

Prevalence of Cerebral Palsy in Lithuania

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Key Words: prevalence of cerebral palsy, epidemiology of cerebral palsy, children.

Summary. The aim was to estimate the prevalence of cerebral palsy of children born in 1987–1998 and living in Kaunas County.

Design and methods. The cross-sectional quantitative study was undertaken in Kaunas County, Lithuania. The criteria for inclusion were the following: children born within the period of 1987–1998; children living in Kaunas County at the time of the study; and diagnosis of cerebral palsy mentioned in medical records at least once. An additional inclusion criterion for children living in orphanages was parents' (or mother's) living address in Kaunas County or unknown at the moment of the study. Refugees temporarily living in a refugees' camp in Kaunas County were not included into the list. Additionally, all cases were included when any information about a neuroinfection at an early age, severe encephalopathy, severe unspecified developmental disorder or any other disorder that could have clinical signs similar to cerebral palsy was found in medical records ("suspected cases"). The study was performed in two stages. In the first stage, a list containing the study population was made. In the second stage, a child neurologist, using Survey Cerebral Palsy Europe Reference and Training Manual, examined every child and confirmed or refuted the diagnosis of cerebral palsy.

Results. There were 728 potential cerebral palsy cases. In 270 cases, diagnoses of cerebral palsy were confirmed. In 1987–1998, the population-based prevalence of cerebral palsy was 2–3.4 (mean 2.5, SD=0.398) per 1,000 children, and the birth rate-based prevalence was 1.9–3.3 (mean 2.3, SD=0.398) per 1,000 live births. In each study year, the population-based prevalence was higher than the birth rate-based prevalence. The difference was significant, $Z=-2.842$, $P=0.004$. There were no significant trends in the population-based prevalence of cerebral palsy (95% CI, 0.693–2.079), nor in the birth rate-based prevalence (95% CI, 0.693–2.079) over the study years.

Conclusion. The population-based prevalence of cerebral palsy over the period of 1987–1998 was 2–3.4 (mean 2.5, SD=0.398) per 1,000 children, and the birth rate-based prevalence was 1.9–3.3 (mean 2.3, SD=0.398) per 1,000 live births. Due to the low number of cerebral palsy cases in separate areas of Kaunas County or separately in each study year, the study data do not give a reliable view of trends of the prevalence of cerebral palsy. Further studies are needed to estimate trends in changes of the prevalence of cerebral palsy in Lithuania.

Introduction

Cerebral palsy (CP) is the most common and one of the most disabling childhood developmental disabilities. Sometimes CP is regarded as a quality criterion for obstetrics and neonatological care (1, 2). There are several available studies analysing prevalence of cerebral palsy in countries of Western Europe (3), Australia (4), United States (5, 6), China (7), Turkey (8), very few studies from former pro-Soviet countries (Slovenia (9, 10) and Slovakia (11)) and none from former Soviet republics. It is possible to find some statistical data about morbidity of cerebral palsy in the former Soviet Union from textbooks or statistical reports, but having in mind

a different attitude to aetiology of cerebral palsy, its definition and classification, those data can hardly be compared with the prevalence of cerebral palsy in Western countries.

There are usually two ways to obtain reliable data on the prevalence of cerebral palsy and other developmental disabilities: by performing a cross-sectional epidemiological study or by establishing a registry. Over the last 40 years, many Western centres (in northern England, Norway, Western Sweden, Australia, United States, etc.) have developed population-based registries of children with cerebral palsy (12). Data collected in the registries not only give a longitudinal perspective on the prevalence of

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cerebral palsy but also allow analysing causes, a natural course and other aspects of the disease, as well as the changes in prevalence, aetiology and clinical presentation of cerebral palsy in relation to progress in perinatal care over years. Cerebral palsy occurs in 2–4 children per 1,000 live births. Due to that, large populations are necessary to answer research and practical questions related to cerebral palsy. The European Commission has funded establishment of a multicentre network of registries on cerebral palsy Survey Cerebral Palsy Europe (SCPE) (3). To our knowledge, there are no functioning registries on cerebral palsy in any of the former pro-Soviet countries or former Soviet republics.

The aim of this study was to estimate the prevalence of cerebral palsy in children born in 1987–1998 and living in Kaunas County at the time of the study.

Material and Methods

The cross-sectional study was undertaken in Kaunas County, the second biggest county of Lithuania. The population of Kaunas County at the time of the study (2002–2006) was 696,100 (20.1% of total population) and it covered 8,089 km² (12.4% of total territory of the country). All rural and urban settlements of the county were involved into the study. Therefore, the study findings can be generalized at the county level.

The study was designed in two stages. During the first stage, a list of children that had or probably had cerebral palsy was developed. At this stage, the names of possible patients were collected from health care and education institutions and non-governmental organisations: kindergartens, special schools, orphanages, local neurologists, Child Neurology Department at Kaunas University Hospital, or parents' organisations. The criteria for inclusion into the list were as follows: children born within the period of 1987–1998 and at the time of the study living in Kaunas County with the diagnosis of cerebral palsy mentioned in medical records at least once. An additional inclusion criterion for children living in orphanages was both parents' (or only the mother's) address in Kaunas County or unknown at the moment of the study. Refugees temporarily living in a refugees' camp in Kaunas County were not included into the list. Additionally, we included all the cases when any information about a neuroinfection at an early age, severe encephalopathy, severe unspecified developmental disorder or any other disorder that could have clinical signs similar to cerebral palsy was found in medical records ("suspected cases").

In the second stage of the study, a child neurologist examined every child to confirm or to ex-

clude the diagnosis of cerebral palsy. Families with a child who was included into the list were invited by written letters to visit the Children's Rehabilitation Hospital to see a child neurologist. The letters were sent twice. If parents did not wish to participate in the study, they were asked to call the Children's Rehabilitation Hospital and express their disagreement. Children who did not arrive at the Children's Rehabilitation Hospital and whose parents did not express their negative attitude regarding their child's participation in the study were visited at home, school or kindergarten and examined. All the children were examined by one of two licensed child neurologists additionally trained by using SCPE Reference and Training Manual (13).

The definition, diagnostic criteria and the classification of cerebral palsy were used as recommended by SCPE (14, 15): CP is a group of disorders, which involves a disorder of movement, posture and motor function, is permanent but not unchanging, is due to a non-progressive interference or lesion or abnormality, and this interference or lesion or abnormality is in the developing or immature brain. CP cases arising from an aetiological event occurring after 27 completed days following birth and up to 5 years of age were defined as post-neonatal. Children with concomitant disorders were included or excluded according to the recommendations of the SCPE group (14) and N. Badavi et al. (16). Bilateral spastic cerebral palsy was divided into diplegia and tetraplegia according to the Swedish classification (17).

Statistical Data Analysis. Statistical analysis was performed using the data collection and analysis SPSS 22 software package. The birth rate-based prevalence estimates were calculated per 1,000 live births, and the population-based prevalence was calculated per 1,000 children who resided in Kaunas County at the time of the study. The birth prevalence and the population-based prevalence in observed years were compared using the Wilcoxon matched pairs test for independent samples. A difference was accepted as statistically significant at $P < 0.05$. Poisson regression was used to model linear trends in the observed single-year prevalence. The birth rate-based prevalence and the population-based prevalence in different areas of the County were compared using the Kruskal-Wallis test. A difference was accepted as statistically significant at $P < 0.05$. Subsequently, we evaluated the time trend of CP prevalence over the 12 birth years by using linear regression analysis. The criterion for statistical significance was $P < 0.05$.

Research Ethics. The study was approved by Kaunas Regional Bioethics Committee (protocol No 35/2003).

Results

There were 706 names in the preliminary list in the first stage of the study. Also, 180 cases were included as “suspected CP cases”. During the second stage of the study (after clinical examination), 22 cases that matched the clinical criteria for CP inclusion criteria were added from the “suspected cases” list. Thus, the final list contained 728 names. After the revision of the list, 173 names were excluded because the age or the living place did not match the inclusion criteria, parents refused to participate in the study, children had passed away, etc. (Table 1). The diagnosis of cerebral palsy was confirmed in 270 cases (48.6%), and in 137 cases, the diagnosis (and the type of CP) matched the diagnosis in the medical records (Table 1). In the rest of the cases, the types of CP diagnosed in the study group did not match the medical records, i.e., dyskinetic cerebral palsy had been diagnosed as spastic diplegia or tetraparesis, or types like double hemiplegia, cerebellar, atonic-astatic CP, spastic paraparesis and others were diagnosed.

Denominators (number of live births and number of living children) were obtained from the Health Information Centre of Lithuania and the Statistics department of the Government of Lithuania (28).

Among the children that were born in 1989–1998 and during the study time lived in the area of Kaunas County, cerebral palsy was diagnosed in 270 patients: 147 boys (54%) and 123 girls (46%).

Clinical Characteristics. Distribution of the cases according to clinical types is presented in Table 2. Spastic forms were diagnosed in 205 cases (76%). Right hemiparesis (27%) prevailed over left hemiparesis (15%). Having in mind that SCPE classification for CP is not widely accepted in Lithuania, bilateral spastic forms were distributed according to the Swedish classification into diplegia (44%) and tetraplegia (14%). Dyskinetic CP was diagnosed in 18% and atactic in 6% cases.

Prevalence. In 1987–1998, the population-based prevalence of CP was 2–3.4 (mean 2.5, SD=0.398) per 1,000 children, and the birth rate-based prevalence was 1.9–3.3 (mean 2.3, SD=0.398) per 1,000 live births (Table 3). In each study year, the population-based prevalence was higher than the birth rate-based prevalence. The difference between the population-based and the birth rate-based prevalence of CP was significant, $Z=-2.842$, $P=0.004$.

No significant trends in the population-based prevalence of CP (95% CI, 0.693–2.079) or the birth rate-based prevalence were observed (95% CI, 0.693–2.079) over 12 study years (Fig. 1). The birth prevalence of CP in different areas of Kaunas County was 1.6 to 3.8 (mean 2.67, SD=0.27) per 1,000 live births. There were no statistically significant differences in the birth prevalence of CP in

Table 1. Study Population

Total number of children on the list:	728
CP mentioned in medical records	706
Other possible cases	22
Excluded due to different reasons:	173
Age, address, double name on the list	96 (55%)
Died*	42 (24%)
Refused to participate	13 (8%)
Not found	23 (13%)
Number of examined children	555
Confirmed diagnosis of cerebral palsy:	270
Matched with medical records	137 (50.7%)
Unmatched with medical records	133 (49.3%)

*The diagnosis of CP was in medical records in 33 cases; there was a different diagnosis in 9 cases.

Table 2. Distribution (in Numbers and Percentage) of Cerebral Palsy According to Clinical Types

Clinical Type	Number (%)
Spastic	205 (75.9)
Unilateral	86 (31.8)
Right	55 (20.4)
Left	31 (11.5)
Bilateral	119 (44.1)
Diplegia	91 (33.7)
Tetraplegia	28 (10.4)
Dyskinetic	49 (18.1)
Atactic	16 (5.9)
Total	270 (100)

those areas ($\chi^2=6$, $P=0.423$). The population-based prevalence in different areas of Kaunas County was 1.9 to 3.6 (mean 2.7, SD=0.209) per 1,000 children. There were no statistically significant differences in the population-based prevalence of CP in those areas ($\chi^2=1$, $P=0.317$).

Discussion

This is the first study on the prevalence of cerebral palsy in Lithuania. The data that were collected on the population in Kaunas County are representative of the entire country due to the number of general population (20.1% of total population) and children (20.35% of total children’s population).

Cerebral palsy is sometimes described as an indicator of the quality of neonatal and obstetrical services (18). Due to the different standards and quality of neonatal and obstetrical care and due to the lack of data on neonatal and infant mortality in 1987–1994, comparison of the prevalence of CP in Lithuania and other countries is quite complicated. Comparison of the prevalence also can be biased

Table 3. Birth Rate-based and Population-based Prevalence of CP in Kaunas County among Children Born in 1987–1998

Birth Year	Number of Cases	Number of Children in 2001	Live Births	Birth Rate Prevalence of CP (Number of CP Cases per 1,000 Live Births)	Population-based Prevalence of CP (Number of CP Cases per 1,000 of Paediatric Population)
1998	20	7,478	7,489	2.7	2.7
1997	16	7,862	7,747	2.1	2.1
1996	18	8,130	8,141	2.2	2.3
1995	28	8,054	8,459	3.3	3.4
1994	18	8,749	8,446	2.1	2.3
1993	18	10,145	9,378	1.9	2.0
1992	26	9,904	10,688	2.4	2.6
1991	22	10,076	11,298	1.9	2.2
1990	22	9,668	10,984	2.0	2.2
1989	26	9,717	10,650	2.4	2.7
1988	27	10,432	10,933	2.5	2.8
1987	29	10,782	11,557	2.5	2.8
Total	270	110,997	115,770	2.3	2.5

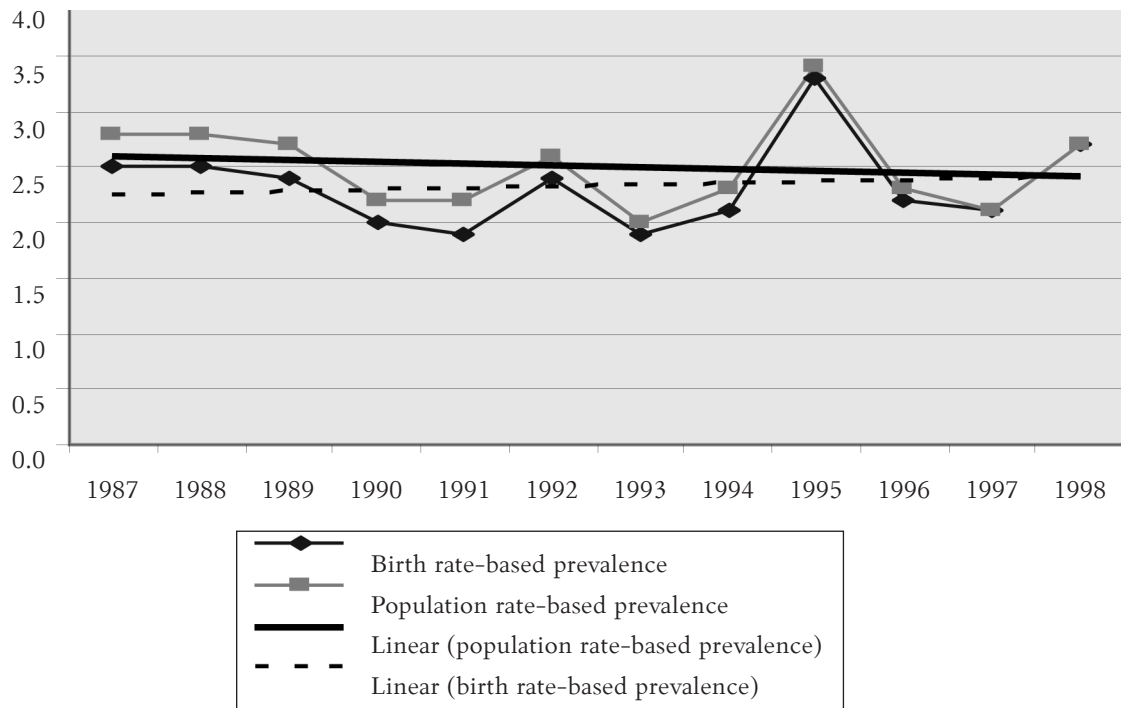


Fig. 1. Linear regression of the prevalence of CP

and complicated by the method of counting the prevalence. As denominators, age-related population or number of live births can be used (18, 19). In counting the prevalence of the condition with

a higher mortality rate, the population-based and the birth rate-based prevalence might differ significantly (19). The same rule can be applied while counting the CP prevalence in countries with high

Table 4. Prevalence of CP in the Areas of Kaunas County

Area	Number of Cases	Number of Children in 2001	Live Births	Birth Rate Prevalence of CP	Population-based Prevalence of CP
Kaunas	128	55,297	61,819	2.1	2.2
Kaunas district	22	14,380	13,965	1.6	1.9
Jonava	34	9,318	9,051	3.8	3.6
Kaišiadorys	18	6,086	5,941	3.0	3.0
Kėdainiai	29	11,201	10,940	2.65	2.6
Prienai	20	6,950	6,528	3.1	2.9
Raseiniai	19	7,765	7,524	2.5	2.7
Total	270	110,997	115,770	2.3	2.4

neonatal and infant mortality rates. In our study, the difference between the population-based CP prevalence (2.5) and the birth rate-related prevalence (2.3) was insignificant. In the studies performed in Western countries, the number of live births was usually used as a denominator in counting the CP prevalence. There also might be some problems in comparing data extracted from registries and population-based epidemiological studies. Registries usually cover big geographical areas. But a high number of children might be missed or excluded due to an incorrect diagnosis (20). Inclusion/exclusion criteria in registries and population-based studies might also differ (21). The use of Swedish (17) and SCPE (15) classifications allowed us to compare the distribution of CP according to clinical forms with studies performed in other European countries. The prevalence of CP per 1,000 live births among children born in 1991–1996 in Kaunas County was 2.2. The prevalence for the same group of children was 2.1 in the United Kingdom, 2.0 in Norway, 1.9 in Ireland and Denmark, 1.8 in Sweden, etc. (22). The distribution of CP according to clinical forms in our study is similar to those in Norway and Sweden (22). A high proportion of spastic tetraplegia observed in some studies might be related to the false differentiation of severe dyskinetic forms and spastic tetraplegia, different diagnostic criteria or worse obstetrical services (in studies performed 2–3 decades ago) (14, 15).

Trends in changes of the prevalence of cerebral palsy in Kaunas County are not significant. Two Norwegian studies that analysed the prevalence of CP in subjects born in 1977–1991 in Nordland and 1970–1989 in Vestfold presented different trends. In the Nordland study, there were no significant changes; meanwhile, in the Vestfold study, there was

a significant decline in the prevalence of CP (23, 24). In both studies, there were quite small numbers of children with CP (93 and 64, respectively). Swedish studies that analysed prevalence of CP among children born in 1987–1990 and 1991–1994 had much higher numbers of CP cases (216 and 241, respectively). The studies showed that after the increasing prevalence of CP in cohorts from 1954 through 1986, this growth stabilised (25–27). Therefore, it is important to analyse big cohorts and long periods of time in order to have a real view of the changes in the prevalence of cerebral palsy.

Conclusion

The population-based prevalence of cerebral palsy over the period of 1987–1998 was 2–3.4 (mean 2.5, SD=0.398) per 1,000 children, and the birth rate-based prevalence was 1.9–3.3 (mean 2.3, SD=0.398) per 1,000 live births. Due to the low number of CP cases in separate areas of Kaunas County or separately in each study year, the study data do not give a reliable view of trends of the CP prevalence. Further studies are needed to estimate trends in changes of the prevalence of cerebral palsy in Lithuania.

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Statement of Conflict of Interest

The authors state no conflict of interest.

Ligotumas cerebriniu paralyžiumi Lietuvoje

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Raktažodžiai: ligotumas cerebriniu paralyžiumi, cerebrinio paralyžiaus epidemiologija, vaikai.

Santrauka. *Tikslas* – nustatyti vaikų, gimusių 1987–1998 metais ir gyvenančių Kauno apskrityje, ligotumą cerebriniu paralyžiumi.

Tyrimo metodika. Kiekybinis skerspjūvio tyrimas buvo atliktas Kauno apskrityje. Įtraukimo į tyrimą kriterijai: vaikai, gimę 1987–1998 m., tyrimo metu gyvenę Kauno apskrities teritorijoje; cerebrinio paralyžiaus diagnozė bent kartą nurodyta medicininiuose dokumentuose. Papildomas įtraukimo į tyrimą kriterijus vaikams, gyvenantiems globos įstaigose: tėvų (arba motinos) adresas tyrimo laikotarpiu yra Kauno apskrityje arba nežinomas. Pabėgėliai, laikinai gyvenantys pabėgėlių centruose, į tyrimą neįtraukti. Į tyrimą taip pat buvo įtraukti vaikai, kurių medicininiuose dokumentuose buvo pateikta informacija apie ankstyvaisiais gyvenimo metais persirgtą neuroinfekciją, sunkią encefalopatiją, sunkų nepatikslintą raidos sutrikimą arba kitą ligą, kurios klinikiniai požymiai būdingi ir cerebriniam paralyžiui (įtariamo cerebrinio paralyžiaus atvejai). Tyrimas buvo atliekamas dviem etapais. Pirmuoju etapu sudaromas į tyrimą įtrauktų vaikų sąrašas. Antruoju etapu vaikų neurologas, vadovaudamasis Europos cerebrinio paralyžiaus tyrimų grupės parengtu vadovu, ištiria į tyrimą įtrauktus vaikus ir patvirtina arba paneigia cerebrinio paralyžiaus diagnozę.

Rezultatai. Į tyrimą įtrauktų vaikų sąrašė buvo 728 pavardės. 270 atvejų cerebrinio paralyžiaus diagnozė buvo patvirtinta. Tarp 1987–1998 m. gimusių vaikų gyvenančių vaikų skaičiumi paremtas ligotumas cerebriniu paralyžiumi buvo 2–3,4 (vid. 2,5, SD = 0,398) tūkstančiui vaikų, gimusiųjų skaičiumi paremtas ligotumas buvo 1,9–3,3 (vid. 2,3, SD = 0,398) tūkstančiui gyvų gimusiųjų. Kiekvienais tyrimo metais gimusių vaikų ligotumas, paremtas gyvenančių vaikų skaičiumi, buvo didesnis nei gimusiųjų skaičiumi paremtas ligotumas. Skirtumas buvo statistiškai reikšmingas, $Z = -2,842$, $p = 0,004$.

Tyrimo metu nenustatyta statistiškai reikšmingų cerebrinio paralyžiaus ligotumo kitimo tendencijų nei skaičiuojant gyvenančių vaikų skaičiumi paremtą (95 proc. PI 0,693–2,079), nei gyvų gimusiųjų skaičiumi paremtą (95 proc. PI 0,693–2,079) cerebrinio paralyžiaus ligotumą.

Išvados. Dėl mažo cerebrinio paralyžiaus atvejų skaičiaus atskiruose Kauno apskrities regionuose arba remiantis atskirų tyrimo metų rezultatais sunku patikimai įvertinti ligotumo cerebriniu paralyžiumi kitimo tendencijas. Reikia tolesnių tyrimų, kuriais remiantis būtų galima įvertinti ligotumo cerebriniu paralyžiumi tendencijas Lietuvoje.

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