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ORIGINAL PAPER

The quality of life in extracorporeal life support survivors: single-center experience of a long-term follow-up

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Abstract

Objective To evaluate the health-related quality of life on a very long-term follow-up in patients treated with extracorporeal membrane oxygenation (ECMO) during neonatal and pediatric age.

Design Prospective follow-up study.

Setting Pediatric Intensive Care Unit of a tertiary-care University-Hospital.

Patients Out of 20 neonates and 21 children treated with ECMO in our center, 24 patients underwent short-term neurological follow-up. Twenty of them underwent long-term neurological follow-up.

Intervention Short-term follow-up was performed at 18 months and consisted in clinical evaluation, electroencephalography, and neuroimaging. Long-term follow-up was performed in 2017, at the mean period 19.72 years from ECMO (median 20.75, range 11.50–24.08) and consisted in a standardized questionnaires self-evaluation (PedsQL 4.0 Generic Core Scale) of health-related quality of life and an interviewed about the presence of organ morbidity, school level, or work position.

Measurements and main results Sixty-one percent (25/41) of the patients survived within 30 days after ECMO treatment. Short-term follow-up was performed in 24 patients (1 patient but died before the evaluation): 21 patients (87%) showed a normal neurological status, and 3 developed severe disability. Long-term follow-up was performed in 20 long-term survivors (3 patients were not possible to be contacted and considered lost to follow-up): mean age of patients at long-term follow-up was 21.23 (median 20.96, range 13.33–35.58) years; 90% (18/20) of them have no disability with a complete normal quality of life and 95% have no cognitive impairment.

Conclusions ECMO represents a life-saving treatment for infants and children with respiratory and/or heart failure; survivors show a good quality of life comparable to healthy peers.

Keywords Extracorporeal membrane oxygenation · Quality of life · Children · Mortality · Morbidity · Neurologic disorders

Introduction

Extracorporeal membrane oxygenation (ECMO) is a therapeutic strategy for patients of all ages affected by respiratory and/or cardiac failure, refractory to conventional management, whose mortality would have otherwise been high.

The first series of neonates were successfully treated with ECMO for respiratory failure in the late 1970s [1, 2]. Over the last 40 years, a significant increase in the use of ECMO was reported by the Extracorporeal Life Support Organization (ELSO) international registry, and progressively, the number of centers performing ECMO increased [3]. It is estimated that since now, 30,000 neonates due to respiratory failure and 6500 neonates due to cardiac failure have undergone ECMO worldwide; the same source data reported an overall survival of approximately 75% and 40% for the two groups respectively. In the pediatric population, the survival rate does not exceed 60% [4].

ECMO is associated with acute central nervous system complications which increase both mortality and long-term morbidity [5–8]. Acute neurologic lesions reported to ELSO registry include clinical and electroencephalography (EEG)-

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registered seizures, hemorrhage, infarction, and brain death. The development of these neurological sequelae may be related to patients' characteristics and clinical condition and to complications developed before or during ECMO [9].

ELSO Register shows the incidence of acute neurological complications according to three age categories (neonates, children, adult). However, their long-term disability is not reported. The neurological follow-up is limited to observational studies supported by single or multiple centers and the period of evaluation usually lasted less than 5 years [10–13].

Despite all is known about the acute and long-term complications of ECMO, little is known about the impact of these events on the health-related quality of life (HRQoL) of survivors. Actually, with the increasing success of ECMO and the expanding population surviving this treatment, the HRQoL has become a necessary end point of all studies on clinical use of ECMO [14–19].

The aim of this study is to evaluate the HRQoL on a long-term follow-up in patients treated with extracorporeal membrane oxygenation (ECMO) during neonatal and pediatric age.

Materials and methods

The studied population is represented by all consecutive patients who received ECMO at the Pediatric Intensive Care Unit of the University Hospital of Padua between 1993 and 2005 (Fig. 1) and underwent a comprehensive neurological assessment 18 months after ECMO (short-term follow-up); a HRQoL evaluation integrated by an interview about the presence of organ morbidity, school level, or work position was administered more than 10 years after ECMO (long-term follow-up).

In accordance with ELSO Registry's criteria, patients 0–30 days of age at treatment were codified as neonates, patients older than 30 days but younger than 18 years as children.

Data from all ECMO patients, including demographic information, diagnosis, indication for ECMO, type of ECMO, treatment course, and outcomes at the discharge have been prospectively collected. There were no exclusion criteria.

Institutional review board (IRB) approved the study design and patients and/or parents were informed and consent being interviewed and using data for publication.

Short-term outcome

For the purpose of the study, all survivors received clinical and instrumental neurodevelopmental assessments at 18 months from ECMO, which was considered a short-term neurological follow-up.

All patients received a clinical neurological assessment by a pediatric neurologist.

EEG was obtained with the EB NeuroGalileo System, using the 21-channels-EEG (the International 10/20 System). Brainstem auditory evoked potentials, visual evoked potentials, and somatosensory evoked potentials were performed using a four-channel Multibasis system [20]. EEG and all evoked potentials responses were interpreted by a pediatric neurophysiologist.

For investigating neurological and cognitive development, we used the Bayley Scale of Infant Development up to age of 30 months [21], the Stanford-Binet Intelligence test [22] between 30 months and 4 years, Wechsler Preschool and Primary Scale of Intelligence [23] between 4 and 6 years, and Wechsler Intelligence Scale for Children-Revised in patients older than 6 years [24]. A global score higher than 84

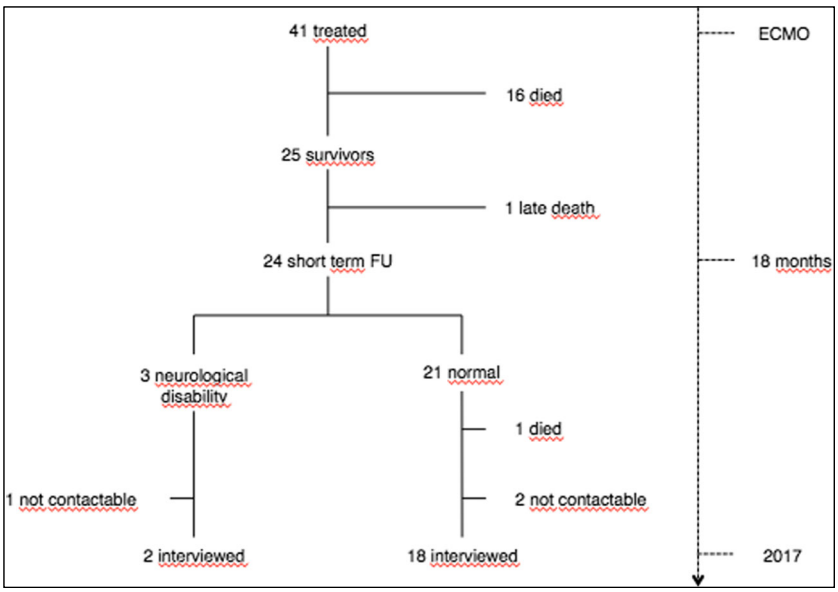

Fig. 1 Algorithm of studied population

was considered "normal," "borderline" between 70 and 84, and "delayed" less than 70. These scales were administered by a psychologist.

Cerebral computed tomography or cerebral magnetic resonance imaging was performed according to neurological assessment.

Long-term outcome

The long-term follow-up was performed on May 2017 (11–24 years after ECMO treatment) by contacting survivors by phone. We administered a standardized questionnaire, the PedsQL 4.0 [25], and we asked other open questions about the presence of organ morbidity, school level, or work position.

The PedsQL 4.0 Generic Core Scale is a validated multidimensional questionnaire, which explores HRQoL through 23-items concerning 4 functional areas: Physical Functioning (8 items), Emotional Functioning (5 items), Social Functioning (5 items), and School/Work Functioning (5 items).

The scoring system to evaluate and then to compare the PedsQL 4.0 is as follows: items are reversed scored and linearly transformed to a 0–100 scale, if more than 50% of the items in the scale are missing, the scale scores should not be computed, the mean score is the sum of the items over the number of items answered. HRQoL could be assessed by the Total Scale Score (23 items) or by considering the Physical Health Summary Score (8 items) or the combination of emotional, social, and school dimensions in the Psychosocial Health Summary Score (15 items).

The PedsQL 4.0 is age-adapted tool: for children between 2 and 18 years old, available in Child Self-Report form and in Parent Proxy-Report form; for patient older than 18, the adult form was used, (one version from 18 to 25 years of age and one over the age of 25).

Considering the age of our long survivors (all > 13 years), we used the PedsQL 4.0 age 13–18 and adult questionnaires. All questions were answered by patients themselves, except for one with a cognitive impairment, for whom the parent had to answer it. We use the PedsQL 4.0 Italian-translated version.

In addition to the standardized and validated questions provided for in PedsQL 4.0, we formulated other questions in order to investigate the organ morbidity (sensorineural, respiratory, cardiac and gastrointestinal) and to further deepening the psychiatric and psychological aspects, the neurological and motor functionality, the level of education, and the practiced sport (Table 1).

Table 1 Non-standardized questionnaire submitted at the long-term follow-up

Does he/she suffer from any diseases? Specify.
Does he/she take any drugs?
Does he/she going to school/university?
Has he/she repeated school years?
Has he/she had a special education teacher?
Does he/she any sport activity? Which? How often?
Does he/she suffer from neurological disorders (epilepsy, other)?
Is he/she indipendent in daily activities?
Does he/she have moving impariment / walking difficulty?
Does he/she suffer from sleeping disorders?
Does he/she suffer from anxiety / psychological disorders / psychosis / aggressive episodes?
Does he/she take any psychotropic medication?
Does he/she underwent neuroimaging? Which / Date / outcome
Does he/she underwent EEG/neurophysyology tests? Date / outcome
Does he/she present eye disorders?
Does he/she present hearing disorders?
Has he/she been suffering respiratory disorders over the years? When? How often?
Does he/she underwent spirometry? Data / outcome
Does he/she take any medications for respiratory disorders?
Has he/she any cardiac disease?
Does he/she take any medications for cardiac disorders?
Does he/she underwent ECG/echocardiography? Data / outcome
Has he/she had any injuries associated with vascular incannulation?
Does he/she underwent Colordoppler US? Data / outcome
Has he/she had any growth deficit?
Has he/she any gastroenterologic disorders?
Does he/she take any medications for gastroenterologic disorders?

Statistical analysis

Data were summarized with frequencies for categorical variables and mean, median, and range for continuous variables. Descriptive tables were used to summarize data from the short-term follow-up.

The analysis of long-term follow-up data was presented by comparing the long-term survivors with published data for a healthy sample and for a group of children with chronic health conditions [26, 27], taking into account the age-related groups of the patients. In the comparative analysis, the 35-year-old patient was not considered due to her age. Obtained mean scores were expressed in percentage with standard deviations (SDs). For the comparison of data, the chi-square test was used. We considered a statistically significant value of $p < 0.05$.

Results

Between April 1993 and June 2005, of the 41 patients treated with ECMO, 16 (39%) died during or within 30 days after treatment. The survival rate was 65% in neonates (13 of 20),

57% (12 of 21) in pediatric patients. Among all survivors (61%, 25/41), 12 (57%) were male.

In the neonatal population, indications for ECMO were inhalation of meconium ($n = 6$), persistent pulmonary hypertension of the newborn (PPHN) ($n = 3$), air leak syndrome ($n = 2$), left diaphragmatic hernia ($n = 1$), and sepsis ($n = 1$). In the pediatric population, indications were pneumonia ($n = 4$), air leak syndrome ($n = 3$), ARDS ($n = 2$), heart failure secondary to myocarditis ($n = 1$), asthma ($n = 1$), and congenital pulmonary fistulas ($n = 1$). No ECMO support was started during cardiopulmonary resuscitation.

The mean duration of treatment per patient was globally 199 h (range 53–688 h), 112 h (range 53–240) in neonates, 294 h (range 11–688) in children. Venous-arterial (VA) ECMO was performed in 7 patients, veno-venous (VV) ECMO in 18 patients (in 3 of them it was converted to VA ECMO).

Short-term follow-up

Of the 25 survivors, 24 underwent a short-term neurological follow-up; one pediatric patient died before the assessment.

Tables 2 and 3 reported, for each patient, clinical and instrumental neurodevelopment assessment and the corresponding results.

Long-term follow-up

In 2017, of the 24 patients evaluated at 18-month follow-up, 20 (49%) survivors were interviewed by the submission of PedsQL 4.0 questionnaire. One child had died 3 years after ECMO treatment for a respiratory failure, 3 patients were not possible to be contacted so we considered them lost to follow-up.

For the 20 patients considered in this long-term follow-up cohort, the mean age at follow-up was 21.23 (median 20.96, range 13.33–35.58) years, and the mean period from ECMO was 19.72 years (median 20.75, range 11.50–24.08). Two out of the three patients with neurologic impairment have been interviewed.

All the questionnaires have been considered valid because the not-answered questions were minimal. Table 4 reports our patients' PedsQL 4.0 Scores.

The non-standardized questionnaire reported 1 patient affected by spastic quadriplegia with vision impairment and seizure controlled by therapy, 1 patient affected by hemiparesis with drug-resistant epilepsy without cognitive disability, and 18 patients without any neurological impairment. Excluding the patient with spastic quadriplegia who has a global dependence in daily activities, 19 patients are 100% self-sufficient. They have regularly completed the school without missing years or receiving any supplementary support; at the moment, 2 children are at middle school, 2 are at high school, 5 have been graduated, 1 was graduated at short course university (3 years), 7 are attending university, and 2 are working. Five patients do regularly sport activity (one tennis coach, one basketball coach). The patient affected by hemiparesis has the driving license. One patient suffers from sleep disorder; none has anxiety disorder. None refers respiratory, cardiac, gastroenterological, or growth deficit.

Discussion

This paper reports the experience of a group of patients undergoing ECMO over a period of 12 years, with an overall survival rate of 61% at 30 days. This rate of survival is higher than what has been reported in previous series [5, 11, 13–15, 28–30] and comparable with ELSO registry data [4]. In a recent study, it was reported that patients undergoing ECMO after cardiac surgery showed a higher mortality especially if extracorporeal support lasted more than 4 days (mean time) [31]. In our study, the characteristics of our sample (96% of patients had a non-cardiac indication for ECMO support) may explain a high survival rate despite a long mean time on ECMO (8.2 days).

In this study, we described neurological morbidity and HRQoL assessment by a very long period of time from ECMO, between 11 and 24 years; to our knowledge, this is the longest one compared with previously reported study [14–16, 28, 32]. Almost all long-term survivors of ECMO in our sample have no disability (18/20), and 95% of evaluated patients have no cognitive impairment. Considering all our ECMO population, the 43.9% of them (18/41) has a complete normal quality of life: a very encouraging rate when we analyze that these patients would had have an 80 to 100% mortality without ECMO treatment.

Moreover, in our report, most of neonates with acute central nervous system's injuries showed by neuroimaging had not neurological deficit at 18-month follow-up, and later. This is probably due to the capability of the neuronal pattern to compensate and change itself after a damage, developing new connections especially in the firsts periods of life. Most studies, however, performed a neurological follow-up in neonates limited to a period of observation up to 5 years after ECMO and reported a risk of cognitive delay or behavioral problems that could contribute to school failure [33–36].

The HRQoL of the children who underwent ECMO we studied is similar to the ones reported in healthy population and in patients affected by chronic conditions (Tables 5 and 6). This is in contrast with what is reported by other authors which indicates a lower HRQoL in children surviving ECMO treatment in comparison with the non-treated population [14–17].

The different instruments used to test the HRQoL, the different "size" of the study populations considered, and the

Table 2 Short-term neonates' follow-up

Patient no.	Diagnosis	Age by ECMO (days)	Neuroimaging during ECMO	18-month neuroimaging	18-month neurologic evaluation	18-month EEG	18-month PEV	18-month BAERS	18-month SEP
1	CDH	1	NP	N	N	N	N	N	N
2	Air leak sdr.	16	P Mild edema. Mild talamic hyperecogenicity	N	N	N	N	N	N
3	Sepsis	1	P Posterior hemispheric hypodensities. 2° hemorrhage	P Atrophy and bilateral hypodensity	P Evolution in tetraparesis. Pathologic Bayley score	P asymmetry and temporal anomalies	P Pathological, retino-cortical transmission	N	P Suffering of the left somatosensorial ascending way
4	MAS	2	P Subarachnoid hemorrhage	N	N	N	N	N	P Cortical suffering (> left)
5	PPHN	2	P Left choroid plexus hemorrhage	N	N	N	N	N	N
6	ALS	2	P Right frontal ischemia. White matter frontal and occipital hypodensities	N	N	N	N	N	N
7	PPHN	1	P Ischemic lesion with left posterior temporal hemorrhagic infarction left	N	N	N	N	N	N
8	MAS	5	N	N	N	N	N	N	N
9	MAS	1	P Mild left periventricular hyperechogenicity	N	N	NE	N	N	N
10	PPHN	3	N	NE	N	N	N	N	N
11	MAS	0	N	NE	N	N	P Mild occipital alterations of retino-cortical transmission and cortical activation	N	N
12	MAS	1	N	NE	N	N	N	N	N
13	MAS	0	N	N	N	N	NE	NE	N

ALS, air leak syndrome; *CHD*, congenital diaphragmatic hernia; *MAS*, meconium aspiration syndrome; *N*, normal; *NP*, not performed; *P*, pathologic; *PPHN*, persistent newborn pulmonary hypertension

different follow-up periods considered might explain the different results.

Castello et al. [14] compared the HRQoL of a population of children, aged 5 and 18 years who underwent ECMO for cardiac conditions with the ones documented in a cohort of healthy children and with a group of young patients affected by cardiac conditions but not treated with ECMO. They used the CHQ-PF87 in 17 patients and the Child Health Questionnaire Parent Form (CHQ-PF-50), in 41 patients' parents. Looking at the psychosocial functioning, the ECMO group obtained similar results to both comparator groups, but a significant better physical

Table 3 Short-term pediatric patients' follow-up

Patient no.	Diagnosis	Age by ECMO (days)	Neuroimaging during ECMO	18-month neuroimaging	18-month neurologic evaluation	18-month EEG	18-month PEV	18-month BAERS	18-month SEP
14	Polmonitis Moebius syndrome	23	N	N	N Compatible with the underlying disease	N	P Right pathologic	P Functional impairment of the ponto-mesencephalic components	P Left pathologic
15	Hearth failure	23	P Right cerebral ischemic hypodensity with axial left deviation	P Right focal lesions. Right cerebral atrophy with ventricular dilatation	P Drug-resistant epilepsy. Spastic left hemiparesis	P Slow right temporal anomalies	P Mild hemispheric asymmetry	N	P cortico-subcortical impairment dx
16	Polmonitis	17	P Atrophy. Mild hypodensity in left semioval center	P Left nuclear hypodensity with traction on ventricle	P Right hemiparesis	P Mild right activity slowdown	N	P suffering of the central acoustic way (> left) by the trunk	P Cortical pathologic response
17	ARDS (inhalation)	160	NP	N	N	N	N	N	P Somatosensory ascending suffering
18	ARDS (burning)	25	P Cortical atrophy without parenchymal alteration	N	N	N	N	N	N
19	Polmonitis	3	NP	N	N	N	N	N	N
20	ALS	21	N	N	N	N	N	N	N
21	ALS	36	NP	NP	NP	N	N	N	N
22	ALS	37	P Left parieto-occipital hemorrhage	P Left calcifications	NE	NE	N	NE	N
23	Asthma	45	NP	N	N	N	N	N	N
24	Polmonitis	12	P Diffuse atrophy, ventricle dilatation	N	P Mild hypotonia. Mild psichomotorial retardation	N	N	P	P Cortical pathologic response
25	PAVFs	8	P Severe cerebral atrophy	NP (dead)	NE	NE	NE	NE	NE

ALS, air leak syndrome; *ARDS*, acute respiratory distress syndrome; *N*, normal; *NP*, not performed; *P*, pathologic; *PAVFs*, pulmonary arteriovenous fistula

Table 4 Long-term follow-up: patients' PedsQL 4.0 scores

Patient no.	PedsQL 4.0	Scores					
		Total	Physical	Psychosocial	Emotional	Social	School/ Work
1	Adult 18–25	79.35	100	68.30	55.00	85.00	65.00
2	Adult 18–25	85.87	100	78.33	60.00	100.00	75.00
3	Adult 18-25[a]	13.75	6.25	20.28	33.33	12.50	15.00
4	Adult 18–25	81.52	90.62	76.67	70.00	90.00	70.00
5	Adult 18–25	86.96	93.75	83.33	70.00	95.00	85.00
6	Adult 18–25	85.87	100	78.33	65.00	90.00	80.00
7	Adult 18–25	76.09	96.87	65.00	40.00	85.00	70.00
8	Adult 18–25	80.43	90.62	75.00	65.00	90.00	70.00
9	Adult 18–25	71.74	84.37	65.00	80.00	55.00	60.00
12	Adolescent 13–18	82.61	93.75	76.67	70.00	80.00	80.00
13	Adolescent 13–18	80.43	84.37	78.33	80.00	80.00	75.00
14	Adult 18–25	59.78	100	78.33	60.00	100.00	75.00
15	Adult 18–25	78.26	75	80.00	85.00	75.00	80.00
17	Adult > 25	91.30	96.87	88.33	80.00	85.00	100.00
18	Adult 18–25	90.22	93.75	88.33	75.00	100.00	90.00
19	Adult 18–25	86.96	96.87	81.67	70.00	95.00	80.00
20	Adult 18–25	83.69	93.75	78.33	65.00	100.00	70.00
21	Adult 18–25	84.78	100	76.67	65.00	100.00	65.00
22	Adolescent 13–18	76.09	65.62	81.67	80.00	80.00	85.00
23	Adolescent 13–18	85.87	96.87	80.00	85.00	80.00	75.00

[a] Parent Proxy Form

summary score was reported in healthy children's respect on patients affected by cardiac diseases and ECMO-treated group. Moreover, parents of patients previously treated with ECMO also reported, in non-negligible percentage, problems such as deficit of attention, speech or auditory disorder, and developmental or mental retardation.

Costello et al. [14] also underlined the relationship between acute neurologic events, occurred during ECMO, and the impact on the quality of life later in time.

Garcia Guerra et al. [16] analyzed the HRQoL of 47 cardiac patients aged up to 5 years, at about 4 years from ECMO treatment, by applying the PedsQL 4.0 Generic Core Scales. The results obtained were compared with those documented in

Table 5 PedsQL 4.0 Scale scores: comparison between ECMO survivors, healthy population, and chronic ill patients (age between 13 and 18 years old)

	ECMO group ($n = 4$)		Healthy group ($n = 5079$)*		p (ECMO vs HEALTHY)	Chronic group ($n = 574$)*		p (ECMO vs CHRONIC)
Scores	%	SD	%	SD		%	SD	
Total	81.25	3.55	83.91	12.47	0.88	74.16	15.38	0.75
Physical	85.15	12.17	87.77	13.12	0.87	79.47	17.07	0.78
Psychosocial	79.16	1.86	81.83	13.97	0.89	71.32	17.13	0.73
Emotional	78.75	5.44	79.21	18.02	0.98	69.32	21.36	0.68
Social	80.00	0.00	84.97	16.71	0.78	76.36	21.57	0.86
School	78.75	4.14	81.31	16.09	0.89	68.27	19.09	0.65

*Varni JW et al. "The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity" Ambul Pediatr. 2003: 329–41

Table 6 PedsQL 4.0 Scale scores: comparison between ECMO survivors, healthy population and chronic ill patients (age between 18 and 25 years old)

	ECMO group ($n = 15$)		Healthy group ($n = 1171$)[a]		p (ECMO vs HEALTHY)	Chronic group ($n = 102$)[a]		p (ECMO vs CHRONIC)
Scores	%	SD	%	SD		%	SD	
Total	75.15	18.79	78.18	9.20	0.77	70.25	11.32	0.69
Physical	83.96	26.21	86.25	10.63	0.80	74.49	16.07	0.42
Psychosocial	74.55	16.07	73.87	10.50	0.95	67.99	11.85	0.61
Emotional	71.21	11.16	66.68	15.00	0.71	60.02	17.30	0.51
Social	82.77	24.40	85.48	11.90	0.77	82.21	13.10	0.96
School/work	69.67	17.17	69.47	13.94	0.98	61.71	16.72	0.55

[a] Varni JW et al. "The PedsQL 4.0 Generic Core Scales Young Adult Version: feasibility, reliability and validity in a university student population". J Health Psychol. 2009:611–22

a cohort of healthy population, in a group of children with chronic disease and in one composed by pediatric patients with congenital heart disease undergoing cardiopulmonary bypass in infancy. They concluded that parents of children undergoing ECMO reported a lower score of HRQoL if compared to the other groups.

Wagner et al. [30] submitted a cohort of 22 children treated with ECMO for cardiac and respiratory failure 7 years after the ECMO treatment to a clinical neurological and neuropsychological assessments, neuroimaging and electrophysiology studies, and HRQoL evaluation. The authors reported a cognitive impairment in 68% of their study population and a parents-reported reduction in quality of life in 36%; 62% of patients had received a supplementary support in kindergarten or school.

Hamrick et al. [32] on follow-up a mental delay in 29% of ECMO survivors, Lequier et al. [33] in 50% of them.

Compared to data published by Wagner, our long-term survivor population had a cognitive deficit of 5% (1/20).

Fleck evaluated the HRQoL by submitting the KINDL questionnaire to 19 patients between 7 months and 30 years old [15] at about 5 years from ECMO. He concluded that the parents' reports of quality of life are lower than those from a healthy population, but in the age group of 12 and above, the self-assessed HRQoL is similar to that of the healthy population. Also, our data confirmed this issue, because all patients were over 13 years old and 19/20 answered the questions on their own, therefore providing a personal opinion on their quality of life that was similar to the report provided by healthy peers. We infer that the perception of being a survivor is acquired with the maturity of the person itself and overs the years; it might influence the evaluation of their quality of life.

Limitations of this report firstly include the small number of patients. Secondly, the neurological (clinical and instrumental) evaluation was not complete for all patients at the short-term follow-up and it was not repeated at the time of long-term follow-up. In our long-term evaluation, validated tests to assess motor and cognitive achievements were not included. Our self-made questionnaire, as it is not standardized, is not comparable with other surveys, it is not also reapplied because not validated, however it investigates aspects of the daily life of these patients which are not dealt in the validated questionnaires.

Conclusions

Our data suggest that survivors from non-cardiac indication ECMO may show a quality of life similar to peers. Due to the increasing number of centers performing this treatment, there is a great interest towards the evaluation of the quality of life in survived pediatric patients; however, a globally recognized instrument to assess their quality of life still not exists.

The necessity of drawing up guidelines for the proper execution of the neurological follow-up, in terms of which exams should be done and when they should be done, and the necessity of determine an useful and globally recognize tool for the quality of life's assessment in these patients must once again be reiterated in order to allow that data, from different centers, would be collecting, comparing, and using for further studies.

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Compliance with ethical standards

Conflict of interest Authors have no conflict of interest to declare.

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