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Burden on the caregivers of children and adolescents with autism spectrum disorder: which variables are related?

Sobrecarga dos cuidadores de crianças e adolescentes com transtorno do espectro autista: quais variáveis estão relacionadas?

Laraflay Viana dos Santos[1], *Patrícia Aparecida Zuanetti*[2], *Larissa Maria de Vito Pimenta*[1], *Ângela Cristina Pontes-Fernandes*[2], *Ana Paula Andrade Hamad*[1]

ABSTRACT

Purpose: To evaluate the factors associated with the burden of caregivers of children and adolescents with autism spectrum disorder (ASD), identifying which variables have the greatest impact on their daily lives. **Methods:** The study evaluated 19 caregivers of children with ASD, aged 2 to 12 years; 18 were boys (94.7%). The diagnosis was made by a multidisciplinary team, and the participants were under the care of a pediatric neurologist. The variables collected included the child's age and sex, comorbidities (intellectual disability, attention-deficit/hyperactivity disorder, and so forth), current complaints, type of ongoing intervention, score on the Childhood Autism Rating Scale (CARS), caregiver age, number of children, and family income. Caregiver burden was assessed using the Zarit Burden Interview. Statistical analysis used linear regression with a stepwise selection method to identify the factors significantly associated with burden. **Results:** only the CARS score was significantly associated with caregiver burden ($p = 0.0077$), indicating that higher levels of impairment in ASD are related to greater burden. The patients' age and sex, comorbidities, current complaints, intervention at the time of assessment, and socioeconomic level were not significant. **Conclusion:** The severity of ASD symptoms, reflected by the CARS score, was the main factor associated with caregiver burden. Other aspects, such as age, comorbidities, and socioeconomic level, may also exert influence, as described in the literature, but were not statistically significantly associated in this study.

Keywords: Autism spectrum disorder; Caregiver burden; Stress psychological; Comorbidity; Caregivers

RESUMO

Objetivo: Avaliar os fatores associados à sobrecarga de cuidadores de crianças e adolescentes com transtorno do espectro autista (TEA), identificando quais variáveis apresentam maior impacto na vida diária desses cuidadores. **Métodos**: Foram avaliados 19 cuidadores de crianças com TEA, com idades entre 2 e 12 anos, sendo 18 meninos (94,7%). O diagnóstico foi realizado por equipe multiprofissional e os participantes estavam em acompanhamento com neurologista infantil. As variáveis coletadas incluíram idade e sexo da criança, presença de comorbidades (deficiência intelectual, transtorno do déficit de atenção e hiperatividade, entre outras), queixas atuais, tipo de intervenção em andamento, pontuação na escala *Childhood Autism Rating Scale* (CARS), idade do cuidador, número de filhos e renda familiar. A sobrecarga do cuidador foi avaliada por meio da escala *Zarit Burden Interview*. Para a análise estatística, utilizou-se regressão linear com método de seleção *stepwise*, a fim de identificar os fatores significativamente associados à sobrecarga. **Resultados**: Apenas a pontuação na escala CARS apresentou associação significativa com a sobrecarga do cuidador ($p = 0,0077$), indicando que níveis mais altos de comprometimento no TEA estão relacionados à maior sobrecarga. As variáveis idade e sexo do paciente, comorbidades, queixa atual, presença de intervenção no momento da avaliação e nível socioeconômico não foram significativas. **Conclusão**: A gravidade dos sintomas do TEA, refletida pela pontuação na escala CARS, foi o principal fator associado à sobrecarga dos cuidadores. Outros aspectos, como idade, comorbidades e nível socioeconômico, podem também exercer influência, conforme descrito pela literatura, mas não demonstraram associação estatisticamente significativa no presente estudo.

Palavras-chave: Transtorno do espectro autista; Sobrecarga do cuidador; Estresse psicológico; Comorbidades; Cuidadores

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[1]Faculdade de Medicina de Ribeirão Preto – FMRP, Universidade de São Paulo – USP – Ribeirão Preto (SP), Brasil.

[2]Hospital das Clínicas de Ribeirão Preto – HCRP, Faculdade de Medicina de Ribeirão Preto – FMRP, Universidade de São Paulo – USP – Ribeirão Preto (SP), Brasil.

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Corresponding author: Patrícia Aparecida Zuanetti. E-mail: pati_zua@yahoo.com.br

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INTRODUCTION

The prevalence of neurodevelopmental disorders has been increasing in recent years[1]. These disorders begin in childhood and directly influence child development, being characterized by deviations or delays in expected milestones for each age. Consequently, they negatively impact personal development, social interaction, and academic and professional performance, affecting the quality of life and adaptive behavior of related individuals[2].

Autism spectrum disorder (ASD) stands out among these disorders, with a significantly growing prevalence. Data from the Autism and Developmental Disabilities Monitoring Network indicate that the estimated prevalence in 2022 was 32.2 per 1,000 children (one in 31) among 8-year-old children in the United States, showing a continuous increase in recent decades[3]. On a global scale, systematic reviews indicate an average prevalence of 0.7%, with variations between geographic regions[4,5]. In Brazil, the 2022 Demographic Census estimated approximately 2.4 million people diagnosed with autism, corresponding to about 1% of the population[6].

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-Revised), ASD is characterized by persistent deficits in social communication and social interaction across multiple contexts, as well as restricted and repetitive patterns of behavior, interests, or activities, including sensory alterations and stereotypies[2]. Specifiers such as cognitive and language deficits may be present[2,7], in addition to associated conditions such as epilepsy and sleep disorders[2].

The signs of ASD manifest from early childhood, with different levels of complexity, which implies varied support needs[2]. Depending on the impairment, it may affect the occupational performance of children and adolescents, also impacting the personal and social lives of their caregivers[8]. These demands, often prolonged, require significant adaptations in family dynamics[9].

Studies indicate that mothers are generally the primary caregivers of children and adolescents with ASD, experiencing emotional overload associated with the search for diagnosis and treatment, feelings of loss for not having the idealized child, stress, fear, and prejudice[10].

Many interventions for neurodevelopmental disorders involve the active participation of the family, making it relevant to assess caregiver overload to understand the impact on family quality of life and interventions[11,12]. Evidence suggests that this overload can be reduced through health promotion strategies, qualified listening, and specialized services for the child and caregiver[13].

One of the first steps to improve care for children and adolescents with ASD and offer a more focused and qualified approach to the caregiver and family is to identify which variables are influencing this process. Hence, this study aimed to evaluate the factors associated with caregiver overload for children and adolescents with ASD, identifying which variables have the greatest impact on the daily lives of these caregivers.

METHODS

Ethical considerations

This study was conducted in accordance with the guidelines of the National Research Ethics Committee (CONEP) and submitted for evaluation by the Research Ethics Committee of the institution where it was carried out, under opinion number 4.686.520 (CAAE no. 45970721.0.0000.5440). Parents/guardians were not required to sign an Informed Consent Form (ICF) since the study collected data from medical records, and the parents/guardians, upon entering the institution, authorize the use of data collected in the healthcare setting for research purposes.

Study design, sample selection, and characterization

This is a cross-sectional, observational study, based on the retrospective analysis of previously collected data.

The study initially analyzed the electronic medical records of 72 children diagnosed with ASD, who had been evaluated by a multidisciplinary team; then, if the ASD diagnosis was confirmed, they were followed up by a pediatric neurologist in a specialized outpatient clinic for the treatment of this condition. The data analyzed were from February 2018 to February 2020, as the results necessary for this research were duly recorded in the medical records of patients treated during this period. Collection was interrupted in 2020 due to the COVID-19 pandemic, when the outpatient clinic began to operate on an emergency basis, exclusively serving patients already linked to the service, focusing on demands related to medication and inappropriate behaviors. From 2023, with the reopening for new cases, the screening flows and protocols were restructured due to changes in demand and availability of human resources, which made it impossible to continue collection with the same criteria used previously.

The following criteria were adopted to include participants: patients diagnosed with ASD, as verified by the multidisciplinary team of the specialized outpatient clinic; aged 2 to 12 years; and whose electronic medical record described the results of the instruments used in this study. The exclusion criteria were medical records with inconsistent/doubtful data regarding ASD diagnosis, incomplete data, and answers to the questionnaires provided by someone other than the child's main caregiver.

Thus, of the 72 medical records analyzed, the final sample comprised 19 dyads – i.e., questionnaires answered by 19 caregivers and data from 19 children aged 2 to 12 years; 18 children (94.74%) were male.

Instruments and procedures

Since this is a retrospective study, data were collected from each patient's medical records, including questionnaire data completed by the primary caregiver and data related to the child's characteristics.

The data obtained were patient's age and sex; presence of comorbidities (intellectual disability, attention-deficit/hyperactivity disorder [ADHD], epilepsy, and other

neuropsychiatric conditions); caregiver's complaints on the day the questionnaires were administered (e.g., speech/communication complaints, sleep complaints, food selectivity complaints, or others); intervention at the time the questionnaires were administered (e.g., psychotherapy, speech therapy, or occupational therapy); current score on the Childhood Autism Rating Scale (CARS)[14,15]; score on the Zarit Burden Interview (ZBI)[16,17]; and the caregiver's sociodemographic data (e.g., family income).

- CARS[14,15]: Its purpose is to assess the presence and severity of ASD symptoms in children. Although it was originally developed based on the DSM-IV criteria, it is still widely used, even with the changes brought about by the DSM-5. This is because the CARS remains a practical and reliable tool for autism screening, helping professionals identify signs of ASD and classify the severity of symptoms quantitatively. In addition, its clinical applicability and correlation with current criteria ensure its relevance in diagnosis and in assessing the progression of the condition.

This scale has 15 items that assess 14 domains of behaviors presented by ASD and one of general impressions about the disorder. The 14 domains on ASD symptoms include social reciprocity, imitation, emotional response, use of body and objects, response to changes, visual and auditory response, taste, smell and touch, fear or nervousness, verbal and nonverbal communication, activity level, and consistency of intellectual response. The score per domain is 1 for normal behavior, 2 for mild behavior, 3 for moderate behavior, and 4 for severe behavior. The final score is the sum of all items, ranging from 15 to 60. The severity level of symptoms is classified as follows: 15 to 30 = no autism, 30 to 36 = mild-moderate autism, and 36 to 60 = severe autism.

- ZBI[16,17]: This instrument assesses the caregiver's perception of their burden in caring for a patient with mental and/or physical disabilities during daily activities. Its 22 questions encompass the impact on personal and social life, physical and emotional health, financial situation, and interpersonal relationships.

The score is based on the points awarded for each item, which indicate how often the caregiver felt that way. The items are scored from 0 to 4, where 0 = never, 1 = rarely, 2 = sometimes, 3 = very often, 4 = almost always. In the last item (22), the response is given by the type of burden, where 0 = none, 1 = a little, 2 and 3 = quite a lot, and 4 = very much. The final result is calculated by the total sum of all items, ranging from 0 to 88. The possible results are as follows: less than 21 = absence of or little burden; 21 to 40 = moderate burden; 41 to 60 = moderate-to-severe burden; and 61 to 88 = severe burden. Inferential statistical analysis used the scale's total score.

- Sociodemographic/family income questionnaire: data were obtained through an instrument on family income, with questions about patient and caregiver identification, primary caregiver's education level, access to basic sanitation, type of dwelling and its ownership, availability of electricity, number of residents and degree of kinship, number of persons with a paid occupation, and monthly family income.

Data analysis

Descriptive statistics were used to characterize the sample. Statistical inference used a linear regression test with a stepwise selection method, via the Akaike Information Criterion (AIC), to find which of the researched variables influenced and were associated with caregiver burden. The variables selected for the regression model were ZBI score, CARS score, age, comorbidities (intellectual disability, ADHD, epilepsy, and others), speech/language, sleep, food selectivity, and/or behavioral complaints (e.g., aggressiveness/agitation), history of non-pharmacological intervention, caregiver's age, number of children, and family income.

RESULTS

The final sample consisted of 19 caregiver/child dyads. Regarding the caregivers' characteristics, 100% were female (mean age: 34.8 years; standard deviation: 5.6). Concerning the number of children, five (23.3%) women had only one child (the child diagnosed with ASD). The predominant family income was less than or equal to two minimum wages (42.1%) (Table 1).

Analysis of the burden on the 19 caregivers using ZBI scores[16,17] obtained a mean of 38.3 points (standard deviation: 13.5) (Table 2). Moderate and moderate-to-severe burden was observed among the caregivers, totaling 17 of them (89.5%).

Regarding the characterization of the 19 children with ASD (Table 3) (mean age: 8.4 years; standard deviation: 2.9), 18 were male (94.7%). Intellectual disability was the most prevalent comorbidity, present in six children (31%).

Table 4 presents the results of the linear regression model, aiming to analyze which variables of caregivers and children with ASD had the greatest impact on caregiver burden. The most significant variable was the CARS score, with a p-value of 0.0077, demonstrating that the presence and severity of signs/symptoms were the most significant factors impacting caregiver burden.

DISCUSSION

The burden on caregivers of children with ASD is a multifaceted phenomenon, involving physical, emotional, social, and financial aspects. The caregiver of a child with ASD (often their mother or primary caregiver) plays a central role in supporting the child's development[10]. Global studies reveal that more than 45% of caregivers experience depressive symptoms, a significantly higher rate than that observed in caregivers of children with other neurodevelopmental disorders[18]. This high level of stress not only compromises the physical and emotional well-being of the caregiver but can also directly affect the child's development, since the quality of interactions and stimuli largely depends on the caregiver's mental health and functioning. This global perspective highlights that caring for a child with ASD transcends therapeutic assistance alone, constituting a continuous and demanding process. The caregiver's mental health and resilience thus become determining factors for building a responsive and stimulating environment, capable of promoting the child's socio-emotional and adaptive development.

The burden faced by caregivers of children and adolescents with ASD became evident in this study: approximately 90%

Table 1. Characterization of the caregivers

Number of caregivers	N = 19			
	Mean	Standard Deviation	Frequency	%
Caregiver's (mother's) age	34.8	5.6		
Number of children				
Only 1 child (the child with ASD)			5	23.30%
More than 1 child			14	73.60%
Family income				
Not reported			5	23.30%
Less than or equal to 2 minimum wages			8	42.10%
More than 2 minimum wages			6	31.50%

Subtitle: ASD = autism spectrum disorder; % = percentage
Source: Developed by the authors

Table 2. Results of caregiver burden as measured by the Zarit Burden Interview

Number of caregivers	N = 19			
	Mean	Standard Deviation	Frequency	%
Score – Zarit Burden Interview	38.3	13.5		
Classification				
Absence of or little burden			1	5.20%
Moderate burden			8	42.10%
Moderate-to-severe burden			9	47.40%
Severe burden			1	5.20%

Subtitle: % = percentage
Source: Developed by the authors

Table 3. Distribution of variables in children and adolescents with autism spectrum disorder

Number of children and adolescents with ASD	N = 19			
	Mean	Standard Deviation	Frequency	%
Age	8.4	2.9		
Sex				
Females			1	5.20%
Males			18	94.70%
Comorbidities				
Intellectual disability			6	31.50%
Epilepsy			4	21.00%
ADHD			2	10.50%
Current speech/language complaints			13	68.40%
Current sleep complaints			6	31.50%
Current food selectivity complaints			4	21.00%
Intervention at the time of application*			6	31.50%
CARS score at the time of application*	40.7	49		
CARS classification				
Mild-moderate autism			8	42.10%
Severe autism			11	57.80%

*CARS was completed, along with questions regarding the intervention and complaints, on the same day the caregiver burden questionnaire was administered.
Subtitle: ASD = autism spectrum disorder; CARS = Childhood Autism Rating Scale; ADHD = Attention-Deficit/Hyperactivity Disorder; % = percentage
Source: Developed by the authors

Table 4. Result of the inferential analysis

	Estimate	p-value
Speech/language complaints at the time of assessment	-1.64	0.9042
CARS score at the time of assessment	1.04	0.0077*

*Presence of significance (α = 0.05) Linear regression with stepwise selection method via Akaike Information Criterion (AIC) selection criteria; the table shows only the variables selected by the stepwise selection method among all the variables collected.
Subtitle: CARS = Childhood Autism Rating Scale
Source: Developed by the authors

of participants were classified as having moderate to severe burden. This percentage is similar to that found in other studies, which also identified about 90% of caregivers with moderate to intense levels of burden[19]. These data reinforce the need for integrated actions that consider the child's needs as well as the caregiver's well-being, as a fundamental condition for the success of interventions in ASD.

The characterization of children diagnosed with ASD indicated a predominance of males, a finding widely documented in the literature. Also, the most frequent comorbidity was intellectual disability (31% of the sample in this study). Being male is considered a risk factor for the disorder, with significantly higher prevalence rates among boys than among girls[2,3,6]. This difference can be partially explained by the fact that girls, especially those with milder clinical presentations, tend to manifest symptoms less clearly and adopt social camouflage strategies, making it difficult to identify and diagnose the disorder[20]. Intellectual disability is described as one of the most frequent comorbidities of ASD. Currently, 39% of children with ASD in the United States of America have intellectual disability as a comorbidity[3].

Furthermore, the mother was the main caregiver for the child/adolescent with ASD, and most families' average income was up to two minimum wages (it should be noted that all patients in this study attended public healthcare). Studies indicate that mothers are the primary caregiver of children and adolescents with ASD[10,13,21], which makes them more prone to having a physical and emotional burden.

According to a study[10], mothers often take on the task of seeking treatment for their children; hence, they adapt their routines, dedicate themselves intensely to their care, and impoverish their social, emotional, and professional lives. Such accumulated responsibilities can generate significant strain, affecting these women's mental health and quality of life. In addition, maternal overload is often associated with a lack of family and institutional support, further hindering the ability to cope with daily difficulties[10]. Thus, care centered on mothers reinforces gender inequalities and a lack of social and marital support[22], highlighting the need for public policies and adequate support to minimize the negative impacts on these caregivers.

The burden on caregivers of children with ASD is strongly related to psychological, social, and economic factors. Studies indicate that the caregiver's mental health, especially symptoms of anxiety and depression, is directly associated with their quality of life and, consequently, the burden experienced[23]. Moreover, parental stress and the caregiver's dealing with adversity (i.e., their coping strategies) significantly influence the level of burden[23]. Higher socioeconomic status and education level stand out among the social and economic variables, which can reduce levels of depression[13-24], helping to improve mental health and cope with the situation. The level of family and marital support is also a relevant factor, since a lack of support can intensify the burden[22]. These findings reinforce the need for interventions aimed not only at the diagnosed child but also at the caregiver's well-being, including psychological support and social support programs.

Regarding variables related to children diagnosed with ASD, studies analyze the impact of autism severity[19], their level of autonomy[21], and communication[25]. In this context, the implementation of communication strategies, such as the Picture Exchange Communication System (PECS), can help reduce stress, promote greater independence for the child, and relieve the maternal burden[25]. The use of augmentative and alternative communication (AAC) resources among children with or without ASD helps to reduce challenging behaviors and expand their expressive and auditory vocabulary[25,26]. Although not all studies have found a statistically significant reduction in maternal burden, a decrease in cases of severe burden and a more positive perception of care are observed among mothers whose children participated in interventions with PECS – i.e., when communication was addressed through AAC[25].

In this study's final linear regression model, only some variables related to the child were significantly associated with caregiver burden. Specifically, the CARS score was the only statistically associated variable, indicating that the more intense the ASD signs and symptoms, the greater the caregiver burden. On the other hand, factors such as maternal age, family income, comorbidities, and multidisciplinary care were not significantly associated, although these variables may be indirectly related to the reduction of ASD symptoms. Access to appropriate therapies can contribute to this reduction, as can comorbidities such as ADHD and epilepsy, which, when left untreated, may negatively impact these children's development.

The small sample size stands out among the limitations of this study. Current published articles on the subject also have limited samples[13,19,25,27,28], with a number of participants similar to that of this study, or are based on qualitative analyses[13], which restricts the comparison of findings. Furthermore, the cross-sectional design makes it impossible to establish causal relationships between the variables analyzed, restricting the conclusions to the identification of associations.

It is also noteworthy that sociodemographic variables were not statistically significantly associated with caregiver burden, a result that should be interpreted with caution. This lack of association can be related to the small sample size, which may have limited the statistical power of the study to detect possible differences between the groups analyzed.

Nonetheless, these studies represent a starting point for understanding a topic that is becoming increasingly relevant in our society. Another aspect to be considered is the possible influence of uncontrolled variables, such as the level of social support, the time since diagnosis, and the presence of a family support network, which may interfere with the perception of burden, but were not included in the analysis. Additionally, the use of self-report instruments, although widely used in the literature, may introduce biases related to the subjectivity of the responses and the caregiver's momentary emotional state at the time of assessment.

It is suggested that future studies monitor children with ASD longitudinally, evaluating their evolution in terms of autonomy, communication, and socialization, as well as the progression of caregiver burden and quality of life. It is also essential to investigate the impact of mental health interventions in this population, analyzing their adaptation over time, rather than focusing only on a single moment. The inclusion of larger and more heterogeneous samples and the integration of objective and subjective measures of burden may increase the robustness of the findings and favor the generalization of the results.

From a practical and political point of view, the results of this study reinforce the need for implementing public policies that offer continuous psychological and social support to caregivers of people with ASD. The recognition that the severity of the child's symptoms is directly associated with caregiver burden indicates that intervention programs should include not only

the patient but also their family, ensuring multidisciplinary follow-up and shared care strategies.

This evidence can support managers and policymakers in expanding rehabilitation and family support services, helping to reduce parental stress, improve quality of life, and achieve greater adherence to therapeutic processes.

CONCLUSION

This research identified that the severity of ASD symptoms, measured by the CARS score, was the main factor associated with caregiver burden. This finding highlights that the more intense the ASD signs and symptoms, the greater the impact on the routine and well-being of caregivers, especially mothers, who often take on most of the responsibilities. Although other variables, such as maternal age, comorbidities, and socioeconomic level, may influence burden, they were not statistically significantly associated in this study.

The relevance of these results reinforces the need to deepen investigations into maternal burden in the context of ASD, considering its complexity and multiple factors. Expanding research in this area is essential to support public policies and care strategies that promote the quality of life of both children with ASD and their caregivers.

Finally, it is worth highlighting the need for future studies with larger samples and more robust methodological designs to overcome the limitations presented here and strengthen scientific evidence on the subject.

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