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**ORIGINAL ARTICLE**

# Dental care access among individuals with Down syndrome: a Malaysian scenario

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**Abstract**
***Objective.*** The purpose of this cross-sectional study was to assess the legal representatives' perceptions on dental care access of individuals with Down syndrome (DS) compared to their non-DS siblings in Peninsular Malaysia. ***Methods:*** This cross-sectional study was conducted throughout community-based rehabilitation centers (CBRC) and the Down Syndrome Organization. Legal representatives of individuals with DS within the criteria were given a structured and validated questionaire. ***Result.*** This study demonstrated that individuals with DS (76.9%) significantly utilized more health services than non-DS siblings (23.1%). The service most regularly used was speech therapy followed by opthalmology and dental services. Twenty-five per cent of respondents reported difficulty in finding dental care services for their DS child and 46.9% admitted that healthcare for their DS child took more time. The majority of DS individuals received less complex dental treatment and none received any orthodontic treatment, despite their severe occlusal problems. ***Conclusion.*** A high proportion of parents appear to be able to access dental and medical care for their DS child. However, some parents perceived difficulty in finding oral healthcare.

**Key Words:** *dental care access, Down syndrome, health services, Malaysia*

## Introduction

Down syndrome (DS) is a well-known chromosomal abnormality characterized by the presence of an extra copy of genetic material on the 21st chromosome [1]. In Malaysia it was reported in 1989 there was one incidence in 950 births, with variation among the three largest ethnic groups (Malay 1:981, Chinese 1:940 and Indians 1:860) [2].

Generally, individuals with DS are characterized by general growth and mental deficiency. The primary skeletal abnormality affecting the orofacial structures are mid-face hypoplasia and nasal bone depression, inevitably causing Class III skeletal pattern and open bite [3]. There is an also increased risk of congenital heart defects (50%), gastroesophageal reflux disease (12%), recurrent ear infections (50%), obstructive sleep apnea (50%) and thyroid dysfunction (15%) [4]. Down syndrome individuals usually suffer from developmental disability, hence categorizing them into the special needs group. The cognitive ability impairment and manual dexterity difficulties in people with DS commonly affect oral health maintenance. This then leads to oral health problems such as gingivitis, halitosis and periodontal disease [3,5].

Access to professional dental care has been defined as the ability to obtain and make use of dental services [6]. People with disabilities have the right to equal standards of healthcare. However, there is evidence that DS individuals experience poorer oral health status, unmet oral health needs and less access to screening services than the general public in the same age group [7]. They also have a higher level of dental care needs than non-DS individuals [5,8-10]. In 2000, Allison et al. [10] studied dental care access among individuals with DS in France and found that parents of children with DS frequently encountered problems of access to oral healthcare and individuals

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with DS were less likely to receive dental services]. Many treatable oral health problems were overlooked due to lack of concern and awareness among caregivers of DS individuals. In particular, oral health may be a low priority in the context of other social and medical challenges. Hence, only 10–20% of the special needs population received comprehensive oral healthcare [7,11].

Clinical guidelines suggest that oral healthcare for people with DS can be improved through an integrated care approach. The guidelines also provide necessary support to enable the individual to achieve and maintain oral health [12]. The main objective of this study was to assess the legal representatives' perceptions on dental care access for DS and non-DS siblings in Malaysia.

## Materials and methods

This study was carried out after obtaining ethical clearance from the Research and Ethical Committee in Universiti Kebangsaan Malaysia Medical Centre (UKMMC) and was supported by Geran Galakan Penyelidik Muda (GGPM). An approval was also obtained from the Social Welfare Department of Malaysia (Research and Development Unit) and Malaysian Down Syndrome Association (NGO).

The sample-size calculation was performed using the Raosoft sample size calculator. The parameters were determined using the probability proportional to population size method with the power of 80% and sampling error was set at 5%. The target sample size was estimated to be 124 (including 10% drop out), based on 28 126 estimated populations of DS in Malaysia.

A structured questionnaire with 10 main items was used to assess the legal representatives' perceptions on dental care access among individuals with DS [10,11]. Prior to that, content validity of the questionnaire was carried out to check suitability of the questionnaire to the local population. Pre-testing was conducted and ambiguous questions were improved (cronbach alpha = 0.7). The questionnaire had three sections covering the following areas; demographic characteristics of respondent, utilization and accessibility of health services and dental treatment received. In section two, the frequency of utilization was categorized into: none (never seen a specialist), seldom (meet a specialist once in 6 months), frequently (meet a specialist every 3 monthly) and regularly (meet a specialist once a month).

In collaboration with the Social Welfare Department of Malaysia, 30 Community-based Rehabilitation Centers (CBRC) which provide services for DS individuals were randomly sampled. Convenience samples of 130 legal representatives of DS individuals were identified. The respondents must also be able to understand basic English and have a non-DS child. An informed consent explaining the purpose and methods of the study was sent to the participants. An assurance of complete confidentiality and anonymity was also given before legal representatives signed a written consent form. A total of 130 questionnaires were distributed to the participants. They were allowed to clarify any question with the researcher if they were in doubt. Valid returned questionnaires were coded and analyzed with the Statistical Package for the Social Science (SPSS) software for Windows version 19.0. Descriptive analysis includes frequencies, percentages, frequency tables for categorical variables and calculation of mean and standard deviation for quantitative variables (age). Comparison and associations were also explored with McNemar Test.

## Results

A total of 130 responses (100%) were obtained from participants. Among the participants, 110 (84.6%) were Malay, 10 (7.7%) Chinese and 10 (7.7%) Indians. The participants were between the ages of 30–73 years (mean = 55.4 years) and the majority (33.8%) were between 41–50 years of age. The majority of the them (60.8%) had education levels of secondary school and below. More than half (73.8%) had an annual household income below RM24000. Just over half of the persons with DS represented by these caregivers were male (53.1%) and the mean age of individuals with DS was 26.4 years.

Table I presents the frequencies of health service utilization among individuals with DS and their siblings. It was evident that individuals with DS (76.9%) significantly ($p < 0.001$) utilized more health services than their non-DS siblings. Furthermore, amongst the DS individuals, speech therapy sessions (20.0%) were the most visited health services followed by ophthalmology (6.9%) and dental services (5.4%).

Generally, more DS individuals attended medical (36.2%) and dental specialist clinics (28.5%) compared to their non-DS siblings and 71.5% of DS individuals had never attended dental specialist clinics. About one quarter of DS individuals reported having difficulty in finding both medical (20.8%) and dental services (25.4%). Nevertheless, this finding is higher than the findings of their non-DS siblings. Almost half of parents (46.9%) admitted that healthcare services for DS required more time than their non-DS siblings (Table II). There was no significant difference in number of subjects receiving dental treatment between the two groups (DS: 49.2%; non-DS: 52.3%). However, only one individual with DS (0.8%) had a prosthesis, whereas none had received any orthodontic treatment (Table III).

Table I. Utilization of health services among DS and non-DS siblings according to their annual frequency.

| | DS (*n* = 130) | | | | Non-DS (*n* = 130) | | | |
|---|---|---|---|---|---|---|---|---|
| | N | S | F | R | N | S | F | R |
| Health services | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) | *n* (%) |
| Heart specialist | 108 (83.1) | 21 (16.2) | — | 1 (0.8) | 126 (96.9) | 3 (2.3) | 1 (0.8) | — |
| Endocrinologist | 128 (98.5) | 1 (0.8) | — | 1 (0.8) | 126 (96.9) | 4 (3.1) | — | — |
| Ear, Nose and Throat (ENT) | 98 (75.4) | 25 (19.2) | 6 (4.6) | 1 (0.8) | 118 (90.8) | 10 (7.7) | 2 (1.5) | |
| Speech | 65 (50.0) | 21 (16.2) | 16 (12.3) | 26 (20.0) | 127 (97.7) | 2 (1.5) | 1 (0.8) | — |
| Ophthalmologist | 98 (75.4) | 23 (17.7) | — | 9 (6.9) | 125 (96.2) | 5 (3.8) | — | — |
| Dental | 68 (52.3) | 48 (36.9) | 7 (5.4) | 7 (5.4) | 113 (86.9) | 15 (11.5) | 1 (0.8) | 1 (0.8) |

N, none; S, seldom; F, frequently; R, regularly.

Table II. Comparing ease of health access among individuals with DS and non-DS siblings.

| | DS (*n* = 130) | | Non-DS (*n* = 130) | |
|---|---|---|---|---|
| Ease of access | Yes, *n* (%) | No, *n* (%) | Yes, *n* (%) | No, *n* (%) |
| Attend medical specialist clinic | 47 (36.2) | 83 (63.8) | 20 (15.4) | 110 (84.6) |
| Attend dental specialist clinic | 37 (28.5) | 93 (71.5) | 17 (13.1) | 113 (86.9) |
| Difficulty in finding a doctor | 27 (20.8) | 103 (79.2) | 9 (6.9) | 121 (93.1) |
| Difficulty in finding a dentist | 33 (25.4) | 97 (74.6) | 9 (6.9) | 121 (93.1) |
| Healthcare takes time | 61 (46.9) | 69 (53.1) | 11 (8.5) | 119 (91.5) |

* $p > 0.001$ (non-significant).

Table III. Dental treatment received by DS and their siblings.

| | DS | | Non-DS | |
|---|---|---|---|---|
| Dental treatment received | Yes, *n* (%) | No, *n* (%) | Yes, *n* (%) | No, *n* (%) |
| Received any dental treatment | 64 (49.2) | 66 (50.8) | 68 (52.3) | 62 (47.7) |
| Child ever had prosthesis or crown | 1 (0.8) | 129 (99.2) | 9 (6.9) | 121 (93.1) |
| Undergone orthodontic treatment | 0 (0) | 130 (100) | 13 (10.0) | 117 (90.0) |

## Discussion

The majority of the parents were within the age group of 41–50 years old. It is widely known that advanced maternal age is associated with increased risk of having a DS child. The level of education amongst the legal representatives or parents reflects their low annual household income of below RM24 000 and level of oral health awareness. Malaysia comprises of three ethnic groups, with Malay being the largest, followed by Chinese and Indian. This explains the majority of respondents being from the Malay ethnic group.

The majority of DS individuals in the present study were able to access health services in Malaysia. This study showed that individuals with DS significantly utilized more health services than their non-DS siblings. However, utilization of dental specialist service is lesser than medical specialist service among individuals with DS. This phenomenon is expected as a newborn with DS is usually referred to a medical specialist from birth for health investigations and supervisions. This was mentioned in several pediatric guidelines for the management of newborns with DS [4,13,14]. The regular review appointment for routine check-up resulted in continuity of healthcare until adulthood. However, referral to a dental specialist is seldom applied to newborns with DS unless the newborn has facial anomalies or deformities such as cleft lip and palate.

Among the health services listed in this study, speech therapy, ophthalmology and dental services were the most regularly utilized services by the DS individuals. This finding is in line with a study done among a French community in France [10]. The utilization of the related health services among the DS individuals reflects their health problems. It was found that speech therapy was the most regularly utilized service by DS individuals. This phenomenon may suggest that parents' perceived speech as an important development for their DS child. It was also reported that speech and language therapy were the most important part of intervention services for children with DS in order to promote their cognitive and social development [15].

The second most regularly utilized health service among DS individuals is the ophthalmology service. The Down Syndrome Research Unit in the UK has found that children with DS have long- or short-sighted eye problem at a very young age and they need to wear glasses [16]. These visual impairments or a reduction in vision may affect language and cognitive development of the affected child [17]. Therefore, it was recommended that children with DS have regular eye-tests throughout their life, 6 monthly checks from the age of 12 months.

Parents also reported their DS child was more likely to utilize dental service than their non-DS child (Table I). The Malaysian government policy on dental health service program requires the dental team to have regular visits to the CBRC and conduct oral health screening, examination and referrals. However, their non-DS siblings tend to utilize dental services when they perceive dental symptoms, instead of attending regular annual visits [10].

A study had reported that the frequency of congenital heart disease (CHD) in children with DS was high and ranged between 40–50%. However, the majority of DS individuals in this study had not seen a cardiologist [18]. This occurs due to lack of concern or awareness from parents to attend follow-up sessions and health screening for their DS children. Geggel et al. [19] had examined 35 DS patients with no known CHD and found that nearly half of them (46.0%) had mitral valve prolapse and 17% had valve regurgitation. Therefore, they recommended screening of adolescent and young adult patients with DS. Screening and diagnosing heart problems in DS individuals is very important for certain forms of CHD and requires antibiotic prophylaxis prior to invasive dental procedures. The most frequent CHD found in DS individuals are atrioventricular septal defect (45%) and ventricular septal defect (35%), which pre-dispose the sufferer to bacteria endocarditis [18,20].

Many publications have reported abnormalities of the immune system in people with DS, mainly immunodeficiency and autoimmunity [20,21]. However, the majority of our DS were less likely to utilize the related health service due to the age group, where the infections were more common in younger DS children. Furthermore, lack of awareness as well as financial support may have contributed to this finding. Nevertheless, older DS individuals do present with higher rates of malignancies and autoimmune phenomena such as hypothyroidism and diabetes mellitus [22].

Middle ear diseases and hearing loss are more common in individuals with DS than in the general population [23]. People with hearing problems often have difficulty in processing speech. This is true from our observations, as many DS individuals have accessed or utilized the ear, nose and throat (ENT) health service as well as speech therapy sessions. This coincides with the study by Allison and Lawrence [24]. In combination with intellectual impairment, slight hearing loss can have a significant impact upon delivery of language and cognitive learning [23]. It also has an impact on routine oral hygiene and dental care, since both are delivered via oral health education. Therefore, a screening procedure is recommended for early detection of middle ear disease and hearing loss, since individuals with DS are unlikely to complain of hearing impairment.

Parents of DS individuals reported difficulty in finding both medical and dental practitioners and this finding is in agreement with other studies [10,25,26]. This could be due to lack of general medical and dental services, especially special need specialists in the respondents living area. As of today, there are only two special needs specialists in Malaysia. Perhaps this also could be related to respondents' financial status that limit them the access to dental services, especially the private practice. Other factors which can be considered as barriers to medical and dental care access for children with developmental disabilities are transportation, workforce capacity shortages and limited insurance coverage. Furthermore, the individuals' behaviors such as fear of the dentist and inability to co-operate also contribute to problems in providing dental care.

Parents also reported that healthcare for their child with DS took more time than their non-DS child. This is true because individuals with DS exhibit more health problems compared to their non-DS siblings. Other contributory factors may include longer waiting time in the public care center and longer time needed bythe health practitioner to clinically manage and handle them, for they are easily restless and have short attention spans, thus impairing their level of co-operation.

There was no significant difference in dental treatment received between the DS group and their non-DS siblings. This is inverse with the previous study by Allison and Lawrence [24], where they reported that non-DS siblings are more likely to receive dental treatment than the DS child. Parents who were the respondents in this study may have confused with the term 'dental treatment' and the exact clinical practice, i.e. maybe their DS child only had routine dental check-ups but they considered it as dental treatment. In contrast, a previous study did a precise survey asking specifically the dental treatment received, i.e. extraction and filling [24].

With regard to complex dental treatment, only one DS had prosthesis/crown and this is much less compared to the previous studies [9,24]. Surprisingly none of the DS individuals had any orthodontic treatment. Parents' lack of awareness may have contributed to this for orthodontic treatment is usually perceived as an esthetic treatment rather than a need. Moreover, orthodontic treatment is expensive and waiting lists are very long in the government clinics. Nevertheless, a study by Becker et al. [27] concluded that parental motivation and ability to assume the responsibility of constant surveillance is a critical factor in delivering orthodontic treatment to DS individuals. Other contributory factors may include dentist or orthodontist willingness to treat special needs individuals and logistic issues. A study was conducted regarding attitudes and behavior of orthodontists in providing care to the under-served patients, including those with mental retardation. They concluded that orthodontists had less positive attitudes concerning the treatment to those patients. Thus, attitudes and professional behaviour, as well as level of confidence were correlated in providing orthodontic care in treating patients with certain special needs [28].

The findings of the present study, although encouraging, should be reviewed with caution. The research was conducted on a relatively small sample size. Since there is no relevant data of the DS population in this country, the sample size was calculated according to the estimated DS population based on the birth rate in 1989 [29]. Unfortunately the estimation has to rely on old data because there is no recent data on the birth rate of DS. Hence, it may be difficult to find a significant relationship from the data and the findings cannot be generalized to the broader community of this sub-population group.

We also had some difficulty in finding parents/caregivers sample since they must possess basic English to answer the questionnaire. This limitation may have discouraged some potential respondents from participating in the study. Nevertheless, pre-test and content validity of the questionnaire were carried out to check suitability of the questionnaire to the local population. The broad nature of some questions also lacks details that can be found with long questionnaires. For future studies, the questionnaire should be translated to the national language.

Our sources of DS subjects were mostly from CBRC centers. In this country, most of the CBRC centers rehabilitate all kinds of disabled persons, including those with cerebral palsy, slow learning, autisms, DS, deafness, etc. Hence, random sampling cannot be conducted. In addition, difficulty in obtaining consent from parents/caregivers for DS individuals caused the researcher to conduct the study by convenience sampling.

## Conclusions

In conclusion, a high proportion of parents used and appeared to be able to access dental and medical care for their DS child. However, the findings also suggested that some parents perceived difficulty in finding oral healthcare for their DS child. The majority of DS individuals received less complex dental treatment and none received any orthodontic treatment despite their severe occlusal problems.

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