Mechanical Circulatory Support: Realistic Expectations and Communication with Families

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• I have no conflicts of interest
• I have no financial disclosures
Objectives

• Discuss:
  – Risks associated with Mechanical Circulatory Support (MCS)
  – Parent/family perspectives of communication issues and their child’s care while on MCS and at end of life
  – Improving communication regarding serious illness care goals
  – Provide a case study for review
ECMO and VAD Support

• Bridge to recovery
• Bridge to decision
• Bridge to transplant
• Destination therapy (VAD support)
## ECMO Outcomes

### Overall Outcomes

<table>
<thead>
<tr>
<th></th>
<th>Total Patients</th>
<th>Survived ECLS</th>
<th>Survived to DC or Transfer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Neonatal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>28,723</td>
<td>24,155</td>
<td>21,274</td>
</tr>
<tr>
<td>Cardiac</td>
<td>6,269</td>
<td>3,885</td>
<td>2,599</td>
</tr>
<tr>
<td>ECPR</td>
<td>1,254</td>
<td>806</td>
<td>514</td>
</tr>
<tr>
<td><strong>Pediatric</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>7,210</td>
<td>4,787</td>
<td>4,155</td>
</tr>
<tr>
<td>Cardiac</td>
<td>8,021</td>
<td>5,341</td>
<td>4,067</td>
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<tr>
<td>ECPR</td>
<td>2,788</td>
<td>1,532</td>
<td>1,144</td>
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<tr>
<td><strong>Adult</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Respiratory</td>
<td>9,102</td>
<td>5,989</td>
<td>5,254</td>
</tr>
<tr>
<td>Cardiac</td>
<td>7,850</td>
<td>4,394</td>
<td>3,233</td>
</tr>
<tr>
<td>ECPR</td>
<td>2,379</td>
<td>948</td>
<td>707</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>73,596</td>
<td>51,837</td>
<td>42,947</td>
</tr>
</tbody>
</table>


Extracorporeal Life Support Organization
2800 Plymouth Road
Building 300, Room 303
Ann Arbor, MI 48109

www.elso.org
ECMO Complications

• Bleeding (38%)
• Thrombosis (30%)
• Mechanical (15%)
• Neurologic (13%)
• Renal failure (12%)
• Health care acquired infection (12%)
• Limb Ischemia (1%)
Pediatric VAD Support

Cumulative Hospital, Patient, and Device Enrollment Counts for Durable Devices
September 19, 2012 - June 30, 2015

Devices
Patients
Hospitals with Enrolled Patients

Implant Date

Ventricular Assist Device Outcomes

• 81% survival at 6 months
• Serious adverse events
  – Device malfunction (~39%)
  – Infection (39%)
  – Bleeding (34%)
  – Neurologic dysfunction (26%)
Parental Perspectives on Suffering and Quality of Life at End-of-Life in Children With Advanced Heart Disease: An Exploratory Study*

Elizabeth D. Blume, MD¹; Emily Morell Balkin, MD¹; Ranjit Aiyagari, MD²; Sonja Ziniel, PhD³; Dorothy M. Beke, RN, MS, CPNP-PC/AC¹; Ravi Thiagarajan, MD¹; Laura Taylor, MD²; Thomas Kulik, MD¹; Kenneth Pituch, MD²; Joanne Wolfe, MD⁴

- 86% intubated, 46% on MCS prior to death
- 78% died during withdrawal of support, 16% during CPR
- According to parents 47% children suffered “a great deal”, “a lot” or “somewhat”
- Parents recognized there was no chance of survival a median of 2 days prior to death
- 84% found quality of care to be “very good” or “excellent”

Blume et al. 2014. PCCM(15)4: 336+
Includes 18% who never realized this

- 40% >14 days
- 26% 7-10 days
- 10% 4-7 days
- 10% 1-3 days
- 22% <1 day

Blume et al. 2014. PCCM(15)4: 336+
25% reassured by hope of ECMO therapy
60% felt they had no choice but to consent to ECMO
Information from clinical team and observation of daily progress decreased fears (94% found ECMO resource book for parents helpful)

Non-survivors
- 22% recalled 1st hearing of possibility of death only after lack of progress
- 25% expected recovery despite withdrawal of support**
- 93% comforted by follow-up contact by clinical team
- Only 72% of non-survivors would consent to ECMO again (p < 0.0001)
Improving End of Life Care

• Honesty and full disclosure
• Accurate and timely information
• Accessibility of providers
• Communication and care coordination
• Emotional expression and support of staff
• Preservation of parent-child relationship
• Faith and spirituality

Parents’ perspectives on physician-parent communication near the time of a child’s death in the pediatric intensive care unit*

Kathleen L. Meert, MD; Susan Eggly, PhD; Murray Pollack, MD; K. J. S. Anand, MBBS, DPhil; Jerry Zimmerman, MD, PhD; Joseph Carcillo, MD; Christopher J. L. Newth, MB, ChB; J. Michael Dean, MD; Douglas F. Willson, MD; Carol Nicholson, MD; and the National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network

• Physician availability and attentiveness to parents’ need for information cited as most frequent communication issue
• Communication issues
  – Honesty and comprehensiveness of information
  – Affect that information was provided
  – Complexity of vocabulary and pace of providing information
  – Contradictory information
  – Nonverbal communication
  – Withholding information and providing false hope

Meert, et al. 2008. PCCM (9)1:2+
Hope

• Hope as a multiple entity
• Allow for other hopes to emerge/remain
• Probe deeper into what the patient/family hopes for
• Allow for the emotions that come with hope to identify guiding principles for making difficult decisions
• Focusing on specific hopes

Feudtner.2009.NEJM(361)24:2306+
Consent

• Provision of accurate and timely information
• Are issues and risks heard and understood?
  – Potential associated complications
  – When mechanical circulatory support is no longer a benefit
  – When to stop support
• Daily discussions
  – Build trust
  – Interdisciplinary team involvement

http://ecmoadvantage.com/ecmo-and-consent-the-importance-of-communication
Early discussions regarding goals of care are associated with

- Better quality of life
- Reduced use of non-beneficial therapies
- Optimized goal-consistent care
- Positive family outcomes
- Reduced costs
Communication About Serious Illness

- Best practices in discussing goals of care
  - Sharing prognostic information
  - Eliciting decision making preferences
  - Understanding fears and goals
  - Exploring views on trade-offs and impaired function
  - Exploring wishes for family involvement
Systematic Approach to Improve Communication

• Identify patients at risk
• Timing conversations in outpatient setting prior to crisis
• Educate patients and families
• Checklists
• Designated section in MR for documentation
• Measure and report performance
• Train clinicians**

Bernacki and Block. 2014. JAMA (174) 12: 1994+
Program to enhance relational and communication skills (PERCS) improved clinicians’
- Preparation
- Communication and relational skills
- Confidence
- Decreased anxiety
Program to Enhance Relational and Communication Skills (PERCS) Training

Meyer et al. 2009. PCCM (10) 3:352+
• Dedicated palliative care teams at all hospitals routinely providing EOL care
• Integration of palliative care in medical plan of care for all children with life-threatening or life-shortening disease
• Education and training requirements for all pediatric general and subspecialty clinicians
Rationale for Early Palliative Care

- Substantial burden of complex illness and death
- Frequent uncertain long-term prognosis
- High potential for therapies causing pain or distress
- Facilitation of complex care planning
- Continuity of care through phases of diagnosis and illness
- Shared goal of optimizing quality of life
- Facilitation of end-of-life planning when appropriate

Carter et al. (2006). Child and Adolesc Psych Clinic NA: 759+
www.ninr.nih.gov/conversationsmatter/pcproviders
Case Study

- 17 yo boy with cystic fibrosis, s/p lung transplant with end-stage respiratory failure, requiring VV-ECMO as bridge to repeat lung transplant
  - Neurologically intact
  - Fully conscious in ICU, mobile, playing video games and visiting with friends and family
- Diagnosed with post-transplantation PTLD after ECMO cannulation
  - Patient removed from transplant list

Troug. et al. 2015. Lancet (3): 597+
Case Study

• Options
  – Discontinuing ECMO support immediately
  – Maintaining ECMO support indefinitely
  – Continuing ECMO support with restricted treatment without escalation of care
• Patient and family informed that lung transplantation no longer an option
• Decision needed to be made: patient deferred to family

Troug. et al. 2015. Lancet (3): 597+
Case Study Follow-up

- ECMO interdisciplinary working group through the department of ethics

- Recommendations included
  - ECMO may continue after delisting if desired by patient/family and benefits outweigh burdens
  - Patient/family consent needed if decision made not to maintain ECMO circuit
  - Informative, compassionate communication strategy for discussions with all patients and families regarding
    - ECMO initiation
    - Continuing ECMO (regular, ongoing updates)
    - Discontinuation of ECMO
Conclusions

• MCS is associated with significant risks of mortality and morbidity
• Families may have a limited understanding of the risks and benefits of MCS
• Early, systematic approach to communication between clinicians and patients is important and should be on-going
• Good communication results in positive patient and family experiences
• Structured education curriculums for clinicians can help improve communication and relational skills with families of critically ill children
Thank You!