Rates of early intervention services in children born extremely preterm/extremely low birth weight

Original article

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Abstract

Aim: To determine rates of early intervention (EI) service use in extremely preterm (EP, <28 weeks' gestation) or extremely low birth weight (ELBW, <1000 g) infants between 1991 and 2013, and identify biological or socioeconomic factors associated with receiving early intervention.

Methods: Participants comprised consecutive EP or ELBW survivors born in 1991-92, 1997 or 2005 in Victoria, Australia, and randomly selected, matched term-born controls. The main outcome measure was parent-reported EI participation up to 8 years of age. Neurodevelopmental outcomes and socioeconomic risk factors were compared with early intervention participation to identify associations among the preterm groups.

Results: The rates of EI were higher in the preterm groups than the control groups overall (odds ratio 4.29, 95% confidence interval 3.28, 5.59, P<0.001), and the rates of EI rose significantly over time – from 42% in the 1991-92 preterm cohort to 64% in the 2005 preterm cohort. Among the preterm groups, postnatal corticosteroid therapy, cystic periventricular leukomalacia and surgery in the newborn period were all independently associated with increased odds of receiving EI. Increased severity of disability was associated with higher rates of EI. The majority (95%) of preterm children with a physical impairment received EI, compared with only 73% of children with a cognitive impairment alone. Early intervention participation rates were independent of social risk.

Conclusions: Early intervention participation is high in the EP population, and rates of EI use have increased over time. Contrary to previous reports, social risk factors were not found to be associated with EI use.

What is already known on this topic:

1. Extremely preterm or extremely low birthweight infant survival rates are increasing, with a concurrent increase in the number of children with neurodevelopmental disabilities from this population
2. Early developmental intervention can reduce the impact of neurodevelopmental disabilities.
3. Uptake of early intervention services is suboptimal in certain high risk groups including children with mild disability and those with high socioeconomic risk.

What this paper adds:

1. Rates of early developmental intervention have increased over the last 2 decades, are higher with increasing severity of disability, and are associated with some neonatal risk factors.
2. Subgroups of extremely preterm or extremely low birthweight infants, such as children with cognitive disability alone, or children with mild disability, had lower rates of early intervention participation.
3. Social risk factors had little impact on early intervention participation in this population.

Key words:

- Infant, Extremely Premature
- Early Intervention (Education)
- Infant, Extremely Low Birth Weight
- Socioeconomic Factors
- Developmental Disabilities

Introduction

Survival rates of extremely preterm (EP, <28 weeks' gestation) or extremely low birth weight (ELBW, <1000 g) infants are increasing due to improvements in perinatal and neonatal care (1, 2). However rates of neurodevelopmental impairment in this group remain high – approximately 50% in survivors (3-6). Over the last 50 years, greater understanding of early childhood development and neural plasticity has highlighted the role of early intervention (EI) in minimising and preventing these neurodevelopmental impairments (7) (8) (9, 10). Early intervention is a wide ranging term encompassing services such as speech, occupational, physical or psychological therapies (11). Although extremely preterm children have increased requirements for EI services due to higher rates of neurodevelopmental and cognitive disability, studies indicate suboptimal uptake of services, particularly in children with higher social risk (12, 13).

The aims of this study were to detail rates of EI in three Victorian cohorts (1991-92, 1997 and 2005) of preterm survivors and controls over time and by disability severity, and to identify socioeconomic risk factors associated with accessing EI services. We hypothesised that (1) the rates of EI service access would increase over time between the 1991 and 2005 cohorts, (2) the rates of EI in the extremely preterm group would be higher than in the term group, (3) children with physical disabilities (with or without cognitive disability) would be more likely to receive EI than those with cognitive disabilities only, and (4) children with higher social risk would have lower rates of EI.

Materials and methods

Participants - Participants comprised two patient groups from the Victorian Infant Collaborative Study (VICS) in the years 1991-92, 1997 and 2005 – all surviving infants born at either <28 weeks' gestation or with birth weight <1000g in the state of Victoria, Australia, and a control group of infants born >36 weeks and >2499 g birth weight in hospitals affiliated with one of three level III perinatal centres in Victoria, Australia. **A control group was included in the study to be able to determine temporal changes in rates of early intervention in the community; neither of the previous Australian studies on early intervention in the preterm population had included a control group for comparison (12, 13).** Controls were randomly selected from births on the expected due date for each EP or ELBW surviving infant, matched for sex, maternal health insurance status (as a proxy for

social class), and mother's country of birth (primarily English-speaking or not). Children were assessed at 2 and 8 years of age and corrected for prematurity where appropriate.

Outcomes - The primary outcome was parent-reported EI, including any of physiotherapy, occupational therapy, speech therapy or behavioural therapy, up to 2 and up to 8 years of age. We relied on the history obtained from the parent and did not try to confirm corroborating data from individual services about individual children, which would have been too labour-intensive.

Children were assessed at 8 years of age by paediatricians and psychologists who were unaware of their previous history, as described elsewhere (14). Intelligence quotient scores were obtained using the Wechsler Intelligence Scale for Children (for the 1991-92 and 1997 cohorts) and the school aged Differential Ability Scales (DAS) (for the 2005 cohort); IQ scores were computed relative to the mean for the respective control groups, adjusted for sociodemographic advantage of the controls (14). Blindness, deafness, intellectual impairment and cerebral palsy (CP) were diagnosed as described elsewhere, with disability severity categorisation also as described elsewhere (see table 2) (6).

Predictor variables - The predictor variables examined were preterm vs. control group, severity and type of neurosensory disability, and social risk variables, which were: lower maternal education (0 = >11 years of schooling for 1991-92 and 1997, >12 years of schooling for 2005; 1 = <12 years of schooling for 1991-92 and 1997, d12 years of schooling for 2005), parents separated (0=no; 1=yes), multilingual family (0=speak only English at home; 1=multilingual), government income either solely or up to 50% of family income (0=no; 1=yes), and lower social class based on employment of major family income earner (0=semi-skilled, skilled or professional occupation; 1=unskilled or unemployed) (5, 12, 15-17). Other variables included gestational age at birth, sex, birthweight z-score, grade 3 or 4 intraventricular haemorrhage, cystic periventricular leukomalacia, postnatal corticosteroids, and surgery during the primary hospitalisation (5, 16, 18).

Ethics- The Human Research Ethics Committees at the Royal Women's Hospital, Mercy Hospital for Women, Monash Medical Centre and the Royal Children's Hospital, all in Melbourne, approved these follow-up studies. Parents gave written informed consent for the children in the control groups, and for the 2005 EP/ELBW cohort to participate in the studies, whereas follow-up for the earlier EP/ELBW cohorts was considered to be routine clinical care.

Analysis plan- The data were analysed using Stata Version 14.1 (19). To allow for clustering of children because of multiple births, data were analysed using Generalized Estimating Equations (20). As there were systematic changes over time in the ages of the mothers and children when they were assessed, those variables were added as covariates to the analyses. Rates of early intervention up to 2 and up to 8 years were compared between eras and between groups using logistic regression models, with an interaction term for group to determine if the rates of change in intervention were systematically different between preterm and control groups. Within the preterm cohorts alone the rates of early intervention were determined for children with any physical impairment (with or without cognitive impairment) and for those with cognitive impairment only. Within the preterm cohorts alone, differences between eras were also adjusted for the potential confounding perinatal variables listed above. For the multivariable regressions, the 2005 cohort was directly compared with the 1991-92 and 1997 cohorts. Comparisons are presented primarily as odds ratios (ORs) or mean differences, both with 95% confidence intervals (CI) and P-values.

Results

Follow up rates to 8 years were high in all eras (Table 1), although not all outcomes were determined for all children assessed. The perinatal and demographic variables for both the preterm and term cohorts were similar across all eras. Controls were generally less disadvantaged socially compared with the preterm groups. The age at assessment was earlier for the 2005 cohort compared with earlier eras. Overall 40% (262/651) of the preterm cohorts had some disability; 13% (87/651) had a physical impairment (72 had cerebral palsy, 15 were deaf and 6 were blind; 3 deaf children and 3 blind children also had cerebral palsy), and 7% (44/650) had an IQ <-2 SD without a physical impairment (one child with moderate cerebral palsy did not have a cognitive assessment). Among the controls 8% (49/579) had some disability; 1% (4/579) had a physical impairment (3 had cerebral palsy and 1 was deaf), and 1% (8/579) had an IQ <-2 SD without a physical impairment.

In general there were no differences in perinatal or demographic variables between those assessed at age 8 and not assessed at age 8 in both the preterm and term groups (Supplementary Table 1). However, in the control group only, there were statistical but clinically unimportant differences in maternal age, gestational age at birth and birthweight between those assessed and not assessed at age 8.

The rates of EI to 2 years of age were higher in the preterm cohorts compared with the controls for each era, and rose over time in both groups: 1991-92, 14% (39/217) vs. 2% (4/215); 1997, 26% (36/139) vs. 1% (1/117); 2005, 48% (89/187) vs. 10% (18/181).

The rates of EI to 8 years of age were higher in the preterm cohorts (46%; 299/651) compared with the controls (18%; 104/580) over all eras (OR 4.29, 95% CI 3.28, 5.59, P<0.001). The rates of EI to 8 years rose between the 1990s and the 2005 cohort, with the odds (for the preterm and control group combined) more than doubling in 2005 compared with earlier eras (Table 2) (2005 vs 1991-92 OR 2.42, 95% CI 1.81, 3.25, P<0.001; 2005 vs 1997 OR 2.87, 95% CI 2.06, 4.00, P<0.001). The rates of change over time in EI were not substantially different between groups (interaction p-values; 2005 compared with 1991-92 = 0.18; 2005 compared with 1997 = 0.62). The child's age when assessed at 8 years and maternal age were not independently related to rates of EI (both P>0.90).

Within the EP/ELBW cohorts alone on multivariable analysis postnatal corticosteroids, cystic periventricular leukomalacia and neonatal surgery were independently associated with receiving any EI (Table 3). Adjusting for perinatal and social variables had little effect on the relationships over time between eras, with EI much more frequent in 2005 compared with both earlier eras (2005 vs 1991-92 unadjusted OR 2.52, 95% CI 1.70, 3.74, P<0.001, adjusted OR 3.74, 95% CI 2.35, 5.97, P<0.001; 2005 vs 1997 unadjusted OR 3.45, 95% CI 2.25, 5.30, P<0.001, adjusted OR 5.01, 95% CI 3.09, 8.42, P<0.001).

Among the EP/ELBW group, 83/87 (95%) children with any physical impairment received early intervention to 8 years; of the four children recorded as having had no EI, one had severe cerebral palsy and intellectual impairment and had been receiving treatment from early in life, one was deaf with a normal IQ and had received hearing aids, one had moderate cerebral palsy and intellectual impairment, but was not recorded as having any early intervention, and the remaining child had mild cerebral palsy only, with a normal IQ. Overall, 32/44 (73%) children in the EP/ELBW group with no physical impairments but with an IQ <-2 SD had received EI. The odds of receiving EI for an EP/ELBW child with any physical impairment, adjusting for era of birth, were 45.4 (95% CI 16.6, 124, P<0.001), and for a child with low IQ only were 5.84 (95% CI 2.87, 11.9, P<0.001), compared with EP/ELBW children without those problems. Among the EP/ELBW children, the odds of receiving EI, adjusted for era of birth, increased progressively with increasing severity of disability (Table 2) (mild vs. nil OR 2.79, 95% CI 1.87, 4.16; moderate vs. nil 12.4, 95% CI

5.94, 26.1; severe vs. nil 16.7, 95% CI 6.66, 42.0; all P<0.001). Rates of EI also rose with increasing severity of disability in the control groups (Table 2). Of note, many children who had no identified disability at 8 years of age in the EP/ELBW and control cohorts had received some intervention (particularly in the 2005 group) (Table 2). Most of this group had received speech therapy (around 45%), with the rest of the children evenly spread between physiotherapy, psychology and occupational therapy.

Discussion

The major findings of the current study were that rates of EI were higher in the EP/ELBW population than in controls, increased over eras in both groups, and were progressively higher with increasing severity of neurodevelopmental disability at 8 years of age. **The inclusion of a control group provided a basis for comparison of the rates of early intervention in extremely preterm children in relation to their term peers.** Children with a physical disability had much higher odds for receiving EI than children with moderate or severe intellectual impairment but with no physical disability. Among the EP/ELBW group there were some identifiable independent perinatal risk variables (postnatal corticosteroids, cystic periventricular leukomalacia and neonatal surgery) for receiving EI. Notably, increased social risk was not associated with reduced participation in EI.

Two other Australian studies have reported EI rates in preterm children. Pritchard et al. (13) reported 55% of preterm infants (<32 weeks gestation) received EI by 12 months of age, while Roberts et al. (12) reported 23. 3% of preterm infants (<30 weeks gestation) received EI by 24 months of age. Roberts et al. (12) also examined EI by disability severity and reported an EI rate at 24 months of 51.1% in their moderate-severe disability cohort – in comparison this study found 100% of moderate-severely disabled children in our 2005 EP/ELBW preterm cohort had received EI services by 8 years of age.

Our results differ from the two Australian studies above that reported a relationship between social risk factors and EI access. Roberts et al. (12) found that children with a higher number of social risk factors were more likely to have moderate to severe disability, and less likely to receive EI (OR 0.25, p=0.001) . Pritchard et al.(13) also found an inverse relationship between socioeconomic risk factors and receiving EI (OR 0.7, p=0.04). Other international

studies report a similar relationship between social risk and EI access (21). The lack of relationship found in the current study may be due to the high follow up rate of all infants, including those with higher social risk compared with other studies. In the current study parents were informed of test results at each follow up and advised on appropriate clinical follow up (including need for EI), which may have led to increased numbers accessing EI.

This study has several strengths- high follow up rates, a long follow up time period, **comparison to a term cohort**, and a geographic cohort, which allows evaluation of a regional service. Ideally, all extremely preterm infants should receive comprehensive long term follow up and intervention recommendations whether enrolled in clinical studies or not (22) (11, 23). Follow up participation is much greater when enrolled in clinical trials compared with usual clinical follow up (24), and this study indicates the importance of perseverance in following up this high risk population as our high follow up rates may have counteracted some socioeconomic risk factors and assisted disadvantaged families in obtaining appropriate EI. The long follow up period to 8 years in comparison to the two other Australian studies reporting EI rates at 12 and 24 months gives a much broader overview of EI rates to school age. A limitation of the study is that EI was determined by parental report, which was not 100% accurate, as evidenced by the child with severe CP and intellectual impairment who had been receiving treatment from early childhood, but was not considered to be receiving EI by the parents.

Provision of early childhood developmental intervention services is currently undergoing change with the progressive introduction of the National Disability Insurance Scheme which will provide funding for EI and behavioural support (25). Early reports indicate that many families have experienced challenges with the new system (26). It will be important to compare historical rates in this study with rates of EI use through this period of change to evaluate the impact of this new system. Overall, this study demonstrates a strong upward trend in EI participation in Victoria over the three cohorts in both preterm and term born children, with increased social risk having little impact on EI use.

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Tables

Table 1. Perinatal and demographic data of children assessed at 8 years of age

Cohort	1991-92		1997		2005	
	Preterm	**Control**	**Preterm**	**Control**	**Preterm**	**Control**
Number of live births	n=298	n=262	n=201	n=199	n=219	n=218
Assessed at 8 years	275 (92%)	224 (85%)	187 (93%)	169 (85%)	190 (87%)	189 (87%)
Multiple birth	86 (31%)	4 (2%)	41 (22%)	1 (1%)	46 (24%)	2 (1%)
Gestational age (completed weeks)	26.6 (1.9)	39.2 (1.4)	26.5 (2.0)	39.3 (1.1)	26.5 (1.9)	39.5 (1.3)
Birthweight (grams)	883 (161)	3404 (440)	832 (162)	3505 (455)	869 (177)	3586 (488)
Birthweight Z score	-0.73 (1.21)	0.00 (0.88)	-0.95 (1.06)	0.15 (0.91)	-0.72 (1.13)	0.25 (0.91)
Male	127 (46.2%)	104 (46.4%)	99 (53%)	91 (54%)	85 (45%)	85 (45%)
Grade 3 or 4 IVH†	18 (7%)	0	7 (4%)	0	14 (7%)	0
Cystic PVL‡	17 (6%)	0	6 (3%)	0	7 (4%)	0
Postnatal corticosteroids	92 (33%)	0	68 (36%)	0	34 (18%)	0
Surgery	72 (26%)	0	56 (30%)	2 (1%)	49 (26%)	1 (1%)
Maternal age (years)	28.7 (5.8)	29.5 (5.0)	29.5 (5.8)	30.8 (5.2)	31.1 (5.7)	32.7 (5.6)

Lower maternal education	140/268 (52%)	82/217 (38%)*	89 (48%)	49/168 (29%)*	78/185 (42%)	40/188 (21%)*
Parents separated	81/271 (30%)	49/220 (22%)	55/184 (30%)	31/168 (18%)*	60/188 (32%)	36/188 (19%)
Multilingual family	47/272 (17%)	30/200 (14%)	38 (20%)	26 (15%)	30/188 (16%)	28/188 (15%)
Some government income §	84/266 (32%)	42/214 (20%)	37/183 (20%)	25/168 (15%)	54/187 (29%)	32/188 (17%)
Lower social class	83/268 (31%)	44/220 (20%)*	48/172 (28%)	25/161 (16%)*	63 (33%)	22 (12%)*
Age at 8 year follow up (years)	8.7 (0.4)	8.9 (0.4)	8.4 (0.5)	8.5 (0.3)	7.7 (0.4)	7.7 (0.5)

† IVH=intraventricular haemorrhage

‡ PVL=periventricular leukomalacia

§ Some income from government, either equally or solely

* $p < 0.05$ comparing preterm with control groups, within eras

Data are n (% assessed), or mean (SD)

Table 2. Disability vs any early intervention up to 8 years of age, compared between preterm and control groups by era of birth

		Preterm		Control	
Birth era	Disability	Total	Intervention	Total	Intervention
1991-92	Nil	171	51 (29.8%)	197	19 (9.6%)
	Mild†	57	26 (45.6%)	16	4 (25.0%)
	Moderate‡	28	22 (78.6%)	3	1 (33.3%)
	Severe§	17	14 (82.4%)	3	1 (33.3%)
	Total	273	113 (41.4%)	273	15 (11.4%)
1997	Nil	99	15 (15.2%)	158	21 (13.3%)
	Mild†	62	28 (45.2%)	8	3 (37.5%)
	Moderate‡	11	8 (72.7%)	1	2 (50.0%)
	Severe§	15	12 (80%)	1	1 (100%)
	Total	187	63 (33.7%)	169	26 (15.4%)
2005	Nil	119	62 (52.1%)	173	43 (24.9%)
	Mild†	41	30 (73.2%)	15	8 (53.3%)
	Moderate‡	21	21 (100.0%)	1	1 (100.0%)
	Severe§	9	9 (100.0%)	-	-
	Total	190	122 (64.2%)	189	122 (27.5%)

† Mild disability comprised mild CP (walking at age 2, GMFCS 1) or mild developmental delay (-2 to <-1 SD full scale IQ compared to term control norms)

‡ Moderate disability comprised moderate CP (walking with difficulty or aides, GMFCS 2 or 3), deafness (use of hearing aids or worse) or moderate developmental delay (-3 to <-2 SD on Bayley scale compared to term control norms)

§ Severe disability comprised severe CP (unlikely to ever walk, GMFCS 4 or 5), blindness (visual acuity 6/60 in better eye) or severe developmental delay (<-3 SD on Bayley scale compared to term control norms)

Table 3. Perinatal and social variables associated with accessing early intervention among the preterm cohorts

	Early intervention n=299	No early intervention n=352	Odds ratio (95% CI) P-value	Adjusted odds ratio (95% CI) P-value*
Multiple birth	85 (28%)	88 (25%)	1.22 (0.84, 1.78) 0.30	1.25 (0.81, 1.92) 0.32
Gestational age (weeks)	26.4 (2.1)	26.7 (1.8)	0.90† (0.83, 0.99) 0.023	1.05 (0.92, 1.20) 0.47
Birthweight Z score	-0.75 (1.17)	-0.83 (1.12)	1.07† (0.93, 1.22) 0.36	1.03 (0.84, 1.26) 0.76
Male	165 (55%)	146 (41%)	1.73 (1.26, 2.38) 0.001	1.41 (0.99, 2.01) 0.056
Grade 3 or 4 IVH‡	30 (10%)	9 (3%)	4.16 (1.97, 8.82) <0.001	2.26 (0.99, 5.15) 0.052
Cystic PVL§	25 (8%)	5 (1%)	7.30 (2.47, 21.6) <0.001	6.98 (1.50, 32.4) 0.013
Postnatal corticosteroids	119 (40%)	75 (21%)	2.65 (1.87, 3.77) <0.001	2.27 (1.46, 3.55) <0.001
Surgery	114 (38%)	63 (18%)	2.90 (2.01, 4.18) <0.001	1.95 (1.29, 2.96) 0.002
Maternal age (years)	30.0 (5.6)	29.4 (6.0)	1.02† (0.99, 1.04) 0.24	1.02† (0.99, 1.05) 0.22
Lower maternal education	134/292 (46%)	173/348 (50%)	0.88 (0.64, 1.21) 0.43	0.85 (0.58, 1.25) 0.42
Parents separated	90/295 (31%)	106/348 (30%)	1.04 (0.73, 1.46) 0.84	1.00 (0.65, 1.54) 1.0

Multilingual family	53/297 (18%)	62/350 (18%)	1.01 (0.67, 1.53) 0.96	0.96 (0.59, 1.55) 0.86
Some government income¶	83/291 (29%)	92/345 (27%)	1.06 (0.83, 1.35) 0.66	1.05 (0.77, 1.43) 0.76
Lower social class	97/292 (33%)	97/338 (29%)	1.26 (0.89, 1.79) 0.19	1.26 (0.81, 1.97) 0.30

† For one unit change in independent variable

‡ IVH=intraventricular haemorrhage

§ PVL=periventricular leukomalacia

¶ Some income from government, either equally or solely

*adjusted for all other variables in the model

Data are n (%), or mean (SD), unless otherwise specified

Supplementary Table- Perinatal characteristic comparison of children assessed at 8 years vs children not assessed at 8 years, within both preterm and control groups

	Preterm			Control		
	Assessed	**Not assessed**	**Statistics**	**Assessed**	**Not assessed**	**Statistics**
	n=652	n=66		n=582	n=97	
Mother's age (years)	29.6 (5.9)	28.4 (5.8)	1.2 (-0.3, 2.7) †	30.9 (5.4)	29.3 (6.3)	1.6 (0.4, 2.8) †*
Multiple birth	173 (27%)	12 (18%)	1.62 (0.85, 3.11) ‡	7 (1%)	4 (4%)	1.62 (0.85, 3.11) ‡
Gestational age (weeks)	26.6 (1.9)	27.0 (1.7)	-0.4 (-0.9, 0.1) †	39.3 (1.3)	39.0 (1.4)	0.4 (0.1, 0.7) †*
Birthweight (grams)	864 (167)	899 (179)	-35 (-77, 8) †	3492 (466)	3371 (484)	121 (20, 222) †*
Male	311 (48%)	34 (52%)	0.86 (0.52, 1.42) ‡	280 (48%)	53 (55%)	0.77 (0.50, 1.18) ‡
Birthweight Z- score	-0.79 (1.15)	-0.70 (1.17)	-0.09 (-0.40, 0.22) †	0.13 (0.90)	0.06 (1.01)	0.07 (-0.13, 0.27) †
Grade 3 or 4 Intraventricular haemorrhage	39 (6%)	3 (5%)	1.34 (0.40, 4.45) ‡			
Cystic Periventricular leukomalacia	30 (5%)	2 (3%)	1.54 (0.36, 6.61) ‡			
Postnatal corticosteroids	194 (30%)	19 (29%)	1.05 (0.60, 1.83) ‡			

Surgery	176 (27%)	15 (23%)	1.26 (0.69, 2.29) ‡

Data are n (%), or mean (SD), unless otherwise specified.

† mean difference (95% confidence interval [CI])

‡ odds ratio (95% CI)

* $p<0.05$ comparing those assessed with those not assessed, within eras

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