Chronic Conditions and Health Care Needs of Adolescents Born at 23 to 25 Weeks' Gestation

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abstract

OBJECTIVE: We examined chronic conditions, functional limitations, and special health care needs in extremely preterm children (EPT; 23–25 weeks' gestation) born between 1992 and 1998 at 2 Swedish tertiary care centers that offered regional and active perinatal care to all live-born EPT infants.

METHODS: Of 134 surviving EPT children, 132 (98%) were assessed at 10 to 15 years of age alongside 103 term-born controls. Identification of children with functional limitations and special health care needs was based on a questionnaire administered to parents. Categorization of medical diagnoses and developmental disabilities was based on child examinations, medical record reviews, and parent questionnaires.

RESULTS: In logistic regression analyses adjusting for social risk factors and sex, the EPT children had significantly more chronic conditions than the term-born controls, including functional limitations (64% vs 6%; odds ratio [OR], 15; 95% confidence interval [CI], 6.1–37.2; $P < .001$), compensatory dependency needs (60% vs 29%; OR, 3.8; 95% CI, 2.2–6.6; $P < .001$), and services above those routinely required by children (64% vs 25%; OR, 5.4; 95% CI, 3.0–9.6; $P < .001$). Specific diagnoses and disabilities for the EPT group versus controls included cerebral palsy (9.1% vs 0%; $P < .001$), asthma (21.2% vs 6.8%; $P = 001$), IQ < –2 SD (31.1% vs 4.9%; $P < .001$), poor motor skills without neurosensory impairment (21.9% vs 1.9%; $P < .001$), and psychiatric conditions (15.2% vs 1.9%; $P < .001$).

CONCLUSIONS: Adolescents born EPT have considerable long-term health and educational needs. Few had severe impairments that curtailed major activities of daily life.

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WHAT'S KNOWN ON THIS SUBJECT: Adolescent children born extremely preterm have significantly higher rates of neurodevelopmental, psychiatric, and other chronic health problems compared with term peers.

WHAT THIS STUDY ADDS: This study focuses on the functional consequences of chronic problems. Functional limitations and special needs were substantially high in children born extremely preterm, but few had impairments that curtailed major activity in daily life.

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Significant improvements in perinatal care and changes in the approach to immediate resuscitation at birth have led to substantial increases in the survival of extremely premature (EPT) infants born at <26 gestational weeks.[1,2] Previous population-based, long-term outcome studies of EPT children consistently showed increased incidences of neurodevelopmental disability and other chronic conditions compared with term peers, which lead to functional limitations and special health care needs.[3–5] There are few reports of the long-term outcomes of EPT infants in early adolescence or at middle school age, especially among EPT infants who received proactive management at birth.

Because early adolescence better indicates disabilities that are likely to be sustained, the aim of this study was to examine the comprehensive health outcomes of 10- to 15-year-old EPT children born at 2 university hospitals in Umea and Uppsala, Sweden from April 1992 through December 1998 and compare the results with those of a matched control group born at term. We report outcomes as functional limitations and special health care needs together with more traditional measures of neurologic and developmental status and other medical conditions. The findings would provide a clearer understanding of the functional capacities of adolescent EPT children and the possibilities of interventions as a basis for planning for and provision of services.

During the early 1990s, approaches to perinatal care in extreme prematurity differed in Sweden.[6] Since 1990, the university hospitals in Umea and Uppsala, 2 of the 7 tertiary-level neonatal care centers in the country, have had a universal and consistent policy of active perinatal care for deliveries at 23 to 25 weeks of gestation. This management includes the
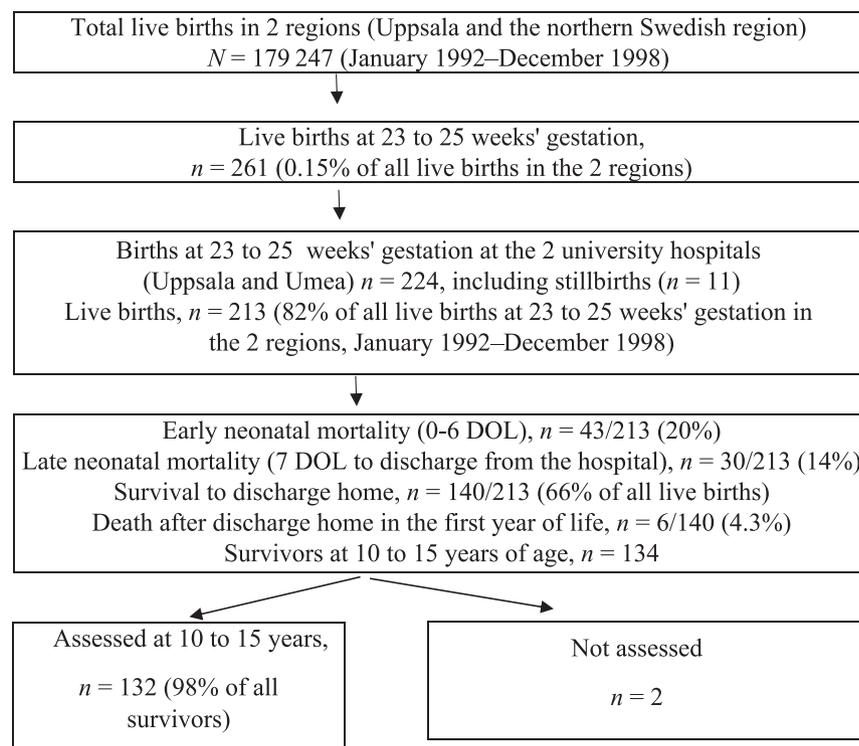

FIGURE 1
Flowchart showing the selection of the study population with successful follow-up and assessment. DOL, day of life.

centralization of deliveries at <28 weeks of gestation with transfers of all threatened deliveries at 23 to 25 weeks whenever possible, the administration of corticosteroids and tocolytics, the presence of a certified neonatologist at all deliveries at <28 weeks of gestation, and resuscitation for all infants born at 23 to 25 weeks gestation with any sign of life. The neonatal outcomes of the present EPT cohort have been previously published.[7]

METHODS

Participants

The study population consisted of all EPT children born at 23 to 25 weeks of gestation at the university hospitals in Umea and Uppsala from April 1992 through December 1998. A flowchart (Fig 1) shows the study sample and the numbers followed to adolescence. A total of 179 246 children were born in the 2 regions

during this time period, and 261 were live births at 23 to 25 gestational weeks. Of these 261 EPT children, 213 were born at tertiary-level care hospitals in Umea and Uppsala, and 140 survived to discharge (66%). We previously evaluated the neonatal outcomes of this EPT cohort.[7] Six EPT children died in their first year of life. At 10 to 15 years of age, 134 were alive and were identified as candidates for the current study. Two families declined to participate; thus, 132 children (98% of all survivors) were assessed.

Control Group

The control group was recruited from the national birth register by selecting a same-sex child with normal birth weight who was born at term at the same hospital and had a birth date near that of the EPT child (±7 days). We selected each control child from a pool of 6 children. The parents of the first child on the list were approached; if they declined

participation, the parents of the second child were approached. If necessary, additional parents were approached until a family agreed to participate or the pool of 6 children was depleted. The recruitment of controls was a difficult process, which is why only 103 (78%) control children were recruited as opposed to 1 control for each EPT child as initially planned.

Recruitment Procedure

Names and addresses of all the study children and their families were obtained from the Swedish national tax board. Recruitment procedures have been described in detail elsewhere[8] and will be described briefly in this article. After obtaining consent from the families of the study children, they were contacted by the research nurse, who explained the procedure and study protocol. The parents of the EPT children were also asked for permission to review all case records and records from the other specialist services to identify neurosensory impairments (NSI) and other medical or psychiatric conditions. If the parents of the controls reported that their child was receiving specialist services, we asked their permission to obtain additional information from these services. The study was approved by the Ethical Review Board of Umea, Sweden.

Measures

Questionnaire for Identifying Chronic Conditions in Children; Parent Interview

The Questionnaire for Identifying Chronic Conditions in Children (QUICCC)[9] was administered to a parent or caregiver of the EPT and the control children (usually the mother). Interviews were conducted by the first author. Seventy percent of the EPT parents and 65% of the control parents were interviewed by telephone, whereas 30% and 35% were interviewed at schools by a research nurse or psychologist,

respectively, at the time of testing. The QUICCC incorporates the consequences of chronic conditions that have a physical, psychological, or cognitive basis and have lasted or are expected to last for >12 months. The interview identifies consequences in 3 domains; functional limitations, dependence on compensatory aids, and need for services above those routinely needed for children. The QUICCC has been validated and it has shown good reliability with a positive predictive value of 86% and a negative predictive value of 92%.[10]

Questionnaires

The Nordic Health and Family Questionnaire (NHFQ)[11] was administered to identify and measure the severity of the children's chronic medical, behavioral, or other psychiatric conditions. The NHFQ also assesses socioeconomic variables, such as the parent's educational level, the family's disposable income, family structure, and parental ethnicity. Social risk was defined as a single-parent family, or mother's educational level ≤9 years, or low family income as described elsewhere.[3] The NHFQ is a well-validated instrument used for research purposes in Sweden.[11]

Five to Fifteen Questionnaire (Motor Skills)

Motor skills were assessed with the Five to Fifteen questionnaire (FTF), a parent questionnaire for assessing attention-deficit/hyperactivity disorder (ADHD) and comorbid conditions.[12] The motor skills domain consists of 17 items; 7 pertain to gross motor skills and 10 pertain to fine motor skills. We converted mean domain scores to z scores (SD scores) in relation to the Swedish age- and sex-specific reference population. Motor skills impairments were defined in terms of SD scores that were either 2 or 3 SDs above the normative mean, corresponding to moderate (92nd–95th percentile) and severe (≥96th percentile)

difficulties, respectively. The FTF questionnaire has been validated in Sweden and norms for the Swedish population have been established.[12] The parts of the FTF that assess motor skills, executive functions, perception, and language correlated significantly with the corresponding developmental neuropsychological assessment (NEPSY) domain scores.[13]

Cognitive Function

Cognitive assessment was performed by trained psychologists using the Wechsler Intelligence Scale for Children, 3rd edition, (Swedish version; WISC-III-R)[14] and has been previously reported.[8] Cognitive function in the EPT children was classified according to the mean and SD of the full-scale IQ (FSIQ) of the control subjects. Major cognitive disability in the current study was defined as a FSIQ score < –2 SD relative to the control group.

NSI at 10 to 15 Years

The prevalence of NSI has been described elsewhere.[8] Major NSI (moderate or severe) was defined as ≥1 of the following: moderate or disabling cerebral palsy (CP); blindness, severe visual impairment (visual acuity <20/200 without glasses in the better eye), or moderate visual impairment, which included children being treated at the Low Vision Center; deafness; or auditory impairment requiring bilateral hearing aids or a cochlear implant. Major neurodevelopmental disability (NDD) in the current study was defined as major NSI or major cognitive impairment.

Statistical Analysis

Standardized forms were used for data collection, and SPSS version 22 (IBM SPSS Statistics, IBM Corporation, Chicago, IL) was used for data analysis. Descriptive statistics, such as frequency distributions, means, and SDs, are

TABLE 1 Sociodemographic Characteristics and Perinatal Data of the EPT and Control Participants

	EPT Total Population (N = 132)	Control Total Population (N = 103)	P for Difference Between EPT and Control Groups[a]
Maternal age, mean (SD), y[b]	29.9 (5.3)	30.2 (4.8)	—
Single-parent family	19 (14.4)	8 (7.8)	—
Two-parent family	113 (85,6)	95 (92.2)	—
Biological parents	80 (60.6)	74 (71.8)	—
Maternal education, y			.016
<9	18 (13.6)	4 (3.8)	.034
10–12	68 (51.5)	44 (42.7)	—
>12	46 (34.8)	55 (54.5)	—
Paternal education, y			.09
<9	15 (12.5)	4 (4.1)	—
10–12	69 (57.5)	55 (56.2)	—
>12	36 (30)	39 (39.8)	—
Not known	12	4	—
Family income, US dollars, mean (SD)	4399 (1910)	4645 (1608)	—
Low income	40 (27)	27 (26)	—
Social risk, any[c]	50 (37.9)	32 (31)	.33
Age at assessment, y, mean (SD)	11.96 (1.7)	12.09 (1.9)	—
Range, y	10.1 -15.6	10.3 -15.9	—
Perinatal data			
Gestational age, wk, mean (SD)	24.4 (0.7)	39.4 (1.29)	.001
23	16 (12)	0	—
24	42 (32)	0	—
25	74 (56)	0	—
Girl	72 (54.5)	51 (49.5)	—
Birth weight, g, mean (SD)	718 (129)	3621 (498)	.001
Multiple birth	23 (17.4)	0	—
SGA (< −2 SDs)[d]	21 (15.9)	0	—
Born at the tertiary care center	132 (100)	132 (100)	—
Antenatal steroids, any	92 (69.7)	0	—
Full course	57 (43.2)	0	—
Surfactant	100%	0	—

Values are n (%) unless otherwise stated. SGA, small for gestational age. —, not applicable.

[a] P value determined using either the unpaired Student's t test or Fisher's exact test.

[b] Mother's age at the birth of an EPT or control child.

[c] Social risk was defined as being a single-parent family, having a mother with ≤9 years of schooling, or having a low family income.[3]

[d] Derived from the Swedish reference population.[15]

presented. Continuous outcome measures were compared by using unpaired t tests. Differences in dichotomous outcomes between the groups were analyzed by using χ^2 or Fisher's exact tests, with odds ratios and 95% confidence intervals (CIs) when appropriate. Multivariate logistic regression analyses were performed to examine the differences in dichotomous outcomes between the groups for all measures of functional limitations, compensatory dependence needs, and service use above routine, when appropriate. We repeated the analyses to compare the outcomes of the EPT and control children who had no NSI. Because of the known effects of social risk and sex on outcomes, we controlled for these factors in logistic regression analyses.

RESULTS

Sociodemographic and Perinatal Data

Perinatal and sociodemographic data for all 132 EPT children and 103 control participants are presented in Table 1. The mean (SD) age at assessment was 12 (1.7) and 12 (1.9) years for the EPT children and controls, respectively. No significant differences were observed between the EPT children and their controls with regard to maternal age, single-parent family, or low income. There was, however, a significantly higher rate of lower maternal educational levels in the EPT cohort compared with their controls (Table 1).

Neurosensory Impairments and Other Specific Diagnoses

Data on major NSI and cognitive, medical, and psychiatric conditions are shown in Table 2. Twelve (9.1%) EPT children had CP (mild, moderate, or severe) and 22 (17%) EPT children had ≥1 NSI (all classes) compared with none of the controls.[8] Major NSI was reported in 17 (12.9%) of the EPT children and none of the controls (P = .001). The 3 most prevalent medical disorders other than NSI in the EPT children were asthma (21.2%), poor motor skills in NSI-free EPT children (22%), and chronic constipation (12%) requiring treatment. The corresponding rates of these 3 disorders in the control group were 6.8%, 1.9%, and 0%, respectively (Table 2). Forty-one EPT children (31.1%) had a low FSIQ score of <73 (< −2 SD), compared with 4.9% of the children in the control group (P < .001). According to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* diagnostic criteria, 20 EPT children (15.2%) had a psychiatric disorder, including ADHD (n = 11) and autism spectrum disorder (n = 9), whereas 2 children (1.9%) in the control group had a psychiatric disorder.

Consequences of Chronic Conditions; Functional Limitations

The overall rate of ≥1 functional limitations was 47% in the total EPT cohort, compared with 6% in the control group (P < .001), and the difference remained significant when the NSI-free subgroup of EPT children was compared with the controls (Table 3). These limitations included reduced time or effort in activity (28% vs 1%; P < .001), mental or emotional delay (27% vs 3%; P < .001), restricted in type of

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TABLE 2 Rates of NSI and Medical and Psychiatric Disorders at 10 to 15 Years of Age

	EPT Total Population (N = 132)	Control Total Population (N = 103)	P for Difference Between EPT and Control Groups[a]
Major neurosensory impairment[b,c]	17 (12.9)	0	.001
CP (moderate or disabling)	7 (5.3)	0	.02
Moderate (ambulant with aid)	1	0	—
Severe (nonambulant, wheelchair dependent)	6	0	.03
Severe or moderate visual impairment	4 (3)	0	.09
Severe or moderate hearing impairment	8 (6)	0	.01
Major cognitive impairment[d]	41 (31.1)	5 (4.9)	<.001
Major NDD[e]	45 (34.1)	5 (4.9)	<.001
Medical condition other than NDD[b]	55 (41.7)	17 (16.5)	<.001
Asthma	28 (21.2)	7 (6.8)	.003
Allergic disorder	3 (2.3)	8 (7.8)	.06
Constipation, moderate or severe	17 (12.1)	0	<.001
Epilepsy	7 (5.3)	1 (1)	.13
Poor motor skills in NSI-free children[f,g] >2 SDs above the mean	24 (21.9)	2 (1.9)	<.001
Height <2 SDs	5 (4)	1	.21
Precocious puberty	2 (1.5)	1	—
Other medical conditions[h]	10 (7.9)	1	.002
Psychiatric condition[b]	20 (15.2)	2 (1.9)	<.001
ADHD/ADD	11 (8.3)	1 (1)	.002
Autism spectrum disorders	9 (6.8)	0	.006
Dyslexia	1	1	—
Medical or psychiatric condition (≥1)	62 (47)	19 (18.4)	<.001
Total with least 1 disorder (neurosensory, medical, or psychiatric)	70 (53)	19 (18.4)	<.001

Values are n (%) of children unless otherwise stated. The list of medical and psychiatric disorders was adapted from the NHFQ[11] and reviews of the case records. ADD, attention deficit disorder. —, not applicable.

[a] P value determined using either the unpaired Student's t test or Fisher's exact test.

[b] Data for the NSI and medical and psychiatric disorders are the numbers and percentages of children with at least 1 condition in that category.

[c] Moderate or disabling CP; blindness, severe visual impairment (visual acuity <20/200 without glasses in the better eye) or moderate visual impairment, which included children being treated at the low vision center; deafness; or auditory impairment requiring bilateral hearing aids or a cochlear implant.

[d] Defined as a FSIQ score <−2 SD relative to the control group. Cognitive function assessed using the WISC-III-R scale.[14]

[e] Major neurodevelopmental disability; ≥1 major NSI[8] or major cognitive impairment on the WISC-III-R scale.[14]

[f] See Methods for a description of motor skills in NSI-free EPT children.

[g] Number of NSI-free EPT children with poor motor skills (n = 110).

[h] Other medical conditions in the EPT group include diabetes, chronic hereditary nephritis, arthrogryposis, scoliosis, a cardiac condition, systemic rheumatoid eye disease, Charcot–Marie–Tooth disease, osteosarcoma, thyroiditis, and psoriasis. In the control group, 1 child had a cardiac condition.

activity (16% vs 2%, P = .02), and inability to play and socialize (15% vs 0%, P < .001). A variety of symptoms or diagnoses contributed to functional disability; 37 EPT parents, compared with 1 control parent, reported that their child had reduced time or effort in physical activities. Of these EPT children, 8 had CP, 7 had poor motor skills without NSI, 7 had asthma, 9 had psychiatric or behavioral problems, 2 were deaf, 2 had severe visual impairment, and 2 had other medical conditions unrelated to extreme prematurity. Severe functional limitations, such as difficulty feeding, dressing, or washing, being blind, or being unable to walk, were restricted to 5% to 9% of the EPT children with NSI (Table 3).

Compensatory Dependence Needs

Significantly more EPT children than term controls regularly took a prescribed medication (Table 4). The need for help with or special equipment for walking, feeding, dressing, washing, and toileting was mainly restricted to only a few EPT children (5% to 9%) with severe NSI. Medication use, the most common compensatory need, was reported in: 21% of EPT children with asthma versus 7% of the control group with asthma; 9% versus 2% of those with ADHD; 2% versus 8% of those with allergic conditions; 9% versus 0% of those

with constipation; and 5% versus 0% of those with epilepsy. Nine EPT children with CP received either botulinum toxin or baclofen medication, 5 needed a wheel chair, 2 needed a walker, and 3 were tube fed.

Service Use Above Routine

Overall, 64% of all EPT children, 57% of the NSI-free EPT subgroup, and 25% of the control subjects received ≥1 services beyond those normally received (Table 5). These services included visiting a physician or specialist for a chronic condition, physical or occupational therapy, nursing care, or special school arrangements, or attending special schools or a rehabiltation

TABLE 3 Functional Limitations Associated With a Chronic Condition Lasting ≥12 Months

	EPT Total Population (N = 132)	EPT NSI-Free (N = 110)	Control Total Population (N = 103)	Total Population EPT Versus Control		NSI-Free EPT Versus Control	
				aOR (95% CI)[a]	P[b]	aOR (95% CI)[a]	P[b]
Physical delay	21 (15.9)	11 (10)	1 (1)	20.6 (2.7–157)	.003	11.4 (1.4–90.8)	.021
Mental or emotional delay	35 (26.5)	20 (18)	3 (2.9)	12.4 (3.7–42.3)	.001	8.6 (2.4–31.1)	.002
Restricted in type of activity	21 (15.9)	6 (20)	2 (1.9)	10.3 (42.3–45.1)	.02	2.9 (0.58–15.1)	.19
Reduced time or effort in activity	37 (28)	22 (20)	1 (1)	40.6 (5.4–301)	<.001	25.5(3.4–193.6)	.002
Unable to participate in sports	11 (8.3)	2 (1.8)	0	—	.003	—	.24
Blindness or difficulty seeing	8 (6.1)	1	0	—	.01	—	.76
Deafness or difficulty hearing	9 (6.8)	0	0	—	.005	—	.01
Difficulty eating	6 (4.5)	3 (2.7)	0	—	.036	—	.24
Trouble understanding simple instructions	11 (8.3)	6 (5.5)	0	—	.003	—	.03
Unable to walk without help	7 (5)	0	0	—	.019	—	—
Unable to play or socialize	20 (15.2)	10 (9.1)	0	—	<.001	—	.001
Trouble speaking/communicating	14 (10.6)	8 (7.3)	0	—	<.001	—	.007
Severe limitations							
Difficulty feeding	6 (4.5)	2 (1.8)	0	—	.03	—	.49
Difficulty dressing	12 (9)	4 (3.6)	0	—	.001	—	.24
Difficulty washing	11 (8.3)	4 (3.6)	0	—	.003	—	.24
Difficulty using toilet	8 (6.1)	1 (0.9)	0	—	.010	—	.23
Any functional limitation	62 (47)	41 (37.3)	6 (5.8)	15 (6.1–37.2)	<.001	9.8 (3.9–24.8)	<.001

Values are n (%) of children unless otherwise stated. —, not applicable.

[a] Derived from the logistic regression adjusting for the social risk (single-parent family, maternal education ≤9 years, or low income)[3] and sex.

[b] Compared with the control group using Fisher's exact test or testing that the odds ratio is unity, whichever is applicable.

TABLE 4 Compensatory Dependence Needs for a Chronic Condition Lasting ≥12 Months

	EPT Total Population (N = 132)	EPT NSI-Free (N = 110)	Control Total Population (N = 103)	Total Population, EPT Versus Control		NSI-Free EPT Versus Control	
				aOR (95% CI)[a]	P[b]	aOR (95% CI)[a]	P[b]
Takes regularly prescribed medication	32 (24.2)	22 (20)	14 (13.6)	2.0 (1.01–4.0)	.04	1.7 (0.8–3.4)	.17
Life-threatening allergic reactions	1 (1)	0	4 (4)	0.2 (0.02–1.8)	.17	0.2 (0.03–2.2)	.20
Follows physician-ordered special diet	7 (5.3)	5 (5)	11 (11)	0.4 (0.2–1.1)	.14	0.3 (0.1–1.0)	.04
Needs glasses	53 (41)	38 (35)	13 (13)	4.3 (2.2–8.3)	<.001	3.4 (1.7–6.8)	<.001
Needs special equipment to see	3 (2)	0	0	—	.25	—	—
Needs special equipment to hear/communicate	7 (5)	0	0	—	.01	—	.27
Needs help or equipment to walk	10 (8)	0	0	—	.003	—	—
Needs help or equipment to feed	4 (3)	0	0	—	.13	—	—
Needs help or equipment to dress	10 (8)	3 (3)	0	—	.003	—	.49
Needs help or equipment to wash	9 (7)	4 (4)	0	—	.006	—	.24
Needs help or equipment for toileting	7 (5)	1 (1)	0	—	.01	—	—
Needs equipment to eat	4 (3)	0	0	—	.13	—	—
Needs equipment for other functions	9 (6.8)	4 (3)	0	—	.005	—	.24
Any compensatory dependence need	78 (60)	60 (54)	29 (29)	3.8 (2.2–6.6)	<.001	3.1 (1.7–5.4)	<.001
Any compensatory dependence need other than glasses	45 (36)	29 (26)	20 (20)	2.1 (1.1–3.9)	.01	1.5 (0.8–2.8)	.25

Values are n (%) of children unless otherwise stated. —, not applicable.

[a] Derived from the logistic regression adjusting for the social risk (single-parent family, maternal education ≤9 years, or low income)[3] and sex.

[b] Compared with the control group using Fisher's exact test or testing that the odds ratio is unity, whichever is applicable.

plan. Forty-nine percent of the EPT cohort, 41% of the NSI-free subgroup, and 10% of the controls had special arrangements in mainstream schools (Table 5). Of the 26 EPT children receiving full-time special education in mainstream schools or attending special schools, 8 had CP with severe intellectual disability, 15 had mental delay and/or behavioral problems, and 3 attended a school for the deaf.

Rates of Chronic Conditions in the Multiple Domains

Based on logistic regression analyses adjusted for sex and social risk, the EPT children, compared with the term control group, had significantly higher rates of consequences of a chronic condition in 1 of the 3 domains of the QUICCC (79% vs 39%; adjusted odds ratio [aOR] 6.2; 95% CI, 3.4–11.1; P < .001). These rates were 75% and 38% in the subgroup without NSIs, respectively (aOR, 4.8; 95% CI, 2.6–8.7; P < .001). Thirty-five percent of the EPT cohort and 4% of the term control group had a

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TABLE 5 Services Needed Beyond Routine for a Chronic Condition Lasting ≥12 Months

	EPT Total Population (N = 132)	EPT NSI-Free (N = 110)	Control Total Population (N = 103)	Total Population EPT Versus Control		NSI-Free EPT Versus Control	
				aOR (95% CI)[a]	P[b]	aOR (95% CI)[a]	P[b]
Visits physician or specialist on a regular basis	47 (36)	31 (28)	11 (11)	4.6 (2.2–9.6)	<.001	3.6 (1.7–7.6)	.001
Visits counselor, psychologist, or a social worker	19 (14)	11 (10)	6 (6)	3.2 (1.2–9.0)	.04	2.6 (0.9–7.5)	.08
Receives physical/occupational or other therapy	23 (17)	10 (9)	1 (1)	22.1 (2.9–166.8)	<.001	11.1 (1.4–87.7)	.02
Receives nursing care or has undergone medical procedures	11 (8)	4 (4)	0	—	.003	—	.21
Hospitalized for a chronic condition	21 (15.9)	9 (8.2)	6 (6)	3.1 (1.2–8.0)	.02	1.4 (0.5–4.2)	.58
Individual rehabilitation plan	27 (20.5)	11 (10)	0	—	.001	—	<.001
Receives full-time separate class instruction or attends special schools[c]	26 (20)	11 (10)	0	—	<.001	—	<.001
Has special arrangement at school[d]	65 (49)	45 (41)	10 (10)	10.4 (4.4–22.6)	<.001	8.1 (3.6–17.9)	<.001
Unable to get a needed medical service	14 (11)	10 (9)	8 (8)	1.4 (0.5–3.4)	.50	1.1 (0.4–2.8)	.91
Any services needed beyond routine	84 (63.6)	63 (57.3)	26 (25.3)	5.4 (3.0–9.6)	<.001	4.1 (2.2–7.5)	<.001

Values are n (%) of children unless otherwise stated. —, not applicable.

[a] Derived from the logistic regression adjusting for the socioeconomic status (single-parent family, maternal education, or low income) and sex.

[b] Compared with the control group using Fisher's exact test or testing that the odds ratio is unity, whichever is applicable.

[c] Attending a special school or training school for the physically disabled and severely mentally retarded or receiving full-time special education at a mainstream school.

[d] Special arrangements at school include a modified schedule (modified class schedule, curriculum, or gym classes), tutoring by a teacher or by other professionals (special teachers) or resource room services, a classroom made accessible with special equipment, the provision of special transportation, and receiving special diets at school.

consequence of a chronic condition in all 3 domains of the QUICCC (aOR, 13.2; 95% CI, 4.6–38.9; P < .001). The corresponding rates in the NSI-free EPT cohort and the term controls were 26% and 4%, respectively (aOR, 8.4; 95% CI, 2.8–25.1; P < .001). When the EPT cohort was examined with respect to gestational age categories, significant differences in the rates in any of the 3 QUICCC domains were found between children born at 23 to 24 weeks (n = 58) and those born at 25 weeks (n = 74) (88% vs 72%; χ² = 5.2; P = .03). EPT children with a birth weight <750 g (n = 76) had significantly higher rates in all 3 QUICCC domains compared with those with a birth weight >750 g (n = 56) (46% vs 20%; χ² = 9.9; P = .002). In the analyses of the total population, including children with NSI, boys showed an increased risk of any functional limitation (aOR, 1.26; 95% CI, 1.1–2.35) and any service use above routine (aOR, 1.3; 95% CI, 1.15–2.35). Social risk was significantly related to 4 outcomes, namely, any functional limitation (aOR, 2.3; 95% CI, 1.2–4.6), mental delay (aOR, 1.6; 95% CI, 1.1–2.5), special arrangement at school

(aOR, 1.46; 95% CI, 1.1–2.3), and receiving full-time special education (aOR, 3.7; 95% CI, 1.6–13.7).

DISCUSSION

Our results reveal that EPT children have significantly high rates of chronic conditions compared with term controls. These conditions include CP, cognitive disability, asthma, poor motor skills, academic underachievement, and poorer skills in social adaptive tasks. These differences remain highly significant in EPT children who do not have NSI and manifest in higher overall rates of functional limitations, special needs, and services above those routinely required by children in general.

We evaluated both categorical and noncategorical outcomes to provide a comprehensive overview of clinical, educational, and health care implications of chronic conditions experienced by the EPT cohort. We believe that this framework provides a common language to document disability characteristics of children in early intervention.[16] We

administered the QUICCC with the objective of identifying children with functional limitations and special health care needs imposed by various medical, behavioral, and cognitive disorders. Children identified in the QUICCC fit the definition of children with health care needs (ie, children who have or are at risk for having physical, behavioral, or cognitive conditions that require health services). The QUICCC comprises most of the items of the World Health Organization international classification of functioning disabilities, which includes limitations in body/structure, personal activity, and participation in society and environmental facilities.[17] However, it is noteworthy that there is variability in reported prevalence rates of chronic health conditions in childhood that could possibly be explained by the considerable diversity in concepts and operationalizations in terms of source of information, method of information retrieval, and study population framed in instruments, such as QUICCC, used in this study.[18]

The NDD outcomes have been reported elsewhere[8] but are mentioned in the current study to provide the necessary background to functional limitations and increased health care needs as identified by QUICCC. As previously discussed,[8] the 34% prevalence of major NDD in our EPT cohort is similar to recent studies providing proactive perinatal care[19,20] and is somewhat lower than a population-based cohort of 11-year-old EPT children born at <26 weeks.[5] Furthermore, major disability needs to be viewed in the context of survival; is increased survival associated with an increase in long-term disability? Compared with studies included in a recent meta-analysis[21] that reported survival rates based on live births at 23 to 25 weeks of gestation, the survival rates in our study were higher,[8] and in this meta-analysis, the rate of moderate to severe NDD at age 4 to 8 years were comparable to our results.

Similar to the comparable studies, our results reveal that in addition to NDD, asthma,[3,4,22,23] poor motor skills in NSI-free children,[3,4,24] and psychiatric disorders[25] play a major role in determining the functional limitations and special health care needs of the EPT cohort.

In accordance with studies that address functional limitations and special health care needs, our EPT children had significantly higher rates of mental or emotional delay, reduced time or effort in activity, and educational underachievement compared with the term controls.[3,4,26,27] Our findings are similar to those of Hack et al,[4] who reported functional limitations and special health care needs in an extremely low birth weight cohort born in the mid-1990s. For their extremely low birth weight children at 8 years of age, they found aORs of 7.4 (95% CI, 4.3–12.2) for special arrangements in school and 7.0 (95% CI, 3.3–17.8) for mental or

emotional delay compared with term controls. Furthermore, the overall rates of consequences of chronic conditions in our EPT cohorts were substantially high and similar to those reported by Hack et al.[4,22] Our group previously reported similar rates of functional limitation and special health care needs in a national cohort of 11-year-old children born at 23 to 25 weeks' gestation in the early 1990s.[3]

The EPT children in our study represent the outcomes of university hospitals providing regional tertiary perinatal care and thus do not represent Sweden as whole. However, perinatal care in these 2 regions was highly centralized.[7] Few infants were delivered outside the 2 regional centers and these infants were not included in the study. We believe that studies from centers that advocate universal resuscitation, have a high degree of centralization, and a consequent ethical strategy can provide reliable data regarding the long-term impact of these practices. The strengths of this study include a high follow-up rate (98%), a relevant control group, and a consistent protocol of active perinatal care.

In Sweden, children born at <26 weeks' gestation comprise 0.2% of all births and represent a small fraction of all children with special health care needs. Although such special needs were much higher among these children than among the controls, few had impairments so severe as to prevent them from conducting major daily activities, such as eating, bathing, and dressing or attending school.

CONCLUSIONS

The current study, which combined the assessment of functional health status and special health care needs with traditional measures of neurologic and developmental status, provides important

research-based information for planning and providing services for the increasing number of EPT infants who now survive. We[28] and others[29,30] have previously shown that the majority of the chronic conditions reported in this study are a consequence of major neonatal complications, such as brain injury, chronic lung disease, and severe retinopathy of prematurity. Research into therapies that reduce and prevent these complications could improve these outcomes.

ABBREVIATIONS

ADHD: attention-deficit/hyperactivity disorder
aOR: adjusted odds ratio
CI: confidence interval
CP: cerebral palsy
EPT: extremely preterm
FSIQ: full-scale IQ
FTF: Five to Fifteen questionnaire
NDD: neurodevelopmental disability
NHFQ: Nordic Health and Family Questionnaire
NSI: neurosensory impairment
OR: odds ratio
QUICCC: Questionnaire for Identifying Children with Chronic Conditions
WISC-III-R: Wechsler Intelligence Scale for Children, 3rd edition

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Antti Holsti, Marie Adamsson, Bruno Hägglöf, Aijaz Farooqi and Fredrik Serenius

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