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

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Aim: The aim of this study was to evaluate their parents' dental knowledge; and the oral hygiene practices of a group of autistic children.

Subjects and Methods: This is a cross-sectional study targeting parents of autistic children enrolled in three different rehabilitation centers in Riyadh. A total of 450 self-administered questionnaires formulated in simple Arabic were distributed to parents of children diagnosed with autism or any form of ASD. The questionnaires consisted of demographic questions and dental-related questions, such as the sources of dental knowledge, causes of dental problems, and opinion about the proper time of first dental visits.

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Results: The majority of the participating parents didn't receive any dental knowledge from dental personnel. More than 60% of the parents reported that their children were unable to brush their teeth by themselves. In addition, the results showed that 90% of the children used toothbrushes and pastes, and only 34% of them brushed their teeth once per day. Furthermore, more than half of the mothers reported that they helped their children during tooth brushing. The parents did not have proper knowledge about the timing of children's first dental visit.

Conclusions: Based on the results, it can be concluded that there is lack in dental knowledge within the participating group of parents in this study. Dental professionals should increase their efforts to educate their patients about dental knowledge.

Keywords: autism, parents' dental knowledge, oral hygiene practices.

1. INTRODUCTION

Autism, or Autistic Spectrum Disorder (ASD), is a neuro-developmental disorder. It is characterized by impairments in behavioral and social interaction; language, communication, imaginative play, and a range of interests and activities *Friedlander AH. 2003, Muhle R, 2004 Cassel TD, 2007*. ASD is not a disease, but a syndrome with multiple interacting causes; both genetic. *Folstein S, Rosen 2001, Bayou N, 2008, Landrigan PJ. W 2010 & Boyd et al. 2010* and non-genetic *Hamilton 2006*. By the definition of ASD, the child must be of an age where his or her social skills

would be expected to be developed enough that such impairments can be noted; typically this is around pre-school age of 3 or 4 years old (*APA 2000*). Recently, it was reported that other social indicators such as shared smiles and direct vocalizations can be used to distinguish children as young as 12 months of age, that are at risk of developing ASD (*Ozonoff et al. 2010*). Due to the difficulty of diagnosing ASD cases, the prevalence of ASD is hard to establish, but is surely increasing rapidly all over the world. *APA 2000*. In Saudi Arabia, an extensive review of the literature revealed no specific numbers regarding diagnosed cases of autistic children reported. A rough estimate was reported in 2009 as 18 per 10,000 (*Al-Salehi, Al-Hifthy, & Ghaziuddin 2009*).

While several prominent researches have been conducted from a medical point of view, the oral health and dental needs of children with ASD "specifically caries incidence studies" have been evaluated by few investigators. Previous studies conducted on this matter reported no statistical significant differences in the prevalence of fillings and caries rates in comparison to those of non-autistic individuals (*Lowe O and Lindemann R. 1985, Backman, Pilebro. 1999, Fahlvik-Planefeldt C, Herrstrom P 2001*). Others reported a lower incidence of caries (*Kopel HM: 1977, Karmen S, Skier I. 1985, Namal et al 2007, Loo et al 2008, and A. Jaber 2011*). Furthermore, previous studies showed that children with ASD showed visible plaque and different degrees of gingivitis (*Lindemann and Lowe 1985, Shapira et al 1989, Murshid 2005, DeMattei et al. 2007, Kopycka-Kedzierawski and-Auinger, 2008*). This might be due to the children lacking the manual dexterity needed for proper OH practices, or as a side effect of the medication used to treat their disorder. Many of the medications used to control the behavior of children with ASD or to increase their concentration and social interactions may have adverse oro-facial side effects due to their anti-cholinergic properties, including xerostomia, sialorrhea, dysphagia, sialadenitis, dysgeusia, stomatitis, gingivitis, gingival enlargement, glossitis, bruxism, edema and discoloration of the tongue (*Loo et al., 2008*).

Several studies reported a significant association between the parents' dental knowledge, routine oral hygiene practices, dietary habits, and children's oral health (*Barker JC and Horton SB 2008 &*

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Bilal Mirza et al 2011). The standard of the children's oral hygiene correlated directly to that of their parents. Parents with better oral hygiene tended to have children with similar high standards of hygiene, and vice versa *Al-Shalan, 2003, Wyne AH, 2004, Saied-Moallemi et al 2007, Kopycka-Kedzierawski and Auinger 2008*. Most of the published studies targeted either parents of healthy children or parents of children with dissimilar medical conditions, but only few published studies were conducted to evaluate the parents' dental knowledge and oral hygiene practices of children with ASD *Stein et al., 2012*. Children with Autism Spectrum Disorders present a unique behavioral challenge to pediatric dentists due in part to the intrinsic communicative disability and altered sensitivities to various stimuli. Given the reported rise in the prevalence of ASD over the last 20 years, pediatric dentists can expect to be faced with the challenge of providing oral care for an increasing number of children with ASD. Increasing the parents' dental knowledge and the focus on the preventive programmes designed particularly to parents of children with ASD becomes highly significant. This can be achieved by investigating the dental knowledge of parents with ASD children. Therefore, the aim of this study was to investigate the dental knowledge of ASD children's parents and the oral hygiene practiced by ASD children.

II. SUBJECTS AND METHODS

a) Questionnaire

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

b) Subjects

The subjects of this study were recruited from three of the major autistic rehabilitation centers in Riyadh (The capital of Saudi Arabia). The centers were registered with the Saudi Autistic Society (SAS). The authorities of each center were contacted and ethical approval was obtained before distributing the

questionnaires to the parents of the autistic children. The staff members in each center distributed the questionnaires to all the parents who initially agreed to answer the survey while dropping their children off at the centers and collected them back later.

c) Methods

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

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

III. RESULTS

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

Table 1 shows the distribution of parents' response to the source(s) of their dental knowledge. The majority of the parents (57.3%) reported that they did not receive any information about dental knowledge. Other sources were from dentists and dental personnel, and from the media (14.2% and 9.6% respectively). Regarding the parents' knowledge about etiology of dental caries, a large number of the parents (48.8%) choose irregular cleaning of the teeth as the main cause

of dental caries. Hereditariness or genetic causes was given by 12.5% of the parents as the main reason of dental caries. Only 11.6% thought bacteria was the main cause. The parents were asked what age the child should have their first dental visit at. The results show

that 28.2% of the parents thought dental visits were necessary only at signs of pain or dental problems. Only 2 parents thought it should be during the first year since the child's birth. Twenty-seven percent of the parents didn't know the answer.

Table 1 : ASD parents' response to the dental knowledge questions (N=344)

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 teeth decay	Irregular cleaning	168 (48.8)
	Multiple reasons	59 (17.15)
	Hereditary/ 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)

Table 2 shows the distribution of the parents' responses regarding the oral hygiene practices of their children. The data shows that 38.7% of the children were able to brush their teeth by themselves, while 61.3% needed help during tooth brushing. More than half (52.3%) of the mothers were helping their children during tooth brushing. Only a few fathers (10.2%) were involved in the brushing practices. Receiving help during brushing from home nurses, helpers and maids represented 13.4%. Only 5.8% of the parents reported irregular or no brushing of their children's teeth. The

parents reported that 32.6% of their children either did not practice tooth brushing (3.8%) or brushed on an irregular basis (28.8%). The rest of the children reported brushing once or twice a day, 34.0% and 29.1% respectively. Only 4.4% of the children brushed 3 times or more. An enormous number of the parents (90.7%) reported that toothbrushes and toothpaste were the main tools used to clean their children's teeth. A few parents (8.5%) used Miswak only and only 0.9% relied solely on water rinses or swabbing the teeth with water and cotton.

Table 2 : ASD parents' response to the oral hygiene practices questions (N=344)

Question	Parents' Response	NO (%)
ASD child's ability to brush his/her teeth by his/her-self	Yes	133 (38.7)
	No	211 (61.3)
Children's help during tooth brushing	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)
Frequencies of tooth brushing practiced by The Children	Never brushing	13 (3.8)
	Irregular brushing	99 (28.8)
	Brushing once per day	117 (34.0)

	Brushing twice per day	100 (29.1)
	Brushing more than twice per day	15 (4.4)
Methods and tools used during brushing	Tooth brush & paste	312 (90.7)
	Miswak only	25 (7.3)
	Tooth paste+ miswak	4 (1.2)
	Water rinse /water swab only	3(0.9)

IV. DISCUSSION

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

In this study, the insufficiency in the distribution of oral hygiene instructions and dental awareness by dentists or dental personnel and dental institutions was reflected in the parents' responses. Only small number of parents received direct oral hygiene instructions from dentists, and even fewer parents received information from other sources like professional dental brochures and the media. Similar findings of shortages in the distribution of oral hygiene instructions was reported by parents of healthy children, or parents of children with different disabilities from the same city. (*Al-Shalan 2002, Al-Bader et al 2006, Wyne 2007,)* Conversely, in other studies conducted with parents of children with Cerebral Palsy (CP) (*Wyne 2007*) and Down syndrome (DS) (*Al_Hussyeen 2006*) the parents reported that they had received dental instructions directly from dentists at an early age. An explanation of this discrepancy could be the differences in the nature of the children's conditions. CP and DS are two conditions that are easily diagnosed at or about the time of birth, so parents usually are educated about their children's condition and the importance of an early intervention in regards to different health aspects before they leave the maternity and delivery ward. However, in the case of autistic children, the child looks absolutely normal at birth. "ASD cases usually diagnosed by the age of 2 years or older" (*APA 2000, WHO 1992, Stone W et al 1999, Moore. V, Goodson S 2003, Amendah, D. et al 2011*) In addition, Autism is considered to be a relatively new condition when compared to CP or DS, so parents with autistic children might be more occupied with the urgency of the medical, behavioral and training condition of their children than the dental condition.

Dental literature define caries as the most common multi-factorial disease of the human race. Parents in this study showed substantial deficiencies in their dental knowledge, which was clearly reflected in their responses regarding the cause of dental caries. A large number of parents attributed the cause of dental

caries to improper tooth brushing only. The role of bacteria was chosen by a very small number of parents in this study, and similar studies conducted with parents of healthy children *Almas K et al 2003* and parents of children with different disabilities (*Al-Bader 2006, Wyne 2007*) (*Al-Bader 2006, Wyne 2007*) Some parents chose genetics and hereditariness as the main cause of caries. This could be due to autism being considered a genetic and/or hereditary disorder, making parents believe that the two are correlated. Some studies point out that autism is a genetic disorder and many characteristics of the disease are still inexplicable, parents may believe that genetics may cause victim-blaming or victim-shaming. These responses merely highlight the necessity of raising awareness about these controversial topics. Parents should be better educated by medical personnel on the procedures that follow the successful diagnosis of autism, or any signs of ASDs in children, so that they may seek dental advice from professionals well-acquainted with these disorders and sufficiently equipped to handle these children (e.g. pediatric dentists).

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

should be sent to the SAS website and different rehabilitation centers to convey this information to the parents and increase their dental awareness.

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

Even though a large number of the parents in this study didn't receive any dental information or oral hygiene instructions, most of them brushed their children's teeth once or twice a day. This could be considered largely adequate on their part, especially if we take into consideration the territorial outlook most ASD children have when it comes to their privacy. (Friedlander 2003, Klein and Nowak 1999, Marshall et al 2007, Loo et al. 2008, , Hulya Bilgin, Leyla Kucuk 2010, Murshid 2011. Fortunately, only a fractional percentage of the parents never brushed for their children. Similar regular oral hygiene practices were reported by different authors, who collected their data from parents of children with different disabilities living in the same area. (Al-Bader et al 2006, Al-Hussyeen, 2006, Wyne 2007)

The use of toothbrushes and toothpaste was reported with the majority of the parents of this study and many other similar studies conducted in the same area (Al-Bader et al 2006, Wyne 2007). Luckily, only a few of the parents in this study used water rinsing and cotton swabs only. Fewer parents still reported the use of the traditional and cultural tool known as Miswak to brush their children's teeth. Miswak is a natural tree branch taken from the *Salvadora persica* tree (a wooden stick) commonly used for brushing teeth in Arabian Countries and other parts of the world. The benefits of Miswak to the gums and teeth were touched upon by the World Health Organization. (T. al-Khateeb, D. O'Mullane, H. Whelton, M. Sulaiman 1991, WHO 2000, Ezoddini-Ardakani 2010) A small percentage of the parents in this study were using Miswak with their

children. Similar findings were reported by parents of children with cerebral palsy in Riyadh. (Wyne 2007) This could be due to the difficulties in controlling the stick during brushing especially in cleaning the back teeth.

In general, the data collected in this study shows that most of the parents seemed to understand the importance of oral hygiene practices. A positive attitude in brushing the children's teeth was shown by the mothers participating in the study. The lack of circulation of dental information by professional dental personnel and dental institutions was clearly reflected in the parents knowledge of the causes of dental caries and the time of first dental visits and regular checkups. It is noteworthy to mention that a child with ASD may not be able to overlook and accept changes in his or her expected environment; most of them may become particularly defensive and obsessive about the variation. (Bogdashina, 2003). The difficulties in controlling and dentally treating children with ASD have been mentioned in a variety of studies. (Klein and Nowak 1999, Friedlander 2003, Loo et al. 2008, Marshall et al 2010, Murshid 2011) Therefore, obviously preventing dental problems in this group of children is more convenient than treating them. Parents should be informed that preventing plaque formation is the key to reducing dental caries and gingival diseases. This can be achieved by mechanical removing of plaque materials, reducing the refined carbohydrate diet intake, fluoride applications and regular dental check-ups.

V. LIMITATIONS

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

VI. CONCLUSIONS

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

VII. RECOMMENDATIONS

- The need for professional dental health awareness lectures, brochures, educational television and radio advertisements, and programs designed especially for children with different disabilities becomes obvious.
- A list of dentists specializing in treating and managing children with autism should be available

for parents either through the Saudi Autistic Societies or other rehabilitation centers, major hospitals and schools.

- Health care professionals other than dentists need to provide information and promote for early dental visits especially for children with disabilities.

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