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Palliative and End-of-Life Care for Infants and Their Families in the NICU: Building a Program of Research

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Every year in the United States, about 4 million babies are born, and more than 500,000 are subsequently admitted to a neonatal intensive care unit (NICU) due to prematurity, respiratory, cardiac, metabolic, or chromosomal abnormalities, syndromes, malformations, infections, and post-anoxic conditions. Advances in technology may allow for intensive life-saving treatment to continue over days, weeks, or even months depending on the infant's gestation and underlying condition. During this time, infants may experience pain or other symptoms that are difficult for clinicians to assess and manage, and for parents to witness, causing emotional distress. Approximately 16,000 of these infants will ultimately die in the NICU, while others will go on to develop chronic complex conditions that require ongoing intensive medical care. Both scenarios carry risk for high infant symptom burden and suffering, as well as having an influence on parental decision-making for treatment.

For families of infants who die in the NICU, the trauma of the experience may have lasting effects, including long-term negative health outcomes for a subset of parents. Parents face unique challenges when the end of life (EOL) comes so closely to the beginning of life. Further, limited opportunities for bonding may occur when mothers must stay at the birthing hospital to recover and parents are not able to fully participate in care activities because of the infant's fragile state. Defining and maintaining the parents' role, while making difficult treatment decisions can be extremely stressful for them during this time. Parents may be further distressed by their infant's appearance, physical symptoms, or perceptions that their infant is suffering. Parent perceptions of infant suffering at EOL have been associated with prolonged grief at 3-years post-death, but even when the infant doesn't die the effect of parent perceptions of infant suffering have effects on their anxiety. Some health care providers also report high levels of distress and compassion fatigue in caring for infants and families with complex chronic illness, especially if death is anticipated.

The American Academy of Pediatrics Committees on Bioethics and Hospital Care (2000), the Institute of Medicine (2003), and an increasing number of research articles have called for greater attention to improving palliative and EOL care in pediatrics, and specifically in infants. Personal experience as a NICU staff nurse, also influenced the pursuit of this line of research inquiry that has begun to highlight a constellation of factors that contribute to the quality of the palliative and EOL care experience for these infants, and their families and health care providers. Early work developed an evidence-based framework that was adapted from the adult literature for use in the evaluation of the quality of neonatal palliative and EOL care in the NICU; identified issues medical record documentation; and highlighted nurse-described barriers to the observation of symptoms in infants who died in the NICU.

The "Framework for a Good Neonatal Death" by Fortney and Steward (2014) identifies key variables across three domains (infant, parent, nurse) that interact within the changing NICU environment and may contribute to a "good death," defined by the Institute of Medicine (2003) as "free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards." The interaction of these variables may influence whether the experience will be more positive or more negative.

The model includes parent and nurse perceptions of infant symptoms and suffering, which are particularly important given the infants are not yet verbal. However, methodological issues, particularly the lack of standardized measures for use in assessing infants, have limited our understanding of symptom manifestation and how to optimize care for infants. Further, perceptions of symptoms and suffering by parents and nurses can be influenced by a variety of factors, such as life experience, social support, family dynamics, education level, clinical experience, and familiarity with the infant. Often perceptions between parents and healthcare providers differ and can lead to issues with communication and trust.

This early work led to a retrospective pilot study where mothers and fathers reported seeing an average of six different symptoms in their infant during their last week of life. Respiratory distress, agitation, pain, and lethargy were described as being the most distressing. Both mothers and fathers also reported moderate levels of suffering for their infant during the last week of life, though the association between the number of symptoms and the amount of suffering was weaker for mothers than for fathers. Collaboration between the medical team and parents in recording symptoms and making medical decisions, therefore, continues to be a highly important and impactful area of the course of treatment.

Further, the original "Framework for a Good Neonatal Death" was expanded to incorporate research results that provide a deeper

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understanding of bereaved parents' experiences with their infants at EOL and highlight opportunities for enhanced care of critically ill infants at high risk of death in the NICU and their families (Baughcum, Fortney, Winning, Shultz, & Keim, et al., 2017). Parents as partners in care, communication with the healthcare team, relationships with staff, and bereavement support were added to the model as influential processes in the determination of quality of the care experience. Parents generally felt positive about their role in treatment decisions, relationships with staff, and memory-making activities. However, parents noted areas for improvement, including team communication, anticipatory guidance, family inclusion at bedside, and bereavement care. Another modification to the model extended the work of NICU nurses to include other types of healthcare providers, including physicians, psychologists, chaplains, and social workers. While more research is needed to determine if the nurse factors identified in the original model also pertain to other NICU personnel, parents have strongly identified them as being valuable resources.

Finally, parents have reported often feeling alone and abandoned after leaving the hospital. They want to maintain connections to the staff members who were intimately involved in their infant's short life and witnessed the family's journey because they may be the only ones who knew their child. However, ongoing contact can be difficult in terms of balancing professional boundaries and staff burnout and needs to be examined further. Further, nurses have reported struggling with identifying and managing infant symptoms, being focused on tasks associated with the level of care they are providing, having limited formal palliative and EOL care training.

The search for the best possible palliative and EOL care experience in the NICU continues to unfold through research with parents and healthcare providers throughout an infant's hospitalization. Ongoing prospective research is assessing views of infant well-being from multiple sources and identifying associations between parents' perceptions of infant symptom experiences and their decision-making around goals of care, as well as their distress and coping. The hope is that this research will inform the development of interventions aimed at reducing symptom burden and suffering for infants and families; that it will shed light on the experiences of health care providers so that strategies for focused palliative and EOL care education and training will be implemented; and that it will help families honor their infant's legacy while laying a positive foundation for life with a complex chronic illness, as well as life after loss.

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