

Quality of life of informal caregivers of children with Autism Spectrum Disorder

Qualidade de vida de cuidadores informais de crianças com Transtorno do Espectro Autista

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Abstract:

Objective: to assess the quality of life and satisfaction of informal caregivers of children with Autism Spectrum Disorder, and to correlate them with the impairment of the child's skills and with the facilitating and hindering environmental factors. **Methods:** quantitative, observational, cross-sectional study, carried out in 2023, at the Specialized Rehabilitation Center III. A form with sociodemographic data, the World Health Organization Quality of Life Bref, the Childhood Autism Rating Scale, and the environmental factors of the International Classification of Functioning, Disability and Health were used. The data were analyzed with absolute values and frequency and the Spearman Correlation Test. **Results:** 87.5% of the caregivers were female, aged between 30 and 50 years. Quality of life showed a moderate correlation with the factors of support and relationships of friends and individual attitudes of friends; while satisfaction with health showed a moderate correlation with the factors of support and relationships of friends and with the factors of norms, practices, and social ideologies. These results indicate that the greater the assessment of the factors mentioned, the greater the assessment of quality of life and satisfaction with the health of the caregivers. **Conclusion:** the quality of life of the caregivers evaluated was impacted by the support and relationships and individual attitudes of friends. Satisfaction with quality of life demonstrated a relationship with the support and relationships of friends and the variable of social norms, practices and ideologies.

Keywords: Quality of Life; Caregivers; Autism Spectrum Disorder; Child; International Classification of Functioning, Disability and Health.

Resumo:

Objetivo: avaliar a qualidade de vida e a satisfação de cuidadores informais de crianças com Transtorno do Espectro Autista, e correlacionar com o comprometimento das habilidades da criança e com os fatores ambientais facilitadores e barreiras. **Método:** estudo quantitativo, observacional, transversal, realizado em 2023, no Centro Especializado de Reabilitação III. Utilizou-se ficha com dados sociodemográficos, o *World Health Organization Quality of Life Bref*, a Escala de Classificação de Autismo na Infância e os fatores ambientais da Classificação Internacional de Funcionalidade, Incapacidade e Saúde. Analisou-se os dados com valores absolutos e frequência e o Teste de Correlação de Spearman. **Resultados:** 87,5% dos cuidadores eram do sexo feminino, com idade entre 30 e 50 anos. A qualidade de vida apresentou correlação moderada com os fatores de apoio e relacionamentos de amigos e atitudes individuais de amigos; já a satisfação com a saúde apresentou correlação moderada com os fatores apoio e relacionamentos de amigos e com os fatores normas, práticas e ideologias sociais. Esses resultados indicam que, quanto maior a avaliação dos fatores citados, maior é a avaliação da qualidade de vida e satisfação com a saúde dos cuidadores. **Conclusão:** a qualidade de vida dos cuidadores avaliados foi impactada pelo apoio e relacionamentos e atitudes individuais de amigos. A satisfação com a qualidade de vida demonstrou relação com o apoio e relacionamentos de amigos e da variável de normas, práticas e ideologias sociais.

Palavras-chave: Qualidade de Vida; Cuidadores; Transtorno do Espectro Autista; Criança; Classificação Internacional de Funcionalidade, Incapacidade e Saúde.

Resumen:

Objetivo: Evaluar la calidad de vida y satisfacción de los cuidadores informales de niños con Trastorno del Espectro Autista, y correlacionarla con la alteración de las capacidades del niño y con los factores ambientales facilitadores y barreras. **Método:** estudio cuantitativo, observacional, transversal, realizado en 2023 en el Centro Especializado de Rehabilitación III. Se utilizó un formulario con datos sociodemográficos, el *World Health Organization Quality of Life Bref*, la Escala de Valoración del Autismo Infantil y los factores ambientales de la Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud. Los datos se analizaron mediante valores absolutos y frecuencias y la Prueba de Correlación de Spearman. **Resultados:** el 87,5% de los cuidadores eran mujeres, con edades comprendidas entre los 30 y los 50 años. La calidad de vida mostró una correlación moderada con los factores de apoyo y relaciones de amigos y actitudes individuales de amigos, mientras que la satisfacción con la salud mostró una correlación moderada con los factores de apoyo y relaciones de amigos y con los factores de normas, prácticas e ideologías sociales. Estos resultados indican que cuanto mayor es la valoración de los factores mencionados, mayor es la calidad de vida y la satisfacción con la salud de los cuidadores. **Conclusión:** la calidad de vida de los cuidadores evaluados se vio afectada por el apoyo y las relaciones y actitudes individuales de los amigos. La satisfacción con la calidad de vida mostró una relación con el apoyo y las relaciones de los amigos y la variable de normas, prácticas e ideologías sociales.

Palabras-clave: Calidad de Vida; Cuidadores; Trastorno del Espectro Autista; Niño; Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud.

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INTRODUCTION

The World Health Organization¹ states that 1 in every 100 children has Autism Spectrum Disorder (ASD). It is also estimated that there are two million autistic people in Brazil². When performing a comparative analysis of autism between boys and girls, the Brazilian Society of Pediatrics³ found a ratio of approximately 4:1, showing a higher prevalence among boys.

ASD is characterized by difficulty in social interaction and communication, also manifesting repetitive and more restricted patterns of behavior⁴. The manifestation of symptoms in childhood varies. Some present them in the first 12 months of life, while others may present them after 24 months⁵. Furthermore, many cases of children with ASD are associated with disorders such as Attention Deficit Hyperactivity Disorder, depression and anxiety³, which are more observed in children with ASD than in children without ASD⁵. Depending on the level of impairment of their skills and needs, individuals with ASD are able to live independently or require constant assistance¹, significantly altering family dynamics. Family members are overwhelmed by the necessary changes in their routine, increasing their levels of worry and stress⁶.

The term caregiver encompasses two aspects: formal and informal. A formal caregiver is an individual who has received training focused on the necessary care, usually receiving remuneration⁷. Meanwhile, an informal caregiver is usually a family member who, given the circumstances, needs to provide support to a loved one⁸. When assuming the role of caregiver for children with ASD, the individual becomes subject to changes in their lifestyle, overloads and insecurities⁹.

In many cases, the family is isolated due to the necessary changes after the discovery of ASD, marked by insecurity and fear of prejudice¹⁰. Linked to this, feelings of frustration arise due to the difficulty of communicating and interacting with the family member with ASD², in addition to insecurities regarding unpredictable behaviors and the community's resistance to the child's idiosyncrasies¹¹. When parents take on the role of caregiver, they suffer emotional impact, financial changes and stress, in addition to increased concern about the child's future¹². Parents, therefore, find themselves faced with new demands, participating in the child's development process, dedicating themselves to stimulating the development of skills¹³. Thus, parents, when correctly guided on how to act and teach, favor positive effects on the social interaction of children¹⁴. In addition, parental participation and the attention they provide to this process can help children in various skills and in their quality of life (QoL)¹⁵. The QoL of these parents and caregivers is an important issue, considering that caregivers, faced with the

demands of care, often forget about themselves and may even become ill in the future⁷. According to the World Health Organization¹⁶, QoL is defined as the individual's perception of their life, considering the social and cultural context, and their relationships, encompassing the emotional, physical, mental aspects and their relationships. In view of this, caregivers of children with ASD have their quality of life affected by the lack of a support network, as well as financial and social issues⁶.

One option for assessing QoL in this scenario is the International Classification of Functioning, Disability and Health (ICF), which provides an organized structure, recognizing the body component, domains related to activities and participation, and contextual factors, such as environmental factors that positively or negatively affect the individual¹⁷. Therefore, the ICF is a biopsychosocial tool that encompasses aspects related to health and significant environmental and personal factors, which present themselves and are classified as barriers or facilitators in the individual's life¹⁸.

In addition, the Childhood Autism Rating Scale (CARS) is an instrument that collects information related to children's skills, encompassing the domains of interpersonal relationships, imitation, emotional response, body expression, use of objects, adaptation to change, reaction to visual and auditory stimuli, response and use of taste, smell and touch; fear and nervousness, verbal communication, nonverbal communication, activity, degree and consistency of intellectual response and general impressions¹⁹.

The World Health Organization Quality of Life (WHOQOL-BREF) questionnaire is used to assess QoL, consisting of 26 questions covering physical, psychological, social relationships and environmental domains, and the results obtained with the questionnaire correspond to the following descriptions: needs improvement (1 to 2.9); fair (3 to 3.9); good (4 to 4.9) and very good (5)²⁰.

Therefore, it is pertinent to conduct research that seeks to assess the QoL of caregivers of children with ASD within a biopsychosocial context and identify contextual environmental factors that influence positively or negatively. Therefore, this study aims to evaluate the quality of life and satisfaction of informal caregivers of children with Autism Spectrum Disorder, and correlate it with the impairment of the child's skills and with the facilitating and barrier environmental factors.

METHODS

This is a quantitative, observational, cross-sectional study carried out in 2023 at the Specialized Rehabilitation Center III (CER III), located at the Teaching and Assistance Unit in

Physical Therapy and Occupational Therapy (UEAFTO) in the city of Belém do Pará, Brazil, which is provided by the Unified Health System (*Sistema Único de Saúde* - SUS). The sample consisted of informal caregivers of children diagnosed with Autism Spectrum Disorder, users of CER III, who signed the Free and Informed Consent Form (FICF).

Informal caregivers of children diagnosed with Autism Spectrum Disorder, of both sexes and users of CER III, were included. Individuals who were not informal caregivers and caregivers of children with associated neuromotor and/or cardiorespiratory diseases were excluded.

Data collection was carried out through individual interviews, lasting an average of 30 minutes. Initially, a data sheet was applied to collect the interviewee's profile, followed by the WHOQOL-BREF questionnaire, consisting of 26 questions covering physical, psychological, social relationships and environmental domains. In addition, the CARS scale and a questionnaire on environmental factors contained in the ICF were applied. Given the need for a shorter instrument, an abbreviated version was developed based on the WHOQOL-100, a quality of life assessment instrument with 100 questions²⁰. The Portuguese version of the WHOQOL-100 was developed at the Department of Psychiatry and Legal Medicine of the Universidade Federal do Rio Grande do Sul, Porto Alegre, Brazil, and the brief version was also made available in Portuguese²¹.

To allow item analysis, the results related to the ICF environmental factors were transformed into a continuous scale and classified: 0 - not applicable, 1 - complete barrier, 2 - severe barrier, 3 - moderate barrier, 4 - mild barrier, 5 - mild facilitator, 6 - moderate facilitator, 7 - considerable facilitator, 8 - complete facilitator.

The data collected were entered into an Excel™ spreadsheet. Spearman's correlation coefficient (RHO) was used for analysis, since these are non-parametric data describing the relationship between variables. RHO was considered as a parameter to classify the degree of correlation: very weak correlation (between 0 and 0.19); weak (between 0.20 and 0.39); fair (between 0.40 and 0.69); strong (between 0.70 and 0.89); and very strong (between 0.90 and 1). Correlations with statistical significance were considered those that presented $p \leq 0.05$. Data analysis was also performed using the SPSS 20.0 statistical package (IBM SPSS™ Statistics).

The study also used the question that addresses satisfaction with health (WHOQOL-SATIS), which can be found in the WHOQOL-BREF instrument. Satisfaction with health was classified as: 1 - very dissatisfied, 2 - dissatisfied, 3 - neither satisfied nor dissatisfied, 4 - satisfied and 5 - very satisfied. Based on the result, it was possible to correlate with data related to environmental factors.

Environmental factors within the ICF are represented by the letter “e”, and are classified with the following codes: e110 to e155 for products and technologies; e225 to e250 for natural environment and human-made environmental changes; e310 to e360 for support and relationships; e410 to e465 for attitudes; and e522 to e590 for services, systems and policies¹⁷.

This study was approved by the Human Research Ethics Committee of the Universidade do Estado do Pará, under opinion no. 1,168,102, CAAE 69196023.7.0000.8767, conducted in accordance with the precepts of the Regulation of Research Involving Human Beings (Res. 466/12) of the National Health Council (CNS).

RESULTS

Sixteen informal caregivers were interviewed, of which 14 (87.5%) were female, while 2 (12.5%) were male. All informal caregivers were the children's parents. The majority were 50 years of age or younger (Table 1).

Table 1. Informal caregivers according to sex and age. Belém-PA/Brazil, 2023.

Variables	Total= 16	% (100%)
Sex		
Male	2	12.5%
Female	14	87.5%
Age group (years)		
< 20	0	0.0
20-30	3	18.75%
30-40	4	25.0%
40-50	7	43.75%
50-60	1	6.25%
60>	1	6.25%

Table 2 shows the results regarding the assessment of QOL using the WHOQOL-BREF scale related to the CARS scale. The physical, psychological, social relationships and environment domains did not show any association with the CARS scale ($p>0.05$).

Table 2. Impact of ASD levels on the physical, psychological, social relationships and environmental domains of informal caregivers. Belém-PA, 2023.

		Physical Domain (n=16)	Psychological Domain (n=16)	Social Relationships (n=16)	Environment (n=16)
CARS¹	Correlation coefficient (RHO)	.015	-.014	.154	.120
	p-value	.955	.959	.570	.659

¹Childhood Autism Rating Scale

It can be seen in Table 3 that the results related to environmental factors e110, e115, e120, e125, e150 and e155 were not related to QoL and health satisfaction ($p > 0.05$).

The variables of the natural environment and human-made environmental changes are represented by the codes e225, e240 and e250, shown in Table 3. From the analysis of the results, it can be seen that they were not related to QoL and health satisfaction ($p > 0.05$).

In Table 4, the variable friends (e320) showed a fair correlation ($RHO=0.538$) with QoL ($p=0.032$) and a fair correlation ($RHO=0.609$) with health satisfaction ($p=0.012$). These results indicate that the greater the support and relationships informal caregivers have with friends, the higher their assessment of quality of life and health satisfaction.

The variable of individual attitudes of friends (e420) analyzed in Table 4 showed a fair correlation (0.595) with the assessment of QoL ($p=0.015$). Likewise, the norms, practices and social ideologies (e465) of the environmental factors of the ICF showed a fair correlation ($RHO=0.517$) with health satisfaction ($p=0.040$).

In turn, in Table 5, referring to services, systems and policies, no relationships were found between these and the QoL or health satisfaction of informal caregivers.

Table 3. Relationship between products and technologies, environmental factors, natural environment and human-made environmental and the quality of life of informal caregivers. Belém-PA/Brazil, 2023.

		Environmental factors products and technologies					
		e110 ³	e115 ⁴	e120 ⁵	e125 ⁶	e150 ⁷	e155 ⁸
WHOQOL ¹	Correlation coefficient (RHO)	,390	,149	,169	,347	,206	,145
	p-value	,136	,582	,530	,188	,445	,593
WHOQOL SATIS ²	Correlation coefficient (RHO)	-,026	-,366	,316	,147	,491	,477
	p-value	,924	,163	,234	,586	,054	,062
		Environmental factors, natural environment and human-made environmental changes					
		e225 ⁹	e240 ¹⁰	e250 ¹¹			
WHOQOL ¹	Correlation coefficient (RHO)	-,044	,295	,345			
	p-value	,871	,267	,190			
WHOQOL SATIS ²	Correlation coefficient (RHO)	-,224	,121	,189			
	p-value	,404	,657	,482			

¹Quality of life assessment; ²Health satisfaction; ³Products and substances for personal consumption; ⁴Products and technology for personal use in daily life; ⁵Products and technology for personal mobility and transportation in indoor and outdoor environments; ⁶Products and technology for communication; ⁷Products and technology used in the design, architecture and construction of buildings for public use; ⁸Products and technology used in the design, architecture and construction of buildings for private use; ⁹Climate; ¹⁰Light; ¹¹Sound.

Table 4. Correlation between environmental factors related to support and relationships, attitudes and quality of life of informal caregivers. Belém-PA/Brazil, 2023.

		Support and relationships						
		e310 ³	e320 ⁴	e325 ⁵	e330 ⁶	e340 ⁷	e355 ⁸	e360 ⁹
WHOQOL ¹	Correlation coefficient (RHO)	,336	,538*	,171	-,018	,095	,238	,060
	p-value	,203	,032	,527	,946	,726	,375	,824
WHOQOL SATIS ²	Correlation coefficient (RHO)	,000	,609*	,221	,191	,141	,389	-,120
	p-value	1,000	,012	,410	,479	,601	,136	,657
		Attitudes						
		e410 ¹⁰	e420 ¹¹	e440 ¹²	e450 ¹³	e455 ¹⁴	e460 ¹⁵	e465 ¹⁶
WHOQOL ¹	Correlation coefficient (RHO)	-,187	,595*	,095	,320	,232	,173	,423
	p-value	,489	,015	,726	,227	,338	,523	,102
WHOQOL SATIS ²	Correlation coefficient (RHO)	-,331	,373	,141	,204	-,111	,433	,517*
	p-value	,211	,155	,601	,448	,683	,094	,040

¹Quality of life assessment; ²Health satisfaction; ³Immediate family; ⁴Friends; ⁵Acquaintances, peers, colleagues, neighbors, and community members; ⁶People in authority; ⁷Caregivers and personal assistants; ⁸Health care professionals; ⁹Other professionals providing health-related services; ¹⁰Individual attitudes of immediate family members; ¹¹Individual attitudes of friends; ¹²Individual attitudes of caregivers and personal assistants; ¹³Individual attitudes of professionals; ¹⁴Individual attitudes of health-related professionals; ¹⁵Social attitudes; ¹⁶Social norms, practices, and ideologies.

Table 5. Correlation between environmental factors related to services, systems and policies and the quality of life of caregivers. Belém-PA/Brazil, 2023.

		Services, systems and policies								
		e522 ³	e535 ⁴	e540 ⁵	e550 ⁶	e570 ⁷	e575 ⁸	e580 ⁹	e585 ¹⁰	e590 ¹¹
WHOQOL ¹	Correlation coefficient (RHO)	-,451	-,264	,050	-,106	,004	-,165	,129	-,271	.
	p-value	,080	,323	,854	,695	,990	,540	,635	,310	.
WHOQOL SATIS ²	Correlation coefficient (RHO)	-,033	,283	-,374	-,030	,064	,164	,069	,128	.
	p-value	,902	,288	,154	,913	,814	,544	,799	,635	.

¹Quality of life assessment; ²Health satisfaction; ³Housing services, systems and policies; ⁴Communication services, systems and policies; ⁵Transportation services, systems and policies; ⁶Legal services, systems and policies; ⁷Social security services, systems and policies; ⁸General social support services, systems and policies; ⁹Health services, systems and policies; ¹⁰Education and training services, systems and policies; ¹¹Labor and employment services, systems and policies.

DISCUSSION

In the present study, it can be observed that 87.5% of the sample was composed of women, all of whom were mothers of children with ASD. Mothers of children with ASD actively participate from the beginning of their diagnostic process, through the search for health care²². As a result of this context, mothers usually withdraw from their social and professional lives, putting their role as caregivers first and accepting this as a responsibility and obligation²². The

phenomenon of mothers being overwhelmed by childcare is related to traditional culture, adopting the role of primary caregiver, while other mothers identify with this role²³.

The factors of support and relationships with friends were significant for the QoL of informal caregivers, given that the result indicates that support and relationships with friends have a moderate positive influence on the assessment of QoL, and a very weak influence on the satisfaction with the health of informal caregivers of children with ASD. It was also identified that individual attitudes of friends, also contained in the environmental factors of the ICF, have a moderate impact on the assessment of the QoL of the interviewees.

The moment of diagnosis is seen as complex, marked by despair, doubts, denial and helplessness²⁴. In addition, with the diagnosis of ASD, factors such as social and professional life, changes in routine and psychological aspects are affected by the overload²⁵. The support of family members, institutions and friends is initially important to facilitate the family's adaptation to the changes in light of the diagnosis²⁶.

One of the forms of support is the social support offered by family members and friends²⁶. From another perspective, support can be assessed based on domains such as apparatus, communication and affective, with the latter, related to the act of empathy and concern, being identified as the most essential in a study with family members of children with ASD²⁷.

A case report demonstrated that friends, among other groups such as family, form the support network of caregivers²⁵. The search for social support is related to a coping strategy for family members when faced with difficulties that cause stress²⁴.

In another study, it was observed that the topic of friends was rarely addressed by caregivers, but it has not yet been possible to determine whether family members do not seek help or whether it is not available in their support network, although there are reports of family members who have support from friends in the workplace²⁶.

Based on the results, it is noted that norms, practices and ideologies have a moderate impact on health satisfaction. The set of norms that prescribe behaviors, actions and thoughts can be defined as ideology²⁸.

Some characteristics of children with ASD related to interaction and communication cause families to isolate themselves socially due to society's estrangement from the child's individuality²⁴. The term "spectrum" is justified by the wide variety of profiles, as can be seen in the assessment based on levels of support, classifying autism as level I, requiring support; level II, requiring substantial support and level III, requiring very substantial support²⁹. One study showed that level III presented more significant aggression, psychomotor agitation,

concentration, anxiety and stereotyped movements, while these symptoms were milder at level I³⁰. Language is also important for the diagnosis of ASD, with reduced manifestation at higher levels³⁰.

According to the Brazilian Ministry of Health³¹, children and their families, after diagnosis, are still subject to historically reported difficulties, such as exclusion from public spaces and reduced access to services. Isolation can be an element of social representation, which acts to justify social behaviors and practices³². In this sense, adopting an isolation stance facilitates the attempt to justify the exclusion of people with ASD³².

CONCLUSION

It is concluded that informal caregivers of children with ASD who receive support from friends (especially individual attitudes) obtained better scores in indexes related to QoL and health satisfaction.

Regarding the assessment of health satisfaction impacted by social norms, practices and ideologies, despite the significant values, few studies address the topic, especially in relation to caregivers, which is a limitation of this research. Thus, it is necessary to highlight the need for further research that relates the effect of social norms, practices and ideologies on the QoL of caregivers, as well as their correlation with health satisfaction.

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