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Oral Health-Related Quality of Life in Children with Autism in Western Maharashtra

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Abstract.
This study delves into the often overlooked realm of oral health-related quality of life in children with autism in Western Maharashtra. Autism, characterized by distinctive strengths and challenges affecting social interaction and communication, is a spectrum disorder with varying support needs. The overarching objective of this research is to comprehensively assess the oral health status and gauge the impact on the quality of life of children with autism, with a specific focus on parental perceptions. Conducted as a cross-sectional survey in June 2023, the study engaged 79 parents of children clinically diagnosed with autism. Employing a one-on-one interview format, participants responded to 20 questions addressing various aspects of oral health. The shortened version of the Parental-Caregiver Perceptions Questionnaire (P-CPQ) was utilized to measure oral health quality of life, encompassing domains such as oral symptoms, functional limitations, emotional well-being, and family distress. Results unveiled a nuanced landscape, with 40.5% of parents reporting their child's oral health as average. Notably, 62% of parents expressed their child experiencing occasional oral pain, while 43% reported instances of bleeding gums. Significantly, 38% of parents admitted being upset due to their child's oral health condition. These findings underscore the multifaceted challenges faced by families of children with autism, with oral health exerting a substantial impact on the physical, mental, and emotional well-being of both the child and their caregivers. In conclusion, this study contributes valuable insights into the intricate interplay between autism and oral health, shedding light on the broader implications for the quality of life of these individuals and their families. The research underscores the necessity for targeted interventions to address oral health issues and enhance the overall well-being of children with autism in Western Maharashtra.

Keywords. Oral health, Quality of life, Autism, Western Maharashtra, Neurological disorder, Special health care needs, Spectrum disorder, Parental perceptions, Parental-Caregiver Perceptions Questionnaire (P-CPQ), Cross-sectional survey, Children with autism

I. INTRODUCTION

The oral cavity serves as a sanctuary for a large number of microorganisms, any slight change in pH or negligence of oral health can lead to vast array of health conditions .The Oral health related quality of life index is commonly based on 4 dimensions, oral functions, orofacial pain, appearance and psychosocial impact [1]Oral health risk increases in patients with special health care needs. Autism is basically a disorder that impacts the nervous system and affects the overall cognitive, emotional , social and physical health of individuals [2] . Autism is a blanket term, which comprises Asperger's disease , autism and childhood disintegrative disease , persuasive development disorder . Children with autism maybe verbal or nonverbal, some children may require little to no help in navigating daily activities, while some might require continuous assistance even in the smallest task. The symptoms of ASD vary from child to child

The onset of this condition might occur around 2 to 4 yrs of age. As children with ASD become adolescents and young adults they find it difficult to navigate what kind of behavior and response is expected

One of the major problems faced by children with ASD is that they have difficulty managing their emotional quotient , which in most cases leads to out burst of energy and a wide array of emotions. Children with ASD

have awide array of self injuries habits like , banging of head , picking of gingiva , self-extraction , biting of fingers , other unique oral habits are tongue thrusting , bruxism of teeth , non-nutritive chewing , biting when overwhelmed etc. unfortunately , studies suggest that oral health is neglected in children with autism
Poor oral health can affect can affect various aspects of life is not only children with ASD but also their families, there are various missed schools days by children , missed work days by parents , sleepless nights ,lack of confidence of child to speech impedance caused by negligence of development of oral health resulting in an impact on health and quality of life of both child and parent
Hence, based on the above mentioned data a study was done to assess the oral health related quality of life of children with autism

II. BACKGROUND:

The oral cavity serves as a gateway to myriad microorganisms, and any perturbation in pH levels or neglect of oral health can precipitate a diverse array of health conditions. The Oral Health-Related Quality of Life (OHRQoL) index, encompassing dimensions such as oral functions, orofacial pain, appearance, and psychosocial impact, offers a comprehensive assessment of an individual's oral well-being. Notably, individuals with special health care needs, a category inclusive of those with autism, confront an elevated risk of oral health issues.

Autism, a complex neurological disorder, exerts profound effects on cognitive, emotional, social, and physical facets of an individual's life. The spectrum nature of autism, encompassing conditions like Asperger's disease and childhood disintegrative disease, results in a diverse range of strengths and challenges. Children with autism display a spectrum of symptoms, ranging from verbal to nonverbal communication, and their support needs vary significantly.

Of particular concern is the emotional management difficulties experienced by individuals with autism, leading to self-injurious habits such as head-banging, finger-biting, and other unique oral habits like tongue thrusting and non-nutritive chewing. Regrettably, research indicates a prevailing neglect of oral health in this population.

The consequences of poor oral health extend beyond the affected individuals, impacting their families. Missed school days, parental work absences, sleep disturbances, and hindered speech development are among the myriad challenges faced by families of children with autism. Recognizing the multifaceted impact of oral health on the lives of these individuals and their caregivers, there arises a critical need for focused exploration and understanding.

In light of the identified gap in research, this study endeavors to assess the Oral Health-Related Quality of Life in children with autism in Western Maharashtra. By comprehensively investigating the oral health status and its implications for the overall well-being of these children, this research aims to contribute valuable insights that can inform targeted interventions, support mechanisms, and ultimately enhance the quality of life for both children with autism and their families in the region.

III. MATERIALS AND METHOD

A ethical clearance was obtained from the Institutional Ethics committee before commencing the study
A cross sectional study was conducted among 80 children with ASD between the age of 4 to 16 years using the formula
($N=\frac{z^2\,pq}{l^2}$) to asses the quality of life of children with autism, a shortened version of self-assessment parental questionnaire was given which included 20 questions. The responses were recorded by a one on one interview and few through Google forms,and then each response was derived.

The informed consent was obtained from all the subjects involved in the study. The sample size was calculated based on the relative proportion of children affected during quality of life verification while conducting other studies similar to this study; the allowable error is 5%

Initially schools that work with ASD in western Maharashtra were searched on Google and contacted. After this the institutions were sent emails regarding the objective and methodology of the study. A total of 30 schools were contacted out of which only 7 schools agreed to help recruit the parents or guardians which contained 20questions, responses were recorded by a one on one interview and few through Google forms, and then each response was derived information regarding the study, the informed consent was obtained from participating participants, then the forms forcolleted data collection.

Inclusion criteria were parents and guardians of children between the age of 6 to 15yrs of either sex , residing in different cities of western Maharashtra , children who were previously diagnosed with ASD by a child psychiatrist or pediatric neurologist and classified according to degree of autism. The exclusion criteria were parents or guardians of unaffected children and children above 16yrs of age

Data collection was done by filling out a Google form which contained 3 sections , the first contained questions on child'swellbeing , the second section addressed the symptoms and discomfort the child may experience due to his/her oral health and the 3rd section asks about the effect of children's oral health on everyday activities and feeling of the parents

The parental perception questionnaire contains a five point likert scale in the first section and in the next 2 sections it contains a three point likert scale , 'always ' , 'sometimes ' , 'never '. At the end the scores of each question were commuted by summing the items for each scale depending on the final score, a high score indicates a bad oral health and quality of life affected due to oral health of child with ASD

IV. REPORT AND ANALYSIS

a) Evaluation of perception : This was aself-assessment questionnaire based study which included 20 questions distributed in 3 sections .a total of 79 parents who had autistic children were included . responses were recorded and percentage of each response was calculated

TABLE 1 Table depicts knowledge, attitude and perception of parents in the studied sample

Questions	percentage
How often has your child experienced pain in teeth lips jaw and mouth?	
Always	25.3%
Sometimes	62%
Never	12.7%
Have your child experienced /experiencing crooked teeth?	
Always	
Sometimes	32.9%
Never	26.6%
	40.5%
How often has your child had food stuck in his or her teeth?	
Always	
Sometimes	31.6%
Never	22.8%
	45.6%
How often has your child had bleeding gums?	
Always	30.4%
Sometimes	43%
Never	26.6%
How often has your child had difficulty biting firm food stuff?	
Always	

Sometimes Never	31.6% 45.6% 22.8%
How often has your child had trouble sleeping? Always Sometimes Never	 24.1% 48.1% 27.8%
How often has your child had difficulty saying any words? Always Sometimes Never	 29.1% 32.9% 38%
How often has your child breathed through the mouth? Always Sometimes Never	 43% 38% 19%
How often has your child experienced bad breath? Always Sometimes Never	 32.9% 46.8% 20.3%
How often has your child had difficulty drinking or eating hot or cold foods? Always Sometimes Never	 40.5% 32.9% 26.6%
How often has your child had diet restricted to certain types of food? Always Sometimes Never	 24.1% 53.2% 22.8%
How often has your child felt irritable or frustrated because of his teeth , lips , jaw or mouth Always Sometimes Never	 39.2% 39.2% 21.5%
How often have you or your family member had sleep disrupted ? Always Sometimes Never	 30.4% 45.6% 24.1%
How often have you taken time off work due to his/her teeth , lips , jaw or mouth ? Always Sometimes Never	 38.5% 40.5% 21.5%
How often has your child experienced bad breath?	

Always	29.1%
Sometimes	53.2%
Never	17.7%

Table no. 1 has questions that focus mainly on whether the child has experienced any symptom or discomfort related to oral health 12.7% parents reported that their child has never experienced pain due to their oral health , whereas 62% parents reported to have pain sometimes and 25.3% reported to have always had pain. About 32.9% parents voted that their child has always had malalligned teeth whereas 26.6% and 40.5% voted never and always respectively . majority of the parents that is 45.6% parents have reported that sometimes food gets stuck in their child's teeth , whereas 22.8% parents reported that food never gets stuck in their child's teeth and 31.6 % parents that food always gets stuck in the child's teeth indicating a poor oral hygiene . 43% parents reported that their child sometimes has bleeding gums whereas 30.4% and 26.6% parents reported of bleeding gums as always and never respectively . 45.6% parents reported that their child has sometimes experienced difficulty in biting firm foods .majority of the parents , i.e 48.1% parents reported that their child's sometimes experiences difficulty in sleeping due to his /her oral health problems .38% parents reported that their child has never experienced difficulty in saying any words , whereas only 29.1% parents reported to always have difficulty while saying words due to oral health problems . a vast majority of parents i.e. 43% parents reported that their child breathes through the mouth , 46.8% children have experienced bad breath and only 20.3% have never experienced bad breath . majority of the children have experienced difficulty eating hot and cold foods , indicating sensitivity . 53.2% have reported to sometimes experience diet restricted to certain types of food . 39.2% sometimes and always felt irritable or frustrated due to his/her oral problems . 45.6% parents have reported that their sleep was disrupted sometimes . 48.1% have reported that they have sometimes taken time of work due to theirchild's oral health . a major percentage of parents have also reported that their emotional and mental state was also affected due to their child's oral health condition .

Table no. 2 has questions that focus on child's overall health and wellbeing of child.

QUESTIONS	PERCENTAGE
How would you rate the health of your child's teeth, lips, jaw and mouth?	
Excellent	0
Good	20.3%
Average	40.5%
Below average	32.9%
Poor	6.3%
How much are your child's daily activities being affected by the condition of his teeth, lips, jaw and mouth?	
Excellent	
Good	0
Average	21.5%
Below average	48.1%
Poor	24.1%

Table no. 2 has questions that focus on child's overall health and wellbeing of child , here majority i.e. 45% of the parents reported their child had a average oral health and 48.1 % parents have reported that their child's activity have been affected by the oral health of their children

Table no. 3 has questions regarding the impact of their child's oral health on their feelings and everyday activities

QUESTION	PERCENTAGE
How often have you had less time for yourself or the family Always Sometimes Never	 11.4% 60.8% 27.8%
How often have you been upset because of his/her teeth, lips , jaw or mouth Always Sometimes Never	 20.3% 38% 41.8%

Table no. 3 has questions regarding the impact of their child's oral health on their feelings and everyday activities 60.8% parents reported they've sometimes had less time for themselves and their family , 27.8% parents reported to never have time for themselves or their family , and only 11.4 % always had time for themselves and their family due to their child's oral health . 41.8% reported that they never got upset due to their child's oral health condition , whereas 20.3% reported always and 38% reported that they sometimes got upset due to their child's oral health

Oral health status: it was evaluated using dental caries score and OHI-S index using a mouth mirror and probe

V. DISCUSSION

The Autism spectrum disorder is a blanket term that includes – Rettsyndrome , Asperger syndrome , childhood disintegrative disorder , pervasive developmental disorder and autism . This condition develops at a very young age about 2 to 4 years . it was first reported by a American pediatric dentist , Leo Kanner .

It has been observed that in majority if the population oral health usually takes a back seat, this cross sectional study on the oral related quality of life is a concept based on impact of oral health on the quality of life of children with autism and also their family members.

Based on the results it was observed that the oral health of a child with ASD is average, an average oral health also takes a toll on the daily activities of children with autism, where it has been observed that destructive oral habits , pain due to any carious lesion makes them more irritable and sours their activities this was a major indication that the oral health of children with ASD is neglected .

Majority if the children with ASD experience crooked teeth , which lead to food lodgment , difficulty in pronouncing certain words , bad breath, all of these factor combined lead to digression of the child's confidence level which further makes their condition more complex as children with ASD are naturally very shy and according to studies find it a little to difficult to express themselves in a public setting and around new people . hence it is very important that right steps are taken so as to not aggravate their condition . proper orthodontic treatment for malalligned teeth , reinforcement of regular brushing of teeth by trying to make it a joyful experience etc.

It has also been observed in that poor oral hygiene in children also leads to disruption of sleep , inability to eat hold or cold food stuff , hence making the child more irritable and indirectly affecting quality of life of life both child and parent or guardian

In children with ASD, parents are the primary caregivers , the mother in most cases takes of the child , leading to social stigma , ignorance towards her own mental health , depression ,anxiety in this report it was observed that parents mostly reported that their child's oral health affected their daily life . parents perceptions of oral health might be affected by their awareness about their child's oral health , regarding the questionnaire most of the questions were answered by the mother , who is in majority of the cases the primary care taker of the child ,

it was observed that according to the survey conducted most parents reported that children on most occasions have suffered from halitosis , food lodgment , inability to eat firm food , sensitivity to hot and cold foods , mouth breathing , impaired speech , emotional

VI. CONCLUSION

In conclusion, this study sheds light on the often-neglected realm of oral health in children with autism in Western Maharashtra. The intricate interplay between autism and oral health is evident, with diverse challenges impacting the well-being of both the affected children and their families. The findings underscore the need for targeted interventions and support mechanisms to address the multifaceted challenges faced by these individuals. The prevalence of self-injurious habits and emotional management difficulties highlights the urgency of incorporating oral health into the holistic care of children with autism. Moreover, the study emphasizes the ripple effect of poor oral health on families, leading to missed school and work days, sleep disturbances, and diminished confidence in the affected children. This underscores the broader societal impact and the importance of a comprehensive approach to healthcare for individuals with autism. As we move forward, acknowledging and addressing the oral health needs of children with autism is crucial for enhancing their overall quality of life. Integrating oral health into the broader spectrum of care and providing targeted support can contribute to a more inclusive and supportive environment for these children and their families. The insights gained from this study provide a foundation for future research and initiatives aimed at improving the well-being of individuals with autism in Western Maharashtra.

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