Legal and Ethical Issues Surrounding Pediatric End-of-Life Decisions

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This roundtable discussion is sponsored by the Children’s Hospital Affinity Group of the In-House Counsel (In-House) and Teaching Hospitals and Academic Medical Centers (TH/AMC) Practice Groups.

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Agenda

• Introduce 5 challenges we sometimes confront in pediatric end-of-life care
• Briefly review what pediatric palliative care is and how this field is growing rapidly
• Use five cases to drill down regarding each of the 5 challenges
5 Challenges

1. **Brain death**
   - What to do when parents do not want to allow the evaluation or dispute the determination of death by neurologic criteria?

2. **Artificially routed nutrition or hydration**
   - When is this permissible to withhold or withdraw, especially in severely impaired infants who would otherwise not die?

3. **“Bad agent”**
   - How to handle cases where the surrogate decision maker (parent or otherwise) is thought to not be representing the best interest of the patient (as in abuse related trauma)?

4. **“Futility”**
   - Is this concept useful in cases where the parents want interventions that the clinical team feels would be in violation of their duty to serve and protect the patient.

5. **Respecting the preferences of minors**
   - How to proceed with a reasonable minor wishes to stop or not receive treatment for a life-threatening condition?
Pediatric Palliative Care

Goals, Hopes

Options, Treatments

Problem-Solving Decision-Making

Problem, Predicament

Coordination

Logistics

Doctors

Nurses

Therapists

Sites

Hospital

Home

Facilities

Payment

Patient

Body

Mind

Social

Family

Staff

Spiritual
Pediatric Palliative Care Programs in Children’s Hospitals: A Cross-Sectional National Survey

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**What’s Known on This Subject:** Over the past 10 years, children’s hospitals increasingly have established pediatric palliative care programs, but little is known about the prevalence of these programs or their geographic distribution, range of services offered, staff composition, or funding.

**What This Study Adds:** Among the 162 hospitals that responded to this survey (71.7% response rate), 69% have a pediatric palliative care program, with substantial variation across programs in terms of how they are staffed and funded and what services they provide.

Remarkable growth of the field
FIGURE 2
Establishment of new hospital-based PPC programs over time.

Remarkable growth of the field
Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study

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WHAT’S KNOWN ON THIS SUBJECT: During the past decade, pediatric palliative care (PPC) has become an established area of medical expertise. Although the number of hospital-based PPC teams is increasing, scant information exists regarding the patients referred for PPC consultations or their subsequent survival pattern.

WHAT THIS STUDY ADDS: Compared with adult patients, pediatric patients who received hospital-based PPC services had a greater diversity of medical conditions and duration of survival, which underscores the need for PPC teams to be properly resourced to meet the needs of these patients and families.

KEY WORDS: pediatric care, palliative care, hospice care, chronic illness, technology dependence, polypharmacy

PPC is care for patients with often chronic serious illness
More than half are alive a year later
Cases
Lauria

- 6-year-old found unconscious in tub with sock stuffed in her mouth
- Non-responsive; initial EEG detects no brain-stem activity, but determination of brain death requires additional testing
- Mother strongly suspected of abuse; history of maltreatment of Lauria and previous CPS involvement
- CPS has temporary custody of Lauria in light of apparent abuse
- Care team routinely offers palliative care in cases involving terminal conditions
- Lauria’s death will change prospect of criminal charges from abuse to homicide
Lauria

• Who makes the decision about Lauria’s care and on what basis?
Lauria

• Who makes the decision about Lauria’s care and on what basis?
• What additional steps in the evaluation of permanent cessation of neurologic function need to be taken to determine brain death?
Determining “Brain Death”

- Protocol differs depending upon age, since infants and young children are different
- Usually 2 examinations at separate times by qualified examiners
- Physical examination
  - Examination of cranial nerves and body responses
  - Apnea “test”
- Ancillary testing
  - EEG, cerebral blood flow
- Does your hospital have a policy and protocol for determining death by neurologic criteria?
Lauria

• Who makes the decision about Lauria’s care and on what basis?
• What additional steps in the evaluation of permanent cessation of neurologic function need to be taken to determine brain death?
• If these steps are taken, and the findings point to brain death, do the physicians have an option to not declare brain death?
Lauria

• Who makes the decision about Lauria’s care and on what basis?
• What additional steps in the evaluation of permanent cessation of neurologic function need to be taken to determine brain death?
• If these steps are taken, and the findings point to brain death, do the physicians have an option to not declare brain death?
• If she is declared brain dead, is it mandatory that all physiology-sustaining interventions be immediately stopped?
Lauria

• Who makes the decision about Lauria’s care and on what basis?
• What additional steps in the evaluation of permanent cessation of neurologic function need to be taken to determine brain death?
• If these steps are taken, and the findings point to brain death, do the physicians have an option to not declare brain death?
• If she is declared brain dead, is it mandatory that all physiology-sustaining interventions be immediately stopped?
• If she is not brain dead, who decides about DNAR status?
Meredith

- 3-week old with severe case of *osteogenesis imperfecta*, currently in NICU
- Francesca (mother) a homeless unmarried 18 y/o high school dropout living in a camper
- Prognosis grim: short life (weeks to months), punctuated by pain of broken bones from incidental contact; already has multiple rib fractures from trip down birth canal (prenatal care might have detected condition and resulted in a C-section); Meredith currently on ventilator
- Due to pain of respiration from broken ribs, RT recommends analgesia & sedation
- Francesca wants loving, motherly interaction; wants to hold, care for, and play with Meredith; believes best thing she can do is pour her love into Meredith during her short life; analgesia-sedation will make interaction impossible
- But Francesca’s interactions cause additional bone breaks audible to care team
Meredith

• What care does this child need, and who decides what she will get?
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• If the mother and the care team decide that the most loving way to care for Francesca is to do a compassionate extubation, is it ethically appropriate to continue the analgesia-sedation?
Meredith

• What care does this child need, and who decides what she will get?
• If the mother and the care team decide that the most loving way to care for Francesca is to do a compassionate extubation, is it ethically appropriate to continue the analgesia-sedation?
• Does your hospital have a compassionate extubation protocol?
Meredith

• What care does this child need, and who decides what she will get?
• If the mother and the care team decide that the most loving way to care for Francesca is to do a compassionate extubation, is it ethically appropriate to continue the analgesia-sedation?
• Does your hospital have a compassionate extubation protocol?
• If Meredith was able to breath on her own but was unable to orally feed, under what circumstances would stopping artificially routed nutrition and hydration (that is, feeding by tube or by vein) be acceptable?
Stopping ARNH

CHOP Process for Discontinuing Artificially Routed Nutrition or Hydration

Has the patient ever been able to express a preference?

If uncertain about how to proceed, request Ethics Consultation

Follow substituted judgment standards

Does the patient have an end-stage condition?

no

Does ARNH directly harm the patient?

no

Does ARNH directly cause suffering?

no

Is the benefit of ARNH worth the harm?

Is the patient imminently dying?

yes

Consider PACT Palliative Care Consultation

Perform benefit-vs-harm analysis of ARNH

no

Withdrawal of ARNH may be warranted

Consult with parents, care team; attempt to reach consensus

Further Discussion

Was consensus reached?

yes

Withdraw ARNH

no

Are the members of the care team ethically uncomfortable

Ethics Consultation

Further Discussion

no
Dennis

- 14 y/o newly diagnosed with acute myelogenous leukemia (AML)
- Birth parents both have histories of drug abuse, life on streets; Dennis adopted at age 11 by aunt, a devout Jehovah’s Witness; Dennis had no prior involvement with JW community
- AML successfully treated in majority (>80%) of cases; treatment involves bone marrow ablation and blood transfusion; alternative therapy without blood transfusion successful in <20% of cases
- Dennis presents as very bright, articulate, and committed to his JW faith; refuses treatment that would involve a blood transfusion
- Aunt supports Dennis’s decision; birth parents hear about his refusal of treatment and urgently want him treated, including transfusion
- Care team divided; some support Dennis’s decision, some consider him immature and aunt’s acquiescence to be child neglect
Dennis

• What are the issues?
Dennis

• What are the issues?
• How should they be decided?
Dennis

• What are the issues?
• How should they be decided?
• What if Dennis was 13 years old? 12? 11? At what point would his preference have less influence?
5 Challenges & Take Home Points

1. Brain death
2. Artificially routed nutrition or hydration
3. “Bad agent”
4. “Futility”
5. Respecting the preferences of minors

- Palliative care teams are invaluable
- Having clear protocols improves quality of care
- Ethics discussions with clinical staff can help address “moral distress”
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