abstract

Few health care professionals have received palliative care training to comfort dying infants and their families. One institution’s development of a palliative care program in the neonatal intensive care unit setting is discussed in this column. 


The commonly held belief that infants should not die makes the decision to implement palliative care difficult for both families and the health care team. Although the history of palliative care or hospice care spans six decades, a national focus on pediatric needs did not begin until 2000. In 2000, the American Academy of Pediatrics published a position statement that recommended five principles to guide end-of-life care: respect for the dignity of patients and families, access to competent and compassionate palliative care, support for the caregivers, improved professional and social support for pediatric palliative care, and continued improvement of pediatric palliative care through research and education (American Academy of Pediatrics Committee on Bioethics and Committee on Hospice Care, 2000). In the United States, approximately 2 million children are living with life-threatening conditions and 18,000 newborns die within the first 28 days of life due to prematurity/immaturity, infection, and congenital anomalies annually (Gale & Brooks, 2006). There is little research on palliative care for infants.

A 42-bed regional III neonatal intensive care unit (NICU) bereavement council, consisting of nurses and nurse practitioners, had been in place at a health care institution for more than 20 years. However, the need for a more formal palliative care program addressing interdisciplinary education and standardization of best practices became evident after several problematic case reviews. As a result, a palliative care NICU nurse leader position was created to spearhead the development of a NICU-specific palliative care program with the mission of standardizing withdrawal of life-sustaining treatments, pain management, and supportive care for both infants and their families during and after death. The new palliative care team included neonatologists, the palliative care NICU nurse, the NICU unit director, three nurse practitioners, the social worker, and the chaplain. The team assessed current processes and resources to identify key areas for improvement, including standardizing withdrawal of life-sustaining treatment, pain management for infants, advocating for the promotion of parental wishes, improving staff awareness of the needs of families during the death experience, and post-death supportive follow-up for both families and staff.

The decision to withdraw life-sustaining treatment is made by both the family and the health care team. Occasionally, conflicts arise surrounding this decision due to differences in perspectives between the family and the health care team. Nationally, more than 80% of neonatal deaths in the critical care unit are preceded by a decision to withdraw life-sustaining treatment, indicating the strong need for identification of best practices to assist families during this difficult time (Koppleman, 2006). NICUs without established palliative care programs must rely on individual physician experience or judgment to address the needs of infants and parents, which leads to inconsistencies in clinical practices. The NICU-specific palliative care team can standardize best practices that facilitate awareness and understanding of this difficult decision process as well as role model communication skills.

Consistent communication of information is key to ensuring families receive the same message from the health care team. The palliative care nurse plays a critical role in effective communication as the liaison between family and staff by conducting daily rounds in the NICU.
provides the opportunity to develop trusting relationships with families to better understand their wishes and level of comprehension of the situation. The palliative care nurse is readily available to schedule family conferences and give daily updates to parents and health care providers to ensure everyone is comfortable with the plan of care.

In some situations, although the medical recommendation is to withdraw life-sustaining treatment, parents may feel that the potential of severe disabilities is not an important outcome and decide to have everything done to save their infant. No decision is easy; no decision is the same for each family. Trust between the family and the health care team is essential in reducing moral distress for both parties. Ethical conflicts may arise when the staff feel that the infant is suffering due to prolongation of treatment. Feelings of guilt and anger among staff are not uncommon. For the parents, ethical conflicts are generally effectively addressed by the palliative care team. However, if the conflict seems unsolvable, families can request a bioethics consultation by either going through the staff or independently accessing an organizational Internet Bioethics Consult webpage. In contrast, conflicts involving the health care team are mediated by the palliative care nurse. The palliative care NICU nurse who schedules sessions, as needed, in a safe place for the staff to discuss their feelings. Having a palliative care nurse with a history of positive working relationships with fellow members of the health care team promotes an atmosphere of safety and trust, with staff feeling that their opinions count. A psychologically safe environment is essential; its absence negatively impacts the authenticity of compassion expressed by staff, promoting staff resentment and potential isolation of the family.

Neonatal palliative care research indicates that not all units provide the same level of comfort care due to the fear of opioid-related dyspnea hastening death. The National Association of Neonatal Nurses (NANN) position statement on palliative care for newborns and infants suggests that pain and distressing symptoms such as gasping should be treated with pain and/or sedation medications using the least invasive route in consultation with a neonatal pharmacologist (NANN, 2012). NANN also suggests the use of validated pain and sedation instruments to frequently assess the dying infant. The palliative care team at this institution developed a comfort care order set to standardize comfort measures, ensuring equitable and accessible palliative care treatment for all infants. By using the validated pain and sedation scales to assess the infant, both the staff and the parents have tangible evidence that the infant is comfortable.

Most health care professionals have received limited training on palliative and hospice care. The palliative care NICU nurse educates and supports each staff member regarding the stages of dying for infants and families as well as their organizational resources for end-of-life care using a palliative care newsletter and small in-services.

The palliative care NICU nurse acts as a role model for the staff to develop communication and comfort care skills for this difficult period as well as advocate for the parents’ wishes at the end of life. The NICU has a private room where family and friends can spend precious time with the dying infant in a private space yet still be close to the health care team and palliative care team members. Preserving these special moments can be done by taking photographs to provide positive memories.

After death, families are encouraged to spend as much time as needed with their infants. The palliative care NICU nurse refers lactating mothers to the lactation consultant to assist with breast engorgement following the death of their infants. The lactation consultant also discusses possible donation of the unused milk to a human milk bank. Caring for the staff after the death of an infant is also important. The palliative care NICU nurse provides structured sessions to assist the staff with processing grief, which is helpful in reducing compassion fatigue. Grieving is normal and to be expected among the health care team.

The palliative care nurse’s added expertise in caring for NICU infants and their families contributes to successful implementation of best practices. Being a respected member of the NICU team provides the palliative care NICU nurse with a solid foundation on which to build the program. Death is a natural part of life, but caring for dying infants and their families may not always be comfortable for health care providers. The palliative care NICU nurse and team can bridge this gap, promoting best practices for the care of dying infants and their families.

REFERENCES