

Analysis of Oral Health Care Delivery in Patients with Autism

SUMMARY

Background/Aim: Autism spectrum disorder (ASD) is pervasive neurodevelopmental condition with raising prevalence over the last decades. Oral health related problems arise mostly due to challenging behavior, communication limitation, and resistance to receiving dental treatment. The aim of this retrospective study was to investigate the frequency, quality and type of dental care during routine appointments and under general anesthesia (GA) in persons with ASD. **Matreial and Methods:** The data were obtained in retrospective cross-sectional study by analyzing patients' records from the central electronic database of the Clinic for Dentistry of Vojvodina. Demographic, medical and dental data were analyzed employing Mann Whitney U test, Kruskal Wallis test and CATREG regression analysis. **Results:** A total of 51 patients from 4.2- 47.6 years of age had an average of 13.2 ± 13.5 dental appointments, with 2.27 ± 4.23 treatments done under GA in a period of 7 years. The average number of restored teeth was 3.64 ± 4.42 and 4.64 ± 5.95 teeth were extracted. Only 21.5% of participants regularly attended scheduled appointments. Patients who started oral health care earlier had more teeth restored and extracted during RDT, and were less subjected to treatment under GA. **Conclusions:** Dental services to patients with ASD are commonly limited to more radical approach comprising multiple teeth extractions and repeated treatment under GA. It is of utmost importance to tailor comprehensive plan for dental care provision in individuals with ASD at earliest possible age.

Keywords: Autism, Behavior, Communication, Oral Health

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Introduction

Autism belongs to a group of developmental, neuropsychiatric disorders, firstly described by Kanner in 1943., which are characterized as difficulties in social communication and interaction, restricted interests and repetitive behaviors¹. The Centers for Disease Control and Prevention estimates that 1 in 68 children is affected by autism spectrum disorder (ASD). The steady increase in the number of children with ASD has been reported worldwide without definite answer whether it is an actual dramatic increase in incidence of this disorder, or the consequence of broader and more vigilant diagnostic procedures^{2,3}. The majority of dentists treating children will

encounter patients with autism on a daily basis. However, due to the difficulties in communication, examination and treatment, only a few dentists will commit to provision of dental care to such patients⁴. Dental appointments are poorly tolerated and perceived as stressful, although some researchers have found that children with autism have less caries than their peers⁵⁻⁷. Anxiety in an unfamiliar environment, common for individuals with ASD, can aggravate agitation and provoke violent behavior in the dental office. All of these factors get in the way of adequate provision of dental care for a child with autism⁸⁻¹¹. Dental care for patients with ASD is full of challenges and controversies³. One of the reasons is that dentists are not always familiar with the ways of treating patients with autism, although, all preventive dental measures and forms of treatment

in cooperative patients can be carried out on regular basis⁵. In order to provide persons with ASD with adequate dental care, dental management is crucial¹². Good communication with both, patient and parent/caregiver are vital in gaining mutual trust and achieving progress in treatment¹³. Research shows that anxiety of patients with autism related to dental appointment is the main reason for incomplete and unsuccessful treatment¹⁴. Dental professionals are faced with lack of time for the implementation of techniques aiming to increase adaptation of children with ASD to dental setting, and consequently improve their cooperation¹⁵. For that reason, patients with ASD are usually referred to the specialist or public health care institutions. Long waiting time for the appointment, lack of education or motivation of parents/caregivers, frequent need for commuting to specialized institution, long waiting time in a waiting room and lack of commitment are objective problems that result in poor dental management¹⁶. As a result, most patients with ASD come to dentists due to the present dental emergencies and neglected oral health¹². Economic, cultural, language, and physical barriers further inhibit patients to accept dental treatment. A higher pain threshold in patients with autism and difficult behavior lead to the infrequent dental appointments focused to alleviation of acute pain and dental emergencies' treatment¹⁷. At that point, no time for patient-centered individualized approach and pursuit to patient cooperation is in place, and required invasive procedures additionally upset the patient, becoming a trigger for potentially aggressive behavior and self-injury¹⁸. Uncooperative behavior and the extent of oral diseases in patients with ASD, due to poor hygiene and eating habits, influence the decision to perform dental treatment under general anesthesia (GA)¹⁹.

Currently, no established protocol for provision of dental care in persons with autism has been proposed²⁰. Dental interventions including preventive, conservative and surgical treatment could be done during routine dental appointments when patient is conscious or sedated, or under GA in hospital setting. GA provides more comfortable setting for both, dental practitioner and patient, but carries substantially higher medical risk compared to routine dental treatment (RDT) using local anesthesia for pain control^{21,22}. It is up to the dental practitioner to decide the best treatment approach for every patient with ASD. The unpredictable behavior and challenging communication with patient, motivation of parent/caregiver to acquire and maintain the best possible level of home dental care, and regular check-ups for the person with autism, access and availability of dental professionals trained for desensitizing techniques are all important parameters in making the decisions of future dental interventions.

The majority of studies published results which are in regards to assessment of oral health, problems associated with the provision of dental care, and epidemiological profile of persons with autism. However, not much is investigated on the outcomes of dental care in persons with ASD. In order to fully understand the effectiveness of dental management of patients with ASD it is essential to provide information on outcomes of different treatment approaches available in clinical practice.

The objective of the present investigation was to report the frequency, quality and types of dental treatments done during routine appointments and under GA in persons with ASD.

Material and Methods

Study design

This retrospective cross-sectional study included 51 patients with ASD treated at the Clinic for Dentistry of Vojvodina during the period 2012-2019. The research was conducted in a complete agreement with the ethical standards and laws applicable in Serbia. The study protocol was approved by the Research Ethical Committee of the Dentistry Clinic of Vojvodina in Novi Sad, Serbia and was in accordance with the World Medical Association's Declaration of Helsinki. In addition, the clinical observation study was approved and registered on the Clin.Trials.gov portal (Oral Health Care and Autism Spectrum Disorder (CREASED) NCT03830541).

Data collection methods

Data were obtained by analysis of medical documentation, dental charts, specialist reports and electronic records from the central electronic database of the Dentistry Clinic of Vojvodina. Patients were diagnosed with ASD by an autism specialist, and were treated at the Clinic for Dentistry of Vojvodina. Signed consent was obtained for every dental procedure from patient/parents/caregiver. In compliance with data privacy protection regulations, all personal identification information was deleted. The following data were collected: date of birth, date of dental treatment(s), age of the patient on the first dental appointment, gender, living arrangements, medical diagnoses, underlying medical conditions, frequency of dental visits, procedures that were conducted under GA and during RDT, total number of extracted and restored teeth (both under GA and during RDT), and the number of emergency visits. Responses regarding living arrangements were classified into two categories: institutionalized persons and those who live with their families. Underlying medical conditions were evaluated as follows: group N- comprised of persons with isolated ASD, while patients with autism and one or more systemic diseases, allergies and/or other chronic medical conditions were included in the group M. For the purpose of analysis, patients were divided into 2 groups based on appointment adherence: regular attenders who visited dentist in less than 6 months period, and irregular attenders. Based on the clinical settings in which the procedures were provided, patients were distinguished as ones who were treated in dental office only (rang 1), both, in dental office and under GA (rang 2), and only under GA (rang 3).

Data analysis

Within the descriptive statistics, the data were presented in the form of mean values, standard deviation and median. To evaluate how far data were from normality, Kolmogorov-Smirnov (KS) test was used. At the level of inferential statistics, due to disturbed distribution normality, the significance of the difference between the examined research groups was tested by the Mann-Whitney U-test and Kruskal Wallis test. The correlation of the examined parameters was determined by Spearman's rank correlation coefficient, since the distributions of values on the variables significantly deviated from the normal distribution. Since most of the explanatory variables used in this analysis were non-numeric variables, we employed the categorical regression analysis with optimal scaling technique otherwise regarded as CATREG. It is a special variant of regression, which

is useful when there is a combination of nominal, ordinal, and interval-level independent variables. It does not rely on the strict assumptions associated with multiple regression and specifically allows the inclusion of ordinal or multi-categorical data. The Statistical Package for Social Sciences (SPSS 20.0) was used for all statistical calculations (SPSS nc., Chicago, IL, USA). Some analyses were completed using Jamovi software (version 0.9.2.8).

Results

A total of 51 patients aged 4.2-47.6 (11.2±8.00) years had an average of 13.2±13.5 (4-47 years) dental appointments, with 2.27±4.23 treatments done under GA during the observation period of 7 years.

Table 1. Descriptive data analysis

	Minimum	Maximum	Mean	Std. Deviation	Median	Shapiro-Wilk p
Age	9.30	46.90	18.34	8.47	16.20	<.001
Age at first visit	3.0	40.80	11.19	8.00	8.20	<.001
N of visits	1	58.00	13.18	13.48	9	<.001
N of GA	0	5.00	0.72	1.03	0.00	<.001
N of RDT	0	70.00	9.02	13.46	4.50	<.001
Emergencies	0	29.00	3.74	3.00	4.52	<.001
Restored GA	0.0	22.0	1.44	3.88	0.00	<.001
Extracted GA	0.0	14.0	2.36	3.53	0.00	<.001
Restored RDT	0.0	25.0	2.43	4.24	1	<.001
Extracted RDT	0.0	9.0	1.39	2.06	0.00	<.001
Total restored	0	25	3.84	5.40	2	<.001
Total extracted	0	18	3.70	4.00	2	<.001
Follow up	0.0	10.20	4.58	2.80	4.80	<.001

Table 2. Investigated variables in relation to type of treatment and the presence of underlying medical conditions

	Rang	Number of visits	Number of GA	Restored GA	Extracted GA	Restored RDT	Total restored	Total extracted	Extracted RDT
N	1	29	29	29	29	29	29	29	29
	2	9	9	9	9	9	9	9	9
	3	13	13	13	13	13	13	13	13
Mean	1	15.75	15.75	0.00	0.00	3.34	3.44	1.75	1.68
	2	14.44	14.44	1.66	5.66	2.77	5.33	7.88	2.22
	3	6.53	6.53	1.53	5.00	0.00	3.69	5.15	0.00
Median	1	12	12	0.0	0.00	2	2	1	1
	2	13	13	2.00	6	2	5	7	1
	3	4	4	1.00	4	0	1	4	0
Standard deviation	1	13.99	13.99	0.00	0.00	5.13	5.09	1.99	1.98
	2	14.95	14.95	0.70	3.00	2.86	3.53	5.01	2.99
	3	9.25	9.25	1.19	4.06	0.00	7.11	4.01	0.00

The average number of restored teeth during the RDT was 3.64±4.42 and 4.64±5.95 teeth were extracted. Twenty-nine (56.8%) of all patients were treated using RDT, 13 (25.4%) were exclusively treated under GA, while for 9 (17.8%) participants, the treatment was provided using the combination of 2 methods. When it comes to the attendance, 11 (21.5%) participants regularly attended scheduled appointments, while 40 (78.5%) respondents were classified as irregular attendants. The type of interventions was analyzed with respect to the type of provided treatment and presented in Table 2, as well as in regards to the presence of underlying systemic condition (graph 1). Kruskal Wallis analysis regarding three different treatment groups revealed significant differences with respect to the following variables: age, number of visits and total number of extracted

teeth ($p < 0.05$). Additional post hoc Dwass-Steel-Critchlow-Fligner pairwise comparisons showed that patients that had interventions during RDT only were significantly younger compared to the patients treated under GA only. Patients from rang 1 had more dental visits than patients from rang 3, while the total number of restored teeth was significantly higher in rang 1 than in rang 2. In addition, the total number of extracted teeth was lower in rang 1 compared to rang 2 and 3.

Analysis according to gender revealed that there was no statistically significant difference in values of observed parameters (Mann Whitney U test, $p < 0.05$). Similarly, there was no statistically significant difference in values of observed parameters according to the presence of underlying medical conditions.

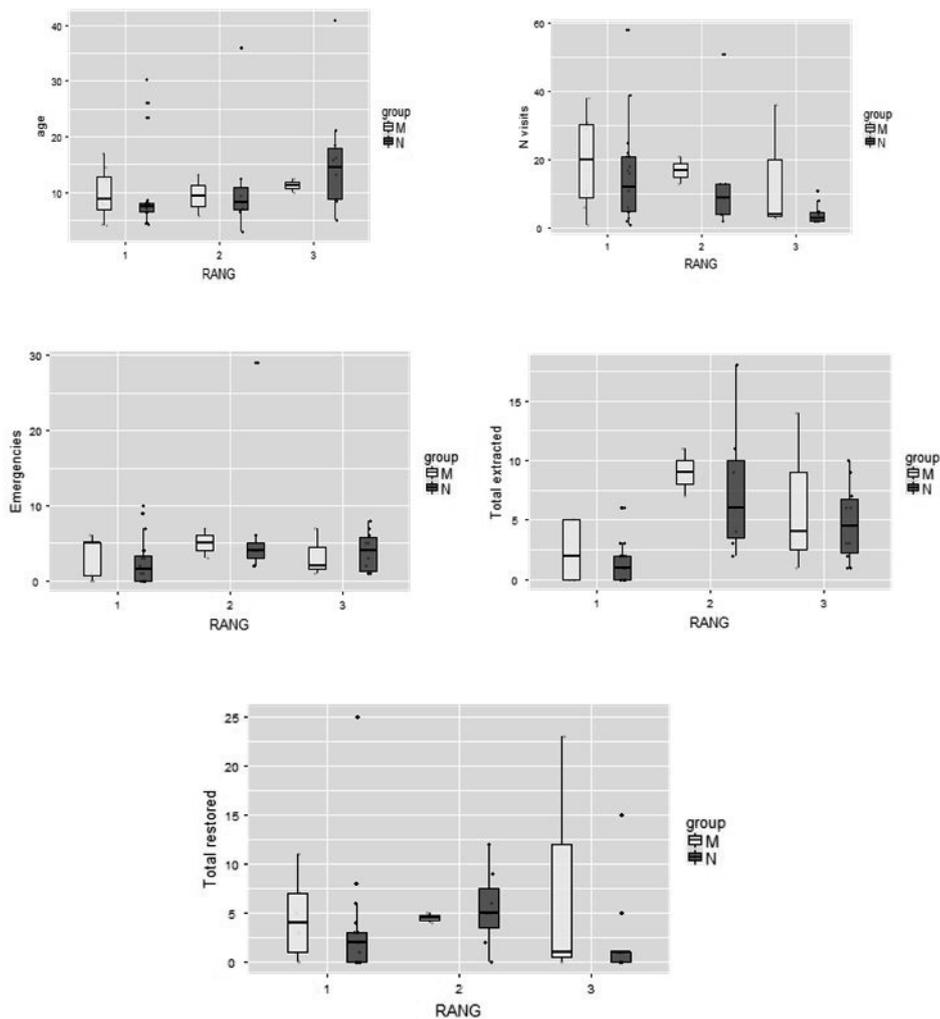


Figure 1. Age, number of dental visits, number of dental emergencies, sum of extracted teeth and sum of restored teeth in relation to type of treatment and the presence of underlying medical conditions

Table 3. Correlation analysis

		N of GA	Restored GA	Extracted GA	Restored RDT	Extracted RDT
Age	Correlation Coefficient	.243	.122	.243	-.196	-.324*
	Sig. (2-tailed)	.089	.397	.089	.168	.020
Age at the first visit	Correlation Coefficient	.284*	.212	.302*	-.358**	-.493**
	Sig. (2-tailed)	.046	.140	.033	.010	.000
Number of visits	Correlation Coefficient	-.203	-.051	-.149	.753**	.608**
	Sig. (2-tailed)	.158	.725	.302	.000	.000
Emergencies	Correlation Coefficient	.376**	.433**	.414**	.325*	.399**
	Sig. (2-tailed)	.007	.002	.003	.021	.004

The three categorical regression analyses were performed between the number of restored and extracted teeth under GA, extracted and restored teeth during RDT, as the dependent variables, and gender, medical conditions, attendance and age at first visit, as independent variables.

The first regression model with extracted teeth under GA, as the dependent variable, was not statistically significant, $F(4, 45) = 1.10, p = .367$, with $R^2 = .089$. The second regression model with extracted teeth during RDT, as the dependent variable, was statistically significant, $F(4, 46) = 2.76, p = .039$,

with $R^2 = .193$. The only statistically significant predictor for the number of extracted teeth during RDT was the age of the patient at the time of the first visit (with a negative sign). The size and direction of the relationships suggest that more restored and extracted teeth during RDT in comparison to restored and extracted teeth under GA were found in patients who had their first dental visits at earlier age.

The third regression model with restored teeth during RDT, as the dependent variable, was statistically significant, $F(4, 46) = 2.40$, $p = .044$, with $R^2 = .188$. The statistically significant predictors for the number of restored teeth during RDT and gender implied that females had more teeth restored than males.

Table 4. CATREG regression with extracted teeth in general anesthesia as dependent variable

Variables	Standardized coefficients			Significance (p-value)
	Beta	Std. error	F-value	
Age at the first visit	.301	.144	4.380	.042
Gender	.128	.112	1.317	.257
Underlying medical condition	.001	.098	.000	.992
Attendance	.010	.088	.014	.906

Table 5. CATREG regression with extracted teeth during RDT as dependent variable

Variables	Standardized coefficients			Significance (p-value)
	Beta	Std. error	F-value	
Age at the first visit	-.441	.106	17.188	.000
Gender	.209	.130	2.596	.114
Underlying medical condition	.094	.095	.979	.328
Attendance	.069	.080	.753	.390

Table 6. CATREG regression with restored teeth during RDT as dependent variable

Variables	Standardized coefficients			Significance (p-value)
	Beta	Std. error	F-value	
Age at the first visit	-.331	.143	5.342	.025
Gender	.302	.150	4.053	.050
Underlying medical condition	.223	.115	3.759	.059
Attendance	.007	.073	.010	.920

Discussion

The present study aimed to systematically identify the pattern of dental management and treatment approaches for provision of dental care in persons with ASD. The findings

from the present investigation go in line with poor oral health, extensive tooth loss and frequent use of GA in persons with autism. Education of dental professionals for implementation of desensitization techniques in order to overcome challenging behavior of children with ASD during dental treatment, and establishment of family/caregiver involvement are foundation for individualized and successful dental treatment. However, everyday challenges of dental practice, staff shortage, lack of time for increasing confidence and adaptation of children with ASD, low adherence to both, oral hygiene regimen at home and appointments for preventive procedures, proved to be a major set-back in providing these children with the best possible treatment approach. Dental professionals cope with the limitations and barriers for the implementation of preventive measures and adequate dental treatment in persons with autism such as: patient-related behavioral factors, anxiety and refusal of treatment; underlying medical conditions, frequent allergies and specific hygiene and diet regimens; and finally, the many controversies surrounding dental materials and techniques that make parents completely distrustful of modern medicine^{3,23}.

Autistic spectrum disorder does not itself affect the oral health of children, although more prevalent bruxism and significantly lower salivary pH was found in these patients²⁴. The occurrence of oral diseases in children with autism has been the subject of numerous clinical studies, without definite conclusion. Results of investigations suggest that the number of decayed, missing and filled permanent teeth (DMFT index) in children with autism is higher than in neurotypical peers²⁵⁻²⁹. However, opposite results are, also, present in the literature⁶. Results of the present study showed that children with ASD had high values of DMFT index, according to the available data on the type of dental interventions, number of tooth restorations and tooth extractions, both under GA and during RDT. The calculation of DMFT index in the present investigation was not done directly. Instead, previously extracted and restored teeth were not included, only the total average number of restored and extracted teeth. That way, overall DMFT index could be considered either as estimated or underestimated. DMFT index was found to be at least four times higher compared to the mean DMFT of 1.6+0.64 reported by Jaber²⁹. Even though, the caries experience in ASD persons without intellectual disabilities was similar in comparison to general population, a higher risk for poor oral health was identified, as a consequence of decreased salivary flow rate and missing or unsuccessful dental appointments²⁶. In addition, the review of 86 studies evaluating oral health in persons with autism pointed to the fact that prevalence of dental caries and periodontal disease in children and young adults with ASD can be considered as high, suggesting the urgent need for oral health policies focused on these individuals²⁷. The results from the present investigation can corroborate these findings, particularly with respect to the significant tooth loss, missed appointments and frequent use of GA for dental treatment.

Mc Kinney and associates came to the conclusion that 15% of children with ASD in America, did not have their dental needs met, compared to 6% of children facing the same problem⁸. Also, children with autism who are either intellectually disabled, or who have major difficulties with communication, behavior or body functions are more predisposed to get incomplete dental treatment in comparison to autistic children with different types of disabilities⁸. A significant correlation was found between the age of the patient with ASD at the first appointment, and the

number of extracted teeth. Less teeth extractions were found in children who started preventive dental treatment early, as preschoolers, in comparison to children who started treatment later. The ones with more emergency visits were found to have more teeth extracted, which is in complete agreement with the general trend when emergency dental treatment needs to be performed under GA³⁰.

Overwhelming experience of caring for person with ASD usually leads caregivers in the direction of unintentional avoidance of visits to the dental health providers. Consequently, they seek help, predominantly, in the situations of emergency and acute pain, neglecting oral health and routine dental appointments²³.

Addressing limitations of both, caregivers and persons with ASD, is essential in the process of improving the quality of care for these patients and promoting patient-centered individual oral health programs³¹⁻³⁴. Creation of good communication with child and parents/caregivers at early age leads to better compliance, adherence to regular preventive and conservative dental procedures with less teeth extractions. Difficulties in dental care management could be overcome if parents/caregivers were familiar with the nature of their child's condition, realizing that dental treatment was demanding both, for the patient and dentists, and insisting on the RDT at early age. Even though, treatment under GA is more comfortable option for reducing stress of all parties involved, efforts should be made to achieve completion of dental treatment during regular dental appointments. Higher rate of extracted teeth under general anesthesia, reported in the present study, adds to the significance of patient-centered individualized approach, positive reinforcement, and desensitizing techniques for enabling provision of regular dental care in persons with ASD²³.

Dentist are apprehensive in providing regular dental care to patients with ASD, which is supported by the fact that all 51 patients with different spectrum of autism symptoms, included in the present study, were referred to the Clinic for Dentistry due to the incompetence of general dentist to provide dental care to these patients. In addition, postponing and neglecting dental health of patients with ASD, who have underlying medical conditions, were even more pronounced. Findings of the present study indicated the higher number of patients with underlying medical conditions referred to the Clinic and higher number of procedures done under GA due to extensive need for dental treatment and poor compliance. Results were in accordance with the opinion of dentists that they possessed poor knowledge of caring for persons with autism²⁵. Additional and continuing education of general dentists is needed for acquiring better understanding of the techniques for dental managing of persons with ASD¹¹⁻¹⁸. Impaired child and family functioning and significant financial, time and care coordination with general dentists who possess insufficient knowledge to providing dental care for persons with ASD, thus avoiding to treat them, indicate almost unavoidable referral to specialist. These factors contribute to extensive referral of these patients to specialized dental care institutions imposing high medical care burden on society which is in accordance to findings worldwide³⁵. Expenditure for hospitalization and treatment under GA is much higher than multiple visits for RDT. However, shortage of educated dental professionals, need for multiple visits when only desensitizing techniques are employed without actual dental treatment, long waiting lists, and dissatisfaction of parents/caregivers, contribute to increasing number of patients with

indications for dental treatment under GA. Dental professionals caring for patients with ASD are required to provide the elimination of pain and prevent effects of oral diseases in limited time frame under GA. Therefore, indications for tooth extractions are widened and more teeth are extracted than restored under GA in comparison to procedures during RDT. Respectively, limitations of the present study were disclosed. The study was retrospective, analyzing available information from the patients' records. Additional data of interest, such as previously restored and extracted teeth, were not consistently available from patient files. The sample could not be considered representative, rather a convenient one, comprising of patients with ASD who were referred from general and pediatric dentists unable to perform dental treatment. A substantial number of patients with ASD, treated during RDT was omitted from the sample, which might have resulted in the overestimation of unfavorable oral health outcomes in the present study.

Conclusions

High number of patients with ASD in need for dental care was treated under GA. More teeth were extracted than restored under GA in comparison to dental procedures during RDT. Provision of dental care was frequently limited to more radical approach comprising multiple teeth extractions and repeated treatment under GA. It is necessary to initiate appropriate, comprehensive, and accessible medical care services for individuals with ASD at the earliest possible age.

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