

Original Article

Quality of Life and low back pain in primary caregivers of children with cerebral palsy

Qualidade de vida e dor lombar em cuidadores primários de crianças com paralisia cerebral

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Abstract

The aim of this study was to evaluate the quality of life of primary caregivers of children with CP, correlating with the presence of low back pain and motor impairment level of the child. For this research to have been carried out there was the participation of 55 primary caregivers that completed the questionnaires of Roland & Morris (QRM) and WHOQOL-Bref. The evaluation of children's motor impairment was measured by Gross Motor function Classification System (GMFCS). The results show that primary caregivers of children with CP had a loss in their quality of life, especially in the environmental domain and facet pain and discomfort (30.45), negative feelings (34.09), and recreation and leisure (37.27). There were no significant correlations between motor impairment in children with CP, the quality of life of their primary caregivers, and the symptoms of low back pain. However, it was observed that the average symptoms of low back pain are lower in caregivers of children with minor motor impairment ($p=0.488$), and that there is a significant negative correlation ($r=-0.508$, $p<0.001$) between the symptoms of back pain and quality of life of caregivers.

Keywords: quality of life; caregivers; cerebral palsy; low back pain.

Resumo

O objetivo deste estudo foi avaliar a qualidade de vida dos cuidadores primários de crianças com PC, correlacionando-a com a presença de dor lombar e o nível de comprometimento motor da criança. Para a realização dessa pesquisa houve a participação de 55 cuidadores primários com o preenchimento dos questionários de Roland & Morris (QRM) e WHOQOL-Bref. A avaliação do comprometimento motor das crianças foi verificada pelo Gross Motor function Classification System (GMFCS). Os resultados demonstram que os cuidadores primários de crianças com PC apresentaram um prejuízo na qualidade de vida, especialmente no domínio ambiente e nas facetas: dor e desconforto (30,45), sentimentos negativos (34,09) e recreação e lazer (37,27). Não foram observadas correlações significativas entre o comprometimento motor de crianças com PC, a qualidade de vida de seus cuidadores primários e os sintomas de dor lombar. Entretanto, observou-se que a média de sintomas de dor lombar é menor em cuidadores de crianças com menor comprometimento motor ($p=0,488$) e uma correlação negativa significativa ($r=-0,508$; $p<0,001$) entre os sintomas de dor lombar e a qualidade de vida do cuidadores.

Palavras-chave: qualidade de vida; cuidadores; paralisia cerebral; dor lombar.

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INTRODUCTION

Cerebral palsy (PC) is a permanent development impairment, but it is not a progressive disorder^{1,2}. The impairments that occur in the brain in fetal or child development might cause a sensorial, cognitive, and motor disorder, with certain functional limitations. Thus, children with PC have limitations when it comes to self-care, such as in feeding, dressing, personal hygiene, and mobility³.

Cerebral palsy is one of the most common infant disorders, having an incidence of 2 to 2.5 per 1,000 live births in developed countries and about 7 each 1,000 newborns in underdeveloped countries⁴.

Primary caregivers dedicate their time to take care of such child, and do not have time to satisfy their own social needs, causing them to bear a feeling of overload and tension, besides having an impact on physical and emotional health, well-being, marital relations, employment, and the financial situation, and might even compromise their psychic well-being⁵

Such overloads might have direct influence over the quality of life (QoL) of these people, for the World Health Organization (WHO) defines quality of life as the perception of the individual for his/her life positioning, context, and the cultural values in which he/she lives, their relations to their goals, objectives, and expectations. The WHO also defines health in three dimensions: physical, mental, and social well-being^{4,6}.

A study developed by Almeida et al.⁷ has concluded that there is a high prevalence of spinal column pain in mothers of children with cerebral palsy. The same authors have pointed out the lumbar area as the most injured spinal segment. Besides the lack of information on the ideal posture to carry their children, they also do not look for medical or physiotherapy care during the painful phase. Such situation may compromise the quality of life of these caregivers.

There are evidences^{1,8} that the quality of life of primary caregivers of children with cerebral palsy is worse than of primary caregivers of healthy children, in aspects related to physical and social well-being, independency, financial stability, and services support^{1,8}. However, there are differences observed between authors as for the correlation between the quality of life of primary caregivers and the level of motor commitment of the children with PC. Some studies^{1,4,8} have showed that the level of motor commitment of the child with PC evaluated through Gross Motor function Classification System (GMFCS) has not interfered directly in the QoL of their caregivers. Nonetheless, Byrne et al.⁶ state that the level of motor commitment affects the QoL of the caregiver in the physical domain. To this effect, the objective of this study was to evaluate the quality of life of the primary caregivers of children with cerebral palsy, relating it with the presence of lumbar pain and with the level of motor commitment of the child.

METHODOLOGY

This paper is related to a quantitative-descriptive study on the theme on quality of life of primary caregivers of children with cerebral palsy. In order to perform that research, there was the participation of 55 primary caregivers of children with PC. The caregivers were selected from the Vivian Marçal Special Education School, at Curitiba, Paraná State, Brazil, in which there are children with PC studying. The School office has identified the voluntary caregivers and sent the research instruments to the caregivers so they could be answered at home.

Data collection was performed between August 2011 and December 2011, by filling up the Roland & Morris (QRM) and the World Health Organization Quality of Life – short version (WHOQOL-Bref) questionnaires for the caregivers and the evaluation of the motor commitment of the children according to the Gross Motor function Classification System⁹ by a physiotherapist with more than 10 years of professional experience.

The QRM questionnaire evaluates the functional incapacity of lumbar pain. That instrument was developed by Roland & Morris in 1983, and was adapted for the Portuguese language by Nusbaum et al.¹⁰ in 2001. Now, the WHOQOL questionnaire was developed by the World Health Organization (WHO), and it is frequently used to measure the quality of life in several populations, presenting an evaluation of the QoL in four domains (physical, psychological, social relations, and the environment)¹¹.

The descriptive statistics was used for the analysis of the data, as well as the Pearson's Correlation Coefficient; Student's *t* test for independent samples, and the paired Student's *t* test. All calculations were performed using the Statistical Package for Social Science for Windows (SPSS) version 17.0. The protocol for this research was submitted to the Research Ethics Committee of the Centro Universitário Campos de Andrade and was approved under nº 000404/11.

RESULTS

The caregivers studied had a academic background varying from incomplete basic education to complete undergraduate degree. The other social and financial characteristics of the sample studied are presented in Table 1.

Table 2 presents the data obtained when applying the WHOQOL-Bref questionnaire of quality of life evaluation and the following domains: physical, psychological, social relations and the environment.

It was observed that the domain of quality of life evaluated by the WHOQOL-Bref with the lower score among the primary caregivers of children with cerebral palsy was the environment.

Table 3 shows the result of the Student's *t* test, which evaluated the difference among the scores in each domain.

For a more profound understanding of the results, Graph 1 presents the scores obtained by facets.

When analyzing Graph 1, it is observed that the primary caregivers of children with cerebral palsy have low results for the following facets: pain and discomfort; drugs or treatments addiction; negative feelings; financial resources, and entertainment and leisure. On the other hand, the highest indexes for

Table 1. Socioeconomic characteristics of the primary caregivers of children with cerebral palsy, Curitiba, Parana State, Brazil, 2011

	Quantity
Gender	
Female	55
Male	0
Age (years old)	
19–29	15
30–44	30
45–59	10
Education Level (years of study)	
≤8	23
9 to 11	8
≥12	24
Activity	
Housewife	34
Has a Job	21
Social Class	
B2 (monthly income of approximately \$ 1,400)	3
C1 (monthly income of approximately \$ 800)	3
C2 (monthly income of approximately \$ 500)	9
D (monthly income of approximately \$ 350)	31
E (monthly income of less than \$ 300)	9

Table 2. Perception as for the quality of life of the primary caregivers of children with cerebral palsy, both general and by domains, Curitiba, Paraná State, Brazil, 2011

Domain	Mean	Standard deviation
Physical	60.91	12.31
Psychological	58.79	13.44
Social Relations	61.82	18.49
Environment	50.63	6.31
Self-evaluation of QoL	59.16	13.96
Total	57.29	11.48

QoL: quality of life

Table 3. Difference between the average of quality of life domains for the primary caregivers of children with cerebral palsy, Curitiba, Paraná State, Brazil, 2011

Domains	t value	p-value
Physical <i>versus</i> Psychological	1.221	0.228
Physical <i>versus</i> Social Relations	-0.319	0.751
Physical <i>versus</i> Environment	4.936	0.000
Psychological <i>versus</i> Social Relations	-1.157	0.252
Psychological <i>versus</i> Environment	3.998	0.000
Social Relations <i>versus</i> Environment	4.213	0.000

satisfaction of the primary caregivers regarding their quality of life refer to the facets: mobility and self-esteem.

Regarding Roland-Morris questionnaire, which evaluates the lumbar pain symptoms, no caregivers have presented an index that suggested a significant functional incapacity. Table 4 presents the results of the Roland-Morris questionnaire and the evaluation result for the level of motor commitment of the children cared by the subjects of the research herein.

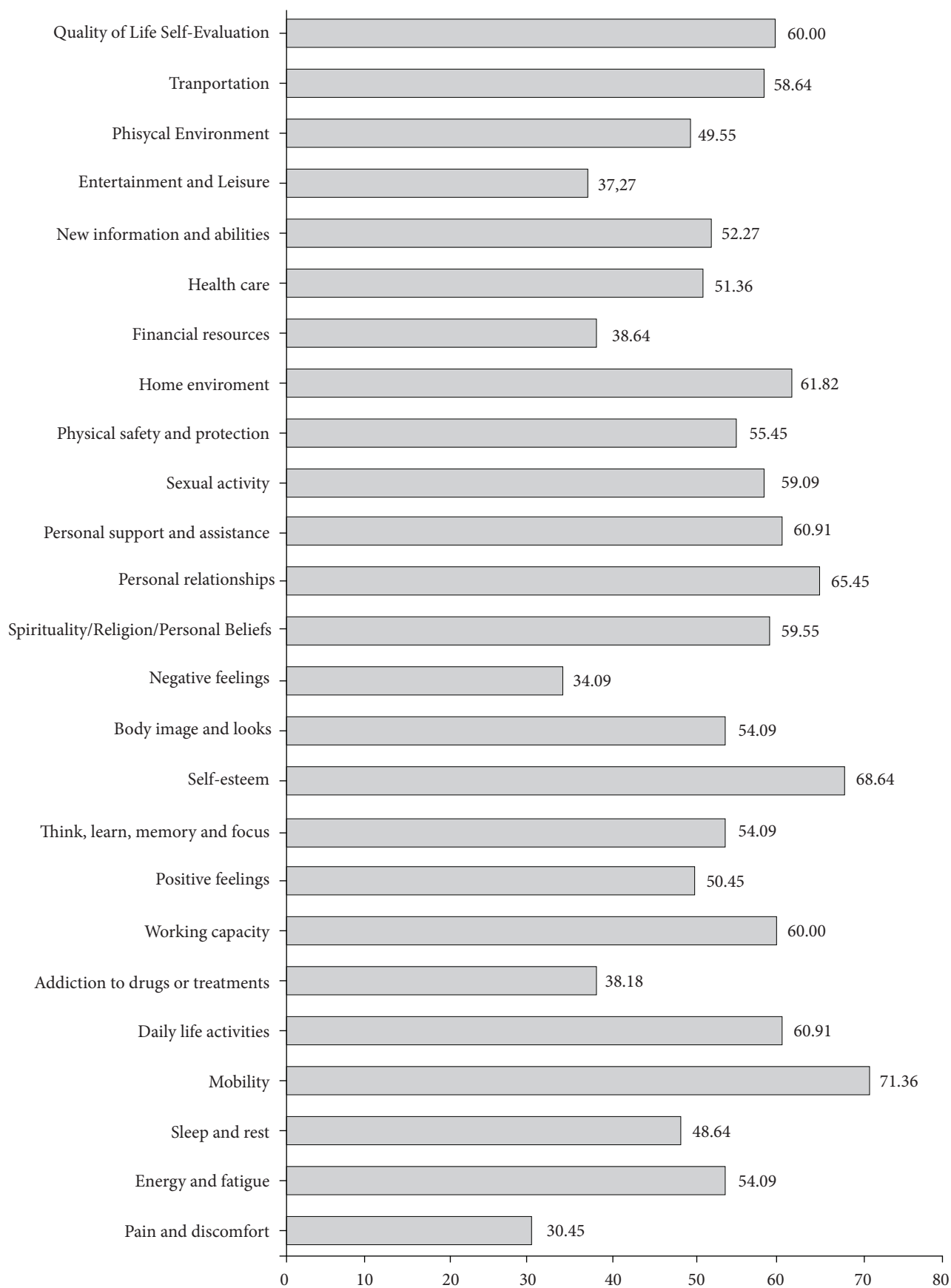
In an evaluation by subgroups on the level of motor commitment of the children, where they were labeled as less limited the children with a level of motor commitment II or III, and as more limited those with a level of motor commitment IV or V, it was observed that the average score in the Roland & Morris questionnaires of the caregivers with less limited children was of 2.53 ± 3.23 , and the caregivers with more limited children was of 3.33 ± 3.91 . However, that difference was not statistically significant in the Student's *t* test for independent samples ($p=0.488$).

The evaluation of the level of motor commitment of children under care (GMFCS) had no significant correlation with the result of the Roland-Morris questionnaire ($r=0.010$; $p=0.942$) nor with the result of the WHOQOL-Bref of the caregivers ($r=0.030$; $p=0.829$). However, there was a significant negative correlation between the result of the quality of life evaluation and the result of the Roland-Morris questionnaire ($r=-0.508$; $p<0.001$).

Regarding the results of quality of life, an analysis was also performed by the subgroups of the level of motor commitment of the children. It was observed that the average QoL of the caregivers of less limited children was of 13.13 ± 3.08 and the caregivers of more limited children was of 13.88 ± 2.50 , not having any statistical significance ($p=0.948$).

DISCUSSION

The analysis of the results by the domains of QoL recommended by the WHO (physical, psychological, social relations, and the environment) showed that the domain environment has presented the lower score 50.63%, with a significant difference for the other domains. Similar results were found in the studies of Veiga Junior et al.¹² with caregivers of children with PC (59.00%); in the study of Oliveira and Limongi¹³ that has evaluated the quality of life of caregivers of children and teenagers with Down's syndrome (53.33%); and in the study of Braccialli et al.¹⁴ with caregivers of people with learning disabilities (48.92%). The facets that have contributed for this study were "financial resources" and "entertainment and leisure". According to Maia et al.¹⁵, a child with PC demands the family to adapt to a new life, with limitations that could lead to high levels of stress and depression.



Graph 1. Results of the score obtained by facets of quality of life of the primary caregivers of children with cerebral palsy, Curitiba, Paraná State, Brazil, 2011

Table 4. Results of the Roland-Morris questionnaire applied to primary caregivers of children with cerebral palsy and the result of the evaluation of the motor commitment level of the children, Curitiba, Paraná State, Brazil, 2011

	Quantity	
Results of GMFCS of children cared		
I (no limits)	0	
II	7	
III	8	
IV	13	
V (totally limited)	27	
Results of the Roland & Morris questionnaire for the caregivers		
From 0 to 7 points	50	
From 8 to 13 points	5	
More than 14 points	0	
	Mean	Standard deviation
Characteristics of the children cared		
Age (years old)	9.32	4.19
Weight (kg)	26.62	10.97

The low score in the environment domain, especially in the financial resources and entertainment and leisure facets, might be related to the fact that the most part of primary caregivers have a low family income, which leads to less opportunities for entertainment and leisure¹⁶.

The results of this study have also shown that the primary caregivers of children with PC had low scores in the negative feelings facet. Such result might be explained by the fact that the families with children with PC have a greater demand for care, and in the case of this study, because of their low income, have also shown worries about their financial situation. All that increases the risk for mental health and well-being disturbances for these caregivers, make them increase unsafety, and as a consequence, the number of thoughts and negative feelings¹⁷.

Previous studies^{1,8,16} had already shown a decrease in the quality of life of the primary caregivers of children with PC. A research performed in Italy⁽¹⁷⁾ has analyzed the quality of life of 100 parents, with a control group comprised by 60 parents of healthy children. The quality of life was evaluated by the WHOQOL-Bref questionnaire, and for the diagnosis of mental problems, the Child Behaviour Checklist (CBCL) questionnaire was used. That study has shown that parents of children with PC have shown lower scores in physical and psychological domains than the control group in quality of life¹⁷. However, that study has not correlated the quality of life to the level of motor commitment of children with PC.

It was observed in the present study that most caregivers studied come from low income families. The presence of a child with PC might have a direct influence over the financial stability of the family. In a study³ performed in Brazil, in which 65 caregivers of people with PC and a control group of 58 caregivers of healthy people were interviewed, the control

group presented a significantly higher percentage of education years and a higher gross monthly income when compared with the group of caregivers of people with PC. Although some mothers in the group of PC perform a paid job, it is not a full-time job, which prevents the financial condition to improve. The results have suggested that the caregivers of people with PC have a worse QoL than the caregivers of healthy people³.

Literature has already established that the quality of life of caregivers of children with PC is lower than the one of caregivers of healthy children. However, there are differences between the authors as for the correlation between quality of life and the level motor commitment of the children with PC. In this study, the evaluation of the level of motor commitment of the children cared for (GMFCS) had no significant correlation with the WHOQOL-Bref result of the caregivers ($r=0.030$; $p=0.829$). This result agrees with several studies^{1,4,8,18} previously developed in several countries, including Brazil.

A study performed in Turkey suggests that the primary caregivers of children with PC had the lowest score for quality of life when compared to the control group¹⁸. Another work¹, performed in the United States, which had quite similar characteristics to the study herein because of the participation of the mothers (86%) and the sample be comprised by low income families, has indicated that the mothers of children with PC had a higher level of stress and depression in relation to the Control Group. However, there was no correlation between the level of motor commitment and the quality of life of their caregivers¹. A third study⁴, performed in Brazil, has observed that there is an impact in the quality of life of moms of children with PC; however in the sample collected by the researchers, there was no relation between the children's functionality and the quality of life of caregivers⁴.

On the other hand, other researches have shown that the motor limitation of the child with PC interferes negatively in the quality of life of their primary caregivers. In one study¹⁹ performed in Turkey, it was observed a correlation between the quality of life of the moms with the motor commitment level of the children. In the study herein, there was no significant difference between the quality of life of caregivers of children more or less functionally limited ($p=0.948$).

Children with PC require special ongoing care, and of complex nature, comprising a great challenge for their caregivers²⁰. Within that context, the need to provide greater attention to the health of the caregivers is highlighted, for these special cares rendered to the child with PC decrease the free time, increase the anxiety and depression indexes, as well as reduce the quality of life of their caregivers.

Indeed, scientific works have reported that routine activity is consuming for the caregiver, unleashing several levels of stress, depression, anxiety, insomnia, and physical symptoms,

such as low-back pain and hypertension^{16,21}. Such changes in the life of the caregiver justify the need to study the quality of life of primary caregivers when there is a child with PC.

A study⁵ performed in Australia has verified that the change from infancy to adolescence of people with PC has had a negative impact over the quality of life of their caregivers. Besides, the same authors state that taking care of people with PC affects the physical and social well-being, the independence, and the financial stability of their caregivers⁵. Such statement corroborates with the results obtained in the study herein, for there was observed a significant negative correlation between the result of the evaluation of the quality of life and the result of the Roland & Morris questionnaire ($r=-0.508$; $p<0.001$). That finding is possibly connected to the results found in the facets: pain and discomfort, and drug and medication addiction, from the WHOQOL-bref.

A prospective study²², with Control Group, has evaluated the presence of lumbar pain and its correlation with the quality of life and the depression symptoms of the caregivers who are moms of children with PC. Eighty-one moms of children with PC and 60 moms of healthy children were interviewed. The results have shown that the moms of children with PC have more complaints about lumbar pain and a higher depression ratio than the ones of healthy children²². In the study herein, there was no correlation between the level of motor commitment of the children under care (GMFCS) and the result of Roland-Morris questionnaire ($r=0.010$; $p=0.942$). However, a significant negative correlation was observed between the evaluation of the quality of life and the result of Roland-Morris questionnaire ($r=-0.508$; $p<0.001$). That last finding is possibly connected to the results found in the facets: pain and discomfort; drug or treatments addiction; and financial resources from the WHOQOL-Bref.

In the present study it was observed that the caregivers of less limited children had lower scores for lumbar pain (2.53 ± 3.23) that

the caregivers of the more limited children (3.33 ± 3.91), although that difference had not been statistically significant ($p=0.948$). That result corroborates the findings from a group of researchers⁶ from Ireland that had observed higher scores for the caregivers of children with greater level of motor commitment⁶ in the body pain aspect.

In Brazil, the effective attention to individuals with disabilities is still limited. Duarte et al.²³ state that it is necessary to adapt health policies for the chronic sickening profile, as well as their caregivers and relatives. The Brazilian National Health Policy for People with Disabilities, established by the Directive MS/GM n° 1,060, of June 5, 2002, restates that the principles of universality, integrality, and equity from the *Sistema Único de Saúde* (SUS – National Health System), establish as main guidelines the promotion of quality of life, the prevention of disabilities, full attention to health issues, improvement in information mechanisms, enabling human resources beyond the organization and operation of the services²⁴. However, it is observed that these actions lack of infrastructure, especially those related to children with cerebral palsy.

CONCLUSION

It can be concluded that the primary caregivers for children with PC have shown low scores of quality of life, especially in the domain related to the environment. There were no significant correlations observed concerning the motor commitment of children with PC, the quality of life from their primary caregivers, and the lumbar pain symptoms (evaluated by the Roland & Morris questionnaire). However, it was observed that the average of lumbar pain symptoms is smaller in caregivers with less motor commitment ($p=0.488$), and a significant negative correlation ($r=-0.508$; $p<0.001$) was found between the lumbar pain symptoms and the quality of life of caregivers.

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