



## PHYSICAL THERAPY INTERVENTION IN PHYSICAL STRESS AND PAIN IN CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

*Atuação fisioterapêutica na sobrecarga física e dor de cuidadores de crianças com paralisia cerebral*

*Actuación fisioterapêutica en la sobrecarga física y el dolor de cuidadores de niños con parálisis cerebral*

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### ABSTRACT

**Objective:** To assess physical therapy intervention in self-reported physical stress and pain in caregivers of children with cerebral palsy. **Methods:** Longitudinal cross-sectional study carried out in 2017 with 14 caregivers of children with cerebral palsy who participated in physical therapy intervention during five consecutive weeks while children were served in the Department of Neuropediatric Physical Therapy of a reference outpatient clinic in the municipality of São Paulo, Brazil. Data were collected using a questionnaire addressing gender, current occupation, household income, number of children, shared caregiving, caregiver overload, and intensity and localization of pain. The Caregiver Burden Interview and the Visual Analog Scale (VAS) were also used. **Results:** Of the participants, 12 (85.7%) were women and 10 (71.4%) had no employment relationships. Moderate and low overload were found in the same proportion in half of the sample ( $n=7$ ; 50%) after the physical therapy intervention. The relationship between presence of pain and moderate overload remained present in 62% ( $n=5$ ) of the participants, but the pain in the visual analog scale decreased, with scores ranging 1 – the lowest – and 10 – the highest. After physical therapy, the score ranged 0 to 4. **Conclusion:** Caregiving is a nonstop activity; therefore, there were no differences in overload. However, after physical therapy and guidance regarding caregivers' posture while handling the child, there was a decrease in self-reported complaints of musculoskeletal pain in the upper limb of the caregivers analyzed.

**Descriptors:** Caregivers; Cerebral Palsy; Quality of Life; Physical Therapy Specialty; Health Promotion.

### RESUMO

**Objetivo:** Avaliar a atuação fisioterapêutica na sobrecarga física e na dor autorreferida de cuidadores de crianças com paralisia cerebral. **Métodos:** Estudo transversal e longitudinal, realizado em 2017 com 14 cuidadores de crianças com paralisia cerebral que participaram de atuação fisioterapêutica durante cinco semanas consecutivas simultaneamente ao atendimento das crianças, realizado no setor de Fisioterapia em Neuropediatria de um ambulatório de referência do município de São Paulo, Brasil. Para a coleta dos dados, utilizou-se questionário contendo as variáveis escolaridade, sexo, ocupação atual, renda familiar, quantidade de filhos, divisão dos cuidados com outrem, sobrecarga de cuidado, intensidade e localização da dor. Também se utilizou a Avaliação da Sobrecarga do Cuidador e a Escala Visual Analógica (EVA). **Resultados:** Dos participantes, 12 (85,7%) eram do sexo feminino e 10 (71,4%) não tinham vínculo empregatício. A sobrecarga moderada e baixa manteve a mesma proporção em metade da amostra ( $n=7$ ; 50%) após a atividade fisioterapêutica. A relação entre a presença de dor e sobrecarga moderada continuou presente em 62,5% ( $n=5$ ), porém a dor pela escala visual analógica diminuiu, pontuando inicialmente entre 1, como a menor nota, e 10, a maior nota. Após a fisioterapia, a pontuação oscilou entre 0 e 4. **Conclusão:** A continuidade da prestação do cuidado não cessa e, desse modo, não foi encontrada diferença entre a sobrecarga. Entretanto, após a atuação fisioterapêutica e as orientações recebidas quanto ao posicionamento do cuidador ao manejar a criança, observou-se diminuição das queixas de dores musculoesqueléticas autorreferidas em membros superiores dos cuidadores investigados.

**Descritores:** Cuidadores; Paralisia Cerebral; Qualidade de Vida; Fisioterapia; Promoção da Saúde.



## RESUMEN

**Objetivo:** Evaluar la actuación de la fisioterapia en la sobrecarga física y en el dolor auto referido de cuidadores de niños con parálisis cerebral. **Métodos:** Estudio transversal y longitudinal realizado en 2017 con 14 cuidadores de niños con parálisis cerebral que participan de la actuación de la fisioterapia durante cinco semanas seguidas en las consultas de los niños realizado en el sector de Fisioterapia en Neuropediatría de un ambulatorio de referencia del municipio de São Paulo, Brasil. Para la recogida de datos se utilizó un cuestionario con las variables escolaridad, sexo, ocupación actual, renta familiar, cantidad de hijos, división de los cuidados con otras personas, sobrecarga de cuidado, intensidad y localización del dolor. También se utilizó la Evaluación de la Sobrecarga del Cuidador y la Escala Visual Analógica (EVA). **Resultados:** De entre los participantes, 12 (85,7%) eran del sexo femenino y 10 (71,4%) no tenían vínculo de empleo. La sobrecarga moderada y baja se mantuvo en la misma proporción en la mitad de la muestra (n=7; 50%) después de la actividad de fisioterapia. La relación entre la presencia de dolor y la sobrecarga moderada continuó presente en el 62,5% (n=5), sin embargo, el dolor disminuyó a través de la escala visual analógica con la puntuación inicial de 1 como la menor nota y 10 la mayor. La puntuación varió entre 0 y 4 después de la fisioterapia. **Conclusión:** La continuidad de la asistencia del cuidado no termina y, de ese modo, no ha sido encontrada diferencia entre la sobrecarga. Sin embargo, después de la actuación de la fisioterapia y las orientaciones recibidas sobre el posicionamiento del cuidador al cuidar del niño se observó la disminución de las quejas de dolores musculoesqueléticos auto referidos en los miembros superiores de los cuidadores investigados.

**Descriptor:** Cuidadores; Parálisis Cerebral; Calidad de Vida; Fisioterapia; Promoción de la Salud.

## INTRODUCTION

Cerebral Palsy (CP) is a predominantly sensorimotor dysfunction involving muscle tone, posture and involuntary movement disorders. The needs presented by children with CP give rise to a new character within the family environment: the formal or informal caregiver, who, in most cases, is the child's mother<sup>(1,2)</sup>.

The caregiver is the person responsible for the care of a patient who presents some special need or condition that that prevents him/her from performing basic daily activities. The informal caregiver can be a family member or friend, someone who takes the responsibility for caring without pay, and the formal caregiver is the qualified professional who takes responsibility for the care of the patient and gets paid for that<sup>(3)</sup>.

The role of the caregiver is to take responsibility for meeting the basic needs of the patient and to provide support for improving health. The intensity of care demands for children with special needs, particularly for those with brain injuries, makes care more complex and constitutes a daily challenge for the family caregiver. The caregiver experiences feelings that are difficult to manage and that leaves him/her emotionally wounded. S/he also experiences feelings of insecurity, powerlessness, guilt and helplessness, which result in life deprivations and changes and lead to the prioritization of actions in favor of the child's needs<sup>(4,5)</sup>.

Thus, the act of caring has negative repercussions for the caregiver's life, interfering with the physical and psychological health of the caregiver<sup>(6)</sup>. Caregivers' physical and psychological exhaustion have been associated with impairments in quality of life. A study carried out with 12 caregivers of children with CP found that they experienced pain in the body, especially in the back, tiredness, trouble sleeping, poor self-rated health, depression, mood disorder, irritability, uncertainty about how to act and problems in social, family and professional life<sup>(7)</sup>.

Caregiver burden is a distress a caregiver experiences that is a result of the care recipient's physical dependence and/or mental incapacity. Thus, the quality of life and maintenance of health is threatened due to the care responsibilities and caregivers experience feelings of powerlessness, concern, fatigue and irritability in many situations. Further, child care causes suffering that is sometimes invisible to health professionals who are focused on the treatment of children with cerebral palsy, and this unrecognized suffering can result in caregivers' illness, which can generate great social impact, changes in the family dynamics and high cost to the health system. Therefore, public health actions are necessary to support caregivers in the promotion of self-care<sup>(8,9)</sup>.

The child with cerebral palsy needs continuous care and assistance or total dependence to perform basic activities of daily living, which causes caregivers' physical burden. Caring for the caregiver is a complex process aimed to improve physical, emotional and social health conditions. Much has been studied about the impact of disease on the life of the caregiver, but health promotion and disease prevention actions targeted at them are still rare, either because they have difficulty sharing the care task, or because of the greater amount of time spent on the care of the child.

Given that, the present study aimed to assess physical therapy intervention in self-reported physical stress and pain in caregivers of children with cerebral palsy.

## METHODS

This is a longitudinal cross-sectional study carried out from March to April 2017 in the Neuropediatric Physical Therapy Department of the Vila Maria Integrated Outpatient Care Clinic (*Ambulatório Integrado de Saúde da Vila Maria – AIS-VM*),

located in São Paulo, São Paulo, Brazil. We invited twenty-nine caregivers, but only 14 accepted the invitation to participate in the study and met the inclusion criteria, which were: being primary caregivers and being interested in participating in the study simultaneously to the physical therapy of the child with cerebral palsy. Exclusion criteria were: users and/or families who were not part of the Neuropediatric Physical Therapy Department and occasional caregivers of children with cerebral palsy. The sample consisted of 14 caregivers who voluntarily agreed to participate in the study.

Data were collected using a questionnaire addressing education, gender, current occupation, household income, number of children, care sharing, caregiving burden, pain intensity and pain location. Caregiving burden was analyzed using the Zarit Burden Interview<sup>(10)</sup>, and the Visual Analog Scale – VAS<sup>(11)</sup> was used to measure the intensity of musculoskeletal pain.

The Zarit Burden Interview<sup>(10)</sup> is a 22-item tool for assessing the burden associated with the patient's functional and behavioral disability and the situation at home. The items refer to areas of concern, such as: health, social life, personal life, financial situation, well-being, and relationships. The items measure objectively and subjectively the caregivers' burden. In the present study, the items were assessed according to what occurred during the month prior to the interview. Each item is scored from 0 to 4, with 0 = Never, 1 = Rarely, 2 = Sometimes, 3 = Quite Frequently, 4 = Nearly Always. All items are summed, with the total score ranging 0 to 88. The higher the score, the greater the burden.

The Visual Analog Scale (VAS)<sup>(11)</sup> is a unidimensional scale to assess pain intensity. It consists of a straight line numbered 0 to 10. The endpoints define extreme limits such as "no pain at all" and "pain as bad as it could be". The patient can indicate on the line the level of pain at the moment.

After data collection, the caregivers were invited to participate in a group physical therapy program. The aim of the program was to reduce the caregiving burden and the self-reported pain of the caregivers through exercises of active and active-assisted stretching (30 seconds) of the following muscles: serratus anterior, levator scapulae, trapezius, cervical paravertebral, pectoralis major, cervical spine flexors, wrist flexors and extensors, lumbar paravertebral, gluteal, and hamstring and quadriceps. Breathing exercises were performed with a diaphragmatic pattern (3 cycles of 5 repetitions), with isometric strengthening of rhomboids, flexors, abductors and rotators of the shoulders, abdomen, quadriceps and lumbar paravertebrae and strengthening of the lower posterior muscles with green and blue elastic bands (3 sets of 10 repetitions). The caregivers also received guidance regarding the manipulation and transfer of children so as not to overload their spine.

The meetings took place twice a week and lasted 45 minutes each, with a total of 10 consecutive sessions of physical therapy. After 5 weeks, the participants were reassessed using the same instruments. Data were recorded in a database and underwent descriptive analysis.

The present research was approved by the Research Ethics Committee of UNINOVE (Approval No. 1912173).

## RESULTS

Of the 14 caregivers analyzed, 12 (85.7%) were women, with a mean age of 38 years. In all, 11 (78.6%) caregivers were mothers of the care recipient and 3 (21.4%) were other relatives.

Household income was predominantly 1 (one) minimum wage, as shown in Table I. Of the caregivers, 10 (71.4%) had no employment relationship and therefore could not contribute to the family's income.

Table I - Distribution of the number and percentage of caregivers of children with cerebral palsy by socioeconomic variables. São Paulo, São Paulo, Brazil, 2017 (n=14).

Variable	n	(%)
<b>Education</b>		
Incomplete primary	2	14.3
Incomplete/complete secondary	10	71.4
Incomplete/complete higher	2	14.3
<b>Household income</b>		
1 minimum wage	9	64.3
2 minimum wages	3	21.4
3 or more minimum wages	2	14.3
<b>Number of children</b>		
1	5	35.7
2	5	35.7
3 or more	4	28.6
<b>Currently employed</b>		
Yes	4	28.6
No	10	71.4
Total	14	100

\* n= number of individuals; %= percentage; \*Minimum wage was, as of January 1<sup>st</sup>, 2017, R\$ 937.00 (Law No. 13.152, of June 29, 2015)

The analysis of the Zarit Burden Interview showed that 7 (50%) caregivers presented moderate burden and the other 7 (50%) presented little burden before physical therapy. A total of 9 (64.3%) caregivers complained of musculoskeletal pain, with the lumbar spine being the most common location of pain 5 (35.8%) (Table II).

In the present study, caregivers were primarily responsible for the care of children and had no time for rest, self-care and leisure, with a relationship between the level of burden and the presence of pain. Table II shows that moderate burden does not change in the presence of pain, since 5 caregivers presented pain and moderate burden before and after physical therapy. Only one (1) caregiver presented with decreased pain and little burden, thus suggesting an association between musculoskeletal pain complaint and a greater burden.

Table II - Level of burden with the presence of musculoskeletal pain complaint before and after physical therapy intervention. São Paulo, São Paulo, Brazil, 2017. (n=14).

Pain	Before		Burden Total	After		Total
	Little n (%)	Moderate n (%)	n (%)	Little n (%)	Moderate n (%)	n (%)
No	3 (60.0)	2 (40.0)	5 (100)	4 (66.7)	2 (33.3)	6 (100)
Yes	4 (44.4)	5 (55.6)	9 (100)	3 (37.5)	5 (62.5)	8 (100)
Total	7 (50.0)	7 (50)	14 (100)	7 (50.0)	7 (50.0)	14 (100)

n= number of individuals; %= percentage.

Among the 9 (64.3%) caregivers who reported pain, the most common location before physical therapy was the lumbar spine (35.8%), with this value remaining unchanged after intervention. However, pain in the upper limbs, which before the intervention was reported by 4 (28.5%) participants decreased to 3 (21.4%) after intervention. There was a decrease from 9 (64.3%) to 8 (57.2%) in the number of caregivers who reported pain after physical therapy.

With regard to the VAS, pain complaint prior to physical therapy presented a score of 1 for the lowest level and 10 for the highest level of self-reported pain. After physical therapy, no pain was reported, and the highest score was 4. These results show an improvement in the perception of self-reported pain by the participants of the present study.

## DISCUSSION

Although the whole family is affected by the child's illness, it is the caregiver who takes care of the patient and provides physical, emotional and even financial assistance. Care is often carried out by female caregivers, because in the Brazilian society women are responsible for caring for their home and children, resulting in loss of their free time and care for their own health, impacting on their social life. In the past, women did not work outside the home and took greater responsibility for caring for the family<sup>(4,12)</sup>.

The low household income found in the present study is in line with the findings from other studies<sup>(2,13)</sup> that have shown that caring for children with disabilities increases the demand for resources and can influence the caregiver burden in families of lower socioeconomic status. Most of the caregivers in the present study did not have a job. The same was found in studies in which 91.6% and 70.8% of the caregivers, respectively, had no occupation or income outside the home, which may contribute to the caring burden<sup>(14,15)</sup>.

As a consequence of care, which is a complex task and requires time and dedication, caregivers end up leaving their well-being behind and live their lives self-giving to the child<sup>(14,16)</sup>. The burden involves not only physical, but also psychological, family, financial and social aspects. In several situations the primary caregiver experiences financial loss, neglect and abandonment on the part of the other relatives, being overwhelmed with the task of caring<sup>(17)</sup>.

The present study was limited to physical burden. The set of efforts made every day, which generally exceed their physical capacities, associated with the lack of time and rest, lead to the neglect of their own health, which may have influenced the result. In the present study, the moderate burden remained the same and only 1 caregiver reduced the burden from moderate to little.

The results of the present study suggest an association between pain and moderate burden, i.e., the greater the burden, the higher the chances of pain complaint, which has been related to the provision of care<sup>(18)</sup>. The accumulation of responsibilities and tasks by the caregiver and the permanent dedication cause continuous physical effort, requiring adequate muscular strength and posture to fulfill children's needs, such as assistance in bath, transfer and locomotion, which become more complicated as the children grow and gain weight<sup>(6,9)</sup>.

Children with CP present with posture and movement disorders that lead to motor loss and difficulties in performing activities of daily living. Consequently, there is a functional dependence that generates physical burden, which was identified

in a study that analyzed 30 mothers and found pain complaint caused by the manipulation of children in daily care in 86.6% of the cases<sup>(19,20)</sup>.

In a study carried out in the city of Salvador, Bahia<sup>(21)</sup>, the caregivers analyzed recognized musculoskeletal burden as an essential component. The frequency of lower back pain did not decrease because the child's care activities required great muscular strength due to the necessity of daily transfers and locomotion. In addition, the child's weight was also an important factor in postural transfers of the child from a bed to a wheelchair. The biomechanics of the body is thus affected by excessive loads in the daily activities. In addition to carrying their own weight, caregivers have to overcome the weight of the child they carry in order to perform the activities<sup>(21)</sup>. The frequency of pain is related to the weight of the child, which overloads the spine<sup>(19)</sup>. Similar results were found in a study in which caregivers reported low back pain at a frequency of 28%<sup>(22,23)</sup>.

The decrease in self-reported upper limb pain confirms the results of the study in which the exercises focused on that region resulted in a significant reduction of pain in a group of 39 women over a 7-week period<sup>(24)</sup>.

There is little research on the impact of intervention on caring burden and pain in caregivers in the literature. A study carried out with 12 caregivers who received physical therapy guidelines and were reassessed after 5 weeks found a small reduction in pain, but not in caregiver burden<sup>(25)</sup>, which was analyzed using the Informal Caregiver Burden Assessment Questionnaire.

Difficulties are not related to the caring task alone, but also to the abdication of one's own needs because of another person, which leads to a decrease in the time spent on self-care and leisure activities. It should be noted that the news of the child's illness is unexpected, and everyone is faced with the unknown and with changes occurring in the family structure. The child will need assistance in the performance of activities such as feeding, dressing, personal hygiene, locomotion, among others<sup>(26)</sup>. This role is taken over by the caregiver and can affect her/his quality of life due to the lack of family support, abandonment of employment and the overload of activities in the home, thus generating caregiver burden<sup>(27)</sup>.

The present study confirms what the literature points out: women, particularly the mothers of the care recipient, bear the main burden of care and are more exposed than other relatives. They are usually more involved in the care, leaving their needs behind and start playing an additional role to those already played. This motivation for care is a personal choice and is associated with feelings of love and respect, especially when there is a strong relationship between the mother and the child, because they feel pleased to note that they can pull themselves together despite the difficulties faced every day<sup>(2,27,28)</sup>.

The present study was limited by caregivers' non-participation in the study. The physical therapy activities took place simultaneously to the physical therapy of the children, resulting in sample loss. Another important point that should be noted is the number of sessions, which may have limited patients' improvement of the caring burden. Nevertheless, the present study shows the importance of caring for the caregiver, who, likewise the care recipient, is also a user of the health care service and requires specific attention, including preventive care. They should be provided with alternatives for self-care without abstaining from the caregiving role and the promotion of health and quality of life, with improvements in their physical, social and emotional conditions<sup>(8)</sup>.

One of the objectives of the present study was to optimize the time in which the caregivers waited in the outpatient clinic for the care of children, seeking to provide self-care for health promotion. Thus, there is a need for future studies with caregivers of children with cerebral palsy to investigate difficulties in self-care due to the child's demands and the development of proposals to minimize the physical and emotional demand inherent to caring, thus preventing possible illnesses among caregivers. Further, specific days should be scheduled for physical therapy and there should be a greater number of sessions, which could allow a more effective physical therapy intervention to change the health profile of this population.

## CONCLUSION

The continuity of the care delivery does not cease and, therefore, no differences were found in the caregiver burden. However, physical therapy and guidelines on the posture of the caregiver while manipulating the child decreased self-reported musculoskeletal pain in the upper limbs of the caregivers investigated.

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