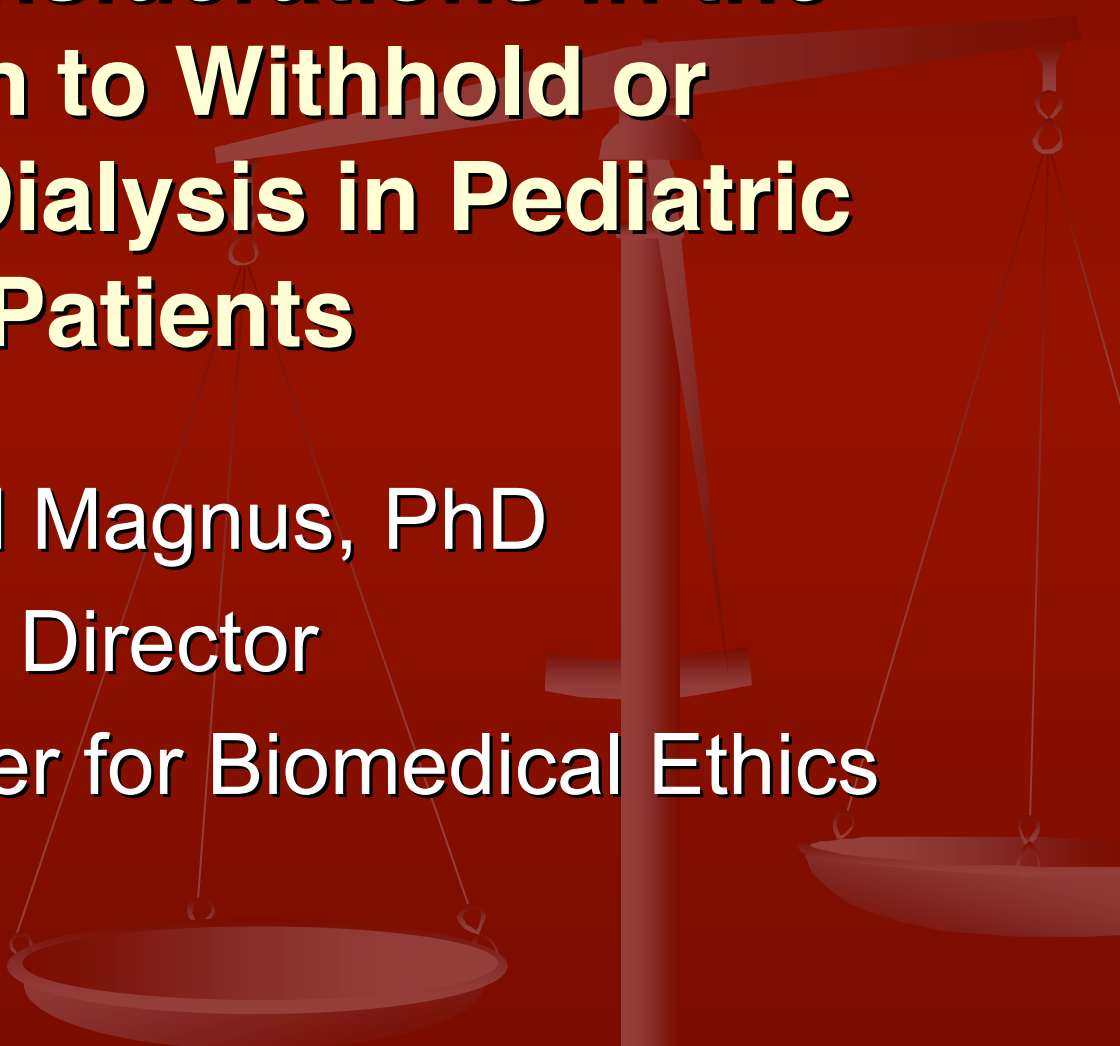


Ethical Considerations in the Decision to Withhold or Withdraw Dialysis in Pediatric Patients

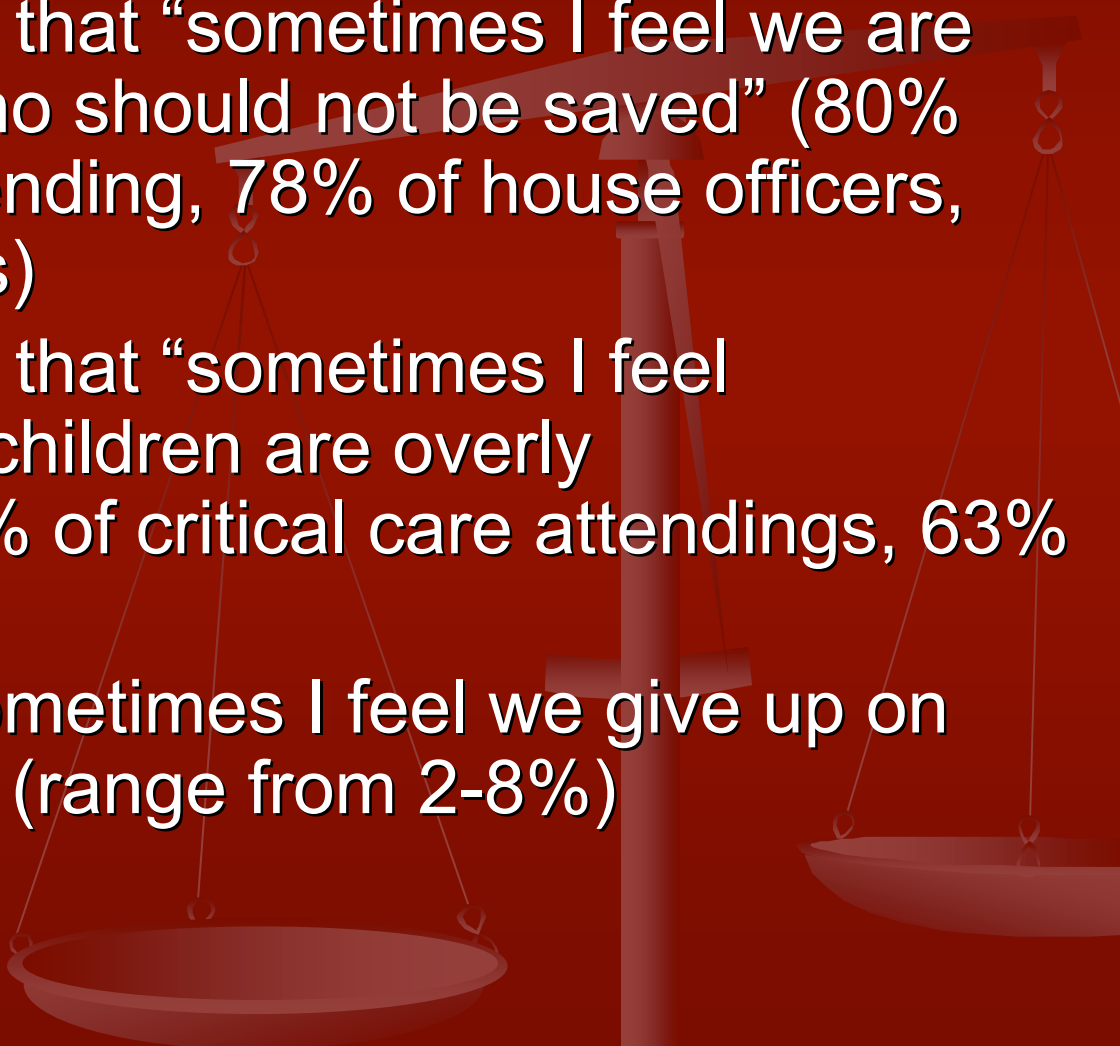


David Magnus, PhD
Director

Stanford Center for Biomedical Ethics

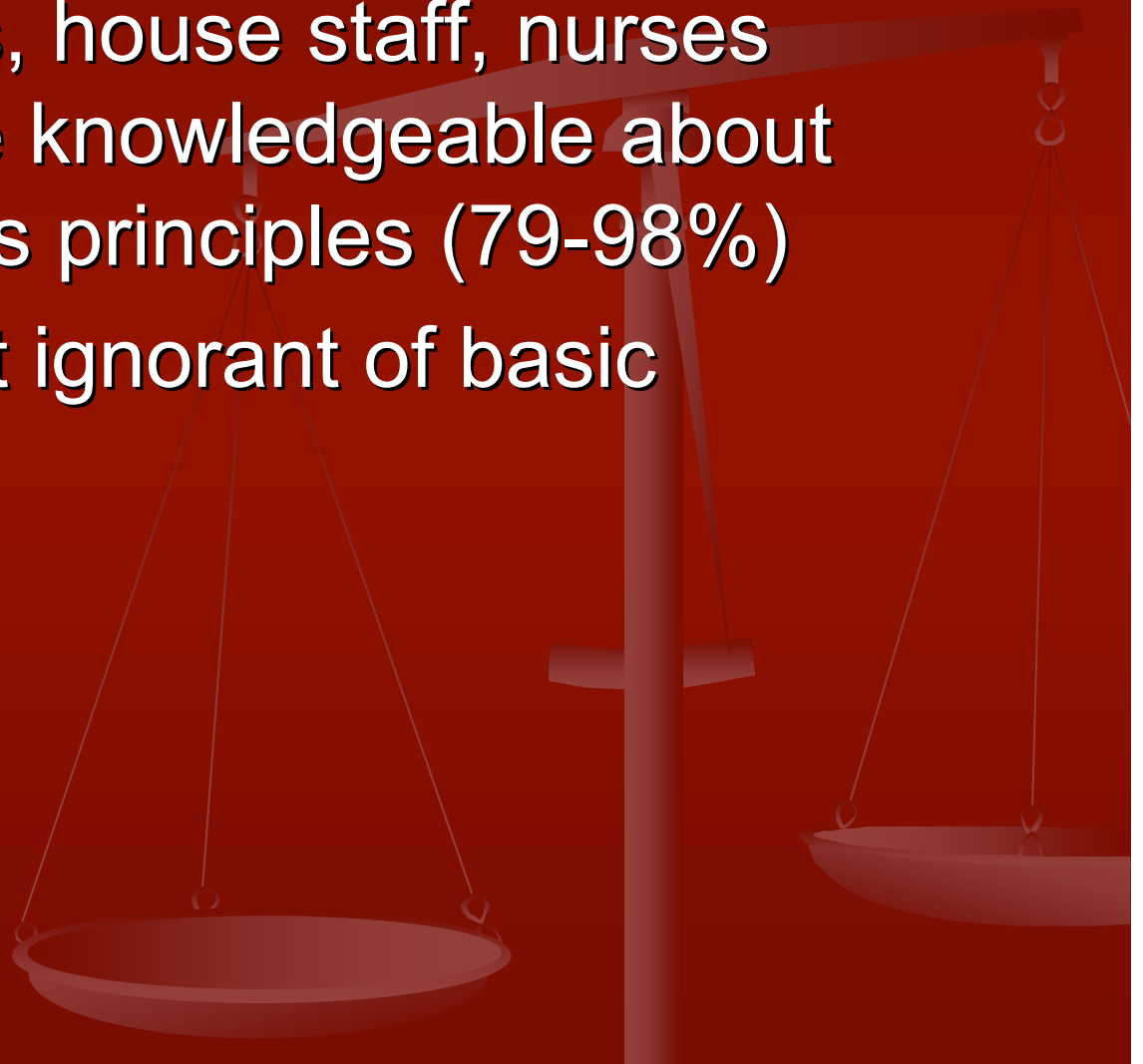
Problems in PICU

Solomon, et al, *Pediatrics*, 116: 872-883

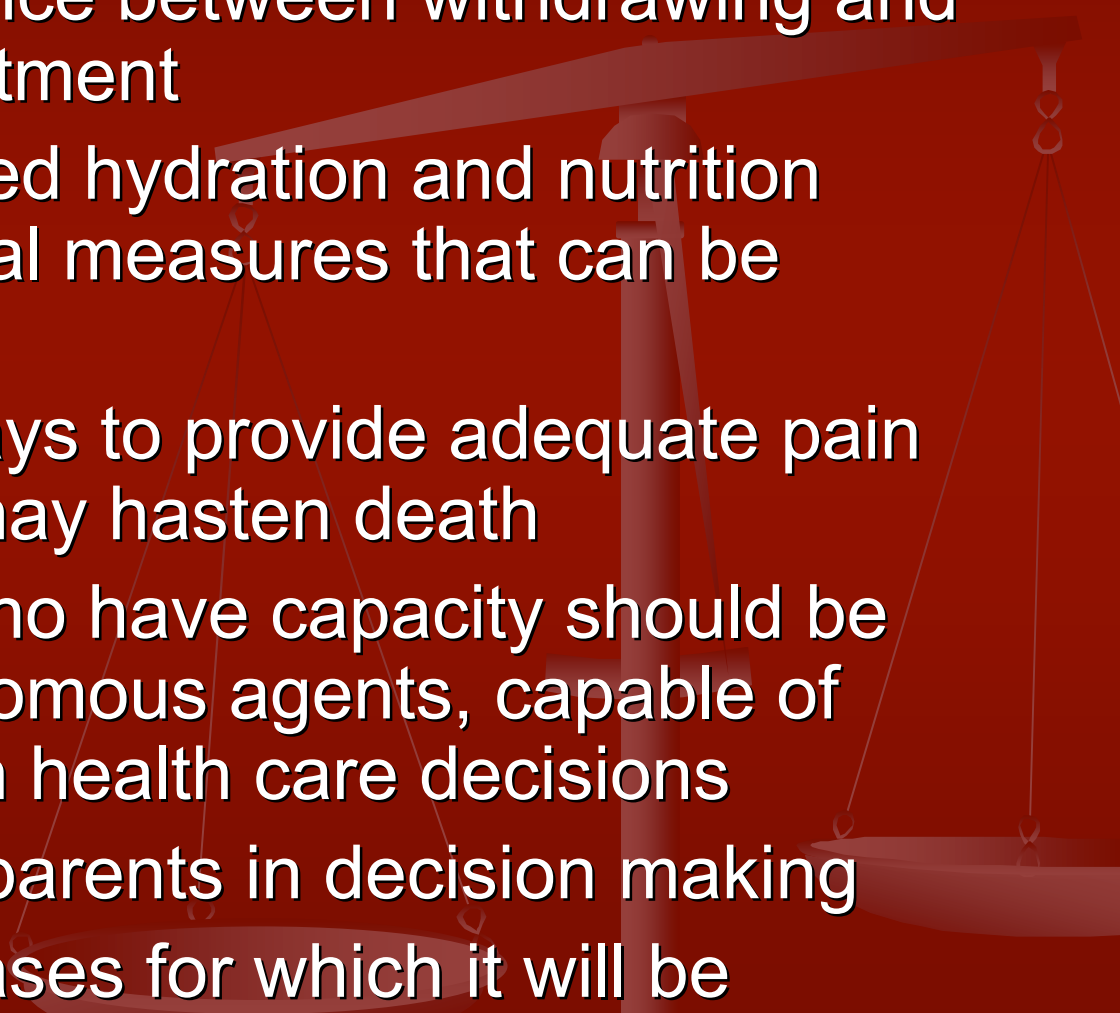
- Common to agree that “sometimes I feel we are saving children who should not be saved” (80% of critical care attending, 78% of house officers, 69% of c.c. nurses)
 - Common to agree that “sometimes I feel treatments I offer children are overly burdensome” (56% of critical care attendings, 63% of house officers)
 - Rarer to agree “sometimes I feel we give up on children too soon” (range from 2-8%)
- 

Knowledge of Principles Solomon, et al, *Pediatrics*, 116: 872-883

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

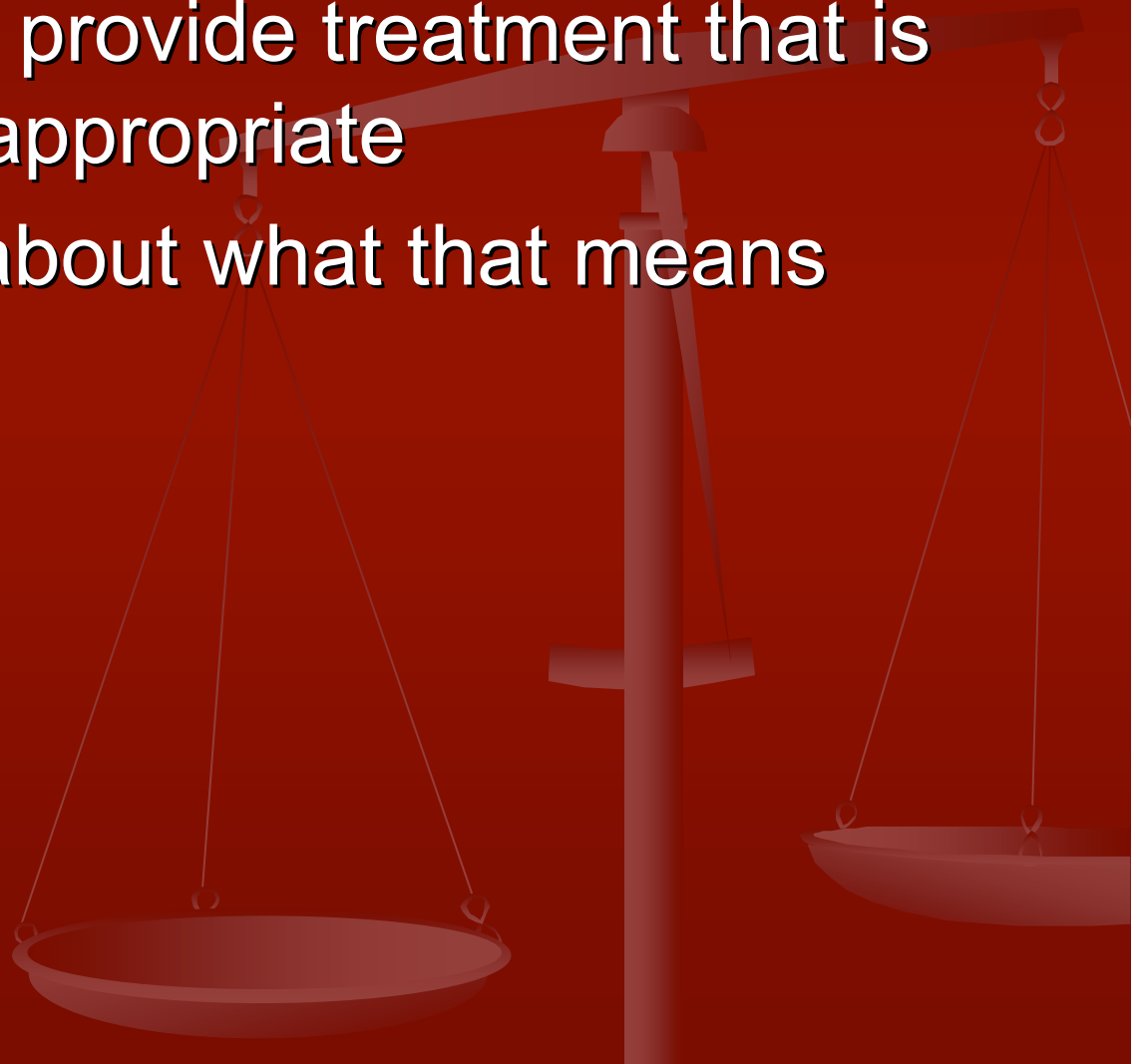


Key Principles

- No moral difference between withdrawing and with-holding 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 with-hold treatment
- 

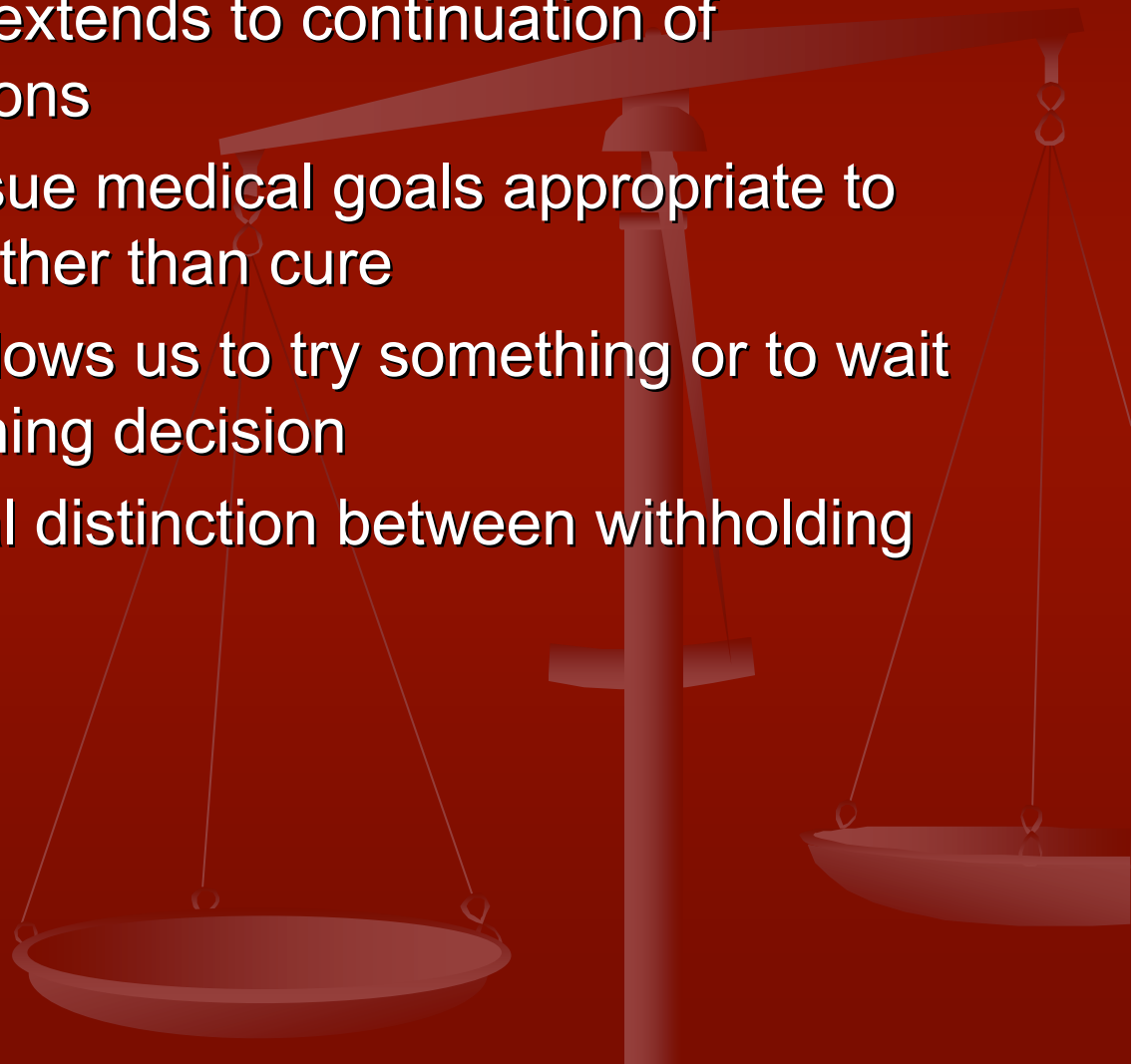
New consensus emerging

- No obligation to provide treatment that is ineffective or inappropriate
- No consensus about what that means



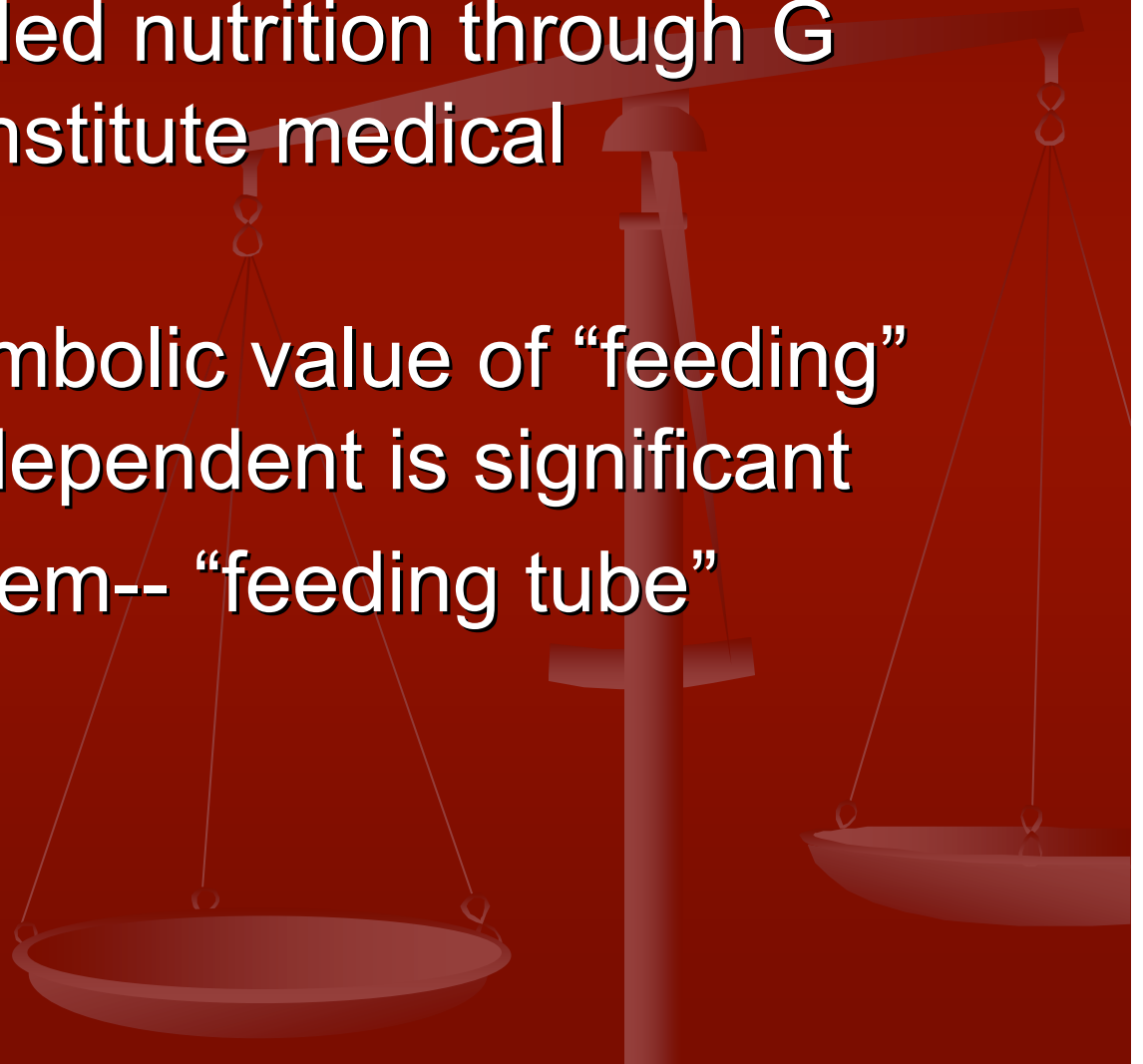
Withdrawal vs withholding tx

- 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



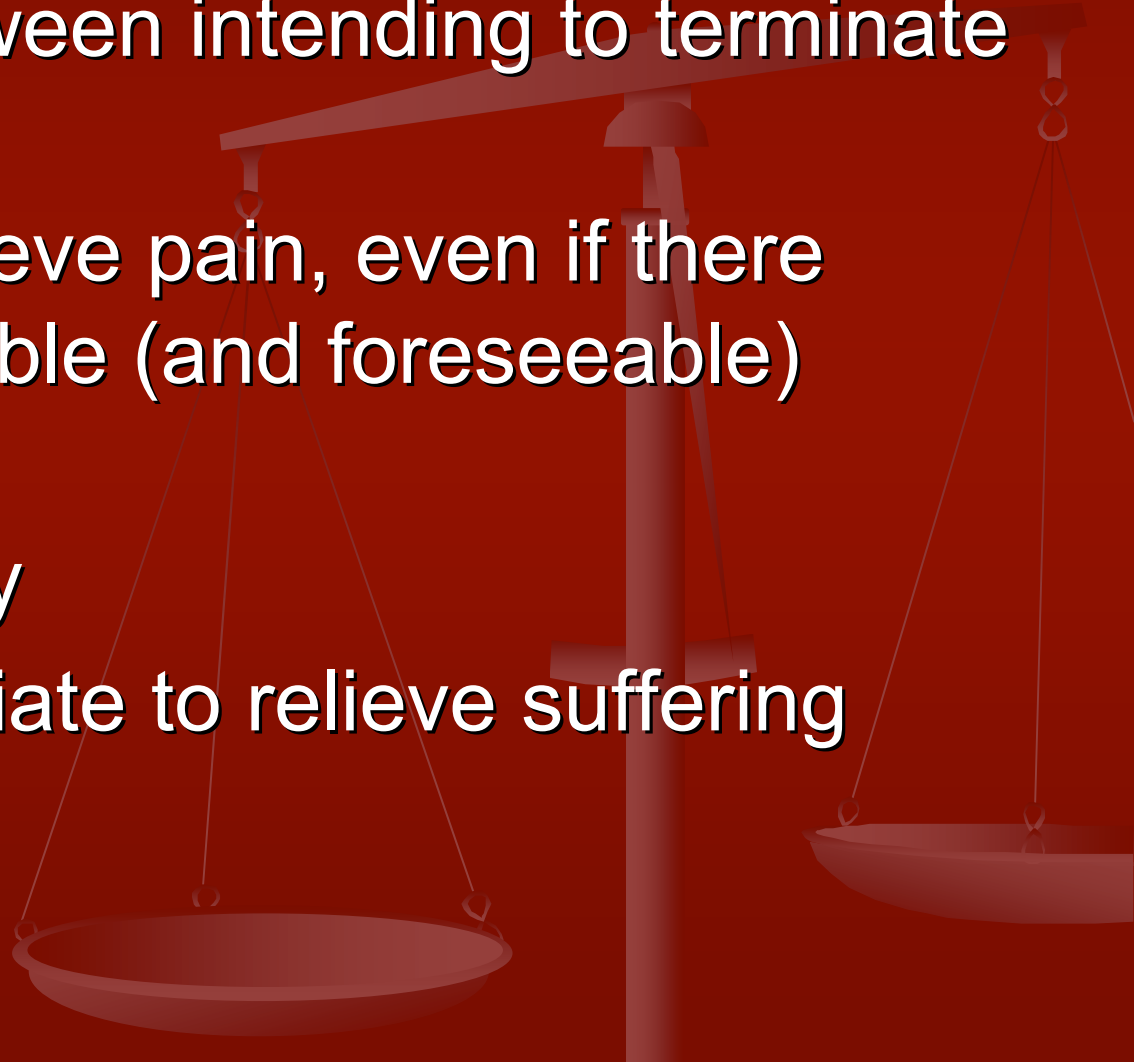
Hydration and Nutrition

- 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



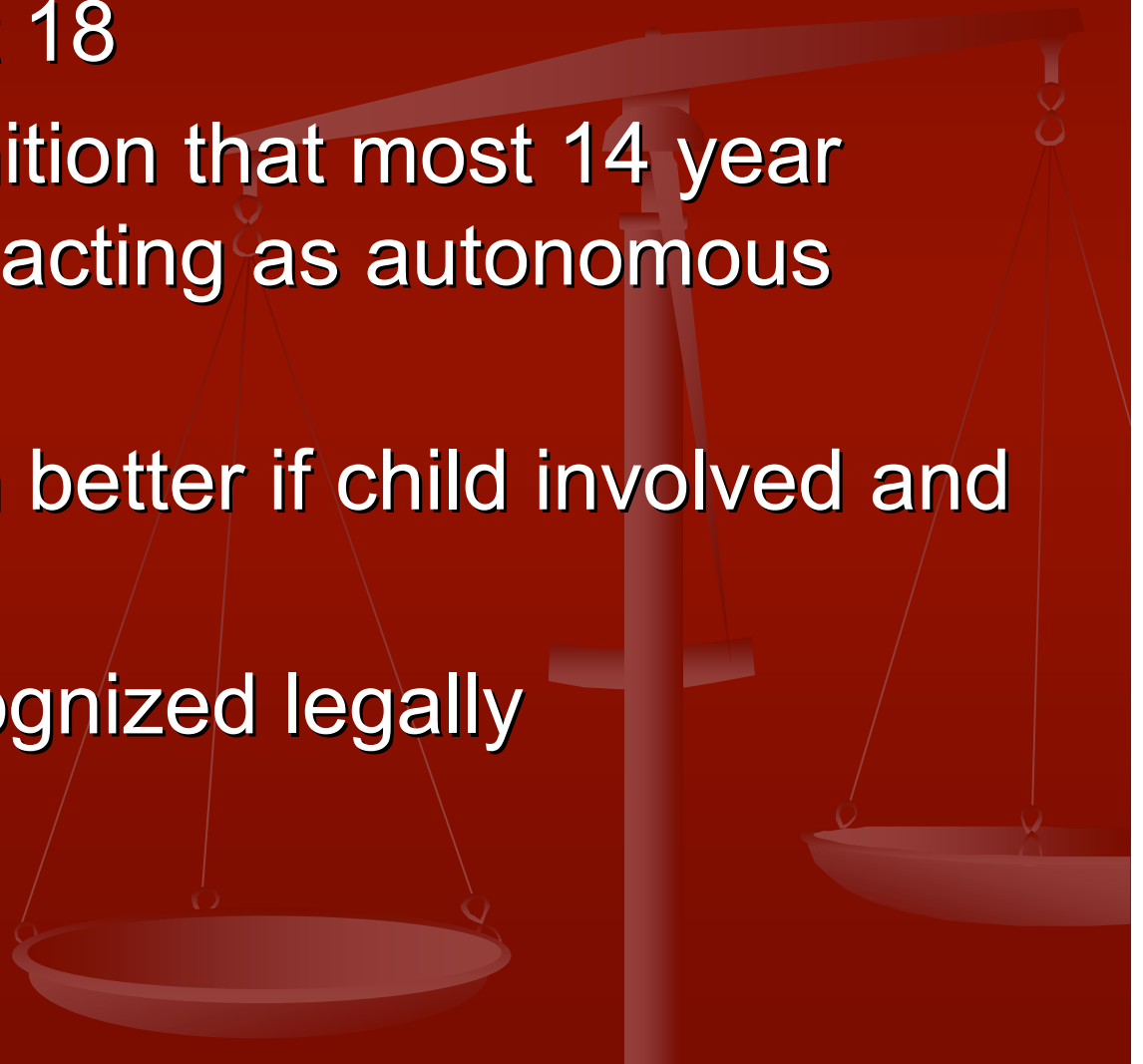
Doctrine of Double Effect

- 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

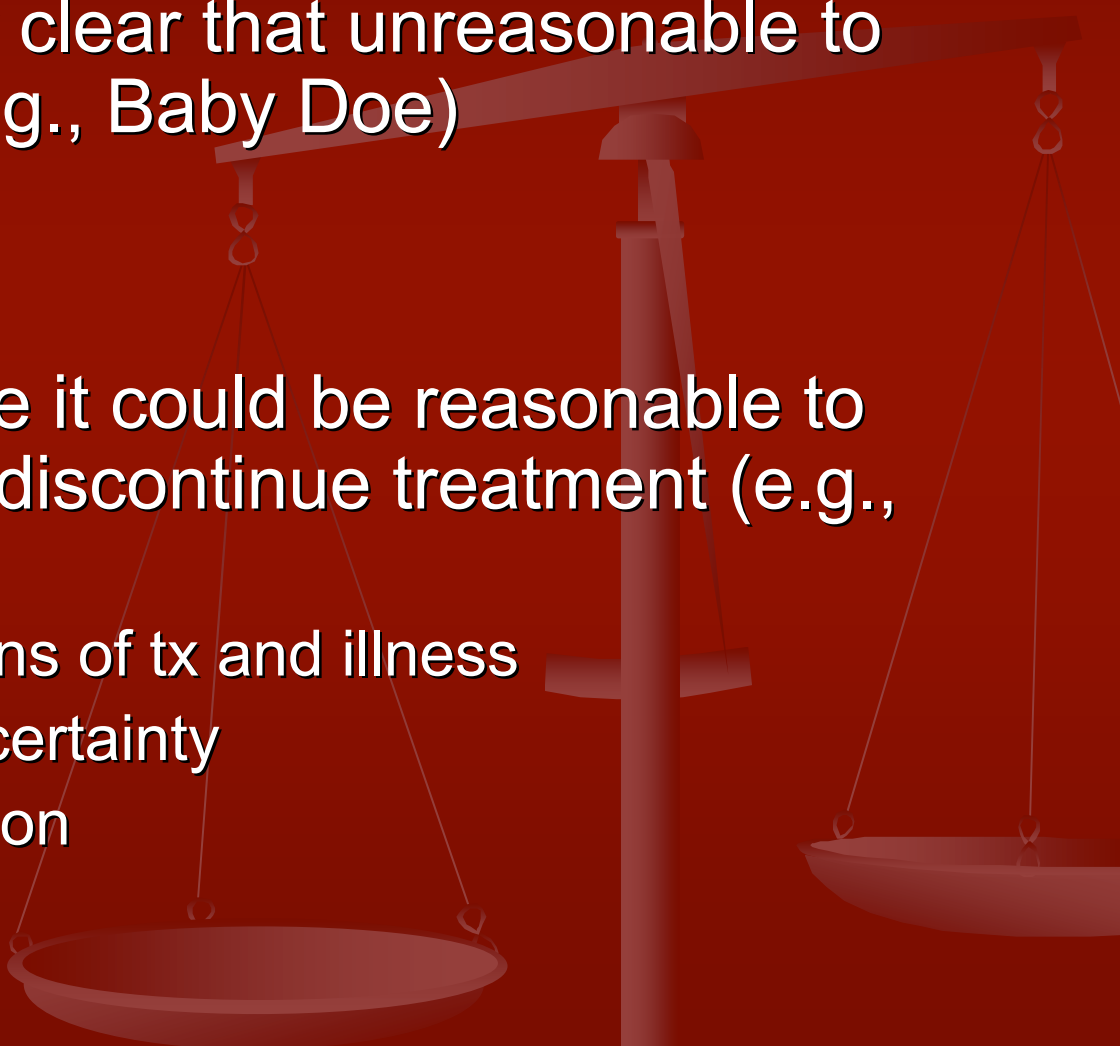


Decision making



- 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

- Wangle
- Baby K
- Baby Sun



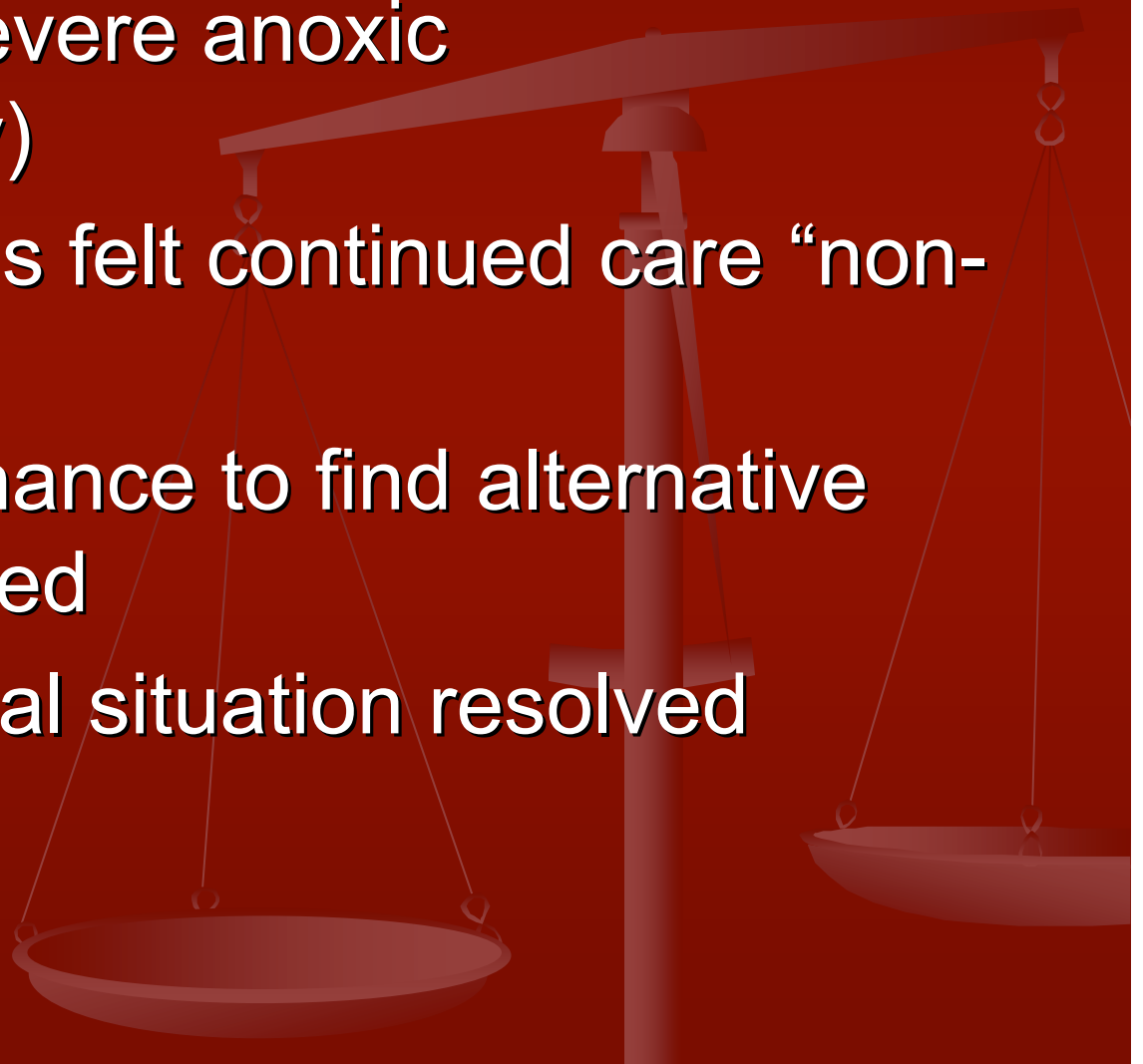
Wanglie (1990)

85 yo f in PVS (severe anoxic encephalopathy)

Nurses, physicians felt continued care “non-beneficial”

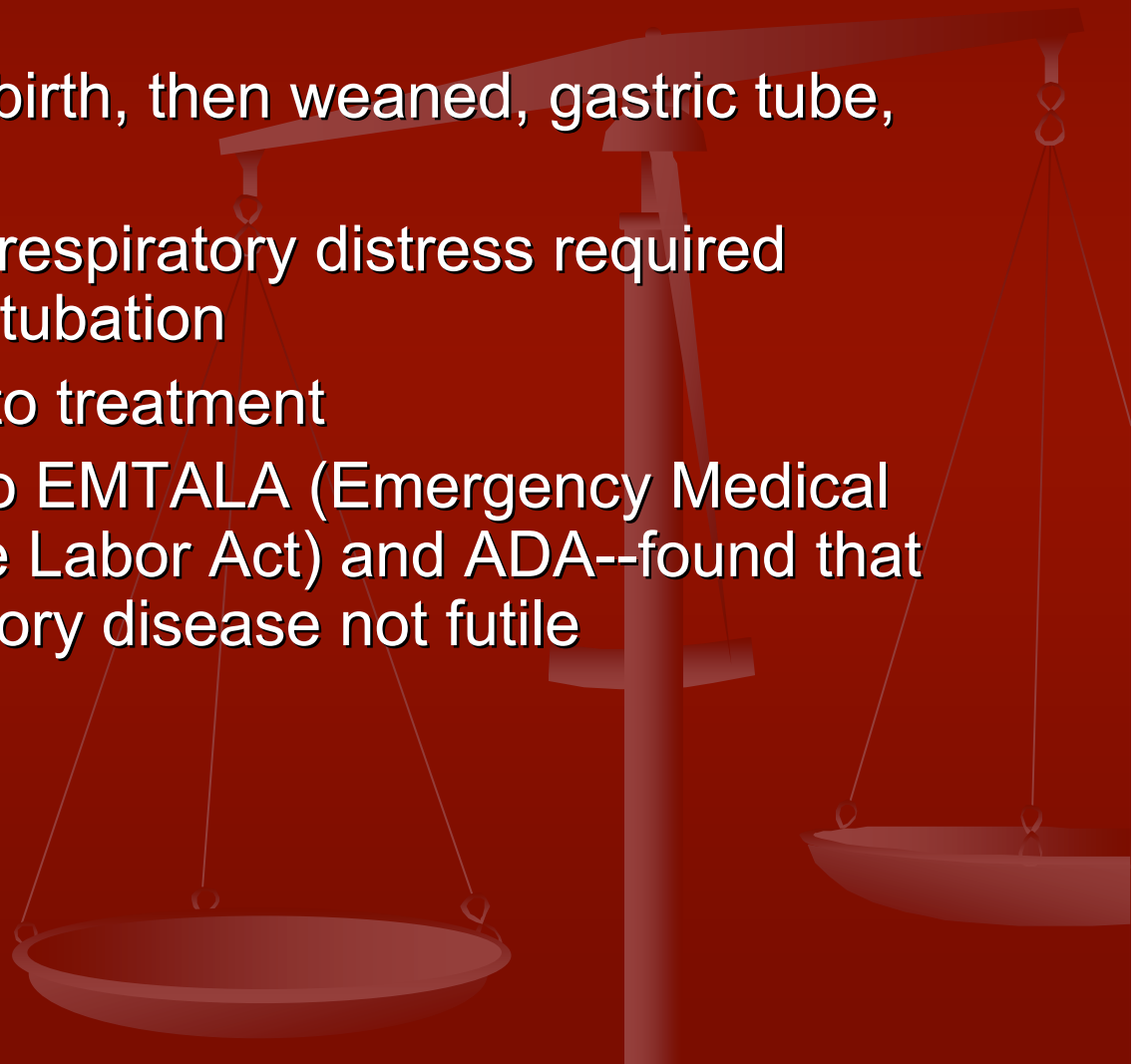
Husband given chance to find alternative hospital and failed

Pt died before legal situation resolved



Baby K

- 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

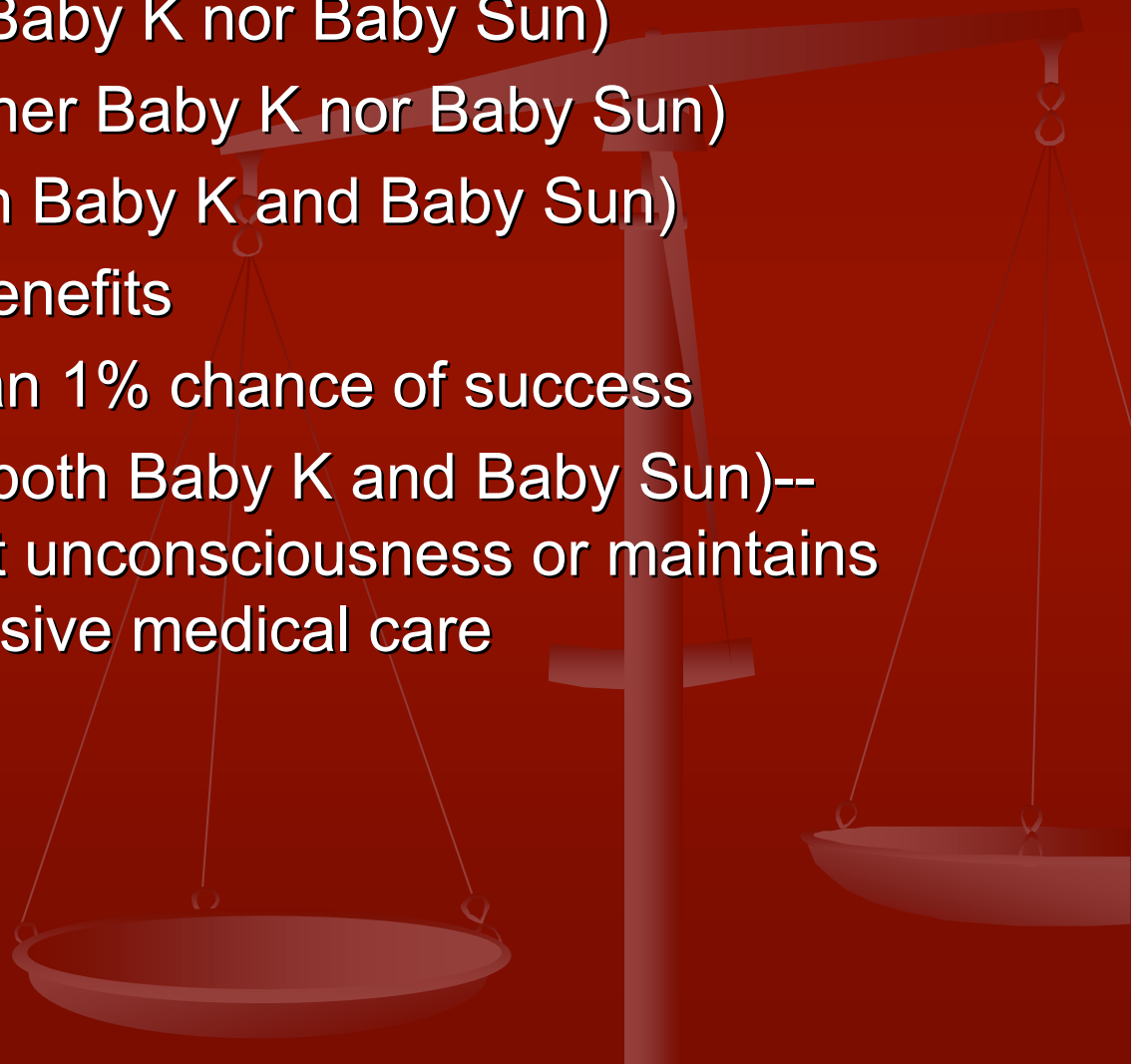


Baby Sun

- 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

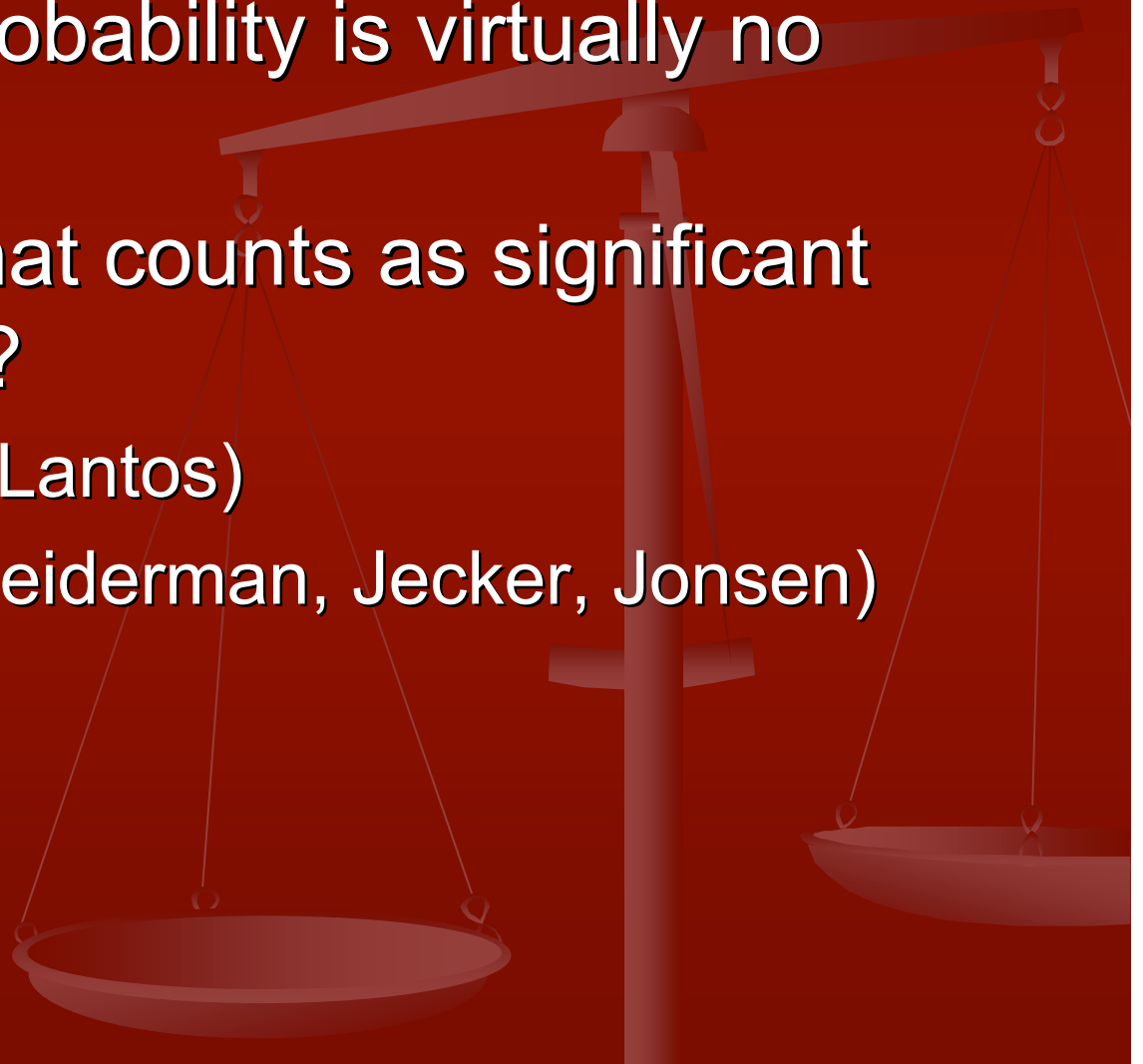
Meaning of Futility

- 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



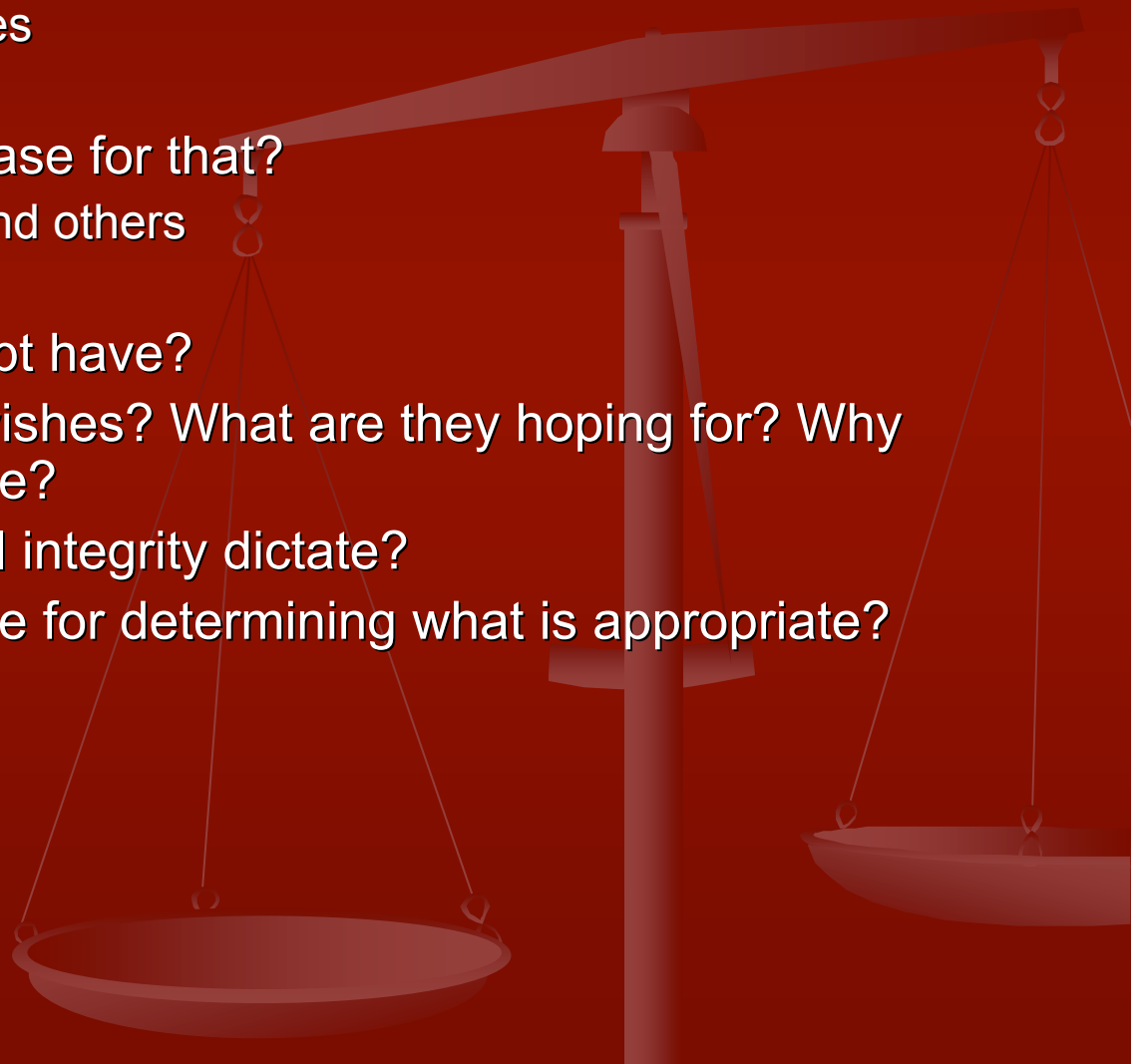
Key questions

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



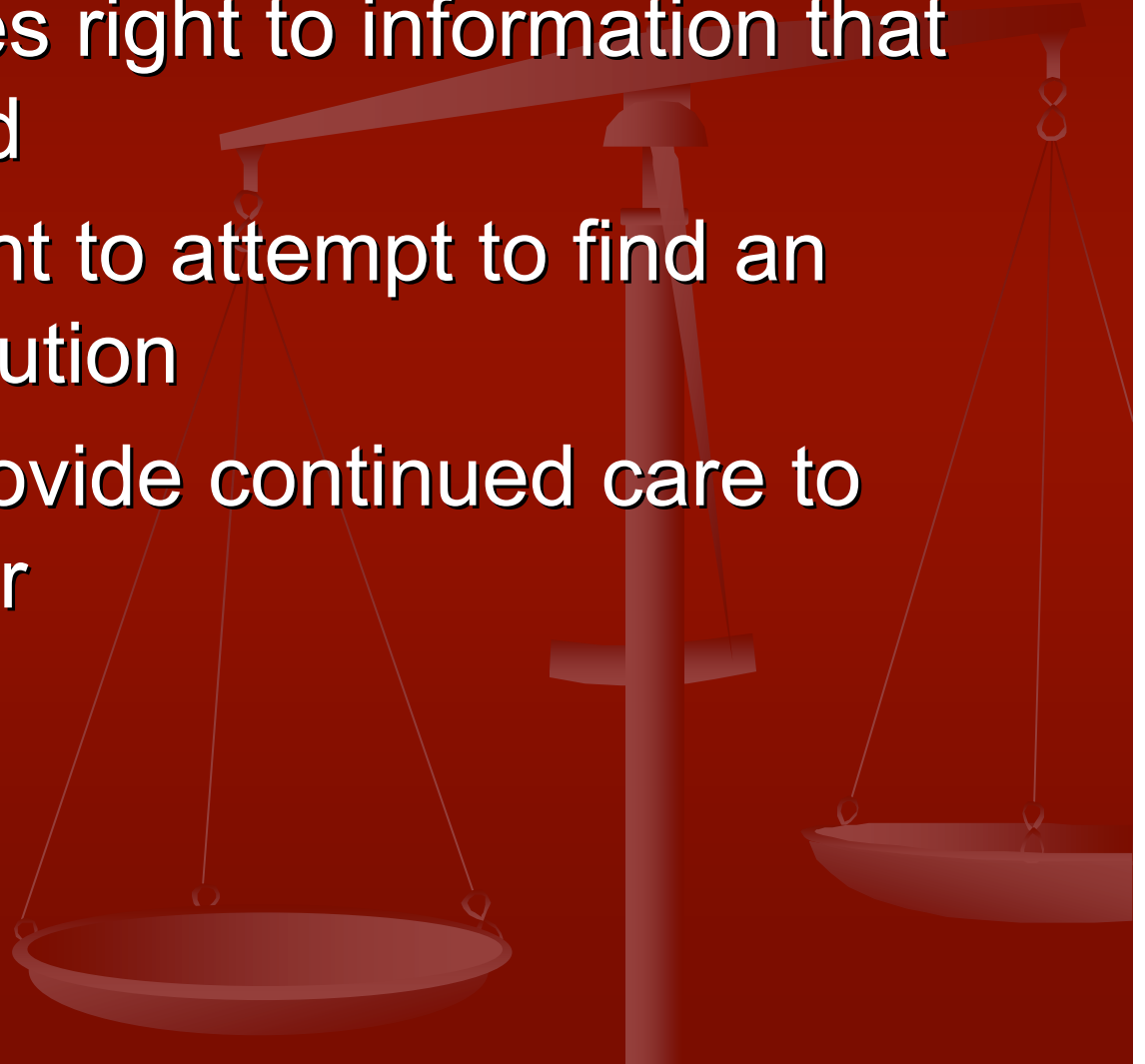
Key questions to ask

- 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

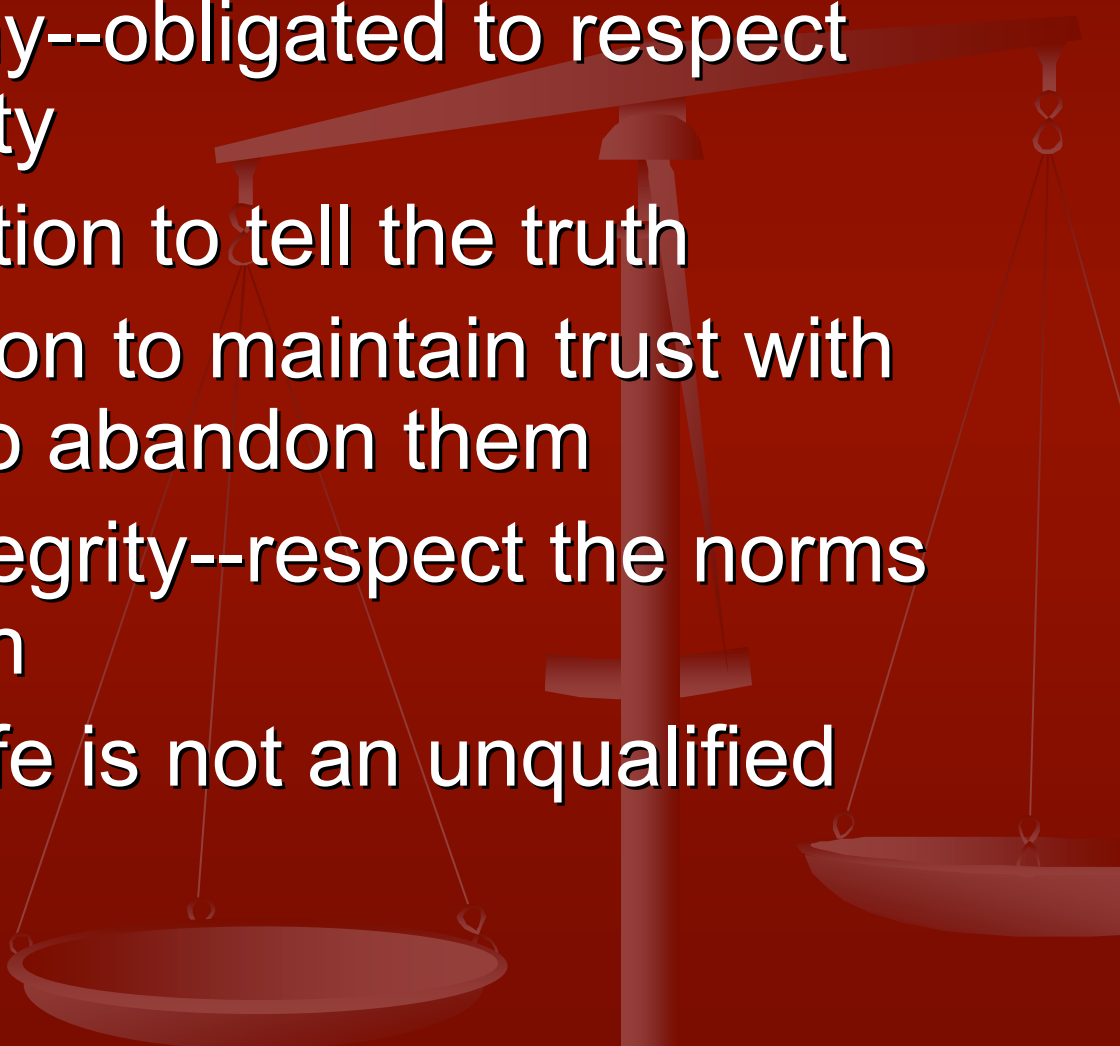


Values



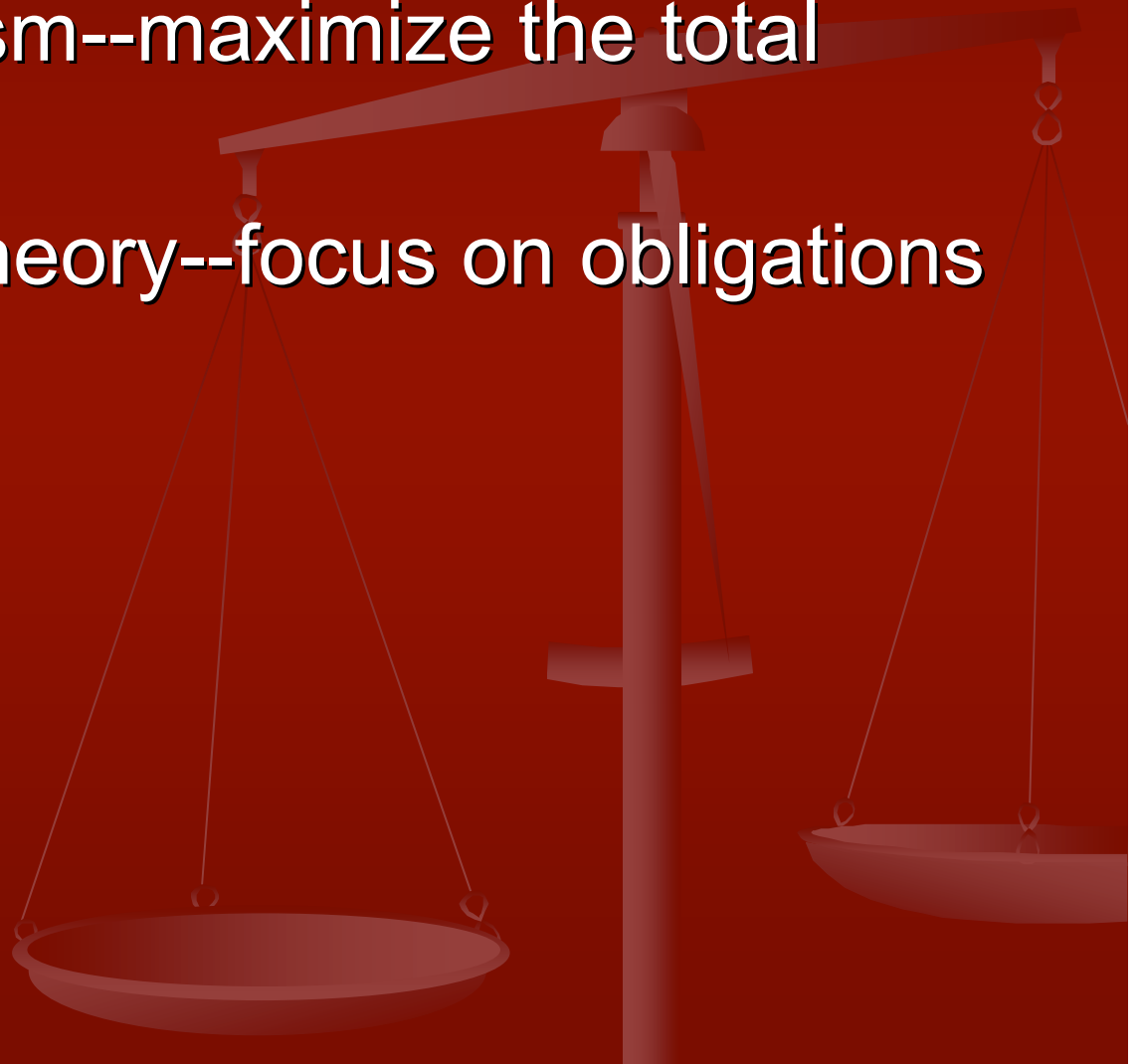
- Respect for Autonomy
- Beneficence--obligation to help patients
- Non-maleficence--obligation to do no harm
- Justice--obligation to act fairly, obligation to treat similar cases in a similar fashion
- Stewardship--obligation to make appropriate uses of scarce resources

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>

