

# Medical issues among children and teenagers with Down syndrome in Hong Kong

Winnie Ka-Ling Yam<sup>1</sup>, Philomena Wan Ting Tse<sup>2</sup>, Chak Man Yu<sup>3</sup>, Chun Bong Chow<sup>4</sup>, Wai Man But<sup>5</sup>, Kit Yu Li<sup>6</sup>, Lai Ping Lee<sup>4</sup>, Eva Lai Wah Fung<sup>7</sup>, Pauline Pui Yee Mak<sup>5</sup> and Joseph Tak Fai Lau<sup>8</sup>

We examined the prevalence of medical problems in children and teenagers with Down syndrome in Hong Kong. **Methods:** Children with Down syndrome receiving care from seven regional hospitals were included and their hospital records were reviewed. A total of 407 patients, aged between 0.06 and 17.16 years were included. Cardiovascular problems were observed in 216 (53%), endocrine problems in 111 (27%), gastrointestinal problems in 46 (11%), haematological problems in 18 (4%), neurological problems in 27 (7%), sleep problems in 36 (9%), skeletal problems in 56 (14%), visual problems in 195 (48%) and auditory problems in 137 (34%). **Conclusions:** The prevalence of medical problems was high in children and teenagers with Down syndrome in Hong Kong and similar to previous findings elsewhere. Future studies on the local prevalence of medical problems in the adult population with Down syndrome would help to define their medical needs.

Around 1 in 767 babies are born with Down syndrome in Hong Kong<sup>[1]</sup>. A number of medical conditions occur more often among children with Down syndrome than among the general population<sup>[2-5]</sup>. These children need a wide range of services delivered by medical specialists, including paediatricians, general surgeons, orthopaedic surgeons, cardiothoracic surgeons, otolaryngologists and ophthalmologists.

Data on the prevalence of medical problems in these children is important for optimal service planning. Previous international and local studies have investigated many issues among children with Down syndrome, including: cardiovascular<sup>[6-8]</sup>, endocrinology<sup>[9-12]</sup>, neurology<sup>[13-15]</sup>, orthopaedics<sup>[16,17]</sup>, sleep<sup>[18]</sup> and visual and auditory<sup>[19-23]</sup>. This study aimed to examine the prevalence of various common medical issues among children with Down syndrome in Hong Kong.

## Methods

A cross-sectional survey method was used. During a study on the growth parameters of children with Down syndrome from 1999 to 2001, information about the health status of these children was collected. Paediatric departments of all hospitals in Hong Kong were invited to par-

ticipate. Children aged below 18 years old were included in the study. Demographic data collected included the name, sex, age, date of birth and identity card number. The age of a child was taken as the date on which the latest growth parameters were recorded. Children with the same name and identity card number were considered to be duplicate cases. For children without an identity card number submitted, they were regarded as duplicate cases if they had the same name, sex, age and date of birth. Hospital records were reviewed by participating paediatricians. Relevant data was recorded according to a pre-set questionnaire (SUPPLEMENTARY FIGURE 1). The questionnaire was designed by the participating paediatricians and epidemiologist who had special interests in Down syndrome. Nine major areas (including cardiovascular, endocrine, gastrointestinal, haematological, neurological, sleep, skeletal, visual and auditory) were studied. Each area was further classified and common conditions were listed. The paediatricians were asked to review the case records and to indicate whether the child had the condition. There was a column for "other problems" in each area so that unlisted conditions might be recorded. The paediatricians were allowed to choose the "don't

(1) Department of Paediatrics and Adolescent Medicine, Alice Ho Miu Ling Nethersole Hospital. Now at Greenfield Integrated Child Health and Neurodevelopmental Centre

(2) Department of Paediatrics and Adolescent Medicine, Caritas Medical Center. Now at Greenfield Integrated Child Health and Neurodevelopmental Centre

(3) Department of Paediatrics and Adolescent Medicine, Pamela Youde Nethersole Eastern Hospital

(4) Department of Paediatrics and Adolescent Medicine, Princess Margaret Hospital

(5) Department of Paediatrics, Queen Elizabeth Hospital

(6) Department of Paediatrics and Adolescent Medicine, Tuen Mun Hospital

(7) Department of Paediatrics and Adolescent Medicine, Prince of Wales Hospital

(8) Centre of Epidemiology and Biostatistics, School of Public Health, The Chinese University of Hong Kong

**Correspondence to** Winnie Ka-Ling Yam • e-mail: wklyam@hotmail.com

doi:10.3104/reports.2005

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	Number of children with the condition +	Percentage
<b>Cardiovascular problems</b>	<b>216</b>	<b>53</b>
Ventricular septal defect	64	16
Atrial septal defect	78	19
Atrioventricular septal defect	23	6
Patent ductus arteriosus	91	22
Tetralogy of Fallot	6	1
Pulmonary hypertension	44	11
Others	38	9
<b>Endocrine problems</b>	<b>111</b>	<b>27</b>
Thyroid problems*	99	24
Diabetes mellitus	2	<1
Others	10	2
<b>Gastrointestinal problems</b>	<b>46</b>	<b>11</b>
Hirschsprung's disease	3	1
Malrotation of gut	3	1
Duodenal atresia	7	2
Esophageal atresia	2	<1
Anal atresia	16	4
Others	23	6
<b>Haematological problems</b>	<b>18</b>	<b>4</b>
Acute leukaemia	8	2
Transient myeloproliferative disease	8	2
Others	6	1
<b>Neurological problems</b>	<b>27</b>	<b>7</b>
Epilepsy	7	2
Severe behavioural problems#	16	4
Others	8	2
<b>Sleep problems</b>	<b>36</b>	<b>9</b>
Sleep apnoea	27	7
Other sleep disturbance	20	5
<b>Skeletal problems</b>	<b>56</b>	<b>14</b>
Atlantoaxial subluxation	20	5
Atlantoaxial dislocation	3	1
Dislocation of patella	0	0
Flat foot	20	5
Unstable hip	1	<1
Others	20	5
<b>Visual problems</b>	<b>195</b>	<b>48</b>
Cataract	4	1
Refractive disorder	143	35
Squint	53	13
Nystagmus	50	12
Amblyopia	12	3
Blepharitis	3	1
Others	16	4
<b>Hearing problems</b>	<b>137</b>	<b>34</b>
Hearing Loss	126	31
Conductive hearing loss	72	
Neurosensory hearing loss	25	
Not specified	29	
Chronic otitis media	21	5
Others	6	1

+ Children might have more than one medical condition, therefore the total number of children in each area might not be equal to the sum of children with various conditions in that area.

\* Detailed study on the thyroid problem had been reported elsewhere<sup>[12]</sup>.

# Behaviour problems should be severe enough to affect normal function and require professional attention or treatment by a psychiatrist, clinical psychologist or paediatrician.

Table 1 | Medical issues identified among children and teenagers with Down syndrome in Hong Kong

know” category if there was insufficient information in the record. Uncompleted questions were classified as “don’t know”. The percentage of children with a particular condition was calculated using the total number of children in the study (including those in the “don’t know” category) as

the denominator. Therefore, the stated percentages reflect a minimum estimate.

## Results

Seven of the 15 public hospitals with paediatric clinics in Hong Kong participated in the study. From 423 records, 407 unique patients under the age of 18 years were identified, of whom 232 were male and 175 were female. Seven children were not of Chinese ethnic origin. The mean age was 5.44 years (standard deviation 4.10 years, range 0.06 – 17.16 years).

Two hundred and sixteen (53%) children had cardiovascular problems, 111 (27%) endocrine problems, 46 (11%) gastrointestinal problems, 18 (4%) haematological problems, 27 (7%) neurological problems, 36 (9%) sleep problems, 56 (14%) skeletal problems, 195 (48%) visual problems and 137 (34%) hearing and ear-nose-throat problems. TABLE 1 provides further detail of the findings concerning each of these areas. Further detail on findings concerning thyroid function have been reported elsewhere<sup>[12]</sup>.

## Discussion

Our results are generally in accordance with other studies<sup>[2-20]</sup>. However, our study differs from previously reported studies in two important respects. Firstly, our sample size was one of the largest reported to date, enabling us to examine the frequency of less commonly reported problems. Secondly, most previously reported studies were performed at a regional centre while our study drew participants from multiple centres.

To determine the proportion of children with Down syndrome covered by our study, the total number of children with Down syndrome in the territory should be ascertained. Such prevalence data was not available because there was no central registry for children with Down syndrome in Hong Kong. We therefore examined information on the birth rate, incidence of Down syndrome among live births and the mortality rate to estimate that the number of children with Down syndrome aged below 18 years in the territory is around 1400. Our study included 407 children (29% of the total number estimated to be living in Hong Kong).

Being a cross-sectional survey, our results essentially reflected the prevalence of medical co-morbidities in this cohort of children at a particular point in time. The results should not be interpreted as the actual prevalence of these medical conditions in all children with Down syndrome. Another limitation of our study was our inability to ascertain the health status of children who were not under medical care. This might post a bias against children who did not

attend a clinic because they did not have any health problems.

Nevertheless the prevalence of various medical problems was shown to be high in children with Down syndrome in Hong Kong. We advocate the use of a medical checklist in the care of these children. A pamphlet had been published jointly by the Hong Kong Paediatric Society and the Hong Kong Down Syndrome Association. In addition to age-specific checklists on medical problems, the pamphlet includes advice on anticipatory health care.

As children with Down syndrome mature into adulthood, medical care remains important. According to a recent survey of 125 adults with Down syndrome aged 35-55 years, conducted by Hong Kong Polytechnic University and the Hong Kong Down Syndrome Association, 56% had health problems and 46% would like to receive medical care (unpublished data). Future studies on the local prevalence of various medical problems in the adult population with Down syndrome would help to define their medical needs.

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## Acknowledgement

We would like to thank the Hong Kong Down Syndrome Association for their assistance in this project.

Received: 21 September 2006; Accepted 14 February 2007; Published online: 9 August 2007.