Beautiful Birth: Perinatal Palliative Care

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Purpose/Goal(s) of this Education Activity
The purpose/goal(s) of this activity is to enable healthcare providers to have increased knowledge of the importance of perinatal palliative care.

1.0 Contact Hour
This continuing nursing education activity was approved by the Northeast Multistate Division (NEMSD), an accredited approver by the American Nurses Credentialing Center’s Commission on Accreditation. Maine, New Hampshire, New York, Rhode Island, and Vermont Nurses Associations are members of the Northeast Multistate Division of the American Nurses Association.
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CME credit is provided for select programs through a partnership with Women & Infants Hospital of Rhode Island (WIHRI).

This activity fulfills core competencies for Continuing Medical Education credit.

Accreditation: Women & Infants Hospital is accredited by the Rhode Island Medical Society to sponsor intrastate continuing education for physicians. Women & Infants Hospital designates this online educational activity for a maximum of 1.0 AMA PRA Category 1 Credit™. Physicians should only claim credit commensurate with the extent of their participation in the activity.
Objectives

- State reasons for quality perinatal palliative care
- List the common diagnoses that lead to palliative care decisions
- Describe the process of decision making in perinatal palliative care
- List ways to help families make memories with their babies
- Discuss the various methods of symptom management in the dying neonate
- List ways to provide care to the family as a whole
- Describe two ways to alleviate the compassion fatigue that may be felt when caring for dying neonates
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Melissa Petersen, RNC, MS, WHNP-BC
Palliative care (PAL-ee-ya-tiv) care means comfort care.
Why are you here?

Why did you sign up for this offering?
Maybe you are here because you want to be the best nurse you can be on the worst day of someone’s life.
Do you take care of dying patients?????
Position Statements on Palliative Care

- Center to Advance Palliative Care’s National Quality Forum Consensus Report
- American Academy of Pediatrics
- NHPCO
- Joint Commission
- WHO
Sudden fetal demise
Vs
Life-limiting diagnosis
Stages of grief

DENIAL
Sorry, there are no French fries any more...

What?

That's not possible! I just saw a guy walking out this shop with a bag full of French fries!

ANGER
You better hand me your French fries or I'll kick your butt!

BARGAINING
Come on! I'm sure you have one or two left. Let's just say, I take what's left and I leave, ok?

DEPRESSION
I'll never taste the sweet flavor of French fries again... boooohooo...

ACCEPTANCE
OK... can I have a hamburger then?
Anticipatory Grief

- Anticipating the possibility of a loss
- Expectation of death, the normal mourning that occurs when a patient’s family is expecting death. Anticipatory grief has many of the same symptoms as those experienced after a death has occurred. (MedicineNet.com)
- The stages of grief are the same. They may just begin at the time of diagnosis, rather than the time of death.
Why carry a baby with a fatal diagnosis??

- It is a rewarding journey.
- It is not about the diagnosis, but about being a parent to that particular child.
- While part of the journey is “bitter”, the part that involves meeting the child that is so loved is very “sweet”
- Families are able to celebrate life.
- May parents feel “peaceful” knowing their baby lived as long as his/her body could sustain life.
- Parents can’t avoid the pain, suffering, and loss whether they choose to carry their baby or terminate.
The Faces of Palliative Care
What conditions are typically life-limiting?

- Certain Neural Tube Defects
  - Anencephaly
  - Acrania
- Lethal Skeletal Dysplasias
  - Thanatophoric dysplasia
  - Severe Osteogenesis Imperfecta
  - Campomelic dysplasia
- Chromosomal abnormalities
  - Trisomies 13, 18 and sometimes 21
  - Monosomy X (Turner’s Syndrome)
  - Triploidy
- Potter’s Sequence
  - Bilateral Renal Agenesis
  - Bladder Outlet Obstruction
Trisomies

Single most common type of genetic disorder a baby may be born with. Most commonly seen trisomies:

- Trisomy 13
- Trisomy 18
- Trisomy 21
- Triploidy (not as common)

Normal male karyotype: 46, XY
Making Decisions

- Prenatal
- Delivery room decisions
- NICU
Prenatal Planning
• Important information: baby’s name, baby’s diagnosis and what the parents understand about it; pregnancy complications, spiritual beliefs
• Wishes for L&D; how are non-reassuring FHT’s going to be handled??
• Wishes for their time with their baby: who will be present? What about siblings? Rituals? Keepsakes?
• Medical decisions: interventions, feeding, Hospice after discharge
• Discussion of DNR consent
• Plans for the baby if he/she dies in the hospital
• What are they most afraid of?
• Is there anything at all they want us to know about them and their baby?
The Patient care plan
What should be included? Who receives it?
Delivery room decisions
NICU decisions
Making Precious Memories
Memories can be made before delivery...

- Pregnancy pictures
- Take a special trip as a family
- Sleep with a special blanket that the baby will use after birth, so that it smells like home...brings a bit of home to the baby in case he/she doesn’t get to go home
- 3D/4D ultrasounds
Bring the Rain

www.angiesmithonline.com; from her blog: Bring the Rain
Parents can make memories during their time with their child...

- Hearing the first cry (videotaping)
- Having family come and spend time with them and their baby
- Being able to parent their baby, even if it is only for a short time
- Taking pictures of all their children together
- Feeling like a new mom or dad
- Providing comfort from the pain
- Taking their baby home
- Taking their baby outside
- Celebrating 1 week, 2 week birthdays, etc.
Keepsakes
Photographs
“There are beginnings and endings and there is living in between.”

~ from Lifetimes by Melanie Ingpen
What does this mean for you as the caregiver?

- You are part of the team.
- You need to understand the policies and protocols.
- You need to be comfortable with the fact that your patient will not live.
- You need to be in touch with your own feelings regarding mortality.
Symptom management

Care is not curative, but is comprehensive care for infants who are not going to ever get better. Care needs to be child centered, yet also needs to attend to the whole family, with the ultimate goal being an enhanced dignity during the child’s time on earth.
Environment of Care

- Bright lights, loud noises, and sleep interruptions are all sources of discomfort for neonates
- Try to maintain low levels of noise and light
- Teach parents how to touch their baby and participate in care
- Encourage parents to provide toys, pictures, or tapes of their voices to make the environment more family-centered
- Restrictions on sibling visitation and visitation from other family members should be minimal
- Relocate to a parent/family room, if possible
- Allow parents to take the baby outside
Pain Management

- Do neonates feel pain?
- NIPS scale
- Regular assessment of pain is crucial for these babies and their families
- Efforts should be made to limit or eliminate painful stimuli
- Non-pharmacologic and pharmacologic pain management
Non-pharmacologic methods

- Swaddling
- Skin to skin
- Nursing
- Oral Sucrose
- Positioning
- Feeding methods: gavage vs breast

Pharmacologic methods

- Narcotics
- Opioids effective for moderate to severe pain
- Ativan for agitation
- Tylenol
- IV/PO methods preferred over IM
Comfort Care Measures
Thermal Care

- Skin to skin
- Blankets, hats, and booties
- Warmer or isolette, if needed
Respiratory comfort

- Nasal cannula may be used
- Blow by supplemental oxygen
- Bulb/oral suction for comfort only
- Respiratory irrigation if needed with normal saline
- Benzodiazepines or opioids
Siblings & Family
Caring for the entire family means including other children in the family...

- Loss of life as they knew it
- New and sometimes changing caretakers
- Sadness and anxiety in their home
- Special treatment for the ill child
- Tension, anxiety, disagreements about the treatment plan or financial stress
- Loss of family routines and traditions
- Birthdays, holidays are disrupted
- Loss of parental focus and attention
- May be expected to take on adult responsibilities
Did I make my brother sick?
How do you include them??

- Involve them in simple care tasks: changing a diaper, holding a bottle, helping with a bath
- Involve them in simple decisions: choosing clothing
- Keepsakes: sound recorders, photographs
- Discuss with the parents during the prenatal planning consult
- Refer them to counselors: Kate’s Club, other organizations
Guiding other family members...

- Provide guidance on how they can help: child care, funeral arrangements, help at home after birth/loss, grocery shopping, offer to take pictures/video
- Provide them guidance on what not to say:
  - “God needs another angel”
  - “It is for the best”
  - “It was all in God’s plan”
  - “There was something wrong with the baby anyway”
- Do say:
  - “I’m sorry”
  - “What can I do to help?”
Compassion fatigue: Who is caring for you??
Compassion Fatigue: a state of physical and mental exhaustion caused by a depleted ability to cope with one’s everyday environment.  

33%

Of L&D nurses in a recent AWHONN survey reported moderate to severe symptoms of traumatic stress as a result of their jobs. (Kendall-Tackett, Kathleen, Burnout, Compassion Fatigue and Self-Care for Members of the Perinatal Team.)
When is the last time you were with you?
Burnout is too late.
You die the way you live. What would your advice be?
What are you afraid of?
There are some places our patients must go alone. We can’t go for them and that is ok. Sometimes our good will can hurt them and us...go where you should go.
Participants are encouraged to ask questions and share comments.

- Please submit any questions or comments via the chat box in the lower left corner of your screen.
- Questions and comments are visible only to presenters.
- Questions will be answered in the order they are received.
Thank You For Attending

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