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**Oral health difficulties in children and adolescents with autism spectrum disorder: parental perception**

Тешкоће у одржавању оралног здравља код деце и адолесцената са поремећајима из аутистичног спектра: перцепција родитеља

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## Oral health difficulties in children and adolescents with autism spectrum disorder: parental perception

Тешкоће у одржавању оралног здравља код деце и адолесцената са поремећајима из аутистичног спектра: перцепција родитеља

### SUMMARY

**Introduction/Objective** Autism spectrum disorder (ASD) is characterized by features that have the potential to make oral hygiene and dental appointments challenging.

The aim of this study was to investigate difficulties related to oral hygiene and dental appointments that may be encountered in children and adolescents with ASD, in comparison to their typically developing peers.

**Methods** A 48-item questionnaire was prepared for the purpose of the study and distributed to parents of children and adolescents with ASD in three specialized daycare centers, as well as to parents of typically developing children and adolescents. Ninety-two questionnaires were considered and statistically analyzed in SPSS program, using Chi square and Mann-Whitney U-test.

**Results** The following statistically significant differences were found between children and adolescents with ASD and their typically developing peers: general difficulties in everyday oral hygiene, need of help for basic oral hygiene tasks, tooth brushing frequency, sensory difficulties related to toothbrush and toothpaste, level of anxiety prior to dental appointment, cooperation during appointment, sensory difficulties related to touch, operatory light and sound of dental unit, number of treatments under general anesthesia and number of refused dental treatments.

**Conclusion** Children and adolescents with ASD face significantly more difficulties concerning everyday oral hygiene and dental appointments in comparison to their typically developing peers. Dentists' awareness of issues that are specific to this population of patients is important in order to enable quality dental care.

**Keywords:** autistic disorder, autism, early infantile, dental care

### САЖЕТАК

**Увод/Циљ** Поремећаји аутистичног спектра (ПАС) могу бити узрок потешкоћа везаних за одржавање оралне хигијене, као и за посете стоматологу.

Циљ рада био је да се утврде разлике између деце и адолесцената са ПАС и контролне групе неуротипичних вршњака, са аспекта одржавања оралне хигијене и посета стоматологу.

**Метод** Упитник од 48 питања дистрибуиран је родитељима деце и адолесцената са ПАС у три специјализована дневна боравка, као и родитељима контролне групе неуротипичних вршњака. Деведесет два упитника је узето у обзир и статистички анализирано у СПСС програму.

**Резултати** Статистички значајне разлике између деце и адолесцената са ПАС и њихових типично развијених вршњака утврђене су у категоријама: тешкоће у свакодневној оралној хигијени, потреба за помоћи у одржавању оралне хигијене, учесталост прања зуба, сензорне тешкоће везане за четкицу и зубну пасту, ниво анксиозности пре посете стоматологу, сарадња током стоматолошког третмана, сензорне тешкоће везане за додир стоматолога, светло и звук стоматолошког уређаја, број третмана под општом анестезијом и број одбијених стоматолошких услуга.

**Закључак** Деца и адолесценти са ПАС суочавају се са знатно већим потешкоћама у погледу свакодневне оралне хигијене и посета стоматологу у поређењу са типично развијеним вршњацима. Свест стоматолога о питањима која су специфична за ову популацију пацијената је важна како би се деци и адолесцентима са ПАС омогућила квалитетна стоматолошка нега.

**Кључне речи:** поремећаји аутистичног спектра, аутизам, стоматолошка нега

### INTRODUCTION

Autism spectrum disorder (ASD) refers to a wide spectrum of heterogeneous neurodevelopmental disorders, characterized by impairments in 2 behavioural domains: 1) social communication and 2) restricted and repetitive patterns of behaviour, interests and activities [1, 2]. The aetiology of ASD, although not yet completely understood, is considered to implicate multiple genetic and environmental causes [3]. This complex developmental disability typically appears during the first three years of life, generally undergoes a steady course without remission through ageing and has no cure [4].

Established autistic features such as great difficulty to interact with other people and to understand and follow instructions may hinder both professionally delivered as well as home dental care. Oral health conditions of children with ASD has been analysed and compared to that of the healthy child population in a recent review [5]. The vast majority of the studies reported poorer oral hygiene [6-9], worse gingival conditions [6, 7, 8] and significantly worse periodontal status with higher periodontal treatment needs [10, 11] in children with ASD in comparison to healthy children. Although children with ASD are also regarded as high-risk group for dental caries according to Caries-Risk Assessment Tool adopted by American Academy of Pediatric Dentistry [12], inconsistent findings exist in the scientific literature regarding dental caries experience in autistic children. Some studies reported that children with autism exhibited higher caries prevalence [6] and higher DMFT score [8] than healthy control group. Conversely, children with ASD were also found to be more likely caries-free and to have lower DMFT scores than unaffected control children [11, 13]. Also, no significant differences were found in caries experience in primary or permanent dentition between children with ASD and healthy children [7, 14]. Nevertheless, prevalence of dental caries [15, 16] and periodontal disease [16] in children and young adults with ASD can still be considered as high. These findings confirm the validity of considering ASD as an indicator of high risk for oral diseases and point to the need for oral health care programs to focus on this condition [15, 16].

Concerns have been raised about the barriers in accessing health care and the unmet needs among children with ASD [17-20]. The most frequently reported major barrier to dental care was the child's difficult behaviour and lack of cooperation by the child [17, 19, 20] as well as behaviour that was liable to change without warning [20]. According to Frankl's behaviour rating scale, children with ASD were more likely to behave 'negatively' or 'definitely negatively' during dental examination than those without ASD [7, 13, 21]. Another common problem is finding a specialist with skills and experience in treating children with special health care needs [17, 18]. Among many other perceived problems, parents reported difficulty in travelling to dental surgery [20], cost of dental treatment and lack of insurance [19].

Furthermore, maintaining good oral hygiene in children with ASD is a significant task for the parents or the guardians of the child. Oral care on a daily basis was found to be challenging for children with ASD as well as those with other disabilities, as reported by their parents [22]. Sensory sensitivities in children with ASD may be one factor that hinders the ability to accomplish tooth brushing in an effective manner. Parents reported that children with ASD showed aversion to the taste of toothpaste and disliked the feeling of the toothbrush in their mouth [22]. Strategies that would modify the sensory environment may enhance effective oral care in children with ASD. One study reported that visual pedagogy could be a suitable way to teach children with autism how to brush their teeth and to help the parents to maintain good oral hygiene in their children [23]. The authors of the study therefore assumed that if proper tooth brushing habits are established at home, the clinical situations would be more easily accepted [23]. Similarly, the use of visual supports has shown to be

able to facilitate children with ASD to undergo dental treatments [24]. Another study also proved that sensory adapted dental environment decreased anxiety and discomfort for children with ASD compared to regular dental environment [25].

Dental care of children with ASD requires adequate training, in-depth understanding of the background of the autism and available behavioural guidance theories [21]. Nevertheless, protective stabilization, sedation and general anaesthesia are often required in ASD children to undergo dental treatment [13, 26, 27].

The aims of this study were to (1) investigate the parental perception on difficulties that encounter children and adolescents with ASD related to maintaining oral hygiene and assessing dental care and (2) compare them to those of their typically developing peers. The null hypothesis tested was that there are no significant differences between children and adolescents with ASD in comparison to their typically developing peers in aspects related to oral hygiene habits and dental appointments experience.

## **METHODS**

A 48-item questionnaire was designed for the purpose of the study. The questionnaire consisted of 3 main sections: general information, oral hygiene habits and dental appointments experience. The questionnaire included YES/NO questions, multiple choice questions and space to comment. Concise written information about the study, along with a consent form, were handed to the parents that participated in this study.

### **Groups**

The study group was comprised of parents of children and adolescents with ASD, aged between 4 and 21 years, from three specialized daycare centres in Serbia. The centres were in the capital city of Serbia, Belgrade, and two other smaller cities, Kragujevac and Sabac. An online version of the questionnaire was also available for the parents. Parents of healthy, typically developing children and adolescents, age- and gender- matched to the study group, were asked to fill in the questionnaires. Children of the parents in the control group were patients in seek of dental care service at the Clinic for Pediatric and Preventive Dentistry in Belgrade, Serbia. Informed, written consent was obtained from each study participant. In total 142 questionnaires completed by parents or guardians were reviewed.

### **Statistical analyses**

Ninety-two questionnaires, 46 from each group, were considered valid and were included in the study. Data between study and control group were compared by Chi square test. The level of significance was set at  $p < 0.05$  in all statistical test and SPSS programme for Windows (SPSS, version 24 ) was used.

## RESULTS

### General information

The mean age of participants in the study was 14.8 years. The majority of children in the study group (76%) had a diagnosis of autism, whereas 18% were diagnosed with non specific developmental disorder, and 5% had Asperger syndrome. The ratio of male to female was 4 to 1. Parental education is shown in table 1.

**Table 1. General information – parental education.**

	Study group (%)	Control group (%)
<b>Mother's educational level</b>		
Primary school	5	0
Secondary school	50	50
College	8	21
University	37	29
<b>Father's educational level</b>		
Primary school	5	5
Secondary school	55	50
College	24	10
University	16	35

**Table 2. Oral hygiene habits –YES/NO questions.**

Question	Study group		Control group		p
	YES (%)	NO (%)	YES (%)	NO (%)	
Is oral hygiene difficult for your child?	68	32	13	87	
Does your child dislike a toothbrush?	42	58	8	92	<0.05
Does your child dislike tooth paste taste?	42	58	13	87	

**Table 3. Oral hygiene habits – multiple choice questions.**

	Study group (%)	Control group (%)	p
<b>How often does your child brush teeth?</b>			
Never	10	0	
Once per day	53	18	<0.05
Twice per day	29	58	
More than two times per day	8	24	
<b>Your main source of information regarding oral hygiene is</b>			
Dentist	50	62	
Friends	11	8	
Media	10	3	>0.05
Internet	10	13	
Other	19	14	

found in 68% of patients in the study group, compared to only 13% in the control group. In the study group the majority of patients brush teeth once a day, whereas in control group the frequency of teeth brushing was twice a day (Table 3). Nearly half of the patients in the study group dislike a toothbrush in comparison to only 8% in the control group. Similar difficulties are encountered with the taste of the tooth paste which is a problem for nearly half of the patients in the study group.

### Oral hygiene habits

In this part of the questionnaire significant differences were found between study and control group for all the main aspects of oral hygiene (Table 2). Firstly, general difficulties in oral hygiene were

found in 68% of patients in the study group, compared to only 13% in the control group. In the study group the majority of patients brush teeth once a day, whereas in control group the frequency of teeth brushing was twice a day (Table 3). Nearly half of the patients in the study group dislike a toothbrush in comparison to only 8% in the control group. Similar difficulties are encountered with the taste of the tooth paste which is a problem for nearly half of the patients in the study group.

### Dental appointments experience

Significant differences were found between study and control

**Table 4: Dental appointments experience –YES/NO questions.**

Question	Study group		Control group		P
	YES (%)	NO (%)	YES (%)	NO (%)	
Is your child anxious prior to dental visit?	75	25	16	84	
Is your child cooperable during dental visit?	36	64	100	0	
Does dentist's touch bother your child?	47	53	3	97	
Do you encounter difficulties during "mirror only" check-ups?	61	39	3	97	
Are you always present during dental exam?	100	0	65	35	
Does dental operatory light bother your child?	36	64	16	84	
Does dental handpiece sound bother your child?	89	11	49	51	<0.05
Was active protective stabilization ever used?	75	25	37	63	
Was mouth prop ever used?	31	69	11	89	
Was general anaesthesia ever used for the purpose of dental treatment of your child?	42	58	0	100	
Was dental service ever refused to your child?	38	62	5	95	
Does the smell of dental office bother your child?	19	81	16	84	>0.05

the parents in the control group. The touch of the dentist was a problem for nearly half of the patients in the study group, in comparison to 3% of patients in the control group. Difficulties during the so called "mirror only" check-ups were reported in 61% of patients in the study group whereas in the control group only 3% of parents reported such a problem. The sound of the dental handpiece and brightness of the operatory light bothered significantly more patients in the study

group. Active protective stabilization (refers to treatment when child is being held by the parent, most commonly sitting in parent's lap) was used significantly more often in patients from the study group. Mouth prop was used in 31% of the patients in the study group, compared to 11% in the control group. General anaesthesia was used for the purpose of dental treatments in almost half of the patients in the study group whereas in the control group in this investigation it was never used. Significantly higher number of patients in the study group than in the control group had the experience of being refused dental services by dental practitioners. The most common reason for refusal was inadequate experience with patients within the autism spectrum (64%), followed by other reasons (28%) and inadequate equipment (7%). The only question related to dental visits for which no difference was found between study and control group was the question about the smell of dental office, to which the parents responded similarly in both groups.

## DISCUSSION

The questionnaire which was used in this study is custom-made and was prepared based on the reported difficulties in maintaining oral hygiene and assessing dental care encountered by children with ASD found in the currently available literature, as well as some problems reported by their parents or guardians throughout previous conversations. Upon an explanation of the research objectives offered by one of the investigators, questionnaires were distributed to the parents in the

control group during children's dental appointment. Parents were asked to fill in a questionnaire at their homes. The questionnaires were obtained during the next dental visit, thus eliminating any potential influence that the investigators might have had on the parents' answers. All parents who were asked to participate in the research were willing to complete the questionnaire, and no refusal was noted in any of the groups.

Significant differences were found between children and adolescents with ASD in comparison to their typically developing peers in aspects related to oral hygiene habits and dental appointments experience, which led to the rejection of the null hypothesis.

The male-to-female ratio observed in this study was 4:1, which is in agreement with previous studies [22]. However, the most recent systematic review on ASD gender distribution suggested that, in fact, true male-to-female ratio is closer to 3:1, thus meaning that females are at disproportionate risk of not receiving a clinical diagnosis [28]. Regardless minor disagreements on the exact ASD gender ratio found in the literature, the results of this study demonstrate higher ASD prevalence among males and therefore confirm the theory of gender-specific ASD epidemiology.

The results of this study are generally in line with the results of previous studies, where significant differences were found in the similar categories, such as general difficulties, tooth brushing frequency, anxiety, uncooperative behaviour, use of general anaesthesia, refusal of dental treatment by dental practitioners and sensory difficulties to touch, taste and light [29]. The questionnaire used in this research provided a thorough insight into the most common obstacles and revealed that even dentist's touch itself represents a problem for a child with ASD. Sensory difficulties with toothbrush, dentist's touch, taste of tooth paste and operatory light may be explained by Sensory Processing Disorder that many people with ASD experience. Sensory processing disorder involves unusual sensitivities to sounds, sights, touch, taste and smells [30]. This recent study has shown that children with ASD have greater prevalence of sensory over-responsivity across all sensory domains. Further more, since not all children with ASD have pronounced sensory difficulties, it was shown that indeed greater prevalence of oral care difficulties at home and in dental office is found in children with ASD characterized as "sensory over responders" vs "sensory not over responders" [30].

When investigating children's access to professional oral care, a significant difference had been noted in number of refused dental treatments between the two groups, with study group experiencing more challenges in finding an adequate dental practice. The most common reason for refusal stated by dentists was: "lack of experience with patients within the autism spectrum" (64%), followed by "other reasons" (28%) and "inadequate equipment" (7%). These results are consistent with ones available in the literature [22], and additionally emphasize parent's difficulties in an attempt to locate and access dental practitioners willing and trained to treat their children.

In another recent study [20], parents of children with ASD responded positively about some of the proposed potential strategies for improving children's dental attendance and compliance, such as: 1) the inclusion of photographs of the dental clinic and staff, for the child to see before dental visit; 2)

the inclusion of a social story about the dental visit with the child's initial appointment; 3) the inclusion of a symbol strip about the dental visit with the child's initial appointment; 4) allowing the parent to take a photograph of the child in the dental waiting room or on the dental chair.

These strategies may be of interest for future research that will aim to improve general dental experience of children with ASD. Enhanced knowledge, understanding and empathy could encourage dentists to strive to build individual solutions within this growing population of patients. Furthermore, a modified version of the questionnaire designed by the authors of this study can be used in investigating oral health care difficulties which can be found in all patients with special needs. Findings from these studies can help clinicians in providing improved and more quality dental care for these groups of patients in the future. For future research, standardizing the design of questionnaires, especially part that refers to dental visits, is advisable since it can lead to the creation of a reliable clinical guide for all patients with special needs. Along with printed forms, providing an online version of questionnaires, similar to the one used in this study, is also desirable. In this way data from registered patients with special needs who, for various reasons do not show for regular dental appointments, can easily be collected and analysed.

## CONCLUSION

Children and adolescents with ASD face significantly more difficulties concerning everyday oral hygiene and dental appointments in comparison to their typically developing peers. Dentists' awareness of issues that are specific to this population of patients is important in order to enable quality dental care.

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