

## ORIGINAL ARTICLE / ОРИГИНАЛНИ РАД

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

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**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 at the Clinic for Pediatric and Preventive Dentistry in Belgrade, Serbia. Ninety-two questionnaires were considered and statistically analyzed in the SPSS program, using  $\chi^2$  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 the 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

**INTRODUCTION**

Autism spectrum disorder (ASD) refers to a wide spectrum of heterogeneous neurodevelopmental disorders, characterized by impairments in two behavioural domains: 1) social communication and 2) restricted and repetitive patterns of behaviour, interests, and activities [1, 2]. The etiology 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 have been analyzed and compared to those of the healthy child population in a recent review [5]. The vast majority of the studies reported poorer oral hygiene, worse gingival conditions and significantly worse periodontal status with higher periodontal treatment needs in children with ASD in comparison to healthy children [6–11]. Although children with ASD

are also regarded as a 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 and higher DMFT score than the healthy control group [6, 8]. 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 and periodontal disease in children and young adults with ASD can still be considered high [15, 16]. 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

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the lack of cooperation by the child, as well as behaviour liable to change without warning [17, 19, 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 healthcare needs [17, 18]. Among many other perceived problems, parents reported difficulties in travelling to dental surgery, the cost of dental treatment, and the lack of insurance [19, 20].

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 for 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 parents to maintain good oral hygiene in their children [23]. The authors of the study therefore assumed that if proper tooth brushing habits were established at home, the clinical situations would be more easily accepted [23]. Similarly, the use of visual aids 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 the 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 anesthesia 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 of difficulties related to maintaining oral hygiene and assessing dental care that children and adolescents with ASD encounter 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 three 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 and a consent form were handed to the parents that participated in this study.

## Groups

The study group comprised parents of children and adolescents with ASD, aged between four and 21 years, from three specialized daycare centers in Serbia. The centers were in the capital city of Serbia, Belgrade, and two other smaller cities, Kragujevac and Šabac. An online version of the questionnaire was also available for the parents. The parents of healthy, typically developing children and adolescents, age- and gender-matched to the study group, were asked to fill out 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 the study and the control group were compared by the  $\chi^2$  test. The level of significance was set at  $p < 0.05$  in all statistical tests and IBM SPSS Statistics for Windows, Version 24.0 (IBM Corp., Armonk, NY, USA) 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

Educational level	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

### Oral hygiene habits

In this part of the questionnaire, significant differences were found between study and control group for all the

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

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

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

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

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 the control group the frequency of teeth brushing was twice a day (Table 3). Nearly half of the patients in the study group dislike the toothbrush in comparison to only 8% in the control group. Similar difficulties are encountered with the taste of toothpaste, which is a problem for nearly half of the patients in the study group.

### Dental appointments experience

Significant differences were found between the study and the control group for the majority of questions related to dental appointments experience (Table 4). The anxiety prior to dental visit was almost five times more frequent in

the study group. When asked about child's cooperativeness, only one third of parents in the study group responded positively, in comparison to all the parents in the control group. Physical contact with the dentist was a problem for nearly half of the patients in the study group, in comparison to 3% of the 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 only 3% of the parents in the control group 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 the 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 anesthesia was used for the purpose of dental treatments in almost half of the patients in the study group, whereas it was never used in the control group in this investigation. 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 the study and the control group was the question about the smell of the 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

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

Question	Study group		Control group		Statistical significance
	YES (%)	NO (%)	YES (%)	NO (%)	
Is your child anxious prior to dental visit?	75	25	16	84	p < 0.05
Is your child cooperative during dental visit?	36	64	100	0	
Does the physical contact with the dentist 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	
Was active protective stabilization ever used?	75	25	37	63	
Was mouth prop ever used?	31	69	11	89	
Was general anesthesia 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	p > 0.05

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 of 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 anesthesia, 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 toothpaste, 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. Furthermore, 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 the 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 the number of refused dental treatments between the two groups, with the study group experiencing more challenges in finding an adequate dental practice. The most common reason for refusal stated by dentists was the "lack of experience with patients within the autism spectrum" (64%), followed by

"other reasons" (28%) and "inadequate equipment" (7%). These results are consistent with those available in the literature, and additionally emphasize parent's difficulties in an attempt to locate and access dental practitioners willing and trained to treat their children [22].

1. In another recent study [20], parents of children with ASD responded positively to some of the proposed potential strategies for improving children's dental attendance and compliance, such as: 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 healthcare difficulties that can be found in all patients with special needs. Findings from these studies can help clinicians in providing improved dental care for these groups of patients in the future. For future research, standardizing the design of questionnaires, especially the 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 up for regular dental appointments, can easily be collected, and analyzed.

## 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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## Тешкоће у одржавању оралног здравља код деце и адолесцената са поремећајима из аутистичног спектра – опажања родитеља

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### САЖЕТАК

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

Циљ рада је био 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 програму SPSS.

**Резултати** Статистички значајне разлике између деце и адолесцената са ПАС и њихових типично развијених вршњака утврђене су у следећим категоријама: тешкоће у свако-

дневној 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