

Surveying a Decade of Cerebral Palsy Prevalence and Characteristics at Thammasat University Hospital, Thailand

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Background: Cerebral palsy (CP) is a movement disorder caused by damage to the developing brain. It affects self-help, family dynamics, and care costs. Data is lacking on its prevalence and characteristics in Thailand. Collection of this data may help to improve awareness and reduce treatment delay consequences.

Materials and Methods: Prevalence, characteristics, and time to rehabilitation data were collected from 50 CP patients, born at Thammasat University Hospital, Thailand between 2005 and 2014.

Results: CP prevalence was 1:1,000 live birth. There was no significant difference in gender (52% male) or in full-term versus preterm birth (48.8% preterm). Among the preterm, 22.45% had a gestational age of 32 to 36 6/7 weeks with spasticity (90%) as the most common motor control abnormality, while 72.34% showed diplegia. Age at first diagnosis averaged 11.79 months with 33.33% at high level IV, under the Gross Motor Function Classification System (GMFCS), 50% of diagnoses were from hypertonia, followed by 23.17% from delayed development. Time post-diagnosis to first treatment averaged 4.12 weeks. Time after diagnosis before rehabilitation was 7.66 weeks, with 6.09 weeks before a visit to the rehabilitation team.

Conclusion: The CP rates fluctuated over time but tended to increase with diplegic spasticity as the most common symptom. GMFCS showed high disability with hypertonia being the major diagnostic clue. Delays hindered rehabilitation. Early surveillance of those at risk incorporating multidisciplinary team treatment management would improve outcomes.

Keywords: Cerebral palsy, Prevalence, Characteristics, Rehabilitation, GMFCS, Thailand

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Cerebral palsy (CP) is a permanent disorder of movement, muscle tone, or posture caused by non-progressive damage to the immature, developing brain. The disturbances of sensation, perception, cognition, communication, and behavior are often combined⁽¹⁾ and regarded as the most common cause of disability in children⁽²⁾. The overall prevalence of CP was 2.11 per 1,000 live births⁽³⁾. Early detection, consistent treatment, and planned management by a multidisciplinary team make the best prognosis

and prevent complications⁽⁴⁾. Unfortunately, there has not been any data regarding CP's prevalence, characteristics, and time to rehabilitation in Thailand. There is likely to be under surveillance with treatment delays, resulting in irreversible complications. If monitoring awareness is further disseminated, vulnerable babies would be properly assessed. Thus, an objective of the present research was to study thoroughly the prevalence, characteristics and factors such as where the gaps existed, to help delineate challenges, improve services, and increase knowledge of the implications associated with delayed CP treatment.

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Materials and Methods

The prevalence, characteristics, and time to rehabilitation data were collected retrospectively

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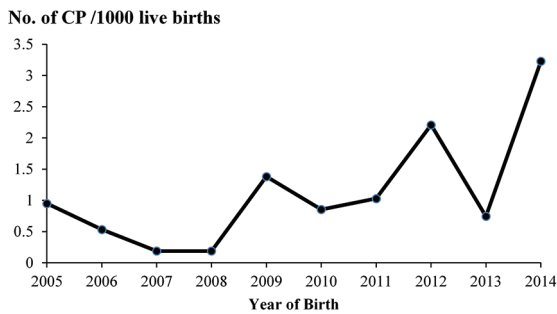


Figure 1. Prevalence of cerebral palsy per 1,000 live births in Thammasat University Hospital from 2005 to 2014.

from our 50 pediatric CP patients born at Thammasat University Hospital, Thailand and alive between 2005 and 2014. Cases were identified by the standard criteria⁽¹⁾. The authors included children diagnosed with CP with no neurological disorders from neonatal stroke, intracerebral hemorrhage, subgaleal hematoma, thrombotic disease, or other nervous system disorders. In addition, patients who suffered an accident or infection fatal to the nervous system after discharge from the hospital were excluded.

Babies born after 37 weeks of pregnancy were defined as term and preterm if born before 37 weeks of pregnancy⁽⁵⁾. Depending on gestational age (GA), there are three preterm sub-classes, moderate to late preterm (32 to 37 weeks), very preterm (28 to 32 weeks), and extremely preterm (less than 28 weeks)⁽⁶⁾. Birth weight was divided into three categories, low birth weight (LBW), determined as birth weight less than 2,500 g, very low birth weight (VLBW) at less than 1,500 g, and extremely low birth weight (ELBW) at less than 1,000 g⁽⁷⁾. Muscle tone abnormality and posture were described as spasticity, ataxia, and dyskinesia⁽⁸⁾. Affected limbs are grouped as quadriplegia, diplegia, and hemiplegia⁽⁹⁾. From the previous systems, we also classified tone abnormality with limb involvement into spastic including bilateral spastic cerebral palsy (BSCP) quadriplegia, BSCP diplegia, and spastic hemiplegia, and as non-spastic with either ataxia or dyskinesia⁽⁸⁾. Characteristics data for the births were reported as percentage and delegated into two periods of five years each, between 2005 and 2009 and between 2010 and 2014, to examine possible trends in the frequency of GA, birth weight, clinical presentation in motor impairment and affected limb distributions. Statistical analysis was done using Stata, version 14 (StataCorp LP, College Station, TX, USA). Comparing percentage over the two 5-year periods data using Fisher's exact test with

p-value of 0.05 or lower considered as statistically significant.

For capability determination and limitation of daily performance in gross motor function at the time of diagnosis, the authors used the Gross Motor Function Classification System, Expanded and Revised (GMFCS-E&R)⁽¹⁰⁾. This has five levels, from I, II, III, IV, and V (best to worst). The discriminations are based on mobility and ambulation limitations and the need for handheld mobility tools (such as walkers, crutches, or canes) or wheeled mobility⁽¹⁰⁾. This measurement is generally recognized to adequately determine functional capability in CP patients^(11,12). Frequency of findings leading to diagnosis were recorded as percentage. CP diagnosis age, the elapsed time after first CP diagnosis to initial rehabilitation consultation and subsequent first meeting with rehabilitation team was also documented in mean and standard deviation (SD).

Results

The average prevalence of CP over 10 years (between 2005 and 2014) in the authors' hospital was 1:1,000 live births. There was a significant increase in the study's last year (2013 to 2014) (Figure 1). There was no dominance of either sex (52% is male), 52% were born term, and 48% were preterm with most in the GA of 32 to 36 6/7 weeks (22.45%). For birth weight, 48% were in the normal range at 2,500 g or heavier, and 52% were less than 2500g. In this latter subgroup, 26% were LBW at less than 2,500 g, 14% were VLBW at less than 1,500 g, and 12% were ELBW at less than 1,000g. Spasticity was the most common motor control abnormality (90%), and diplegia was predominant (72.34%).

Over the two 5-year periods, there were no significant differences in characteristics (Table 1), however, there is a decrease in quadriplegia from 37.50% (between 2005 and 2009) to 9.68% (between 2010 and 2014) but an increase in diplegia from 56.25% to 80.65%. Clinical presentation in spasticity (90% of cases) was mainly BSCP (86.66%), followed by hemiplegia (8.88%). In the non-spastic group (10% of cases), there was only ataxia, dyskinesia being absent. In the BSCP, diplegia was the most common (71.11%), followed by quadriplegia (15.55%) (Table 2). GMFCS data for all and each CP clinical presentation is given in Figure 2. The presentations (n=48) were mostly were level IV (33.33%), followed by level III (29.17%), level II (18.75%), level I (12.50%), and level V (6.25%).

In each clinical presentation, BSCP quadriplegia

Table 1. Characteristics of cerebral palsy patients born at Thammasat University Hospital from 2005 to 2014

| Characteristics | Total (n=50) n (%) | 2005 to 2009 (n=16) n (%) | 2010 to 2014 (n=34) n (%) | p-value |
|--------------------|-----------------------|------------------------------|------------------------------|---------|
| Sex (male) | 26 (52.00) | 10 (62.50) | 16 (47.06) | 0.372 |
| Gestational age | | | | 0.091 |
| ≥37 weeks | 26 (52.00) | 10 (66.67) | 15 (44.12) | |
| 32 to 36 6/7 weeks | 11 (22.00) | 1 (6.67) | 10 (29.41) | |
| 28 to 31 6/7 weeks | 6 (12.00) | 3 (20.00) | 3 (8.82) | |
| <28 weeks | 7 (14.00) | 1 (6.67) | 6 (17.65) | |
| Birth weight | | | | 0.256 |
| Normal (≥2,500g) | 24 (48.00) | 11 (68.75) | 13 (38.24) | |
| LBW (<2,500g) | 13 (26.00) | 2 (12.50) | 11 (32.35) | |
| VLBW (<1,500g) | 7 (14.00) | 2 (12.50) | 5 (14.71) | |
| ELBW (<1,000g) | 6 (12.00) | 1 (6.25) | 5 (14.71) | |
| Motor impairment | | | | 1.000 |
| Spasticity | 45 (90.00) | 14 (87.50) | 29 (90.63) | |
| Ataxic | 5 (10.00) | 2 (12.50) | 3 (9.38) | |
| Dyskinesia | 0 (0.00) | | | |
| Limb distribution* | | | | 0.133 |
| Quadriplegia | 9 (19.15) | 6 (37.50) | 3 (9.68) | |
| Diplegia | 34 (72.34) | 9 (56.25) | 25 (80.65) | |
| Hemiplegia | 4 (8.51) | 1 (6.25) | 3 (9.67) | |

LBW=low birth weight; VLBW=very low birth weight; ELBW=extremely low birth weight

* 3 patients excluded due to absence of data

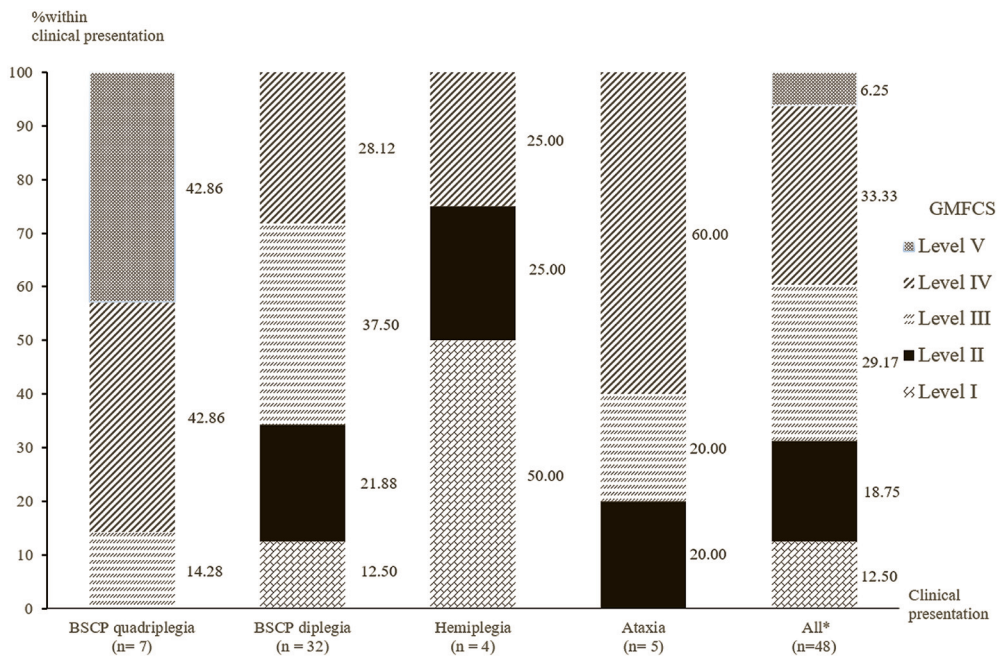


Figure 2. Percentage of GMFCS in cerebral palsy clinical presentations.

* 2 patients excluded due to absence of GMFCS data

Table 2. Clinical presentation of cerebral palsy at Thammasat University Hospital

| Type | n (% of total) | % of spastic type |
|---------------------|----------------|-------------------|
| Spastic* | 45 (90.00) | |
| BSCP total | 39 | 86.66 |
| • BSCP quadriplegia | 7 | 15.55 |
| • BSCP diplegia | 32 | 71.11 |
| Hemiplegia | 4 | 8.88 |
| Non-spastic | 5 (10.00) | |
| Ataxic | 5 | |
| Dyskinesia | 0 | |

BSCP=bilateral spastic cerebral palsy

* 2 patients excluded due to absence of limb distribution data

Table 3. Diagnostic characteristics/management for cerebral palsy patients born at Thammasat University Hospital from 2005 to 2014

| | Mean±SD |
|---|------------|
| Age of first diagnosis (in months) | 11.79±1.04 |
| Duration to first treatment (weeks)*† | 4.12±2.59 |
| Duration to rehabilitation consultation (weeks)* | 7.66±3.04 |
| Duration to first meeting with rehabilitation team (weeks)‡ | 6.09±2.49 |
| Symptoms leading to the diagnosis; n (%) | |
| Hypertonia | 41 (50.00) |
| Hypotonia | 3 (3.66) |
| Delayed development | 19 (23.17) |
| Toe walking | 3 (3.66) |
| Hyperreflexia/clonus positive | 16 (19.51) |

SD=standard deviation

* From the diagnosis date, † This can include any therapy advised for general cerebral palsy treatment, ‡ From the rehabilitation consultation date

(n=7) was the most severe disability with 42.86% at level V, 42.86% at level IV, and 14.28% at level III. For BSCP diplegia (n=32), most were level III (37.50%), followed by level IV (28.12%), level II (21.88%) and level I (12.50%). Most spastic hemiplegia (n=4) patients were level I (50%), then distributed equally between level II and IV (25%).

In the ataxia (n=5) group, many children had challenging disabilities, and most were level IV (60%), followed by level III (20%) and II (20%). The age of first diagnosis averaged at 11.79 months. Findings leading to diagnosis were usually regarding hypertonia (50%), delayed development (23.17%), hyperreflexia or clonus positive (19.51%), and

hypotonia and toe walking, both at 3.66%. The duration from diagnosis to first treatment, including any therapy advised for general CP was around 4.12 weeks, to rehab consultation approximated 7.66 weeks, and the average time from rehab consultation to treatment was 6.09 weeks (Table 3).

Discussion

Other sources demonstrated lower or higher rates of CP prevalence, for example, 1.77 to 3.2 per 1,000 live births⁽¹³⁻¹⁵⁾. These rates may vary in comparison with our own rate of 1 per 1,000 live births due to differing CP definitions, alternate times considered as early detection, variable diagnosis standards, and non-consistent inclusion and exclusion criteria⁽¹⁶⁾. Furthermore, the present study only included children born in the authors' hospital and excluded children who had neurological disorders from specific causes that may later prove to be progressive conditions. This, in itself, may explain our lower prevalence rate. Another consideration would be lack of parental knowledge and awareness of what is CP and its signs. Often parents believe their children are normal and do not bring them for follow-up or treatment even if they are determined to be high risk.

CP numbers appear to be rising in the United States^(14,17), as in the present study. One of the most obvious reasons for this would be changes made in medical technology or training, resulting in increased survival rates of VLBW babies⁽¹⁸⁾, preterm infants, and multiple births⁽¹⁶⁾. However, in Europe and Australia^(15,19), there was a decreasing trend due to improved quality of neonatal care such as hypothermia treatment for hypoxic-ischemic encephalopathy, which reduced CP incidence⁽¹⁹⁾. Apart from treatment, differences may be attributed to the different study method in the United States where information was received from parent-reported questionnaires rather than from clinical reports^(14,17).

In the present study, there was no gender variation for CP diagnosis. It was almost evenly split between males (52%) and females (48%), similar to a 1992 Scottish survey found male CP at 58%⁽²⁰⁾. However, this contrasts with other researches^(21,22) in which the male infant CP rate is 30% higher⁽²¹⁾. One speculation is male infants, especially in preterm, are more susceptible to white matter injuries and have more intraventricular hemorrhage (IVH) than female⁽²²⁾. Nonetheless, this possible dominance and pathogenesis in males is still widely discussed and poorly interpreted⁽²³⁾. CP has multiple factors^(24,25), and there is currently no exploration in the total

risks adjusted for CP. These referenced gender ratios exist from records^(21,22), possibly reflecting incidental differences.

For the authors, incidence at term was 52% and preterm was 48%. When compared the proportion of preterm (9.6%) to all live births⁽²⁶⁾, the present study had a high percentage of CP in preterm. It is important to remember that most babies are born at term. This is consistent with other studies stating that lower GA has a higher rate of CP^(3,27,28). Regarding birth weight, 48% of the present study cases were in the normal range, which is heavier than $\geq 2,500$ g, and 52% were less than 2,500 g. A large proportion of CP incidence, as compared to overall live births, was in the LBW group at 14%, comparable to prior research⁽²⁹⁾. The most common motor impairment was spasticity, akin to previous data^(16,30). Most were diplegic (72.34%). Over the two 5-year periods between 2005 and 2009 and between 2010 and 2014, there were no significant statistical differences in limb distribution, but there were interesting details. There was a decrease in quadriplegia and an increase in diplegia in the 2010 to 2014 period. The less severe impairments might be from the lower proportion of CP in the normal birth weight infant group from 68.75% to 38.24%. Studies showed high impairment in normal birth weight, which reflects less compensated brain ability than in LBW infants^(31,32).

When grouping tone abnormality and limb involvement, a greater proportion was spastic in BSCP, again very similar with other studies^(16,30). BSCP quadriplegia had significantly challenging disabilities, as expected and reported elsewhere^(12,30,33), and most were level V (42.86%) and IV (42.86%). BSCP diplegia presented with less disabilities than quadriplegia, mostly at level III (37.50%). Spastic hemiplegia had the predicted high functionality, as most are level I (50%). From these results, it appears necessary to sub-categorize BSCP and unilateral spastic CP, by using limb distribution. This is helpful because there are obvious differences in function and disability. Physicians can then customize treatment to each type of CP. However, most GMFCS were level IV (33.33%), showing high severity in our CP patients at the time of diagnosis. The authors did not find another research to compare with this. As stated before, the age of first diagnosis was much in line with previous authors, averaging 11.79 months^(34,35), this might have delayed treatment. The odds of diagnostic delays rise if a patient is referred from a general practice physician and if a child does not have any CP risk factors⁽³⁴⁾. Symptoms leading

to diagnosis were mostly from hypertonia (50%), delayed development (23.17%), and hyperreflexia or clonus positive (19.51%), followed by hypotonia and toe walking, both at 3.66%. Being aware of these most common symptoms is useful for both doctors and parents of children who have CP risk factors. Parents in all risk groups need to receive knowledge about developmental levels and expectations according to age and other underlying diseases, as well as CP signs and symptoms, so parents can help in surveillance and have early intervention to improve the outcomes.

Obviously, rehabilitation cannot start unless diagnosis is first made, and there is indeed some cause for concern regarding the rehabilitation process. The earliest record of advised therapy appears, on average 4.12 weeks after initial diagnosis. Physicians may have treated the patients or advised some management within this period, but no record of it exists in the files. Initial consultation for rehabilitation occurs, on average, 7.66 weeks after initial diagnosis, which is approximately three weeks after any first recorded therapy. This management is reasonable and practical when CP patients do not improve from the treatment.

The duration to first see the rehabilitation team after this consultation is 6.09 weeks. The reasons behind these delays vary. Most of the present study cases actually had an appointment with the rehab team three to four weeks after consultation, but eight cases had more than four weeks delays. Of these, four patients had unstable medical conditions such as seizure, pneumonia, and other challenges. These conditions necessarily suspended the rehab appointments until the patients ameliorated enough to begin therapy. The other four cases appeared to be victims of possible administrative errors, limited staff resources in a public hospital and unintentional misunderstandings by the patient's caregivers. For example, sometimes parents do not understand the departmental systems at the hospital, especially for first-time appointments, such as where and when to present their child, and they unfortunately missed their appointments. Thammasat University Hospital is a large and extremely busy tertiary-care facility serving a densely-populated province adjacent to Bangkok. Unlike in private hospitals, the desk staff has scarce time and cannot "walk" the patient and caregivers to different areas to meet various rehab team members. Compounding this situation, many of the parents are from lower-income strata and lack the confidence and background knowledge to ask questions when they do not clearly understand the procedures. The onus thus often falls on the consulting rehab physician to

later explain procedures after the first appointment was missed. This results in further delays.

At present, rehabilitation services are generally limited in Thailand. The rehabilitation treatment is still not widely known, not only in the general population but also in medical profession. In addition, rehabilitation doctors and associated teams consisting of physical, occupational, and speech therapists as well as the necessary tools and equipment tend to be concentrated in urban areas. The reasons for this are multifactorial, doctors or therapists want to have good quality of life. Many of these professionals lack career opportunities when working in a rural area. Many patients and caregivers do not have access to these professional services due to lack of knowledge, financial, geographic, and time if they live outside of typical catchment areas. Information in rehabilitation, access, and opportunity to medical rehabilitation in both urban and rural areas should be investigated further. In the past, government priorities were more concerned with patients' essential services such as emergency room facilities and basic health care, but as Thailand's economic progress is continuing, quality of life standards for those with chronic ailments should be improved as well.

Limitation

The present research was a retrospective, small, and single hospital-based, and not a population-based study. Future larger-scale, population-based research in the epidemiological patterns and characteristics of CP in Thailand could obtain more reliable information leading to improvement in services and better patient management for these children.

Conclusion

The rate of CP continues to rise each year in Thailand, consistent with figures from elsewhere. BSCP diplegia is the most common CP type at the authors' center. For the present study patients, there is high disability with BSCP quadriplegia and ataxic types, but high functionality is possible for patients with spastic hemiplegic CP. Hypertonia remains the major clue for diagnosis. Therefore, it is important for pediatricians and general physicians to be aware of this in children with CP risk factors. Delayed development is most likely to be the symptom that parents first notice. With the average age of diagnosis being at nearly one year of age at the authors' hospital, similar to worldwide figures, the rehabilitative team is concerned about potential delays for children to access therapy. In a large public hospital like the authors'

hospital, not only do we need to improve early surveillance of CP but we should attempt to create an easier referral system for the patients' parents to prevent any delays in rehabilitation. Solutions such as a one-stop center for CP patients might be feasible if funding and administrative policy agreed. This would benefit both patients and staff by bringing the multidisciplinary team together, and most likely improve outcomes. Many CP patients can attain a good quality of life and be included in society if they had access to adequate rehabilitative services.

What is already known on this topic?

The overall worldwide prevalence, characteristics, and etiology of CP is well documented. However, certain countries lack contextual data in areas such as management and quality of life throughout different demographics.

What this study adds?

This study reveals the first clear data regarding CP's prevalence, characteristics, treatment, as well as times to rehabilitation at Thammasat University Hospital, Thailand. The present data was acquired over a decade, which is rather long-term for the region.

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Conflicts of interest

The authors declare no conflict of interest.

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