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Ethical and end of life considerations for neonates requiring ECMO support

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ABSTRACT

ECMO has proven to be a life-saving intervention for a variety of disease entities with a high rate of survival in the neonatal population. However, ECMO requires clinical teams to engage in many ethical considerations. Even with ongoing improvements in technology and expertise, some patients will not survive a course of ECMO. An unsuccessful course of ECMO can be difficult to accept and cause a great deal of angst. These questions can result in real conflict both within the care team, and between the care team and the family. Herein we explore a range of ethical considerations that may be encountered when caring for a patient on ECMO, with a particular focus on those courses where it appears likely that the patient will not survive. We then consider how a palliative care approach may provide a tool set to help engage the team and family in confronting the difficult decision to discontinue ECMO.

Introduction

Initially established for use in neonates, extracorporeal membrane oxygenation (ECMO) utilization continues to expand at unprecedented rates in the pediatric and adult populations. However, given continued advancements in medical care, numbers of neonatal ECMO runs have declined steadily.[1] In the current era, neonatal patients being supported with ECMO are typically more complex, with frequent co-morbidities, and increased risk of mortality. ECMO is used in neonates electively to stabilize from ongoing deterioration, urgently for rescue prior to imminent cardiovascular collapse, and emergently when cardiopulmonary resuscitation (CPR) is ongoing (E-CPR).[2–4] With ever increasing use for new indications, it is important for the clinician at the bedside to have a solid understanding of ethical issues associated with ECMO, appropriate management of the unsuccessful ECMO course, and key components of palliative and high quality end of life care for the patient on ECMO. We will therefore discuss ethical considerations surrounding ECMO initiation and utilization, challenges in stopping the unsuccessful ECMO course, palliative care for the patient on ECMO, and practical considerations for withdrawal of ECMO support.

Ethical considerations when initiating ECMO

Generally, ECMO is initiated for a few broad purposes: bridge to recovery (known reversible disease), bridge to decision (providing time for recovery, diagnosis, clarification of prognosis, or determination of candidacy for alternate mechanical support or organ replacement)[5,6] and rarely in neonates as a

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Table 1 – Purposes for ECMO utilization across neonatal, pediatric and adult populations.

Bridge to recovery—time of ECMO support to allow recovery from injury or illness and ability to regain adequate cardiopulmonary function to allow successful decannulation
Bridge to decision—time of ECMO support to allow investigation, diagnosis, or prognostic data gathering to determine potential for recovery or organ replacement candidacy
Bridge to organ replacement—time of ECMO support while awaiting heart, lung, or heart-lung transplantation; often transition to longer-term extracorporeal device (e.g., ventricular assist device) would be considered
Bridge to a bridge—time of ECMO support to recover end organ function and investigate and confirm candidacy before transitioning to longer-term device (e.g., implantable ventricular assist device)

bridge to a bridge (stabilize to transition to longer-term assist device), or a bridge to organ transplant (Table 1). Overtime, ECMO has been used in complex multi-organ illness and novel situations, making standard of care difficult to define and contraindications blurry. For this reason, when initiating ECMO, being clear on the broad purpose can help both care providers and families to better understand later the threshold for stopping in a course that is unsuccessful in accomplishing the intended goal.[7]

Informed consent

The intended goal is also relevant to improving informed consent. Due to the urgent nature of ECMO utilization and the state of illness prompting the need to initiate, informed consent is challenging. Neonates, additionally, can have made no indication of preference and decisions are left to the surrogate (generally parents) and the medical team. Emotional distress, complexity of the intervention, speed of initiation that may limit full disclosure, and risk for therapeutic misconception (ECMO as curative rather than supportive therapy), combined with a tendency of surrogates to favor information biased toward survival present challenges.[8–13] Overall, a complete understanding of risks and even benefits, particularly in the long term is likely to be incompletely comprehended by families when their child is ill enough for ECMO to be considered. Additionally, uncertainty in outcomes and prognostic difficulty surrounding intact survival often leaves the medical team with a limited ability to know if ECMO is in the best interest of the patient at the outset.

To mitigate the inherent challenges of fully informed consent in ECMO it is imperative that ongoing communication about risks, benefits, and potential for failure occurs early, transparently, and repeatedly throughout the ECMO course.[2,7,14] Timelines for reassessment of the balance of benefits and burdens, identification of key markers indicating progress or worsening, and emphasis on the temporary nature of the support, can help families understand how to interpret success or lack thereof as the course continues.[2] While conversations about the potential need to stop ECMO without successful achievement of the broad purpose should be undertaken early and repeated as the clinical course progresses, true consent for decannulation cannot be properly achieved when starting. Here, consent for decannulation would be made under duress and the knowledge that the technology will otherwise be withheld can be deemed coercive. Should stopping an unsuccessful ECMO course be met with disagreement by the surrogate decision makers, the withdrawal of previous consent to decannulate is not only permissible, but also likely. Additionally, previous consent would not supersede the need for extensive communication, mediation and support for both the family and the medical team. Consequently, such conflict is likely best avoided by clear communication throughout the course about the goals of ECMO, and whether the goals are being met.

Finally, at both the initiation of ECMO and around a decision to stop ECMO, providing appropriate information on potential future quality of life (QOL) is challenging. Many people live and thrive with complex medical problems and a quality of life that differs from others without complex medical problems, but is on par with those similarly challenged.[15–18] Studies exploring QOL judgments recurrently demonstrate inaccurate assessments that over or underestimate parental or patient rated quality of life,[17,19,20] a changing impression of QOL across a lifespan, and a higher than anticipated judgment after recovery from illness than prior or during the acute phases.[17,20–22] Finally, the range of acceptable QOL is subjective, individual, and value based for the family and for care team members.

Resource utilization

Beyond the day-to-day challenges of consent associated with initiating ECMO in the individual patient are concerns for resource allocation when utilizing this expensive technology. Importantly, allocations should be made prior to an individual contentious patient course, particularly when restricting ECMO use. Good allocation should ensure fair and equal access to the therapy for patient populations with specific diseases or indications. It should also include a mechanism for team discussion and consensus on offering ECMO at a particular institution in novel circumstances. Policies to ensure fair allocation should ensure a balance of potential benefit for cost and appropriate team and institutional support for offering (or restricting). Considerations for just resource allocation are listed in Table 2. As data accumulate on the effectiveness of ECMO in certain indications, outcomes-based review of appropriateness can better inform such policies.[7]

Creating policy that appropriately allocates resources, however, requires assessment of cost-effectiveness. Employing measures of quality-adjusted life years (QALY) saved can be utilized and has been used in some assessments of ECMO cost effectiveness,[23,24] although defining a QALY also requires subjective judgment.[25–27] Studies done comparing outcomes with