
Prevalence of Cerebral Palsy in Alberta

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ABSTRACT: Background: In spite of scattered reports to the contrary, concern is continually expressed that the frequency of cerebral palsy has not decreased with modern perinatal/neonatal care. Overall, epidemiological information on cerebral palsy is scant. The generally accepted prevalence is 2 to 2.5 per thousand school-age children. **Methods:** A population-based record linkage study of a presently living cohort of 96,359 children born from April, 1985 through March, 1988 and followed over an eight-year tracking period captured the diagnostic codes for all fee-for-service physician claims, all hospital separations and individual birth data from the Department of Vital Statistics of the Government of Alberta. The ICD-9 code "343" was used to identify subjects. The childhood prevalence and frequency by birthweight-specific sub-groups of cerebral palsy were determined. **Results:** Two hundred and forty-eight living children with confirmed cerebral palsy after age three years (congenital, 229 [92.3%]; probable acquired 19 [7.7%]) were identified giving an overall prevalence of 2.57 per 1000. Seventy percent were diagnosed before their third birthday. Cohort prevalence of cerebral palsy for low birthweight children (< 2500 grams) was 17.7, very low birthweight (< 1500 grams), 78.5; and extremely low birthweight (< 1000 grams), 98.4. Low birthweight children made up just over one-third of cases in this study. **Conclusions:** Cerebral palsy continues to affect a significant number of children suggesting the prevalence of cerebral palsy has not decreased. The proportion of affected children with low birthweight in this study is less than that reported in the literature.

RÉSUMÉ: Prévalence de la paralysie cérébrale en Alberta. Introduction: Bien qu'il existe certains rapports qui font état du contraire, on se préoccupe toujours du fait que la fréquence de la paralysie cérébrale n'a pas diminué avec l'avènement des soins péri et néonataux. Dans l'ensemble, l'information épidémiologique sur la paralysie cérébrale est rare. La prévalence généralement acceptée est de 2 à 2.5 par mille enfants d'âge scolaire. **Méthodes:** Il s'agit d'une étude de population par couplage de dossiers portant sur une cohorte de 96,359 enfants toujours vivants, nés entre avril 1985 et mars 1988. Nous avons capturé sur une période de huit ans les codes diagnostiques de toutes les réclamations des médecins payés à l'acte, de tous les congés hospitaliers et de toutes les données sur les naissances du Département des statistiques de l'état civil du Gouvernement de l'Alberta. Le code CIM-9 "343" a été utilisé pour identifier les sujets. Nous avons déterminé la prévalence dans l'enfance et la fréquence par sous-groupes de poids à la naissance. **Résultats:** Deux cent quarante-huit enfants vivants dont le diagnostic de paralysie cérébrale était confirmé après l'âge de trois ans (congénitale, 229 [92.3%]; probablement acquise 19 [7.7%]) ont été identifiés, ce qui donne une prévalence générale de 2.57 pour 1000. Soixante-dix pourcent avaient reçu ce diagnostic avant leur troisième anniversaire. La prévalence de la paralysie cérébrale pour les enfants de petit poids à la naissance (< 2500 grammes) était de 17.7, de très petit poids (< 1500 grammes), 78.5; et de poids extrêmement bas (< 1000 grammes), 98.4. Seulement le tiers des cas de notre étude étaient des enfants de petit poids à la naissance. **Conclusions:** La paralysie cérébrale continue d'atteindre un nombre significatif d'enfants dans cette province, ce qui suggère que la prévalence de la paralysie cérébrale n'a pas diminué. Dans notre étude, la proportion des enfants atteints de petit poids à la naissance est plus faible que celle qui est rapportée dans la littérature.

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Cerebral palsy is one of the most frequent motor disabilities of childhood. Common definitions of cerebral palsy include that of Bax "a disorder of movement and posture due to a defect or lesion of the immature brain"¹, and that of Nelson and Ellenberg, "a chronic disability characterized by aberrant control of movement or posture appearing early in life and not the result of recognized progressive disease".² Implicit in these definitions is the exclusion of progressive neurological disorders or motor dysfunction associated with well-defined congenital malformations or chromosomal abnormalities affecting the central nervous system.³

While the diagnosis of cerebral palsy has been found to be a useful indicator of motor disability for epidemiological studies,⁴ a number of issues about cerebral palsy must be considered in

population studies. The cerebral palsy syndrome is a clinical diagnosis characterized by the following: no universally accepted minimal diagnostic criteria;⁵ diagnosis based on serial examinations and validated;³ variable age of diagnosis, in part, depending on severity;^{2,5} wide variations in clinical descriptions of the motor deficits;^{5,6} early death of some of the more severely involved children, possibly before formal diagnosis;² and

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over-diagnosis early in life with some children known to “out-grow” cerebral palsy by school age.⁷ The lack of interobserver reliability of some of the diagnostic subtypes⁸ and changes in subtype diagnoses over time makes⁹ the use of subtypes less useful than the diagnosis of cerebral palsy for these epidemiological studies.

In addition to diagnostic considerations, epidemiological studies of cerebral palsy are limited by the type of rate used, by variation in yearly case numbers, and in recent years, by enhanced attention to earlier diagnosis. For today’s Western world, Paneth and Kiely, 1984³ and Stanley and Blair,^{10,11} and Murphy et al.¹² give a prevalence of cerebral palsy of 2 to 2.5 per thousand school-age children. A more recent study gives the rate for moderate and severe cerebral palsy in preschool children of 1.2 per 1000.¹³ About ten percent of children with cerebral palsy are thought to have a post-natal origin (such as infection or trauma after the first month of life) for their disability.³ This so-called acquired cerebral palsy has been reported to be as high as 16% in 10-year-old children.¹² Congenital cerebral palsy is the term given to those children where the cerebral palsy is considered not to be acquired in the post-natal period. It may have its origins in the antenatal, natal or in early infancy period where the cause is related in some manner to pregnancy, e.g., prematurity. A composite rate of congenital cerebral palsy calculated from frequency studies published since 1980 shows 2.7 children with cerebral palsy per 1000 live births (including deaths and excluding acquired cases) at age 5- to 7-years.¹⁴ Concern has been expressed that increasing survival of preterm infants of less than 1500 grams at birth is linked to the increased occurrence of cerebral palsy among these children, and that there may be improved survival of prenatally impaired infants.^{10,11,15-18} A meta-analysis report of hospital- and regional-based studies of very-low-birthweight infants from the 1980s gave a rate of 77 per 1000 live-births.¹⁹ This province has reported early childhood cerebral palsy among those born in 1990 at less than 1250 grams to be 46 per 1000 live-births,²⁰ however the prevalence of cerebral palsy among all children here remains unknown. Using a population administrative data source, this study was undertaken to determine the overall prevalence of cerebral palsy in Alberta and, secondarily, to determine its frequency among surviving low birthweight newborns.

METHODS

The Province of Alberta (661,185 square km or 225,285 square miles) had an average yearly population during the study-subject birth years (April, 1985 through March, 1988) of 2.5 million. The percentage of live born infants with low birthweight (500-2500 grams) was 5.7%.^{21,22} In this province all births of 20 weeks or more gestation and/or 500 grams or more birthweight are registered. Live birth is defined according to the definition adopted by the World Health Assembly.²³

Diagnostic codes

Subjects were determined by documenting diagnostic codes. Diagnostic codes used by physicians and hospitals during the years reviewed for this study were from the International Classification of Diseases, 1975 Version (ICD-9).²⁴ All diagnostic code fields for all physician billings (three digit codes) and hos-

pital separations (more detailed, four digit codes) from administrative databases were searched in order to identify subjects. Code “343” incorporates the traditional way of classifying cerebral palsy by pattern of motor impairment including the subtypes of diplegia (paraplegia), hemiplegia, quadriplegia, monoplegia, infantile (post-natal) hemiplegia, other, unspecified, and excludes hereditary cerebral paralysis.²⁴ Code “343” includes bilateral spastic cerebral palsy, that is, the diagnosis reported to be commonly linked to changes in cerebral palsy trends in relation to preterm infants.²⁵

Subjects

Inclusion criteria Two-hundred and forty-eight living eight-year-old Alberta children, born April 1985 through March 1988 with universal health care insurance registration numbers active from the first year of life were identified as having cerebral palsy if the code “343” was recorded at (1) three years of age or older, or (2) prior to the third birthday and confirmed after three years. This included three children with additional codes of athetosis (333.7) or cerebral ataxia (334.3). No additional subjects were identified by the code hemiplegia (342) or other paralytic syndromes (344). These latter two codes are used with conditions of long-standing nature and of unspecified cause.²⁴ Twenty-six (10.5%) of these 248 children with cerebral palsy were born outside of the Province of Alberta.

Exclusion criteria included (1) Thirteen children with unconfirmed cerebral palsy diagnostic code(s) prior to age 3 years, two of whom died, (2) Seven children with unconfirmed cerebral palsy code “343” whose health care insurance registration was not continuous over the eight-year tracking periods (6 deaths, 1 moved out of province), (3) Two children with a diagnostic code of cerebral palsy “343”, but with an additional diagnostic code of chromosomal abnormality (758). No children with cerebral palsy were found with additional codes of progressive neurological disorders (330, 331, 334, 335, 340, 341) or spina bifida (741).

Further subject description

All diagnostic codes and all fields of physician claims or hospital separations for subjects were manually reviewed, cross-checked and verified. In addition to the codes given above, those codes used to clarify subject diagnoses were congenital abnormalities of the nervous system (742) and other congenital abnormalities (743-757, 759). Those codes used to identify children with cerebral palsy with a likely post-natal etiology include malignant neoplasms of brain (191), inflammatory disease of the nervous system (320-326), other conditions of brain and nervous system (348, 349), intracranial hemorrhage (430-432) (excludes perinatal diagnoses), aborted sudden infant death syndrome (798), fracture of skull (800-840), other injuries (950-959, 990-995), intracranial injury excluding skull fracture (850-854), late effects of injuries (905-909), and poisoning (960-989).

Linkage

Information was obtained from linked health care utilization data from the Registration File of the Alberta Health Care Insurance Plan where Government financed universal health care pays all billings including fee-for-service Physician Claim Files completed by attending or consulting physicians, Hospital Separation

Files compiled by Health Record Administrators based on physician's diagnoses, and Vital Statistics individual birth data. Each diagnosis of cerebral palsy for all children was documented. The specialty of the physician recording all diagnoses was noted. As it is the common practice for all children with cerebral palsy in this province to receive a multidisciplinary assessment at one of two children's rehabilitation facilities, the identification numbers of these facilities were recorded. The location of the child's home community within one of Alberta's 17 Health Regions was noted and the cerebral palsy prevalence for births for specific regions calculated. Using deterministic record linkage, 88,733 (92.1%) children were successfully linked to their birth registration record held by the Department of Vital Statistics of the Province of Alberta.

Data Handling

Provincial prevalence of cerebral palsy

The prevalence of childhood cerebral palsy was established for three separate cohorts determined by birth year and an overall prevalence for those three years was determined.

Denominator: The denominator for each cohort was the number of living Alberta children (followed over an eight-year tracking period) with universal Health Care Insurance registration numbers where registration was active to infancy. This number is 99.95% of all children. Three cohorts were defined: birth year 1985-1986, 32,070; 1986-1987, 31,613; 1987-1988, 32,676. The total number of individuals used for the overall denominator was 96,359.

Numerator: The numerator(s) for each birth cohort was based on diagnoses of cerebral palsy over an eight-year tracking period for each child in each cohort. The sum of the individually identified children with confirmed cerebral palsy in each of the three cohorts is the numerator, 248.

Cohort prevalence of cerebral palsy among low birthweight children

Denominator: The frequency of childhood cerebral palsy was calculated using the number of children within the cohort whose birthweights were found to be < 2500 grams and where record linkage to birth data was complete.

Numerator: The numerator included those children with confirmed cerebral palsy whose birthweights were < 2500 grams and where linkage to birth records was complete.

Results were compared using the chi-square statistic.

RESULTS

A review of the physician's codes accompanying the ICD-9 codes indicate 98.9% of diagnoses of cerebral palsy were made by or confirmed by pediatricians, pediatric neurologists, or pediatric neurosurgeons; 1.1 % were by family physicians. The number of newly diagnosed children with cerebral palsy in each of the eight-year tracking time periods is recorded on Table 1. Cerebral palsy was diagnosed in 248 of 96,359 children of this cohort giving an overall prevalence of 2.57 per 1000 (Table 2). More than two-thirds (69.7%) were diagnosed before their third birthday. Of the 248 confirmed living cases up to their eighth birthday, 19 (7.7%) had a definite post-natal event considered likely to be the cause of the cerebral palsy.

Table 1: Number and proportion of children with cerebral palsy* by age at first recorded diagnosis.

Cohort (birth year)	Children's Ages at Diagnosis								Total Individuals Diagnosed
	0-1	1	2	3	4	5	6	7	
Cohort I (1985-1986)	25	18	10	11	12	5	3	3	87
Cohort II (1986-1987)	20	15	9	9	5	8	4	2	72
Cohort III (1987-1988)	23	34	9	10	7	4	1	1	89
Total	68	67	28	30	24	17	8	6	248
% of total	27.4	27.0	11.3	12.1	9.7	6.9	3.2	2.4	100

*includes 19 children with cerebral palsy of probable post-natal etiology.

Table 2: Prevalence of childhood cerebral palsy* by cohort in Alberta.

Cohort (birth year)	Number in Cohort	Prevalence	95% CI
I (1985-1986)	32,070	2.71	2.1.3, 3.26
II (1986-1987)	31,613	2.28	1.77, 2.79
III (1987-1988)	32,676	2.72	2.45, 2.99
Total	96,359	2.57	2.41, 2.79

*includes 19 children with probable acquired (post-natal) cerebral palsy. CI = confidence interval.

The probable acquired causes for the motor disability were determined from the ICD-9 codes. These included, traumatic brain injury (8), inflammatory disease of the nervous system (including meningitis) (5), acute acquired hemiparesis (2), malignant neoplasm of brain and its treatment (2), acute respiratory failure and collapse (1), and aborted sudden infant death syndrome (1). One of the 19 children with probable acquired cerebral palsy had a birthweight of < 2500 grams.

Excluding those with acquired cerebral palsy, the remaining 229 children were considered to have congenital cerebral palsy, giving a prevalence of 2.37. Although the number of children diagnosed with cerebral palsy varied among the three cohorts as seen in Table 2, this variability was not statistically significant. Gender differences were not found. The proportion of children with cerebral palsy from either an urban or rural background was similar. The prevalence of cerebral palsy varied according to the home Health Region but regional differences were not statistically significant and were associated with wide variations in birth population numbers.

A review of all ICD-9 diagnostic codes for all contacts for the 229 children with congenital cerebral palsy showed that 33 (14%) code "742", "other congenital abnormalities of the nervous system". The code "742" includes conditions such as encephalocele, reduction deformities of brain, congenital hydrocephalus (excluding acquired hydrocephalus, thus does not

include neonatal post-hemorrhagic hydrocephalus), other specific abnormalities of brain, such as, lissencephaly, etc.²⁴ An additional 15 children had one or more codes diagnosing other congenital abnormalities, codes 743 through 757, and 759.²⁴ Thus 48, or 20% of those diagnosed with cerebral palsy not thought to be post-natally acquired were coded as having congenital abnormalities. As there was no uniform protocol for brain imaging for children diagnosed with cerebral palsy during this period the exact proportion of children with brain abnormality is not known. Children with known chromosomal abnormalities (code 758) and spina bifida (741) were excluded from this cohort. Thus no child with these diagnoses were identified.

In separate analyses the cohort prevalence of cerebral palsy by birth-weight-specific groups was calculated for those 222 children for whom linkage to their birth registration record was made (Table 3). Low birthweight (< 2500 grams) accounted for 77 (34.7%) of the 222 children with cerebral palsy and record linkage. Those 34 with a birthweight of 500 through 1499 grams made up 15.3% and those 12 that were 500 through 999 grams at birth made up 5.4% of children with cerebral palsy and successful linkage. Of the 222 children with congenital cerebral palsy and linkage to birth data, 13 (5.8%) were one of a multiple birth: 2, > 2500 grams birthweight, 11, low birthweight. Three of the 11 latter children were one of triplets.

Table 3: Number and proportion of children with cerebral palsy in the cohort by birthweight groups* (n = 222).

Groups by Birthweight (grams)	Cohort Size	Number of Children With Congenital Cerebral Palsy	Prevalence by Birthweight Group per 1000 in the Cohort	
			95% CI	
500- 999	122	12	98.4	59.4, 137.4
1000-1499	311	22	70.7	43.8, 97.6
1500-2499	3,917	43	11.0	7.9, 14.1
2500-3999	74,469	136	1.8	1.5, 2.1
≥ 4000	9,913	9	0.9	0.4, 1.4

*excludes 26 children with cerebral palsy but without birth record linkage data as they were born outside of Alberta (10.5% of total confirmed cerebral palsy).

Note: Data from 92% (88,732) of the total cohort of 96,359 were successfully linked to records of birthweight.

DISCUSSION

This population-based linkage study from administrative data gives needed epidemiological information on cerebral palsy for comparison with information of children born in the 1980s from geographic areas throughout the developed world.^{11-13,16-18,25,26-31} The prevalence of acquired and congenital childhood cerebral palsy in Albertan children was determined to be 2.57. The prevalence of congenital cerebral palsy in this cohort was 2.37. This figure is similar to the published range of 2 to 2.5.^{3,10-12,33} Had the 33 children with known well-defined abnormalities of the central nervous system (code 742) been excluded as has been recommended,³ the prevalence for mild, moderate, and severe congenital cerebral palsy for children ages 3 to 7 years would have been calculated as 2.0 per 1000. This would have

been higher than the prevalence of the more restricted moderate or severe cerebral palsy group of 3-year-old Californian children born in the years just prior to this cohort with a rate of 1.23 per 1000 (CI, 1.1-1.4).¹³ The proportion of children with cerebral palsy that had low birthweight was 34.7% in this study, less than the 47.4% in the California study¹³ and the 50% of a recent British study.³⁴

The frequency of childhood cerebral palsy in Alberta for low birthweight children born in the late 1980s is at the lower range of figures previously reported.^{11,17,19,26-32} For those of less than 1500 grams birthweight, this study reports a cohort frequency of cerebral palsy of 78.5 per 1000. The proportion of children with cerebral palsy that were one of a multiple birth was 5.8%, slightly lower than the 10% in previous studies.^{13,35,36} However, our study indicates multiple birth is a risk for cerebral palsy as has been previously reported.^{37,38} Among those with cerebral palsy, birthweight of less than the 10th percentile was present in just under 10% of cases, hence low weight for gestational age was found less frequently than reported by others.³⁹ The proportion of all cerebral palsy cases in this study that were assessed as post-natal in origin was 7.7%, slightly less than reported.^{3,12,40} Although commonly known factors (low birthweight, multiple births, low weight for gestational age, and post-natal origin) contribute to the number of children with cerebral palsy, the majority of children with cerebral palsy in this study were singleton children with birthweight above 2500 grams.

The use of population-based record linkage for the epidemiological study of childhood cerebral palsy has a number of advantages over survey or cohort methods. These include the avoidance of recall bias, absence of the need for direct subject contact, cost effectiveness, large sample size, and generalizability of results.⁴³⁻⁴⁶ Limitations include case ascertainment based on subject utilization of the services of a fee-for-service physician or hospital, variations in utilization pattern, accuracy of diagnosis made by multiple physicians, and incomplete linkage.⁴⁴⁻⁴⁶ In this study the linkage of cohort childhood data and Vital Statistics birth data of children born in this province was 222 of 248 children or 92.1%. This compares favourably with the success of 92.5% of a similar study on low birthweight infants linking Vital Statistic records and Medicare claims where ICD-9 diagnostic codes were also used.⁴⁷

Brain imaging of all children with cerebral palsy would probably show more than 14% to have code 742 "other congenital abnormalities of the nervous system". Neuroimaging (Magnetic Resonance Imaging) has been recommended for all children with cerebral palsy in order to exclude cerebral malformations. This is not yet part of our routine clinical practice. With known antenatal, intrapartum, and neonatal factors contributing to preterm births, an improved integrated approach to these babies may assist in reducing the prevalence of cerebral palsy.⁴²

Although population-based linkage studies on childhood cerebral palsy have been previously carried out, this is a particularly difficult subject to study. To overcome complications directly related to the diagnosis of cerebral palsy including early death of subjects, early over-diagnosis, absence of universally accepted minimal diagnostic criteria, and variations in clinicians' diagnoses, a number of safeguards were included in this study. The specialty of the physician care provider and location of service were included as part of the data recovered associated with the unique identifier. Thus we determined that almost all

diagnoses were made or confirmed by members of one of three specialty groups, pediatricians, pediatric neurologists, or pediatric neurosurgeons. As well, all but 1.1% of the children were assessed in one of two children's rehabilitation facilities. The reading of all diagnostic code fields for ICD-9 diagnostic code "343" for fee-for-service physician visits and hospitalization separations would identify all children diagnosed with spastic cerebral palsy that utilized services. During this time period, it was very unlikely that children with any significant spasticity would not receive care; however, it is possible that some children with mild cerebral palsy may have been missed. Validation of diagnosis was obtained by recording all diagnoses over eight tracking years for each child. Over diagnosis of very young children without later confirmed diagnosis was avoided by omitting 13 children (2 of whom died) without a diagnosis of cerebral palsy after their third birthday. In spite of awareness of the possibility of early death of some children before the formal diagnosis of cerebral palsy is recorded, this problem could not be avoided in this study and may have resulted in a slight under-recording of cases.

One of the most difficult and controversial tasks in launching an epidemiological study of chronic childhood disease with a congenital component is the choice of measures of disease frequency. Prevalence may be defined as the proportion of a population that is affected by disease at a given point in time⁴⁸ and is the term often used for congenital malformation and congenital cerebral palsy. Ideally it would be best to measure the incident cases of cerebral palsy but for congenital cerebral palsy this is not possible because of the time lag between onset and recognition and, in some cases, early death. The term cumulative incidence has been used to include those with cerebral palsy dying after diagnosis.¹⁴ Presently Pharoah recommends that prevalence measurements are those appropriately used in relation to the origins of cerebral palsy.⁴⁹ When the number of cases of cerebral palsy is related to live births then the term birth cohort prevalence is used.¹⁰ Prevalence has been calculated in this study with the denominator of living children tracked over eight years.

This study was generated by our need to know the epidemiology of cerebral palsy in this province. As population-based cerebral palsy prevalence data for North America are limited, it was considered that these data would have a wide interest. The study shows that cerebral palsy continues to affect a significant number of children in a province where there is well-established regional perinatal/neonatal care and universal health care. We must become more diligent in searching for and averting the multiple factors that predispose to this chronic childhood neurological disability. The population-based record linkage study approach has been most useful in giving to us previously unavailable data. Similar data from other provinces would be valuable for future comparison studies.

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