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Article

# Relationship Between Perception of Anxiety Symptoms and Quality of Life of Caregivers of Children with Autism Spectrum Disorder in a Reference Center in Amazon

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**Abstract:** The relationship between perception of anxiety and quality of life in caregivers of children with autism was verified. To verify quality of life, the Short Form Healthy Survey Item was used; perception of anxiety 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 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 quality of life ( $p < 0.001$ ). It was found that caregivers of children with ASD present losses related to psychological factors, quality of life and the lack of social support.

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

## 1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that mainly affects males. It is possible to observe the warning signs for ASD at the beginning of early childhood, however, the diagnosis is generally made from the age of three years old. People affected by these disorders have deficits in communication, social interaction, restricted interests and repetitive movements. The severity of the disorder can vary from mild, moderate or severe, with such classifications being characterized according to the person's level of dependence [1,2].

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 dependence. 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].

Taking the general population into account, the number of children diagnosed with ASD represents an important repercussion for the development of scientific studies, and, according to research, currently the number of researchers interested in understanding the particularities of this disorder is increasing. However, studies aimed at the caregivers/parents of these children, specifically regarding their quality of life (QoL), are still scarce [3].

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 dependence, 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].

Considering the relevance of studies related to QoL and the high number of children diagnosed with ASD, an interface between these two themes became necessary to promote improvements in the lives of children's caregivers/parents. According to Koffka [4] and Ribeiro [5], every human being is part of a context that will influence, depending on the relationships established, the development of healthy or ill behaviors. Therefore, in addition to a child with ASD, there are families and cultures that need to be guided so that they can understand the possibilities of these relationships.

According to existing research, being in contact with an autistic child, as a caregiver, can cause a significant emotional impact on families, in addition to generating higher levels of stress, when compared to caregivers of children with typical development [6,7].

Still considering that parents of children with ASD have changes in their QoL, it is important to highlight that not all parents will necessarily have high levels of stress. According to Hayes and Watson [8], 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 QoL 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. Therefore, we sought to verify the relationship with the perception of anxiety symptoms and quality of life of 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*

This cross-sectional, descriptive and analytical study, with its target audience being children with ASD and their respective caregivers assisted by NATEA (Autism Spectrum Disorder Service Center), located at the Integrated Center for Inclusion and Rehabilitation (CIIR) in Belém- PA, from June to August/2022, on Fridays, in the morning and afternoon shifts.

The Autism Spectrum Disorder Care Center (NATEA) is a reference in the North of Brazil in the care of people with autism, providing a range of therapies to enhance the rehabilitation of users, which belongs to the Integrated Center for Inclusion and Rehabilitation (CIIR) which is a public institution created to serve people with disabilities throughout the state of Pará.

### *2.2. Participants*

Eighty parents/caregivers and their respective children participated in the research. The inclusion criteria adopted were caregivers of children diagnosed with ASD, aged between 3 years and 11 years and 11 months old, who were monitored at the CIIR; be a CIIR attendee; the caregiver agrees to participate in the research by signing the Free and Informed Consent Form (TCLE). And caregivers of children who did not have a closed diagnosis of ASD were excluded; caregivers of children under 3 years of age or over 12 years of age; being a twin; do 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 Management and Research Sector of the CIIR, and 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.

Firstly, the caregivers were approached in the NATEA waiting room, while they waited for the therapies to begin, in which the reasons that led to carrying out this research and the benefits of it for the participants were clarified, as well as the invitation was made for them to participate in the study. Through an interview completed by legal guardians, after accepting to participate in the research, after reading and signing the TCLE and the Consent Form for the Participation of the Minor as a Research Participant. In addition, it was ensured that the information was kept in secrecy.

#### 2.4. Instruments

To assess the perception of caregivers' 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 [12]. 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 [13].

In addition, data were collected to assess the children's nutritional status, with weight collected using a digital scale, with a variation of 0.1 kg and capacity of up to 150 kg, and height using an aluminum anthropometer with 0.1 cm precision. (certified by the National Institute of Metrology, Quality and Technology - INMETRO and recently calibrated) provided by the researcher. The children were weighed and measured with clothes on and without shoes. The Body Mass Index (BMI) was calculated using the formula of weight (W) over height (H) squared ( $W/H^2$ ). The children had their anthropometric assessment carried out in accordance with the instructions of the Food and Nutrition Surveillance System (SISVAN) [9].

The BMI Growth Charts for Age, for females and males, from the World Health Organization [10,11] were used to classify children as underweight for their age, eutrophic, overweight or obese.

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#### 2.5. Statistical Analysis

The data were tabulated and analyzed using SPSS (Statistical Package for the Social Sciences), 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 quality of life. 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 and the number of children with ASD was  $1.2 \pm 0.4$ . The average age of the children was  $6.9 \pm 2.5$  years. Of the total number of caregivers, 68.8% ( $n=55$ ) had a severe level of anxiety. Regarding 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.

Table 1 below presents data from the children's caregivers in relation to the degree of kinship (whether father, mother or grandmother), level of anxiety, and classification in the items on the quality of life scale.

**Table 1.** General characteristics, level of anxiety and perception of quality of life of caregivers of children with Autism Spectrum Disorder followed in a public reference service in Amazon, 2022.

Type of Caregivers	n (%)	p-Value
Mother	55 (68.7)	<0.001
Father	15 (18.8)	
Grandmother	10 (12.5)	
Level of anxiety	n (%)	p-value
Minimum level	0(0.0)	0.001
Light level	0(0.0)	
Moderate level	25 (31.3)	
Severe level	55 (68.8)	
	Average ( $\pm$ SD)	Interval
Total anxiety score	39.7 ( $\pm$ 15.5)	16.0 – 63.0
Age of children	6.9 ( $\pm$ 2.5)	4.0 – 11.0
Number of children with ASD	1.2 ( $\pm$ 0.4)	1.0 – 2.0
Quality of life	Average ( $\pm$ SD)	Interval
Functional capacity	76.1 ( $\pm$ 20.4)	30.0 – 100.0
Limitation due to physical aspects	38.4 ( $\pm$ 30.0)	0.0 – 100.0
Pain	44.6 ( $\pm$ 18.0)	4.0 – 72.0
General health status	52.9 ( $\pm$ 10.1)	25.0 – 65.0
Vitality	41.8 ( $\pm$ 15.0)	0.0 – 75.0
Emotional aspects	53.9 ( $\pm$ 19.4)	12.5 – 100.0
Limitation due to emotional aspects	40.2 ( $\pm$ 36.2)	0.0 – 100.0
Mental health	57.7 ( $\pm$ 16.4)	20.0 – 100.0

Chi-square test; ASD = Autism Spectrum Disorder.

Table 2 presents 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.** Perception of 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.

Quality of Life	Moderate Level of Anxiety (n=25)		Several Level of Anxiety (n=55)		p-Value
	Average ( $\pm$ DP)	Median (P5 – P95)	Average ( $\pm$ SD)	Median (P5 – P95)	
Functional capacity	85.6 ( $\pm$ 17.5)	90.0 (35.0-100.0)	71.7 ( $\pm$ 20.2)	75.0 (30.0-100.0)	0.001
Limitation due to physical aspects	48.0 ( $\pm$ 35.3)	25.0 (0.0-100.0)	34.0 ( $\pm$ 26.5)	25.0 (0.0-100.0)	0.168
Pain	37.5 ( $\pm$ 17.9)	40.0 (4.0 -72.0)	47.8 ( $\pm$ 17.2)	50.0 (20.0-72.0)	0.012
General health status	54.0 ( $\pm$ 10.5)	60.0 (30.0-65.0)	52.4 ( $\pm$ 10.0)	55.0 (25.0-65.0)	0.258
Vitality	46.4 ( $\pm$ 17.8)	45.0 (25.0-75.0)	39.7 ( $\pm$ 13.2)	40.0 (0.0-65.0)	0.149
Social aspects	66.5 ( $\pm$ 13.8)	62.5 (50.0-100.0)	48.2 ( $\pm$ 19.0)	50.0 (13.0-100.0)	<0.001
Limitation due to emotional aspects	60.2 ( $\pm$ 34.7)	67.0 (0.0-100.0)	31.1 ( $\pm$ 33.3)	33.0 (0.0-100.0)	0.001
Mental health	72.3 ( $\pm$ 11.3)	64.0 (64.0-100.0)	51.0 ( $\pm$ 13.8)	52.0 (20.0-88.0)	<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) and the child's BMI ( $\rho^2= 0.233$ ; p-value=0.019) ; a correlation was also observed between the general physical component of the caregiver's quality of life and the number of children's siblings with ASD ( $\rho^2= 0.210$ ; p-value=0.031); and the General emotional component of the caregiver's quality of life and the number of children's siblings with ASD ( $\rho^2= 0.211$ ; 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 quality of life ( $\rho^2= -0.213$ ; p-value=0.029) and the general emotional component of the quality of life ( $\rho^2= -0.435$ ; p-value=<0.001).

**Table 3.** Correlation between level of anxiety symptoms and perception of caregivers' 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			
	General Anxiety Score	Age (Years)	BMI (kg/m <sup>2</sup> )	Number of Siblings with ASD
$\rho^2$		0.187	0.233	-0,033
p-value		0.049	0.019	0,385
General physical component of quality of life				
$\rho^2$		0.129	-0.025	0.210
p-value		0.128	0.413	0.031
General emotional component of quality of life				
$\rho^2$		0.056	0.012	0.211
p-value		0.310	0.457	0.030
		Perception of quality of life		
General anxiety score		General physical component of quality of life	General emotional component of quality of life	
$\rho^2$		-0.213	-0.435	
p-value		0.029	<0.001	

Spearman correlation test; ASD= Autism Spectrum Disorder; BMI = Body Mass Index.

Finally, a correlation was observed between the general emotional component of quality of life and the general anxiety score (p<0.0001), 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 perception of quality of life of these caregivers, as shown in Table 4.

**Table 4.** Multiple linear regression analysis between the emotional component of 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)	<i>p</i> -Value
Model 1			
General anxiety score	-0.455	-0.658; -0.255	<0.001
Model 2			
General anxiety score	-0.485	-0.688; -0.285	<0.001
Child's age	0.183	-0.110; 2.359	0.074
Model 3			
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

Given the results found, 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, who is usually the mother of the child with autism spectrum disorder (ASD). 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 [14]. These data corroborate those of studies carried out by Anjos et al. [15] and Tavares et al. [14] who demonstrated the prevalence of mother caregivers in their research. However, studies by Alshekaili [16] and Alshahrani and Algashmari [17] found a prevalence of male caregivers.

These data suggest that the diagnosis of autism can cause possible impacts on the family environment, such as stressful situations and overloads [18]. In the present study, severe anxiety levels were found in most caregivers, in addition to lower scores in the quality of life domains, indicating deeper impairments in Limitation due to physical aspects, Vitality and Limitation due to emotional aspects measured by the scale. These results 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, that is, several factors can trigger high levels of stress, physical overload and mental health for caregivers and other family members.

Furthermore, it was observed that the correlation between the general emotional component of quality of life and the general anxiety score remained regardless of the child's age and the number of children with ASD. Studies show that caregivers/parents of children with ASD generally present a greater loss in emotional health compared to other groups, 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 [19].

For Sprovier and Assumpção [20], 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.

Filha et al. [21] observed results of this nature, when analyzing the daily lives of caregivers of autistic children, they found that the majority of caregivers reported that their daily life is extremely focused on caring for the autistic child, 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 quality of life is compromised due to the daily care of children with ASD.

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 suggested that further research be carried out on this topic. Thus, it will be possible to contribute to a better quality of scientific evidence and cooperate in clarifying families who have 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 quality of life of caregivers of children with autism was observed, and also the correlation between these aspects and nutritional characteristics of children with ASD. It was found that the higher the child's age, BMI 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' perception of quality of life in emotional aspects, regardless of the child's age and the number of children with ASD, a result This is a pioneer in the literature, which will serve as a path for future research, since there is little literature on this topic.

It was found that caregivers of children with ASD present losses related to psychological factors, quality of life and the lack of social support and the importance of multidisciplinary monitoring to improve this condition.

**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.d.S.; formatting, D.L.G. and R.V.d.S.; resources, data curatorship, R.V.d.S.; writing—preparation of the original draft, D.L.G.; writing—proofreading and editing, D.L.G. and R.V.d.S. All authors have read and agreed to the published version of the manuscript.

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**Institutional Review Board Statement:** This study was approved by the Ethics Committee for Research with Human Beings (CEP) of the Tropical Medicine Center of the Federal University of Pará (UFGA) under opinion No. 5.354.653, in June 2022.

**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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