Ethics of Decision Making in Pediatric Palliative Care

Jon Mullin MD
Washington University School of Medicine
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Learning Objectives

- Identify ethical dilemmas related to decision-making that occur in pediatric palliative care
- Construct frameworks for assessing parental decision making in pediatric care
- Describe ethical considerations for end-of-life practices in pediatric care

Case 1

- EM is a 3 yo girl with history of congenital CMV, severe global developmental delay, worsening seizure disorder, oropharyngeal dysphagia s/p G tube
- Has multiple admissions for recurrent feeding intolerance
- Evaluation includes normal imaging, trial of antacids, with no change
- GI specialist proposes upper endoscopy, trial of GJ feeds
- Mother declines proposed interventions, asks about options to feed for comfort or to discontinue fluids and nutrition

Ethical Principles

- Autonomy
- Beneficence
- Non-Maleficence
- Justice

Ethical Dilemmas

- Competing appeals to more than one principle:
  - Beneficence vs Justice
  - Autonomy vs Beneficence
  - Autonomy vs Non-Maleficence

Capacity

- Necessary component of true autonomy
- Adults may have fluctuating capacity
- Loss of capacity can be permanent or temporary
- Children, by definition, do not have capacity

Surrogate Decision Making

- For individuals that have lost capacity or who never had capacity
- Defined by tradition, or more often, via hierarchy of legal precedent
- How should surrogates make decisions?

Substituted Judgment

- Make the decision that the patient would have made if she was able
- Driven by advance directive
- Courts have allowed “meaningful conversation”
- Can lead to questions about whose values are being represented

Historical Consideration in Pediatrics

- Child as property of parent
- Parental preference irrelevant with lack of treatment options
- Shift to paternalism with advances in medicine
- Decision-making now takes into account family values and medical realities

Best Interest Standard

- "Parents possess what a child lacks in maturity, experience and the capacity for judgment required for making life's decisions"
- "Natural bonds of affection lead parents to act in the best interest of their children."
- "…Absent abuse or neglect"
- However, do we really hold parents to *best* interest?

Rational Parent Standard

- Requires parents to prioritize options for a child within a coherent and consistent value system
- Parents do not meet standard if:
  - Ignorance of medical facts
  - Evidence of neglect or abuse
  - Lack of awareness of family integrity or responsibility
- How to handle religion?
- Rationality often defined by end decision
- How to resolve value differences?

Harm Principle

- Recognizes parental authority is not absolute
- Decision places child at risk of avoidable harm, immediately
- Interfering with decision will prevent harm
- Prevented harm is greater than harm of intervening
- Intervention as least intrusive as possible
- Harm of intervening outweighed by harm prevented

Open Future

- Protects the child against having important life choices determined by others before she has the ability to make them for herself
- Restricts parents (and others)
  - Negative right
- Implores parents (and others)
  - Positive right
- Implies future capacity

Additional Approaches

- Zone of Parental Discretion
  - Tool based on harm principle
  - Allows for “suboptimal decisions” as long as not harmful
- Constrained Parental Autonomy
  - Parents responsible for child’s health even as children approach capacity
  - Decision-making not absolute
  - Constrained by respect for persons

Case 2

- DJ is a 16 yo boy with pelvic osteosarcoma
- Underwent surgery and chemotherapy, disease free for 18 months
- Presents with recurrence in pelvis, lungs, vertebrae
- Surgery not an option, no further chemotherapy

- Eligible for Phase I trial
  - Drug with efficacy in lung cancer, not osteosarcoma
  - Risk of bone marrow suppression
  - At a cancer center 2 hours away

Case 2

- Option for community-based palliative care with transition to hospice presented as option

- Parents express desire for DJ to pursue Phase I trial

- DJ does not want to undergo treatment

Informed Consent

- Based on principle of autonomy

- Capacity
- Disclosure
- Voluntariness

Assent

- A consideration

- Empowers opinion of child to the limit of their capacity

- May be overridden by parental

Child's Role in Decision Making

- 1) Made exclusively by child, minimal or no parental input
- 2) Child in central role
- 3) Made exclusively by parents, child "ratifies"

Decision Making for Critically Ill Children

- Amount of suffering, potential for relief
- Severity of disability and disease, potential restoration
- Expected prognosis and lifespan
- Potential for child to experience satisfaction/enjoyment
- Possibility of developing capacity or self-determination

Case 3

- BB is a 7 yo boy with recurrent metastatic medulloblastoma despite surgery, chemotherapy and radiation
- Discharged home with hospice
- At home has significant discomfort and agitation despite increasing doses of opioids and adjuvant analgesia

- Family calls, “please, he’s in so much pain, what can we do, we have to do something?”

Withholding vs Withdrawing

- Withholding and withdrawing are morally equivalent
- May feel different
- Often start with presumption of curative treatment or intervention

- Treatment not providing benefit should be stopped

Doctrine of Double Effect

- One action with two forseen outcomes
  - one good, one bad
- Action itself is not bad
- Intent of action is the good outcome
- The bad outcome is not the cause of the good outcome

- Examples: rapid titration of opioids at end-of-life

Requests for Hastening Death

- Not legal
- Request often due to concerns about suffering
- Response should be to understand rationale for request
- Alternatives include better symptom management, palliative sedation

Palliative Sedation

- Sedation to unconsciousness for refractory symptoms
- Used when death is imminent

- Cited as preferable alternative in US Supreme Court rulings on Physician Assisted Death

Case 4

- RF is a 6 week old baby girl, born at 23 weeks
- He has severe bronchopulmonary dysplasia
- Continued desaturations on maximal ventilatory and pressor support
- Family has expressed a desire to continue any therapy that would prolong her life

- Providers begin to wonder if interventions are futile

Futility

- Treatments unable to achieve intended goal
- Physiological
  - Impossibility to achieve mechanistic action
- Quantitative
  - Low probability to achieve goal
  - What number should be threshold?
- Qualitative
  - Does not advance goals
  - Open to subjectivity, value differences

Futility and Value Differences

- No clear, objective, definition of futility exists
- Allows for subjectivity to be presented as objectivity
- Often reflects value differences in providers, patients, surrogates

Moral Distress

- One knows the right thing to do but is constrained from doing so
- Most often from prolonged aggressive treatment that the professional believes is unlikely to have a positive outcome

Strategies for Challenging Situations

- Importance of communication
- Introspection into own biases and opinions
- Support from colleagues, third parties
- Understanding of how challenges or distress may represent ethical considerations or dilemmas
- Become familiar with established ethical frameworks, precedent