced by NICU nurses merits much more intense scrutiny through future research. Interventions based on current research should be constructed, implemented, and their effects measured in an attempt to mitigate the negative feelings associated with EOLC situations in the NICU: anger, guilt, powerlessness, and helplessness. Additionally, the relationship between moral distress and lack of feelings of identification is an interesting one and further examination is needed to better determine whether it is universal in NICU EOLC or exclusive to this study's participant group. Catlin et al.'s (2008) concept of conscientious objection in response to feelings of moral distress also merits more research to help formulate a possible intervention to mitigate such negative feelings often associated with futile care.

The interesting phenomenon of “knowing first” is innately connected to moral distress that is rooted in futile care. Examination of this concept in the NICU nurse population through concept analyses and qualitative studies will facilitate the design of effective strategies to educate nurses about this phenomenon and how to process the related feelings. Likewise, many unanswered questions remain about NICU nurses’ feelings of spirituality and how they affect the EOLC they provide. From this study, it seems that nurses who have feelings of acceptance, peace, meaning making, and faithfulness also naturally reflect and grow in their EOLC practice. More research is needed to verify this finding and examining the effects of nurse spirituality on the spiritual care given to families of dying infants.

Conclusion

Despite advanced technology that allows extremely ill neonates to recover, many infants still die every year in NICUs. Quality EOLC, promoted and supported by most professional nursing organizations, continues to be an important and worthwhile goal that can help produce positive experiences for all patient populations. Vital research into facilitators and barriers of this care has been completed and the findings revealed important considerations related to unit design, staffing, and support. However, research related to nurses’ affective responses to EOLC in the NICU environment was lacking.

This study revealed that NICU nurses have strong and varied affective responses while providing EOLC. Some of the responses can be considered positive, such as responsibility, spirituality, and pride. Others, however, are negative in nature, including moral distress, aloneness, survivor-like guilt, and professional inadequacy, and can sometimes produce long-lasting consequences, including nurse avoidance of EOLC situations. Moral distress associated with futile care, when present, may trump all other affective responses, including the more positive ones, such as shared grief.

Certain NICU nurse characteristics related to EOLC also were revealed. Nursing experience seems to engender emotions that are more positive. These findings also brought into question the helpfulness of EOLC education. Neonatal nurse practitioners may feel greater aloneness than bedside nurses do and may be more likely to seek continuing EOLC education. The presence of an EOLC unit policy may not be as supportive to the nurses providing care as previously believed.

NICU nurses use a variety of coping methods to manage their emotions. Some, such as using colleague support and debriefing, are more therapeutic. Other methods, such as avoidance, merit further exploration to decrease nurses' reliance on them. Reflective practice is used as a method to improve EOLC, but also may serve as a coping method that produces something significant and meaningful from an anguish-producing situation.

These findings can be considered and used immediately by NICU nurse educators and managers as they work with bedside RNs. Based on these findings, unit nurse educators are encouraged to explore how to leverage seasoned NICU nurses' EOLC experiences to benefit novice NICU nurses. Nursing faculty likewise can use these findings to introduce students to the realities of providing such emotionally laden care, especially to infants and their families.

However, many related questions remain unanswered. Exploration of new concepts unique to NICU nurses, such as excess attachment, advocacy, and survivor-like guilt, are needed to gain a comprehensive picture of NICU EOLC dynamics. The coping strategies used by these nurses also merit a closer look. Future research will play an important role in the development of interventions to address the moderation of negative emotional responses and the mediation of positive responses to EOLC care, improve the quality of care, and reduce nurse burn-out and attrition. Critical reflection has the potential to moderate negative affective responses and improve professional performance, and therefore deserves further study.

Because the NICU is a unique environment, study findings with other patient populations and nursing environments may not apply. NICU-specific research has revealed some of this environment's distinctions. Ideally, more research will elaborate on the dynamics of the NICU during EOL. These findings have the potential to improve care for infants and families and give nurses information they can use to moderate their emotional responses during intense EOLC situations and improve their EOLC practice.

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Appendices

Appendix A: Demographic Data Tool

Age in years today: ______________

Sex: Male ☐ Female ☐

Race: American Indian or Alaska Native_____ Asian_____ Black or African American_____ Native Hawaiian or Other Pacific Islander (NHOPI) _____, White_____

State of Residence: _____________________________________

Highest Degree Earned in Nursing:
Associate ☐ Diploma ☐ Bachelors ☐ Masters ☐ Doctorate

Did you receive education in end-of-life care during your nursing program?
___yes ____no

If yes, do you feel it adequately prepared you to deliver end-of-life care to dying infants and their families?
___yes ____no

Have you completed any additional end-of-life education since your undergraduate or graduate program?
___yes ____no

If yes, what additional education did you receive (ELNEC-PPC, Continuing Education, etc.)? ____

What level (I, II, III, or IV) NICU do you work in? ____

What is the total number of years' experience you have had in a newborn intensive care unit? ___________

What is the total number of years you have held a nursing license? _____________

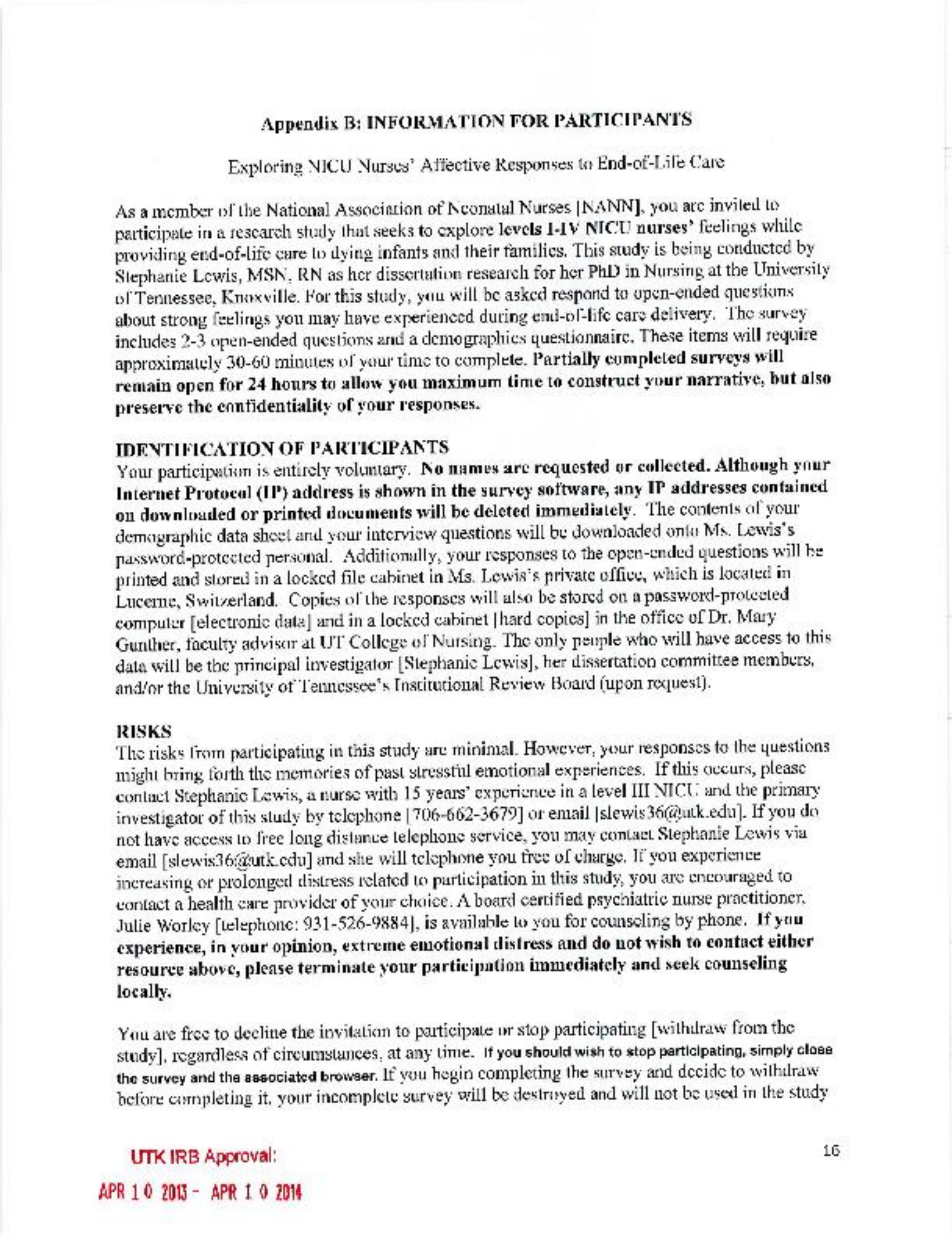
Appendix B: Narrative Participant Survey Question

End-of-Life Care in the NICU

The purpose of this study is to understand NICU nurses' experiences as they care for dying neonates and their families. The way that this information is best uncovered is through the stories, the accounts that practicing nurses give about providing this care, and how it affects the nurse personally and emotionally. Collecting such narratives is the main goal of this research. Share your story as follows:

> *Think of an instance that evoked strong feelings when you were in the situation of providing neonatal end of life care. It may be recent or some time ago. What happened? What stood out for you in the experience? Please include as many details as possible concerning time frames, interactions with others, decisions you made, your responses to this episode (immediate or later) and how you managed feelings that emerged in the process.*

Appendix C: IRB Approval Form



Appendix B: INFORMATION FOR PARTICIPANTS

Exploring NICU Nurses' Affective Responses to End-of-Life Care

As a member of the National Association of Neonatal Nurses [NANN], you are invited to participate in a research study that seeks to explore **levels I-IV NICU nurses'** feelings while providing end-of-life care to dying infants and their families. This study is being conducted by Stephanie Lewis, MSN, RN as her dissertation research for her PhD in Nursing at the University of Tennessee, Knoxville. For this study, you will be asked respond to open-ended questions about strong feelings you may have experienced during end-of-life care delivery. The survey includes 2-3 open-ended questions and a demographics questionnaire. These items will require approximately 30-60 minutes of your time to complete. **Partially completed surveys will remain open for 24 hours to allow you maximum time to construct your narrative, but also preserve the confidentiality of your responses.**

IDENTIFICATION OF PARTICIPANTS

Your participation is entirely voluntary. **No names are requested or collected. Although your Internet Protocol (IP) address is shown in the survey software, any IP addresses contained on downloaded or printed documents will be deleted immediately**. The contents of your demographic data sheet and your interview questions will be downloaded onto Ms. Lewis's password-protected personal. Additionally, your responses to the open-ended questions will be printed and stored in a locked file cabinet in Ms. Lewis's private office, which is located in Lucerne, Switzerland. Copies of the responses will also be stored on a password-protected computer [electronic data] and in a locked cabinet [hard copies] in the office of Dr. Mary Gunther, faculty advisor at UT College of Nursing. The only people who will have access to this data will be the principal investigator [Stephanie Lewis], her dissertation committee members, and/or the University of Tennessee's Institutional Review Board (upon request).

RISKS

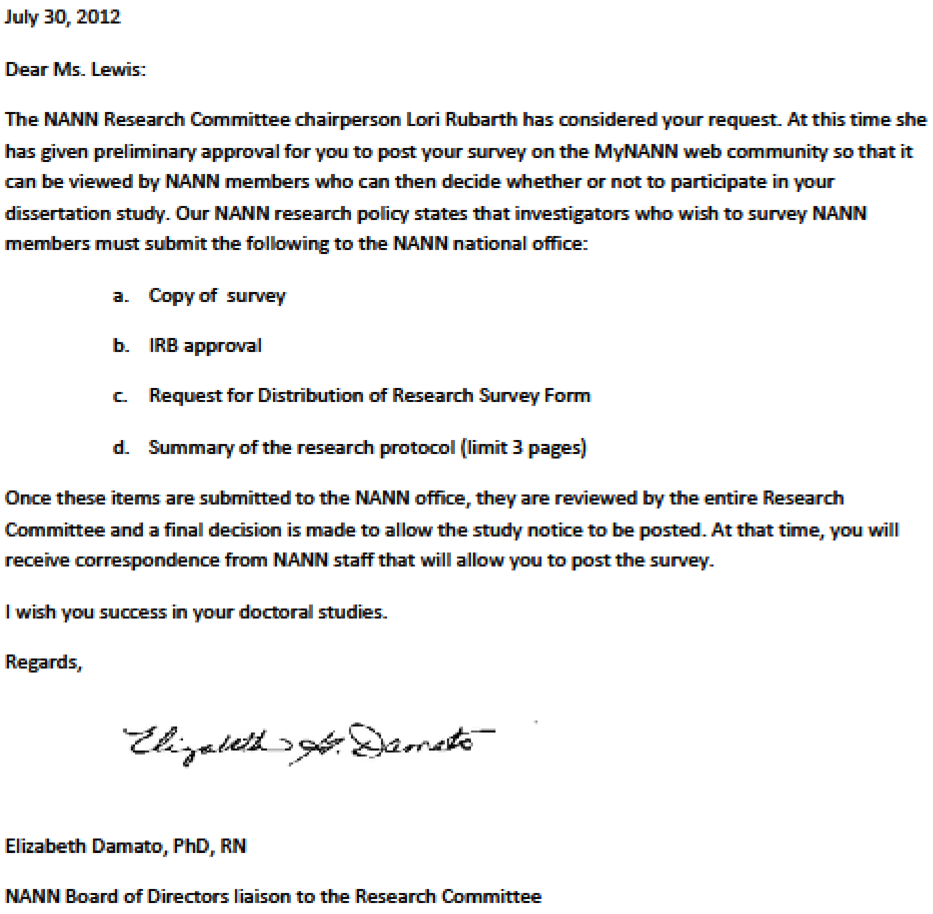
The risks from participating in this study are minimal. However, your responses to the questions might bring forth the memories of past stressful emotional experiences. If this occurs, please contact Stephanie Lewis, a nurse with 15 years' experience in a level III NICU and the primary investigator of this study by telephone [706-662-3679] or email [slewis36@utk.edu]. If you do not have access to free long distance telephone service, you may contact Stephanie Lewis via email [slewis36@utk.edu] and she will telephone you free of charge. If you experience increasing or prolonged distress related to participation in this study, you are encouraged to contact a health care provider of your choice. A board certified psychiatric nurse practitioner, Julie Worley [telephone: 931-526-9884], is available to you for counseling by phone. **If you experience, in your opinion, extreme emotional distress and do not wish to contact either resource above, please terminate your participation immediately and seek counseling locally.**

You are free to decline the invitation to participate or stop participating [withdraw from the study], regardless of circumstances, at any time. **If you should wish to stop participating, simply close the survey and the associated browser.** If you begin completing the survey and decide to withdraw before completing it, your incomplete survey will be destroyed and will not be used in the study

UTK IRB Approval:

APR 1 0 2013 - APR 1 0 2014

Appendix D: NANN Letter of Approval



July 30, 2012

Dear Ms. Lewis:

The NANN Research Committee chairperson Lori Rubarth has considered your request. At this time she has given preliminary approval for you to post your survey on the MyNANN web community so that it can be viewed by NANN members who can then decide whether or not to participate in your dissertation study. Our NANN research policy states that investigators who wish to survey NANN members must submit the following to the NANN national office:

a. Copy of survey

b. IRB approval

c. Request for Distribution of Research Survey Form

d. Summary of the research protocol (limit 3 pages)

Once these items are submitted to the NANN office, they are reviewed by the entire Research Committee and a final decision is made to allow the study notice to be posted. At that time, you will receive correspondence from NANN staff that will allow you to post the survey.

I wish you success in your doctoral studies.

Regards,

Elizabeth G. Damato

Elizabeth Damato, PhD, RN

NANN Board of Directors liaison to the Research Committee

Appendix E: Informed Consent Statement

INFORMED CONSENT STATEMENT

Exploring NICU Nurses' Affective Responses to End-of-Life Care

INTRODUCTION

You are invited to participate in a research study that seeks to explore NICU nurses' feelings while providing end-of-life care to dying infants and their families. This study is seeking participants through the National Association of Neonatal Nurses membership. Your participation will contribute to a study sample size of at least 20 and perhaps, much higher. This study is part of Stephanie Lewis's dissertation research at the University of Tennessee and she will in no way benefit from this study. This survey includes 2–3 open-ended questions and a demographics questionnaire. These items will require approximately 30 minutes of your time to complete: approximately 5–10 minutes to read the informed consent and demographic data sheet, approximately 20 minutes to complete the open-ended question. The survey will remain open for 24 hours to provide you maximum time to construct your narrative and also to increase the confidentiality of your responses. Your participation is entirely voluntary. Although your Internet Protocol (IP) address is shown in the survey software, it will be fully disregarded and any IP addresses contained on downloaded or printed documents will be deleted immediately. *Please exclude any individual and institutional names, as well as city names from any data submitted to increase the anonymity of your identity.*

The contents of your demographic data sheet and your interview questions will be downloaded onto Ms. Lewis's personal computer that is password protected. Additionally, your response to the open-ended question will be printed and stored for a period of three years in a locked file cabinet in Ms. Lewis's private office. The only people who will have access to this data will be Ms. Lewis, the primary investigator, her dissertation committee, or the University of Tennessee's Institutional Review Board (IRB), upon request. The original narratives in their entirety will only be read by the primary investigator and only if necessary by Dr. Mary Gunther and Dr. Joanne Hall, members of the dissertation committee. This data may be re-analyzed in the next three years to explore it for other purposes, such as theory construction. Please indicate on the consent form if you consent to having this data used in future studies. Approval from NANN's Research Committee will be sought for any additional studies that use the data collected here.

INFORMATION ABOUT PARTICIPANTS' INVOLVEMENT IN THE STUDY

For this study, you will be asked respond to an open-ended question about strong feelings you may have experienced during end-of-life care delivery. There are risks and benefits to participating, which are outlined below.

RISKS

Risks from participating in this study are minimal and include that your responses to the questions might bring forth the memories of stressful emotional experiences. If this occurs, please contact Stephanie Lewis, a nurse with 15 years' experience in a level III NICU and the primary investigator of this study by telephone [706-662-3679] or email [slewis36@utk.edu]. If you do not have access to free long distance telephone service, you may contact Stephanie Lewis via email [slewis36@utk.edu] and she will telephone you free of charge. If you experience increasing or prolonged distress related to participation in this study, you are encouraged to contact a health care provider of your choice. A board certified psychiatric nurse practitioner, Julie Worley [telephone: 931-526-9884], is available to you for counseling by phone. If you experience, in your opinion, extreme emotional distress and do not wish to contact either resource above, please terminate your participation immediately and seek counseling locally. You are free to stop participating and to withdraw at any time, regardless of circumstances. If you withdraw before completing the study, your incomplete data results will be destroyed and not used in the study analysis. The information for participants and informed consent are available to participants at all times through the use of the back button. This will ensure that resource contact numbers are available to you if needed. Resources are also listed again at the end of the survey.

BENEFITS

The primary benefit to participants in this study will be the identification of specific feelings and a greater understanding of those feelings that NICU nurses experience while delivering end-of-life care to dying infants and their families. After data analysis is complete, findings will be posted, with NANN’s permission, on the membership discussion board for participants and non-participants to review. This study aspires to build a foundation for future interventional studies that will ultimately improve nurse, patient, and family outcomes in this area.

CONFIDENTIALITY

All information collected about you will be kept confidential. No names or IP addresses will be collected by the primary investigator, but the survey software collects IP addresses as a usual practice. The information will not be shared with anyone who is not directly related to the research study with the exception that that some of the data may be analyzed in future research designs within the next three years. No one will have access to the materials of this study or any future studies using these data except Stephanie Lewis (the principal investigator), her dissertation committee, and the University of Tennessee IRB. Completed interviews and demographic data will be stored securely with password protection in the computer of the principal investigator, Stephanie Lewis. At the end of three years, all data collected during this study will be destroyed. No reference will be made in oral or written reports that could link you to the study.

CONTACT INFORMATION

If you have questions at any time about the study or the procedures, you may contact the researcher, Stephanie Lewis by mail at Brunnhalde 11, 6066 Lucerne, Switzerland or by e-mail at slewis36@utk.edu. If you have questions about your rights as a participant, contact the Office of Research Compliance Officer at (865) 974-3466. Dr. Mary Gunther, my advisor, can also be contacted by mail at The University of Tennessee—Knoxville, College of Nursing, 1200 Volunteer Blvd., Room 239, Knoxville, TN 37996-4180. You may reach Dr. Gunther by phone and email, as well, @ (865) 974-7589 and mgunther@utk.edu.

CONSENT

I have read the above information. I have indicated below that I agree to participate in this study. I have the option of choosing to participate in this study only or participate in this study and consent to have any information I submit used in additional, future studies.

__I agree to participate in this study only

__I agree to participate in this study and consent to my responses being utilized, without identifiers, in future studies.

Appendix F: Recruitment Invitation

After IRB and NANN final approval, the researcher posted a message and link to the survey on the NANN membership discussion board. The following message appeared first in the link:

You are invited to participate in a research study that seeks to explore RNs', who practice in levels I-IV NICUs, feelings while providing end-of-life care to dying infants and their families. This survey includes 2-3 open-ended questions and a demographics questionnaire. These items will require approximately 30-60 minutes of your time to complete. Partially completed surveys will be available to you for further comment for a period of 24 hours, at which time your responses will be recorded. This allows you maximum time to construct your narrative without jeopardizing confidentiality of your responses. Your participation is entirely voluntary; the content of your responses will be confidential. No names are requested or collected. Although your Internet Protocol (IP) address is shown in the survey software, any IP addresses contained on downloaded documents will be deleted immediately. There are [minimal]risks and benefits to participation in this study and they are outlined in detail on the consent screen. You may choose to stop participating at any time. You will be asked to please exclude any individual and institutional names, as well as city names from any data submitted to increase the anonymity of your identity.

If you would like to read about the risks, benefits, and confidentiality of your responses, and participate in this study, please click Continue and you will be taken to the Participant Information screen. If you choose to participate, you will be asked to share a story about a time when you experienced strong feelings while you were providing end-of-life care. Please provide as many details as you can remember and feel comfortable sharing. Thank you for your time.

The *Informed Consent Statement* (Appendix E) contains specific information regarding consent.

Appendix G: Summary Narrative Assessment Template

Summary Narrative Assessment Template

"Affective Responses of NICU Nurses Providing EOLC"

Primary affective response (degree of or magnitude of presence):

Key others present in story:

Key others' behaviors:

Family behaviors:

Spiritual, personal, or religious beliefs (Personal or family):

EOLC education (During school and/or continuing education):

Perceptions of helpfulness of EOLC education:

Additional EOLC education: Yes_____ No _____

NICU level:

Unit policy:

Coping strategies present in story, if any:

Changes in EOLC over time, if indicated:

Age: Gender:

Race:

State:

Level of Education:

Nursing experience (in years; General and NICU)

Vita

Stephanie Lacefield Lewis earned her Bachelors of Science in Nursing from Purdue University in 1988. In 2006, she earned her Master's Degree in Nursing, with a certificate in education, from the University of Phoenix. Most recently, she returned to complete her PhD in nursing through the University of Tennessee–Knoxville.

Over the past 25 years, Ms. Lewis gained extensive NICU and pediatric experience through bedside practice in level III NICUs in St. Paul, Minnesota; Hartford, Connecticut; and Columbus, Georgia. She has served as a clinical instructor in NICUs and adult medical-surgical units during her 10-year tenure at Columbus State University (CSU) in Columbus, Georgia, At CSU, Ms. Lewis reached the level of associate professor of nursing while teaching many courses across the baccalaureate curriculum, in both face-to-face and online formats. Ms. Lewis has extensive experience in curriculum building and revision, having served as CSU's chair of the curriculum committee. She has successfully designed numerous courses and on-line learning modules. Ms. Lewis is certified in nursing education and end-of-life care.

In addition to receiving promotion to associate professor, Ms. Lewis was nominated and selected to attend the Governor's Teaching Fellowship, a yearlong intensive study program, during the 2009–2010 academic year. She was selected as outstanding faculty member in 2009 and chosen by students to pin senior graduates during the honor's ceremony in 2010 and 2012.

During her years at CSU, Ms. Lewis actively presented on numerous topics related to nursing education: online teaching methods, student success, clinical teaching methods, integrating writing across nursing curriculums, and encouraging professional growth among nurse faculty (see references below).

Fostering Collaboration and Critical Thinking in Adult Nursing Student Distance Learners using a Web 2.0 Tool: Wikispaces. 2011 Distance Learning Conference. Columbus, Georgia. **S. Lewis.** September 2011. Podium Presentation.

Cultivating Growth in Nurse Educators. 2011 Annual Georgia Association for Nursing Education Conference, Savannah, Georgia. A. Hawkins, E. Frander, & **S. Lewis**. February 2011. Podium Presentation.

Reducing Student Attrition through a Student Success Program. 2010 American Association of Colleges of Nursing, Orlando, Florida. **S. Lewis**, A. Hawkins, & E. Frander. November 2010. Podium presentation.

Facilitating Critical Thinking in Clinical: The Why and How Method. 2010 Annual Georgia Association for Nursing Education Conference, Callaway Gardens, Pine Mountain, Georgia. **S. Lewis**. February 18–20. Podium presentation.

Integration of Writing across the Nursing Curriculum: Using University QEP Grants. Transitions: Facilitating Excellence in Nursing Education. 2010 Annual Georgia Association for Nursing Education Conference. Callaway Gardens, Pine Mountain, Georgia. C. Smith, S. Noviello, **S. Lewis**, & A. Hawkins. February 18-20. 2010. Podium presentation.

Student Success in a Baccalaureate Nursing Program. 2009 Annual Georgia Association for Nursing Education Conference, St. Simons Island, Georgia. A. Hawkins, **S. Lewis**, E. Frander, G. Jones, & L. Santo. February, 2009. Poster Presentation.

Ms. Lewis also published an article focused on nurse educators:

Hawkins, M., Frander, E. & **Lewis, S.** (2012). Cultivating an Environment for Continued Growth in Nurse Educators. *Perspectives in Learning: A Journal of the College of Education & Health Professions*, *13*(1), 39–45.

Focusing on end-of-life care in the NICU setting, Ms. Lewis published research findings and an editorial while in doctoral school:

Lewis, S. (2013). What's in a name? [Editorial] *Journal of Palliative Medicine*. *16*(3): 220–221. doi:10.1089/jpm.2012.0454.

Lewis, S. (2012). Critical reflection as a facilitator of palliative care in the NICU. Journal of Hospice and Palliative Nursing, 14(6), 405-413. doi:10.1097/NJH.0b013e318258d083.

Lewis, S. (2012). Palliative care in the NICU: Our past and our future. *Journal of Hospice and Palliative Nursing, 14*(2).

During her course of study at UTK, Ms. Lewis was awarded the Baron Scholarship and was inducted into the Phi Kappa Phi Honor Society. Ms. Lewis is active as a reviewer for *Issues in Mental Health Nursing* and *Dove Medical Press Journals,* lending her expertise in the areas of research methods, NICU, end-of-life care and pediatric care.

Currently, Ms. Lewis lives in Switzerland with her family. In 2015, she hopes to return to the United States and obtain a position with a research-intensive university. Until then, she plans to teach nursing on-line and continue her research in end-of-life care in the NICU setting.