



ORIGINALES

Perception of burden of a group of caregivers of adolescents with cerebral palsy

Percepción de carga de un grupo de cuidadores de adolescentes con parálisis cerebral

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ABSTRACT:

Introduction: Cerebral palsy is an irreversible neurological condition. It is described as a group of posture and movement disorders caused by injury to the immature brain; it is not progressive and may be associated with perceptual, sensory, communication, or behavioral problems. The experience of care creates significant changes both in family life and in the social structures in which they live together.

Objective: The objective of this study was to know the perception of burden in caregivers of severely compromised adolescents with cerebral palsy, spastic in their greater proportion, based on sociodemographic and clinical aspects.

Materials and methods: Cross-sectional quantitative study. Two questionnaires with sociodemographic and clinical information were applied in which the Gross Motor Function Classification was used to 60 adolescents with cerebral palsy and the Zarit Burden Scale to their caregivers.

Results: 55% of the patients were male. The mean age was 16 years, 70% were quadriparetic and 75% spastic. 48% of caregivers perceived intense overload. It was also found that the socioeconomic status has a statistically significant negative relationship with the level of perceived burden ($p=0.0262$). 45% of caregivers perceive that due to the time they spend with their relative, they do not have enough time for themselves.

Conclusions: Caregivers perceive high dependency on the part of the patients and insufficient economic resources for care; Additionally, they report that their family situation or interpersonal relationships are not affected by the care.

Keywords: Burden perception; cerebral palsy; teenagers; caregivers.

RESUMEN:

Introducción: La parálisis cerebral es una condición neurológica irreversible. Se describe como un grupo de trastornos de postura y movimiento causados por una lesión en el cerebro inmaduro; no es progresiva y puede estar asociada a problemas perceptuales, sensoriales, de comunicación o de conducta. La experiencia de cuidado crea cambios significativos tanto en la vida familiar como en las estructuras sociales en las que conviven.

Objetivo: El objetivo de este estudio fue conocer la percepción de carga en cuidadores de adolescentes con parálisis cerebral severamente comprometidos, espásticos en su mayor proporción, a partir de aspectos sociodemográficos y clínicos.

Materiales y métodos: Estudio cuantitativo transversal. Se aplicaron dos cuestionarios con información sociodemográfica y clínica en la que se usó la Clasificación de la función motora gruesa a 60 adolescentes con parálisis cerebral y la Escala de carga de Zarit a sus cuidadores.

Resultados: El 55% de los pacientes fue de sexo masculino. La edad media fue 16 años, el 70% eran cuadriparéticos y el 75% espásticos. El 48% de los cuidadores percibieron sobrecarga intensa. También se encontró que el estrato socioeconómico tiene una relación negativa estadísticamente significativa con el nivel de carga percibido ($p=0,0262$). El 45% de los cuidadores perciben que debido al tiempo que pasan con su familiar, no tienen suficiente tiempo para sí mismos.

Conclusiones: Los cuidadores perciben alta dependencia por parte de los pacientes e insuficiencia de recursos económicos para el cuidado; adicionalmente refieren que su situación familiar o relaciones interpersonales no se ven afectados a causa del cuidado.

Palabras clave: Percepción de carga; parálisis cerebral; adolescentes; cuidadores.

INTRODUCTION

Cerebral palsy (CP) is an irreversible neurological condition, causing physical disability⁽¹⁾; mobility limitations occur as a result of decreased selective motor control, altered tone, balance, and coordination⁽¹⁾; difficulties in handling, communication, and feeding, as well as behavioral problems, may also occur⁽¹⁾. The disability generated by CP accompanies the patient and his family throughout life and its repercussions intensify as the patient ages⁽²⁾.

The experience of caring for people with severe CP creates significant changes in family life⁽²⁾; the disability generated and the difficulties to carry out an independent and participatory life in daily activities, require that there be a caregiver to supply these activities. The person who performs this work on a daily basis often has exclusive dedication, is considered the caregiver⁽³⁾.

In 1999, the World Health Organization defined the primary caregiver as "the person in a patient's environment who voluntarily assumes the role of responsible for the patient in a broad sense; this individual is willing to make decisions by and for the patient, and to cover the basic needs of the same, either directly or indirectly⁽⁴⁾. According to Roth et al.⁽⁵⁾ informal caregivers are those people who offer continuous, unpaid assistance in activities of daily living, to a person with a chronic illness or disability, for Wijesinghe et al.⁽⁶⁾, caregiver burden is defined as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the experience of care".

The Zarit burden scale - Zarit burden interview (ZBI) has been used to determine the burden generated by care; There is ample evidence on its use. In Colombia it is reported that it has been used with caregivers of people with chronic kidney disease⁽⁷⁾ with chronic non-communicable disease, in the elderly⁽⁸⁾, in infants with disabilities⁽⁹⁾ and in people with oncological pathology⁽¹⁰⁾; however, there are few reports on the burden perceived by caregivers of adolescents severely compromised with CP in the Colombian population, considering this aspect, relevant and important to study. Therefore, the objective of this study was to know the perception of burden in caregivers of severely compromised adolescents with cerebral palsy, spastic in their greater proportion, based on sociodemographic and clinical aspects.

MATERIALS AND METHODS

Type of study

A cross-sectional quantitative study was carried out because it sought to establish the perception of burden of caregivers of adolescents with CP based on sociodemographic and clinical data.

Population and sample

A convenience sampling was carried out. The universe was made up of 121 people who attended a neurological rehabilitation center in the city of Cali Colombia in 2017, of which 117 agreed to participate in the research. To form the sample frame, inclusion criteria were established that the patients were 12 years old or older, that they were in Level IV or V of the Gross Motor Function Classification System (GMFCS), and that their caregivers were informal. Finally, the sample that met the defined criteria was made up of 60 patients.

Instruments

Questionnaire for the sociodemographic characterization of patients and caregivers prepared by the researcher; aspects such as gender, socioeconomic status, educational level reached by the caregiver, postural tone and extent of the patient's injury were inquired about. To complete the patient's clinical information, the GMFCS was used; To obtain information on the caregivers' perceived burden, the ZBI scale was used.

For the field work, a physiotherapist with a postgraduate degree and experience in neurorehabilitation was in charge of collecting the information through the application of sociodemographic and clinical characterization questionnaires, as well as through direct observation of the participants, defined the level of commitment of their condition according to the GMFCS⁽¹¹⁾, which classifies CP in five levels, being V the one with the greatest commitment and I the one with the best functioning.

Likewise, this professional filled out the 22-item ZBI scale with each caregiver, which was validated for Colombia by Barreto-Osorio et al⁽¹²⁾; that qualifies the level of overload based on the following qualification scores, where the absence of overload (< or equal to 46), slight overload (47 to 55), intense overload (> or equal to 56) is delimited. The scale has psychometric tests in different languages in which it is reported, an intra-observer reliability (intraclass coefficient) between 0.71 - 0.85, a validity of 0.92 and an internal consistency (Cronbach's alpha) between 0.85-0.93. Thus, it has also been found that it is capable of discriminating psychological distress with a sensitivity of 93% and a specificity of 80%⁽¹³⁾.

Statistic analysis

The analysis of the study was carried out using complementary quantitative and qualitative strategies, given the characteristics found in the population. For the quantitative analysis, the statistical program STATA-14 was used. To determine the existing correlation between the variables, descriptive statistics, and the crossing of

the independent variables with the response variable were performed. Subsequently, the respective correlations were made, taking into account the nature of the variables to make use of the appropriate tests for each case. Correlations were evaluated using Pearson and Spearman's R test and Kendall's Tau nonparametric test.

The results of the analysis with the 5-domain ZBI scale proposed by Rankin et al⁽¹⁴⁾. were presented through counts and percentages. For correlations between nominal qualitative variables, Pearson's chi-square test was used.

Ethical considerations

This study adopted the standards established in the Declaration of Helsinki of 1975 and the parameters of the Colombian legislation included in Resolution 8430 of 1993 of the Ministry of Health. The informed consent format was explained to the caregivers and their acceptance or not of their participation was received, which was clarified, it was voluntary. To carry out the work, we also had the assent of the patients and the express permission of the person in charge of those patients who presented intellectual disability. It had the endorsement of the Rehabilitation Center and the Ethics Committee of the Universidad del Valle (endorsement 017–016). There was endorsement for the use of the ZBI scale (User Agreement_March2016_5.0)

RESULTS

Regarding the sociodemographic characteristics of adolescents and young people with CP, and the clinical characteristics of the caregiver, Table 1 shows that 55% of the patients are male, their age ranged between 15 and 17 years, with an average 16.33 years old. Regarding its clinical characteristics, there was a higher prevalence of patients with quadriplegia 70% and 75% were spastic; 100% of the patient population was classified between levels IV and V according to the GMFCS.

Regarding the characteristics of the caregivers, 45% were in the range of 40 to 49 years, with a mean of 42.25; 45% belonged to the low socioeconomic stratum (1 and 2), 40% of them were married, 70% were the mothers and 10% were the fathers of the patients.

Table 1. Patient and caregiver characteristics.

Characteristic	n=60 (%)
Patient age - Average (range)	16,33 (15,29 – 17,37)
Patient sex	
Feminine	27 (45,00)
Male	33 (55,00)
Tone	
Spasticity	45 (75,00)
Hypotonia	9 (15,00)
Dyskinesia	3 (5,00)
Ataxia	1 (1,67)
Mixed	2 (3,33)
Tone extension	
Quadriplegia	42 (70,00)
Hemiparesis	8 (13,33)

Characteristic	n=60 (%)
Dysparensis	10 (16,67)
GMFCS level	
IV	22 (36,67)
V	38 (63,33)
Caregiver age - Average (range)	42,25 (39,90 – 44,60)
Caregiver sex	
Feminine	50 (83,33)
Male	10 (16,67)
Relationship with the patient	
Father	10 (16,67)
Mother	42 (70,00)
Uncle	1 (1,67)
Grandfather-Grandmother	1 (1,67)
Other family	1 (1,67)
Neighbors and others	5 (8,33)
Marital status of the caregiver	
Single	11 (18,33)
Married	24 (40,00)
Free Union	14 (23,33)
Separated or Divorced	9 (15,00)
Widower	2 (3,33)
Socioeconomic status of the caregiver	
Low (1,2)	27 (45,00)
Medium (3.4)	24 (40,00)
High (5.6)	9 (15,00)

Table 2 shows the level of reported load, where it is observed that the majority of caregivers perceived an intense overload (48.33%).

Table 2. Caregiver burden level according to Zarit burden scale

Burden level	n=60 (%)
No overload	14 (23,33)
Light overload	17 (28,33)
Severe overload	29 (48,33)

Correlations

The relationship between the perceived load level and the patient's age was analyzed using the Pearson and Spearman's R test, however, no statistically significant correlations were found (Pearson's R = -0.190, p = 0.145; Spearman = -0.212, p = 0.103). No significant correlations were found between perceived burden level and caregiver age (Pearson's R = 0.080, p = 0.548; Spearman's = 0.054, p = 0.682).

According to Kendall's Tau non-parametric test (Table 3), socioeconomic status has a statistically significant negative relationship with perceived burden level (p-value= 0.0262). It is important to consider that, in high socioeconomic levels, families can access constant support personnel for their children, which facilitates the organization of the different tasks, achieving an adequate level of load, both emotional and physical.

Table 3. Burden level with respect to socioeconomic status, educational level, and classification of gross motor function.

Variables	Tau Kendall	p-value
Socioeconomic status	-0,2621	0,0262*
Educational level	-0,1380	0,2264
GMFCS	-0,091	0,510

*p<0.05

For the nominal qualitative variables (Table 4), the Pearson chi-square test was used, finding a statistically significant correlation for the tone distribution with the sex of the caregiver, as well as for the sex of the caregiver with the relationship established with the patient and for the relationship with the patient and the marital status of the caregiver.

Table 4. Correlation among nominal qualitative variables

	Burden	Tone type	Tone Distribution	Patient gender	Caregiver gender	Relationship with the patient	Marital status
Burden	1,00						
Tone type	9,255 (0,321)	1,00					
Tone distribution	6,541 (0,162)	4,787 (0,780)	1,00				
Patient gender	0,055 (0,973)	3,793 (0,435)	1,106 (0,575)	1,00			
Caregiver gender	2,275 (0,321)	1,769 (0,780)	5,691* (0,058)	1,091 (0,296)	1,00		
Relationship to patient	1,061 (0,900)	3,657 (1,000)	11,137 (0,347)	3,415 (0,636)	34,766* (0,000)	1,00	
Marital status	9,894 (0,273)	11,476 (0,779)	8,888 (0,352)	2,364 (0,669)	3,329 (0,504)	50,992* (0,000)	1,00

*p<0.001

Table 5 shows the results obtained from the ZBI scale from five domains as proposed by Rankin et al⁽¹⁴⁾. ; the frequency is determined and the percentages whose response was in the ranges of 3 (quite often - a lot) and 4 (almost always - too much) are presented.

Table 5. Domains of the Scale of Zarit. Answers with the highest percentage

Domains	Questions	n=60 (%)
Burden on the relationship	You feel that your family member is asking for more help than he or she needs.	24 (40,00)
	You feel that your relative depends on you.	51 (85,00)
	You feel that your family member seems to expect you to take care of him/her as if you are the only person he/she can depend on.	26 (43,33)
	You feel you should be doing more for your	20 (33,33)

	family member.	
Emotional well-being	You feel that because of the time you spend with your family member, you don't have enough time for yourself	27 (45,00)
	You feel you could take better care of your family member.	24 (40,00)
Social and family life	You feel stressed about having to take care of your family member and also having to fulfill other responsibilities of your family or your job.	16 (26,67)
Finance	You feel that you do not have enough money to take care of your relative, added to the rest of your expenses.	27 (45,00)
Loss of control over one's life	You are worried about what might happen to your family member in the future.	36 (60,00)

This analysis shows that, in terms of the burden domain in the relationship, the perception of dependency on the part of their family member was present in 85% of the caregivers. In the Emotional Well-being domain, 45% of the caregivers perceive that due to the time they spend with their relative, they do not have enough time for themselves.

The domain of social and family life was the best perceived; only 26.6% report that caring for their family member causes them stress, in contrast to the finance domain in which 45% of caregivers reported that they did not have enough money to care for their family member, added to the difficulties to the personal and family support of their expenses and obligations. Finally, in the domain of loss of control over their own life, concern about what might happen to their family member in the future was present in 60% of the caregivers.

DISCUSSION

This research aimed to evidence the burden perceived by caregivers of severely compromised adolescents (Level IV or V according to the GMFCS) due to CP; This information is useful for health professionals, other social areas and government entities because in the presence of severe disability, the caregiver-patient dyad becomes a highly vulnerable population, as mentioned by Gómez-Galindo et al⁽¹⁵⁾., in their study on the conditions of caregivers of people with severe disabilities in Bogotá.

The best known conceptual model to measure the burden of care in CP is the one proposed by Raina et al⁽¹⁶⁾., however, was not used in this research because it was designed for the pediatric population and not for adolescents. The present analysis was carried out based on the integrative model of the informal caregiver by Pierre Gérain and Zech⁽¹⁷⁾, which has been proposed to evaluate the burden of caregivers of people with chronic diseases. The model defines as determinants of informal caregiver exhaustion, the environment where care is given, the caregiver and the environment for which it is postulated that the impact of the determinants is mediated by the caregiver's assessment of their experience and the relationship with the person being cared for. In this research, regarding the aforementioned determinants, the

sociodemographic characteristics of patients and caregivers, clinical characteristics of the patients were considered and some significant aspects of the caregiver's experience and their relationship with the patient object of care are highlighted, considering the results of the correlations and analysis with the ZBI scale.

In many cultures, including the Colombian, caring for family members and especially for people with dependency levels, has been considered an exclusive responsibility of women^(18,19). In fact, in the present study, 96% of the caregivers were women, and 70% of them were mothers of the patients. On the other hand, the perception of intense overload occurred in 48.33% of the caregivers. Prakash et al⁽²⁰⁾. in their study with mothers of children and adolescents in levels IV and V of GMFCS reported high levels of stress compared to children who walk (levels I and II); In the same way, these authors affirm that care harms the quality of life of the caregiver, who usually suffers from stress and depression, which are inversely proportional to their self-efficacy and level of social support. In this sense, these findings may be a call to comprehensive networks of health service providers to consider the importance of assigning a formal caregiver for a few hours a day for their severely disabled users.

According to the results obtained in this study, there is a statistically significant relationship between the marital status of the caregiver and the relationship with the patient. This suggests that staying as a couple represents a protective factor for the family, to the extent that care responsibilities tend to be shared and the possibility of emotional support is increased⁽²¹⁾. however, and as mentioned by Vadivelan et al⁽³⁾. in a study carried out in India, it is important to know the type of partner relationship that the caregiver has and to consider the presence or not of gender and intra-family violence, since this situation can become, on the contrary, an important source of stress.

Regarding physical compromise, 100% of the patient population is between levels IV and V according to the GMFCS. Some investigations report that the severity of the deterioration is not unanimously identified as an aggravating factor of load⁽²²⁾; On the other hand, there are other studies that report that a higher level of functional disability in individuals with CP correlates significantly with a greater burden among their caregivers^(6,20).

In the analysis carried out, it was found that 85% of caregivers report that their family object of care depends on them and in this regard, several considerations can be made: On the one hand, size, weight, spasticity (87% of the adolescents in this study are spastic) and the contractures of the patients require greater physical effort for the caregiver⁽²³⁾, in addition, it is important to consider that in Colombia, the assistance devices to facilitate transfers are difficult to access due to the high costs; In this sense, it is extremely important that nurses lead actions to promote health and prevent complications in caregivers⁽¹⁹⁾.

Another consideration is that the physiological changes that occur when caregivers get older (in this study, 45% are in the range of 40 to 49 years) suggest that physical exertion can generate musculoskeletal pain or other comorbidities, such as mentioned by Burkhard et al⁽²⁴⁾., who in their study, refer that mothers usually worry if they will be able, over time, to maintain the level of care towards the family member with CP. Finally, there are reviews that support the assumption of a negative impact of the level of dependency on family adaptation⁽²⁵⁾. The aforementioned aspects can serve as a

wake-up call to therapists, nurses and health professionals in general so that they include within their intervention programs for adolescents with CP the teaching of effective strategies for postural hygiene and the inclusion of healthy life habits in caregivers; On the other hand, the intervention of social workers and psychologists can surely contribute to improving family and personal dynamics so that the processes of resilience and assessment of their experience of living with a family member with disabilities can be facilitated.

In the present study, 76.67% of the caregivers reported that the presence of their family member did not affect their relationships with family or friends. Natural supports are those that are not paid and are provided by the people associated with the caregiver⁽²⁶⁾, which can represent an important help to generate well-being and decrease the burden for caregivers; however, some studies report that social support can be a source of stress; caregivers may feel that visits or offers of support are more intrusive than helpful⁽²⁷⁾.

As mentioned by Ortiz et al⁽²⁸⁾., the role of the caregiver of a person with a chronic and severe disability includes a number of demanding tasks focused on health care; The caregiver must also comply with recommendations aimed at reinforcing the care practices given by nurses and therapists in the face of the appearance of musculoskeletal complications, feeding care, socialization opportunities, in such a way that complying with all these activities requires high time reversal⁽²⁵⁾. In this study, one of the greatest concerns of the caregiver population is the little time available to them (45%); Campos de Aldana et al⁽¹⁹⁾., mention that one of the characteristics with the greatest influence on the caregiver's burden is the daily hours of care. Sawyer et al⁽²¹⁾. found that mothers who felt more pressed for time had higher levels of psychological impairment and depressive symptoms⁽²⁹⁾ chronic stress and emotional and physical exhaustion; therefore, mothers are encouraged to be supported in finding ways to counteract the real and perceived impact of caregiving.

Another consequence of an exclusive dedication of the caregiver in a good percentage of their daily time in the care of their family member with CP is that it possibly hinders their performance in a formal job and therefore economic difficulties are generated. In the present study, 45% of the caregivers live in a low socioeconomic stratum, also finding a statistically significant and inverse relationship, showing that the lower the stratum, the greater the care burden. This same percentage refers that they do not have enough money to take care of their relative, added to the rest of their expenses, which can generate a high risk of anguish in the parents⁽²⁵⁾; however, some studies fail to find a relationship between family income and burden⁽²⁷⁾. Another aspect related to this perception is the frequent concern reported by 60% of the caregivers in this study, regarding what may happen to their family member in the future. According to Lee et al⁽²⁶⁾. many families of patients with developmental disabilities report that planning for the future makes them less vulnerable and allows them to be less anxious about changes that may occur over time or over the years. The fact that in Colombia, monetary poverty was 35.7% according to the National Administrative Department of Statistics -DANE- in 2019⁽³⁰⁾, suggests that financial planning is not within the possibilities of a good percentage of the population.; therefore, it is the duty of the professionals involved in the care process aimed at the population with CP, to alert and sensitize both caregivers and their families about the current legislation on protection for people with disabilities and their relatives. Finally, a limitation of the

study is that it only worked with the main caregivers and the other members of the patient's primary (family) and institutional support networks were not included.

CONCLUSIONS

A high percentage of caregivers of severely compromised adolescents with CP perceive intense burden for care. The caregivers perceive a high dependency on the part of the patients, added to the insufficiency of economic resources for care and that they do not find any incidence of care on the family situation or with their friends. In this sense, health professionals, nurses, and rehabilitators (physiotherapists, occupational therapists, and speech therapists) can include caregivers in teaching effective strategies for strengthening family, social, and institutional support networks that allow coping with care more safely and with greater confidence.

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