Prevalence of Pervasive Developmental Disorders Among Children at the English Montreal School Board

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Objectives: The prevalence of pervasive developmental disorders (PDDs) has increased. There has been speculation regarding a role of thimerosal-containing vaccines (TCVs) in this trend. Our objectives were to determine prevalence rates of PDDs among school-aged children, and to evaluate the impact of discontinuation of thimerosal use in 1996 in routine childhood vaccines on PDD rates.

Method: Children (n = 23 635) attending kindergarten to Grade 11 were surveyed in 71 schools from the English Montreal School Board. For children with PDD, information was obtained about their diagnostic subtype, age, sex, grade, and school. Prevalence rates were calculated for the entire school population and for each grade. Prevalence rates were also compared for children born before or after 1996.

Results: Students (n = 187; male to female ratio: 5.4:1) with PDD were identified, corresponding to a prevalence of 79.1/10 000 (95% CI 67.8 to 90.4/10 000). The prevalence was 25.4, 43.6, 9.7, and 0.4 for autistic disorder, PDD not otherwise specified, Asperger syndrome, and childhood disintegrative disorder, respectively. During the study period, there was a significant linear increase in prevalence (OR 1.17 per year; 95% CI 1.12 to 1.23). The trend in prevalence of PDDs was unrelated to the discontinuation of TCVs.

Conclusion: Our study provides additional evidence that the PDD rate is close to 1%. We estimate that at least 11 500 Canadian children aged 2 to 5 years suffer from a PDD. The reasons for the upward trend in prevalence could not be determined with our methods. Discontinuation of thimerosal use in vaccines did not modify the risk of PDD.


Clinical Implications

- This prevalence study confirms our previous study performed in Montreal 5 years ago. The slightly higher prevalence rate of 0.8% is consistent with recent figures obtained by the Center for Disease Control in the United States.
- The prevalence estimates for each subtype of PDD (autistic disorder, PDD not otherwise specified, childhood disintegrative disorder, Asperger syndrome) are also highly consistent with recent reviews of prevalence studies of autistic spectrum disorders (ASDs).
- As in other surveys, prevalence rates have been increasing in recent birth cohorts. Our study provides preliminary evidence that in the youngest school-aged birth cohorts, aged 5 to 9 years, the prevalence may have stabilized around figures of 1.2% to 1.4%.

Limitations

- Although many of the children included in our study have been diagnosed in our McGill tertiary pediatric hospital, no clinical validation of the administrative definition of the cases could be performed.
- The lack of association between increasing rates of ASD and changes in the exposure to TCV during our study was based on aggregated data. Therefore, the usual limitations of ecological analyses apply to our findings of no association.
- Some special schools in Montreal that provide services to children with mental retardation, sometimes associated with PDD, were not included in our study, leading to a potential underestimation of the true population rate.
Key Words: epidemiology, autism, pervasive developmental disorder, prevalence, school-aged, immunizations, vaccines

Pervasive developmental disorders are a group of disorders beginning in early childhood that cause marked impairments in language and communication, social interaction, and the presence of repetitive or stereotypic patterns of behaviour.1 The group of disorders is comprised of ASD, PDD-NOS, Asperger syndrome, and CDD. Despite substantial progress in the discovery of genetic mechanisms,2 the precise causes of PDDs have not yet been determined. Nevertheless, research has shown that early intensive behaviour interventions have been able to alter trajectories, and can lead to gains in language and cognitive functioning.3,4 However, additional services are still required for numerous children who do not make significant gains with current methods of behaviour interventions.4

The significant increase in the number of epidemiologic surveys reporting a rise in prevalence rates of PDD has been suggestive of a possible epidemic.5–7 While prevalence rates of PDD have in fact gone up, a true increase in the incidence of the disorder remains uncertain. Factors including the broadening of diagnostic concepts, growing awareness of the disorder, and improved detection in surveys, may account for the elevated rates.5–10 Only 2 studies have been conducted in Canada to date. The first study,11 which screened 20,800 children aged 4 to 6 years residing in a specific region in Nova Scotia, was carried out in 1985 and did not generate a prevalence figure for the entire PDD spectrum. The second survey was completed in 2003/2004 in the Lester B Pearson school board in Montreal, and reported a prevalence of 64.9 per 10,000.12 Further investigations regarding prevalence rates of PDDs in populations are imperative to planning for proper distribution of resources such as therapies, diagnosticians, and other health care providers. Prevalence rates can also help us understand the variability of PDD across various geographic locations of different groups of people. In addition, the reporting of rates of PDD can lead to greater awareness and commitment to research, which can result in more effective intervention and prevention.

Our prevalence survey of PDDs reports on rates of PDD in the EMSB in 2007 to 2008. The goals of our survey were to generate an estimate of the prevalence of the PDD spectrum and the prevalence of specific diagnostic subtypes within the PDD spectrum that could be applied to the province of Quebec for service planning, evaluate trends in prevalence rates in successive birth cohorts, and evaluate the impact of the discontinuation of the use of thimerosal in vaccines on rates of children with PDD.

Method

Subjects

The education system in the province of Quebec is divided linguistically into French and English school boards. French and English schools belonging to their respective school boards offer education to children in both languages. The largest public school board for anglophone children is the EMSB, which provides education to people in the central and eastern regions of the island of Montreal. The EMSB is made up of 71 schools and provides education from kindergarten to Grade 11 (ages 5 to 17 years). A total of 23,635 were registered with the EMSB by the survey date of April 1, 2008.

Case Identification

In Quebec, children with special education needs are integrated into regular classrooms, segregated in separate classrooms within a regular school, or placed within a special school. Funding, in addition to the base grant received for all students, is provided to school boards when the special needs of a student are classifiable according to criteria established by the MEQ. Among the 10 medical or psychiatric categories allowing the school to receive extra funding from the MEQ, PDD is one of the conditions that lead to the highest incremental funding. Each year, a list of children with identified PDDs attending any one of the schools within each of the province school boards is sent to the MEQ. Using this list, the MEQ determines the amount of extra funding each school board receives to meet the needs of children with PDDs. Until 2000, children with PDDs were administratively identified only if their diagnosis was specifically stated as autism (Code 51). In 2000, the category was broadened to ASD (Code 50). The list of children who are assigned a Code 50 is kept in a confidential school database. The children with PDD who are the focus of our study were identified through this list.

Data

Children with a diagnosis of PDD were identified by school personnel from the confidential school database and given a study code to preserve the anonymity of the data. In Grade 11, 39 PDD subjects aged 17 to 21 years allowed to prolong their high school education were excluded from the survey, as they could not be related to a meaningful denominator. Children’s diagnoses were extracted from school records but were not verified by direct assessments, although most children (n = 129; 69%) were diagnosed at the Montreal Children’s Hospital. School personnel further identified the age, grade, school the child was attending, and type of support the child was
receiving. Denominators used for further prevalence calculations were obtained through the EMSB, and included the total number of children in each grade registered in any of the schools at the EMSB.

**Exposure to TCVs**

Individual immunization data were not available for study subjects. In Quebec, thimerosal was removed from vaccines used as part of the recommended childhood vaccine schedule in 1996. In previous years, exposure to thimerosal varied from 125 to 200 micrograms for birth cohorts included in our study (see Fombonne et al. for further details).

**Statistical Analysis**

Prevalence rates could be computed for each grade by dividing the number of children with a PDD diagnosis in a given grade by the corresponding denominator. Because birthdates were only available for the PDD children but not for the whole school population, age-specific prevalence rates were estimated by allocating to all children of a given grade the birth year most consistent with their grade attendance. Thus children in kindergarten were assumed to all be born in 2002, children in Grade 1 in 2001, and so forth. We validated this imputation method by examining the correspondence between grade and year of birth using the PDD sample for which precise birthdates were known. We used 95% confidence intervals to calculate for each prevalence proportion using exact binomial calculations. Logistic regression models were fitted to the data to evaluate time trends and the impact of thimerosal discontinuation on these trends. A P value of 0.05 was retained as criterion for statistical significance.

**Authorization**

The study was approved in July 2008 by the Commission d’Accès à l’Information du Québec and the Montreal Children’s Hospital Ethics Research Board in 2009.

**Results**

**Prevalence**

Table 1 provides the full prevalence data, as well as prevalence estimates calculated separately for each grade that are used here as a proxy indicator for birth cohort. There was an important variability in prevalence estimates by grade, with the highest prevalence of 149.8/10 000 observed in Grade 2 (for example, children born around 2000), and the lowest prevalence of 13.8/10 000 observed in Grade 10 (among children roughly aged 16 years).

Prevalence rose steadily from kindergarten through Grade 11 (Figure 1). Using logistic regression, a statistically significant effect on prevalence was found for birth cohort (OR 1.17 per year; 95% CI 1.12 to 1.23), with an average annual increase of 17% in prevalence rate. Inclusion of quadratic terms for birth cohort did not improve the fit of the model, suggesting that the increase of prevalence was linear during the study period.

Table 2 displays sex distribution and prevalence rates by PDD diagnostic subtype. Overall, the male to female ratio

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**Table 1 PDD prevalence in Montreal children aged 6 to 17 years (born 1991–2002)**

<table>
<thead>
<tr>
<th>Grade</th>
<th>Year of birth</th>
<th>Elementary schools $n = 38$</th>
<th>High schools $n = 33$</th>
<th>Total</th>
<th>Students with PDD</th>
<th>Rate</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kinder-</td>
<td>2002</td>
<td>1594</td>
<td>33</td>
<td>1627</td>
<td>21</td>
<td>129.1</td>
<td>74.2–183.9</td>
</tr>
<tr>
<td>garden</td>
<td>1</td>
<td>2001</td>
<td>1716</td>
<td>1748</td>
<td>25</td>
<td>143.0</td>
<td>87.4–198.7</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>2000</td>
<td>1711</td>
<td>1736</td>
<td>26</td>
<td>149.8</td>
<td>92.6–206.9</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>1999</td>
<td>1737</td>
<td>1769</td>
<td>23</td>
<td>130.0</td>
<td>77.2–182.8</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>1998</td>
<td>1862</td>
<td>1888</td>
<td>15</td>
<td>79.4</td>
<td>39.4–119.5</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>1997</td>
<td>1967</td>
<td>1987</td>
<td>17</td>
<td>85.6</td>
<td>45.1–126.1</td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>1996</td>
<td>2153</td>
<td>2169</td>
<td>19</td>
<td>87.6</td>
<td>48.4–126.8</td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>1995</td>
<td>0</td>
<td>2222</td>
<td>13</td>
<td>58.5</td>
<td>26.8–90.2</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>1994</td>
<td>0</td>
<td>2062</td>
<td>9</td>
<td>43.6</td>
<td>15.2–72.1</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>1993</td>
<td>0</td>
<td>2282</td>
<td>11</td>
<td>48.2</td>
<td>19.8–76.6</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>1992</td>
<td>0</td>
<td>2173</td>
<td>3</td>
<td>13.8</td>
<td>3.0–40.0</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>1991</td>
<td>0</td>
<td>1972</td>
<td>5</td>
<td>25.4</td>
<td>8.0–59.0</td>
</tr>
<tr>
<td>Total</td>
<td>12 740</td>
<td>10 895</td>
<td>23 635</td>
<td>187</td>
<td>79.1</td>
<td>7.8–90.4</td>
<td></td>
</tr>
</tbody>
</table>

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was 5.4:1 (5.9:1 for PDD-NOS; 5.0:1 for autistic disorder; 4.8:1 for Asperger; \( \chi^2 = 0.19, df = 2, \) not significant). PDD-NOS was 1.7 times more frequent than autistic disorder, accounting for 55% of all PDD cases.

**Discontinuation of TCVs**

The prevalence in each individual birth cohort born in or after 1996 was consistently higher than that in cohorts born prior to 1996 (Table 1). The prevalence of PDD in all children born before 1996 was significantly \( (P < 0.001) \) lower (38.3/10 000; 95% CI 26.6 to 50.0/10 000) than that (113/10 000; 95% CI 94.7 to 131.2/10 000) in all children born in 1996 or after. Further, the inclusion of a dummy predictor variable indicating exposure or not to thimerosal (before or after 1996) to the model predicting prevalence with birth cohort did not improve the model and was not significant (Wald \( \chi^2 = 1.7, df = 1, \) not significant). Taken together, the results suggest that the risk of PDD was not reduced by the discontinuation of thimerosal use in Quebec routine vaccines around that year.

**Interpretation**

The estimate of 79.1/10 000 confirms that PDDs are relatively frequent disorders among children, affecting roughly 1 child in 126 in the group aged 6 to 17 years. When PDDs were broken down by subtypes, a fairly typical pattern emerged, with the prevalence of PDD-NOS 1.7 times higher than for autistic disorder, and the prevalence of CDD extremely low, consistent with available estimates. As in our previous Montreal survey, the prevalence varied by birth year, with a significant linear increase of about 17% for each successive birth cohort for the period of 1991 to 2002. This
increase was unaffected by the discontinuation of thimerosal use in routine child vaccines in Quebec in 1996.

This survey resulted in a comparable, albeit slightly higher, prevalence figure than the 64.9/10,000 reported in our previous Montreal survey. The likely explanation is that this survey was carried out in the spring of 2008, 4.5 years later than the previous survey. The later survey date may have led to a higher average prevalence rate that could have been predicted based on the upward trend already detected then. Our study therefore serves as a replication of our previous Montreal survey, and confirms that the results of the previous study were not reflecting migration factors into that particular school board area, which is notorious for having excellent special needs student support services. The high prevalence rate in the EMSB simply confirms the high rate in the target population. The statistically significant trend for increasing prevalence rates in successive birth cohorts is consistent with trends in other studies that have repeatedly shown increasing prevalence rates in younger birth cohorts in the last 15 years. It is concerning, in terms of both causal mechanisms and service needs, that this trend is not abating. A rate at, or over, 1.3% was found in children aged 5 to 8 years, a figure considerably higher than previous figures but consistent with some recent studies performed in New Jersey, Japan, and the United Kingdom. A trend for stabilization of rates at that level can be seen in the 4 youngest birth cohorts of our study, but this finding requires confirmation.

As in other studies where the effect of the discontinuation of thimerosal in childhood vaccines was examined, no change in the underlying population trends for PDD rates could be observed in relation to thimerosal discontinuation.

Several limitations of our study must be acknowledged. First, diagnosis could not be directly confirmed, and it is therefore possible that PDD diagnoses were overused, leading to diagnostic miscategorization. Second, some special schools in Montreal that provide services to children with mental retardation, sometimes associated with PDD, were not included in our study, leading to a potential underestimation of the true population rate. However, because the school board has a policy of integration and changes in educational policies have contributed to PDD diagnoses to be used more frequently. In Quebec, the change in the special needs educational code for PDD (see Methods section) most certainly encouraged the use of PDD diagnosis and changes in diagnostic practices. Finally, the finding on the absence of effect of thimerosal discontinuation is based on aggregated data, and therefore typical limitations of epidemiologic studies should be considered. However, our results are highly consistent with those of epidemiologic studies that have examined the putative links between PDD and thimerosal exposure, including those from stronger case-control or cohort study designs.

With rates approaching 0.8%, PDDs are among the most prevalent conditions impairing young children’s lives. Based on population statistics for Canada, the prevalence found in this survey translates to about 63,000 Canadian children aged 19 years and younger affected with this impairing neurodevelopmental disorder, including 11,500 young children aged 2 to 5 years who could benefit from early intensive behavioural interventions. This figure would rise to 20,000 if prevalence estimates obtained in our study for ages 5 to 8 years were used. The implications for developing more services within the health care and education systems are obvious. As the upward trend remains concerning, it is essential to continue to develop surveillance systems in Canada that will track trends over time in incidence and prevalence.

Acknowledgements

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The study was approved in July 2008 by the Commission d’Accès à l’Information du Québec and in 2009 by the Research Ethics Board of the Montreal Children’s Hospital.

Disclosure

Dr Fombonne has been an expert witness for vaccine manufacturers and for the US Department of Justice and the US Department of Health and Social Services in the US thimerosal litigation. None of his research has ever been funded by the industry.

References

Résumen : La prévalence des troubles envahissants du développement chez les enfants de la Commission scolaire English-Montreal


Résultats : Les élèves (n = 187; ratio de garçons sur filles : 5,4:1) souffrant de TED ont été identifiés, correspondant à une prévalence de 79,1/10 000 (IC à 95 % 67,8 à 90,4/10 000). La prévalence était de 25,4; 43,6; 9,7; et 0,4 pour le trouble autistique, le TED non spécifié, le syndrome d’Asperger, et le trouble désintègratif de l’enfance, respectivement. Durant la période de l’étude, il y a eu une augmentation linéaire significative de la prévalence (RC 1,17 par année; IC à 95 % 1,12 à 1,23). La tendance de la prévalence des TED n’était pas reliée à la cessation des VCT.

Conclusion : Notre étude offre des données probantes additionnelles indiquant que le taux de TED est près de 1 %. Nous estimons qu’au moins 11 500 enfants canadiens âgés de 2 à 5 ans souffrent d’un TED. Nos méthodes n’ont pas pu déterminer les raisons de cette tendance à la hausse. La cessation de l’utilisation du thimérosal dans les vaccins n’a pas modifié le risque de TED.