Palliative Care and Bereavement in the Neonatal Population

Sonya N. McLaughlin

East Carolina University

 The birth of a baby is one of the most joyous times in a person’s life. Feelings of hope, love, and pride are prevalent. Nevertheless, in some situations these feelings of elation can change to hopelessness, failure, and grief. These situations arise when a family learns their baby going to die. In the recent past, advances in technology have given medical professionals the opportunity to save infants who otherwise would have died at birth. According to De Lisle-Porter and Podruchny (2009), “in 2004 there were 27, 860 infant deaths in the US” (p. 75). Furthermore, these authors note that “the most frequent causes of infant deaths in the US were birth defects, prematurity and low birth weight, maternal complications, and respiratory distress syndrome” (p. 75). With more therapies and interventions available, these infants are routinely being given life saving measures at birth and admitted into the neonatal intensive care unit (NICU) for further treatment. As a result of these life saving measures, “parents are often faced with the immense, heartbreaking responsibility to decide to withdraw life-sustaining treatments for their infant. Similarly, health care providers are confronted with the ethical dilemma to continue or withdraw care of critically ill neonates” (Eden, Callister, 2010, p. 29). While the attributes and antecedents of palliative care and bereavement are mostly rooted in positivity, failure to effectively implement these practices can result in violence toward this vulnerable population. Consequences from failure to implement palliative care practices and bereavement support can be devastating and lasting to families and most importantly to the infant. The following serves to look at palliative care and bereavement in the neonatal population more closely by dissecting key components of the issue. Evaluations of necessary elements of palliative care and bereavement as well as investigation into the unique ethical and moral problems that arise are discussed. In short, this paper aims to explore the impact palliative care and bereavement have on dying infants, their families, and the healthcare professionals involved.

**Definitions and Attributes of Palliative Care and Bereavement**

The terms bereavement and palliative care are often used in conjunction and occasionally, interchangeably. It is important, however, to acknowledge their differences and clarify the relationship they have. Morgan (2008) describes the origins and history of palliative care including its introduction in 1990 by the World Health Organization (p. 86). Even though the concept and practice of palliative care have been around for centuries, the adaptation of palliative care into the neonatal population is still relatively new. According to Kain (2001), “neonatal palliative care can be defined as ‘holistic and extensive care for an infant who is not going to get better’” (p. 9). Palliative care specifically refers to nursing and medical interventions which are aimed at reducing suffering and providing comfort at end of life. In contrast, “bereavement encompasses the entire experience of anticipating a death, the death itself, and the subsequent adjustment to living” (Meert, Schim, Briller, 2011, p. 591). From this vague description, it can be postulated that bereavement in the neonatal population addresses the ever changing needs of the family whose infant has, or will soon be dying. Although they are two separate entities, palliative care and bereavement merge at end of life in an effort to provide support and comfort to the patient and their family.

Attributes in palliative care and bereavement focus primarily on the healthcare professionals involved at end of life. As numerous admirable characteristics are found in effective care givers of those who are dying, a select few have been chosen to focus on. Characteristics to be highlighted include compassion, caring, and empathy. Engler et al. (2004) state that “parents of critically ill infants need and want compassionate support from the infants’ caregivers during an extremely stressful time in the parents’ lives” (p. 495). Having a genuine concern for the patient and family, and wanting to do anything to alleviate even some of their suffering is an integral characteristic for healthcare providers and nursing staff to possess. Those providers and nurses who interact with the patient and family on a consistent basis must be receptive to feelings of helplessness and devastation and be able to react in a manner that promotes bonding with the infant. In addition to compassion, “studies have shown that a caring attitude in one of the most critical attributes for a nurse working with a bereaved family” (De Lisle-Porter & Podruchny, 2009, p. 77). Excellent care must be provided not only to the infant, but must extend to the family during their time of need. De Lisle-Porter and Podruchny (2009) state “positive perceptions of care quality can help the family cope during the grieving period and promote precious memories; negative perceptions can overshadow even good quality care and leave the family with nothing positive to hold on to (p. 77). From this research it is obvious that accomplishing tasks is not in itself care. The attitude behind the tasks has the ability to change a family’s perception and experience. Empathy, while similar to compassion is defined as being able to relate to another person’s feelings. (Webster, 1995, p. 145) An empathetic nurse has the ability not only to understand the family’s suffering but may have similar experiences from which similar emotions can be drawn. Compassion, care and empathy are all necessary components in a positive neonatal palliative care and bereavement situation.

**Possible Antecedents of Neonatal Palliative Care and Bereavement**

**Death is Inevitable**

 The primary issue that must be addressed in order for a palliative care plan to be initiated is the acceptance that an infant is not going to survive. According to work by Romesberg 2004, “the majority of neonatal conditions requiring end-of-life care include extreme prematurity, lethal anomalies (eg, trisomy 13, trisomy 18, and anencephaly), and situations requiring continuing and aggressive care that is considered to be more burdensome than beneficial (eg, severe intraventricular hemorrhage and hypoxic ischemic encephalopathy)” (p. 162). While many of these infants are routinely given life saving measures at birth, it is after their admittance into the NICU that responsibility falls to the provider to identify that there is no cure. The clinician must accept that the infant would not be able to sustain life without medical interventions. This can be especially difficult in the neonatal population since “children, the hope and the future of our society are not supposed to die” (Morgan, 2009, p. 87). Healthcare providers struggle with failure and parents fight to hold on to the hope that their child can beat the odds. It is at this juncture that an open relationship between the healthcare team and the family becomes invaluable.

**Establishing a Relationship through Communication**

 Many thoughts and opinions exist as to what extent parents should be involved in end-of-life decisions for their infant. Some studies discuss views that parents are unable to make choices due to their intense grief. Many other studies, however, state that with open communication, trust, and proper education to the dying process, parents are able to make decisions for their infant. In an article by De Lisle-Porter and Podruchny (2009), the authors write that communication “is vital- and the words spoken should validate the infant’s life and death” (p. 79). These authors also suggest “to use language that does not confuse the parents” (p. 79) and that “it is preferable to use specific words such as ‘death,’ ‘die,’ and ‘dying’ rather that euphemisms like ‘not doing well,’ ‘passing away,’ ‘lost,’ or ‘expired’” (p. 79). In order for healthcare providers and families have a productive relationship with a common goal, there must also be a high level of trust in the healthcare team. Trust can only be earned when the lines of communication are open. Eden and Callister (2010) agree. In their article the authors note that “good communication between the health-care provider and the parents is essential when making end-of-life decisions. If parents perceive the health-care providers as caring, they are more likely to trust the information given to them about their infant” (p. 35). Nurses are often on the forefront of this team. In many situations, nurses have the most opportunity to interact with families and “have an excellent opportunity to forge a relationship of trust” (Engler, et al, 2004, p. 489). From this front line, nurses are often first to know what factors may change this relationship such as spirituality, culture, and ethnicity. Nurses and providers should be aware of religious and cultural preferences and possible rituals that need to be included in palliative care practices. Baptisms, bathing of the body, and other ceremonies or services may need to occur in order for a family to be able to accept the impending death of their infant. There are numerous avenues through which effective communication and a trusting relationship can be achieved. Family care conferences have become a way to communicate with families not only about their infant’s current condition but also to discuss plans going forward. In addition to providers and nurses, social workers, spiritual support, and other consultants can be brought together to answer any questions the family may have. Parents should be educated to what dying will look like and should be assured in their decision to move from curative care to palliative care. It is also through a positive relationship that parents’ feelings of loss should be acknowledged. Bereavement support should continually be offered and parents should be allowed to grieve.

**Understanding Grief**

 An understanding of grief by the nurse must be accomplished for palliation and bereavement to occur. “Grief is a healthy human response that facilitates our ability to cope with crisis and loss. People grieve at different rates and intensities” (De Lisle-Porter & Podruchny, 2009, p. 79). Grief is not only felt by parents but also by nursing staff and providers. In addition to Dr. Kubler-Ross’ (1972) five stages of death, several authors have proposed alternate theories and steps to the bereavement process. Wherever a family is in their grief process, support must be available. According to Romesberg (2004), “understanding grief and offering bereavement support are key components to providing beneficent neonatal palliative care” (p. 161). Within her 2004 article, Romesberg also states that parents should be allowed and encouraged to touch or hold their dead baby and also to participate in after death care such as bathing the body and dressing the baby (p. 162). These practices may allow the family to grieve and may facilitate the grief process. Another way to help a family while grieving is to collect memoirs. Keepsakes such as a lock of hair, footprint impression, and photos, give parents something to hold on to following the death of their baby. In any situation, a family’s wishes should be acknowledged with regard to care of the infant after death. It is important to remember that grief is an individual process and a family’s needs vary in each situation.

**Possible Consequences of Neonatal Palliative Care and Bereavement**

 The consequences of a successful palliative care plan and bereavement support often arise from moral and ethical dilemmas faced by parents and caregivers. “Ethical complexities in neonatology have always been propelled by 2 distinct forces. Advances in technology and pharmacology have placed larger and larger numbers of newborns within the scope of neonatal intensive care unit (NICU) care, and more and more controversy has evolved over whether we are doing the right thing” (Singh, Lantos, & Meadow, 2004, p. 1620). While initial stabilization is often achieved in the NICU, care of the extremely preterm infant of infant that is incompatible with life is often futile. The death of an infant is never easy to accept but the goal of palliative care should always be to reduce the amount of pain and suffering by the infant. Even though the best interest of the patient is to die, parents and caregivers alike can experience negative consequences during this highly stressful time. As healthcare professionals, however, it must remain a goal to stay focused on the patient to ensure no negative consequences befall onto them.

**Consequences to the Patient**

 The main focus in neonatal palliative is care for the infant as they progress toward dying. It is therefore not surprising that the primary consequences in neonatal palliative care center on the infant. Of greatest concern is pain and comfort management. Historically, “it was believed that premature and term infants were unable to experience pain because of an immature central nervous system, lack of pain memory, and inability to verbalize the pain experience” (De Lisle-Porter & Podruchny, 2009, p. 81). Current research, however, knows this previous speculation to be false. It is now known that infants can feel pain and in fact are more sensitive to pain than older children and adults. (De Lisle-Porter & Podruchny, 2009, p. 81). Using the neonatal pain and sedation scoring (NPASS) system, it is possible to assign the infant a pain score and react accordingly. Pain medication should be continued throughout palliation including following the removal of mechanical ventilators. Dying continues to be painful even after life support is removed and parents will find comfort knowing their baby is not in any pain. According to De Lisle-Porter & Podruchny (2009), “the ill premature infant or term infant will benefit from dying pain-free, in the arms of a loving parent” (p. 81). In addition to pain management, thought should be given to interventions that occur leading up to death. Neonatal units may have in place a palliative care protocol for nursing care which dictates the manner in which care of a dying infant should occur. Such protocols limit the number of nursing assessments necessary, vital signs monitored, procedures to be continued or stopped, and guidelines regarding blood draws. By monitoring and dealing with pain and limiting interruptions, the consequences of pain reduction and increased comfort can be achieved.

**Psychological Needs of the Family**

It is logical to presume that the death of an infant will emotionally affect the parents and family of the infant the most. In one study examining the need for continued bereavement support following a child’s death, the authors state that “death of one’s child may lead to intense and immobilizing grief reactions for parents” (Reilly-Smorawski, Armstrong, & Catlin, 2002, p. 21). This fact should be of no surprise. Hopes and dreams for that child are shattered and parents are left with only a small number of memories. Vance et al. (1995) conducted a study focusing on parents eight months after the death of the infant. The authors found a number of commonalities between families with regard to their mental health. Some of these include “general ill health, psychosomatic or psychiatric disorders, and altered relationships and roles within the family and society” (p. 933). While the occurrence of grief is normal, support while coping during and after the death of an infant can lessen the effects. Romesberg (2004) in a paper about grief highlights a number of factors that make this especially difficult. Loss of power, loss of a family member, and loss of part of self were all listed as barriers to a healthy grief process (p. 162). Healthcare providers can combat these feelings by validating the infant’s life, creating memories for parents, and acknowledging their feelings of loss.

**Personal Pain**

 Painful emotions are not only felt by parents and families but also by those providing care to a dying baby. According to Morgan (2009), “professionals who witness the pain and suffering of children and their families may also experience pain and suffering themselves” (p. 86). The author goes on to say “healthcare workers may experience emotions such as helplessness, anger, sadness, and anxiety while providing care to dying children” (p.86). While these feelings are normal to have, healthcare workers often inadequately deal with these emotions which can lead to personal pain, continued suffering, and burnout. In an article by McGrath (2011), the author speaks to suffering, more specifically a concept identified as layered suffering. “Layered suffering is the accumulation of grief and suffering both in the workplace and in the personal lives of nurses” (p. 8). Symptoms of layered suffering can include fatigue, anxiety, mood swings, and insomnia. (McGrath, 2011, p. 8). Another phenomenon healthcare workers may experience is termed disenfranchised grief. Disenfranchised grief refers to the minimization or even avoidance of emotional reactions while in the workplace. (Romesberg, 2004, p. 163). While it may be necessary in some situations to remain professional, emotions stemming from the death of an infant should be properly addressed. Avenues in which this can happen include de-briefing sessions with the entire team, time away from work, or meeting with a counselor. No matter the situation, healthcare workers must be able to handle these situations as families look to them for answers and support.

**Moral Distress**

Aside from emotions healthcare workers may be experiencing, there are also feelings that arise from the morality of caring for an infant after it has been established that the baby will not survive. The Born-Alive Infants Protection Act of 2002 mandates that infants who show signs of life at birth are to be treated as people so legally life saving measures are often justified. (Romesberg, 2003, p. 213). After this initial action, however, care can become futile. Romesberg (2003) defines futility as follows; “futile care refers to medical care that either prolongs suffering, does not improve the quality of life, or fails to achieve a good outcome for the patient” (p. 213). Futile care can occur due to any number of reasons: some of these include false hope that the infant will get better, denial that the infant is ill, believing a false diagnosis has been given, belief in a higher power, and an attitude not to give up on the baby. (Romesberg, 2003, p. 216). In a majority of situations, these views are those of the parents but it should be noted that there are instances where a medical professional is not willing to stop curative measures. When parents continually demand treatments are given to their baby “health care providers may find it difficult to adhere to the principles of nonmaleficence and beneficence, when providing care that may be considered futile” (Romesberg, 2003, p. 216). The principles to do no harm and promote good for the patient become compromised when parents refuse to accept the inevitable. In addition to this, Kain’s (2011) research found that “parental expectations regarding the long-term outcome of critically ill newborns may be idealistically high and so might the expectations placed upon neonatologists and neonatal nurses” (p. 12). The high hopes of a family coupled with the ongoing futile care of the infant can consequently lead to intense moral distress. Kain (2011) describes moral distress as an inability to translate moral thoughts into action. (p. 12). In order to combat feelings of moral distress and futility of care, infants who are not going to survive need to be identified quickly, communication established with family, and plan of care transitioned from curative to palliative.

**Benevolent Injustice**

Possible the most disturbing possible consequence of a failed palliative care plan in termed benevolent injustice. “A benevolent injustice occurs when the well-intentioned treatment efforts of a physician or medical team produce an outcome that limits the potential of a patient or renders them technologically dependent” (Barnum, 2009, p. 133). Infants who survive the initial life saving measures and endure the treatments in the NICU often times have debilitating morbidities and disabilities as a direct result of the care given. (Barnum, 2009, p. 133). This cohort of patients, who remain in the NICU for extended periods of time and are chronically and acutely ill, has become a reality in many NICU settings. These patients may eventually be transferred to step down units, long term care facilities, and on some occasions, home. Many of them will die in the NICU regardless of continuous medical treatment. Of the babies that do leave, most have repeated visits to the hospitals for infections and other complications and the reality is many of them will still die. “Newborn babies and children are among the most cherished members of our society. They represent the future, vitality, and limitless possibility. When a baby is faced with a serious illness-or even death- many believe that there is no question that the life must be saved at all costs” (Barnum, 2009, p. 132). This belief for some babies means a lifetime of illness and pain even if the intentions were pure.

**Implications for Nursing Practice**

Bedside nurses, advanced practice nurses, and nursing as an institution should be concerned about the consequences previously discussed. Foremost, there should be no doubt that the patient is the priority of care at all times. Nursing has the ability to minimize negative consequences felt by a patient. Through pain assessment, pharmacological interventions can be made available; through palliative care fewer disturbances can maximize comfort measures put in place. Families of dying infants rely on nurses to communicate with them honestly, provide support, and facilitate time to bond with their infant. Families needs impact nursing due to the nature of this relationship. The nurse can be the difference between a positive palliative care and death experience and a negative one. Personal pain felt by a nurse providing care for a dying infant should also be of concern. If the bedside nurse or advanced care nurse caring for the baby is unable to process and adequately deal with painful emotions surrounding the infant’s death those feelings can manifest in other ways. Nurses can feel helplessness, hopelessness and can be get burnt out if emotions are not properly identified. Moral distress is an issue that, more than likely, will be present in many situations a nurse is involved in. Once again, if the nurse is unable or unwilling to cope with and manage these feelings it can impact practice negatively. As technology continues to advance, moral distress must be reviewed and as always, the patients’ best interest should be held in the highest regard. Lastly, benevolent injustice can impact nursing due to the major implications it has for our patients. When a benevolent injustice occurs it can reflect directly on the nurse who, for whatever reason, was unable to implement a palliative care plan. Nursing as an institution is effected when nurses themselves are impacted. Changes in practice, development of new policies and protocols and continued research all have the ability to shape nursing as it progresses into the future. It is essential to examine and evaluate consequences, both positive and negative, to appreciate their impact and how these outcomes can shape nursing in the future.

**Peaceful End of Life Theory**

 The peaceful end of life theory is a middle range theory developed by Cornelia M. Ruland and Shirley M. Moore. Compared to grand theories, middle range theories are more specific, have fewer concepts, and encompass a more limited aspect of the real world” (McEwen, 2011, p. 204). This type of theory has the ability to focus on issues that arise in nursing practice. Some characteristics of middle range theories include that they are simple straightforward and general, are focused, and pertain to the practice of nursing. (McEwen, 2011, p. 206). The peaceful end of life theory, more specifically was developed from a standard of care which was implemented to facilitate care at end of life for terminally ill patients in Norway. (Ruland, Moore, 1998, p. 171). The authors primarily identified 16 outcome criteria for a peaceful end of life which were then condensed into 5 outcome indicators. These indicators include not being in pain, experiencing comfort, experiencing dignity and respect, being at peace, and being close to significant others and other caring people. (Ruland & Moore, 1998, p. 172). Additionally, the authors include a number of interventions to achieve these outcome criteria.

**Peaceful End of Life as it Relates to Neonatal Palliative Care and Bereavement**

 The peaceful end of life theory relates to neonatal palliative care and bereavement in several ways. Many of the aforementioned attributes, antecedents, and consequences are parallel to the nursing interventions in the theory. The first and second outcome indicators in the end of life theory are the reduction of pain and experience of comfort respectively. In neonatal palliative care, the focus should always remain on pain reduction and comfort. A description of palliative care offered by De Lisle-Porter and Podruchny affirms that “palliative care consists of three components (1) pain and comfort management (2) assistance with end-of-life decision making and (3) bereavement support” (p. 75). The third indicator in the end of life theory is to experience dignity and respect. To translate this into the neonatal population we must review the definitions of dignity and respect. Both characterizations, according to Webster(1995), speak to the worthiness of a person and holding the recipient in high regard. (p. 196, 571). In the neonatal population, dignity and respect translate to the nurses’ fidelity and the ability to advocate for the infant. The nurse must ensure that the patient is being cared for in the best possible way in each situation. This respect must also extend to the family by including them in end of life decisions and respecting their wishes for the infant. Being at peace is largely subjective and difficult to measure in neonates and thereby would be transferred to the parents and families of these infants. Parents should be assured of their decision and that it is the right thing to do for their baby and “perhaps most importantly, all involved parties must have mutually agreed-upon plan: to reduce the potential for the family to doubt their decision” (Romesberg, 2003, p. 217). Parents should be at peace with their decision to withdraw care and should be as comfortable with the situation as possible moving forward. The final objective is closeness to significant others and other caring people. In the NICU this would refer to the parents and other family members of the infant. The end of life theory suggests family members assist in patient care, attend to grief, worries, and questions, and facilitate closeness. In neonates, the same interventions are effective. Promoting time for parents to hold their baby prior to and after death, providing parents with mementos of the baby’s short life, and offering bereavement support are all interventions that should be implemented in palliative care. This theory was developed for nurses because “nurses are usually the providers of knowledgeable and compassionate care for patients at this stage” (Ruland & Moore, 1998, 174). The integration of neonatal palliative care into the peaceful end of life theory is not difficult. Following the identification of an infant who is going to die, the same outcome criteria should be given consideration. Disparities only exist as to who the criteria target but even then nursing interventions are still applicable.

**Conclusion**

The death of an infant is never a pleasant experience for anyone involved. The pain and heartache felt can be far reaching and encompass not only the parents and families but the nursing staff and providers. It is of the utmost importance to remember, however, that in some situations the death of the infant is necessary. “In the NICU, palliative care includes bereavement support for the family after the infant’s death but begins with care for the living infant” (Eden & Callister, 2010, p. 35). The infant must remain the primary focus of the healthcare team and their best interest should always be the first consideration. The need for palliative care and bereavement in the neonatal population will continue to increase as technology advances and more infants are saved. The consequences of a negative or absent palliative care plan are substantial but can harm no person more than the infant. It is possible through a positive death experience to leave the parents with fond memories of their baby, healthcare providers with feelings of acceptance, and nurses without the distress of futility of care. Neonatal nurses and providers should focus on adding life to the time the baby has, not adding time to the baby’s life.

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