



OBJN
Online Brazilian Journal of Nursing

ENGLISH

Federal Fluminense University

AURORA DE AFONSO COSTA
NURSING SCHOOL



Original Articles



Domains of Quality of Life of Children suffering from Cerebral Palsy: a Cross-sectional Study

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ABSTRACT

Aim: To evaluate the correlation between domains for the quality of life of children with cerebral palsy from the CP QoL Child-application and their parents. **Method:** This is a descriptive and cross-sectional study, conducted in two reference institutions in the city of Fortaleza, and involved one hundred parents of children suffering from cerebral palsy. Data collection occurred through the application of the Cerebral Palsy scale, Quality of Children. **Results:** We identified a statistically significant moderate correlation between the family and friends' domain and the domain's collective activity ($r=0.5145$), communication ($r=0.2585$) and child health ($r=0.3277$). We also noticed a statistically significant correlation of moderate and weak, between the collective activity domain and the domain of child health ($r=0.4669$) and special equipment ($r=0.2120$), respectively. **Conclusion:** The family and friends domain directly affects others, requiring early intervention in this influential aspect, in order to achieve an improved quality of life for these children.

Descriptors: Quality of Life; Cerebral Palsy; Nursing.

INTRODUCTION

Cerebral Palsy (CP) causes limitations in children and, consequently, in the family, because when it comes to pediatrics, the feelings may be more intense for cultural reasons, for the protection of children and the bonds that are formed from gestation⁽¹⁾. The CP is a complex clinical entity of high incidence, with a range of severity levels and several complications, often requiring special care. Changes occur in the family routine, with a possible direct impact on patients' lives, as well as on the caregivers', especially mothers⁽²⁾.

In children, the quality of life (QoL) has been defined as a subjective and multidimensional concept that includes the functional capacity and psychosocial interaction between the child and its family⁽³⁾. All children are entitled to live with quality in order to meet their needs; however, we realize that living standards are not always respected; hence the need for assessing the QoL of children, especially those with another associated disease.

The group, World Health Organization Quality of Life Group (WHOQOL) of 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 systems by which they live, and in relation to their goals, expectations, standards and concerns⁽⁴⁾.

From the foregoing, it is clear that many aspects can impact upon the QoL of children with CP. Thus, the health professionals who are part of the rehabilitation team have, in addition to their functional independence, the QoL as their main goal regarding the treatment of children with CP⁽⁵⁾.

That is why the care of the child and the family should be multidisciplinary, in order to identify the coping strategies, demystifying concepts and forming bonds, favoring adaptation to the chronic situation and minimizing suffering⁽⁶⁾.

Confronting a chronic disease is an ongoing and necessary process for an individual to adapt to a permanent situation that can cause stress or become a threat⁽⁶⁾ that resonates all over the family's microenvironment. The main caregivers may be the most affected individuals in the family environment, as providing continuous care can generate a burden on their physical, psychological and cultural needs⁽⁷⁾ and this may reflect upon the CP children and can influence the different domains of their quality of life.

Given the above, it is possible to show that knowledge, in terms of the relationship and possible interference between the domains, can enhance the development of intervention strategies for this population. Thus, the aim of this study was to evaluate the correlation between the domains of the quality of life of children suffering from CP, as from the CP QoL Child - application with their parents.

METHOD

This is a descriptive cross-sectional study carried out in two health institutions that serve children with CP on an outpatient and rehabilitation basis. The justification for the choice of these collection sites is due to the fact that they are reference sites for the care of children with CP.

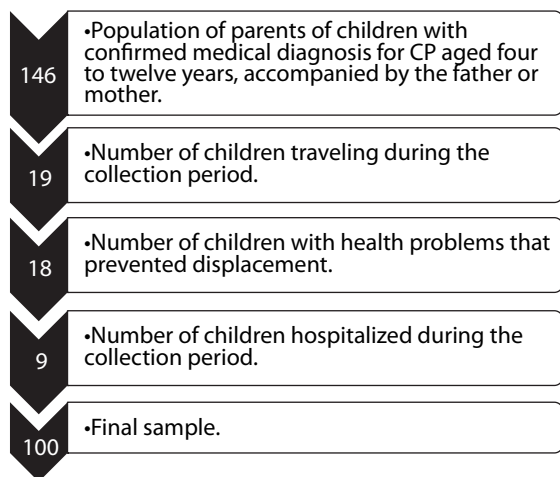
The study's target population involved parents of children suffering from CP treated at established locations for data collection. The search for cases came about through medical records, as well as with the collaboration of professionals who provided care for these children. For sample composition, the following inclusion criteria were adopted: parents (father or mother) of children with confirmed medical diagnosis for CP aged four to twelve years - this age is advocated by the translated and validated scale.

Parents of children with CP who were not attending the respective clinics during the collection period, but that had been seen at institutions cited by health problems, which led to hospital admissions or were traveling in the data collection period, were excluded.

The following discontinuation criteria were also established: a waiver to participate in the research by parents, after the beginning of collection; location change of monitoring/treatment during the study that prevented the continuation of data collection and death of the child during the course of the study. The sample consisted of the entire population of parents of children suffering from CP treated locally, during the data collection period, which met the established inclusion criteria.

A priori, the total number of children in both collection sites was 146; however, due to several factors, such as health problems, hospitalizations and trips to the state's countryside that prevented them from attending the rehabilitation facilities during the data collection period, the final sample consisted of 100 children.

Flowchart 1: Characterization of the sample recruitment from the inclusion and exclusion criteria established until the achievement of the final sample, highlighting any segment losses. (Fortaleza, 2013.)



Data collection took place between October 2012 and January 2013 through the application of the Cerebral Palsy scale Quality of Children - Child CP QoL in the version applied to parents.

The Cerebral Palsy Quality of Children - CP QoL Child is a scale specifically used to assess the QoL of children aged four to twelve years, suffering from CP, according to parents' reports. It can be applied in the form of an interview or self-administered; it was used in this study as an interview. It consists of sixty-six items, distributed among eight domains (friends and family, participation, communication, health, use of special equipment, pain and annoyance, access to services and parent's health). It was developed by a multidisciplinary international team of clinical and child health researchers from Australia, the United States, Germany and Scotland, in collaboration with parents and children suffering from CP, and later translated and also validated in Mandarin⁽⁸⁾.

This study was approved by the Ethics Committee of the Federal University of Ceará (FUC) on November 8/2011 under the registration number 197/11. All participants read and signed the Informed Consent, according to Resolution 466/12⁽⁹⁾.

The data were entered into SPSS (Statistical Package for Social Sciences) version 20.0 and exported to the statistical software STATA v.8 to generate the results presented in a table form. The responses to the scale items were summarized in average scores by domain and were correlated with each other. Then the possible correlation between the domains, by applying the Spearman correlation coefficient, was assessed. In all analyzes, we adopted the level of statistical significance of 5% ($p \leq 0.05$).

RESULTS

In Table 1, there is the matrix of correlations between the average values of the domains of the scale. By analyzing the relationship between the average values of items per domain, we observed a statistically significant moderate correlation between the family and friends' domain and the domains collective activity ($r=0.5145$), communication ($r=0.2585$) and child health ($r=0.3277$).

We identified a statistically significant moderate and weak correlation between the collective activity domain and the domains of child health ($r=0.4669$) and special equipment ($r=0.2120$), respectively. Finally, still in Table 1, there was a statistically significant weak correlation between the child health domain and the domains of special equipment ($r=0.4205$) and parents' health ($r=0.3209$), and between the domain access to health services and parents' health ($r=0.3041$).

Graph 1 shows the correlations between the domains. You can see that there is linearity between items in the domains that presented correlation.

The linearity of the points shown in Graph 1 represent what was shown in Table 1 with

respect to the correlation between the family and friends' domain and the domains of collective activity, communication and child health. Moreover, there is a convergence of points from the collective activity domain and the domains of child health and special equipment.

DISCUSSION

With the application of the scale in the target population, it was possible to make a correlation between the average values of the domains of the scale by means of the matrix. The data revealed that the performance of activities of daily living (recreational, sports, social events inside and outside the school and community) contribute to improving the health of children with CP.

The motor dysfunction of these children results in disability and limitations in the activities of their daily lives and that of their families. However, the characterization of daily tasks and child participation are still little explored in the literature and in assessment, in terms of care practice⁽¹⁰⁾.

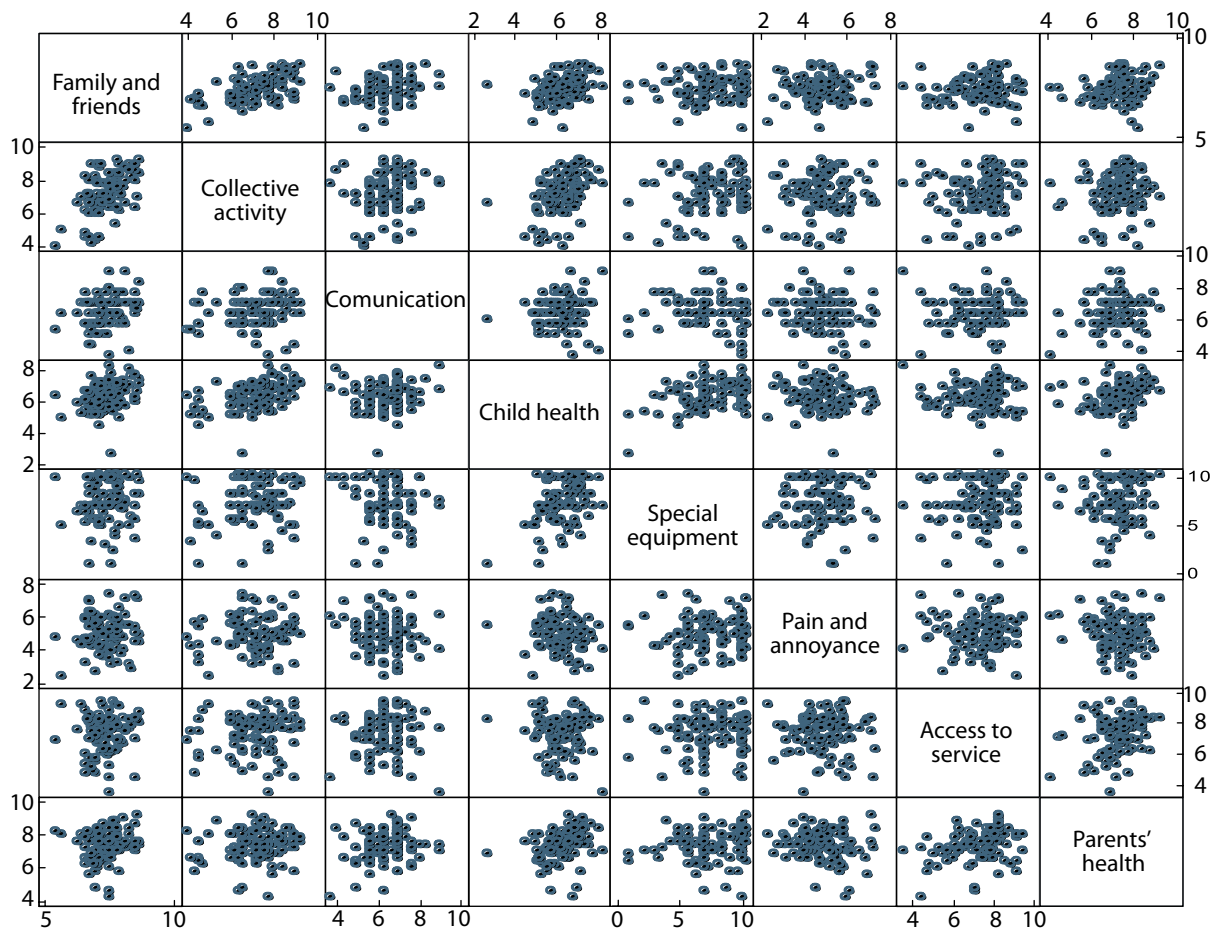
Another evident aspect: the child who performed well in the development of daily tasks

Table 1 - Correlation matrix between the average values of the scale domains CP QoL-Child, (Fortaleza, 2013).

Domains	Family and Friends	Collective Activity	Communication	Child Health	Special Equipment	Pain and Annoyance	Access to Services	Parents' Health
Family and friends	1							
Collective Activity	0,5145***	1						
Communication	0,2585*	0,1839	1					
Child Health	0,3277***	0,4669***	0,1307 ns	1				
Special Equipment	0,0714ns	0,2120*	-0,0582 ns	0,4205***	1			
Pain and Annoyance	0,0884ns	0,0925 ns	-0,1533 ns	-0,1198 ns	0,0719 ns	1		
Access to Services	0,0965ns	0,1156 ns	0,0437 ns	-0,0168 ns	0,0879 ns	-0,0248 ns	1	
Parents' Health	0,1494ns	0,0936 ns	0,1956 ns	0,3209**	0,1159 ns	-0,1573 ns	0,3041**	1

Source: Authors' Contribution.

Graph 1 – Correlation matrix between the average values of the scale domains CP QoL-Child, (Fortaleza, CE, Brazil, October/2012 to January/2013, 2013).



Source: Authors' Contribution.

had a greater ability when using special equipment (e.g. wheelchairs and supports to stay upright). The improvement in the health status of the child, with a decrease in motor sequelae and even spasticity⁽¹¹⁾, results in a greater ability to use equipment that allows for locomotion and consequent socialization.

It has also revealed that the children with CP who presented a better health status had a greater ability to use special equipment. In the approach with disabled persons, in which children with CP were included, "Assistive Technology" (AT) was used, as this area encompasses products, resources, methodologies, strategies, practices and services to promote the functionality, related to the activity and participation of individuals

with deficiency, disability or reduced mobility⁽¹²⁾. Thus, the use of AT is directly proportional to the advancement in child health, as it may offer opportunities for maturity, conviviality, cultural insertion, participation and social inclusion⁽¹³⁾.

The AT is necessary, as the children with CP are extremely limited in relation to functional capacity - a result indicated in a study aiming to describe the characteristics of a group of children suffering from CP from an institution of Fortaleza, as to their ability to perform tasks and participate in activities of daily living by means of the International Classification of Functioning (ICF), Disability and Health⁽¹⁰⁾.

Other results of this study provide evidence that the family's environment is directly res-

possible for the social life of children, contributes to the improvement in communication for the development of the activities of daily life and, consequently, for their health. With the report from mothers of children suffering from CP in the study of Vasconcelos (14), it was found that the evolution in children's QoL is perceived when children develop skills related to their interaction with the environment, in establishing an active social life.

In the study conducted by Rosebaum⁽¹⁵⁾, we observe that, besides taking care of the rehabilitation process of the children who suffer from CP, the needs of the families must be addressed as part of the well-being of the developing child, confirming the data from this study.

This family need is observed in the decision support model, to identify the coping strategies of family caregivers before the chronic disease in childhood. The study conducted by Leite et al.⁽¹⁶⁾ demonstrated that the coping strategies developed by family caregivers can be positive when professionals seek to know the child's illness or when they frankly exchange dialogue on the situation; when they have a religious or spiritual belief or manage to reconcile the scientific issues of diseases with religiosity and/or spirituality; when there is a report of the caregivers regarding their need for help in caring for the sick child, when seeking help in the family and community, and even when they can share the care provided for the child with other family members. Negative coping can also be revealed, especially when the caregiver avoids talking about the disease or spends time in silence or even uses terms that are difficult to understand with regard to the chronic situation.

Thus, the health professionals who treat children with a chronic situation such as CP, especially nurses who expend more time in the care process, which is inherent in their profession, must know the possible coping strategies

of family members in their intent to provide subsidies for overcoming and improving QoL, when they manage to reverse confrontations from negative to positive.

As reported in the previous study, religious institutions can be part of the social network in which caregivers are inserted, providing a source of social support.

In the study conducted in the state of Paraíba⁽⁶⁾, it is also observed that the coping strategies used by families, their beliefs and conflicts favored the planning of specific actions in the health area. However, caregivers used the following as strategies: dialogue escape and problems resulting from the disease; the search for knowledge and communication with the child (trying to educate them with regard to their condition and prepare them for self-care), and religiosity to cope with and accept the child's condition. It was also identified that social support is undermined by concentrating attention on the main caregiver.

From the data of this study we can also consider that the health of parents was directly related to their children's health. This aspect was highlighted because children with CP, in general, depend entirely upon another person to perform their daily activities and require therapeutic support for their ongoing rehabilitation⁽¹⁷⁾. This condition shows how vital is the presence of the caregiver in maintaining the well-being of these children; however, it is necessary to point out that they will directly interfere in their lives as a result of this dependence.

Numerous studies address the factors that interfere in the lives of the caregivers of children suffering from CP, pointing out that family background was affected by the birth of children with CP⁽¹⁸⁾ and that some factors, such as the socioeconomic status, parental education and the gravity of the gross motor function of children with CP have a negative influence on the QoL

of caregivers⁽¹⁹⁾. From the foregoing, the study of Camargos et al.⁽¹⁹⁾ reveals that knowledge of the factors influencing the burden on caregivers of children with CP is another factor to be added to the planning for care and intervention for that specific audience. It is suggested that such data can be useful for protection strategies and the monitoring and care of children with disabilities.

Another aspect that should be considered is that parents with better health status have better access to the service. During data collection, it was clear that parents had difficulties when moving from home to take their children to the monitoring service, due to the obvious problems of locomotion; thence, the data from this study show that parents need to be in perfect health condition themselves, to facilitate the access of children with CP to the health services.

The health status mentioned earlier, in addition to the physical state, includes the mental aspect, caused mainly by stress. Parents of children with CP have higher stress levels than the parents of children without disabilities and this fact affects their health. Changes in behavior and the psychological and emotional disorders of children presented in a study carried out by Ribeiro, Porto and Vandenberghe⁽²⁰⁾, were the most common factors associated with higher levels of stress, which can lead to great social impact, changes in the family dynamics and a high cost to the health system. Social support, satisfaction with the role of father/mother, good family functioning, the emotional bond between father/mother-child, spousal support and the feeling of actively participating in their social life all help to reduce stress levels.

CONCLUSION

After knowing the peculiarities of life of children with CP, through QoL domains, it may

be concluded that one domain directly affects the other, so that in this study the *family and friends* domain affects other domains directly, requiring an early intervention in this influential aspect, in order to achieve an improved quality of life for these children who, despite having a chronic disease, may have a decent quality of life.

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Mariana Cavalcante Martins – writing, critical review and final approval.

All authors participated in the phases of this publication in one or more of the following steps, in According to the recommendations of the International Committee of Medical Journal Editors (ICMJE, 2013): (a) substantial involvement in the planning or preparation of the manuscript or in the collection, analysis or interpretation of data; (b) preparation of the manuscript or conducting critical revision of intellectual content; (c) approval of the versión submitted of this manuscript. All authors declare for the appropriate purposes that the responsibilities related to all aspects of the manuscript submitted to OBJN are yours. They ensure that issues related to the accuracy or integrity of any part of the article were properly investigated and resolved. Therefore, they exempt the OBJN of any participation whatsoever in any imbroglios concerning the content under consideration. All authors declare that they have no conflict of interest of financial or personal nature concerning this manuscript which may influence the writing and/or interpretation of the findings. This statement has been digitally signed by all authors as recommended by the ICMJE, whose model is available in http://www.objnursing.uff.br/normas/DUDE_eng_13-06-2013.pdf

Received: 24/7/2014

Revised: 27/10/2014

Approved: 1/12/2014