End of Life Care and the Technological Imperative

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Case I

- ‘Abby’ suffers from severe hypoxic ischemic encephalopathy (HIE)
- She is unable to swallow or protect her airway
- After a viral respiratory infection, she is unable to wean off the ventilator
- Her parents request tracheostomy and gastrostomy tube placement
Jeremy was born with hypoplastic lungs because of severe bladder obstruction and hydronephrosis.

Prior to his birth, his mother was informed that he was unlikely to survive for more than a few hours. She requested full supportive care for him and remained hopeful.

When Jeremy survived his first 24 hours, he was transferred to the regional tertiary center for further evaluation.

Jeremy deteriorated following transport and extracorporeal membrane oxygenation (ECMO) was initiated. He also required dialysis.

http://www.allkids.org
### Case III

- Baby Hope was born at 25 weeks. Her hospital course had been uncomplicated until she developed severe necrotizing enterocolitis (NEC) at 6 weeks of age.
- Hope was transferred to the tertiary care hospital where an emergency laparotomy was performed. Extensive bowel was resected and only 35cm of small bowel remained.
- Months later, Hope is ready for discharge on partial nasogastric feeds and home hyperalimentation via her central venous line.
- She has moderate cholestasis and is followed by the intestinal rehab program. It is possible that she may need a bowel transplant in the future.
### Case IV

- Baby Daniel is born with hypoplastic left heart syndrome (HLHS)
- His mother is a special education teacher and his father is a psychiatrist. They have researched HLHS extensively, speaking with many cardiologists and families of children with congenital heart disease.
- Daniel’s parents choose to bring him home with hospice care and not pursue surgical palliation for his HLHS.
The Technological Imperative

The belief that life sustaining technologies should be utilized whenever necessary in an effort to extend life as long as possible

We can, so we should...
- Operate
- Ventilate
- Dialyze
- Put on ECMO, insert LVAD
- Transplant etc

Both caregivers and parents may hold strongly to this belief
<table>
<thead>
<tr>
<th>Organ System Failure</th>
<th>Supportive therapy (Examples)</th>
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<tbody>
<tr>
<td><strong>Respiratory</strong></td>
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<tr>
<td>(Congenital diaphragmatic hernia, BPD)</td>
<td>ECMO (extra corporeal membrane oxygenation)</td>
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<td></td>
<td>Mechanical ventilation</td>
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<td></td>
<td>Tracheostomy</td>
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<td>Cardiovascular</td>
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<td>(Hypoplastic left heart, cardiomyopathy)</td>
<td>Palliative heart surgery</td>
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<td></td>
<td>Left ventricular assist device</td>
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<td></td>
<td>ECMO</td>
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<td></td>
<td>Heart transplant</td>
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<td>Gastrointestinal</td>
<td></td>
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<tr>
<td>(Short bowel syndrome)</td>
<td>Total parenteral nutrition</td>
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<td></td>
<td>Intestinal transplant</td>
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<tr>
<td>Renal</td>
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<td>(Acute tubular necrosis, posterior urethral valves)</td>
<td>Continuous venovenous hemofiltration (CVVH)</td>
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<tr>
<td></td>
<td>Peritoneal dialysis</td>
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<td>Hemodialysis</td>
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<td>Hepatic</td>
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<tr>
<td>(Biliary atresia, gestational autoimmune liver disease)</td>
<td>Kasai procedure (biliary atresia)</td>
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<td>Liver transplant</td>
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<tr>
<td>Neurologic</td>
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<tr>
<td>(Hypoxic ischemic encephalopathy, intraventricular hemorrhage with hydrocephalus)</td>
<td>Tracheostomy</td>
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<td></td>
<td>Gastrostomy tube</td>
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<td>Salivary botox injections</td>
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<td>Baclofen pumps</td>
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<td>Genetic</td>
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<td>Urea cycle defects</td>
<td>Gene therapy</td>
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<td>Hematologic</td>
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<td>Hemophilia, Diamond blackfan anemia)</td>
<td>Transfusion</td>
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<td>Factor replacement</td>
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<td>Bone marrow transplant</td>
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Elements of the Imperative

The imperative of **possibility and action** – That which is possible to be done should be done

The imperative of **commitment** – Acceptance of a patient to a tertiary facility implies technologies will be employed – the last hope

The imperative of **procedure** – the availability of technology compels its use – it doesn’t hurt to try.

The imperative of **demand** – informed patients/families demand new therapies

The imperative of the **unknown** – uncertainty about the outcome compels us to try the technology. “If we don't some body else will”

The imperative of **means as ends** - technology has shifted the goal of medicine from caring for sick persons to merely diagnosing disease. Therefore technology has made our means our ends.

The imperative of **implementation** – Novel technology unlike new medication is not subject to rigorous oversight. Therefore technology is often applied too frequently and before its efficacy is proven.

The imperative of **proliferation** – use of technology leads to the use of other technologies

## The Ethical Conflict

<table>
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<tr>
<th>INTERVENTION</th>
<th>WITHHOLDING TREATMENT</th>
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<tr>
<td>❑ Financially costly</td>
<td>❑ Most likely life-limiting</td>
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<tr>
<td>❑ Resource intensive</td>
<td>❑ Quality of life concerns</td>
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<tr>
<td>❑ Quality of life concerns</td>
<td>❑ Emotionally costly</td>
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<td>❑ Complex care burden may be shifted to parents – family impact</td>
<td>❑ Decision may not be made using the best interest standard</td>
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Autonomy vs Beneficence
Autonomy vs Justice
Beneficence vs Justice
Historical Context – Baby Doe

1982 Bloomington, Indiana

Parents of a newborn with Down syndrome refuse to allow surgical treatment of a tracheal esophageal fistula. At that time, the operation would have had a 90 percent chance of success.

The hospital and doctors sought a court order mandating the treatment.

The Indiana court denied their request on the basis that the parents had the right to make the decision.

Forty years ago, parents were routinely offered the option of nontreatment for their babies with Down syndrome who required surgery. Now the standard has changed.
The Paradigm Shift

Impermissible – The harm of treatment exceeds any possible benefit
Obligatory – Outcome data confirm significant short and long-term benefits to the patient
Factors in Choosing Novel Technologies

- Data on outcomes
- Availability and feasibility of technology
- Rights and obligations of all involved
  - The Baby
    - The right to medical treatment that has the reasonable potential to preserve life
    - The right to mercy – freedom from burdensome pain and suffering unlikely to alter the natural course of disease
    - The right to equal and just treatment
  - The parents
    - The right to accurate information regarding prognosis and all available treatment options
    - The right to guidance and support throughout this decision-making process
    - The right to decide for their child, and to make decisions on his or her behalf, based primarily on his or her best interests
  - Other family members
  - Society

“In the setting of an acute, life-threatening illness in which decisions must be made quickly, it can be overwhelmingly compelling for clinicians to offer treatments including those that are mechanistically plausible, yet unproven, to patients. Faced with impending mortality, it is extremely difficult for patients (or their loved ones) to refuse the offer. Furthermore, saying “no” and electing a palliative approach can be unattractive, particularly for young, previously healthy patients.”

Palliative care begins at diagnosis. Palliative treatments should continue alongside treatments aimed at curing disease.
Decision making

Surrogate decision makers - authorized to make medical decisions for patients who are not competent to make decisions on their own behalf

Parents have the right to make medical decisions for their children (parental authority).
- Parents are most likely to make decisions that are in their child’s best interest.
- They will (typically) have to bear the consequences of the decisions they make.
The Ethics of Using Advanced Technologies

Beneficence – Technology should only be used for conditions that respond to the intervention

Nonmaleficence – Technology should not be used if it merely prolongs the process of dying
(The anticipated benefits should outweigh the cost)

Justice – Technology should be made available where there is a likelihood for a good outcome. Expensive technologies should not divert from basic medical care or other healthcare activities (i.e. preventative care) that may have better results

Autonomy – Novel technologies, not clearly shown to have benefit (or to be detrimental) should only be employed after thorough informed consent
Difficult Decisions

QUALITY OF LIFE (QOL)

QOL is a moral judgment

QOL shifts the focus from whether a treatment is beneficial to patients to whether patients’ lives are beneficial to them – Paul Ramsey.

To whom does the QOL judgment belong – the patient/parents or the medical team?

JUSTICE

The ethical principle concerned with the equitable distribution of resources

Also requires that like patients be treated similarly

Not usually considered a bedside judgment but rather a societal concern
Our Cases

Abby – HIE, ventilator dependent
Jeremy – Pulmonary hypoplasia, Renal failure
Hope – Short bowel syndrome, TPN dependent
Danial – Hypoplastic left heart syndrome

What is imperative in these cases?
Discussion