

# Dental Services Use and Barriers to Dental Care for Individuals with Autism Spectrum Disorder in Jordan: Case-Control Study

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## Research article

**Keywords:** Oral health, dental care, dental access, dental service use, Autism Spectrum Disorder (ASD), dental barriers, Jordan

**Posted Date:** August 28th, 2019

**DOI:** <https://doi.org/10.21203/rs.2.13634/v1>

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# Abstract

**Background** Oral health is acknowledged as an integral component of general health and plays an essential role in establishing a desired level of quality of life. Individuals with disabilities are at a higher risk for oral diseases due to underlying congenital anomalies and inability to receive the needed care to maintain oral health. Regular dental care is essential to maintaining optimal oral health. However, to date, there are no studies conducted in Jordan addressing the dental challenges and barriers to oral care faced by individuals with autism. The objectives of this study were to examine the use of dental services for individuals with autism and identify barriers that affect their access to dental care in comparison with healthy individuals in Jordan.

**Methods** A case-control study was conducted. Participants included 296 Caregivers of individuals with autism and healthy developing individuals who completed a self-designed questionnaire that assessed access and barriers to dental services.

**Results** The majority of the participants in the current study in both the control and the ASD groups have visited the dentist within the last year prior to completing the present survey. The main reason for visiting dental services was toothache (43%) while the least was routine checkup (11.6%) with significant difference ( $P < 0.05$ ) between the groups. Barriers like; embarrassment (43.5%), lack of specialized dental staff (28.6%), lack of knowledge of how to treat disabled dental patients (26.6%), and inadequate facilities (34%) were significantly ( $P < 0.05$ ) higher among patients with ASD than the control.

**Conclusion** Knowing and understanding the barriers for accessing dental care might improve overall health for individuals with autism. Furthermore, recognizing the challenges to accessing dental care for this population might help the oral health professionals to minimize these difficulties.

## Background

Disability has been described as any condition (body or mind) with impairments, activity limitations, and participation restrictions<sup>1</sup>. More than one billion, about (15 %), people with disabilities are estimated worldwide<sup>2</sup>. The estimated number of moderate and severe disabled persons in developing countries is 200 million people. The population of the disabled in Jordan is about 250,000 persons<sup>3</sup>. Autism is one example of disability. The American Psychiatric Association, defined autism spectrum disorder (ASD) as a neurodevelopmental disorder characterized by social and communication impairment, restricted interests, and repetitive behaviors<sup>4</sup>. The Diagnostic and Statistical Manual of Mental Disorders (DSM) in 2013 defined ASD as a single disorder after many subtypes of ASD were merged under one definition. ASD is one diagnosis which includes autistic disorder, pervasive developmental disorder-not otherwise specified, and Asperger syndrome<sup>5</sup>. The prevalence of ASD is rising globally. According to the Centers for Disease Control and Prevention CDC, one in 59 children has been identified with ASD<sup>6</sup>. Although, it is estimated that in 2018, the cases of ASD in Jordan is 8,000 people<sup>7</sup>. However, tracking the prevalence of ASD in Jordan poses a challenge due to little research and information available on ASD.

Dental care has been retained as a foremost unmet health care need in children with Special Health Care Needs disabilities<sup>8,9</sup>. In fact, autistic children have greater dental needs compared to individuals without ASD<sup>10</sup>. Individuals with disabilities are more likely to have poorer oral health than individuals without such disabilities<sup>11-13</sup>. Research has shown that individuals with ASD are more likely to have oral health problems than individuals without ASD. A systemic review and meta-analysis have found that autistic children and young adults have a high prevalence of dental caries and periodontal disease<sup>11</sup>. Furthermore, delayed tooth eruption, mouth trauma and injury (biting lips & picking at gingiva), bruxism, non-nutritive chewing (eating object), tongue thrusting, are all oral health problems associated with autistic individuals. The risk for poorer oral health in individuals with ASD might be due to specific medications, certain behaviors, and difficulty in maintaining daily hygiene<sup>13</sup>. For example, hyperactivity, quick frustration, unpredictable body movements, and self-injuries behavior may make regular dental care very challenging for autistic individuals<sup>14</sup>.

Despite previously mentioned factors, ASD individuals might face some challenges and barriers which might limit their access to dental care. Some of the barriers to access dental care has been identified among this population were family income and history of uncooperative behavior in the dental office<sup>15</sup>. Furthermore, inability to find a dentist who has the needed skills or willing to work with these population were reasons for not having routine dental visits for individuals with ASD<sup>15</sup>. Dental care is essential to maintaining optimal oral health. However, to date, there are no studies conducted in Jordan addressing the challenges, and barriers faced by individuals with autism and their caregivers in providing the needed oral care for their children.

Knowing and understanding these barriers might improve overall health and quality of life of individuals with autism. In addition, identifying and determining the challenges to accessing dental care for this population might help the oral health professionals to minimize these obstacles.

Therefore, the objectives of this study are:

1. To analyze the dental service utilization among Jordanian Individuals with autism during the past year compared to healthy individuals.
2. To identify perceived barriers to accessing dental care among Jordanian individuals with ASD in Jordan compared to healthy individuals.

## Methods

A cross-sectional study was conducted for individuals with autism, after the approval of the Institutional Review Board (IRB) of Jordan University of Science and Technology (JUST). A self-designed questionnaire was constructed in English by the authors and then translated into the Arabic language, the official language in Jordan. The content validity of the self-designed questionnaire was established by a panel of applied medical sciences faculty at JUST. The questionnaire was pilot tested using 10 volunteer

parents or caregivers who were asked to answer the questionnaire and provide feedback. Test-retest reliability was achieved by administering the questionnaire twice to the same individuals (n=10).

## **Study Population**

The participants with ASD were recruited from special-care centers/schools associated with ASD in Jordan by using a convenience sample. A list of these centers/schools was obtained from the Ministry of Social Development. The centers and the schools were asked to distribute a questionnaire to the parent/caregiver of their members. A paper format of the questionnaire was made available for the parent/caregiver to answer the questions on the respondent's behalf covered by a letter explaining the study. The cover letter contained information about the purpose of the research, how participation is voluntary, how responses would be anonymous, and the principal investigator contact information.

From August 2018-February 2019, during normal working hours, different special-care centers associated with autism in Jordan; private and public centers were visited. Total of 200 questionnaires were sent to the parents/caregivers of all individuals with autism. One hundred forty-seven parents/caregivers agreed to participate in which the questionnaires were filled and sent back for participation. The questionnaire included questions addressing participant's demographic information, caregiver information, participant's dental service use, and barriers to access to dental care. The same questionnaire forms (n=200) except for a few questions, specific to individuals with ASD, were sent to individuals without ASD from the same regions as a control group.

## **Results**

### **Data Analysis:**

The data was analyzed by the software package, SPSS Version 22, with a 0.05 level of significance. A descriptive analysis of univariate distributions was obtained for each of the 25 questionnaire items. Since not all respondents answered each question, the denominator used to calculate the proportions was the total number of non-missing values.

From the 200 potential respondents for each group, the response rate was 75% for individuals with ASD and healthy individuals. The average age of the participants with ASD and the control was 35 and 23 respectively. The male to female ratio in the study population was comparable between autistic individuals (71%: 29%) and control group (67%: 32%). Also, the educational level shows no significant difference ( $p>0.05$ ). More than 90% of both groups were unmarried. Table 1 demonstrates other demographical items like; distribution of the Autism centers, the severity of disability among the ASD participants, the insurance and the family income.

The results of dental service use indicated that there is no statistically significant difference between the time since the last visit to any dental services between autistic individuals and healthy participants, where the majority last visited the dental clinic less than a year ago, 64%-66% respectively.

with regards to the main reason for the last visit to dental services, results revealed that of the participants with/without ASD, 42.9% and 62.4%, respectively received dental treatment for toothache, this difference was statistically significant ( $P = 0.000$ ). Furthermore, results showed that 15% of the participants with/without ASD have visited the dental clinic for an emergency. The least frequently encountered reason for the last dental visit given by individuals with ASD (11.6%) was routine checkup (Figure 1).

Table 2, identified the common barriers that prevent individuals from accessing and visiting dental services. Common factors as long waiting time, high cost or the absence of any insurance, as well as the inconvenience of working hours for dental clinics, exhibited no significant difference between individuals with ASD compared with the control ( $P > 0.05$ ). Whilst, other barriers like; embarrassment (43.5%), the lack of specialized dental staff (28.6%), lack of knowledge of how to treat disabled dental patients (26.6%), and inadequate facilities (34%) are significantly ( $P < 0.05$ ) higher among patients with ASD than the control.

## Discussion

A similar percentage of participants in the healthy group and ASD group have visited dentists. Almost 2/3 of ASD participants and control subjects visited the dentist within the last year. This was comparable to findings reported in the UK<sup>16</sup> and Saudi Arabia<sup>17</sup> for dentist's visiting pattern by ASD children. However, the current findings do not agree with a previous study<sup>18</sup> that revealed significant differences between the two groups of participants as healthy children significantly visited a dentist more than autistic children.

The findings of the current study reiterate on past literature with regard to the difficulty of ASD patients in accessing professional dental care, and locating dental practitioners willing or qualified enough to provide the necessary dental care to this group of individuals<sup>19-21</sup>. Majority of general practitioners reported previously their unwillingness to treat patients with autism<sup>22</sup>. In the current study, about 27% of dentists reported lack of adequate knowledge to manage autistic patients. This is consistent with a past parental survey in which dentist rejection to treat ASD patients was attributed to dental education where 58% of dentists reported inadequacy of their training to treat children with autism<sup>20</sup>. This explanation is supported by similar findings where specialized pediatric dentists were reported to treat more autistic individuals compared to general practitioners which can be related to receiving more specialized didactic and clinical training in the management of special need patients<sup>22</sup>. General practitioners have also expressed their willingness to treat individuals with autism provided they received more training in special oral health care needs<sup>23</sup>. The current study findings supported the notion that the shortage of specialized dentist like pediatric dentists was amongst the barrier to accessing proper oral health care. A significantly larger number of ASD participant cited this as a potential barrier compared to healthy control participants.

The common uncooperative behavior was also considered as one important reason for the unwillingness of dentists to treat ASD patients and presents an obstacle to access appropriate oral health care facilities<sup>24</sup>. Our study demonstrated that fear from dental treatment and feeling of embarrassment were amongst the significant barriers towards seeking dental care. This can be explained by the exaggerated sensory sensitivities of autistic patients, lack of psychological or emotional maturity, and their socially aversive nature. Furthermore, ASD participants reported that non-spacious dental office was deterrent to accommodating dental treatment. The uniqueness of autistic patients justifies adopting individualized measures to make dental office more comfortable environment to this group of special need population.

In the view of increasing access to oral care of autistic individuals, it is worth to utilize the least traumatic environment to accommodate the unique sensory and behavioral aberrations of this population. Multiple and simultaneous strategies, including visual, auditory, tactile and video goggles, are advocated to overcome difficulties in communication, social interactions, anxiety and sensory adaptation with dental office environment during providing dental care for ASD patients<sup>25-27</sup>. Adaptation strategies in dental environment proved efficacious in decreasing the negative reactions of ASD patients<sup>26</sup>. These measures may reduce the need to resort to more advanced techniques of behavioral management like protective stabilization and general anesthesia.

Economic restrictions did not appear to pose a significant barrier to access dental treatment. Both groups reported their financial abilities to cover treatment costs. This is probably due to the fact that both groups did not differ significantly with regard to having insurance coverage. Needless to say that most children and especially children with special needs have medical insurance in Jordan. This also can partially explain the non-significant differences between autistic and healthy participants with regard to visiting a dentist.

The ASD participants' caregivers perceived "dental office is too far away" and "inaccessible parking areas" as significantly important factors that may challenge their accessibility to dental care. These difficulties may be attributed to the awareness of ASD participants and their families to their pressing need for a specialized dentist who can provide professional special care, which may possibly involve increased travel time and other related difficulties<sup>18</sup>.

The above-discussed barriers to access to dental care patients especially ASD patients may raise the need to adopt measures that facilitate the access of this group of people to an appropriate oral health care facility. This enlightens the need to increase the number of specialized dentists in special need oral health to provide the needed professional dental treatment and education for autistic children. The increased awareness of ASD participants about the need for a qualified dentist is emphasized by the findings of the current study. Thus, more professional training is required for dentists at the predoctoral and postdoctoral level. Furthermore, dentists should be educated to introduce adaptation methods into their practice to meet the needs of this special need group of people. Special practical guidelines should be disseminated to further educate dentists working with autistic patients. ASD children and their families

should also receive appropriate education in special need oral health care to be prepared for dental appointments.

Web-based networks dedicated to dental care of autistic children can be valuable in helping families locating the dental offices that provide qualified dental treatment to individuals with ASD. These networks can be informative and supportive to this special need population and increase the awareness and prepare ASD children to receive dental treatment more positively.

Several limitations in this should be noted. The current study investigated the ASD group was formed on the basis of registration in special care centers, so those who are not could not be investigated. In addition, this study is based on information collected by self-reported questionnaires, where it is difficult to confirm the trueness of the reported information from any other sources.

## **Conclusion**

The current study helps to identified and understand the important challenges and barriers to oral health care for individuals with autism in Jordan.

## **Abbreviations**

ASD: autism spectrum disorder (ASD).

DSM: Diagnostic and Statistical Manual of Mental Disorders

JUST: Jordan University of Science and Technology

## **Declarations**

### **Ethics approval and consent to participate**

Our research was conducted in full accordance with the World Medical Association Declaration of Helsinki. The study protocol was approved by the Jordan University of Science and Technology (JUST) Institutional Review Board (Reference: 2017/0032). The data was anonymized and de-identified prior to analysis. All data was reported in group form. The completion and returning of the questionnaire was a proxy of consent to participate in the study.

The submitted manuscript has been read and approved by all authors. The requirements for authorship have been met and the submitted manuscript represents honest work. We confirm that this work is original and has not been published elsewhere, nor is it currently under consideration for publication elsewhere.

### **Consent for publication**

Not applicable.

### **Availability of the data and materials**

The data analyzed during this study are included in this published paper. The dataset is available from the the corresponding author upon reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

### **Funding**

This study was funded by the Jordan University of Science and Technology

### **Authors' contributions**

SA Conceptualized and designed the study, reviewed the literature, analysed the data, interpreted the results and wrote the original draft and approved the manuscript. IA contributed to study conception, study design, literature review, data analysis and manuscript writing and approval. WA: contributed to the study idea, data collection manuscript writing and approval.

### **Acknowledgments**

No acknowledgments

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## Tables

Table 1: Socio-demographic characteristics of participants with ASD and control group

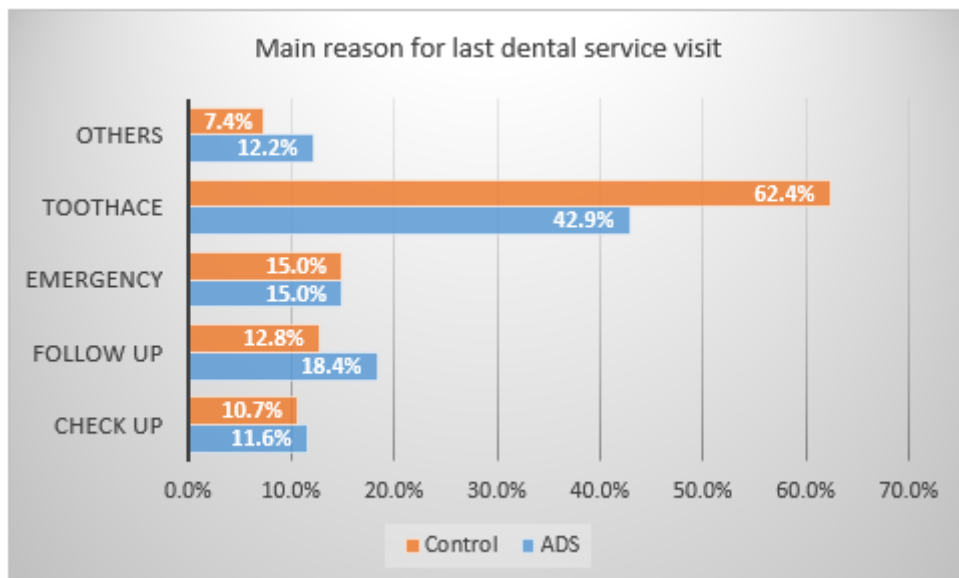
Characteristics		Autistic		Control	
Family Income (JD)					
	<250	74	74(50.3%)	2	2(1.3%)
	250-500	58	58(39.5%)	70	70(47.0%)
	500-1000	14	14(9.5%)	64	64(43.0%)
	>1000	1	1(0.7%)	13	13(8.7%)
Insurance					
	Yes	109	(74.1%)	100	(67.1%)
	No	38	(25.9%)	49	(32.9%)
Disability Centerregion					
	Amman	118	(80.3%)	55	(36.9%)
	North	25	(17.0%)	68	(45.6%)
	South	4	(2.7%)	26	(17.4%)
Severity of disability					
	None	0	(0%)	149	(100%)
	Mild	41	(27.9%)	0	(0%)
	Moderate	65	(44.2%)	0	(0%)
	Severe	41	(27.9%)	0	(0%)

Table 2: Barriers to dental care among participants with ASD and control group.

Barrier	ASD N (%)	Control N (%)	P-value
Could not afford the cost	64(43.5)	57(38.3)	.058
Dental office is too far away	39(26.5)	19(12.8)	.003*
Dental office is not open at convenient times	34(23.1)	40(26.8)	.460
Dental office has no or difficult access for wheelchair	61(41.5)	10(6.7)	.000*
Dental office has inaccessible parking areas	52(35.4)	9(6.0)	.000*
Dental office has small space	42(28.6)	7(4.8)	.000*
Dental office has inadequate facilities to provide dental care	50(34)	5(3.4)	.000*
Dentist lack of knowledge of how to treat people with disability	42(26.6)	9(6.1)	.000*
Dental office has a general dentist not a specialist	42(28.6)	14(9.4)	.000*
Long waiting time	72(49)	62(41.6)	.203
Fear of dental work	99(67.3)	77(51.7)	.006*
No Insurance coverage/dental coverage	57(39)	52(34.9)	.461
Embarrassment or any psychological barriers	64(43.5)	14(9.4)	.000*

\*Significant result,  $p < .05$

## Figures



**Figure 1**

Reasons for last visit to dental service for ASD and control.

