Extremely premature (≤ 800 g) schoolchildren: multiple areas of hidden disability

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Abstract

Aim—To examine the functional abilities of extremely low birthweight (ELBW, \leq 800 g) children at school age compared with full term children.

Methods-ELBW children (n=115) in a geographically defined regional cohort born between 1974 and mid-1985 (comprising 96% of 120 survivors of 400 ELBW infants admitted to the Provincial Tertiary neonatal intensive care unit), were compared with (n = 50) children of comparable age and sociodemographic status. Each child was categorised by the pattern and degree of disability, using a system derived from the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM IV). Psycho-educational, behavioural, and motor results for ELBW children free of severe/multiple neurosensory disabilities (n=90; 91% return rate) were compared with the term children. Results-Severe/multiple neurosensory disabilities were present in 16 ELBW children (14%), and 15 (13%) had borderline intelligence. ELBW children of global IQ ≥ 85 scored significantly lower in standardised tests of fine and gross motor control, visuo-motor pencil output, visual memory, and academic achievement (reading, arithmetic, written language). ELBW survivors were three times more likely to have learning disorders (47% vs 18%) and 22 (41%) of the 54 ELBW children with learning disorders had multiple areas of learning difficulty. Of the ELBW group, 30 (26%) were not disabled compared with 41 (82%) of the term group. Only five (12%) of the ELBW boys were not disabled, compared with 25 (35%) of the ELBW girls. Finally, ELBW children had significantly worse scores on ratings of behaviour during testing by the psychologist and behaviour by parental report.

Conclusion—The most likely outcome for ELBW survivors at school age is a learning disorder, often multiple, or borderline intellectual functioning, combined with behavioural and motor risk factors rather than severe/multiple disability. Mean scores on psycho-educational testing showed poorer performance of the ELBW children, but grossly understated the complex nature of the individual degree of educational difficulty faced by these children.

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Keywords: extremely low birthweight; psychology; disability; motor skills; learning disorder

Long term outcome and the potential educational needs of extremely low birthweight infants (ELBW ≤ 800 g) are of increasing concern as larger numbers of survivors in this birthweight range enter the school system. There have been several studies of psychoeducational outcome in 8 to 9 year old children of birthweight ≤1000 g, but few have specifically examined outcomes in a substantial number of the smallest babies who are at the highest risk for adverse neurodevelopmental sequelae.1-8 These studies show lower mean scores on psychological testing of children of 1000 g and below at school age compared with controls, with the difference in mean scores about 10 IQ points, equivalent to 0.6 standard deviation. One major limitation of these studies is that mean values and ranges mask the complex profiles of individual children with multiple areas of weakness which are likely to be

Table 1	Measures of psycho-educational, motor, and
academic	achievement

Cognition	*Wechsler Intelligence Scale for Children (1974; 1991) ⁹ or
	Stanford-Binet Scale of Intelligence ¹⁰
Visual and auditory recall	†Stanford-Binet Memory Area ¹⁰
Visual-motor	*Developmental Test of Visual-Motor
function	Integration (1989) ¹¹
Motor (gross/fine)	#Bruininks-Oseretsky Test of Motor
0	Proficiency (1978) ¹²
Reading (word	*Wide Range Achievement Test
decoding)	(1984) ¹³
Arithmetic	*Wide Range Achievement Test
	(1984) ¹³
Spelling	*Wide Range Achievement Test
opening	$(1984)^{13}$
Reading (passages)	*Gray Oral Reading Test (1986) ¹⁴
Written expression	*Test of Written Language
witten expression	(spontaneous subtests) ¹⁵
Task-related	Stanford-Binet Behaviour Rating
behaviour	Scale ¹⁰
Parental ratings of behaviour	[†] Personality Inventory for Children ¹⁶

* Mean 100 (SD 15); † Mean 50 (SD 8); ‡ Mean 50 (SD 10).

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Severe/multiple disability Bilateral blindness (visual acuity worse than 20/200 in better eye with optimal refractive correction) Hearing loss uncorrectable by amplification Non-ambulant cerebral palsy at 8 years Cognitive disability (IQ < 69) Any combination of the above Borderline IQ Global IQ 70-84 Learning disorder (1) Global IQ \ge 85 and (2) Discrepancy* between verbal IQ and reading decod and/or arithmetic, and/or written output; and (3) Below average (\le 89) reading decoding, and/or arithmetic, and/or written output score No disability	
None of the above	

* While the discrepancy was usually -1 to -2 standard deviations between verbal IQ and one or more academic test scores, a regression approach was used in which the discrepancy criterion was decreased with low average IQ.

Table 3	Sociodemographic chara	

	ELBW (n=115)	Comparison (n=50)
Mother's education (years)		
mean (range)	11.9 (5-19)	12.4 (7-16)
Mother's age at delivery (years)		
mean (range)	27.1 (16-40)	28.6 (23-43)
Marital status (% married)	76	86
Ethnicity (% white)	87	84
Gender (% male)	37	40

Table 4 Perinatal characteristics

	ELBW (n=115)	Comparison (n=50)
Birthweight (g):		
mean (range)	730.6 (520-800)	3487.6 (2614-4706)
Gestation (weeks):		
mean (range)	26.0 (23-38)	40.0 (38-42)
NICU stay (days):		
mean (range)	112.5 (7-500)	0
Ventilation (days):		
mean (range)	53.0 (0-155)	0
Oxygen (days):		
mean (range)	93.8 (2-480)	0
Small for		
gestational age	32%	0
Twin	31%	0
Birthweight:		
701-800 g	72%	0
601-700 g	21%	0
501-600 g	7%	0

important in relation to learning and interaction in the school environment. Sociodemographic status is acknowledged to be a significant variable in determining outcome, with results varying across different populations. Similarly, access to health care may contribute to outcome. Thus in the study of Hack *et al*³ the larger proportion of children of low social class was associated with a high incidence of global intellectual disability, not found by Saigal *et al*² in a population of higher social status with the benefits of universal health care. Furthermore, few data compare differences in outcome by gender, although it is recognised that, both in relation to perinatal illness variables and learning problems, boys are at higher risk than girls for neurodevelopmental problems across all birthweight ranges.

In the present study the occurrence of severe/multiple disabilities and functional cognitive, academic, behavioural and motor outcomes at school age were examined in a large comprehensive population of survivors of birthweight ≤800 g, and the results compared with a group of socially comparable term born children. The ELBW survivors were children whose mothers were predominantly middle class, married, and were from a birth population from a geographically defined region with universal medical coverage. The main aim of this study was to provide a detailed description of individual functional outcome, encompassing all surviving ELBW children at school age in a defined geographical area, compared with a group of children of similar social class. Secondly, gender differences in long term outcome of ELBW children were investigated. This study provides an overall picture of sequelae likely to impede classroom participation among children at the lowest end of the birthweight range. This information will be useful in describing long term prognosis for counselling parents of extremely premature neonates, and for estimating additional classroom needs generated by increasing survival of these tiny babies.

Methods

Between January 1974 and June 1985 there were 453 139 live births in the province of British Columbia. All survivors of 500-800 g birthweight in the province were followed prospectively, and seen in the Neonatal Follow Up Programme at British Columbia's Children's Hospital for neurodevelopmental evaluation. During this period 400 infants of birthweight \leq 800 g were admitted for tertiary care in the single provincial tertiary neonatal intensive care unit, of whom 125 (31%) survived to discharge. Five children died between discharge and school entry. Of the 120 long term survivors, follow up information was available for 115 (96%) at a mean age of 8.6 years; 113 children had multidisciplinary evaluations, and information on two was obtained by report. The parents of seven children refused assessment after 5 years of age. So that these children would not be lost from the overall estimation of disability rate, their functional outcome was derived from the detailed assessment obtained just before school entry. These seven children did not differ significantly in birthweight, gestational age, days on oxygen or mechanical

Table 5 Perinatal characteristics of ELBW children by functional classification; mean (SD) and range

	Severe/multiple disability (n=16)	Borderline IQ (IQ 70-84) (n=15)	Learning disorder (n=54)	No disability (n=30)
Birthweight (g)	714 (70) 580-800	728 (70) 560-800	731 (70) 520-800	741 (57) 580-800
Gestational age (weeks)	24.9 (1.4)* 23-29	27.2 (3.7) 23-38	25.7 (1.5) 23-30	26.4 (2.4) 23-34
Ventilation (days)	68 (32) 2-155	62 (39) 2-126	50 (26) 0-127	46 (33) 0-134
Oxygen therapy (days)	113 (51) 28-231	114 (122) 4-480	98 (68) 3-320	66 (36) 2-137
NICU stay (days)	141 (56) 51-254	128 (120) 7-500	110 (69) 43-417	92 (55) 23-255

* Gestational age significantly smaller for severe/multiple disability group; P = 0.003.

Table 6 Children with severe/multiple major disability

Birth year	Sex	Birthweight	Gestation completed weeks	NICU days	Disability(s)
1975	М	800	24	138	HD/MH
1976	М	750	26	195	VD/MH/HD
1979	F	750	25	127	VD
1982	F	650	25	99	VD/MH
1982	F	780	25	198	VD/MH
1982	F	800	26	95	VD
1983	М	650	23	180	VD
1983	М	670	24	97	VD
1984	М	750	25	90	VD/CP
1984	М	760	25	195	VD/CP/MH*
1984	М	790	24	254	MH/CP
1984	F	580	24	193	VD/MH/CP*
1984	F	615	25	129	MH
1984	F	720	23	72	VD
1984	F	720	29	51	MH/CP
1985	F	640	25	140	VD/MH

CP: cerebral palsy; HD: hearing disabled; MH: mentally handicapped; VD: visually disabled; * twin.

Table 7 Comparison of functional outcome classification by group and gender

	ELBW		Comparison	
	Boys (n=43)	Girls (n=72)	Boys (n=20)	Girls (n=30)
Severe/multiple disability	7 (16%)	9 (12%)	0	0
Borderline IQ*	8 (19%)	7 (10%)	0	0
Learning disorder† No disability	23 (53%) 5 (12%)	31 (43%) 25 (35%)	5 (25%) 15 (75%)	4 (13%) 26 (87%)

 \star Of the 15 ELBW children with borderline IQ, two had mild cerebral palsy and one was blind in one eye.

† Of the 54 learning disordered children, four had mild cerebral palsy and one had sensorineural hearing loss requiring amplification.

ventilation, days in intensive care, years of mother's education, or maternal age at delivery from the other study children. Psycho-educational evaluation was carried out on 90 children at school age (mean 9.0 years; range 6.4–14.3), a 91% return rate.

COMPARISON GROUP

Two groups of term born children were recruited. When the first survivors ≤ 800 g born between 1974 and 1982 reached school age, they were case matched for race, gender, and birth date with children (n = 21) recruited from an elementary school in a middle to lower middle social class catchment area. A further 40 children born between 1983 and 1984 were recruited to the clinic at age 3 years through community centres and health units in districts with similar social class distribution to the ELBW children, and were followed up sequentially in the neonatal follow up clinic with 37/40 (93%) seen at school age. From among these 61 full term children, a comparison group of 50 were selected for this study who most closely matched the ELBW group in gender and maternal education, by excluding the 11

Table 8 Psycho-educational, motor, and academic achievement (values are mean (SD))

	ELBW (n=90)	Comparison (n=50)	Mean difference	95% CI	P value
Full scale IQ	98.7 (12.6)	111.6 (13.1)	12.9	8.4-17.3	0.0001
Visual-motor integration	92.5 (10.6)	105.4 (8.4)	12.9	9.5-16.4	0.0001
Word reading	95.7 (18.3)	104.6 (14.1)	8.9	3.0-14.8	0.002
Passage reading	92.6 (15.8)	102.5 (15.4)	9.9	4.2-15.6	0.001
Written expression	89.7 (19.4)	104.4 (16.3)	14.7	6.5-23.0	0.0001
Arithmetic	88.2 (15.2)	99.5 (10.3)	11.3	6.6-16.1	0.0001
Visual memory	44.6 (8.0)	49.8 (7.6)	5.1	2.3-7.9	0.0001
Auditory memory	51.3 (8.7)	52.7 (7.0)	1.2	-1.7-4.1	NS
Fine motor	47.1 (11.8)	58.7 (8.2)	11.6	5.3-18.0	0.0001
Gross motor	43.7 (12.8)	52.7 (8.8)	9.0	2.2-15.9	0.01

children of highest social class. The mean age at assessment of these 50 comparison children was 9.0 years (range 6.5–12.1).

MEASURES

Multidisciplinary assessments were carried out in the neonatal follow up clinic, and included clinical and neurological examination, standardised psycho-educational, gross and fine motor testing, and assessment of vision and hearing. Standardised testing included assessments of cognition, memory, visuo-motor skills, academic achievement, psychomotor skills, and fine and gross motor function, ratings of task related attention and behaviour and parental ratings of behaviour using the measures presented in table 1. Of the children born between 1974 and 1981, 24 ELBW and 21 comparison children were given the Stanford Binet Intelligence Scale (4th Edn)¹⁰; all other children were given either the Wechsler Intelligence Scale for Children (WISC) or the revised version (WISC-R).9 Children last assessed below the age of 6 years were given the Wechsler Preschool and Primary Scale of Intelligence.17 Composite IQ and area scores were adjusted to a standard deviation of 15 to correspond to the Wechsler scales. Standardised tests were scored using age from date of birth with no adjustment for prematurity. The Stanford Binet Behaviour Rating Scale was completed for each child by the psychologist at the end of the assessment. Each behaviour is rated from 1 (most positive) to 5 (most negative). The clinical scales of the Personality Inventory for Children¹⁶ were used for parent ratings of behaviour.

FUNCTIONAL CLASSIFICATION

A functional outcome classification system was derived from the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-IV).18 Each child was classified into one outcome category based on his/her functional abilities, namely severe/multiple disability, or borderline IQ, or learning disorder, or no disability, as defined in table 2. Borderline IQ was defined as an IQ of 70-84 following the criterion of DSM-IV. Two psychologists blinded to the group status, perinatal, medical, and demographic data, jointly classified the children as having a learning disorder or no disability. For the seven children last seen before the age of 6 years, classification of the child as having potential educational problems was based on deficits in visual memory and/or visuo-motor output.

Within the functional outcome classification categories (except for those in the severe/ multiple group), children were further classified according to the number of problem areas within the fine motor domain. A problem area was defined as a subtest scale score below -1 SD on the Fine Motor Subtest of the Bruininks-Oseretsky Test of Motor Proficiency.¹²

The following markers of severity of illness in the neonatal period were analysed in relation to functional outcome: number of days of mechanical ventilation; number of days of oxygen

Table 9	Behaviour during psycho-educational assessment (Stanford Binet Behaviour
Rating S	Scale); % of scores in problem range

	ELBW (n=90) %	Comparison (n=50) %	OR	95% CI	P value
Attention:					
Distractability	33	4	12.1	2.7-52.6	0.0001
Activity:					
High activity level	37	1	5.2	1.9-14.5	0.001
Waits to respond	55	46	1.4	0.7-2.9	NS
Needs urging to respond	26	1	3.2	1.1-9.2	0.02
Independence:					
Insecure vs socially confident	33	1	3.7	1.4-9.6	0.006
Distrusts own ability	47	2	4.7	2.0-11.1	0.0001
Uncomfortable in adult company	20	2	11.9	1.5-90.1	0.003
Anxious	28	1	3.9	1.6-9.8	0.002
Problem solving:					
Gives up easily	30	2	20.8	2.7 - 166.7	0.0001
Reacts to failure unrealistically	33	1	3.7	1.4-9.6	0.006
Seeks to terminate	31	4	10.7	2.4 - 47.6	0.0001
Prefers only easy tasks	49	8	11.2	3.7-34.5	0.0001
Examiner support:					
Needs constant praise and encouragement	59	8	16.4	5.4-50.0	0.0001
Rapport:					
Establishing rapport	18	0	*	*	0.001

* Odds ratio not calculable due to 0 occurrence in comparison group.

treatment; and number of days spent in the neonatal intensive care unit.

STATISTICAL ANALYSIS

Functional outcome classification and other categorical variables were compared using the χ^2 test. Standardised test scores and behaviour ratings were analysed, excluding children with severe/multiple disabilities. Continuous measures were analysed by group and gender (unless otherwise stated) with univariate analysis of variance. Personality scores were first analysed using multivariate analysis of variance, followed by univariate analyses. Stanford-Binet Behaviour Rating scores were categorised as normal (1 to 2) or problem (3 to 5), and analysed across groups (2 × 2 tables) using the χ^2 test.

Results

DEMOGRAPHIC AND PERINATAL VARIABLES

There were no significant differences between the ELBW and comparison groups in sociodemographic variables (table 3). Perinatal characteristics are presented in table 4. The birthweights and gestational ages of the comparison group were representative of the normal birth population in our geographical region. There was a preponderance of girls among the ELBW survivors, due to higher neonatal survival rates amongst ELBW girls. One third of the ELBW group were small for gestational age (below the 10th percentile for weight) and one third were the result of multiple pregnancy. The perinatal variables of the ELBW group are presented by functional outcome category in table 5. Gestational age was significantly lower in the severe/multiple disability group (P=0.0003). No significant differences, overall, were found between the functional outcome categories for number of days of ventilation, days of oxygen treatment, or days in the intensive care unit. However, ELBW boys, regardless of disability, spent longer in the unit (P=0.02) and longer on oxygen (P=0.004) than girls, but were not on mechanical ventilation longer.

FUNCTIONAL CLASSIFICATION

Details of the 16 children (14%) with severe/ multiple disability are shown in table 6. Of these 16 children, 12 had severe visual disability (10% of all ELBW survivors). Functional outcome classification is shown for the ELBW and comparison groups, categorised by gender in table 7. When the functional outcome categories were compared by gender within the ELBW group $(4 \times 2 \text{ table})$, boys had worse outcomes than girls (P < 0.05). Among the ELBW children with no disability there were significantly fewer boys (5/43, 12% boys; 25/72, 35% girls; P=0.04). Indeed, of the 30 surviving ELBW children free of disability 25 (83%) were girls. Fewer comparison boys had no disability compared with comparison girls (75% boys, 87% girls); however, this difference was not significant.

COGNITIVE AND ACADEMIC ACHIEVEMENT

Group analysis of the cognitive, memory, academic visuo-motor, and gross and fine motor scores and behaviour ratings was carried out for the children who were free of severe/multiple disability. The ELBW children as a group performed significantly below the comparison group for all measures of cognition, memory, visuo-motor performance, and academic achievement, except for a test of short term auditory memory (table 8). The results were the same following re-analysis including only the children with IQ > 85. There were no significant differences between boys and girls on any cognitive, memory, or visuo-motor tests, yet boys were grossly underrepresented in the no disability group (table 7). Academically, the only significant gender difference was that boys performed below the girls in written language (P=0.02), in both the ELBW and comparison groups.

FINE AND GROSS MOTOR FUNCTIONING

ELBW children did significantly less well than the comparison children on standardised assessment of fine and gross motor skills (table 8). There were no differences between boys and girls. Moreover, 64% of the children with borderline IQ had more than one fine motor problem area. Of the ELBW children with learning disorders, 40% had more than one fine motor problem area compared with none of the comparison group. Of the children with no disability, 32% of the ELBW group and 10% of the comparison group had a problem in one fine motor area.

BEHAVIOUR

There was an overall group difference in parental ratings of child behaviours on the clinical scales of the Personality Inventory for Children.¹⁶ Significant differences were found in the scales of Achievement (academics; P = 0.0001), Development (cognitive and physical; P = 0.0001), Intellectual (specific intellectual deficits; P = 0.001), Psychosis (unusual behavioural characteristics; P = 0.005), Social Skills (P = 0.006), and Withdrawal (from social contact; P = 0.05) with the ELBW children having higher problem scores than the com-

parison group. There were no differences found in Anxiety, Depression, Delinquency, Family Relations, Hyperactivity and Somatic Concern.

Results of analyses of ratings of behaviour during psycho-educational assessment using the Stanford Binet Behaviour Rating Scale are presented in table 9. In the one to one testing situation, mean scores for ELBW children were significantly poorer than comparison children in nine of the 14 behavioural areas likely to be of significance to success in the classroom situation. Although there were some differences between boys and girls in behaviour ratings (for both the ELBW and comparison children), on multivariate analysis gender as a factor did not reach significance.

Discussion

The main contribution of this study is the presentation of detailed psycho-educational outcomes of a large cohort of ELBW children \leq 800 g, categorised by functional outcome, as group mean scores mask profiles of learning difficulties of individual children. Mean scores on psycho-educational testing and motor tests show poorer performance in general of the ELBW children but understate the complexity of educational problems faced by these children at school. Most studies of ELBW children have included few children at the lowest end of the birthweight spectrum.¹⁻⁸ We have focused on this population because of the need to obtain detailed outcome information in a group of children about whom questions of treatment or non-treatment in the neonatal period are frequently raised.

The major disability rate in our cohort (14%) is comparable with that found in other studies of populations with universal medical care, despite our focus on the smallest babies, and differences in criteria for major disability.^{1 2} Our criteria for major disability were conservative, including only those children severely functionally affected, whereas other studies have included neurological criteria such as hydrocephalus, seizure, and microcephaly.^{1 2}

This study shows that ELBW children who escape severe disability are at significant risk of major disadvantage in every domain likely to be required for successful functioning in the school system. Learning disability or borderline IQ occurred in 60% of the ELBW children compared with 18% of the comparison group. In the children with learning disabilities, the learning problem affected multiple areas in 41% (22/54) of ELBW children compared with 11% (1/9) in the comparison group. Although these children received universal medical care and were not in general socially deprived, only 26% of the ELBW children (12% boys, 35% girls) appeared free of disability, as defined in this study.

These estimates of functional disability are conservative for two reasons. First, in this study the criteria for a learning disorder required both a score in reading and/or arithmetic and/or written output below the average range, and a discrepancy between the academic score and intellectual ability. The limitation of discrepancy based estimates of learning disabilities¹⁹ is that children with low average intelligence (85–89) and low academic achievement are viewed as progressing commensurate with their intelligence. However, in the ELBW population one result of being born very small is an overall reduction in IQ.

Secondly, behavioural and fine motor coordination problems were not included in the criteria for classification of functional outcome, so some children included in the non-disability group had these problems.

As expected, our ELBW children had higher average intelligence than the more socially disadvantaged children in the study of Hack et al.3 However, the overall abilities of our reference sample of socially comparable peers was also higher, giving the same relative discrepancy between the ELBW children and comparison children in the two studies. Global IQ, visual short term memory, visuo-motor, and fine and gross motor functioning were all significantly lower for ELBW children compared with socially comparable peers. Academically, word decoding, passage reading and comprehension, arithmetic and written language were all more difficult for these children in the elementary school years. Subtle differences in language development apparent in the early years may contribute to these later academic deficiencies.20

On task related behaviour ELBW children showed significant problems working independently, and needed adult support in learning situations, with constant feedback, praise, and encouragement to persist. On parental questionnaire, overall adjustment problems, poor social skills, and unusual behaviours were significantly more prevalent among the ELBW children. Notably, for this sample, withdrawal from challenging tasks was significantly more of a concern than hyperactivity, the levels of which did not differ between the two groups. The prevalence of unusual behaviours may be part of the complex syndrome of non-verbal learning disabilities, characterised by visuospatial and visuo-motor problems, poor arithmetic and written output achievement, and social difficulties.²¹ The gap between the extremely low birthweight children and their peers is likely to widen even further in high school as school work demands increase, including those for written output. In the classroom setting the deficits in underlying learning abilities are evidently compounded by intrinsic attention and behaviour differences between these children and their peers, which also hinder achievement.

Increasing survival of ELBW babies can be expected to increase the need for educational assistance in the school system. Although there are relatively few ELBW children, their problems are complex, and will require significant educational and other resources in the future.^{5 22 23} Society's decision to support these babies in the newborn period must be matched by a continuing commitment to provide educational support for these families and their children. Families, neonatal care givers, and society are faced with a difficult ethical

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