Ethical Considerations in the Decision to Withhold or Withdraw Dialysis in Pediatric Patients

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Problems in PICU

- Common to agree that “sometimes I feel we are saving children who should not be saved” (80% of critical care attending, 78% of house officers, 69% of c.c. nurses)

- Common to agree that “sometimes I feel treatments I offer children are overly burdensome” (56% of critical care attendings, 63% of house officers)

- Rarer to agree “sometimes I feel we give up on children too soon” (range from 2-8%)

- Most attendings, house staff, nurses believe they are knowledgeable about basic consensus principles (79-98%)
- Many are in fact ignorant of basic principles
Key Principles

- No moral difference between withdrawing and withholding treatment
- Medically provided hydration and nutrition constitute medical measures that can be refused
- Appropriate always to provide adequate pain relief, even if it may hasten death
- Older children who have capacity should be treated as autonomous agents, capable of making their own health care decisions
- Primary role for parents in decision making
- Wide range of cases for which it will be reasonable to withdraw or withhold treatment
New consensus emerging

- No obligation to provide treatment that is ineffective or inappropriate
- No consensus about what that means
Withdrawal vs withholding tx

- Pts right to refuse tx extends to continuation of aggressive interventions
- Pts have right to pursue medical goals appropriate to them--e.g. comfort rather than cure
- Moral equivalence allows us to try something or to wait rather than all or nothing decision
- Consensus: No moral distinction between withholding and withdrawing tx
Hydration and Nutrition

- Medically provided nutrition through G tube or TPN constitute medical interventions
- Caution--the symbolic value of “feeding” those who are dependent is significant
- Language problem-- “feeding tube” misleading
Doctrine of Double Effect

- Distinguish between intending to terminate life and
- Intending to relieve pain, even if there death is a possible (and foreseeable) consequence
- Surgery analogy
- Always appropriate to relieve suffering
Decision making for older children

- No bright line at 18
- Growing recognition that most 14 year olds capable of acting as autonomous agents
- Outcomes often better if child involved and informed
- Not always recognized legally
Decision making

- Importance of “shared decision making” is widely cited
- Parents normally given control
  - Presumed to have child’s best interest
  - Know child best
  - Important to fulfill parental responsibilities
  - Social interest in promoting family as institution rather than state
  - Best interest is a value laden concept
Constraints on parental authority

- Benefit sufficiently clear that unreasonable to deny treatment (e.g., Baby Doe)
- Futility

- Broad range where it could be reasonable to either continue or discontinue treatment (e.g., Messenger)
  - Benefits vs. burdens of tx and illness
  - Prognosis and uncertainty
  - Value laden decision
Futility

- Wanglie
- Baby K
- Baby Sun
Wanglie (1990)

85 yo f in PVS (severe anoxic encephalopathy)

Nurses, physicians felt continued care “non-beneficial”

Husband given chance to find alternative hospital and failed

Pt died before legal situation resolved
1992--anencephaly

Baby K ventilated at birth, then weaned, gastric tube, SNF

Periodic episodes of respiratory distress required hospitalization and intubation

Hospital sought end to treatment

Courts refused due to EMTALA (Emergency Medical Treatment and Active Labor Act) and ADA--found that treatment for respiratory disease not futile
Baby Sun

- Baby Sun--genetic dwarfism--lungs too small to support life--ventilator dependent, terminal diagnosis
- Texas law allows discontinuation if HEC concurs as long as family allowed 10 days to transfer (initially law for adults, applied to peds in 2003)
- Pt at 5 months--hospital invoked futility
- No other hospital in state would take pt
- Withdrew against wishes of mother and pt expired
Meaning of Futility

- Physiologic (neither Baby K nor Baby Sun)
- Imminent death (neither Baby K nor Baby Sun)
- Lethal condition (both Baby K and Baby Sun)
- Burdens outweigh benefits
- Quantitative--less than 1% chance of success
- Qualitative concept (both Baby K and Baby Sun)--preserves permanent unconsciousness or maintains dependence on intensive medical care
Key questions

- What level of probability is virtually no prospect?
- Who defines what counts as significant medical benefit?
  - Pts or parents (Lantos)
  - Medicine (Schneiderman, Jecker, Jonsen)
Key questions to ask

- What is prognosis?
  - Probability of outcomes
  - Nature of outcomes
- What is the evidence base for that?
  - Experience of team and others
  - Published studies
- What quality of life will pt have?
- What are the parents wishes? What are they hoping for? Why do they want to continue?
- What does professional integrity dictate?
- What process is in place for determining what is appropriate?
Additional Requirements

- Pts or surrogates right to information that futility is invoked
- Time limited right to attempt to find an alternative institution
- Obligation to provide continued care to facilitate transfer
Values

- Respect for Autonomy
- Beneficence--obligation to help patients
- Non-maleficence--obligation to do no harm
- Justice--obligation to act fairly, obligation to treat similar cases in a similar fashion
- Stewardship--obligation to make appropriate uses of scarce resources
Values

- Family autonomy--obligated to respect parental authority
- Veracity--obligation to tell the truth
- Fidelity--obligation to maintain trust with family and not to abandon them
- Professional integrity--respect the norms of the profession
- Quality of life--life is not an unqualified good
Values

- Consequentialism--maximize the total good
- Deontological theory--focus on obligations and rights
Values

- Principlism
  - Respect for autonomy
  - Beneficence
  - Non-maleficence
  - Justice
- “Family autonomy”
- Stewardship
- Veracity
- Fidelity
- Professional integrity
- Quality of Life
- Consequentialist values
- Deontological values
Dual aspect of dialysis

- Medical treatment
- Bridge to transplant
- May lead to very different ways of looking at values, e.g. stewardship
Slides available at:

http://scbe.stanford.edu