When is Doing More Too Much?  
The Ethics of Modern Medicine

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Disclosure Statement:

I have nothing to disclose.
Pediatric Resident Grand Rounds

Disclaimer:

This is an ethics talk.

PARTICIPATE!!
Pediatric Resident Grand Rounds

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PARTICIPATE!! (please)
Objectives

- Foster communication amongst all levels of training about this difficult topic
- Understand physiologic vs qualitative futility
- Discern among coma, brain death, persistent vegetative state, and minimally conscious state
- Elucidate the AAP’s stance on these points
- Learn about Institutional Ethics Committees
What is Life?
Life (līf) noun:

1. the condition that distinguishes animals and plants from inorganic matter, including the capacity for growth, reproduction, functional activity, and continual change preceding death.

2. the existence of an individual human being or animal.

3. the period between the birth and death of a living thing, especially a human being.
What is Living?
What care is futile?

- Physiologic vs qualitative futility
Physiologic Futility

- Intervention would not achieve its intended immediate physiologic effect

- Examples:
  - Giving antibiotics for a viral illness
  - Starting CPR on a patient who has been pulseless for 2 hours
Qualitative Futility

- Weighing the potential benefit of an intervention with the quality of its effects
- Requires a value judgment about the results of the treatment plan
  - Whose values do you use?
  - What happens if the physician’s values differ from the parent’s?
Case 1
Case 1

- Ex-40 WGA F born with a prenatal diagnosis of semilobar holoprosencephaly
- Also diagnosed with DI and adrenal insufficiency
- Discharged from the NICU on DOL 19 on room air and ad lib PO feeds but notably decreased tone
Holoprosencephaly

- Developmental defect of the embryonic forebrain from incomplete development of the CNS structures

- Spectrum of presentation:
  - Lobar
  - Semilobar
  - Alobar
Holoprosencephaly

- **Prognosis:**
  - Alobar is incompatible with life.
  - Lobar is considered a mild form with a varied prognosis.
  - Semilobar is intermediate form.
    - About 50% of patients with semilobar or lobar are still alive after 12 months.
    - Most patients will still require ongoing, extensive medical care.
Case 1

- Represented at 6mo with failure to thrive and apneic spells with cyanosis and was quickly intubated
- Initially DNR but family recanted
- Failed numerous extubation attempts
- Pt eventually self-extubated and remained on room air
- Family declared her full code but no desire for trach
Case 1

- Reintubated for apnea a few days later.
- Parents again refuse DNR and request a trach
Case 1

- Who should decide on the treatment plan?
- What are the best interests of this patient?
- What are the rights of this patient?
- What are the rights of the parents?
- What would you do?
Principles of Medical Ethics

1. **Autonomy**
   - Patient/parent has the right to his/her own thought, intention, and action when making decisions regarding health care.

2. **Justice**
   - The right that scarce resources, competing needs, rights and obligations, and potential conflicts with established legislation be spread equally amongst all levels of society.

3. **Beneficence**
   - Healthcare should be provided with the intent of doing good for the patient involved.

4. **Non-maleficence**
   - Healthcare should not harm the patient involved or others in society.
Parents’ Rights

- **Right to Autonomy (Parental authority)**
  - Broad but not unlimited right to make decision on their child’s behalf

- **Right to refuse unwanted therapy**
  - Not the right to demand any therapy

- **Not absolute**
  - “Parents are free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.” - *Prince vs Massachusetts* (1944)
What is a child’s best interest?

- To live as long as possible, regardless of prognosis?
- Does quality of life matter?

- Similar to qualitative futility
- It is the patient’s best interest
  - Not the family!
  - Not the medical team!
  - Not society!
Patient’s Rights

“All children are entitled to effective medical treatment that is likely to prevent serious harm, or suffering, or death.” - AAP Committee on Bioethics

- Right to life
  - Includes a right to treatment that has a reasonable chance of resulting in a significant extension of life

- Right to mercy

- Right to justice (fair and equal medical care)

- Right to be informed
LW

- She received her trach and was discharged home one month later.

- Recently seen in clinic:
  “The trach is really helping her a lot. She is developmentally delayed, but she is a pretty engaging little girl, and I get the sense that she is doing a lot more than expected of her from her physicians at Children’s and in the NICU.”
Case 2
Case 2

- Ex-36WGA M diagnosed with open lip bilateral schizencephaly
- Discharged from the NICU on room air on DOL 31 s/p G tube/Nissen
- Initial neuro exam wnl
- VPS placed at 3mo
- Globally delayed but interactive at 6mo
- At 3yo smiles, rolls over, says 4 words
Schizencephaly

- Rare cortical malformation of clefts of grey matter extend from the ventricles to the pia mater
- Open or closed lip
- Unilateral or bilateral
- Spectrum of disease
  - Most patients will have seizures and hypotonia
Schizencephaly
Case 2

- At 3yo, began progression to respiratory failure
  - Began requiring BiPAP
    - Overall prognosis poor
  - Trach required for further management of care

- What would you do?
Case 2

- Family offered DNR vs hospice vs trach
  - Decided on full code but no trach
  - Home on BiPAP

- Suffered brain herniation shortly afterward
  - Improved with VPS revision but with worsened neuro status
  - Family no longer able to care for pt
  - No facilities available without trach

- What do you do?
Futility and Depressed Mental Status

- There is a spectrum of mental status
  - “coma”
  - Minimally Conscious State
  - Persistent Vegetative State
  - Brain Death

- Besides brain death, these diagnoses do not specify that further treatment is physiologically futile.
Coma

- A state of deep, unarousable, sustained pathologic unconsciousness with the eyes closed which results from dysfunction of the ascending reticular activating system either in the brain stem or both cerebral hemispheres

- Must last for more than 1 hour

- Lack both wakefulness and awareness
Brain Death

- Irreversible cessation of all functions of the brain, including the brainstem
  - Cessation means absent cerebral and brainstem functions
  - Irreversible when
    - Cause of coma is established and sufficient to account for loss of brain function
    - No possibility of recovery of any brain function
    - Cessation persists for an appropriate period

- There must be no confounding variables
  - Intoxicating drugs or metabolic disturbances
  - Hypothermia
Persistent Vegetative State

- Complete unawareness of the self and the environment accompanied by sleep-wake cycles with either complete or partial preservation of hypothalamic and brain stem autonomic functions

- Must be in this state for 3-12 months

- Poor prognosis
  - 50% die within 1 year
  - 25% of patients will live >3 years

- Unlikely to be transient
Persistent Vegetative State

- Intermittent wakefulness manifested by sleep-wake cycles
- Sufficiently preserved hypothalamic and brain stem autonomic functions to survive if given medical care
- Bowel and bladder incontinence
- Variably preserved cranial nerve and spinal reflexes
Persistent Vegetative State

- No evidence of awareness of themselves or their environment
- No interaction with others
- No evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli
- No language comprehension or expression
Minimally Conscious State

- Severely altered consciousness in which minimal but definite behavioral self or environmental awareness is demonstrated

- May be transient or permanent
  - More likely to improve than patients in PVS
Minimally Conscious State

- Simple command following
- Gesture or verbal “yes” or “no” responses (regardless of accuracy)
- Intelligible verbalization
- Purposeful behavior in relation to environmental stimuli and not due to a reflex activity.
  - Appropriate smiling/crying to cues
  - Vocalizing/gesturing in response to questions
  - Reaching for objects
  - Pursuit eye movement or salient sustained fixation
PVS and MCS

- Not considered physiologically futile states
- Require judgment/value decisions by caretakers
  - However, the AAP admits that this may increase morbidity in patients.
  - Very contentious point, especially in PVS
    - Could be another source of transplantable organs
    - Unfair allocation of resources
    - Concern for dignity of patient
Case 2

- Likely falls between PVS and MCS
- Remained a full code
- Received trach for placement in long term nursing facility
Case 3
Case 3

- 14yo Ex-32WGA F with short gut syndrome with ileostomy and resultant TPN dependence
- Also Dx’d with CP, developmental delay
- Prolonged hospital course secondary to feeding intolerance with increased ostomy output
- Long-term TPN dependence
Case 3

- Chronic access issues
  - Multiple central line infections
  - Eventual lack of access points

- Guardian requests that she remains in the hospital for safeguarding of her last remaining IV site to prolong her life.

- Made DNR.
Case 3

**Pros**
- Prolong access/life
- Family is comfortable
- Pt is happy with quality of life in hospital

**Cons**
- No other active medical issues needing inpatient care
- Not a long-term care facility
- Futile care?
- Waste of hospital resources?

*What would you do?*
Resource Allocation

- The AAP rejects formulaic principles to decide who should receive care and who should not in those with similar diagnoses.

- Monetary values of treatment/ability to pay should not be used in a case-by-case basis.

- Do not confuse cost-effectiveness with futility
Resource Allocation

“The AAP thinks that judgments about which diagnostic categories of patients should be received or be denied intensive care based on considerations of resource use are social policy deliberations and should be made after considerable public discussion, not ad hoc at the bedside”
Case 3

- Pt was allowed to remain in the hospital receiving TPN until her CVL finally came out, 6mo after she was made DNR.

- She was discharged home and returned for end-of-life comfort care 2 months later.
Institutional Ethics Committees

- Mechanism to handle ethically challenging issues in a hospital or health care institution
- Started in the 1960’s
- Suggested by the court system in the 1970’s
- Required by Baby Doe regulations in the 1980’s
- Became a Joint Commission accreditation requirement in the 1990’s
Institutional Ethics Committees

- Serves to
  - Review and develop institutional policies
  - Educate staff
  - Provide consultations and case reviews

- Made up of at least physicians, nurses, and social workers
  - +/- chaplains, administrators, legal counsel
  - +/- people unaffiliated with the hospital
Institutional Ethics Committees

- Consult to:
  - Facilitate discussion among different/differing parties
  - Elucidate and clarify values-based concerns
  - Mediate disputes to dissolve or resolve conflicts
  - Analyze ethical concerns

- Consult by
  - Single consultant
  - Small team consultant
  - Full committee consult

- No decision-making authority
Institutional Ethics Committees

- CHNOLA committee
  - Includes physicians, nursing, SW, chaplain, and child life
  - Offer all three consult styles

- All cases discussed involved the ethics committee to reach the decisions made.
Right to Compassion

- Patients, parents and families should be respected.
- Always remember to recognize families’ hardships, especially regarding making these difficult decisions.
- Open communication is always the best way for everyone to make the best decision for the patient together.
Thanks to Dr. Duhon and my fellow residents!

Thanks to all the patients and their families who have taught me so much through their experiences.
Resources:


7. UpToDate