The Withdrawal of Artificial Nutrition and Hydration in Children: Why Feeding (Still) Matters

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The Case

A 7 year old healthy female was left unattended near the family swimming pool, while the mother ran inside to take a phone call. The mother returned to find the girl floating face-down in the pool. The child was started on CPR, and resuscitation continued for more than 30 minutes as the child was life-flighted to the children’s hospital. Examination in the PICU showed a neurologically devastated child, on a ventilator, but one with brain-stem activity.

After 10 days, the child came off the ventilator and could spontaneously draw breath, but was still neurologically without improvement. A nurse coordinator described what occurred next:

“This child was a near drowning; neurologically devastated, self-extubated and the parents would have to make the decision about G tube feedings and long term care. Over 10 days, they had hoped that she would recover but she was anoxic for too long. She was having decorticate positioning and thalamic storming. She may have died anyway, but the family withdrew IVF and nutrition and she died peacefully 4 days later with parents present. There were several care conferences with a variety of attendings involved as well as all palliative care team members. The time period really did matter to this family, they were in so much pain and they wanted their daughter to die peacefully.”
“Never deny, seldom affirm, always distinguish.”

BASIC DEFINITIONS
Killing vs Letting Die: Is there a difference?

- **NO:**
  - Outcome (death of the person) is the same
  - Allows the hastening of death (euthanasia)
  - Pain control (narcotics) which decrease respirations is really just euthanasia

- **YES:**
  - Intent is different and agent is different (killing involves a person as the proximate cause of death; letting die involves the disease)
  - Euthanasia is impermissible
  - Principle of the Double Effect
The Principle of the Double Effect

- Originated in medieval/natural law philosophical thought

- Principles essentially upheld by US Supreme Court (1997)

- An act with 2 consequences—one good and one bad, may be permitted if:
  - The act itself is not intrinsically evil
  - The good consequence is foreseen and intended; the bad consequences is foreseen but unintended
  - The good effect cannot be brought about by means of the bad effect (e.g., actively killing a patient to relieve their pain)
  - The good and bad effect must be proportionate
Extraordinary vs Ordinary Means

- Roots in Roman Catholic moral philosophy—secularized in the 20th century (e.g., AMA Code of Ethics)

- Some prolongation of life may be an affront to human dignity

- Extraordinary means need not be employed:
  - Ineffective treatment/unlikely to be effective
  - Insufficient economic resources
  - Heroic sacrifices needed by family
  - Not readily available

- Ordinary means of treatment must be provided:
  - Scientifically established benefit
  - Statistically successful
  - Reasonably available
  - Includes food and water
Brief History of Landmark Cases in Pediatric End of Life

- **1963 Johns Hopkins**: Child with Down syndrome and duodenal atresia left untreated

- **1974 Maine Medical Center vs. Houle**: Profoundly compromised newborn suffering from multiple maladies whose family and physician decided to forgo treatment

- **1976 Baby Andrew**: Baby born with less than 5% chance of survival - Parents wanted to forgo treatment

- **1982 Bloomington "Baby Doe"**: Parents upon obstetrician recommendation decided to forgo surgical intervention on newborn with Down syndrome, tracheoesophageal fistula, and esophageal atresia
<table>
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<tr>
<th>What They Were</th>
<th>Criticisms</th>
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<td>• Amendments to the Child Abuse Prevention and Treatment Act (CAPTA)</td>
<td>• “Hotlines” initially set up for enforcement were abused, unreasonable</td>
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<td>• Child protective services which receive federal funding must have procedures to ensure medical neglect does not take place with disabled newborns</td>
<td>• Led to overtreatment, even in futile cases</td>
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<td>• Meant to add a layer of protection for vulnerable newborns</td>
<td>• Constrained parents and physicians from “exercising reasonable judgments about whether to forgo life-sustaining treatment”</td>
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<td>• Quality of life is not a valid reason to not forgo treatment</td>
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<td>• Do not mandate unnecessary treatment</td>
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The “Baby Doe” Regulations (1984)
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- Can forgo all treatment other than “appropriate nutrition, hydration, and medication” if: (1) irreversibly comatose; (2) treatment prolongs dying; (3) treatment would be “virtually futile” and “inhumane”

- The AAP (and others) “get around” this by defining what is “appropriate”
Underlying Issues in End of Life Care

- Who decides, and how?
  - Parents? Physicians? (Patients?)
  - A Hierarchy of Decision-making:
    - “Competent” person (technically none in pediatrics—so we strive for assent/informed permission)
    - Substituted judgment—how one would decide if they could (written, verbal)
    - Best-interest standard

- How much treatment for fatal disorders?
  - Over-treating vs. under-treating
  - Withholding vs. withdrawing care
  - Use of “exotic” technologies vs. limited resources
Early AAP Policy Statements

- Guidelines on Forgoing Life-Sustaining Medical Treatment (1996)
  - Treatment decisions should be based on judgment of whether infant will derive net benefit
  - Treatment that offers no benefit or is futile is inappropriate

- The Initiation or Withdrawal of Treatment for High Risk Newborns (1995)
  - Establishes rights of parents in decision making
  - Does not require physicians to over or under treat
  - Physicians should make parents as aware as possible to the condition and prognosis of the infant

  - Clarifications of aspects of two above statements
Shortfalls of Past Policy Statements

• Do not explicitly discuss suffering of the patient

• Do not provide confidence that the initiation or withdrawal of any life sustaining medical treatment will not cause suffering

• Included in policy statements was attempted resuscitation, ventilators, critical care medications, and artificial hydration and nutrition (ANH)—without discussing their differences/nuances
New Ethical Standards from our “Leaders”
Forgoing Medically Provided Nutrition and Hydration in Children
Douglas S. Diekema, Jeffrey R. Botkin and Committee on Bioethics

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AAP Statement (2009)-Summary

- Reaffirms best interest principle, surrogate decision makers and right of competent individuals to refuse treatment
- Distinction made between those capable of oral intake vs. those who depend on it through medical devices
- Dehydration as a cause of death does not entail (much) suffering
- In certain circumstances, ANH may be futile and should be avoided
- Pediatricians and other health care providers should not be required to participate in treatment plans to which they have objections
“Starvation,” “Dehydration,” and Dying

- Adult literature says starvation and dehydration are not bad ways to die

- Movement arose from Karen Ann Quinlan (1976), Nancy Cruzan (1990) cases and physician-assisted suicide debate
  - Seen as acceptable way to die that didn't require the intrusion of the physician

- Starvation or dehydration is postulated to be analgesic
  - Mostly anecdotal evidence, case reports
  - Increase in ketone bodies and endorphins postulated to be analgesic
  - Scant data on frequency of such decisions or how acceptable they are to patients, families, physicians or nurses involved in care.
  - (For the unconscious patient, does analgesia provide benefit?)
AAP Statement (2009)

The Context

- NOT binding, but guiding
- Withdrawal of ANH is controversial because of the “strong emotional and social symbolism associated with feeding.”
- Does not deal with po feeds—ANH is not the same as eating a meal

Counterarguments

- Position papers often become “binding”
- “emotional and social symbolism” of feeding is not the only reason it is controversial—nutrition sustains life
- Emotional and social symbolism is still important
- No claim that ANH=meal
“suffering rarely present” when ANH withdrawn
“When medically provided fluids and nutrition are withheld, death does not occur from starvation but as a result of dehydration and the patient’s underlying condition.” (814)

Questions:
? Is “rarely” good enough?
? Is dying of “dehydration” worse than dying of “starvation?”
? The patient dies of the underlying condition only because the condition is what necessitates the dependency on another for nutrition
Why Not This Child?

- He is completely dependent on another for feeding.
- Suppose the person with the spoon is a nurse at a home for the profoundly disabled—is this “medically provided nutrition?”
- Does the degree of technical expertise somehow change the moral equation? Or is this about cost?
- Suppose we sedate him and withhold feeds—he dies of dehydration and his underlying condition, right? (para/quadriplegia, limited cognition)

“When medically provided fluids and nutrition are withheld, death does not occur from starvation but as a result of dehydration and the patient’s underlying condition.”
AAP Statement (2009)

Examples are given of situations in which withdrawal of ANH is warranted:

- Severe CNS injuries
- PVS
- Congenital CNS injury with no capacity for po feeds
- Any child where burdens outweigh benefits (e.g., terminal)
- Severe GI disease
- Conditions “incompatible with long-term survival and for which significant burden is associated with continued existence.”
AAP Statement

- Withdrawal of ANH justified if “risks and burdens” of ANH outweigh a minimal benefit (816).

The Counterarguments

- “Risks” of ANH seem irrelevant if the intent is to hasten death
- “Burden” is key—Is the intervention the burden, or existence the burden?
- “Benefit” is life, which is what all other qualities of life depend on
- Has the pendulum swung from “biological life as everything” (vitalism) to “biological life as (next to) nothing?”
AAP Statement

- “Disability alone is not a sufficient reason to forgo medically provided fluids and hydration.” (818)

Other Major Questions: The Disabled Child

The Counterargument

- Depends on how you define it:
  - a disability (dependency) is a necessary condition of ANH
  - Every example and major case has involved a child with a disability
  - Normal infants cannot feed themselves either
  - Disability seems to play a prominent or even dominant role in decisions about “burdens”—is this a decision about the burden of an intervention, or the burden of a life? (Donovan, GK, 2009)
Other Major Questions

- **Decision-making:** How do we use the “best interest” standard?
  - ? What most would do?
  - ? What we think should be done?
  - ? Are there cultural, ethnic, religious variations?

- **Consciousness:** Does consciousness of dehydration make a difference? Can one suffer when one is not conscious?

- **Timeframe:** Do the AAP arguments apply in temporary states of dependency?

- **Slippery slope:**
  - ? Are those born dependent automatically more vulnerable?
  - ? Why not euthanasia?
**AAP Statement (2009)**

- “Because of the value-laden nature of the decision to withdraw fluids and nutrition, this option should only be pursued with the full knowledge and support of a child’s parents or legal guardian.” (818)

**The Counterarguments**

- Why? If continuing ANH has risks, and is unwarranted medical treatment, why not override the parents’ wishes (i.e., mandate withdrawal if criteria are met?)
- AAP Statement argues physicians may refuse to participate in ANH, but **must refer** to a caregiver who would continue it
Aspects of Policy Not in Question

- ANH should provide net benefit

- Shared decision making between parents, physicians and patient (if possible)

- No moral/ethical difference between stopping medical interventions and not starting them

- Physicians are not morally or legally obligated to provide or withdraw care if not deemed medically appropriate
Christian Perspectives

Catholic Ethical & Religious Directives

- 58. In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.”

Center for Bioethics & Human Dignity (Trinity University)

- The American Medical Association, the American Academy of Neurology, health insurers, and most Christian ethicists agree that the provision of AN&H is a medical intervention and not simply a part of ordinary, routine care for patients...
- Godly people may end up on different sides of the complex decisions regarding AN&H...We should carefully seek God's will in making the decisions that will confront us, be loving, prayerful and supportive of our friends and fellow believers who struggle with these choices, and realize that for the Christian, ultimate reality is eternal life with God.
Back to The Case... Some Lessons Learned...

“This child was a near drowning; neurologically devastated, self-extubated and the parents would have to make the decision about G tube feedings and long term care. Over 10 days, they had hoped that she would recover but she was anoxic for too long. She was having decorticate positioning and thalamic storming. She may have died anyway, but the family withdrew IVF and nutrition and she died peacefully 4 days later with parents present. There were several care conferences with a variety of attendings involved as well as all palliative care team members. The time period really did matter to this family, they were in so much pain and they wanted their daughter to die peacefully.”

- I sought to develop a policy guideline for ANH withdrawal that would require, under certain conditions, additional scrutiny under the auspices of the ethics committee.
A. Withdrawal of MPNH may only be considered in those children who are imminently dying of another cause. (The clinical team should ask, “What is the likely cause of death of this patient?”)

B. The withdrawal of MPNH with the intent (as opposed to the foresight) to cause or accelerate the death of a child is akin to euthanasia and is never permissible.

C. The provision of MPNH is not obligatory if Policy Points A and B above are met, AND:
   1. MPNH brings no comfort to the imminently dying patient; or
   2. MPNH is not assimilated by the dying patient’s body; or
   3. The burdens of MPNH to the patient (as distinct from the family, caregivers, or society) outweigh the benefits
I floated my proposal to a national listserve of clinical ethics consultants…and…

All Hell Breaks Loose!!
Some select responses…

- “Protecting patient rights is a potential but different goal of [an] ethics committee. It may create an adversarial relationship between the committee and health care providers.”

- “Ethics committee members should never provide a ‘barrier of protection’ between children and their parents, nor between children and their physicians. Clinical ethics consultants should be available to assist those who care most for children make decisions.”

- “I think the original email (and I thought this as soon as I read it) was a well meaning but potentially disastrous idea. It sounds like an attempt to use ethics to fight for a personal agenda, or perhaps a Roman Catholic agenda. The use of the emotionally loaded term ‘starvation’ was a dead giveaway…if ethics is allowed to cause such mischief, it would be the death of the field.”

- “was this a Catholic hospital? [If so] Ouch!”
Summary Questions

- What is the cause of death in ANH withdrawal?
- Whose Suffering?
- What are legitimate exceptions?
- What is the motive for withdrawal? (what is the difference between this & PAS?)
- Is dependency the key factor?
- What do you do if you disagree with a decision to withdraw ANH?
“Nothing is so strong as gentleness, nothing so gentle as real strength.”

Saint Francis de Sales
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