Resilience in the Face of Grief and Loss:
A Curriculum for Pediatric Learners

Part A: Section A.6
Ethics at the End of Life: Futility and Care
Learning Objectives

Describe the ethical principles involved in end of life decision-making (e.g., resuscitation and DNR orders) and discussion of goals of care:

a. Develop capacity to identify ethical issues that complicate end of life experiences for patients, families and providers.

b. Discuss a simple method to describe and analyze ethical issues.

c. Focus on issues of futility as a common and complex ethical concern.

d. Develop strategies to help families and providers discuss and manage futility in a way that will help reduce burden on families and avoid excessive moral distress for providers.
Case 1

- An 11 year old boy has a recurrent cranio-pharyngioma. He has received maximal radiation therapy and has gone through all the chemotherapeutic regimens currently available. His brain function has deteriorated; his GCS is less than 6 and he cannot communicate.

- His mother has asked for a review of further chemotherapeutic possibilities, including any experimental therapies.

- The primary medical and nursing teams have cared for this child through two recurrences of his brain tumor and are now anxious that further chemotherapy will be inhumane.

- The neurosurgery team has expressed a willingness to continue to try and place shunts to decompress his brain, although they do not see any reason to hope for improvement in his neurologic status.
Case 1 (continued)

- This child is the only child of 2 professional parents. He was the product of IVF and a complex pregnancy.
- His mother was usually present at the hospital during the first recurrence, she has been much less available during this second recurrence. The team is not sure why.
- The mother has expressed a desire to continue to try all available therapies and conveys a belief that her son will regain consciousness. She accepts that death is likely inevitable, but does not think it is near. She has refused to discuss palliative care or hospice care.
- The team has no knowledge of the child’s wishes.
- There is no DNR order in this child’s chart.
Case 1 (continued)

- What medical therapies should be offered?
- Can the primary team refuse to consider further chemotherapy?
- Should the neurosurgery team limit options?
- What should the child’s DNR status be and who should decide?
- Other issues?
- Other questions?
Clinical Ethics Review:
Moral Obligations in Medicine

- Respect Autonomy
- Promote Well-being / Beneficence
- Avoid Harm / Non-maleficence
- Promote Justice
- Others?
  - Virtue, ethics of care, communitarian ethics….
Moral Obligations: Related Questions

- Respect Autonomy
  - Whose autonomy?
  - How much autonomy?
  - Questions of capacity / competence
  - Limits of parental autonomy

- Avoid Harm
  - Whose definition of harm?
  - Balance between benefit and harm
  - Inhumane care?

- Promote Well-being
  - Whose definition of well being?
  - Medical vs patient/family
  - At what cost?

- Promote Justice
  - Justice as fairness?
  - Justice as a problem of resource allocation?
Clinical Ethics: Review

Moral challenges are created by competing obligations

- Moral Obligations in Medicine
  - Respect Autonomy
  - Promote Well-being
  - Beneficence
  - Avoid Harm
  - Non-maleficence
  - Promote Justice

- Some Competing Obligations
  - Autonomy vs. beneficence
  - Limits of parental autonomy
  - Beneficence vs. avoiding harm
  - Duties to parent vs. child?
  - Inhumane care?
  - Justice in allocation of resources vs. beneficence

*Ethics* is the process of identifying and clarifying the conflicts, then working systematically toward a justifiable resolution.
Ethics case discussion format

1. Why does this case bother you?
2. What are the moral obligations driving the case?
3. Are there conflicts between these obligations?
4. What are the facts?
5. Review conflicts in light of facts.
   *What sort of case is this? Have we seen similar cases before?*
6. What negotiation is possible, reasonable?
7. What do we as providers bring to the table?
   *What values, what goals, what worries?*
End of Life Issues: Case Analysis

- What bothers you about the case (be specific)?
- How do the moral obligations apply here?
- Does the concern arise from a problem of conflicting moral obligations?
  - Ex: duty to respect parental autonomy vs. duty to avoid the harms of futile care
  - Ex: duty to respect the wishes of a dying child vs. duty to respect parental authority
  - Ex: duty to protect the team from moral distress vs. duty to promote parental well being
Clarify Competing Obligations

- 4 topic method (Jonsen, Siegler, Winslade) organizes information needed to assess conflicts between moral obligations.
  - Medical indications
  - Patient preferences
  - Quality of life considerations
  - Contextual factors

- 2 general considerations:
  - Personal and professional values and anxieties affect interpretation of facts.
  - Understanding the family narrative is important.
# 4 Topic Method

<table>
<thead>
<tr>
<th><strong>Medical Indications</strong></th>
<th><strong>Patient Preferences</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the goals of treatment?</td>
<td>Does the patient have decision making capacity?</td>
</tr>
<tr>
<td>What is possible?</td>
<td>If not, who is the surrogate?</td>
</tr>
<tr>
<td>What is likely?</td>
<td>What are the wishes of the patient, the goals of care?</td>
</tr>
<tr>
<td>How well is prognosis known?</td>
<td>Can goals be realized?</td>
</tr>
<tr>
<td>Is there conflict between teams?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Quality of Life</strong></th>
<th><strong>Contextual Factors</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient/family perception is key; avoid medical overlay</td>
<td>Financial /Social/ Religious factors</td>
</tr>
<tr>
<td>Rationale to forego therapy?</td>
<td>Legal concerns</td>
</tr>
<tr>
<td>Palliative care possibilities?</td>
<td>Conflicts of interest</td>
</tr>
<tr>
<td></td>
<td>• Family issues</td>
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<td></td>
<td>• Medical team conflicts of interest?</td>
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One of the most common concerns at the end of life is a family demand for care that seems futile to the medical team.

Futility is a challenging concept and subject to widely varied interpretation.

From an ethics perspective....
Considering “Futility”

Futility = mismatch between therapeutic goals and the potential for success of available therapies.

Treatment that cannot achieve goals = futility
### 4 Topic Method: With Focus on Family

<table>
<thead>
<tr>
<th>Medical Indications</th>
<th>Patient Preferences</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is possible?</td>
<td>What are they?</td>
</tr>
<tr>
<td>What is likely?</td>
<td>How well are they understood?</td>
</tr>
<tr>
<td>Which goals, if any, are achievable?</td>
<td>Are the goals reasonable / valid?</td>
</tr>
<tr>
<td>What would futility look like?</td>
<td>Can any of the goals be realized?</td>
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<tr>
<td></td>
<td>Futility again</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Quality of Life Considerations</th>
<th>Contextual Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider the quality of life for the survivors – impact on futility.</td>
<td>Financial / Social/ Religious</td>
</tr>
<tr>
<td>Duty to avoid harm for survivors?</td>
<td>Legal</td>
</tr>
<tr>
<td></td>
<td>Conflicts of interest</td>
</tr>
<tr>
<td></td>
<td>Values of medical team</td>
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</table>
Futility (again)

Futility = mismatch between therapeutic goals and the potential for success of available therapies.

• Treatment cannot achieve goals.
• Hmmm. …. Like any good definition in moral philosophy, this one begs a few questions.
Futility Questions

Futility = mismatch between therapeutic goals and the potential for success of available therapies.

1. What counts as acceptable therapeutic goals?
   • Whose goals? Which goals?

2. What counts as adequate certainty that the treatment cannot achieve the goal?
   • Who has to be certain? How certain?
Futility Questions

1. What are the acceptable or valid goals of treatment?

2. Is the available treatment likely to succeed in meeting the valid goals?
Futility Question #1: Which therapeutic goals are “valid”?

Keep this child alive…

- indefinitely waiting for a miracle?
- if oncology is willing to devise another “last ditch” chemotherapeutic regimen?
- as long as neurosurgery is willing to keep replacing shunts?
- as long as necessary for the parents to feel that they have tried everything to save their child.
- as long as his suffering seems manageable?
Futility Questions #1: Which therapeutic goals are “valid”?

Examples from other recent cases:

- A 17 year old with AIDS, end stage renal disease and pneumonia suffered a stroke. Child has made it clear that she does not want to be intubated again; foster family requests PICU management of respiratory compromise until extent of damage from stroke is clear.

Whose therapeutic goals are most ethically relevant?
Futility #1: Valid Therapeutic Goals?
Example from another case

- Parents of a devastated newborn continue to insist that they want “everything done”. He has:
  - multi-system organ failure
  - head CT shows only a ring of cortex left after grade IV IVH damage
  - chronic lung disease and damage from multiple chest tubes is so devastating that the pulmonologists give him at most 1 yr, even without other medical conditions
  - has severe contractile heart problems still requiring dopamine
  - has never tolerated feeds; still on TPN
  - has had a bowel perforation, reanastomosis and now end-stage liver failure…
Futility Question #1: Valid goals of treatment

“Should a family who has completely unrealistic expectations for survival and recovery be allowed to make medical decisions?” (Pediatric resident)

- Patient/family-driven assessment is the primary consideration in defining goals of treatment.
- Like quality of life, goals often include a wide sense of well being.
- Understanding the goals is often tricky – for both families and doctors.
- There are limits, although hard to define.
Futility Question # 2
Is the available treatment likely to succeed in meeting those goals?

What do we mean by “likely to succeed?”

There are Quantitative and Qualitative measures:

Quantitative (medical) assessment is evidence based.

- “Useless” = <1%, 2%, 5%, 10% chance?
- No uniform definition of medical futility in the medical or ethics literature.
Futility Question #2
Likelihood of success: Qualitative assessment

Qualitative assessment is **values influenced**

1. Physiologic futility: no physiologic benefit
   - cannot restore respiratory or cardiac function

2. Benefit centered futility: treatment won’t benefit patient
   - low probability, low efficacy, poor quality of life

3. Operational futility: costs of treatment exceed measurable benefits
   - Utilitarian idea

4. Inhumane = treatment fails to respect patient as human
Futility in Pediatrics: 3 Scenarios

1. Parents request care that medical team considers futile.
2. Doctors order care that parents feel is futile or contrary to best interests of the child.
3. Doctors order care that other care providers consider futile.
Futility Scenario 1
Parents request “futile” care

○ What are the limits of our duty to respect parental autonomy?

○ Courts are reluctant to support unilateral futility-based decisions to withhold or withdraw care against parental wishes.
  ○ No consensus definition of futility from medical community
  ○ Hospital policies help define options

○ Physicians who withdraw care, even for virtuous reasons, usually do it against legal advice.
  ○ However, courts have tended to give forgiveness even when they would not have given permission.
Challenges

- Utility (real or perceived) does not change a physician’s moral duty to the patient and family.
  - Futile care is one end of the spectrum of treatment options.
  - Clarification of patient and family goals is crucial.

- Preventive Ethics:
  - Incorporate discussions of goals of treatment and identifiable futility early and often.
  - While treatment may be futile, care for the child and family is never futile.
Futility Scenario 2
Physicians order “futile” care

- Occurs when the patient or family choice is to forego care that will not meet their goals.

- It is equally rare that courts allow parents to refuse care that physicians deem necessary or potentially valuable.
  - Success does not have to be guaranteed.

  - Numbers game: how much likelihood tips the decision as to which care is futile?
    - No consensus
    - Value judgment
Futility Scenario 3
Clinician vs. Clinician

- Medical team includes range of interpretations of futility.
  - Attending
  - Consultant
  - Fellow
  - Resident
  - Nurse

- Making the decisions and implementing decisions may be equally difficult roles.

- Impact of professional experience on determinations of futility.

- Value of open discussion of issues / moral distress.
Futile care

- Definitions of futility are necessarily vague
- Necessarily values based?
  - Clear guidelines
  - Vague guidelines
  - No guidelines
- In tertiary care, high tech medicine, “futility” becomes part of the envelope we push
  - Impact of teaching / research on clinical care
Preventive Ethics: Managing Futility

Family perspective
- Clarify goals of care
- Identify impact of care

Team understanding
- Evidence and experience
- Institutional and personal values
- Level of evidence

Consensus within team
- Are the boundaries between clinical care and research always clear?
- Manage disagreement so that family isn’t confused
Preventive Ethics: Managing Futility
(continued)

Medical Indications
What is possible?
What is likely?
What would *futility* look like?

Patient Preferences
What are they?
Can any of the goals be realized?

Quality of Life Considerations
Consider survivors

Contextual Factors
Financial/Legal
Social/Religious
Culture
Managing Futility

1. Physicians are not obligated to provide care they believe is futile or harmful.
   - DNR is a medical decision; a doctor’s order

2. However, the “just say no” approach is almost guaranteed to fail.
   - Careful, open minded and sincere communication is necessary

3. Ethics consultation may be valuable.
   - Neutral party, aid in communication, expertise in identifying wishes, clarifying goals
   - Education for family and team
Managing Futility

**Key Point: Care is never futile.**

- Treatments or specific interventions may be futile.
- Patients may associate withholding or withdrawal with abandonment.
- Parents deserve care and concern to help them manage grief.