

# Role of Dental Discomfort Questionnaire-Based Approach in Recognition of Symptomatic Expressions Due to Dental Pain in Children with Autism Spectrum Disorders

## Abstract

**Aim:** The aim of this study is to investigate whether the Dental Discomfort Questionnaire (DDQ) could help to identify toothaches in children with autism spectrum disorder (ASD). **Materials and Methods:** This study involved sixty children between the age groups of 6–16 years, attending the day-care schools diagnosed with ASD. Five different groups of children were identified based on the presence of a toothache and/or carious teeth. The DDQ-8 was completed by parents and evaluated by a single examiner. Data were analyzed using descriptive statistics (SPSS version 17), and a correlation was observed between the total DDQ score and the decayed, missing, and filled teeth (dmft–DMFT) score. **Results:** Analysis of the data showed that DDQ-8 had a significant correlation with that of DMFT score in a group “with carious teeth but no toothache” ( $r = 0.497$ ,  $P = 0.019$ ) and group “with carious teeth and a toothache” ( $r = 0.682$ ,  $P = 0.043$ ). A group “without carious teeth where the parents were not sure whether or not the child had a toothache” had higher mean compared to other groups with DDQ-8 scores. **Conclusion:** There was a significant difference in the total mean DDQ scores when they were compared with that of the control group. Children with high DDQ-8 often had a high DMFT/dmft score. A significant correlation was found when the total DDQ-8 scores were compared with that of the DMFT score.

**Keywords:** Autism, behavior, caries, Dental Discomfort Questionnaire, toothache

## Introduction

Autism is a spectrum of pervasive developmental disorder (PDD) and an organically based neurodevelopment syndrome that usually begins in the first 30 months of life. Autism is associated with abnormalities in the brain structure and function with high concordance rate in monozygotic twins, and it causes long-term disability.<sup>[1]</sup> The physical and behavioral manifestations of autism can greatly impact the day-to-day activities of a child. Due to their hypersensitivity to sensory stimulation, everyday tasks can be overwhelming and lengthy to accomplish.<sup>[2]</sup> Bathing, feeding, and even brushing teeth can be overly stimulating to a child with autism. They often obsessively follow routines or schedules and play repetitively. Any deviation from the routine can be very troublesome to the child. It is characterized by poor social skills, lack of interpersonal relationships,

abnormal speech and language, ritualistic or compulsive behavior with repetitive stereotyped activities, and also self-injurious behavior such as head banging, lip chewing, and scratching. Kanner<sup>[3]</sup> described a clinical syndrome in children and named it as early infantile autism. PDDs are more commonly referred as autism spectrum disorders (ASDs), an umbrella term for five disorders which includes: (1) autistic disorder, (2) Rett's disorder, (3) childhood disintegrative disorder, (4) Asperger's disorder, and (5) PDD not otherwise specified.<sup>[1]</sup>

Common oral findings in patients with ASD include traumatic ulcerated lesions usually brought on by self-injury from head banging, picking, or face tapping. All of these factors, along with poor oral hygiene, may be related to different problems in these individuals. Inability to establish a communication is a hallmark feature in children with ASD, being the assessment of dental pain and distress

**Chandana  
Penmetsa, Sarada  
Penmetcha,  
Sampath Reddy  
Cheruku, Sreekanth  
Kumar Mallineni<sup>1,2</sup>,  
Anil Kumar Patil,  
Srinivas Namineni**

*Department of Pedodontics  
and Preventive Dentistry, Sri  
Sai College of Dental Surgery,  
Hyderabad, Telangana,*

*<sup>1</sup>Department of Pedodontics and  
Preventive Dentistry, Narayana  
Dental College and Hospital,  
Nellore, Andhra Pradesh, India,*

*<sup>2</sup>Department of Preventive  
Dental Science, College of  
Dentistry, Majmaah University,  
Al-Zulfi, KSA*

## Address for correspondence:

*Dr. Chandana Penmetsa,  
Department of Pedodontics  
and Preventive Dentistry,  
Sri Sai College of Dental  
Surgery, Vikarabad,  
Hyderabad, Telangana, India.  
E-mail: drchandanamds@gmail.  
com*

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always a challenge. As symptomatic expression of pain in them remains vary and bizarre.<sup>[4]</sup> Children with ASD have an increased risk that the pain they may feel remains unrecognized and underestimated. Hence, these children usually depend on their parents or caregivers for recognition of their pain. Pain due to dental caries can alter children to eating, and sleeping may favor a child to exhibit negative behaviors.<sup>[5]</sup>

The Dental Discomfort Questionnaire (DDQ) was developed on the assumption that a toothache causes certain behaviors to occur more often.<sup>[6]</sup> It has been reported that the DDQ-8 could be useful for nondental health-care workers, parents, and researchers in predicting the existence of toothache in children with preverbal communication.<sup>[6]</sup> Versloot *et al.*<sup>[7]</sup> suggested that the DDQ seems to be an efficient and easy-to-use instrument to alert parents and caregivers to the presence of a toothache in children with a learning disability. Previous research<sup>[7,8]</sup> investigated whether the behaviors from the DDQ occur more often in children with a learning disability or not. To date, there are no studies published till recently assessing toothaches specifically on children with ASD. Therefore, the aim of this study is to investigate whether the DDQ could help identify toothaches in children with ASD who have a limited capacity to self-report pain.

## Materials and Methods

This questionnaire study was conducted in the Department of Pedodontics and Preventive Dentistry, Sri Sai College of Dental Surgery, Vikarabad, in association with day-care schools for autism in Hyderabad.

A convenience sample of sixty children between 6 and 16 years old was recruited, 43 males and 17 females. These children were attending day-care schools for autism and children who are diagnosed under ASD were included in the study. Parents of children who did not consent to participate in the study and children having intelligence quotient <50 as per school records were excluded from the study.

A detailed case history about the child was recorded by the examiner from the parent to know whether any relationship exists between consanguineous marriages and autism; pre-, postnatal development; and autism and also to know about associated systemic problems. The oral hygiene status was also recorded to make a distinction from the children attending special schools.

The DDQ was developed on the premise that a toothache causes certain behaviors to occur more often. Versloot *et al.*<sup>[5]</sup> introduced DDQ for predicting toothache in young children. Children with ASD can experience cognitive, language, and social barriers in communicating their pain. For this reason, it would be helpful to use behavioral clues as indicators of the presence of pain.

## Dental Discomfort Questionnaire

The DDQ includes a question concerning the occurrence of a toothache, for example, if the parent was asked whether he/she noticed that the child had a toothache; this question could be answered as “never” or “sometimes” or “often” or “I do not know” and also regarding different behaviors associated with toothache or caries such as crying during meals or problems during chewing and excessive drooling. For each item, the parent was asked to rate the occurrence of their child’s specific behavior. The questions could be answered on a three-point scale: 0 – never, 1 – sometimes, and 2 – often.<sup>[6]</sup> The final score was calculated by summing the answers, and thus, the score ranges from 0 to 28.

## Caries status

Caries experience was assessed using the WHO Oral Health Surveys: Basic Methods, 4<sup>th</sup> edition 1997 [Annexure III].<sup>[8]</sup> The protocol recognizes occlusal caries and also caries which extends into the dentin and pulp. A single calibrated examiner examined all the children using diagnostic instruments (mouth mirror and probe) with the help of a pen torch which was focused by the assistant. The recordings were noted by the same examiner after each child’s examination. Missing deciduous teeth were assumed to have been extracted as a result of caries unless the chronology of tooth eruption coincides with the age of the child. Since the presence of a deciduous tooth normally excludes the presence of its successor, in the data file the decayed, missing, and filled teeth (dmft) and DMFT were combined to provide an overall score for caries experience.

## Data analysis

Five different groups of children were identified based on the presence of a toothache and/or carious teeth: Group I the control group children with no carious teeth and no toothache, Group II children with carious teeth but no toothache, Group III children without carious teeth but with a toothache, Group IV children with carious teeth and a toothache, and Group V children without carious teeth where the parents were not sure whether or not the child had a toothache. Chi-square tests were used to compare the occurrence of the 14 different pain-associated behaviors from the DDQ between the different groups of children. Because of the great number of tests, the level of significance was set at  $P < 0.01$ . Descriptive statistics such as means, standard deviation, and frequencies were calculated. One-way ANOVA was used to test the difference between mean values, and Chi-square test was assessed to see the association between variables. A correlation was observed between the total DDQ score and the dmft–DMFT score.

## Results

The sample involves the children in the mixed dentition period, so both dmft and DMFT were recorded. Of the total sample of sixty children, there were five different groups based on the presence of toothache and/or carious teeth. In Group I, there were 21 children; in Group II, there were 22 children; in Group IV, there were 9 children; and in Group V, there were 8 children. No children were convened under Group III because they have no such symptoms. In Group I, there were 15 males and 6 females; in Group II, there were 15 males and 7 females; in Group IV, there were 6 males and 3 females; and in Group V, there were 8 males and no females. While recording the case history, when the parents were asked “Whether the mother suffered from any serious illness and/or taken any medications during the time of pregnancy,” there were only five parents who answered that the mothers have taken some medication during the time of pregnancy. When the parent was asked “Did the child had any past dental history” of the sixty parents, only 3 parents answered that their child visited the dentist. When they were asked “Whether the child has any indigestion problem” among sixty parents, 15 parents answered that their child has problem. When the parents were asked about the reason for the difficulty in brushing the teeth of their children, about 43 parents answered that their child had difficulty due to oral sensitivity, 9 parents gave the reason as dental caries, and 8 parents were not sure why the child had difficulty in brushing. Table 1 shows the percentage of children with/without toothaches in overall sample; the results were significant ( $P < 0.05$ ) among three responses (no, yes, and uncertain). Among all, 31.66% ( $n = 19$ ) children had enamel caries, 48.33% ( $n = 29$ ) had no obvious carious lesions, and only 20% ( $n = 12$ ) children had deep carious lesions. Twenty-nine percent of the children had caries and a toothache, and they have at least one tooth with caries extending into dentin. About 27.6% parents ( $n = 8$ ) of the children without carious teeth were not sure if their child had a toothache. Of the total sample, 71.7% children have no toothache and 15% children have toothache. The DDQ includes a question concerning the occurrence of a toothache, and the questions were answered on a three-point scale: 0 – never, 1 – sometimes, and 2 – often. The percentages that were reported in the study for DDQ are shown in Table 2. The frequencies of the DDQ items were calculated for each group, except Group 3 (without carious teeth but with a toothache) because there were

no children who belong to that group. All the other three groups were compared with the control group.

When the percentage of children who had specific behaviors “sometimes” or “often” was calculated the behaviors, “difficulty during the time of eating,” “disturbed sleep often during nights,” “child is having food only on one side,” “grabbing his/her cheek away,” “putting his/her hands in the mouth frequently,” and “child ever suffers from a toothache” resulted to be more significant when compared to the control group.

The distribution of the total means of DDQ scores in each group is shown in Table 3. The mean DDQ scores were compared; it was found that children without caries or toothaches had a significantly lower mean DDQ score than the children from the other three groups. Children with caries and toothaches had a higher mean DDQ score compared to children with Group I and Group II. The mean is highest in Group V (children without caries and the parents were not sure whether the child had caries or not) when compared to other groups. The correlation coefficient was made between total DDQ score and dmft–DMFT score; there was a significant correlation found between Group II and Group IV. In Group II ( $r = 0.497$ ,  $P = 0.019$ ) and Group IV ( $r = 0.682$ ,  $P = 0.043$ ), there was a significant positive correlation between DMFT and DDQ [Table 4].

## Discussion

The DDQ was first introduced by Versloot *et al.*,<sup>[6]</sup> and the questionnaire was developed based on specific behaviors that are often shown by young children who suffer from toothache such as crying during meals and problems in chewing or with brushing teeth. These behavior clues would be helpful as indicators of the presence of pain.<sup>[6,7]</sup> The literature available on the use of DDQ was mostly on preverbal children and also in children with learning disability. As the major concern in ASD children is inability to communicate, this study is aimed at identifying various symptomatic expressions by the children with ASD. All the children included in the study were diagnosed with ASD. Due to the children’s limited abilities, their parents were asked to answer the questions of DDQ on their behalf, and the questionnaire was completed by a single pediatric dental surgeon. All the children were examined, and their dmft-DMFT was recorded to observe the correlation with that of DDQ.

The DDQ was developed considering a 3-point scale: 0 – never, 1 – sometimes, and 2 – often, and for each item, the parents were asked to rate how often their child showed a given specific behavior. In the DDQ, children “with caries and toothache” exhibited five of fourteen behaviors more common than children “without caries and toothache.” In contrast, children “with caries but without toothaches” had only two behaviors more often than children with no obvious caries or toothaches. Among all

**Table 1: Percentage of children with toothaches in overall sample**

Toothache	No caries, <i>n</i> (%)	Caries, <i>n</i> (%)	Total, <i>n</i> (%)	<i>P</i>
No	21 (72.4)	22 (71)	43 (71.7)	<0.001
Yes	0	9 (29)	9 (15)	
Uncertain	8 (27.6)	0	8 (13.3)	

**Table 2: Percentage of children who had specific behaviors “sometimes” or “often” in each group**

Question in DDQ	Group I (n=21), n (%)	Group II (n=22), n (%)	Group IV (n=9), n (%)	Group V (n=8), n (%)	P
Difficulty in brushing their upper front teeth	33.3	22.7	33.3	50.0	0.55
Difficulty in brushing their lower front teeth	19.0	18.2	44.4	12.5	0.33
Difficulty in brushing their upper back teeth	42.9	59.1	77.8	87.5	0.09
Difficulty in brushing their lower back teeth	33.3	54.5	77.8	37.5	0.12
Any difficulty during the time of eating	0.0	0.0	22.2	0.0	0.01
Whether the child bites with back teeth instead of front teeth	0.0	9.1	11.1	12.5	0.48
Did the child has any difficulty in taking hot and cold things	4.8	0.0	11.1	0.0	0.41
Did the child suffer from disturbed sleep often during nights	57.1	40.9	77.8	12.5	0.03
Did the child puts the sweets away even though he/she likes	0.0	4.5	0.0	12.5	0.35
Whether the child is having food only on one side	0.0	13.6	55.6	0.0	<0.001
Whether the child is grabbing his/her cheek away	0.0	0.0	0.0	25.0	0.004
Whether the child is producing more saliva	38.1	36.4	33.3	25.0	0.926
Whether the child is putting his/her hands in the mouth frequently	0.0	27.3	44.4	0.0	0.006
Did the child ever suffer from a toothache	0.0	0.0	55.6	0.0	<0.001

DDQ: Dental Discomfort Questionnaire

**Table 3: Distribution of the total means of Dental Discomfort Questionnaire scores**

Group	Group I (n=21)	Group II (n=22)	Group IV (n=9)	Group V (n=8)	P	Post hoc test
DDQ	2.71 (2.05)	3.59 (3.22)	7.67 (3.04)	8.75 (3.41)	<0.001*	4>1.2 5>1.2

\*Significant. DDQ: Dental Discomfort Questionnaire

**Table 4: Correlation coefficient between total Dental Discomfort Questionnaire score and dmft-DMFT score among all the groups**

Group	DMFT	One-way-ANOVA	DDQ score
Group I	DMFT	Correlation coefficient Significant (two-tailed) n	21
Group II	DMFT	Correlation coefficient P n	0.497* 0.019 22
Group IV	DMFT	Correlation coefficient P n	0.682* 0.043 9
Group V	DMFT	Correlation coefficient Significant (two-tailed) n	8

\*Significant. n: Number of participants; DMFT: Decayed, missing, and filled teeth; DDQ: Dental Discomfort Questionnaire

the five groups, only Group II and Group IV had DMFT/dmft scores, so a significant correlation was observed only in these groups. In our study, the DDQ scores were found to have a good association with the DMFT/dmft scores in Group II ( $r = 0.497$ ,  $P = 0.019$ ) and Group IV ( $r = 0.682$ ,  $P = 0.043$ ). Children who scored high on the questionnaires

often had a high DMFT/dmft score; DDQ score was found to have a statistically significant relation with dmft/DMFT.

Pain is an important warning signal for discomfort or illness and is known to influence negatively in the daily life. Children with cognitive impairment have serious problems in communicating their emotions, feelings, needs, and sufferings. The pain in these children becomes undetected and often leads to insufficient pain management.<sup>[9]</sup> Due to their unconventional expression of pain and discomfort, their parents frequently rely upon nonverbal behavior to determine if their child is in pain. Caring for a child with ASD is demanding and presents significant challenges to parents, particularly mothers who are often the primary caregivers. The children with ASD when compared to normal siblings require extra caregiving needs due to the lack of self-care skills.<sup>[10]</sup> Despite advances in early detection, intensive intervention, and therapeutic approaches, quality of life for children with autism remains poor.<sup>[11]</sup> Children with ASD tend to have poorer oral hygiene when compared to normal children because of deficiency in manual dexterity.<sup>[12]</sup> The toothache in these children is often not noticed until the symptoms become severe as they visit the dentist at a later age.<sup>[13]</sup> Bodfish *et al.* were the first to find the Pain and Discomfort



Scale to assess pain in individuals without the cognitive capacity to convert internal experiences into expressed language, based on the research of facial expressions and body movements.<sup>[14]</sup>

Literature on ASD did not describe exclusive unique features of hard or soft intra- or perioral tissues and the prevalence of dental disease in this population. Oral problems might arise because of autism-related behaviors. Shapira *et al.*<sup>[15]</sup> also inferred that caries susceptibility and prevalence of periodontal disease are not remarkably different from nonautistic individuals and may be even lower. In contrast, McDonald and Avery<sup>[16]</sup> noted that children with autism prefer soft and sweetened foods and they tend to pouch food inside the mouth instead of swallowing it due to poor tongue coordination, thereby increasing the susceptibility to caries. Moreover, the risk for dental caries can be expected to be higher in these patients due to difficulties in brushing and flossing.<sup>[12,17]</sup>

When DDQ mean scores were compared with that of the control group, our study showed that the group “without carious teeth where the parents were not sure whether or not the child had a toothache” had a slightly higher mean value than that of obtained from the group “with caries and toothache.” The reason might be because of over responsiveness of the children and the parents getting confused with those behaviors. Children with ASD frequently report to exhibit behaviors associated with sensory sensitivity (e.g., covering ears to loud, unexpected sounds, and restricted food preferences). It has been described in the literature that the large percentage of children with ASD (78%–90%) has sensory processing problems<sup>[18,19]</sup> being these more common in children with ASD than in typically developing children.

Sensory processing problems in children with ASD are not a well-studied area. In this study, it was difficult to reach a firm conclusion in relation with children “without caries and the parents are not sure whether or not the child had a toothache” as there are many limitations which were already reported in previous studies.<sup>[20]</sup> This study emphasizes the need for further investigation into the sensory processing problems in ASD children.

In the present study questionnaire when parents were asked about the reason for difficulty in brushing, those of Group V answered that they were not sure why their child had “difficulty during the time of brushing.” They also answered that their “child is grabbing his or her cheek more often.” That could be because the children in Group V might be overresponsive compared to other groups. In the present study, eight children belong to a group “without carious teeth where the parents were not sure whether or not the child had a toothache.” None of the parents responded to the category of “without carious teeth but with a toothache.” One-third of the parents of the caries-free children did not know whether their child

was suffering from a toothache; two-thirds of these parents stated that their children tended to “produce more saliva” and “their child suffers from disturbed sleep often during nights.” Among the total sample, two-thirds of the parents answered that the child had difficulty in brushing due to oral sensitivity. Stein *et al.*<sup>[21]</sup> found that both aversions to the taste of toothpaste and dislike for the feeling of the toothbrush in the child’s mouth were associated with oral care difficulty at home. As sensory hypersensitivity is the major problem in ASD, they exhibit negative emotional reactions to specific responsivity. No significant correlation was found between autism and prenatal, natal and postnatal histories of the child, and also consanguineous marriage of their parents. These results are in agreement with Nelson<sup>[22]</sup> who examined the literature on autism and a variety of birth complications and reports that there is no consistent or specific link between maternal history, pregnancy, delivery or neonatal events, and autism. The parents were asked about the indigestion problem in their child, 15 of sixty parents answered that their child had a problem, as it was found in the previous studies that children with ASD had more gut-related symptoms (e.g., diarrhea, constipation, and/or bloating) and they suffer from at least one gastrointestinal problem compared to children without ASD. The prevalence of ASD is more in boys compared to girls (male-to-female ratio being 3:1), and the same was depicted in our sample also.<sup>[1]</sup> An interesting aspect noticed in the present study was only three children with ASD had past dental history. The low percentage of children with ASD visiting the dentist may be due in part to the children’s fear and anxiety surrounding dental visits, need for rigidity and routine, or behavioral or sensory processing difficulties. The behavioral section of the DDQ had a good predictive value for toothaches in ASD children. This study helps the parents of children with ASD to identify alterations in their behaviors that can be related to specific changes in their oral health. Their knowledge and awareness are valuable resources, which can be utilized by the application of the DDQ.

There are some limitations to this study. Groups were formed on the basis of parent report of diagnosis, which was not confirmed by gold standard diagnostic tools, such as the Autism Diagnostic Interview-Revised or the Autism Diagnostic Observation Schedule. The sample in each group was very small, and the assessment made by the parents of those children is different for the various changes in the behaviors due to hypersensitivity. Hence, more research is needed in children with ASD to identify their pain-related behaviors and making the assessment easy and beneficial for both the parents and the clinicians. The behaviors such as “difficulty during the time of eating,” “child suffers from disturbed sleep often during nights,” “child is having food only on one side,” “child is putting his/her hands in the mouth frequently,” and “child ever suffers from a toothache” were found to be more

significant when compared to children “with no caries and toothache.” There was a significant difference in the total mean DDQ scores when they were compared with that of the control group. Although, in the group 'without carious teeth where the parents were not sure whether or not the child had a toothache apparently this group had showed a higher mean DDQ score compared to that of the group “with caries and a toothache.” Children who scored high on the questionnaires often had a high DMFT/dmft score. A significant correlation was found when the total DDQ scores were compared with that of the DMFT score.

## Conclusion

Thus, the DDQ seems to be a functional and easy-to-use instrument for parents and caregivers to utilize in this group of children, to recognize if they have a toothache. It also emphasized the importance of a behavioral approach in recognizing pain in children with ASD who are unable to effectively communicate pain and distress.

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## Conflicts of interest

There are no conflicts of interest.

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