


2016

# Making a Difference: Evidence Based Palliative Care Education for Neonatal Nurses

Sherry Elaine Pye  
*Walden University*

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# Walden University

College of Health Sciences

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Sherry Pye

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2016

Abstract

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by

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MNSc, University of Arkansas for Medical Sciences 1998

BSN, University of Arkansas at Pine Bluff, 1989

Project Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Nursing Practice

Walden University

May 2016

## Abstract

The death of a neonate is a life-changing and tragic experience for the individuals involved in the final moments of the infant's life. As the frontline provider in this clinical scenario, the bedside nurse supports the patient and family through their individual journey of loss. If the nurse does not possess the palliative care educational background and communication skills to support this unique care delivery process, the journey of death can evolve into a particularly negative experience for the parents and the nurse. This specific delivery of care concern was identified and gleaned from a parental bereavement exit interview after the loss of an infant in the neonatal intensive care unit (NICU) at Arkansas Children's Hospital (ACH). Due to the lack of educational preparation, the NICU nursing staff members had demonstrated inexperience, awkwardness, and insecurity in their provision of the end-of-life care activities and family support interventions. The purpose of this doctor of nursing practice project was to develop an evidence-based neonatal palliative care educational program to support the NICU nursing staff and families at ACH. The educational program is multimodal in approach to address the cognitive, affective, and psychomotor domains of adult learning through the use of palliative care informational modules, videos, and simulation training. The clinical outcome of this new palliative care educational program will promote a positive change in the NICU nursing staff's clinical practice during the provision of nursing care when faced with neonatal end-of-life situations at ACH. This capstone project on adult education should be read by professional frontline nursing staff who care for these fragile patients in the specialized intensive care world of neonatology.

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## Dedication

To my daughter, Renee, and my mom, Ruth - Without your love, support, and ongoing words of encouragement, this accomplishment would not be possible. Your belief in me has given me the opportunity to fulfill my educational goals. I love you!

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## Section 1: Overview of the Evidenced Based Project

### **Introduction**

Death. The concept and final reality of human death is a basic facet of life that everyone encounters and must endure. The process leading up to death can be visualized and addressed from a developmental standpoint in which this specific milestone should occur after one's journey has been completed over a lifetime of experiences. As human beings, we will all encounter and eventually experience the death of a loved one or a close acquaintance. However, when death occurs unexpectedly in the young, the aftermath can be truly unorganized, chaotic, and devastating.

The death of a neonate is a life changing experience. This unfortunate tragedy affects all of the individuals involved in the final moments of the infant's life. Providing the end-of-life care for critically ill neonatal patients and their families is within the complicated care continuum that neonatal intensive care unit (NICU) nurses face in their scope of practice and clinical realm. This tragedy can be emotionally distressing for all professionals involved in this experience but especially for the frontline nursing staff as a negative patient outcome becomes realized and the loss of life occurs.

Nurses in the NICU face life and death on a daily basis. Without adequate palliative care education and communication skills, this challenging environment can negatively impact the nursing staff. Cavaliere, Daly, Dowling, and Montgomery (2010) performed a descriptive, correlation study to evaluate the intensity and frequency of moral distress in NICU nurses ( $N = 94$ ). The outcome data in specific participant responses demonstrated the incidence and effects of moral distress. The issue of moral

distress in the NICU nursing staff is concerning for issues of burn out and turnover (Cavaliere, Daly, Dowling, & Montgomery, 2010). The repetitive occurrence of these negative clinical outcomes can affect the overall quality of delivered nursing care due to the loss of experienced staff members, and from a budgetary standpoint, the additional expenses and time that are mandated to meet the provision of orientation for replacement of lost staff members.

### **Background**

Over the past 15 years, the specialty of palliative care has evolved into clinical practice and the discussion of end-of-life care has surfaced in the literature (Himmelstein, 2006; Lewis, 2012). Himmelstein (2006) discussed and outlined the initial goals of palliative care which can be vast and include the following: (a) patient care that is coordinated and communicated across all avenues of the care delivery spectrum and multidisciplinary in approach; (b) clinical care that is patient focused, relationship centered, and family oriented; (c) clinical care interventions that are individualized for any child who may be experiencing a disease entity that may be life threatening, chronic, or terminal in nature; (d) medical and nursing care that is goal oriented towards the quality of life for the child and family; (e) promotion of patient and family advocacy through the care continuum process and across medical providers; and (f) specific patient care interventions focused on the relief of suffering. Many medical personnel associate the provision of palliative care as the physical end-of-life care interventions that are focused on comfort with the goal of a peaceful death (Himmelstein, 2006). An important facet of palliative care that is not readily identified is that of communication (Feudtner,

2007). How does one communicate to the dying? How does the frontline nurse communicate to the dying infant's parents and family members? Palliative care education creates a foundation of communication skills that are essential in meeting the needs of those involved in this specific clinical scenario of loss (Feudtner, 2007).

The medical and clinical care specialty of palliative care has evolved into further subspecialties required to meet the specific needs of different patient populations. Palliative care subspecialties have been identified in a variety of different pediatric patient populations such as childhood oncology, neonatal, newborn, and pediatric (Gale & Brooks, 2006; Himmelstein, 2006; Lewis, 2012; Romesberg, 2007).

### **Problem Statement**

The problem statement for this doctor of nursing practice (DNP) project was as follows: the NICU nursing staff at Arkansas Children's Hospital (ACH) demonstrate inexperience in the provision of end-of-life care activities and family support interventions due to limited neonatal palliative care education and training. A parental bereavement exit interview after the loss of her child in the NICU at ACH highlighted this glaring clinical deficit in the practice of the frontline nursing staff. The mother returned to the institution after 6 months to share her concerns and thoughts which had occurred during this unfortunate life changing experience of loss. She stated that during her child's passing, she had felt that the inexperience of the NICU nursing staff had complicated the personal and painful experience of loss by being awkward (L. Jones, DNP, personal communication, March 3, 2015).

### **Purpose Statement**

The purpose of this DNP project was to collectively develop an educational program focused on the provision of neonatal palliative care education for the NICU nursing staff at ACH. The proposed educational program was designed as multimodal in approach to be facilitated in two paired timed learning stages. The three domains of adult learning, which are cognitive, affective, and psychomotor, was used to address and facilitate the learning process of the NICU nursing staff (Hand, 2006; Krathwohl, 2002; Yaeger et al., 2004). The specific communication skills required for the provision of effective and quality neonatal palliative care was highlighted in the didactic and video learning materials of this educational program. The palliative care content and required communication skills will be expanded upon and solidified during the return demonstration phase of the education program during specific simulation training exercises.

### **Project Objectives**

The main objective for this educational program was to provide the NICU nursing staff at ACH a beginning foundational platform focused on the specific concepts of neonatal palliative care and required communication skills. After completing the multimodal education program, the individual NICU nurses will be able to effectively care for and meet the end-of-life needs of these unfortunate neonates and their families. Effective clinical interventions and communication skills will be used and executed so that no family leaves the NICU after the horrible tragedy of a neonatal loss with feelings, thoughts, or concerns that the experience was complicated or overshadowed by



inexperienced nursing personnel. The second objective will be to build a foundational educational program that can be revised over time and collectively strengthened through the addition of newly available or cutting edge educational materials and skills as evidenced through new research and literature. The format of the education program will make execution of the program feasible based on institutional resources and funding. Annual usage and execution of the educational program will meet the needs of new employees and reinforce palliative care education for experienced nursing staff members thus promoting the sustainability of the overall program over time.

### **Guiding and Practice**

The unique needs of the neonate and family at the time of death has prompted care efforts aimed at the standardization of end-of-life care into the specialty of neonatal palliative care (De Lisle-Porter & Podruchny, 2009; Gale & Brooks, 2006; Himmelstein, 2006; Lewis, 2012; Moro, Kavanaugh, Okuno-Jones, & Vankleef, 2006; Romesberg, 2007 ). Inadequate nursing staff preparation and education have been identified as a barrier in the literature to effective neonatal palliative care (Browning & Solomon, 2005; Gale & Brooks, 2006; Kain, 2011; Lewis, 2012; Martin, 2013; Peng et al., 2013; Romesberg, 2007). This was unfortunately highlighted and identified in the personal NICU parent's bereavement exit interview at ACH.

### **Significance of the Project**

Compared to 30 years ago, the NICU is now a bright and shiny technologically advanced environment of intensive care where infant mortality unfortunately remains a stark reality. The rate of infant mortality in the United States for 2008 was calculated as

6.61 per 1,000 live births with the highest percentage of 35.4% of the total infant deaths from the preterm and low birth weight patient populations (Centers for Disease Control and Prevention [CDC], 2012). The NICU at ACH averages a loss of approximately 30 neonates or infants annually (L. Jones, DNP, personal communication, March 3, 2015).

This loss of life in the NICU is a devastating outcome that unfortunately continues to occur due to pathophysiological states such as prematurity, complex congenital lesions, or malformations that are not responsive to the current advances in neonatology intensive care. When medical technology and clinical efforts fail to cure, sustain, or treat end-stage disease or non-life sustaining pathophysiology, the clinical focus must change and new patient care goals be created and achieved (Kang & Feudtner, 2012). Neonatal end-of-life care should be provided and communicated efficiently to promote the infant's comfort and a peaceful death (Kain, 2011). The provision of support for the infant's parents and support family members should be concurrently provided.

The provision of neonatal palliative care is best addressed and provided from a multidisciplinary approach. The components of a NICU palliative care program may include the following: palliative care team consultation model before death with collaboration after death, family-centered in focus, pain management, comfort strategies, organ donation, nursing assignments, nursing protocols for infant care, parent priorities with family input, memory making interventions, communication skills, educational resources for caregivers and nursing staff, and family follow-up (Gale & Brooks, 2006). The provision of neonatal palliative care education through the use of this evidence-based project will provide the frontline nursing staff team members a beginning foundation of

tools and communication skills aimed at supporting the patient and family during their end-of-life journey and will also prepare them to become strong members of the multidisciplinary team.

### **Reduction of Gaps**

Although evidenced-based literature (EBL) focused on the multiple facets concerning the availability and provision of neonatal palliative care is present in the literature and its use supported within many published medical organizational positional statements, the execution of consistent neonatal palliative care is limited at the clinical bedside in the NICU environment. This gap in the clinical practice of the NICU nurses was highlighted through the parental exited interview. This multimodal program was aimed at reducing the gap in the nursing palliative care education that exists in the frontline NICU nursing staff's repertoire.

### **Implications for Social Change**

The current state of palliative care use in the NICU clinical environment has been reviewed in the literature and documents a limitation in its use. A review of the research literature performed by Moro, Kavanaugh, Okuno-Jones, and Vankleef (2006) documented the current application of neonatal palliative care. The 10 articles which met inclusive criteria identified the following areas of palliative care practice as an area of concern: practices of withholding or withdrawing treatment, parental involvement in decision making process, pain management, the dying process, and low percentage of use of palliative care consultation (Moro, Kavanaugh, Okuno-Jones, & Vankleef, 2006).

This educational project focused on the provision of supported neonatal palliative care that has the ability to begin a new movement of social change in this specific NICU environment. The use of this multimodal educational program focused on neonatal palliative care and communication skills has the potential of building a beginning foundational platform that will improve the clinical practice of approximately 150 registered nurses (RN). Through annual repetition and mentoring through experience, this evidence-based practice (EBP) standard of clinical practice shifts the clinical performance paradigm in a positive direction as the provision of individual neonatal detailed end-of-life care for patients and families in the NICU becomes transformative and positive in their journey of death.

### **Definition of Terms**

The following phrases or words have been defined for the purposes of this DNP project:

*Arkansas Children's Hospital (ACH):* The only pediatric designated medical facility in the state of Arkansas (AR) which is focused on providing world-class medical care and treatment to children in the state of AR and the surrounding geographic areas. ACH is a 370 bed medical facility that spans nearly 30 city blocks that is staffed by approximately 500 physicians, pediatric residents, and pediatric specialists (ACH, 2015a.).

*Congenital malformations or lesions:* A physical anomaly that occurs in early fetal conception and development that varies in severity and functional outcome.

Approximately 2% to 4% of the infants who are born in the United States are diagnosed

with a congenital malformation that is either developmental or genetic in origin (Marcdante, Kliegman, Jenson, & Behrman, 2011). The predicted clinical outcome will be dependent on the specific diagnosis, genetic disorder, or spectrum of dysfunction.

*Death:* The end-of-life or clinical state in which all vital functions have permanent cessation (*Merriam-Webster Dictionary*, n.d.a).

*End-of-life care:* The provision of care that is provided as one is experiencing the journey of death. Care that is goal oriented to provide comfort and peace while meeting the many aspects of physical, spiritual, social, and cognitive domains (Marcdante, Kliegman, Jenson, & Behrman, 2011).

*Infant:* An infant or a child that is chronologically older than 1 month of age but remains in the first year of life (*Merriam-Webster Dictionary*, n.d.b)

*Infant mortality rate:* The statistical calculation and epidemiological expression of the rate of death of infants for an expressed period of time and location. The rate is determined by dividing the number of reported infant deaths by the number of live births reported for a specific calendar year (Friis & Sellers, 2014).

*Neonatal:* Described as actions or situations surrounding the time period of a newborn child that is less than 1 month old in age (*Merriam-Webster Dictionary*, n.d.d).

*Neonate:* A neonate can be defined as a newborn child that is chronologically less than 1 month old in age (*Merriam-Webster Dictionary*, n.d.c).

*Neonatal Intensive Care Unit (NICU):* The specialized intensive care unit (ICU) environment that is technologically prepared and focused on the provision of medical care and interventions that are required to meet the particular needs of the neonate and

infant populations. These specific acute and chronic care medical needs may include but are not limited to the issues of prematurity, congenital malformations, or acquired diagnoses such as infection or birth related illnesses (Mathews & Macdorman, 2012).

*Pediatrics*: A term used to describe the health care of children which includes prevention and treatment of childhood diseases (*Mosby's Medical Dictionary*, 2009).

*Palliative care*: Has been defined by the World Health Organization (WHO) as follows:

“is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (WHO, n.d.).

*Palliative care education*: The specialized area of education focused on the didactic information and communication skills required during the provision of the palliative care and interventions (Bush & Shahwan-Akl, 2013; Rogers, Babgi, Gomez, & Catlin, 2008).

*Prematurity*: A clinical state that is used to describe the age of a newborn who is born after a gestational state of less than 37 weeks of a full term pregnancy (*Merriam-Webster Dictionary*, n.d.e).

*The Pediatric Understanding and Learning through Simulation Education (PULSE) Center*: The PULSE Center is a dedicated program located on the ACH campus that specializes in the art of comprehensive simulation education in pediatrics (ACH,

2015e). The PULSE Center uses high fidelity manikins and a standardized patient program to make the simulation learning scenarios a cutting edge educational experienced for the learners of pediatric care (ACH, 2015e).

*Registered Nurse (RN)*: An individual who has undergone specialized educational training and possesses licensure by a state authority to provide clinical care to patients of different ages in a multitude of clinical situations (*Merriam-Webster Dictionary*, n.d.f).

### **Theoretical Foundations**

Three theoretical frameworks were identified to guide this DNP project that was focused on the adult learning of neonatal palliative care education and associated communication skills. The first theory is the social cognitive theory by Bandura (1977), which is based on the inclusive concepts “that individuals learn by direct experiences, human dialogue, and interaction” (White & Dudley-Brown, 2012, p. 54). The multimodal format of this program integrates and interacts with the individual nurses’ cognitive, affective, and psychomotor domains of adult learning identified from Blooms Taxonomy, which are comprised as the personal components that affect behavior change (Krathwohl, 2002; White & Dudley-Brown, 2012). The social cognitive theory integrates the different learning patterns and domains into the learning experience to allow the nurse to facilitate the provided new knowledge concepts and skills into everyday clinical practice. White and Dudley-Brown (2012) discussed that this theory was very useful when integrating positive change into clinical practice through the use of an educational program. The adult learning theory created by Knowles (1981) provides a theoretical framework that guides learning conceptually by stating that “adults need to know why they need to learn

something” (McEwen & Wills, 2011, p. 364). The registered nurses (RNs) in the NICU will have to actualize the purpose and end goal of this educational program that is the provision of prepared and experienced end-of-life care for dying neonates or infants and their family members. Lastly, Benner’s model of skill acquisition in nursing is applicable to this educational program that focuses on the obtainment of didactic education and communication skills for clinical practice (McEwen & Wills, 2011; Rogers, Babgi, Gomez, & Catlin, 2008). The clinical experience of the frontline nursing staff in the NICU comprises of a range of new graduate RNs to those who have practiced in this specialized field of neonatal nursing for greater than 20 years. The 5 stages of skill acquisition meet the individual needs of these learners who are in their own unique stage of learning and promotes their own ongoing process of skill acquisition (McEwen & Wills, 2011).

### **Nature of the Project**

This scholarly DNP project focused on the development of an educational program on the topic of neonatal palliative care education directed at the frontline nursing staff of the NICU at ACH. The educational program was planned and designed as multimodal in approach that will be facilitated in 2 learning stages that will address the domains of adult learning (Hand, 2006; Krathwohl, 2002; Yaeger et al., 2004). The first stage of the educational intervention will be delivered in a self-paced, independent didactic format that addresses the domains of cognitive and affective learning by using 3 learning models focused on the concepts of pediatric and neonatal grief and bereavement. The online ACH Training system will be used to deliver these palliative care educational



models. The NICU nursing staff can access the educational materials 24/7 so that independent review and learning can be used to promote self-paced adult learning. A post-test format is included within each learning model that will allow the learner to evaluate the accomplishment of the learned content. Two online videos accessed through the ACH online training system will be used to facilitate learning in the affective domain. The videos will be selected from the Initiative for Pediatric Palliative Care (IPPC) learning videos (IPPC, 2015). These learning videos focus on the use of palliative care communication skills during parent interactions surrounding the experience of grief and loss of a child.

The second stage of the planned educational program will address the psychomotor domain of adult learning. The PULSE Center at ACH will be used to facilitate simulation training on palliative care. Specific neonatal clinical scenarios will be developed utilizing trained standardized persons to focus on the specialized communication skills used in effective neonatal palliative care. The neonatal nurse will be able to learn, interact, and exercise new communication skills focused around the loss of a neonate in the NICU. The PULSE Center provides a safe and supportive environment to facilitate the learning of new skills. A randomized controlled trial by Hsu, Chang, and Hsieh (2015) was performed to compare communication self-efficacy, performance, and competency through the use of simulation training compared to traditional training. The outcome data demonstrated that improved communication skills and performance were promoted through the use of the simulation training (Hsu, Chang, & Hsieh, 2015).

### **Assumptions**

I made several assumptions associated and delineated with and within this educational program for this DNP project. First, the RNs comprising the frontline NICU nursing staff have to be accepting and ready for the introduction of a new educational program focused on palliative care education and training in their clinical practice environment. This beginning acceptance has been demonstrated by the establishment of a new clinical nursing committee focused on the deficit in the delivery of nursing palliative care in the NICU. The NICU Helping Our Parents Endure (HOPE) committee was conceptualized and established in the spring of 2015 (L. Jones, DNP, personal communication, March 3, 2015). The nursing members of the HOPE committee have been strategizing on ways to assist and support the NICU parents who are unfortunate in their journey of loss. Second, successful completion of this educational program is dependent on the use of available organizational resources that may include personnel from the instructional media department, the online educational training system, and the resources found in the PULSE Center. Lastly, the support and championing for the success of this educational program must be facilitated by the NICU administrative and educational teams. Through the use of positive communication and mentoring activities, the frontline staff will align with the clinical significance of this educational offering.

### **Scope and Delimitations**

In an effort to pursue and successfully manage the completion of this DNP project, I identified and set parameters. The specialized ICU environment of the NICU at ACH was selected as the setting for the introduction of this educational program focused

on neonatal palliative care. The RNs comprising the NICU frontline nursing staff were identified as candidates and recipients for the educational offering and simulation training. The ACH PULSE Center was selected as a safe, protected environment for the frontline nursing staff to explore, execute, and use the new communication skills required for the provision of neonatal palliative care in specialized simulation training exercises.

### **Limitations**

When proposing or strategizing the conception of a new endeavor, one must perform an assessment of any potential barriers or limitations that may occur to prevent the success of the task (Kettner, Moroney, & Martin, 2013). The focused goal of this DNP project was to deliver an educational experience that will provide a foundational platform on neonatal palliative care for the NICU frontline nursing staff. The value of the individual learner's readiness, which is delineated into the realms of physical, emotional, experiential, and knowledge, is an important concept that may be readily identified as a potential limitation to the success of the program (White & Dudley-Brown, 2012). The institution has been undergoing a continuous process of change over the last 2 years due to restructuring of services and management personnel. This unstable environment may compound the readiness value and acceptance of the nursing staff.

### **Summary**

The journey of loss from the death of a neonate affects the parents and nursing professionals involved in the care of the dying infant. The execution of this educational program focused on neonatal palliative care will be instrumental in informing and affecting policy and clinical practice within the nursing professionals and discipline at

ACH. The potential clinical outcomes facilitated from this DNP project are far-reaching and underpinned in facilitating the journey of loss for future families in the NICU.

Section 2 provides an overview of the theoretical foundation and the current evidence in the literature supporting this multimodal educational program.

## Section 2: Review of Literature and Theoretical and Conceptual Frameworks

### **Literature Review**

The purpose of this project was to delineate an argument for the conceptualization and facilitation of my multimodal educational program for the frontline NICU nursing staff. The implementation of this project will provide an educational platform on neonatal palliative care for the frontline nursing staff in the NICU at ACH. Over time, this will facilitate and impact patient care in the NICU clinical environment and the unfortunate experience of death. In this chapter, I will discuss the theoretical underpinnings focused upon adult learners and educational experiences. The in-depth literature review revealed the evidence in support of and need for palliative education with a neonatal focus along with the gaps in the current level of research.

### **Library Database Search**

A thorough and methodical search of the literature was performed using the following electronic databases: (a) CINAHL, (b) Ovid Nursing Journals Full Text, (c) PubMed, (d) Google Scholar, (e) Cochrane Database of Systematic Reviews, (f) Medline with Full Text, (g) Joanna Briggs Institute EBP Database, (h) PsycINFO, and (i) National Guideline Clearing House. The following key terms were used to explore the body of literature: *palliative care*, *pediatric palliative care*, *neonatal palliative care*, *end-of-life*, *adult learner*, *simulation training*, *simulation education*, *palliative care communication*, *social cognitive theory*, *Bloom's Taxonomy*, *adult learning theory*, *Benner's theory of skill acquisition*, and *high fidelity simulation training*. The investigation of the literature revealed evidence that supported the educational project focused on neonatal palliative

care, and unfortunately, revealed existing gaps in the current level of research and literature.

### **Scope of the Literature**

To fully encompass the current state of the literature and research data surrounding palliative care in clinical practice, literature in the field was searched and reviewed between the years of 2000 and 2015. The search revealed a vast amount of research data and literature so limiting boundaries were enacted upon to focus solely on the specific neonatal and pediatric patient populations. The topics pertaining to adult and cancer care as related to palliative care activities were excluded from the extensive literature review.

### **Concepts, Models, and Theories**

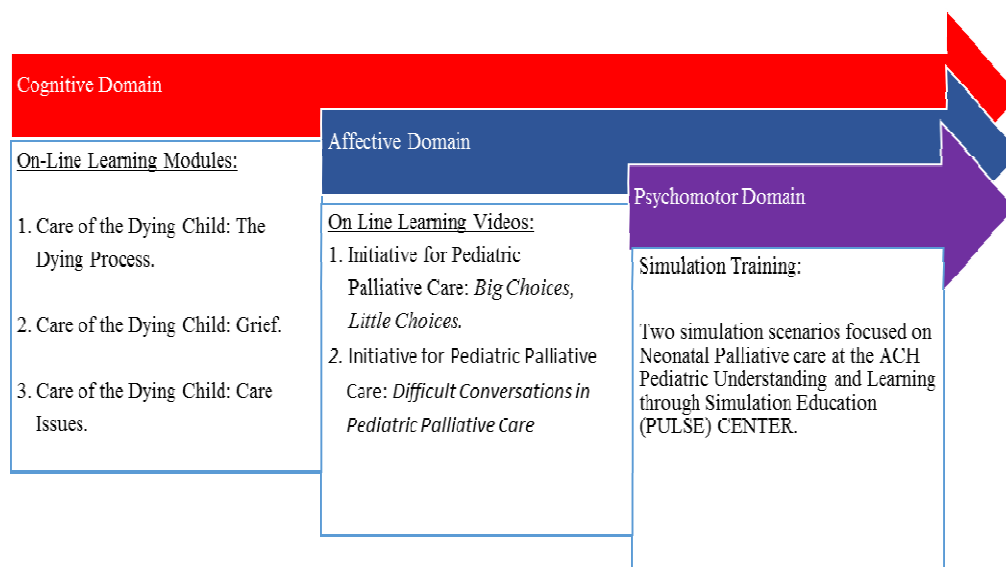
The daily clinical practice of today's nurses is founded upon and guided by the various concepts and constructs found in a large range of multidisciplinary theories. The use of theory provides structure, function, and tradition to nursing practice that evolves and promotes nursing as a profession and as an academic discipline (McEwen & Willis, 2011). Three theories that focused on the principles of adult learning and behavioral change were selected to guide this DNP-led educational program.

#### **Social Cognitive Theory**

Bandura's (1977) social cognitive theory, previously called the social learning theory, posits that individuals learn and change their behavior through direct experiences, observation, human dialogue, and human interaction (White & Dudley-Brown, 2012). Interaction with the environment provides the learner with influences and stimuli that

affect the learning process. Individuals learn through their senses and as a learner, their behavior undergoes change due to environmental influences, personal factors, and attributes of the behavior itself (McEwen & Wills, 2011; White & Dudley-Brown, 2012). We as individuals are human and are affected in different ways by different experiences and environmental influences. Our learning journeys as nurses are a blend of our educational and clinical experiences.

The cognitive, social, and psychomotor learning domains of Bloom's Taxonomy blends and leads change within this learning theory (Krathwohl, 2002). The multimodal approach of this educational program is guided by the learning domains and influences of the learning environment. The nursing leadership and educational team of the NICU set forth the professional expectations and provide learning opportunities for the frontline nursing staff. This educational charged environment provides the stimuli and experiences for the NICU nurses. Figure 1 demonstrates a schematic representation of the multimodal educational program on neonatal palliative care that actively engages the theoretical concepts and constructs of this theory that was developed by me.

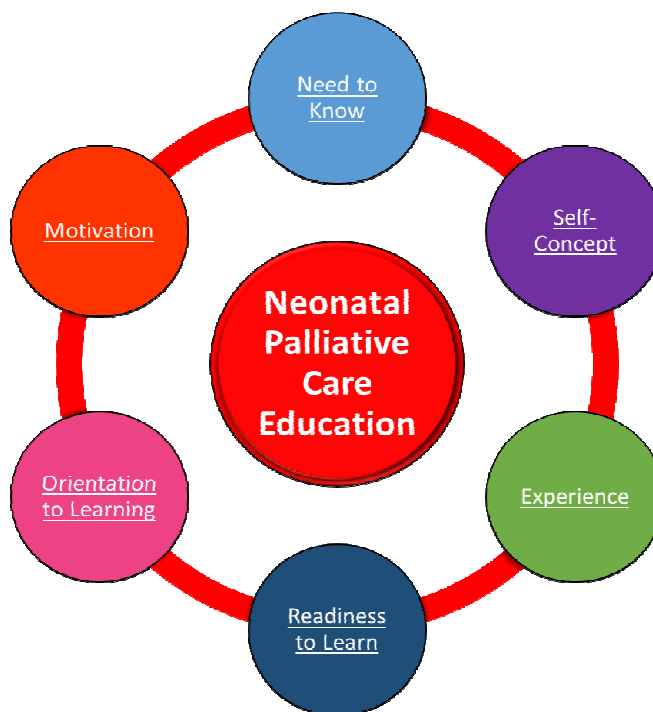


*Figure 1.* Multimodal Neonatal Palliative Care Educational Program. Adapted from Krathwohl, 2002; McEwen & Wills, 2011; IPPC, 2015.

### **Adult Learning Theory**

Knowles (1981) postulated one of the first adult learning theories that focused on the needs and readiness of the learner (McEwen & Wills, 2011). The assumptions of this learning theory are accumulated and burdened by the learner (McEwen & Willis, 2011). Associated learning assumptions include the following: motivation, orientation to learning, experience, readiness to learn, self-concept, and need to know (McEwen & Wills, 2011). Figure 2 is a schematic representation of the adult learner approaching a new learning experience as conceptualized by me.





*Figure 2.* Application of Adult Learning Theory. Adapted from McEwen & Wills, 2011, p. 364.

The members of the frontline nursing staff are adult learners who face new clinical challenges and experiences on a daily basis in the high technological environment of the ICU. From a developmental standpoint, the adult learner is an individual, in this particular scenario a NICU nurse, who has evolved in his or her own educational journey and has achieved a certain level of knowledge and experience. The progression of an adult through this learning theory is facilitated by a natural progression that evolves, hopefully, with success into a higher level of thinking and comprehension (McEwen & Wills, 2011). It is a professional obligation for nurses at ACH to demonstrate growth in educational foundation and clinical expertise (L. Jones, DNP, personal communication,

March 3, 2015). Gallagher (2007) performed a concept analysis on continuing education in the discipline of nursing. Obtainment and completion of ongoing continuing education is an expected professional behavior that is beneficial to the nurse through academic credibility and professional status and to the patient as evidenced by the quality of delivered healthcare (Gallagher, 2007). The NICU frontline nursing staff are adult learners who have a professional commitment to provide cutting edge and quality-assured nursing care. Their participation in the quarterly educational requirements demonstrate their learning evolution and journey which will include the upcoming program focused on palliative care education and simulation training.

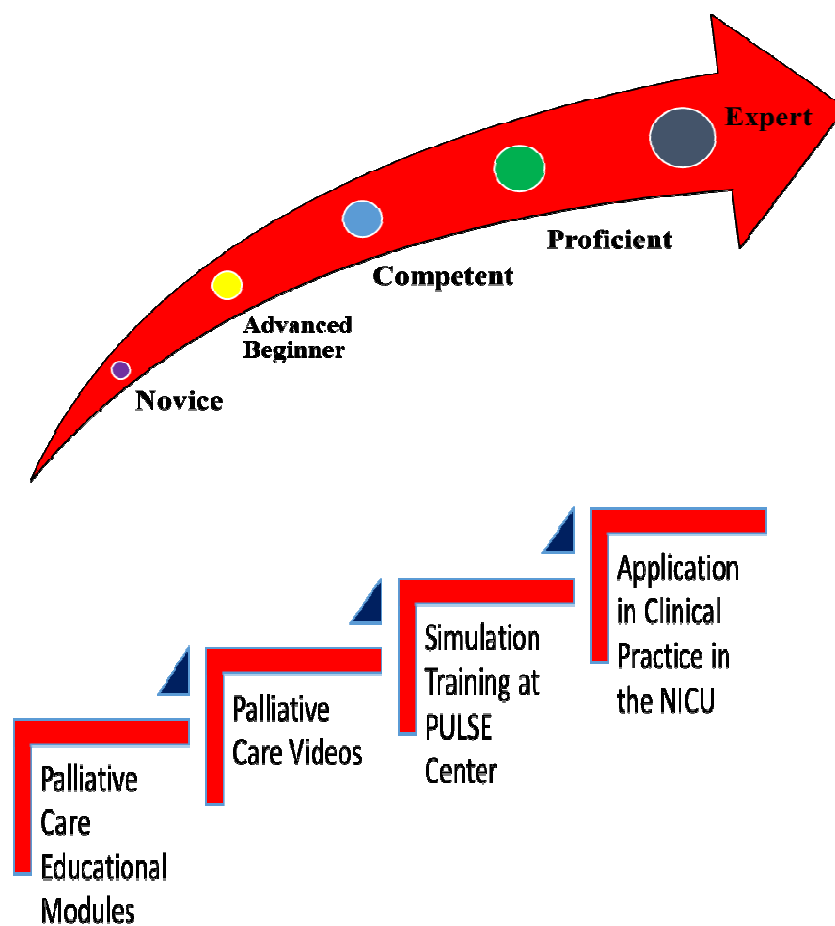
### **Benner's Model of Skill Acquisition in Nursing**

The high middle range theory by Benner (1984) focuses on and describes the evolution of nursing skill acquisition that can be described through the different stages of “novice, advanced beginner, competent, proficient, and expert” (McEwen & Wills, 2011, p. 221). In daily clinical practice, a nurse combines conceptual constructs, foundational theories, and clinical information to develop individual knowledge that is practice driven, evolves over time, and specific to the clinical experiences and settings (McEwen & Wills, 2011). The core constructs that are integral to this model include practical knowledge, experience, competence, skill acquisition, and clinical knowledge (McEwen & Wills, 2011). The conceptual evaluation and application of this theory has been documented in clinical practice as evidenced in the literature. Standing (2007) performed a qualitative study to explore the journey of clinical experience of nursing students as they evolved into the role of an RN. In this specific sample ( $N = 20$ ), the concepts and perceptions of

the respondents were identified as a pattern of developmental milestones that were accomplished over time through experience as the nursing student evolved in their roles from student to practicing graduate nurse.

Larew, Lessans, Spunt, Foster, and Covington (2006) applied Benner's concepts of skill acquisition to clinical protocols as part of an interactive patient care simulation exercise. Their simulation scenarios focused upon common postoperative problems found in the adult population. The training allowed the participants to refine and grow in their skill proficiency focused on their individual communication and management skills (Larew, Lessans, Spunt, Foster, & Covington, 2006).

Individually, each nurse evolves through the stages of skill acquisition, either partially or completely, with each new encountered learning activity or patient care situation. The final stage of skill proficiency is individual and may fall somewhere along the continuum of the acquisition success (McEwen & Wills, 2011). Each individual nurse may have different levels of stage achievement for different skills and clinical situations. Handwerker (2012) discussed the use of constructs found in behaviorism to create a transformation in today's nursing education. Educators can facilitate skill acquisition through repetitive behaviors that allow for an exchange of perception, judgment, cognitive knowledge, and skill action (Handwerker, 2012). Benner's model can be applied to the proposed neonatal palliative care education program. Figure 3 is a schematic representation of Benner's model of skill acquisition that has been conceptualized by me.



*Figure 3.* Application of Benner's Model of Nursing Skill Acquisition Theory. Adapted from McEwen & Wills, 2011, p. 364.

Each of the NICU nurses' have developed their own level of educational foundation and experience within the NICU environment and with the death of a neonate as a frontline provider. The multimodal approach of this program will allow the nurses to build upon and advance their skills in providing palliative care and communicating with parents and family members during their unfortunate journey of loss.

### **Literature Review Related to Methods**

The death of a neonate or young infant is an occurrence that happens in the spectrum of outcomes experienced in the NICU environment, and this clinical reality touches all individuals involved in this journey of loss. In 2006, the subspecialty of palliative medicine and hospice was officially recognized by the American Board of Medical Specialties to address the complex care needs of these end-of-life scenarios (American Academy of Pediatrics [AAP], 2013). Thereafter, the role of palliative care was integrated into the specialties of pediatrics and neonatology (Klick et al., 2014). An extensive literature search revealed common themes and research outcomes from the past 15 years that focused on the concepts, barriers, and outcomes surrounding palliative care.

#### **Existing Scholarship and Rationale**

Multiple medical authorities and organizations have outlined and published positional statements focused on the concepts and required inclusive components of palliative care. WHO in 1998 outlined the principles of pediatric palliative care as follows: (a) active patient care that is inclusive of the mind, spirit, body, and family; (b) providers of care must evaluate and alleviate distress related to the aspects of social, physical, and psychological; (c) utilization of a multidisciplinary approach within existing resources; and (d) provision of care in available environment which may include the home, community, or tertiary care facility (WHO, n.d.). In 2000, the AAP published their initial statement focused on the principles of palliative care in the subspecialty of pediatrics that included child-specific guidelines and standards (AAP, 2000). In 2013, the AAP published their refined and updated policy statement which was further delineated

into the following areas: (a) utilization of pediatric palliative or hospice care teams; (b) utilization of national standards; (c) multimodal collaborative care; (d) provision quality and safe care; (e) therapeutic communication that is forthright, compassionate, and clear; (f) family support measures; (g) sibling support measures; (h) support of health care team; (i) palliative care and training; (j) measures involved in quality improvement and research; and (k) ethical considerations (AAP, 2013). The provision of palliative care transverses the continuum of clinical care from primary to acute settings and vice versa. The American College of Critical Care Medicine published a consensus statement that focused on the provision of palliative care in the intensive care setting on the end-of-life decision making and care interventions (Truog et al., 2008). Embedded within each of these positional statements and proposed guidelines for the provision of pediatric palliative care is the common core recommendation that specialized staff and provider education should be focused on the concepts and communication skills that are required for end-of-life clinical situations (AAP, 2000, 2013; Truog et al., 2008).

### **Background and Context**

Himmelstein (2006) and Lewis (2012) described and documented the evolution of palliative care in clinical practice with the dying. As time evolved, integration of this specialized practice into the environment of pediatric and neonatology subspecialties occurred, but remains as an evolving discipline. Multiple research endeavors have been located in the literature that highlight the ongoing process of integrating the provision of palliative care into the clinical arenas of pediatrics and neonatology.

## **Pediatric Palliative Care**

Yearly, it is estimated that 54,000 children die in the United States (Schmidt, 2011). Pediatric palliative care interventions and measures are enacted in an effort to meet the end-of-life needs and comfort measures required of these unfortunate children. Himmelstein (2006) and Schmidt (2011) reviewed the complex care required in the quality delivery of palliative care to include pain and symptom management, ethical decision making, psychological and spiritual issues, staff support, and use of a hospital-based program. Integration of pediatric palliative care crosses the spectrum of care. Boss et al. (2014) published a report from the ICU advisory board that stated that the integration and delivery of pediatric palliative care should occur at the identification and diagnosis of a life-limiting disease process.

The current state of delivery of pediatric palliative care has been researched with associated outcomes documented. Feudtner et al. (2011) performed a prospective multicenter cohort study to describe and document the clinical characteristics and outcomes of pediatric patients who had received palliative care. The cohort of participants ( $N = 515$ ) from the 6 participating programs displayed an age range from less than 1 month of age to older than 19 years of age. The life-limiting diagnoses included (10.7%) gastrointestinal, (19.8%) cancer, (12.8%) respiratory, (39.2%) neuromuscular, and (40.8%) genetic or congenital (Feudtner et al., 2011). The single identified difference in care compared to adult palliative care was that the length or time span of care provided was longer as most of the pediatric patients were alive on palliative care for more than a year after initiation (Feudtner et al., 2011).

Feudtner et al. (2013) performed a cross-sectional national survey to assess the utilization of pediatric palliative care programs in children's hospitals on a national level. The respondent rate was 71.7% of solicited hospitals ( $N = 162$ ). The outcome data demonstrated that the implementation of new programs peaked in 2008 with 10 new programs being initiated in 2011. Palliative care programs were documented as common practice entities in pediatric facilities with various levels of utilization that was dependent on hospital size and individual funding sources (Feudtner et al., 2013).

Barriers to the implementation and utilization pediatric palliative care have been identified. Himmelstein (2006) discussed existing barriers as care fragmentation due to involvement of multiple specialists and avenues, financial aspects, and lack of provider education. Davies et al. (2008) echoed these same barriers to pediatric palliative care with an emphasis on unclear communication from clinical providers.

### **Neonatal Palliative Care**

Moving directed care measures and interventions from curative to palliative in focus is an unfortunate occurrence in the field of neonatology for clinical situations that encompass the following: (a) neonates with lethal congenital anomalies, (b) neonates who are not responding to maximum medical or surgical interventions, or (c) premature neonates born at the limits of viability (Bhatia, 2006). The positive facilitation of neonatal palliative care is best delivered as a family centered approach. Clear communication and interventions between the multidisciplinary medical providers and members of the family structure facilitate a compassionate bereavement journey that



support the dying infant and family members (Burns, Majchrowskim, & Jellison, 2013; De Lisle-Porter & Podruchny, 2009; Harris & Douma, 2010).

The current state of practice for utilizing palliative care measures in the NICU environment has been reviewed and documented in the literature. Singh, Lantos, and Meadow (2004) performed a quantitative, retrospective chart review to accurately assess the end-of-life processes in their institution's NICU practice. The outcome data demonstrated that >40% of the deaths ( $N = 178$ ) actively utilized withdrawal of support measures and died without the use of cardiopulmonary support actions.

Moro, Kavanaugh, Okuno-Jones, and VanKleef (2006) performed a review of the research literature to assess and provide an overview of the current state of neonatal end-of-life care. Ten research articles met inclusive criteria and common categories or themes were actualized. The themes were as follows: (a) the actual dying process; (b) parental interaction during the decision making process; (c) pain management; and (d) the actual practice of withholding treatment that is life-sustaining (Moro, Kavanaugh, Okuno-Jones, & VanKleef, 2006). The review documented a variety of differences in approach to clinical practice in this specialized decision making process and that full implementation and differences of palliative care practice was dependent on institutional practices and medical provider driven.

Moura et al. (2011) performed a retrospective chart review to compare the palliative care measures utilized in the neonatal deaths at their institution between 2 different time periods (1992-1995 and 2002-2005). The later time period (2002-2005) demonstrated outcome measures that were more in alignment with palliative care efforts.

There was documentation of limiting interventions and measures with increased communication and visitation by the parents and family members. Unfortunately, the data documented that in the later time period that many of the neonates still received aggressive, curative interventions at the end-of-life.

Ongoing barriers have been identified and exist in clinical practice that impact and prevent the implementation of palliative care measures in the NICU environment. Martin (2013) utilized a case study to identify these barriers which were as follows: (a) conflict within the care team members that leads to moral distress; (b) inadequate support and training of staff on palliative care; and (c) concerns surrounding the use of opiates during the dying process. Catlin (2011) utilized a quantitative approach in an attempt to identify when the threshold in neonatal care transitioned from curative to palliative. The respondents ( $N = 285$ ) identified a 96% consensus that the determining factor was parental agreement as the transition point for end-of-life care. The respondents identified that ongoing palliative care education was needed to facilitate the palliative care process. This lack of palliative care education among neonatal health care providers has been echoed and documented in the current literature (Lewis, 2012; Romesberg, 2007). Williams-Reade et al. (2013) performed a focused ethnography qualitative study to peer into the world of neonatal palliative care. They documented the following key themes: (a) the provision of neonatal palliative care was a unique process; (b) discrepancies in protocols and policies exist in actual practice; (c) conflict among providers and utilization of ineffective communication skills; (d) the existence of protocol and policy

discrepancies are present in practice which includes educational deficits; and (e) administrative support deficiencies (Williams-Reade et al., 2013).

Wright, Prasun, and Hilgenberg (2011) performed a quantitative study of prospective, cross sectional in design to identify barriers and facilitators of palliative care delivery. The study sample consisted of ( $N = 50$ ) of RNs in a Level III NICU facility from the Midwest. Identified barriers included limitations of physical environment, lack of nurses' inclusion of opinions or beliefs, lack of education, parental demands, and technological issues. The identified facilitators included the following: available counseling, supportive policies and guidelines of palliative care, staffing, time spent with baby during moment of loss, medical team support to nurses and family, and parents informed of options and participated in decision making process (Wright, Prasun, & Hilgenberg, 2011).

### **Institutional Context**

The provision and delivery of pediatric and neonatal palliative care should be the evidence-based standard that all professionals of multidisciplinary care teams strive for in their individual clinical practice. As evidenced by the literature, barriers and gaps exist in this delivery process. The educational foundation for the delivery of palliative care interventions varies in the curriculum and experience of the providers. This has become an important barrier to the delivery of palliative care by the nursing staff in the NICU at ACH.

## **Student Context**

Throughout this extensive literature review and critique, this writer identified a major component of palliative care that is crucial to its success and quality of delivery. The success of the delivery of palliative care whether in the realm of pediatric or neonatal is dependent on the utilization of communication skills that lend to difficult conversations and are supportive to those enduring the journey of loss. Communication that is clear in intent and goal focused must be utilized to ensure avoidance of miscommunication and confusion of terminology and proposed outcomes when dealing with end-of-life clinical scenarios. Feudtner (2007) delineated and outlined the key components and foundation to building collaborative communication for pediatric palliative care. Browning et al. (2007) discussed the addition of communication skills for difficult conversations in palliative and health care into educational curriculum programs to strengthen end-of-life care. Kersun, Gyi, and Morrison (2009) performed a quantitative survey to assess training preparedness focused on communication skills. The respondents ( $N = 171$ ) associated comfort and skill with difficult conversations to frequency of conversations ( $p = 0.009$ ) and attendance of workshops ( $p = 0.019$ ).

## **Summary and Conclusions**

The frontline nursing staff spend countless hours at the bedside caring for of these fragile patients while the child's parents attempt to visit and share time with their child as much as physically possible. Through this proximity, the death of a neonate or infant affects everyone involved in the end-of-life process. The extensive literature review

revealed important themes that were congruent to the affective experience of those involved in this death experience.

### **Major Literary Themes**

My personal clinical nursing experience obtained in a pediatric cardiac ICU has allowed me to unfortunately experience the death of different pediatric patients over the years. It can be very difficult to describe and fully share how this emotional process changes one. Extensive research endeavors were encountered in the literature search that focused on the experience of the bedside nurse and parent in their individual journeys of loss. The following identifies the involvement of the nurse and family in the death experience.

**Nurses.** As the frontline providers, nurses carry and share the burden of delivering the majority of clinical care and experience the journey of death with their patients and families. Fegran, Fagermoen, and Helseth (2008) utilized a hermeneutic approach to observe the development of parent nurse relationships in an NICU environment and found that this relationship evolved through the stages of acute critical, stabilizing, and discharge.

Nursing research endeavors have been utilized to document the nursing experience in the provision of end-of-life care. Yam, Rossiter, and Cheung (2001) explored in a qualitative study the experiences of NICU nurses in Hong Kong. The outcome data ( $N = 10$ ) demonstrated 8 categories as follows: values that conflicted towards care, lack of counseling skills and education, expression of empathy, provision of emotional support to family members, providing physical care for the neonate,

disbelieving, and feelings of helpless and ambivalent. Cavaliere, Daly, Dowling, and Montgomery (2010) performed a descriptive, correlational study to explore the frequency and intensity of moral distress in the NICU frontline nursing staff. Collectively the respondents ( $N= 94$ ) did not report the frequency of great distress, but individually 4 characteristics were identified. The common characteristics included the following: lack of spirituality; a change in approach to patient care; consideration to leaving their position from a previous job due to moral distress; and a desire to leave the current position (Cavaliere, Daly, Dowling, & Montgomery, 2010).

Espinosa et al. (2010) utilized a phenomenological approach in a qualitative study to explore the ICU nurses' experience in the provision of end-of-life care. The sample respondents ( $N= 18$ ) from a single ICU discussed the provision of terminal care was a struggle for one as an individual and as a professional. Common barriers were identified as follows: (a) lack of inclusion with the plan of care; (b) lack of experience and educational preparation; (c) family's unrealistic expectations; (d) disagreement between health care team members; (e) unnecessary suffering and futile care; and (f) conflict between care delivery and models of proposed care (Espinosa et al., 2010).

Cavinder (2014) performed an integrative review to assess the relationship between moral distress and nurses providing neonatal palliative care. The 6 articles that met inclusion criteria demonstrated support of moral distress with the provision of palliative care in the neonate population. Tubbs-Cooley et al. (2011) performed a quantitative cross-sectional survey to assess nurse's individual and group assessment of the provision of palliative care. Respondent nurses from the pediatric intensive care unit

(PICU) and the NICU ( $N= 410$ ) reported the most important goals of palliative care as maintaining quality of life, managing pain and comfort, and improvement of communication. The overall conclusion from this sample population was the endorsement of the use of palliative care interventions, but the clear communication of palliative care goals should be present within the collaborative practice (Tubbs-Cooley et al., 2011).

Holms, Milligan, and Kydd (2014) performed a qualitative study to explore end-of-life experiences of ICU nurses. The interview analysis from the responding participants ( $N = 5$ ) which was from one ICU revealed the common themes of staff distress, use of integrated care systems, inadequate communication skills, lack of staff education and training, and environment.

**Parents.** The individuals most impacted from the loss of a neonate or young infant are the child's parents. Words and thoughts cannot begin to describe their individual journeys of loss in the NICU environment. This experience of loss affects the parents and family members for the rest of their lives. Multiple research endeavors have been performed to document in the literature the meaning of losing a child from a parent's viewpoint. Gold (2007) performed a systematic review of the literature to explore parental experiences with health care providers during the loss of a baby. Sixty-one studies were included in the review which represented greater than 6,000 parental experiences. The parents appreciated attention to the mother and child, grief education, and emotional support while the negative aspects of insensitivity, poor communication by staff members, and avoidance were identified (Gold, 2007).

Widger and Picot (2008) performed a qualitative study to explore the parental perceptions surrounding the quality of delivered end-of-life experiences. Parental responses ( $N= 38$ ) revealed the common experience was negative in the experience of death and loss. Identified areas of concern included the following: bereavement follow-up, specific care issues at the time of loss, relationship with health care team members, and communication issues with health professionals (Widger & Picot, 2008). Meert, Briller, Schim, Thurston, and Kabel (2009) undertook a qualitative study to document the needs of the bereaved parents during their journey of loss in the PICU. The participants ( $N = 33$ ) were parents who had lost their child in the PICU over a 3 year time period. Interviews and focus groups were utilized to identify 4 distinct categories descriptive of parental needs which included the following: (a) “Who I Am”, (b) “While My Child Was Dying”, (c) “My Child’s Death Context”, and (d) “My Bereavement Journey” (Meert, Briller, Schim, Thurston, & Kabel, 2009, pp. 719–720). Honest communication and support were identified as important elements by the bereaved parents.

Price, Jordan, Prior, and Parkes (2011) performed a qualitative study to document the experiences of bereaved parents. Through semi-structured interviews, facilitating and allowing the parents to participate in the care and decision making in their journey of loss was important to the sample participants ( $N = 25$ ). Longden (2011) performed a literature review to examine parental perceptions focused on the end-of-life care in the PICU setting. Thirteen studies met inclusive criteria and the common theme identified was the acknowledgement and identification of the fundamental needs of the family members. It



was expected that the health care professionals be compassionate and proficient in their provision of end-of-life care (Longden, 2011).

Aschenbrenner, Winters, and Belknap (2012) performed an integrative review to describe parental perspectives on the loss of their child. Fifteen research articles was included in this complex review and common themes were teased out of the outcome data. The themes included the following:

“poor communication/lack of information, strained relationships/inadequate emotional support, parental need to maintain parent/child relationships in life and death, quality of care continues after the death of the child, influence of services/planning on parent/child impacts quality of life, and the difficult decision to terminate life support” (Aschenbrenner, Winters, & Belknap, 2012, p. 514).

Melin-Johansson, Axelsson, Grundberg, and Hallqvist (2014) performed an integrative literature review to identify parental experiences with palliative care. Nine research studies met inclusive criteria that identified 5 important categories or themes. Parents identified the following as important to the parental experience: (a) need of support, (b) alleviation of suffering, (c) genuine communication, (d) sincere relationships, and (e) respect as an expert (Melin-Johansson, Axelsson, Grundberg, & Hallqvist, 2014).

### **Advancing Nursing Practice**

Educational endeavors focused on palliative care education are needed to address the identified gap in palliative care practice. Haut, Michael, and Moloney-Harmon (2012) performed a quantitative study with a pre and post-test design to evaluate the impact of an educational program focused on palliative care. The participants ( $N = 25$ ) from a large

metropolitan medical facility demonstrated the following outcomes: (a) post educational program nursing attitudes improved toward pediatric palliative care ( $p = 0.001$ ) and (b) individual nursing knowledge was increased post program ( $p = 0.02$ ). Zhang and Lang (2013) performed a quantitative study of pre and post-test design to evaluate neonatal nurses' comfort with bereavement and end-of-life care after a bereavement seminar. In the convenience sample ( $N = 14$ ), the seminar attendees demonstrated improved levels of comfort ( $p = 0.04$ ) in the provision of end-of-life care compared to the control group. Tiemann et al. (2014) described the use of a framework approach to deliver and evaluate the delivery of quality improvement actions focused on palliative care education. The participants ( $N = 55$ ) reported a positive evaluation of the educational format and an increased feeling of confidence with the materials focused on palliative care delivery.

Additional research studies have demonstrated congruent outcome data that supports palliative care education for nursing personnel. Rogers, Babgi, Gomez, and Catlin (2008) performed a quantitative study to evaluate the effectiveness of an educational intervention aimed at end-of-life care. The outcome data demonstrated increased levels of comfort ( $p < 0.001$ ) by the NICU nurses who had attended the educational sessions in providing end-of-life care. Twamley et al. (2013) used a mixed method approach to evaluate the impact of educational workshops focused on neonatal palliative care. The outcome data revealed that the workshops increased individual knowledge base information on palliative care and increased individual attitudes about palliative care in the questionnaire respondents ( $N = 264$ ).

## **Innovations in Nursing Education**

This program focused on palliative care education for the NICU nurse is innovated in the fact that it is multimodal in format and that high-fidelity simulation will be utilized to promote the use of required communication skills that are essential in the delivery of quality palliative care for the neonate and family. The use of simulation training has been documented in other occupations such as the military and aviation to promote staff development and obtainment of critical thinking skills (Sharp, Newberry, Fleishauer, & Doucette, 2014). Simulation training as a tool for nursing and staff development has evolved over the past 10 years. Hallenbeck (2012) performed a systematic review of the literature looking at the use of high-fidelity simulation for the development and education of nursing staff. This systematic review documented the use of simulation training in nursing education, staff orientation, certification programs, continuing education, staff development, and in the ICU environment (Hallenbeck, 2012). It was identified in this review that simulation training is a safe training method, but no outcome data currently exists demonstrating that it was superior to any other traditional educational method. Cato and Murray (2010) discussed the use of simulation training in the ICU environment. ICU simulation training benefits the trainee through the educational concepts of skill development, communication skills, collegial collaboration, and critical thinking. The following highlights the use of high-fidelity simulation in nursing education.

Yaeger et al. (2004) discussed the use of high-fidelity simulation training in the NICU environment. Proposed benefits to this mode of training includes the following:

improved technical, behavioral, and cognitive skills, higher levels of confidence in the trainee, decreased training times and costs, improved quality of care, and adaptability to a variety of technology (Yaeger et al., 2004). Raurell-Torreda et al. (2015) performed a nonrandomized clinical trial to compare obtainment of clinical skills through traditional methods versus simulation training. The intervention group who underwent simulation training demonstrated higher assessment skills than the control group. Hsu, Chang, and Hsieh (2015) performed a quantitative study to compare communication training through the utilization of simulation training. The paired *t* tests demonstrated simulation training to be more effective with communication skills and performance.

The newly developed simulation training will be unique in the fact that standardized persons will be utilized to simulate grieving parents who going through the loss of a child in the NICU. Parental presence in simulation training has been utilized and documented in the literature in clinical scenarios of pediatric resuscitation, nursing education, medical education, and emergency department triage training (Dunnington, 2014; Pye, Kane, & Jones, 2010; Wee, Davies, & Holt, 2008; Wolf, 2008). Utilizing standardized persons as bereaved parents and family caregivers will provide the trainees with simulated scenarios that are realistic to the NICU clinical environment. The targeted skill for the simulation exercises is effective communication that is compassionate towards the grieving parents. The NICU scenarios will allow the trainee to develop confidence in their communication skills and experience with grieving parents and caregivers.

## Summary

DNP prepared clinicians are change agents who are educationally prepared and experienced to advance nursing practice and mentor others in this arena. The goal and promise of pediatric palliative care “embodies core commitments that represent a fundamental promise to care for all children with serious life threatening and inevitable life-shortening conditions and their families” (AAP, 2013, p. 970). This DNP multimodal education program will contribute to clinical practice and change nursing care focused on end-of-life in the NICU at ACH. The addition of simulation training in this educational program is innovative and will be the first documented use in my institution and in the literature upon future publication. Section 3 outlines the individual components of this multimodal educational program.

## Section 3: Methodology

### **Introduction**

The development of this educational program was focused on addressing the identified clinical practice deficit in the NICU environment and making a social change through the future delivery of improved frontline nursing end-of-life palliative care and communication. The financial climate and management environment of today's medical organizations is focused upon the delivery of high quality patient care under fiscal responsibility. The development of this educational program was guided by evidence present in the research literature and within the fiscal and resource restraints of the ACH institution.

### **Project Design and Methodology**

This educational program focused on the concepts of neonatal palliative care with the inclusion of the specific communication skills that are required in end-of-life clinical scenarios. The program was developed in a multimodal format to address the different theoretical domains of adult learning and to build a consecutive foundation of information through the phases of the learning process. The different elements of the multimodal education program are as follows.

### **Didactic Modules**

ACH is a member of the Children's Hospital Association (CHA), which is a national association that advances the health of children through the delivery of innovative care that is quality driven and cost effective (CHA, 2015). CHA is a provider of evidence-based continuing education for pediatric nurses. Three didactic modules were

selected from the organization's online training system which had been previously purchased by ACH from CHA. The modules have not been previously used in the NICU environment. The modules will be available for NICU staff utilization on a 24/7 basis online. The modules are self-directed and self-paced with periodic questions for evaluation and feedback for the learner. The modules were authored by Jan Borgman, a master's prepared social worker, who is nationally known for her specialization in bereavement care and education (ACH, 2015b). The selected modules are as follows:

1. *Care of the Dying Child: The Dying Process* – The module describes the physiological dying process as experienced by children with end stage illnesses (ACH, 2015c).
2. *Care of the Dying Child: Grief* – This module provides an in-depth developmental look at the grieving process and the varied grief responses displayed by those undergoing the journey of loss (ACH, 2015d).
3. *Care of the Dying Child: Care Issues* – The module covers the 4 major concepts inclusive in the provision of end-of-life care which are communication skills, pain and suffering, palliative care, and support for the parents (ACH, 2015b).

### **Video Modules**

In 1998, IPPC was started with the focused goal of improving the lives of children with life-threatening conditions through the endeavors of education, research, and quality improvement (IPPC, 2015). As part of the palliative care training, educational videos were developed by IPPC for staff education. Two of the IPPC videos were selected to

promote the affective component of adult learning. The selected videos are as follows: (a) *Big Choices, Little Choices* and (b) *Difficult Conversations in Pediatric Palliative Care* (IPPC, 2015). The videos will be uploaded to the institutional online training system and be available to the frontline nursing staff on a 24/7 basis.

### **Simulation Training**

The final component of the multimodal educational program will be performed through the use of simulation training at the PULSE Center at ACH. This proposed simulation training will be the first training on campus to address the communication skills required of end-of-life scenarios for the NICU clinical arena. Two scenarios have been developed by me to depict real end-of-life clinical situations that could be encountered in the NICU. The scenarios will demonstrate the following: (a) a neonate experiencing an acute life-threatening event who arrests and passes away and (b) an infant with a chronic illness in which medical support is withdrawn and the infant passes away. Standardized persons will be trained to simulate parents in these 2 scenarios. In the simulation training, the NICU nurses will be able to learn and use communication skills that are required to respond and care for the grieving standardized persons.

At the beginning of each simulation training session, the expectations of the learner will be explained and outlined. The participants will be asked to not discuss the different scenarios outside the safe environment of the PULSE Center to protect learner confidentiality. After completion of the scenarios, a debriefing will be facilitated in a private conference room to discuss the scenarios. This opportunity will be used to reinforce the nursing staff's use of the communication skills required in end-of-life



situations in the NICU and answer any questions that the NICU staff may have on the death process in general. Appendices A and B depict the NICU simulation scenarios that were developed for the simulation training exercises.

### **Targeted Population**

The frontline nursing staff of the NICU at ACH will be the targeted population for receiving this multimodal educational program. The inclusion criteria will include: (a) possession of an active registered nursing license, (b) working within the NICU clinical practice environment, and (c) English speaking. There will be no exclusion reason for not participating in the proposed educational program. It is a professional obligation that is expected by the NICU nursing management and educational teams that all frontline nursing staff will participate in identified organizational and unit specific educational exercises (L. Jones, DNP, personal communication, March 3, 2015).

### **Project Evaluation Plan**

This proposed multimodal educational program underwent the process of content validation. The purpose of this process of content validity was to critically examine and document that the educational program included and used the specific content items and constructs that are relevant to the process (Grove, Burns, & Gray, 2013). The educational program was evaluated by five local nursing experts at ACH with professional credentials that include advanced practice registered nurse (APRN), Master's preparation, and nationally certification in the specialized patient population fields of neonatal or pediatrics.

A 10 question questionnaire using a Likert scale was used by the content validators to critically analyze and evaluate the specific contents and constructs of this multimodal educational plan focused on neonatal palliative care education. The Likert scale allowed the content validators to express their opinion about the content of the educational program while using a predetermined scale of responses (Grove, Burns, & Gray, 2013). I developed the 10 question evaluation questionnaire to specifically focus on determining the content validation of this educational program. The Likert scale response categories were as follows: 1 = Not Applicable, 2 = Strongly Disagree, 3 = Disagree, 4 = Agree, and 5 = Strongly Agree. The questionnaire focused on the specific program constructs of purpose, format, evidence, process, and future impact of the adult educational program. Figure 4 delineates the content of the program evaluation questionnaire with the Likert scale. A descriptive analysis was performed on the collected content evaluation data.

### **Educational Program Evaluation**

Please respond to the following questions using the below scale:

- 1 = Not applicable
- 2 = Strongly Disagree
- 3 = Disagree
- 4 = Agree
- 5 = Strongly Agree

Does the multi-modal educational program focused on neonatal palliative care meet the stated goals and objectives of the program? \_\_\_\_\_

Is this educational program evidence-based in content and format? \_\_\_\_\_

Will the content of the program contribute to the overall educational foundation and skills of the frontline NICU nursing staff? \_\_\_\_\_

<b><u>Educational Program Evaluation Con't</u></b>	
Does the incorporation of the multiple learning strategies of this program meet the needs of the adult nurse learner?	_____
Is there evidence of theoretical guidance in the construction and future implementation of this educational program?	_____
Does the education program make good utilization of the available resources of the health organization and is cost effective in focus?	_____
Is the platform of delivery an easy format that is attainable by the end user?	_____
Is the amount of content included in the educational program manageable from a time perspective for the end user?	_____
Do you feel that this multimodal educational program will impact the frontline nursing staff's end-of-life care delivery?	_____
Would you recommend the use of this educational program to another nursing unit at ACH?	_____

*Figure 4.* Educational Program Evaluation. Developed by S. Pye, Walden DNP Student.

### **Summary**

The hallmark goal of the DNP project was to demonstrate the acquired scholarship skills of the future DNP graduate. This educational program demonstrated the utilization of my newly acquired DNP knowledge, educational foundation, and skills

obtained through the specialized Walden curriculum. The multimodal format of this palliative care training program has the potential to create social change and impact the end-of-life care provided by the NICU nurses. Section 4 discusses the results and future implications that were obtained from the process of content validation.

## Section 4: Findings, Discussion, and Implications

### **Introduction**

The overall purpose of my DNP capstone project was to develop an evidence-based supported multimodal educational program that was focused on the core foundational information and communication skills required in the delivery of neonatal end-of-life palliative care. This multimodal educational program was developed through the use of the key resources and limitations found in the medical institution. My proposal has undergone the critical process of content evaluation as described in Section 3. The purpose of Section 4 is to provide a summary and discussion of the content validation findings and implications for the future implementation of this project.

### **Summary and Evaluation Findings**

When initiating a new health care program or intervention, the evaluation plan must be incorporated into the beginning planning efforts and related to the overall projected outcome goals (White & Dudley-Brown, 2012). The evaluation phase provides the planners, in this context--me, with valuable outcome information and findings. Evaluation feedback allows the planner to critically assess, analyze, and measure if the intended purpose/s and goal/s were met. After obtaining the official approval on 02/17/2016 from the Walden University's Institutional Review Board (IRB), the planned structured content validation for this DNP proposal was initiated. The Walden IRB approval number was 02-17-16-0472029.

Five randomly selected APRNs working in the medical institution under study were approached and asked for their voluntary and professional participation in the

content validation process. Their voluntary consent was obtained after a thorough presentation on the purpose of this activity along with the identified risks and benefits as outlined in the consent form. The sample participants were given a copy of the project's consent form and a content validation packet which consisted of a summary of the DNP proposal with a reference copy of the DNP proposal and a blank program evaluation tool. The validators were given a period of 5 working days to return the completed program evaluation tool to me. The content validation data collection time period was 02/18/16 through 02/24/16 due to the occurrence of a weekend. The completed evaluations were linked to no participant identifiers, and the raw data was securely stored at my personal residence in a locked file cabinet upon completion and return by the participants. The 5 completed evaluation tools underwent summation, statistical analysis using the central tendency measurement of the mean, and critical analysis for meaning and implications. The mean is a commonly used statistical tool of central tendency that provides a numerical average of the raw data scores (Polit, 2010). A summary of the content validation results was placed in table format for review (Figure 5).

Question	Domain	APRN Validators ( <i>N</i> = 5)		
		Likert Scale Response "4"	Likert Scale Response "5"	Mean %
Does the multimodal educational program focused on neonatal palliative care meet the stated goals and objectives of the program?	Content		(100%)	5
Is this educational program evidence-based in content and format?	Content		(100%)	5

Will the content of the program contribute to the the overall educational foundation and skills of the NICU nursing staff?	Content	(100%)	5	
Does the incorporation of the multiple learning strategies of this program meet the needs of the adult nurse learner?	Process	(100%)	5	
Is there evidence of theoretical guidance in the construction and future implementation of this educational program?	Process	(100%)	5	
Does the education program make good utilization of the available resources of the health organization and is cost effective in focus?	Process	(20%)	(80%)	4.8
Is the platform of delivery an easy format that is attainable by the end users?	Process	(100%)	5	
Is the amount of content included in the educational program manageable from a time perspective for the end user?	Time	(100%)	5	
Do you feel that this multi modal educational program will impact the frontline nursing staff's end-of-life care delivery?	Overall	(100%)	5	
Would you recommend the use of this educational program to another nursing unit at ACH?	Overall	(100%)	5	

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*Figure 5. Content Validation Results.*

### Discussion of Findings

The content validation questionnaire was developed to evaluate the DNP project domains of content, process, time constraint, and overall contribution to the nursing clinical practice development at ACH. The first 3 questions in the validation questionnaire focused on the domain of content. The purpose of this domain was to determine the following through the validator responses: (a) if the proposal met the stated goals and purpose of the educational program, (b) was the content evidence-based in foundation, and (c) would the program contribute to the educational foundation of the ACH NICU frontline nursing staff? Figure 6 demonstrates that the content validators ( $N = 5$ ) appraised that the content domain of this DNP project as “strongly agree” (100%;  $M = 5$ ) and met the goal of translating evidence into clinical practice.

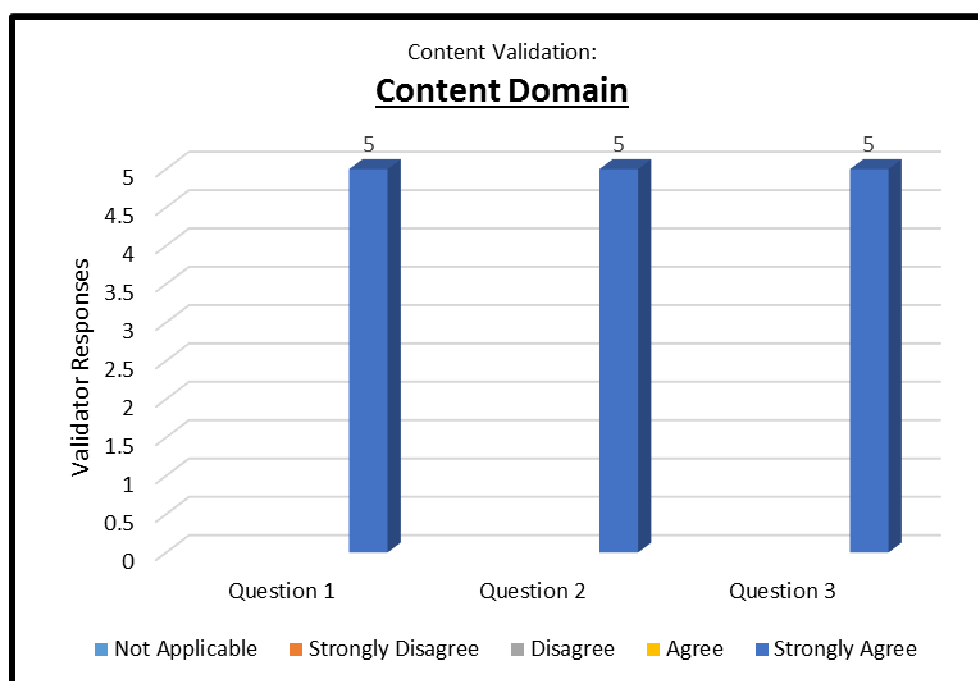
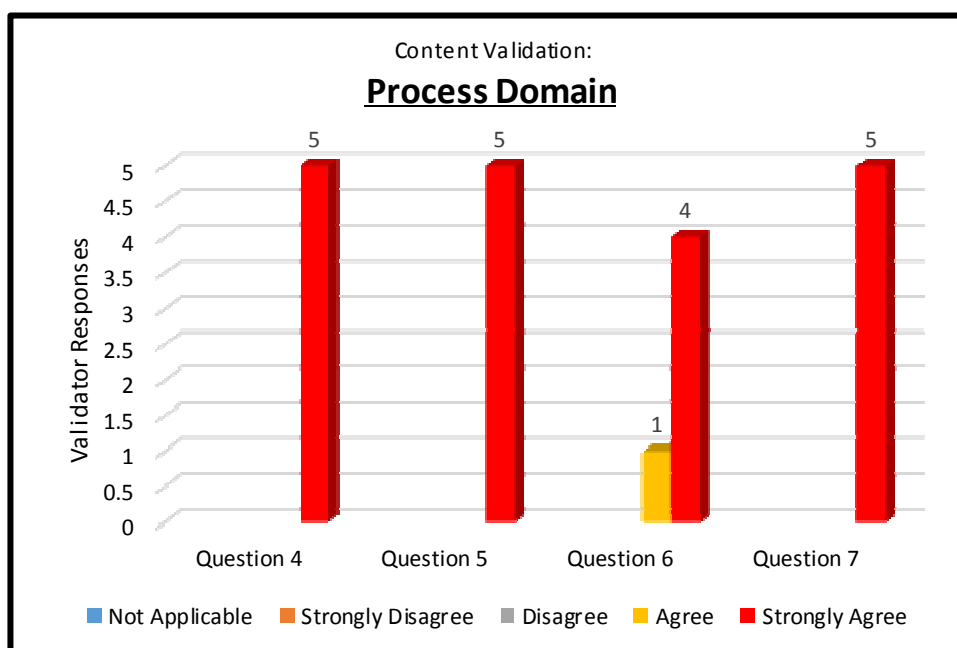


Figure 6. Content Validation - Content Domain



The domain of process was explored in questions 4 through 7 in the content validation questionnaire. This domain was focused on the use of theoretical guidance for the construction of the educational project and its potential for future execution within the constraints of the organization. Figure 7 graphically displays the collective outcome data from the validator's responses ( $N = 5$ ).



*Figure 7.* Content Validation - Process Domain

The content validators responded that the process domain was strong within this DNP project through their response of “strongly agree” (100%;  $M = 5$ ). The incorporation of the constructs of 3 different adult learning and nursing theories made this multimodal educational program theoretically sound. This will allow the future learner/s to develop an educational foundation on neonatal end-of-life care starting with didactic information

and progressing to the psychomotor skill of communication through the activity of return demonstration. The adult educational program was innovative in approach due to the use of simulation training scenarios to develop end-of-life communication skills. Within this process domain, the evaluation data for question number 6 was mixed as the data reflected the response of “agree” (20%) and “strongly agree” (80%) with a mean of 4.8. The slight difference in validator responses was probably reflective of the current climate of ongoing change in the medical institution. Over the past 2 years, ACH has quickly transitioned to a data driven and strategic goal oriented hospital. The frontline providers have had to adjust to this ongoing climate of administrative changes while balancing the delivery of pediatric care with minimal input or preparation.

In question number 8, the third domain provided an assessment of the time demand that the multimodal educational program would place on the future nurse learners. Figure 8 demonstrates through the consistent validator responses of “strongly agree” (100%;  $M = 5$ ) that the format and content of this multimodal program would be feasible for completion by the adult learner/s within the required time constraints of the program.

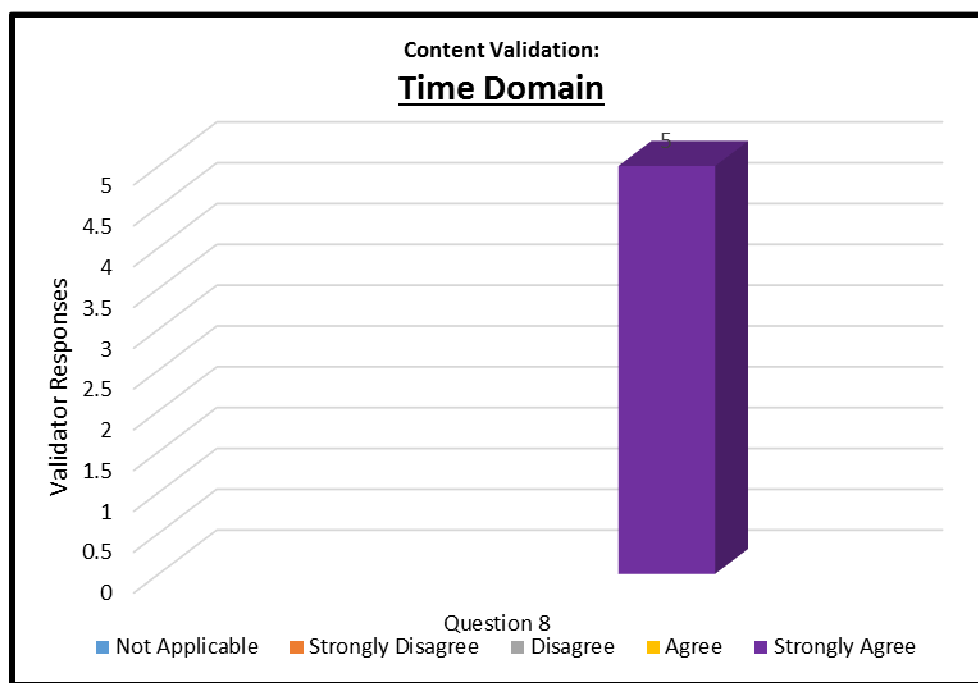
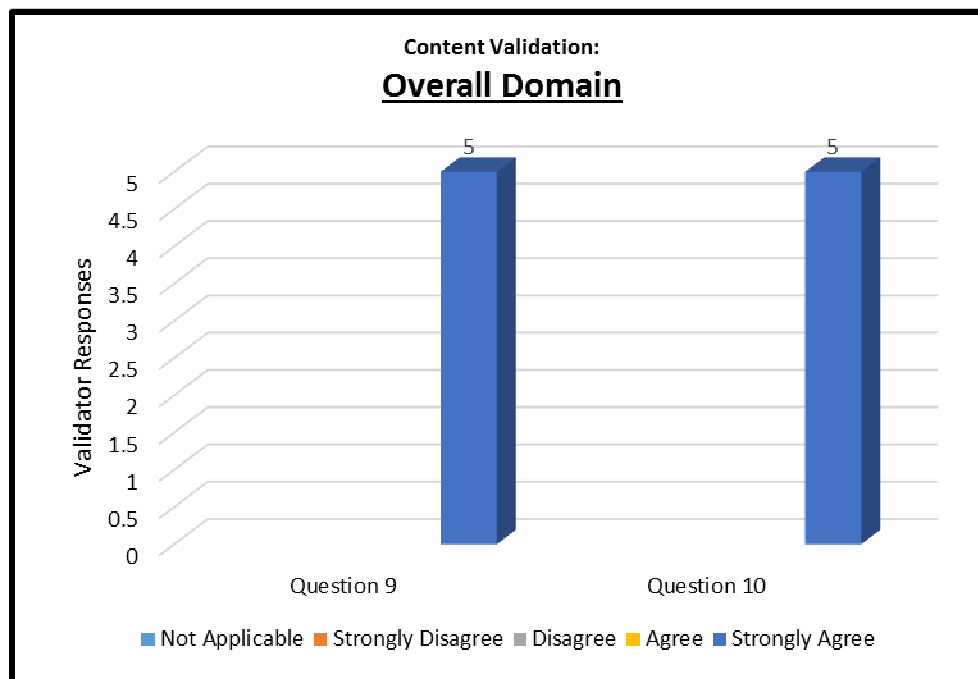


Figure 8. Content Validation - Time Domain

The fourth domain that was analyzed by the content validators was the overall potential impact that this proposal could contribute to the clinical practice of the frontline NICU nursing staff and the potential for universal application in other nursing departments in the institution. Questions 9 and 10 reflected the fourth domain under content evaluation. Figure 9 demonstrates that the validators “strongly agreed” (100%;  $M = 5$ ) that this DNP project has the strong potential to impact nursing practice in the NICU and the organization upon future implementation.



*Figure 9.* Content Validation – Overall Domain

## Literature

The comprehensive literature review that I performed provided significant evidence that inadequate nursing staff education was a barrier to the delivery of effective neonatal and pediatric end-of-life care (Browning & Solomon, 2005; Gale & Brooks, 2006; Kain, 2011; Lewis, 2012; Martin, 2013; Peng et al., 2013; Romesberg, 2007). This barrier was identified in the clinical practice of the frontline nursing staff at ACH through the comments relayed in a parental bereavement exit interview. Addressing this barrier became the foundational basis for the development of this adult educational project that is

an evidence-based intervention supported by the research literature (Haut, Michael, & Moloney Harmon, 2012; Rogers, Babgi, Gomez, & Catlin, 2008; Tiemann et al., 2014; Twamley et al., 2013; Zhang & Lang, 2013).

### **Frameworks**

The translation of evidence into the clinical realm to promote a change in practice outcomes is most successful through the use of theory and models (White & Dudley-Brown, 2012). Theoretical guidance was sought for the core foundational constructs in this multimodal adult educational program. The 3 theories that were used for this DNP project consisted of the following: social cognitive theory, adult learning theory, and Benner's model of skill acquisition in nursing. The successful progression through the different phases of this educational program will allow the learner to glean palliative care didactic information and perform end-of-life skill of communication through the use of simulation training. This multimodal program will allow the learner to transverse the palliative care educational journey from novice to expert as depicted by Benner (Grove, Burns, & Gray, 2013).

### **Implications**

#### **Clinical Practice**

Critical analysis of the content validation data demonstrated that this multimodal program was foundationally strong through the use of theory guidance and has the potential to affect the clinical practice of the frontline NICU nursing staff. The multimodal format is adaptable to different didactic content which makes this palliative care program applicable to the other nursing departments at ACH. The fundamental basis

of DNP nursing practice is the translation of the evidence (White & Dudley-Brown, 2012). Within this project, the evidence was translated into the components of adult nursing education and clinical practice to promote a program of change in the NICU nursing environment.

### **Future Research**

The role of the DNP prepared individual is to translate, implement, and evaluate the use of research evidence in clinical practice (Grove, Burns, & Gray, 2013). I plan to implement this multimodal educational program proposal as a quantitative nursing pilot study after graduation. This pilot study would provide a secondary method of rigorous evaluation for this educational proposal and demonstrate the educational accomplishment of Essential III for an individual with doctoral preparation for advanced nursing practice by the American Association of Colleges of Nursing (AACN; AACN, 2006; Grove, Burns, & Gray, 2013). This professional nursing endeavor is the expected performance of a graduate with the terminal degree of doctoral preparation. The pre and post-test outcome data would provide further validation on the effectiveness of this adult educational program.

### **Social Change**

When I walked into the NICU on my first practicum day for the 2015 Walden spring quarter course, I had no idea where my DNP educational journey would lead me. The DNP foundational courses allowed me to perform a thorough needs assessment and develop this multimodal adult educational program on neonatal palliative care. This project has the ability to affect the professional lives of the NICU nursing staff as they

deliver evidence-based end-of-life care and create an atmosphere of professional satisfaction with improved nursing retention rates. The delivery of EBP neonatal palliative care will positively affect the lives of the fragile children who lose their courageous journey in life. The ultimate goal will be that no parent will leave the NICU environment with feelings that they received inadequate nursing support during their journey of loss. The implication for social change created through the delivery of this DNP student capstone project is an exemplar that is congruent with the educational mission for Walden University graduates (Walden, 2016).

### **Project Evaluation**

The process of program evaluation begins with idea conception and continues throughout the phases of planning and implementation (Hodges and Videto, 2011). During the development phase of this educational program, the content validation questionnaire was developed with specific focus on the content constructs. The evaluation process allowed me to glean the associated strengths and potential weaknesses of this EBP DNP program.

#### **Strengths**

My DNP capstone project has several strengths. First, the multimodal adult educational program was conceptualized and developed through the use of structured theory guidance. This endeavor demonstrates the core educational skills found in a professional nursing foundation that is cognizant of doctoral preparation. Second, the comprehensive literature review validated the barrier of inadequate palliative care delivery found in the frontline NICU nursing staff, and the research evidence supported

the project for the educational intervention. These 2 strengths are in alignment with Essential III for DNP education (AACN, 2006).

### **Limitations**

The main limitation of my capstone project is that it has not been implemented into actual clinical practice and validated through the pre and post evaluation outcome data. The outcome data from this project's content validation process was representative of the specific participant evaluators found in this sample ( $N = 5$ ). Repetition of the content validation process using a different set of voluntary APRN evaluators would provide additional outcome data for comparative analysis and potential generalizability.

### **Recommendations for Remediation of Limitations**

Upon graduation, I plan to transition this DNP capstone project into a nursing pilot research study in the NICU nursing environment after obtaining IRB approval. This professional activity is expected of doctoral prepared advanced practice nurses and congruent with DNP practice of validating outcomes of EBP interventions and programs. The delivery modalities of this program may have to be reconstructed depending on the current environment of the organization. ACH just announced that the purchase of a new electronic medical record and online educational program had been incorporated into the strategic goals for the upcoming year.

### **Analysis of Self**

Over the past 2 and a half years, the rigorous nature of this DNP program of study has allowed for and demanded many areas of personal and professional growth for me. I



have learned to balance the demands of my professional and personal life. The following subsections discuss my analysis of self.

### **Scholar**

My DNP journey, through this nursing doctoral program at Walden University, has been one of intense rigor and personal discovery that has allowed me to grow in the area of scholarship. The project has allowed me to utilize my new DNP educational foundation and skills to develop this comprehensive multimodal nursing education program that is theory guided and evidenced-based in format. This adult educational program can be integrated into the future clinical practice of the frontline neonatal nurses at ACH. The integration and future application of this program is an exciting endeavor and has the potential to affect many lives of people who have to endure the unfortunate individual journey of loss in this critical care environment. This process has allowed me, the DNP learner, to achieve the art of translation and integration of knowledge into my nursing practice. This behavior demonstrates the essential activities required of clinical scholarship for professional DNP practice (AACN, 2006).

### **Practitioner**

As I have evolved through my DNP program of study, I have grown as a person, a scholar, and as a skilled clinician. I continue to be amazed every day as I see and feel how that the different components of my clinical practice have grown, changed, and become specialized in focus. This DNP project has allowed me to utilize my new skills and information from the doctoral foundational classes and develop an evidenced-based educational program. The DNP project demonstrates my synthesis and utilization of the

foundational practice competencies that are required for the practice of a DNP prepared advanced practice nurse (AACN, 2006).

### **Project Developer Proposal**

The journey that I have undertaken to complete this DNP project demonstrates the scholarly process required of program development which is a core essential of doctoral education (AACN, 2006). The collaborative relationship between student and chair has been a fulfilling experience for guidance, mentoring, and direction that was collegially provided, received, and applied by me. The process of creating a successful DNP project has very similar characteristics to the complex process of program development and implementation (Hodges & Videto, 2011). The multiple revisions, which occurred through the evolution of this project, allowed me to synthesize and succinctly focus on the goals and outcomes to produce a finished DNP capstone project that I am very proud of and excited to share with the professional nursing community.

### **Future Professional Development**

My personal growth as a professional nurse has evolved from that of one of advance practice to an individual with doctoral preparation in the field of nursing. I feel that my journey as a DNP prepared nurse has just started as I begin to evolve through Benner's stages of professional growth of novice to expert. The accomplishment of this DNP project is just the initial stage in addressing the identified gap of insufficient palliative care education in the frontline NICU nursing staff. The future application of this multimodal educational program in the NICU will have the ability to create social change in the professional development and practice of the targeted frontline nursing

staff. Future research endeavors will be needed to provide outcome data in this selected area of nursing education and guide the advancement of professional practice in the delivery of neonatal palliative care.

### **Summary and Conclusions**

The outcome data from this program's content validation demonstrated positive feasibility and the strong potential that this DNP project has in addressing the identified educational gap in the clinical practice of the NICU frontline nursing staff. The evolution of this project has allowed me to consistently utilize newly acquired doctoral foundational skills that are required of the DNP prepared graduate. Through the development of this project, I have been able to glean and accomplish a scholarly vision that serves as a launching platform for the successful future of DNP professional practice. Section 5 outlines my future plans for dissemination of this DNP Capstone project to the nursing profession.

## Section 5: Scholarly Product

### **Executive Summary Introduction**

This DNP project was developed to address the identified social need of neonatal palliative care education for the frontline NICU nursing staff at ACH. The educational program is theory driven and multimodal in format to incorporate the learning needs of the learner/s in balance with the available technological and financial resources of the institution. The complexity of this EBP driven proposal demonstrates the core essentials of DNP scholarship and future application in clinical practice as outlined by the AACN (2006). The formative evaluation of this DNP project demonstrated the potential feasibility of execution and future outcome impact on NICU nursing practice in the provision arena of neonatal palliative care.

### **Background**

The death of a neonate is not an expected or wanted result in the daily practice of a RN in the advanced technological environment of the NICU, but unfortunately, the loss of such a young child is a reality in today's clinical practice environment. The NICU frontline nursing staff must have an educational background inclusive of the palliative care requirements for the neonate and family to meet the unique and complex needs of this specialty patient population in their journey of loss. The delivery of nursing care for a neonate who is losing the battle of life should be delivered with honor and the advanced skills that meet the specialized needs of the infant and grieving family.

This educational program focused on neonatal palliative care and specialized communication skills was developed in the following multimodal format:

- Didactic modules developed by CHA: (a) *Care of the Dying Child: The Dying Process*, (b) *Care of the Dying Child: Grief*, and (c) *Care of the Dying Child: Care Issues*.
- Video modules developed by IPPC: (a) *Big Choices, Little Choices* and (b) *Difficult Conversations in Pediatric Palliative Care*.
- Simulation training in the PULSE Center at ACH: (a) Scenario 1 – a neonate experiencing an acute life-threatening illness with the transition to death and (b) Scenario 2 – a neonate with a progressive chronic illness in which medical support was withdrawn.

As the nurse learner progresses through the different formats, a consecutive educational foundation focused on the provision of neonatal palliative care with the specialized end-of-life communication skills is assimilated into the learner's experience and level of understanding. This DNP project demonstrates the "distinctive specialization" that is unique to the doctoral educational preparation for one at the end of their DNP obtainment journey (AACN, 2006, p. 16).

### **Future Project Strengths**

The strength of this project lays in my belief that education is the key to improving one's clinical practice as a professional nurse. Through the utilization of theory guidance, this educational program was developed as multimodal in format to facilitate the learner's assimilation and use of the educational content. The delivery format of using simulation training is evidenced-based and technologically advanced for the pediatric institution. The future dissemination of the outcome data from this

educational program would be the first of its kind in the nursing literature. The ultimate goal is to improve clinical practice and the delivery of palliative care by the NICU frontline nursing staff.

### **Recommendations for Future Project Study**

This multimodal educational program remains in the formative stage. Future application of this educational endeavor in the NICU environment is a feasible intervention and goal for me. The development of a formal educational program focused on neonatal palliative care education and training was the first step in its application process. The use of a formal program planning process, as discussed in Hodges and Videto (2011), would assist me. Utilization of the logic model would help in the planning phase/s of this educational program by providing a visualization and tangible demonstration of the multiple stages of program development, execution, and evaluation (Hodges & Videto, 2011). Assimilation and inclusion of the key stakeholders from the NICU frontline nursing staff and associated multidisciplinary personnel in the early planning stages would provide an enriched contribution and experience to this multimodal educational intervention.

After IRB approval, the application of this educational intervention could be introduced into the clinical arena through the conduction of a nursing quantitative research endeavor. The NICU frontline nursing staff could potentially be used as a convenience sample and randomized into a control group versus the intervention group who would receive the multimodal palliative care education modules. The outcome data and findings from this quantitative research would begin to provide early information on

the feasibility and potential statistical significance of this educational proposal. Further study would be indicated in this area of palliative care education for nurses to produce a larger body of evidence that would be generalizable to other patient populations. Future nursing studies in this specific area of interest should be implemented with the ultimate goal of providing quality patient care surrounding the event of neonatal death.

### **Dissemination Plan**

Dissemination of nursing scholarly endeavors and research outcomes is a professional obligation for the DNP prepared nurse (AACN, 2006). Zaccagnini and White (2011) described two purposes for disseminating nursing outcomes: (a) to communicate and share information with peers and other multidisciplinary professionals who are practicing with similar patients and settings and (b) to report research findings to the academic community and key stakeholders. It is essential in the pursuit of EBP nursing to disseminate research outcomes to ensure the verification of clinical interventions and to guide the development of new patient care guidelines or protocols (Oermann, 2012; Oermann & Hays, 2016; Oermann, Shaw-Kokot, Knafl, & Dowell, 2010). There are many formal and informal avenues for one to share the exciting outcomes and one's hard work associated with a nursing DNP project.

### **Written Dissemination**

The time-honored form and the gold standard of disseminating projects or research outcomes is written publication within a peer-reviewed journal (Zaccagnini & White, 2011). One must critically analyze and select the journal that matches the target audience and environment of the project with the patient population (Oermann, & Hays,

2016). After transitioning and crafting my DNP project into manuscript format, the selected nursing journal for publication consideration would be the *Journal of Neonatal Nursing*. The scope and aim of this journal are focused on the care of neonates and their families that would be congruent with the overall focus and goal of my DNP project on neonatal palliative care education (Neonatal Nurses Association [NNA], 2015). The process of written manuscript publication can be complicated and frustrating due to manuscript rejection/s or requests for complicated revision/s from the reviewers. I have learned from the manuscript preparation experience that the critical analysis of one's work with multiple subsequent revisions can produce a very valuable and polished written product that contributes to the professionalism of the nursing discipline and the body of nursing literature.

### **Oral Dissemination**

The second venue of DNP project dissemination that I have selected is an oral podium presentation for Nursing Grand Rounds at ACH. The DNP prepared nurse must demonstrate and use professionally advanced communication skills in everyday practice endeavors (AACN, 2006). Oral presentations allow the speaker to engage with members of the audience and to share one's passion, thoughts, and feelings on the topic in addition to the importance of the outcome data (Zaccagnini & White, 2011). The oral presentation would allow me to share with the frontline NICU nursing staff and other nursing personnel in the institution the outcomes associated with all of their hard work upon completing this multimodal educational program. I would be able to communicate with them from the perspective of the whole program and provide highlights with positive



feedback on their contribution to the intervention and delivery of the specialized neonatal palliative care. I feel it is very important to keep the key stakeholders engaged in this project and not have them feel as if this educational program was placed on them as another burden or educational requirement that they had to fulfill. This oral presentation would be presented as a gift of information to the frontline nursing staff. I enjoy the challenge in preparing for and providing oral presentations. It allows one to share clinical work or research outcomes and receive interactive feedback from a live, participating audience.

### **Conclusion**

Dissemination of scholarly work is the final stage in advancing nursing practice and promoting the use of EBP within the profession. Vincent, Hasting-Tolsma, and Stevens (2013) discussed that through the dissemination of outcomes and the sharing of clinical practice that that information is translated into the delivery of quality patient care. Oermann, Shaw-Kokot, Knafl, and Dowell (2010) performed a quantitative study to evaluate and describe the dissemination of outcomes in the nursing literature. A citation analysis approach was used to analyze nursing research endeavors ( $N = 28$ ) for citation use during the period of 1999 to 2009. A total of 759 citations were revealed in the nursing literature that originated from the selected 28 publications with 717 (94.5%) of the citations having been published in the nursing journal literature (Oermann, Shaw-Kokot, Knafl, & Dowell, 2010). Through the selected venues of dissemination, it is my goal and passion to share this important DNP project focused on the core concepts of neonatal palliative care education and communication skills. We, as clinicians, play an

important role in every death in the NICU environment and it is our responsibility to be professionally prepared to deliver the best possible care to these vulnerable babies and their parents.

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## Appendix A: Case Scenario 1 Acute Clinical Deterioration

Clinical Simulation

Your patient assignment today is bed # 2 in POD 1. The morning shift report stated that the neonate was an early morning admission that was still getting settled and critically ill. At the bedside, the night shift nurse gives you the following report “Jill is a now one day old premature 25 week by gestation female with intrauterine growth retardation (IUGR). Birth weight 1.3 kg. She was born by vaginal delivery at an outside hospital due to premature rupture of membrane. The mother had not received any prenatal care during the pregnancy. The APGARS were 1 & 2 at the time of delivery. She required aggressive resuscitation with delivery due to apnea and persistent cyanosis. Delivery room stabilization efforts included intubation and mechanical ventilation, placement of a UAC and UVC, and infusions of PGE1, Dopamine, and Epinephrine.”

She was medically transported to Arkansas Children’s Hospital for further evaluation and care. She arrived at 0100 to the NICU. Her medical evaluation at ACH included an ECHO which demonstrated Hypoplastic Left Heart Syndrome with poor right ventricular function and moderate tricuspid regurgitation and the admission physical examination reveal dysmorphic features. Since admission, the neonate’s vital signs have been very unstable with heart rate in the 190 to 200’s range, pulse ox 65% – 70%, systolic blood pressure 30’s, and hypothermic with skin temp of 35. Clinical examination reveals poor perfusion with delayed capillary refill and cold extremities. She has made very little urine since admission and her abdomen has become acutely distended. After you receive report, you perform your clinical assessment and become organized for the shift. Over the next two hours, it become increasingly difficult to ventilate the patient. The patient’s vital signs continue to be unstable with heart rate of 202, systolic blood pressure in low 30’s and pulse ox 64%. The medical team continues with aggressive medical interventions with volume administration and ventilator changes.

The mother arrives to the NICU and see her baby for the first time.

*Simulated Parent Information:*

You are a single mother and this is your first baby. You have not had any contact with the baby's father for the past three months. Your elderly parents drove you to the hospital and are resting in the waiting room. You had a premature birth via a vaginal delivery. You were not able to hold your baby after delivery and only saw her once as the ACH transport team was leaving. You have had a two hour car ride and do not feel well. You see your baby for the first time at ACH. She is laying in an isolette warmer with multiple lines and tubes coming from different parts of her little body and her color is not very good. You hear the monitors alarming and people rushing around her bedside. The nurse introduces herself and states "The NICU physician would like to have a meeting about Jill's condition". The NICU social worker escorts you to the parent conference room where you meet with the NICU physician. He explains that Jill was born very early and has complications with being premature. Additionally, she has a lethal congenital heart defect and cannot undergo surgical palliation at this point in time due to her low birth weight and prematurity status. The physician stated that Jill was critically ill and may not survive. The next twenty-four to forty eight hours were would be touch and go. You are numb and shocked at this information. You could not ask any questions at that time. The physician leaves the room and the social worker obtains basic information from you.

You are escorted back to the bedside to be with Jill. You look at Jill's nurse and begin to cry.

- You state out loud "How can this be happening to me and my baby?"
- After the nurse responds, you ask "What does the doctor mean by premature complications and heart defect?" "She looks horrible!"
- If the nurse fails to provide a clinical explanation, ask again "I do not understand all of this medical stuff!"

- You ask “Is she going to die?”
- If the nurse fails to respond, you ask “Do you think she is dying?”
- You ask “Why can they not just fix her lungs and heart?”

During the conversation, the alarms go off and the baby’s heart rate falls and the team begins resuscitation efforts and including CPR with chest compression.

- You ask “What is happening?” “Is she dying?”
- If you are asked to leave the bedside, become loud, insist on staying, and start crying.
- If the nurse steps forward and starts talking with you. Listen and cry softly.

Resuscitation efforts are unsuccessful and the baby passes away. The NICU physician quietly talks with you about Jill, what just happened, and confirms that she has passed away. He states that she did not have a chance for survival due to the prematurity and lethal heart defect. There was paper work to fill out now. You return to the bedside to spend time with Jill.

You ask the following questions?

- “Was she in any pain?”
- “Do you think she knew I was here?”
- “The doctor keeps telling me she was too premature and had a bad heart problem. Is that what you understand?”
- “What happens now?”

## Appendix B: Case Scenario 2 Chronic Deterioration

Clinical Simulation

John is a five month old male with the diagnosis of a surfactant deficiency and surgical history of gastroschisis. He has been ventilator dependent since birth. He underwent gastroschisis repair in the first week of life and has had long term feeding issues with intolerance. He had a tracheostomy tube placed at three weeks of age along with a GT button. He has had multiple sepsis episodes and feeding complications over the past five months. The genetics consultant just confirmed his diagnosis of type 4 surfactant production deficiency which is an autosomal recessive condition. John's father is in the military and is currently out of the country. A multi-disciplinary team meeting was held with the mother and the maternal grandmother. The NICU attending explained during the meeting that John has a genetic disorder that is not curable. There are only a few potentially life lengthening procedures which all required continued hospitalization (flushing the tracheostomy with surfactant, high dose steroids, and long term increasing, ventilator support) left to give to John. He stated that John would not live very long (hours or days) without mechanical ventilation. If aggressive treatment was continued, John might survive only a few more months but long term survival was unlikely. The team introduced and discussed palliative care and measures of comfort to include withdrawal of medical support.

Simulated Parent Information:

You as the mother are returning to John's bedside after meeting with the medical team. You are in shock. You have never heard anyone talk about a poor outcome or the possibility of John dying before. All conversations have been about the next step or next procedure or the next ventilator change. It has been a long five months in the NICU, but John has continued to live and recover through each hurdle that he has faced.

The mom asks the bedside nurse the following questions:

- What do you think about the possibility of him dying?
- Can you explain how support is withdrawn?
- Will it hurt when he dies?
- Can I be with him if the ventilator is stopped?
- What would you do in this situation?
- Why is the medical team calling this other team of people?

The mom breaks down crying and asking for her mother.