Palliative Care...When a Cure is Not Possible

Terri A. Cavaliere, DNP, NNP-BC
Clinical Assistant Professor
Stony Brook University School of Nursing
Neonatal Nurse Practitioner
Cohen Children’s Hospital at North Shore, Manhasset, NY

The speaker has signed a disclosure form and indicated she has no significant financial interest or relationship with the companies or the manufacturer(s) of any commercial product and/or service that will be discussed as part of this presentation.

Session Summary

In today’s high-tech healthcare milieu emphasis is placed on life-saving interventions. Palliative care is frequently an afterthought when it is recognized that a cure may not be possible. It is important that neonatal nurses acquire expertise in providing palliative care. This interactive session will assist neonatal nurse practitioners in acquiring knowledge and skill to develop proficiency in this area. Emphasis will be placed on participants sharing their experiences and expertise in neonatal/perinatal palliative care.

Session Objectives

Upon completion of this presentation, the participant will be able to:

- define palliative care;
- identify barriers to providing palliative care services;
- describe an approach to a family in need of palliative care services.

Resources & References


Balaguer, A., et al. (2012). The model of palliative care in the perinatal setting: A review of the literature. BMC Pediatrics, 12: 25. The electronic version of this article is the complete one and can be found online at: http://www.biomedcentral.com/1471-2431/12/25


**Session Outline**

See presentation handout on the following pages.
Neonatal (& Fetal) Palliative Care

Terri A. Cavaliere, DNP, RN, NNP-BC
FANNP
© CavEnterprise 2014

Palliative Care

• No longer restricted to provision of end-of-life care
• Encompasses a combination of medical, psychosocial, & spiritual care that enables maximizing quality of life while making medical decisions based on goals and values of the family

Palliative Care

• AAP [2013] policy – promote the welfare of infants & children living with life-threatening or inevitably life-shortening conditions; provide support to patient & family through provision of effective curative, life prolonging and QOL enhancing care
• Incorporating pediatric palliative care [PPC] into the general medical care, stressed need for interdisciplinary care teams, & preparedness of HCPs to provide basic palliative care

Palliative Care

• American Society Clinical Oncology [2009] suggested integration of palliative care into routine comprehensive cancer care into routine comprehensive cancer care by 2020

Barriers to PPC

• Inadequate training
• Lack of funding
• Professional attitudes
• Lack of evidence base for PPC assessments or interventions
Fairy tale #1
• Palliative Care is only for dying patients

Fairy tale #2
• There’s no evidence

Fairy tale #3
• PPC means we are giving up

Affordable Care Act
• Includes Concurrent Care for Children provision
• Programs for children in state Medicaid or CHIP allow hospice care in addition to curative care for those patients under 21 years of age
• Life expectancy of 6 months or less if the disease follows its normal course

Limitations of CCC
• Does not expand services available
• Limited to Medicaid or CHIP
• Does not provide home-based services when prognosis falls outside of 6 months

NANN Position Statement
• PPC offered at any period in which infant’s life may be limited- prenatally, at time of birth, or after birth; in initially in NICU and then at home
• If prenatal diagnosis exists, PPC should be offered
• Units should have printed material available that explains services and identifies team members to parents
NANN Position Statement

- When transport to higher level of care occurs, parents should be informed that PPC may be an option
- Parents should be included in decisions
- Support services should be available: social work, child life, family advocate, lactation specialist

NANN Position Statement

- Review orders for appropriateness
- Pain control and symptom management
- Comfort measures
- Provide support for family and for staff
- Relationship with outpatient services [hospice or palliative care organizations] to coordinate services and avoid unnecessary, unwanted treatment

NANN Position Statement

- Privacy should be maintained
- Strive to keep the family together
- Attend to alarms, pagers, telephones, lights
- Evaluate need for routine measurements of vital signs and lab analyses
- Monitor pain; avoid painful assessments
- Discuss artificial nutrition & hydration
- Bathe, dress and holding are important

NANN Position Statement

- Can infant be brought outside [?]  
- Spiritual support is important
- Visiting restrictions should be waived
- Memory making activities should be encourages
- If family is not available, staff can step in

NANN Position Statement

- When life sustaining technology is discontinued:  
  - There should be a plan in place in the event baby continues breathing independently  
  - Parents should decide who will be present & should be told what will happen  
  - Vasopressors should be d/c'd; neuromuscular blockers should be removed prior to removal of respirator

NANN Position Statement

- When life sustaining technology is discontinued  
  - Parent or “other” should hold baby  
  - Medications (MS) for respiratory discomfort; O2 usually not given
NANN Position Statement

• Palliative care should continue after death as bereavement.
• Support includes.......