

Clinical profile of young children with mental retardation and developmental delay in Hong Kong

CME

Kitty ML Tang 鄧美寧
Theresa YK Chen 陳玉琪
Vanessa WY Lau 劉慧然
Morris MF Wu 胡文輝

- Objective** To report the clinical profile of children with mental retardation and developmental delay diagnosed by the Child Assessment Service.
- Design** Retrospective study.
- Setting** Child Assessment Service, Department of Health, Hong Kong.
- Participants** Data pertaining to the children with mental retardation and developmental delay were drawn from an in-house clinical information system in the year 2004.
- Main outcome measures** Clinical profiles including: sources, reasons and age of referral, diagnosis, gender ratio, co-morbidities, and socio-economic background.
- Results** In 2004, 23% (1463 of 6439) of Child Assessment Service referrals were diagnosed to have mental retardation or developmental delay. The Family Health Service was the major source of referral (64%). The majority (93%) of children were referred before the age of 6 years. The most common reason for referral was language delay (39%). More boys were affected (3 boys: 1 girl). The two most common co-morbidities were autistic spectrum disorders (33% in mental retardation and 19% in developmental delay) and discrepant language delay (17% in mental retardation and 47% in developmental delay). The socio-economic status of these families was higher than those in the general population.
- Conclusion** The data presented here provide information on the descriptive epidemiology of mental retardation and developmental delay among Hong Kong children. Since mental retardation and developmental delay are common developmental disabilities in Hong Kong, public health education to promote and ensure early screening and identification of cases is an important prelude to early training and guidance for families with children having these conditions.

Introduction

Mental retardation (MR) is the most common developmental disability in many countries around the world.¹⁻³ It is characterised by significant limitations both in intellectual functioning and adaptive behaviour, as measured by standardised intelligence tests and parent-reported scales of adaptive behaviour.⁴ In the United States, the prevalence rate is estimated to be around 1% in the population and ranks first among chronic conditions causing major activity limitation.⁴ On the other hand, developmental delay (DD) is a term that is commonly applied to a preschool child whose development is substantially behind the average expectations of children of the same age in two or more developmental domains.⁵ Very often, DD represents an early warning sign of later developmental problems, such as MR and other developmental disorders.

In Hong Kong, the local prevalence of MR is estimated to be around 0.9 to 1.3% of the general population.⁶ However, there is a paucity of data describing the epidemiology of MR and DD among the paediatric population. An area-specific measure of the epidemiology of MR or DD could assist in targeting aspects of need and allocating resources within a society. This is the first study in Hong Kong to report the clinical profile of children diagnosed as having MR and DD by the Child Assessment Service (CAS) of the Department of Health. The year 2004 was targeted. This study also aimed to explore the familial and socio-economic background of these children.

Key words

Mental retardation; Developmental disabilities; Health services needs and demand

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Child Assessment Service, Department of Health, Hong Kong

KML Tang, MMedSc, FHKAM (Paediatrics)

TYK Chen, MPhil (Clin Psy)

VWY Lau, MSocSc (Clin Psy), Phil PgD (Psy)

MMF Wu, MSW, Dip Epidemiology

Correspondence to: Dr KML Tang
E-mail: kitty_tang@dh.gov.hk

香港智力障礙和發展遲緩兒童的臨床概況

目的	研究香港兒童中，被兒童體能智力測驗服務診斷為智力障礙和發展遲緩兒童的臨床概況。
設計	回顧研究。
安排	衛生署兒童體能智力測驗服務。
參與者	是次研究在2004年進行，透過一個內部臨床數據系統，提取智力障礙和發展遲緩兒童的資料進行分析。
主要結果測量	臨床概況包括：轉介來源、原因、轉介年齡、診斷、性別比例、患上相關的疾病、社會經濟背景等。
結果	2004年被轉介到兒童體能智力測驗服務的兒童中，有23% (1463/6439)被診斷為智力障礙和發展遲緩。這些個案主要由衛生署家庭健康服務轉介(64%)，大部分病童(93%)被轉介時都少於六歲。最普遍的轉介原因，是發現他們語言能力遲緩(39%)，受影響者以男童較多(男女比例為3:1)。病童中最普遍出現的相關疾病為自閉症疾患(智力障礙者和發展遲緩者的比例分別為33%和19%)和語言發展特別遲緩(智力障礙者和發展遲緩者的比例分別為17%和47%)。病童多來自較高社會經濟地位的家庭。
結論	這個報告講述香港兒童智力障礙和發展遲緩的普及概況。由於智力障礙和發展遲緩是香港普遍的發展障礙病症，加強宣傳教育，以及及早發現患病兒童，才能令這些病童的家庭及早接受訓練和輔導。

Methods

Source of data

The CAS of the Department of Health serves all Hong Kong children aged below 12 years. In 2004, there were seven child assessment centres (CACs) distributed across the territory. They are secondary referral centres serving children with suspected developmental problems. One of the main referrers was the Family Health Service (FHS) of the Department of Health. According to the annual statistics of CAS, there were around 6000 referrals in 2004 and FHS accounted for nearly 60% of them.⁷ Based on unpublished statistics of the FHS in 2004, more than half of the preschool children aged 18 months or older in Hong Kong (ranging from 55% in the urban area of Kwun Tong to 95% in the New Territories of Fanling) visited the FHS for free preventative care and immunisation.⁸ Because of the coverage provided by the FHS and the CAS, a high proportion of Hong Kong preschool children with suspected developmental problems are referred for assessment. Therefore, the data of CAS can be regarded as a reasonably representative sample of children with various paediatric conditions in Hong Kong.

In this study, the data were retrieved from an in-house clinical information system of the CAS for the period of January to December of 2004. The clinical

information system serves both operations and analysis needs of the CAS. Regular quality assurance exercises were conducted to secure the accuracy and validity of the data collected.

Subjects

During the relevant period, a total of 6439 children with complaints of developmental, emotional, and behaviour problems were newly referred to CAS. Among them, 1463 (23%) were later diagnosed to have DD or MR, which represented a substantial proportion of the new referrals received. Children with initial diagnoses of MR and DD were selected and their data were included in this study.

Procedure

Demographic and familial data were collected by registered nurses of various CACs from the major caretakers of the children at the parent intake interview, shortly after registration for service. The majority of the subjects were evaluated by developmental paediatricians of the CAS using the Griffiths Mental and Developmental Scales (GMDS).⁹ As stated in the introduction, DD is a term commonly applied to a preschool child whose developmental level is substantially behind the average expectations of children of the same age in two or more developmental domains. These domains include cognitive and intellectual, gross motor, fine motor, language, social, and adaptive development.⁵ Significant delay is taken to refer to scores 1.5 to 2.0 standard deviation (SD) below the mean on norm-referenced age-appropriate developmental tests.¹⁰ At the CAS, borderline delay was taken to refer to scores 1.0 to 1.5 SD below the mean of GMDS. A small group of children were evaluated by clinical psychologists using standardised intelligence tests, such as the Hong Kong Wechsler Scale for Children.¹¹ All cases assessed to have significant DD or worse than moderate-grade MR were referred to hospital paediatricians for further investigation of any underlying medical conditions. Children with suspected childhood behavioural disorders such as autistic spectrum disorders (ASD) were evaluated either by paediatricians or clinical psychologists, using the International Classification of Diseases¹² and the Diagnostic and Statistical Manual of Mental Disorders (4th ed)⁴ classification systems.

For common co-morbidities, ASD is a clinical condition where qualitative impairments were evident in the domains of social interaction, communication, as well as presence of restricted and repetitive behaviours. Disturbance in at least one of these areas must be manifested prior to the age of 3 years. Whereas, 'discrepant language delay' or 'discrepant gross motor delay' is considered as a subset of DD,

whenever language or gross motor development is particularly delayed. For the latter therefore, additional training on speech or gross motor skills is required, apart from the usual developmental training.

The responsible case managers entered the data, including the co-morbidities and demographics into the clinical information system. In this two-step analysis, data were first retrieved from the information system, based on predefined selection criteria. Then, a professional team (comprised one paediatrician and two clinical psychologists) reviewed the records on a case-by-case basis, to ensure the coding accuracy.

Data analysis

The Statistical Package for the Social Sciences (Windows version 10.0; SPSS Inc, Chicago [IL], US) was used to analyse the data. Descriptive statistics of the clinical profile of these children, including sources, reasons and age of referral, diagnosis, gender ratio, co-morbidities and socio-economic background, were also logged. To reflect the socio-economic status of the families of children with MR and DD, the education level and occupation of the children's parents were also analysed.

Results

Sources of referral

In 2004, 1463 (23%) of CAS referrals were diagnosed to have DD or MR. Figure 1 shows that FHS was the major source of referral, which accounted for approximately 64% of the cases from the CAS. Other common referrers included the Hospital Authority, general practitioners, and other units of the Department of Health, eg School Dental Health Service and Student Health Service. A small percentage of patients were referred by educational psychologists of the Education and Manpower Bureau and the Social Welfare Department.

Age at referral

In this study, children with MR and DD usually presented problems in the preschool years. The majority (93%) were referred before the age of 6 years. One third (35%) were referred for assessment between the ages of 2 years and 2 years 11 months. Nearly one quarter (22%) were referred when they were 1 year to 1 year 11 months old (Fig 2).

Reasons for referral

The most common reason for referral was language delay (39%). Global DD (30%) was the second major reason and the third most common was emotional or

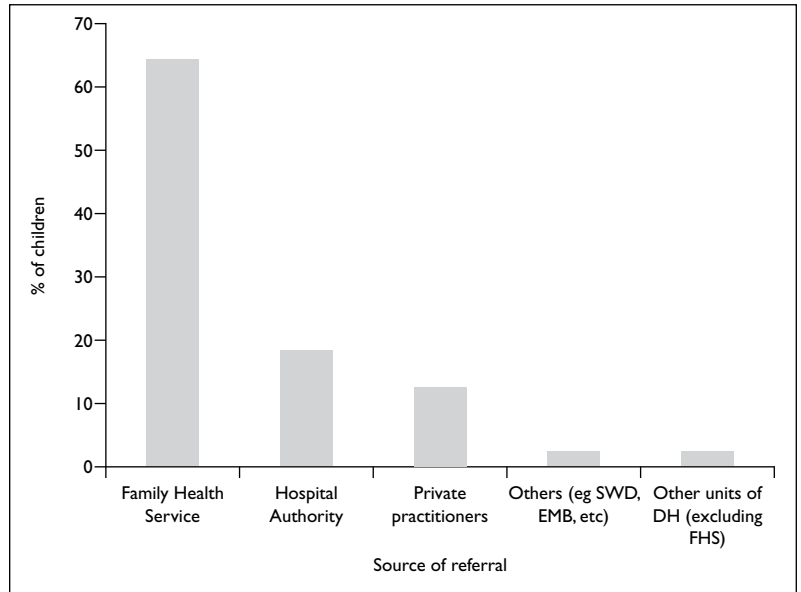


FIG 1. Percentage of children with mental retardation and developmental delay according to source of referral
SWD denotes Social Welfare Department, EMB Education and Manpower Bureau, DH Department of Health, and FHS Family Health Service

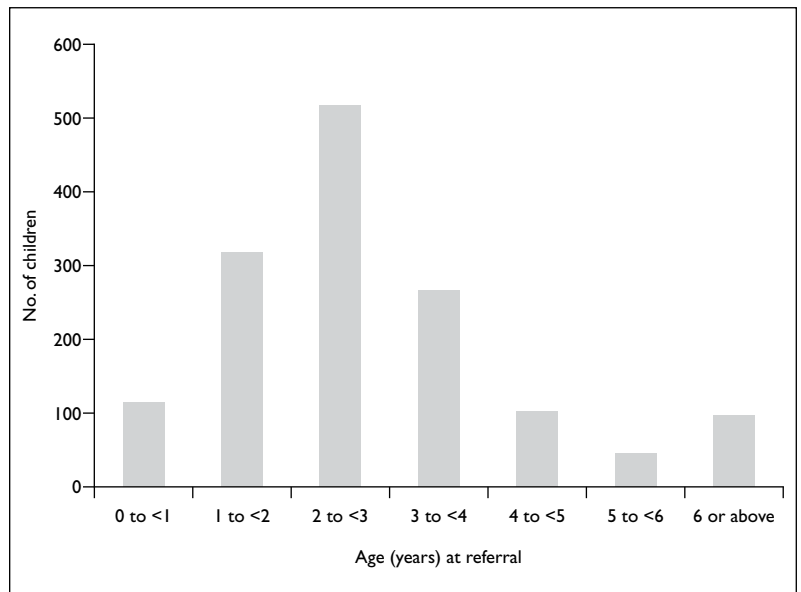


FIG 2. Number of children with mental retardation and developmental delay according to age at referral

behavioural difficulties (13%) [Fig 3].

Diagnosis and gender ratio

Two thirds of the children were assessed to have borderline DD (975/1463), and the remaining one third (488/1463) had significant DD. The male-to-

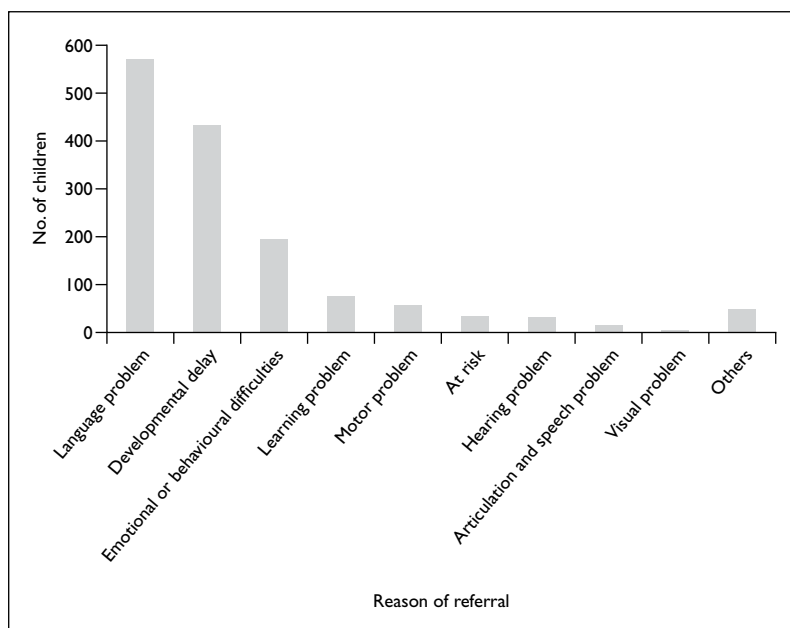


FIG 3. Number of children with mental retardation and developmental delay according to reason for referral

TABLE 1. Number of children with associated clinical conditions*

Condition	Developmental delay (n=975)	Mental retardation (n=488)	Total (n=1463)
Very low birth weight	14	11	25
Cerebral palsy	5	16	21
Epilepsy	0	17	17
Autistic spectrum disorders	186	160	346
Hearing impairment	9	5	14
Visual impairment	3	12	15
Discrepant language delay	459	84	543
Discrepant gross motor delay	69	37	106
Discrepant fine motor delay	32	20	52
Clinical syndromes	5	26	31
Behavioural problems	53	12	65

* Each child could have none or more than one associated condition

TABLE 2. Distribution of education attainment in parents of children with mental retardation and developmental delay and in the general population in 2004

Education level	No. (%)		General population of Hong Kong (%) ⁶
	Father (n=1341)	Mother (n=1360)	
Primary school or below	141 (10)	145 (11)	27
Secondary school level	817 (61)	884 (65)	47
Matriculation or above	293 (22)	224 (16)	27
Others and unknown	90 (7)	107 (8)	-

female ratio was about 3:1 for both groups.

Common associated features

The most common co-morbidity was ASD. Table 1 shows that 19% (186/975) of the children with DD and 33% (160/488) of those with MR were diagnosed to have ASD. Other common associated features were discrepant language delay (47% in DD and 17% in MR), and 7% of the total had discrepant gross motor delay. In our locality, co-morbidity in the form of epilepsy (1.2%), cerebral palsy (1.4%), and clinical syndromes (2.1%) were encountered only occasionally (Table 1).

Socio-economic background

As shown in Table 2, around two thirds of parents of children with MR and DD had completed secondary school (61% for fathers and 65% for mothers). About one fifth of the parents had matriculation level education or above (22% for fathers and 16% for mothers). Around 10% of the parents had only attained primary school level education or below (10% for fathers and 11% for mothers).

Over half of the fathers of these children had non-manual jobs (58%); mainly they were managers and administrators, professionals, associated professionals, clerks, and service workers.¹³ About half of the mothers (48%) were housewives (Table 3).

Discussion

This study was the first attempt in Hong Kong to report the epidemiological profiles of children with MR and DD. Its major limitation was that children not served by the CAS were not included and hence the figures reported may be underestimates of the real situation. Despite this, the data analysed a reasonable comprehensive study population, which was likely to represent the profile of children with MR and DD in Hong Kong. Our findings show that children with MR and DD are one of the major groups of preschool children (ie 1463 or 23% of all cases) served by the CAS. This indicates a considerable demand for

TABLE 3. Distribution of occupation in parents of children with mental retardation and developmental delay and in the general population in 2004

Occupation	No. (%)		General population of Hong Kong (%) ⁶
	Father (n=1272)	Mother (n=1220)	
Manual workers	263 (21)	39 (3)	22
Non-manual workers	734 (58)	461 (38)	39
Others and unknown	206 (16)	132 (11)	0.1
Unemployed or non-working	69 (5)	588 (48)	39

early interventions and parent support networks to meet the special needs of the developmental and educational aspects of these children.

Most children in our study were referred by doctors from FHS and other public institutions, which highlights the important role of public institutions in early detection and screening in Hong Kong. According to our data, most children were referred to the CAS because of language delay. A language problem is generally obvious and language ability is critical to school performance and social functioning, thus its presence is more likely to draw the attention of parents or medical professionals to potential developmental problems. Since a language problem was one of the important referring symptoms in this study, health education about the importance of language delay as an alert for abnormality in child development needs to be emphasised in the future.

Our findings regarding the clinical profiles of children with MR and DD are interesting, compared to findings reported from elsewhere. According to the American Psychiatric Association, in the year 2000 the male-to-female ratio of children with MR in the United States was 1.5:1.⁴ However, our local finding revealed a ratio as high as 3:1.

In our study, ASD was the most common co-morbidity, which was similar to the situation reported in the West.¹⁴ However, compared to the United States, where epilepsy (15%) and cerebral palsy (30%) are the most common co-morbid conditions in people with MR,⁴ these two diseases were encountered only occasionally in our locality.

Analysis of the family background of the children also revealed a surprise. Parents of the children with MR and DD tended to have higher

education levels and belonged to a higher social class, which was presumably related to their types of occupation. According to the local census statistics, less than half (47%) of Hong Kong citizens attain secondary school level education, a quarter (27%) attain matriculation and another quarter (27%) an education level equivalent to primary school or below.⁶ Moreover, 39% of Hong Kong citizens have non-manual jobs.⁶ On the contrary, most parents of the children studied attained a secondary school and or even a tertiary level of education (ie around 70% of the study population) and a high percentage were holding non-manual jobs (ie around half of the mothers and more than half of the fathers). Although no association can be derived from such crude statistics, the findings are consistent with parents with high educational backgrounds and social status having more concern about the general health of their children and thus a higher demand for the CAS. For this reason, promotion of awareness among parents with disadvantaged social background about childhood developmental problem would seem to be an important focus for the future.

Conclusion

The findings presented here provide information on the descriptive epidemiology of MR and DD in the Hong Kong paediatric population. Since MR and DD represent a substantial proportion of the new cases among local children with developmental disabilities, public health education to promote and ensure early screening and identification of cases is important. Such awareness could facilitate early training and guidance to families rearing children with these conditions.

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