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RESEARCH

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EMOTIONAL AND PHYSICAL EXHAUSTION OF FAMILY CAREGIVERS

Exaustão emocional e física de cuidadores familiares

Agotamiento emocional y físico de los cuidadores familiares

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ABSTRACT

Objective: The study's main purpose has been to verify the profile of musculoskeletal disorders, emotional burden and health profile of caregivers of people bearing central nervous system injury sequelae. **Methods:** It is a descriptive study with 23 participating caregivers. There were applied musculoskeletal injury tests (Nordic Musculoskeletal Questionnaire), overload tests (Caregiver Burden Scale) and the Physical Mobility and Transfer Risk Assessment Scale. **Results:** The caregivers' profile were as follows: average age of 52.9 years old, women, spouses, elementary school, responsible for providing care to the patient, residence without a salary, and an average working hours of 15.8 hours per day. A total of 47.8% received little guidance on how to provide care services. Older people suffer more with pain (spine and upper limbs) and stay more away from activities from activities compared to younger ones (p-value = 0.01). Overall tension, isolation, and emotional burden were impactful (p-value = 0.03). **Conclusion:** The caregivers are family members, low income, have musculoskeletal pain, considerable emotional burden and physical pain, as well as they need support from the health team.

Descriptors: Aging, Family, Caregivers, Patient's safety.

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RESUMO

Objetivo: Verificar o perfil de distúrbios osteomusculares, a sobrecarga emocional e a saúde de cuidadores de pessoas com sequelas de lesão no Sistema Nervoso Central. **Método:** estudo descritivo com 23 cuidadores. Foram aplicados testes de lesão osteomusculares (Nórdico), de sobrecarga (*Carregiver Burden Scale*) e a Escala de Avaliação do Risco na Movimentação e Transferência. **Resultados:** os cuidadores tinham idade média de 52,9, mulheres, cônjuges, ensino fundamental e com função de cuidar do paciente e residência sem renumeração, média de 15,8h/dia de trabalho. 47,8% receberam poucas orientações sobre como cuidar. Os de maior idade sofrem mais com dor (coluna e membros superiores) e se afastam mais das atividades comparados aos mais jovens (valor-p=0,01). A tensão geral, o isolamento e a sobrecarga emocional foram impactantes (valor-p=0,03). **Conclusão:** as cuidadoras são familiares, de baixa renda, apresentam dores osteomusculares, considerável sobrecarga emocional e dor física e necessitam de cuidados da equipe de saúde.

Descritores: Envelhecimento, Família, Cuidadores, Segurança do paciente.

RESUMEN

Objetivo: Verificar el perfil de los trastornos musculoesqueléticos, la carga emocional y la salud de los cuidadores de personas con secuelas de lesiones del sistema nervioso central. **Método:** estudio descriptivo. Se aplicaron lo Nórdico, lo Carregiver Burden Scale y la escala de evaluación de riesgo de movimiento y transferencia. **Resultados:** los cuidadores (n=23) tenían promedio de 52.9 años, mujeres, cónyuges, escuela primaria y con la función de cuidar al paciente y la residencia sin renumeración, promedio de 15.8h/día de trabajo. Las personas mayores sufren más con dolor (columna vertebral y extremidades superiores) y se alejan más de las actividades en comparación con las más jóvenes (valor-p=0.01). La tensión general, el aislamiento y la sobrecarga emocional fueron impactantes (valor-p =0.03). **Conclusión:** los cuidadores son miembros de la familia, de bajos ingresos, tienen dolor musculoesquelético, una carga emocional considerable y dolor físico y necesitan atención del equipo de salud.

Descriptores: Envejecimiento, Familia, Cuidadores, Seguridad del paciente.

INTRODUCTION

The concept of disability has been discussed, has social and economic relevance for most countries, and constitutes a growing and heterogeneous field of political activism and research in the world. About 80% of these people live in developing countries.¹

Given this framework, there is a need to consider the care of this population in different scenarios, one of which is that of the one who takes care of the affected individual, the caregiver. This new professional that appears is partly due to the high costs of hospital admissions, but it is also related to the humanization of treatment, the stimulation, the reduction in the risk of hospital infection, and the maintenance and increase in the patient's quality of life.²

Home caregivers are a new and growing professional category that accompanies elderly people or not, from the diagnosis to either the rehabilitation phase or death. Most care is performed at the patient's residence and are daily activities and most often without scientific complexity.³

The main responsible for these attributions, in general, is the family caregiver, responsible for carrying out in

practice the recommendations of health professionals. Lay people in the activity, these caregivers are friends, neighbors, volunteers, family members, or someone hired to "provide care". As a more common alternative, these informal caregivers assume 80% to 90% of home care in Brazil.⁴

The qualification of caregivers must be focused on the development and improvement of skills to perform specific functions regarding the care of patients in daily activities and actions to promote autonomy and empowerment. Role of both Primary Care and Home Care teams that should guide and supervise people who are caring for individuals at home.⁵

Unlike the assistance provided by a health professional, the caregiver's work means attention, precaution, caution, dedication, affection, responsibility, and accountability. This care must go beyond the care of the physical body, because, in addition to the physical suffering resulting from a disease or limitation, it is necessary to take into account the emotional issues, the life history, and the feelings of the person to be taken care.⁵

Permeated by different and contradictory feelings, the task of caregivers is complex and, often, given to individuals who are not prepared for such responsibility, then causing among other injuries, those of the osteoneuromuscular system.

Work-related Musculoskeletal Disorders (WMSDs) can affect caregivers even more than a professional who is believed to be more prepared for caring activities. WMSDs include a variety of inflammatory and degenerative conditions, affecting muscles, tendons, ligaments, joints, peripheral nerves, and encompassing inflammation in tendons (tendinitis), tenosynovitis, bursitis, nerve compressions, as well as other conditions such as myalgia and low back pain.⁶ They do not occur for a single cause, and clinical conditions are generally related to the musculoskeletal system subjected to certain working conditions.⁶

Risk factors for the emergence of WMSDs are the use of muscle strength, repetition of movements, and prolonged static postures. These multifactorial factors are associated with the dimensions of intensity, speed, and time exposure, involving physical, organizational, psychosocial factors, and individual and socio-cultural aspects,⁷ where such overloads can affect the physical and psychological systems when under adverse conditions.^{8,9}

Since the population aging and the increased survival of individuals with disabilities, there is a need for caregivers in practically full time. Nevertheless, scientific studies have shown that caregivers have presented different health problems. Thus, the need to identify individuals with central nervous system injuries, identify their caregivers, and better understand the health of both is justified.

Bearing the aforementioned in mind, the objective of this study was to verify the profile of musculoskeletal

disorders, emotional burden and health profile of caregivers of people bearing Central Nervous System (CNS) injury sequelae.

METHODS

It is a descriptive, cross-sectional, survey-type study. There were assessed 23 medical records of patients bearing CNS neurological injuries, as well as 23 caregivers were interviewed from January 2016 to August 2016.

The study focused on data collection in an area covered by the *São José do Rio Preto* city, *São Paulo* State, with a large number of elderly patients with brain injuries (44.5%), assisted by the *Sistema Único de Saúde (SUS)* [Brazilian Unified Health System]. Home caregivers were selected as long as they were responsible for moving the bed, transfers, bathing, and feeding; who stayed more than 2 hours at home/service and who worked for more than three months. A home visit was scheduled for telephone interviews and four data collection instruments were used. The 1st instrument gathered general data about the caregiver. The 2nd instrument, the Nordic Musculoskeletal Questionnaire (NMQ),¹⁰ which identifies the profile of musculoskeletal disorders and provides descriptions addressing the occurrence of symptoms (pain, discomfort or numbness),

Figure 1.

Neck	Cervical region.
Upper limbs	Shoulder, elbow, forearm, wrist, hand, fingers and dorsal region.
Spine	Thoracic and lumbar regions.
Lower limbs	Hip, knee, ankle.

Figure 1 - Anatomical regions considered in this study for analysis of the NMQ.

The dependent variables are the areas of discomfort for each region in the last 12 months, 7 days, and absence from work in the last 12 months. The Symptom Severity Index varies from 0 to 4, with zero representing the absence of symptoms¹⁰ and for analysis, the variables were coded for the presentation of results.

The 3rd instrument was the Caregiver Burden Scale (CBS),¹¹ which assesses emotional burden (overall tension, isolation, disappointment, emotional involvement, and the environment). The score ranges from 1 to 4 points and after averaging each item and the overall burden of caregiver, the greater the impact felt by the caregiver in the different dimensions, the higher the score.

The 4th instrument served to observe how the patient's handling is performed, from which musculoskeletal injuries in the caregiver can be triggered, the Physical Mobility and Transfer Risk Assessment Scale.¹² This determines the ergonomic risk of the patient and the caregiver. It consists of eight topics considered on a scale from one (1) to three (3), **Figure 2.**

Figure 2 - Ergonomic risk of the patient and caregiver by the Physical Mobility and Transfer Risk Assessment Scale.¹²

Scale	Risk during customer movement and transfer
8-12	Low risk
13-18	Medium risk
19-24	High risk

Descriptive analysis with frequency distribution was performed to describe the clinical and sociodemographic variables. To verify the association between the variables, Fisher, Kruskal-Wallis, or Chi-square tests were applied as appropriate and p-values ≤ 0.05 were considered significant. The research was approved by the Research Ethics Committee from the *Faculdade de Medicina de São José do Rio Preto (FAMERP)*, on 12/21/2015, under the Legal Opinion No. 1.378.072 and complies with both Resolution No. 466/2012 and Resolution No. 510/2016. All participants signed the Informed Consent Form (ICF).

RESULTS

Considering the 23 patients, 12 (52.2%) were male, the average age was 73.82 years old (± 13.6), 40 to 90 years old, 12 (42.2%) were married, low education, low personal and family income, retirees, bedridden due to a stroke event, with the time of physical dependence <10 years. Bearing in mind the total, eight (34.8%) had difficulty hearing and reading, 18 (78%) had some difficulty eating, 20 (87%) needed assistance with some type of personal hygiene, and 18 (78%) they walked with some type of assistance and 12 (52.2%) were unable to move around in bed.

The 23 caregivers interviewed were within the age group from 19 to 77 years old, with an average of 52.9 years old (± 16.2), 20 (86.9%) of whom were female, 12 (52.1%) were the patients' spouses, six (26.0%) children, two (8.6%) daughters-in-law, one (4.3%) granddaughter. Only two (8.6%) were not related to people with sequelae.

Table 1 addresses the socioeconomic aspects.

Table 1 - Distribution of the sociodemographic profile of caregivers of individuals bearing CNS injury. *São José do Rio Preto* city, *São Paulo* State, 2018

	Variable	n (%)
Gender	Female	20 (86.9)
	Male	3 (13.1)
Age	19 to 30	2 (8.6)
	31 to 40	5 (22.0)
	41 to 50	2 (8.6)
	51 to 60	4 (17.3)
	61 to 70	7 (30.4)
	71 to 80	3 (13.1)
Education	Illiterate	1 (4.3)
	Incomplete elementary school	5 (22.0)
	Complete elementary school	4 (17.4)
	Incomplete high school	6 (26.1)
	Complete high school	7 (30.4)
Marital status	Never has been married	3 (13.1)
	Currently married	17 (74.0)
	Widower	1 (4.3)
	Divorced	1 (4.3)
	Didn't know/didn't want to inform	1 (4.3)

Occupation	Self-employed caregiver, who also takes care of the house.	12 (52.2)
	Self-employed caregiver, who carries out another paid work without leaving home.	5 (21.7)
	Salaried caregiver	2 (8.6)
	Retired	3 (13.1)
Personal income (Minimum wage)	Unemployed	1 (4.3)
	Up to 1	10 (43.4)
	From one to 3	7 (30.4)
	3 to 10	3 (13.1)
Family income (Minimum wage)	Other	3 (13.1)
	Up to 1	5 (22.0)
	From one to three	10 (43.4)
	From three to ten	7 (30.4)
	Ten or more	1 (4.3)

The average caregivers working hours was 15.8 hours per day.

Considering the 23 caregivers interviewed, 11 (47.8%) received guidance from health professionals concerning patient care at some point, and nine (39.1%) received them shortly after hospital discharge. The guidelines received were mainly on hygiene and other more specific care, such as transpostural movements, medication, and physical therapy.

The individuals who performed the guidelines were five (45%) registered nurses, two (18%) physiotherapists, two (18%) people from multidisciplinary teams, one (9%) physician, one (9%) from another caregiver, and one (9%) from a caregiver course.

Concerning the 23 caregivers, ten (43.4%) had neck pain, 14 (60.8%) in upper limbs, 15 (65.2%) in the spine, and 11 (47.8%) in lower limbs. The spine was the area (severity level IV) that had the most reserve from activities (10 reports), followed by six events in the lower limbs.

Table 2 shows the severity of indices according to the NMQ.

Table 2 - Severity and pain site indices of patients bearing CNS injury, according to the NMQ (N=23). São José do Rio Preto city, São Paulo State, 2018

Site	Pain		Severity level (Number of events occurred)				
	Yes n (%)	No n (%)	0	I	II	III	IV
Neck	10 (43.4)	13 (56.5)	13	4	1	3	2
Upper limbs	14 (60.8)	9 (39.1)	9	3	5	2	4
Spine	15 (65.2)	8 (34.7)	8	1	1	3	10
Lower limbs	11 (47.8)	12 (52.1)	12	4	1	0	6

Subtitles:

Considering the severity level, it reads as follows:

0= no pain,

I= pain and/or discomfort in the last 7 days or 12 months,

II= pain and/or discomfort in the last 7 days and 12 months,

III= absence from activities in the last 7 days or 12 months,

IV= absence from activities in the last 7 days and 12 months.

Older caregivers suffer more from pain and stay more away from activities when compared to younger ones. There was a significant association between older caregivers and changes found in the NMQ (p-value = 0.013).

Among the dimensions assessed by CBS, the overall tension, isolation, and disappointment were the most impactful according to the caregivers' answers (n = 23), as shown in **Table 3**.

Table 3 - Representation of the emotional burden assessment (overall tension, isolation, disappointment, emotional involvement and environment) according to the Caregiver Burden Scale questionnaire, São José do Rio Preto city, São Paulo State, 2018

Emotional burden	Average *	Variation	Standard deviation	Minimum	Medium	Maximum	Mode
Overall tension	3.13	1.78	1.33	1.00	3.50	7.50	3.50
Insulation	2.45	1.19	1.09	1.00	3.00	4.00	1.00
Disappointment	2.83	1.01	1.00	1.00	2.80	4.00	4.00
Emotional involvement	1.71	0.88	0.93	1.00	1.00	3.66	1.00
Environment	1.68	0.58	0.76	1.00	1.66	3.66	1.00
Overall total	2.36	0.54	0.73	1.00	2.48	3.57	1.00

Subtitle: *variation of answers from 1 to 4, and the higher the score assigned by the caregiver, the greater the impact felt by the caregiver in the different dimensions.

The greater the overall emotional burden reported by caregivers (CBS), the more pain and withdrawal from activities (NMQ) have a p-value = 0.03 (Kruskal-Wallis test).

After using the Physical Mobility and Transfer Risk Assessment Scale, which is the observation of how the handling of the patient is performed and where musculoskeletal injuries can be triggered in the caregiver, it was noted that, considering the 23 patients and caregivers analyzed, five (21.7%) had low risk, 15 (65.2%) medium risk and three (13.1%) high risk during the patient's mobility and transfer. Considering the 18 (78.3%) caregivers who presented medium and high risk during the patient's mobility and transfer, only eight (34.8%) received information about patient care.

The results reveal that the average age was not associated with the risk of injury that the caregiver might suffer during the patient's mobility and transfer (p-value = 0.11).

DISCUSSION

The physical and emotional burden of caregivers needs to be investigated in the face of the current dizzying population aging.

The interviewed caregivers had an average age of 52.9 years old, mostly women and were spouses or relatives of the bedridden, only two caregivers were hired to perform the care task. Similar data were found in different studies on caregivers.^{7,13,14} Women play traditional roles of caring.³

Facing different cultures such as France, Japan, and Brazil, the common challenge is the aging of their populations and the people dedicated to this occupation share in their characteristics, the most notable, the fact that they are women.¹⁵ They are no different from Portugal, where the characteristics of the caregiver profile are young adults, married, cohabitation with the patient, and the reasons for caring are related to the caregiver's duty and emotional connection with the subject.¹⁶

This work showed that, in addition to the issues aforesaid, there is a socioeconomic factor. Most families survive on up to three minimum wages (US\$ 792.00), whose health, psychosocial, and functional performance conditions are directly influenced by socioeconomic

variables.¹⁷ Here, more than half of the caregivers (52.1%) had the function of caring for the patient and residence without payment and needed the sick individual's income/retirement to survive. Furthermore, 21.7%, in addition to providing care, carried out another function at home to improve family income.

In the national and worldwide scenario, studies have been giving progressive attention to family caregivers of elderly people with physical and/or mental disabilities, mainly, the study of the impact that the disease causes in their lives.^{15,18,19}

The municipality studied has a Multiprofessional Home Care Team, which offers care and training for bedridden patients and their families. Nonetheless, it was found that 47.8% of caregivers received specific guidance, especially shortly after hospital discharge, and reported having difficulty understanding and applying them.

Another important fact found in this study was that, in addition to the lack of general information about care, caregivers did not have any accessories that would facilitate patient transfers, or even simple adaptations, such as the special height of the bed, or bath chair. It is important to highlight that, as long as the patient has the prescription and indication, resources of assistive technologies are provided within the municipality by the Prosthesis, Orthosis and auxiliary means of locomotion program, however, this service was not activated by the health team or informed to the patient and/or caregiver about their right. The lack of ergonomics and accessories for handling these patients, as well as the lack of guidance on how to provide care, contributes to these pains and detachment from everyday activities.

The average caregivers working hours was 15.8 hours per day. Evidence suggests that caring for an individual with a chronic illness is an arduous task, which can lead the caregiver to develop emotional and physical problems.^{13,14} Furthermore, the withdrawal from caring activities, such as holidays and vacations, is not a habit among interviewed caregivers, as they were family caregivers, which makes care even more exhausting. The only caregiver who, even in conditions of social precariousness, took turns working with someone else, did not complain of pain. It is believed that, when the care work is shared, the physical and/or emotional burden decreases.

With the application of the NMQ, it was found that, in the studied group, the lumbar spine was the most affected segment, evidenced by the higher incidence of complaints, with severity. According to the ranking of low back pain sickness aid, it is the disease that most leaves workers in Brazil for more than 15 days, 116,371 people in 2016, a number that represents 4.71% of all withdrawals.²⁰

In addition to full-time care, they also performed household tasks, which overload the joints. The study proved that older caregivers suffer more from pain and stay more away from activities when compared to younger

people.

According to the results found after applying the NMQ, the upper limbs are in second place in the degree of involvement of the interviewed caregivers, considering here the shoulders, elbows, wrists, and hands. Pain in the shoulder region is a frequent complaint among workers.²¹ Muscle strength begins to decrease after the age of thirty and there is a reduction in reach and flexibility, especially in the upper limbs. Shoulder tendinopathies are associated with the dominant limb and are related to domestic chores plus labor work.²² Double-shift work (employment and home)²² shows the need for actions to promote and prevent health for caregivers with the indication of programs already installed in the municipality.

When assessing emotional burden, with the application of the Caregiver Burden Scale (CBS), the items "overall tension", "disappointment" and "isolation" were the most impactful according to the responses of the caregivers and presented higher scores on the exam when compared to other studies.^{13,14,23} Patients who were assisted by the interviewed caregivers had CNS injuries caused by various factors, which may justify emotional burden. Another point to be considered is the extensive and double workday without relay or external collaboration.

This study proved that the greater the emotional burden (CBS) reported by caregivers, the more pain and withdrawal from activities (NMQ) they have (p-value = 0.03). The emotional burden experienced by caregivers can result in feelings of guilt, anger, aggression, possession, and mix with affection, experience, security, and knowledge of the patient and their reactions,^{14,23,24} having seen the degree of proximity found in this study. A study showed that caregivers are more likely to have psychopathologies than physical complications, register more visits to doctors, and have worse health in relation to the general population.²⁴

After using the Physical Mobility and Transfer Risk Assessment Scale, it was noted that 18 (78.3%) caregivers had medium and high risk during the movement and transfer of the patient. The authors did not find studies using this scale in-home caregivers, its use is frequent in nursing teams working in hospitals and in specialized areas, and in professionals who have technical training and training in handling and moving patients. Even so, these teams registered 55.3% of medium risk and high ergonomic risk. Considering the evaluated units, Intensive Care and Intensive Cardiology²⁵ and the General Intensive Care Unit²⁶ were the ones with the highest ergonomic risks, with 83.3% and 64% respectively. Patients who offered little ergonomic risk are located, for the most part, in medical clinic units.²⁶

There is a need for public health policies that provide lines of care towards stroke survivors and other disabling diseases that create physical dependence on a caregiver. Brazilian families face great economic and instrumental difficulties in caring for their elderly with dignity and

respect. Public health programs are insufficient to meet this population demand that requires specialized services.¹⁵ France faces the same challenge, in 2050 the French population over 75 years old will be 15%, in which there will be 10 million elderly people in need and a decreasing number of responsible adult persons.¹⁵

Assessing these conditions, educational programs for the prevention and promotion of health, information about caring for others and oneself, and the need to introduce auxiliary equipment and materials into the daily routine, considering their particularities, should be planned. The formation of educational groups of caregivers is a space for the exchange of experiences and knowledge and, due to its reach and effectiveness, can alleviate the physical and emotional burden of its participants.

The results obtained in this study can guide strategy planning, aiming to reduce the impact caused by the disease on the caregivers' life and health.

CONCLUSIONS

Herein, it is concluded that in the studied municipality the caregivers are of low income and rely on sick individual's income/retirement to survive. These are family caregivers, with low education and 52 years old on average. Most do not have outside help and do not receive guidance after the patient's discharge.

It was found that most caregivers have musculoskeletal pain and significant emotional burden; that physical pain proved to be inseparable from emotional pain; that the patient considered in this study is at risk of falling when handled by the caregiver, and that, in addition to not having guidance on handling, muscle strength is decreased by aging itself, in addition to presenting pain in the spine and upper limbs.

Caregivers need care from the health team as well as patients.

This work contributes to a better understanding of the caregiver's health and the need for health services to provide preventive care for such population.

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