

# Impact of the burden of caregivers of children with ASD on oral health

Impacto da sobrecarga dos cuidadores de crianças com TEA na saúde bucal

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**How to cite:** Falquetti BB, Rodrigues JVS, Paino-Sant'Ana A, Deroide MB, Mulinari-Santos G, Theodoro LH. Impact of the burden of caregivers of children with ASD on oral health. Rev Odontol UNESP. 2023;52:e20230030. <https://doi.org/10.1590/1807-2577.03023>

## Resumo

**Introdução:** a demanda do cuidador em atender as necessidades de indivíduos com transtorno do espectro autista (TEA), pode influenciar na sua qualidade de vida. **Objetivo:** o objetivo do presente estudo foi comparar a sobrecarga de cuidadores de indivíduos com TEA com indivíduos neurotípicos (N) e avaliar a correlação do impacto da saúde bucal com a sobrecarga desses cuidadores. **Material e método:** os participantes foram divididos em dois grupos: Grupo TEA (TEA; n=35) e Grupo Neurotípico (N; n=35). Foi aplicado aos cuidadores um questionário de características sociodemográficas. A sobrecarga dos cuidadores foi medida pelo questionário *Burden Interview* (BI). Foi analisado o índice de placa visível (IPV) das crianças. Os dados foram submetidos a análise estatística ( $\alpha=5\%$ ). **Resultado:** no grupo TEA a maioria dos participantes eram parcialmente dependentes, sendo a maioria dependentes na higienização bucal. No grupo N a maioria eram independentes e autossuficientes na higienização bucal. Metade dos cuidadores do grupo TEA apresentaram sobrecargas leve à moderada (54,3%). No grupo N constatou-se que a maioria enquadrava-se em nenhuma sobrecarga (65,7%). Na análise comparativa dos dados do questionário BI foram observadas diferenças significantes entre os grupos nas questões ( $p<0,001$ ) que são diretamente relacionadas com os cuidados com os filhos. Com relação ao IPV das crianças do grupo TEA e N comparadas ao nível de sobrecarga, observou-se que não houve diferenças significativas entre os grupos. **Conclusão:** os cuidadores do grupo TEA apresentam maior sobrecarga quando comparados ao grupo N e não houve correlação entre a sobrecarga e o grau de higiene bucal.

**Descritores:** Transtorno do espectro autista; sobrecarga do cuidador; higiene bucal.

## Abstract

**Introduction:** the caregiver's demand to meet the needs of individuals with autism spectrum disorder (ASD) can influence their quality of life. **Objective:** the objective of the present study was to compare the burden on caregivers of individuals with ASD with individuals neurotypical (N) and to evaluate the correlation of the impact of oral health with the burden on these caregivers. **Material and method:** participants were divided into two groups: ASD Group (ASD; n=35) and Neurotypical Group (N; n=35). A sociodemographic characteristics questionnaire was administered to caregivers. Caregiver burden was measured using the Burden Interview (BI) questionnaire. The visible plaque index (VPI) of children was analyzed. The data were submitted to statistical analysis ( $\alpha=5\%$ ). **Result:** in the group ASD, the majority of participants were partially dependent, with the majority being dependent on oral hygiene. In group N, the majority were independent and self-sufficient in oral hygiene. Half of the caregivers in the group ASD felt mild to moderate burden (54.3%), while in group N it was found that more than half of them had no burden (65.7%). In the comparative analysis of data from the BI questionnaire, significant differences were observed between the groups in questions ( $p < 0.001$ ), which are directly related to childcare. Regarding the VPI of children in the group ASD



and N groups compared to the level of burden, it was observed that there were no significant differences between the groups. **Conclusion:** ASD caregivers have a greater burden when compared to N caregivers and the degree of burden did not influence the oral hygiene of the child with ASD.

**Descriptors:** Autism spectrum disorder; caregiver burden; oral hygiene.

## INTRODUCTION

Autism spectrum disorder (ASD) is a neurological development disorder, impairing communication, social, behavioral and intellectual performance, with impaired communication and social interaction, demonstrated by withdrawal and lack of interest in other people<sup>1,2</sup>. The prevalence of ASD has increased over the last 2 decades<sup>3</sup>. According to 2020 data, the prevalence in the United States of America (USA), one in 36 children aged 8 years (approximately 4% of boys and 1% of girls) was estimated to have ASD<sup>4</sup>. In Brazil there is still no estimate; however, it is believed to be close to what was found in the USA and Europe<sup>3</sup>.

Oral hygiene in patients with ASD may be deficient due to the lack of manual dexterity and the need for help with correct hygiene, which may result in an increase in bacterial plaque and a higher rate of gingivitis<sup>5,6</sup>. Authors report that these individuals have a higher prevalence of periodontal diseases such as gingivitis and gingival hyperplasia<sup>7,8</sup>. In this context, a study demonstrated that individuals with ASD who lived with their parents had a lower rate of gingivitis compared to those who did not live with their parents, but the manifestations and clinical signs of bruxism were greater in those who lived with their parents<sup>9</sup>.

The caregiver has a fundamental importance in helping the autistic person to carry out their daily activities and maintain their connection with society throughout their growth and development into adulthood<sup>10,11</sup>. However, time spent on excessive tasks, such as meeting a child's social, physical, emotional and learning needs, coupled with few specialized guidance and social support services, can cause stress, depression and anxiety and directly affect the caregiver's quality of life (QoL)<sup>11,12</sup>.

Furthermore, the lifelong responsibility of caring for a person who is within the spectrum related to reduced attention to their own health, leads caregivers to feel overwhelmed. Caregiver burden has been determined as a multidimensional reaction to the set of physical, mental and socioeconomic problems suffered by those who care for sick people, and the effects can be physical and mental disorders and low quality of life<sup>13,14</sup>. Thus, burden can be a significant predictor of worse QoL and could also influence the maintenance of oral health<sup>11,15,16</sup>. Thus, the objective of the present study was to compare the burden on caregivers of individuals with ASD with individuals neurotypical (N) and to evaluate the correlation of the burden on these caregivers on the impact of oral health.

## MATERIAL AND METHOD

This is a cross-sectional observational clinical study with a convenience sample approved by the Ethics and Research Committee (CAAE: 59159422.0.0000.5420). The project followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines<sup>17</sup>.

### Selection of Patients

The sample was selected by simple random sampling. A total of seventy patients were included in the study. Thirty-five diagnosed with ASD were studied in outpatient care at the Dental Care Center for People with Disabilities (CAOE) to form the group ASD. Thirty-five patients with neurotypical were recruited from the Pediatric Dentistry clinic of the Faculty of Dentistry of Araçatuba and comprised the group N. Those responsible for the patients were individually

informed about the nature of the study and signed an informed consent form. Patients who understood were presented with the consent form, which was also signed by their legal guardians.

Individuals with ASD must meet the following inclusion criteria: patients diagnosed with ASD levels 1, 2 and 3; both sexes; age  $\geq 5$  and  $\leq 12$  years; being monitored at the specialized assistance center. In the case of individuals N, the same inclusion criteria were considered with the exception of the diagnosis of ASD.

The exclusion criteria were: non-collaborating patients; need for sedation; unstable health condition; blood disorders; edentulous patients; active cancer; patients supplemented with vitamins in the last two months; use of anti-inflammatory drugs or antibiotics in the last 3 months<sup>18,19</sup>.

### **Personal, Sociodemographic and Oral Questionnaire**

Initially, a questionnaire was applied to the parents/guardians of the research participants. The questionnaire addressed issues related to patient identification and length of outpatient follow-up, systemic and behavioral characteristics, assessment of oral habits/care and assessment of parents/guardians' knowledge about oral health.

### **Overload Questionnaire**

Parents/guardians were examined according to the burden felt using the Burden Interview (BI) questionnaire, translated, culturally adapted and validated for use in Brazil<sup>20</sup>. The BI contains 22 items used to assess the health, social and personal life, financial situation, emotional well-being, and interpersonal relationships of caregivers. Responses were graded on a *Likert scale* of 5 points, ranging from 0 to 4 (never, rarely, sometimes, often, and always). All items were evaluated, and the total scale score was obtained by adding all items, which could range from 0 to 88. In the present research, the level of overload was categorized according to the scores obtained by parents and includes: little or no overload (0 – 21 points); light to moderate load (21 – 40 points); moderate to severe load (41 – 60 points); severe load (61 – 88 points)<sup>21</sup>.

### **Visible Plaque Index (VPI)**

The of VPI (present or absent) in individuals with ASD and N was assessed in six sites of six teeth in the oral cavity (first permanent molars, upper central incisor, lower central incisor), totaling 36 sites. In the absence of any permanent tooth, its corresponding deciduous tooth or the closest tooth (mesial) of the hemiarch was evaluated<sup>22</sup>. This clinical parameter was performed with a millimeter periodontal probe (PCPUNC-15, Hu- Friedy, Chicago, IL, USA). The assessment was conducted by a single calibrated examiner (JVSR).

### **Statistical Analysis**

The collected data were tabulated and organized in the JAMOVI 2.2.5 program (Sydney, Australia). For all tests, a significance level of 5% was considered. The Shapiro-Wilk normality test was applied for each parameter.

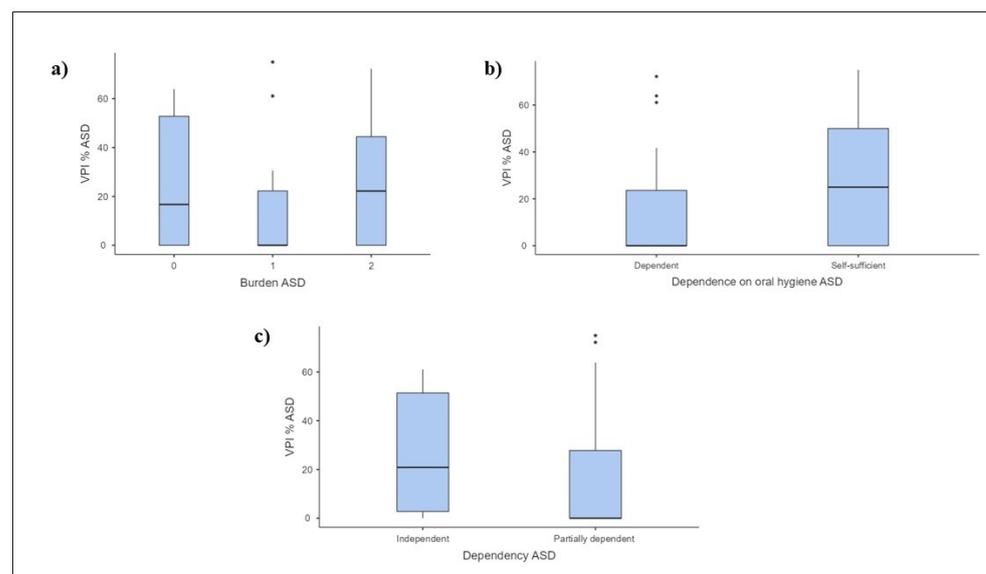
For both groups, caregiver burden and VPI were compared using the Spearman Correlation test; dependence on hygiene and dependence on caregivers were compared to VPI using the Mann-Whitney U test; and VPI was analyzed between groups using the Mann-Whitney U test. For the ASD group, the degree of autism and VPI were compared using the Spearman Correlation test.

## RESULTS

In the ASD group, 35 patients were included, 26 boys and 9 girls (age  $7.63 \pm 1.82$ ). In the N group, 35 patients were included, 20 boys and 15 girls (age  $8.17 \pm 1.98$ ). Regarding the general dependence of individuals in the ASD group, 25 of them were dependent on their guardians for basic daily activities. In the N group, of the 35 children, only 13 were dependent on their parents. When evaluating the degree of dependence in oral hygiene, the ASD group had 24 dependent children, and in the N group, only 3 depended on their guardians for mouth brushing.

When evaluating the level of overload of caregivers in the ASD group, 9 fell into the “no overload” category, 19 parents with “little overload” and 7 parents with “moderate overload”. Regarding the parents in N group, 23 fell into the “no overload” category, 11 parents with “little overload” and only 1 with “moderate overload”. According to statistical data, no person in charge of either group fell into the “severe overload” category. Questions 2, 7, 10, 12, 17, 19 and 22 showed a statistically significant difference between the two groups ( $p < 0.001$ ).

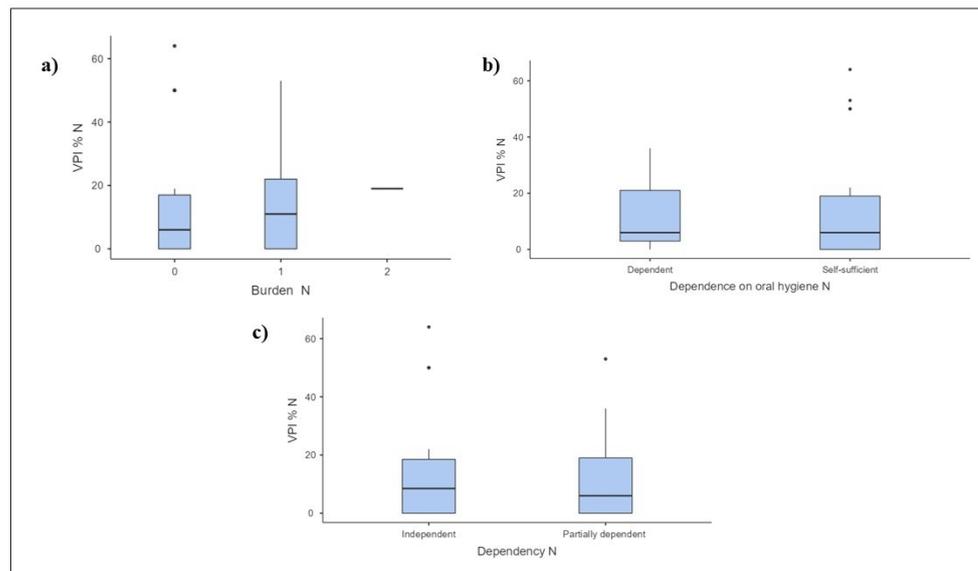
In ASD group it was observed that there was no statistical difference between the VPI and the “no overload”, “mild to moderate”, “moderate to severe” and “severe” groups (Figure 1). There was also no statistical difference in VPI between the “self-sufficient” and “dependent” groups. There was no statistical difference in VPI between the “independent” and “partially dependent” groups of the ASD group.



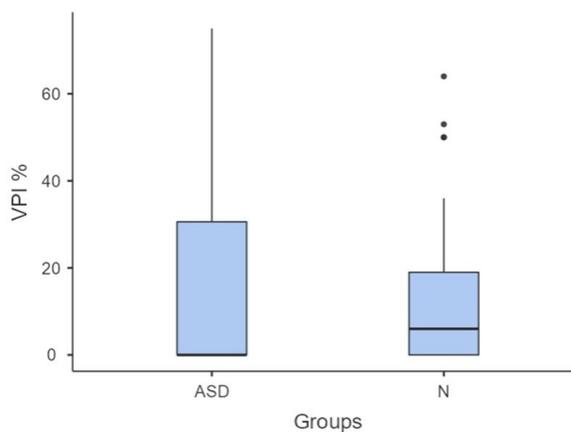
**Figure 1.** a) Spearman Correlation test for VPI in the ASD group with the degrees of overload “no overload”, “mild to moderate”, “moderate to severe” and “severe”. b) Mann-Whitney U test for VPI in the ASD group with the degree of dependence on oral hygiene. c) Mann-Whitney U test for VPI in the ASD group with the degree of general dependence.

In N group there was no statistical difference between the VPI and the “no burden”, “mild to moderate”, “moderate to severe” and “severe” groups (Figure 2). There was also no significant difference in VPI between the “self-sufficient” and “dependent” groups. There was no statistical difference in VPI between the “independent” and “partially dependent” groups of the N group.

There was no statistical difference in the VPI analysis between the N and ASD groups (Figure 3).



**Figure 2.** a) Spearman Correlation test for VPI in the N group with the degrees of overload “no overload”, “mild to moderate”, “moderate to severe” and “severe” b) Mann-Whitney U test for VPI in the N group with the degree of dependence on oral hygiene c) Mann-Whitney U test for VPI in the ASD group with the degree of general dependence.



**Figure 3.** Mann-Whitney U test for VPI between the N and ASD groups.

## DISCUSSION

The prevalence of ASD is 3.5 times higher in men compared to women<sup>3</sup>. The present study was able to reaffirm data from the literature, since there was a prevalence of male children in the ASD group. In relation to neurotypical children, going to the dentist is more common among male children aged 2 to 7 years, this is because there is a higher incidence of trauma to primary teeth<sup>23</sup>. Another study in the literature states that female children are more prone to tooth decay due to reduced salivary flow and biochemical changes in saliva<sup>24</sup>. In this study, there was a prevalence of males in the N group. However, the main complaint was not related to trauma, but rather the prevention and treatment of caries disease.

ASD brings behavioral and intellectual changes to individuals, thus compromising their development and learning, depending on constant care from parents and guardians<sup>25</sup>. From the results obtained in this study, it is clear that children with ASD are more dependent on their parents, both related to general dependence and dependence on oral hygiene. The data shows

that 71% (25 children) of children with ASD depended on their parents to carry out general daily activities and 68% (24 children) depended on their parents for oral hygiene.

Those responsible for individuals with disabilities may present different ways to deal with challenging situations, in the face of different stressful situations<sup>26</sup>. With the increase in the diagnosis of children with ASD, it is necessary to understand the burden that these caregivers carry<sup>26</sup>. During the development of the research, those responsible for children with ASD did not personally appear, for the most part, to be overburdened with caring for their children. However, when answering the BI questionnaire, the results showed that more than half of them fell into some category of burden (mild or moderate).

The burden on parents of individuals with ASD is greater than that of neurotypical individuals<sup>27</sup>. The results of the present study corroborate this statement because, according to the BI questionnaire, 66% of those responsible for neurotypical children classified as “no overload”, 31% “mild burden” and 3% “moderate burden”, compared to those responsible for individuals with ASD, of which 26% classified as “no burden”, 54% “mild burden” and 20% “moderate burden”.

Caregivers of children with ASD may experience feelings of anguish and sadness, as families are often prone to uncomfortable exposure situations<sup>28</sup>. When observing questions 2, 7, 10, 12, 17, 19, 22 of the BI questionnaire, which were specifically aimed at the burden of children, these statements become very evident. There was a significant difference between the groups, demonstrating that parents of individuals with ASD are more overwhelmed.

When analyzing the VPI of the ASD group, it was observed that there were no statistical differences compared to the burden level of parents and guardians. The same results also indicate that there are no differences in the VPI of the ASD group when related to general dependence and dependence on oral hygiene. VPI is the result of poor hygiene in neurotypical children, showing a greater need for parental supervision when brushing. Comparing the VPI of the N group with the burden level of parents and guardians, the same results were obtained as in the ASD group. There was no statistical difference in IPV between the N and ASD groups.

## CONCLUSION

In conclusion, ASD group caregivers have greater burden when compared to N group and the degree of burden did not influence the level of oral hygiene of the child with ASD.

## ACKNOWLEDGMENTS

The authors thank the Center for Dental Assistance to Persons with Disabilities (CAOE) for its support during this project and the “Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq)” for the PIBIC scholarship for scientific initiation (Process: #5732) by academic Beatriz Bueno Falquetti.

## AUTHOR CONTRIBUTIONS

Conceptualization, L.H.T., B.B.F. and J.V.S.R.; methodology, A.P.-S., J.V.S.R., M.B.D. and L.H.T.; software, A.P.-S.; validation, L.H.T., J.V.S.R., and G.M.-S.; formal analysis, B.B.F. and A.P.-S.; investigation, G.M.-S., J.V.S.R. and B.B.F.; resources, J.V.S.R., L.H.T.; data curation, M.B.D. and A.P.-S.; writing - original draft preparation, B.B.F. and L.H.T.; writing - review and editing, B.B.F., J.V.S.R. and L.H.T.; visualization, L.H.T.; supervision, L.H.T. and J.V.S.R.; project administration, L.H.T.; funding acquisition, L.H.T. All authors have read and agreed to the published version of the manuscript.

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## CONFLICTS OF INTERESTS

The authors declare no conflicts of interest.

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Received: October 30, 2023

Accepted: October 30, 2023