Pediatric Palliative and Hospice Care: Clinical and Ethics Considerations

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Background: Pattern of Childhood Death in United States

- Death in childhood rare (~55k/yr in US)
  - These constitute < 2% of US deaths/yr
- More than 50% of deaths acute
  - Traumatic (accidents, homicides, suicides)
  - Neonatal (prematurity, congenital anomalies)
  - Catastrophic illness
  - Role of palliative/hospice care not clear
- Of non-acute deaths, most due to
  - Cancer
  - Congenital anomalies
  - Neurodegenerative/neuromuscular conditions
Clinical and Moral Goals of Palliative Care

• Symptom control
  - Relief of pain, nausea, itching, hunger, etc.

• Family support
  - Address prognostic uncertainty
  - Ascertain impact of situation on family (money, time, attention to sibs, dependent parents, spouses, etc.)
  - Address influences of extended family and community members, especially religious “elders” or leaders (e.g., Amish)
Palliative Care Ethics

• Basic Premise: goals of care depend on inherently *subjective* values and beliefs
  - Religious/spiritual beliefs by definition non-rational

• No principled reason why values of clinicians better than values of families

• Conflicts between professionals’ values and those of family should generally be resolved in favor of family preferences
Symptom Control Issues

• Pain management and impact of narcotics

  ● Narcotics/myths
    - Opioids more likely to depress respiration in children (True in acidotic newborns, but most of them getting mechanical ventilation)
    - Narcotics more likely to cause “addiction” children
      - Nonsense, (do cause dependence after ~5-7 days of continuous use and require tapering)
  
  ● Long-term developmental impact of narcotic infusions on young children unclear
    - Irrelevant in end-of-life care
    - Not clear what alternatives exist
      - Seems wrong to permit repeated experience of painful stimuli without analgesia
Who Ought to Qualify for Services?

• Little agreement on answer
  ❖ “Poor” prognosis?
  ❖ No expectation of cure?
  ❖ Any time limitations?

• Should we place limits on intervention (as with Medicaid)?
  ❖ Stop “curative” efforts?
  ❖ Blood products, TPN, antibiotics, mechanical ventilation, dialysis?
Additional Goals

• Clarify values/beliefs family brings to situation
  ❖ Religious/spiritual
  ❖ Impact of prior experience with medical care (esp. ICU care)
  ❖ Attitudes and feelings of family and community toward medical care system (e.g., African-American mistrust of “white” professionals)
Conflicts over Goals

• Different types
   Conflicts between families and professionals
   Conflicts within families/support systems
    ➢ Conflict between (adolescent) patient and parents
    ➢ Conflict between parents
    ➢ Conflicts between parents and others
    ➢ Conflicts between family members and their community, e.g. person with religious authority
   Conflicts among professionals
    ➢ Doctors vs. nurses
    ➢ Among subspecialists
Myths of Decision Making

- Evidence strongly suggests parents want involvement in end-of-life decisions
  - No support for claims of heavy guilt burden
  - Most families prefer shared decisions with staff
- Many children with life-threatening illness want role in deciding about: limits of treatment
  - E.g., teen with CF and prior mechanical ventilation: “no more ICU”
- Leaving minor out leads to feelings of isolation because of fear of hurting parents
  - Don’t yield to parents request for silence
End-of-Life Particulars

• DNR/DNI/DNAR
  ❖ Problematic practices
    ➢ Requiring parental signatures (POLST)
    ➢ Requiring specific limitations before instituting palliative or hospice care

• Decisions about intubation independent of decisions about chest compressions, other measures
Futility as Issue for Palliative Care

• Maintenance of life support is NOT futile for vitalists, i.e., those who value continued biological/CV function ***regardless of cognitive or interactive capacity***

• ~15-20% of U.S. population are vitalists (from different faith traditions)

• Philosophy has not produced an agreed-upon means by which clinicians justifiably substitute their views for the views of their patients and the patients’ family members

• While also painful for palliative care practitioners, most do not support unilateral refusal to provide ongoing treatment with no apparent benefit to the patient
  
   Families will have to live with consequences of decisions in ways we do not
Stopping Artificial Fluids and Nutrition as Ethically Appropriate Palliative Care

- Medical administration of food/water involves risks and discomfort
- Good patient-oriented decision making necessarily contextual
- Pediatrics/NICU care typically involves *indicated* artificial feeding in expectation of eventual move to normal oral feeding
Forgoing Medically Provided Fluids and Nutrition

- Any food/water given other than orally
- General legal (judicial) and bioethical view: not different from other forms of life support
- General public view: not clear
- Pediatrics view: divided
Factors to Consider

- We understand from *adults* that hunger dissipates quickly, ~24 hrs
- Thirst ↓ more slowly, ~48-72 hrs
- Ketosis, acidosis powerful hunger suppressants
- Renal failure (rising BUN) powerful thirst suppressant
- Narcotics and sedatives *probably* ablate hunger and thirst
- Assuming normal circulatory health, death may take 3 weeks, occasionally longer
  - This prolonged period of dying very hard on bedside providers and parents
Roman Catholic Perspective

• Important to ~25% of those in U.S.

• For centuries Church taught proportionality in deciding obligatory medical care

• 1980 Vatican *Declaration on Euthanasia*
  
  ⚫ Withdrawing treatment “is not the equivalent of suicide...it should be considered as acceptance of the human condition, or as a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or as a desire not to impose excessive expenses on the family or community.”
Newer Catholic Perspective

- Late 1980s conservative bishops began arguing that discontinuing fluids and nutrition introduces new causes of death: dehydration and “starvation” in PVS.
- In 2004 John Paul II issued allocution on feeding tubes:
  - Always natural means of preserving life (?)
  - If removed knowingly and willingly equates to “euthanasia by omission.”
Official Statement

• August 2007 Congregation for the Doctrine of the Faith:

• Q: Is administration of food and water to patient in “vegetative state” morally obligatory...?

• A: “Yes.” “...even by artificial means...as long as, it is shown to accomplish its proper finality, which is hydration and nourishment of the patient....”

• Q: May artificial nutrition/hydration be discontinued in PVS when competent doctors judge patient cannot recover?

• A: “No.” Such a person’s fundamental dignity requires administration of food and water.
Catholic Position Definitive?

- Some Catholic thinkers believe John Paul II’s and CDF statements leave room for choice
- My view: hard to see how Vatican can intend anything other than plain language of text: do not remove artificial fluids/nutrition even in permanent unconsciousness
Conscientious Objection: Religiously or Otherwise

• Really = conscientious refusal to provide care
• Again, rarely adequate philosophical justification for claim “my values are better than yours”
• Part of being a professional → setting aside self-regarding interests for those of patient or client
• Exercising “conscience” clauses often political and abuse of (raw) power
• Professionals typically enjoy substantial socio-economic advantage
Case Example I

- Twin infant born at 27 wk

- At 7 weeks old with bilateral IVH (grade ≥3), persistent need for high $F_iO_2$ mechanical ventilation, high inspiratory pressures, probable sepsis, need for inotropes

- Neonatologists → baby has 15% chance of “good” outcome → urged continuing treatment

- Parents → baby “been through enough”
Ethical Questions

• What is relevance of (correct) statistical information?
  ❖ Group-wise vs. individual prediction

• What does “good” outcome mean (and to whom)?

• What % predicted good outcome might (ethically) justify attempt to over-ride parental authority?

• What process is appropriate for over-riding parents?
More Questions

- If literature suggests similar infants have 75% likelihood of Developmental Quotient in range of 70-80→good enough?

- If individual neonatologist or nurse feels strongly that discontinuing life-support is “wrong,” what should she do?

- How should unit deal with individual clinician’s dissent from parents’ or colleagues’ decision?
Case II

- School-aged boy with metabolic disorder presented with diplopia, otherwise well
- Eye doctor referred to geneticist who involved stem cell transplanters
- Patient underwent “ideal” HSC tx from sibling
- Severe GVHD and Herpes encephalopathy, moaning
- Despite minimal consciousness, parents insisted on curative treatment and all supportive care
- Patient lingered in hospital for ~ 1 yr
Issues in Child’s Care

• ? Inconsistent messages to family
  - Can’t recover, but antibiotics for fever, blood products for low counts, etc.
• Family lived in hospital and abandoned sibling (donor)
• Parents periodically refused to talk with palliative care team when limits on intervention raised
• Team meetings and family conferences produced little substantive change
Challenges We Faced

- Anger at colleagues for perceived hypocrisy and inconsistency
- Anger at parents for undignified and perhaps painful prolongation of life
- Anger at parents for treatment of other son
- Sense of helplessness
Case II

- 9 mo old with epidermolysis bullosa (Herlitz type)
  - Similar patients die within 1-2 years (sepsis or airway obstruction)
- 1st encountered child after imprecise dermatologic diagnosis at another hospital
- Parents initially accepted prognosis and aggressive pain management, esp. for dressing changes
- Parents joined support group on-line and then in person, with mixed messages about outlook, especially with regard to HSC transplantation
Scream and Scream Again

• Dressing changes took 2-4 hours with both long acting narcotic and sublingual fentanyl
• Despite industrial dosing, child often cried through dressing changes
• Nevertheless, parents would periodically insist we prescribed too much narcotic and would reduce amount they administered
Painful Ambivalence

• Dermatologist offered and referred patient for gastrostomy
• Surgeon reluctantly agreed to operate
• Subsequently, child had escalating problems with breakdown at G-tube site
• Parents sometimes accepted inevitability of complications, at other times did not
• Some nurses unable to care for child because he seemed so miserable
Challenges We Faced

• Dedication to protecting baby from suffering
• Desire to support parents through their emotional roller coaster
• Inability to control (mis)information parents got about disease and interventions (social media, “support” groups)
• Parents periodically “fired” one or another of palliative care team for discussing resuscitation
Case: Is Enough Enough?

- 4 yr old girl with DIPG
- 6 months into course—dramatic decline in function, moaning as if in pain.
  - Parents ask: “Can’t we get this over-with?”
  - Different from use of barbiturates in ICU post-extubation for apparent struggles breathing?
  - Different from extubation while neuromuscular blockade still evident?
- What is palliative sedation, anyway?