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Oral Hygiene Practice and Home-Care Challenges in Children with Autism Spectrum Disorder in San Francisco

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Oral Hygiene Practice and Home-Care Challenges in Children with Autism Spectrum Disorder in San Francisco

by

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THESIS

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ABSTRACT

Oral Hygiene Practice and Home-Care Challenges in Children with Autism Spectrum Disorder in San Francisco

by Rahul Nagda

INTRODUCTION: Autism spectrum disorder (ASD) is characterized by challenges in social interaction, communication, and stereotypical patterns of behavior. They are more likely to have tooth brushing issues and need help with routine dental care. Children with ASD could face difficulty in accessing dental care as the parents have a challenging task in finding a dentist that would treat the child with special needs. As a result, dental care is often neglected. The aims of this study are to evaluate oral hygiene practices and challenges in children with autism spectrum disorder (ASD) and compare it with typically developing peers (TDP).

METHOD: Parents of children aged 3-10 were recruited with 30 in each group. Age and gender of children were matched. Parents were asked to complete the questionnaire which asked about their demographic information, child's oral care regimens, and their knowledge about dental care. Chi-squared tests were used to compare the distribution of categorical variables between the two groups, and we summarized the distribution of categorical and continuous variables in the two groups using frequencies, and means with standard deviations, respectively. We compared differences in patient age using the two-sided t-test and unpaired t-tests for comparing means between the two groups. A sample size of 54 achieved 80% power to detect an effect size (W) of

0.45 using a 3 degrees of freedom Chi-Square Test with a significance level (alpha) of 0.05.

RESULTS: 47% of children with ASD had to travel more than 20 miles for their dental home compared to 13% with TDP (P<.05). Only 60% of ASD patients brushed twice a day with 70% of parents reporting it is difficult to brush their child's teeth compared to TDP with 93% of children brush twice daily (P<.05). Significantly a smaller number of children with ASD (47%) allowed their parent to brush their teeth as compared to 93% of TSD children (P<.001).

CONCLUSION: Parents of children with autism spectrum disorder travel longer distance to find a dental home and face more difficulty in maintaining their child's daily oral hygiene.

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INTRODUCTION:

Autism spectrum disorder (ASD) is a well-studied neuro-developmental disorder. It is defined as an occurrence of persistent impairments in social interaction and the presence of restricted, repetitive pattern of behaviors, interest, or activities by the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5). It is characterized by challenges in social interaction, communication, and stereotypical patterns of behavior.[1] Overt symptoms start to begin after 6 months of age and become established by 24 to 36 months.[2] Features such as language barrier, concurrent diagnosis, medications, learning disabilities, heightened sensory perceptions and inability to generalize past learned behaviors may impact oral care in variety of ways. Language barrier or impaired communication skills may hinder child's ability to relay if they are uncomfortable in a dental chair or express their fears. This may also limit dentist's ability to use several basic behavior guidance techniques. Adjusting to changes can be difficult for such children which may affect their dental experience.[3]

Oral health has a significant impact on systemic health. Dental caries and poor oral hygiene can negatively impact life of children with ASD along with typically developing peers (TDP).[4] Children with ASD could face difficulty is accessing dental care as the parents have an arduous task in finding a dentist that would treat the child with special needs. As a result, dental care is often neglected.[5] Access to dental care may also be affected by lack of pediatric dentist in a geographical region or shortage of dentist with appropriate training willing to accept children with ASD.[6] Children with ASD may have

normal caries prevalence compared to typically developing peers (TDP) but poor oral hygiene. They are more likely to have tooth brushing issues and need help with tooth brushing.[7] Children with ASD experience more challenges and barriers to oral care than TDP.[8] Children with ASD have a high risk for developing dental caries with high unmet dental needs. Many children who have a dental home still has dental problems due to child's cooperation being one of the biggest barrier and dentist not accepting Medicaid insurance.[9] Higher prevalence of caries and periodontal disease have been found in children with ASD due to difficulty in maintaining daily oral care.[10] On the contrary, some studies report low prevalence of caries among ASD children.[11]

Parents of children with ASD encounter several difficulties and challenges in at-home oral care and maintaining good oral hygiene due to child's sensory and behavioral impairments.[12] The number of people diagnosed with ASD has dramatically increased since the 1980s, partly due to changes in diagnostic practice, referral patterns, availability of services, age at diagnosis, and public awareness.[13] As per the recent report from CDC, the overall ASD prevalence was 23 per 1000 children aged 8 years in the USA and 38.9 per 1000 in California. Males are four times more affected compared to females. [14] Hence, dentists are increasingly more likely to see children with ASD in their practice. Therefore, it is essential for dentist to understand the experiences and challenges encountered by parents and children at home so that dentist can tailor their dental visits per individual's needs. This can also help guide policies and allocate resources which can alleviate some of the hardship faced by children with ASD.

Not many studies are done on this subject in Northern California and last study in California was done more than 10 years ago.[17] The studies conducted in the past had a high variability in the age range and included children without medical diagnosis of ASD.[16,17] We intent to update the literature as patient demographic, access to dental care and other services may differ based on differences in geographical areas.

The objectives of this study are to evaluate and compare home care regimens of ASD and TDP children, to evaluate parental understanding of optimal oral hygiene practices, parental challenges in maintaining good oral hygiene at home and access to care for children with ASD who reside in Northern California.

MATERIALS AND METHODS:

Study Design:

A cross-sectional study was caried out from February 2022 to November 2022. Data was based on 21- item self-administered questionnaire. The participants were divided in two groups: A) Children with Autism Spectrum Disorder and B) Typically developing peers. Both groups were age and gender matched. Parents of children in both groups were enrolled in the study during their children's dental appointments at the University of California San Francisco's (UCSF) Parnassus pediatric dental resident clinic who reside in the Northern California region. Survey forms were distributed by one person only and parents were randomly selected. Only parents who can understand English participated in the study. A consent was taken from each parent prior to participation in

the study. This study was approved by Institutional Review board (IRB) of University of California, San Francisco. IRB reference number 21-35015.

Inclusion and Exclusion criteria:

Participants were parents of children aged between 3 and 10 years old, only to limit the variability with higher age. ASD group included children with medical diagnosis of ASD only and no other co-morbidities. Children in TDP group had no diagnosis of ASD, and reported no disability, or any other diagnosis. Children who did not meet the inclusion criteria of these two groups were excluded from the study.

Sample Size:

A sample size of 54 achieved 80% power to detect an effect size (W) of 0.45 using a 3 degrees of freedom Chi-Square Test with a significance level (alpha) of 0.05.
The study was carried out with a total of 60 participants. There were 30 participants in each group.

Questionnaire:

The survey of 21- item questionnaire was designed by the authors which was divided in three parts: 1) Demographic information, 2) Current home care regimens, and 3) Parental knowledge about home care regimens. The surveys were distributed in paper format and the data were then transferred in electronic format.

Statistical analysis:

We summarized the distribution of categorical and continuous variables in the two groups using frequencies, and means with standard deviations, respectively. We compared differences in patient age using the two-sided t-test. Differences in other demographic variables, responses to home care regimens and responses to parental knowledge survey questions were evaluated using chi-square analyses. A p-value of 0.05 was used for determining statistical significance. All statistical analysis was performed with Stata version 17 (Stata Corp LLC).

RESULTS:

Demographic Data: Table 1

In this study there were 60 participants with 30 in each group. There were 18 male children (60%) and 12 female children (40%) in each group. The mean age of the children was 6.33. In both groups, participants were from diverse races residing in Northern California region. More than 50% of the participants identified as Hispanic (26.7%) or Asian (33.3%). There was no statistical difference in the parental education between ASD and TDP group. More than 85% of the children had Denti-Cal (Medicaid) as their insurance in both groups. Majority of the children with ASD (73.3%) went to regular schools with special support programs, and 13.30% went to special schools. Significantly higher number of parents of children with ASD travelled more than 20 miles for their dental home (46.60%) compared to parents of TDP (13.30%).

Table 1: Demographic Data. Statistical difference was found in distance to dental home in ASD group.

DEMOGRAPHIC DATA					
	TDP		Children with ASD		
	N	Percentage (%)	N	Percentage (%)	p-value
RACE					0.970
White	3	10	2	6.7	
Black	2	6.7	3	10	
American Indian	1	3.3	1	3.3	
Asian	10	33.3	11	36.7	
Hispanic	8	26.70	9	30	
Multiple	6	20	4	13.3	
HIGHEST PARENTAL EDUCATION					0.141
Doctor/Professional	2	6.7	0	0	
Master's degree	5	16.7	3	10	
Bachelor's degree	6	20	8	26.7	
Associate degree	0	0	4	13.3	
Postsecondary non degree	2	6.7	0	0	
Some college, no degree	9	30	5	16.7	
High school diploma	5	16.7	8	26.7	
No formal education	1	3.3	2	6.7	
INSURANCE					0.688
Government	26	86.7	27	90	
Private	4	13.3	3	10	
No insurance/Self-pay	0	0	0	0	
DISTANCE OF DENTAL HOME					**0.014***
Less than 20 miles	26	86.7	16	53.3	
21- 50 miles	3	10	7	23.3	
More than 50 miles	1	3.3	7	23.3	
SCHOOL TYPE					**<0.001***
Home school	0	0	2	6.7	
No school	1	3.3	1	3.3	
Regular	29	96.7	1	3.3	
Special support program	0	0	22	73.3	
Special	0	0	4	13.3	

*Statistical significance

Current home-care regimen: Table 2

Significantly, a smaller number of children in ASD group (60%) brushed their teeth twice a day as compared to TSD with 93.3 % of children brushed twice daily. Only 43.3% of children in ASD group allowed their parents to brush their teeth daily, and another 43.3% would allow to brush sometimes per week. Significantly larger number of parents (70%) reported that they had difficulties trying to brush their children's teeth compared to 10% of parent in TDP group.

Majority of children in both the groups used manual toothbrushes with ASD group reporting 76.7% and TDP group as 63.3%. Overall important, regular flossing was not commonly practiced in both groups with 33.3% in TDP group vs. 16.7% in ASD group. A large proportion of parents in the ASD group (40%) reported that they never flossed their child's teeth and 43.3% reported of flossing sometimes. Parents of both groups reported that their children would eat sugary snack or a drink once or twice daily, but no statistical difference was found between the two groups.

Table 2: Summary of home-care regimen between ASD and TDP group. Statistical difference was found in tooth brushing frequency and difficulty faced by parents to brush their children's teeth.

HOME CARE REGIMEN					
	TDP		CHILDREN WITH ASD		
	N	Percentage %	N	Percentage %	p-value
Brushing frequency					**0.009***
1x	2	6.7	11	36.7	
2x	28	93.3	18	60	
>2x	0	0	1	3.3	
Does child allow to brush?					**<0.001***
Never	2	6.7	4	13.3	
Sometime	0	0	13	43.3	
Yes	28	93.3	13	43.3	
Is it easy to brush child's teeth?					**<0.001***
No	3	10	21	70	
Yes	27	90	9	30	
Type of Toothbrush					0.260
Electric	11	36.7	7	23.3	
Manual	19	63.3	23	76.7	
Flossing frequency					0.323
Never	9	30	12	40	
sometime	11	36.7	13	43.3	
Yes	10	33.3	5	16.7	
Sugary snack/drink daily					0.743
1x	12	40	10	33.3	
2x	10	33.3	13	43.3	
3x	7	23.3	5	16.7	
>3x	1	3.3	2	6.7	

*Statistical significance

Parental knowledge about home care regimen: Table 3

Approximately 70% of the children in both groups used toothpaste containing fluoride. Over 42% of children in TDP group used excess amount of toothpaste compared to 20 % in ASD group. Very few parents reported that children had gingival bleeding while brushing (6.7%). Overall, few parents (36.7% in TDP and 26.7% in ASD) reported that they always checked sugar contents of the products.

Most of the parent in both groups took their children twice a year for routine dental check-up. Although, not statistically significant, 83.3% of parent in ASD group reached out to dentists first for dental related concerns compared to 63.3% in TDP group. Many parents of TDP group (30%) reported that they first used social media or internet for dental related questions before approaching the dentists. Closer to half of the children with ASD (40%) had their first dental visit after age 3 as compared to 20% in TDP. Large number of parents in the ASD group (63.3%) reported their children had dental caries during their dental visits compared to 36.7% in TDP.

Table 3: Parental knowledge about home care regimen: No Statistical difference was found in parental knowledge regarding home care regimens.

Parental knowledge about home care regimens					
	TDP		Children with ASD		p-value
	N	Percentage %	N	Percentage %	
Does your child use a fluoride containing toothpaste?					1.000
Don't know	7	23.3	7	23.3	
No	2	6.7	2	6.7	
Yes	21	70	21	70	

Table 3: Parental knowledge about home care regimen, Continued

Toothpaste size					0.198
Pea	14	46.7	17	56.7	
Rice	3	10	7	23.3	
Half length	8	26.7	3	10	
Full length	5	16.7	3	10	
Gum Bleeding					0.243
Never	25	83.3	20	66.7	
Sometime	3	10	8	26.7	
Yes	2	6.7	2	6.7	
Check for sugar content					0.517
Never	11	36.7	10	33.3	
Sometime	8	26.7	12	40	
Yes	11	36.7	8	26.7	
Routine dental exam					0.618
1x/ year	6	20	7	23.3	
Only when concern	2	6.7	4	13.3	
2x/year	22	73.3	19	63.3	
Whom do you generally first reach out to for dental related question?					0.065
Dentist	19	63.3	25	83.3	
Family and friends	2	6.7	3	10	
Social media/internet	9	30	2	6.7	
Child's 1st dental visit					0.223
Age 1 or younger	8	26.7	5	16.7	
Between 1 and 3	16	53.3	13	43.3	
After age 3	6	20	12	40	
Does your child have a cavity					0.110
Don't know	4	13.3	3	10	
No	15	50	8	26.7	
Yes	11	36.7	19	63.3	

*Statistical significance

DISCUSSION:

There were more recruited males than females in ASD group with a 3:2 ratio, which was similarly seen in other studies.[13,14] Participants in this study were age and gender matched with an age range of 3- 10 years with an average age of 6.33 years old to reduce the confounding factors and variability associated between male and female with higher age.[15] The study population was from northern California region. The geographic boundary between north and south was not very well defined. Some of the participants drove 50 miles to seek care at the UCSF Pediatric Dentistry clinic. Participants represented a diversity in ethnicity and had variable parental education levels. Over 85% of the participants in both the groups had government insurance which can be expected in a dental school clinic.

The results of this study demonstrated that children with ASD brushed their teeth with less frequency compared to TDP. At the same time, 70% of the parents of children with ASD had difficulty brushing their child's teeth daily, significantly more than the parents of typically developing peers. In addition, nearly half of the children would not allow or seldom allow parents to brush. This finding is consistent with other studies in the literature which also reported that children with ASD had increased chances of negative behavior at dental offices, which resulted in higher frequency of utilization of protective stabilization and pharmacological methods.[8,16,17]

There was no statistical difference between the groups with respect to the types of toothbrushes and floss usage. Children in both groups mainly used manual toothbrushes and with low overall daily flossing rate.

Overall sugar consumption was high with 70% parents reporting giving 1 or 2 sugary snack or drink daily to their children, but no difference was detected between groups. Only 36.7% of parents in TDP group and 26.7% in ASD group always checked for sugar contents when buying food from the grocery store. Many parents give sweets as rewards which could suggest higher sugar consumption in our study.[18]

These findings suggest that dentists have a larger role to educate and reinforce the parents about routine oral hygiene regimens and provide solutions to alleviate some of the challenges faced by the parents of children with ASD. Parents can get distracted and overwhelmed by children's other problems and stressors at home which may lead to less attention towards routine dental care.[12] Some solutions that may help improve oral care includes having a specific routine for brushing every day and using electric toothbrush.[12] Dentist also need to have an individualized approach when providing services to children with ASD.[12]

Two-thirds of the parents knew that their children are using fluoride containing toothpaste. Many parents in the TDP group (43.4%) used improper amount of toothpaste compared to 20% in ASD group with no statistical difference observed between both groups. This finding is consistent with other studies in the USA where nearly 40% of children and adolescent used excessive toothpaste.[19]
Parents in both groups routinely brought their children for dental exams twice a year (73.3 in TDP; 63.3 in ASD). About 30% of the parents of TDP reported of using social

media or internet for dental related questions before going to the dentists compared 6.7% in ASD group. There is no statistical difference between the groups. A study from Saudi Arabia reported the 58% of the participants searched on social media for any dental issue [20]. Social media can broaden access to health care information at the same time there is a potential of getting misinformation from an unlicensed healthcare person. Further research is required to determine the impact of social media on oral healthcare. About 40% of the children with ASD had their first dental visit after age 3 compared to 20% in TDP. More than half of the parents of children with ASD (63.3%) reported that their children had a cavity during their dental exam compared to 36.7 % in TDP group, which suggests increased prevalence of caries in ASD group. There was no statistical difference between the groups. Literature showed that caries risk for children enrolled in Medicaid insurance when their first dental exams were at 4 years old is 5 times higher than those whose dental exams were before the age 1.[20],[21] Hence, more awareness is needed so that children could be seen for their first dental exam by age 1.

Lastly, significantly higher number of children with ASD (46.6%) had to travel more than 20 miles, and among them 23.3% travelled more than 50 miles for their dental homes. This data highlights a distance issue as a major problem in access to care for children with ASD. In a study done in Southern California, 37% of parents of children with ASD reported that it was more challenging to find and access dental care for their special-needs children than for their typically developing siblings[17]. This leads to increased financial burden on the family due to increased cost of fuel and inability to work when visiting a dentist. Many studies in the past have cited this problem faced by parents in

finding a dentist willing to work with special healthcare needs population. This issue could be due to inadequately trained dental providers who are comfortable managing special-needs children and compounded by difficulty in locating dental offices that accept government funded insurance due to substantially lower reimbursement fees vs. private dental insurances.[5,6,9,21,22]

A recent study reported that in California 5% of dentists in suburban areas and 3% in rural areas participated in Medicaid program.[23] Only 11% of pediatric dentists in California participated in state's Medicaid program, which is one of the lowest in the USA.[23] This further exacerbates the access to oral health care for children on government insurance.

Our study highlights the presence of this issue even today. It is unknown if Covid-19 impacted dentist participation in government funded insurance and requires future investigation. We hope these findings further encourage policy makers and healthcare professionals to understand the problems and work towards a more stable long-term solution.

LIMITATIONS:

The sample size of this study was low. There was also a possibility of Hawthorne bias as parents filled the questionnaire forms in a dental clinic with tendency to mark for ideal responses. This study only included parents who could understand English. This study only highlighted basic home care regimens and challenges faced by parents of children with ASD. Thus, further research is required to explore the detailed reasons behind

these challenges to better prepare the dental professionals providing optimal care for this special-needs population.

CONCLUSION:

1. Parents of children with autism spectrum disorder encounter increased difficulty in maintaining routine oral hygiene for their children at home.
2. Parents of children with autism spectrum disorder travel longer distance to find a dental home. To this day, issues on access to care still exists.
3. We believe enhancing pre-doctoral training in treating special needs population, increasing reimbursement rate of government funded insurance, and frequent recall visit to desensitize the child and educate the parents can help alleviate some of the challenges faced by children with ASD.

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APPENDIX:

Questionnaire

A. <u>DEMOGRAPHIC DATA:</u>

1. AGE

2. GENDER

3. ETHINICITY
   White
   Black or African American
   American Indian or Alaska Native
   Asian
   Native Hawaiian or Other Pacific Islander
   Hispanic or Latino

4. HIGHEST PARENTAL EDUCATION
   Doctoral or professional degree
   Master's degree
   Bachelor's degree
   Associate's degree
   Postsecondary nondegree award
   Some college, no degree
   High school diploma or equivalent
   No formal educational credential

5. TYPE of INSURANCE
   Government insurance
   Private insurance
   No insurance/ Self-pay

6. Distance of your recent Dental home from your house
   Less than 20 miles 21 – 50 miles More than 50 miles

7. Which type of school does your child go to?
   Regular school
   Regular school with special support program
   Special school
   Home school
   No school

B. CURRENT HOME CARE REGIMEN

1- How many times does your child brush in a day?
0 1x 2x >2x

2- Does your child allow you to brush his/her teeth?
Yes Sometimes Never

3- Do you find it easy to brush your child's teeth?
Yes No

4- Which type of toothbrush does your child use?
Manual Electric

5- Do you floss your child's teeth daily?
Yes Sometimes Never

6- How many times does your child eat sugary snack in a day?
1x 2x 3x >3x

C. PARENTAL KNOWLEDGE ABOUT HOME CARE REGIMEN

1. Do you use a toothpaste that has fluoride?
Yes No Don't know

2. How much toothpaste do you dispense for your child?
Rice size Pea size Half-length of brush Full-length of brush

3. Does your child's gum bleed while brushing?
Yes Sometimes No

4. Do you read nutrition label before buying food/snack for sugar content?
Always Sometimes Never

5. How many times a year do you take your child to the dentist for a routine check-up?
Once Twice Only when there is a concern

6. Whom do you generally reach out to for dental related question?
Dentist Family and friends Social media or internet

7. When was your child's 1st dental visit?
Age 1 or younger Between age 1-3 After age 3

8. Does your child have a cavity?
Yes No Don't know

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