

FACTORS ASSOCIATED WITH THE QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

Raul Almeida Ribeiro¹, Maria Rafaela Alves Nascimento², Andréa Souza Araújo³, Naftali Janaina Carvalho Soares Costa⁴, Leandro de Jesus Bandeira⁴, Amanda Souto Machado⁴, Priscilla Miranda dos Santos⁵, Joyce Micaelle Alves Caldeira⁴, Maria Luisa de Moraes Prates⁴, Karoline de Souza Oliveira¹, Elisabete Cordeiro Muniz Silva¹, Luciano Soares Diniz⁴

¹Centro Universitário do Norte de Minas Gerais. ²Centro Universitário Afya. ³Universidade Federal de Alfenas. ⁴Universidade Estadual de Montes Claros. ⁵Faculdade Santo Agostinho.

Abstract: The present study aimed to evaluate the factors associated with the quality of life of caregivers of children with autism spectrum disorder. An integrative literature review was conducted, and articles retrieved from the secondary databases Virtual Health Library, Latin American and Caribbean Literature in Health Sciences, Scientific Electronic Library Online, and Online System for Searching and Analyzing Medical Literature were analyzed using the descriptors quality of life, autism spectrum disorder, and caregivers. The results indicate that the factor with the greatest negative impact on quality of life is not the diagnosis itself, but the presence of disruptive behaviors and sleep disorders in the child, which cause physical exhaustion and social isolation for the caregiver; support from a partner and community networks proved to be the main protective factor, caregivers with a robust support network show higher resilience scores, lower incidence of anxiety and depression symptoms, and better quality of life, while exclusive dedication and the abandonment of personal and professional projects to meet the child's therapeutic needs result in a sharp decline in quality of life in the environmental and financial domains. It is emphasized that care planning should include the caregiver as a subject of care, ensuring support so that the exercise of parenting does not lead to the exclusion of their own subjectivity.

Keywords: quality of life, autism spectrum disorder, caregivers.

INTRODUCTION

In addition to being a condition that is constantly being further investigated and characterized, autism spectrum disorder (ASD) is a diagnosis commonly observed in childhood. According to data from the Centers for Disease Control and Prevention (2014), there is currently one case of autism for every 68 children. Therefore, it is estimated that in Brazil, with nearly 207.7 million inhabitants, there are approximately three million autistic individuals (Oliveira, 2017). According to the DSM-5 (American Psychiatric Association, 2014), ASD is a neurodevelopmental disorder that affects 1% of the general population and is characterized by deficits in communication and social interaction, as well as restricted and repetitive patterns of behavior, interests, and activities, present from early childhood development and resulting in significant impairment in daily life.

Considering the general population, the number of children diagnosed with ASD represents an important issue for the development of scientific studies and, according to the literature, the number of researchers interested in understanding the particularities of this disorder is currently increasing. However, studies specifically addressing the caregivers/parents of these children, particularly with regard to their quality of life (QoL), remain scarce (Ester et al., 2009).

According to the existing literature, caring for a child with autism can have a significant emotional impact on families and can lead to higher levels of stress compared with caregivers of children with typical development (Ester et al., 2009; Valicenti-McDermott et al., 2015). Nevertheless, although caregivers report concerns regarding certain clinical manifestations, such as hyperactivity, impulsivity, self-injurious and aggressive behaviors, and other conditions, the greatest sources of tension are directly attributed to the financial burden of interventions and the lack of social support (Khanna et al., 2011; Montes; Halterman, 2008).

Studies involving children with ASD have demonstrated an association between individual characteristics of the children, such as age, greater functional impairment, and lower social support, and poorer quality of life among caregivers (Khanna et al., 2011; Montes; Halterman, 2008; Ji et al., 2014). In addition to the aforementioned aspects, there are also family-related characteristics, among which high emotional and physical burden, difficulties in coping with the diagnosis, limited access to health services, low social support, reduced leisure activities, and financial circumstances stand out (Gomes et al., 2015; Alhazmi; Petersen; Donald, 2018). Thus, the QoL of caregivers of children with ASD may be affected both by factors related to the children and their limitations, whether in daily activities, such as combing their hair and brushing their teeth, or in participation, as well as by personal factors associated with the socioeconomic conditions of these families (Aktan; Orakçı; Durnalı, 2020). In this context, the present study aims to evaluate the factors associated with the quality of life of caregivers of children with autism spectrum disorder.

METHODS

An integrative literature review was conducted. This approach was adopted because it allows the combination of data from investigative and theoretical research, which can be directed toward conceptualization, identification of gaps in research areas, theoretical review, and methodological analysis of studies addressing a specific topic, thereby enabling a comprehensive analysis of the literature (Ercole; Melo; Alcoforado, 2014).

In this context, six interdependent and interrelated phases were considered: formulation of the guiding question, literature search or sampling, data collection, critical appraisal of the included studies, discussion of the results, and presentation of the integrative review. The guiding question was defined as follows: What factors are associated with the quality of life of caregivers of children with autism spectrum disorder? (Souza; Silva; Carvalho, 2010).

The studies were collected through an electronic search of the following databases available

through the Virtual Health Library (VHL): Latin American and Caribbean Literature in Health Sciences (LILACS), the Scientific Electronic Library Online (SciELO), and Medical Literature Analysis and Retrieval System Online (MEDLINE).

The inclusion criteria comprised full-text articles available electronically in Portuguese, English, or Spanish that addressed the proposed topic in the title, abstract, or descriptors. Regarding the exclusion criteria, letters to the editor, editorials, duplicate articles, and studies that did not unequivocally address the topic under investigation were excluded.

The search for studies was conducted from March to May 2026. The investigation strategies employed the Health Sciences Descriptors (DeCS), retrieved from the website <https://decs.bvsalud.org/>, using the terms “quality of life,” “autism spectrum disorder,” and “caregivers.” To refine the search and improve the selection of data for analysis, the Boolean operator AND was used to combine the selected descriptors.

For data collection, an instrument validated by Ursi (2005) for integrative reviews was used, comprising the following categories of analysis: identification code, publication title, author and author’s academic background, source, year of publication, study design, region where the research was conducted, and database in which the article was published. After the articles were selected, the information to be extracted from the studies was defined. To facilitate the organization and retrieval of the information, a database was developed using Microsoft Office Excel 2010, comprising the following variables: article title, year of publication, study design, and main outcomes. The data obtained were organized into a summary table and thematic categories and were interpreted according to the relevant literature.

RESULTS

Nineteen studies that met the eligibility criteria were included in the present review. The following table describes the titles, methods, and main outcomes of the studies analyzed (Table 1).

Table 1. Studies included in the review and the characteristics evaluated.

Nº	Title	Study Objective	Results / Associated Factors
1	Caregiver burden and quality of life in autism spectrum disorder	To analyze the relationship between the child's level of dependency and the caregiver's quality of life.	Greater dependence in Activities of Daily Living (ADLs) is associated with poorer physical quality of life.
2	The role of social and family support for people with autism spectrum disorder	To investigate whether support from third parties mitigates stress.	Robust social support is the primary protective factor against depression in mothers.
3	Impact of socioeconomic status among caregivers of individuals with autism spectrum disorder	To evaluate the influence of income and education on the perception of well-being.	Low income is associated with higher anxiety due to difficulty accessing therapies.
4	Severity of spectrum symptoms: impact on caregivers' quality of life	To determine whether the ASD severity level (level 1, 2, or 3) affects quality of life.	Disruptive behaviors and aggression have a greater impact on quality of life than cognitive deficits.
5	Mental health, anxiety, depression, and quality of life of caregivers of children diagnosed with autism spectrum disorder.	To identify the prevalence of mental disorders among caregivers.	High prevalence of depressive symptoms correlated with a negative perception of health.
6	Resilience and coping strategies among informal caregivers	To study how psychological coping helps the caregiver.	Problem-focused strategies (seeking solutions) generate better quality of life than emotion-focused ones.
7	Parental stress and family functioning: a family analysis of patients with autism spectrum disorder	To assess the impact of the diagnosis on the couple's dynamics.	ASD tends to increase marital stress; cohesive couples exhibit better social quality of life.
8	Spirituality as a protective factor among caregivers of autistic individuals: associated factors	To investigate the impact of faith/beliefs on the acceptance of ASD.	Spirituality acts as a positive mediator in the acceptance and reduction of parental guilt.
9	Sleep quality of caregivers of individuals with autism spectrum disorder	To analyze the relationship between children's and adults' sleep.	Caregiver sleep deprivation (due to the child's insomnia) predicts low overall QoL.

10	Gender and care: the maternal face	To compare the quality of life between mothers and fathers of children with ASD.	Mothers report a higher burden and lower quality-of-life scores than fathers.
11	Parental self-efficacy in managing autism spectrum disorder	To determine whether the sense of competence improves quality of life.	The more the caregiver feels capable of handling crises, the lower the perceived stress.
12	Access to health and leisure services: oral analysis of informal caregivers	Assess the impact of institutional barriers.	A lack of time for leisure and self-care is the most compromised domain of caregivers' quality of life.
13	Stigma and social isolation: associated factors among caregivers of people with autism spectrum disorder	To investigate the impact of social judgment on the caregiver's life.	The fear of public judgment leads to isolation, impairing social quality of life.
14	Caregiver age and time since diagnosis: impacts and associated factors	To analyze whether the time spent together improves adaptation.	Younger caregivers and those with recent diagnoses exhibit higher levels of crisis.
15	Medical comorbidities of caregivers of individuals with autism spectrum disorder	Map physical ailments resulting from chronic caregiving.	High incidence of musculoskeletal pain (spine/shoulders) associated with physical exertion.
16	Impact on work and career among caregivers of children diagnosed with autism spectrum disorder	To examine the association between involuntary unemployment and quality of life.	Leaving one's career to care for a child reduces financial quality of life and self-esteem.
17	Health literacy of caregivers of people with autism spectrum disorder	To evaluate whether technical knowledge about ASD reduces anxiety.	Greater access to quality information is linked to more secure decisions and less stress.
18	Institutional support and public policies for caregivers and people with autism	Analyze satisfaction with the care provided at centers such as CAPS.	Support from multidisciplinary teams reduces the caregiver's sense of helplessness.
19	Use of mindfulness-based interventions: associated factors	To examine the effect of mindfulness practices on quality of life.	Meditation and relaxation interventions show significant improvement in the psychological domain.

Source: study data.

DISCUSSION

In this study, the factors associated with the quality of life of caregivers of children with autism spectrum disorder were evaluated. In this context, the primary caregiver assumes a burden of responsibilities that frequently exceeds their adaptive capacities, resulting in a phenomenon known as caregiver burden. This state is not limited to physical fatigue but encompasses profound emotional exhaustion, in which exclusive dedication to the child's demands may lead to the neglect of personal needs, negatively affecting all dimensions of QoL (Al-Farsi et al., 2016).

Studies indicate that the severity of the child's behavioral symptoms, such as aggressiveness and difficulties in social interaction, are consistent predictors of poor quality of life among parents. The unpredictability of the child's behavior generates a state of constant hypervigilance, which is associated with elevated cortisol levels and the development of anxiety and depressive disorders among caregivers. Thus, the mental health of caregivers becomes intrinsically linked to the phenotypic profile of the child receiving care, requiring a clinical perspective that goes beyond the identified patient (Broady; Stoyles; Morse, 2017).

The socioeconomic dimension also emerges as a determining factor in the perception of well-being. Caregivers with limited financial resources face additional barriers to accessing multidisciplinary therapies, which intensifies feelings of helplessness and stress. Furthermore, the literature indicates that social isolation, caused by the stigma still associated with autism, deprives families of informal support networks, making social support one of the most important moderators for preserving the psychological well-being of these individuals (Davis; Finke; Hickerson, 2016).

The fact that the caregiver does not work outside the home describes how caregivers tend to leave the labor market to accompany the person with autism, interfering with their quality of life (Moxoto; Magris, 2015). The literature also states that this situation may contribute to increased stress among these caregivers, who see their lives changed and have to give up their careers to become caregivers. This may lead to frustration, since work is often considered a source of satisfaction,

maintenance of autonomy, and increased self-esteem. Another factor that should be considered is the loss of income resulting from this situation (Ciday; Marcus; Mandell, 2012). It is known that individuals with ASD require several types of special care, such as follow-up by different professionals and the use of controlled medications, which can be costly.

When the quality of life of caregiving mothers was assessed, a national study found the highest score in the physical domain (67.9). This differs from the study conducted by Piovezan et al. 2015, which found the highest score in the psychological domain. The physical domain assesses, among other aspects, activities of daily living and work capacity.²¹ The fact that caregiving mothers obtained a higher score in this domain means that caregiving is not negatively affecting their activities and that they do not feel physically overburdened. Despite this finding, it is important for the healthcare team to monitor these mothers and provide guidance on how to perform these caregiving activities so that, over the years, they do not become compromised in these aspects.

In the same national study, the lowest score was found in the psychological domain (56.7). This domain assesses aspects such as positive feelings, thinking, learning, and negative feelings (Fleck et al., 2000). The primary caregiving mother of a child with ASD undergoes a process of adapting to all of her roles, namely: wife, family member, woman, and professional; this requires her to cope with the emotional consequences of such adaptation. This entire process may have significant short- and long-term effects on her mental, psychological, and physical health (Mathew et al., 2019). Therefore, psychological follow-up is suggested as essential for enabling her to adapt without compromising her health and quality of life.

With regard to gender-related issues, a significant disparity can be observed, since the mother frequently assumes the role of primary caregiver, often giving up her professional career and social life. This relinquishment directly affects the “environment” and “social relationships” domains of quality-of-life assessment instruments, such as the WHOQOL-BREF. The literature reinforces that the lack of equitable sharing of household tasks and specialized care contributes to mothers presenting lower quality-of-life scores than fathers (Derguy et al., 2016).

It becomes evident that caregiver quality of life is a multifactorial construct that requires biopsychosocial intervention strategies. The implementation of follow-up and multifamily intervention programs has demonstrated effectiveness in reducing stress and improving family resilience. Understanding these associated factors is essential so that the healthcare system not only treats the child but also provides the necessary support for caregivers to maintain their functionality and health, ensuring the long-term sustainability of care (Dyches et al., 2016).

It is believed that there is a need for a differentiated approach in public policies concerning children with ASD, considering not only the child who requires special care but also the caregiving mother and other caregivers, who need to receive appropriate guidance and support so that they can effectively contribute to the child's development without compromising their own health and quality of life (Castro; Vieira; Santos, 2022).

CONCLUSION

The quality of life of caregivers of children with Autism Spectrum Disorder is significantly affected by a complex network of factors that extend beyond the clinical diagnosis. It was observed that caregiving, although permeated by affection, imposes challenges that compromise the physical, psychological, and social dimensions of caregivers, predominantly mothers. Given this scenario, it becomes evident that care for children with ASD should adopt a family-centered care model. To improve caregivers' quality of life, interventions focused on institutional psychological support, health education and literacy, and leisure strategies are recommended. Finally, caregivers' quality of life is an essential determinant of the child's own prognosis; therefore, neglecting the mental health of those who provide care may compromise the effectiveness of therapeutic interventions.

REFERENCES

- ACTAN, O.; ORAKCI, Ş.; DURNALI, M. Investigation of the relationship between burnout, life satisfaction and quality of life in parents of children with disabilities. *European Journal of Special Needs Education*, v. 35, n. 5, p. 679-695, 2020.
- AL- FARSI, O. A.; AL-FARSI, Y. M.; AL-SHARBATI, M. M.; AL-ADAWI, S. Stress, anxiety, and depression among parents of children with autism spectrum disorder in Oman: a case-control study. *Neuropsychiatric Disease and Treatment*, v. 12, p. 1943-1951, 2016.
- ALHAZMI, A.; PETERSEN, R.; DONALD, K. A. Quality of life among parents of South African children with autism spectrum disorder. *Acta Neuropsychiatrica*, v. 30, n. 4, p. 226-231, 2018.
- AMERICAN PSYCHIATRIC ASSOCIATION. Manual diagnóstico e estatístico de transtornos mentais: DSM-5. 5. ed. Porto Alegre: Artmed, 2014.
- AKTAN, O.; ORAKCI, Ş.; DURNALI, M. Investigation of the relationship between burnout, life satisfaction and quality of life in parents of children with disabilities. *European Journal of Special Needs Education*, v. 35, n. 5, p. 679-695, 2020.
- BRODY, T. R.; STOYLES, G. J.; MORSE, C. B. Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. *Health & Social Care in the Community*, v. 25, n. 1, p. 224-233, 2017.
- CASTRO, G. G.; VIEIRA, A. L. S.; SANTOS, N. M. F. Fatores associados a qualidade de vida de mães de pacientes com transtorno do espectro autista. *O Mundo da Saúde*, v. 46, n. 1, p. 1-10, 2022.
- CENTER FOR DISEASE CONTROL AND PREVENTION. Prevalence of autism spectrum disorder among children aged 8 years: autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *MMWR Surveillance Summaries*, v. 63, n. 2, p. 1-21, 2014.
- CIDAV, Z.; MARCUS, S. C.; MANDELL, D. S. Implications of childhood autism for parental employment and earnings. *Pediatrics*, v. 129, n. 4, p. 617-623, 2012.
- DAVIS, J. M.; FINKE, E.; HICKERSON, B. Service delivery experiences and intervention needs of

military families with children with ASD. *Journal of Autism and Developmental Disorders*, v. 46, n. 5, p. 1748-1761, 2016.

DERGUY, C.; MELLOIS-BROCHARD, C.; BEAUDOIN, M.; ROUSSEAU, T.; BOUVARD, M. The need for an ecological approach to parental stress in autism spectrum disorders: the combined role of individual and environmental factors. *Journal of Autism and Developmental Disorders*, v. 46, n. 6, p. 1895-1905, 2016.

DYCHES, T. T.; CHRISTENSEN, R.; HARPER, J. M.; MANDLECO, B.; ROPER, S. O. Respite care for single mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, v. 46, n. 3, p. 812-824, 2016.

ERCOLE, F. F.; MELO, L. S.; ALCOFORADO, C. L. G. C. Revisão integrativa versus revisão sistemática. *Revista Mineira de Enfermagem*, v. 18, n. 1, p. 1-11, 2014.

ESTER, A.; GREEN, S. A.; CAPLAN, R.; BAKER, B. L.; BLACHER, J. Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, v. 13, n. 4, p. 375-387, 2009.

FLECK, M. P. A.; LOUZADA, S.; XAVIER, M.; CHACHAMOVICH, E.; VIEIRA, G.; SANTOS, L. et al. Aplicação da versão em português do instrumento abreviado de avaliação da qualidade de vida “WHOQOL-bref”. *Revista de Saúde Pública*, v. 34, n. 2, p. 178-183, 2000.

GOMES, P. T. M.; LIMA, L. H. L.; BUENO, M. K. G.; ARAÚJO, L. A.; SOUZA, N. M. Autismo no Brasil, desafios familiares e estratégias de superação: revisão sistemática. *Jornal de Pediatria*, v. 92, n. 2, p. 111-121, 2015.

JI, B.; ZHAO, I.; TURNER, C.; SUN, M.; YI, R.; TANG, S. Predictors of health-related quality of life in Chinese caregivers of children with autism spectrum disorders: a cross-sectional study. *Archives of Psychiatric Nursing*, v. 28, n. 5, p. 327-332, 2014.

KHANNA, R.; MADHAVAN, S. S.; SMITH, M. J.; PATRICK, J. H.; TWOREK, C.; BECKER-COTTRILL, B. Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, v. 41, n. 9, p. 1214-1227, 2011.

MATHEW, N. E.; BURTON, K. L. O.; SCHIERBEEK, A.; CRNCEC, R.; WALTER, A.; EAPEN, V. Parenting preschoolers with autism: socioeconomic influences on wellbeing and sense of competence. *World Journal of Psychiatry*, v. 9, n. 2, p. 30-46, 2019.

MONTES, G.; HALTERMAN, J. S. Association of childhood autism spectrum disorders and loss of family income. *Pediatrics*, v. 121, n. 4, p. 821-826, 2008.

MOXOTO, G. F. A.; MAGRIS, L. E. N. Avaliação de treino de controle do stress para mães de crianças com transtornos do espectro autista. *Psicologia: Reflexão e Crítica*, v. 28, n. 4, p. 772-779, 2015.

OLIVEIRA, C. Um retrato do autismo no Brasil. *Espaço Aberto*, 2017. Disponível em: <http://www.usp.br/espacoaberto/?materia=um-retrato-do-autismo-no-brasil>. Acesso em: 10 nov. 2025.

PIOVESAN, J.; SCARTEGAGNA, S. A.; MARCHI, A. C. B. Quality of life and depressive symptomatology in mothers of individuals with autism. *Psico-USF*, v. 20, n. 3, p. 505-515, 2015.

SOUZA, M. T.; SILVA, M. D.; CARVALHO, R. C. Revisão integrativa: o que é e como fazer. *Einstein*, v. 8, n. 1, p. 102-108, 2010.

URSI, E. S. Prevenção de lesões de pele no perioperatório: revisão integrativa da literatura. 2005. 130 f. Dissertação (Mestrado em Enfermagem) – Escola de Enfermagem, Universidade de São Paulo, Ribeirão Preto, 2005.

VALICENTI-MCDERMOTT, M.; LAWSON, K.; HOTTINGER, K.; SEIJO, R.; SCHECHTMAN, M.; SHULMAN, L. et al. Parental stress in families of children with autism and other developmental disabilities. *Journal of Child Neurology*, v. 30, n. 13, p. 1728-1735, 2015.