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Keywords: quality of life; anxiety; autism; caregivers



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Article

# Relationship between Anxiety Symptoms and Perceived of Quality of Life among Caregivers of Children with Autism Spectrum Disorder in a Reference Center in Amazon

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**Abstract:** The relationship between anxiety symptoms and perceived quality of life among caregivers of children with autism was verified. To assess perceived quality of life, the Short Form Healthy Survey Item was used; perception of anxiety symptoms was assessed using the Beck Anxiety Inventory. 80 caregivers of children with autism participated, with 68.7% of caregivers being mothers. Of the total number of caregivers, 68.8% had a severe level of anxiety. Regarding perceived quality of life, they demonstrated greater impairment in Limitation due to physical aspects, Limitation due to emotional aspects, Vitality and Pain. Caregivers with severe anxiety levels had worse quality of life in the domains of pain ( $p = 0.012$ ), social aspects ( $p < 0.001$ ), limitation due to emotional aspects ( $p = 0.001$ ) and mental health ( $p < 0.001$ ). However, in the functional capacity domain, caregivers with a moderate level of anxiety had a better physical capacity score ( $p = 0.001$ ). There was a negative correlation between the general anxiety score and the general physical ( $p = 0.029$ ) and general emotional component of perceived quality of life ( $p < 0.001$ ). It was found that caregivers of children with ASD present changes related to psychological factors and quality of life.

**Keywords:** quality of life; anxiety; autism; caregivers

## 1. Introduction

Autism spectrum disorder (ASD) is a pervasive neurodevelopmental disorder characterized by atypical development in social communication and social interactions across different domains, along with restricted, repetitive, and stereotyped patterns of behavior, interests, or activities [1].

Children diagnosed with ASD have an increased need for attention from caregivers compared to neurotypical children. The amount of attention given to the child depends on the child's level of independence. Furthermore, it is recommended that the child and caregiver undergo early monitoring to help manage and minimize the symptoms of the disorder, through individual and collective interventions [2].

The role of caring for a person with special needs can generally be performed by a family member or another person, whether paid or unpaid. Some studies have already described the consequences faced by caregivers, such as: responsibility for care, social isolation, anxiety, emotional burden, among others, and this leads to a decrease in quality of life. The literature shows that generally a family member of the child is dedicated to the care provided, with the mother being primarily responsible for this task. Depending on the child's level of independence, the caregiver must give up their occupations such as work, study and even social relationships to dedicate themselves to the demands and responsibilities of the child [3].

According to existing research, being in contact with a child with autism, as a caregiver, can cause a significant emotional impact on families, when compared to caregivers of children with typical development [4,5]. Additionally, studies show that parents of children with ASD experience

higher levels of depression, stress, and anxiety [6,7] and greater impact on their quality of life [8,9]. Many theories address the family structure and its impact on the care of neurodivergent children, such as the ecological model, in which children with different types of disabilities can develop through the interaction of their skills with a responsive context [10]. But the burden that caring for children with ASD can cause still needs more studies.

In the study of Vernhet et al., [8] which aimed to compare the perceptions of mothers and fathers about the impact of autism spectrum disorder on their quality of life, mothers perceived a greater negative impact than fathers on their global quality of life, being an alert to parents' needs in terms of social and educational support.

Musseti et al. [11] mentions that several variables are associated with lower quality of life among parents of children and adolescents with ASD, including parental characteristics (being a mother, parental mental health problems, maladaptive parental coping strategies and low parental self-efficacy), child characteristics (behavioral problems, emotional problems, level of ASD support and age of the child) and contextual factors (low employment status, low family income, low availability of social and professional support and lack of participation in health promotion activities).

According to Hayes and Watson [12], the main factor that will contribute to a more pleasant life is directly related to the way families organize themselves to deal with adversity. Therefore, even though the diagnosis favors a decrease in the quality of life of caregivers, the way in which families create adaptation strategies and receive social support is of great relevance.

Considering the above that may be experienced by caregivers/parents of children with ASD, the importance of developing an attentive and welcoming approach to these individuals becomes evident. In this context, aware of the importance of taking into account aspects related to the psychological well-being of caregivers of children with ASD, the hypothesis is raised that they present greater symptoms of anxiety and lower quality of life, and having higher levels of anxiety could worsen the perception of quality of life. Therefore, we sought to verify the relationship with the perception of anxiety symptoms and perceived quality of life among caregivers/parents of children on the autism spectrum in a reference center in Belém, Amazon, Brazil.

## **2. Materials and Methods**

### *2.1. Type of Study and Localization*

This is a cross-sectional, descriptive and analytical study, carried out from June to August/2022, at the Autistic Spectrum Disorder Assistance Center (NATEA). The place is a reference in the care of people with autism in the North of Brazil, and is located in the Integrated Center for Inclusion and Rehabilitation (CIIR) in Belém-PA, a public institution created to serve people with disabilities throughout the state of Pará.

### *2.2. Participants*

Non-probabilistic convenience sampling was performed. With regard to inclusion and exclusion criteria, the following were selected: caregivers of children aged between 3 years and 11 years and 11 months diagnosed with ASD, who were monitored at CIIR; be a CIIR participant; the caregiver who agreed to participate in the research by signing the free and informed consent form.

Caregivers of children who did not have a confirmed diagnosis of ASD were excluded; caregivers of children under 3 years old or over 12 years old; caregivers of twins with autism; did not attend CIIR; caregivers who did not agree to participate in the study; parents or guardians present at the time of the consultation who did not actively participate in the child's care.

### *2.3. Ethical Aspects*

The study was submitted to the Ethics and Research Committee of the Tropical Medicine Center – NMT of the Federal University of Pará – UFPA, respecting the Norms for Research Involving Human Beings (Resolution no. 466/2012) of the National Health Council, being approved under Opinion number 5.354.653, complying with the legal requirements of Resolutions 466/12 and 510/16

of the Brazilian National Health Council and the Declaration of Helsinki. All participants signed the free and informed consent form.

#### 2.4. Instruments

A form containing questions on sociodemographic characteristics was applied through interviews, addressing the questions of: type of caregivers (mother, father, grandmother), age of children (average) and number of children with ASD (average).

To assess perceived quality of life, the Short Form Healthy Survey (SF-36) item was used, translated and validated into Portuguese by Ciconelli, Ferraz, Santos, Meinão, and Quaresma [13]. This inventory uses 36 questions on various aspects that may relate to health-related perception and quality of life. To analyze the results, the domains of this instrument will be grouped into: Physical Component (CF), which groups the domains of functional capacity, physical aspects, pain and vitality; and Emotional Component (EC), which encompasses the domains of mental health, general health status, emotional and social aspects. Each category ranges from 2 to 10 items that can be summarized with the overall physical component score and the overall emotional component score. The results were expressed on a scale from 0 to 100 (obtained through Raw Scale calculation), where 0 corresponds to the worst perception and 100 to the best perception of quality of life.

To check anxiety symptoms, the Beck Anxiety Inventory (BAI) was applied, a symptomatic scale designed to measure the severity of anxiety symptoms. It consists of 21 items, in which the participant must score according to the symptoms that affect them, on a four (4) point scale, which reflects the levels of increasing severity of each symptom: 1 "absolutely not", 2 "slightly, it didn't bother me much", 3 "moderately, it was very unpleasant, but I could bear it", 4 "severely, I could hardly bear it". The total score is the sum of the scores of the individual items, allowing classification into levels of intensity of anxiety symptoms, where the minimum level presents total scores from 0 to 7, mild level, total scores from 8 to 15, moderate level, scores total scores from 16 to 25 and severe level, total scores from 26 to 63 [14].

#### 2.5. Statistical Analysis

The data were tabulated and analyzed using Statistical Package for the Social Sciences (SPSS), version 25.0. The results for categorical variables were expressed as absolute frequency and proportion and for continuous variables they were expressed as mean and standard deviation. The Chi-square test was applied to identify differences between categories of categorical variables; the Mann-Whitney Test to compare the scores of the quality of life domains according to the level of anxiety of the caregivers; the Spearman brightness test to verify bivariate consolidation and those variables that were demonstrated in the Spearman test were entered into the Multiple Linear Regression model to evaluate the predictors of the general emotional component of perceived quality of life. They were considered as dependent variable the general emotional component; and as co-variables, general anxiety score, child's age (years) and number of children with ASD. For all analyses, a statistical significance level of  $p < 0.05$  was considered.

### 3. Results

Eighty caregivers of children with ASD participated in the study. In 68.7%, mothers were the caregivers responsible for autistic children. The average age of the children was  $6.9 \pm 2.5$  years and the average of the number of siblings with ASD was  $1.2 (\pm 0.4)$ . Regarding perceived quality of life, the items with the lowest scores, on average, and which, therefore, demonstrated greater commitment on the part of caregivers, were, in this order (1) Limitation due to physical aspects, (2) Limitation due to emotional aspects, (3) Vitality and (4) Pain. About anxiety symptoms, of the total number of caregivers, 68.8% ( $n = 55$ ) had a severe level of anxiety (Table 1).

**Table 1.** Type of caregivers, age of children, number of siblings, perceived quality of life and level of anxiety symptoms of caregivers of children with Autism Spectrum Disorder followed in a public reference service in Amazon, 2022.

	n (%) / Average ( $\pm$ SD)
Type of caregivers	
Mother	55 (68.7)
Father	15 (18.8)
Grandmother	10 (12.5)
Age of children	6.9 ( $\pm$ 2.5)
Number of siblings with ASD	1.2 ( $\pm$ 0.4)
Perceived Quality of life	
Functional capacity	76.1 ( $\pm$ 20.4)
Limitation due to physical aspects	38.4 ( $\pm$ 30.0)
Pain	44.6 ( $\pm$ 18.0)
General health status	52.9 ( $\pm$ 10.1)
Vitality	41.8 ( $\pm$ 15.0)
Emotional aspects	53.9 ( $\pm$ 19.4)
Limitation due to emotional aspects	40.2 ( $\pm$ 36.2)
Mental health	57.7 ( $\pm$ 16.4)
Level of anxiety	
Minimum level	0 (0.0)
Light level	0 (0.0)
Moderate level	25 (31.3)
Severe level	55 (68.8)
Total anxiety score	39.7 ( $\pm$ 15.5)

Chi-square test; ASD = Autism Spectrum Disorder.

Table 2 presents perceived quality of life data according to the level of anxiety in caregivers of children with ASD. We can verify that caregivers with severe anxiety levels had a worse perception of quality of life in the domains of pain (p- value= 0.012), social aspects (p- value <0.001), limitation due to emotional aspects (p- value= 0.001) and mental health (p- value <0.001), when compared to caregivers with a moderate level of anxiety. However, in terms of functional capacity, caregivers with a moderate level of anxiety had a better functional capacity score (p- value= 0.001).

**Table 2.** Perceived quality of life according to the level of anxiety of caregivers of children with Autism Spectrum Disorder followed in a public reference service in Amazon, 2022.

Perceived Quality of Life	Moderate level of anxiety (n= 25)	Several level of anxiety (n= 55)	p- value
	Average ( $\pm$ DP)	Average ( $\pm$ SD)	
Functional capacity	85.6 ( $\pm$ 17.5)	71.7 ( $\pm$ 20.2)	0.001
Limitation due to physical aspects	48.0 ( $\pm$ 35.3)	34.0 ( $\pm$ 26.5)	0.168
Pain	37.5 ( $\pm$ 17.9)	47.8 ( $\pm$ 17.2)	0.012

General health status	54.0 ( $\pm$ 10.5)	52.4 ( $\pm$ 10.0)	0.258
Vitality	46.4 ( $\pm$ 17.8)	39.7 ( $\pm$ 13.2)	0.149
Social aspects	66.5 ( $\pm$ 13.8)	48.2 ( $\pm$ 19.0)	<0.001
Limitation due to emotional aspects	60.2 ( $\pm$ 34.7)	31.1 ( $\pm$ 33.3)	0.001
Mental health	72.3 ( $\pm$ 11.3)	51.0 ( $\pm$ 13.8)	<0.001

Mann-Whitney test.

The Table 3 shows a positive correlation between the caregiver's general anxiety score and the child's age in years ( $\rho^2= 0.187$ ; p- value= 0.049); a correlation was also observed between the number of children's siblings with ASD and general physical component of the caregiver's perceived quality of life ( $\rho^2= 0.210$ ; p- value= 0.031) and general emotional component of the caregiver's perceived quality of life ( $\rho^2= 0.211$ ; p-value= 0.030). However, there was a negative correlation between the caregiver's general anxiety score and the general physical component of the caregiver's perceived quality of life ( $\rho^2= -0.213$ ; p- value= 0.029) and the general emotional component of the perceived quality of life ( $\rho^2= -0.435$ ; p- value <0.001).

**Table 3.** Correlation between level of anxiety symptoms and caregivers' perceived quality of life and characteristics of children with Autism Spectrum Disorder monitored in a public reference service in Amazon, 2022.

Characteristics of caregivers	Characteristics of children with ASD	
	Age (years)	Number of siblings with ASD
General anxiety score		
$\rho^2$	0.187	-0,033
p-value	0.049	0,385
General physical component of quality of life		
$\rho^2$	0.129	0.210
p-value	0.128	0.031
General emotional component of quality of life		
$\rho^2$	0.056	0.211
p-value	0.310	0.030
Characteristics of caregivers	Perceived quality of life	
	General physical component of quality of life	General emotional component of quality of life
General anxiety score		
$\rho^2$	-0.213	-0.435
p-value	0.029	<0.001

Spearman correlation test; ASD= Autism Spectrum Disorder;.

The variables that showed statistically significant correlations in the bivariate analyses were included in the multiple linear regression model. Was observed correlation between the general emotional component of perceived quality of life and the general anxiety score, which remained significant in the multiple linear regression, regardless of the child's age and the number of children

with ASD ( $B = -0.471$ ;  $CI = -0.671; -0.274$ ;  $p < 0.0001$ ), that is, the level of anxiety is a predictor of the perceived quality of life of these caregivers, as shown in Table 4.

**Table 4.** Multiple linear regression analysis between the emotional component of perceived quality of life and the general anxiety score of caregivers of children with Autism Spectrum Disorder, monitored in a public reference service in Northern Brazil, 2022.

	<i>B</i>	IC 95% (minimum - maximum)	p- value
<b>Model 1</b>			
General anxiety score	-0.455	-0.658; -0.255	<0.001
<b>Model 2</b>			
General anxiety score	-0.485	-0.688; -0.285	<0.001
Child's age	0.183	-0.110; 2.359	0.074
<b>Model 3</b>			
General anxiety score	-0.471	-0.671; -0.274	<0.0001
Child's age	0.134	-0.435; 2.079	0.197
Number of children with ASD	0.190	-0.447; 14.824	0.065

Multiple linear regression; Dependent variable: General emotional component; co-variables: general anxiety score, child's age (years) and number of children with Autism Spectrum Disorder. *B*= regression coefficient.

#### 4. Discussion

The present study evaluated the relationship with the perception of anxiety symptoms and perceived quality of life of caregivers/parents of children on the ASD. It was observed that the majority of caregivers for children with autism were mothers, the average age of the children was  $6.9 \pm 2.5$  years and the average of the number of siblings with ASD was  $1.2 (\pm 0.4)$ . Similar to the study of Demsar and Bakracevic [15] in which the authors aimed to determine the level of stress, anxiety, and depression among Slovenian parents of children with autism spectrum disorder and their coping mechanisms, and they observed that the most caregivers were mothers, mean age of the children was  $6.29 (\pm 2.04)$ , and most families had one (45.2%) or two (42.9%) children, while a smaller proportion (11.9%) had three.

The mother, as the child's caregiver, is responsible for seeking treatment, for the daily care of her child, and as such, needs to make adaptations in her daily life that can result in the impoverishment of her social, emotional and professional life, and consequent physical and of this woman [16]. In this context, the responsibility of the caregiver has been presented as an exhausting task, resulting in increased levels of anxiety and reduced quality of life for the caregiver.

According to Samadi and Samadi [17], the authors aimed to understand the potential of caregivers and caregiving process for an individual with ASD, and mention that most studies carried out to identify the challenges associated with caring for a member with ASD in family environments, focus mainly on quality of life and maternal stress, as mothers are generally the main caregivers of individuals with ASD in the family.

The results of the present study corroborate those of study carried out by Asahar, Malek and Isa [18] who demonstrated the prevalence of mother caregivers in their research. In study of Traustadottir [19] the authors believed that in families with children with developmental disabilities, mothers are less likely to have paid employment and are therefore expected to have greater childcare responsibilities.

In the present study, severe anxiety levels were found in most caregivers, in addition to lower scores in the perceived quality of life domains, indicating deeper impairments in Limitation due to

physical aspects, Vitality and Limitation due to emotional aspects measured by the scale. Furthermore, it was observed that caregivers with severe anxiety levels had a worse perception of quality of life in the domains of pain, social aspects, limitation due to emotional aspects and mental health, when compared to caregivers with a moderate level of anxiety. However, in terms of functional capacity, caregivers with a moderate level of anxiety had a better functional capacity score.

Hoopen et al. [20] observed in their study with caregivers of children with autism, that the lower quality of life related to the care of primary caregivers was associated, among other factors, with their own anxiety/depression, but also with more anxiety/depression in the affected children.

In study by Öz, Yüksel and Nasiroğlu [21] the authors aimed to evaluate the effect of ASD on the perception of internalized stigma, symptoms of depression and anxiety and the quality of life of mothers of children with this disorder, and they observed that the mothers presented moderate symptoms of anxiety, and quality of life score were found to be low. The authors also observed that mothers whose children presented major difficulties specific to autism had higher levels of anxiety and lower quality of life.

According to Patel et al. [22] and Akram et al. [23] the quality of life of these caregivers is greatly affected in the “physical health” and “psychological” domains, as they need to perform different functions in their lives to face the challenges of their children with ASD and, consequently, they become anxious, depressed, exhausted and commonly frustrated while caring for their child. Patel et al. [22] also observed that parents who have children with ASD have physical health problems.

Turnage and Conner [24] carried out an integrated review of the literature on quality of life in parents of individuals with ASD, and observed that quality of life was lower in parents of children with ASD in physical, psychological and social health and spirituality, compared to adults who were not parents of children with ASD. The strongest risk factor for parental quality of life was the severity of the ASD diagnosis. The protective factors for parental quality of life were the parents’ level of education and the severity levels of ASD in the child.

Therefore, although the main reasons identified as causes of anxiety and reduced perceived quality of life have not been investigated in the present study, several factors involved in caring for a child with autism may be related. Tathgur and Kang [25] aimed to explore the concerns of the caregivers of children suffering from ASD, and they observed that caregivers face various challenges while caring for a child with ASD, with a negative impact on physical health, psychological well-being, societal reactions, and financial balance. Caregivers reported concerns related to service availability for ASD, poorly coping with the diagnostics, and disease processes.

In the study by Papadopoulos [26] the author evaluated the lived experiences and challenges of parenting among mothers of children with autism in Greece, and observed that families raising a child with ASD experience diverse consequences in many aspects, from the emotional burden and family to social and financial burden.

According to Almeida et al. [27] the diagnosis of autism can cause possible impacts on the family environment, such as stressful situations and overloads. Therefore, the results found in the present study can be justified by the hypothesis that caregivers have more than one autistic child, with feeding difficulties, exacerbated financial expenses, deterioration of social and sometimes professional relationships.

It was observed correlation between the general emotional component of perceived quality of life and the general anxiety score remained regardless of the child’s age and the number of children with ASD. In the study by Vernhet et al. [8] the authors observed that the perception of mothers and fathers about the impact on their quality of life was not associated with the age of their children.

Studies show that caregivers/parents of children with ASD generally present a greater loss in emotional health compared to typical families, this is because ASD presents characteristics that directly reflect on the family environment, such as low social interaction, inability to relate to other people, resulting in behavioral problems, requiring more prolonged stress due to daily care [28].

For Sprovier and Assumpção [29], the way the family deals with the disease is influenced by acceptance, interpretation and the way the individual deals with the challenges to which they are subjected.

Carvalho-Filha et al. [30] observed results of this nature, when analyzing the daily lives of caregivers of children with autism, they found that the majority of caregivers reported that their daily life is extremely focused on caring for the child with autism, and that the greatest difficulties were in relation to communication and feeding, in addition, the areas most affected in daily life were leisure and work.

The results show the need for an approach aimed not only at children, but also at their caregivers, as their perceived quality of life is compromised due to the daily care of children with ASD. According to Samadi and Samadi [17] involving parents in treatment implementation is advisable but to be able to facilitate this involvement different aspects of caregiving should be understood and taken into account.

Furthermore, it is essential to raise community awareness about the particularities of the universe of individuals with ASD, in favor of more empathy, solidarity, spaces for listening, and support for the families of individuals with ASD.

It is important to highlight that the present study has the limitations of being a cross-sectional study with non-probabilistic convenience sampling and economic and demographic data of caregivers were not investigated. Furthermore, it is important to mention that individuals with ASD are a very heterogeneous group with different types of skills and challenges, so a variety of impacts on caregivers may be an inevitable result of this heterogeneity. However, despite the limitations, the present study made it possible to know the psychological well-being of caregivers, contributing to reinforcing the need for patient- and family-centered care, to help caregivers develop positive coping strategies to deal with the problems they may encounter when caring for a child with autism, thus contributing to reducing anxiety symptoms and improving the perceived quality of life. Furthermore, no studies on this topic were found carried out in the northern region of Brazil.

It is suggested that further research be carried out on this topic, with better investigation into the influence of the parental style and lifestyle of the child with ASD and their family members, such as screen time, physical exercise, in addition to considering the support level, child's social impairment, parental knowledge about ASD, among others. Thus, it will be possible to contribute to a better quality of scientific evidence and cooperate in clarifying families who have child with ASD, in order to help in the development of care and therapeutic assistance programs for caregivers.

## 5. Conclusions

In the present study, the perception of high levels of anxiety and impairment in the perceived quality of life of caregivers of children with autism was observed, and also the correlation between these aspects and characteristics of children with ASD. It was found that the higher the child's age and the number of children with ASD, the higher the level of anxiety and the lower the perception of quality of these caregivers.

In our research, it was possible to demonstrate through linear regression analysis that the anxiety symptom score is a predictor of caregivers' perceived quality of life in emotional aspects, regardless of the child's age and the number of children with ASD. Therefore, the need for multidisciplinary monitoring and patient- and family-centered care is highlighted. Early intervention approaches to improve children's autism-specific difficulties can contribute to a positive effect on the children themselves, as well as alleviating anxiety symptoms in caregivers and consequently improving quality of life.

**Author Contributions:** For the elaboration of this work, each author contributed as follows: conceptualization, D.L.G.; methodology, D.L.G. and R.V.d.S.; validation, D.L.G. and R.V.d.S.; formal analysis, D.L.G.; investigation, R.V.S.; formatting, D.L.G., M.M.L.C. and R.V.S.; resources, data curatorship, R.V.S.; writing—preparation of the original draft, D.L.G.; writing—proofreading and editing, D.L.G., M.M.L.C. and R.V.d.S. All authors have read and agreed to the published version of the manuscript.

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**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study.

**Data Availability Statement:** The data is not publicly available as it contains the personal information of the participants involved. Therefore, the data of this work is confidential, to maintain the privacy of those involved.

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**Conflicts of Interest:** The authors declare no conflicts of interest.

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