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Oral health challenges facing Dubai children with Autism Spectrum Disorder at home and in accessing oral health care

ABSTRACT

Aims To investigate the challenges faced by Autism Spectrum Disorder (ASD) children and their families in Dubai from three different perspectives of dental care: oral care at home, oral care at the dentist and access to oral care, and to compare the results to their normally developing peers.

Methods A case-control comparative study of 84 ASD and 53 healthy children attending special needs centres and schools in Dubai including siblings of the autistic children. Data collection was by a survey questionnaire completed by parents or guardians.

Results More parents of ASD children compared to parents of healthy children reported difficulties across almost all oral care variables explored. The majority of ASD children's parents (83.3%) reported that their children need assistance in brushing their teeth compared with 15.4% of the healthy controls (p -value < 0.001). The ASD children's uncooperative behaviour increased during dental visits and significantly more parents (37%) rated their child's experience as

negative compared with 9.5% among the parents of control children (p -value=0.006). The autistic children had visited a dentist mostly for extractions.

Conclusion This study indicates that autistic children in Dubai experience more challenges and barriers to oral care than their typically developing healthy peers.

Keywords Autism Spectrum Disorder, Oral healthcare, Dubai children, United Arab Emirates.

Introduction

Autism is a complex developmental disability that typically appears during the first three years of life as a result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills [Barbarese et al., 2006]. It is characterised by impairment in social interaction, impaired communication and restricted, repetitive, or stereotyped behaviours [Barbarese et al., 2006]. Aberrant development of social skills and impaired ability to engage in reciprocal social interactions are hallmark symptoms of autism [Kliegman et al., 2011].

Autism is known as one of the pervasive developmental disorders. Pervasive developmental disorders are disturbances of brain development with genetic underpinnings, these include: autistic, Aspergers, childhood disintegrative, Rett's, and pervasive developmental disorders not otherwise specified. With the publication of the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders in May 2013, all autism disorder subtypes were merged under one definition of Autism Spectrum Disorder (ASD) or autism [American Psychiatric Association, 2013].

Children with autism have the inability to attain expected social, communication, emotional, cognitive and adaptive abilities [Kliegman et al., 2011]. Overt symptoms gradually begin after the age of six months, become established by age two or three years [Rogers, 2009] and tend to continue through adulthood, although often in more muted forms [Rapin and Tuchman, 2008]. Some individuals with the condition are able to lead independent and fulfilling lives, whereas for others, the impact can be severe, interfering significantly with quality of life [Farley et al., 2009].

ASD prevalence is four times higher in males than in females; however females are more likely to show signs of more severe mental retardation [American Psychiatric Association, 2013]. The number of people diagnosed with autism has increased dramatically since the 1980s, partly due to changes in diagnostic practice, referral patterns, availability of services, age at diagnosis, and public awareness [Fombonne, 2009].

Autisms characteristics of impaired social interaction, abnormalities in communication, restricted interests, and

repetitive and stereotyped behaviours have the potential to make oral care difficult in a variety of ways thus increasing the risk of dental caries and periodontal disease [American Psychiatric Association, 2013]. Difficulties with social interactions could prove challenging when parents/caregivers teach or perform oral hygiene techniques to their autistic children. If these techniques are not part of the children's daily routine and performed by the same caregiver, they might reject doing so due to their aversion to change. In addition to that, lack of necessary manual dexterity, lack of eye contact, resulting in communication failure compound the problem [Marshall et al., 2007; Weil et al., 2011].

Primary caregivers play a central role in the supervision and guidance of these children's oral hygiene activities [Jaber, 2011] thus it's important for the dentist to provide them with the necessary information about oral hygiene and its implications and to understand the barriers to care from the perspective of the primary caregivers.

There were few studies in the United Arab Emirates (UAE) and the Arabian Gulf region describing oral health and dental needs of children with Autism. These studies reported high prevalence of caries, gingivitis and poor oral hygiene in comparison with non-autistic individuals [Murshid, 2005; Jaber, 2010; Jaber, 2011]. However, to date, there are no studies conducted in the UAE addressing the challenges and barriers faced by the autistic children and their families in providing proper oral care for their children. International studies from the UK [Barry et al., 2014] and USA [Capozza and Bimstein, 2012; Stein and Polido, 2012; Weil et al., 2011] regarding barriers to dental care are available but their results may not be applicable to the UAE population due to the differences in the rules and procedures governing the dental sector such as the dental referral routes, dental appointments, waiting list, payment methods and the travel distances to the dental clinics which cannot be compared to the USA and the UK, which are larger countries with larger remote areas and more internal travel distances. The differences in culture and in dental knowledge and awareness might also necessitate conducting regional and local studies to investigate this very important topic.

Thus, we conducted this study to investigate these challenges faced by the autistic children and their families regarding providing proper oral health care and comparing it to normal healthy children and their families in Dubai, UAE.

Materials and methods

This was a case-control comparative questionnaire study, which measured the dental care challenges of the autistic and normally developing children and compared the frequency of dental care challenges in the two groups. Dubai Healthcare City Authority-Research Ethics Review Committee (RERC) approved this research project.

Permission was obtained from the United Arab Emirates Ministry of Social Affairs to contact the special needs and Autism centres to invite the parents to participate in the research survey. Another approval letter was also obtained from the Ministry of Health in Dubai to access the control group in the public and private schools in Dubai.

Study population

The sample comprised children attending special needs centres and Autism centres in Dubai. The methodology for this study was census sampling where every parent of an autistic child attending the special needs centre in Dubai was given the opportunity to participate in the survey. The control group was chosen from school children in the same geographic areas of the centre's and included the siblings of autistic children whenever available. The estimated sample size was 78 autistic children which was calculated using Cochran sample size that was based on the oral hygiene status of autistic children from a previous UAE study [Jaber, 2011].

Questionnaire

A structured questionnaire was used that was similar to other questionnaires used in similar published studies [Capozza and Bimstein, 2012; Stein et al., 2012; Weil et al., 2011]. A pilot study to test the feasibility of the questionnaire was conducted among 20 parents. The questionnaire consisted of four sections, the first section was related to the child's and parent's demographics including: child's age and nationality; the parents age, working status and educational level. Other sections were related to oral care at home, oral care at the dentist and access to oral care. These included a total of 20 close and open-ended questions. Each questionnaire had an English and Arabic version and included an introductory front page, which contain information about the purpose of the research, the relevance of the study, how responses would be anonymous, how participation is voluntary, and the contact information of the principal investigator. For the study population, 151 questionnaires were sent to the parents/guardians of all autistic children in five special needs centres through the centre's administration and a total of 91 questionnaires were filled and sent back for participation, seven questionnaires did not fit the inclusion criteria and were excluded. For the control group, a total of 211 questionnaires were sent, however only 56 questionnaires were filled and sent back for participation, three questionnaires, which did not fit the inclusion criteria, were excluded.

Statistical methods

Data analysis consisted of choosing the questionnaires that matched the inclusion criteria, coding the sheets and keying the data into a computerised database in the Statistical Package for Social Sciences (SPSS, version 20, Chicago, SPSS Inc.), performing key analysis according to frequency distributions and descriptive analysis, then using

the T-test to compare the results of the autistic children to the results of healthy children. A p-value of < 0.05 was considered significant.

Results

Study sample characteristics

Gender distribution varied significantly between the 83 children with Autism compared with the 53 healthy controls, high proportion of males 67 (80.7%) among ASD compared with 29 (54.7%) males among healthy controls, with p-value < 0.001. Age is significantly higher among the autism group 10.87 (3.85%), compared with healthy controls 8.83 (3.67%), with p-value = 0.003. Mothers' age and occupation were not statistically different between autistic children and healthy controls. There was a statistically significant difference in the status of mothers' education in the autistic and control group. A significantly higher percentage of mothers with university degrees or higher in the control group compared to the mothers of the autism group, p value = 0.012.

No statistically significant difference was found between the two groups regarding the father's age, occupation and education. Furthermore, no statistically significant correlation existed between the mothers' and fathers' ages and having an autistic child. Considering the nationality, the proportion of autism was higher among the non-UAE nationals 63 (75.0%) compared with the UAE nationals 21 (25.0%), with p-value = 0.034.

Oral care at home

Table 1 demonstrates that the average time spent on tooth brushing per day was not significantly different between children with autism and the healthy controls, (p = 0.206). For the autism group, 70 (83.3%) parents reported that their children need assistance in brushing their teeth compared with 8 (15.4%) of the healthy controls (p-value < 0.001). For both children with autism and healthy controls group the assistance for brushing teeth is most likely from parents.

As expected, a quarter of parents of autistic children (24.5%) reported that their children always resisted and the rest (75.5%) either occasionally or rarely resisted tooth brushing, significantly more than the 45 (100%) parents of healthy children, who only reported that their children either occasionally or rarely resisted tooth brushing. Disliking of both the feeling of the toothpaste and toothbrush in the mouth were reported significantly more often in the autistic group versus the healthy group (p-value < 0.001).

Response regarding the use of fluoride indicated that most of the autistic and healthy children use fluoridated toothpaste but do not drink fluoridated water because the parents do not support water fluoridation (Table 1).

Access to oral care

Data showed that 65% of autistic children have visited a

Variables	Control Nr (%)	Autism Nr (%)	P-value
On average how many times a day does your child brush his/her teeth?			
Once/none	19 (36.5)	38 (45.2)	0.206
Two or more	33 (63.5)	46 (54.2)	
Is your child assisted in brushing his/her teeth?			
No	44 (84.6)	14 (16.7)	< 0.001
Yes	8 (15.4)	70 (83.3)	
If so, who usually assists with tooth brushing?			
Parent	10 (100)	57 (81.4)	0.151
Other & parents	0	13 (18.6)	
Does your child resist having his/her teeth cleaned at home?			
Always	0 (0)	20 (24.4)	< 0.001
Occasionally or rarely	45 (100)	62 (75.6)	
Does your child dislike the feeling of the toothpaste in his/her mouth?			
No	46 (88.4)	45 (54.0)	0.001
Yes	6 (11.5)	38 (45.8)	
Does your child dislike the feeling of the toothbrush in his/her mouth?			
No	49 (94.2)	39 (45.4)	< 0.001
Yes	3 (5.7)	45 (53.0)	
Does your child use fluoridated toothpaste?			
No	6 (11.3)	17 (20.5)	
Yes	41 (77.4)	58 (69.9)	0.379
Sometimes	6 (11.3)	8 (9.6)	
Is your child's drinking fluoridated water?			
No	40 (75.5)	53 (63.1)	
Yes	9 (17.0)	21 (25.0)	0.318
I don't know	4 (7.5)	10 (11.9)	
Do you support water fluoridation?			
No	23 (44.2)	32 (38.6)	
Yes	14 (26.9)	21 (25.3)	0.672
I don't know	15 (28.8)	30 (36.1)	

TABLE 1 Oral care at home for children with autism and healthy subjects.

dentist compared to 79.2% of healthy children. Surprisingly, the autistic children have mostly visited the general dental practitioner rather than a paediatric dentist, 38.8% and 22.5% respectively. On the other hand the healthy children have mostly visited by a paediatric dentist rather than a general dental practitioner, 41.5% and 32.1% respectively (p-value = 0.074) (Figure 1). The autistic children had visited a dentist mostly for extractions followed by fillings and check-ups, while the healthy children mostly visited the dentist for fillings followed by extractions then check-ups (Figure 2).

Over one third (35%) of autistic children had not been to a dentist before; the most common reason reported by 5.3% of parents was due to their child being uncooperative.

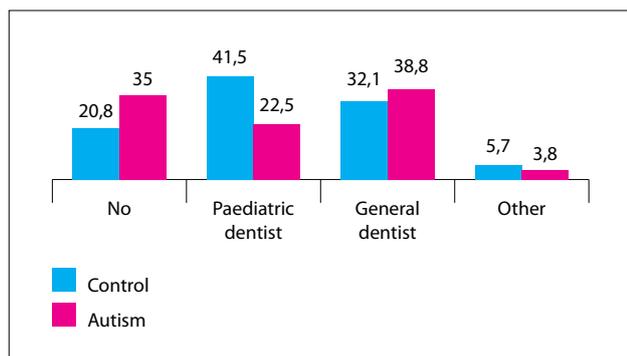


FIG. 1 Dental visits for children with autism and healthy subjects.

Other parents all equally reported that their child did not go to the dentist due to being afraid, having no complaint or they did not find a dentist who can handle the child.

Figure 3 shows that no significant difference was found between autistic children and their healthy counterparts regarding visiting a dentist, adjusted over nationality, (P-value = 0.059).

Challenges and barriers of oral health care during dental visit

Table 1 demonstrates that when parents were asked about their child’s experience in the last dental visit, significantly more parents among the autistic group rated their child’s experience as negative, 20 (37%), compared with 4 (9.5%) parents of control children (p-value=0.006). The parents of the children with ASD reported significantly more difficulty having the dentist clean their child’s teeth 32 (59.3%) compared with 4 (9.5%) of parents of healthy controls (p-value <0.001). Moreover, significantly more parents of autistic children, 36 (66.6%), reported that their children’s uncooperative behaviour increased at the dentist compared with the parents of healthy children, 7 (16.7%), with p-value <0.001. Additionally, significantly more parents of autism children reported that their children’s sensory sensitivities increased at the dentist compared with parents of the healthy controls 31 (56.4%) and 3 (7.5%) respectively with p-value <0.001.

Use of physical restraint to routinely clean a child’s teeth or child requiring general anaesthesia, sedation or other drugs were not significantly different between the two groups, p-value was 0.076 and 0.091 respectively. Twenty-one (38.9%) autistic children had general anaesthesia for dental treatment. Also, significantly more parents of children with Autism versus healthy controls reported that if their child had to go to the dentist tomorrow he or she would be afraid or extremely afraid (16.4 % vs. 15% for the afraid and 32.7% vs. 7.5% for the extremely afraid), p-value was 0.009 for the extremely afraid answer. Lastly, significantly more parents of autistic children reported their children’s reaction to the dentist will not encourage them for taking him / her to regular dental check-ups, compared

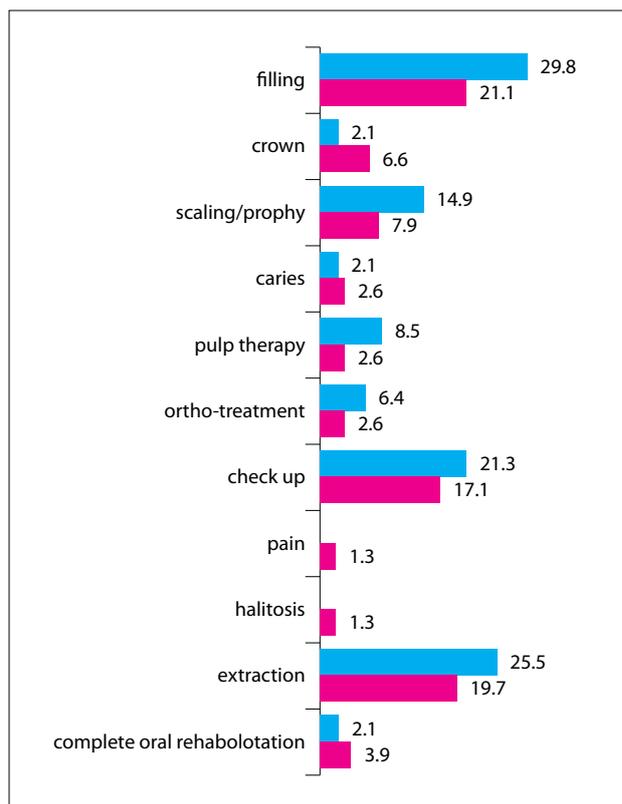


FIG. 2 Reasons (%) for visiting a dentist for autistic and healthy children.

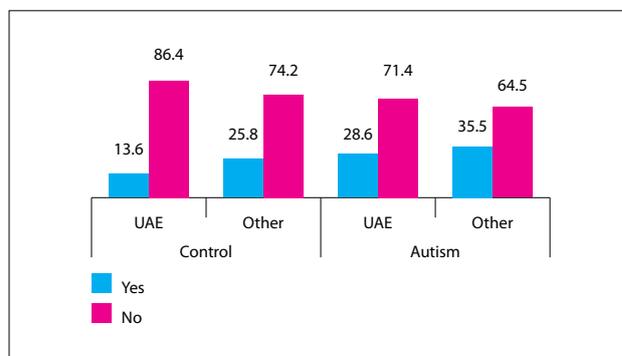


FIG. 3 Distribution of case and control by nationality and their experience of visiting a dentist.

with parents of the healthy controls, 21 (38.2%) and 7 (16.7%) respectively, p-value was 0.023.

Table 2 shows the univariate analysis for oral care during dental visit: aspects that the child is afraid of, dislikes or complains about. Dentist drill and smell were almost the same between the two groups of children. But data showed that the autistic group had more dislikes at the dentist compared to the healthy group. The autistic children disliked mostly in a descending order: dentist drill and leaning back in the dental chair, loud sounds, bright light, and smell.

Discussion

In the United Arab Emirates the only published research about autistic children and their dental status is the 2011 research by Jaber et al., who described the oral health and dental needs of children with autism and concluded that these subjects exhibited higher caries prevalence, poor oral hygiene and extensive unmet needs for dental treatment than the non-autistic healthy control group. The autistic groups mean DMFT/dmft was 2.4 compared to 0.9 in the healthy group, 59% of autistic patients had poor oral hygiene and their extensive unmet needs for dental treatment was 0.3 [Jaber, 2011]. The study showed that this paediatric group had a problem with their oral health status. To put an effective action plan to try to eliminate this problem, we need to know the reasons leading to its occurrences. We hypothesised that the autistic children might be facing more barriers to dental care at home and/or have difficulties in accessing oral care compared to the non-autistic healthy children. Questionnaires were distributed to parents of autistic and healthy children in Dubai and the results demonstrated that difficulties and barriers to dental care do exist for autistic children in Dubai and these difficulties are manifested throughout the dental experience. These results are in agreement with studies reported in the dental literature [Barry et al., 2014; Lewis et al., 2015; Marshall et al., 2010; Stein and Polido, 2012].

Oral care at home

The autistic children in Dubai have difficulty in their daily oral care at home compared to healthy children. The results in this study addressing the difficulties faced with oral care at home are consistent with other study results present in the literature [Capozza and Bimstein, 2012; Lewis et al., 2015; Stein and Polido, 2012], the only difference was found in the autistic children's use of fluoride.

Lauren's study in 2012 revealed that in the USA, the autistic children were using less fluoridated toothpaste compared to the healthy children and they did not drink fluoridated water although their parents reported their support for water fluoridation [Capozza and Bimstein, 2012]. If we compare our results in Dubai with this USA study, we would observe a difference in the autistic children's parents' views towards the use of fluoride. In Dubai there was no difference in the response between the autistic and healthy children's use of fluoride, both groups used fluoridated toothpaste and didn't drink fluoridated water because parents did not support it.

In our study, parents of autistic children experienced more difficulty in tooth brushing and a greater need in physically assisting their children compared to the parents of healthy children. This is due to the presence of difficulties in social interactions and lack of manual dexterity, which present a challenge to the parents or caregivers when providing oral care to the autistic child. Some parents might be more focused on other problems and needs of their child and unintentionally neglect the daily home oral care [Lewis et

Variables	Control Nr (%)	Autism Nr (%)	p-value
Dentist drill	17 (41.5)	25 (46.3)	0.397
Bright light	1 (2.4)	15 (27.8)	0.001
Loud sound	5 (12.2)	17 (31.5)	0.023
Leaning back in dentist chair	3 (7.3)	25 (46.3)	0.001
Smell	2 (4.9)	5 (9.3)	0.374
Having instruments in mouth	14 (34.1)	31 (57.4)	0.02
None	15 (36.6)	5 (9.6)	0.002

TABLE 2 Oral care at the dentist, children's fears, dislikes and complaints.

al., 2015]. If the brushing and flossing is not part of their daily routine, they might be more likely to reject it due to their aversion to change [Lewis et al., 2015; Marshall et al., 2007; Weil et al., 2011].

The autistic child's oversensitivity to sensory stimuli such as different sounds, tastes and smells which has been reported in the literature [Marshall et al., 2007] might explain why their dislike of the feeling of the toothpaste and dental brush was reported in this study significantly more than the healthy children, 83.3% compared to 15.4% respectively.

Ways to overcome these difficulties have been suggested by parents of autistic children in the 2015 study by Charlotte Lewis [2015]. From their daily experience with their children they noticed that having a specific routine as to the time of day they brush the child's teeth made it easier for the child to accept brushing and by time some children started to brush their own teeth under their parents supervision. Other suggestions given by parents are the use of the electrical toothbrush whose vibrating motion is more tolerated by some children more than a manual toothbrush. Another way to overcome the sensitivity towards the toothpaste taste or texture is dipping the toothbrush in fluoride mouthwash for the children who dislike the feeling of toothpaste [Lewis et al., 2015].

Access to oral care

Our study demonstrated a significant difference in visiting a dentist between the two groups of children. It was found that the healthy children visited a dentist more than the autistic children, 79.2% versus 65% respectively. But in the UK no significant difference was reported in visiting a dentist between the two groups, although numerically more healthy children visited a dentist compared to autistic children [Barry et al., 2014]. Even in the Kingdom of Saudi Arabia, a research published in 2005 by Murshid et al. [2005] concluded that in Riyadh 65% of autistic children have been to the dentist but half of these children had only minimal treatment done due to their difficult behaviour in the dental office.

Autistic children have mostly visited the general dental

practitioner rather than a paediatric dentist, 38.8% and 22.5% respectively. This might have led to the reported negative experience and increased behavioural difficulties by the autistic children during their dental visit because general dental practitioners are not trained like specialist paediatric dentists in the management of the oral health of the patient with special healthcare needs. This might be due to the lack of general awareness about the important role the paediatric dentist plays in the management of children with special needs in general and autistic children in particular. Another reason might be that, according to the governmental dental clinic system, all children have to be referred to a paediatric dentistry specialist by the general dentist, so may be the general dentist did refer the autistic child due to difficulty in managing but the parents did not go to the referral due to the negative dental experience their child had at the general dentist clinic. Also, as previously mentioned, in our study the age of the control group was significantly lower than the autistic group.

Autistic children in our study visited a dentist mostly for extractions, then fillings and check-ups. While the healthy children mostly visited the dentist for fillings, then extraction then check-ups. This might indicate that the autistic children visited the dentist with non-restorable teeth due to being irregular attenders to the dental clinic or being too uncooperative to facilitate the process of tooth restorations so extraction can be the only available long-term option. Interestingly, it was found that autistic children had their teeth crowned more than their healthy controls, this might be due to having more carious teeth surfaces which required the teeth to be crowned rather than filled or that the dentists preferred to restore the carious teeth with a crown which has longer durability and is more effective in high risk uncooperative patients such as the autistic children [Kindelan et al., 2008].

Of the 35% of autistic children in our study group who had never been to a dentist before, the most common reported barrier by their parents was that their children were too uncooperative to go to a dentist, although other study reported the most common reason to be difficulty in finding a dentist with the skills for treating an autistic child [Lai et al., 2012]. The other parents all equally reported that their children had never been to the dentist due to being afraid, having no complaint and because they cannot find a dental specialist who can handle treating them. Parents who reported that their children were too uncooperative to go to a dentist might have based their assumption on the child's behaviour during his visits to the medical practitioner or that they had tried to go to a dentist but their child's behaviour prevented it.

Parents experienced difficulty with their child's behaviour when it came to physically convincing him/her to enter the dental clinic facility, child cannot tolerate waiting in the waiting room area and gets agitated and anxious, child won't sit still in the waiting room if she/he sees something she/he might be obsessed with, and lastly parents reported that it is too embarrassing to go through all this in front of

other parents and they had a fear of being judged as bad parents who cannot handle their child's behaviour [Lewis et al., 2015].

No significant differences were found between autistic children and their healthy counterparts regarding visiting a dentist, adjusted over nationality because in Dubai most of the UAE nationals and non-UAE nationals have health insurance which covers dental treatment, and also the UAE nationals are treated free of charge in the governmental dental clinics of the Ministry of Health and Dubai Health Authority, while the non-UAE nationals with special needs are treated free of charge in the Ministry of health dental clinics. Free treatment is available in Dubai for all autistic children and other special needs children regardless of their nationality.

Challenges and barriers of oral health care during dental visit

The Basic behavioural management techniques, which is the tell-show-do, is usually used for any paediatric patient to familiarise them to the dental surroundings and treatments. It is difficult to use this simple and effective technique for the autistic children due to their impaired receptive and expressive language. Our study revealed that significantly more parents of autistic children reported that dental visits are a very challenging task where their child's sensory sensitivity to their surroundings and uncooperative behaviour increases (66.6% of parents). This has impacted their child's dental experience which 37% of parents have rated as being negative and has discouraged them from going for regular dental check-ups negatively impacting their dental health.

Behavioural difficulties during dental visits are more common in autistic children so non-pharmacological and pharmacological behavioural management techniques, such as restraint or dental treatment under general anaesthesia, might be more often required for providing a proper dental treatment safely and effectively. Our study showed that there was no significant difference between the use of restraint or general anaesthesia between the groups of autistic and healthy children. This could be due to the parents showing an increased acceptance to different options available for providing dental treatment to their children [Carr et al., 1999; Eaton et al., 2005]. These result were contrary to the ones demonstrated by Stein et al., who found that autistic children had significantly higher incidence of the use of physical restraint and more dental treatment provided under general anaesthesia than the healthy children [2012]. Differences in these results might be due to cultural attitudes towards restraint and more parental awareness and availability of resources for providing dental treatment under general anaesthesia. A point worth noting here is that the age of the control group in our study was significantly lower than the autistic group. This undoubtedly might have had an effect on the behaviour management techniques employed in dental treatment and might have increased the possibility for

the need for treatment under general anaesthesia in the healthy group.

Conclusions

Although the research satisfactorily reached its aims, there were certain unavoidable limitations. Firstly, there is no central autism registry data in the United Arab Emirates, hence only autistic children attending special needs schools and centre's were invited to participate in the study. Autistic children who are raised at home are out of reach and cannot be tracked. This might have affected the results. Secondly, this is a case control study that captured the population in a single point in time and might have produced different results if another time frame had been chosen. Thirdly, Information gathered was through a questionnaire and not face-to-face interview. The problems encountered with mailed questionnaires include refusal or delay in replying. Also, the truthfulness of the respondent could not be verified and could have been affected by different interpretation of the questions.

Significantly more children with autism experienced difficulty in oral care at home compared to healthy children. Their parents experienced more difficulty in tooth brushing and needed to use physical restraint to accomplish the task. Due to their sensory sensitivities, they disliked the feeling of the toothbrush and toothpaste more than their healthy counterparts.

Significantly more children with autism experienced difficulty in accessing oral care. Children with autism visited a dentist less than the healthy children and parents reported that the cause was their child's uncooperative behaviour. Surprisingly, autistic children had mostly visited the general dental practitioner rather than a paediatric dentist.

Recommendations

Looking at the outcome of this study, the following recommendations are suggested.

- Establish a data registry for autistic children in the UAE that is run by the government. This will help in epidemiological studies and the provision of comprehensive oral healthcare plans for these children.
- Raise the awareness of the workers and medical practitioners at the special needs centre's to the importance of maintaining the autistic child's dental health and should give the dental hygiene and annual dental check-ups as much importance as the autistic child's behavioural and medical condition.
- Dentists should spend more time educating parents and involving them in the task of maintaining their child's oral hygiene at home and to put realistic achievable

goals with the parents concerning their child's oral health.

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