ORIGINAL ARTICLE

Prevalence study of cerebral palsy in Hong Kong children

研究大腦麻痺在香港兒童的普遍情況

WKL Yam 任嘉玲
HSS Chan 陳凱珊
KW Tsui 徐炯環
BPHL Yiu 劉佩香
SSL Fong 方少麗
CYK Cheng 鄭毓君
CW Chan 陳作耘
Working Group
on Cerebral Palsy,
Hong Kong Society of
Child Neurology and
Developmental Paediatrics

Objectives. To investigate the prevalence of cerebral palsy in local children aged 6 to 12 years and to evaluate service utilisation by those children who attend mainstream schools.
Design. Cross-sectional survey.
Setting. Mainstream primary schools and special needs schools in Hong Kong.
Participants. Headmasters or headmistresses of special needs schools, and various organisations that provide services to children with cerebral palsy in the school year September 2003 to June 2004.
Main outcome measures. Prevalence of cerebral palsy and support services used by children with cerebral palsy who attend a mainstream school.
Results. Of 435 572 children, 578 with cerebral palsy were identified. The overall point prevalence was 1.3 per 1000 children. The age-specific prevalence rate varied from 1.04 to 1.50 per 1000 children. Approximately 38% of children with cerebral palsy attended a mainstream school. Among those studying in special needs schools, 96% attended a school for the physically handicapped or a school for the severely mentally handicapped. Among 219 children with cerebral palsy in mainstream schools, 57 (26%) received educational support, and 134 (61%) received out-patient therapy support. Only 12% received both supporting services. No educational or therapeutic support was received by 26% of children.
Conclusions. Compared with overseas data, the low prevalence of cerebral palsy detected in local children in this investigation may be due to the differences in study design or a genuinely low prevalence. Setting up a cerebral palsy registry could help monitor the local prevalence of this childhood disability more accurately, thereby providing more reliable information for planning support services for this subgroup of children.

Key words:
Cerebral palsy;
Children;
Prevalence;
Survey

關鍵詞：
大腦麻痺；
兒童；
普遍性；
調查

Hong Kong Med J 2006;12:180-4

Department of Paediatrics and Adolescent Medicine, Alice Ho Miu Ling Nethersole Hospital, Chuen On Road, Tai Po, Hong Kong
WKL Yam, MRCP, FHKAM (Paediatrics)
KW Tsui, MRCP, FHKAM (Paediatrics)
Central Kowloon Child Assessment Centre, Department of Health, Hong Kong
HSS Chan, MB, BS, FHKAM (Paediatrics)
BPHL Yiu, MCSP, MSc
Occupational Therapy Department, Princess Margaret Hospital, Laichikok, Hong Kong
SSL Fong, MPhil, PDOT
Jockey Club Marion Fang Conductive Learning Centre, The Spastics Association of Hong Kong
CYK Cheng, HKRPT, M Ed Stud
Hong Kong Society of Child Neurology and Developmental Paediatrics
CW Chan, FRCP, FHKAM (Paediatrics)

Correspondence to: Dr WKL Yam
(e-mail: wklyam@hotmail.com)

目的：調查本地6至12歲兒童出現大腦麻痺的普遍性，並評估當中就讀主流學校的兒童的支援服務使用情況。
設計：橫斷面調查。
安排：香港的主流小學和特殊學校。
參與者：2003年9月至2004年6月的學年中特殊學校的校長，以及提供支援服務給予大腦麻痺兒童的機構。
主要結果測量：大腦麻痺的普遍情況，和就讀主流學校的大腦麻痺兒童使用支援服務的情況。
結果：在435 572名兒童中，578人被證實患有大腦麻痺，整體普遍比率為每1000名兒童有1.3人，而按年齡劃分的普遍比率則介乎每1000名兒童有1.04至1.50人。約有38%大腦麻痺兒童就讀主流學校，而就讀特殊學校的兒童中，有96%是在為身體殘障或嚴重智力殘障人仕而設的學校接受教育。219名就讀主流學校的大腦麻痺兒童中，57人（佔26%）接受教育支援，134人（佔61%）接受門診治療支援，只有12%兒童同時接受這兩種支援。有26%兒童沒有接受教育或治療支援。
結論：與外地數據比較，本研究顯示大腦麻痺兒童的現患率甚低。這可能與研究採用的設計不同有關，但亦可能是低估了香港的情況。設立一個中央大腦麻痺登記冊，可以幫助監察這種兒童病的確實普遍情況，從而獲得準確資料以規劃支援這類病人的服務。

Introduction

Cerebral palsy (CP) is a major cause of childhood developmental disability. It is an umbrella term that covers a range of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain that arise in the early stages of development.[1] In addition to motor disabilities, children with CP often have co-morbidities including epilepsy, learning difficulties, behavioural problems, and visual and hearing impairment.[2] Affected children may therefore need a wide range of services including medical care, therapy training, rehabilitation equipment, and special education programmes. In addition, children may require multidisciplinary input at various stages of development because CP is a lifelong condition. Expensive interventions such as medication, surgery, equipment, and assistive technology are often needed to improve the functional ability of children with CP and their participation in society. Thus, there are significant resource implications in supporting this unique group of children. Good service planning and adequate funding depends on the availability of local statistics and figures.

The prevalence of CP in overseas populations varies from 1.2 to 2.5 per 1000 live births.[3-9] No prevalence data are available for Hong Kong mainly because there is no central registry for handicapped children and a multiparty health care system complicates the continuous follow-up of at-risk children.[10] Two methods may be adopted to determine the prevalence of CP in a geographically defined area such as Hong Kong: birth cohort registry and cross-sectional survey.[3,11] A cross-sectional survey is usually applied to study the prevalence of any condition and is useful for service planning. A registry is another commonly used method when the prevalence is studied to determine the possible underlying aetiology and risk factors.[3] Nonetheless, to establish reliable estimates with survey methodology requires a large sample size and the inclusion of institutionalised populations.[3] The enormous resources required for such a population-based survey have been vividly described in the Hong Kong Government 1995 White Paper on Rehabilitation: “a territory-wide prevalence study (on the disability prevalence rate) would be a highly specialized area…we have concluded that it cannot be conducted in the context of the 1996 by-census…to conduct a special survey with a clinical type of approach would, however, be an enormous task…in terms of time, effort and expenditure”.[12] Nonetheless, the Working Group on Cerebral Palsy of the Hong Kong Society of Child Neurology and Developmental Paediatrics considered it a worthwhile challenge to carry out the first territory-wide study of the prevalence of CP in local children. The Working Group also reviewed service utilisation by this subgroup of children who attended mainstream schools.

In Hong Kong, children with CP attend special needs or mainstream schools. In special needs schools, they receive school-based educational assistance and supportive therapy.[13] Supportive services for children with CP who attend mainstream schools are more variable. They may include educational support from the Resource Help Support (RHS) service or from the Integrated Education (IE) programme, which both come under the jurisdiction of the Education and Manpower Bureau (EMB).[12,14] The RHS service comprises a team of specially trained teachers who provide remedial teaching, follow-up, and recommendations on support for children with CP in mainstream schools.[12] The IE programme advocates a whole-school approach where an inclusive environment is promoted and all school personnel are encouraged to support students with CP to fully integrate in the school.[14] Teachers are encouraged to adapt the curriculum, and to use differential teaching methods for different learning styles and a variety of assessment methods. Children with CP may receive physiotherapy and/or occupational therapy at out-patient departments of the Hospital Authority. There is also an Integrated Support Project of the Jockey Club Marion Fang Conductive Learning Centre (CLC) of the Spastics Association of Hong Kong. This is a community-based 3-year programme funded by the Hong Kong Jockey Club.[15] The programme provides comprehensive support to children with CP studying in a mainstream school and ranges from therapy training to school visits, school talks, and specific recommendations to teachers for relevant accommodation for these children. To facilitate the current trend of integrating students with mild CP back into mainstream schools, it is essential to ensure that support for these children is accessible, adequate, and appropriate.

Methods

The prevalence of children with CP aged between 6 and 12 years was determined using a cross-sectional survey. The study was carried out in the school year September 2003 to June 2004. The study was designed to capture as many children with CP as possible who studied in mainstream primary schools and all special needs schools. The total number of children enrolled in the education system in the school year 2003/2004 formed the denominator, which was provided by the EMB. The number of identified children with CP formed the numerator and the prevalence rate was calculated. An important step in establishing this local prevalence study was to identify all possible sources (ie mainstream primary schools and special needs schools) that could capture children with CP within the predetermined age range. The current central disability registry of the Social Welfare Department and the central registry of students with special needs under the EMB had local statistics classified according to the broad functional disability groups (eg blind, deaf, physically handicapped).[13] Local statistics based on specific neurodevelopmental disorders such as CP were not available. Unlike many developed countries, Hong Kong does not have a CP registry or birth cohort. Nevertheless all children in Hong Kong are required to receive a minimum of 9 years’ education that includes 6 years of primary school and 3 years of junior secondary school.[16] It was therefore feasible to identify all children in the educational system. Children usually enter mainstream primary schools at or after 6 years of age and graduate from primary to secondary school at or around 12 years of age. In special needs schools, the age of school entrance and graduation are more flexible.

We approached all special needs schools to identify the total number of children with CP. There were two schools for visually impaired children, four for the hearing impaired, seven for children with physical disability, 31 for children with mild-to-moderate mental handicap, and 10 for children with severe mental handicap.[17] A letter was sent to the headmasters/mistresses in September 2003. They were invited to report all children with CP aged between 6 and 12 years studying in their schools. A standardised form was used to obtain information on each child with CP and included sex, date of birth, and type of CP. The school staff was advised to confirm the presence of CP based on the diagnosis stated in the medical file. Follow-up phone calls were carried out. A total of 52 special needs schools returned the survey forms. No reply was obtained from two schools for children with mild-to-moderate mental handicap. Children with CP studying in mainstream schools were identified from multiple sources. They were identified if they received one of the following services: (i) IE programme under EMB; (ii) RHS service under EMB; (iii) CLC of the Spastics Association of Hong Kong; (iv) treatment at a Physiotherapy Out-patient Department of the Hospital Authority; (v) treatment at an Occupational Out-patient Department of the Hospital Authority; and (vi) Child Assessment Service (CAS) under the Department of Health. We chose not to approach all the 780 mainstream primary schools in Hong Kong because the actual number of children with CP in each school would be small and it would be difficult to ensure a good response rate from all schools.[18] We contacted the EMB, CLC, CAS, the Hong Kong Physiotherapy Association, and the Hong Kong Occupational Therapy Association. We gained the cooperation of all the Physiotherapy Out-patient Departments and Occupational Therapy Out-patient Departments. A standardised form was given that requested information on type of CP, sex, date of birth, and first four digits of the Hong Kong Identity Card (HKID) number of each child with CP. Since a child might receive more than one service at the same time, we cross-checked for overlapping or multiple entries of the same child from the replies of various services. Those who had the same first four digits of the HKID number, sex, date of birth, and type of CP were considered as duplicate cases. We advised all services to ascertain the diagnosis of CP from their case files.

In addition to the local prevalence rate, demographic and clinical characteristics of the children were also studied. Cerebral palsy was classified as spastic, dyskinetic, ataxic, mixed, or unclassified. Children with spastic CP were further divided according to topographic distribution: hemiplegic, diplegic, triplegic, quadriplegic, or unclassified. The current pattern of service utilisation by children with CP studying in a mainstream school was also analysed.

Table 1. Number of children in special needs and mainstream schools

School	Children with cerebral palsy No. (%)	All children No. (%)
Special needs schools	359 (62)	2897 (1)
Mainstream schools	219 (38)	432 675 (99)
Total	578 (100)	435 572 (100)

Results

Among 435 572 children aged 6 to 12 years, 578 children with CP were identified (Table 1). The overall point prevalence rate was 1.3 per 1000 children. Approximately 38% of children with CP were studying in a mainstream school. The age-specific prevalence rates ranged from 1.04 to 1.50 per 1000 children (Table 2). Among those studying in a special needs school, 96% were in a school for children with physical disability (58%) or severe mental handicap (38%). The overall male to female ratio was 3:2. This sex ratio was similar for both types of schools and among different age-groups.

Spastic CP was the most common type reported (Table 3). Dyskinetic CP was more common in the special needs schools. Hemiplegia and diplegia were common in children in mainstream schools whereas quadriplegia and diplegia were common in special needs schools (Table 3).

Table 4 shows the services used by the 219 children with CP in mainstream schools. Among them, 57 (26%) received educational support through the RHS or IE teams under EMB or the Integrated Support Project under CLC. A total of 134 (61%) children received out-patient physiotherapy and/or occupational therapy. Only 12% received both educational and therapy services, whereas 26% received neither.

Discussion

One of the aims of this cross-sectional survey of school-aged children was to identify the local prevalence rate of CP. We chose the lower age limit of 6 years because the diagnosis of CP can be confirmed by this age. In most studies, 5 years old is the age at which clinical description is considered reliable for a diagnosis of CP.[19] Our case ascertainment of CP depended on the information quoted in medical or case files. We believed these files provided the most reliable source of information on the diagnosis of CP unless examination could be performed on every child. However, the information could be incorrect if the files were not up-to-date. Another limitation was the inability to apply more stringent diagnostic criteria for CP because of limited information on file.

The prevalence of CP estimated from this study was lower than the rates of 2.0 to 2.5 per 1000 children recorded in European CP registries.[3] Nevertheless, it was compara-

Table 2. Age distribution of children with cerebral palsy and age-specific prevalence rates

Age (years)	No. of children with cerebral palsy		Total No. of children	Prevalence rate per 1000 children
	Special needs schools	Mainstream schools		
6.0-6.9	36	34	67 237	1.04
7.0-7.9	49	57	73 223	1.45
8.0-8.9	62	54	77 318	1.50
9.0-9.9	78	33	77 916	1.42
10.0-10.9	72	25	79 007	1.23
11.0-12.0	62	16	60 871	1.28
Total	359	219	435 572	1.33

Table 3. Classification of children with cerebral palsy

	Children with cerebral palsy in special needs schools, n=359 No. (%)	Children with cerebral palsy in mainstream schools, n=219 No. (%)
Spastic	237 (66)	192 (88)
Hemiplegia	29 (12)	103 (54)
Diplegia	78 (33)	78 (41)
Triplegia	10 (4)	6 (3)
Quadriplegia	107 (45)	2 (1)
Unclassified or others	13 (5)	3 (2)
Dyskinetic	33 (9)	5 (2)
Ataxic	15 (4)	5 (2)
Mixed	14 (4)	5 (2)
Unclassified or others	60 (17)	12 (5)

Table 4. Services utilisation of children with cerebral palsy in mainstream schools

Programme*	Children with cerebral palsy in mainstream schools, n=219 No. (%)
Educational support	57 (26)
EMB RHS service	31 (14)
EMB IE support	20 (9)
CLC Integrated Support Project	6 (3)
Therapy support	134 (61)†
Hospital Authority PT	123 (56)
Hospital Authority OT	37 (17)
Assessment service	
Child Assessment Service	69 (32)

* EMB denotes Education and Manpower Bureau, RHS Resource Help Support, IE Integrated Education, CLC Jockey Club Marion Fang Conductive Learning Centre, PT physiotherapy, and OT occupational therapy

† Some children might receive both physiotherapy and occupational therapy; therefore the total number of children on therapy support was less than the summation of subgroups

ble with estimates from other surveys in Asia; 1.6 per 1000 children aged below 7 years for a population-based cross-sectional study in China[8] and 1.34 per 1000 6-year-old children in Japan.[9] Our lower prevalence rate could be due to the differences in study design or genuine. Different prevalence rates can arise from different study designs.[3,9] While a birth cohort registry has been used in many overseas studies, we adopted a cross-sectional survey approach. The denominator of our prevalence rate was not restricted to the number of live births in Hong Kong. Our numerator and denominator included children who immigrated from other parts of the world (including China) if they studied in Hong Kong but excluded those born in Hong Kong but attending schools elsewhere. In addition children who died before the study period, regardless of whether they had CP, were excluded. The method to determine prevalence is also different for the two designs. When birth cohort registry was used, children were usually followed up for a number of years and the prevalence of CP derived after excluding losses from mortality and migration. The cross-sectional survey method gave a direct estimate of the prevalence of CP within the defined survey period.

A high response rate by the special needs schools and the use of multiple sources for mainstream schools provided extensive coverage of our population. Yet not all children with CP in mainstream schools could be included because of resource implications. We therefore decided to track children with CP in mainstream schools according to the supporting services they received. Children with CP might nevertheless be missed if they did not require any service or had graduated from the services, as would those around 6 years old if they were still receiving early interventional services from the Social Welfare Department. Similarly, CP children receiving therapy from the private sector or English-speaking organisations and those who were medically unfit and remained hospitalised could not be identified.

We did not use the Hospital Authority database because computerisation of out-patient clinical information had not been implemented by many hospitals. Future studies should include both out-patient and in-patient data from the Hospital Authority as well as for children followed up by private practitioners.

Age-specific prevalence rates were lower at both ends of the age range (Table 2). We believed this was due to difficulty in capturing data for these children. For those with CP about 6 years old, some might still be attending nurseries or kindergartens. As there are over 700 local nurseries and kindergartens, it was beyond our means to include them in the present study.[20] For the upper end of the age range, a low CP prevalence might be due to some having graduated or defaulted from the services.

In order to comply with the Personal Data (Privacy) Ordinance in Hong Kong[21] under which personal data (including HKID number) should not be identifiable without the person's consent, we decided to obtain a portion of the HKID number only when collecting information. While this method was effective for most cases, it might not distinguish twins or children born on the same date, if their sex and type of CP were the same. To exclude duplication, in future we propose to include the first 4 digits as well as the last digit of the HKID number.

Despite the above-mentioned limitations, this study was the first local, population-based study of school-aged children with CP. It provided a minimum estimate of the prevalence of CP. The slight male predominance, higher rate of quadriplegic and dyskinetic CP sufferers in special needs schools, and the high proportion of children with CP in special needs schools that catered for the physically handicapped or severe mentally handicapped, provides valuable information for planning future facilities (eg residential amenities, staffing, toilets, etc) and curricula.

Data on the current service availability for children with CP who attend mainstream schools was also enlightening. Our results showed that a high proportion (approximately 40%) were attending a mainstream school. Only 12% of these children were supported by both educational and therapy services, while 26% received no supporting service at all. Rehabilitation professionals and special educators need to evaluate factors that limit service provision to this subgroup of children. Further studies should determine the best model to facilitate coordination of educational and therapy services.

We strongly recommend the setting up of a Hong Kong CP registry to monitor the prevalence and characteristics of this common childhood disability. Information on impairment, disability level, as well as co-morbidities of children with CP should also be collected for optimal service planning.[2] Educators, rehabilitation professionals, and policy makers could obtain useful information from the registry to match current and projected needs of children with CP in medical, educational, and social services. A registry differs from the current information systems because data in a registry will be more accurate and case ascertainment more complete. A registry can provide accurate information when communicating with parents, for examples, co-morbid conditions and survival rates. It may also provide a sampling frame that allows selection of children with similar characteristics for recruitment to randomised trials. There is nonetheless a need for rigorous methods when compiling a registry. Highly specialised personnel with adequate time, manpower, and stable funding support must be available to maintain such a registry so that information can be continuously collected.[11]

Acknowledgements

We are grateful to the following organisations for their invaluable assistance in this survey: EMB and all special needs schools, Physiotherapy Departments and Occupational Therapy Departments under the Hospital Authority, Hong Kong Physiotherapy Association, Hong Kong Occupational Therapy Association, CAS of Department of Health and CLC of the Spastics Association of Hong Kong. We would also like to thank Mr Morris Wu and Ms Ashley Yu for their excellent help on statistical analysis. Last but the least, we are indebted to the Council of the Hong Kong Society of Child Neurology and Developmental Paediatrics for its unwavering support and guidance throughout this project.

References

1. Mutch L, Alberman E, Hagberg B, Kodama K, Perat MV. Cerebral palsy epidemiology: where are we now and where are we going? Dev Med Child Neuro 1992;34:547-51.
2. Rosenbaum P. Cerebral palsy: what parents and doctors want to know. BMJ 2003;326:970-4.
3. Stanley F, Blair E, Alberman E, editors. Cerebral palsy: epidemiology and causal pathways. Mac Keith Press: London; 2000.
4. Prevalence and characteristics of children with cerebral palsy in Europe. Dev Med Child Neuro 2002;44:633-40.
5. Hagberg B, Hagberg G, Beckung E, Uvebrant P. Changing panorama of cerebral palsy in Sweden. VIII. Prevalence and origin in the birth year period 1991-94. Acta Paediatr 2001;90:271-7.
6. Colver AF, Gibson M, Hey EN, Jarvis SN, Mackie PC, Richmond S. Increasing rates of cerebral palsy across the severity spectrum in north-east England 1964-1993. The North of England Collaborative Cerebral Palsy Survey. Arch Dis Child Fetal Neonatal Ed 2000;83:F7-F12.
7. Reddihough DS, Collins KJ. The epidemiology and causes of cerebral palsy. Aust J Physiother 2003;49:7-12.
8. Liu JM, Li S, Lin Q, Li Z. Prevalence of cerebral palsy in China. Int J Epidemiol 1999;28:949-54.
9. Suzuki J, Ito M. Incidence patterns of cerebral palsy in Shiga Prefecture, Japan, 1977-1991. Brain Dev 2002;24:39-48.
10. Chan-Lui WY. Cerebral palsy in Hong Kong [dissertation]. Hong Kong: University of Hong Kong; 1980.
11. Cans C, Surman G, McManus V, Coghlan D, Hensey O, Johnson A. Cerebral palsy registries. Semin Pediatr Neurol 2004;11:18-23.
12. 1995 White paper on rehabilitation: disability prevalence rates. HKSAR Health, Welfare and Food Bureau website: http://www.hwfb.gov.hk/hw/text/english/consult/index.htm. Accessed 27 Jul 05.
13. Special education. HKSAR Education and Manpower Bureau website: http://www.emb.gov.hk/index.aspx?nodeID=154&langno=1. Accessed 27 Jul 05.
14. Whole school approach to integrated education. HKSAR Education and Manpower Bureau website: http://www.emb.gov.hk/index.aspx?nodeID=185&langno=1. Accessed 27 Jul 05.
15. Integrated Support Project of Conductive Learning Centre (2003-2004 Annual Report, p.24). The Spastics Association of Hong Kong website: http://www.spastic.org.hk/eng/pdf/2004annualreport.pdf. Accessed 27 Jul 05.
16. Policy highlights of the primary and secondary education. HKSAR Education and Manpower Bureau website: http://www.emb.gov.hk/index.aspx?nodeID=139&langno=1. Accessed 27 Jul 05.
17. Special schools. HKSAR Education and Manpower Bureau website: http://www.emb.gov.hk/index.aspx?langno=1&nodeid=154#SpecialSchools. Accessed 27 Jul 05.
18. Primary schools. HKSAR Education and Manpower Bureau website: http://www.emb.gov.hk/index.aspx?langno=1&nodeID=396. Accessed 27 Jul 05.
19. Surveillance of Cerebral Palsy in Europe. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). Dev Med Child Neuro 2000;42:816-24.
20. Kindergarten education. HKSAR Education and Manpower Bureau website: http://www.emb.gov.hk/index.aspx?langno=1&nodeID=916. Accessed 27 Jul 05.
21. Hong Kong Privacy Ordinance. Office of the Privacy Commissioner for Personal Data, Hong Kong website: http://www.pco.org.hk/english/ordinance/code_id.html. Accessed 27 Jul 05.