ETHICAL CHALLENGES IN PEDIATRIC PALLIATIVE CARE

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Learning Objectives

- Define the basic principles of ethical analysis when engaging in advance care planning for children with complex chronic conditions.
- Apply ethical principles to difficult and morally ambiguous real-life pediatric palliative care case scenarios.
- Describe when and why it is permissible to offer limitations in therapy options or stop current therapies.

Disclosure

- I have no financial relationships to disclose.
What is palliative care?

Curative Model
- Primary goal: cure
- Disease Process
- Symptoms treated as clues to diagnosis
- The patient’s body is differentiated from the patient’s mind
- Death is the ultimate failure

Palliative Model
- Primary goal: relieve suffering
- Patients and Family
- Distressing symptoms treated as entities in themselves
- The patient is viewed as a complex being comprising physical, emotional, social and spiritual dimensions
- Enabling a patient to live fully and comfortably until he or she dies is a success

My Questions
- When do we move from supporting life to fighting death?
- When is life so intolerable that death is better?
- How does incurable illness alter decision-making?
- What is the role of cognitive impairment?
Issues

- Parental Autonomy – How is that different from patient autonomy?
- What is society’s responsibility for protecting children?
- Who can best decide the best interest of a child?

The Best Interest Standard

- Ultimately, caregivers must compare the burdens, consequences, and potential complications of the treatment itself against the burdens, consequences and potential complications of non-treatment; and they must compare the likely realities of life after treatment against the likely realities of life without treatment

President’s Council on Bioethics, 2005

Indiana Baby Doe (1982)

- Born with Trisomy 21
- Tracheo-esophageal fistula
- Doctors gave conflicting medical opinions to parents

Medical Indications

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<thead>
<tr>
<th>Quality of Life</th>
<th>Contextual Features</th>
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<tbody>
<tr>
<td>Patient Preferences</td>
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Percentage split during the moments of decision:

- Yes: 7.8%
- No: 6.7%
- Other: 85.5%
- Do not know: 1.4%
- Do not care: 4.2%
Real Life Decision

- Parents declined surgery
- Illinois courts upheld parent’s right to decide fate of their child
- Baby died on day 7 of life

Baby Jane Doe (1983)

- Born with spina bifida, microcephaly and hydrocephalus
- Doctors gave conflicting medical opinions to parents as to whether the myeloencephalocele should be repaired
- Her parents wanted to forgo surgery and provide only nutrition, medication and protective coverings for their daughter’s open-spine condition.

Bowen vs. American Hospital Association, US Supreme Court, 1983

Medical Indications

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Patient Preferences

Your Turn

- What characteristics of the surgery or of baby’s situation lead you to believe that surgical intervention is or is not beneficial?
- How would you advise patient?

Real Life Decision

- Parents declined surgery
- She developed meningitis with worsening neurologic outcome
- She survived and meningocele closed up

Bowen vs. American Hospital Association, US Supreme Court, 1983
**Withholding Interventions**

1. The infant is chronically and irreversibly comatose;
2. The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant’s life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or
3. The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane.

DHHS, 1985: 1340.15(B)2, p. 14887

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**Lydia**

- Holoprosencephaly
  - Severe congenital brain malformation
  - Cognitive impairment
  - Quadriplegia
  - Seizure disorder
  - Pan-hypopituitarism
  - Cleft lip and palate

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**3 months of age**

- Admitted for increased seizure activity.
- Modified barium swallow study shows silent aspiration.

**Question of gastrostomy tube is raised:**

- Should we prolong life by placing a gastrostomy tube?
- Is it permissible to allow her to aspirate by continuing to nipple feed?
**Medical Indications**

- Encephalocele
- Cleft Palate
- Rest of body perfect
- No surgical options for repair

**Patient Preferences**

**Quality of Life**

**Contextual Features**
Julie

- 3 year old with infantile Spinal Muscular Atrophy
- Normal twin brother
- Progressive illness – pediatric equivalent of Amyotrophic Lateral Sclerosis (ALS)
- Lose ability to eat, then breath, and then finally move
- Pain due to immobility, contractures and neuropathy

- Gastrostomy dependent since 6 months of age
- Ventilator dependent since 9 months of age
- For past 6 months 7 admissions for pneumonia due to chronic lung disease and aspiration
- Parents perceive a lot of suffering in their child
- Hospitalizations are very stressful, weakness prevents her from playing with her brother, she is too young to understand what is going on.
Parents feel that the ventilator is no longer supporting a tolerable quality of life. They request withdrawal under controlled circumstances rather than waiting for her to die from fulminant pneumonia.

### Medical Indications
- Quality of Life
- Contextual Features

### Patient Preferences
- Sammy is a quiet guy and rarely participates in discussions of his cancer.

### Samuel
- 18 y/o male with osteosarcoma right distal femur.
- 12 y/o: limb salvage procedure of right knee with chemotherapy.
- 16 y/o: local recurrence, with amputation of right leg and another course of chemo.
- Parents have been very involved in decision-making and have sought care at nationally recognized cancer centers.
- Sammy is a quiet guy and rarely participates in discussions of his cancer.

- On a surveillance visit, studies show new metastatic lesions bilateral humerus and multiple pulmonary nodules.
- The parents discuss with the pediatric hematologist and request that Sammy not be told of metastases and poor prognosis.
### Medical Indications

### Patient Preferences

| Quality of Life | Contextual Features |

### Summary

- In these and similar cases, there may not be a "good" outcome

### Professional Obligations

- Work with parents to clarify goals of care
- Anticipate and ensure that the parents fully understand the potential consequences of all treatment options
- Provide your own recommendation and rationale
- Work with parents and children to devise a treatment plan based on their priorities
- Treat the parents with compassion and respect. Affirmation is critical
- Prevent suffering for the child and family