

PALLIATIVE CARE

ISSUE:

Despite medical advances in diagnostics, treatments, and technology, mortality continues to exist in the perinatal field. Infants are born too early and with congenital conditions that are incompatible with meaningful life. These children deserve the best end-of-life care that health care providers can deliver. The National Perinatal Association (NPA) recognizes that perinatal and neonatal palliative and hospice care services have increased in the last decade with aims to help parents identify and achieve goals of care and coordinate such care. Lack of standardization in programs continues and significant barriers to program development, sustainability, quality measures and funding still exist.

BACKGROUND:

Palliative care is defined by the World Health Organization (WHO) as “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 recommends that palliative care be offered at the beginning of any life-limiting condition at the same time as curative efforts, recognizing that the transition to purely palliative or hospice care may later occur. Hospice care is a defined insurance benefit offered through private insurers, Medicaid or Medicare. Hospice care often has similar goals to palliative care and differs in that services are funded for people who have been given a terminal diagnosis of six months’ time by their physicians and who no longer will attempt curative measures. Bringing hospice services to neonatology and pediatrics has required Medicare waivers, as some newborns will not die within the six-month designated period.

The NPA is in full support of current scientific consensus to offer palliative care as a legitimate and safe alternative for women making decisions about pregnancy continuation after learning prenatally their fetus has a life-limiting condition (LLC). Palliative care, beginning at confirmatory diagnosis of a LLC, continues through the pregnancy, birth, and postnatal period. Services are offered through an interdisciplinary approach as parent(s) make decisions about future parenting and create an advance care plan for the birth and the infant’s anticipated postnatal needs. At birth palliative care extends to the newborn patient and is coupled with treatments tailored to alleviate the infant’s symptoms and ensure dignified, respectful end of life care. Palliative care may be coupled with curative care or transition to hospice services. Hospice care may be delivered in the newborn nursery, neonatal intensive care unit (NICU) or upon discharge to home or a perinatal hospice. The NPA realizes that some parents chose to terminate the pregnancy and fully endorses evidence-based bereavement interventions that recognize the loss of a much-loved child and support parents in their grief.

Perinatal Palliative Care

Perinatal palliative care supports families who are notified prenatally that the fetus has a LLC. PPC is family-centered and aims to assess family preferences, develop advance care plans for the birth and infant after the birth, and deliver culturally-sensitive medical and psychosocial interventions. Advance care planning includes choosing who will deliver the baby, where the delivery will take place, and who will be present; notifying all members of the obstetric and neonatal team that palliative care will be offered; delineation of resuscitation status; planning for comfort measures immediately at birth; having on-hand availability of medications to treat symptoms buccally if IV access is not available; deciding which diagnostic interventions, if any, will be done; arranging for spiritual/cultural care; and planning for family support. Comfort and support for infants who will not receive artificial food and fluids is ensured. In addition, planning must include how the family wishes to proceed after the birth and where the infant will receive ongoing palliative care and hospice services.

Neonatal Palliative Care

Infants who are born too early, who are too sick, who are not responding to intensive care efforts, who are suffering to the point of therapies being a burden, or whose condition will not allow any kind of meaningful life are offered palliative care. A protocol for neonatal palliative care has been developed. The protocol delineates the emotional, physical, psychological, and existential support that are necessary for families and their infants.

Language is an essential component of palliative care. It is imperative that providers of care to families with extremely premature infants or newborns with LLC do not use terms such as “doing nothing” or “stopping all care.” More appropriate words are, “Now is the time to cherish your infant, hold your infant, and spend time as a family.” Neonatal palliative care offers positive therapeutic actions that are the opposite of “doing nothing,” and aggressive comfort therapies provided are essential and are not stopped. The focus of the infant’s life turns to comfort and quality. The family and newborn are allowed time to get to know each other, take photos, and create keepsakes and memories. Staff ensure that the time the family has together is filled with meaning.

POLICY:

The NPA wishes to confirm the value of palliative care and hospice for affected parents and their children, from prenatal diagnosis through childhood. Bereavement support for the family is an essential component of any loss. The NPA wishes to ensure that all children and their families receive culturally competent care at the end of life.

The NPA realizes that palliative care can be a difficult concept for caregivers, but leadership, support and role models are available. Organizations such as Pregnancy Loss and Infant Death Alliance, Resolve through Sharing, and Share Pregnancy and Infant Loss Support, Inc. provide evidence-based education and training for professionals and materials for families in need.

STRATEGY:

Training in pediatric palliative care can be obtained through the End of Life Nursing Education Consortium which is a national endeavor to prepare nurses in end of life care. It is now being used to train all health professionals in end of life care, and the pediatric-specific course includes perinatal and neonatal content. The Hospice and Palliative Credentialing Center offers Certification in Perinatal Loss Care.

Important aspects of the palliative care training are team planning, creating a supportive and educated staff, anticipating and alleviating all infant suffering, the process for dignified removal of life-extending therapies, encompassing spiritual and extended family support, planning for potential discharge, and creation of bereavement mementos. A dignified, pain-free, and symptom-free living and dying is ensured for the infant, however short the life might be.

REFERENCES

- American College of Obstetricians and Gynecologists, & Society for Maternal-Fetal Medicine. (2016). *Practice bulletin: Prenatal diagnostic testing for genetic disorders*. Retrieved from <https://s3.amazonaws.com/cdn.smfm.org/publications/223/download-f5260f3bc6686c15e4780f8100c74448.pdf>
- Balaguer, A., Martín-Ancel, A., Ortigoza-Escobar, D., Escribano, J., & Argemi, J. (2012). The model of palliative care in the perinatal setting: A review of the literature. *BMC Pediatrics*, 12(1), 1-7.
- Carter, B. S., & Leuthner, S. R. (2003). The ethics of withholding/withdrawing nutrition in the newborn. *Seminars in Perinatology*, 27(6), 480-487.
- Carter, B. S., Levetown, M., & Friebert, S. E. (Eds.). (2013). *Palliative care for infants, children, and adolescents: a practical handbook, 2nd Ed.* Johns Hopkins University Press.
- Catlin A., Carter B.S. (2002). "Creation of a Neonatal End-of-Life Palliative Care Protocol. (2002). *Journal of Perinatology* 22(3),184-95.
- ELNEC Pediatrics Training. Retrieved <http://www.aacn.nche.edu/elnecc/about/pediatric-palliative-care>
- Shah, MA, Campbell, D, Eds. (2004). *Transcultural Aspects of Perinatal Health Care: A Resource Guide*. American Academy of Pediatrics.
- The World Health Organization. (2014). *The Global Atlas of Palliative Care*. Retrieved from http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf
- Wilkinson, D., De Crespigny, L., & Xafis, V. (2014). Ethical language and decision-making for prenatally diagnosed lethal malformations. *Seminars in Fetal and Neonatal Medicine*, 19(5), 306-311.
- Wool, C. (2013). State of the science on perinatal palliative care. *Journal of Obstetric, Gynecologic and Neonatal Nurses*, 42(3), 372-382.
- Wool, C., Côté-Arsenault, D., Perry-Black, B., Denney-Koelsch, E., Kim, S. & Kavanaugh, K. (2016). Provision of service in perinatal palliative care: A multicenter survey in the United States. *Journal of Palliative Medicine* 19(3):279-85.

ONLINE RESOURCES:

Hospice and Palliative Credentialing Center:

<http://hpcc.advancingexpertcare.org/competence/perinatal-loss-cplc/>

National SHARE Office: <https://www.nationalshareoffice.com>

Perinatal Hospice and Palliative Care: <http://www.perinatalhospice.org/resources-for-caregivers.html>

Pregnancy Loss and Infant Death: <http://www.plida.org>

Resolve Through Sharing Bereavement Services: <http://www.bereavementprograms.com>

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