

# End-of-Life Care for Children

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# Patterns of Childhood Death

- Death in childhood rare
- Most deaths acute
  - ◆ traumatic (accidents, homicides, suicides)
  - ◆ neonatal
  - ◆ catastrophic illness
- Of nonacute deaths most due to
  - ◆ cancer
  - ◆ congenital anomalies

# Patterns of Care

- Given epidemiology of childhood death:
  - ◆ care of dying children by
    - ◆ intensivists
    - ◆ subspecialists
- Primary care physicians provide relatively little care for dying children and their families

# Question

- Who should provide medical care for dying children?
  - ◆ Primary care pediatricians?
  - ◆ Pediatric subspecialists who provide continuity (oncologists, cardiologists, etc.)?
  - ◆ Pediatric palliative care/hospice physicians?

# Hospice “Eligibility”

- Payment driven
  - ◆ follows federal Medicare rules: six months life expectancy
- Problem for pediatrics
  - ◆ Very few children covered by Medicare
  - ◆ Prediction more difficult
  - ◆ Insurers may not include benefit for children even if adults covered

# Who Ought to Qualify?

- Little agreement

- ◆ “Poor prognosis?”

- ◆ No expectation of cure?

- ◆ Any time limitations?

- Limits on intervention?

- ◆ Stop “curative” efforts?

- ◆ Blood products, TPN, antibiotics, mechanical ventilation, dialysis?

# Examples

- “Failed” cancer therapy
- Chronic lung disease
  - ◆ Cystic fibrosis or progressive bronchiectasis
- Progressive cardiomyopathy
- Progressive neuromuscular disease
- Short bowel syndrome

# Philosophy of Hospice

- Maximize patient's quality of life
  - ◆ control symptoms: pain, itching, nausea, discomfort from constipation, etc.
  - ◆ address psychological needs: fear and anxiety about abandonment, death
  - ◆ maintain pleasurable activities: school, play, family life

# More Philosophy

- Maximize family quality of life
  - ◆ Provide respite care: give parents breaks from patient care
  - ◆ Address psychological and spiritual needs: guilt, fear of moment of death
  - ◆ Prepare plan for death (home vs. in-patient facility), funeral, bereavement
  - ◆ Note: beyond child's best interests

# Treatment Principles

- Use everything available
  - ◆ oral and transdermal narcotics very effective
  - ◆ PCA and constant narcotic infusions as manageable as with adults
- Children (except premature infants) no more likely to experience respiratory depression than adults
- Addiction is irrelevant
- DEA and State agencies don't "get it"

# More Questions

- How about stopping *artificial* fluids and nutrition?
- Is there ever a role for clinician-assisted suicide in pediatrics?
- What do you do when clinicians have not offered palliative and/or hospice care in cases you believe appropriate?

# Two Stories

## ■ Anna

- ◆ 23 month old with severe intrapartum anoxic encephalopathy

## ■ Cameron

- ◆ 11 month old with cystic leukoencephalopathy (presumed perinatal insult)