

A cross-sectional study on oral hygiene practices, home care challenges, and barriers to seek dental care for children with autism spectrum disorder from the caregiver's perspective

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ABSTRACT

Objectives: To collect and analyse data regarding the oral hygiene practices, home care challenges, and the barriers faced by children with autism in seeking dental care from the caregiver's perspective. **Methods:** A cross-sectional study was conducted on 80 subjects comprising 40 subjects in the autism spectrum disorder (ASD) group and 40 in the comparison group of the typically developing peer (TDP) group. Caregivers of children diagnosed with ASD aged between 4 and 12 and attending therapy centres in Ahmedabad city were included. Matching was done between the ASD and TDP groups for age and sex for both children and caregivers as well as educational qualification of the caregiver. Data were collected using a self-designed, validated questionnaire and analysed using Chi-square test at a 5% level of significance. **Results:** ASD individuals were brushing less frequently, needing more supervision during brushing and using fingers to clean the teeth over TDPs. Caregivers of ASD individuals display significantly lower awareness of various dental issues explored, less proactive engagement with dental professionals, and significantly more barriers in seeking dental care for their ward for all the variables explored than caregivers of the TDP group. **Conclusions:** Caregivers of children with ASD were not adequately aware about their child's oral health and encountered increased difficulty in maintaining routine oral hygiene for their children at home and accessing suitable dental care compared to the caregivers of children from the TDP.

Keywords: Autism spectrum disorder, barriers, caregivers, dental care, oral health

Introduction

Autism spectrum disorder (ASD) encompasses a broad range of neurodevelopmental disabilities ranging from mild to severe, in which behaviors vary substantially and alter the typical pattern of child development, characterised by repetitive behaviors,

social interaction difficulties, and limited interests that usually manifest in early childhood and have potential long-term consequences.^[1] ASD affects approximately 0.6% of children worldwide^[2] and approximately 0.09–0.11% of children in India.^[3] Children with ASD often struggle with adapting to changes in their environment and may experience challenges in maintaining personal hygiene and seeking appropriate healthcare.^[4]

Health is a fundamental right, and it has been reported that among children with special healthcare needs, oral health

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care and dental treatment are often reported as neglected as parents might be facing other major problems in bringing them up.^[5,6] Neglecting oral health in childhood can lead to various consequences, including pain, diminished quality of life, increased healthcare costs, and missed school or work days.^[7,8] Given the significant impact of early childhood oral health on overall well-being, it is imperative to promote and utilise dental preventive services, starting from infancy to mitigate the burden of dental disease and improve long-term oral health outcomes for children, families, and healthcare systems.^[9,10]

Autism traits of lack of manual dexterity, eye contact, communication failure, and repetitive behaviours can complicate maintenance of oral hygiene in many ways and thus can increase risk of dental disease.^[11] Primary caregivers play a crucial role in the performing, supervision, and guidance of these children's oral hygiene activities. Additionally, these caregivers ensure that the child receives necessary healthcare services.^[12] Therefore, it is important that the dentist educates them on the importance of maintaining good oral hygiene and its consequences as well as understand the obstacles to dental care from the viewpoint of the primary caregivers.

Careful search of available literature revealed that only a few studies have been published highlighting on how ASD affects the dental health care of children from the caregiver's perspective. Hence, the present study was carried out with an aim to collect and analyse data regarding the oral hygiene practices, home care challenges, and the barriers faced by children with autism in seeking dental care from their respective caregiver's perspective. The results of these can be further studied to develop practices that could help us cater better towards the oral health needs of autistic children and hence improve their well-being.

Methods

A descriptive, cross-sectional study was conducted to collect the data during a period from January 2024 to March 2024. The sample of children with ASD was taken from four conveniently chosen occupational therapy centres based in Ahmedabad. A control group of typically developing peers (TDPs) was also taken to compare the findings. The study protocol was reviewed and approved by the Institutional Review Board of AMC Dental College on 15/1/2024 [AMC/IRB/PCD/UG/198/23]. A sample size of 80 was achieved at an 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 5%. The study was carried out with a total of 80 participants divided into two groups (A): caregivers of children with ASD and (B) caregivers of TDPs), comprising 40 participants in each group. Only primary caregivers of individuals from both the groups were considered. Caregivers of children diagnosed with ASD aged between 4 and 12 and attending therapy centres in Ahmedabad city were included in the study. Subjects with any other medical diagnosis in combination with ASD were excluded from the study. Caregivers who can understand English or Gujarati were included in the

study. Children in the TDP group had no diagnosis of ASD and reported no disability or any other diagnosis. Matching was done between the ASD and TDP groups for age and sex for both children and caregivers as well as educational qualification of the caregiver.

To collect the data, a self-designed questionnaire was built based on a pre-validated questionnaire^[13] which was modified to suit the specific objectives and the context of the study. The questionnaire was used in two languages, English and Gujarati, and consisted of a total of 28 close-ended questions comprising five domains, namely, child's personal information, caregiver's personal information, the child's oral hygiene practice history, caregiver's knowledge about oral health of the child, and barriers. The validity and reliability of the questionnaire were pre-tested.

After taking related permissions, the day and date to collect the data were finalised. For both the groups, caregivers who were present on the day of the survey, were willing to participate, and gave their informed consent were included in the study. All the proformas were distributed in paper format. Fifteen minutes were given to the participants to fill the proforma. Filled proformas were collected by the principal investigators, and the data were then transferred in electronic format. The data from the filled questionnaires were then summarised and analysed descriptively and inferentially by applying Chi-square test. A *P* value of 0.05 was used for determining statistical significance.

Results

Among the 80 participants, 46 (57.5%) were aged 3–6 years, with 23 in each group. Meanwhile, 34 (42.5%) were aged 7–12 years, with 17 in each group. In terms of gender distribution, 54 (66.25%) participants were male, comprising 27 in each group, and 26 (33.75%) participants were female, with 13 in each group. Caregivers were distributed across different age groups, with the majority falling within the 30–39 age range for both groups. The majority of caregivers were female, with 36 in each group. A significant proportion of caregivers were housewives/househusbands in the ASD group (*n* = 33) compared to the TDP group (*n* = 4). Caregivers had varying levels of education, with post-graduation being the most common category for both groups. The majority of caregivers were mothers, with 33 in each group. Other relations included fathers, grandmothers, and grandfathers, though those were less common.

Table 1 provides insights into the oral hygiene practices of a sample size of 80 individuals, categorised into ASD and TDP groups, along with associated *P* values indicating the significance of observed differences. Notably, a significantly higher proportion of ASD individuals brushed once a day (60%) as compared to TDP individuals who were more likely to brush twice a day (52.5%). ASD individuals were less likely to brush their teeth independently, with a higher proportion requiring parental supervision compared to TDP individuals. This difference was statistically significant (*P* < 0.00001). TDPs' caregivers were more

Table 1: Comparison of oral home care practices in children with and without ASD

Variable	ASD (n=40) n (%)	TDPs (n=40) n (%)	P
How many times in a day are the child's teeth being brushed?			
Does not brush	1 (2.5%)	0 (0%)	P=0.002399 (H.S)
Once a day	24 (60%)	19 (47.5%)	
Once in 2-3 days	7 (17.5%)	0 (0%)	
Twice a day	8 (20%)	21 (52.5%)	
Does the child brush his/her teeth?			
No	3 (7.5%)	0 (0%)	P<0.00001 (H.S.)
Yes, on their own	6 (15%)	32 (80%)	
Yes, under parent's supervision	31 (77.5%)	8 (20%)	
If the caregiver brushes the child's teeth, do you as a caregiver think that it is easy to brush the child's teeth?			
Strongly agree	1 (2.5%)	36 (90%)	P<0.00001 (H.S.)
Agree	8 (5%)	4 (10%)	
Neither agree nor disagree	2 (5%)	0 (0%)	
Disagree	9 (22.5%)	0 (0%)	
Strongly disagree	20 (50%)	0 (0%)	
How are the child's teeth being brushed?			
By use of an electric brush	5 (12.5%)	6 (15%)	P=0.00082 (H.S.)
By finger	12 (30%)	0 (0%)	
By use of a manual brush	23 (57.5%)	34 (85%)	
Does the child use an alternative inter-dental aid to clean their teeth?			
No	36 (90%)	30 (75%)	P=0.077489 (H.S.)
Yes	4 (10%)	10 (25%)	
What is the child's daily sugary snack/drink consumption frequency?			
0 time	21 (52.5%)	1 (2.5%)	P<0.00001 (H.S.)
1-2 times	17 (42.5%)	2 (5%)	
3 times or more	2 (5%)	37 (92.5%)	
Is a fluoride containing toothpaste being used to clean the child's teeth?			
Yes	12 (30%)	25 (62.5%)	P=0.006516 (H.S.)
No	3 (7.5%)	0 (0%)	
Don't know	25 (62.5%)	15 (37.5%)	
Does the child prefer a specific flavoured toothpaste?			
Yes	24 (60%)	2 (5%)	P<0.00001 (H.S.)
No	16 (40%)	38 (95%)	

H.S. - statistically highly significant

likely to strongly agree that brushing their child's teeth is easy compared to ASD individuals' caregivers. Brushing with the help of a finger (30%) was more prevalent among ASD individuals, while TDP individuals were more likely to use a toothbrush (85%). This difference was statistically significant ($P = 0.00082$). TDP individuals (92.5%) were more likely to consume sugary snacks/drinks three times or more daily compared to ASD individuals (5%), indicating a significant difference ($P < 0.00001$). A significantly higher number of caregivers of TDP had knowledge that they were using (62.5%) fluoride-containing toothpaste to clean the child's teeth as compared to caregivers of ASD individuals (30%). A significantly higher number of caregivers of ASD individuals (60%) reported that the child preferred specific flavoured toothpaste compared to TDPs (5%).

Table 2 illustrates caregivers' awareness about oral health of their ward. Results show that caregivers of ASD children were less likely to observe gum bleeding and observe cavities or discoloration in their children's teeth compared to those of TDPs. This difference was statistically significant. ASD

children have significantly less visited the dentist for treatment compared to TDP children. It was observed that ASD children tend to have their first dental visit at a later age compared to TDP children ($P = 0.000326$). Routine treatments were less common among ASD children compared to TDP children, and the caregivers of ASD children were less likely to reach out to dentists for dental-related questions compared to caregivers of TDPs children. This difference is statistically significant.

Table 3 presents caregivers' perspective on barriers to accessing dental care. Caregivers of ASD individuals encountered multiple significant barriers to access dental care compared to caregivers of TDPs. They struggled to find dentists who can accommodate their child's needs and perceived their child's uncooperative behaviour as a hindrance to oral hygiene and dental visits. Additionally, they strongly felt that dental environments inadequately addressed sensory concerns and children with ASD experienced heightened anxiety due to unfamiliar places and people. Furthermore, the cost of dental treatment posed a significant obstacle for them. These differences were statistically

Table 2: Comparison of caregiver's awareness about oral health of the child with and without ASD

Variable	ASD (n=40) n (%)	TDPs (n=40) n (%)	P
Have you as a caregiver observed gum bleeding in the child's mouth?			P=0.000125 (H.S.)
Yes	2 (5%)	0 (0%)	
No	22 (55%)	39 (97.5%)	
Don't know	16 (40%)	1 (2.5%)	
Have you as a caregiver observed cavities or discoloration in the child's teeth?			P=0.000011 (H.S.)
Yes	1 (2.5%)	12 (30%)	
No	23 (57.5%)	27 (67.5%)	
Don't know	16 (40%)	1 (2.5%)	
Has the child visited the dentist for a treatment?			P=0.042525 (H.S.)
Yes	18 (45%)	27 (67.5%)	
No	22 (55%)	13 (32.5%)	
At what age was the child's first dental visit?			P=0.000326 (H.S.)
3-6	18 (22.5%)	21 (26.25%)	
7-12	0 (0%)	5 (6.25%)	
Never been	22 (27.5%)	14 (17.5%)	
How was the treatment performed?			P=0.00458 (H.S.)
Routine	9 (11.25%)	19 (23.75%)	
Sedation	7 (8.75%)	0 (0%)	
GA	0 (0%)	0 (0%)	
Never been	24 (30%)	21 (26.25%)	
Whom do you generally first reach out to for dental related questions for the child?			P=0.001631 (H.S.)
Dentist	20 (25%)	34 (42.5%)	
Family or friends	4 (5%)	4 (5%)	
Paediatrician	14 (17.5%)	1 (1.25%)	
Social media or internet	2 (2.5%)	1 (1.25%)	

H.S - statistically highly significant

significant, highlighting the unique challenges faced by ASD individuals and their caregivers in accessing dental care.

Discussion

ASD is characterised by repetitive complex behaviour with a static brain disorder.^[14] As children having ASD are dependent on their caregivers for many routine activities, caregivers play a crucial role in maintenance of oral health care for them. It can be challenging for the caregivers to mandate these subjects' oral care as it requires a great deal of patience as well as sufficient knowledge and understanding about importance of maintenance of oral health in their wards.^[15] Review of published literature suggests that within the demographics of children with special healthcare needs, oral health care and dental treatment frequently go unaddressed, highlighting significant gaps in care.^[5] Furthermore, the scarcity of good-quality population-based studies on addressing challenges and barriers to maintain oral health in the ASD-affected population in developing countries like India emphasises a clear need to address this issue comprehensively.

In the present study, in terms of oral hygiene practices, ASD individuals demonstrate distinct patterns, such as brushing less frequently, needing more supervision during brushing, and using fingers to clean the teeth over TDPs. This observation was concurrent to the results obtained from researches conducted on brushing behaviours of ASD children by Floríndez LI *et al.*,^[16] Mirtala Orellana L *et al.*,^[17] and Mansoor D *et al.*^[18] This might

be due to the variable sensory profiles and behavioural or communication challenges faced by ASD children. Additionally, sensory stimuli often interfere with toothbrushing routines, leading some ASD children to skip the essential task.^[18,19] In the present study, TDPs exhibit higher consumption of sugary snacks/drinks compared to their ASD counterparts, which demonstrates the unique oral health behaviours within these groups. This might be because caregivers of the children with ASD likely to be aware of the psychological effects of a high-sugar diet on their child's behaviour, which might have contributed to low consumption of sugary snacks in the ASD group.^[20] The results are in contrast with a study carried out by Junnarkar *et al.*^[21] and Mathew NE *et al.*,^[22] who have reported higher sugar intake among ASD children. In this study, caregivers of ASD individuals display lower awareness of dental issues like noticing gum bleeding and cavities/discoloration, along with fewer routine dental visits and less proactive engagement with dental professionals compared to caregivers of TDPs. This observation was in line with a previous study done on parental perceptions regarding oral care of children with ASD by Parry JA *et al.*^[23] Findings of the first dental visit at a later age and not reaching out to dentists for dental-related questions are similar to those of the study carried out by Mansoor D *et al.*^[18] and Omer R *et al.*^[24] Lower awareness on noticing dental issues and less proactive engagement with dental professionals among the caregivers of the ASD group might be due to various barriers such as sensory sensitivities, communication challenges, and behavioural traits associated with autism. These disparities suggest the necessity for increased education and outreach

Table 3: Comparison of barriers to seek dental care from caregiver's perspective for the child with ASD and without ASD (n=80)

Variable	ASD (n=40) n (%)	TDPs (n=40) n (%)	P
Do you think you found it difficult finding a dentist who caters to your child's needs?			
Strongly Agree	7 (17.5%)	0 (0%)	P<0.00001 (H.S.)
Agree	21 (52.5%)	0 (0%)	
Neither agree nor disagree	2 (5%)	0 (0%)	
Disagree	5 (12.5%)	3 (7.5%)	
Strongly disagree	5 (12.5%)	37 (92.5%)	
Do you feel that the uncooperative behaviour of the child makes it difficult for the child to maintain oral hygiene and receive much needed dental care?			
Strongly Agree	23 (57.5%)	0 (0%)	P<0.00001 (H.S.)
Agree	9 (22.5%)	6 (15%)	
Neither agree nor disagree	0 (0%)	13 (32.5%)	
Disagree	2 (5%)	8 (20%)	
Strongly disagree	6 (15%)	13 (32.5%)	
Do you feel that the dental clinical environment does not fulfill your child's sensory concerns?			
Strongly Agree	30 (75%)	0 (0%)	P<0.00001 (H.S.)
Agree	3 (7.5%)	0 (0%)	
Neither agree nor disagree	0 (0%)	0 (0%)	
Disagree	1 (2.5%)	0 (0%)	
Strongly disagree	6 (15%)	40 (100%)	
Do you feel that the anxiety induced by exposure to unfamiliar people and places makes it difficult to seek much needed dental care?			
Strongly Agree	21 (52.5%)	1 (2.5%)	P<0.00001 (H.S.)
Agree	11 (27.5%)	13 (32.5%)	
Neither agree nor disagree	1 (2.5%)	16 (40%)	
Disagree	3 (7.5%)	5 (12.5%)	
Strongly disagree	4 (10%)	5 (12.5%)	
Do you feel that the cost of dental treatment makes it difficult to seek much needed dental care?			
Strongly Agree	5 (12.5%)	0 (0%)	P<0.00001 (H.S.)
Agree	16 (40%)	4 (10%)	
Neither agree nor disagree	1 (2.5%)	14 (35%)	
Disagree	13 (32.5%)	8 (20%)	
Strongly disagree	5 (12.5%)	14 (35%)	

H.S. - statistically highly significant

efforts to improve caregivers' knowledge and promote regular dental care for ASD individuals. Furthermore, in the present study, there were significant barriers reported by the caregivers of the ASD group in seeking dental care for their ward, which include difficulties in finding dentists who can accommodate the needs of ASD patients, challenges posed by the child's behaviour during dental visits, inadequate addressing of sensory concerns in dental environments, heightened anxiety experienced by ASD individuals in unfamiliar settings, and financial obstacles related to the cost of dental treatment in accessing dental care. These results were found to be in congruence with the result obtained in studies conducted by Thomas NA *et al.*,^[6] Junnarkar *et al.*,^[21] and Stein Duker LI *et al.*^[25] Addressing these barriers is crucial to ensure equitable access to dental services for ASD individuals.^[26]

Certain limitations inherent in the study include a low sample size and a possibility of Hawthorne bias as a questionnaire form used to collect the data. However, this is one of the first few studies of this kind in the said demographic area and the questionnaire form is the most commonly used method to collect such information which can justify the use of a

questionnaire as a tool for this present study. Our study did not classify the participants in the ASD group based on levels of support. This study only highlighted basic home care regimens and challenges faced by parents of children with ASD. Sensations such as visual, tactile, olfactory, and gustatory were not evaluated, which can influence brushing difficulty and dental management. However, the findings from this study will help to address logistical barriers to improve dental care accessibility as well as reduce stigma and promote inclusivity in healthcare for ASD children. Moreover, 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.

Conclusions and Recommendations

Caregivers of children with ASD were not adequately aware about their child's oral health and encountered increased difficulty in maintaining routine oral hygiene for their children at home and accessing suitable dental care compared to the caregivers of children from the typically developing peer group.

It is recommended to plan out tailored dental care programs that consider the unique needs and challenges faced by ASD individuals, along with increased training for dental professionals in understanding and accommodating ASD patients. Additionally, providing support services^[27,28] and resources to assist caregivers in navigating dental care for their ASD children can help mitigate barriers and improve access to essential dental services. A lot of these challenges can be addressed by equipping the paediatric dentists with specialised training to cater to the specific needs of children with ASD, which may include strategies for creating sensory-friendly environments, effective communication techniques, and behaviour management strategies tailored to the unique needs of children with ASD to better accommodate and support these individuals during dental visits.^[29] Furthermore, occupational therapists who often spend significant time with children with special needs as part of their therapy sessions should be encouraged to integrate training on oral hygiene practices and techniques into their therapy sessions.^[30] Through collaborative efforts and inter-disciplinary approaches, healthcare professionals can work together to address the multifaceted challenges faced by families and improve the quality of dental care and overall well-being of children with special needs.

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Conflicts of interest

There are no conflicts of interest.

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