

Assessing the burden on primary caregivers of children with cerebral palsy and its relation to quality of life and socioeconomic aspects

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ABSTRACT

Children with Cerebral Palsy (CP) present a permanent disturbance of posture and movement, characterized by a motor loss that causes difficulty in the execution of day-to-day activities and a consequent occupational dependence. Therefore, the task of assisting children with CP can lead to the caregivers' tiredness, isolation, and stress, also generating a physical and emotional burden and a possible decrease in the quality of life of this population. **Objective:** To evaluate the burden on the primary caregivers of children with CP, comparing the quality of life and the age between caregivers with and without excessive burden, as well as to compare the economic class and work status variables to the burden variable. **Method:** The study was characterized as analytical and transversal. There were 31 primary caregivers of children from 0 to 18 years old with a CP diagnosis who participated in the study. The instruments utilized in the research were a socio-demographic questionnaire designed to characterize the sample, the questionnaire from the *Associação Brasileira de Empresas de Pesquisa (ABEP)* for economic classification, the Medical Outcome Study 36 (SF-36) for the assessment of the caregivers' quality of life, and the Zarit Burden Interview (ZBI) to assess the caregiver's subjective and objective burdens. **Results:** The results pointed out that 67.7% of the caregivers presented burden and that the averages of some domains of the SF-36 ("limitation by physical aspects", "pain", "vitality" and "limitation by social aspects") for this group were significantly smaller than for the group with no burden. There was no statistically significant association in the chi-square test between the socioeconomic class of the caregivers and the burden and between the work status and the burden. **Conclusion:** The presence of burden on caregivers of children with CP is related to a lesser quality of life, but the burden was not associated with the caregiver's age, work status, or economic class.

Keywords: Cerebral Palsy, Cost of Illness, Quality of Life, Caregivers

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INTRODUCTION

Cerebral Palsy (CP) encompasses many permanent posture and movement disorders that cause limitations for activities and are attributed to non-progressive disturbances that occurred in the fetus or in the first years of encephalic development. The motor disorders are frequently accompanied by alterations of sensation, perception, cognition, communication, and behavior, and can as well result in epilepsy and secondary musculoskeletal problems.^{1,2}

The literature describes CP as being the most common cause of severe physical disability affecting children and presents an incidence of 2 to 2.5 cases for every thousand births in developed countries, while in underdeveloped countries there is a prevalence of 7 cases for every thousand births.³⁻⁶ In Brazil, it is estimated that approximately thirty to forty thousand new cases of this condition occur annually.⁷

The birth of a child that needs intense care generates great changes in family dynamics, which represents a moment of great impact and culminates in the family stability being disrupted.⁸ This stability disrupting is directly related to the breach of the routine in family life. No parent expects a child who will need special care, breaking the expectations held by the family members.⁹ The difficulties shown by the family, as much in accepting as in the caring for children with CP, generate a burden on those who are the primary caregivers.⁸

A primary caregiver is defined as the person in charge of the main, complete, or greatest responsibility of caring for the child, and who performs this activity for at least six weeks every three months and is not remunerated for the tasks involved in the care rendered.^{10,11}

Santos et al.¹² defines burden as a disturbance resulting from dealing with the physical dependence and mental disability of the individual receiving attention and care. It can be understood also as a set of physical, mental, and socioeconomic problems that the primary caregivers of people with illnesses suffer and that affects their daily activities, social relationships, and emotional balance. It is influenced by the way in which the caregiver perceives the physical, psychological, emotional, social, and financial problems that result from caring for a family member.⁹

The burden includes two aspects: objective and subjective. The objective aspects include changes in routine, reduction of social

and professional life, financial losses, performance of excessive tasks, and supervision of the problematic behaviors of the patient. The subjective aspects are related to the perception, expectations, and positive and negative thoughts of the caregiver.^{3,9}

In general, the physical and psychological health of primary caregivers, normally the mothers, is strongly related to the behavior and time demand that the child requires. In many cases, the caregivers change the dynamics of their lives and stop performing their social roles due to the child with CP. Thus, the responsibilities that this function promotes lead to the tiredness, isolation, and stress on the part of the caregivers.¹³

Almeida et al.¹⁴ also highlights that the functional dependence of a child with CP generates a physical and emotional burden for its caregivers that is related to a diminishing quality of life.

Because the family plays an influential role in the treatment of the child with CP and the environment in which the child is inserted will directly influence the evolution of its development, the importance of studies that analyze the health condition of caregivers is justified, since it will reflect on the well-being of their ward-the child being cared for.¹⁵

OBJECTIVE

The proposal of this study was to evaluate the burden index of a sample of primary caregivers of children with CP, determining the prevalence of burden in the sample. Another objective was to compare the quality of life and age of the caregivers with and without burden, as well as associate the economic class and work status variables to the burden variable.

METHODS

The present study was characterized as analytical and transversal. The sample of convenience was composed of 31 primary caregivers of children with CP aged from 0 to 18 years. These individuals were selected by the researchers from the group of patients seen at the CORAE (*Centro de Orientação, Reabilitação e Assistência ao Encefalopata*), located in the city of Goiânia, state of Goiás.

The inclusion criteria were to be the primary caregiver of a child aged from 0 to 18

years and diagnosed with CP, of either gender and duly registered at the CORAE, and sign the Free and Informed Consent form. The exclusion criteria were to be secondary caregivers of children diagnosed with CP, primary caregivers who performed this activity in exchange for payment, primary caregivers of children with other neurological diseases, and primary caregivers who presented limited cognitive conditions to understand the questionnaires.

This study was conducted in accordance with the Regulatory Directives and Norms for Research involving humans (Resolution 466/12, of the National Health Council) and was approved by the Research Ethics Committee of the *Sociedade Goiana de Cultura/Pontifícia Universidade Católica de Goiás* (PUC) under the number 014361/2014.

Instruments

The instruments used in the study were the Sociodemographic questionnaire, the questionnaire from the *Associação Brasileira de Empresas de Pesquisa* (ABEP), the Medical Outcome Study 36 - Short-Form Health Survey (SF - 36), and the Zarit Burden Interview (ZBI).

The sociodemographic questionnaire prepared by the authors of the study was used to collect data that characterized the sample. This questionnaire contained data such as: name, age, gender, work status, schooling, religion, marital status, family income, and type of living situation.

The ABEP's economic classification criteria were used to categorize the sample into economic classes and subclasses based on the number of durable goods that the family owns. There are eight subclasses: A1 refers to the class with the greatest buying power and E refers to the class with the least buying power.¹⁴

The SF-36 is a generic instrument to evaluate quality of life, translated and adapted for the Brazilian population. This questionnaire contains 36 items divided into eight domains: functional capacity, physical aspects, pain, general state of health, vitality, social aspects, emotional aspects, and mental health. The final scores go from zero to one hundred, with zero for the worst general state of health and one hundred for the best state of health.¹⁶

The ZBI scale is an instrument to evaluate the caregiver's burden and it was also translated and adapted to Portuguese. It contains 22 questions on the health, social and personal life, financial situation, emotional state, and type of relationship of the caregiver. Each answer is scored in qualitative/quantitative form varying

from 0 (never) and 4 (almost always). At the end, the answers are added and the score can vary from 0-88. A higher score corresponds to a greater perception of burden.¹⁷

Procedures

After the approval by the Research Ethics Committee, the researchers initiated the study and selected the individuals who satisfied the inclusion criteria. Later, the researchers informed those individuals of the objectives and relevance of the study, as well as its volunteer nature. Questions were answered and the subjects who were willing to participate in the study signed the Free and Informed Consent form.

After explaining how the questionnaires should be filled out and answering questions from the participant, the data collection was initiated. First, the researchers applied the Sociodemographic Questionnaire and the ABEP Questionnaire to survey the general data of the participants and to analyze their socioeconomic situation. Then, the SF-36 was applied to evaluate the quality of life and, finally, the ZBI was applied to evaluate the burden of the caregivers. All the questionnaires were applied by duly trained researchers, so as to prevent any ambiguity, doubt, influence, or embarrassment during the questioning procedure, which lasted approximately 20 minutes.

Data analysis

For the statistical analysis of the data was used the Statistics Package of Social Sciences program (SPSS) version 15.0. Non-parametric tests were used for the inferential statistics, since the variables tested were either from the ordinal data obtained from psychometric evaluation instruments (ZBI, SF-36) that have no normal distribution or from nominal data (ABEP questionnaire, work status). The Mann-Whitney test was used to compare means and medians and the chi-square test was used to associate categorical variables.

RESULTS

In the study, 31 caregivers of children and adolescents with CP were included. Table 1 shows the frequencies of burden diagnoses. Approximately 2/3 of the studied sample presented burden in the Zarit Burden Interview (ZBI).

Table 2 shows the comparison between the means and medians of the SF-36 domains and the age of caregivers with and without burden.

In the Mann-Whitney test, for the domains "limitation by physical aspects," "pain," "vitality," and "limitation by social aspects," the means and medians of the group without burden were significantly higher than the group with burden. Thus, the quality of life in those domains was worse in the group with burden. The age difference between the groups with and without burden was not significant.

Table 3 shows the distribution of economic classes between the groups with and without a burden diagnosis by the ZBI. There was no statistically significant association in the chi-square test between the socioeconomic class and the burden and, therefore, no prevalence of burden in any class.

Table 4 shows the distribution of work status (whether the caregiver works outside the house to obtain income) between the groups with and without the ZBI burden diagnosis. No statistically significant association was found in the chi-square test between work status and burden. Thus, the group of subjects who worked outside the house as well as those who did not and dedicated themselves exclusively

to care for the house and for the child with CP showed high prevalence of burden.

DISCUSSION

Children with CP present permanent disorders in posture and movement that provoke motor loss and generate difficulties in the performance of daily life activities and, consequently, functional dependence. These disturbances can cause difficulties in the execution of simple and trivial tasks and the caregivers alter their routine to provide adequate living conditions for the child. Thus, the task of assisting children with CP, along with the increase in responsibility that this function brings, may lead caregivers to tiredness, isolation, burden, and stress.^{10,13,18}

The results of the sample in this study showed that 67.7% of the caregivers presented with burden, coinciding with authors who evaluated caregivers of children with CP and of people with neurological diseases and found burden in most of them in their samples.^{9,19}

Table 1. Distribution of the burden diagnoses

ZBI diagnoses of burden	Frequency	Percentage
Without burden	10	32.30%
Moderate burden	19	61.30%
Moderate to severe burden	2	6.40%

Table 2. Comparison of quality of life and age in the subjects with and without burden in the ZBI

Variables for quality of life and age of caregiver	Burden in the ZBI	Mean	Median	Mann-Whitney test																																																														
SF-36 "functional capacity" domain	Yes	75.5	80	$p = 0.178$																																																														
	No	86	90		SF-36 "limitation by physical aspects" domain	Yes	63.1	75	$p = 0.018$	No	97.5	100	SF-36 "pain" domain	Yes	48.6	51	$p = 0.023$	No	62.8	67	SF-36 "general state of health" domain	Yes	52.6	52	$p = 0.279$	No	57.1	63.5	SF-36 "vitality" domain	Yes	49.5	55	$p = 0.027$	No	69	70	SF-36 "limitation by social aspects" domain	Yes	69.8	75	$p = 0.007$	No	91.2	93.75	SF-36 "limitation by emotional aspects" domain	Yes	57.1	66.7	$p = 0.067$	No	86.7	100	SF-36 "mental health" domain	Yes	60.6	60	$p = 0.102$	No	71.6	78	Age of caregiver	Yes	35.4	35	$p = 0.212$	No
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ZBI: Zarit Burden Interview; SF-36: Medical Outcome Study 36 - Short-Form Health Survey

Table 3. Distribution of economic class according to the burden diagnosis

Burden	Economic class by ABEP questionnaire			Chi-square Test
	D	D	B2	
Yes	2	16	3	$p = 0.275$
No	3	5	2	

ABEP: Associação Brasileira de Empresas de Pesquisa (Brazilian Association of Research Companies)

Table 4. Distribution of work status according to the burden diagnosis

Burden	Caregiver works outside the house		Chi-square Test
	Yes	No	
Yes	9	12	$p = 0.492$
No	3	7	

Some authors reported that the burden of caregivers of people with chronic diseases depended on various social and economic factors, cultural context, family support, characteristics of their ward, the relationship of the caregiver with their ward, physical and mental conditions of the caregiver, and his/her demographic characteristics such as gender, schooling, and work status.^{3,4}

In the group of caregivers with burden, 61.3% of the sample presented moderate burden and only 6.4% presented moderate to severe burden. This low percentage of caregivers with moderate to severe burden is justified by this sample being composed of older children and, as reported by some authors, the caregivers having gone through enough psychosocial adaptation with the passage of time and having a less negative perception of the situation.¹⁸ Because of that, they develop better care strategies, so what used to be seen as a difficulty becomes naturally aggregated into the family routine. When added, these factors can soften the emotional burden of caregivers.^{7,20}

The perception of burden can influence the state of health of the caregivers as shown by the results in the present study, in which the quality of life in the domains "limitation by physical aspects," "pain," "vitality," and "limitation by social aspects" was worse in the group with burden. These characteristics are similar to what has been reported by studies involving caregivers of children with Down syndrome and of children with cancer during chemotherapy. All of them found a significant correlation between the total ZBI scores and a few domains of the SF-36, with the domains "vitality" and "limitation by social aspects" coinciding with this study.²¹⁻²³

Primary caregivers, spending long hours serving the needs of a dependent individual,

may suffer social stress and, many times, suffer the consequent alienation from their own families, friends, and social milieu. Furthermore, they may face other problems such as pains, tiredness, sleep disorders, weight loss, hypertension, depression, loss of perspective in life, and greater use of psychotropics. Some authors affirm that all these factors together can restrict the possibilities of a better quality of life for the caregiver and, consequently for their ward.^{11,19,23}

The comparison between the age of the caregiver and the caregiver's burden index showed no statistically significant difference in this study, which is in agreement with authors who reported that all the caregivers in their sample, regardless of their age, showed some burden and the results of the analysis indicated no correlation or significant difference between the levels of burden according to the age brackets of the caregivers.¹²

The association between economic class and the caregiver's burden showed no statistically significant difference and, thus, no prevalence of burden on any class. These results differ from a study that evaluated the burden of caregivers of children with CP and the factors that influenced it, finding a socioeconomic association with the caregiver's burden. Those authors interviewed 56 caregivers of children with CP, using the ZBI and collected data on the socioeconomic level of the family using the questionnaire by ABIPEME (Associação Brasileira de Institutos de pesquisa de mercado/Brazilian Association of Market Research Institutes). They found a significant difference between the two groups of socioeconomic levels according to the association's criteria (classes B and C/D and E), finding greater caregiver burden in families with less favorable conditions.¹³

The caregiver of children with CP has a prominent position because he or she provides and coordinates the basic care required by the child, besides answering for it, whether being the legal guardian or not. Due to the constant attention that this population requires, it is necessary to have a caregiver who will be at their disposal a major part of the time. Nevertheless, when the socioeconomic condition is not favorable, this family has no way to pay a person to care for the child, hence they become caregivers themselves. This makes it difficult to work outside the house and compromises the family income still further.^{21,24,25}

A study made at the *Universidade Federal de São Paulo* (UNIFESP) and at the Hospital do Câncer do Mato Grosso used the Caregiver Burden Scale (CBS) to evaluate the burden of 160 caregivers of children with cancer during chemotherapy. A statistically significant association between the work status and the caregiver burden was found, observing that the caregivers who did not work outside the house presented more burden, which differs from the results of the present study.²³

The sample in this study showed no statistically significant association between work status and burden. Therefore, the group of subjects who worked outside the house as well as those who did not work and dedicated themselves to the house and the child with CP presented high prevalence of burden. The divergence found in this result may be attributed to the use of different instruments to evaluate burden, the number of subjects interviewed, and the distinct pathologies of the children in the studies.

Despite the results found in the present study, the association between the caregiver not working outside the house and a greater burden is common. According to some authors, an increase in the time the caregivers spend with the child, in addition to generating a physical burden, provokes the social stress of not going out of the house even to work.²³

CONCLUSION

Great prevalence of burden was found in the sample studied. The group of individuals with burden showed less quality of life in various SF-36 domains, when compared to the group of caregivers without burden. The groups were homogeneous in age. Burden was not associated with the work status or with the socioeconomic class of the caregiver.

The present study had limitations as to the generalization of its results, since the sample studied was small and restricted to only one institution. New studies are needed that investigate the burden in caregivers of children with CP and its relationship with quality of life and sociodemographic aspects, so as to facilitate the planning and implementation of health policies directed to caregivers, since their state of health can interfere with the health of their wards.

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