

Parental perception of oral health-related quality of life in children with autism. An observational study

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ABSTRACT

Background: Autism is reportedly the most severe neuropsychiatric disorder affecting children. Autistic subjects can be characterized by impairments in social interactive behavior along with restricted interests and quite frequently, are seen exhibiting repetitive behavior patterns in stereotyped manner. The inability to perform routine tasks can widely impact the oral health and also, the constant care and sense of helplessness might drastically affect quality of life. **Aim:** The aim of the study was to assess the oral health status and perceptions regarding an autistic child's oral health among parents. **Materials and Methods:** Parental perception regarding the quality of life among the afflicted autistic children was done using a self-assessment questionnaire that included eight questions which were replied to in an affirmation or negative answer. 300 parents of autism affected children formed the study participants. Recorded responses were evaluated and percentage of each response was derived. Oral health status was measured by determination of dental caries prevalence and OHI-S index using chair light illumination, mouth mirror, diagnostic probe and a standard WHO periodontal probe. For statistical analysis, the calculations were performed by using the paired *t* test. Statistical significance, which was fixed at $P < 0.05$, which is statistically significant. **Results:** Approximately 18.33% of parents showed were aware that oral health can influence general health; 15% did have exhibit awareness. 15% of parents did not consider that primary teeth were important; 59.1% visited any dentist only when suffering from pain; 5% went for an annual dental examination; 15% and 24.6% parents visited dental practitioners at intervals of 3 and 6 months, respectively. 30%, 25% and 51.66% parents considered obtaining consultation and getting treatment from pediatric dentist; general dentist and general physician. 41.6% parents had taken their children for restorations. 52% reported constant stress whereas 48% reported with constant distressed emotions. No significant difference was determined between the parameters. 75% of autistic children suffered from dental caries whereas oral hygiene scores demonstrated high mean value of 4. **Conclusion:** Autism is a severely distressing condition wherein oral health along with general physical health is affected. Since parents are directly involved in upbringing of these individuals, they also subsequently show a reduction in quality of life.

Keywords: Autism, oral health, perception, questionnaire

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Introduction

Oral health broadly encompasses a state of complete freedom from pain of orofacial region, infections, periodontal diseases,

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dental caries, loss of teeth, and oral cancer. This limitation may severely inhibit a subject's capacity in eating, smiling, biting and chewing along with psychological wellness.^[1]

The World Health Organization (WHO) has defined "Quality of Life (QoL)" as a subject's perspective views on their exact position wherein they live in relation to their goals, expectations, standards and various concerns.^[2]

The "Oral-health-related Quality of Life (OHRQoL)" has been defined as per the US surgeon General report as "multi-dimensional construct which reflects a person's comfort while masticating, sleeping and engagement in social interactions, self-esteem and satisfaction related to oral health". Oral health risk increases in subjects with special health care needs. These special-care need children present with various oral symptoms, problems related to daily life and concerns regarding a child's oral health and impact over the child along with the family's quality of life. It has also been reported that families of autistic children and the subject itself suffers from low oral health-related quality of life.^[3]

Autism is basically a disease occurring due to neurodevelopment that can be detected in early growing years itself i.e. prior to attaining three years of age. Its presentation includes delay or abnormalities affecting communication and social skills; repetition or restricted and fixed activity behavioral patterns. "Autism" is an umbrella term, which comprises of Asperger's disease, autism and childhood disintegrative disease and pervasive developmental disorders- not specified.^[3]

Prevalence of autism spectrum in developed nations is reported to be approximately 60 cases per 10,000 population with male-to-female ratio of 4:1.^[3] However, the prevalence of autism spectrum disorders have increased in a significant manner in past few decades. However, the gender ratio has remained the same.^[4,5]

In a study conducted in Saudi Arabia, its prevalence is approximately 18 cases per 10,000 population.^[6]

The World Health Organization (WHO) has predicted a prevalence rate of ASD at 1:160 people at global level.^[7] Usually children with impairments possess good oral health compared to later stages in life. Hence, good perception regarding oral health and its general health is a necessity among affected subjects and their care-givers.

Various self-injuries causing behaviors affecting head and neck are- continuous banging of head, tapping of face, picking of gingival and auto- or self-extraction of teeth. Other unique oral habits are- thrusting of tongue, bruxism of teeth, non-nutritive chewing of objects like- pencils and pens. Thus, maintaining an optimal oral health in these affected children with autism is a significant challenge since intensification of pre-existing dental diseases significantly impairs the overall quality of life of a family unit. There is a greater disease burden in this particular group

of subjects as evident by the 1981 joint statement by WHO and FDI, "that by 2020, global average dental caries should not be more than a DMFT score of 3 at the age of 12 years. However, this could not be managed, thus, indicating that more stringent measures are required to be taken."^[8]

Oral care may be a challenging task due to their inability to communicate properly and problems linked with behavioral patterns. In addition, children suffering from autism might be requiring specific medications or might be in continuous practice of pernicious oral habits which may manifest in unusual manners. Cases of trauma are more frequently seen among these children due to more frequency of seizure cases.^[5] In a study conducted in UAE (United Arab Emirates), an overall prevalence of dental caries was found to be 77%.^[6]

In another study conducted in Saudi Arabia, it was observed that 33% of autistic children had dental treatment performed under general anesthesia whereas 53.7% did not have any previous history of dental treatment. Higher numbers of cases of extra-oral trauma with evident signs of self-injury were seen. Generally, studies have reported high dental caries prevalence due to preference of soft, sweetened foods and the habit of pouching food within mouth.^[9]

In a study conducted by Alaki *et al.*^[3] pain in tooth and halitosis were most commonly presenting symptoms in autistic pediatric subjects.

Children diagnosed with Autism Spectrum Disorder (ASD) are usually not capable of cooperation during dental treatment due to their inability toward interactions. Altamad also made an observation that an autistic child is difficult to manage during the treatment process. Rather, a child is prepared for dental treatment mainly by means of reinforcement rather than willingness for the same.^[4]

Based upon the above background this study was done with the aim of assessing oral health status and parental perception of child oral health-related quality of life in children suffering with autism in India.

Materials and Methods

This study was carried out after obtaining ethical approval from the institutional ethical committee (EC/21/198/MM). All guidelines laid down by "Declaration of Helsinki" were followed in conducting the study due to sensitiveness of the study.

Study design and measurement

- a. Evaluation of perception: This was a self-assessment questionnaire-based study which included seven questions that had to be answered in simple affirmative or negative response [Table 1]. Subject selection: A total of 300 parents who had autistic children were included. Both fathers and mothers were selected (n = 150, each, respectively) for

Table 1: Table demonstrating knowledge, attitude and perception of parents in the studied sample (n=300)

Questions	Frequency	Percentage	P
Does the oral health affect overall general health of a child?			
Yes	55	18.33%	0.08
No	45	15%	
Is the maintenance and subsequent treatment of primary teeth important?			
Yes	45	15%	0.089
No	55	18.3%	
When should a dentist be considered for consultation and/or treatment ?			
When in pain	157	59.1%	0.6
Once every 6 months	83	24.6%	
Once every 3 months	45	15%	
On an annual basis	15	5%	
If your child has a complaint of pain in a tooth, you would consult-			
General dental practitioner	75	25%	0.09
Pediatric dentist	90	30%	
General physician	155	51.66%	
Have you gotten a restoration/filling done for your child?			
Yes	125	41.6%	1.1
No	175	38.4%	
Have often do you felt distressed over your child's medical condition?			
Constantly	156	52%	0.67
Not very frequently	144	48%	

evaluation. Responses were recorded and percentage of each response was calculated.

- b. Oral health status: Oral health status was evaluated by determining dental caries scores and OHI-S index using mouth mirror, probe and a WHO periodontal probe.

Statistical analysis

Mean values were calculated and paired T test was applied for statistical analysis for deriving statistical significance which was set at a *P* value of less than 0.05 that is considered statistically significant.

Results and observations

- a. Perception regarding oral health-related quality of life: 18.33% of parents showed were of the knowledge that oral health can closely impact the general health while 15% did have any awareness regarding this. Approximately 15% of study participant did not consider primary teeth of much importance; 59.1% considered visiting a dentist only when in pain; 5% advocated an annual dental check-up; 15% considered visiting a dental practitioner at an interval of 3 months while 24.6% were in favor of a 6 monthly visit. 30% of parents considered consulting and obtaining treatment from a pediatric dentist; 25% wanted to visit any general dental practitioner and 51.66% thought of going to a general physician. 41.6% of parents reported positively about taking their children for restorative procedures while 38.4% did not consider the same. 52% of parents reported constantly feeling stressed about their child's well-being while 48% did not feel constant distress over their child's medical condition [Table 1]. However, no significant difference could be ascertained between any of the parameters as shown in Table 1 after applying statistics.

- b. Oral health status: 75% of studied autistic children demonstrated dental caries while oral hygiene scores as evaluated using the OHI-S score showed high mean scores of 4 oral hygiene. Thus, indicating poor oral hygiene and dental caries scores in this group.

Discussion

The oral health-related quality of life is a concept applied upon impact of oral diseases on daily functioning and general wellness. Subjects of pediatric age-group significantly affect quality of life as they cannot fend for themselves and are dependent upon their parents, hence, also, in turn affecting the oral health-related quality of life (OHRQoL).^[10]

The Autism spectrum disorder (ASD) includes the following entities- Rett's syndrome, sparger syndrome, Childhood disintegrative disorder, pervasive developmental disorder and autism. All of these disorders are present and evident since birth.^[11]

Autism, a neuropsychiatric developmental disease was first reported by Leo Kanner who was an American pediatric psychiatrist in 1943.^[12]

Cancio *et al.* in their study made an observation that habits that inflicted bodily harm on self, such as, trauma, lip biting, biting of extremities and pulling of hair were associated significantly with autism in a child. Few of the children demonstrated the presence of more than one habit at a time. Also, the mean Oral Hygiene Index- Simplified (OHI-S), dmft, dmfs, DMFT and DMFS scores were found to be higher in autistic children when compared with normal children. However, no real correlation was noted between oral health related variables and quality of life.^[13]

The study also found similar findings related to higher caries prevalence (75%) and poor oral hygiene status among the autistic children studied.

Bossu *et al.*^[14] in their study on evaluation of oral health and Central Italian children suffering from autism. The sample size was 229 affected children falling within age range of 5 to 14 years. Clinical examination showed that 79.26% of subjects suffered from gingivitis, 66.38% had dental caries while total mean dmft and DMFT score was found to be 2.91.

Qiao *et al.*^[15] conducted a study to compare the oral health status of children with and without autism spectrum disorders (ASD) in China. It was concluded that oral health issues like halitosis and bad oral habits were more prevalent among children with ASD. These children also lack oral hygiene practice and dental visits.

Alshatrat *et al.*^[16] conducted a study to evaluate the oral health status and knowledge in individuals with ASD in comparison with individuals without ASD in Jordan. It was found that individuals with autism suffered from a significant lack of knowledge related to oral hygiene practice compared to their controls, leading to a misunderstanding of the basic and highly important dental health aspects.

Orellana *et al.*^[17] in their analysis reported that approximately 25% of autistic children were capable of brushing their teeth unassisted while a majority of them required parental assistance. Hence, this is a small example wherein a child's well-being can significantly affect the quality of life (QoL) of parents.

Female pediatric subjects who have been diagnosed clinically with ASD have been said to be placed at the advanced edge of Intelligence Quotient (IQ) spectrum. Additionally, these female children with ASD often have average levels of IQ which demonstrates their amplified functional attributes when compared with male counterparts.^[18]

Cancio *et al.*^[13] in a cross-sectional analysis evaluated dental caries on 227 Brazilian subjects with special needs and the impact over their families oral health related quality of life. The 14-itemed family impact scale was employed to assess the family's QoL. Moderate to high caries experience was seen. However, no association was observed between high caries experience and negative impact over the families' quality of life. It has been commonly seen that parents of children with special health care requirements tend to neglect oral health. Thus in turn, results in causation of pain, associated with discomfort, development of malnutrition due to feeding issues and regular absence from school.

Parental attitude alongside day to day standard practice of child care is very important factor that influences parental care of teeth in children. In this study, the studied parental population did not exhibit any sharp contrasts between any perceptive conceptions which were held by the parents.

In a study, conducted by Mounissamy, it was found that 78.3% had made a visit to dental practice on experience of tooth pain or trauma by children while 9.4% visited for dental caries management, 6.6.% visited for correction of esthetics and 5.7% visited on complain of halitosis. Hence, this study stressed upon the need for heightened dental and oral awareness in parents regarding pediatric oral health care and treatment needs.^[19]

Also, in our study, majority of parents considered taking their affected children to a general physician for primary consultation even in dental or oral disease first rather than consulting a Pediatric dentist or General dental practitioner first.

Acs *et al.*^[20] in their study surmised parental satisfaction derived from good treatment initiates positive impact which helps in seeking treatment in future.

Since mothers are the primary care-givers of a child suffering from autism, they have to face numerous problems such as stigma, social discrimination, increased financial pressure and less effective or insufficient therapy. As a result of this, there is an elevated risk of development of anxiety and depression in mothers of these affected children.^[21] Zablotsky *et al.*^[22] has reported that there is an association between maternal emotional status and low income status. It has been a common observation that there is a positive association between behavioral problem shown by children with maternal emotional quotient or distress.^[23,24]

In a study conducted by Zhou *et al.*^[21] elevated scores of depression were more frequently seen among mothers (50%) of autistic children as compared to fathers (21%). It was concluded from the study that due to higher overall levels of anxiety along with depression, a psychiatric interventional management is mandatory in mothers of these children. However, in present study it was seen that parents did not have any significant difference in stress levels when evaluated as being under constant stress or having episodes of distressful episodes.

However, McStay *et al.*^[25] reported that higher levels of stress led to developing symptoms of depression, however, no statistically significant association was noted between maternal stress levels and social responsiveness associated with this health problem.^[24] Other important finding was that mothers with a low level of education suffered from higher mental stress and related anxiety and depression.

In a study conducted by Lee related to perceptions on oral health, various barriers for parental care of children with special needs was noted residing in South Bedfordshire. It was observed that 47% of parents underestimated the importance of oral health and also, a concomitant lack of education regarding oral and dental health.^[26]

Magoo *et al.*^[27] performed a study on parents of children suffering with disorders of autism spectrum. The sample size was 60 and

the data were collected using a self-administered questionnaire. Study results showed that 76.9% parents possessed the knowledge regarding the effects of oral health over general systemic health of these, 71.2% were aware of the fact that primary teeth are important for good permanent dentition while 61.5% refused for any treatment for primary teeth. Once-a-day tooth brushing was performed in parents on their children in 82.7% cases while 92.4% patients made conventional use of tooth-brushes for their wards. The primary factor governing the parental attitude and practice were- restraints due to finances and expected behavior of their children while undergoing treatment. These investigators also observed that parental knowledge regarding oral health was 51.44% however, the practical knowledge was restricted to only 39.37% of the study population.

Implications for clinical practice

Autistic patients constitute small percentage of special child population and they require unique management because of their behavioral characteristics. During the oral treatment, the main challenge is reduced ability of autistic kids to communicate and relate to others. Other problems like lack of capability to manage their emotions, repetitive body movements, hyperactivity associated with attention deficiency, and low frustration threshold can lead to peevishness and bizarre vocalizations.^[28]

There is an important role of family parental counseling in managing these children. Previsit meeting is to prepare the family for first dental visit, which will be beneficial for both parents as well as dental team. Previsit meeting will help the parents in preparing the child for dental treatment and any hesitant problems related to child behavior should be discussed and must conquer. Motivational interviewing and parental training programs should be conducted to acknowledge the importance of such care in maintaining the oral health of their children.^[29]

Conclusion

Autism is a neurodevelopment disorder that mainly affects the cognitive functions and patterns dependent upon these. Since parents are essential and direct care providers they get affected equally by their child's systemic condition. This study analyzed the perceptions regarding the quality of life related to oral health among the families of children who have been clinically diagnosed with autism.

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Conflicts of interest

There are no conflicts of interest.

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