Special Care and School Difficulties in 8-Year-Old Very Preterm Children: The Epipage Cohort Study

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Abstract

Objectives: To investigate school difficulties, special care and behavioral problems in 8-year-old very preterm (VPT) children.

Patient and Methods: Longitudinal population-based cohort in nine regions of France of VPT children and a reference group born at 39–40 weeks of gestation (WG). The main outcome measures were information about school, special care and behavioral problems using Strengths and Difficulties Questionnaire from a questionnaire to parents.

Results: Among the 1439 VPT children, 5% (75/1439) were in a specialised school or class, 18% (259/1439) had repeated a grade in a mainstream class and 77% (1105/1439) were in the appropriate grade-level in mainstream class; these figures were 1% (3/327), 5% (16/327) and 94% (308/327), respectively, for the reference group. Also, 15% (221/1435) of VPT children in a mainstream class received support at school versus 5% (16/326) of reference group. More VPT children between the ages of five and eight years received special care (55% (794/1436)) than children born at term (38% (124/325)); more VPT children (21% (292/1387)) had behavioral difficulties than the reference group (11% (35/319)). School difficulties, support at school, special care and behavioral difficulties in VPT children without neuromotor or sensory deficits varied with gestational age, socioeconomic status, and cognitive score at the age of five.

Conclusions: Most 8-year-old VPT children are in mainstream schools. However, they have a high risk of difficulty in school, with more than half requiring additional support at school and/or special care. Referral to special services has increased between the ages of 5 and 8 years, but remained insufficient for those with borderline cognitive scores.

Citation: Larroque B, Ancel P-Y, Marchand-Martin L, Cambonie G, Fresson J, et al. (2011) Special Care and School Difficulties in 8-Year-Old Very Preterm Children: The Epipage Cohort Study. PLoS ONE 6(7): e21361. doi:10.1371/journal.pone.0021361

Editor: Olivier Baud, Hôpital Robert Debré, France

Received March 10, 2011; Accepted May 26, 2011; Published July 8, 2011

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Funding: This study was supported by grants from INSERM (National Institute of Health and Medical Research)(http://www.inserm.fr/), the Directorate General for Health at the Ministry for Social Affairs (http://www.sante.gouv.fr/), Merck–Sharp and Dohme-Chibret (http://www.msd-france.com/content/corporate/index.html), Medical Research Foundation (http://www.frm.org/), and “Hospital Program for Clinical Research 2001 n° AOM01117” of the French Department of Health (http://www.sante.gouv.fr/le-programme-hospitalier-de-recherche-clinique-phrc.html). The eight year follow-up was supported by the “Hospital Program for Clinical Research 2004/054/HP” at the French Department of Health and the Wyeth Foundation for Children and Adolescents (http://www.fondation-pfizer.org/).

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing Interests: The authors have declared that no competing interests exist.

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Introduction

Most very preterm children (VPT) are now discharged from the hospital alive, due to recent progress in obstetrics and neonatal care [1]. However, clinicians and parents are highly concerned by the long-term consequences of preterm delivery, such as disabilities, health problems and school difficulties for these children. Preterm birth is associated with abnormalities in brain development, leading to high rates of severe long-term neurodisability (cerebral palsy, sensory impairments, mental retardation) [1]. For these children, little is known about educational achievement by mid childhood (5–8 years old), support at school or special care outside school. Very few studies are available on children at primary school ages, with most studies focusing on extremely low birth weight children born in the 80’s [2] or extremely premature newborns [3,4]. Although the gestational age at birth plays a major role in school outcomes, behavioral problems and the socio-economic status of the family can interfere with school learning [5]. Hence, we investigated educational outcome and special care in a large population of very preterm children aged eight. We first aimed to assess the prevalence of difficulties in school, special health care, and behavioral
difficulties, and then investigated how school difficulties and special care are associated with social levels of the family, grade of immaturity and cognitive deficits assessed at the age of five.

**Methods**

**Study design and population**

We included all births between 22 and 32 completed weeks of gestation (WG) in maternity units of nine French regions in 1997 [6,7]. Of the 2901 live-born children, 85% (n = 2459) were discharged from the hospital alive (figure 1). In order to decrease the size of the sample to follow two regions included only one of every two infants born at exactly 32 WG. Thus, the population followed consisted of 2382 infants born preterm. At 8 years, there were 2249 survivors whose parents had agreed to the follow-up at birth. A full term reference group was included at birth in the same regions (one of every four births at 39 or 40 WG during one week in 1997; 555 children to follow). At recruitment in the maternity or neonatal unit, parents were told about the study and given written information, and verbal consent was provided to the medical team in charge of the study. At 8 years old, parents were sent the questionnaire and the study is done on parents who sent back the questionnaire filled.

The study and the verbal consent were approved by the French Commission Nationale de l'Informatique et des Libertés (the French data protection agency). There was no ethic approval from ethics committee because it is not necessary in France for an observational study.

**Data collection and measures**

Gestational age refers to the number of completed weeks of amenorrhea. When five years old, children were invited for a medical examination and a cognitive assessment using the Kaufman assessment battery for children (K-ABC) at local centres [6].

A postal questionnaire investigating school outcome, special care and behavioral problems was sent to parents in the first trimester of 2006, the year when children of the cohort would have been in the third grade of primary school. School outcome included special schooling (institution or special school, special class in mainstream school, mainstream class), whether the child has repeated a school year, and the results of the national tests at school in mathematics and French for children in the third grade of primary school. We defined a variable for the type of schooling: institution or special school or class, mainstream class with grade retention, and mainstream class with appropriate grade level where the child was in the correct year for their age. Support at school was defined according to whether the child was enrolled at a particular institution, special school or class, or a mainstream class.

**Figure 1. Number of children in very preterm and term groups.**

doi:10.1371/journal.pone.0021361.g001
class with support at school (extra teacher in or outside of the class room, extra teaching hours at the school itself, intervention of a psychologist or another person at school). Special care was defined as at least one visit to a physiotherapist, speech therapist, psychomotor therapist, occupational therapist, orthoptist, psychologist/psychiatrist between five and eight years of age.

The French version of the Strengths and Difficulties Questionnaire was included in the questionnaire in order to assess behavioral problems [8]. It includes four scales that assess psychiatric symptoms (hyperactivity-inattention, conduct, emotional and peer problems) summed in a score of “total difficulties” and an additional scale, reflecting prosocial behavior. Cut-offs were defined based on the 90th percentiles of the observed scores in the reference group.

Family SES (socioeconomic status) was recorded according to the national French classification of occupations and social position [http://www.insee.fr/fr/methodes/default.asp?page=nomenclatures/pc2003/liste_n1.htm] and grouped into five categories: 1 professional; 2 intermediate; 3 administrative/public service, self-employed or student; 4 shop assistant, service worker; and 5 manual worker or unemployed. SES was defined as the higher occupation between the two parents or occupation of the mother if she lived alone.

Analysis

School outcome, special care/support at school, and behavioral problems were reported according to gestational age (24–28, 29–30, 31–32, 24–32, 39–40 WG). We used the chi2 test to compare outcomes between VPT children and the reference group. These outcomes among VPT children were studied according to sex, multiple/singleton pregnancy and family SES. The comparisons according to sex and multiple/singleton pregnancy were further adjusted for gestational age and family SES. Hence, we compared type of schooling, special care and/or support at school, behavioral problems between VPT children and the reference group using logistic regression models to control for potentially confounding variables. This analysis was performed for the 1324 children who also had an assessment at five years old, after exclusion of those with severe motor deficiencies (cerebral palsy, unable to walk without aid) or severe sensory deficiencies (visual acuity<3/10 for both eyes or severe auditory deficiency) at five years of age. Factors known to be related to school outcome or behavior were included in the models: maternal age at childbirth, parity, maternal level of education, maternal birth place (France/abroad), SES, and sex. Finally, we compared the type of schooling, and whether the child received special care and/or support at school by level of cognitive score at five years old (<55, 55–69, 70–84, ≥85, not assessed); these comparisons were also adjusted for family SES. We used weighting to take into account the differences in the proportion of 32 WG children included in the various regions. Only weighted percentages or means are shown in the tables. Stata software was used (version 10.1).

Results

Parents of 1444 VPT (64% of the 2249 VPT children included in follow-up who survived) and 327 born at term’ eight-year-old children (59% of the reference group included in follow-up who survived) answered to the 8 year questionnaire. The main reason for non-response (911 VPT children) was a change of address (462 address unknown at 8 years) (figure 1); VPT responders and non-responders did not differ for gestational age, but non-responders had more cerebral lesions in the neonatal period. Mothers of non-responders had a lower level of education, a lower SES and were more often born outside of France in both the VPT group and the reference group.

Two percent of VPT children were enrolled in special schools or institutions, 3% in a special class in a mainstream school, 10% in a mainstream class with grade retention, and 77% in a mainstream class with appropriate grade level compared with 0.3%, 0.6%, 5% and 94%, respectively, for those born between at 39–40 WG (table 1). The proportion of children with appropriate grade level was 63% for those born at 24–25 WG, 79% for those born at 32 weeks and 94% for those born at 39–40 WG (Figure 2). VPT children had significantly lower mathematics and French scores than the reference group for available year 3 national evaluation results. A total of 15% of VPT children and 5% of the reference group received support at school in mainstream classes (table 2).

Fifty-five per cent of VPT children received special care between the ages of 5 and 8 years compared with 58% of the reference group; this percentage increased to 65% for children born between 24 and 28 WG (table 2). When considering children with appropriate grade level and without special care or support at school, the rate was 29% (99/340) in 24–28 weeks, 44% (171/388) in 29–30 weeks, 42% (292/708) in 31–32 weeks.

VPT children were more likely to have high scores in total behavioral difficulty, hyperactivity, emotional problems, and peer problems (table 3). Except for peer problems, the association between VPT and behavioral scores remained significant after adjusting for maternal age, parity, maternal level of education, mother born in France/abroad, SES and sex.

Boys born VPT were less likely to be in a mainstream class with appropriate grade level than girls (table 4). They had significantly more special care and/or support at school and behavioral difficulties, than girls. VPT children from a singleton pregnancy had more behavioral difficulties than children from a multiple pregnancy. The percentage of VPT children in a mainstream class with appropriate grade level decreased with SES, from 90% for professionals to 57% for manual workers or the unemployed (table 4). A similar trend was seen in the reference group, from 98% for professionals to 86% for manual workers or the unemployed. Special care and/or support at school was more frequent in children with manual workers or the unemployed as parents (63%) than in children with professional parents (51%).

If considering only the 1292 children assessed at five years free from severe neuromotor or sensory deficit VPT children were three times more likely to be in an institution or a special school or class and four times more likely to be in a mainstream class with grade retention than the reference group after controlling for confounders (table 5). The risk of having special care and/or support at school and behavioral difficulties was doubled. A total of 41% of VPT and 62% of reference group children were enrolled in the appropriate grade level without special care or support at school.

The proportion in an institution or a specialised class or school varied from 14% when the cognitive score was between 55 and 69 to 1% when the score was between 70 and 84 for children free from severe sensory-motor deficiencies (table 6). Almost all
Table 1. Schooling at 8 years of age by group of gestational age.

|                     | 24–28 weeks | 29–30 weeks | 31–32 weeks | 24–32 weeks | 39–40 weeks | p value |
|---------------------|-------------|-------------|-------------|-------------|-------------|---------|
| n                   | 341         | 389         | 709         | 1439        | 327         |         |
| Age at response to questionnaire | 86 (25%)   | 100 (26%)   | 215 (29%)   | 401 (27%)   | 80 (24%)    | 0.26    |
| 8 years–8 years 6 months | 341         | 389         | 709         | 1439        | 327         |         |
| 8 years 7 months–9 years | 192 (56%)  | 231 (59%)   | 367 (53%)   | 790 (56%)   | 198 (61%)   |         |
| ≥9 years 1 month    | 63 (19%)    | 58 (15%)    | 127 (18%)   | 248 (17%)   | 49 (15%)    |         |
| Special schooling   | 341         | 389         | 709         | 1439        | 327         | 0.003   |
| Institution or special school | 18 (5%)    | 9 (2%)      | 8 (1%)      | 35 (2%)     | 1 (1%)      |         |
| Special class in mainstream school | 14 (4%)    | 11 (3%)     | 15 (2%)     | 40 (3%)     | 2 (1%)      |         |
| Mainstream class    | 309 (91%)   | 369 (95%)   | 686 (97%)   | 1364 (95%)  | 324 (99%)   |         |
| For children in mainstream class | 309         | 369         | 686         | 1364        | 324         |         |
| - with grade retention | 85 (28%)  | 55 (15%)    | 119 (18%)   | 259 (19%)   | 16 (5%)     | <0.0001 |
| Children in 3rd grade of mainstream school | 214         | 301         | 521         | 1036        | 271         |         |
| - Mathematics scorea mean(sd) | 145 (68 (19) | 188 (71 (15) | 327 (73 (15) | 660 (71 (16) | 173 (78 (15) | <0.0001 |
| - French scorea mean(sd) | 145 (75 (14) | 188 (74 (14) | 329 (75 (14) | 662 (75 (14) | 172 (78 (14) | 0.014   |
| Type of schooling   | 341         | 389         | 709         | 1439        | 327         | <0.0001 |
| Institution or special school or class | 32 (9%)    | 20 (5%)     | 23 (3%)     | 75 (5%)     | 3 (1%)      |         |
| Mainstream class with year repeated | 85 (25%)  | 55 (14%)    | 119 (17%)   | 259 (18%)   | 16 (5%)     |         |
| Mainstream class with correct class for age | 224 (66%)  | 314 (81%)   | 567 (80%)   | 1105 (77%)  | 308 (94%)   |         |

Data are number (weighted %) or weighted mean (SD).

aAt national evaluation organized in 3rd grade of mainstream school.

doi:10.1371/journal.pone.0021361.t001

Figure 2. Type of schooling at 8 years of age and gestational age at birth (weeks).

doi:10.1371/journal.pone.0021361.g002
children had special care and/or support when their cognitive score was less than 70 compared with 65% of children when the cognitive score was 70–84 and 48% for VPT children with scores of 85 or more. The proportion of children in the appropriate grade level without special care or support at school increased from 0 for cognitive scores of less than 55 to 51% for cognitive scores of 85 or more. Results were only slightly modified when taking family SES into account.

Discussion

At the age of eight, most VPT children (95%) were in a mainstream class. However, 19% of them had repeated a grade compared to 5% of the reference group. Only 41% of VPT children (62% in the reference group) were in the appropriate grade level in a mainstream class without support at school and/or special care. School performance, use of special care and/or support at school and behavioral impairment were strongly related to gestational age at birth and family SES.

The strengths of the Epipage study are its geographical basis, the large sample size, the assessment of outcomes at school age (8 years) in comparison to a contemporary cohort of children born at term, the inclusion of the entire range of very preterm children and not only the extreme gestational age. It suggests that innovations, such as antenatal corticosteroid therapy, surfactant and in utero transfer, which have been associated with a reduction in infant mortality and/or neonatal cerebral lesions, did not prevent from high risks of difficulties at school.

A limitation inherent to long-term cohort studies is an attrition bias: a high proportion of families moved without the possibility for us to collect their new address. Although there was no difference of gestational age between responders and non-responders for gestational age at 8 years, an underestimation of unfavourable outcome is highly likely, as children lost to follow up

Table 2. Special care and support at 8 years of age by gestational age group at birth.

|                     | 24–28 weeks | 29–30 weeks | 31–32 weeks | 24–32 weeks | 39–40 weeks | p value        |
|---------------------|-------------|-------------|-------------|-------------|-------------|----------------|
| Support at school   |             |             |             |             |             | <0.0001        |
| Institution or special school or class | 32/340 (9%) | 20/387 (5%) | 23/708 (3%) | 75/1435 (5%) | 3/326 (1%)  |                |
| Support at school in mainstream class | 77/340 (23%) | 40/387 (10%) | 104/708 (14%) | 221/1435 (15%) | 16/326 (5%) |                |
| Special care since the age of 5 yearsa | 223/341 (65%) | 202/389 (52%) | 369/706 (51%) | 794/1436 (55%) | 124/325 (38%) | <0.0001        |
| Orthoptic therapy since the age of 5 years | 65/329 (20%) | 55/376 (15%) | 89/664 (13%) | 209/1369 (15%) | 17/310 (5%) | <0.0001        |
| Speech therapy since the age of 5 years | 126/331 (38%) | 110/379 (29%) | 203/681 (29%) | 439/1391 (31%) | 77/318 (24%) | 0.018          |
| Physical therapy since the age of 5 years | 55/339 (16%) | 29/379 (7%) | 40/670 (5%) | 118/1427 (8%) | 1/321 (<1%) |                |
| Psychomotor or occupational therapy since the age of 5 years | 81/341 (24%) | 46/389 (12%) | 56/705 (8%) | 183/1435 (12%) | 10/325 (3%) | <0.0001        |
| Psychologist or psychiatrist visit since the age of 5 years | 17/330 (5%) | 25/379 (7%) | 34/696 (5%) | 76/1405 (5%) | 10/323 (3%) |                |
| 1                   |             |             |             |             |             | 0.001          |
| (2–5) times         |             |             |             |             |             |                |
| 24/330 (7%)         |             |             |             |             |             |                |
| >5 time             | 63/330 (19%) | 54/376 (14%) | 79/696 (11%) | 196/1405 (14%) | 21/321 (6%) |                |
| Wearing glasses     |             |             |             |             |             |                |
| 157/340 (46%)       |             |             |             |             |             |                |
| Wearing auditive aid|             |             |             |             |             |                |
| 4/342 (1%)          |             |             |             |             |             |                |
| Special care and/or support at schoolb | 239/343 (70%) | 208/388 (54%) | 394/707 (55%) | 841/1438 (58%) | 128/326 (39%) | <0.0001        |

*aAt least one of orthoptic therapy, speech therapy, physical therapy, psychomotor therapy, occupational therapy, psychologist/psychiatrist therapy.

bSpecial care since the age of 5 years and/or support at school.

doi:10.1371/journal.pone.0021361.t002

Table 3. Behavioural problems assessed with the Strength and Difficulty Questionnaire at 8 years of age by gestational age group at birth.

|                     | 24–28 weeks | 29–30 weeks | 31–32 weeks | 24–32 weeks | 39–40 weeks | p value        |
|---------------------|-------------|-------------|-------------|-------------|-------------|----------------|
| Behavioural evaluation |            |             |             |             |             | 24–32/39–40   |
| Total behavioural difficulties | 93 (28%) | 65 (17%) | 134 (19%) | 292 (21%) | 35 (11%) | 0.0001         |
| Hyperactivity         | 62 (19%) | 57 (15%) | 120 (17%) | 239 (17%) | 35 (11%) | 0.009          |
| Conduct problems      | 30 (9%) | 32 (8%) | 69 (10%) | 131 (9%) | 22 (7%) | 0.17           |
| Emotional problems    | 68 (20%) | 54 (14%) | 116 (18%) | 238 (17%) | 30 (9%) | 0.0004         |
| Peer problems         | 65 (19%) | 72 (19%) | 104 (15%) | 241 (17%) | 39 (12%) | 0.028          |
| Prosocial behaviour   | 46 (14%) | 36 (10%) | 98 (14%) | 180 (13%) | 36 (11%) | 0.43           |

doi:10.1371/journal.pone.0021361.t003
had more cerebral lesions at neonatal ultrasound scans and were from lower SES, as previously observed in other studies [9]. For practical reasons, data were obtained from parents thus the requested information was limited and simple (type of school, grade repetition) for which parents were expected to be reliable informants. Besides, for questions regarding support and care given to their child, parents are those who have the global viewpoint.

Integration policies and educational support for children with handicaps or learning difficulties differ between countries thus they are not directly comparable between studies. However, as observed in several earlier studies [3,5,10,12,13,14,15], children born VPT performed less well in school (77% of children in the appropriate grade level vs 94% in the reference group; lower results for national evaluations) and were more likely to receive special support at school than children born at term (20% vs 6%...
for reference group. VPT children born in the lowest gestational age group (24–28 weeks) functioned less well than those born in the higher gestational age group (29–32 weeks), and required higher rates of special care and/or support at school (70% vs 55%). Vulnerability to the processes that guide post-natal maturation, cognitive and behavioral development and learning abilities increases as the gestational age at birth decreases [16]. Studies investigating children born extremely preterm show that a large proportion have learning disabilities and behavioral problems [3,17,18]. Children born before 26 WG were assessed at eleven years old in the Epicure study: 13% attended a special class or institution was 13% for lower SES families and 1% for VPT children from the highest SES families. By contrast, the percentage of VPT children being educated in a special school, special care and/or support at school seemed appropriate, but in cases of moderately low cognitive scores (70–84), only 65% received special care and/or support at school.

Table 6. Type of schooling and special care for very preterm children without severe deficiencies1 at the age of 5 by cognitive score2 at the age of 5.

| Type of schooling | Cognitive score | Crude | p value |
|------------------|----------------|-------|---------|
|                  | <55 | 55–69 | 70–84 | ≥85 | not assessed |         |
| Institution or special school or class | 9/24 (38%) | 13/93 (14%) | 4/238 (1%) | 4/796 (0.5%) | 22/141 (16%) | <0.0001 |
| Mainstream class with grade retention | 13/24 (54%) | 40/93 (44%) | 73/238 (30%) | 64/796 (8%) | 33/141 (25%) |         |
| Mainstream class with appropriate grade level | 2/24 (8%) | 40/93 (43%) | 161/238 (69%) | 728/796 (92%) | 86/141 (59%) |         |
| Special care and/or support between 5 and 8 years | 23/24 (96%) | 85/93 (91%) | 157/238 (65%) | 384/796 (48%) | 93/141 (66%) | <0.0001 |
| Children with appropriate grade level and without special care or support at school | 0/24 (0%) | 6/93 (6%) | 71/238 (31%) | 402/796 (51%) | 43/141 (30%) | <0.0001 |

1Children assessed at 5 excluding children with cerebral palsy unable to walk without aid and those with severe visual deficiency (<3/10 for both eyes) or severe hearing deficit.
2Cognitive score: Mental Processing Composite Scale of the Kaufman Assessment Battery for Children.

The statistical test includes only children with a cognitive score.

doi:10.1371/journal.pone.0021361.t006

Special Care and School Outcome in Very Preterm Children

The consequences of living in a socially underprivileged environment and those of VPT birth are cumulative. Fifty-seven percent of VPT children from lowest SES families were in a mainstream school in the appropriate grade level versus 90% of VPT children from the highest SES families. By contrast, the percentage of VPT children being educated in a special school, special class or institution was 13% for lower SES families and 1% for families from the highest SES. Poor social environment, maternal stress or depression influence the development and the functioning of the brain, particularly for children born VPT [20,21,22,23,24]. Altogether, suppression of endogenous maternal/placental factors induced by preterm birth, perinatal brain injury, caused by factors such as inflammation, hypoxic-ischemia or undernutrition, as well as environmental factors in infancy have a negative impact on continued brain maturation and development in young people as they get older; this results in lower academic achievement and persisting disadvantages at adult age compared with full term peers [25,26,27,28].

Efforts should be made to improve access to services and organisation of care for VPT children, including those without mental retardation, as it is important to develop their potential and to prevent further handicaps. There is a need for further research on the effects of developmental intervention programmes throughout childhood using measurements of outcome sensitive enough to detect subtle changes. These should not only include
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