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Original article

Decreasing prevalence and severity of cerebral palsy in Norway among children born 1999 to 2010 concomitant with improvements in perinatal health

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ABSTRACT

Background: The aim of our study was to explore if the prevalence and clinical characteristics of cerebral palsy (CP), concomitant with perinatal health indicators in the general population, remained unchanged for children born in Norway between 1999 and 2010.

Methods: This national multi-register cohort study included 711 174 children recorded in the Medical Birth Registry of Norway. Among these, 707 916 were born alive, and 1664 had a validated diagnosis of CP recorded in the Cerebral Palsy Registry of Norway and/or the Norwegian Patient Registry. Prevalence per 1000 live births as a function of birth year was analyzed using logistic regression with fractional polynomials to allow for non-linear trends. Chi-square statistics were used to estimate trends in proportions of clinical characteristics.

Results: The prevalence of CP in Norway decreased from 2.62 per 1000 live births in 1999 to 1.89 in 2010. The reduction was most evident among children with bilateral CP, in particular those with diplegia. During the study period, the proportions of children with severe motor impairments, epilepsy, intellectual impairment and reduced speech also decreased. At the same time, perinatal mortality has decreased in Norway, along with the proportion of women with preeclampsia, children born preterm or as a multiple.

Conclusion: We observed a significant decrease in the prevalence and severity of CP subtypes and associated impairments among children with CP in Norway. This coincided with

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improvements in perinatal health indicators in the general population. These improvements are most likely explained by advancements in obstetric and neonatal care.

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1. Introduction

Cerebral palsy (CP), the most common cause of permanent motor disabilities in children, is the result of a nonprogressive injury in the immature brain that occurs before birth, during delivery or in the neonatal period, and up to two years of age. The injury may be caused by a congenital brain anomaly, infection, trauma, or acute hypoxic-ischemic insults. Known risk factors include preterm birth, restricted fetal growth, and complications during pregnancy and birth.^{1–3} Research shows that the panorama of causes has changed over time.^{4–7}

CP is categorized into subtypes based on the dominating motor disturbance and on which part of the body is affected. Further classification is regularly based on motor impairment. Associated impairments such as epilepsy, impaired ability to speak/communicate, cognitive impairments, impaired vision and/or hearing, and nutritional problems are common.⁸

The prevalence of CP has been reported to vary between 1.5 and 3 per 1000 in various populations.^{9,10} Several studies have reported that the prevalence has been stable for more than fifty years.^{4,9–11} This has been taken as evidence that CP is mainly due to events before birth and that improvements in obstetric and neonatal care have not resulted in a measurable prevention of CP.^{11,12} However, the stable prevalence may have concealed significant changes in the causes leading to CP and to the various CP subtypes. It is also noteworthy that the prevalence of CP was stable despite a significant reduction in perinatal mortality in the developed world from around 20 per 1000 in the 1970s to less than five per 1000 in the 21st century.¹³ In fact, two studies by the Surveillance of Cerebral Palsy in Europe in populations born during the last two decades of the 20th century suggested slight decreases in the prevalence of CP among children born with a very low birth weight¹⁴ or moderately preterm.¹⁵ More recently, Sellier et al. showed a reduction in the prevalence of CP from 1.90 to 1.77 per 1000 live births in populations covered by 20 European registries for children born from 1980 to 2003.¹⁶ A strength of all three studies was the large number of children included, as well as the uniform and validated diagnostic criteria of the CP diagnosis and classifications. These studies attributed the decrease in prevalence of CP to improvements in obstetric and neonatal care of preterm infants towards the end of the 20th and beginning of the 21st century. However, ascertainment of cases was a challenge, and in fact, the reported overall prevalence in the Sellier et al. study was lower than in areas with a documented complete ascertainment of cases.7,17,18 Despite these findings, the debate continues whether CP may be

prevented or whether it is mainly caused by antenatal factors that are less likely to be modified by obstetric and neonatal care. 11,19,20

We have recently reported high completeness and correctness of CP diagnosis codes in Norway by combining information from two national health registers, resulting in a prevalence of CP of 2.4 per 1000 for children born 1996 to 2007.¹⁷ Since then, new national guidelines have been introduced in Norway aiming to improve obstetric and neonatal care including cardiotocography (CTG), ST waveform analysis of fetal electrocardiogram (STAN), as well as therapeutic hypothermia of term born children with moderate or severe neonatal encephalopathy.^{21–23}

On this background, the aim of this study was to examine if the prevalence of CP as well as clinical characteristics have changed in Norway during the first decade of the 21st century. We also wanted to assess potential concomitant changes in other indicators of perinatal health in the general population (e.g. prevalence of preterm birth and perinatal mortality) during the same time period.

2. Method

2.1. Study design

In this register-based cohort study, all children born in Norway during 1999 to 2010 and registered in the Medical Birth Registry of Norway (MBRN) were included. The MBRN has recorded data on all births since 1967, including information on the mother's health during pregnancy, the birth, and the child's health after birth. Registration in the MBRN is compulsory. Data used in this study were collected from the birth notification form dated December 1, 1998.13 Children with CP were identified through the Cerebral Palsy Registry of Norway (CPRN). The CPRN is a consent-based national medical quality registry that has systematically recorded detailed clinical information on all children with CP born since 1996. In this study, data were collected for children born 1999 and onward on the CPRN Five Year Consultation Form.²⁴ Children with postneonatally acquired CP were excluded. The completeness of the CPRN for birth years 1999 to 2010 is approximately 90%. This was ascertained by linking the CPRN with the Norwegian Patient Registry (NPR) using the 11-digit personal identification number unique to each resident.¹⁷ The NPR is a compulsory administrative registry that receives standardized data on all patients treated by the national specialist heath care services, with person-identifiable data since 2008.

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