Perinatal and Neonatal Palliative Care and Hospice

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Objectives

• Define perinatal/neonatal hospice and palliative care
• Identify those who should be referred for perinatal/neonatal hospice and palliative care
• Understand the role/function of perinatal/neonatal hospice and palliative care
• Discuss barriers to care and potential opportunities

Case: Baby E

• Twin gestation, demise of co-twin
• Baby E survives with massive stroke, microcephaly, questionable survival
• Family informed of diagnosis, poor/grim/fatal prognosis
• Multiple options presented
• Palliative care consulted
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Definitions: Perinatal PC / H

Comprehensive team approach that:

- Supports families throughout the pregnancy following diagnosis
- Assists families in creating plans for the birth and care after birth
- Aids in transition to neonatal PC/H programs, including home care

Goal of Perinatal PC/H:

Honor the baby, the parents, and extended family before birth

after birth at the time of death
**Definitions: Neonatal PC / H**

Comprehensive **team** approach that:
- **Supports families** from the time of birth OR transition from disease-directed care
- **Provides care in the home setting**
  - symptom management, care coordination, goals of care discussion
  - Hours, days, weeks, months, years
  - Includes hospice-provided grief support

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**Definitions**

Perinatal and Neonatal PC/H are:
- **Virtual** in the sense of time and location
  - Blend together and **merge** with one another

Perinatal and Neonatal PC/H are **NOT:**
- an alternative for, replacement of, or competitor with standard perinatal and neonatal care

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### Disease/Condition Basis

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*Adapted from*

*Pediatric Palliative Care Referral Criteria*

Prepared by Sarah Friebert, MD (Akron Children’s Hospital) and Kaci Osenga, MD (Minneapolis Children’s Hospital)

- General issues AND system-based list
- Provides recommendations for “automatic” and “suggested” consultation
- May be diagnosed pre- or post-natally
  - Timing, level of involvement, identification of values and goals

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### Disease/Condition Basis

- Examples of **prenatal** diagnoses:
  - Trisomy 18 (Edwards syndrome)
  - Trisomy 13 (Patau syndrome)
  - Anencephaly or other severe CNS differences
  - Renal agenesis/Potter syndrome
  - Cardiac anomalies
  - Congenital diaphragmatic hernia
  - Orthopedic differences (thanatophoric dwarfism, OI)
Diagnosis of Fetal Anomaly

- **First Trimester**
  - 10-14 weeks: US and serum
- **Second Trimester**
  - 15-20 weeks: quad screen
- **Anatomy Scan**
  - 18-20 weeks
- **NIPT- Non-Invasive Perinatal Testing aka Cell Free DNA**
  - As early as 7 weeks

Disease/Condition Basis

- **Examples of post-natal diagnoses**
  - All the prenatal diagnoses
  - Complications of pre-term delivery or traumatic delivery
  - Metabolic, genetic diagnoses
  - Sequelae of infectious diseases

  See supplemental handout

Diagnosis. Now what?
Diagnosis. Now what?

- Who provides diagnostic, prognostic, treatment options?
- What values inform parental decision making?
  - Who elicits this information?
- Who provides ongoing prenatal care?
- Who provides fetal/pediatric care?
- What if provider and parental values clash?

Experience at Diagnosis

- Shock
- Grief
  - Grieving multiple losses
- Pressure to make difficult decisions
- Feelings of isolation

Options for These Pregnancies?

**Termination**
- Personal values/beliefs
- Gestational age
- State laws
- Access
- Fear baby will suffer after birth

**Continuation of Pregnancy**
- Personal values/beliefs
- Support from providers/family
- Hope for better outcome
- Gestational age at diagnosis
- History of infertility
- Familiar with disabled person(s)
19 Families: Trisomy 18

- All families reported being told there was no hope for survival
- Most families told pregnancy termination was best option
- Many families reported loss of continuity of care after diagnosis
- Some who continued pregnancy felt it was against medical advice

Walker, 2008

2014: 332 Parents Trisomy 13, 18 Pregnancy

- 23% told would destroy their marriage
- 87% told anomaly was incompatible with life
- 50% told baby would have “meaningless life”
- 57% told baby would live life of suffering
- 60% told may live short, meaningful life
- 16% told child could enrich life of others

Janvier, 2012

Take away.

- What may be said versus what may be heard
- What may be offensive
- Importance of language
- Importance of timing
- Importance of communication skills, especially receptive communication
- “Selection bias” and the power of social networks
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Perinatal Team

Similar to traditional teams
- Physicians
- Nurses
- Social worker
- Chaplain
- Midwives

Team Goals

- Collaborate and Educate
  - Diagnosis/Prognosis
  - Available/Appropriate therapies and interventions
Team Goals

• Ideally, referral takes place AT DIAGNOSIS
• Comprehensive, seamless care through pregnancy, birth, and death processes
• Shared decision making
  – Birth plan/advanced care planning
  – Plan for Care after birth
  – May need home hospice services
  – Bereavement

Wool, 2015; Engelder, 2012

Realizing the uncertainty...

There may be demise during pregnancy
Demise during labor
Baby may surprise us
  Born weaker than expected
  Born stronger than expected
  Rarely, born without abnormality


Planning

• Birth Plan
  – Map of parents wishes for:
    • Birth
      – Who
      – Goals of care > aggressive/palliative
      – Medications
    • Life
      – Memory-making
      – Baptism
    • Death
      – Care of body
      – Funeral arrangements

Leong Marc Aurele 2013; Kate McNamara Carousel team- birth plan
Photo credit: Birds in V-formation
Planning: transitions

Transition in

- goals of care
- location of care
- condition

Transition in: GOALS

- Baby may do better, do worse, do as predicted
- Parents may change goals of care based on the above, at any point, in the baby’s life
- Goals may become less aggressive, more aggressive, and may change multiple times
- Ongoing conversations, discussions → impossible to over-communicate
- “Hospice graduates”

Transition in: LOCATION

- Can be within the hospital, level of care, etc
- Can be transition from hospital to home setting
- Can be transition between home and outpatient services/supports
- The GOALS continue to drive the plan
Transition in: CONDITION

- May be anticipated or surprise changes, for better or worse
- Continuity presence, including home hospice team
- Management of symptoms and complications
- The GOALS continue to drive the plan

Transition in: CONDITION

SYMPTOM MANAGEMENT

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- Discuss barriers to care and understand potential pitfalls
Barriers to perinatal/neonatal PC/H

- Lack of access
- Lack of awareness of services
- Lack of understanding of services
- Perceived conflict in goals of services
- Fear of “over-burdening” families
- Fear of losing control
- Legal/ethical/risk issues

Questions, concerns, requests?

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References


