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Research

Accuracy of administrative claims data for cerebral palsy diagnosis: a retrospective cohort study

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Abstract

Background: Cerebral palsy is the most common cause of childhood physical disability, with multiple associated comorbidities. Administrative claims data provide population-level prevalence estimates for cerebral palsy surveillance; however, their diagnostic accuracy has never been validated in Quebec. This study aimed to assess the accuracy of administrative claims data for the diagnosis of cerebral palsy.

Methods: We conducted a retrospective cohort study of children with cerebral palsy born between 1999 and 2002 within 6 health administrative regions of Quebec. Provincial cerebral palsy registry data (reference standard) and administrative physician claims were linked. We explored differences between true-positive and false-negative cases using subgroup sensitivity analysis.

Results: A total of 301 children were identified with confirmed cerebral palsy from the provincial registry, for an estimated prevalence of 1.8 (95% confidence interval [CI] 1.6–2.1) per 1000 children 5 years of age. The sensitivity and specificity of administrative claims data for cerebral palsy were 65.5% (95% CI 59.8%–70.8%) and 99.9% (95% CI 99.9%–99.9%), respectively, yielding a prevalence of 2.0 (95% CI 1.9–2.3) per 1000 children 5 years of age. The positive and negative predictive values were 58.8% (95% CI 53.3%–64.1%) and 99.9% (95% CI 99.9%–99.9%), respectively. The κ value was 0.62 (95% CI 0.57–0.67). Administrative claims data were more sensitive for children from rural regions, born preterm, with spastic quadriparesis and with higher levels of motor impairment.

Interpretation: Administrative claims data do not capture the full spectrum of children with cerebral palsy. This suggests the need for a more sensitive case definition and caution when using such data without validation.

Cerebral palsy encompasses a heterogeneous group of nonprogressive neuromotor disorders of early onset.[1] It is the most common cause of chronic physical disability encountered in children, with an estimated prevalence of 2.0 to 2.5 per 1000 live births in Western populations.[2,3] As a lifelong disorder with multiple associated functional limitations and comorbidities, it is not surprising that cerebral palsy has substantial societal costs related to coexisting medical, rehabilitation and educational needs,[4] with a substantial apparent impact on the quality of life of those affected and their families.[5]

There is currently no systematic surveillance method for cerebral palsy. Patient registries are favoured as more accurate data sources than population surveys, medical record reviews or health administrative databases. However, they are associated with higher operational costs and an inherent delay in data generation compared with large preexisting health administrative databases, such as physician billing claims or hospital discharge abstracts.[6]

Health administrative databases are commonly used in health services research and surveillance. Databases created for administrative purposes are largely conceptualized and implemented to keep track of patients and facilitate reim-

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bursement mechanisms.[6] These databases are not without their limitations, including potential inaccuracy in diagnostic code entry that may reflect biases in recall, multiple entries from varying sources, a lack of clear, universally accepted case definitions and "diagnostic undershadowing," wherein only 1 diagnosis is entered for a child with multiple comorbidities. Such databases do have potential advantages related to a large sampling frame (population), lower costs associated with a lack of direct additional patient contact and assessment for case ascertainment, and the ability to obtain records over a longitudinal time frame from multiple sources. This convenience has been translated into a preference for using such administrative databases for surveillance and health outcomes research. Indeed, validated case definitions have been developed and applied to a number of conditions, such as asthma, diabetes and chronic obstructive pulmonary disease, to identify cohorts of affected people.[7–9]

The validity of diagnostic codes for cerebral palsy used in administrative databases has not yet been established. As data from health administrative databases can potentially influence the formulation of health policy decisions, affecting resource allocation, the validation of diagnostic codes for cerebral palsy is required. The primary goal of the current study was to assess the accuracy of using health administrative databases to identify children with cerebral palsy in the province of Quebec. Our secondary goal was to compare prevalence estimates between a patient registry and health administrative databases.

Methods

Data sources

This retrospective cohort study made use of 2 data sources: a national population-based cerebral palsy registry and provincial health records. The Canadian Cerebral Palsy Registry was first established in Quebec as the Registre de la paralysie cérébrale du Québec (REPACQ). To be enrolled in the REPACQ, a child must be at least 2 years old and must meet current international diagnostic consensus criteria for cerebral palsy, which include a clinical diagnosis of a nonprogressive motor impairment of early onset that is presumably cerebral in origin, which may or may not be associated with cognitive disability, feeding difficulties, language impairment, epilepsy, auditory or visual loss, orthopedic abnormalities or behavioural difficulties.[1] Children with cerebral palsy who die before 2 years of age are not captured in the registry.[2] The diagnosis is confirmed at 5 years of age by a developmental pediatrician or child neurologist. If the original diagnosis of cerebral palsy is changed, the child's data are removed from the registry. Clinical information from the mother's and child's charts and rehabilitation records are accessed for chart review to complement data obtained by interviewing the primary caregiver. The REPACQ provides a comprehensive source of data, with over 200 clinical (antepartum, intrapartum and postpartum risk factors) and sociodemographic (e.g., parent level of education, deprivation index and ethnicity) variables collected for each child.[10–12]

Setting

The REPACQ currently covers 6 of the 17 health administrative regions in Quebec (Capitale-Nationale, Estrie, Montréal, Outaouais, Lanaudière and Laurentides) and half of the province's pediatric population, spanning urban, suburban and rural areas of the province. In Quebec, once the diagnosis of cerebral palsy is confirmed, pediatric neurologists, developmental pediatricians and physiatrists refer the child to regional rehabilitation centres where services are offered. Most recruitment occurs at these centres.

The Quebec Ministry of Health documents hospital discharge information across the province within the Maintenance et exploitation des données pour l'étude de la clientèle hospitalière (MED-ÉCHO) database. This database includes information on date of hospital admission, hospital length of stay, primary diagnosis (International Classification of Diseases, 9th revision [ICD-9] codes until March 2006, and 10th revision [ICD-10] codes since April 2006) and up to 15 secondary diagnoses per hospital admission. Children who have lived in Quebec for at least 3 months are covered by universal health care and are registered with the Régie de l'assurance maladie du Québec (RAMQ), which uses a computerized database to reimburse health service providers. The available RAMQ demographic data include date of birth, sex, postal code (first 3 digits) and, when applicable, year and month of death. The RAMQ physician billing claims data contain information on both outpatient and inpatient physician visits including a single diagnostic code (clinical modification of the ICD-9), date and location of visit, region of residence, specialty of physician rendering the service and cost for the service.

Participant selection

The source population for the reference standard population of cerebral palsy cases consisted of children residing within the 6 health administrative regions covered by the REPACQ who were born between Jan. 1, 1999, and Dec. 31, 2002, and whom we identified through the registry as having a definite diagnosis of cerebral palsy by 5 years of age. We selected this cohort as it represents the longest follow-up period in the registry, allowing for more complete case ascertainment and minimizing misclassification of cases. Published prevalence estimates from this cohort are in line with North American estimates, and all cases are true-positive cases of children with cerebral palsy. This population was linked to health administrative records (RAMQ and MED-ECHO) from birth until Dec. 31, 2012. The diagnostic codes tested within administrative databases were ICD-9 code 343.* and ICD-10 code G80.* to identify children with cerebral palsy. A single code at age 2–15 years was considered a positive test of identification. We identified the reference standard population of children without cerebral palsy using Quebec census data to determine the average number of 5-year-old children from the 1999–2002 birth cohort living in the 6 administrative regions covered by the registry.

Statistical analysis

We used the REPACQ cohort as the reference population (i.e., gold standard assuming 100% sensitivity and specificity

across all eligible children living within the 6 regions included in the study). We calculated rates of true-positive, false-negative, false-positive and true-negative ICD codes, and sensitivity and specificity for health administrative data case definition of cerebral palsy. We calculated sensitivity as the proportion of children identified in the REPACQ who are correctly identified as having cerebral palsy with each administrative data case definition, and specificity as the proportion of children without cerebral palsy who are correctly identified as not having cerebral palsy with each administrative data case definition. We explored differences between children with true-positive and false-negative codes using subgroup sensitivity analysis. In addition, we calculated positive and negative predictive values for health administrative database diagnostic coding of cerebral palsy. We calculated prevalence estimates using Quebec census data as the denominator to determine the number of 5-year-old children from the 1999–2002 birth cohorts living within the 6 health administrative regions covered by the REPACQ. We used SAS version 9.3 software (SAS Institute Inc.) for statistical analysis.

Ethics approval

Approval for this study was obtained from the Research Ethics Board of the Montreal Children's Hospital, the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, Hôpital Sainte-Justine and the Commission d'accès à l'information. A file containing the REPACQ-based identifying information (including RAMQ insurance number, name, sex and REPACQ subject identification number) was sent by registered mail to the RAMQ. Once the study was approved by the Commission d'accès à l'information, data from the RAMQ, MED-ÉCHO and REPACQ databases were linked and de-identified to maintain subject confidentiality at all times.

Results

A total of 301 children from the 1999–2002 birth cohorts with confirmed cerebral palsy by 5 years of age were identified in the REPACQ (Figure 1), for an estimated prevalence of 1.8 (95% confidence interval [CI] 1.6–2.1) per 1000 children aged 5 years. The characteristics of the 11 children who were unmatched to administrative data were similar to those of the children who were matched. Of the 301 children, 197 had at least 1 diagnostic code for cerebral palsy in health administrative databases (true-positive cases), and 104 could not be identified as having cerebral palsy in health administrative databases (false-negative cases) (Table 1). A total of 138 children with at least 1 diagnostic code for cerebral palsy were identified in the administrative databases but were not identified in the REPACQ (presumed false-positive cases). The average age at diagnosis for children identified in the REPACQ but not in health administrative databases was 6.6 (standard deviation 3.5) years. The diagnosing physician was most often a pediatrician (54.3% of cases), with neurologists (35.7%), general practitioners (8.7%) and other specialists (1.4%) also entering the diagnosis. The sensitivity of the cerebral palsy case definition from the health administrative databases was calculated as 65.5% (95% CI 59.8%–70.8%), and the specificity, 99.9% (95% CI 99.9%–99.9%). The estimated prevalence of cerebral palsy determined from administrative database diagnostic coding was 2.0 (95% CI 1.9–2.3) per 1000 children aged 5 years. The positive and negative predictive values were 58.8% (95% CI 53.3%–64.1%) and 99.9% (95% CI 99.9%–99.9%) respectively. The κ value was 0.62 (95% CI 0.57–0.67).

The sensitivity of the administrative database definition was higher for patients in rural areas (87.5% [95% CI 76.0%–99.0%]) than for those in urban areas (62.8% [95% CI 57.1%–68.6%]) (Table 2). The definition was also more sensitive for patients born preterm than for those born at term (76.2% [95% CI 68.0%–84.3%] v. 65.2% [95% CI 57.4%–73.1%]), for patients with the spastic quadriparetic cerebral palsy subtype than for those with the spastic hemiplegic cerebral palsy subtype (90.2% [95% CI 83.8%–96.7%] v. 51.8%] [95% CI 41.1 to 62.4%]) and for patients with a Gross Motor Function Classification Scale level of IV–V (nonambulant) than for those with a level of I–III (85.7% [95% CI 77.5%–93.9%] v. 63.7% [95% CI 56.8%–70.7%]).

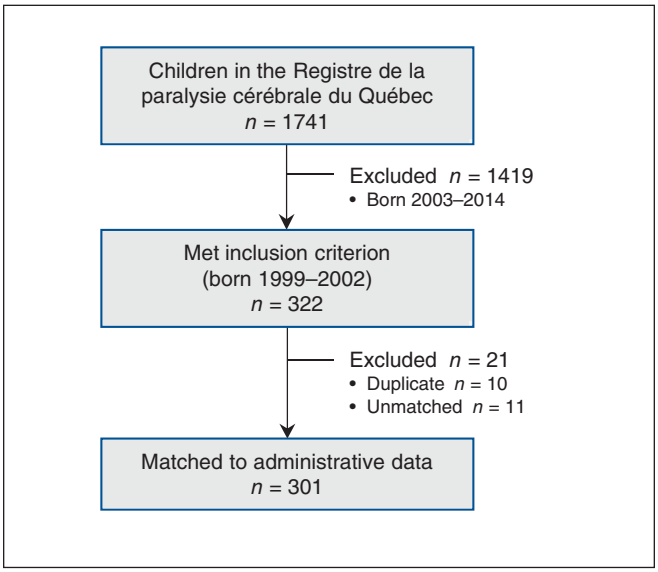

Figure 1: Participant flow diagram.

Table 1: 2 × 2 table showing accuracy of coding of cerebral palsy in Quebec health administrative databases*

Diagnosis in health administrative databases	Diagnosis in Registre de la paralysie cérébrale du Québec (gold standard); no. of cases		
	Present	Absent	Total
Present	197	138	335
Absent	104	163 561	163 655
Total	301	163 699	164 000

*Régie de l'assurance maladie du Québec and Maintenance et exploitation des données pour l'étude de la clientèle hospitalière.

Table 2: Characteristics of children with cerebral palsy identified in the Registre de la paralysie cérébrale du Québec by accuracy of coding in health administrative databases

Characteristic	No. (%) of children*		Sensitivity (95% CI)
	True-positive ICD code for cerebral palsy	False-negative ICD code for cerebral palsy	
Sex	*n* = 197	*n* = 104	
Male	107 (54.3)	60 (57.7)	64.1 (56.8–71.3)
Female	90 (45.7)	44 (42.3)	67.2 (59.2–75.1)
Location	*n* = 197	*n* = 104	
Urban	169 (85.8)	100 (96.2)	62.8 (57.1–68.6)
Rural	28 (14.2)	4 (3.8)	87.5 (76.0–99.0)
Gestational age, mean ± SD, wk	*n* = 172	*n* = 74	
	35.0 ± 5.3	36.0 ± 5.2	–
Gestational age < 37 wk	*n* = 172	*n* = 74	
Yes	80 (46.5)	25 (33.8)	76.2 (68.0–84.3)
No	92 (53.5)	49 (66.2)	65.2 (57.4–73.1)
Cerebral palsy subtype	*n* = 176	*n* = 76	
Spastic hemiplegia	44 (25.0)	41 (53.9)	51.8 (41.1–62.4)
Spastic diplegia	40 (22.7)	16 (21.0)	71.4 (59.6–83.3)
Spastic quadriplegia	74 (42.0)	8 (10.5)	90.2 (83.8–96.7)
Dyskinetic	14 (8.0)	5 (6.6)	73.7 (53.9–93.5)
Ataxic	4 (2.3)	6 (7.9)	40.0 (9.6–70.4)
Gross Motor Function Classification Scale level	*n* = 176	*n* = 76	
I–III	116 (65.9)	66 (86.8)	63.7 (56.8–70.7)
IV–V	60 (34.1)	10 (13.2)	85.7 (77.5–93.9)
Epilepsy	*n* = 177	*n* = 76	
Yes	74 (41.8)	31 (40.8)	70.5 (61.8–79.2)
No	103 (58.2)	45 (59.2)	69.6 (69.2–77.0)
Cortical visual impairment	*n* = 176	*n* = 76	
Yes	47 (26.7)	8 (10.5)	85.5 (76.1–94.8)
No	127 (72.2)	62 (81.6)	67.2 (60.5–73.9)
Uncertain	2 (1.1)	6 (7.9)	
Sensorineural auditory impairment	*n* = 176	*n* = 76	
Yes	19 (10.8)	8 (10.5)	70.4 (53.1–87.6)
No	151 (85.8)	66 (86.8)	69.6 (63.5–75.7)
Uncertain	6 (3.4)	2 (2.6)	
Cognitive impairment	*n* = 176	*n* = 76	
Yes	69 (39.2)	28 (36.8)	71.1 (62.1–80.2)
No	78 (44.3)	35 (46.0)	69.0 (60.5–77.6)
Uncertain	29 (16.5)	13 (17.1)	69.0 (55.1–83.0)
Communication difficulties	*n* = 176	*n* = 76	
Yes	119 (67.6)	42 (55.3)	73.0 (67.1–80.7)
No	56 (31.8)	33 (43.4)	62.9 (52.9–73.0)
Uncertain	1 (0.6)	1 (1.3)	
Feeding difficulties	*n* = 176	*n* = 74	
Yes	12 (6.8)	3 (4.0)	80.0 (59.8–100.0)
No	164 (93.2)	71 (95.9)	69.8 (63.9–75.7)

Note: CI = confidence interval, ICD = International Classification of Diseases, SD = standard deviation.
*Except where noted otherwise.

Interpretation

We found that health administrative claims data are highly specific but much less sensitive than the REPACQ for the diagnosis of cerebral palsy. Children with cerebral palsy born preterm, those with spastic quadriparesis and those with higher levels of motor impairment were captured better within health administrative databases than those born at term, those with the spastic diplegic or ataxic cerebral palsy subtype, and those with lower levels of motor impairment.

The overall prevalence of cerebral palsy has been studied in Alberta and British Columbia with the use of unvalidated algorithms applied to administrative data sets.[13,14] In the latter province, Smith and colleagues[13] conducted a record search of the Medical Services Plan billing files and hospital separation abstracts for the birth cohorts 1991–1995 using the ICD-9 cerebral palsy diagnostic code 343 and reported a prevalence of 2.68 per 1000 live births. In Alberta, Robertson and colleagues[14] searched administrative databases using similar inclusion and exclusion criteria as were used in British Columbia and found a prevalence of 2.57 per 1000 children alive at 8 years. Similar prevalence estimates have been reported internationally, with prevalence estimates of 2.4 per 1000 live births between 1996 and 2007 in Norway and 2.4 per 1000 live births between 1990 and 1997 in Sweden. The estimated prevalence from administrative databases of 2.0 per 1000 children aged 5 years in the current study falls slightly below international and national estimates. This is likely owing to the observation that children with cerebral palsy may not always receive a diagnostic code for cerebral palsy, as they are seen primarily for their comorbidities, such as epilepsy, spasticity or scoliosis, which may potentially result in reduced sensitivity of the ICD code.[15] Furthermore, variation in billing codes used among physicians may contribute to the suboptimal levels of sensitivity of the health administrative database definition of cerebral palsy. Our estimate is in agreement with the pooled estimate of cerebral palsy from a recent meta-analysis.[3] Data linkage between the Norwegian cerebral palsy register and hospital records highlighted the lower sensitivity of health administrative databases, which would give an overestimate of cerebral palsy prevalence.[15]

In our cohort, children with confirmed cerebral palsy who were born preterm were more likely than those born at term to be captured within health administrative databases. Preterm children receive more standardized developmental surveillance, with access to pediatricians, who may be more likely to correctly code the condition of these children for each visit. Children with the hemiplegic subtype of cerebral palsy were less well captured in administrative databases than those with spastic quadriparesis, which suggests that these children's condition is perhaps coded differently by the physicians who see them, or the physicians do not recognize that they meet the criteria for cerebral palsy. Children with spastic quadriparesis have more severe motor impairment and more associated comorbidities, and are more easily identified by health care workers as having a diagnosis of cerebral palsy. Indeed, we found that children with milder motor deficits (Gross Motor Function Classification Scale level I) were not well captured in health administrative databases, whereas those who were nonambulant were more likely captured. This reflects either more frequent health care visits or easier recognition of their underlying diagnosis.

Strengths and limitations

Our study has several strengths. We used a population-based registry and captured older cohorts to ensure best ascertainment of all cases. The fact that all children in Quebec are covered by universal health care allows capture of all health care visits within this population. The richness of the registry data also allowed us to explore individual characteristics that predict capture within health administrative databases. A limitation of our study is the potential for misclassification, as some of the cases of cerebral palsy in the REPACQ may be false-positive cases if an initially unsuspected underlying progressive disorder is identified when the child is older. However, by choosing children with the longest follow-up within the registry (5 yr of age), we hope to have minimized this risk. Another limitation is the gold standard used, a population-based registry with imperfect sensitivity, as some children with cerebral palsy may have been missed, including those who died before 2 years of age and those with such mild functional impairments that they never came to the attention of a physician or other health care professional. The generalizability of our findings across Canada may also be limited. Physicians from other provinces may have different billing practices that can affect the accuracy of their health administrative claims.

Conclusion

The findings of the current study suggest the need to develop a more sensitive case definition algorithm to better identify the spectrum of children with cerebral palsy within health administrative databases. A comprehensive case algorithm with additional diagnostic codes for associated comorbidities and procedures could be developed with the use of Bayesian approaches that take into consideration knowledge on prior probability to inform the analysis. This would allow improved accuracy of estimates of cerebral palsy prevalence and enable surveillance of regional and temporal cerebral palsy trends. Furthermore, a more comprehensive case definition algorithm could be applied to older populations with cerebral palsy, for better assessment of use of health care services by adults with cerebral palsy and their associated later-onset morbidity. Our findings support the importance of population-based registries as the backbone of policy planning and research in such a heterogeneous disorder. Implementation of unique patient identifiers could increase the return on investment and engagement in patient registries by facilitating linkage across multiple complementary databases, such as education and rehabilitation services. This would provide a more complete and accurate picture of current needs and costs, and could be used to inform policy and resource allocation.

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Contributors: Maryam Oskoui led the study conception and design. Maryam Oskoui, Nicole Pigeon, Louise Koclas, Céline Lamarre, Francine Malouin, Carol Richards and Michael Shevell contributed to data acquisition. Maryam Oskoui, Marc Dorais, Pamela Ng and Lawrence Joseph analyzed the data. Maryam Oskoui drafted the manuscript. All of the authors contributed to interpretation of the data and revision of the manuscript, approved the final version to be published and agreed to act as guarantors of the work.

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