The 1-Year Follow-Up Clinic for Neonates and Children After Respiratory Extracorporeal Membrane Oxygenation Support: A 10-Year Single Institution Experience*

Suzan Kakat, MD[1]; Maura O'Callaghan, RN, MSc[1]; Liz Smith, RN, MSc[1]; Raymond Hreiche, MD[1]; Deborah A. Ridout, MSc[2]; Jo Wray, PhD[1]; Timothy Thiruchelvam, MBChB[1]; Katherine L. Brown, MD, MPH[1]; Aparna U. Hoskote, MD, MRCP[1]

Objectives: To establish the effectiveness of a "1-year extracorporeal membrane oxygenation follow-up clinic" and to characterize any neurodevelopmental concerns identified.

Design: Single-center retrospective cohort of respiratory extracorporeal membrane oxygenation survivors over 10 years.

Setting: Nationally commissioned center for neonatal and pediatric (> 28 d of life) respiratory extracorporeal membrane oxygenation.

Patients: Children attending the follow-up clinic 1 year after receiving respiratory extracorporeal membrane oxygenation between 2003 and 2013.

Interventions: Standardized follow-up 1 year after extracorporeal membrane oxygenation.

Measurements and Main Results: In 10 years, 290 children received extracorporeal membrane oxygenation, 194 (67%) survived; all were offered 1-year follow-up, and 98 (51%) attended the clinic. Among these, 51 of 98 (52%) had meconium aspiration syndrome, and 74 of 98 (75%) were on veno-arterial extracorporeal membrane oxygenation with a median (interquartile range) duration of 6 days (4–8 d). Neurodevelopmental problems were identified in 30 of 98 (30%). The specific abnormalities noted included neurologic (seizures, motor, or vision abnormalities) ($n = 8$), hearing with/without language delay ($n = 8$), and behavioral problems (as reported by parents) ($n = 6$), with eight of 30 (27%) having difficulties spanning these domains. An acute neurologic event on extracorporeal membrane oxygenation was found to be the only risk factor for neurodevelopmental concerns ($p = 0.006$ with odds ratio 5.4 [95% CI, 1.63–17.92]). Despite having neither a cardiac arrest nor an acute neurologic event documented, 18 of 74 (24.3%), 95% CI (15.1–35.7), had neurodevelopmental concerns at 1-year follow-up. Among the nonattenders, 30 (15%) had local follow-up, and 66 (34%) were lost to follow-up.

Conclusions: All extracorporeal membrane oxygenation survivors need follow-up either at the extracorporeal membrane oxygenation center or in their community, as evidenced by the 1-year follow-up data. Our 1-year extracorporeal membrane oxygenation follow-up clinic provides an opportunity to engage with families, identify neurodevelopmental concerns, and signpost to appropriate services. Of concern, one third of survivors are lost to follow-up, some with an acute neurologic event on extracorporeal membrane oxygenation, a significant risk factor. A consensus-based standardized national follow-up program is vital. (*Pediatr Crit Care Med* 2017; 18:1047–1054)

Key Words: extracorporeal membrane oxygenation; follow-up pathway; neonates; neurodevelopmental outcome; pediatrics

With advances in neonatal and pediatric critical care, the use of extracorporeal membrane oxygenation (ECMO) for reversible cardiorespiratory failure has resulted in improved survival, thus resulting in a growing population of childhood survivors (1–3). Longitudinal follow-up studies in the United Kingdom from the Collaborative U.K. ECMO Trial (4–7) and the recent multicenter intervention trial, Neonatal ECMO Study of Temperature (NEST) (8), have shown that up to 50% of neonatal respiratory ECMO survivors have neurodevelopmental issues. Furthermore, longitudinal multidisciplinary follow-up studies of neonatal ECMO survivors from the Netherlands describe a spectrum of neurodevelopmental problems faced by some of these children from early

*See also p. 1070.

[1]Cardiac Intensive Care Unit, Charles West Division, Great Ormond Street Hospital NHS Foundation Trust, London, United Kingdom.

[2]Population, Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, United Kingdom.

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For information regarding this article, E-mail: Aparna.hoskote@gosh.nhs.uk

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childhood to adolescence, thus highlighting the benefits of surveillance and early intervention (9–12). Certain primary diagnostic groups such as congenital diaphragmatic hernia (CDH) are associated with long-term neurodevelopmental sequelae regardless of whether supported on ECMO or not (13, 14). In neonatal and pediatric cardiac ECMO survivors, up to 50% have notable neurodevelopmental problems (5, 6, 15–18). Reports on long-term outcome after non-neonatal respiratory ECMO also demonstrate neurodevelopmental concerns (19, 20). Despite this body of evidence, established ECMO follow-up clinics are not widely provided as a routine service. These gross or subtle neurodevelopmental issues may manifest over time with significant implications for children's health, educational attainments, and integration into society (10, 21–23). The Extracorporeal Life Support Organization (ELSO) recommends regular follow-up of ECMO survivors. However, understanding what the optimal follow-up should constitute in terms of the type and frequency of testing remains unclear, and there is no national or international consensus on optimal follow-up guidelines.

The 1-year ECMO follow-up clinic at our specialist pediatric hospital has been in operation since 1995 for children supported on respiratory ECMO and is run by an ECMO nurse specialist and/or ECMO physician. The ECMO specialist nurse is a senior pediatric nurse, and the ECMO physician is a consultant pediatrician, both trained in the basic developmental examination of a child. The aim of the clinic is to identify areas of neurodevelopmental concern, especially those that have previously been unrecognized, and to facilitate referral to appropriate services for more detailed assessment and intervention. The clinic also gives parents the opportunity to discuss any concerns following discharge from the initial ECMO admission. For those unable to attend, a letter is sent to the general practitioner (GP) with the request for outcome information. We reviewed the 1-year ECMO follow-up clinic to assess uptake with ECMO families and to study the utility and effectiveness in identifying neurodevelopmental concerns and facilitating appropriate referrals, with the overarching aim of using this information to develop a framework for structured national follow-up of these children at high risk of neurologic morbidity.

METHODS

The study was approved as a retrospective audit and quality improvement project by our institution. All children supported on respiratory ECMO and those who attended the 1-year ECMO follow-up clinic from 2003 to 2013 were identified from the institutional ECMO database. The demographics, primary diagnosis, clinical course, ECMO run, including any mechanical complications that necessitated coming off ECMO, acute neurologic events (ANEs), relevant electrophysiology and neuroimaging on ECMO, and reconstruction of neck vessels were recorded. In our institution, all children supported on ECMO have routine surveillance for seizures with an electroencephalogram and have cranial ultrasound scans (if the fontanelle provides an acoustic window) within 24 hours of going on to ECMO. Repeat tests are done routinely every week or more frequently if any clinical concerns are identified. An ANE on ECMO was defined as one or more of the following: seizures (clinical or electroencephalographic), intracerebral hemorrhage, infarct or generalized edema (the latter three from neuroimaging scans). All children attending the clinic had a detailed medical and developmental history taken from their parents and underwent a clinical and a basic developmental examination to identify any concerns and to facilitate further investigations and referral, if appropriate. Follow-up data on those children who did not attend the clinic were collected from GP letters and other relevant correspondence, when available.

Categorical data are summarized as frequency and percentage and continuous data using mean and SD for normally distributed data and median and interquartile range (IQR) for skewed data. On the basis of the detailed medical and developmental history taken from parents, and a clinical and a basic developmental examination performed, neurodevelopmental concerns were grouped into three domains: neurologic (seizures and/or motor abnormalities and/or visual problems), hearing (as diagnosed by standard audiology tests) with or without language delay, and behavioral problems. Comparisons between neonatal and pediatric (29 d to 16 yr old) ECMO patients were made using chi-square tests for categorical data and a Mann-Whitney *U* test for skewed data; similarly for comparisons between children with and without neurodevelopmental concerns at 1 year. Logistic regression analysis was used to examine the relationship between potential predictors of interest and the presence of neurodevelopmental concerns at 1 year. Factors considered were neonate/pediatric age group, primary diagnosis of CDH, cardiac arrest prior to ECMO cannulation, type of ECMO—veno-arterial versus veno-venous—duration of ECMO, ANE on ECMO, mechanical complication on ECMO, and reconstruction of neck vessels following decannulation from ECMO. For the skewed data, the use of various transformations was investigated but was found not to improve the fit of the models, and hence untransformed results are presented. Odds ratios (ORs) and 95% CIs are presented for each factor, and a p value of less than 0.05 was deemed significant.

RESULTS

Demographics of Entire Cohort

Over the study period of 10 years, 290 children (median age 4 d [IQR, 1–198 d]) were supported on ECMO for intractable respiratory failure, and 194 (67%) survived to 1 year after ECMO (**Fig. 1**). Of these, 130 were neonates (median age 1 d [IQR, 1–2 d]), and 64 were infants and children (median age 1.3 yr[IQR, 0.6–4.8 yr]), 146 were supported on veno-arterial ECMO and 48 on veno-venous ECMO. The demographics, primary diagnosis, cardiac arrest before going on to ECMO, details of the ECMO run, neurologic investigations, and type of ANE identified are shown in **Table 1**. Thirty-five (18%) had suffered a cardiac arrest peri-ECMO support. Thirty-four (18%) suffered an ANE on ECMO. All survivors were offered a 1-year follow-up clinic appointment by correspondence, and 98 (51%) attended the 1-year ECMO follow-up clinic, 30 had

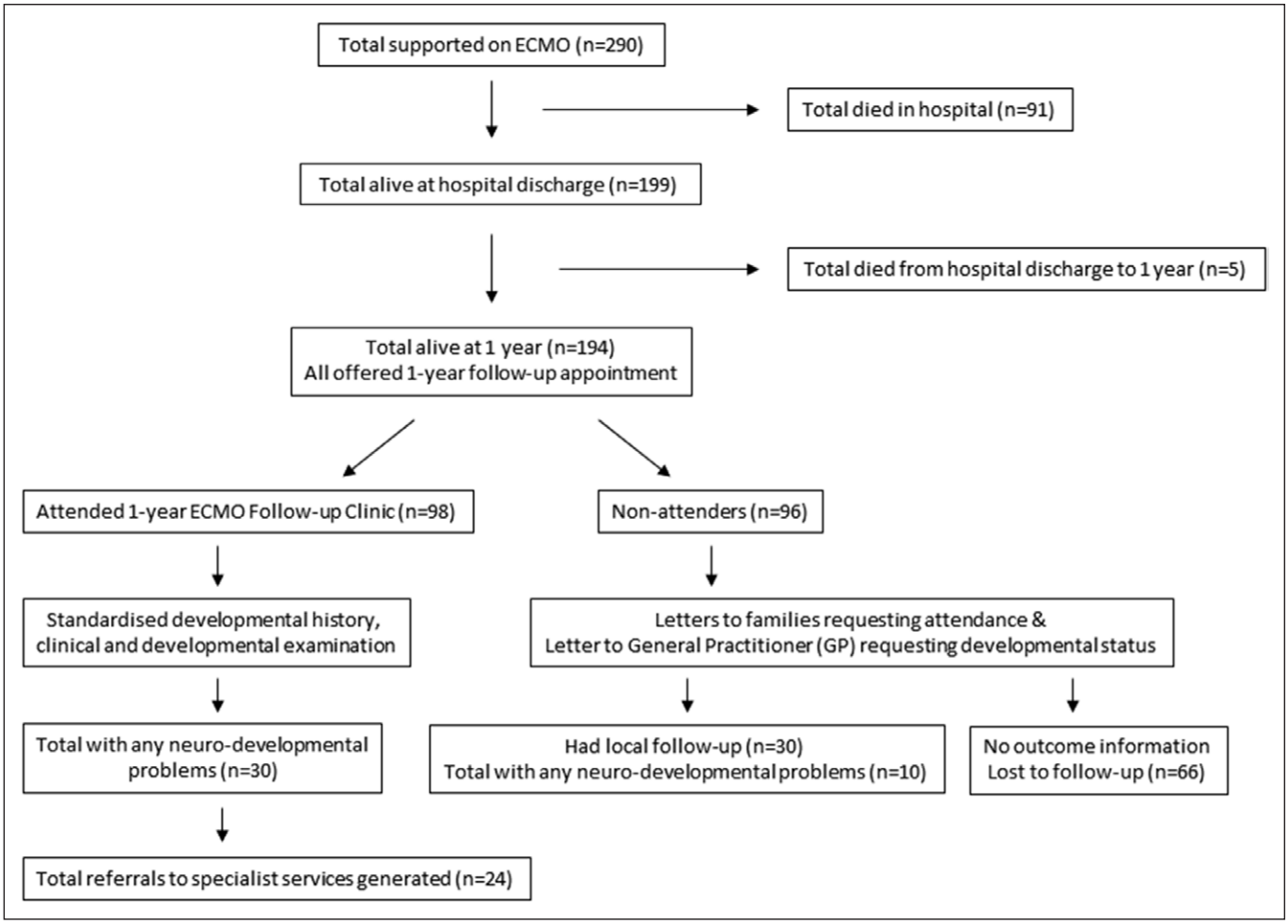

Figure 1. Flow chart of all children supported on extracorporeal membrane oxygenation (ECMO) for respiratory failure supported from 2003 to 2013. This is a flow chart depicting the follow-up of neonates and children who were supported for respiratory ECMO at our institution from 2003 to 2013. All survivors at 1 year ($n = 194$) were offered a 1-yr ECMO follow-up clinic appointment, and 98 (51%) attended the 1-yr ECMO follow-up clinic, 30 had local follow-up, and no follow-up information was available for the remaining 66 children. Out of the 98 who attended the 1-yr ECMO follow-up clinic, 30 had neurodevelopmental problems, and 24 referrals to specialist services were made.

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In those who attended the 1-year ECMO follow-up clinic ($n = 98$), the most common diagnosis was meconium aspiration syndrome (52%). While on ECMO, 14 of 98 (14.3%) developed ANE: nine had seizures (confirmed on electroencephalogram), three developed intracranial bleeds, one had a cerebral infarct, and one had significant cerebral edema. Among the nine who developed seizures, one was associated with intracerebral bleed and another with infarct. Both had suffered a cardiac arrest in the pre-ECMO period.

Of the 96 children who did not attend the 1-year ECMO follow-up clinic, 30 had local follow-up although information was only available for 26. These comprised of 16 neonates and 14 pediatric patients, of whom three had a history of peri-ECMO cardiac arrest, six had ANE on ECMO, and 10 had neurodevelopmental concerns, predominantly of motor and vision; however, details of follow-up with specialist services were not available.

The reasons for nonattendance in the remaining 66 patients were no response to appointment letters in 32 of 66 (48%), geographical distance from the specialist center in 21 of 66 (31%), the parents of four children (6%) declined the follow-up appointment, three (5%) already attended different speciality outpatient clinics at our hospital, and in six (9%), the reason was unclear. For these 66, there was no follow-up information available from their GP or from any relevant correspondence.

The groups with and without any follow-up were largely similar in demographics with the only differences being that the group with follow-up information included more neonates ($p = 0.05$) and fewer patients with cardiac arrest pre-ECMO ($p = 0.05$). The proportion of children with ANE on ECMO was similar between the group who attended the follow-up clinic and those for whom there was no available follow-up information.

Clinical and Basic Developmental Examination Findings at the 1-Year ECMO Follow-Up Clinic ($n = 98$)

Data from the 98 children with known outcomes from the 1-year ECMO follow-up clinic highlighted specific neurodevelopmental concerns in 30 of 98 (30%) in the following domains: neurologic, including seizures or motor or vision

TABLE 1. Clinical Details of the Extracorporeal Membrane Oxygenation Survivors Supported for Respiratory Failure From 2003 to 2013

	Total ECMO Survivors (*n* = 194)	1-Year Clinic Follow-Up (*n* = 98)	Local Follow-Up (*n* = 30)	No Information Available (*n* = 66)
Demographics, *n* (%)				
Neonates < 28 d of life	130 (67)	76 (77)	16 (53)	38 (58)
Infants and children	64 (33)	22 (23)	14 (47)	28 (42)
Primary diagnosis, *n* (%)				
Meconium aspiration syndrome	81 (42)	51 (52)	8 (27)	22 (33)
Persistent pulmonary hypertension of the newborn	18 (9)	8 (8)	5 (17)	7 (10)
Congenital diaphragmatic hernia	18 (9)	7 (7)	3 (10)	8 (12)
Sepsis	13 (7)	10 (10)	1 (3)	4 (18)
Bacterial pneumonia	12 (6)	7 (7)	2 (6)	3 (5)
Viral pneumonia	25 (13)	8 (8)	5 (17)	10 (15)
Acute respiratory distress syndrome	12 (6)	4 (4)	3 (10)	5 (8)
Other	28 (14)	3 (3)	3 (10)	7 (10)
ECMO run				
Veno-venous/veno-arterial	48/129	24/74	12/18	12/54
ECMO duration (d), median (interquartile range)	6 (4–9)	6 (4–8)	6 (5–9)	6 (4–10)
Cardiac arrest pre-ECMO cannulation, *n* (%)				
Yes	35 (18)	15 (15)	3 (10)	17 (25)
Acute neurologic event on ECMO (seizures, intracranial bleeds, cerebral infarcts), *n* (%)				
Yes	34 (17)	14 (14)	6 (20)	14 (21)
Seizures	24 (12)	9 (9)	5 (13)	10 (15)
Bleeds	6 (3)	3 (3)	0	3 (4.5)
Infarcts	3 (1.5)	1 (1)	1 (3.3)	1 (1.5)
Generalized oedema	1 (0.5)	1 (1)	0	0
Abnormal neurologic investigations on ECMO, *n* (%)				
Abnormal electroencephalogram findings	37 (19)	20 (20)	5 (16)	12 (18)
Abnormal cranial ultrasound scan	24 (12.3)	11 (11.2)	3 (10)	10 (15)
Abnormal CT scan	12 (6.1)	4 (4)	1 (3)	7 (10)

ECMO = extracorporeal membrane oxygenation.

The patients who attended follow-up either at our institution or locally were similar to those on whom there was no follow-up information, though there was some evidence that the ones with outcome information included more neonates and fewer with cardiac arrest ($p = 0.05$)

abnormalities ($n = 8$; 27%), hearing ($n = 8$; 27%), and behavior ($n = 6$; 20%), and eight children (27%) had difficulties across multiple domains. Out of these 30 children, a referral or recommendation was made for ongoing specialist support, such as physiotherapy ($n = 5$; 17%), clinical psychology ($n = 5$; 17%), neurology ($n = 5$; 17%), community development center ($n = 3$; 10%), ophthalmology ($n = 2$; 7%), audiology ($n = 2$; 7%), and speech and language therapy ($n = 2$; 7%). Some children needed a referral to more than one specialist service.

The distribution of the potential risk factors of abnormal neurodevelopmental outcome in the two groups with and without neurodevelopmental concerns is shown in **Table 2**. Of the 68 children with no neurodevelopmental concerns at the 1-year follow-up, nine (13%) had a history of cardiac arrest, and five (7%) had an ANE on ECMO. In the 30 children with neurodevelopmental concerns, six (20%) had a cardiac arrest, and nine (30%) had an ANE on ECMO. The proportion of neurodevelopmental problems at 1 year was three of

TABLE 2. Neurodevelopmental Concerns at 1-Year Post Extracorporeal Membrane Oxygenation as Assessed in the Follow-Up Clinic

Variables	Neurodevelopmental Concerns at 1 Yr, *n* = 30	No Neurodevelopmental Concerns at 1 Yr, *n* = 68	*p*
Age (d), median (interquartile range)	1.5 (1–64)	1 (1–11.5)	0.61
Neonate, *n* (%)	22 (73.3)	54 (79.4)	0.51
Congenital diaphragmatic hernia, *n* (%)	3 (10)	4 (5.9)	0.47
Cardiac arrest, *n* (%)	6 (20)	9 (13.2)	0.39
Veno arterial, *n* (%)	24 (80)	50 (73.5)	0.49
ANE, *n* (%)	9 (30)	5 (7.4)	< 0.01
Extracorporeal membrane oxygenation duration (d), median (interquartile range)	6 (5–8)	6 (4–9)	0.46
Reconstruction, *n* (%)	18 (60)	41 (60.3)	0.98
Mechanical complications, *n* (%)	14 (46.7)	36 (52.9)	0.57
No cardiac arrest and no ANE, *n* (%)	18 (60)	56 (82.4)	0.02[a]
Either cardiac arrest or ANE, *n* (%)	9 (30)	10 (14.7)	
Both cardiac arrest and ANE, *n* (%)	3 (10)	2 (2.9)	

ANE = acute neurologic event.
[a]This "*p* value" represents significance between no cardiac arrest and no ANE versus either cardiac arrest or ANE or both (binary categorization).

five (60.0%) if both ANE and cardiac arrest were present, nine of 19 (47.4%) if either one was present, and 18 of 74 (24.3%) if neither a cardiac arrest nor an ANE was present. Of these 18 patients (with neurodevelopmental concerns and neither ANE nor cardiac arrest), two were neonates diagnosed with clinical syndromes (fetal alcohol syndrome and Smith-Magenis syndrome), and one who required ECMO at 27 months old was born at 26 weeks gestation with no associated comorbidities. Excluding infants born prematurely and those having a syndrome from the dataset of those with follow-up data ($n = 98$) left 66 children, of whom 15 (22%) had neurodevelopmental concerns at 1 year. There was no evidence of an increased risk of abnormal neurodevelopmental outcome if a child had a cardiac arrest and then went on to develop an ANE, compared with those who had an ANE without having suffered a cardiac arrest. Furthermore, there was no temporal trend for outcome over the 10-year period.

Univariate logistic regression of risk factors in relation to outcome are shown in **Table 3** and indicate that only ANE on ECMO was significantly related to neurodevelopmental concerns in our cohort with an OR of 5.4 (95% CI, 1.63–17.92), *p* value of less than 0.01. Perhaps surprisingly, cardiac arrest was not associated with the outcome with an OR of 1.64 (95% CI, 0.53–5.11).

Up to 40% of the children in the pediatric (non-neonatal) respiratory group for whom we had follow-up data had suffered a cardiac arrest at the time of going on to support. At follow-up, a significant proportion had behavioral abnormalities as reported by parents (18%), and more than one third (36%) needed referral or recommendation for additional specialist support. Of the 22 children supported on respiratory ECMO in the pediatric age group, five had been born prematurely at a median gestational age of 28.5 weeks (IQR, 27–34 wk), but only one had some preexisting neurodevelopmental concerns and had had an abnormal cranial USS in the neonatal period showing small bilateral intraventricular hemorrhages.

TABLE 3. Logistic Regression of Neurologic Risk Factors in Relation to Outcome (*n* = 98)

Variables	Univariate Odds Ratio (95% CIs)	Univariate *p*
Extracorporeal membrane oxygenation duration (d)	0.99 (0.92–1.07)	0.76
Neonate	0.71 (0.26–1.94)	0.51
Veno-venous vs veno-arterial	0.69 (0.24–1.97)	0.49
CDH vs non-CDH	1.78 (0.37–8.49)	0.47
Cardiac arrest	1.64 (0.53–5.11)	0.39
Acute neurologic event	5.40 (1.63–17.92)	< 0.01
Mechanical complications	0.78 (0.33–1.84)	0.57
Reconstruction	0.14 (0.02–0.99)	0.05
Single vessel vs no	0.21 (0.02–1.88)	0.16
Two vessels vs no	0.22 (0.04–1.31)	0.10

CDH = congenital diaphragmatic hernia.

DISCUSSION

In this study, we describe a single-center experience of a structured 1-year ECMO follow-up clinic of respiratory ECMO

survivors in the 10-year epoch following the completion of the U.K. ECMO Collaborative Trial. We found that 50% of the survivors returned for the 1-year follow-up, and neurodevelopmental morbidity was identified in one third, as assessed by parental reports supplemented by a clinical and developmental examination. The clinic provided an opportunity for the ECMO nurse specialist and/or ECMO physician to meet with the family and an open forum for parents and often children to discuss their experience of ECMO and beyond. Specific clinical concerns were addressed and new referrals made, where necessary. The main reasons for nonattendance were geographical distance and local follow-up; a significant proportion (32/66 [48%]) were lost to follow-up (no response to letters) despite some having significant neurologic morbidity (14/66 [21%]) on ECMO.

Risk Factors for Neurodevelopmental Issues Following ECMO

Several studies, including ELSO registry based studies, have identified risk factors for later neurodisability in ECMO survivors (5, 24–26). In our study, ANE on ECMO (but not cardiopulmonary resuscitation, primary diagnosis of CDH, mode of ECMO, major mechanical complications, or reconstruction of neck vessels) was, not surprisingly, strongly associated with neurodevelopmental concerns at 1 year. Although the proportion of patients supported on veno-arterial ECMO in our study cohort was comparatively high with a potential higher risk of neurologic complications on ECMO (as shown by Polito et al [24] in their study with an OR of 1.7 [95% CI, 1.7–2.0]), there was no similar association between the mode of ECMO support and neurodevelopmental concerns (Table 2). Importantly, concerns were also identified in 22% of patients who had no recognized associated neurologic risk factors such as cardiac arrest prior to ECMO or an ANE on ECMO. Bedside neuromonitoring on ECMO is limited, and neuroimaging such as cranial ultrasound scans (in neonates and infants) and CT scans only provide a one-point assessment; furthermore, findings may evolve during the course of the ECMO run. Although we know that if these tests are abnormal, there is a higher chance of later neurologic morbidity, the converse is not necessarily true, thus highlighting the need for continual vigilance on ECMO and a structured follow-up program aimed at early identification and intervention.

Neurodevelopmental Sequelae in ECMO Survivors

Neurodevelopmental sequelae, in the range of 17–50% of the ECMO survivors, are commonly reported in follow-up studies (4–6, 8, 10, 12, 15–17, 24, 27, 28). The underlying causes are multifactorial (18, 29–32) and are not necessarily preventable. There are several single-center studies with different follow-up protocols comprising neuroimaging and neuropsychologic testing, reflecting the degree of variability in the follow-up data that are acquired (16, 26, 33–37). The U.K. ECMO Collaborative Study is a single study from which sequential neurodevelopmental follow-up data of the survivors who were either randomized to conventional management or ECMO have been published at 1, 4, and 7 years (4–6). At the 1-year follow-up, they reported a higher neurologic morbidity in the ECMO arm with one in four of the ECMO survivors having evidence of impairment with or without disability (6). This is of particular relevance to our 1-year ECMO follow-up clinic, which was established as a follow-on from the U.K. ECMO Trial. The investigators further followed up the trial patients at 4 years and at 7 years, the latter being a permitted assessment at school, and 68 of 89 (76%) were identified as having a cognitive ability in the normal range but with notable difficulties in reading comprehension, memory, and spatial and processing tasks (4).

Comprehensive longitudinal studies of neonatal ECMO survivors from the Netherlands have highlighted the importance of sequential follow-up for identifying problems (10–12, 38–40). Survivors were found to have learning difficulties, and particularly problems with concentration and behavior, when tested around 8 years old (10). However, very few ECMO programs have the resources and capability to offer such detailed follow-up to respiratory ECMO survivors.

In a study of comorbidities and quality of life in pediatric respiratory ECMO survivors (> 30 d and < 18 yr old at the time of ECMO), only 70% reported a normal quality of life. The children had a high degree of hospital readmission (47%) in the first year after ECMO, and a quarter had problems at school (23). In our cohort, behavioral issues were reported by parents in older children supported on ECMO, which may have a long-term impact on social integration and educational potential. This may represent a significant burden to these children and their families and is likely underappreciated. Furthermore, there are few, if any, structured support systems in place for these children in the school and/or community described, both in the United Kingdom and worldwide.

Children supported on ECMO may be at risk of neuropsychologic and behavioral issues as they grow up, with specific difficulties related to spatial ability tasks, memory, judgement, and novel problem solving (4, 9, 12, 41, 42). Wagner et al (43) has documented a discrepancy between parent reports and observer-rated (psychologist) measures of behavioral problems highlighting the importance of professional assessments alongside parent-reported measures, in order to identify any behavioral sequelae and to plan for ongoing support.

Benefits of the 1-Year ECMO Follow-Up Program

The findings from our 1-year ECMO follow-up clinic, together with the unequivocal reports of post-ECMO sequelae in the literature, highlight the need for a directed follow-up clinic for "all" ECMO survivors (regardless of whether they have suffered an ANE), which offers screening and an opportunity to direct ongoing supportive care as necessary. This is evidenced by the experience of our clinic where 24 new referrals were made for 98 attendees. It is an opportunity for the ECMO nurse specialist/physician to have a dialogue with the parents who have been through a traumatic experience with their child having survived a life-threatening illness (44). Primary care providers such as GPs and/or local pediatricians may not be fully

cognizant of the complexities and impact of ECMO support, and parents may find it easier to discuss this directly with the ECMO physicians and nurse specialists. A further benefit for parents, beyond offering a neurodevelopmental assessment of their child, is a subjective one: the positive, shared experience of coming back to meet the nurses/physicians who cared for their child when critically ill.

Performing complex neuropsychologic testing may not always be practical or feasible for a child or family, is time consuming, and needs the expertise of dedicated trained staff. Furthermore, logistics may make it difficult for families to return to the ECMO center, as demonstrated by those who did not attend the 1-year ECMO follow-up clinic. Despite this, the 1-year follow-up clinic provides information to develop a tailored roadmap for follow-up/intervention for an individual child but may require access to the expertise of a physiotherapist, clinical neuropsychologist, speech and language therapist, and pediatrician specialized in developmental assessment within the community. Explaining the importance of follow-up to families at the time of discharge from the ECMO center may improve the attendance rate at the 1-year clinic. For those who are a distance away from the ECMO center, establishing access to identified local services from the time of discharge may be an option so as to ensure that they remain part of an ongoing developmental review. A standardized nationally accepted follow-up pathway would ensure that the local clinicians have the information and knowledge to evaluate and support the infant/child's ongoing developmental needs. Furthermore, if this information was collated and analyzed, it could facilitate the identification of risk factors for specific patterns of brain injury and their clinical correlates.

Limitations

The study describes neurodevelopmental issues assessed in the context of a 1-year ECMO follow-up clinic in a single center. Standard neuropsychologic assessments and behavioral tests were not performed. We acknowledge that these results may have been different had this information been available. In addition, there were survivors who were lost to follow-up with no outcome information, and this may skew the results. ECMO practices vary between institutions, and our single-center experience may be different to other ECMO centers worldwide. However, these observations are important nationally and highlight the lack of capture of this high-risk population in the community and the need to establish cost-effective structured follow-up programs within the constraints of healthcare resources.

Structured Follow-Up and Recommendations for Neonates and Children Supported on ECMO

Despite the awareness over the last 2 decades of late neurodevelopmental problems and recommendations by the ELSO Registry, there is currently no standardized follow-up pathway for ECMO survivors, and there is an urgent, important need for structured follow-up. Nationally agreed recommendations for follow-up, developed in conjunction with other ECMO centers and local agencies including educational psychology services, together with families, are crucial to minimize variability in follow-up care. Our results from a 10-year experience could be translated to other ECMO institutions to help them develop similar clinics in their centers. Furthermore, this could inform a national program for standardized follow-up of these high-risk children where they would have at least, as a minimum standard, a 1-year post-ECMO follow-up assessment, either at the ECMO center or at a local facility, targeted at triaging/signposting those with difficulties. Importantly, the 1-year follow-up could serve as a quality metric for centers providing ECMO care.

CONCLUSIONS

Surveillance of the neonatal and pediatric respiratory ECMO survivors attending the 1-year ECMO follow-up clinic identified neurodevelopmental morbidity requiring referral and/or recommendation for further support. Despite the absence of some ECMO risk factors for later neurodevelopmental morbidity, concerns were evident at the 1-year ECMO follow-up clinic that warranted further referral. A significant proportion of pediatric respiratory ECMO survivors have neurologic morbidity and behavioral issues. There is a need to standardize neurodevelopmental follow-up with at least one follow-up assessment to ensure early recognition and timely intervention in order to maximize the potential for neonatal and pediatric respiratory ECMO survivors.

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