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ORIGINAL ARTICLE

Motor-related health care for 5-year-old children born extremely preterm with movement impairments

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Aim: To (1) determine the proportion of 5-year-old children born extremely preterm (EPT) with movement difficulties including cerebral palsy (CP) and the proportion of these children receiving motor-related health care (MRHC), and (2) describe factors associated with receiving MRHC.

Method: Children born before 28 weeks' gestation in 2011 to 2012 in 11 European countries were assessed with the Movement Assessment Battery for Children, Second Edition (MABC-2) at 5 years of age. Information on family characteristics, child health including CP diagnosis, and health care use were collected using parent-report questionnaires. MRHC was defined as visits in the previous year with health care providers (physical and occupational therapists) specialized in assessing/treating motor problems. We analysed receipt of MRHC and associated factors among children at risk of movement difficulties (MABC-2 score 6th–15th centiles), with significant movement difficulties (SMD; ≤5th centile) or with CP.

Results: Of 807 children assessed at 5 years 7 months (SD 4 months; 4 years 7 months–7 years 1 month), 412 were males (51.1%), 170 (21.1%) were at risk of movement difficulties, 201 (24.9%) had SMD, and 92 (11.4%) had CP. Those who received MRHC comprised 89.1% of children with CP, 42.8% with SMD, and 25.9% at risk of movement difficulties. MRHC for children with SMD varied from 23.3% to 66.7% between countries. Children were more likely to receive MRHC if they had other developmental problems or socioemotional, conduct, or attention difficulties.

Interpretation: Efforts are needed to increase MRHC for 5-year-old children born EPT with movement difficulties.

This original article is commented on by Cameron on pages 1055–1056 of this issue.

Abbreviations: EPT, extremely preterm; ISCED, International Standard Classification of Education; MABC-2, Movement Assessment Battery for Children, Second Edition; MRHC, motor-related health care; SHIPS, Screening to improve Health In very Preterm infantS in Europe; SMD, significant movement difficulties.

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Movement difficulties are a frequent complication after extremely preterm (EPT) birth, before 28 weeks gestational age, and include cerebral palsy (CP), developmental coordination disorder, and other movement difficulties.[1] Together, movement difficulties affect about one-third of 5-year-old children born EPT.[2,3] Comorbidity with other developmental problems is common.[4–7]

Motor development implies the reorganization of the neural connections required for the acquisition of skilled movement control in the postnatal period.[8,9] Early instigation of motor-related health care (MRHC) is important to take advantage of the developing brain's greater neuroplasticity and ability to reorganize neural connectivity in response to new experiences or training during this period.[10] European standards of care for infants born very preterm recommend assessment of motor development in the first years,[11] and studies show that interventions to prevent motor impairment and to improve motor performance in children born preterm are beneficial.[12,13]

However, there is sparse information on the contacts that children born EPT with movement difficulties have with health care providers. This study aimed to determine the proportion of children born EPT with movement difficulties or CP who received MRHC at 5 years of age, as well as the factors related to receiving MRHC in a prospective European birth cohort. We hypothesized that many children born EPT with movement difficulties would receive multidisciplinary care[14] because of the co-occurrence of movement difficulties with other developmental difficulties and that MRHC use would vary across countries, given differences in routine health care follow-up and specialist use.[15–17]

What this paper adds

- Children born extremely preterm without cerebral palsy frequently experienced motor difficulties.
- Most of these children were not receiving motor-related health care (MRHC).
- Large geographical differences throughout Europe were observed in receipt of MRHC.
- Socioemotional problems were related to MRHC use.

METHOD

Study design

Data are from the Screening to improve Health In very Preterm infantS in Europe (SHIPS) project, which followed up the Effective Perinatal Intensive Care in Europe population-based cohort of children born very preterm (<32 weeks gestational age) at 5 years of age.[18] This cohort included all very preterm births over a 12-month period (except in France where it was 6 months) in 2011 to 2012 from 19 regions in 11 European countries.[18] In this cohort, 6792 infants (1671 EPT) survived to discharge from neonatal care. Ethical authorizations from local regional or hospital ethics boards were received, as required by national legislation, and written parental consent was obtained for follow-up. The European SHIPS study was approved by the French Advisory Committee on Use of Health Data in Medical Research and the French National Commission for Data Protection and Liberties.

Study population

Of children born EPT in the cohort who survived to discharge from neonatal care, 17 died between discharge and 5 years (Figure S1). At 5 years, 1021 children were followed up (61.7% participation rate, from 38.7% for the UK to 100% for Estonia). The study population included children born EPT (n = 807), either with a diagnosis of CP (n = 92; CP defined as having a formal clinical diagnosis as reported by parents or diagnosed by a doctor) or without a diagnosis of CP and a valid motor assessment (n = 715) and no severe neurodevelopmental impairment (i.e. deafness or difficulties hearing even with hearing aid or implant; blindness or seeing light only; an IQ score below 55 points [<–3 SD]), and with information on health care service use.

Perinatal data collection

Data on maternal, pregnancy, and neonatal characteristics were collected from obstetric and neonatal records using a

standardized questionnaire. Information included maternal age at delivery, maternal country of birth, parity, multiple birth, premature rupture of membranes, pre-eclampsia/eclampsia/haemolysis, elevated liver enzymes, and low platelets, child sex, birthweight, congenital anomalies, and gestational age. Gestational age was defined as the best estimate determined by the obstetrical team on the basis of information for last menstrual period and antenatal ultrasounds. Small for gestational age was defined as a birthweight less than the 10th centile of European references developed for the cohort.[19] Bronchopulmonary dysplasia was defined as oxygen dependency at 36 weeks postmenstrual age. Severe neonatal morbidity was defined as a composite measure of cystic periventricular leukomalacia, intraventricular haemorrhage grades III and IV, severe necrotizing enterocolitis requiring surgery or peritoneal drainage, or retinopathy of prematurity at least stage 3.

Five-year follow-up

The 5-year follow-up protocol included a neurodevelopmental assessment and a parental questionnaire.

Neurodevelopmental assessments

The Movement Assessment Battery for Children, Second Edition (MABC-2) was administered by trained psychologists or physiotherapists. Assessments were performed by staff in local routine follow-up programmes where available (Belgium, the Netherlands, Sweden) or by the SHIPS research team (Denmark, Estonia, France, Germany, Italy, Poland, Portugal, UK). Although it was not possible to assess interrater reliability across countries, common data collection guidelines and a core data collection form were developed to standardize procedures and to ensure consistent reporting of the assessment results. Training sessions were held locally and an online discussion forum was set up to discuss possible problems emerging during the data collection. The MABC-2[20] was used to assess motor development with the original UK norms. Scores greater than the 15th centile indicate no movement difficulties; those greater than the 5th and up to the 15th centiles indicate that the child is at risk of movement difficulties; and scores no greater than the 5th centile denote significant movement difficulties (SMD).[20] Eight Belgian children were assessed with the MABC, First Edition,[21] but the converted centile scores allow the same classification of movement difficulties.

A group composed of neurodevelopmental specialists and an epidemiologist (RC, UA, SJ, and JZ) examined children with missing MABC-2 scores on a case-by-case basis. Where the MABC-2 test could not be completed owing to a severe motor impairment described by the clinical team, a composite score of 1 (i.e. centile 0.1) was assigned ($n = 7$). When a subtest was missing and the child had no other neurosensory or developmental problem that could explain the missing value, the average of the other subtests was assigned ($n = 11$); otherwise, data were not imputed.

The Wechsler Preschool and Primary Scale of Intelligence Revised, Third Edition, or Fourth Edition[22,23] was administered to assess full-scale IQ. Scores were calculated using local norms; full-scale IQ scores of at least 85 (>−1 SD) indicate cognition in or above the average range; scores between 70 and 84 (<−1 SD; −2 SD) mild impairment; scores between 55 and 69 (<−2 SD; −3 SD) moderate impairment; and scores no more than 54 (<−3 SD) severe impairment.

Parent-report questionnaires

Data on the children's health, including CP diagnosis, health care use, and parental sociodemographic status, were collected using a parental questionnaire (completed by mothers, fathers, or other caregivers). We used information on mothers' educational level, coded using the International Standard Classification of Education (ISCED)[24] into low (ISCED 0–2), intermediate (ISCED 3–5), and high (ISCED 6–8), parental cohabitation status, and household employment status.

Participants indicated the number of visits over the previous year to specific health care providers from a pre-established, pre-tested list adapted to each country.[15] Receiving MRHC was defined as having at least one visit to any of the following: (1) physiotherapist, motor development or psychomotor therapist, or kinesiologist; (2) occupational therapist, or (3) early intervention specialist. Receiving specialized health care was defined as having at least one visit to any of the following: (1) neurologist/developmental paediatrician; (2) psychologist/neuropsychologist or psychiatrist/neuropsychiatrist; (3) speech/language therapist; (4) ear specialist/ear, nose, and throat specialist/hearing test; (5) eye specialist, ophthalmologist, optometrist, or orthoptist; (6) respiratory or allergy specialist; or (7) dietitian or nutritionist. Receiving general health care was defined as having at least one visit in the previous year to any of the following: (1) paediatrician; (2) family doctor/general practitioner; (3) hospital accident and emergency department/hospitalization overnight; or (4) school nurse/nurse/health visitor.

Parents also completed the Strengths and Difficulties Questionnaire[25] which is a well-validated and widely used measure of children's behaviour, inattention/hyperactivity, and social and emotional problems over the previous 6 months that provides a total score and five subscales. The scores were categorized as 'normal', 'borderline', or 'abnormal'.[26]

Statistical analysis

We first described the sociodemographic and clinical characteristics of participants and non-participants. Since there were differences in the follow-up rates by country,[18] these comparisons were adjusted for country using logistic

regression. Then, we reported the median number of visits to health care services, and, using χ^2 tests, we compared the health care services received by children in four groups: no movement difficulties; at risk of movement difficulties; SMD; CP. We compared health care service use by country; however, for our primary analysis we focused on a subset of countries with larger samples (France [*n* = 160], Italy [*n* = 137], Portugal [*n* = 94], and the UK [*n* = 102]). We then investigated factors related to MRHC service use among the combined group of children without CP at risk of movement difficulties or with SMD. Logistic regressions adjusting only for country and adjusting for country and level of motor development (MABC-2 total score) were performed to obtain the odds ratio (OR) and 95% confidence interval (CI) of receiving MRHC among children at risk of movement difficulties or with SMD according to the family socioeconomic characteristics and the child's perinatal and socioemotional characteristics. We performed sensitivity analyses by rerunning models with inverse probability weighting to take into account loss to follow-up,[27,28] as described previously in this cohort.[29–31] All analyses used SPSS version 26.0 (IBM Corp., Armonk, NY, USA).

RESULTS

The mean gestational age at birth was 26 weeks 4 days (SD 8 days), the mean birthweight was 876.8g (SD 188.6), and 412 children were male (51.1%) (Table 1). Most children were singleton (71.4%) and about one-quarter were small for gestational age (24.5%) or had severe neonatal morbidity (24.5%). Children who survived to discharge from neonatal care but who were: not followed up at 5 years, had mothers who were younger, non-European born, or multiparous were compared with those followed up (Table S1). There were also fewer pregnancies complicated by pre-eclampsia/eclampsia/haemolysis, elevated liver enzymes, and low platelet count, and fewer infants who were small for gestational age among children not followed up compared with those who were. Children without MABC-2 scores or missing health care data had lower gestational age and birthweight, and their mothers were more likely to be younger, non-European born, and have lower educational level than children in the analysis (Table S2). MABC-2 assessments were performed at an average age of 5 years 7 months (SD 4 months; 4 years 7 months–7 years 1 month). Of the 807 participants included in the analysis (Table 1), 170 (21.1%) were at risk of movement difficulties, 201 (24.9%) had SMD, and 92 (11.4%) had CP.

Most children with CP received MRHC (89.1%) in addition to other specialized health care (91.3%) and general health care (95.7%) (Table 2). These proportions were substantially higher than for children without CP but with SMD or at risk of movement difficulties, especially for MRHC (MRHC, 42.8%/25.9%; other specialized health care, 85.6%/71.2%; and general health care, 89.6%/91.2%). For children without CP and at risk of movement difficulties or with SMD, the main MRHC providers were physiotherapists, motor development/psychomotor therapists, or kinesiologists (23.5%), followed by early intervention services (12.4%) and occupational therapists (10.5%).

In countries with sample sizes above 90 children, the proportion of children at risk of movement difficulties or with SMD receiving MRHC varied from 4.5%/23.3% in the UK to 33.3%/66.7% in France (Figure 1). Variation in the provision of MRHC for children with CP was lower. Similar patterns were observed for countries with sample sizes below 90 (Figure S2).

Receiving MRHC (Table 3) was associated with unemployment in the household (OR 2.59; 95% CI 1.41–4.76), severe neonatal morbidity (OR 2.26; 95% CI 1.32–3.86), receiving other specialized health care (OR 2.76; 95% CI 1.09–7.00), or general health care (2.82; 95% CI 1.42–5.60). Not receiving MRHC was associated with non-European-born mothers (0.28; 95% CI 0.13–0.63). Children with emotional problems, peer relationship problems, conduct problems, or inattention/hyperactivity or abnormal total scores on the Strengths and Difficulties Questionnaire were more likely to receive MRHC (Table 4). Sensitivity analyses with inverse probability weighting yielded similar results (Tables S3 and S4).

DISCUSSION

This study found high use of MRHC among children born EPT with CP (89.0%), but lower use among children without CP with SMD (42.8%) or at risk of movement difficulties (25.9%). Additionally, there was higher variation in MRHC use between countries for children without CP but at risk of movement difficulties or with SMD, compared with children with CP. Children who received MRHC were most likely to receive it from physiotherapists, motor development/psychomotor therapists, or kinesiologists, followed by early intervention services. The median number of visits to specialized MRHC providers varied between one and two visits per month during the previous year, depending on the service, indicating care beyond a single visit for assessment of motor function. We found that comorbidity with other behavioural, social, or emotional problems, or receiving other specialized or general health care, were associated with a higher likelihood of receiving MRHC.

The low proportion of children with SMD receiving MRHC compared with children with CP is striking. Several non-exclusive hypotheses may explain these low levels of care. First, the duration of routine follow-up for children born EPT may not be long enough to detect evolving movement difficulties in some children. In our cohort, 90.3% children used routine follow-up services at some point after discharge, but at the age of 5 years only 27.3% were using follow-up services.[16] The proportion of children with SMD receiving MRHC was higher in France and Portugal, which have higher rates of routine follow-up at the age of 5 years (31.2% and 58.4%), compared with Italy and the UK (12.3%

TABLE 1 Characteristics of the sample of all children born extremely preterm included in the study overall and by motor status

	Total (*n* = 807) *n* (%)	No movement difficulties (*n* = 344) *n* (%)	At risk movement difficulties (*n* = 170) *n* (%)	SMD (*n* = 201) *n* (%)	CP (*n* = 92) *n* (%)
Maternal education					
Low ISCED 0–2	138 (17.3)	49 (14.4)	28 (16.7)	45 (22.6)	16 (18.0)
Intermediate ISCED 3–5	341 (42.8)	142 (41.8)	70 (41.7)	88 (44.2)	41 (46.1)
High ISCED 6–8	317 (39.8)	149 (43.8)	70 (41.7)	66 (33.2)	32 (36.0)
Missing	11 (1.4)	4 (1.2)	2 (1.2)	3 (1.5)	3 (3.3)
Household unemployment					
At least one parent unemployed	100 (12.6)	25 (7.3)	31 (18.5)	28 (14.1)	16 (18.4)
Other situations[a]	695 (87.4)	317 (92.7)	137 (81.5)	170 (85.9)	71 (81.6)
Missing	12 (1.5)	2 (0.6)	2 (1.2)	3 (1.5)	5 (5.4)
Parental cohabiting status					
Single parent or other situation	138 (17.2)	58 (16.9)	31 (18.3)	33 (16.6)	16 (17.4)
Married/couple/cohabiting	666 (82.8)	286 (83.1)	138 (81.7)	166 (83.4)	76 (82.6)
Missing	3 (0.4)	0 (0.0)	1 (0.6)	2 (1.0)	0 (0.0)
Maternal age at childbirth (years)					
≤24	87 (10.8)	26 (7.6)	20 (11.9)	28 (13.9)	13 (14.4)
25–34	471 (58.7)	198 (57.6)	111 (66.1)	109 (54.2)	53 (58.9)
≥35	245 (30.5)	120 (34.9)	37 (22.0)	64 (31.8)	24 (26.7)
Missing	4 (0.5)	0 (0.0)	2 (1.2)	0 (0.0)	2 (2.2)
Maternal country of birth					
Native	637 (79.2)	270 (78.9)	142 (84.0)	152 (75.6)	73 (79.3)
Born in another European country	53 (6.6)	19 (5.6)	12 (7.1)	17 (8.5)	5 (5.4)
Born in a non-European country	114 (14.2)	53 (15.5)	15 (8.9)	32 (15.9)	14 (15.2)
Missing	3 (0.4)	2 (0.6)	1 (0.6)	0 (0.0)	0 (0.0)
Parity					
Nulliparous	483 (60.7)	197 (58.3)	116 (69.0)	125 (62.5)	45 (50.0)
Multiparous	313 (39.3)	141 (41.7)	52 (31.0)	75 (37.5)	45 (50.0)
Missing	11 (1.4)	6 (1.7)	2 (1.2)	1 (0.5)	2 (2.2)
Multiple birth					
Singleton	576 (71.4)	225 (65.4)	126 (74.1)	156 (77.6)	69 (75.0)
Multiple	231 (28.6)	119 (34.6)	44 (25.9)	45 (22.4)	23 (25.0)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
PROM					
Yes	199 (24.9)	82 (24.1)	43 (25.6)	52 (26.1)	22 (24.2)
Missing	9 (1.1)	4 (1.2)	2 (1.2)	2 (1.0)	1 (1.1)
Eclampsia/pre-eclampsia/HELLP					
Yes	90 (11.3)	38 (11.1)	19 (11.4)	25 (12.5)	8 (8.8)
Missing	9 (1.1)	3 (0.9)	4 (2.4)	1 (0.5)	1 (1.1)
Sex					
Male	412 (51.1)	137 (39.8)	90 (52.9)	124 (61.7)	61 (66.3)
Female	395 (48.9)	207 (60.2)	80 (47.1)	77 (38.3)	31 (33.7)
Missing	0 (0.0)	0 (0.0)	0 (0,0)	0 (0.0)	0 (0.0)
Gestational age (completed weeks)					
≤24	82 (10.2)	22 (6.4)	19 (11.2)	29 (14.4)	12 (13.0)
25	153 (19.0)	55 (16.0)	25 (14.7)	45 (22.4)	28 (30.4)
26	239 (29.6)	111 (32.3)	48 (28.2)	59 (29.4)	21 (22.8)
27	333 (41.3)	156 (45.3)	78 (45.9)	68 (33.8)	31 (33.7)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Mean (SD)	27 (1)	2.7 (1)	27 (1)	26 (1)	26 (1)
Birthweight (g)					
Mean (SD)	876.8 (188.6)	902.9 (177.1)	870.4 (203.1)	844.8 (193.8)	860.9 (179.6)

(Continues)

TABLE 1 (Continued)

	Total (*n* = 807) *n* (%)	No movement difficulties (*n* = 344) *n* (%)	At risk movement difficulties (*n* = 170) *n* (%)	SMD (*n* = 201) *n* (%)	CP (*n* = 92) *n* (%)
SGA (EURO-Peristat)					
<10	198 (24.5)	74 (21.5)	48 (28.2)	58 (28.8)	18 (19.6)
≥10	609 (75.5)	270 (78.5)	122 (71.8)	143 (71.2)	74 (80.4)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Congenital anomalies					
Yes	67 (8.3)	18 (5.2)	10 (5.9)	26 (12.9)	13 (14.1)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
BPD					
Yes	253 (32.2)	65 (19.6)	58 (34.7)	89 (45.2)	41 (46.1)
Missing	22 (2.7)	12 (3.5)	3 (1.8)	4 (2.0)	3 (3.3)
Severe neonatal morbidity[b]					
Yes	194 (24.5)	45 (13.3)	36 (21.6)	58 (29.4)	55 (61.1)
Missing	15 (1.9)	6 (1.7)	3 (1.8)	4 (2.0)	2 (2.2)
MABC-2 scores[c]					
Mean (SD)	7.1 (3.5)	10.3 (2.0)	6.6 (0.5)	3.6 (1.5)	2.7 (2.6)
Cognitive status[d]					
No impairment	548 (70.6)	300 (88.0)	125 (73.5)	95 (47.7)	28 (42.4)
Mild impairment	158 (20.4)	37 (10.9)	42 (24.7)	64 (32.2)	15 (22.7)
Moderate impairment	57 (7.3)	4 (1.2)	3 (1.8)	40 (20.1)	10 (15.2)
Severe impairment	13 (1.7)	0 (0.0)	0 (0.0)	0 (0.0)	13 (19.7)
Missing	31 (3.8)	3 (0.9)	0 (0.0)	2 (1.0)	26 (28.3)
SDQ total score[e]					
Normal	566 (71.1)	276 (80.7)	122 (72.6)	127 (63.8)	41 (47.1)
Borderline	101 (12.7)	32 (9.4)	16 (9.5)	34 (17.1)	19 (21.8)
Abnormal	129 (16.2)	34 (9.9)	30 (17.9)	38 (19.1)	27 (31.0)
Missing	11 (1.4)	2 (0.6)	2 (1.2)	2 (1.0)	5 (5.4)
Country (regions)					
Belgium (Flanders)	47 (5.8)	14 (4.1)	17 (10.0)	8 (4.0)	8 (8.7)
Denmark (eastern region)	42 (5.2)	23 (6.7)	10 (5.9)	7 (3.5)	2 (2.2)
Estonia (entire country)	33 (4.1)	18 (5.2)	3 (1.8)	10 (5.0)	2 (2.2)
France (Burgundy, Ile-de-France, northern region)	160 (19.8)	99 (28.8)	24 (14.1)	15 (7.5)	22 (23.9)
Germany (Hesse, Saarland)	59 (7.3)	28 (8.1)	10 (5.9)	13 (6.5)	8 (8.7)
Italy (Emilia-Romagna, Lazio, Marche)	137 (17.0)	50 (14.5)	29 (17.1)	43 (21.4)	15 (16.3)
The Netherlands (central eastern region)	63 (7.8)	33 (9.6)	21 (12.4)	7 (3.5)	2 (2.2)
Poland (Wielkopolska)	41 (5.1)	4 (1.2)	4 (2.4)	23 (11.4)	10 (10.9)
Portugal (Lisbon, northern region)	94 (11.6)	35 (10.2)	27 (15.9)	26 (12.9)	6 (6.5)
UK (East Midlands, northern, Yorkshire, the Humber)	102 (12.6)	26 (7.6)	22 (12.9)	43 (21.4)	11 (12.0)
Sweden (greater Stockholm)	29 (3.6)	14 (4.1)	3 (1.8)	6 (3.0)	6 (6.5)
Missing	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)

Abbreviations: BPD, bronchopulmonary dysplasia was defined as oxygen dependency at 36 weeks postmenstrual age; PROM, premature rupture of membranes; SGA, small for gestational age was defined as a birthweight less than the 10th centile of European references;[19] ISCED, International Standard Classification of Education; SMD, significant movement difficulties; CP, cerebral palsy; HELLP, hemolysis, elevated liver enzymes, and low platelets count.

[a]Other situations included student, parental leave, home parent, and other.

[b]Defined as a composite measure of cystic periventricular leukomalacia, intraventricular haemorrhage grades III and IV, necrotizing enterocolitis that required surgery or peritoneal drainage, or retinopathy of prematurity ≥ stage 3.

[c]Movement Assessment Battery for Children, Second Edition (MABC-2): for the group of children with CP, scores are available for 71 children, owing to some of these children's inability to perform the assessment.

[d]Severe impairment was considered if IQ < 55; moderate impairment was considered if IQ was between 55 and 69; mild impairment was considered if IQ was between 70 and 84; no impairment was considered if IQ ≥ 85.

[e]Strengths and Difficulties Questionnaire total score derived from emotional symptoms, conduct problems, hyperactivity/inattention, and peer relationship problems scores.

TABLE 2 Health care use among children born extremely preterm according to movement difficulties and cerebral palsy

	Movement difficulties				
	Number (*n* = 344) *n* (%)	**Movement difficulties (*n* = 170) *n* (%)**	**SMD (*n* = 201) *n* (%)**	**CP (*n* = 92) *n* (%)**	**Total (*n* = 807) *n* (%)**
Physiotherapist/motor development or psychomotor therapist/kinesiologist[a]	**33 (9.6)**	**29 (17.1)**	**58 (28.9)**	**75 (81.5)**	**195 (24.2)**
Number of visits,[b] median (Q1–Q3)	2.0 (1.0–15.0)	24.0 (1.3–49.0)	14.0 (3.0–52.0)	60.0 (26.0–130.0)	25.0 (3.0–60.0)
Occupational therapist[a]	**12 (3.5)**	**9 (5.3)**	**30 (14.9)**	**36 (39.1)**	**87 (10.8)**
Number of visits,[b] median (Q1–Q3)	1.0 (1.0–19.0)	27.0 (2.0–40.0)	16.0 (2.0–46)	35.0 (9.3–59.0)	22.0 (2.0–48.0)
Early intervention[c]	**3 (0.9)**	**13 (7.6)**	**33 (16.4)**	**20 (21.7)**	**69 (8.6)**
Number of visits,[b] median (Q1–Q3)	2.0 (2.0–2.0)	8.0 (2.5–33.5)	12.0 (2.0–44.0)	11.0 (5.3–50.0)	10.0 (2.0–40.0)
MRHC[d]	**42 (12.2)**	**44 (25.9)**	**86 (42.8)**	**82 (89.1)**	**254 (31.5)**
Number of visits,[b] median (Q1–Q3)	2.0 (1.0–15.5)	24.0 (3.0–45.0)	18.0 (3.0–52.0)	70.0 (31.5–150.0)	26.0 (3.0–60.0)
Other specialized health care[e]	**232 (67.4)**	**121 (71.2)**	**172 (85.6)**	**84 (91.3)**	**609 (75.5)**
Number of visits,[b] median (Q1–Q3)	3.0 (1.0–6.8)	3.0 (2.0–11.5)	6.0 (2.0–28.0)	23.0 (5.3–72.8)	4.0 (2.0–18.0)
General health care[f]	314 (91.3)	155 (91.2)	180 (89.6)	88 (95.7)	737 (91.3)
Number of visits,[b] median (Q1–Q3)	3.0 (2.0–6.0)	4.0 (2.0–7.0)	4.0 (2.0–8.0)	7.0 (2.0–18.8)	4.0 (2.0–7.5)
Health care use					
No health care at all	**102 (29.7)**	**34 (20.0)**	**34 (16.9)**	**5 (5.4)**	**175 (21.7)**
Only MRHC	**1 (0.3)**	**1 (0.6)**	**0 (0.0)**	**1 (1.1)**	**3 (0.4)**
Only other than MRHC	**200 (58.1)**	**92 (54.1)**	**81 (40.3)**	**5 (5.4)**	**378 (46.8)**
MRHC and other health care	**41 (11.9)**	**43 (25.3)**	**86 (42.8)**	**81 (88.0)**	**251 (31.1)**

Note: Bold type indicates statistically significant results.

Abbreviations: MRHC, motor-related health care; SMD, significant movement difficulties; CP, cerebral palsy.

[a]At least one visit to any of these specialists over the previous year.

[b]Number of visits calculated for participants that reported at least one visit over the previous year.

[c]At least one visit over the previous year.

[d]Defined as having at least one visit to a motor-related health specialist over the previous year: (1) physiotherapist, motor development or psychomotor therapist, or kinesiologist; (2) occupational therapist; or (3) early intervention specialist.

[e]Defined as having at least one visit in the previous year to a (1) neurologist/developmental paediatrician; (2) psychologist/neuropsychologist or psychiatrist/neuropsychiatrist; (3) speech/language therapist; (4) ear specialist/ear, nose, and throat specialist/hearing test; (5) eye specialist, ophthalmologist, optometrist, or orthoptist; (6) respiratory specialist or allergologist; or (7) dietitian or nutritionist.

[f]Defined as having at least one visit in the previous year to (1) paediatrician; (2) family doctor/general practitioner; (3) hospital accident and emergency department/hospitalization overnight; or (4) school nurse/nurse/health visitor.

and 17.0%).[16] Longer systematic follow-up beyond 2 years of age may be needed to identify children with movement difficulties, since about one-third of children born preterm with CP are only diagnosed after 2 years 6 months of age[32] and because motor skills may decline until at least the age of 5 years in children born very preterm, especially for those who had higher scores on tests of motor performance at the age of 2 years.[33]

A second hypothesis is that movement difficulties may not be assessed as part of routine clinical follow-up protocols. The European Foundation for the Care of Newborn Infants Standards of Care for children born very preterm recommends conducting several assessments of motor development in the first 2 years and again at transition to school.[11] We currently lack information about the extent to which the follow-up protocols follow these recommendations, including whether motor function is part of those protocols, at what ages it is assessed, how it is assessed, and whether specific risk-groups are targeted. In some follow-up programmes, movement difficulties may not be recognized as a developmental area in need of assessment, meaning it would only be assessed within the scope of in-depth neurodevelopmental assessments when there is suspicion of other developmental problems.

Another hypothesis might be that parents of children born EPT underestimate children's motor problems.[34] They may not feel that these difficulties affect the child's daily life, and therefore they do not recognize them as problematic, especially if the child has no other behavioural or emotional problems. Similarly, movement difficulties with subtle or no ostensible impact on the child's daily activities may be underestimated or undiagnosed by health care providers;[35] or providers may be reluctant to refer the child for care, particularly in contexts where there is insufficient supply of services in both the private and the public sectors even for children born preterm with more complex special needs.[36–38] This would be of concern because some health care interventions have yielded benefits for children with

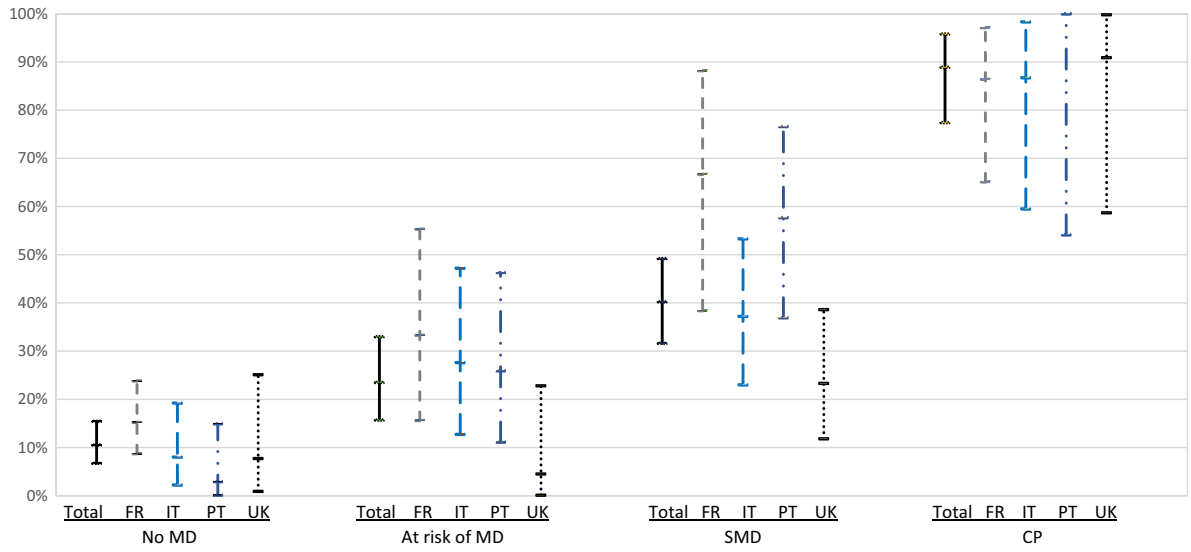

FIGURE 1 Percentage of children born extremely preterm who received motor-related health care (MHRC) with 95% confidence intervals according to motor status in France, Italy, Portugal, and the UK. MHRC is defined as having at least one visit to any MHRC specialist over the last year: (1) physiotherapist, motor development or psychomotor therapist, or kinesiologist; (2) occupational therapist; or (3) early intervention specialist. Abbreviations: MD, movement difficulties; SMD, significant movement difficulties; CP, cerebral palsy; FR, France; IT, Italy; PT, Portugal; UK, United Kingdom

developmental coordination disorder.[12,39–40] Another possibility is that health care providers believe that movement difficulties with subtle impacts on daily activities will be overcome with preschool activities that promote fine and gross motor skills.

Large differences in the use of MRHC for children with SMD were observed by country which may be explained by variability in routine follow-up protocols and intervention approaches, as described above, or potentially by service availability.[17] Heterogeneity is known to exist between countries in routine follow-up policies and programmes,[16] but we did not collect information on the specific follow-up protocols used for motor function assessment for the children in our sample. Our data come from selected regions in each country – except for Estonia where the entire country is represented – and therefore results may not be representative of the situation in the whole country given regional differences in the organization of follow-up services and health care provision. Further research comparing follow-up for these children in more detail in regions and countries with different levels of MRHC use could help refine explanatory hypotheses.

These geographical differences illustrate a lack of consensus on optimal care for children with movement difficulties, which is reflected in the absence of international guidelines for the follow-up of children born EPT without a formal diagnosis of impairment[41] until very recently.[11] Indeed, health care providers are more likely to work with children with a diagnosed condition.[42] This hypothesis is consistent with the much lower variation between countries in MRHC provided to children with a formal diagnosis of CP, for which there are established guidelines for health care provision.[43–45] This suggests that implementation of the recently published European standards for developmental follow-up care[11] and the international clinical practice on recommendations for intervention in children with developmental coordination disorder[46] may improve recognition and treatment of health conditions.[47]

Children born EPT with perinatal risk factors for health and developmental problems had increased use of specialized health care, including MRHC, as also found in our sample at 2 years.[15] In contrast, children of non-European-born mothers were less likely to receive MRHC, which is consistent with data showing these children are less likely to use routine follow-up services[16] and with reports of barriers to accessing appropriate health care faced by migrant parents with newborn infants or young children.[48] Having at least one parent unemployed was associated with greater use of MRHC, but causality is hard to assess because parents may drop out of the workforce when children require a lot of care.[49] Reassuringly, other social indicators such as maternal age, educational level, or family situation were not associated with the likelihood of health care use. Nevertheless, since non-participation in our study was more common among younger, non-native, and less educated mothers, this population may be underrepresented.

The strengths of this study are data from a population-based cohort with a large sample of children born EPT followed until 5 years of age in 11 countries in Europe. Another strength is standardized and harmonized data collection, including data collected at baseline from medical records, parental report questionnaires, and motor assessments using the same instrument across countries. Limitations include parent-reported information on health care service use, which may be subject to recall bias. Furthermore, we did not have information on the purpose of the health care received

TABLE 3 Social and clinical characteristics associated with receiving motor-related health care (MRHC) among children without cerebral palsy at risk of movement difficulties or with significant movement difficulties

	MRHC[a]			Model 1[b]		Model 2[c]	
	No, *n* (%)	Yes, *n* (%)	Total, *n*	OR	95% CI	OR	95% CI
Maternal age at childbirth (years)							
<25	31 (64.6)	17 (35.4)	48	0.94	0.44–2.03	0.94	0.42–2.08
25–34	146 (66.4)	74 (33.6)	220	0.92	0.54–1.55	1.04	0.60–1.80
≥35	63 (62.4)	38 (37.6)	101	Ref.		Ref.	
Maternal education							
Low education ISCED 0–2	45 (61.6)	28 (38.4)	73	1.09	0.57–2.09	0.82	0.41–1.63
Intermediate education ISCED 3–5	98 (62.0)	60 (38.0)	158	**1.70**	**1.00–2.88**	1.52	0.88–2.64
High education ISCED 6–8	96 (70.6)	40 (29.4)	136	Ref.		Ref.	
Maternal country of birth							
Native	187 (63.6)	107 (36.4)	294	Ref.		Ref.	
Born in another European country	17 (58.6)	12 (41.4)	29	1.19	0.52–2.69	1.09	0.46–2.56
Born in a non-European country	**36 (76.6)**	**11 (23.4)**	**47**	**0.42**	**0.20–0.88**	**0.29**	**0.13–0.64**
Household unemployment							
At least one parent unemployed	**29 (49.2)**	**30 (50.8)**	**59**	**2.26**	**1.26–4.06**	**2.48**	**1.34–4.58**
Other situations[d]	211 (68.7)	96 (31.3)	307	Ref.		Ref.	
Parental cohabitation status							
Single parent or other situation	39 (60.9)	25 (39.1)	64	Ref.		Ref.	
Married/couple/cohabiting	201 (66.1)	103 (33.9)	304	0.84	0.47–1.51	0.79	0.43–1.45
Parity							
Nulliparous	152 (63.1)	89 (36.9)	241	Ref.		Ref.	
Multiparous	88 (69.3)	39 (30.7)	127	0.76	0.47–1.23	0.72	0.43–1.20
Multiple gestation							
Singleton	182 (64.5)	100 (35.5)	282	Ref.		Ref.	
Multiple	59 (66.3)	30 (33.7)	89	0.94	0.55–1.59	1.00	0.58–1.73
Premature rupture of membranes							
Yes	57 (60.0)	38 (40.0)	95	1.19	0.72–1.97	1.20	0.71–2.04
No	180 (66.2)	92 (33.8)	272	Ref.		Ref.	
Pre-eclampsia/eclampsia/HELLP							
Yes	25 (56.8)	19 (43.2)	44	1.25	0.64–2.44	1.17	0.59–2.36
No	211 (65.5)	111 (34.5)	322	Ref.		Ref.	
Sex							
Male	128 (59.8)	86 (40.2)	214	1.59	1.00–2.53	1.41	0.87–2.28
Female	113 (72.0)	44 (28.0)	157	Ref.		Ref.	
Gestational age (completed weeks)							
≤24	30 (62.5)	18 (37.5)	48	1.38	0.67–2.87	1.18	0.55–2.54
25	**36 (51.4)**	**34 (48.6)**	**70**	2.21	1.19–4.11	1.77	0.93–3.36
26	76 (71.0)	31 (29.0)	107	0.82	0.47–1.44	0.72	0.40–1.30
27	99 (67.8)	47 (32.2)	146	Ref.		Ref.	
Mean (SD)	27 (1)	26 (1)	371				

(Continues)

TABLE 3 (Continued)

	MRHC[a]			Model 1[b]		Model 2[c]	
	No, *n* (%)	Yes, *n* (%)	Total, *n*	OR	95% CI	OR	95% CI
SGA[e] (EURO-Peristat)							
<10	62 (58.5)	44 (41.5)	106	0.73	0.45–1.18	0.74	0.44–1.22
≥10	179 (67.5)	86 (32.5)	265	Ref.		Ref.	
Congenital anomalies							
No	223 (66.6)	112 (33.4)	335	Ref.		Ref.	
Yes	18 (50.0)	18 (50.0)	36	2.08	0.96–4.50	1.52	0.67–3.46
BPD[f]							
No	146 (67.3)	71 (32.7)	217	Ref.		Ref.	
Yes	**91 (61.9)**	**56 (38.1)**	**147**	**1.66**	**1.02–2.68**	1.43	0.86–2.37
Severe neonatal morbidity[g]							
No	190 (70.4)	80 (29.6)	270	Ref.		Ref.	
Yes	**48 (51.1)**	**46 (48.9)**	**94**	**2.59**	**1.55–4.34**	**2.29**	**1.34–3.91**
Use of specialized health care[h]							
No	65 (83.3)	13 (16.7)	78	Ref.		Ref.	
Yes	**176 (60.1)**	**117 (39.9)**	**293**	**3.34**	**1.71–6.53**	**2.82**	**1.42–5.60**
Use of general health care[i]							
No	29 (80.6)	7 (19.4)	36	Ref.		Ref.	
Yes	**212 (63.3)**	**123 (36.7)**	**335**	**2.25**	**0.92–5.47**	**2.76**	**1.09–7.00**

Note: Bold type indicates statistically significant results.

Abbreviations: OR, odds ratio; CI, confidence interval; ISCED, International Standard Classification of Education; HELLP, hemolysis, elevated liver enzymes, and low platelets count.

[a]MRHC was defined as having at least one visit to a motor-related health specialist over the previous year: (1) physiotherapist, motor development or psychomotor therapist, or kinesiologist; (2) occupational therapist; or (3) early intervention specialist.

[b]Model 1 was adjusted for country.

[c]Model 2 was adjusted for country and total score on the Movement Assessment Battery for Children, Second Edition.

[d]Other situations included student, parental leave, home parent, and other.

[e]SGA, small for gestational age was defined as a birthweight less than the 10th centile of European references.[19]

[f]BPD, bronchopulmonary dysplasia was defined as oxygen dependency at 36 weeks postmenstrual age.

[g]Severe neonatal morbidity was defined as a composite measure of cystic periventricular leukomalacia, intraventricular haemorrhage grades III and IV, necrotizing enterocolitis that required surgery or peritoneal drainage, or retinopathy of prematurity ≥ stage 3.

[h]Use of specialized health care was defined as having at least one visit in the previous year to any of the following: (1) neurologist/developmental paediatrician; (2) psychologist/neuropsychologist or psychiatrist/neuropsychiatrist; (3) speech/language therapist; (4) ear specialist/ear, nose, and throat specialist/hearing test; (5) eye specialist, ophthalmologist, optometrist, or orthoptist; (6) respiratory specialist or allergologist; or (7) dietitian or nutritionist.

[i]Use of general health care was defined as having at least one visit in the previous year to any of the following: (1) paediatrician; (2) family doctor/general practitioner; (3) hospital accident and emergency department/hospitalization overnight; or (4) school nurse/nurse/health visitor.

and whether they were for assessment or intervention. We also relied on parental reports of CP diagnosis. However, given the high use of health care services in this sample, in general it is likely that most children with CP would have received a diagnosis by the age of 5 years. Additionally, we have considered early intervention in the category of MRHC since, in the participating countries, early intervention is delivered by multidisciplinary professionals who include MRHC professionals. Still, some children undergoing early intervention may not be receiving MRHC which may have led to an overestimation of MRHC use.

As the study cohort was composed of children born EPT without a comparison group, assessors were not blinded to the very preterm status of children participating in the study which might have led to some bias. However, the MABC-2 is a well-established research tool with objective subtests and clear administration and interpretation instructions.[20,21] Finally, study attrition was a challenge in this cohort, including differences by region as discussed previously,[18] and by social factors, with lower social status among families lost to follow-up which may be associated with lower access to health care, meaning our results may have overestimated health care use. Because we had full data on the cohort at inclusion, we were able to conduct sensitivity analyses using inverse probability weighting to adjust for loss to follow-up and found similar results. However, children born EPT with other impairments and risk factors were less likely to be able to participate in the MABC-2 assessment and had missing data which may have underestimated the prevalence of movement difficulties and health care use.

TABLE 4 Cognitive, behavioural, and socioemotional problems associated with receiving motor-related health care (MRHC) among children born extremely preterm at risk of movement difficulties or with significant movement difficulties

	MRHC[a]			Model 1[b]		Model 2[c]	
	No, *n* (%)	Yes, *n* (%)	Total, *n* (%)	OR	95% CI	OR	95% CI
Cognitive status[d]							
No impairment	154 (69.7)	67 (30.3)	221	Ref.		Ref.	
Mild impairment	67 (63.2)	39 (36.8)	106	1.42	0.84–2.40	1.15	0.66–1.98
Moderate impairment	**18 (41.9)**	**25 (58.1)**	**43**	**3.62**	**1.73–7.56**	1.76	0.78–3.97
Internalizing problems							
Emotional symptoms							
Normal	181 (65.3)	96 (34.7)	277	Ref.		Ref.	
Borderline	28 (70.0)	12 (30.0)	40	0.88	0.42–1.87	0.79	0.36–1.73
Abnormal	28 (54.9)	23 (45.1)	51	1.63	0.86–3.06	1.77	0.92–3.42
Peer relationship problems							
Normal	181 (69.3)	80 (30.7)	261	Ref.		Ref.	
Borderline	23 (59.0)	16 (41.0)	39	1.57	0.76–3.24	1.45	0.68–3.09
Abnormal	**33 (48.5)**	**35 (51.5)**	**68**	**2.31**	**1.31–4.07**	**1.93**	**1.07–3.49**
Externalizing problems							
Conduct problems							
Normal	152 (67.6)	73 (32.4)	225	Ref.		Ref.	
Borderline	**39 (52.7)**	**35 (47.3)**	**74**	**1.85**	**1.05–3.28**	**2.16**	**1.19–3.94**
Abnormal	47 (67.1)	23 (32.9)	70	0.90	0.49–1.64	0.85	0.45–1.60
Hyperactivity/inattention							
Normal	161 (72.5)	61 (27.5)	222	Ref.		Ref.	
Borderline	**25 (50.0)**	**25 (50.0)**	**50**	**3.04**	**1.57–5.88**	**2.74**	**1.38–5.43**
Abnormal	**52 (53.6)**	**45 (46.4)**	**97**	**2.21**	**1.30–3.77**	**1.88**	**1.08–3.26**
Prosocial behaviour							
Normal	214 (66.9)	106 (33.1)	320	Ref.		Ref.	
Borderline	15 (48.4)	16 (51.6)	31	2.10	0.97–4.55	1.83	0.82–4.08
Abnormal	8 (47.1)	9 (52.9)	17	1.95	0.68–5.61	1.96	0.65–5.87
Strengths and Difficulties Questionnaire total score[e]							
Normal	175 (70.0)	75 (30.0)	250	Ref.		Ref.	
Borderline	**22 (44.0)**	**28 (56.0)**	**50**	**3.40**	**1.75–6.62**	**2.73**	**1.37–5.47**
Abnormal	40 (58.8)	28 (41.2)	68	1.56	0.87–2.80	1.31	0.71–2.41

Note: Bold type indicates statistically significant results.

Abbreviations: OR, odds ratio; CI, confidence interval.

[a]MRHC was defined as having at least one visit to any of the following motor-related health specialists over the previous year: (1) physiotherapist, motor development or psychomotor therapist, or kinesiologist; (2) occupational therapist; or (3) early intervention specialist.

[b]Model 1 was adjusted for country.

[c]Model 2 was adjusted for country and total score on the Movement Assessment Battery for Children, Second Edition.

[d]Moderate impairment was considered if IQ was between 55 and 69; mild impairment was considered if IQ was between 70 and 84; no impairment was considered if IQ ≥ 85.

[e]Strengths and Difficulties Questionnaire total score derived from emotional symptoms, conduct problems, hyperactivity/inattention, and peer relationship problems.

CONCLUSION

SMD among children without CP were frequent, but most of these children were not receiving MRHC. Our results suggest that efforts are needed to increase awareness and treatment of movement difficulties in the EPT population. Standardized clinical guidelines incorporating screening and assessment for detecting motor problems in early childhood may increase recognition of these problems and early instigation of specialized interventions in this at-risk population.

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DATA AVAILABILITY STATEMENT

Due to the ethical and privacy authorizations for the SHIPS study, supporting data cannot be made openly available. Further information about the data and conditions for access are available from the authors.

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SUPPORTING INFORMATION

The following additional material may be found online.

Table S1: Characteristics associated with loss to follow-up.
Table S2: Participants included in the analysis vs participants in the study follow-up excluded from the main analysis.
Table S3: Social and clinical characteristics associated with receiving motor-related health care among children without CP at risk of movement difficulties or with significant movement difficulties.

Table S4: Cognitive, behavioral, and socioemotional problems associated with receiving motor-related health care among extremely preterm children at risk of movement difficulties or with significant movement difficulties.
Figure S1: Participation flowchart.
Figure S2: Percentage of children born extremely preterm who received motor-related health care with 95% confidence intervals according to motor status overall and by country.

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