

The Good, The Bad, The Ugly: End-of-Life Withholding of Food & Water in Pediatrics

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Changing Roman Catholic Perspective

- For centuries RC 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”

Catholic Perspective II

- In late 1980s conservative bishops began arguing that discontinuing fluids and nutrition introduced new cause of death: dehydration and starvation in PVS
- In 2004 John Paul II issued allocution on feeding tubes:
 - Always natural [sic] means of preserving life
 - If removed knowingly and willingly equates to “euthanasia by omission.”

Definitive (?) Current Statement

- August 2007 Congregation for the Doctrine of the Faith on “Certain Questions”
- Q: Is administration of food and water to pt 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 n/h be discontinued in PVS when competent doctors judge pt cannot recover?
- A: “No.” Such a person’s fundamental dignity requires administration of food and water

Catholic Position

- Some “liberal” Catholic thinkers have attempted to spin JP II’s and CDF statements as leaving room for choice
- Hard to see how Vatican can intend anything other than message: do not remove artificial fluids/nutrition even in permanent unconsciousness

Case I Pertinent Background

- Successful couple run high-profile retail business
- Married 10 years, both now 40 years old
- Having a child important to them
- Had nine IVF cycles
- Usual prenatal testing (including amniocentesis and ultrasound) negative

Index Patient

- Labor at 36 weeks
- Child delivered without major problems
- Fever in nursery
- Septic work-up, presumed Group B *strep* infection treated two weeks
- Murmur noted
 - Cardiac echo: multiple VSDs and ASDs
- Poor feeding, poor tone –chromosomes sent

Outpatient Course

- Infant followed weekly by primary care pediatrician and cardiologist
- Started on digoxin and furosemide
- Minimal weight gain
- Admitted at 3 months of age to manage congestive failure and improve nutrition

Inpatient Stay

- Poor tone and poor feeding again noted
- Unclear if infant could see or hear
- Genetics consultation:
 - Results of prior karyotype reviewed for first time
 - Deletion of region 1P26 noted
 - Parents told of genetic abnormality by geneticist

Initial Parental Reaction

- Distress and anger that genetic diagnosis not made during pregnancy
- Parents also angry no one had followed-up on genetic test sent from nursery
- Parents immediately did independent research to understand implication of deletion

Genetic Condition

- Reported cases:
 - Moderate to severe cognitive impairment
 - Poor feeding, poor weight gain in infancy
 - Moderate to severe behavioral problems
 - 75% + have seizures, may be difficult to control
- May be huge spectrum in phenotype including many normal, undiagnosed individuals

Further Parental Reaction

- With knowledge of reported cases, parental shock and anger grew
- Parents declared infant would be better off dead—requested palliative care consult and consideration of stopping oral and tube provision of fluids and nutrition
- Parent: 'Don't you think it would be better if we took her to Holland for euthanasia?'
- Parents lashed out at staff, including nurses, residents, some consultants
- Cardiologists requested psychiatric consultation with parents re: parental behavior

Another Case

- 3 year old with severe traumatic brain injury (MVA) in which her sister and parents killed
- Spent 3 months a trauma center in coma
- Grandparents and doctors agreed that she would not recover and best to stop artificial nutrition and hydration
- Sent out of state for that purpose for legal reasons

Trauma Case II

- On exam at receiving hospital neurologic exam better than expected
- New imaging and exams suggested emerging recovery
- Began rehab in acute care hospital then transferred to peds rehab facility
- 2 years later performing normally except for some one-sided mild leg weakness

Conclusions

- Catholic Church's objections to stopping artificial fluids and nutrition may affect 20-25% of patient and provider populations
- Grief of one sort or another may prompt requests to stop AFN before:
 - Enough time has elapsed for emotional processing
 - Enough time and information has accrued for accurate prognostication
- Great care and caution needed