

# 1 Parents' Dental Knowledge and Oral Hygiene Habits in Saudi 2 Children with Autism Spectrum Disorder

3 Ebtissam Zakaria Murshid<sup>1</sup> and Ebtissam Zakaria Murshid<sup>2</sup>

4 <sup>1</sup> King Saud University, College of Dentistry

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## 7 **Abstract**

8 Background: In Saudi Arabia, too few studies are published regarding the dental health habits  
9 of children with Autistic Spectrum Disorders (ASD).Aim: The aim of this study was to  
10 evaluate their parents' dental knowledge; and the oral hygiene practices of a group of autistic  
11 children.Subjects and Methods: This is a cross-sectional study targeting parents of autistic  
12 children enrolled in three different rehabilitation centers in Riyadh. A total of 450  
13 self-administered questionnaires formulated in simple Arabic were distributed to parents of  
14 children diagnosed with autism or any form of ASD. The questionnaires consisted of  
15 demographic questions and dentalrelated questions, such as the sources of dental knowledge,  
16 causes of dental problems, and opinion about the proper time of first dental visits.Results:  
17 The majority of the participating parents didn't receive any dental knowledge from dental  
18 personnel. More than 60

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20 **Index terms**— autism, parents? dental knowledge, oral hygiene practices.

## 21 **1 Introduction**

22 utism, or Autistic Spectrum Disorder (ASD), is a neuro-developmental disorder. It is characterized by  
23 impairments in behavioral and social interaction; language, communication, imaginative play, and a range of  
24 interests and activities Friedlander AH. 2003, Muhle R, 2004Cassel TD, 2007. ASD is not a disease, but a  
25 syndrome with multiple interacting causes; both genetic. Folstein S, Rosen 2001, Bayou N, 2008, . ??andrigan  
26 would be expected to be developed enough that such impairments can be noted; typically this is around preschool  
27 age of 3 or 4 years old ??APA 2000) Recently, it was reported that other social indicators such as shared smiles  
28 and direct vocalizations can be used to distinguish children as young as 12 months of age, that are at risk of  
29 developing ASD (Ozonoff et al. 2010) Due to the difficulty of diagnosing ASD cases, the prevalence of ASD is  
30 hard to establish, but is surely increasing rapidly all over the world.APA 2000. In Saudi Arabia, an extensive  
31 review of the literature revealed no specific numbers regarding diagnosed cases of autistic children reported. A  
32 rough estimate was reported in 2009 as 18 per 10,000 (Al-Salehi, Al-Hifthy, & Ghaziuddin 2009 ) While several  
33 prominent researches have been conducted from a medical point of view, the oral health and dental needs of  
34 children with ASD "specifically caries incidence studies" have been evaluated by few investigators. Previous  
35 studies conducted on this matter reported no statistical significant differences in the prevalence of fillings and  
36 caries rates in comparison to those of non-autistic individuals (Lowe O and Lindemann R. 1985, Backman,  
37 Pilebro. 1999 , Fahlvik-Planefeldt C, Herrstrom P 2001) Others reported a lower incidence of caries (Kopel HM:  
38 1977 ?? Karmen S, Skier I. 1985, Namal et al 2007, and A. Jaber 2011) Furthermore, previous studies showed  
39 that children with ASD showed visible plaque and different degrees of gingivitis (Lindemann and Lowe 1985,  
40 Shapira et al 1989, Murshid 2005, DeMattei et al. 2007. This might be due to the children lacking the manual  
41 dexterity needed for proper OH practices, or as a side effect of the medication used to treat their disorder.  
42 Many of the medications used to control the behavior of children with ASD or to increase their concentration  
43 and social interactions may have adverse oro-facial side effects due to their anti-cholinergic properties, including

## 6 RESULTS

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44 xerostomia, sialorrhea, dysphagia, sialadenitis, dysgeusia, stomatitis, gingivitis, gingival enlargement, glossitis,  
45 bruxism, edema and discoloration of the tongue .

46 Several studies reported a significant association between the parents' dental knowledge, routine oral hygiene  
47 practices, dietary habits, and children's oral health ( Barker JC and Horton SB 2008 & Bilal Mirza et al 2011).  
48 The standard of the children's oral hygiene correlated directly to that of their parents. Parents with better oral  
49 hygiene tended to have children with similar high standards of hygiene, and vice versa Al-Shalan, 2003, Wyne AH,  
50 2004 Children with Autism Spectrum Disorders present a unique behavioral challenge to pediatric dentists due  
51 in part to the intrinsic communicative disability and altered sensitivities to various stimuli, Given the reported  
52 rise in the prevalence of ASD over the last 20 years, pediatric dentists can expect to be faced with the challenge  
53 of providing oral care for an increasing number of children with ASD. Increasing the parents' dental knowledge  
54 and the focus on the preventive programmers designed particularly to parents of children with ASD becomes  
55 highly significant. This can be achieved by investigating the dental knowledge of parents with ASD children.  
56 Therefore, the aim of this study was to investigate the dental knowledge of ASD children's parents and the oral  
57 hygiene practiced by ASD children.

## 58 2 Subjects and Methods

### 59 3 Questionnaire

60 This cross-sectional survey was approved by the Ethical Committee of Human Studies at the College of Dentistry  
61 Research Center (CDRC). A selfadministered questionnaire was formulated in simple Arabic language. To assess  
62 the questionnaire's readability, a group of 30 parents with autistic children attending the dental college at King  
63 Saud University were asked to answer the questionnaire and write their comments. Taking into consideration  
64 the comments of the pilot group of parents, a modified version of the questionnaire was distributed to parents  
65 of children diagnosed with any form of Autism or ASD. The questionnaire consisted of questions regarding the  
66 child's age, gender, and if the child was professionally diagnosed with any kind of Autistic Spectrum Disorder  
67 (ASD). In addition, it included dental questions like the sources of parents' dental knowledge, causes of dental  
68 problems, and their opinion about time of first dental visits.

### 69 4 Subjects

70 The subjects of this study were recruited from three of the major autistic rehabilitation centers in Riyadh (The  
71 capital of Saudi Arabia). The centers were registered with the Saudi Autistic Society (SAS). The authorities  
72 of each center were contacted and ethical approval was obtained before distributing the questionnaires to the  
73 parents of the autistic children. The staff members in each center distributed the questionnaires to all the parents  
74 who initially agreed to answer the survey while dropping their children off at the centers and collected them back  
75 later.

### 76 5 Methods

77 A cover letter of invitation to participate in the study was sent with the questionnaires. The letter included  
78 an explanation of the purpose, the importance of the study, and a short introduction of the investigator. The  
79 questionnaires requested information like the child's age, gender, and if the child was professionally diagnosed  
80 with autism, semi-autism, or any kind of Autistic Spectrum Disorder (ASD). In addition, dental questions like  
81 sources of parents' dental knowledge, causes of dental problems, and their opinion about time of first dental  
82 visits. Parents were asked to answer questions in regard to the frequencies of brushing, methods and tools of  
83 oral hygiene practiced by the autistic children or their caregivers. It was thought that the distribution of the  
84 questionnaire by a 3rd person and not by the investigators would be advantageous, as the bias would be reduced  
85 if the parents answered the questionnaire away from the dentist.

86 The total number of questionnaires distributed was 450. The copies were distributed taking into consideration  
87 the number of children enrolled in each center and the parents' initial agreement to participate in the survey.  
88 Every family was assured of the confidentiality of the collected data and that the resultant information would  
89 be used only for research purposes. The questionnaires were distributed to all the families with the help of  
90 the staff members working in the three selected centers during the month of May in 2012. All the answered  
91 questionnaires were collected by the author. Only children who were professionally diagnosed with ASD and  
92 the completed questionnaires were included in the study. The collected data was entered in the computer using  
93 Statistical Package for Social Sciences (SPSS) software for frequencies distribution of all variables in number and  
94 percentage.

## 95 6 Results

96 Out of 450 questionnaires distributed, 344 were returned and with an overall response rate of 76.4%. The  
97 children's ages ranged from 3 to 14 years old (mean age  $\pm 6.4$ ) with 75.9% males and 24.1% females.

98 Table 1 shows the distribution of parents' response to the source(s) of their dental knowledge. The majority  
99 of the parents (57.3%) reported that they did not receive any information about dental knowledge. Other  
100 sources were from dentists and dental personnel, and from the media (14.2% and 9.6% respectively). Regarding

101 the parents' knowledge about etiology of dental caries, a large number of the parents (48.8%) choose irregular  
102 cleaning of the teeth as the main cause of dental caries. Hereditariness or genetic causes was given by 12.5% of  
103 the parents as the main reason of dental caries. Only 11.6% thought bacteria was the main cause. The parents  
104 were asked what age the child should have their first dental visit at. The results show that 28.2% of the parents  
105 thought dental visits were necessary only at signs of pain or dental problems. Only 2 parents thought it should  
106 be during the first year since the child's birth. Twenty-seven percent of the parents didn't know the answer.  
107 Table 2 shows the distribution of the parents' responses regarding the oral hygiene practices of their children.  
108 The data shows that 38.7% of the children were able to brush their teeth by themselves, while 61.3% needed help  
109 during tooth brushing. More than half (52.3%) of the mothers were helping their children during tooth brushing.  
110 Only a few fathers (10.2%) were involved in the brushing practices. Receiving help during brushing from home  
111 nurses, helpers and maids represented 13.4%. Only 5.8% of the parents reported irregular or no brushing of their  
112 children's teeth. The parents reported that 32.6% of their children either did not practice tooth brushing (3.8%)  
113 or brushed on an irregular basis (28.8%). The rest of the children reported brushing once or twice a day, 34.0%  
114 and 29.1% respectively. Only 4.4% of the children brushed 3 times or more. An enormous number of the parents  
115 (90.7%) reported that toothbrushes and toothpaste were the main tools used to clean their children's teeth. A  
116 few parents (8.5%) used Miswak only and only 0.9% relied solely on water rinses or swabbing the teeth with  
117 water and cotton. Water rinse /water swab only 3(0.9)

118 In Saudi Arabia, the amount of consequent research on Autism Spectrum Disorders (ASD) is sorely lacking,  
119 at least from the dental aspect. While several prominent researches have been conducted from a medical point  
120 of view, far too few studies have focused on the dental, which drew forth the inspiration behind this research.  
121 The cooperation and enthusiasm of the staff in the three selected centers had a great effect on the response rate  
122 of the parents.

123 In this study, the insufficiency in the distribution of oral hygiene instructions and dental awareness by dentists  
124 or dental personnel and dental institutions was reflected in the parents' responses. Only small number of parents  
125 received direct oral hygiene instructions from dentists, and even fewer parents received information from other  
126 sources like professional dental brochures and the media. Similar findings of shortages in the distribution of oral  
127 hygiene instructions was reported by parents of healthy children, or parents of children with different disabilities  
128 from the same city. ) the parents reported that they had received dental instructions directly from dentists at an  
129 early age. An explanation of this discrepancy could be the differences in the nature of the children's conditions.  
130 CP and DS are two conditions that are easily diagnosed at or about the time of birth, so parents usually are  
131 educated about their children's condition and the importance of an early intervention in regards to different  
132 health aspects before they leave the maternity and delivery ward. However, in the case of autistic children, the  
133 child looks absolutely normal at birth. "ASD cases usually diagnosed by the age of 2 years or older" (APA 2000,  
134 WHO 1992, Stone W et al 1999, Moore. V, ??oodson S 2003, Amendah, D. et al 2011) In addition, Autism is  
135 considered to be a relatively new condition when compared to CP or DS, so parents with autistic children might  
136 be more occupied with the urgency of the medical, behavioral and training condition of their children than the  
137 dental condition.

138 Dental literature define caries as the most common multi-factorial disease of the human race. . Parents in this  
139 study showed substantial deficiencies in their dental knowledge, which was clearly reflected in their responses  
140 regarding the cause of dental caries. A large number of parents attributed the cause of dental caries to improper  
141 tooth brushing only. The role of bacteria was chosen by a very small number of parents in this study, and similar  
142 studies conducted with parents of healthy children This could be due to autism being considered a genetic and/or  
143 hereditary disorder, making parents believe that the two are correlated. Some studies point out that autism is a  
144 genetic disorder and many characteristics of the disease are still inexplicable, parents may believe that genetics  
145 may cause victim-blaming or victimshaming. These responses merely highlight the necessity of raising awareness  
146 about these controversial topics. Parents should be better educated by medical personnel on the procedures that  
147 follow the successful diagnosis of autism, or any signs of ASDs in children, so that they may seek dental advice  
148 from professionals well-acquainted with these disorders and sufficiently equipped to handle these children (e.g.  
149 pediatric dentists).

150 While the American Academy of Pediatric Dentistry (American Academy of Pediatric Dentistry: [www.aapd.org](http://www.aapd.org)), calls for the first dental visit to be by one year of age, a large number of the participating  
151 parents believed dental visits should be an option only in the case of pain or dental problems. Similar responses  
152 were reported by mothers of children with Down's syndrome (Al-Hussyeen 2006). Unfortunately, only two  
153 parents in this study thought their children should visit a dental clinic during their first year of age and many  
154 others chose the ages 3-6 to do so. Similar findings of delaying first dental visits were reported by other studies  
155 conducted in the same area ??AlShalan et al. 2002, Al-Bader 2006, Al-Hussyeen A 2006, Wyne 2007). The delay  
156 in performing dental visits could be due to many reasons such as; the difficulty in managing the behavior of ASD  
157 children, or the unavailability of specialist clinics to treat children with Autism. Parents were likely unaware  
158 that dentists specializing in pediatric dentistry are trained in and capable of managing patients with different  
159 medical conditions and special needs. The lack of simple language brochures explaining the wide selection of  
160 behavioral management techniques that can be used in dentistry can be linked to this response. Cooperation  
161 between the different dental service providers in designing and distributing brochures customized for children  
162 with special needs is essential. Furthermore, a list of pediatric dentists and clinics Volume XIV Issue II Version  
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## 9 RECOMMENDATIONS

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164 I Year ( ) J should be sent to the SAS website and different rehabilitation centers to convey this information to  
165 the parents and increase their dental awareness.

166 Most of the children in the present study needed help during tooth brushing, which given the nature of disorder  
167 (wherein physical impairments or poor manual dexterity skills are counted amongst the characteristics of autism)  
168 was to be expected. ??AAP 2000 ?? Vivian Nordian, Ch Gillberg 1996 ?? NIH 2008 ?? Amendah, D.et al  
169 .2011) Another expectation was the large number of mothers helping during brushing. The mothers' role and  
170 enthusiasm in regards to their disabled children's oral health was acknowledged in many studies (Petersen PE  
171 1995, Al-Tamimi S. 1998, Al-Hussyeen 2006, Hulya Bilgin, Leyla Kucuk 2010, ) It is also worth noting that most  
172 Saudi families are in the habit of hiring live-in help, usually nannies or maids, to help care for their children and  
173 perform household chores. Therefore it makes sense that some of the participant children were helped by their  
174 caretakers as well. It is important to highlight that the number of fathers assisting during tooth brushing was  
175 not particularly high. This could be due to the fact that most of the fathers in Saudi society are the main source  
176 of their families' income, and mothers usually are the ones caring for the children and homes.

177 Even though a large number of the parents in this study didn't receive any dental information or oral hygiene  
178 instructions, most of them brushed their children's teeth once or twice a day. This could be considered largely  
179 adequate on their part, especially if we take into consideration the territorial outlook most ASD children have  
180 when it comes to their privacy. Friedlander 2003, Klein and Nowak 1999 ?? Marshall et all 2007, , Hulya Bilgin,  
181 Leyla Kucuk 2010 ?? Murshid 2011. Fortunately, only a fractional percentage of the parents never brushed for  
182 their children. Similar regular oral hygiene practices were reported by different authors, who collected their data  
183 from parents of children with different disabilities living in the same area. (Al-Bader et al 2006, ??l-Hussyeen,2006,  
184 Wyne 2007 ) The use of toothbrushes and toothpaste was reported with the majority of the parents of this study  
185 and many other similar studies conducted in the same area (Al-Bader et al 2006, Wyne 2007). Luckily, only a  
186 few of the parents in this study used water rinsing and cotton swabs only. Fewer parents still reported the use  
187 of the traditional and cultural tool known as Miswak to brush their children's teeth. Miswak is a natural tree  
188 branch taken from the Salvadoria persica tree (a wooden stick) commonly used for brushing teeth in Arabian  
189 Countries and other parts of the world. The benefits of Miswak to the gums and teeth were touched upon by  
190 the World Health Organization. (T. al-Khateeb, D. O'Mullane, H. Whelton, M. Sulaiman 1991, WHO 2000,  
191 Ezoddini-Ardakani 2010) A small percentage of the parents in this study were using Miswak with their children.  
192 Similar findings were reported by parents of children with cerebral palsy in Riyadh. (Wyne 2007) This could be  
193 due to the difficulties in controlling the stick during brushing especially in cleaning the back teeth.

194 In general, the data collected in this study shows that most of the parents seemed to understand the importance  
195 of oral hygiene practices. A positive attitude in brushing the children's teeth was shown by the mothers  
196 participating in the study. The lack of circulation of dental information by professional dental personnel and  
197 dental institutions was clearly reflected in the parents knowledge of the causes of dental caries and the time of  
198 first dental visits and regular checkups. It is noteworthy to mention that a child with ASD may not be able  
199 to overlook and accept changes in his or her expected environment; most of them may become particularly  
200 defensive and obsessive about the variation. (Bogdashina, 2003). The difficulties in controlling and dentally  
201 treating children with ASD have been mentioned in a variety of studies. (Klein and Nowak 1999, Friedlander  
202 2003 ?? Marshall et all 2010 ?? Murshid 2011) Therefore, obviously preventing dental problems in this group of  
203 children is more convenient than treating them. Parents should be informed that preventing plaque formation is  
204 the key to reducing dental caries and gingival diseases. This can be achieved by mechanical removing of plaque  
205 materials, reducing the refined carbohydrate diet intake, fluoride applications and regular dental check-ups.

## 206 7 Limitations

207 The questionnaire and data collection methods in this study may have certain limitations. For example, the  
208 educational level and socioeconomic status of the participants were not included though this could affect the  
209 results. To overcome these shortcomings, future studies are recommended. With the limitation of this study, it  
210 can be concluded that:

## 211 8 Conclusions

212 ? There is lack of dental knowledge amongst the participating parents of children with ASD in this study,  
213 especially in regards to causes of dental caries, and the appropriate time of a child's first dental visit. ? Parents  
214 of children with ASD showed satisfactory oral hygiene practices.

## 215 9 Recommendations

216 ? The need for professional dental health awareness lectures, brochures, educational television and radio  
217 advertisements, and programs designed especially for children with different disabilities becomes obvious.



Figure 1:

*[Note: Author : Associate Professor in the Department of Pediatric Dentistry and Orthodontics College of Dentistry, King Saud University Riyadh,]*

Figure 2:

Figure 3:

1

Question	Parents' Response	NO (%)
Parents' sources of dental knowledge	No information was received	197 (57.3)
	Information received from Dentist/dental personal	49 (14.2)
	Information received from media	33 (9.6)
	Information received from folds and brochures	19 (5.5)
	Information received from friends, relatives	10 (2.9)
	Multiple resources	36 (10.5)
Reason for tooth decay	Irregular cleaning	168 (48.8)
	Multiple reasons	59 (17.15)
	Heredity/ Genetics	43 (12.5)
	Don't know	44 (12.8)
	Bacteria	40 (11.6)
	Consuming food high in sugar	35 (10.1)
Time of first dental visit	Only in case of pain or dental problems	97 (28.2)
	Don't know	94 (27.3)
	From 3-6 years	65 (18.9)
	After 6 years	46 (13.4)
	From 1-3 years	40 (11.6)
	During the first year	2 (0.6)

Figure 4: Table 1 :

## 9 RECOMMENDATIONS

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Question	Parents' Response	NO (%)
ASD child's ability to brush his/her teeth by his/her self	Yes	133 (38.7)
Children's help during tooth brushing	No	211 (61.3)
	Mother	180 (52.3)
	Children are able to brush by themselves	133 (38.7)
	Father	35 (10.2)
	Maid, helper, home nurse	46 (13.4)
	More than one person	55 (16.0)
	Siblings	9 (2.6)
	No or irregular brushing	19 (5.8)
	Never brushing	13 (3.8)
Frequencies of tooth brushing practiced by The Children	Irregular brushing	99 (28.8)
	Brushing once per day	117 (34.0)

Figure 5: Table 2 :

Parents' Dental Knowledge and Oral Hygiene Habits in Saudi Children with Autism Spectrum Disorder Part

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[Note: © 2014 Global Journals Inc. (US) Year ( ) J Volume XIV Issue II Version I © 2014 Global Journals Inc. (US)]

Figure 6:

### 219 .1 Acknowledgment

220 The author would like to address her thanks to all the staff members and the directors of all the three centers  
221 for their help in distributing and collecting the questionnaires of this study. The author also would like to thank  
222 all the parents who agreed to complete the questionnaires of the study and for Mr. Ibrahim Abu-AlHassan for  
223 his help with the data entry and analysis.

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