Extending Pediatric Palliative Care into a Perinatal Palliative Care Program

Bethaney Kaye, FNP, DNP
Children’s Hospital of Los Angeles
A Little About Me …

- Nurse Practitioner at Children’s Hospital of Los Angeles
- Created a perinatal palliative care program within the high-risk infant clinic at Hollywood Presbyterian Hospital in 2014 (~25 pts since development)
- Research Interests: impact of perinatal palliative care, RN moral distress, pediatric palliative care misconceptions and challenges of care delivery
Disclosures

- I have no conflicts of interest to disclose.
Objectives

- Recognize where pediatric palliative care may be extended to perinatal palliative care
- Gain an increased understanding of the role of perinatal palliative care on the fetus/newborn, families, and their care team
- Identify key issues and care needs within perinatal palliative care
- Identify potential outcomes of a perinatal palliative care program
History of and Need for

- Testing and diagnostic technology advances
- Medical and technology advancements in medicine
  - What is viability?
  - Home trachestomy/ventilation programs
  - Changes in practice – approach to trisomy 13 and 18
- Development of emerging pediatric palliative care and hospice programs
- Advances in research
Perinatal Palliative Care Teams

- Focus on continuum of care from diagnosis until death of fetus or infant
- Interdisciplinary team: physician, nurse practitioner, nurse care manager and social worker
- Provide support
  - throughout pregnancy
  - delivery
  - immediate post-partum
  - NICU
  - Home care of infant
  - Death of infant
  - Bereavement and grief support
  - Anniversaries of infant’s death
Table 1. Malformations cited in lists of LM (arranged in descending order of frequency of citation)\textsuperscript{7,16,18,23-25,38,56-58}

<table>
<thead>
<tr>
<th>Lethal malformations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potter's syndrome/renal agenesis</td>
</tr>
<tr>
<td>Anencephaly/acrania</td>
</tr>
<tr>
<td>Thanatophoric dwarfism</td>
</tr>
<tr>
<td>Trisomy 13 or 18</td>
</tr>
<tr>
<td>Holoprosencephaly</td>
</tr>
<tr>
<td>Triploidy</td>
</tr>
<tr>
<td>Hydranencephaly</td>
</tr>
<tr>
<td>Some cases of hypoplastic left heart syndrome and pentalogy of Cantrell</td>
</tr>
<tr>
<td>Severe osteogenesis imperfecta</td>
</tr>
<tr>
<td>Multicystic/dysplastic kidneys</td>
</tr>
<tr>
<td>Polycystic kidney disease</td>
</tr>
<tr>
<td>Congenital severe hydrocephalus with absent or minimal brain growth</td>
</tr>
<tr>
<td>Severe congenital diaphragmatic hernia with hypoplastic lungs</td>
</tr>
<tr>
<td>Sirenomelia</td>
</tr>
<tr>
<td>Complex or severe cases of meningomyelocele</td>
</tr>
<tr>
<td>Large encephaloceles</td>
</tr>
<tr>
<td>Acardia</td>
</tr>
<tr>
<td>Some cases of giant omphalocele</td>
</tr>
<tr>
<td>Inoperable conjoined twins</td>
</tr>
<tr>
<td>Cranioradischisis</td>
</tr>
<tr>
<td>Exencephaly</td>
</tr>
<tr>
<td>Iniencephaly</td>
</tr>
<tr>
<td>Harlequin fetus</td>
</tr>
<tr>
<td>Meckel–Gruber syndrome</td>
</tr>
<tr>
<td>Non-immune hydrops with major cardiac defects</td>
</tr>
</tbody>
</table>

Types of Perinatal Loss

- Ectopic Pregnancy
- Spontaneous abortion/miscarriage
- Termination of Pregnancy
- Stillbirth
- Neonatal Death
- Life-limiting conditions
Approach To Perinatal Palliative Care Consult

- Explore parents’ understanding of condition and potential outcomes, options for care
- If needed, develop an approach to discussing with siblings
- Discuss care setting and expectations regarding delivery (develop advanced birth plan)
- Plan for potential threats to comfort (almost always dyspnea)
  - Address misconceptions re: opioids
- Consider pre-drawn medications for nasal/buccal administration for possible pain, respiratory distress, restlessness
- Home as a possible care setting if baby survives long enough
- Create legacy and connections for infant/families
- Autopsy/coroner/tissue donation (genetic implications important for future pregnancies)
- Breast milk donation versus lactation suppression
- Bereavement follow-up
Potential Roles For Neonatal Palliative Care

- Explore potential “what-if” scenarios and inform the discussion about possible approaches
- Regardless of the prognostic certainty or the approach taken, ensure vigilance towards:
  - Comfort of the newborn
  - Support of family
  - Support of team/stakeholders
  - Connections – siblings, other relatives
  - Legacy/Memory – footprints, photos, etc
- Participate in dialogue around difficult ethical considerations
  - Limitations in care (Trisomy 13/18 (CHLA): No trach/vent, no cardiac surgery)
  - Inappropriate use of advanced life-saving technology
- On occasion – consolidate information from multiple involved specialists; serve as a steady presence in the context of turnover of attending physicians
- Participate in exploration of alternate care settings
- Develop a process supported by education, policies, and procedures
Stakeholders/Team in Perinatal Palliative Care

- Baby, Parents, Siblings and Extended Family
- Nurses
- Geneticists/Genetic counselors
- Insurers
- Perinatologists
- Pregnancy counselors
- Sonographers
- Child birth educators
- Midwives
- Obstetricians
- Labor and delivery wards
- Pediatric pharmacists
- Neonatal nurse practitioners
- Neonatologists
- Pediatricians
- Home health agencies
- Faith community
- Funeral directors
- Grief counselors

*Source: ELNEC*
Advanced Birth Plan

- Support from time of diagnosis through bereavement process.

- Create a personalized birthing plan:
  - How and where delivery occurs
  - Measures that will be taken once baby is born
  - Honor the values and beliefs of parents
    - Spiritual offering, naming of baby
  - Discuss supportive care treatments for baby

- Unique legacy building opportunities
  - Comfort Cub

- Bereavement options and rituals
## Section A

These are our wishes for the **personal care** of our baby at time of birth.

<table>
<thead>
<tr>
<th></th>
<th>Comments/Date</th>
<th>Revisions/Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Hold our baby as soon as possible and as much as possible</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Establish a plan for family and friends to celebrate our baby's birth/visitation on the floor.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Designate __________________________ to give updates to family and friends.</td>
<td></td>
</tr>
</tbody>
</table>
| 3. | Designate __________________________ as adult chaperone for siblings.  
Siblings names/ages: |   |   |
<p>| 4. | Have a family member cut the umbilical cord |   |   |
| 5. | After delivery, give my baby to me after being quickly wiped and suctioned - Wrapped or placed skin to skin. |   |   |
| 6. | Perform religious ceremonies / Spiritual rituals |   |   |
| 7. | Videotape our baby |   |   |
| 8. | Take pictures of our baby |   |   |
| 9. | Make footprints &amp; handprints of our baby |   |   |
| 10. | Bathe our baby |   |   |
| 11. | Allow teaching services (Medical residents and/or nursing students) present |   |   |
|     | □ YES □ NO |   |   |
| 12. |   |   |   |</p>
<table>
<thead>
<tr>
<th>Section B</th>
</tr>
</thead>
<tbody>
<tr>
<td>♥ These are our wishes for the <em>comfort care</em> of our baby at time of birth</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Comments/Date</th>
<th>Revisions/Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>[ ] Continuous [ ] Intermittent [ ] No Monitoring</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Perform oral/nasal suctioning, blow by oxygen, skin to skin, oral sucrose for comfort only</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Do not perform advanced life support without explaining why it is necessary</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Delay taking vital signs, weighing our baby, giving medications and obtaining lab work if not medically necessary</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Allow our baby to feed: ___ breastfeeding or ___ drops of expressed milk or formula</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>I am considering donating my breast milk to the Mother’s Milk Bank</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>Provide our baby with medications as needed for comfort care</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>Provide our baby with pacifier, breast, oral sucrose for comfort</td>
<td></td>
</tr>
<tr>
<td></td>
<td>End of life care</td>
<td>Comments/Date</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>1</td>
<td>Hold our baby while dying and after death</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Obtain keepsakes such as: lock of hair, ID band, tape measure, crib card, hat, blanket and clothes</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Organ Donation Wishes:</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>☐ Autopsy ☐ Genetic Testing</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Barriers to Perinatal Palliative Care

- Barriers in the environment of care
- Feelings and beliefs of staff/providers
- Family expectations
- Society expectations
- Issues of hope
- Financial and regulatory barriers
Strategies to Overcome Barriers

- Staff Training
- Access to care
- Environment of Care
- Parent education and preparation
- Development of Advanced Birth Plans
- Model programs
What’s in a word?

- Lethal condition
  - Potentially life limiting
  - Incurable condition
  - Advance in technology – what is lethal?

- Futile care
  - Non-beneficial care
  - Benefit versus harm

- Communication:
  - Use gentle, but direct language about death and dying
  - There are typically non-survivable conditions. The parents should never be deciding whether their child will live or die … this has already been determined by the condition
  - Convey empathy
  - Wait quietly
  - Review goals – focus on compassion and prevention of suffering
  - Address spirituality
Perinatal Communication: What Parents Want

- Knowledge
  - Providing unbiased information

- Preparation
  - Helping parents navigate the system and creating a therapeutic environment for them in which to make decisions

- Anticipation
  - Describing all possibilities

- Continuity

- Support
  - Understanding parents' experiences and their continued need to protect their infant
  - Physically and emotionally engaging with the parents

- Respect
  - Respecting parents and believing in their capacity to make the best decisions for their family

What does Perinatal Comfort Care Look Like?

- Live birth: Addressing comfort in first few minutes
  - No vitals/monitoring. No resuscitation. Give to parents to hold.
  - Treat symptoms, have medication available as needed

- Next 1-2 hours:
  - Try feeding
  - Connections
  - Legacy

- Next 3-4 hours:
  - Feeding/hydration – decisions if not feeding

- By 12-24 hours:
  - Explore options for care setting – palliative care at home?

- Begin path home
Perinatal Palliative Care Outcomes

- Infants with an active palliative care plan at birth had a statistically significant decrease in:
  - Number of NICU days \( (p=0.001) \)
  - Invasive procedures performed \( (p=0.0008) \)
  - CPR \( (p=0.002) \)
  - Resuscitation medication administered \( (p=0.008) \)

- Conclusion: Perinatal palliative care programs can alter interactions with the health care system after birth for newborns with life-limiting conditions
  - May lead to decreased stress burden on families, staff, and infant
  - May decrease cost of care for these infants

# Infant Diagnoses

<table>
<thead>
<tr>
<th>Infant Diagnosis (n)</th>
<th>PPCP Infants (n=18)</th>
<th>No PPCP Infants (n=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trisomy 13</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Trisomy 18</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Skeletal Dysplasia</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>CNS Malformation</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Cardiac Anomaly</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Renal Anomaly</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Hydrops</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Metabolic</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Airway</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>CDH with associated anomalies</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>
Events Surrounding Death

*PPCP = Perinatal Palliative Care Program
# Infant Interaction with Healthcare System

<table>
<thead>
<tr>
<th></th>
<th>PPCP Infants (n=18)</th>
<th>No PPCP Infants (n=20)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median (range) days of hospitalization</td>
<td>1 (0-6)</td>
<td>1 (1-34)</td>
<td>0.18</td>
</tr>
<tr>
<td>Median (range) days in intensive care</td>
<td>0 (0-6)</td>
<td>1 (1-34)</td>
<td>0.001</td>
</tr>
<tr>
<td>Median (range) invasive procedures per patient</td>
<td>0 (0-4)</td>
<td>3 (0-10)</td>
<td>0.0008</td>
</tr>
<tr>
<td>Number (percent) of patients who received CPR</td>
<td>1 (6)</td>
<td>6 (67)</td>
<td>0.002</td>
</tr>
<tr>
<td>Number (percent) of patients who received resuscitation medications</td>
<td>1 (6)</td>
<td>5 (56)</td>
<td>0.008</td>
</tr>
</tbody>
</table>
Discussion:

- Perinatal Palliative Care Programs and Planning can:
  - Provide longitudinal medical and psychosocial support through diagnosis, pregnancy, termination or birth, and death or continued life.
  - Allow and support parents in the ability to choose the manner in which children will die.
  - Continue care after death through legacy and bereavement work with families.
  - Allow providers confidence in the decision to withhold life-sustaining treatment.
  - Support stakeholders/team.
References

- End-of-Life Nursing Education Consortium (ELNEC). Perinatal and Neonatal Palliative Care Module.


http://www.perinatalhospice.org/resources-for-caregivers.html
Thanks for Listening.

Questions?
Common Concerns About Aggressive Use of Opioids at End-Of-Life

- How do you know that the aggressive use of opioids for dyspnea doesn't actually bring about or speed up the patient's death?
- “I gave the last dose of morphine and he died a few minutes later... did the medication cause the death?”
• Literature: The literature supports that opioids administered in doses proportionate to the degree of distress do not hasten death and may in fact delay death.

• Clinical context: Breathing patterns usually seen in progression towards dying (clusters with apnea, irreg. pattern) versus opioid effects (progressive slowing, regular breathing, pinpoint pupils).

• Medication history: usually “the last dose” is the same as those given throughout recent hours/days, and was well tolerated.
Analgesia For Dying Infants Whose Life Support Is Withdrawn Or Withheld

Time Until Death (minutes) vs. Morphine Dose

- No Morphine: 18 min
- ≤ 0.2 mg/kg Morphine: 18 min
- > 0.2 mg/kg Morphine: 20 min

n = 121 deaths in the context of withdrawing life-sustaining treatment