American Academy of
Hospice and Palliative Medicine

PEDIATRIC PALLIATIVE CARE: NEURO/NEONATAL AND COMMUNICATION AND ETHICS

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AAHPM Intensive Board Review Course

Pediatric Palliative Care:

Neurologic Conditions, Prenatal and Perinatal Care, Ethical Issues and Communication

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Disclosure Information

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Has no financial relationships to disclosure.

Pediatric Palliative Care Objectives:

- Describe common life limiting neurologic conditions in pediatric patients
- Discuss unique issues and needs in neonatal palliative care
- Communicate effectively with children
- Discuss ethical and legal issues for dying children

NEUROLOGIC CONDITIONS IN PEDIATRIC PALLIATIVE CARE

Frequently Fatal Neurologic Conditions of Children:

- Holoprosencephaly
- Non- accidental head trauma
- Intraventricular Hemorrhage
- Hypoxic Ischemic Encephalopathy
- Spinal Muscle Atrophy and Hypotonias

Frequently Fatal Neurologic Conditions of Children:

- Mitochondrial Disorders
- Muscular Dystrophies
- Inborn Errors of Metabolism
- Static CNS injury

Symptoms in Neurologically Impaired Children:

- Pain: joint fatigue, spasticity, joint dislocations, seizures (OT and PT very valuable)
- Seizures: multifactorial, multifocal, subclinical
- Airway control: secretions, positioning, swallow
- GERD: supine, tube feedings, side effects of treating

Symptoms in Neurologically Impaired Children:

- Constipation: immobility
- Linear Growth: Chiari malformations, scoliosis, tethered cord
- Increased intracranial pressure

Trajectories of neurologic illness:

- CNS tumors & malformations dependent on cranial development
- Microcephaly sign of very poor prognosis
- Feeding and medication delivery for Sx management offer opportunity for goals and plan of care decisions

Trajectories of neurologic illness:

- Musculoskeletal disease associated with hunger for significant period prior to respiratory failure
- Hypoxia short course very symptomatic, hypercarbia longer than expected
- Life expectancy from Lansky (Karnofsky) of <30, over 3 years

Complementary Therapies in Pediatric Palliative Care:

- Require intact CNS and moderately normal cognition
- Distraction very helpful for pain, dyspnea, spasticity, anxiety, nausea
- Counterstimulation effective (rubbing, NUMBY Stuff, blowing)

Complementary Therapies in Pediatric Palliative Care:

- Engage in play or art (fine motor, gross motor, distraction, coping, adaption)
- Hypnosis, biofeedback, and CBT helpful in older children and adolescents assoc dyspnea, spasticity, anxiety, wound management

Neurologic Conditions: Pearls

- Open fontanelles, shunts extend life
- Microcephaly very bad sign
- Feeding decisions just as significant as adults, under appreciated for severity of illness
- Immobility hurts
- Trajectories in severely affected very very long (years)
- Many symptoms associated need frequent monitoring and treatment

PERINATAL PALLIATIVE CARE

Perinatal Palliative Care:

- 700,000 to 1 million desired pregnancy losses in US each year
- > 20% patients choose to deliver children with severe chromosomal or anatomic anomalies
- Antepartum care:
  - Dx, hospice referral (admit), anticipatory grief, birth/death plan, memory planning
- Intrapartum care:
  - Birth plan, spiritual care, family time, memory making, continuity of care

Perinatal Hospice:

- Postpartum care:
  - Presence with infant, bathing, dressing, memory work, measurements, documentation (Certificate of Birth-Stillborn)
- Aftercare:
  - Funereal or memorial service, grief support, reproductive counseling, support services, announcements

How is Perinatal Palliative Care different?

- Fetus is the patient
- Anticipation of birth and impending infant's death
- Care and support of the parent role
- Option of pregnancy termination

(Leuthner SA, Fetal Concerns, MCN Sept 2007;32 (5):272-8)

How is Perinatal Palliative Care different?

- Continuation of pregnancy (often against advice)
  - Plans for aggressive labor management and operative delivery
- Prioritization of care of mother vs. infant
- Unique decision making
  - Prognostic certainty, Diagnostic certainty, Best Interest

(Leuthner SA, Fetal Concerns, MCN Sept 2007;32 (5):272-8)

Perinatal Hospice

- Madigan Army Medical Center
- Tacoma, WA
- 33 patients with fetuses with lethal congenital anomaly
- 28 (85%) chose perinatal hospice
  - 5 VIP
- 11 of 28 (39%) intrauterine death

Perinatal Hospice

- 17/28 (61%) delivered live-born
  - 12 vaginal: 4 preterm, 8 term
  - 5/28 (18%) by C/S (OB indication or maternal request) 4 preterm, 1 term
- All liveborn died: 20 minutes to 2 months
- No maternal complications

Calhoun BC et al, Perinatal hospice: comprehensive care for the family of the fetus with lethal condition. J Reprod Med. 2003; 48 (5): 343-8.

What do parents want in perinatal end of life care?

(Bosig CL et al. J Perinatol 2007;27(8)467-8)

- Honesty
- Empowered Decision-making
- Support for plan of care
- Delivery environment
- Trust in nursing care
- Physicians bearing witness
- Support from other hospital care providers

Clinical Services for Perinatal Hospice:

- Expertise in Care of the Premature Infant
- Technological experience
- Relationship with Genetics, Mat/Fetal Medicine, L&D
- Transport capability
- Symptom management
- Coordination of Care
  - DME, Pharmacy, Nutrition, Specialists

Clinical Services for Perinatal Hospice:

- Memory Making
- Family Support
- Memorial Planning
- Skilled Respite
- Reimbursement
- Health Maintenance
- Bereavement

Parental Experience with Life-Threatening Fetal Diagnosis

- **Grieving Multiple Losses**
  - Normal pregnancy
  - Healthy baby
  - Future parenting
- **Arrested Parenting**
  - Interruption of normal process of becoming a parent
- **My Baby is a Person**
  - Unanimous desire to honor and legitimize humanity of unborn baby
- **Fragmented Health Care**
  - Encounters with multiple providers
- **Disconnected Family and Friends**
- **Utterly Alone**

Cote-Arsenault, Denney-Koetsch: J Pall Med,vol14, number 12, 2011; p 1302-8

Perinatal Palliative Care: Pearls

- Over 1,000,000 pregnancies affected with fatal pathology annually in US
- Families often choose to continue pregnancy when given choice (often against medical advice)
- Coordination of care complex
- Need expertise in delivery room, neonatal technology and service

ETHICAL ISSUES AND COMMUNICATING WITH CHILDREN

Pediatric Admission requirements:

- disease process that will likely prevent entry into adulthood
- application of the six month rule in view of pediatric conditions
- no limits on resuscitation required
- curative therapies appropriate
- assent preferred when developmentally appropriate

Palliative Care for children differs from adult care:

- relative rarity of childhood death
- epidemiology of childhood death:
  - rare syndromes
  - defects
  - abnormalities
- interpersonal dynamics:
  - professional
  - familial

Palliative Care in children differs from adult care:

- developmental issues:
  - communication
  - assessment of Sx
  - assessment of quality of life
  - the child's experience of dying

Palliative Care for children differs from adult care:

- legal and ethical issues of non-autonomous individuals
- school and community issues
- nature and duration of bereavement

Interfacing Goals:

- proper role of life-saving and life- prolonging treatments
- palliative therapies
- life- enhancing therapies
- health maintaining therapies
- life completion
- being a child
- anticipatory grieving
- memory making

Ethical dilemmas in children with life limiting conditions:

- uncertainty of prognosis
  - especially prematures and infants
- informed consent and assent
- decisional capacity
- withhold/withdraw treatments
- forgoing nutrition and hydration
- futility vs. quality of life

Brain Death in Children:

- Very complicated
- Unable to declare less than 1 week of age
- Open fontanelles for at least first three months
- Ability to dissipate intracranial pressure
- Blood flow persists
- EEG very “disorganized” in infants, much slowing

Brain Death in Children:

- Clinical criteria only
- Serial Exams at least 24 to 48 hours apart
- Perception of severity of injury by parent and family
- Implications for organ donation

Communication with children:

- concrete
  - euphemisms can be dangerous
- subject to finalism
  - bad things happen when people are bad
  - being good protects people from bad
- egocentric
  - everyone knows what they are thinking,
  - know their thoughts without talking

Communicating effectively with ill children: Betty Davies

- **listen** to what the child needs and wants
- children are **curious**:
  - about their disease
  - about prognosis
  - about dying
- allow them to talk, **let them control the pace** for questioning
- do not lecture
- be **truthful**

Common Requests:

- "Please don't tell my child s/he is dying…"
- "We believe in miracles…"
- "I want to protect my child"(sibling) from the dying, so they should not be present for:
  - Functional decline
  - Anticipatory grief
  - Active dying
  - At memorials

Words that Hurt:

- Infant has condition…"incompatible with life"
- Recommendations for termination of pregnancy of infant with disability or difference to "protect" the family from disappointment, grief, or struggle
- Communicating that the life of a baby not yet born is any less valuable than one already here.
- "you can have another"…

Death: Developmental Milestones

- infant: no sense of time
  - death is separation
- toddler: links time with concrete events
  - dead things disappear, temporary, rescue possible
- school age: can tell time, future a long way off
  - death selective, old die, physical limitations
- adolescence: future understood
  - death final and irreversible, unlikely

Ethics and Communication: Pearls

- Uncertainty of prognosis and rarity of childhood dying problematic
- Know your development
- No ability to consent (substituted judgement)
- Assent possible
- Be specific, children are concrete
- Declaration of death by neurologic criteria complicated
- Tell the truth

Growth:

Great problems of life may not be solved, but they may be outgrown. - Carl Jung

If I had to read just one article:

- Himelstein, BP. Palliative care for infants, children, adolescents, and their families. **J Pall Med** 9 (1) 2006, 163-181.

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