Parent's attitudes and knowledge on oral health in a group of individual with Down syndrome in Turkey

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Abstract

Objectives: To evaluate the knowledge and attitude of families having some Down syndrome patient about problems related to oral cavity and dental health issues.

Methods: The cross-sectional study was conducted at Marmara University, Faculty of Dentistry in July 2017. Families of individuals with Down Syndrome, who are members of the Turkish Down Syndrome Association, were included in the study. A self-generated questionnaire was used to collect information in 3 different sections through 43 questions related to patient's socio-demographic and medical information, data on dental visit(s) and tooth-brushing. The questionnaire was sent to the families via the Internet. They were asked to return the completed questionnaires within a month. SPSS 22 was used to analyse data.

Results: Of the 103 families, 25(24.27%) had never taken their children to a dentist; 12(11.65 %) thought their children were too young, 6(5.82%) thought they would have difficulty in the dental environment, and 2(1.94%) could not find a suitable dentist. There was a statistically significant relationship between the oral and dental health and the tooth-brushing frequency ($p<0.05$). There was a statistically significant difference between the frequency of helping the children brush their teeth and the mean age ($p<0.05$).

Conclusion: Parents of individuals with Down syndrome needed high-level information and guidance to take proper care of affected individuals.

Keywords: Down syndrome, Quality of life, Oral health. (JPMA 68: 1368; 2018)

Introduction

Down Syndrome (DS) is an autosomal chromosomal abnormality that results from trisomy of chromosome 21. It occurs in approximately 1 out of 700-800 live births.[1] The effects of DS include intellectual disability and several other medical conditions, which might be detected at birth or which might develop during life. Medical problems associated with DS directly affect the oral and dental health, which indirectly affect their overall quality of life. DS is accompanied by physical functional problems that are highly specific for the orofacial region.[1] These functional problems include speech, swallowing and chewing difficulties, and there also appears to be an increase in facial, skeletal and orthodontic problems.[1,2] Among the soft tissue characteristics of oral cavity, there exists relative macroglossia since there is a protrusive tongue with deep fissures and a smaller oral cavity due to the deformity in the midface.[1,3,4] More periodontal diseases and more need for periodontal treatments in individuals with DS have been reported by many studies.[5] In addition, numerical and structural dental abnormalities, delayed tooth eruption and irregularities during tooth eruption are among the general features related to the oral cavity in individuals with DS.[1,3,4]

Although individuals with DS have many problems related to the oral and dental health, and these problems have direct effects on the quality of life of individuals with DS, the effects of these problems cannot be fully evaluated by the families concerned. Moreover, there are limited studies in which orofacial problems and their effects are evaluated from the point of view of families of individuals with DS. Using evaluations of health status that are based on patients and health-related quality of life instruments (and similar means) is known to make a significant contribution to the understanding of the health problems and treatments, especially chronic diseases. The current study was planned to evaluate the knowledge and attitude of families of individuals with DS about these issues in order to be able to provide more qualified and comprehensive oral and dental health services to individuals with DS in line with their needs and to well understand the importance of these issues.

Subjects and Method

The cross-sectional study was conducted in July, 2017; at Marmara University, Faculty of Dentistry, Paediatric Dentistry Department and families of individuals with Down Syndrome, who are members of the Turkish Down

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Syndrome Association, were included in the study. Approval was obtained by the Clinical Research Ethics Committee of Marmara University, Faculty of Dentistry and informed consent was obtained from the participating families. The questionnaire was sent to the families via the Internet. They were asked to return the completed questionnaires within a month. The return of the completed questionnaire demonstrated their consent to participate in the study. During this period, reminding e-mail messages with one week intervals. Returns at the end of this period were taken into consideration. A self-generated questionnaire consisting of 3 sections and 43 questions was prepared in the light of international studies.[3,6-9] Socio-demographic and medical data of the patients was collected in the first part. Data on dental visit(s) was collected in the second part that was about dental examination, treatments, interaction between the patients and the dentist and vice versa. Habits in oral hygiene and tooth-brushing were asked in the third part. The questionnaires which were not completely filled out were not included in the study. Families with DS patient aged 1 year or less were also excluded.

The collected data was evaluated using Microsoft Excel 2010, and SPSS 22 was used for statistical analysis. Shapiro-Wilk test was used to determine if the parameters showed normal distribution. For categorical data, descriptive statistics like mean, standard deviation and frequency and percentage were used. For comparing quantitative data, one-way analysis of variance (ANOVA) was used for normally distributed parameters, and the Tukey honest significant difference test was used for determining the group causing the difference. Chi-square test was used to compare the qualitative data. $P<0.05$ was considered statistically significant.

Results

Of 164 questionnaires sent out, 111(67.68%) were returned duly filled. Out of them, 8(7.2%) families were excluded because their children were aged 1 year or younger. The mean age of the 103(63%) DS individuals who were included in the study was 15.5±9.64 (range: 2-34

Table-1: The relationship between the children's general health and oral health.

		General Health				
		Poor n (%)	Moderate n (%)	Good n (%)	Very good n (%)	p
Oral health	Poor	2 (28.6%)	8 (27.6%)	14 (25.0%)	1 (16.7%)	0.251
	Moderate	4 (57.1%)	13 (44.8%)	29 (51.8%)	2 (33.3%)	
	Good	1 (14.3%)	7 (24.1%)	11 (19.6%)	1 (16.7%)	
	Very good	0 (0%)	1 (3.4%)	2 (3.6%)	2 (33.3%)	

Chi-square test.

Table-2: The relationship between the children's oral health status and the daily tooth-brushing frequency, type of toothbrush, helping the children brush their teeth.

		Oral and Dental Health				
		Poor n (%)	Moderate n (%)	Good n (%)	Very good n (%)	p
Daily tooth-brushing	Do not know	0 (0%)	4 (8.9%)	0 (0%)	0 (0%)	0.039*
	too young to brush	3 (12.5%)	3 (6.7%)	4 (20%)	0 (0%)	
	1 /day	6 (25.0%)	16 (35.6%)	7 (35%)	4 (80%)	
	2 or more times/ day	4 (16.7%)	6 (13.3%)	6 (30%)	1 (20%)	
	1 or less / week	8 (33.3%)	4 (8.9%)	2 (10%)	0 (0%)	
	at least once/ week	3 (12.5%)	12 (26.7%)	1 (5%)	0 (0%)	
Toothbrush	Manual	20 (95.2%)	40 (93%)	12 (75%)	3 (75%)	0.210
	Rotating/battery/electric	0 (0%)	2 (4.7%)	2 (12.5%)	0 (0%)	
	both	1 (4.8%)	1 (2.3%)	2 (12.5%)	1 (25%)	
Helping children	Every day	5 (25%)	6 (15%)	5 (33.3%)	2 (40%)	0.324
	More than once/ week	2 (10%)	9 (22.5%)	2 (13.3%)	0 (0%)	
	1 or less/ week	6 (30%)	5 (12.5%)	1 (6.7%)	0 (0%)	
	never	7 (35%)	20 (50%)	7 (46.7%)	3 (60%)	

Chi-square test.
* $p<0.05$.

Table-3: The relationship between the frequency of helping the children brush their teeth and the mean age.

		Age Mean±SD	P
Helping children	Every day	12.67±8.61	0.002*
	more than once / week	13.84±9.51	
	1 time or less /week	14.43±6.59	
	never	20.87±8.23	

One-way ANOVA Test.
* p<0.05.

years). Overall, 40(38.83%) subjects were girls and 63(61.16%) were boys.

There was no statistically significant relationship between the patient's general health status and oral and dental health status (p>0.05) (Table-1).

There was a statistically significant relationship between the oral and dental health and the tooth-brushing frequency (p<0.05). There was no statistically significant relationship between the oral and dental health status and the type of toothbrush, and helping the children brush their teeth (p>0.05) (Table-2).

There was a statistically significant difference between the frequency of helping the children brush their teeth and the mean age (p<0.05). The mean age of the children who did not receive help from their families for tooth-brushing was significantly higher than that of the children who received help from their families for tooth-brushing everyday (p=0.004) or once a week (p=0.047). There was no significant difference between the other groups (p>0.05) (Table-3).

Besides, 49(47.57%) families learnt about oral hygiene through dentist, 19(18.44%) from the teachers or caregivers in rehabilitation centres, 18(17.47%) from websites, 13(12.62%) from school, 10(9.70%) from physicians or paediatricians, while 11(11%) of them never had guidance on the subject. Overall, 22(21.3%) parents reported having taken their children to a dentist within the preceding six months, and 14(13.6%) had done that in the preceding one year. A total of 25(24.27%) families had never taken their children to a dentist. When examining their reasons for not going to a dentist, it was seen that 12(11.65%) families thought that their children were too young to go to the dentist, 6(5.82%) thought they would have difficulty in a dental environment, 7(6.8%) did not know that they should go to the dentist, 2(1.94%) could not find a suitable dentist for their children, and 1(0.97%) had more important general health problems than oral and dental health. Overall, 59(57.28%) parents took their children to a dentist for oral examination, 52(50.48%) went with a complaint of tooth decay, and 29(28.15%) for tooth ache.

When the families were asked about three most important features of the dentists they prefer, 68(66%) reported that dentists should have received special dental training. The other features that the families looked for in a dentist was the capability to involve the child into the treatment for 49(47.57%) families and 46(44.66%) required their dentist to be reassuring.

A total of 44(42.71%) subjects had difficulties during dental examination, 33(32%) had difficulties during dental treatment, and 16(15.53%) had dental treatment under general anaesthesia.

Discussion

This study about the knowledge and awareness level of families having a DS individuals about their children's oral and dental health is one of the few studies investigating a broader aspect of oral health, using parental evaluation, as opposed to researcher-led clinical studies. This approach makes it possible to consider the interrelated oral pathology problems and functional impairment simultaneously.[7]

Out of all the families participating in our study, 25% reported that their children's oral and dental health was good or very good. A lower prevalence of caries was reported in previously conducted studies for this group when compared with groups not affected by DS and groups with other disabilities. On the other hand, there are also some other studies reporting an equivalent or higher prevalence of caries in patients with DS.[10] Many studies have claimed that the reduced rates of dental caries in DS patients was associated with congenital oligodontia, diastema, delayed eruption, abda different salivary composition.[10-14] The widespread presence of diastemas in the mouth leads to a significant reduction in the formation of interface caries.[7,10] Theoretically, small-spaced teeth associated with delayed tooth dentition decrease the chance of food stagnating between the teeth which consequently diminishes the smooth surface area for colonisation by cariogenic bacteria.[7,10,15]

Although many studies have suggested that tooth decay rates are lower in individuals with DS than in individuals without DS, periodontal disease is the most significant oral health problem in people with DS.[16] Although a study reported[4] that 90% of individuals with DS needed periodontal treatment another research[17] reported that all people with DS needed periodontal treatment. Among the recruited families in our study 53% stated that their

children regularly brushed their teeth at least once every day. This rate was 18% and 59.4% in the other studies.[4,17] The low oral hygiene index scores are the basis of periodontal problems. In addition, individuals with DS also have some specific motor disabilities.[1] Sometimes, manual dexterity problems might cause oral hygiene problems. This may cause accumulation of plaque and debris on the teeth. This situation leads to the development of gingivitis and other periodontal diseases.[17] Studies reported that 50% of young children and 23% of older children with DS could apply efficient brushing.[15] Special training, adaptation and practice are required to use the toothbrush most effectively. Our study found that most of the children used a manual toothbrush and that almost half of them did not receive help from their families. In this situation, effective oral hygiene control is not achieved at the desired level, and the problems that arise in these individuals, who are more prone to periodontal problems, are progressing faster. In a study which evaluated the effectiveness of supervised tooth-brushing and oral health education in children and young adults with DS, it was reported that the mean dental plaque score decreased from 1.93 to 0.95 at the end of the 3-month supervised tooth-brushing programme ($p<0.001$).[18] Therefore, parents supervising their children during tooth-brushing would help to achieve better oral health. Parents who have been trained in this subject would have less difficulty in brushing their young children's teeth. However, since adolescents and young adults want to brush their teeth by themselves, this would adversely affect their oral hygiene.[19]

Among the families who were part of this study, 24% who were aware of many diseases related to general health status stated that they have never taken their children to the dentist before. Although 1% of these parents said that they did not go to the dentist because they were suffering from more serious health problems. The main reason for other parents, who had never taken their children to the dentist was that they did not have enough knowledge about the importance of regular dental examination on oral and dental health. Particularly, while there are other social and medical problems, oral health may have a low priority. Usually, a newborn baby with DS is referred to a medical specialist from birth for health investigations and supervisions. On the other hand, referring children with DS to dentists is rare unless there are facial anomalies or deformities such as cleft lip and palate.[20]

Parents of DS individuals stated that they had difficulty in finding dental practitioners, which is in agreement with other studies,[2,20] because dentists who deal with general individuals in society may not be familiar with special techniques to manage a child with DS.[1] Most of the individuals with DS have difficulties in the dental environment, and therefore most of the parents in our study reported that the dentists examining and treating their children should have received special dental training in this subject. However, the number of specially-trained dentists in our country is not sufficient. Families, as such, face trouble finding a dental centre for their DS children. The fact that there is little advice from a specialist, paediatrician, or school in terms of sharing information about the oral and dental health shows that other healthcare professionals and educators interested in DS are not sufficiently equipped to guide oral healthcare.

When dental treatments for the individuals with DS in our study were examined, protective practices were not among the treatments, and the tooth extraction was in the second place after routine oral and dental examination. When tooth decay and treatment options in other studies, which investigated oral and dental health in individuals with DS, were examined, it was reported that the restorative dental procedures were less and the effects of protective practices were scarce in this group.[21] This is because parents and caregivers lack sufficient good oral hygiene practices, do not have adequate motivation, low priority is given to dental care in society, dentists who are trained in this field are rare, the treatment needs are accumulated and extraction of teeth is considered a choice in dental therapy.[16]

Conclusion

Parents of children with DS have difficulties in finding oral healthcare. There is a need to improve the dental services available to individuals with DS. The interrelations between the health problems of children with DS must also be investigated. Parents of DS children have the most important role as the primary caretakers. For this reason, high-level information and guidance must be provided to them so that they may properly look after DS patients.

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