

Association Between the Level of Support for Children with ASD and the Caregiver's Quality of Life

Associação Entre o Nível de Suporte de Crianças com TEA e a Qualidade de Vida do Cuidador

Asociación Entre el Nivel de Apoyo a los Niños con TEA y la Calidad de Vida del Cuidador

RESUMO

Objetivo: Analisar a associação entre o nível de suporte necessário por crianças com Transtorno do Espectro Autista (TEA) e a qualidade de vida dos seus cuidadores. **Método:** Estudo quantitativo, transversal e analítico, realizado com 102 cuidadores de crianças com TEA atendidas em um município de Sergipe, Brasil. Foram aplicados questionários sociodemográficos e o WHOQOL-Bref. Os dados foram submetidos aos testes de Kruskal-Wallis, Mann-Whitney U e correlação de Spearman, adotando-se $p < 0,05$ como significância estatística. **Resultados:** A amostra foi composta majoritariamente por mulheres (95,1%), sem companheiro (52,9%) e com média de idade entre 31 e 40 anos. As crianças eram predominantemente do sexo masculino (72,5%), diagnosticadas principalmente com autismo infantil (89,2%). Observou-se correlação negativa significativa entre o nível de suporte exigido pela criança e os domínios físico, social, ambiental e satisfação com a saúde do cuidador, evidenciando que maiores demandas de suporte comprometem de forma expressiva a qualidade de vida. **Conclusão:** O aumento da necessidade de suporte da criança com TEA associa-se à piora da qualidade de vida do cuidador. Os achados ressaltam a importância de estratégias intersetoriais e do papel da Enfermagem na construção de ações de apoio que minimizem a sobrecarga e promovam o bem-estar desses indivíduos.

DESCRIPTORES: Transtorno do Espectro Autista; Qualidade de Vida; Cuidadores; Saúde Mental; Serviços de Saúde.

ABSTRACT

Objective: To analyze the association between the level of support needed by children with Autism Spectrum Disorder (ASD) and the quality of life of their caregivers. **Method:** Quantitative, cross-sectional, and analytical study conducted with 102 caregivers of children with ASD treated in a city in Sergipe, Brazil. Sociodemographic questionnaires and the WHOQOL-Bref were administered. Data were subjected to the Kruskal-Wallis, Mann-Whitney U, and Spearman correlation tests, adopting $p < 0.05$ as statistical significance. **Results:** The sample was composed mostly of women (95.1%), without a partner (52.9%), and with a mean age between 31 and 40 years. The children were predominantly male (72.5%), diagnosed mainly with childhood autism (89.2%). A significant negative correlation was observed between the level of support required by the child and the physical, social, and environmental domains, as well as the caregiver's health satisfaction, demonstrating that greater support demands significantly compromise quality of life. **Conclusion:** The increased need for support in children with ASD is associated with a worsening quality of life for the caregiver. The findings highlight the importance of intersectoral strategies and the role of nursing in developing support actions that minimize burden and promote the well-being of these individuals.

DESCRIPTORS: Autism Spectrum Disorder; Quality of Life; Caregivers; Mental Health; Health Services.

RESUMEN

Objetivo: Analizar la asociación entre el nivel de apoyo que necesitan los niños con Trastorno del Espectro Autista (TEA) y la calidad de vida de sus cuidadores. **Método:** Estudio cuantitativo, transversal y analítico realizado con 102 cuidadores de niños con TEA atendidos en una ciudad de Sergipe, Brasil. Se administraron cuestionarios sociodemográficos y el WHOQOL-Bref. Los datos se sometieron a las pruebas de Kruskal-Wallis, U de Mann-Whitney y correlación de Spearman, adoptando $p < 0,05$ como significación estadística. **Resultados:** La muestra estuvo compuesta mayoritariamente por mujeres (95,1%), sin pareja (52,9%) y con una edad media entre 31 y 40 años. Los niños eran predominantemente varones (72,5%), diagnosticados principalmente con autismo infantil (89,2%). Se observó una correlación negativa significativa entre el nivel de apoyo requerido por el niño y los dominios físico, social y ambiental, así como la

satisfacción con la salud del cuidador, lo que demuestra que una mayor demanda de apoyo compromete significativamente la calidad de vida. **Conclusión:** La mayor necesidad de apoyo en niños con TEA se asocia con un deterioro en la calidad de vida del cuidador. Los hallazgos resaltan la importancia de las estrategias intersectoriales y el papel de la enfermería en el desarrollo de acciones de apoyo que minimicen la carga y promuevan el bienestar de estas personas.

DESCRIPTORES: Trastorno del Espectro Autista; Calidad de Vida; Cuidadores; Salud Mental; Servicios de Salud.

RECEIVED: 09/30/2025 APPROVED: 10/15/2025

How to cite this article: Mahl C, Freitas CKAC, Oliveira YKC, Araújo YS, Lisboa AS. Association Between the Level of Support for Children with ASD and the Caregiver's Quality of Life. *Saúde Coletiva* (Edição Brasileira) [Internet]. 2025 [acesso ano mês dia];16(101):17376-17389. Disponível em: DOI: 10.36489/saudecoletiva.2025v16i101p17376-17389



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INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that manifests itself through persistent difficulties in communication, behavior, and social interactions. The intensity of the signs varies among individuals, which means that some require greater monitoring and daily support. The DSM-5 organizes this condition into three levels of support—from minimal to very substantial—a classification that guides both therapeutic strategies and the demands placed on the family and primary caregivers⁽¹⁾.

The literature has shown that caregivers of children with ASD face significant challenges that negatively im-

pact their quality of life. Among the most affected aspects are the physical, social, and environmental domains, often associated with overload, stress, and limitation of personal activities⁽²⁾.

Several factors aggravate this scenario, such as the absence of support networks, the accumulation of responsibilities, financial difficulties, and the fragility of public policies to support families⁽³⁾. These conditions contribute to increased physical and emotional exhaustion, affecting the caregiver's mental health and overall well-being.

Previous research also indicates that the growing need for support from children with ASD is directly related to the deterioration of the caregiver's quality of life. The greater

the demand for care, the greater the tendency for the health and social balance of these individuals to be compromised^(2,5).

Given this, it is essential to understand how the level of support required by the child interferes with different areas of the caregiver's life. This analysis provides input for intersectoral actions aimed not only at the development of children with ASD, but also at strengthening the physical, mental, and social health of those who take on the role of caregiver^(3,4).

METHOD

This is a cross-sectional, descriptive, and analytical study conducted with caregivers of children with Au-

tism Spectrum Disorder (ASD) who use the public health service in a municipality in the interior of Sergipe. The data collection period covered the months of May 2024 and November 2024. The study population included primary caregivers of children with ASD, aged up to 12 years, regis-

tered with the public health service.

To calculate the sample size, the estimated population of children with ASD in the city was considered ($N = 100$, obtained from 1%⁽⁶⁾ of 10,000 children ≤ 14 years old⁽⁷⁾). The formula for the finite population of Barbetta (2002)⁽⁸⁾ was applied.

using the Kolmogorov-Smirnov and Shapiro-Wilk tests. To compare the groups in terms of the child's level of support and the caregiver's quality of life, the Kruskal-Wallis test was used, followed by the Mann-Whitney U post hoc test to identify specific differences. The relationship between variables was verified using Spearman's correlation.

The research was approved by the Research Ethics Committee of the Federal University of Sergipe (CEP/UFS) on May 10, 2023, Opinion number 6,052,410, CAAE 68632623.1.0000.5546, ensuring compliance with the standards of CNS Resolution No. 510/2016. All participants signed the Free and Informed Consent Form (FICF), and measures were taken to ensure the privacy and well-being of the participants.

RESULTS

The sample consisted mainly of female caregivers (95.1%), with a mean age between 31 and 40 years (40.2%). Most participants did not have a partner (52.9%) and reported low average monthly income (R\$ 1,341.87; SD = 648.81). A significant portion of their total income was spent on the care of children with ASD, with an average investment of R\$ 584.31 per month (SD = 373.32) (Table 1).

Figure 1 – Sample calculation for finite populations (Barbetta formula).

$$n = \frac{\sigma^2 p \cdot q \cdot N}{e^2 (N - 1) + \sigma^2 p \cdot q}$$

onde: n = Tamanho da amostra

σ^2 = Nível de confiança escolhido, expresso em número de desvios-padrão

p = Percentagem com a qual o fenômeno se verifica

q = Percentagem complementar

N = Tamanho da população

e^2 = Erro máximo permitido

Source: adapted from "Figure 5. Sampling calculation for finite populations," ResearchGate.

Adopting a confidence level of 95% ($z = 1.96$), absolute sampling error of 5% ($e = 0.05$), and maximum heterogeneity $p = 0.5$. Substituting the values: numerator = $100 \times 1.96^2 \times 0.5 = 96.04$; denominator = $0.05^2 \times 99 + 1.96^2 \times 0.5 \times 0.5 = 0.2475 + 0.9604 = 1.2079$; therefore $n = 96.04/1.2079 = 79.51$, rounded up to $n = 80$ caregivers.

Caregivers over 18 years of age, legally responsible for the child and who have accompanied them in therapy for at least one year, were included. Caregivers of children without a confirmed diagnosis or with ASD secondary to genetic syndromes or specific neurological diseases were excluded.

Data were collected through structured interviews conducted by trained interviewers in a private setting within the municipality's specialty center. The questionnaire addressed socio-

demographic, clinical, and psychosocial data on the caregiver and child, in addition to the application of the WHOQOL-Bref⁽⁹⁾ to assess quality of life.

The data were analyzed using JASP software, version 15.0 (JASP Team, Amsterdam, 2024)⁽¹⁰⁾, using descriptive and inferential statistics; The normality of the variables was assessed

Table 1. Socioeconomic and health characteristics of primary caregivers of children with ASD in a municipality in the interior of Sergipe, Brazil, 2025.

Variable	n	%
Gender		
Female	97	95,1
Male	5	4,9
Age		
Up to 30 years old	34	33,3
31 to 40 years old	41	40,2
Over 40	27	26,5

Has a partner		
Yes	48	47,1
No	54	52,9
Has support in caregiving		
Yes	47	46,1
No	55	53,9
Monthly income (R\$)	Média ± DP	1341,87 ± 648,81
Monthly investment in the child (R\$)	Média ± DP	584,31 ± 373,32

Source: Survey data, 2025.

Regarding the children, there was a predominance of males (72.5%) and a mean age of 6.9 years (SD = 2.89). The most frequent diagnosis was Childhood Autism (F84.0), present in 89.2% of cases. Regarding the support needed, more than half required minimal support (52.9%), while 26.5% needed very substantial support (Table 2).

Table 2. Clinical characteristics of children with ASD in a municipality in the interior of Sergipe, Brazil, 2025.		
Variable	n	%
Sex		
Female	28	27,5
Male	74	72,5
Age (years)	Média ± DP	6,88 ± 2,89
ASD Diagnosis		
Childhood Autism (F84.0)	91	89,2
Atypical Autism (F84.1)	6	5,9
Pervasive Developmental Disorder (F84.8)	4	4,0
Hyperkinetic Disorder (F84.4)	1	1,0
Level of Support Required		
Minimal support	54	52,9
Substantial support	21	20,6
Very substantial support	27	26,5

Source: Survey data, 2025.

Table 3 shows the comparison between the levels of support for the child and the domains of caregivers' quality of life. The Kruskal-Wallis test indicated statistically significant differences in the physical ($p = 0.023$), social ($p = 0.006$), environmental ($p = 0.010$), and health satisfaction ($p < 0.001$) domains, suggesting that caregivers' quality of life varies according to the level of support required by the child. The Mann-Whitney U post hoc test revealed that the most striking differences occur between caregivers of children with minimal support and very substantial support, indicating that caregivers of children who require greater support have a poorer quality of life in these domains. In addition, a significant difference was observed between the substantial support level and the very substantial support level in health satisfaction ($p = 0.013$), suggesting that the increased need for support directly impacts the caregiver's perception of their health.

Table 3. Comparison of caregivers' quality of life domains according to the level of support needed by children with ASD in a municipality in the interior of Sergipe, Brazil, 2025.

Domain	Kruskal-Wallis χ^2 (p-value)	Post Hoc (Mann-Whitney U) Comparison between Groups		
		NIVSUP 1 vs 2	NIVSUP 2 vs 3	NIVSUP 2 vs 3
Physical	7,566 (p = 0,023)	p = 0,142	p = 0,283	p = 0,283
Social	10,245 (p = 0,006)	p = 0,077	p = 0,257	p = 0,257
Environmental	9,279 (p = 0,010)	p = 0,126	p = 0,566	p = 0,566
Health satisfaction	15,432 (p = 0,000)	p = 0,157	p = 0,013	p = 0,013

Source: Survey data, 2025.

To complement the analysis, Spearman's correlation was performed between the level of support needed by the child and the domains of caregivers' quality of life (Table 4). The results indicated negative and statistically significant correlations in the physical ($\rho = -0.273$, $p = 0.005$), social ($\rho = -0.318$, $p = 0.001$), environmental ($\rho = -0.303$, $p = 0.002$), and

health satisfaction ($\rho = -0.377$, $p < 0.001$) domains. These findings reinforce that the greater the child's need for support, the worse the caregiver's quality of life in these aspects.

The domain with the greatest impact was health satisfaction ($\rho = -0.377$, $p < 0.001$), suggesting that caregivers of children with greater support needs report a worse perception of their own health. In contrast,

the psychological domain ($\rho = -0.121$, $p = 0.226$) and overall perception of quality of life ($\rho = -0.030$, $p = 0.763$) did not show a significant correlation with the child's level of support, indicating that, although the support required affects several aspects of quality of life, caregivers seem to maintain a certain emotional stability and overall perception of quality of life.

Table 4. Spearman's correlation between the level of support provided to the child and the domains of quality of life of caregivers in a municipality in the interior of Sergipe, Brazil, 2025.

Quality of Life Domain	Spearman's correlation (ρ)	p-value
Physical	-0,273	0,005
Psychological	-0,121	0,226
Social	-0,318	0,001
Environmental	-0,303	0,002
Perception of Quality of Life	-0,030	0,763
Satisfaction with Health	-0,377	0,000

Legend: Negative ρ indicates that the greater the support needed by the child, the lower the caregiver's quality of life. $p < 0.05$ indicates statistical significance (significant correlations are highlighted in bold).

Source: Survey data, 2025.

DISCUSSION

The data analysis shows a socioeconomic profile characterized predominantly by female caregivers. This finding is consistent with the literature, which points out that family care has historically been attributed to women as wives, mothers, sisters, and daughters, reflecting a long-standing cultural process. Another point to highlight

is the significant number of caregivers who did not have partners, a relevant aspect, since social support plays a fundamental role in reducing overload, providing greater acceptance and security in child care⁽¹¹⁾.

With regard to the epidemiology of ASD, studies indicate a prevalence approximately four times higher in boys than in girls⁽¹²⁾, corroborating the results found in this study.

Another relevant finding refers to the impact of the level of support required by the child on the quality of life (QoL) of caregivers. Our results reinforce recent evidence^(13,14) that

increased care demands have a negative impact on physical, social, environmental, and health satisfaction domains. The negative correlation between greater need for support and poorer perception of health highlights the burden experienced by caregivers, which tends to intensify as the complexity of care increases.

Previous studies have shown that caregivers of children with ASD face high physical and emotional stress, as well as limitations in social and financial aspects of life. The use of the WHOQOL-BREF in this study allowed us to identify these vulnerabili-

ties in a multidimensional way, aligning with other investigations that point to the environmental and social domains as the most compromised⁽¹⁵⁾.

In this context, social support from family, friends, and social groups plays a central role in mitigating overload, offering practical and emotional resources that help relieve tension and provide valuable tools and a foundation for the family to deal with ASD and the changes inherent in the diagnosis. Conversely, the absence of a consistent support network can trigger emotional overload, stress, and worsening mental health in caregivers^(16,17).

Nursing, as a profession committed to comprehensive, family-centered care, plays a strategic role in the early identification of these difficulties and in the development of adaptive coping strategies with caregivers. Nurses, as part of multidisciplinary teams, can welcome, guide, and refer caregivers, in addition to promoting educational and emotional support actions that contribute to reducing the negative impact of overload.

The stratification of caregivers according to the levels of support provided to the child—based on the DSM-5⁽¹⁾—is a unique feature of

this study, as it allows for a more refined analysis of the relationship between the intensity of care and the domains of QoL. This provides practical support for health professionals, especially nurses, to develop targeted interventions according to the caregiver's profile and needs, strengthening longitudinal care.

These findings have significant implications for nursing practice, particularly in primary health care, where nurses can play a key role in coordinating support networks, implementing listening groups, integrative practices, and continuous assessment of caregivers' psychosocial conditions. In addition, they can inform public policies aimed at assisting families of children with ASD.

This study has some limitations that should be considered. The sample was restricted to a single municipality, which may limit the generalization of the findings to other sociocultural realities. In addition, the cross-sectional design makes it impossible to establish causal relationships between the variables investigated. Future research should include larger, multi-center samples and adopt longitudinal designs that allow for monitoring the evolution of caregivers' quality of

life over time. Qualitative investigations are also recommended in order to deepen understanding of the subjective experiences of caregiving and identify coping strategies that can support more effective interventions.

CONCLUSION

The results show that caregivers of children with Autism Spectrum Disorder who need greater support have a poorer quality of life in the physical, social, environmental, and health domains. The level of support required by the child directly impacts the caregiver's perception and well-being, reinforcing the importance of strategies aimed at promoting the health of these individuals.

In this context, nursing plays a central role in recognizing the caregiver as an integral part of the care process, acting to identify specific demands and implement individualized and collective interventions that favor the reduction of overload, the strengthening of support networks, and the improvement of quality of life. By adopting this stance, nursing practice contributes to the construction of more humane, equitable, and effective care.

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ACKNOWLEDGMENTS, FINANCIAL OR TECHNICAL SUPPORT, DECLARATION OF FINANCIAL CONFLICT OF INTEREST AND/OR AFFILIATIONS:

Acknowledgements

We are grateful for the support of the Federal University of Sergipe through its research program (COPES/PIBIC).

Financial and/or Technical Support

This work received financial support from COPES through public notice no. 01/2025, which enabled the implementation and maintenance of the research.

Declaration of Conflict of Interest

The authors declare that they have no financial conflicts of interest or affiliations that may have influenced the results or interpretations of this work .