Treatment of Impaired Newborns

• Usually the birth of a baby is a happy event.
• 94-97% of all babies are born “healthy”.

The remaining 3-6% are identified as having either:

• A Genetic defect – a problem or disease that is passed from generation to generation through genes OR is a result of a mutation in a gene.

• Congenital defect – “apparent at birth”. Usually refers to a defect that occurred during the embryonic development process.

Background: Baby Doe Regulations and Ethics Committees

• “Baby Doe” cases led to federal regulations recommending hospital ethics committees.
• Once rare, ethics committees now exist in most hospitals.
• Purpose has evolved since Baby Doe days
• Each develops its own rules for membership and procedure.
Ethics Committee Issues

- Who should be on the committee?
  - Community members?
  - Clergy?
- Who has bioethical “expertise”?
- Should referrals ever be required and should committee recommendations be binding?
- Usual: optional-optional model

Two Key Questions

- What do we consider, rationally, the right thing to do?
- Who should decide?
  - Specifically, how much weight should be given to the views of parents?
  - Do they have a right of autonomy to act for their child?

Now: You Be an Ethics Committee

- What follows is an actual case (disguised to preserve confidentiality), one of the most memorable in the history of the University of Michigan Health System’s Pediatric Ethics Committee.
- You decide.
Kenny – Medical Information

- Age: four years
- Spinal muscular atrophy
- Has lost previous crawling and walking abilities
- Needs a body jacket for support and a by-path assist device to aid in breathing
- Independent in a wheelchair, but dependent in bathing and dressing
- Problems chewing, mild scoliosis, contractures of his legs, easily-managed constipation and tremors
- Active and mentally precocious child

Prognosis

- Expected to become weaker with inability to swallow and handle secretions
- Will eventually require nasogastric tube or gastrostomy for feeding
- Will eventually die of his disease; the likelihood of prolonged survival appears to be quite limited

What the Treatment Team Said

- Tracheostomy and ventilator support recommended at this time to eliminate choking and breathing crises disturbing Kenny's sleep
- Tracheostomy may slow deterioration since his breathing problems may aggravate the weakness associated with his disease
What the Family Said

- Parents no longer have hope of a cure for Kenny
- Parents have done research and talked with parents of ventilator dependent children.
- They believe that life immobilized and sustained by a ventilator would not be an acceptable quality life for Kenny.
- Kenny said he does not want a hole in his throat and that he wants to be left alone
- Five-year-old sister experiences trauma coping with her brother's illness

Ethical Issues and Actual Committee Recommendation

In class

Robertson and Engelhardt Clash on Key Issues

- Are defective infants full persons with right to life?
- Is it morally permissible (maybe even obligatory) to stop life-sustaining treatment for the sake of the child?
- Is it morally permissible to stop treatment for the sake of others; e.g., family?
- Is it morally permissible to stop treatment because costs are too great?
Robertson Responds to These Arguments for Non-Treatment

- Infants are not persons
- Non-treatment may be appropriate for the sake of the child to avoid a life worse than death
- Non-treatment may be appropriate for the sake of others (or costs)

“Infants Are Not Persons” Robertson’s Response

- Infants must be considered persons.
  (Is Robertson’s argument completely non-consequentia list, as one would expect?)
- Tooley’s argument (opposed by Robertson):
  - To have a right to life one must have a desire to continue to exist
  - To have a desire to continue to exist, one must have the sense of self over time
  - Tooley: since early infants lack this, they are not persons with a right to life

Problems with Tooley’s argument

- Surely one who becomes unconscious is still a person with rights
- Tooley: their prior status is not lost
- Why should prior status be more important than future likely status?
- For infants who will never gain self-consciousness, is their status different from those adults who become permanently impaired? Why?
Robertson: both rights oriented and consequentialist

- Rights (implied): “…based on the view that all living creatures are sacred, contain a spark of the divine…”
- Consequentialist: Excluding some from care poses dangers of abuse
- Denying care has an effect on our whole view of what it is to be a child and affects other children (cf. genetic abortion)
- Implicitly: consider “symbolic significance”

“No Obligation to Treat When Infant’s Own Life Would Be Terrible”—Robertson’s Response

- Robertson: Even impaired life better than often portrayed
- Robertson: nearly impossible for someone else to judge that infant’s life not worth living
- What about grossly deformed, retarded, institutionalized child with incessant pain “where continued life is itself torture”?

Larger Issue: Can We Judge that An Infant’s Life is Worse than Death?

- Robertson: “one who has never known [normal capacities] will judge differently
- Proxy judgment likely to invoke its own interests
- BUT: can we not judge that an infant is suffering?
“No Obligation to Treat When Burden On Others Is Too Great” – Robertson’s Response

- Families can be helped so that burden not overwhelming and even some benefit
  - “assistance MAY be available” (p. 652-1; my emphasis)
  - “the problem may not be insurmountable” (652-2)
- Health professionals’ problems are significant but comparatively minor
- Costs to society
  - Questions the cost-benefit calculations of others
  - Saving money doesn’t justify violating rights.

Engelhardt: Parents May Decide Not to Treat in Many Cases

- Children are not persons in full sense
- Nontreatment justified if either
  - Quality of life will be very poor
  - Costs (financial, psychological) great
- The decision is one for parents
  - Exception: children should be protected from parental decision not to treat if child can have good quality of life and not a severe burden

Engelhardt on personhood

- Infants and small children not persons in strict sense, only in social sense
- They are not bearers of rights and duties.
- (Why not rights?)
- “A newborn or young child is…valued highly because it will grow to become a person.”
Costs Alone Can Justify Not Treating

- “Treatment that is very costly is not obligatory”
- The argument should hold as well where the expected future life would surely be of normal quality, though its attainment would be extremely costly

Symbolic or Expressive Significance

- “As long as parents do not unjustifiably neglect the humans in those roles so that the value and purpose of that role (that is, child) stands to be eroded (thus endangering other children), society need not intervene.
- “In short, parents may decide for or against the treatment of their severely deformed children.”

Engelhardt: May Even Be an Obligation Not to Treat

- In some cases continued existence is an injury for the child
- Legal idea developing of child suing for “wrongful life.”
- Is there a parallel ethical idea that we should accept?