

Perinatal and Neonatal Palliative Care

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Objectives

- Learner will be able to :
 - Identify clinical situations where utilizing perinatal/neonatal palliative care would be appropriate
 - Describe important concepts related to preparing for and leading a family meeting to determine perinatal/neonatal “goals of care”
 - Name 5 communication “pitfalls” and be able to choose alternative words/phrases to avoid them
 - List ways to help families appreciate “quality of life” even in a situation of potential/probable infant loss

Acknowledgements

- I do not have any potential conflicts of interest regarding the information presented today
- Portions of the information presented today are drawn from the ELNEC Pediatric Palliative Care Curriculum prepared by the End-of-Life Nursing Education Consortium
- Case presentations are presented anonymously and/or family permission has been obtained for their use in my education efforts in pediatric palliative care

Epidemiology

- In 2010, 24,586 deaths occurred in children under the age of 1 year
- Infant mortality rate 6.15 per 1,000 live births
- Neonatal mortality rate 4.05 per 1,000 live births (16,188 deaths)
- Congenital malformations account for 20% of deaths

Murphy et al., 2013

Principles of Perinatal and Neonatal Hospice and Palliative Care

- Child and family as unit of care with attention to caregiver support
- Attention to physical, psychological, social, and spiritual needs
- Interdisciplinary team approach
- Education and support of child and family
- Extends across illnesses and care settings
- Bereavement support
- Hospital-based and Community-based programs

Perinatal Palliative Care

- Create a safe place for discussion ***without assumption*** to help a family decide whether termination, induction of labor or carrying to term is right for them
- Preparing for “Hello” and “Good-bye”
- Involves education about medical diagnosis and expected complications, benefits and burdens of treatment
- Ask about the baby’s name – this is a “real baby” being born to a “real family”

Perinatal Palliative Care

- Requires coordinated care plan with multiple participants – OB/GYN, Perinatal specialists, NICU, Palliative Care specialists, and family
- Develop a “Birth Plan”
 - Care coordination is ***critical*** in the hospital setting
 - Working through this process helps families prepare for what they will face
 - Encourage a “step-by-step” approach – concentrate on initial issues they will face but introduce possibilities for “transitions of care” i.e. to home hospice

Neonatal Palliative Care

Newborns who should receive palliative care:

- Newborns at threshold of viability
- Newborns with complex or multiple congenital anomalies/disorders incompatible with prolonged life
- Newborns not responding to intensive care intervention, deteriorating despite all efforts, or have a life-threatening acute event

Case Presentation: Baby A

- Baby A is a 10 month old female born at 28 weeks gestation (BW 990gm) who has never left the NICU. She was born after a pregnancy complicated by oligohydramnios and was diagnosed with Potter's Sequence with severe pulmonary hypoplasia. She has severe oral steroid- dependent, ventilator-dependent, frequent bronchodilator-dependent BPD and has failed repeated trials to transition to home ventilator settings. She is on FiO2 0.50 with high pressure settings. A recent chest CT showed extensive interstitial thickening, interstitial emphysema with pneumatocele formation, areas of air trapping, and bi-basilar atelectasis. Comorbidities include GER with hx of aspiration PNA (S/P Nissen fundoplication and G-tube placement), trach-dependency, and hypertonia (receiving PT/OT, on Baclofen). I was asked to meet with her family to help formulate new goals for her care.

Setting the Stage for a Family Meeting

- Ask the family who they would like to be present for a multi-disciplinary meeting – may include friends, extended family members, clergy
- Find a private place to sit and talk with no interruptions
- Involve the infant's primary nurse if at all possible
- Sit across from parent so good eye contact can be established
- Have Kleenex available in the room
- Team involvement may include NICU, Palliative Care, Hospice or appropriate sub-specialty consultant physicians or staff

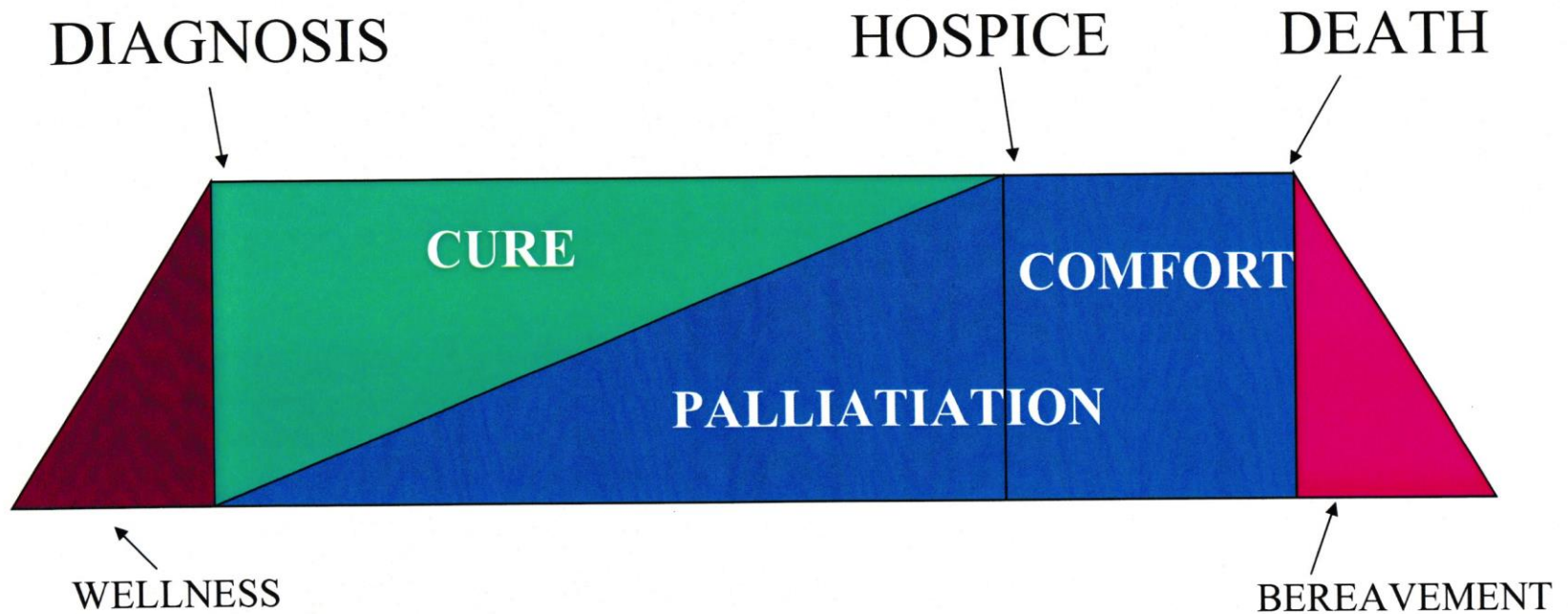
Progression of the Family Meeting

- Start with introducing all those “at the table”
- Make an assessment of the family’s understanding of the infant’s clinical status
- Describe the goal of the meeting: the development and/or modification of a plan of care (includes attention to physical, psychological, social, and spiritual needs)
- Have NICU or Palliative Care physician review the infant’s main clinical diagnosis and co-morbidities including important prognosis information

Progression of the Family Meeting

- Review options for future clinical care including a description of the spectrum of palliative care – must consider the current clinical context. You are ***never*** “withdrawing care” – you are changing the ***focus*** of the care to meet new goals of care. This ***may*** involve withdrawal of artificial support.
 - Continuing the “NICU Train” – aggressive care, “roller-coaster” course
 - Limiting *further* escalation of “artificial” support
 - Transition to “comfort care” measures with or without hospice
 - Inpatient hospice
 - Home hospice

MODERN HEALTHCARE MODEL



CONTINUUM OF CARE

Communication Strategies

- Convey empathy - “I wish things were different”
- Speak directly – use the “D” word
- Focus on compassion and prevention of suffering – how best to love this baby
- Wait quietly – use the power of silence
- Review the goals – adding time vs adding quality
- Guide (don’t force) parents through the process
- Address spirituality – many families rely on this for coping to some degree
- Provide contact information and plan follow-up

Communication Pearls

- Use phrases which give information and guidelines without being vague or insensitive
 - “Let’s discuss discontinuing treatments which are not providing benefit or causing more symptoms” **rather than** “It’s time to pull back”
 - “We can’t cure your child, but we can provide care to make her as comfortable as possible until death” **rather than** “There is nothing more we can do”
 - “In my experience, it is rare for a child in this situation to survive” **rather than** “A miracle may turn things around”

More Communication Pearls

- Helpful Phrases:
 - May I just sit here with you?
 - Is there anyone I can call for you (family, chaplain)?
 - What might be helpful to you at this time?
 - Would you like me to talk with your other family members, or be there with you when you talk with them?
- Phrases to Avoid:
 - This will make you a stronger/better person
 - I know how you feel
 - This happened for a reason
 - Life doesn't give you anything you can't handle

Back to Baby A

- Family came to understand that further increases in ventilatory pressures was only further damaging her lungs and elected to have ***no further escalation of pulmonary care***
- They chose to ***allow natural death*** in case of cardiopulmonary arrest
- NICU staff and Palliative Care continued to provide supportive care including comfort medication treatment with lorazepam and morphine (both scheduled and prn), emotional support, and “memory-making”
- Baby developed an episode of increased respiratory distress over the course of one day which partially responded to extra bronchodilator treatments and comfort medications, but then abruptly arrested and died

Alternate Ending to Baby A

- Family expressed understanding of their baby's very poor prognosis but expressed the desire to continue an aggressive care plan to "give her a chance" – they expressed that they had fought so long, they just didn't feel like they could "give up" now. They did consent to adjustment of "comfort medication" regimen to ensure she was as comfortable as possible.
- NICU and Palliative Care honored their goals of care and over the next 5 months, she slowly improved and was able to be dc'd home with home mechanical ventilation. Now 2 years old, she is off home mechanical ventilation, is about to have her trach decannulated, and is making slow but steady developmental progress.

Case Presentation: Baby B

- Baby B is a term infant delivered at an outside hospital to a 20yo G1P0 unmarried Mother after limited prenatal care. Dysmorphic features were noted on physical exam (microcephaly, low-set ears, clenched hands with overlapping fingers, rocker bottom feet) as well as a heart murmur so the infant was sent to CHOG for further evaluation. FISH was positive for Trisomy 18. The NICU team informed the Mom of the infant's diagnosis and requested that I come by to meet with the family to develop a plan of care for the baby.

Baby B: continued

- Echocardiogram showed a VSD, ASD, and a small PDA
- Renal US showed bilateral Grade 1 hydronephrosis
- Swallowing study demonstrated poor suck-swallow coordination with frequent penetration and intermittent aspiration
- NG feedings with reflux precautions were initiated – infant tolerated feeds well
- A meeting was set up with Mom, Dad, and MGMo to talk with the NICU and Palliative Care staff regarding the baby's future care

Planning for Discharge Home: With or Without Hospice

- Need to assess family's willingness, ability, and resources to care for an infant with special needs
- Anticipate symptoms which are likely to develop and describe these to the family – be sure to include what will be prepared/done to treat these symptoms when/if they occur
 - Central/obstructive apnea
 - Seizures
 - Aspiration pneumonias/Episodic respiratory distress
 - Feeding problems

Planning for Discharge Home: With or Without Hospice

- Emphasize support that home hospice can afford them
- Infants ***do not*** have to be DNR to have home hospice – but parents do need to be aware that 911 would need to be called in case of cardiopulmonary arrest (rather than the hospice number they are typically encouraged to call)
- Multiple caregivers need to be trained in the infant's care including medication administration, NG tube placement, use of "technology"
- Caregiver(s) should "room in" and demonstrate adequate provision of all care prior to d/c home from the hospital

Planning for Discharge Home: With or Without Hospice

- Family should have a letter detailing the infant's life-limiting diagnosis, whether or not they have a DNR order or not, and a brief description of the typical life expectancy
- A local hospice organization should be located ***who will accept infants***, and a discharge plan of care should be developed by the NICU/Palliative Care team and reviewed with the hospice organization
- A local PCP should be identified and similar information sent to that medical caregiver as well

Back to Baby B

- Parents elected to take him home with home hospice services. Hospice team met with parents while they were learning the infants' care to review hospice philosophy, care delivery, etc. Equipment needs were assessed, ordered and delivered
- Hospice nurse arrived at their home shortly after they arrived home and provided further education
- One week later, his Mom went in at 3 am to check on him and found him apneic and pulseless. The palliative care physician was contacted and hospice nursing staff were dispatched to support the family until the infant's body was collected by the funeral home. Bereavement support was provided by the hospice staff for 13 months after the infant's death (and thereafter on a prn basis as family requested)

“99 Balloons” Video

“99 Balloons” - Debriefing

- One of the most important parts of palliative care is maintaining **HOPE** – not unrealistic expectations but fostering the family making the most of whatever time they are given with their infant – emphasizing **Quality over Quantity**.
 - This couple celebrated (literally) the time they had with their son.
 - Requires careful attention to symptom management for the infant to remain as comfortable as possible
 - Should include emotional support for the caregivers

“99 Balloons” - Debriefing

- Other things to note from the video:
 - Parents can be easily overwhelmed with having to do “medical tasks” (replacing the NG tube) that seem mundane to medical providers – preparing them ahead of time (training and equipment) is very important
 - These parents didn’t let “technology” needs keep them from being parents (loving on him, holding him, taking him on outings, sharing him with family and friends)
 - When a life-limiting diagnosis is known prenatally, helping families develop a birth plan and educating them about anticipated issues is very important – the mother’s **choice** of whether or not to carry the infant to term should be honored (regardless of the medical caregivers “opinion” about what is “right”)

- Be loved by many
- listen to music
- Be read lots of books
- get lots of snuggles & lovings
- have an awesome faux-hawk
- get a warm bath (Thanks, grandmas!)
- Get Baptised
- Received 1st stuffed animal. (blue puppy)
- feel the wind blow
- Swing
- Take a selfie
- DANCE (Thanks Stephanie!)
- Smell a flower
- feel the sunshine



LIST

- Listen to AC/DC with Daddy
- Listen to a Christmas song
- SLEEP WITH MY PUPPY
- meet a real puppy