

# Quality of life of caregivers of children with neurodevelopmental disorders

*Qualidade de vida de cuidadores de crianças com transtornos do neurodesenvolvimento*

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## ABSTRACT

**Objective:** To identify the health-related quality of life of caregivers of children with neurodevelopmental disorders and analyze the associated factors. **Method:** Observational, cross-sectional, quantitative study. A characterization instrument and The Medical Outcomes Study 36-Item Short were applied to 25 caregivers. The Mann-Whitney test and the Spearman's correlation were used with a significance level of 5%. Among the health-related quality of life domains, vitality and bodily pain had the lowest scores. There was a significant difference between religious belief and social role functioning ( $p=0.046$ ) and mental health ( $p=0.008$ ) domains; and between marital status and the domains of social role functioning ( $p=0.029$ ) and emotional role functioning ( $p=0.035$ ). There was a negative correlation between physical functioning and the caregiver's age. **Conclusion:** Caregivers of children with neurodevelopmental disorders feel tired and unwell. Religious belief, marital status and age were related factors.

**Descriptors:** Child; Nursing; Health-related Quality of Life; Neurodevelopmental Disorders; Caregivers.

## RESUMO

**Objetivo:** Identificar a qualidade de vida relacionada à saúde de cuidadores de crianças com transtornos do neurodesenvolvimento e analisar os fatores associados. **Método:** Estudo com delineamento observacional, transversal de abordagem quantitativa. Aplicado instrumento de caracterização e *The Medical Outcomes Study 36-Item Short* em 25 cuidadores. Utilizou-se o teste de Mann-Whitney e Correlação de Spearman, com nível de significância de 5%. Dentre os domínios da qualidade de vida relacionada à saúde, vitalidade e dor apresentaram os menores escores. Houve diferença significativa entre crença religiosa e os domínios aspectos sociais ( $p=0,046$ ) e saúde mental ( $p=0,008$ ) e, entre estado marital e os domínios aspectos sociais ( $p=0,029$ ) e aspectos emocionais ( $p=0,035$ ). Observou-se correlação negativa entre capacidade funcional e idade do cuidador. **Conclusão:** Cuidadores de crianças com transtornos do neurodesenvolvimento se percebem cansados e pouco dispostos. Crença religiosa, estado marital e idade se constituíram em fatores relacionados.

**Descritores:** Criança; Enfermagem; Qualidade de vida relacionada à saúde; Transtornos do Neurodesenvolvimento; Cuidadores.

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## INTRODUCTION

The term Children with Special Health Care Needs (CSHCN) is used for children with one or more physical, developmental, behavioral or emotional conditions who need specific, continuous and long-term care beyond that required by their peers<sup>(1)</sup>. Children with neurodevelopmental disorders have complex life-long disorders that affect their physical, cognitive, social and behavioral development, and constitute a subgroup of CSHCN<sup>(2)</sup>.

According to the American Psychiatric Association (APA), neurodevelopmental disorders typically manifest in childhood before the child enters school. Such disorders range from very specific learning limitations to global impairments in language and communication, social or intelligence skills<sup>(3)</sup>. In an international study aimed at determining the prevalence of these disorders among children aged between two and nine years and identifying potential risk factors, Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) were highlighted as the main neurodevelopmental disorders. The study also reinforced that one out of every eight children aged between two and nine years has at least one neurodevelopmental disorder<sup>(4)</sup>. Although in Brazil research on the subject is scarce, the estimated prevalence is of 7–20% of mental disorders in children and adolescents<sup>(5)</sup>.

In the literature, ADHD is considered the most common behavioral disorder of childhood with a worldwide prevalence of 2–7%, average of 5%<sup>(6)</sup>. Its manifestations include inattention, impulsivity and hyperactivity and the disorder is more often associated with school-age children. Regarding ASD, characteristic symptoms are observed, such as social, language and communication deficits and the presence of repetitive and restrictive behaviors<sup>(7)</sup>. ASD affects approximately 2–4% of the population<sup>(8)</sup> in a 3:1 ratio between males and females<sup>(9)</sup>.

Neurodevelopmental disorders often impact the daily life of the whole family due to changes in the social and financial routine. Parents start to spend time and energy in controlling inappropriate behaviors and end up not prioritizing activities that promote their own wellbeing<sup>(10)</sup>. In addition, feelings such as irritation, depression, hopelessness, emotional hypersensitivity, among others, also arise<sup>(11)</sup>. According to a systematic review on the subject, mothers of children with mental and neurological impairment have high scores of burden and low quality of life<sup>(12)</sup>.

Addressing the health-related quality of life (HRQoL) of caregivers of children with neurodevelopmental disorders becomes relevant because it values the perceptions of their health and wellbeing, and identifies the limits and daily challenges in the face of health conditions, disease or treatment of the child under their care<sup>(12)</sup>. Thus, the development of this study is justified by its social relevance,

with the look to caregivers, who are often precariously assisted by health services and the community. In addition, identifying the elements of the social and family context possibly associated with the HRQoL of this population is opportune for helping health professionals in the management of cases.

In view of the above, the present investigation starts from the following research questions: how is the HRQoL of caregivers of children with neurodevelopmental disorders? What factors are associated with the HRQoL of caregivers of children with neurodevelopmental disorders? Thus, the aim of this study was to identify the HRQoL of caregivers of children with neurodevelopmental disorders and analyze the associated factors.

## METHOD

Observational, cross-sectional, quantitative study<sup>(13)</sup> conducted between May 2017 and April 2018 in a multidisciplinary outpatient clinic located in a city in the inlands of the State of São Paulo that develops Teaching, Research and Extension activities for children with neurodevelopmental disorders and their caregivers.

The study participants were 25 caregivers of children with neurodevelopmental disorders cared for in the aforementioned clinic during the data collection period. All professionals were included, since there was no refusal. The inclusion criteria were caregivers over 18 years old and responsible for most of the care for children aged between 0 and 12 years. Individuals with less than three months of care experience and paid to exercise the caregiver role were excluded.

An initial contact with the institution was made to explain about the project and request authorization to conduct the study. The contact with participants took place during their follow-up treatment at the institution. After reading and signing the Informed Consent form (IC), participants answered an electronic form in a reserved space in the service itself during approximately 15 minutes. The application of the forms was intermediated by two previously trained researchers, who used their own cell phones for accessing and completing the forms.

The electronic form consisted of the characterization instrument and The Medical Outcomes Study 36-Item Short Form (SF-36). This is a generic instrument of 36 items for the assessment of HRQoL. It is divided into eight domains: physical functioning (10 items), physical role functioning (4 items), bodily pain (2 items), general health perceptions (5 items), vitality (4 items), social role functioning (2 items), emotional role functioning (3 items), mental health (5 items) and an assessment question comparing the current state of health with that from one year before. The eight domains can be grouped into two components: physical

(physical functioning, general health perceptions, bodily pain and physical role functioning) and mental (mental health, vitality, social role functioning and emotional role functioning). For each component, the final result was calculated on a 0–100 scale, in which 0 is the worst and 100 is the best health status<sup>(14)</sup>.

The eight domains of the HRQoL of caregivers of children with developmental disorder, classified as numerical, were considered as dependent variables. The independent variables were obtained with application of the characterization instrument, and they were the following: caregiver's age, monthly family income, caregiver's education, marital status, religious belief, occupation and number of residents in the domicile.

After data collection was completed, the database was exported to the SAS System for Windows (Statistical Analysis System), version 9.2, where analyzes were performed. Initially, the Shapiro-Wilk and Kolmogorov-Smirnov normality tests were performed and the distribution of variables was not normal in both. In the descriptive phase of the statistical analysis, categorical variables were described from measures of absolute and relative frequency, while numerical variables were described from measures of central tendency, variability and position. In the analytical stage, the HRQoL scores were compared between the dichotomous

categorical variables using the Mann-Whitney test. To analyze the relationship between numerical variables and HRQoL scores, the Spearman's correlation coefficient was calculated. A significance level of 5% was adopted for the tests.

The development of the study complied with national and international standards of ethics in research involving human beings and was approved by the Research Ethics Committee of the Federal University of São Carlos (CAAE: 63061716.2.0000.5504).

## RESULTS

Twenty-five (100.0%) caregivers of children with neurodevelopmental disorders participated in the study. Regarding marital status, 20 (76.9%) caregivers said they had a partner. In relation to occupation, 15 (57.7%) performed some type of paid work, while the others performed other forms of work. Approximately 66.0% of participants affirmed having some religious belief.

Table 1 shows the description of characteristics of the caregiver according to age, family income, schooling and number of residents in the domicile. About the HRQoL, Table 2 presents the description of the eight domains according to mean, standard deviation, minimum and maximum value, quartiles and median.

**Table 1.** Description of characteristics of the caregiver (n=25) according to age, family income, schooling and number of residents in the domicile. São Carlos, SP, Brazil, 2017–2018.

Variables	Mean	Standard deviation	Minimum	Q1	Median	Q3	Maximum
Age	42.56	9.28	26.00	36.00	40.00	49.00	62.00
Family income (reais)	3480	1.889	900	2.500	3.000	3.500	10.000
Schooling (years)	12.56	3.60	4.00	11.00	11.00	15.00	23.00
Residents in the domicile	2.76	1.01	1.00	2.00	3.00	3.00	6.00

Q1: first quartile; Q3: third quartile.

**Table 2.** Description of the eight health-related quality of life domains according to mean, standard deviation, minimum and maximum value, quartiles and median. São Carlos, SP, Brazil, 2017–2018.

HRQoL domains	Mean	Standard deviation	Minimum	Q1	Median	Q3	Maximum
Physical functioning	90.6	12.8	60.0	85.0	85.0	100.0	100.0
Physical role functioning	87.0	28.9	0.0	100.0	100.0	100.0	100.0
Bodily pain	63.7	25.5	10.0	41.0	62.0	84.0	100.0
General health perceptions	70.9	25.9	0.0	62.0	82.0	92.0	97.0
Vitality	56.6	21.2	15.0	40.0	55.0	70.0	100.0
Social role functioning	73.5	30.5	12.5	62.5	75.0	100.0	100.0
Emotional role functioning	74.7	40.0	0.0	66.7	100.0	100.0	100.0
Mental health	71.4	23.1	28	52.0	76.0	92.0	100.0

HRQoL: health-related quality of life; Q1: first quartile; Q3: third quartile.

Next, the scores of each domain of HRQoL and the categorical variables (occupation, marital status and religious belief) were compared with use of the Mann-Whitney test. As shown in Table 3, there was a significant difference for the religious belief variable (higher score for social role functioning and mental health in caregivers who affirmed having a religious belief) and for the marital status variable

(higher score for social role functioning and emotional role functioning among caregivers with a partner).

In the correlation matrix between numerical variables and scores of the HRQoL domains (Table 4), a negative correlation was observed between the score of the physical functioning domain and the caregiver's age variable, i.e., the greater the age of the caregiver the lower the physical functioning-related score.

**Table 3.** Distribution of scores of the health-related quality of life domains according to categorical variables. São Carlos, SP, Brazil, 2017–2018.

	Marital status			Religious belief			Caregiver's occupation		
	With partner	No partner	p*	Yes	No	p*	Paid work	Other forms of work	p*
Physical functioning	89.75	94.00	.516	90.59	90.63	1.000	90.67	90.50	0.658
Physical role functioning	87.50	85.00	0.961	85.29	90.63	0.559	85.00	90.00	0.905
Bodily pain	63.80	63.40	0.837	60.35	70.88	0.332	68.60	56.40	0.188
General health perceptions	72.80	63.60	0.584	77.06	58.00	0.113	68.60	74.50	1.000
Vitality	60.25	42.00	0.109	60.00	49.38	0.267	57.33	55.50	0.717
Social role functioning	81.88	40.00	<b>0.029</b>	83.09	53.13	<b>0.046</b>	75.83	70.00	0.584
Emotional role functioning	81.67	46.67	<b>0.035</b>	84.31	54.17	0.060	68.89	83.33	0.495
Mental health	74.40	59.20	0.233	80.71	51.50	<b>0.008</b>	74.67	66.40	0.344

\*Mann-Whitney test.

**Table 4.** Spearman's correlation between scores of the health-related quality of life domains and numerical variables. São Carlos, SP, Brazil, 2017–2018.

Variables		Caregiver age	Family income	Caregiver education	Number of residents
Physical functioning	r	-0.39916	-0.30379	0.18652	-0.16995
	p	<b>0.0481</b>	0.1399	0.3720	0.4167
Physical role functioning	r	-0.11274	0.26548	0.00849	-0.03845
	p	0.5916	0.1996	0.9679	0.8552
Bodily pain	r	-0.06576	-0.23335	-0.20642	-0.19513
	p	0.7548	0.2616	0.3222	0.3499
General health perceptions	r	0.04989	0.07213	-0.28494	0.03696
	p	0.8128	0.7319	0.1674	0.8607
Vitality	r	0.17646	0.09620	-0.24159	0.01797
	p	0.3988	0.6474	0.2446	0.9320
Social role functioning	r	-0.00800	-0.12505	-0.18148	0.19803
	p	0.9697	0.5515	0.3853	0.3427
Emotional role functioning	r	0.10277	0.18196	-0.19333	0.26553
	p	0.6250	0.3840	0.3545	0.1996
Mental health	r	0.13143	0.06049	-0.37706	0.23278
	p	0.5312	0.7739	0.0632	0.2628

r: Spearman's correlation coefficient; p: p-value; n: number of subjects.

## DISCUSSION

The results demonstrate that most caregivers affirmed having a partner. This information is corroborated by a study conducted in South Africa with the aim to investigate the relationship between family routines and the quality of life of families of children with ASD, which showed that only 20% of families were of single parents<sup>(15)</sup>. In the same direction, a survey conducted in Japan also found that approximately 70% of parents of children with disabilities live together<sup>(16)</sup>.

Still regarding marital status, the statistical analyzes of the present investigation identified a higher score of HRQoL for domains of social role functioning and emotional role functioning among caregivers with a partner. In this direction, an international study aimed at analyzing the factors associated with the stress of caregivers of children with cancer (another subgroup of CSHCNs) identified higher stress among single caregivers<sup>(17)</sup>. A study that investigated the association between HRQoL and the sociodemographic characteristics of caregivers of individuals with sequelae of cerebrovascular accident (CVA) also identified a significant difference in the mean scores of the domain “emotional role functioning” among married caregivers, compared to single, divorced or widowed caregivers<sup>(18)</sup>. According to this study, the presence of a partner can emotionally strengthen the caregiver as it alleviates loneliness and provides general support.

On the other hand, a systematic review on the quality of life of mothers of children and adolescents with chronic diseases indicated marital disharmony as a factor related to overload and consequent low quality of life<sup>(19)</sup>. The lack of studies addressing the relationship between marital status and the quality of life of caregivers of CSHCNs in general justifies the decision to discuss the present result with those of other investigations analyzing the quality of life of informal caregivers, regardless of the medical diagnosis or the age of the individual receiving care.

According to the results, the average schooling time of caregivers was 12.56 years, equivalent to the time of complete high school education. However, the caregiver’s educational level did not show a statistically significant relationship with the HRQoL domains. According to a study conducted in South Africa with families of children with ASD, parents’ schooling also had little effect on the family’s general quality of life<sup>(20)</sup>.

Among the eight domains of HRQoL, vitality and bodily pain were those with the lowest score. The lowest score for the vitality domain (energy and fatigue) characterizes an individual who feels tired and worn out all the time. In addition, according to the SF-36 instrument, the vitality domain corresponds to the mental component of HRQoL<sup>(14)</sup>. According to a North American study, the presence of psychiatric disorders such as anxiety and depression is common among caregivers of CSHCNs in general, and they

are almost twice as likely to attend mental health services<sup>(21)</sup>. However, the same study shows that parents of children with emotional or behavioral problems are more susceptible to mental health problems than parents of children with other conditions<sup>(21)</sup>.

With regard to the low HRQoL scores for the bodily pain domain, the present study was also supported by the perspective presented by the aforementioned study. In addition to emotional role functioning, the care demands can affect the general health perceptions as these caregivers are more likely to report problems such as migraine, stomachache, arthritis/rheumatic diseases and recent pain experience than the general population<sup>(21)</sup>.

In this study, a statistically significant difference was observed when comparing religious belief and the HRQoL domains “social role functioning” and “mental health” ( $p=0.029$  and  $0.035$ , respectively). An American study was aimed at analyzing religious coping as a potential predictor of wellbeing among parents of autistic children, and the religiosity variable was significantly associated with wellbeing outcomes in bivariate analyzes, such as in the present study. However, a significant association was not found in multivariate analyzes<sup>(22)</sup>. According to the authors, the strong effect of stress as a predictor of wellbeing overshadowed the effect of religiosity in more accurate statistical analyzes.

Finally, the physical functioning variable showed a negative correlation with the caregiver’s age, that is, the older the caregiver, the lower his/her willingness and energy to perform daily activities. This result reinforces a concern already presented by an American study<sup>(23)</sup>. Such a study analyzed the burden and quality of life of 320 parents over 50 years old of adults with ASD. The literature is generally focused on young children with ASD and their parents and disregards the needs of elderly parents of adult children with ASD. It also highlights that little is known about the concerns and challenges faced by adolescents and adults with ASD and their parental caregivers.

## CONCLUSION

The aim of the present investigation was to identify the HRQoL of caregivers of children with neurodevelopmental disorders and analyze the associated factors. The results presented have reached the proposed objectives, hence the following conclusions: the HRQoL for the vitality and bodily pain domains had lower score, indicating perception of tiredness and exhaustion among caregivers of children with neurodevelopment disorders; caregivers who have a religious belief obtained higher HRQoL scores in domains of social role functioning and mental health; caregivers with a partner showed better HRQoL for social role functioning and emotional role functioning domains. Finally, the caregiver’s

age was negatively correlated with the HRQoL of the physical functioning domain, that is, older caregivers are less willing to perform daily activities.

The contribution of this study is to move the caregivers of children with neurodevelopmental disorders to the centrality of care. Investigating the repercussions on the HRQoL of this clientele is essential for offering effective support strategies, otherwise, the excessive burden can result in failure or interruption of the care offered to children. It is expected that the results of this study will sensitize nursing professionals about the importance of paying attention to factors in the family and social context that can negatively affect the health-related quality of life of these caregivers, as well as about the need to plan actions for the promotion of their wellbeing.

Finally, a limitation of the study is its cross-sectional design that makes it impossible to identify cause and effect relationships. Another relevant limitation concerns the number of participants, although it dealt with the total population under follow-up in that period. Such limitations signal the importance of developing new studies with a longitudinal design and a larger number of participants.

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