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Estimating the prevalence of cerebral palsy in Taiwan: A comparison of different case definitions

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ABSTRACT

The estimated prevalence of cerebral palsy (CP) worldwide ranged from 0.74 to 3.6 per 1000 live births according to different studies, which may be due to different data sources and case definitions used. We used a representative sample of one million patients (about 1/23 of total population) covered by Taiwan's National Health Insurance (NHI) to estimate the prevalence using different case definitions. Eight years of NHI Research Database claims data for all children born between 1996 and 2000 were reviewed for CP diagnoses. The estimated prevalence of CP (cases per 1000 live births) varied from 4.1 to 1.3 for different case definitions. For a minimum age of 4 years old at diagnosis, a diagnosis made by specialists (pediatricians and physicians of physical medicine and rehabilitation), and the CP diagnosis was mentioned at least three times in claims data, the mean estimated prevalence of CP was 3.2 (95% CI 2.8–3.7). According to this definition, which is most compatible with previous studies, the estimated prevalence in Taiwan was 3.4 (95% CI 2.8–4.0) for boys and 3.1 (95% CI 2.5–3.7) for girls, significantly higher than that in other countries. Additional studies are needed to determine the reasons of higher prevalence in Taiwan.

1. Introduction

Cerebral palsy (CP) consists of a group of permanent and nonprogressive disorders of the development of movement and posture caused by central nervous system lesions, damage, or dysfunction from early life (Rosenbaum et al., 2007). Children with CP often have epilepsy, secondary musculoskeletal problems, and disturbances of sensation, perception, cognition, communication, and behavior (Rosenbaum et al., 2007). These problems have huge effects on their activities of daily living, quality of life, and even life expectancy (Hutton, Cooke, & Pharoah, 1994; Rosenbaum et al., 2007). Because of the multiple problems children with CP have, they often need special health, social, and educational services. Therefore, estimating the prevalence of CP is important for providing information to plan effective service programs (Bramlett, Read, Bethell, & Blumberg, 2009).

Although many studies have tried to estimate the prevalence of CP, their findings yield a wide prevalence ranged from 0.74 to 3.6 per 1000 live births (Himmelmann, Hagberg, Beckung, Hagberg, & Uvebrant, 2005; Smith, Kelly, Prkachin, &

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Voaklander, 2008; Wichers, van der Schouw, Moons, Stam, & van Nieuwenhuizen, 2001; Yeargin-Allsopp et al., 2008). One possible explanation for these huge variations is that different studies used different data sources and case definitions (Table 1). The minimum age at which children can be reliably diagnosed with CP might be one factor that contributes to the variation in reported prevalence (Paneth, Hong, & Korzeniewski, 2006). It is generally believed that a diagnosis of CP cannot be confirmed before a child is 2 years old (Paneth et al., 2006; Voss, Neubauer, Wachtendorf, Verhey, & Kattner, 2007) and that the majority of studies use 4 years old as the minimum age (Himmelmann et al., 2005; Himmelmann, Hagberg, & Uvebrant, 2010; Meberg & Broch, 1995; Surveillance of Cerebral Palsy in Europe, 2002).

Most CP prevalence studies (Table 1) used multiple sources and CP registries, which are resources-intensive and unaffordable in many countries. One alternative to estimating the prevalence is to use population-based administrative datasets. For example, Park et al. (2011) used South Korea's National Health Insurance (NHI) review and assessment service data to estimate the prevalence of CP. Their case definition was a child born in 1999 in South Korea (denominator) who had used medical services in 2004 with a documented diagnosis of CP by qualified physicians (numerator), specifically, pediatricians, pediatric orthopedic surgeons, pediatric neurosurgeons, and physiatrists. The study reported that the prevalence of CP increased from 2.2 per 1000 children in 2004 to 3.2 in 2008. Unfortunately, they did not do a sensitivity analysis, i.e., they did not compare the estimated prevalence of CP according to different case definitions. Review studies have suggested that diagnoses reported in insurance claims data are not necessarily confirmed diagnoses (Schneeweiss & Avorn, 2005; Terris, Litaker, & Koroukian, 2007; Virnig & McBean, 2001). We thus wanted to estimate the prevalence of CP in Taiwan using the Taiwan NHI claims data with different operational definitions to have a more complete picture of the prevalence of CP in Taiwan.

2. Methods

2.1. Data source

The Taiwan NHI program is a compulsory and universal insurance plan launched by the government in 1995. It has covered more than 99.6% of Taiwan's citizens since 1999 (Bureau of National Health Insurance, 2012; Chi, Lee, & Schoon, 2012). The NHI Research Database (NHIRD) inpatient and outpatient claims dataset includes variables such as encrypted patient identification numbers, gender, birthdate, dates of visits, admissions, and discharges, three diagnostic codes for outpatient claims and five diagnosis codes and five procedure codes for inpatient claims, drug prescriptions, fees paid for various kinds of medical services, characteristics of medical settings, and disposition after discharge (Hsiao, Yang, Huang, & Huang, 2007).

Data for this study were obtained from the NHIRD sample dataset registry of beneficiaries, which contains all original claims data (from 1996 to 2008) of 1,000,000 individuals randomly sampled from all NHI subscribers in Taiwan in 2000. The gender and age distributions are not significantly different from those of the entire insured population registered with the Ministry of Interior (National Health Insurance Research Database, 2012). The sample dataset also indicates whether a patient has a catastrophic illness or disability certification.

The NHI will issue catastrophic illness certificates to qualified patients. These certificates exempt patients from copayments to relieve their financial burden because of expected high medical care expenditures. Moderate and severe

Table 1
Different data source and case confirmation methods used.

Study	Country	Study period	Data source	Minimum age	Prevalence
Takeshita, Ando, Ohtani, and Takashima (1989)	Japan	1955–1985	Hospital records	≤3 years	1.4
Murphy, Yeargin-Allsopp, Decouflé, Murphy, Yeargin-Allsopp, Decouflé, and Drews (1993)	United States	1975–1977	Multiple sources	1 and 2 years	2.3
Meberg and Broch (1995)	Norway	1970–1989	Multiple sources	4 years	2.4
Pharoah, Cooke, Johnson, King, and Mutch (1998)	England & Scotland	1984–1989	CP registry	Not mentioned	2.1
Liu, Li, Lin, and Li (1999)	China	1990–1997	Hospital records	≤7 years	1.6
Sciberras and Spencer (1999)	Malta	1981–1990	Multiple sources	3.5 years	2.4
Wichers et al. (2001)	The Netherlands	1977–1988	Hospital records	Not mentioned	0.7
SCPE (2002)	Europe	1976–1990	CP registry	≥4 years	2.1
Suzuki and Ito (2002)	Japan	1977–1992	Hospital records	6 years	1.3
Winter, Autry, Boyle, and Yeargin-Allsopp (2002)	United States	1975–1991	Multiple sources	3–10 years	1.7
Himmelmann et al. (2005)	Sweden	1990–1997	CP registry	4–8 years	1.9
Westbom, Hagglund, and Nordmark (2007)	Sweden	1990–1997	CP registry	4–11 years	2.7
Andersen et al. (2008)	Norway	1996–1998	CP registry	≥4 years	2.1
Smith et al. (2008)	Canada	1991–1995	Hospital records	≥3 years	2.7
Yeargin-Allsopp et al. (2008)	United States	1994	Multiple sources	8 years	3.6
Sigurdardottir, Thorkelsson, Halldorsdottir, Thorarensen (2009)	Iceland	1997–2003	CP registry	5 years	2.3
Himmelmann et al. (2010)	Sweden	1999–2002	CP registry	4–8 years	2.2
Kirby et al. (2011)	United States	1998	Multiple sources	≥2 years	3.3
Park et al. (2011)	South Korea	2004–2008	National Health Insurance data	5 years	2.6