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Original Researh Article

Dental Care Barriers among a Sample of Sudanese Children with Autistic Spectrum Disorder

Ensaf H. AbdAlgabbar[1] and Amal H Abuaffan[2*]

[1]Dentistry section, Ministry of Health, Khartoum, Sudan
[2] Department of Orthodontic, Pedodontic and preventive Dentistry. Faculty of Dentistry, Khartoum University, Sudan

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Background: Autistic spectrum disorder is a long life neuro-developmental disorder. Recognition of service barriers for autistic individuals and their families is important in the development of different types of dental services for them.
Objective: To evaluate the reported use of dental services for autistic children and to identify barriers that prevent access to dental care for autistic individuals in Khartoum state.
Materials and Methods: A descriptive cross-sectional study of parents of forty five autistic children attending 8 autistic centres in Khartoum sate. Data was collected by a self-administered questionnaire through the autistic centres.
Results: The majority of autistic's parents (66.7%) mentioned that their children had never visited the dental clinic. Un-cooperation of the autistic child during the dental procedure was the most frequent barrier reported in (24.4%), followed by barriers related to the dentist (17.8%).
Conclusion: Difficult behaviour of the autistic child was the most frequent barrier to accessing dental care.

Key words: Autism, barriers, dental, parent.

INTRODUCTION

Special Care Dentistry (SCD) is a part of dental services concerned with providing and enabling the delivery of oral care for people with an impairment or disability. In the broadest term, this terminology is defined as "the improvement of oral health of individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or a combination of a number of these factors." [1]

Individuals with disabilities are at a greater risk for oral diseases, which in turn further jeopardized their general health. [2] So they are in need of equal access to high-quality, gender-sensitive healthcare, including preventative care, rehabilitation and other specific services. [3] However, several barriers have been reported in accessing oral health services for individuals with developmental disabilities, such as family, caregivers and dental professionals. [4]

The first definition of Autism was introduced by an American child psychiatrist, Dr. Leo Kanner in 1943, as a pervasive developmental disorder.[5] Recently the National Institute of Mental Health defined autism as, "A group of developmental brain disorders, collectively called Autism Spectrum Disorder (ASD). The term spectrum refers to the wide range of symptoms, skills, and levels of impairment, or disability, that children with ASD can have, some children are mildly impaired by their symptoms, but others are severely disabled". [6]

Although global prevalence of ASD was estimated to be 62/10000, [7] no study exclusively addressed the epidemiology of ASD in Africa. [8] Autistic individuals and their families face several barriers to accessing dental services. These barriers are considered important in the development of different types of services for individuals with autism and their families. [9] Treating patients with autism can be challenging for dental professionals. [10, 11] The most significant challenges in providing oral care for autistic individuals are communication and behavioral problems, in addition to unpredictable body movements and unusual responses to stimuli and seizures. [12]

As a result the Pediatric dentists should have accurate knowledge about dental care barriers for individuals with ASD and the characteristics of their families to improve the quality of dental care for this vulnerable population. [13] Therefore, this study was designed to assess difficulties that may prevent the Sudanese autistic children in Khartoum State to receive dental care in order to improve and control challenges for oral health

Corresponding Author: amalabuaffan@yahoo.com

care providers in relation to treatment planning and behaviour management of the autistic population.

Material and Methods

The study population was comprised of all parents of children with Autistic Spectrum Disorder (ASD) attending the educational and rehabilitation institutes in Khartoum State. The total number of special needs centres was 53, as obtained from the directorate of special needs in the Ministry of Education- Khartoum State. All of the headmasters of the 53 centres were contacted by phone to identify the current available numbers of autistic individuals and only 10 centres were found to offer care for ASD children. However, 2 of the 10 centres refused to inform the researcher about the numbers of autistic individuals and the contact numbers of their parents. The total number of children with ASD attending educational and rehabilitation centres in Khartoum state was limited. Therefore, all the autistic children in the 8 centres were included in this study. A total number of 65 autistic children were found to be in the 8 centres.

The data were collected between August and December (2013) based on a self-administered questionnaire which was adopted from Abbasnezhad-Ghadi master thesis, with a slight modification to meet the criteria of the study. [14] The questionnaire was designed into twenty five close-ended questions, including two to four choices of answers. The questionnaire fields were developed and designed into four sections; parent's background; history of visiting the dental clinic; perceived dental treatment and barriers to attending the dental clinic. The questionnaire was translated into Arabic language because it is the country's local language.

The questionnaires were delivered by the headmasters of the autistic centre to all autistic's parents. A direct contact through telephone to the parents was made to follow up and gain a maximum response for answering the questions. The response of the autistic's parents was 45 out of 65 parents.

Data processing and analysis

The data were processed and analyzed using computer software programs Statistical Package for Social Sciences (SPSS) version1.7. Specific frequencies and percentages were obtained for all questions and the final results obtained were presented in the form of tables and figures.

Results

A total of 45 autistic's parents participated in this study and the majority of them were mothers (73.3%) and (26.7%) fathers. The educational level of (71.1%) of the parents was university level or above (Table 1).

Table 1: Distribution of the educational level of autistic children's parents

Relation to the child	Level of education		Total
	University level or above	High school level	
Mother	23(51.1%)	10(22.2%)	33(73.3%)
Father	9(20.0%)	3 (6.7%)	12(26.7%)
Total	32(71.1%)	13(28.9%)	45(100.0%)

Table 2 shows that (71.1%) of children were diagnosed as autistic at the age of 3 years or less, whereas only (40%) of them attended the institution at the time of diagnosis.

Table 2: Distribution of autistic children by age when diagnosed as autistic and attended the institutions (%)

Age group	Age when diagnosed as autism	Age of attendance the institution
3 years or less	32 (71.1%)	18 (40.0%)
Above 3 years	11 (24.4%)	26 (57.8%)
Can't remember	2 (4.4%)	1 (2.2%)
Total	45 (100%)	45 (100%)

The majority of dental procedures was performed with local anesthesia (LA), and only one child had an extraction under general anesthesia (GA). Moreover, no child had fluoride application as a preventive measure (Table 3).

Table 3: Type of the perceived dental treatment to autistic children

Type of treatment	Without LA	With LA	Sedation or GA
Only medication	2	0	0
Fluoride application	0	0	0
Extraction	0	5	1
Periodontal scaling	1	0	0
Tooth Filling	1	3	0
Pulp therapy	0	2	0
Total	4	10	1

LA: local anesthesia, GA: general anesthesia

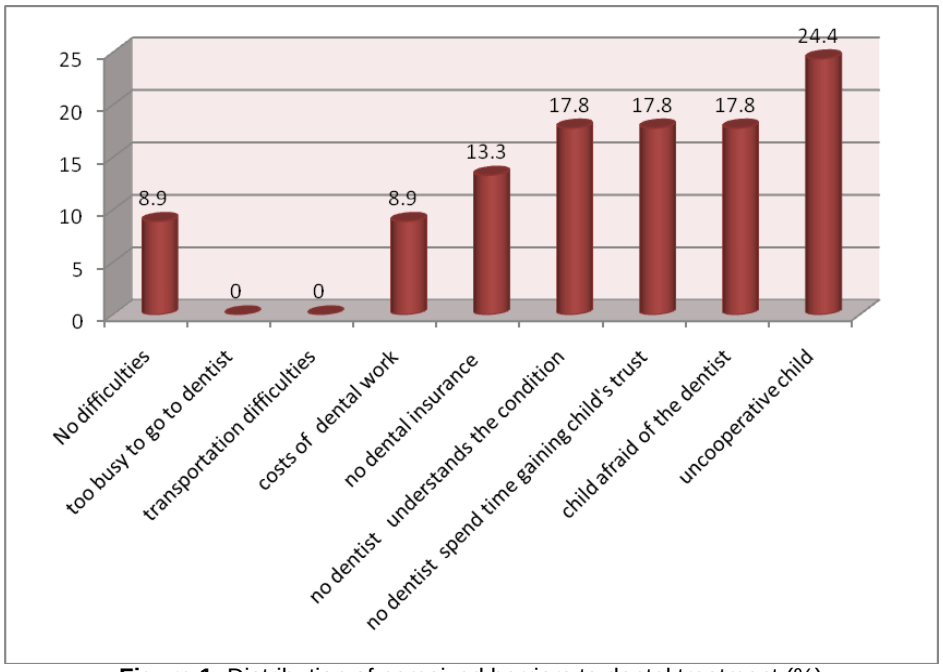

Figure 1: Distribution of perceived barriers to dental treatment (%)

A high percentage of autistic children (66.7%) had no past experience with the dental clinic. While (22.2%) visited the dental clinic more than 12 months ago and (11.1%) visited the dental clinic less than 12 months.

Concerning the group of autistic children, (15) had an experience with the dental clinic, whereas, most of them (73.3%) visited the dental clinic for the first time after the age of 3 years old and mainly for emergency dental care as mentioned by 46.7% of the parents.

The majority of dental procedures was performed with local anesthesia (LA), and only one child had an extraction under general anesthesia (GA). Moreover, no child had fluoride application as a preventive measure (Table 3).

Most of the autistic children who visited the dental clinic (60%) received dental care in private, non-specialized dental clinics and their parents described the received dental treatment as inadequate. Furthermore, only (13.3%) of them used to visit the dental clinic regularly.

Thirty parents out of 45 mentioned that they had no past experience with dental treatment. The 15 autistic's parents who visited the dental clinic before reporting that the most frequent barrier (24.4%) was un-cooperation of their autistic child during dental treatment, followed by a fear from the dentist (17.8%). However, no parent reported transportation difficulty and time factor as a barrier to take their child to the dental clinic (Figure 1).

Discussion

The response rate among eligible respondents in the present study was 69.2% (45 out of 65) and it was considered low which can be attributed to parents whom may have thought that their child will gain no benefit from the results of the present study, in addition to the un-cooperation of headmasters of some the autistic centres. These limitations make the results inapplicable to the whole Sudanese autistic

population. Furthermore, the results of this study cannot be applied to the whole Sudanese autistic population, due to the fact that not all autistic children attend school. This can be attributed to the fact that there is a lack of knowledge about autism spectrum disorder among the majority of Sudanese parents.

This study shows that only 33.3% of autistic children had a history of visiting a dental clinic, although most of their parents (66.7%) had a higher level of education which is unlikely to those parents of autistic children in developed countries. [14-16] In Toronto the educational level of the parents had an important impact on dental access and markedly increased utilization of dental care. [14] A possible explanation for this would be that, the educational level of Sudanese parents had no positive impact on seeking dental care for their autistic child.

The dental treatment received by the autistic children was described as inadequate by the majority of parents (60%), in contrast to Abbasnezhad-Ghadi study in which (64.3%) of the parents described the received dental treatment as adequate. [14] In addition, in the current study most of the dental visits were in non-specialized dental offices, which differ from the results reported by Lai et al and Brickhouse et al in which 57.5% and 61% of autistic children visited a paediatric dental clinic .[15, 16]

In the present study, many barriers regarding dental care were reported by parents in different frequencies. Therefore, it would be more appropriate to discuss these barriers in the form of four main categories: barriers related to the autistic child, barriers related to the dentist, barriers related to dental services and barriers related to parenting.

In this study the most frequent barrier (42.2%) hindering the autistic child from receiving dental care as reported by the parents was related to the child himself; un-cooperative behavior during dental visits (24.4%) followed by phobia from the dentist (17.8%) respectively. This finding was consistent with results among autistic children in Toronto, Virginia, California & North Carolina. [14-17]

The second frequent barrier (35.6%) recorded by the parents was related to dentists; either difficult to find a dentist who understands the autism condition or an unwilling dentist to spend time gaining the child's trust. This finding was supported by Abbasnezhad-Ghadi study in Toronto, where (37%) of parents face lack of dentist knowledge about autism spectrum disorder as a barrier and (23%) of them reported difficulty to find a dentist willing to spend time gaining trust of an autistic child. [14] Moreover, Stein et al reported that most of the autistic's parents experienced difficulty in finding dentists willing to provide dental care to their autistic children and even refuse to accept treating them. [17]

Barriers related to dental service cost and lack of dental insurance were stated by (22.2%) of the parents in the present study, which is inconsistent with the finding among autism spectrum disorder children in North Carolina, in which (61.6%) of parents reported that cost of dental treatment and lack of dental insurance were the main barriers. [16]

In this study barriers related to parents; neither of transportation difficulties nor time constrain were mentioned by parents as difficulties to take their child for dental care. Therefore, parents blamed themselves as being irresponsible for the inadequate dental care received from their child. This in contrast to the finding obtained by Abbasnezhad-Ghadi in Toronto in which difficulties accessing dental care for autistic children were related to their family structure and parents' education. [14]

Conclusion

The majority of Sudanese autistic children never visited a dental clinic, and their intricate characteristic behavior is the most frequent barrier to accessing dental care.

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