



## ORIGINAL ARTICLE

Carolina Hernández.  
Poliette Oyarzún.

Facultad de Odontología, Universidad  
Andrés Bello Sede Concepción, Chile.

Corresponding author: Carolina Hernández. Yolando Pino 3391 Talcahuano. Chile. Phono: +56 9- 85485312. E-mail: carolina.h.osorio@gmail.com

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## Perceptions of autistic children's parents about dental care: Preliminary study. Concepción, 2012.

The aim of this study was to describe perceptions among parents of children with autistic disorder (AD) from the School of the Autistics' Parents and Friends Association (Asociación de Padres y Amigos de los Autistas, ASPAUT) in Chiguayante. A cross-sectional and exploratory study was conducted. The target population was 60 schoolchildren's parents from the ASPAUT School. The measuring instrument was a survey with thirty closed questions and one open question. Of the 60 surveys sent out, 26 were recovered with different answers to each of the questions. Almost all children with AD had received dental care about once a year mainly by pediatric dentists. Generally, there was a good perception of the care provided, but the need for professionals who are specialized in autism spectrum disorders, specific dental programs and to reduce the associated costs are recognized. The issues identified by parents as most relevant for improving care were: specialized dental care (26.9%), more humane treatment (19.2%) and distracting techniques (11.5%). Only three parents (11.5%) reported being satisfied with care. In Chile, dental care for this population is just beginning and there are many areas which need to be improved.

**Keywords:** *Autism, Child, Delivery of Health Care, Dental Care, Attitude.*

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### INTRODUCTION.

Autistic disorder (AD), known as "classic autism", is a condition belonging to Pervasive Developmental Disorders, which include severe behavior disorders. Its origin is unknown, although its pathogenesis has been associated with sensitivity to dietary and environmental antigens. It is defined as a behavioral syndrome consisting of an abnormal development of social skills (withdrawal, lack of interest in peers), limitations in the use of interactive language (speech and non-verbal communication) and sensorimotor deficits. AD has a variable incidence depending on the place and date of study. It ranges from 5.2 to 7.6 cases per 1000 live births, with a gender ratio of 3: 1 to 4: 1, presenting more severe when it affects females. Prevalence estimates vary from two to six per 1,000 children<sup>1-3</sup>.

Dental problems are a common comorbidity in patients

with AD and may arise due to disorder-related behaviors, such as limitations of communication, self-care, self-injurious behavior, dietary habits, resistance to dental care, hyposensitivity to pain and difficulty socializing<sup>4</sup>. Also, there are certain associations such as decreased motor activity and total lack of food swallowing. Moreover, nocturnal bruxism is common in children with AD, plus consumption of certain drugs cause xerostomia, oral ulcers, dysgeusia, stomatitis, glossitis, delayed healing or gingival enlargement<sup>2</sup>. This can severely increase the rate of caries and periodontal disease in this population which shows high levels of plaque, gingivitis, calculus, halitosis and cariogenic food constantly remaining in the oral cavity<sup>1,2</sup>.

Given the above, dental care of the population with AD is a very delicate issue and the interaction with parents and/or caregivers plays a central role in the successful

management of these patients. However, the perception of parents of children with AD about the attention has been little-studied worldwide<sup>5-8</sup> and there are not national data published in indexed journals, which hinders the implementation of dental interventions for which parents' comprehension and cooperation is fundamental. The aim of this study is to describe the perceptions of parents of children with AD from the differential School of the Autistics' Parents and Friends Association (Asociación de Padres y Amigos de los Autistas, ASPAUT) in Chiguayante during 2012.

### MATERIALS AND METHODS.

This was a cross-sectional and exploratory study. The target population consisted of 60 parents of children with AD from the differential School of the Autistics' Parents and Friends Association (Asociación de Padres y Amigos de los Autistas, ASPAUT) in Chiguayante.

Given the exploratory nature of the study, sample size and sampling were not estimated. Instead, all parents and guardians from the school were invited to participate. In a meeting, the research was explained through a talk and a leaflet with the most important topics was delivered. Subsequently, the informed consents were sent through the children's agenda. Two weeks later, each parent or guardian was contacted by telephone to be reminded about the informed consent. Also, they were told the survey would be sent soon. They were given one week to answer the survey and send it back to the school through the children's agenda.

To assess parents' perception, a survey of thirty closed questions and one open question was designed consider-

**Table 1.** Characterization of the sample according to sex and age.

AGE RANGE	SEX		TOTAL
	MALE	FEMALE	
<12 years old	10	1	11
12-18 years old	7	3	10
>18 years old	4	1	5
Total	21	5	26

**Table 2.** Percentage distribution of responses gathered from the Dental Care section.

ITEM	RESPONSE DISTRIBUTION
Your child has received dental care.	92.3% received dental care.
Type of dental health service you have attended to.	38.5% public, 30.8% private and 23.1% both. (*7.6%)
When you have been there, it has been for.	30.8% check-up, 3.8% emergency, 57.7% both. (*7.7%)
Have you experienced differences between private or public care?	50% experienced differences in public-private care, 23% did not notice any differences. (*27%)
Type of specialist you are attending for dental check.	57.7% had seen a pediatric dentist, 7% a general dentist. (*64.7%)
When did you last visit the dentist?	38% saw the dentist a year or more ago, 34.5% between 3-6 months ago, 15.4% a month ago, 3.8% two weeks ago. (*8.3%)
Does your child currently have a preferential dentist?	52% did have a preferential dentist. (*48%)
If your child has received dental care, where have the procedures been executed?	46,2% had been assisted on a dental chair, 30.8% in an operating room (*23%)
How often does your child see the dentist?	42.3% once a year, 26.9% every 3 months, 3.8% once a month. (*27%)
What do you think of dental care?	26.9% considered it is average, 23.1% very good, 15.4% good and excellent and 3.8 bad or very bad. (*30.8%)
Do you think it is important to implement health programs for dental care of children with special needs?	100% said yes
Do you think Chile should improve dental care?	92% answered it needs to be improved. (*8%)
Regarding the monetary cost of dental care, you think it is:	69.2% said it was too high and 26.9% said it was high. (*3.9%)
How much do you think dental care for your child improved over time?	46.2% said it has improved little and 19.2% a lot and also none. (*34.6%)

\*Percentage of invalid responses.

**Table 3.** Percentage distribution of responses gathered from the Dentist-Patient Relationship section.

ITEM	RESPONSE DISTRIBUTION
In general, do you think the dentists you have visited are trained to provide proper care for your child?	53.5% believe that dentists are trained. (*46.5%)
Do other parents' experiences influence your determination to see a dentist?	69.2% believe others' experiences do not influence them for their dental visits. (*30.8%)
Has the dentist educated you about your child's oral hygiene and health?	42.3% said they almost always received oral hygiene education, 38.5% rarely and 15.4% had never received it. (*3.8%)
Is your child willing to see the dentist?	26.9% always or rarely shows willingness to attend, 23.1% never and 15.4% usually. (*34.6%)
In relation to the previous question: What factors have contributed to such willingness?	65.4% mentioned factors other than the options have affected them, 11.5% past traumatic care and 7.7% their parents experience. (*15.4%)
Has the dentist used accessory items to capture your child's attention during treatment? (For example: music, toys, pictures, etc.)	42.3% said the dentist has never used any accessory items, 23.1% always, 19.2% sometimes and 7.7% usually (*7.7%)
What is the dentist's attitude in the dental office?	69.2% see the dentist with a friendly attitude and 7.7% see him/her distant, indifferent and insecure. (*23.1%)
Factors influence your child's disposition to dental care?	The child's attitude, 11.5% the dentist's gender, 7.7% the dentist's age and 3.8% both. (*19.7)

\* Percentage of invalid responses.

ring the main aspects described in literature<sup>1-8</sup> adjusted to local realities. The questions were divided in 4 sections: Dental Care, Dentist-Patient Relationship, Oral Health – Parent or Guardian's Everyday Life and Perspective.

Data were tabulated and analyzed using the statistical software SPSS 17 (IBM Corp., New York, USA). Descriptive statistics were performed to generate frequency distribution and percentage tables for the response categories.

**Table 4.** Percentage distribution of responses gathered from the Oral Health and Daily Life section.

QUESTION	RESPONSE DISTRIBUTION
Is your child's dental care a priority?	76.9% consider dental care as a priority. (*23.1%)
Dental care for your child causes you:	50% concern, 23.1%, worry and anxiety, 11.5% anguish and only 7.7% none of the above. (*7.7%)
Have you ever postponed dental treatment indicated for your child for any reason?	46.2% mentioned they had postponed their child's dental treatment. (*53.8)
If so, why did you postpone it? (If the answer is NO, do not answer and go to the next question)	23.1% for lack of funds, 7.7% for lack of time and other reasons and 3.8% because they prioritized other treatments. (*65.4)
Have you ever had to travel outside the region for your child to receive dental care?	88.5% did not have to leave the region for dental care. (*11.5)
Who does accompany the child to visit the dentist?	73.1% the mother accompanies. (*26.9)

\* Percentage of invalid responses.

## RESULTS.

Of the 60 surveys rates sent out, 26 were recovered with different responses to each question. Table 1 shows the description of the sample based on the characteristics of children with learning disabilities whose parents answered the survey.

The results for the following sections: Dental Care, Dentist-Patient Relationship and Oral Health - Everyday Life are shown in Tables 2, 3 and 4, respectively.

These issues were identified by parents as the most important to improve their children's care: specialized dental care (26.9%), more humane treatment from the dentist (19.2%) and the use of distracting attention techniques (11.5%). A 15.4% of parents think dental care is good and excellent.

## DISCUSSION.

The present study was exploratory in nature, given the lack of publications on the subject in the national reality and the worldwide reduced amount of articles. Because of this, the study has some limitations, such as the nature of the sample and the instrument used, which should be

considered in assessing the results. Regarding the sample, it should be noted it was small and not randomly chosen. Therefore, the results may not be representative due to some bias as the volunteer. Second, there are no validated or at least widely used instruments to assess parents' perception about dental care. Therefore, an unprecedented survey, condensing the main issues reported in literature, was compiled<sup>1-18</sup>.

In the present study, it is possible to identify at least two key macro-results which are useful for understanding dental care received by people with AD and their parents' perception. First, almost all children with AD receive dental care about once a year mainly by pediatric dentists. Secondly, there is generally a good perception of the care provided, but the need for many improvements such as specialization of professionals providing care, specific programs for this population and reducing the associated costs are recognized.

If we compare these results with a few published reports, it is possible to see that the local reality has several similarities. In the United States, Lai *et al.*<sup>7</sup> reported that 93% of children with AD have attended a dental exam and 11% of them still have unmet dental needs. The main barriers are the child's behavior and the economic cost and the percentages and barriers are almost identical to those found in this study. However, in the United States it has been reported that, in spite of some barriers, access to preventive treatment for children with intellectual or development deficits is close to 50%, similar to that of children without these disorders<sup>12</sup>. On the other hand, the results of this study indicate that a third of such population attends only for check-up, very few only for emergency and they are mostly attended by pediatric dentists. Then, it is expected that more than half of children have access to preventive treatments. This does not seem to be the result of a public policy, but of the parents' personal effort and that of the ASPAUT organization.

When comparing the places where dental care is provided, Chiri *et al.*<sup>13</sup> reported that almost 60% of respondents took their children only to a private service and

almost 30% reported taking them to the public service. On the contrary, in the present study, the public service is the most used by the respondents (38.5%). This could be related to economic differences between the American and Chilean reality.

Recently, in England, Brown *et al.*<sup>5</sup> performed a methodologically similar pilot study. It indicates that, when assessing parents' perception, favorable results were obtained when dentists were willing to listen and seek advice from parents prior to consultation and treatment, describing it as a key aspect for good care. However, they reported a general lack of acceptance, understanding and preparation to treat anxiety in children. The study results suggest that parents who reported positive experiences said the dental staff listened to them, changing their practice behavior to meet individual needs. Meanwhile, negative experiences were often caused by a breakdown in communication between the child's parents and the dental staff, lack of awareness from the practitioner about the characteristics of AD or unwillingness to adapt practice to meet their sensory difficulties. While the variables analyzed are not exactly the same, it can be seen that the results of this study are consistent with those reported by Brown *et al.*<sup>5</sup>. They point to the need for specialized professionals and basically in building and keeping a good dentist-patient behavior and relationship for successful care of children with AD<sup>2</sup>.

To better understand this, we must consider that dentists who treat children should be familiar with AD and informed of all the possible manifestations of the disease, as well as their associated characteristics, in order to get the highest cooperation from the patient to achieve their optimal care<sup>1-5</sup>. Autistic children's parents expect the professional who attends them has knowledge, skills and attitudes to treat their children according to their special needs<sup>14</sup>, which are generally more difficult to care than those of other groups with intellectual or developmental deficits<sup>15</sup>.

Also, it requires a team effort from parents or guardians, the child psychiatrist/neurologist and the dentist,

who should be involved in maintaining oral health care and worried about making early intervention and long term regular monitoring. While there is no standard treatment, the assessment interview conducted with the child's parents or guardians is very important. Marshall *et al.*<sup>16</sup> found that almost 90% of parents can accurately predict the disposition and behavior that their children will have towards various forms of dental care.

All factors collected will help optimize treatment<sup>2,4</sup>. But handling parents should be special because they are more likely to have beliefs and special preferences for dental materials used in their children's dental care. It reinforces the need to consider their opinion when performing different procedures<sup>8,15,16-18</sup>.

There are special techniques to make dental care easier for patients with AD, such as say - show - do, communication (voice control and non-verbal communication) distractions, rewards and the presence of parents during the intervention. Another group of advanced techniques use nitrous oxide, intravenous sedation, protective stabilization and general anesthesia; but these are often unnecessary procedures<sup>9</sup>. The use of music, especially classical and jazz, has successfully been tested as an effective therapy because it is creative and spontaneous, attracting attention and promoting relaxation of patients with autism. On the contrary, the smells (acrylic and fluorine) and sounds (the handpiece, the ejector) generated in the office can trigger adverse reactions in the patient's behavior, such as hyperactivity, aggression, and a negative response towards dental appointments<sup>1</sup>.

### **Percepciones de padres de niños autistas respecto a la atención odontológica: Estudio preliminar. Concepción, 2012.**

**Resumen:** El objetivo del presente estudio es describir la percepción de los padres de niños con trastorno autista (TA) de la escuela diferencial de la Asociación de Padres y Amigos de los Autistas (ASPAUT) de Chiguayante. Se realizó un estudio de corte transversal y carácter exploratorio. La población objetivo fueron los apoderados de 60 esco-

Regarding the professionals who provide care, the results are similar to those reported in literature: it is pediatric dentists who mostly treat children with AD. This is because they have more preparation and training in treating patients with special needs and often use appropriate behavior modification strategies to treat patients with AD, correlated with the quality of their educational experiences. This is consistent with the attitude of general dentists and pediatric dentists in care of children with AD since disposition in both groups was 89% and 32%, respectively<sup>10,11</sup>. In many cases, this would explain the quality of dental care for these patients and the general perception in this and other studies for the need of specialized dentists in the care of patients with special needs, considering they generally have greater impairment in quality of life related to oral health than the general population<sup>19</sup>.

Finally, it is important to note that, in Chile, care for such patients has barely begun. Therefore, it is necessary to support the implementation of initiatives which directly improve dental care<sup>20</sup>, which seems to be supported by the parents' personal efforts and willingness of a reduced group of dentists rather than a proper infrastructure and professional training so far.

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lares de la escuela ASPAUT. El instrumento de medición fue una encuesta de 30 preguntas cerradas y 1 pregunta abierta. De las 60 encuestas enviadas se recuperaron 26 con grados variables de respuesta a cada una de las preguntas. Casi la totalidad de los niños con TA recibe atención dental, aproximadamente 1 vez por año y en su mayoría por odontopediatras. Existe en general una buena percepción de la atención recibida, pero se reconoce la necesidad de profesionales especializados en los trastornos del espectro



autista, la existencia de programas odontológicos específicos y la reducción de los costos asociados.

Los aspectos identificados por los padres como más relevantes para mejorar la atención fueron: atención de un dentista especializado (26,9%), trato más humano (19,2%) y el uso de técnicas distractoras (11,5%). Un 15,4% de los

padres considera la atención dental buena así como también excelente. En Chile la atención de este tipo de pacientes presenta un desarrollo incipiente, existiendo aún muchos puntos por mejorar.

**Palabras clave:** *Autismo, niño, prestación de atención de salud, atención dental, actitud.*

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