

Perceived motor competence differs from actual performance in 8-year-old neonatal ecmo survivors

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Pediatrics 2016;137(3):e20152724

ABSTRACT

Objective

To assess perceived motor competence, social competence, self-worth, health-related quality of life, and actual motor performance in 8-year-old survivors of neonatal extracorporeal membrane oxygenation (ECMO).

Methods

In a prospective nationwide study, 135 children completed the extended version of the "athletic competence" domain of the Self Perception Profile for Children (SPPC) called the m-CBSK (Motor supplement of the Competentie BelevingsSchaal voor Kinderen) to assess perceived motor competence, the SPPC, and the Pediatric Quality of Life Inventory (PedsQL), and were tested with the Movement Assessment Battery for Children. SD scores (SDS) were used to compare with the norm.

Results

The mean (SD) SDS for perceived motor competence, social competence, and self-worth were all significantly higher than the norm: 0.18 (0.94), $p=0.03$; 0.35 (1.03), $p<0.001$; and 0.32 (1.08), $p<0.001$, respectively. The total PedsQL score was significantly below the norm: mean (SD) SDS: -1.26 (1.53), $p<0.001$. Twenty-two percent of children had actual motor problems. The SDS m-CBSK and actual motor performance did not correlate ($r=0.12$; $p=0.17$). The SDS m-CBSK significantly correlated with the athletic competence domain of the SPPC ($r=0.63$; $p<0.001$).

Conclusions

Eight-year-old ECMO survivors feel satisfied with their motor- and social competence, despite impaired PedsQL scores and motor problems. Because motor problems in ECMO survivors deteriorate throughout childhood, clinicians should be aware that these patients may tend to "overrate" their actual motor performance. Education and strict monitoring of actual motor performance are important to enable timely intervention.

INTRODUCTION

Neonatal extracorporeal membrane oxygenation (ECMO) is a technique to support critically ill newborns with severe, but potentially reversible, cardiorespiratory failure. In the past decades, ECMO has mainly been used in neonates suffering from meconium aspiration syndrome, congenital diaphragmatic hernia (CDH), sepsis, or persistent pulmonary hypertension.¹ In the UK Collaborative ECMO Trial Group, ECMO treatment was associated with higher survival rates than conventional management in neonates with critical illness.^{1,2} Currently, the overall survival rate is 75%. However, ECMO survivors may suffer from long-term morbidity, depending on the severity of primary underlying diagnoses, respiratory failure before ECMO, and several factors during ECMO.^{1–4} Because more children survive the neonatal period, physical and neurodevelopmental morbidities at older ages are on the rise.^{5–9}

Thus far, most studies in ECMO survivors have focused on children's health status until age 5 years. At this age, they seemed to have more motor problems than healthy age-related peers.^{6,7,9} Only 2 large studies have examined motor performance at older age; the UK collaborative trial found motor problems in 57% of 7-year-olds.⁸ More recently, a longitudinal nationwide evaluation of ECMO survivors at ages 5, 8, and 12 years in the Netherlands implicated that these children are growing into their motor function deficit.¹⁰

In general, motor impairments in childhood may lead to low self-worth and difficulties with peer relations.^{11–13} To the best of our knowledge, the domains of self-worth, as well as perceived motor competence and social competence, have not yet been studied in ECMO survivors, except in those with CDH.¹⁴ These domains may influence health-related quality of life (HRQoL).¹⁵ Five-year-old and younger ECMO survivors had lower HRQoL scores on both physical and psychosocial domains.^{16,17} HRQoL beyond the age of 5 in neonatal ECMO survivors is not known yet.

On the basis of previous studies on motor impairments in neonatal ECMO survivors,^{3,6–8,10,14,18,19} we hypothesized that these children are likely to have low perceptions of competence in the physical domain because of repeated experiences of poor movement skills with loss of interest in the motor domain and avoidance of motor activities, due to fear of failure and peer criticism. It is conceivable that this may reduce opportunities to practice skills and participate socially and hence result in impaired HRQoL.

In this nationwide study in 8-year-old neonatal ECMO survivors, we primarily aimed to evaluate the perceived motor competence, actual motor performance, the importance of the motor domain, the perceived social competence, feelings of self-worth, and self-reported HRQoL. Moreover, we analyzed the possible relations between these parameters. Lastly, we calculated the correlation between 2 questionnaires on self-perception of motor competence. More precisely, between the athletic competence domain of the

Self Perception Profile for Children (SPPC) and the motor self-perception questionnaire of the Dutch extended version of the SPPC (m-CBSK; Motor supplement of the Competentie BelevingsSchaal voor Kinderen).

METHODS

Patients, Procedures, and Study Design

We assessed 8-year-old children who received ECMO support within 28 days of birth in either of the 2 ECMO centers in the Netherlands (Radboud University Medical Center - Amalia Children's Hospital, Nijmegen; Erasmus University Medical Center - Sophia Children's Hospital, Rotterdam) between 1996 and 2004. Entry and exclusion criteria for neonatal ECMO have previously been described^{6,7} and did not change during the study period. The study was part of a structured prospective nationwide follow-up program. Demographic and clinical data were retrieved from medical records and a computerized patient data management system. Cranial ultrasound examinations had been performed before and serially during ECMO (started on daily basis, with lower frequency after stabilization).⁴ On the basis of the national consensus on neonatal follow-up and the Dutch Ministry of Health's requirement to provide relevant data, the assessment protocol is the Dutch standard of care in ECMO follow-up. As a consequence, institutional review board approval was waived. Parents of all children were routinely informed about the study.

Questionnaires

Perceived Motor Competence: m-CBSK

Self-perception of motor competence was tested with the m-CBSK. The m-CBSK is an extended version of the "athletic competence" domain of the SPPC¹¹ and was developed for Dutch children aged 8 to 12 years.²⁰

The m-CBSK consists of 2 questionnaires: a motor self-perception questionnaire and a domain importance questionnaire.

Motor Self-Perception Questionnaire

The motor self-perception questionnaire consists of 17 questions covering a range of motor skills needed for outdoor activities, physical education, and sports. Children are asked to rate their motor competence in relation to the motor performance of their peers. To discourage socially desirable responses, the questions have a 2-tiered format.^{20,21} Children first choose the statement that describes them best and then decide whether this is "really true" or "sort of true" in their case. The total score was transformed into

a gender-specific SD score (SDS). A score below -1 SD was considered as an impaired feeling of motor competence.

Domain Importance Questionnaire

The importance of the motor domain was measured with the domain importance questionnaire. Scores ranged from 1 to 4, with higher scores representing greater importance.²⁰ The score was transformed into a gender-specific SDS.

Self-Perceived Competence: SPPC

The SPPC measures the self-perceived competence in children aged 8 to 12 years.²² The SPPC assesses competence in cognitive, social, and physical domains and yields a measure of general self-worth. The physical domain contains a specific item on athletic competence. The structure of the questionnaire is similar to that of the m-CBSK. Each item is scored from 1 to 4, with higher scores representing greater self-perceived competence.²² The total score was transformed into a gender-specific SDS. Dutch reference norms were used. A score below -1 SD was considered to reflect impaired self-perceived competence.

HRQoL: Pediatric Quality of Life Inventory

The Pediatric Quality of Life Inventory (PedsQL) 4.0 measures HRQoL in children and encompasses 23 items on 4 Generic Core Scales: physical (8 items), emotional (5 items), social (5 items), and school functioning (5 items). A psychosocial functioning scale can be derived from the emotional, social, and school functioning items. All 23 items together provide the total functioning score. The children indicate on a 5-point scale the frequency in which they experience the problem and these scores are linearly transformed to a 0 to 100 scale. Higher scores indicate better functioning. The Dutch version of the PedsQL has adequate psychometric properties and can be used as a HRQoL instrument in pediatric research in the Netherlands.²³ A scale score and total functioning score of 1 SD below the mean of healthy reference norm was taken to indicate impaired HRQoL.²⁴

Sports Participation

We asked the children whether they participated in sports other than gymnastic classes at school.

Motor Performance Test: Movement Assessment Battery for Children

Motor performance was evaluated with the first edition of the Movement Assessment Battery for Children (MABC). Eight items are divided into 3 domains: manual dexterity (3 items), ball skills (2 items), and static and dynamic balance (3 items). Summation of the item scores produces domain scores and the total impairment score. The 3 domain

scores and the total impairment score can be converted into age-related percentile scores. Scores above the 15th percentile are considered “normal” and between the 15th and sixth percentile as “borderline.” The fifth percentile and below is regarded as a “definite motor problem.” A Dutch standardization study has shown that the original norm scores and cutoff points can also be applied to Dutch children.^{25,26}

Data Analysis

Mean SDS motor competence, social competence, importance of motor competence, global feeling of self-worth, and HRQoL were compared with 0 (the expected average of the reference group) using one-sample t tests. Differences in medical background variables between the groups “participants,” “children lost to follow-up,” and “children unable to perform the MABC” were evaluated by using Kruskal-Wallis tests, and differences between the 2 centers were evaluated by using Mann-Whitney tests. Percentages of MABC outcome (normal/borderline/problem) were compared with normative proportions by using χ^2 tests.

Spearman correlation between actual motor performance (MABC) and perceived motor competence (m-CBSK) or sports participation was calculated. The Pearson correlation was used to calculate relations between SPPC (social, athletic, and feeling of self-worth), importance of motor competence, and PedsQL. Two-sample t test and Mann-Whitney U test were used to examine possible differences between diagnosis subgroups. Analyses were performed by using SPSS 21.0 (IBM, Chicago, IL).

RESULTS

A total of 333 children underwent neonatal ECMO between January 1996 and July 2004. Eighty-two children (25%) died during their first hospitalization. Of the 251 survivors, 189 (75%) participated in the follow-up. However, 12 (6%) of those 189 had no standard assessment because of cerebral palsy (n = 7), psychomotor retardation (n = 3), or behavior problems (n = 2). Forty-two (24%) of the 177 children who were routinely assessed did not complete the m-CBSK for logistical reasons. Thus, 135 children who completed the m-CBSK and were tested with the MABC were considered as participants of this study (see flowchart: Figure 1).

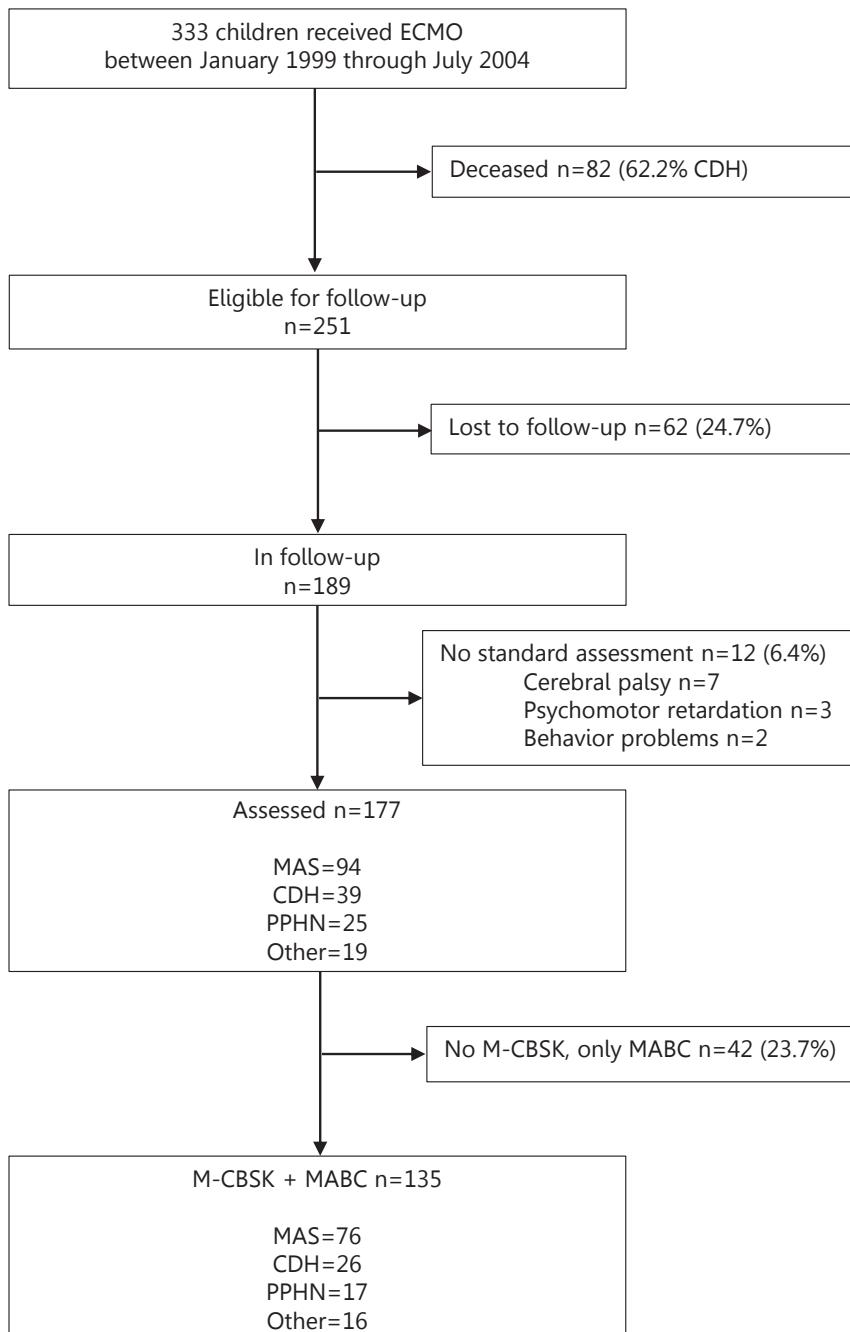


Figure 1 - Flowchart: study participants comprised 135 children who completed the m-CBSK and were tested with the MABC.

MAS = meconium aspiration syndrome; PPHN = persistent pulmonary hypertension of the newborn; VA = venoarterial

Table 1 - Perinatal and ECMO characteristics

	All survivors n = 251	Lost to follow up n = 62	Participants n = 135	MABC assessed, no M-CBSK n = 42	Inability to perform MABC n = 12
Boys/girls	141/110	37/25	70/65	29/13	5/7
Rotterdam/Nijmegen	138/113	35/27	78/57	13/29	12/- ^a
Diagnosis, n(%)					
MAS,	137 (54.6)	37 (59.7)	76 (56.3)	18 (42.9)	6 (50.0)
CDH	48 (19.1)	7 (11.3)	26 (19.3)	13 (31.0)	2 (16.7)
PPHN	33 (13.1)	7 (11.3)	17 (12.6)	8 (19.0)	1 (8.3)
Other ^b	33 (13.1)	11 (17.7)	16 (11.9)	3 (7.1)	3 (25.0)
VA ECMO, n (%)	246 (98.0)	61 (98.4)	131 (97.0)	42 (100.0)	12 (100.0)
VV ECMO, n(%)	5 (2.0)	1 (1.6)	4 (3.0)	-	-
Gestational age, wk	40 (34-43)	40 (34-42)	40 (34-43)	40 (35-42)	39 (35-43)
Birth weight, kg	3.4 (2.1-5.0)	3.5 (2.4-4.9)	3.4 (2.1-5.0)	3.5 (2.2-4.8)	3.3 (2.2-4.5)
OI	44 (13-143)	48 (28-111)	41 (20-143)	44 (16-90)	47 (13-100)
MAP	20 (11-64)	20 (14-28)	20 (11-64)	20 (15-45)	21 (14-33)
Time on ECMO, hours	145 (48-510)	148 (48-510)	142 (53-369)	152 (68-287)	100 (54-356)
Ventilatory support, days	15 (2-130)	15 (5-54)	14 (6-70)	19 (3-42)	12 (2-130)
CLD, n(%)					
Yes	72 (28.7)	17 (27.4)	36 (26.7)	17 (40.5)	7 (58.3)
No	166 (66.2)	37 (59.7)	97 (71.8)	25 (59.5)	2 (16.7)
Unknown	13 (5.1)	8 (12.9)	2 (1.5)	-	3 (25.0)
Abnormal CUS, n(%)					
Yes	36 (14.3)	11 (17.7)	16 (11.9)	6 (14.3)	3 (25.0)
No	212 (84.5)	50 (80.7)	117 (86.6)	36 (85.7)	9 (75.0)
Unknown	3 (1.2)	1 (1.6)	2 (1.5)	-	-

Data shown are n (%) or median (range)

^a p ≤ 0.001; ^b Other diagnoses included sepsis (n=12), pneumonia (n=3), cardiorespiratory problems (n=1)

MAS = meconium aspiration syndrome; CDH = congenital diaphragmatic hernia; PPHN = persistent pulmonary hypertension of the newborn; VA = venoarterial; VV = venovenous; OI = highest oxygenation index before ECMO; MAP = highest mean airway pressure prior to ECMO in cm H₂O; CUS = cranial ultrasound; CLD = chronic lung disease defined as oxygen dependency at 28 days; M-CBSK = motor supplement of the 'Competentie Belevings-Schaal voor Kinderen'; MABC = Movement Assessment Battery for Children, first version

Questionnaires

Perceived Motor Competence: m-CBSK

All 135 participants completed the m-CBSK questionnaire. Fourteen children (10%) scored below average (less than -1 SD), and 121 (90%) average to above average (greater than or equal to -1 SD). The total group scored significantly higher (mean [SD] SDS: 0.18 [0.94], p=0.03) than the reference population, which means they are satisfied, even slightly more satisfied with their motor performance than their healthy peers (Table 2).

Table 2 - Test results; perceived competence, health-related quality of life, actual motor performance and sports participation

Instrument	Total group	MAS	CDH	PPHN	Other
m-CBSK; SDS mean (SD)	n=135	n=76	n=26	n=17	n=16
Motor competence	0.18 (0.94) ^a	0.23 (0.87) ^a	-0.23 (1.10)	0.46 (0.83) ^a	0.26 (0.95)
Importance	0.02 (1.00)	-0.07 (1.02)	-0.10 (0.96)	0.30 (0.95)	0.33 (0.97)
SPPC; SDS mean (SD)	n=117	n=67	n=21	n=16	n=13
Athletic competence	0.30 (1.11) ^b	0.30 (1.07) ^a	-0.17 (1.33)	0.84 (0.73) ^b	0.39 (1.11)
Social competence	0.35 (1.03) ^b	0.30 (1.09) ^a	0.42 (0.83) ^a	0.45 (0.94)	0.41 (1.14)
Scholastic competence	-0.02 (1.07)	-0.17 (1.10)	0.02 (1.03)	0.63 (0.78) ^c	-0.14 (1.10)
Physical appearance	0.37 (0.83) ^b	0.28 (0.95) ^a	0.42 (0.68) ^c	0.68 (0.48) ^b	0.34 (0.64)
Behavioral conduct	0.26 (1.26) ^a	0.19 (1.21)	0.50 (1.22)	0.44 (1.04)	0.03 (1.78)
Self-worth	0.32 (1.08) ^b	0.20 (1.18)	0.35 (1.03)	0.43 (1.01)	0.74 (0.50) ^b
PedsQL; SDS mean (SD)	n=103	n=63	n=18	n=13	n=9
Total functioning	-1.26 (1.53) ^b	-1.32 (1.66) ^b	-1.43 (1.29) ^b	-0.86 (1.19) ^a	-1.06 (1.51)
Physical functioning	-1.20 (1.71) ^b	-1.07 (1.73) ^b	-1.65 (1.96) ^b	-1.12 (1.28) ^c	-1.28 (1.70)
Emotional functioning	-0.75 (1.32) ^b	-0.94 (1.37) ^b	-0.60 (1.26)	-0.27 (1.26)	-0.42 (1.15)
Social functioning	-1.08 (1.46) ^b	-1.11 (1.68) ^b	-1.30 (0.87) ^b	-0.88 (1.24) ^a	-0.67 (1.14)
School functioning	-0.81 (1.29) ^b	-0.93 (1.37) ^b	-0.77 (1.02) ^c	-0.33 (0.94)	-0.75 (1.63)
Psychosocial functioning	-1.11 (1.46) ^b	-1.24 (1.63) ^b	-1.13 (1.03) ^b	-0.62 (1.14)	-0.82 (1.34)
MABC; n (%)	n=135	n=76	n=26	n=17	n=16
Total impairment score					
Normal	105 (77.8) ^a	63 (82.9)	16 (61.6) ^b	14 (82.4)	12 (75.0)
Borderline	18 (13.3)	9 (11.8)	5 (19.2)	2 (11.8)	2 (12.5)
Motor problem	12 (8.9)	4 (5.3)	9 (19.2)	1 (5.9)	2 (12.5)
Sports participation	n=134	n=76	n=26	n=16	n=17
Yes	109 (81%)	62 (82%)	21 (81%)	11 (65%)	15 (64%)
No	25 (19%)	14 (18%)	5 (19%)	5 (29%)	1 (4%)
Unknown	-	-	-	1 (6%)	-

Data are presented as number (%) of patients or mean (SD)

One sample t-test (compared with zero) or χ^2 test (observed vs expected distribution): ^ap ≤ 0.05; ^bp ≤ 0.001;

^cp ≤ 0.01

MAS = meconium aspiration syndrome; CDH = congenital diaphragmatic hernia; PPHN = persistent pulmonary hypertension of the newborn; Other = other diagnoses including sepsis, pneumonia, cardio-respiratory problems and miscellaneous diagnosis. M-CBSK = motor supplement of the 'Competentie BelevingsSchaal voor Kinderen'; MABC = Movement Assessment Battery for Children, first version; SPPC = Self Perception Profile for Children; PedsQI = Pediatric Quality of Life Inventory.

Importance of the Motor Domain: m-CBSK

All participants also completed the questionnaire that measures the importance in the motor domain. Twenty children (15%) scored below average (less than -1 SD) and 115 (85%) average to above average (greater than or equal to -1 SD). The scores on the questionnaire indicate these children labeled the motor domain as important (mean SDS [SD]; 0.02 [1.00]; Table 2).

Self-Perceived Competence: Athletic Competence, Social Competence, and Self-Worth: SPPC

The SPPC was completed by 117 of 135 (87%) participants. On the athletic competence domain, 18 children (15%) scored below average (less than -1 SD) and 99 (85%) average to above average (greater than or equal to -1 SD). On the domain of social competence, 10 children (9%) scored below average (less than -1 SD) and 107 (91%) average to above average (greater than or equal to -1 SD) and on the domain of self-worth, this was 14 (9%) and 103 (91%), respectively. The scores on all 3 domains were significantly higher compared with the reference group, which means the participants feel more competent on athletic and social level and have greater self-worth than healthy peers (Table 2).

HRQoL: PedsQL

The PedsQL was completed by 103 of 135 (76%) participants. Fifty-five (57%) of them indicated an impaired HRQoL (less than -1 SD). Compared with the reference group, scores on all the PedsQL scales (physical, emotional, social, school, and psychosocial functioning) were significantly lower (Table 2).

Motor Performance Test: MABC

All participants were assessed with the MABC. The total impairment score was within the normal range for 105 children (78% vs 85% expected), 18 children (13% vs 10% expected) were classified as borderline, and another 12 (9% vs 5% expected) as having a definite motor problem. This distribution is significantly different from reference values (χ^2 p<0.001; Table 2). Most problems were encountered in ball skills (χ^2 p<0.001)

Correlations Between Parameters

Social competence (SPPC) had a weak but significant positive correlation with actual motor performance ($r=0.22$; $p=0.02$). The other parameters analyzed, that is, perceived motor competence (m-CBSK), interest in the motor domain (m-CBSK), athletic competence (SPPC), global feeling of self-worth (SPPC), as well as the total score of the PedsQL, did not correlate with actual motor performance (MABC) ($r=0.12$, -0.03 , 0.09 , 0.07 , and 0.12 , respectively).

Perceived motor competence (m-CBSK) was significantly positively correlated with importance of the motor domain (m-CBSK domain importance questionnaire; $r=0.31$, $p<0.001$), athletic competence of the SPPC ($r=0.63$; $p<0.001$), global feeling of self-worth ($r=0.29$, $p=0.001$), and social competence ($r=0.23$, $p=0.02$).

Global feeling of self-worth (SPPC) correlated positively with all domains of HRQoL (PedsQL): total functioning ($r=0.50$, $p<0.001$); physical functioning ($r=0.26$, $p=0.01$); emotional functioning ($r=0.44$, $p<0.001$); social functioning ($r=0.48$, $p<0.001$); school functioning ($r=0.42$, $p<0.001$); and psychosocial functioning ($r=0.50$, $p<0.001$).

Sport participation correlated weakly with actual motor performance ($r=0.19$, $p=0.03$).

DISCUSSION

We hypothesized that ECMO survivors would have a low self-perception of competence in the motor domain and be reluctant to engage in physical activities with their peers. This, in turn, might negatively influence perception of social competence and also affect feelings of self-worth and HRQoL. However, this did not hold true for the 8-year-old ECMO survivors in the present nationwide study, despite impaired motor performance and impaired HRQoL.

The importance of the motor domain was significantly related to the perceived motor competence level but not to their actual motor performance level. Therefore, our observations do not support the hypothesis that skills are not sufficiently practiced and developed because of a lack of interest in motor activities. Indeed, the majority of the children in this cohort were active in sports.

The greater feeling of motor competence indicates that these children "overrate" their actual motor performance, a phenomenon known as the illusory superiority or superiority bias.²⁷ This may have implications for the approach to motivate these children and their parents to undertake physical activities and to adhere to physical therapy and therapeutic advice. Interestingly, these children do not overrate their scholastic performance. Parents of ECMO survivors who had been critically ill as neonates may consider their child more vulnerable than healthy peers and provide extra compliments and encouragement once motor milestones have been reached. Moreover, as motor function problems in neonatal ECMO survivors already exist at preschool age and seem to persist,^{6–10} it can be speculated that these children have an altered perception of normal motor function. This phenomenon might be different with respect to scholastic performance because academic problems arise when the children get older.²⁸ However, these assumptions are speculative and not within the scope of the current study.

The significant correlations between the domains of the PedsQL and the global feeling of self-worth (SPPC) showed that self-reported problems in physical, social, and psychosocial functioning affect the feeling of self-worth, whereas actual motor performance problems did not. Thus, the perception of functioning determines self-worth instead of actual functioning.

To our knowledge, the relationships among perceived motor competence, social competence, actual motor performance, self-worth, and HRQoL in a single study has not been studied. Yet in various studies of children with chronic (medical) conditions, such as attention-deficit/hyperactivity disorder and osteogenesis imperfecta, discrepancy between perceived and actual motor performance was reported as well.^{29,30} This issue has been little studied in children who were born critically ill. In 6-year-old children born preterm, an association between self-perceptions of physical competence and actual motor performance was found.³¹

Normal or even better perceived feelings of self-worth are not unusual; this has also been reported in children with congenital heart disease³² and in CDH patients, whether or not treated with neonatal ECMO.¹⁴ We showed that CDH patients were satisfied with their motor performance and had normal feelings of self-worth despite a higher proportion of actual motor function problems compared with the ECMO survivors without CDH.

Impaired quality of life has also been reported in congenital heart disease patients, aged 4 to 18 years, both ECMO-treated and non-ECMO children.^{17,33,34}

In the current study we evaluate the correlation between the athletic competence of the SPPC and the m-CBSK. In view of the strong positive correlation between these questionnaires, we recommend evaluating a child's perceived motor competence with the athletic competence domain of the SPPC.

A limitation of the study is that 42 participants had to be excluded because they had not completed the m-CBSK. One reason could be lack of time because 26% of these children had impaired motor performance (less than or equal to fifth percentile) and needed more time to perform the motor function tests (with complete follow-up assessment being performed in 1 day). For this group of excluded patients, the correlation between the athletic competence scale of the SPPC and actual motor performance was not significant ($r=0.27$, $p=0.14$). Because the athletic competence domain of the SPPC has a strong correlation with the m-CBSK, we assume that this subgroup overrated their motor performance too. The 62 children who were lost to follow-up did not differ from the participants with respect to background characteristics. Therefore, we assume that our data set is generalizable for neonatal ECMO survivors without serious neurologic or behavioral comorbidity who are eligible to perform standardized motor function assessments.

Another limitation of this study is that we evaluated perceptions of the children only. It can be assumed that parents who consider their child vulnerable may refrain from stimulating physical activity.

In the current study, details on type and level of sports activities were lacking. Future studies should take these details into account to clarify the impact of motor function on real-life activities.

CONCLUSIONS

Eight-year-old ECMO survivors without serious neurologic or behavioral comorbidity feel satisfied with their motor and social competence, despite their impaired motor performance. Even though they indicate more problems in the physical, social, and

psychosocial domain than their healthy peers, they do not have a lack of self-worth. They experience even more self-worth than their healthy related peers.

We previously showed that motor problems in neonatal ECMO survivors persist throughout childhood and seem to deteriorate as they get older. The discrepancy between actual motor performance and perceived motor competence may result in a lack of motivation for intervention. Clinicians should be aware of the phenomenon of "overrating" motor performance.

Therefore, clinicians should not only ask about motor skills but also evaluate actual motor performance. Education with adequate counseling for sports participation should be provided to children and their parents. Timely referral to a pediatric physical therapist is recommended for tailor-made practice of motor skills.

Future studies, especially those focusing on intervention, should take into account the parents' perception of motor competence, vulnerability of the child, and impact on participation.

ACKNOWLEDGEMENTS

The authors thank all members of the Dutch ECMO follow-up team for their contribution and especially the psychologists Anne Zirar-Vroegindeweij, Annabel van Gils-Frijters (Erasmus MC–Sophia Children's Hospital, Rotterdam), and Jolanda Reuser (Radboud UMC, Nijmegen). Ko Hagoort provided editorial advice.

REFERENCES

1. ECLS Registry Report: International Summary. Ann Arbor, MI: Extracorporeal Life Support Organization; July 2013.
2. UK Collaborative ECMO Trial Group. UK collaborative randomised trial of neonatal extracorporeal membrane oxygenation. Lancet. 1996;348(9020):75–82.
3. Bernbaum J, Schwartz IP, Gerdes M, D'Agostino JA, Coburn CE, Polin RA. Survivors of extracorporeal membrane oxygenation at 1 year of age: the relationship of primary diagnosis with health and neurodevelopmental sequelae. Pediatrics. 1995;96(5 pt 1):907–913.
4. Raets MMA, Dudink J, IJsselstijn H, et al. Brain injury associated with neonatal extracorporeal membrane oxygenation in the Netherlands: a nationwide evaluation spanning two decades. Pediatr Crit Care Med. 2013;14(9):884–892.
5. IJsselstijn H, van Heijst AF. Long-term outcome of children treated with neonatal extracorporeal membrane oxygenation: increasing problems with increasing age. Semin Perinatol. 2014;38(2):114–121.
6. Hanekamp MN, Mazer P, van der Cammen-van Zijp MH, et al. Follow-up of newborns treated with extracorporeal membrane oxygenation: a nationwide evaluation at 5 years of age. Crit Care. 2006;10(5):R127.
7. Nijhuis-van der Sanden MW, van der Cammen-van Zijp MH, Janssen AJ, et al. Motor performance in five year-old extracorporeal membrane oxygenation survivors: a population-based study. Crit Care. 2009;13(2):R47.
8. McNally H, Bennett CC, Elbourne D, Field DJ; UK Collaborative ECMO Trial Group. United Kingdom collaborative randomized trial of neonatal extracorporeal membrane oxygenation: follow-up to age 7 years. Pediatrics. 2006;117(5).
9. Bennett CC, Johnson A, Field DJ, Elbourne D; UK Collaborative ECMO Trial Group. UK collaborative randomised trial of neonatal extracorporeal membrane oxygenation: follow-up to age 4 years. Lancet. 2001;357(9262):1094–1096.
10. van der Cammen-van Zijp MHM, Janssen AJWM, Raets MMA, et al; Dutch ECMO follow-up team. Motor performance after neonatal extracorporeal membrane oxygenation: a longitudinal evaluation. Pediatrics. 2014;134(2).
11. Harter S. Manual for the Self-Perception Profile for Children. Denver, CO: University of Denver; 1985.
12. Skinner RA, Piek JP. Psychosocial implications of poor motor coordination in children and adolescents. Hum Mov Sci. 2001;20(1–2):73–94.
13. Varni JW, Rubenfeld LA, Talbot D, Setoguchi Y. Determinants of self-esteem in children with congenital acquired limb deficiencies. J Dev Behav Pediatr. 1989;10(1):13–16.
14. Madderom MJ, Toussaint L, van der Cammen-van Zijp MH, et al. Congenital diaphragmatic hernia with(out) ECMO: impaired development at 8 years. Arch Dis Child Fetal Neonatal Ed. 2013;98(4):F316–F322.
15. WHOQOL Group. Development of the WHOQOL: rationale and current status. Int J Ment Health. 1994;23(2): 24–56.
16. Madderom MJ, Gischler SJ, Duivenvoorden H, Tibboel D, IJsselstijn H. Neonatal extracorporeal membrane oxygenation: impaired health at 5 years of age. Pediatr Crit Care Med. 2013;14(2):183–193.

17. Garcia Guerra G, Robertson CMT, Alton GY, et al; Western Canadian Complex Pediatric Therapies Follow-Up Group. Health-related quality of life in pediatric cardiac extracorporeal life support survivors. *Pediatr Crit Care Med.* 2014;15(8):720–727.
18. Khambekar K, Nichani S, Luyt DK, et al. Developmental outcome in newborn infants treated for acute respiratory failure with extracorporeal membrane oxygenation: present experience. *Arch Dis Child Fetal Neonatal Ed.* 2006;91(1):F21–F25.
19. Nield TA, Langenbacher D, Poulsen MK, Platzker AC. Neurodevelopmental outcome at 3.5 years of age in children treated with extracorporeal life support: relationship to primary diagnosis. *J Pediatr.* 2000;136(3):338–344.
20. van Rossum J, Vermeer A. Handleiding motorische competentiezelbeoordeling. Lisse, Netherlands: Swets-Zeitlinger; 2000.
21. Harter S, Pike R. The pictorial scale of perceived competence and social acceptance for young children. *Child Dev.* 1984;55(6):1969–1982.
22. Veerman JW, Straathof MAE, Treffers DA. Competentie-Belevingsschaal voor Kinderen (CBSK). Lisse, Netherlands: Swets-Zeitlinger; 1997.
23. Engelen V, Haentjens MM, Detmar SB, Koopman HM, Grootenhuis MA. Health related quality of life of Dutch children: psychometric properties of the PedsQL in the Netherlands. *BMC Pediatr.* 2009;9:68.
24. Varni JW, Burwinkle TM, Seid M. The PedsQL as a pediatric patient-reported outcome: reliability and validity of the PedsQL Measurement Model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res.* 2005;5(6):705–719.
25. Smits-Engelsman B. Dutch Manual Movement Assessment Battery for Children. Lisse, Netherlands: Swets-Zeitlinger; 1998.
26. Smits-Engelsman BC, Fiers MJ, Henderson SE, Henderson L. Interrater reliability of the Movement Assessment Battery for Children. *Phys Ther.* 2008;88(2):286–294.
27. Hoorens V. Self-enhancement and superiority biases in social comparison. *Eur Rev Soc Psychol.* 1993;4(1):113–139.
28. Madderom MJ, Reuser JJ, Utens EM, et al. Neurodevelopmental, educational and behavioral outcome at 8 years after neonatal ECMO: a nationwide multicenter study. *Intensive Care Med.* 2013;39(9):1584–1593.
29. Fliers EA, de Hoog ML, Franke B, et al. Actual motor performance and self-perceived motor competence in children with attention-deficit hyperactivity disorder compared with healthy siblings and peers. *J Dev Behav Pediatr.* 2010;31(1): 35–40.
30. Tolboom N, Cats EA, Helders PJM, Pruijs JEH, Engelbert RHH. Osteogenesis imperfecta in childhood: effects of spondylodesis on functional ability, ambulation and perceived competence. *Eur Spine J.* 2004;13(2):108–113.
31. Jongmans M, Demetre JD, Dubowitz L, Henderson SE. How local is the impact of a specific learning difficulty on premature children's evaluation of their own competence? *J Child Psychol Psychiatry.* 1996;37(5): 563–568.
32. Perricone G, Polizzi C, De Luca F. Self-representation of children suffering from congenital heart disease and maternal competence. *Pediatr Rep.* 2013;5(1):e1.
33. Knowles RL, Day T, Wade A, Bull C, Wren C, Dezateux C; UK Collaborative Study of Congenital Heart Defects (UKCSCHD). Patient-reported quality of life outcomes for children with serious congenital heart defects. *Arch Dis Child.* 2014;99(5): 413–419.
34. Costello JM, O'Brien M, Wypij D, et al. Quality of life of pediatric cardiac patients who previously required extracorporeal membrane oxygenation. *Pediatr Crit Care Med.* 2012;13(4): 428–434.