Artículo de investigación

Perceived Quality of Life in Parents of Children with Autism Spectrum Disorder

Calidad de vida percibida por los padres de niños con trastorno del espectro autista

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Abstract

Objective: To examine the relationships among generic quality of life, caregiver burden, and autism-specific quality of life in primary caregivers of children and adolescents with Autism Spectrum Disorder (ASD) using complementary validated assessment instruments.

Methods: This cross-sectional study included 105 primary caregivers of children and adolescents with ASD. Participants were recruited from specialized services in Minas Gerais, Brazil. Caregivers completed the Brazilian Economic Classification Criterion, the World Health Organization Quality of Life Assessment (WHOQOL-BREF), the Zarit Caregiver Burden Interview, and the Quality of Life of Caregivers of Children and Adolescents with ASD (QVTEA). Correlations among caregiver burden, quality of life, educational level, and socioeconomic status were examined.

Results: Most participants were mothers (n = 96). Caregivers reported reduced quality of life and moderate to high levels of caregiver burden, with the physical domain presenting the lowest WHOQOL-BREF scores. Higher educational attainment was associated with higher socioeconomic status. Significant correlations were observed among the assessment instruments: greater caregiver burden was associated with poorer generic quality of life and poorer autism-specific quality of life. No significant association was found between socioeconomic status and caregiver burden or quality of life.

Conclusion: Primary caregivers of children and adolescents with ASD experience substantial caregiver burden and reduced quality of life. The combined use of complementary assessment instruments provided a broader understanding of caregivers' experiences and may support family-centered assessment and intervention strategies in clinical practice and research.

Keywords

Autism spectrum disorder; parents; family relations; gender role; caregiver burden; quality of life

Resumo

Objetivo: Examinar as relações entre qualidade de vida geral, sobrecarga do cuidador e qualidade de vida específica relacionada ao autismo em cuidadores principais de crianças e adolescentes com Transtorno do Espectro Autista (TEA), utilizando instrumentos complementares validados.

Métodos: Estudo transversal com 105 cuidadores principais de crianças e adolescentes com TEA. Os participantes foram recrutados em serviços especializados de Minas Gerais, Brasil. Foram aplicados o Critério de Classificação Econômica Brasil, o World Health Organization Quality of Life Assessment (WHOQOL-BREF), a Zarit Caregiver Burden Interview e o Quality of Life of Caregivers of Children and Adolescents with ASD (QVTEA). Foram analisadas as relações entre sobrecarga do cuidador, qualidade de vida, escolaridade e nível socioeconômico.

Resultados: A maioria dos participantes era composta por mães (n = 96). Os cuidadores apresentaram redução da qualidade de vida e níveis moderados a elevados de sobrecarga, sendo o domínio físico do WHOQOL-BREF o mais comprometido. Maior escolaridade esteve associada a uma melhor classificação socioeconômica. Foram observadas correlações significativas entre os instrumentos de avaliação: maior sobrecarga esteve associada à pior qualidade de vida geral e à pior qualidade de vida específica relacionada ao autismo. Não foi observada associação significativa entre nível socioeconômico e sobrecarga ou qualidade de vida.

Conclusão: Cuidadores principais de crianças e adolescentes com TEA apresentam elevada sobrecarga e redução da qualidade de vida. A utilização conjunta de instrumentos complementares permitiu uma compreensão mais abrangente da experiência dos cuidadores e pode contribuir para avaliações e intervenções centradas na família na prática clínica e na pesquisa.

Palavras-chave

Transtorno do espectro autista; pais; relações familiares; papel de gênero; sobrecarga do cuidador; qualidade de vida

Resumen

Objetivo: Examinar las relaciones entre la calidad de vida general, la sobrecarga del cuidador y la calidad de vida específica relacionada con el autismo en cuidadores principales de niños y adolescentes con Trastorno del Espectro Autista (TEA), utilizando instrumentos complementarios validados.

Métodos: Estudio transversal realizado con 105 cuidadores principales de niños y adolescentes con TEA. Los participantes fueron reclutados en servicios especializados del estado de Minas Gerais, Brasil. Se aplicaron el Criterio de Clasificación Económica de Brasil, el World Health Organization Quality of Life Assessment (WHOQOL-BREF), la Zarit Caregiver Burden Interview y el Quality of Life of Caregivers of Children and Adolescents with ASD (QVTEA). Se analizaron las relaciones entre la sobrecarga del cuidador, la calidad de vida, el nivel educativo y el nivel socioeconómico.

Resultados: La mayoría de los participantes fueron madres (*n* = 96). Los cuidadores presentaron una reducción de la calidad de vida y niveles moderados a elevados de sobrecarga, siendo el dominio físico del WHOQOL-BREF el más afectado. Un mayor nivel educativo se asoció con una mejor clasificación socioeconómica. Se observaron correlaciones significativas entre los instrumentos de evaluación: una mayor sobrecarga se asoció con una peor calidad de vida general y una peor calidad de vida específica relacionada con el autismo. No se encontró una asociación significativa entre el nivel socioeconómico y la sobrecarga del cuidador o la calidad de vida.

Conclusión: Los cuidadores principales de niños y adolescentes con TEA presentan una elevada sobrecarga y una reducción de la calidad de vida. El uso combinado de instrumentos de evaluación complementarios permitió una comprensión más amplia de la experiencia de los cuidadores y puede contribuir al desarrollo de estrategias de evaluación e intervención centradas en la familia tanto en la práctica clínica como en la investigación.

Palabras clave

Trastorno del espectro autista; padres; relaciones familiares; rol de género; carga del cuidador; calidad de vida

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition characterized by differences in social communication and interaction, as well as restricted or repetitive patterns of behavior, interests, or activities. Individuals on the autism spectrum present diverse profiles of strengths, challenges, and support needs, which vary considerably across the lifespan (American Psychiatric Association, 2022). These characteristics may influence development, participation, and daily functioning to varying degrees depending on the individual's support needs and the interaction between personal and environmental factors (American Psychiatric Association, 2022; World Health Organization, 2001).

Given that autism may influence participation and functioning across different life domains, an ASD diagnosis often affects not only the autistic individual but also the experiences and routines of the entire family. Upon receiving the diagnosis, family members often experience distress and helplessness, requiring emotional support and encouragement to care for their child (Fonsêca et al., 2024; Magalhães et al., 2021). The family, regardless of its structure (nuclear or traditional, remarried, single-parent, homosexual, etc.), will be impacted by the diagnosis and the development of the condition. Although every family has unique characteristics, the diagnosis of ASD has repercussions for all families. Nevertheless, the ways in which families respond to and adapt to these challenges vary according to their individual circumstances, resources, and contextual factors (Figueiredo et al., 2020). Following diagnosis, many families experience uncertainty regarding their child's future, available interventions, long-term support needs, and future expectations. These experiences are shaped not only by the child's characteristics but also by families' access to information, services, financial resources, and social support (Figueiredo et al., 2020; Pellicano & den Houting, 2022). Consequently, the moment of diagnosis represents a complex scenario that disrupts family identity, functioning, and structure, leading to feelings such as grief, denial, and guilt, particularly among parents (Passos & Kishimoto, 2022).

The manner in which the diagnosis is communicated to the family can influence its impact (Aguiar & Pondé, 2020). Despite increased attention to the subject in recent years, information about ASD and access to appropriate services and resources remain difficult for many families. As a result, caregivers often struggle to obtain reliable guidance about the diagnosis and to identify the interventions and support needed to address their child's developmental needs (Segeren & Françozo, 2014).

Beyond understanding the diagnosis itself, many families experience considerable challenges in navigating health, educational, and social care systems. Delays in obtaining specialized assessments and interventions, fragmented service provision, financial constraints, and limited availability of family-centered support may substantially increase caregiver stress. Consequently, caregiver well-being is influenced not only by the child's support needs but also by broader environmental and systemic factors that shape access to opportunities and participation (Kapp, 2020; Pellicano & den Houting, 2022; World Health Organization, 2001). Experiences of stigma and social exclusion may further limit families' access to community participation, support networks, and appropriate services, thereby contributing to caregiver burden and reducing quality of life (Pellicano & den Houting, 2022).

Recent neurodiversity-informed perspectives propose that autism should be understood as a natural form of human neurodevelopmental diversity, while acknowledging that many autistic individuals continue to require individualized and sometimes substantial support throughout life. From this perspective, many of the challenges experienced by autistic individuals and their families emerge from the interaction between individual characteristics and environmental barriers, including stigma, insufficient institutional support, and limited opportunities for participation. This perspective complements, rather than replaces, the clinical understanding of autism by recognizing both the diversity of autistic experiences and the support needs of many autistic people and their families (Kapp, 2020; Leadbitter et al., 2021; Liñares-de-Marcos et al., 2026; Pellicano & den Houting, 2022).

As a result, most families report feelings of vulnerability upon receiving the diagnosis and struggle to cope with the diagnosis and its implications for their child's development and future participation (Magalhães et al., 2021). Evidence indicates that within a nuclear family, the maternal figure is the most affected and burdened emotionally, psychologically, and physically. Social expectations often place the primary responsibility for the child's care on the mother rather than the father, leading to a loss of occupational roles and a life increasingly centered around the diagnosis. Common feelings expressed by these mothers include uncertainty, sadness, disbelief, and guilt (Passos & Kishimoto, 2022). In contrast, fathers typically focus on meeting the family's financial needs and prioritize work commitments, although these caregiving roles may vary according to family composition, socioeconomic conditions, and cultural contexts (Figueiredo et al., 2020). These caregiving responsibilities should also be understood within broader sociocultural contexts in which gender roles and unequal access to formal

support services may contribute to disparities in caregiver burden (Pellicano & den Houting, 2022).

Recent evidence indicates that caregiver quality of life is determined by multiple interacting factors rather than by the child's characteristics alone. A similarly multidimensional pattern has been identified among caregivers of children and adolescents with chronic conditions (Cardoso et al., 2021). Limited social support, financial strain, caregiving demands, and difficulties accessing specialized services have consistently been associated with increased caregiver burden and poorer quality of life. Conversely, strong social support networks and coordinated family-centered services appear to buffer stress and promote caregiver well-being (Bermeo et al., 2025; Rezq et al., 2025; Simpson et al., 2024). These findings reinforce the importance of adopting family-centered approaches that address not only children's developmental needs but also caregivers' health, participation, and quality of life.

In light of these considerations, understanding the impact of caring for a child with ASD on family experiences and caregiver well-being, as well as the factors that shape caregiver well-being, is essential. Strengthening professional practices directed toward families is particularly important, as caregivers represent the primary source of support for autistic children and adolescents. Although an increasing number of studies have investigated caregiver burden or quality of life, these constructs have often been examined independently. However, caregiver well-being is multidimensional and cannot be fully captured by a single outcome measure. Generic quality of life, caregiver burden, and autism-specific quality of life represent complementary dimensions of caregivers' experiences, each providing distinct but interrelated information about family functioning. Simultaneously assessing these constructs through complementary validated instruments may offer a more comprehensive understanding of caregivers' experiences and help identify different targets for clinical practice, family-centered interventions, and public policies (Simpson et al., 2024; Skevington et al., 2004). Furthermore, despite the growing body of international research, evidence from Brazil remains limited, highlighting the need for studies that consider the specific sociocultural context of Brazilian families. Therefore, this study aimed to examine the relationships among generic quality of life, caregiver burden, and autism-specific quality of life in primary caregivers of children and adolescents with ASD using complementary validated assessment instruments.

Methods

Study Design and Ethics

This was an observational, cross-sectional, descriptive study of a quantitative nature, conducted from March 2024 to April 2025, in accordance with STROBE recommendations. The impact of an ASD diagnosis on the quality of life and burden of primary caregivers was analyzed.

This study was approved by the Research Ethics Committee of the Federal University of Minas Gerais (CAAE: 65802722.9.0000.5149; protocol No. 5.926.970, 06/03/2023). All participants were informed of the procedures, agreed to participate, and signed the Informed Consent Form (ICF).

Participants

The sample size calculation was based on a study that assessed 52 relatives of children diagnosed with ASD (Pisula & Porębowicz-Dörsmann, 2017). Considering a statistical power of 90%, a significance level of 5%, and the inclusion of multiple outcome variables, a sample of 105 caregivers of children with ASD was considered adequate to investigate the impact of the diagnosis on family relationships and caregivers' quality of life.

Participants in this study were recruited from both public and private services specializing in the care of children and adolescents with ASD in Minas Gerais, Brazil. Family members or primary caregivers of children and adolescents diagnosed with ASD were included. Conversely, family members and/or primary caregivers of children with diagnoses other than ASD were excluded from this study.

Procedures

Data collection was conducted through interviews held on a single occasion, either in person or online, based on the caregivers' preference. Both modalities followed the same standardized interview protocol. The process involved administering the World Health Organization Quality of Life Assessment (WHOQOL-BREF), the Brazilian Economic Classification Criterion (BECC), the Zarit Caregiver Burden Interview Scale, and the *Questionário de Qualidade de Vida de Cuidadores de Crianças e Adolescentes com Transtorno do Espectro Autista* (QVTEA). All interviews and questionnaires were administered jointly by two researchers trained in data collection. Inter-examiner reliability was verified ($\kappa = .87$).

World Health Organization Quality of Life Assessment (WHOQOL-BREF)

The WHOQOL-BREF consists of 26 questions, with two general questions on quality of life and the remaining 24 representing each of the 24 facets comprising the original instrument. Each domain (psychological, physical, social, and environmental) receives an average score from 1 to 5, where higher scores denote a higher quality of life. Therefore, averages between 1 and 2.9 are classified as "needs improvement," from 3 to 3.9 as "fair," from 4 to 4.9 as "good," and an average of 5 as "very good" (World Health Organization, n.d.).

Zarit Caregiver Burden Interview Scale

This questionnaire comprises 22 questions focused on identifying signs of burden experienced by the caregiver. Responses include never (0), rarely (1), sometimes (2), frequently (3), and always (4). The total score is obtained by summing the scores for all questions and ranges from 0 to 88 points. Scores from 0 to 20 indicate little or no burden, 21 to 40 indicate mild to moderate burden, 41 to 60 indicate moderate to severe burden, and scores above 61 are classified as severe burden (Gratão et al., 2019).

Questionnaire on the Quality of Life of Caregivers of Children and Adolescents with Autism Spectrum Disorder (QVTEA)

This questionnaire was developed to assess the quality of life of caregivers of children and adolescents with ASD, comprising 28 items. Response options include always, almost always, sometimes, almost never, and never. Developed in Brazil as part of a master's thesis in 2021, it addresses aspects related to self-care, depressive symptoms, social support, and caregiving for children diagnosed with ASD (Garcia, 2021).

The possible responses to each question were associated with a Likert scale ranging from 1 to 5, where lower scores indicate less impact of caregiving on daily life (Garcia, 2021).

Brazilian Economic Classification Criterion (BECC)

The Brazilian Economic Classification Criterion (BECC) is a system for classifying the purchasing power of the Brazilian population, dividing the market into economic

classes. It is based on the possession of consumer goods and the education level of the head of the household, and it classifies the classes as A1, A2, B1, B2, C1, C2, and DE. Scores between 0 and 16 points are classified as DE; scores from 17 to 22 points as class C2; 23 to 28 points as class C1; 29 to 37 points as class B2; 38 to 44 points as class B1; and 45 points or more as class A, with a maximum possible score of 100 points. It can be used to classify families by social class (Associação Brasileira de Empresas de Pesquisa, 2024).

Data Analysis

Qualitative variables were expressed as absolute frequencies and percentages. The Gaussian distribution of quantitative variables was verified using the Shapiro–Wilk test. All quantitative variables were treated as parametric. The Pearson correlation coefficient was used for correlation analysis.

Statistical analyses were performed using IBM SPSS Statistics® software version 22.0 (IBM SPSS Statistics, Armonk, NY, USA).

Results

The participant group in this study consisted of 105 primary caregivers of children or adolescents with ASD, with a mean age of 39.88 years (*SD* = 7.13), including 96 mothers and nine fathers. Regarding the caregivers' occupations, 34.29% were homemakers, all of whom were women, while 65.71% held formal jobs. Concerning the families' income, the Brazilian Economic Classification Criterion revealed that most of the sample was classified at level B2, with a total income of R$5,755.23/US$1,151.05, and at level C1, with a total income of R$3,276.00/US$655.20. USD equivalents were calculated using a fixed exchange rate of R$5.00 per US$1.00. Regarding the children, 100% had a confirmed diagnosis of ASD, with 5.72% having additional comorbidities such as attention-deficit/hyperactivity disorder (ADHD) and/or dyslexia. The majority of the children were male (77.14%), aged 3 to 13 years, with an average age of 6 years. In terms of education, the predominant levels were completed high school, with 33 of the interviewed caregivers (31.43%), and completed higher education, with 39 respondents (37.14%) (Table 1).

Table 1
Sociodemographic characteristics of the study sample

Variables	*n* (%)
Relationship	
Mother	96 (91.43)
Father	9 (8.57)
Gender of the child	
Male	81 (77.14)
Female	24 (22.86)
Diagnosis	
ASD	99 (94.29)
ASD and ADHD	3 (2.86)
ASD, ADHD, and dyslexia	3 (2.86)
Family structure	
Single-parent family	27 (25.71)
Nuclear family	78 (74.29)
Socioeconomic classification (BECC)	
A	18 (17.14)
B1	15 (14.29)
B2	36 (34.29)
C1	30 (28.57)
C2	6 (5.71)
Education level	
Completed elementary school	3 (2.86)
Completed high school	33 (31.43)
Incomplete higher education	12 (11.43)
Completed higher education	39 (37.14)
Postgraduate	15 (14.29)
Postgraduate in progress	3 (2.86)
Caregivers' age	39.9 (7.13)*
Child's age	6.3 (2.52)*

Note. **M* (*SD*). ASD = Autism Spectrum Disorder; ADHD = attention-deficit/hyperactivity disorder; BECC = Brazilian Economic Classification Criterion; *SD* = standard deviation.

The analysis provided insights into the quality of life and perceived health of the participants, highlighting various aspects through specific questionnaires. Regarding caregiver burden, the Zarit questionnaire showed a mean score of 45.8, indicating a considerable level of burden, with a standard deviation of 15.38, suggesting variability in participants' responses. The analysis of quality of life using the WHOQOL-BREF showed mean scores across different domains, reflecting a fair assessment, although the standard deviation indicated some variability in responses, particularly in the physical domain. According to the domains assessed in the WHOQOL-BREF questionnaire, a lower mean was observed in the physical

domain, classified as “needs improvement” (2.95), while all other domains had means classified as “fair” (between 3 and 3.9). The QVTEA questionnaire, which addresses mental and physical health, social aspects, and concerns, presented mean scores that reflected an overall unfavorable perception of quality of life (Table 2).

Regarding the QVTEA, the analysis of response frequencies showed a mean score of 83.57, equivalent to 60% of the total possible points, indicating a significant impact on the quality of life of the families within the sample. Among these, the mean scores in the areas of concern and mental health were the highest, at 23.29 and 23.09, respectively. However, the standard deviations in some dimensions revealed variations in responses, highlighting the complexity and individuality of participants' perceptions of their quality of life and health.

Table 2
Results obtained in the questionnaires

Questionnaires	*M* (*SD*)
Zarit	45.8 (15.38)
WHOQOL-BREF	
Perception of quality of life	3.37 (0.88)
Satisfaction with health	3 (1.09)
Physical domain	2.95 (0.45)
Psychological domain	3.26 (0.48)
Social relationships	3 (0.73)
Environment	3.03 (0.63)
QVTEA	
Mental health	23.09 (6.14)
Physical health	16.23 (3.38)
Social aspects	20.97 (1.06)
Concerns	23.29 (4.82)
Total	83.57 (14.69)

Note. SD = standard deviation; WHOQOL-BREF = World Health Organization Quality of Life–BREF; QVTEA = Quality of Life of Caregivers of Children and Adolescents with Autism Spectrum Disorder.

The Pearson correlation test revealed a correlation between the respondents' education level and the economic classification of the family unit (p = .565). Thus, individuals with higher education levels in the sample were classified in higher economic tiers. Additionally, a correlation was observed between the results of the questionnaires: caregivers who scored higher on the Zarit questionnaire also obtained higher scores on the QVTEA and lower scores on the WHOQOL, and vice versa. This demonstrates an inverse proportionality between the results of these

questionnaires, with significance levels below .05. These findings suggest significant impacts on the quality of life of these family members. Therefore, family members who reported higher levels of burden and stress also reported greater impacts on their quality of life. On the other hand, our study did not find a correlation between socioeconomic status and quality of life or stress (p = .114).

Discussion

The present findings suggest that caring for children and adolescents with ASD may substantially affect caregivers' quality of life and perceived burden. Rather than reflecting caregiving demands alone, these findings highlight the complex interaction between individual, family, and contextual factors that shape caregivers' well-being. This interpretation is consistent with contemporary biopsychosocial and socioecological perspectives, which recognize caregiver well-being as the result of dynamic interactions between children's support needs, family resources, environmental barriers, and access to coordinated support systems.

Within this broader context, the diagnosis of ASD often represents a critical turning point for families and may be experienced in distinct and ambivalent ways. As a complex neurodevelopmental condition affecting communication, social interaction, and behavior, ASD may lead families to attribute different meanings to the diagnosis (Gomes et al., 2015). While some caregivers perceive the diagnosis as a source of suffering and uncertainty, others report a sense of relief resulting from a clearer understanding of their child’s behaviors and support needs. This emotional adjustment process is often accompanied by feelings such as guilt, fear, grief, anger, and anxiety (Gomes et al., 2015). Among mothers, adjustment may also be influenced by autism knowledge and cultural context (Gordillo et al., 2020).

The emotional impact of the diagnosis, combined with the ongoing demands of care, may result in sustained psychological stress that affects family functioning and quality of life. Caregivers of children with ASD frequently experience higher levels of stress, depression, and anxiety, as well as poorer physical health, which collectively contribute to reduced quality of life (Rezq et al., 2025). These findings are consistent with the results observed in the present study, in which caregivers reported substantial burden and compromised well-being across multiple life domains.

Although caregiving burden is frequently conceptualized as an individual or family outcome, contemporary socioecological perspectives suggest that caregiver well-being emerges from the interaction between personal, family, community, and societal factors. Beyond children's support needs, environmental barriers—including fragmented health and educational services, limited access to coordinated family-centered care, financial constraints, social stigma, and insufficient

institutional support—may substantially amplify caregivers' psychological distress and reduce opportunities for social participation. From this perspective, caregiver burden should not be interpreted solely as a consequence of autism itself but rather as the result of dynamic interactions between individual characteristics and environmental contexts. This interpretation is consistent with recent integrative models that combine neurodiversity perspectives with quality-of-life frameworks, recognizing that both autistic individuals and their families experience outcomes shaped by societal structures as much as by individual support needs (Leadbitter et al., 2021; Liñares-de-Marcos et al., 2026; Pellicano & den Houting, 2022).

In the present study, primary caregiving was predominantly provided by women, particularly mothers, a finding that is consistent with previous research (Rondini et al., 2011). Traditionally, women's social roles have been closely associated with domestic responsibilities, motherhood, and caregiving activities. However, most caregivers in this sample also reported formal employment, reflecting broader social changes related to women's participation in the workforce and the reconfiguration of female identity over time (Pasquoto de Freitas & Moraes da Costa, 2020).

Despite advances in women's social and professional inclusion, caregiving responsibilities continue to disproportionately affect women. Employed women often face a double workload, balancing paid employment with domestic and caregiving tasks, which intensifies physical and emotional exhaustion (Duarte & Spinelli, 2019). National data indicate that women dedicate significantly more time than men to unpaid domestic work and care activities, whether employed or not (Instituto Brasileiro de Geografia e Estatística, 2023). This unequal distribution of responsibilities may help explain the elevated burden and reduced quality of life observed among female caregivers in this and other studies.

Evidence consistently indicates that mothers of children with ASD experience greater emotional, social, physical, and psychological burden than fathers (Christmann et al., 2017; Perzolli et al., 2025). A cross-sectional study involving 127 mothers of children with ASD reported high prevalence rates of anxiety and depression, along with low health-related quality of life scores (Kousha et al., 2016). These findings align with the present results and highlight the disproportionate emotional burden borne by mothers within the caregiving context.

As expected, educational attainment was positively associated with socioeconomic status, consistent with the established relationship between education and labor income in Brazil (Banco Central do Brasil, 2019; Bastos et al., 2022). However, socioeconomic status was not significantly associated with caregiver burden or quality of life in the present sample. Although previous studies have reported socioeconomic disparities in caregiver outcomes, our findings suggest that caregiver well-being is likely influenced by multiple interacting factors that extend beyond economic indicators alone.

Regarding the children and adolescents under the participants' care, most had a confirmed diagnosis of ASD, and a subset had co-occurring conditions such as attention-deficit/hyperactivity disorder and dyslexia. According to the DSM-5-TR, approximately 70% of individuals with ASD may have at least one co-occurring mental disorder, and mental health diagnoses are substantially more prevalent in autistic populations than in the general population (American Psychiatric Association, 2022; Lai et al., 2019). This clinical complexity increases caregiving demands and may further intensify caregiver burden and stress.

The instruments used in this study, WHOQOL-BREF and QVTEA, are grounded in the multidimensional concept of quality of life proposed by the WHOQOL Group, which emphasizes individuals' perceptions within their cultural and value systems (The WHOQOL Group, 1995). This approach incorporates physical health, psychological well-being, social relationships, and environmental factors, allowing for a comprehensive assessment of caregivers' lived experiences (Eapen et al., 2023; Simpson et al., 2024).

Caregiver burden, as measured by the Zarit scale, revealed a mean score indicative of moderate to severe burden. This finding underscores the substantial demands associated with caring for a child with ASD, including disruptions to family routines, social participation, and professional life. The need for continuous supervision, specialized educational support, and long-term care often requires sustained commitment from family members, contributing to elevated stress levels and reduced quality of life (Dijkstra-de Neijs et al., 2024; MacDuffie et al., 2020; Smith et al., 2025; Soccorso et al., 2023). The poorer scores observed in the physical domain of quality of life likely reflect the cumulative demands associated with long-term caregiving rather than a single isolated factor. Continuous supervision, disrupted sleep, physical assistance with daily activities, frequent healthcare appointments, and the need to coordinate educational and therapeutic services may contribute to persistent fatigue and reduced opportunities for self-care. Furthermore, caregivers often postpone their own health needs, leisure activities, and physical exercise because caregiving responsibilities take priority. Although these mechanisms were not directly measured in the present study, they have been consistently identified in previous research as important contributors to physical exhaustion and reduced quality of life among caregivers of autistic children (Dijkstra-de Neijs et al., 2024; Eapen et al., 2023; Simpson et al., 2024).

The cumulative demands associated with caregiving may progressively restrict caregivers' participation in employment, leisure, community engagement, and other meaningful occupations, thereby reducing opportunities for recovery, social connectedness, and personal well-being. However, these consequences should not be understood exclusively as an inevitable result of autism or caregiving responsibilities. Contemporary socioecological models emphasize that caregiver

outcomes are strongly influenced by contextual factors, including the availability of coordinated health and educational services, family-centered interventions, social support networks, workplace flexibility, and inclusive community environments. Conversely, fragmented service systems, stigma, financial constraints, and insufficient institutional support may intensify caregiver burden by increasing the practical and emotional demands placed on families. Likewise, limited opportunities for caregivers' own occupational participation may further compromise their physical and psychological well-being over time. This broader perspective shifts the focus from individual deficits toward the interaction between caregiving demands and environmental conditions, providing a more comprehensive understanding of caregivers' quality of life (American Occupational Therapy Association, 2020; Leadbitter et al., 2021; Liñares-de-Marcos et al., 2026; Pellicano & den Houting, 2022; World Health Organization, 2001). This interpretation is consistent with the biopsychosocial model, which recognizes that health and quality of life emerge from continuous interactions between personal characteristics and environmental contexts rather than from individual conditions alone.

Within the Brazilian context, regional inequalities in access to specialized services, long waiting times for diagnostic assessment and intervention, and unequal distribution of rehabilitation resources may further increase the demands placed on families. These structural challenges reinforce the importance of strengthening public policies aimed at expanding coordinated and family-centered care across health, education, and social assistance systems (Ministério da Saúde, 2015; Pellicano & den Houting, 2022). These challenges may be particularly relevant in low- and middle-income countries, where disparities in access to specialized services remain substantial.

These findings reinforce the importance of strengthening coordinated family-centered services that address not only children's developmental needs but also caregivers' own health, participation, and quality of life. This perspective recognizes caregivers not only as providers of care but also as individuals whose own health and participation influence children's developmental opportunities and overall family functioning. Interventions that promote caregiver well-being, facilitate access to multidisciplinary services, reduce environmental barriers, and expand formal and informal support networks may contribute to healthier family functioning and more sustainable caregiving over time (Kuo et al., 2012; Simpson et al., 2024).

From a clinical perspective, these findings highlight the relevance of interventions that extend beyond child-focused rehabilitation. Occupational therapists are particularly well positioned to facilitate caregiver participation in meaningful occupations, promote environmental adaptations, strengthen family routines, and support collaborative goal setting within family-centered practice. Supporting caregivers in maintaining participation in meaningful daily occupations,

strengthening coping strategies, and facilitating access to community resources may contribute to improved family quality of life while promoting children's participation and development. Taken together, these findings suggest that caregiver burden should be understood as a multidimensional phenomenon shaped not only by children's support needs but also by broader contextual conditions that influence family functioning and participation.

Some limitations of this study should be acknowledged. The sample was drawn from a single geographic region, which may limit generalizability. Additionally, the cross-sectional design precludes causal inferences. Nevertheless, the inclusion of participants from diverse socioeconomic and educational backgrounds strengthens the representativeness of the findings. The study also relied exclusively on caregiver-reported outcome measures, which may be influenced by subjective perceptions and response bias. Future studies should include longitudinal designs, participants from different regions, and comparison groups to further explore factors associated with caregiver burden and quality of life. Future research should also investigate potentially modifiable contextual factors—including access to services, social support, environmental barriers, and family-centered interventions—that may contribute to caregiver well-being across different cultural contexts.

Conclusions

This study provides a comprehensive assessment of caregiver well-being by simultaneously examining generic quality of life, autism-specific quality of life, and caregiver burden among primary caregivers of children and adolescents with ASD. The findings indicate substantial caregiver burden and reduced quality of life across multiple domains, highlighting the complex and multidimensional nature of caregivers' experiences. Contrary to findings from some previous studies, socioeconomic status was not significantly associated with caregiver burden or quality of life in this sample, suggesting that caregiver well-being is influenced by multiple interacting factors that extend beyond economic conditions alone.

These findings reinforce the importance of adopting biopsychosocial and socioecological perspectives that recognize caregiver well-being as shaped by the interaction between children's support needs, family resources, environmental conditions, and access to coordinated services. They also support the implementation of family-centered approaches that recognize caregivers not only as providers of care but also as individuals whose own health, participation, and quality of life are essential to sustainable family functioning. By simultaneously assessing complementary dimensions of caregiver well-being, this study contributes to the growing international evidence base and may help inform clinical practice, family-centered interventions, and future research aimed at improving support for families of autistic children and adolescents.

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References

Aguiar, M. C. M., & Pondé, M. P. (2020). Autismo: Impacto do diagnóstico nos pais [Autism: Impact of the diagnosis on parents]. *Jornal Brasileiro de Psiquiatria*, *69*(3), 149–155. https://doi.org/10.1590/0047-2085000000276

American Occupational Therapy Association. (2020). Occupational therapy practice framework: Domain and process (4th ed.). *American Journal of Occupational Therapy*, *74*(Suppl. 2), 7412410010. https://doi.org/10.5014/ajot.2020.74S2001

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.; DSM-5-TR). American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890425787

Associação Brasileira de Empresas de Pesquisa. (2024). *Critério Brasil*. https://www.abep.org/criterio-brasil

Banco Central do Brasil. (2019). *Escolaridade e rendimentos do trabalho*. Boletim Regional. https://www.bcb.gov.br/content/publicacoes/boletimregional/201901/br201901b1p.pdf

Bastos, E. V. P., Carvalho, M. S., & Macedo, M. A. (2022). Análise da relação entre a remuneração do trabalho e o nível de instrução: Uma abordagem estatística [Analysis of the relationship between work remuneration and level of education: A statistical approach]. *Revista Contexto & Educação*, *37*(116), 226–238. https://doi.org/10.21527/2179-1309.2022.116.10317

Bermeo, F. F. A., Alvarez, K. L. P., & Bermeo, M. J. A. (2025). Síndrome del cuidador en familiares de niños con espectro autista. *Polo del Conocimiento*, *10*(1), 539–570.

Cardoso, É. L. S., Santos, S. R., Araújo, Y. B., Neves, N. T. A. T., & Nascimento, J. A. D. (2021). Fatores associados à qualidade de vida de cuidadores de crianças e adolescentes com condições crônicas [Factors associated with the quality of life of caregivers of children and adolescents with chronic conditions]. *Revista Gaúcha de Enfermagem*, *42*, e20190318. https://doi.org/10.1590/1983-1447.2021.20190318

Christmann, M., Marques, M. A. A., Rocha, M. M. D., Carreiro, L. R. R., & Ribeiro, M. C. C. (20*17*). Estresse materno e necessidade de cuidado dos filhos com

TEA na perspectiva das mães. *Cadernos de Pós-Graduação em Distúrbios do Desenvolvimento*, *17*(2), 8–17. https://doi.org/10.5935/cadernosdisturbios.v17n2p8-17

Dijkstra-de Neijs, L., Boeke, D. B., van Berckelaer-Onnes, I. A., Swaab, H., & Ester, W. A. (2024). Parental stress and quality of life in parents of young children with autism. *Child Psychiatry & Human Development*, *57*(1), 226–240. https://doi.org/10.1007/s10578-024-01693-3

Duarte, G., & Spinelli, L. M. (2019). Estereótipos de gênero, divisão sexual do trabalho e dupla jornada [Gender stereotypes, sexual division of labor, and double workload]. *Revista Sociais e Humanas*, *32*(2). https://doi.org/10.5902/2317175836316

Eapen, V., Karlov, L., John, J. R., Beneytez, C., Grimes, P. Z., Kang, Y. Q., Mardare, I., Minca, D. G., Voicu, L., Malek, K. A., Ramkumar, A., Stefanik, K., Gyori, M., & Volgyesi-Molnar, M. (2023). Quality of life in parents of autistic children: A transcultural perspective. *Frontiers in Psychology*, *14*, 1022094. https://doi.org/10.3389/fpsyg.2023.1022094

Figueiredo, S. L. de, Rangel, J. M. S., & Lima, M. N. C. F. de. (2020). O diagnóstico do transtorno do espectro autista e suas implicações na vivência da família [The diagnosis of autism spectrum disorder and its implications for family experience]. *Revista AMAzônica*, *25*(2), 93–107.

Fonsêca, M. A., Parreiras, L. de A., & Modena, C. M. (2024). Primeiro ele, depois o resto: Repercussões da paternidade de crianças com autismo na saúde dos homens [First him, then the rest: Repercussions of fathering children with autism on men's health]. *Desafios: Revista Interdisciplinar da Universidade Federal do Tocantins*, *11*(5). https://doi.org/10.20873/2024_jul_18634

Garcia, A. M. B. (2021). *Construção e validação de questionário para avaliação da qualidade de vida de cuidadores de crianças e adolescentes com transtorno do espectro autista* [Master's thesis, Universidade de Brasília]. Repositório Institucional da Universidade de Brasília. https://repositorio.unb.br/handle/10482/42199

Gomes, P. T. M., Lima, L. H. L., Bueno, M. K. G., Araújo, L. A., & Souza, N. M. (2015). Autism in Brazil: A systematic review of family challenges and coping strategies. *Jornal de Pediatria*, *91*(2), 111–121. https://doi.org/10.1016/j.jped.2014.08.009

Gordillo, M. L., Chu, A., & Long, K. (2020). Mothers' adjustment to autism: Exploring the roles of autism knowledge and culture. *Journal of Pediatric Psychology*, *45*(8), 877–886. https://doi.org/10.1093/jpepsy/jsaa044

Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., Oliveira, N. A., Terassi, M., & Pavarini, S. C. I. (2019). Brief version of the Zarit Burden Interview for burden assessment in older caregivers. *Dementia & Neuropsychologia*, *13*(1), 122–129. https://doi.org/10.1590/1980-57642018dn13-010015

Instituto Brasileiro *de* Geografia e Estatística. (2023). *Pesquisa Nacional por Amostra* de *Domicílios Contínua: Outras formas* de *trabalho 2022*. https://biblioteca.ibge.gov.br/visualizacao/livros/liv102020_informativo.pdf

Kapp, S. K. (Ed.). (2020). *Autistic community and the neurodiversity movement: Stories from the frontline*. Palgrave Macmillan. https://doi.org/10.1007/978-981-13-8437-0

Kousha, M., Attar, H. A., & Shoar, Z. (*20*16). Anxiety, depression, and quality of life in Iranian mothers of children with autism spectrum disorder. *Journal of Child Health Care*, 20(3), 405–414. https://doi.org/10.1177/1367493515598644

Kuo, D. Z., Houtrow, A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-centered care: Current applications and future directions in pediatric health care. *Maternal and Child Health Journal*, *16*(2), 297–305. https://doi.org/10.1007/s10995-011-0751-7

Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. *Frontiers in Psychology*, *12*, 635690. https://doi.org/10.3389/fpsyg.2021.635690

Liñares-de-Marcos, J., Palomero-Sierra, B., Sánchez-Gómez, V., Fernández-Álvarez, C. J., & Canal-Bedia, R. (2026). An integrative approach between neurodiversity perspectives and quality of life models for autistic people across the spectrum of support needs. *Frontiers in Psychiatry*, *16*, 1756323. https://doi.org/10.3389/fpsyt.2025.1756323

MacDuffie, K. E., Turner-Brown, L., & Estes, A. M. (2020). "If he has it, we know what to do": Parent perspectives on familial risk for autism spectrum disorder. *Journal of Pediatric Psychology*, *45*(2), 121–130. https://doi.org/10.1093/jpepsy/jsz076

Magalhães, J. M., Rodrigues, T. A., Rêgo Neta, M. M., Damasceno, C. K. C. S., Sousa, K. H. J. F., & Arisawa, E. Â. L. S. (2021). Vivências de familiares de crianças diagnosticadas com Transtorno do Espectro Autista [Experiences of family members of children diagnosed with autism spectrum disorder]. *Revista Gaúcha de Enfermagem*, *42*, e20200437. https://doi.org/10.1590/1983-1447.2021.20200437

Ministério da Saúde. (2015). *Linha de cuidado para a atenção às pessoas com transtornos do espectro do autismo e suas famílias na Rede de Atenção Psicossocial do Sistema Único de Saúde*. https://bvsms.saude.gov.br/bvs/publicacoes/linha_cuidado_atencao_pessoas_transtorno.pdf

Pasquoto de Freitas, M. V., & Moraes da Costa, M. M. (2020). A desconstrução do conceito de mulher-família para mulher-para-si: Uma análise sobre a (re) inclusão das mulheres na sociedade e no mercado de trabalho contemporâneo [The deconstruction of the family-woman concept to woman-for-herself: An analysis on the (re) inclusion of women in society and in the contemporary labor market]. *Argumenta Journal Law*, (32), 297–316. https://doi.org/10.35356/argumenta.v0i32.316

Passos, B. C., & Kishimoto, M. S. C. (2022). O impacto do diagnóstico de transtorno do espectro autista na família e relações familiares [The impact of the diagnosis of autism spectrum disorder on the family and family relationships]. *Brazilian Journal of Development*, *8*(1), 5827–5832. https://doi.org/10.34117/bjdv8n1-394

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from "normal science" to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, *63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Perzolli, S., Bertamini, G., Venuti, P., & Bentenuto, A. (2025). Parental stress, mental health, and child traits in Italian mothers and fathers of autistic children. *Frontiers in Psychology*, *16*, 1593255. https://doi.org/10.3389/fpsyg.2025.1593255

Pisula, E., & Porębowicz-Dörsmann, A. (2017). Family functioning, parenting stress and quality of life in mothers and fathers of Polish children with high functioning autism or Asperger syndrome. *PLOS ONE*, *12*(10), e0186536. https://doi.org/10.1371/journal.pone.0186536

Rezq, K. A., Albalawi, H. M. H., & Alharbi, H. F. (2025). Exploring social support and quality of life among mothers of children with autism spectrum disorders. *Healthcare*, *13*(2), 95. https://doi.org/10.3390/healthcare13020095

Rondini, C. A., Justo, J. S., Teixeira Filho, F. S., Lucca, J. A. C. de, & Oliveira, P. A. de. (20*11*). Análise das relações entre qualidade de vida e sobrecarga de cuidadoras de idosos de Assis, SP [Analysis of quality of life and burden of female caretakers for elder people in Assis, interior of São Paulo, Brazil]. *Estudos e Pesquisas em Psicologia*, 11(3), 796–820. https://doi.org/10.12957/epp.2011.8336

Segeren, L., & Françozo, M. F. C. (2014). As vivências de mães de jovens autistas. *Psicologia em Estudo*, *19*(1), 39–46. https://doi.org/10.1590/1413-7372189590004

Simpson, K., Paynter, J., Westerveld, M., van der Meer, L., Patrick, L., Hogg, G., Heussler, H., Heyworth, M., Gable, A., Chandran, H. S., Bowen, R., & Adams, D. (2024). Time to change how we measure quality of life and well-being in autism: A systematic review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-024-00440-7

Skevington, S. M., Lotfy, M., & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial. *Quality of Life Research*, *13*(2), 299–310. https://doi.org/10.1023/B:QURE.0000018486.91360.00

Smith, M. J., Thompson, T. J., & Brown, H. K. (2025). Parenting stress in parents of children with autism spectrum disorder: Associations with social support, child behavior, and caregiver well-being. *Journal of Autism and Developmental Disorders*, *55*(5), 2284–2293. https://doi.org/10.1007/s10803-024-06377-4

Soccorso, C., Milliken, A., Hojlo, M., Pawlowski, K., Weas, S., Sideridis, G., & Baumer, N. (2023). Quality of life and family impact in Down syndrome, autism spectrum disorder, and co-occurring Down syndrome and autism spectrum disorder. *Journal of Developmental & Behavioral Pediatrics*, *44*(3), e185–e195. https://doi.org/10.1097/DBP.0000000000001171

The WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper. *Social Science & Medicine*, *41*(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*.

World Health Organization. (n.d.). *Measuring quality of life*. https://www.who.int/tools/whoqol