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Evaluating quality of life of extracorporeal membrane oxygenation survivors using the pediatric quality of life inventory survey☆

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ABSTRACT

Purpose: This study assesses the impact of extracorporeal membrane oxygenation (ECMO) associated morbidities on long-term quality of life (QOL) outcomes.
Methods: A single center, retrospective review of neonatal and pediatric non-cardiac ECMO survivors from 1/2005–7/2016 was performed. The 2012 Pediatric Quality of Life Inventory™ (PedsQL™) survey was administered. Clinical outcomes and QOL scores between groups were compared.
Results: Of 74 patients eligible, 64% (35 NICU, 12 PICU) completed the survey. Mean time since ECMO was 5.5 ± 3 years. ECMO duration for venoarterial (VA) and venovenous (VV) were similar (median 9 vs. 7.5 days, $p = 0.09$). VA ECMO had higher overall complication rate (64% vs. 36%, $p = 0.06$) and higher neurologic complication rate (52% vs. 9%, $p = 0.002$). ECMO mode and ICU type did not impact QOL. However, patients with neurologic complications ($n = 15$) showed a trend towards lower overall QOL (63/100 ± 20 vs. 74/100 ± 18, $p = 0.06$) compared to patients without neurologic complications. A subset analysis of patients with ischemic or hemorrhagic intracranial injuries ($n = 13$) had significantly lower overall QOL (59/100 ± 19 vs. 75/100 ± 18, $p = 0.01$) compared to patients without intracranial injuries.
Conclusion: Neurologic complication following ECMO is common, associated with VA mode, and negatively impacts long-term QOL. Given these associations, when clinically feasible, VV ECMO may be considered as first line ECMO therapy.
Type of study: Retrospective review.
Level of evidence: II

1. Background

Extracorporeal membrane oxygenation (ECMO) is a form of cardiopulmonary bypass used in patients with cardiopulmonary failure refractory to conventional medical therapy. Initial experience using ECMO in neonates with respiratory failure showed a mortality rate of 63% with intracranial bleeding occurring in 43% of patients [1]. With advances in technology and critical care, mortality rates in neonates and children receiving ECMO have improved to 41–43% [2,3].

With improvements in mortality, efforts have focused on improving short and long-term morbidity. Neurologic complications including intracranial hemorrhage and stroke are associated with ECMO, particularly with the use of venoarterial (VA) mode of support [4–6]. Despite the significant neurologic morbidity, few studies have evaluated the quality of life in neonatal and pediatric ECMO survivors. This knowledge deficit limits the ability of physicians to accurately counsel patients and their families on the implications of ECMO on quality of life in long-term survivors.

In this study, we performed a prospective cross-sectional evaluation of the impact of ECMO associated morbidities on long-term quality of life (QOL) outcomes using the Pediatric Quality of Life Inventory™ (PedsQL™) [7,8]. We hypothesize that neonatal and pediatric non-cardiac ECMO patients who undergo VA ECMO have a high risk of neurologic complications which negatively impacts their long-term quality of life.

☆ Disclosures: The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

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2. Methods

2.1. Study design and patient selection

After approval for this study by the Baylor College of Medicine Institutional Review Board (H-39373), we performed a retrospective review of all children in the neonatal intensive care unit (NICU) and pediatric intensive care unit (PICU) who underwent extracorporeal membrane oxygenation at Texas Children's Hospital from January 2005 to July 2016. Patients were identified using the International Classification of Diseases (ICD-9) diagnosis code 39.65 (extracorporeal membrane oxygenation) and the following Current Procedural Terminology (CPT) codes for initiation, insertion, repositioning, or removal of central or peripheral catheter for ECMO: 33946, 33947, 36823, 33951, 33952, 33953, 33954, 33955, 33956, 33957, 33958, 33959, 33962, 33963, 33964, 36822, 33965, 33966, 33969, 33984, 33985, and 33986. All cannulations were placed by pediatric general surgeons. Patients who have died after ECMO or underwent ECMO for primary cardiac indications such as congenital heart disease, myocarditis, etc. were excluded. Children under the age of 2 years or over 18 years at time of survey administration were excluded due to age restrictions of the survey tool.

A prospective telephone survey was performed. All eligible patients were initially contacted by mail. In the letter, this study was introduced and potential participants were given the option of opting out of receiving a telephone call to complete a survey. Two weeks later, patients who did not opt out of the study were contacted. Consent to participate in the study was obtained over the telephone prior to survey administration.

Data collected from the medical record included demographics, age at time of surgery, duration of ECMO, indication for ECMO, and complications. Complications are defined according to the Extracorporeal Life Support Organization (ELSO) registry [9,10]. Complication categories include mechanical, hemorrhagic, neurologic, renal, pulmonary, cardiopulmonary, infectious, and metabolic. Mechanical complications include equipment failures, pump malfunction, and clots in the system requiring change of equipment or intervention. Neurologic complications include clinical brain death, seizures, infarction, or hemorrhage. Pulmonary complications include pneumothorax and pulmonary hemorrhage requiring intervention.

2.2. Quality of life survey

The 2012 Pediatric Quality of Life Inventory™ (PedsQL™), version 4.0, MAPI Research Trust (Texas A&M University) was used to assess quality of life. This tool has been validated and been shown to be applicable across multiple ages and health conditions [7,8]. Four forms were available for different age groups. The Parent Report for Toddlers (Ages 2–4 years) contains 21 items split between four domains: Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning. School functioning questions were omitted for children not attending school or daycare, per survey design. The Parent Report for Young Children (Ages 5–7 years), Children (Ages 8–12 years) and Teens (Ages 13–18 years) each contain an additional 2 questions in the School Functioning domain ("paying attention in class" and "forgetting things") for a total of 23 questions. All questions are phrased "Please tell us how much of a problem each one has been for your child during the past ONE month." Answer choices are on a 5-point Likert scale representing never a problem, almost never a problem, sometimes a problem, often a problem, and almost always a problem. The PedsQL™ Generic Core Scales system was used to compute quality of life scores. Scores from the Likert scale were transformed to a scale from 0 to 100, with 100 representing the highest quality of life score. Scores for each domain were summated. An overall quality of life score was computed by averaging the scores for all questions answered. In addition, the Physical Functioning Summary Score (Physical Functioning domain alone) and the Psychosocial Functioning Summary Score (Emotional, Social, and School Functioning domains) were calculated by averaging scores from specific domains. We compared quality of life scores for intensive care unit (ICU) type, ECMO mode, and neurologic complications.

2.3. Statistical analysis

Baseline patient demographics were analyzed using descriptive statistics. We compared outcomes and quality of life scores by ICU type (PICU vs. NICU), ECMO modality (venovenous [VV] vs. venoarterial [VA]), and complication category. Quality of life scores for patients with intracranial injury were also compared to patients without an intracranial injury. All continuous data including PedsQL™ scores were analyzed using Mann–Whitney *U* test for nonparametric and Student's *t* test for parametric data. Categorical variables were compared using χ^2 test or Fisher's Exact test. To determine the internal consistency of responses to the survey, a Cronbach's alpha reliability coefficient was calculated. All statistical analysis was performed using SPSS (version 24, IBM SPSS). A p-value <0.05 was considered significant.

3. Results

3.1. Patient cohort and demographics

During the study period, a total of 219 patients underwent ECMO cannulation (Fig. 1). Of these, 71 died prior to survey administration. Fifty-one patients who received ECMO for primary cardiac indications were excluded. At the time of survey administration 19 patients were under 2 years of age and 2 patients were over 18 years old. As the PedsQL™ is validated only for use in children ages 2 to 18 years old, these 21 patients were excluded. Letters were mailed to the remaining 76 patients for participation in the study. Two addresses were undeliverable and they were not contacted via telephone. Thus, 74 patients were eligible for survey participation. A total of 47 patients completed the survey questionnaire and formed the final cohort for our analysis. This represents a 64% survey response rate. Median age at initiation of ECMO was 1 day old (Table 1). Thirty-five patients were in the NICU

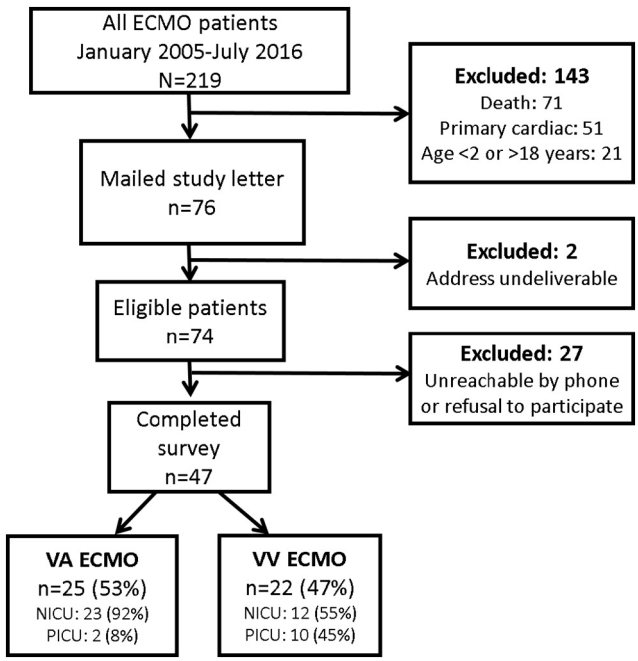

Fig. 1. Study population inclusion and exclusion criteria. ECMO (extracorporeal membrane oxygenation), VA (venoarterial), VV (venovenous), NICU (neonatal intensive care unit), PICU (pediatric intensive care unit).

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