Perinatal palliative care: A Spectrum of Caring

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Objectives

The learner shall be able to:

• Describe fetuses and newborns appropriate for perinatal palliative care
• Identify the components of perinatal palliative care
• Apply perinatal palliative care principles in their local setting

The presenters have nothing to disclose

In the past 12 months neither presenter has had a significant financial interest or other relationship with the manufacturers or any products or providers of services that will be discussed in this presentation.

This presentation will not include discussion of pharmaceuticals or devices that have not been approved by the FDA. We will not be discussing off label uses of pharmaceuticals or devices.

Mortality Rates

US 2009

• Infant: 6.39/1000 live births
• Neonatal: 4.19/1000 live births
• Fetal > 20 weeks: 6.22/1000 live births + fetal deaths

Wisconsin 2010

• Infant: 5.7/1000 live births
• Neonatal: 3.8/1000
• Fetal > 20 weeks: 5.3/1000 live births + fetal deaths

About 20% of these deaths are due to congenital anomalies.

Settings for fetal or neonatal death

• Emergency department
• Labor and delivery
• Postpartum settings
• Nursery
• Neonatal Intensive Care
• Home
• Hospice programs

The context is challenging

When life and death share each other’s company

BIRTH

DEATH

In settings associated with joy and celebration
Who is involved?

- Genetic Counselors
- Child Birth Educators
- Insurers
- Pediatricians
- Radiologists
- Perinatologists
- Pregnancy Counselors
- Ethics committees
- Baby
- Parents
- Siblings
- Grandparents
- YOU
- N.I.C.U.
- Midwives
- Family Doctors
- Sonographers
- Obstetricians
- N.I.C.U.
- Family Doctors
- Labor & Delivery
- Child Birth Educators
- Geneticists
- YOU
- Baby

What makes perinatal palliative care possible?

- Accurate prenatal diagnosis
- Modern palliative care
- Understanding perinatal grief
- Perinatal palliative care

Practice Changes

- Early ultrasound is becoming more standard practice
- Advances in diagnostic technology
  - NT screening
  - MaterniT testing
- Earlier and more effective referral and assessment by specialists

Assurance and reassurance after initial diagnosis

- Offer to repeat the ultrasound
- Offer further diagnostic testing
- Offer referral to another perinatal clinic for second opinion/validation of results

Considerations in determining treatment decisions

- The certainty of the diagnosis
- The certainty of the prognosis
- The meaning of the diagnosis to the family

Leuthner, 2007

Uncertainty

“An uncertain prognosis should serve as a signal to initiate palliative care, rather than to avoid it, even when it is not yet appropriate to begin end-of-life care.”

Davies, 2008
Identifying the fetus/newborn

- Fetal life limiting conditions able to be diagnosed with near certainty
- Newborns who are imminently dying
  - Ask yourself if you would be surprised if the newborn died in the next ~6 months
- Newborns who may be expected to die before adulthood
  - 10 per 10,000 children have life limiting conditions
  - Half may need palliative care

Conditions where the fetus or newborn is appropriate for palliative care

- Progressive conditions where treatment is exclusively palliative
  - Trisomies 13, 18
  - Anencephaly
  - Renal agenesis/pulmonary hypoplasia
  - Progressive severe inborn errors of metabolism
- Conditions involving severe, nonprogressive disability associated with health complications
  - Extreme prematurity
  - Severe perinatal encephalopathy
  - Holoprosencephaly and other brain disorders

Conditions appropriate for palliative care (cont.)

- Conditions for which curative treatment is possible but can fail
  - Severe congenital heart disease, i.e. Hypoplastic left heart
  - Congenital diaphragmatic hernia
- Conditions requiring intensive long-term treatment aimed at maintaining quality of life
  - Short gut from gastroschisis, NEC etc
  - Spinal muscular atrophy, other myopathies

Components of perinatal palliative care

- Relief of physical symptoms
- Emotional, psychosocial, and spiritual support of parents and extended family
- Advance care planning & decisional support
- Logistical support

A tale of three babies

David
Elise
Eden

What options should parents be given?

- After prenatal diagnosis, counseling should be balanced and all options discussed
  - Termination for fetal anomaly
  - Perinatal palliative care
  - (Doing nothing is not an option!)
- For newborns, all options where benefits might outweigh burdens
  - Even if health care team would recommend against trial of treatment
  - Don’t give any options that are not acceptable

Himelstein, NEJM 2004;350:1752
Emotional, psychosocial, and spiritual support

“As soon as I heard the diagnosis, I started mourning.”

Cote-Arsenault, 2011

Parents experiences: Emotional, psychosocial, and spiritual suffering

- Grieving multiple losses
  - Loss of their healthy baby/normal pregnancy experience
  - Arrested parenting
  - Loss of the “personhood” for their infant
- Interactions with others
  - Fragmented health care
  - Disconnected family and friends
  - Feeling utterly alone

Cote-Arsenault, 2011

What do parents want?

- Information
- Shared decision making
- Honesty, empathy, presence, hope
- Emotional, psychosocial, spiritual support
- Sensitive communication with them and among health care providers
- Listening

What do parents want? (cont.)

- Validation of the fetus/newborn
- Pain and symptom management
- Support in decision making
- Compliance with advance care preferences, written care plan
- Access, continuity and transition


Decision making: What should parents be told?

- Information including survival, long term disability, anticipated clinical course
- Be honest and unbiased
- Provide ranges of outcomes
- Provide national data and your data
- Specify degree of uncertainty
- Words matter


TOPFA: Termination of Pregnancy for Fetal Anomaly

- Socially stigmatized procedure
- May not be an option due to:
  - legalities
  - insurance coverage
  - finances
- Medical or surgical procedures
- Can be stressful
- Some parents may feel pressured to choose this option
**Safety net for those choosing TOPFA**

- Higher levels of trauma
- Intense emotions
- Higher levels of depression and anxiety
- Long term??

Wool (2011)

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**The decision to continue the pregnancy**

“The primary goal in perinatal palliative care is to help families with the process of making choices about pregnancy management and after-birth care that incorporate their personal and religious beliefs, and are in the best interest of their baby.”

Summer, Kavanaugh & Moro, 2006

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**Perinatal palliative care as an alternative**

“If you’d never been born, then you might be an ISN’T! An isn’t has no fun at all! No he didn’t.”

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**Advance care planning**

“Plans are useless, but planning is invaluable.”

− Winston Churchill

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**Advance care planning**

1. Information
2. Goals
3. Decision making
4. Written plan of care
5. Communication
6. Follow up/re-evaluation

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**Why is advance care planning important?**

- Disease in newborns and children has an unpredictable course and prognosis
- Builds trust
- Helps to avoid confusion and conflict
- Proactive decision making avoids reactive decision making during crises
- Helps to avoid treatments not furthering the goals
- Empowers the family & reduces burden
Think positively

Advance care planning ≠ DNR

Advance care planning is about what you CAN do

Birth plan components

- Clear goals
- Site of delivery
- Fetal monitoring
- Mode of delivery
- Who will be in attendance
- Maternal and neonatal medications
- Specified components of resuscitation
- Site of care of the baby
- Feeding plan
- Baptism, ceremonies desired
- Special memories & mementoes
- Contingency post discharge plan

"There is no cure for birth and death save to enjoy the interval"

George Santayana 1863-1952

Logistical support: The practical stuff

- Who is going to care for the sibs during delivery?
- Where will you get discharge pain meds at 0200?
- How do you get a car bed because of airway obstruction?
- Who will help ou at home?
- Who will declare death at home?
- How do you transport the baby’s body across state lines?

Involve and support the family

Don’t forget the siblings!

Facilitate rituals
Community support

What are the current challenges with perinatal palliative care?

- Fragmentation & discontinuity
- Poor goal recognition and decisional support
- Ethical crises & overuse of technology
- Inattention to physical comfort, spiritual & psychosocial issues
- Inadequate advance care planning & planning for uncertainty

Challenges (cont.)

- Society is death denying
  - “death = failure”
- Varying levels of professionals’ skills and training
  - Staff unfamiliarity with palliative care in general
  - Poor recognition of appropriate fetuses/newborns
  - Lack of identification of goals of the family
- Limited access to services and funding
  - Few programs willing to start care prenatally
  - Delayed implementation
- Unbalanced counseling
- Limited site resources
- Clinician stressors including time limitation

"There are beginnings and endings and there is living in between."

(from *Lifetimes* by Melonie Ingpen)

Organizational processes to optimize care

- Identify task force team members & “stakeholders”
- Identify patients – which fetuses/newborns
- Describe the current and the ideal patient flow
- Identify existing and needed community resources
- Identify barriers to optimal care
- Develop plans for communication, care coordination, documentation
- Develop and distribute parent education materials
- Disseminate new process to health care providers and provide needed education
- Verify success via parent surveys & quality improvement evaluation

The task force

- Bereavement services
- Physicians and staff from OB, pediatrics, genetics, labor and delivery, postpartum, nursery
- Ethics
- Home care
- Pastoral care
- Social services
- Information systems
- Registration
- Ultrasound
- Quality improvement
- The organization
The perinatal palliative care team
- Family
- Obstetrician/perinatologist
- Social worker
- RN bereavement coordinator
- Neonatologist/pediatrician/neonatal RNs
- L & D RNs
- Chaplains, psychosocial counselors
- Others as needed

Working together
Patients, physicians, nurses in the ambulatory setting and the inpatient setting, social workers, etc., all play a part in bridging the care during and after the delivery of the baby.

Staff education and support
- Information about perinatal death
  - Death ≠ failure
- Concepts of perinatal palliative care
- Communication tools to support families
  - Conversation “scripts”
- Staff support
  - This is stressful work!
  - Advance in-services in challenging cases
  - Debriefing after a death

How to measure good care
- Processes/Steps to good care
  - Advance care planning
  - Following preferences
- Results of care
  - Pain and symptom control
- Experience/satisfaction with care
  - Community
  - Emotional support
  - Coordination/continuity
  - Caregiver experience

Perinatal palliative care does not mean only EOL care
Perinatal palliative care is quality care

The Outcome
David was transferred to a NICU, enrolled in a palliative care program and discharged home at 10 days with a home visiting RN. He died 3 days later.

Elise was born still. Her parents had prayed for her to survive through birth so that the family could have time with her alive. Despite this they felt they had chosen the right path for their family and that they were well supported in their decisions.

Eden was home at 24 hours with a visiting home peds hospice RN. Every day was celebrated. She died at 10 days surrounded by her family.
Summary

- Fetuses and newborns appropriate for perinatal palliative care can be identified allowing for early entry into care.
- Components of perinatal palliative care can be applied regardless of setting of care and will improve quality of care.
- Any organization with a delivery service can provide perinatal palliative care.

Advance care planning early in course of disease

- Anticipate potential course of disease.
- Anticipate potential symptoms associated with disease or treatment.
- Review decision making guidelines.
- Assess role of spirituality, religion, culture.
- Determine appropriate goals and a treatment plan.
- Explore circumstances in which goals might change from life prolongation to primarily comfort.
- Plan on regularly reviewing goals and the advance care plan.

Initial Care

- Team addresses grief and support for loss of a normal pregnancy.
- Present options.
- Allow time for decision making.
- Support provided through the end of the pregnancy, regardless of the choice made.
- Continuity of care, “may alleviate medical and social isolation and give parents time to decide how to make the most of their time with their baby.”

For further information

- ACT: http://www.ACT.org.uk > help for professionals: Care pathways > neonatal care pathway: End of life > child and family wishes when life is limited and other great resources.
- Blueprint for a Perinatal Palliative Care Program® Tool Kit http://www.bereavementservices.org
- British Association for Perinatal Medicine http://www.bapm.org/publications/index.php >guidelines>
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• SSM Cardinal Glennon Children’s Hospital and Seattle Children’s tools http://www.promotingexcellence.org/i4a/pages/index.cfm?pageI D=3310
• When Children Die. IOM 2002

Interactions with Others

- Fragmented healthcare
  - Disjointed/confusing appointments
  - Many different specialists
- Disconnected family and friends
  - Awkwardness with family and friends
  - Lack of understanding
- Utterly alone
  - Sense of being alone/marginalized
  - Accumulated separations

Cote-Arnesault, 2011