

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 provide. The National Perinatal Association (NPA) recognizes that hospice and palliative care services are often offered very late in the trajectory of adult illness and, for infants and children, are often not offered at all.

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 has very similar goals and differs only in that services are paid for entirely by Medicare 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 offering palliative care at any time in the pregnancy cycle—when the fetus is in utero, when the pregnancy is ended, when there is an early induction, after a live birth and transition to palliative care in the neonatal intensive care unit (NICU), or upon discharge to a perinatal hospice.

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 this model of care. It is essential that providers of care to families with extremely premature infants or anomalous fetuses do not use the term of “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 memory boxes, and the staff ensures that the time the family has together is filled with meaning.

Perinatal Hospice

Perinatal hospice and palliative service support those families who are notified prenatally that the fetus being carried has a potentially lethal anomaly. The perinatal hospice has been offered as an alternative to pregnancy termination for a non-viable fetus. In this model, time and support are offered after birth for a dignified life and death. Both perinatal hospice and neonatal palliative care may be provided in a stand-alone location, in an in-hospital area, or simply in a conceptual place in the hearts of those caring for the woman, family, and infant. Planning for future decision-making is the essence of prenatal palliative care, which 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. Oral 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.

Bereavement support for the family is an essential component of hospice and palliative care. Organizations such as Share Pregnancy and Infant Loss Support, Inc. (SHARE), Bereavement Services with Resolve through Sharing (RTS), and Pregnancy Loss and Infant Death Alliance (PLIDA) have assured grassroots support for families in need and education of professionals interacting with those families.

POLICY:

The NPA therefore wishes to confirm the value of palliative care and hospice for all infants with terminal conditions from prenatal to post-birth, and to infants and children. The NPA wishes to ensure that all children and their families receive culturally competent care at the end of life.

The NPA realizes that neonatal palliative care is a difficult concept for caregivers and that leadership in this area is essential. References for assistance in these efforts are available.

STRATEGY:

Training in pediatric palliative care can be obtained through the ELNEC program. This program, the End of Life Nursing Education Consortium (ELNEC), a Robert Wood Johnson Foundation funded project, is a national education curriculum to prepare nurses in end of life care. It is now being used to train all health professionals in pediatric end of life care, and a new unit on neonatal end of life care is under construction.

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.

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ONLINE RESOURCES:

National SHARE Office: <https://www.nationalshareoffice.com/index.shtml>
 Resolve Through Sharing Bereavement: <http://www.bereavementprograms.com>
 Pregnancy Loss and Infant Death: <http://www.plida.org>

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