Complex Decision-Making Around the Use of Extreme Technologies at the Edges of Medicine in the Pediatric ICU: The Case of Extracorporeal Life Support

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Background
Imagine for a moment...

You are the doctor in the neonatal ICU and you have just admitted a newborn baby with respiratory failure after meconium aspiration during birth.

The baby remains severely hypoxic and hypotensive despite full life support and is dying.

Her only chance for survival is to place her on extracorporeal life support (ECLS). With this extraordinary technology her chances of survival are >90%.
Extracorporeal Life Support
However, ECLS is also...

- Expensive
- Resource intensive
- There are significant risks of
  - Serious infection
  - Life threatening bleeding
  - Stroke and other neurologic injury
  - Other serious life threatening complications

- For some it is life-saving with an excellent long-term outcome.
- For others, it may merely prolong death or result in survival with severe neurologic injury.
Rapidly expanding use of ECLS

- Traditionally used in neonates with respiratory failure
- Expanding indications in pediatrics
- Increasing use in adult patients
- Transport ECLS
- Extracorporeal–CPR
- Rapidly improving technologies
- Boundaries and limits are continually challenged, broken, and re-written
But, let us pause...

Expanding indications, technologic advancements, and increased utilization of ECLS may be outpacing ethical and societal considerations.

Without simultaneously attending to the ethical implications there is an increased risk of making decisions that may lead to unnecessary burdens for:

- Patients
- Families
- Clinical Staff
- Health care systems
To cannulate or not to cannulate...

• A 14 yo girl with diffuse alveolar hemorrhage after a bone marrow transplant

• An 8 yo girl with static encephalopathy and tracheostomy and ventilator dependency presenting with acute septic shock

• A 5 do boy with an acute disseminated herpes viral sepsis with lung injury, capillary leak, acute kidney injury, DIC, and encephalopathy

• An 18 mo boy with acute cardiac failure after cardiac surgery who has been on ECLS twice in the last month

• A 2 mo girl who is brought from home in acute cardiac arrest with on-going CPR

• A 17 yo boy with Duchenne’s Muscular Dystrophy who is in acute decompensated heart failure and is not a candidate for heart transplant
How do we decide?

“Almost every action within the medical setting either explicitly or implicitly contains two judgements, one ethical and one scientific, and there is constant interplay between what is technically possible and what is morally desirable.”

Current Research
Seattle Ethics in ECLS (SEE) Consortium

- ECLS
- Critical Care
- Surgery
- Bioethics
- Nursing
- Palliative Care
Ethics in ECLS Research Agenda

- Goal: identify needed research to characterize and address ethical dilemmas that arise in the provision of ECLS
- Literature review
- Iterative consensus process
  - Developed comprehensive list of unanswered ethical questions
  - Refined and categorized questions
  - Selectively narrowed questions based on:
    - Prevalence in ECLS
    - Uniqueness to ECLS
    - Urgency
    - Feasibility to study
    - Potential to advance the practice of ECLS and improve quality of patient care
Comprehensive Literature Search Results

Publications addressing “ethics” and “ECLS” 1985-present
## Research Agenda

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Impact of Scholarship

Presentations

• Ethical Struggles in Extracorporeal Life Support
  *Extracorporeal Life Support Organization 23rd Annual Conference, 2012*

• End of Life Decisions and Palliative Care in ECLS
  *Children’s National 30th Annual ECLS Conference, 2014*

Abstracts

• Are Medically Complex Children at Risk for the Underutilization of ECLS?
  *American Society for Bioethics and Humanities Annual Meeting, 2012*

• Providers’ Opinions about the Use of ECLS during Crisis Standards of Care
  *Pediatric Academic Societies Annual Meeting, 2013*
Impact of Scholarship

Publications

• Examining Palliative Care Team Involvement in Automatic Consults for Children on Extracorporeal Life Support (ECLS) in the Pediatric ICU

• Ethics in Extracorporeal Life Support: A Research Agenda
  *Submitted to Ped Crit Care Med*

• Clinicians’ Attitudes about the Use of ECLS during Crisis Standards of Care
  *Manuscript in progress*

• Determining Eligibility Criteria for Pediatric ECLS: How do Physicians Decide?
  *Manuscript in progress*
Future Research
Optimizing Shared Decision-Making in ECLS

The Problem

• The decision-making process to utilize ECLS is highly variable
• It is poorly understood how ECLS clinicians incorporate parents into the ECLS decision
• The benefits and burdens of shared decision-making are not well understood for parents and clinicians in these circumstances
• Existing models for shared decision making models may not be well suited for the unique conditions of ECLS

The Question

• How can we optimally support parents to participate in shared decision-making while minimizing burden and ultimately reduce the risk of both long-term mental illness as well as decisional regret?
The Shared Decision-Making Continuum

- **Greater Parentalism**
- **Greater Supported Parental Authority**
- **ECLS not offered to family**
- **Degree of shared decision making**
- **High risk of mortality or morbidity**
- **50/50 chance of survival**
- **Good chance of survival**
- **Near 100% survival**

- **Can we relieve parents of some of the burden of shared decision making when we strongly recommend ECLS?**
- **ECLS may be compelled if family declines**
- **Steady shift over time to utilize ECLS in cases of lower and lower predicted survival ("pushing the envelope")**
- **Utilization of ECLS in this range is likely very variable between institutions**

- **Death highly likely**
Optimizing Shared Decision-Making in ECLS

Objectives

• Describe current decision making practices (technique and variability)
• Assess ECLS clinicians’ views on optimal shared decision making models
• Assess parents’ understanding of the risks of mortality and morbidities
• Assess parents’ experience and desires of their role in decision making
• Inform a proposal for a shared decision-making tool for future research

Outcomes of Interest

• Parental comprehension
• Parental stress
• Parental satisfaction
• Parental decisional regret
• Clinical team satisfaction
• Clinical team moral distress
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