



**National
Association of
Neonatal
Nurses**

Palliative Care for Newborns and Infants

Position Statement #3051

NANN Board of Directors
September 2010

Infants in the care of neonatal nurses are sometimes born with life-limiting conditions, and some infants develop life-limiting conditions during their neonatal hospitalization. Nurses and other caregivers determine when intensive therapies no longer offer hope for a cure or recovery, and they then shift the focus of treatment toward maximizing quality of life. End-of-life care, one aspect of palliative care, supports a peaceful, dignified death for the infant and the provision of loving support to the family and healthcare providers. Neonatal nurses are essential to the provision of palliative and end-of-life care.

As the professional voice of neonatal nurses, the National Association of Neonatal Nurses (NANN) recommends that neonatal nurses be trained and participate in offering services entailed in providing palliative and end-of-life care.



Association Position

Palliative and end-of-life care for infants and their families are an integral component of neonatal care, and neonatal nurses should be trained and participate in providing services involved in this essential care.

Background and Significance

More than 29,000 infants under 1 year of age die each year in the United States, and 66% of these deaths occur during the neonatal period (Xu, Kochanek, & Tejada-Vera, 2009), many in the neonatal intensive care unit (NICU) (Brandon, Docherty, & Thorpe, 2007). Every year, more than 500,000 children live with a life-limiting illness (Himmelstein, Hilden, Boldt, & Weissman, 2004). Palliative care is appropriate for neonates with a wide range of life-limiting conditions, including severe prematurity and its accompanying complications or complex congenital anomalies, whether the condition will result in death during the infant's first few hours of life or after several years.

The model of palliative care is focused on quality of life, and within that model curative and comfort interventions may coexist. The World Health Organization (2010) states that, in the case of life-limiting conditions, palliative care should begin at the same time that curative care begins. The International Council of Nurses (2006) views the nurse's role as "fundamental to a palliative approach that aims to reduce suffering and improve the quality of life for dying patients and their families through early assessment, identification and management of pain and physical, social, psychological, spiritual and cultural needs."

Recommendations

1. Palliative care should be offered at any period in which the infant's life may be limited—prenatally, at the time of birth, and after the birth, initially in the NICU and at home following discharge.
2. When a prenatal diagnosis is made, palliative care should be offered while the fetus is in utero. Families should be supported in decision making for a pregnancy termination, an early induction of labor, or a live birth, and supportive palliative care should be provided after the birth. Planning and decision making for the birth include choosing who will deliver the baby, where the delivery will take place, and who will be present; delineating the resuscitation plan for the infant; and planning for comfort measures immediately at birth.
3. Brochures that define *palliative care*, identify team members, and explain the services offered should be available to parents in the NICU.
4. When an infant with a potentially life-limiting condition is being transported to a tertiary care center, the parents should be informed that palliative care may be the focus of care.

5. Parents are part of the caregiving team and should participate in the decision-making process. Family conferences are essential to caregivers' understanding of families' needs and hopes and goals for their infant. Use of a family medical record (e.g., the Penticuff Family Medical Record [Penticuff & Arheart, 2005]) allows families to track their infant's progress and better understand when the infant is not "getting better."
6. Appropriate family support services should be provided, including those of
 - perinatal social workers, hospital chaplains, and clergy to provide emotional and spiritual support
 - a child life specialist or family support specialist to support the infant's siblings
 - a family advocate (a parent who has had a child in the NICU) to assist with navigating the NICU experience
 - a lactation consultant to assist mothers who want to breastfeed their infant or donate breast milk at the end of life and to help mothers manage cessation of lactation at the end of life (Moore & Catlin, 2003).
7. The proper focus of palliative care should be maintained.
 - Active orders should be reviewed to determine whether they should be continued when palliative care is initiated.
 - Pain and distressing symptoms, such as gasping or seizures, should be treated in consultation with a neonatal pharmacist, with the least invasive route considered the desired method of delivery (i.e., buccal, dermal, or rectal delivery if intravenous access is no longer desired or available).
 - Comfort measures including holding and kangaroo care should be encouraged.
 - A validated instrument to measure infant pain and sedation should be used. Available options include the following:
 - Premature Infant Pain Profile (PIP) scale (Stevens, Johnston, Petryshen, & Taddio, 1996)
 - Neonatal Pain Agitation and Sedation Scale (Hummel, Puchalski, Creech, & Weiss, 2008)
 - Neonatal Infant Pain Scale (NIPS) (Lawrence et al., 1993)
 - Pain Assessment in Neonates (PAIN) (Hudson-Barr et al., 2002)
 - Modified Infant Pain Scale (Buchholz, Karl, Pomietto, & Lynn, 1998)
 - Children's and Infants' Postoperative Pain Scale (Buttner & Finke, 2000).
8. NICUs should have a relationship with a local hospice or palliative care organization in order to offer seamless continuity of care. Where local hospices do not provide pediatric care, pediatric home health agencies and a primary care pediatrician may oversee the palliative care needs. Infants who are discharged with life-limiting illnesses should have a plan of care, including

necessary resources and a portable nonresuscitation plan to avoid unnecessary resuscitation.

9. End-of-life care should give attention to the following concerns:
 - Care should be provided in a private location within or near the NICU, with the goal of keeping the family members together.
 - Alarms and pagers of those in attendance should be turned off.
 - Light levels should be adjusted for family comfort.
 - Routine measurement of vital signs and lab analyses should cease.
 - Pain assessments to identify infant distress should be performed frequently.
 - No painful assessments (e.g., heel sticks, measurement of blood gases) should be made.
 - Appropriate access to medications (intravenous, rectal, buccal, or topical) should be given.
 - Artificial nutrition and hydration intervention should be discussed.
 - Offering small amounts of oral fluids as a comfort measure is appropriate.
 - Decisions should be made on the basis of information on the risks and benefits for the infant. (When adults are being fed at the same time that organs are shutting down, they often develop complications such as pulmonary edema, cardiac failure, painful abdominal distention, and aspiration pneumonia. Insertion of a feeding tube has the potential to extend life and prevent the natural dying process. Recent research has found that adult patients at the end of life are more comfortable when they are not fed. When not receiving nutrients, the body releases endorphins that provide analgesia [Carter & Leuthner, 2003; Winter, 2000]).
 - Infants should be bathed, dressed, and held.
 - Infants should be taken outside into the sunlight if possible.
 - Spiritual support should be offered to the family.
 - Family and friends should be welcomed, and visiting restrictions should be waived.
 - Memory-making activities should be encouraged, including taking family photographs (by lay or professional photographers), making handprints and footprints, cutting locks of hair, and holding special spiritual or religious ceremonies.
 - If the family is not available, nurses should hold and comfort the infant.
10. When palliative care includes the removal of life-sustaining technology in the NICU or at home, support from a hospice or palliative care organization should be provided. Before life-sustaining technology is removed, a plan should be in place for the eventuality that the infant continues to breathe independently. When ventilatory support of an infant is removed, caregivers should attend to the following concerns:
 - The infant's parents should decide who will be present.

- Vasopressors should be discontinued.
 - The infant should be weaned from neuromuscular blocking agents prior to the removal of life-sustaining technology.
 - Nurses should explain as much of the process to the parents as the parents wish to hear.
 - The infant should be held by a parent or, if the parents do not wish to hold the infant, by a staff member. (Some parents may find it difficult to hold a dying infant.)
 - Gentle suction may be performed, and the endotracheal tube may be removed.
 - Tape and additional lines may be removed.
 - Medication such as morphine should be given if respiratory discomfort exists; oxygen is usually not given.
 - Medications to treat respiratory distress or to prevent discomfort should be given in normal milligram per kilogram doses and may be repeated if necessary. (Bolus medications in larger than normal doses are not appropriate.)
11. Palliative care should be continued after an infant's death in the form of bereavement support. NICUs may do their own bereavement follow-up of families, or they may connect families with identified community services. Support includes
- giving the parents a gift such as a stuffed teddy bear to take home (which allows them to leave the hospital without empty arms)
 - calling the family the next day
 - sending the family a card or letter from the staff
 - contacting the family on anniversaries of the infant's birth or death, as the family wishes
 - introducing the family to a member of a local support group or a support organization such as Share: Pregnancy and Infant Loss Support (www.nationalshare.org), Pregnancy Loss and Infant Death Alliance (www.plida.org), and the National Infertility Association's RESOLVE, (www.resolve.org).
12. Support services should be offered to all members of the healthcare team. Facilitated debriefing after difficult deaths is essential.

Conclusions

Palliative nursing care requires a mindset of providing loving support for family members to help them go through the illness and loss of both a child and the family's dreams for that child. Care of the family is a central focus, and the nurse is the consistent caregiver. Palliative care is an interdisciplinary endeavor and is best given when the team is in consensus and all disciplines support the transition from curative to palliative efforts. Consensus includes decisions about appropriate treatment options for individual infants. Case conferences, palliative care conferences, and consultation with the ethics committee can help the

interdisciplinary team to resolve conflict and reach consensus. Communication among team members and with the infant's family is essential to the ongoing assessment and provision of care to maximize the infant's quality of life.

References

- Brandon, D., Docherty, S. L., & Thorpe, J. (2007). Infant and child deaths in acute care settings: Implications for palliative care. *Journal of Palliative Medicine, 10*(4), 910–918.
- Buchholz, M., Karl, H. W., Pomietto, M., & Lynn, A. (1998). Pain scores in infants: A modified infant pain scale versus visual analogue. *Journal of Pain and Symptom Management, 15*(2), 117–124.
- Buttner, W., & Finke, W. (2000). Children's and Infant's Postoperative Pain Scale. *Pediatric Anesthesia, 10*, 303–318.
- Carter, B. S., & Leuthner, S. R. (2003). The ethics of withholding/withdrawing nutrition in the newborn. *Seminars in Perinatology, 27*(6), 480-487.
- Himmelstein, B. P., Hilden, J. M., Boldt, A. M., & Weissman, D. (2004, April 22). Pediatric palliative care. *New England Journal of Medicine, 350*(17), 1752–1762.
- Hudson-Barr, D., Capper-Michel, B., Lambert, S., Palermo, T. M., Morbeto, K., & Lombardo, S. (2002). Validation of Pain Assessment in Neonates (PAIN) scale with the Neonatal Infant Pain Scale (NIPS). *Neonatal Network, 21*(6), 15–21.
- Hummel, P., Puchalski, M., Creech, S. D., & Weiss, M. G. (2008). Clinical reliability and validity of the N-PASS: Neonatal Pain, Agitation and Sedation Scale with prolonged pain. *Journal of Perinatology, 28*(1), 55–60. Epub October 25, 2007.
- International Council of Nurses. (2006). *Nurses' role in providing care to dying patients and their families* [Position statement]. Retrieved June 20, 2010, from www.icn.ch/images/stories/documents/publications/position_statements/A12_Nurses_Role_Care_Dying_Patients.pdf.
- Lawrence, J., Alcock, D., McGrath, P., Kay, J., MacMurray, S. B., & Dulberg, C. (1993). The development of a tool to assess neonatal pain. *Neonatal Network, 12*(6), 59–66.
- Moore, D. B., & Catlin, A. (2003). Lactation suppression: Forgotten aspect of care for the mother of a dying child. *Pediatric Nursing, 29*(5), 383–384.
- Penticuff, J. H., & Arheart, K. L. (2005). Effectiveness of an intervention to improve parent-professional collaboration in neonatal intensive care. *Journal of Perinatal and Neonatal Nursing, 19*(2), 169–176.
- Stevens, B., Johnston, C., Petryshen, P., & Taddio, A. (1996). Premature Infant Pain Profile: Development and initial validation. *Clinical Journal of Pain, 12*(1), 13–22.
- Winter, S. M. (2000). Terminal nutrition: Framing the debate for the withdrawal of nutritional support in terminally ill patients. *American Journal of Medicine, 109*(9), 723–726.
- World Health Organization. (2010). *WHO definition of palliative care*. Retrieved June 20, 2010, from www.who.int/cancer/palliative/definition/en/.
- Xu, J., Kochanek, K. D., & Tejada-Vera, B. (2009, August 19). Deaths: Preliminary data for 2007. *National Vital Statistics Report, 58*(1), 1–51.

Bibliography

- Anand, K. J. S., Stevens, B. J., & McGrath, P. J. (2007). *Pain in neonates and infants*. Philadelphia: Elsevier.
- Carter, B. S., & Levetown, M. (2010). *Palliative care for infants, children, and adolescents* (2nd ed.). Baltimore: Johns Hopkins University Press.
- Catlin, A., & Carter, B. (2002). Creation of a neonatal end of life palliative care protocol. *Journal of Perinatology*, *22*, 184–195.
- Clark, P. (2001). Building a policy in pediatrics for medical futility. *Pediatric Nursing*, *27*(2), 180–184.
- Docherty, S. L., Miles, M. S., & Brandon, D. (2007). Searching for "the dying point": Providers' experiences with palliative care in pediatric acute care. *Pediatric Nursing*, *33*(4), 335–341.
- Dokken, D. L. (2006). In their own voices: Families discuss end-of-life decision making—Part 1. Interview by Elizabeth Ahmann. *Pediatric Nursing*, *32*(2), 173–175.
- Ferrell, B. R., & Coyle, N. (2010). *Oxford textbook of palliative nursing* (3rd ed.). New York: Oxford University Press.
- Gale, G., & Brooks, A. (2006a). Family teaching toolbox. A parents' guide to palliative care. *Advances in Neonatal Care*, *6*(1), 54–55.
- Gale, G., & Brooks, A. (2006b). Implementing a palliative care program in a newborn intensive care unit. *Advances in Neonatal Care*, *6*(1), 37–53.
- Kavanaugh, K., Moro, T. T., Savage, T. A., Reyes, M., & Wydra, M. (2009). Supporting parents' decision making surrounding the anticipated birth of an extremely premature infant. *Journal of Perinatal and Neonatal Nursing*, *23*(2), 159–170.
- Kavanaugh, K., Savage, T., Kilpatrick, S., Kimura, R., & Hershberger, P. (2005). Life support decisions for extremely premature infants: Report of a pilot study. *Journal of Pediatric Nursing*, *20*(5), 347–359.
- Kopelman, A. E. (2006). Understanding, avoiding, and resolving end-of-life conflicts in the NICU. *Mount Sinai Journal of Medicine*, *73*(3), 580–586.
- Petersen, A. (2005, July 26). A new approach for the sickest babies: Some hospice programs begin accepting infants, managing pain in the NICU. *Wall Street Journal* (East edition), pp. D1, D4.
- Ward, F. R. (2005). Parents and professionals in the NICU: Communication within the context of ethical decision making—An integrative review. *Neonatal Network*, *24*(3), 25–33.

Copyright © 2010 by the National Association of Neonatal Nurses. No part of this statement may be reproduced without the written consent of the National Association of Neonatal Nurses.



**National
Association of
Neonatal
Nurses**

4700 W. Lake Avenue, Glenview, IL 60025-1485
800.451.3795 • 847.375.3660 • Fax 866.927.5321
www.nann.org