



QUALITY OF LIFE AND BURDEN IN CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

Qualidade de vida e sobrecarga de cuidadores de crianças com paralisia cerebral

Calidad de vida y sobrecarga de cuidadores de niños con parálisis cerebral

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ABSTRACT

Objective: To analyze the association of Quality of Life (QoL) and caregiving burden with the degree of neuromotor impairment in children with cerebral palsy (CP). **Methods:** Cross-sectional study carried out in 2014 with 38 caregivers of children with cerebral palsy attending the Psychiatry and Rehabilitation Clinic of the Hospital de Clínicas of Porto Alegre, Rio Grande do Sul, Brazil. The World Health Organization Quality of Life Questionnaire (WHOQOL - BREF), the Beck Depression Inventory (BDI), the Beck Anxiety Inventory (BAI), the State-Trait Anxiety Inventory (STAI), and the Zarit Burden Interview (ZBI) were used. The degree of children's motor development was assessed using the Gross Motor Function Classification System (GMFCS). We checked for associations (Pearson's coefficient) between variables and they were described as mean and standard deviation, or median, and interquartile range. **Results:** There were 20 caregivers (52.6%) with a moderate burden. The domain Social Relationships, of the WHOQOL - BREF, was associated with children's motor development ($rs=0.355$; $p=0.029$), and there was a positive association between ZBI and STAI scores ($rs=0.540$; $p<0.001$). The results suggest that the higher the degree of anxiety, depression and burden in caregivers, the lower the QoL scores in caregivers. The QoL scores were not associated with the child's degree of motor impairment or caregivers' depression and anxiety scores. **Conclusion:** There were interactions between caregivers' QoL and other emotional aspects, but there were no associations between caregivers' QoL and degree of motor development.

Descriptors: Cerebral Palsy; Quality of Life; Depression; Anxiety; Caregivers.

RESUMO

Objetivo: Analisar a relação entre qualidade de vida (QV) e sobrecarga dos cuidadores relacionados ao grau de comprometimento neuromotor de crianças com paralisia cerebral (PC). **Métodos:** Estudo transversal realizado em 2014, com 38 cuidadores de crianças com paralisia cerebral atendidas pelo serviço de Fisiatria e Reabilitação do Hospital de Clínicas de Porto Alegre, Rio Grande do Sul, Brasil. Utilizaram-se os instrumentos World Health Organization Quality of Life Questionnaire (WHOQOL - BREF), Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), Inventário de Ansiedade Traço-Estado (IDATE) e Zarit Caregiver Burden Interview (ZCBI). Avaliou-se o grau de desenvolvimento motor das crianças pelo Gross Motor Function Classification System (GMFCS). Avaliaram-se as associações (coeficiente de Pearson) entre as variáveis descritas por média e desvio padrão.



ou mediana, e amplitude interquartilica. **Resultados:** Encontraram-se 20 cuidadores (52,6%) com sobrecarga moderada. Encontraram-se associações no domínio social da WHOQOL-BREF em relação ao desenvolvimento motor das crianças ($r_s=0,355$; $p=0,029$) e associação positiva entre a ZCBI e os escores do IDATE ($r_s=0,540$; $p<0,001$). Os resultados sugerem que, quanto maiores os níveis de ansiedade, de depressão e de sobrecarga dos cuidadores, menores serão os escores de QV dos cuidadores. Não se observaram associações entre os escores de QV e o grau de prejuízo motor da criança, e os escores de depressão e a ansiedade do cuidador. **Conclusão:** Há interações entre QV e demais aspectos emocionais dos cuidadores, entretanto não se constatou relações entre a QV dos cuidadores e o nível de desenvolvimento motor de crianças.

Descritores: Paralisia Cerebral; Qualidade de Vida; Depressão; Ansiedade; Cuidadores.

RESUMEN

Objetivo: Analizar la relación entre la calidad de vida (CV) y la sobrecarga de los cuidadores relacionados al grado de comprometimiento neuromotor de niños con parálisis cerebral (PC). **Métodos:** Estudio transversal realizado en 2014 con 38 cuidadores de niños con parálisis cerebral asistidos por el servicio de Fisiatria y Rehabilitación del Hospital de las Clínicas de Porto Alegre, Rio Grande do Sul, Brasil. Se utilizaron los instrumentos World Health Organization Quality of Life Questionnaire (WHOQOL – BREF), el Beck Depression Inventory (BDI), el Beck Anxiety Inventory (BAI), el Inventario de Ansiedad Trazo-Estado (IDATE) y el Zarit Caregiver Burden Interview (ZCBI). Se evaluó el grado de desarrollo motor de los niños con el Gross Motor Function Classification System (GMFCS). Se evaluaron las asociaciones (coeficiente de Pearson) entre las variables descritas por la media y la desviación típica o la mediana, y la amplitud intercuartilica. **Resultados:** Se han encontrado 20 cuidadores (52,6%) con sobrecarga moderada. Se han encontrado asociaciones en el dominio social del WHOQOL-BREF respecto el desarrollo motor de los niños ($r_s=0,355$; $p=0,029$) y asociación positiva entre la ZCBI y las puntuaciones del IDATE ($r_s=0,540$; $p<0,001$). Los resultados sugieren que a mayores niveles de ansiedad, depresión y sobrecarga de los cuidadores menores son sus puntuaciones para la CV. No se ha observado asociaciones entre las puntuaciones de la CV y el grado de perjuicio motor del niño y las puntuaciones de depresión y ansiedad del cuidador. **Conclusión:** Hay interacciones entre la CV y los demás aspectos emocionales de los cuidadores, sin embargo, no se ha constatado relaciones entre la CV de los cuidadores y el nivel de desarrollo motor de los niños.

Descriptores: Parálisis Cerebral; Calidad de Vida; Trastornos de Adaptación; Ansiedad; Cuidadores.

INTRODUCTION

Health promotion policies play a key role in reducing the prevalence of cases of cerebral palsy (CP) in developing countries where the incidence is higher than in developed countries⁽¹⁻³⁾. The promotion of the health of caregivers of children with CP is strongly related to quality of life (QoL) and levels of caregiving burden⁽¹⁻³⁾. These individuals often report feeling overwhelmed with their activities, which generate stress and difficulties in interpersonal relationships and may even cause illness, thus requiring physical and mental health support^(4,5).

CP is characterized by altered controlled or postural movements and is secondary to injury, damage or dysfunction of the central nervous system and not recognized as the result of progressive or degenerative brain disease⁽⁴⁾. CP is a pathological condition resulting from a perinatal event and its main related cause of morbidity and mortality is preterm birth before the thirty-seventh week of pregnancy^(5,6).

The main alteration observed in children with CP is motor impairment, which affects body biomechanics and thus interfere in daily life. Children with CP may also present cognitive, sensory, visual and auditory disturbances that, in addition to motor alterations and task and environmental restrictions, will have different repercussions on their functional performance⁽⁷⁾. In fact, the heterogeneity of the clinical presentation presented by children with CP makes it difficult to classify the impairment of motor dysfunction. Therefore, multi-professional teams involved in rehabilitation are challenged to work with measures based on their functional performance^(8,9).

CP can be classified according to two criteria: the type of motor dysfunction, i.e., the resulting clinical presentation, which includes the extrapyramidal or dyskinetic (athetosis, chorea and dystonia), the ataxic, the mixed, and the spastic types; and the topography of the impairment, i.e., the location of the affected parts of the body – this type includes quadriplegia, monoplegia, paraplegia or diplegia, and hemiplegia. Spastic CP is the most frequent type, accounting for 88% of the cases^(10,11).

The prevalence rate of CP is 2-3 per 1,000 live births and it is the most common cause of severe physical disability in children. CP diagnosis usually involves delays in motor development, persistence of primitive reflexes, presence of abnormal reflexes, and failure to develop protective reflexes^(12,13).

Family members associated the consequences of CP with feelings of sadness, fragility and dependence^(14,15). The caregiver of a child with CP experiences different situations within the family regarding family and financial roles and also feelings of helplessness, loss of control, exclusion and overload, which can generate anxiety and depression as responses to physical and emotional difficulties⁽¹⁶⁻¹⁹⁾. This situation may compromise the QoL of these caregivers^(20,21).

The World Health Organization (WHO) defines QoL as the individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns⁽²²⁾. It also corresponds to the degree of satisfaction with family, emotional, social and environmental relations and with one's own existence, and it is the expression of many meanings deriving from knowledge, experiences and values in one's life^(16,23,24). These aspects are important in health promotion and disease prevention, treatment and rehabilitation⁽²⁴⁻²⁷⁾. Thus, the QoL and the level of overload imposed on caregivers of children with CP under rehabilitation require intense involvement of those responsible for it.

Given that, the present study aimed to analyze the association of Quality of Life (QoL) and caregiving burden with the degree of neuromotor impairment in children with cerebral palsy.

METHODS

This cross-sectional study was carried out with caregivers of children with cerebral palsy in Porto Alegre, Rio Grande do Sul, Brazil, in 2014.

The convenience sample consisted of 38 caregivers of 38 children diagnosed with CP aged between zero and 11 years, of both sexes. The children were served by the Physiatry and Rehabilitation Clinic of the Clinics Hospital of Porto Alegre (*Hospital de Clínicas de Porto Alegre – HCPA*) and classified at all levels of the Gross Motor Function Classification System (GMFCS) scale.

The following instruments validated for the Brazilian population were used: World Health Organization Quality of Life - Short Version (WHOQOL-BREF), Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), State-Trait Anxiety Inventory (STAI), Zarit Burden Interview (ZBI) and Gross Motor Function Classification System (GMFCS).

The first instrument used was the WHOQOL-BREF, which consists of 26 questions divided into four domains: physical, psychological, social and environmental. The total score of each domain ranges 0 to 100 and higher scores denote better QoL⁽²²⁾. In Brazil, the validated instrument exhibited an internal consistency of $\alpha=0.9054$ ⁽²²⁾. However, to date there are no population normative data on the scores of the WHOQOL, which is the questionnaire that originated the WHOQOL-BREF⁽²²⁾.

BAI and BDI were applied next. The first inventory aims to evaluate the intensity of anxiety symptoms and consists of 21 descriptive affirmations of anxiety symptoms scored on a 4-point scale that depicts the level of severity of each symptom in an increasing order (mild, moderate and severe). The second inventory evaluates the intensity of depressive symptoms. It is a self-report inventory consisting of 21 items with a set of four possible responses each. The responses indicate the level of severity of symptoms intensity in an increasing order (mild, moderate, and severe). The total inventory score is the sum of the individual items⁽²⁹⁾. Beck inventories are widely used in clinical and preclinical studies with various populations and are validated for use in Brazil exhibiting high internal consistency of $\alpha=0.91$ ⁽²⁹⁾.

The State-Trait Anxiety Inventory (STAI) was used to assess anxiety with more permanent characteristics inherent to the person (trait-anxiety) and the person's reactions to the current situation (state-anxiety)⁽³⁰⁾. This instrument is divided into two parts: the first, corresponding to the moment of assessment, is composed of 20 items; the second part consists of 20 items that assess how the person behaves most of the time⁽³¹⁾. This test has exhibited internal consistency of $\alpha=0.89$ ⁽³⁰⁾.

Caregiving burden was assessed using the ZBI⁽³¹⁾ is a 22-item questionnaire that assesses the impact of caregiving activities on social and financial life, interpersonal relationships and the physical and emotional well-being of the caregiver. Responses are given on a five-point scale that describes how each statement affects the person. Higher scores denote greater caregiving burden. This test exhibited internal consistency of $\alpha=0.80$ ⁽³²⁾.

In the last stage of the study, children were assessed using the GMFCS scale in order to determine the level of present performance and impairment in general motor function in these patients. GMFCS for PC is based on voluntarily initiated movement, with emphasis on sitting, transfer and mobility, and its classification is based on the following levels: level I - the child walks without limitations; level II - the child walks with limitations; level III - the child walks using a hand-held mobility device; level IV - self-mobility with limitations: children may use methods of powered mobility; level V - the child is transported in a manual wheelchair^(33,34).

The statistical analysis of data was performed by describing quantitative variables as mean and standard deviation, or median, and interquartile range, depending on the distribution of the variable. The categorical variables were described as absolute and relative frequencies. Student's t-test was used to compare means between the civil status categories (with or without partner). Pearson's correlation coefficient (symmetric distribution) or Spearman's correlation coefficient (asymmetric distribution) were used to check for associations between the variables. Multivariate linear regression analysis was used to control for confounding factors. The multiple linear regression test was used to assess the following variables: age, marital status, trait-anxiety, state-anxiety, anxiety symptoms, depressive symptoms, burden and child's level of motor development. To evaluate the effect of each factor on QoL scores, the angular coefficient (b) was calculated considering a 95% confidence interval. The standardized coefficient (β) was used to compare the effect between the factors, and the Backward selection method was used to determine the final model. The significance level was set at 5% ($p \leq 0.05$), and the analyses were performed in the SPSS software version 21.0.

The present study was approved by the Research Ethics Committee of the Federal University of Health Sciences of Porto Alegre (*Universidade Federal de Ciências da Saúde de Porto Alegre*) under Approval No. 602.177-0. All participants signed the Free Informed Consent Form.

RESULTS

The mean age of the 38 caregivers included in the sample was 39.8 years (standard deviation = 8.2). As for sex, 35 participants (92.1%) were women and only 3 (7.9%) were men. Regarding marital status, 26 (68.4%) caregivers were married, 10 (26.3%) were single and 2 (5.3%) were divorced, as shown in Table I.

Table I - Characterization of the sample of caregivers. Porto Alegre, Rio Grande do Sul, 2014.

Variables	n=38
Age (years) mean \pm SD	39.8 \pm 8.2
Sex	n (%)
Men	3 (7.9)
Women	35 (92.1)
Marital status	n (%)
Single	10 (26.3)
Married	26 (68.4)
Divorced	2 (5.3)

SD: standard deviation; n(%): number in percentage; n: number

Children's level of CP was distributed as follows: 19 children (50%) scored level II in the GMFCS; 11 children (28.9%) scored level III; 4 children (10.5%) scored level V; and 2 children (5.3%) scored level I and level IV, as depicted in Table II.

Table II - Assessment of the level of children's motor development by the Gross Motor Function Classification System (GMFCS) scale. Porto Alegre, Rio Grande do Sul, 2014.

Level of motor development	n	%
I – The child walks without limitations	2	5.3
II – The child walks with limitations	19	50.0
III – The child walks using a hand-held mobility device	11	28.9
IV – Self-mobility with limitations: the child may use methods of powered mobility	2	5.3
V – The child is transported in a manual wheelchair	4	10.5

n: number; %: percentage

With regard to the intensity of the anxiety symptoms assessed by the BAI: 18 caregivers (47.4%) presented minimal anxiety; 13 (34.2%) presented moderate anxiety; 6 (15.8%) presented mild anxiety; and only 1 (2.6%) presented

severe anxiety. Regarding the intensity of depressive symptoms, the BDI results indicated that: 20 caregivers (52.65%) presented a minimal depression; 10 (26.3%) presented moderate depression; 6 (15.8%) presented mild depression; and only 2 caregivers (5.3%) presented severe depression.

Regarding the classification of state-trait anxiety measured by STAI, in the trait anxiety scale 22 caregivers (57.9%) presented anxiety, 12 (31.6%) presented normal anxiety, and 4 (10.5%) presented depression. As for state anxiety, 28 caregivers (73.7%) presented anxiety, 7 (18.4%) presented normal anxiety, and 3 (7.9%) presented depression. There was no significant association of trait anxiety measured by STAI with BAI anxiety classification ($p=0.258$). However, there was a significant association ($p=0.020$) between BAI and state anxiety measured by STAI. All the participants who presented at least mild anxiety in BAI tended to respond with anxiety in STAI.

Regarding caregiving burden, the ZBI findings indicated that: 20 caregivers (52.6%) presented moderate burden; 13 (34.2%) presented little or no burden; and 5 (13.2%) presented moderate to severe burden. As for QoL measured by WHOQOL-BREF, caregivers exhibited greater impairment in the environmental domain (an individual's perception of various aspects related to the environment in which they live), as shown in Table III.

Table III - Caregivers' quality of life scores by domain (WHOQOL-BREF). Porto Alegre, Rio Grande do Sul, 2014.

Domains	Mean/SD	Median	Min-Max
Physical	65.7/19.3	71.4	21.4-100
Psychological	65.7/20.5	70.8	8.3-100
Social	66.4/22.0	66.7	25-100
Environmental	57.8/18.2	57.8	21.9-100
Overall	61.8/20.9	62.5	0-100

SD: standard deviation; Min: minimum; Max: maximum

Pearson' or Spearman' correlation coefficients were used according to the type of variable to check for associations of the variables analyzed (age, STAI, BAI, BDI and ZBI) with the QoL domains assessed by WHOQOL-BREF. There was no significant association between the age of the caregiver and the QoL scores, but there was a significant inverse association of BDI, BAI, ZBI and state anxiety measured by STAI with QoL scores (except the social domain). Therefore, higher levels of anxiety, depression and burden denoted lower QoL scores among caregivers.

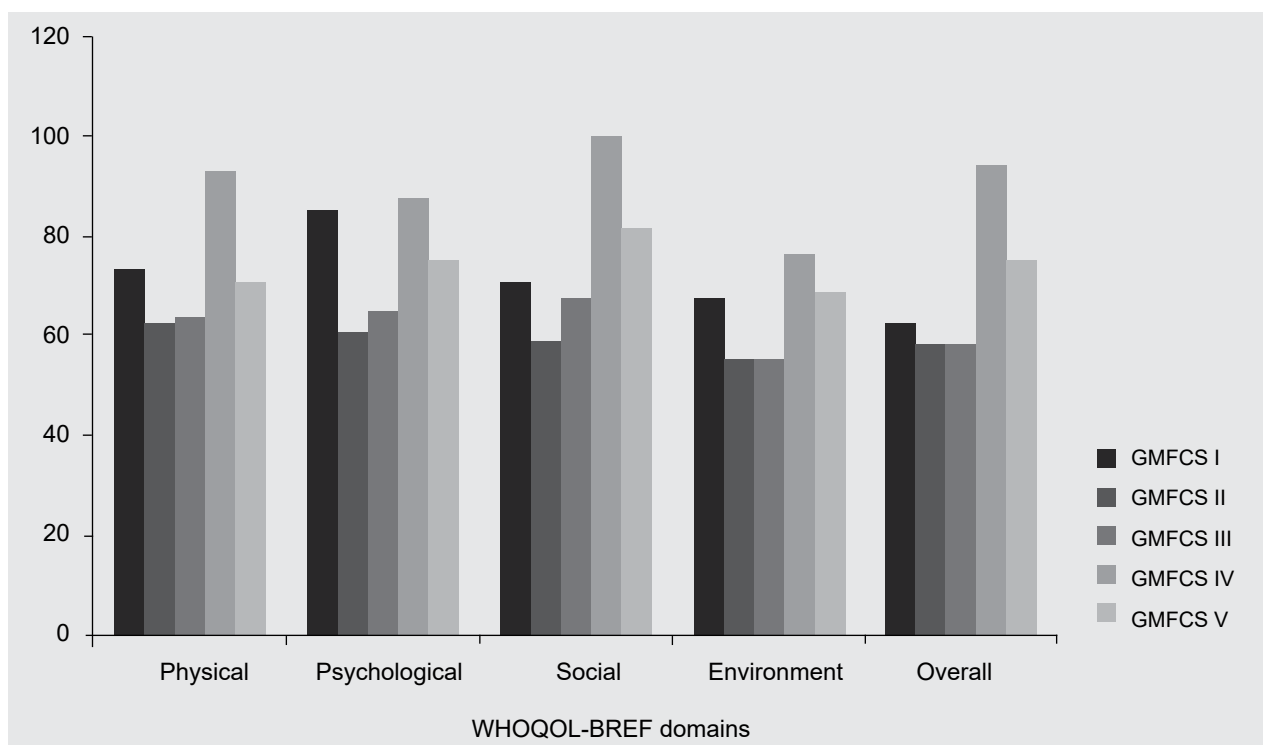
The motor development of the child (GMFCS) was significantly associated only with the social domain of QoL ($r_s=0.355$; $p=0.029$), i.e., better motor development levels (higher scores in GMFCS) denoted higher QoL scores in this domain among caregivers. Table IV shows the association of the variables with the QoL domains of the WHOQOL-BREF measured by the Pearson' or Spearman' correlation coefficients.

Table IV - Association between emotional variables, quality of life and motor development. Porto Alegre, Rio Grande do Sul, 2014.

Variables	WHOQOL-BREF					GMFCS
	Physical##	Psychological	Social	Environmental	Overall	r_s
STAI - Part I	0.186	0.121	0.258	0.240	0.117	0.076
STAI - Part II	-0.499**	-0.526**	-0.280	-0.364*	-0.556***	-0.039
BAI#	-0.743***	-0.851***	-0.657***	-0.739***	-0.759***	-0.112
BDI#	-0.761***	-0.762***	-0.726***	-0.794***	-0.737***	-0.081
Burden	-0.668***	-0.629***	-0.622***	-0.608***	-0.664***	-0.070

GMFCS: Gross Motor Function Classification System; STAI: State-Trait Anxiety Inventory; BDI: Beck Depression Inventory; BAI: Beck Anxiety Inventory; r_s : Spearman's correlation; #: Spearman's correlation coefficient; ##: Pearson's correlation coefficient; ***: $p<0.001$; **: $p<0.01$; *: $p<0.05$

The analysis of the mean QoL scores in all domains in relation to the level of motor development measured by GMFCS is shown in Figure 1. The columns represent mean with standard deviation lines. The social domain was associated ($p=0.029$).



GMFCS I: Gross Motor Function Classification System level I; GMFCS II: Gross Motor Function Classification System level II; GMFCS III: Gross Motor Function Classification System level III; GMFCS IV: Gross Motor Function Classification System level IV; GMFCS V: Gross Motor Function Classification System level V.

Figure 1 - Caregivers' quality of life (QoL) scores in relation to WHOQOL-BREF domains and level of motor development of the child (Gross Motor Function Classification System – GMFCS scale). Porto Alegre, Rio Grande do Sul, 2014.

Regarding the assessment of factors independently associated with QoL scores, the following factors remained associated with all QoL scores: level of caregiving burden and intensity of depressive symptoms. In the social and overall domains, in addition to these variables, the level of motor development of the child and the intensity of anxiety were independently associated with the QoL scores. Thus, higher levels of the child's motor development denoted better caregiver's QoL in these domains. Finally, in the psychological domain, the intensity of anxiety symptoms remained associated in addition to the previously mentioned variables.

There was a significant positive association between the ZBI (caregiving burden) and STAI (State) scores ($r_s=0.540$; $p<0.001$), i.e., caregivers who reported higher levels of burden also tended to present higher levels of depression. This association was not found for STAI (Trace) ($r_s=-0.072$; $p=0.666$). Finally, there was a significant association of caregiving burden score with intensity of depressive symptoms measured by BDI ($r_s=0.580$; $p<0.001$) and anxiety symptoms measured by BAI ($r_s=0.656$; $p<0.001$), thus demonstrating that higher levels of depression and anxiety are found in caregivers with higher levels of burden.

DISCUSSION

The results of the present study are in line with other studies that found a relationship of other childhood pathological conditions with the quality of life and health promotion of caregivers. There is agreement regarding the age and sex of the caregivers included in our sample compared with caregivers analyzed in other studies, with female caregivers predominating as accompanying persons in the process of rehabilitation of the children^(35,36).

The high proportion of mothers as caregivers also confirms the findings pointed out in the literature related to diseases such as asthma and childhood cancer^(35,36) and is followed by fathers and grandparents. These results suggest the influence of cultural and social factors that support the idea that the woman plays the specific role of caring for the children⁽³⁶⁾.

The absence of a significant association between the level of motor development of children with CP and the levels of anxiety, depression and burden of their caregivers refuted the initial hypotheses of the present study. This

result could be expected given the similar occurrences reported in the literature⁽³⁷⁾. Improvement in this aspect did not influence the changes in mothers' anxiety, depression and burden.

An important finding of the present study was the association between children's scores in GMFCS and caregivers' scores in the social domain of QoL. This finding supports the discussion of health promotion strategies targeted at both the caregiver and the child with CP as improvements in motor performance are related to the quality of life of caregivers in the social domain^(4,5).

In the present study, higher levels of motor impairment measured represented by GMFCS scores denoted caregivers' poorer quality of life in the social domain. In this regard, health promotion and prevention actions should be incorporated into the context of the child with CP as the social domain of the caregiver's quality of life is affected by the child's disease and physical disability. Therefore, the importance of the caregiver's quality of life for the improvement of the child's condition should be emphasized because it is the caregiver who will meet the needs of the child with CP^(4,5).

The results found in the present research regarding the domain related to personal relationships, support, sexual activity and the involvement of other people to assist in the care provided to the child showed that these factors can have positive effects on the child's motor development and, consequently, on the improvement of the caregiver's QoL. On the other hand, children with CP who present less motor impairment have less impact on the social relations of their caregivers in terms of prejudice, social exclusion, exclusive dedication to the child's care, among others⁽³⁸⁾.

Another finding of the present study refers to caregivers' perception of their physical condition measured by the WHOQOL-BREF scale, which found a positive perception of physical aspects. This finding is in agreement with results pointed out in another study⁽³⁹⁾ carried out with caregivers of children with brain cancer.

The psychological domain, the third-best scored domain in this study, takes into consideration the person's perception of their affective and cognitive conditions. As for the second-best scored domain, the social domain, there was a huge variation: 15 caregivers rated it as very good and other 15 caregivers rated it as very bad. Finally, the environmental domain, which consists of the perception of various aspects related to the environment, exhibited the worst scores⁽³⁸⁾.

There is agreement in relation to the environmental domain and there was too much impairment in QoL, which highlights the personal perception of the environment in which the caregiver lives. This indicates the various aspects involved in QoL, such house structure, leisure and other indicators⁽³⁸⁾.

In the present study, there was an absence of burden in 13 caregivers, a result that is similar to those found in another study⁽³⁹⁾. In some cases, factors such as the child's behavioral problems, particularly social interactions, difficulties in school inclusion or unfavorable economic conditions can be predictive of the caregiver's burden. This finding may indicate that, even if there are predictive factors for caregiving burden, these aspects should not always be considered as exclusive factors for the onset of caregiving burden⁽³⁹⁾.

Although the initial hypothesis that there was an association between caregivers' QoL and children's motor development level was not confirmed, the results demonstrate the importance of focusing on the development of strategies for health promotion and disease prevention directed to the needs of the caregivers of children with CP⁽²²⁾.

CONCLUSION

The interaction between the quality of life and the emotional state of caregivers are not related to the level of motor development of children with cerebral palsy. However, it is important to note that the increase in levels of anxiety, depression and burden correlated with the decrease in QoL scores among the caregivers analyzed.

CONTRIBUTIONS

Jandara de Moura Souza contributed to the study development and design; acquisition, analysis and interpretation of data; drafting and/or revision of the manuscript. **Fabiana Rita Câmara Machado and Priscilla Pereira Antunes** contributed to the acquisition, analysis and interpretation of data; and drafting of the manuscript. **Antônio Cardoso dos Santos** contributed to the study development and design; and revision of the manuscript. **Daniela Centenaro Levandowski** contributed to the study development and design; analysis and interpretation of data; and revision of the manuscript. **Alcyr Alves de Oliveira Junior** contributed to the study development and design, analysis and interpretation of data; and drafting and/or revision of the manuscript.

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