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Dental Care Barriers and Oral Hygiene Challenges for Parents of Children with Autism Spectrum Disorder

<sup>1</sup>Dr. Reem AlMadani, General Dentist, Riyadh, Saudi Arabia.

<sup>2</sup>Dr. Sunil Babu Kotha, Lecturer, Department of Pediatric Dentistry, Riyadh Colleges of Dentistry and Pharmacy, Riyadh, Saudi Arabia

<sup>3</sup>Madawi M. Al Otaibi, Senior social worker, Ministry of Health, Riyadh, Saudi Arabia

<sup>4</sup>Dr. Mohammed S. Aldossary, Specialist in Pediatric Dentistry, Ministry of Health, Riyadh, Saudi Arabia

Corresponding Author: Dr. Reem AlMadani, General Dentist, Riyadh, Saudi Arabia.

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### Abstract

**Introduction:** Autistic children as a result of the intellectual deficiency which interferes with their normal functions, require more care and supervision in all their activities in life, including those related to their oral health. The oral health of autistic children may be neglected because of their special needs, lack of cooperation or communication, difficulties during teeth brushing, or limited access to oral health care.

**Aims:**To report oral hygiene challenges for parents and factors impacting on oral health of their autistic children, and to investigate the barriers to dental care services for their children.

**Methods:**Cross-sectional survey using 50-items questionnaires were completed by 142 parents of autistic children enrolled in two societies of autism in Riyadh. The questionnaire addressed information of sociodemographic, at-home oral hygiene practice and challenges, previous dental visits, and barriers to dental care. Descriptive, Chi-square, Pearson's correlation, and multiple logistic regression analysis were performed with significance level of P < 0.05.

**Results:** The mean age of children was 7.8 years old (SD: 2.9), with male to female ratio of 3.9:1.

Parents reported their children brushing once (35.2%), or twice a day (12%).35.9% brushed on an irregular basis, and 16.9% not brushing at all. Supervision while brushing was a challenge for 49.2% of parents. 27.1% of the children had gingival bleeding during brushing. History of dental trauma was reported by 31%.

31% of the children had no previous dental visit, 32.7% had undergone dental treatment under general anesthesia.Most barriers to dental care were: Cost (75.4%), finding a dentist treating their autistic child (74.6%), and behavior of their child (45.1%). 62% of parents never received preventive dental education. Noise

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at dental clinics was the most trigger of their autistic child (43%).

Child's age, socioeconomic status, and severity of autism were not significant predictors of the challenges at-home or in dental clinics (P>0.05).

**Conclusions:** Parents of children with autism experience difficulties and barriers to dental care in both at-home and dental clinics. Children in this study showed improper oral hygiene practices and insufficient dental visitsnecessitating the urgent need for effective preventive programs for this population.

### Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition that cause significant social, communication and behavioral challenges.(Gandhi and Klein, 2014). The behavioral abnormalities that characterize ASD include a developmental impairment of reciprocal social interaction, a restricted repertoire of activities and interests and impairments in verbal and nonverbal communication skills (Gupta, 2014).

Most autistic children have problems with their day to day activities such as eating, drinking, sleeping, bathing and tooth brushing (Gandhi and Klein, 2014). Maintaining good oral hygiene in children with ASD is a difficult task for children and their parents because of hypersensitivity to various stimulus and lack of manual dexterity (Murshid, 2014). There is an evidence that children with ASD, had poor oral hygiene, elevated plaque levels, and greater prevalence of periodontitis, compared to healthy children (Jaber, 2011; Vajawat and Deepika, 2012).

Furthermore, they have more untreated oral diseases and have problems in accessing oral health services and finding a dentist because these children present a special challenge to the dental health care team and difficult to treat (Lai et al., 2012; Richa et al., 2014). Many parents do not take their ASD children to the dentist because of the highly uncooperative behavior of their autistic children and the cost of dental treatment under general anesthesia when needed (Loo et al., 2008; Jaber, 2011).

Children with ASD as a result of the intellectual deficiency which interferes with their normal functions, require more care and supervision in all their activities in life, including those related to their oral health (Richa et al., 2014). However, the oral health of autistic children may be neglected because of their special needs, lack of cooperation or communication, difficulties during teeth brushing, or limited access to oral health care (Gupta, 2014).

Cooperation of autistic children is another issue, which plays an important role in determining whether the parents would take them to dentist or not. However, dental care in public healthcare setups has been seen to be satisfactory when it comes to the provision of dental treatment to children with autism (Fahlvik-Planefeldt and Herrstrom, 2001). Furthermore, several techniques can be utilized by the dental practitioners when treating autistic patients in order to control their behavior. One of these methods includes positive reinforcement, tell, show and do. It was noticed from the findings that almost fifty percent of the patients were examined (Lowe and Lindemann, 1985).

#### The aims of this study were to

1- Investigate the views and experiences of parents of children with Autism regarding oral healthcare.

2- Explore oral hygiene challenges for parents and factors impacting on oral health of their autistic children.

3- Investigate the barriers to dental care services for their children.

#### **Materials and Methods**

Cross-sectional survey using 50-items questionnaires were completed by 142 parents of autistic children enrolled in two societies of autism in Riyadh. The questionnaire addressed information of socio-demographic, at-home oral

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hygiene practice and challenges, previous dental visits, and barriers to dental care. Descriptive, Chi-square, Pearson's correlation, and multiple logistic regression analysis were performed with significance level of P < 0.05.

Study Design: Cross-sectional survey.

**Setting:** Two societies in Riyadh, Saudi Arabia: Charitable Society of Autism Families, and Saudi Society of Autism.

**Participants:** Parents of autistic children attending these two societies.

### **Methods (Procedures)**

- Ethical Approval Informed written consents.
- Self-administered questionnaire and systematic interviews (to be validated):
- Invited parents: Socio-demographic, educational level, and age for both the parent and the child. Additionally, the child medical history.
- Personal in-depth interview with the caregiver: using structured form with open-ended and close-ended questions addressing the following areas:
- Oral hygiene practice routine: frequency, duration, using of manual or powered toothbrush, supervision and assisting in teeth brushing.
- Challenges during oral hygiene practice (teeth brushing) at home: behavioral, communication, cooperation.
- Dental visits: Ease of access to dental care, difficulty finding a dentist willing to provide care, dental treatment done and cooperation, and any oral health care information received.
- > Other specific challenges/ barriers.

### **Data Analysis**

• Descriptive statistics: count and frequency distributions.

- Chi-square test to compare categorical variables (between different factors), Pearson's correlation and multiple logistic regression analyses for the association between variables
- The significance level: p < 0.05

### Results

The mean age of children was 7.8 years old (SD: 2.9), with male to female ratio of 3.9:1. Parents reported their children brushing once (35.2%), or twice a day (12%). 35.9% brushed on an irregular basis, and 16.9% not brushing at all. Supervision while brushing was a challenge for 49.2% of parents. 27.1% of the children had gingival bleeding during brushing. History of dental trauma was reported by 31%.

31% of the children had no previous dental visit, 32.7% had undergone dental treatment under general anesthesia. Most barriers to dental care were: Cost (75.4%), finding a dentist treating their autistic child (74.6%), and behavior of their child (45.1%). 62% of parents never received preventive dental education. Noise at dental clinics was the most trigger of their autistic child (43%). Child's age, socioeconomic status, and severity of autism were not significant predictors of the challenges at-home or in dental clinics (P>0.05).

## Level Ratio



Fig. 1: Gender Ratio

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Fig. 2: Education Level Distribution of study Participants



Fig. 3: Socio EconomicStatus Distribution of study Participants

### Table 1

Parents:	
Mother	108 (76.1%)
Father	34 (23.9%)
Parents' Age	Range: 22 to 57 [Mean: 38.0,
	SD: 6.8]
Parents' Education level:	
Primary	4 (2.8%)
Intermediate	17 (12%)
High school	40 (28.2%)
University	81 (57%)
Social Class: [Income]	
Low	18 (12.7%)
Moderate	118 (83.1%)
High	6 (4.2%)
Siblings:	Range 0-9
No	8 (5.6%)
Yes	134 (94.4%) Mean Number=

2.8 S		SD=1.9	
Schools:			
No 35 (		(24.6%) [of them n=14	
	older	than 6 years] = $11.6\%$	
Private	(14/1	121), school aged	
Government (Public)	BUT	not going to school	
	66 (4	46.5%)	
	41 (2	28.9%)	
Insurance:			
No	107	(75.4%)	
Yes	35 (2	24.6%)	
Table 2			
Autistic Children		M:F ratio = 3.9:1	
Male		113 (79.6%)	
Female		29 (20.4%)	
Age		Range: 2.5 to 16	
		[Mean: 7.8, SD=2.9]	
Severity of Autism:			
Mild		50 (35.2%)	
Moderate		80 (56.3%)	
Severe		12 (8.5%)	
Autism diagnosed at age of	of:	Range: 1 to 6 [Mean:	
		3.2, SD=1.1]	
Medications:			
None		66 (59.5%)	
RISPERDAL® (Risperio	lone/	29 (26.1%)	
Risidone)		5 (4.5%)	
Depakene (Valproic Acid)	)	5 (4.5%)	
CONCERTA®		4 (3.6%)	
(methylphenidate HCI)			
Strattera (AtomoxetineHCl)			
Other Diagnoses			
None		30 (21.1%)	
ADHD		94 (66.2%)	
Mental retardation		26 (18.3%)	

Other	6 (4.2%)	Brushing by:	[Among children
Communication with the		Self	brushing; n=118]
child:	95 (66.9%)	Mother	25 (21.2%)
Speech	68 (47.9%)	Family member	76 (64.4%)
Looking/signs	39 (27.5%)		17 (14.4%)
Hearing/Listening	32 (22.5%)	Allow brushing supervision?	[Among children
Touching		Yes	brushing; n=118]
Medical Problems:		Sometimes	60 (50.8%)
None	34 (26.1%)	No	46 (39%)
Speech	93 (65.5%)		12 (10.2%)
Allergy	17 (12%)	Fluoride in tooth paste?	[Among children
Epilepsy	8 (5.6%)	Yes	brushing; n=118]
Dry mouth	6 (4.2%)	No	55 (46.6%)
Asthma	5 (3.5%)	I don't know	23 (16.2%)
Vomiting	4 (2.8%)		40 (28.2%)
Cardiac	3 (2.1%)	Type of toothbrush:	[Among children
Blood disease	3 (2.1%)	Manual	brushing; n=118]
Things that bother the child		Electronic	104 (88.1%)
[Triggers]:	18 (12.7%)		14 (11.9%)
None	103 (72.5%)	Gingival bleeding while	[Among children
Noise	28 (19.7%)	brushing?	brushing; n=118]
Touch	17 (12%)	No	86 (72.9%)
Light		Sometimes	25 (21.2%)
Self-Injury/hurt:		Yes	7 (5.9%)
No	116 (81.7%)	Parent's opinion about child's	
Yes	26 (18.3%)	oral health:	18 (12.7%)
Injury/hurt to others:		Bad	84 (59.2%)
No	119 (83.8%)	Moderate	40 (28.2)
Yes	23 (16.2%)	Good	
Table 3		Mouth wash?	
Brushing Frequency:		No	126 (88.7%)
Not at all	24 (16.9%)	Sometimes	16 (11.3%)
Less than Once a day	51 (35.9%)	Yes	0 (0%)
Once per day	50 (35.2%)	Dental floss?	
Two or more per day	17 (12%)	No	136 (95.8%)

Sometimes	4 (2.8%)	
Yes	2 (1.4%)	
Chewing gum?		
No	83 (58.5%)	
Yes, sugar type	54 (38%)	
Yes, sugar-free type	5 (3.5%)	
Bruxism?		
No	112 (78.9%)	
Yes, awake	17 (12%)	
Yes, sleep	13 (9.2%)	
Bad oral habits:		
None	35 (24.6%)	
Nails bite	35 (24.6%)	
Using teeth for cutting &	22 (15.5%)	
opening	19 (13.4%)	
Finger sucking	12 (8.5%)	
Tongue thrust	11 (7.7%)	
Lip bite		
History of Dental Trauma?		
No	98 (69%)	
Yes	44 (31%)	
Favorite Food:		
Sweets	67 (47.2%)	
Carbohydrates	63 (44.4%)	
Juices	61 (43%)	
Vegetables & fruits	33 (23.2%)	
Table 4	1	
Had been to a dentist?		
Yes	98 (69%)	
Never	44 (31%)	
Regular dental visits?	[Of the 98 children	
Yes	had been to a	
No	dentist]	
	28 (28.6%)	
	70 (71.4%)	

Last dental visit:	[Of the 98 children		
< 6 months	had been to a		
6-12 months	dentist]		
>1 year	26 (26.5%)		
	20 (20.4%)		
	52 (53.1%)		
Same dentist of siblings?	[Of the 98 children		
No	had been to a		
Yes	dentist]		
	69 (70.4%)		
	29 (29.6%)		
Sector Type:	[Of the 98 children		
Private	had been to a		
Public	dentist]		
	71 (72.4%)		
	27 (27.6%)		
Dentist specialty:	[Of the 98 children		
Pedodontist	had been to a		
General dental practitioner	dentist]		
I don't know 55 (56.1%)			
	30 (30.6%)		
	13 (13.3%)		
Previous Bad Dental experience?	[Of the 98 children		
Yes	had been to a		
No	dentist]		
	42 (42.9%)		
	56 (57.1%)		
Difficulty finding dental care?			
Yes	97 (68.3%)		
No	45 (31.7%)		
Cost of treatment affect seeking			
dental care?	107 (75.4%)		
Yes	35 (24.6%)		
No			
Child's behavior affect seeking			
	1		

dontal agrag	64 (45 10/)		D -		1.1.1
dental care?	64 (45.1%)		Do	es your c	child
Yes	78 (54.9%)		allo	ow you	to
No			hel	p him bru	ısh?
Difficulty finding a dentist who					
accepts autistic children?		Age	0	06	
Yes	106 (74.6%)	Occupation	.11	6	
No	36 (25.4%)	Education	.02	.022	
Dental treatment done:	[Of the 98 children	Standard	of0	11	
Restorations	had been to a	living			
Extractions	dentist]	Autism Intensit	y .21	5	
Examination only	40 (40.8%)				
Prophylaxis/polishing	34 (34.7%)	Table: Pearson's	Correla	ations am	ong
Topical fluoride application	29 (29.6%)	Regression	conten	ations and	ong
	25 (25.5%)	Coefficients <sup>a</sup>			
	14 (14.3%)		Unstanda	ardized	Stan
Dental treatment under:	[Of the 98 children		Coefficie	ents	Coef
NoLA	had been to a	Model	В	Std. Error	Beta
LA	dentist]	1 (Constant)	1.939	.690	025
Nitrous oxide	23 (23 5%)	Age	005	.012	03
GA	23(23.5%)	StandardofLiving	044	.236	018
UA .	14(14.20%)	Autism Intensity	.225	.137	.154
	14(14.5%)	a. Dependent Variable	: DoesYou	urChildAllov	vsYou
	32 (32.7%)				
Received education about the		Coefficients <sup>a</sup>			
health of your baby's teeth?	54 (38%)		Unstanda Coefficie	ardized	Stan
Yes	88 (62%)	Model	В	Std. Error	Beta
No		1 (Constant)	1.354	.332	
Things that bother your child		Age	.005	.006	.085
when he goes to a dentist:	61 (43%)	Education	.005	.051	.010
Noise	27 (19%)	StandardofLiving	006	.114	005
Instruments shape	23 (16.2%)	Autism Intensity	148	.066	208
Touching	19 (13.4%)	a. Dependent Variable	: DoYouH	IaveDifficult	yGetti
Dentist's attitude	16 (11.3%)	L			-
Light	15 (10.6%)				
Taste	9 (6.3%)				
Smell					

difficulty getting you to him brush? dental appointments? .039 -.135 .023 -.009 .046

Do

you

have

ons among variables

		Unstandardized Coefficients		Standardized Coefficients		
М	odel	В	Std. Error	Beta	t	Sig.
1	(Constant)	1.939	.690		2.811	.006
	Age	005	.012	037	393	.695
	Education	006	.106	005	053	.958
	StandardofLiving	044	.236	018	185	.854
	Autism Intensity	.225	.137	.154	1.637	.104

hildAllowsYouToHelpHimBrush

	Unstandardized		Standardized		
	Coefficients		Coefficients		
Model	В	Std. Error	Beta	t	Sig.
1 (Constant)	1.354	.332		4.073	.000
Age	.005	.006	.085	.908	.366
Education	.005	.051	.010	.108	.915
StandardofLiving	006	.114	005	055	.956
Autism Intensity	148	.066	208	- 2.233	.027

eDifficultyGettingdentalAppointments

Item	Child	Autism	of grinding his teeth?		
	Gender	Intensity	Does your child have bad	0.899	0.124
Gender	0.986		habits?		
		0.552	What is your child's favorite	0.583	0.810
Age	0.607	0.123	eating		
Occupation	0.842	0.526	Does your child toothpaste	0.550	0.077
Education	0.479	0.641	contain fluoride?		
Standard of Living	0.180	0.712	What do you think of your	0.739	0.036
Does Your child have brothers	0.750	0.179	child's teeth and gums		
and sisters			Does your child's gum bleed	0.972	0.363
Number of children	0.062	0.669	while brushing his teeth		
Where is the child studying	0.397	0.132	Does your child eat	0.884	0.857
Does your child have medical	0.326	0.564	frankincense		
insurance?			What type of brush your child	0.759	0.534
Child Age	0.337	0.133	use?		
What age Autism was	0.351	0.000	Does your child use a mouth	0.913	0.784
diagnosed			rinse		
What medicine you used for	0.449	0.732	Does your child use dental	0.494	0.540
autism child?			floss		
Additional condition or	0.067	0.103	Are there previous injuries to	0.462	0.021
syndrome			mouth and teeth		
How to communicate with the	0.510	0.266	Does your child go to dentist	0.710	0.963
child			regularly		
Any health problems	0.822	0.483	When was your child's last	0.722	0.767
Things that bother your child	0.733	0.012	visit to the dentist		
Does your child hurt himself	0.869	0.193	Do all your children go to the	0.285	0.280
Does your child hurt others?	0.595	0.932	same dentist		
How often your child brush	0.545	0.167	Do you have difficulty in	0.096	0.077
his teeth			getting dental appointments		
Does your child brush his	0.132	0.948	Where is your child's teeth	0.561	0.026
teeth with the help of			treated		
someone?			Does cost of treatment affect	.023	0.739
Does your child allows you to	0.080	0.253	your care		
help him brush?			Do you consider your child's	0.310	0.190
Does your child have a habit	0.351	0.392	actions		

Dentist that accepts your child	0.467	0.285
for autism treatment		
What type of dentist your	0.046	0.098
child visiting		
Does your child have bad	0.719	0.776
experience		
What treatment have you done	0.625	0.855
How your child was treated	0.348	0.094
Have you received medical	0.350	0.978
advice and education		
What are the most important	-	-
problems		
What are the things that	0.978	0.202
bother your child		

### Discussion

In Saudi, children with developmental disorder are unable to have a good oral care routine at home as compared to children who are mentally and socially healthy. Our study have shown similar results to the studies conducted present in the literature. The only difference that was found in the results was the use of fluoride in the autistic children(Barry, O'Sullivan and Toumba, 2013).

In 2012, a study conducted by Lauren in USA discovered that children with autism consumed toothpaste with less fluoride and also didn't consume fluoridated water. Although their parents supported the use of both. The difference between the studies conducted in the USA and Saudi is that the parents of both the autistic and healthy children agreed to the use of fluoride toothpaste but didn't support the consumption of fluoridated water(Brown, Brown and Woodburn, 2014).

Parents have faced much difficulty in helping out their children brushing their teeth specifically in physically assisting as compared to the healthy children's parents. The main and obvious reason behind this is the lack of social interaction and communication of the children

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suffering from autism. This becomes a proper challenge for the caretakers or parents of these children. Other reasons might include the divided attention of the parents towards their child's other needs and problems(Samadi and McConkey, 2009).

Once the children get used to not flossing and brushing their teeth, it becomes more difficult to change this habit(Vasilopoulou and Nisbet, 2016).

The core reason behind not brushing and flossing is that the autistic children are over sensitive towards the senses including sounds, smells and tastes due to which they even dislike the taste of paste. This was discovered statistically as only 15.4% of the healthy children had this issue while 83.3% of the autistic children are having this issue(Chan and Lam, 2018).

Parents in this study have suggested some suitable methods to overcome these problems as they have stated that if they follow the same brushing routine as their children, their children will themselves start following the brushing routine. And after some time, they will themselves start to brush their teeth regularly under their observation. Besides this, many parents have told that using electrical toothbrush makes it easy or reduces the energy required by their children. Many parents have tried the method of dipping the brush in fluoride mouthwash which makes the taste for the children bearable(Rayan and Ahmad, 2016).

A notable difference was observed between children for which we divided them into groups, the fact seems quite obvious that the number of autistic children visiting dentists is much less than healthy children. In United Kingdom there was not much difference between the number of healthy and autistic children visiting the dentists on regular basis. In the city of Riyadh, Saudi Arabia the number of autistic children visiting the dentist was quite impressive as 65% of them visited on the

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regular basis but very few of them get their treatments done properly due to their resisting behavior in the office(Sinha, Verma and Hershe, 2016).

Autistic children, according to the stats autistic children visit general dentists more (33.8%) than the pediatric dentists 22.5%. this has gradually increased the behavioral problems among the autistic children as the general dentitions are not trained at required level comparatively to deal with such children (Delli et al., 2013).

Although the pediatric dentists are so important when it comes to the managing of autistic children and healthy children too in general behavior, people are not much aware of their importance in the society. Another reason behind this matter can be that in the government system dealing with dentistry, the general dentists are to be visited by the people who will then refer them to the pediatric dentists. This must be the routine of the procedure but after when the general dentitions refer the patients to pediatric dentists, they might not take their children to them. The reason might be the experience that the parents had at the general practitioners(Mohamed Rohani et al., 2018).

Our study showed that the most visits autistic children made to the dentists was for extractions, the for fillings and then checkups. In the case of the healthy children, most visits were for fillings, then for extraction and lastly for the checkups. This shows that the irregular visits to dentists and the behavior that the autistic children have towards the treatments, the only option left to deal with affected tooth is the extraction. There was another finding that the autistic children, due to having more carious surfaces get their teeth crowned more than the healthy children, as crowning becomes more preferable. Furthermore doctors prefer to crown the teeth which last longer and is suitable for such non cooperative children(Ku, Stinson and MacDonald, 2019). Out of 35% autistic children who have never visited the dentist for a long time, the most common reason behind the fact is the children are too stubborn when it comes to coping up with their behavior while treating them. Many parents have also stated that they find it difficult to find a suitable dentist who can deal with such behavior and autistic children. Moreover many said that their children have been very afraid of the treatments, as they have never visited before plus the general practitioners finding it difficult to deal with this behavior(Stein Duker et al., 2017).

Physically convincing them to set their brushing routine or visit the dental clinic is even more difficult as being comfortable with parents, it's easy for them to say NO to them. Many parents have mentioned that their child finds it difficult to sit and wait in for their turn in the clinic as they get more anxious and agitated. And so the children won't sit patiently or sit still in the waiting room as they are afraid to be the next one to get treated. This makes the parents uncomfortable too as they feel ashamed in front of the other parents(Lloyd, Osborne and Reed, 2019).

There was not any notable difference between the autistic children and their siblings in their visits to the dentists as in Saudi most of the residents have health insurance which includes dental treatment too. Furthermore in governmental hospitals and clinics the patients are treated free of cost by the Ministry of health dental clinics. Besides this, government has provided free treatment for all the autistic children and children with other difference special needs whether they have the nationality or not(McDaniels, 2016).

### Conclusions

Parents of children with autism experience difficulties and barriers to dental care in both at-home and dental clinics. Children in this study showed improper oral hygiene practices and insufficient dental visits necessitating the

urgent need for effective preventive programs for this population.

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