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Factors associated with symptoms of physical and emotional burden in informal caregivers of the elderly

Fatores associados aos sintomas de sobrecarga física e emocional em cuidadores informais de idosos

Factores relacionados a los síntomas de sobrecarga física y emocional en cuidadores informales de ancianos

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ABSTRACT

Objectives: to analyze the personal and work-related burden factors associated with physical and emotional symptoms of informal caregivers of the elderly. **Methods**: cross-sectional study conducted with 121 informal caregivers and 121 seniors who received care, assessed individually for the risk of: physical overload, musculoskeletal symptoms, Self-Reporting Questionnaire, effort perception, and Katz index. **Results**: a greater perception of effort raises up to 3.3 times the chances of presenting symptoms of pain in the spine region (p=0.01), and lower functional capacity of the elderly increases up to 1.3 times the chances of presenting pain symptoms in the spine region (p=0.02). The symptoms of emotional overload were associated with the caregiver's low income (p=0.02). **Conclusions**: the perception of effort, dependence of the elderly, caregiver's age, and symptoms of emotional overload are involved with caregivers' symptoms of physical overload, and low income, with emotional overload. **Descriptors:** Caregivers; Elderly; Musculoskeletal Pain; Psychological Distress; Caregiver Burden.

RESUMO

Objetivos: analisar os fatores de sobrecarga pessoal e relacionados ao trabalho associados a sintomas físicos e emocionais de cuidadores informais de idosos. **Método:** estudo transversal realizado com 121 cuidadores informais e 121 idosos que recebem cuidados, avaliados individualmente pelo risco de sobrecarga física, sintomas musculoesqueléticos, *Self-Reporting Questionnaire*, percepção de esforço e Índice de Katz. **Resultados:** uma maior percepção do esforço aumenta até 3,3 vezes as chances de apresentar sintomas de dor na região da coluna vertebral (p=0,01), e a menor capacidade funcional do idoso aumenta até 1,3 vez as chances de apresentar sintomas de dor na região da coluna vertebral (p=0,02). Os sintomas de sobrecarga emocional apresentaram associação com a baixa renda do cuidador (p=0,02). **Conclusões:** a percepção do esforço, dependência do idoso, idade do cuidador e sintomas de sobrecarga emocional estão envolvidos com os sintomas de sobrecarga física dos cuidadores; e a baixa renda, com sintomas de sobrecarga emocional.
Descritores: Cuidadores; Idoso; Dor Musculoesquelética; Estresse Emocional; Carga de Cuidar.

RESUMEN

Objetivos: analizar factores de sobrecarga personal y relacionados al trabajo relacionados a síntomas físicos y emocionales de cuidadores informales de ancianos. **Métodos:** estudio transversal realizado con 121 cuidadores informales y 121 ancianos que reciben cuidados, evaluados individualmente por riesgo de sobrecarga física, síntomas musculoesqueléticos, *Self-Reporting Questionnaire*, percepción de esfuerzo e Índice de Katz. **Resultados:** una mayor percepción del esfuerzo aumenta hasta 3,3 veces las chances de presentar síntomas de dolor en la región de la columna vertebral (p=0,01), y la menor capacidad funcional del anciano aumenta hasta 1,3 vez las chances de presentar síntomas de dolor en la región de la columna vertebral (p=0,02). Los síntomas de sobrecarga emocional presentaron relación a baja renta del cuidador (p=0,02). **Conclusiones:** la percepción del esfuerzo, dependencia del anciano, edad del cuidador y síntomas de sobrecarga emocional están involucrados a síntomas de sobrecarga física de cuidadores; y baja renta, con síntomas de sobrecarga emocional.
Descriptores: Cuidadores; Anciano; Dolor Musculoesquelético; Distrés Psicológico; Carga del Cuidador.

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INTRODUCTION

In the family context, caregiver burden was first published by Zarit, Reever, and Bach-Peterson[1] and evaluates physical, psychological, emotional, social, and financial problems experienced by caregivers represented by both subjective and objective aspects, arising from the impact of caring.

The multidimensional concept of caregiver burden is related to the search for balance between the variables involved in the care activity, such as time to provide care, financial resources, psychophysiological, physical, mental, and social conditions[2].

Factors related to work, such as the functional capacity of the elderly, high workload in caring activities, insufficient guidance, inadequate postures when providing care, among others, can interfere in this balance, generating a set of physical and emotional symptoms, characterized by emotional exhaustion, negative feelings, isolation, and symptoms of musculoskeletal pain, resulting from the overload of the activity of caring for an elder[3-4].

Although some caregivers do not identify the activity of caring as a job, some authors do, even when the person does not receive a financial benefit[5]. Thus, the labor aspects that is involved in this function deserves investigation.

A problem related to occupational health is musculoskeletal disorders. Internal burdens such as body weight, mental burden, and health impairment collectively affect workers. Those who use workstations and workplaces with dimensions that are less suited to their anthropometry will be required to perform more unnatural movements and work postures, causing more severe musculoskeletal disorders to occur earlier. Muscle fatigue is a very painful symptom, when muscles suffer from excessive stress, while general fatigue is a stage marked by a decrease in readiness to use energy[6].

In gerontological literature, it is possible to identify that caregivers have more symptoms of burden than non-caregivers; however, until now, only emotional overload related symptoms have been deeply explored by the authors[7], leaving a gap of information pertaining symptoms of physical burden in caregivers of the elderly, especially among the informal ones. Studies that have explored the symptoms of physical and emotional overload have not investigated the various regions of the body in which these symptoms manifest, nor whether the factors associated with these symptoms are similar[8-9].

OBJECTIVES

To analyze the personal and work-related burden factors associated with physical and emotional symptoms of informal caregivers of the elderly.

METHODS

Ethical aspects

This study complied with the terms of Resolution no. 466/2012 of the Brazilian Health Council, which deals with research involving human beings. The study was approved by the Research Ethics Committee of the Federal University of São Carlos (UFSCar) on August 28, 2014. All participants were informed of the research objectives and data confidentiality and consented by signing the informed consent form.

Study design

Descriptive and cross-sectional study conducted in the urban area of São Carlos, São Paulo, Brazil. The data were collected between the second half of 2016 and the second half of 2017. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement was used to guide the research.

Sample, inclusion, and exclusion criteria

The study was conducted with a non-probabilistic sample (convenience sample) of informal caregivers of the elderly living in the community. Lists with informal caregivers' home location data were obtained through Community Health Agents by visiting all Family Health Units in the municipality. Only primary caregivers were included. Specifically, those primarily responsible for the care, who had been performing the function for at least one month, and who did not receive any type of financial benefit for the activity[8]. Excluded were people who reported formal and informal caregiver activity with work-related characteristics, homes with more than one senior being cared for; and senior residents considered independent by the Katz scale[9], thus characterized as being a companion and not a caregiver.

Of the 265 total addresses of caregivers and elderly provided by the Community Health Agents, 54 were not located, 24 refused to participate, 30 elderly had died, 34 were considered independent by the Katz scale, and 2 addresses had more than one senior being cared for. Thus, 121 informal caregivers and 121 elderly were evaluated.

Study protocol

Participants were interviewed in their own houses. The questions for caregivers were answered in private. For the elderly who were unable to answer, the answers provided by the caregivers were considered. In cases where the caregivers were unable to read, the questionnaires were read by the interviewer strictly following their original description. The interviews lasted about 30 minutes.

In this study, the following instruments were used:

- Demographic questionnaire (caregiver and elderly): The questionnaire includes personal questions about both the senior person and the caregiver, as well as information related to the activity of caring for the caregiver, in addition to an open question: "In your opinion, what most harms your physical health when you are providing care?". The answers to this question were categorized and those that represented less than 5% of the total answers were grouped in the "other" category.
- An instrument to assess the risk of caregiver's physical burden when moving and transferring the patients: It is an instrument that assesses the characteristics of the elderly and the environment in which the transfers are carried out. It was developed by Radovanovic and Alexandre[10]. This instrument consists of a scale, completed by a health professional, which comprises eight topics (weight, height,

level of consciousness/psychomotricity, mobility in bed, transfer from bed/stretcher or stretcher/chair and vice versa, walking, catheters and other equipment used by the patient, and environment) corresponding to the patient and the environment. The results estimate the level of risk to which the caregiver is exposed when moving the senior person, being categorized as low risk (08-12 points), medium risk (13-18 points), or high risk (19-24 points).

- Katz Index (applied to the elderly): Developed to assess the individual's functional capacity in six activities of daily living based on a hierarchy of complexity: feeding, sphincter control, transferring, personal hygiene, and ability to dress and shower oneself. Its score reveals whether the individual has maximum (A) or minimum (G) independence in the performance of functions[11].
- Nordic Musculoskeletal Questionnaire (applied to caregivers): It was validated by Pinheiro, Tróccoli, and Carvalho[12] and consists of a human body figure divided into nine regions: shoulders, elbows, wrist/hand, neck, upper and lower part of the back, hips/thighs, knees, and ankles/feet. In each of these regions the individual responds about the occurrence of pain or tingling/numbness in the last 12 months and in the last seven days, the search for health professionals due to the symptoms in the last 12 months, and the impediment to carry out activities of daily living due to symptoms. For better understanding, at the time of the analyses, it was decided to group the body regions into three macro-regions. The "neck, upper, and lower back" regions were grouped into the category "spine"; "shoulders, elbows, and wrists/hands" became "upper limbs"; and "hips/thighs, knees, and ankles/feet" the "lower limbs". In this study, only the responses of the symptoms of pain or tingling/numbness in the last 12 months and the last seven days were considered.
- Self-Reporting Questionnaire (SRQ-20): Instrument applied to the caregivers, recommended by the World Health Organization for tracking non-psychotic mental disorders represented by emotional discomfort. This scale is composed of 20 questions with "yes" or "no" answer options. Each affirmative answer scores with a value of one to compose the final score. The cutoff point was eight, that is, scores equal to or greater than eight were considered positive for the probability of non-psychotic mental disorders[13].
- Borg's perceived exertion scale (Rating of Perceived Exertion - RPE): Scale used to estimate the sensation of effort, tiredness, and fatigue during the caregiver's work. Composed of numbers ranging from six to 20, with six considered as no effort and 20 considered maximum effort[14]. The scale was applied right after the moment when caregivers reported performing the greatest amount of effort.

Analysis of results and statistics

The results were analyzed using the Statistical Package for the Social Science (SPSS, version 19.0). Initially, descriptive analysis and the Kolmogorov-Smirnov normality test were employed. As the data did not present a normal distribution, the Spearman correlation test was applied to assess the correlations between the independent variables (risk scale for movement and transfer; seniors' Katz score; perception of effort, time working as caregiver for current senior client; daily work hours as a caregiver; number of days off in the week; and always transferring the elderly without assistance) and dependent variables (symptoms of pain or tingling/numbness in the macro regions of the spine, upper and lower limbs in the last 12 months and in the last seven days for physical symptoms, and the SRQ-20 score for emotional symptoms).

Univariate logistic regression was applied to verify associations between the presence of musculoskeletal symptoms in the last 12 months and in the last seven days in each body macro-region, with dichotomous responses (presence or absence). For the association with emotional symptoms, the outcome variable was the SRQ-20 score, with a positive response for symptoms of emotional discomfort (score ≥8) or negative (score <8).

The independent variables tested were: caregiver's age, sex, income, marital status, educational level, level of physical activity, smoking, alcohol consumption, effort perception scale score, time as current caregiver, working hours per day as caregiver, time off, performing other activities besides caregiving, SRQ-20 score, functional capacity of the elderly (Katz score), score on the risk scale for movement and transfer, transferring the elderly without the help of another person, and guidance on caring for the elderly (specific, basic, or none). Associations with a p value ≤0.2 entered the final multiple regression model using the stepwise forward method. The level of significance adopted was 5%.

RESULTS

The sample consisted of 121 caregivers and 121 seniors who received care. Table 1 shows the main demographic characteristics of caregivers and seniors. It is possible to observe in both groups the majority is female, with an average age of 57.2 years for the caregiver and 81.1 years for the seniors.

Regarding the occupational characteristics of caregivers, Table 2 shows almost 85% are family members, carry out this function over eight hours/day (69%), and most do not have weekly time off from the care activity (86%).

The main factor of physical overload reported by caregivers was "transferring the elderly" as the one that most affects their physical health (38%), followed by "nothing harms me" (28%), "stress/emotional factors" (22%), and "other factors" (12%).

More than half of the seniors were at moderate risk for movement and transfer and, if added to the seniors at high risk, this percentage reaches almost 80%. Among the risk aspects found, the Body Mass Index of the elderly (average of 26.8 kg/m^2) and the poorly adapted environment which included beds without height adjustment and chairs and stretchers without wheel locks stand out. In addition, most seniors were highly dependent for activities of daily living (Katz F and G).

Musculoskeletal symptoms in the last 12 months were more frequent in the spine (69%), followed by the upper (47%) and lower (41%) limbs. As per the last seven days, the spine was also the region with the highest prevalence (39%), followed by lower (41%) and upper (22%) limbs (Table 3). Regarding emotional symptoms, 33% of caregivers obtained SRQ-20 results greater than or equal to eight.

Table 1 – Demographic characterization of the sample of informal caregivers (N=121) and seniors (N=121), São Carlos, São Paulo, Brazil, 2017

Variables	Seniors	Caregivers
Sex [n (%)]		
Female	77 (63.6)	95 (78.5)
Male	44 (36.4)	26 (21.5)
Age in years [Mean (SD)]	81.1 (9.6)	57.2 (13.9)
Marital Status [n (%)]		
With a partner	39 (32.2)	77 (63.3)
Without a partner	82 (67.8)	44 (36.4)
Relation [n (%)]		
Son/daughter	-	66 (54.5)
Partner	-	30 (24.8)
Father/mother	-	1 (0.8)
Brother/sister	-	5 (4.1)
None	-	19 (15.7)
Educational level [n (%)]		
Illiterate	77 (63.6)	39 (32.2)
Elementary school	31 (25.6)	46 (38.0)
High School	6 (5.0)	22 (18.2)
College	2 (1.7)	9 (7.4)
Graduate	5 (4.1)	5 (4.1)

SD – Standard Deviation.

Table 2 – Occupational characterization of the sample of informal caregivers (N=121), São Carlos, São Paulo, Brazil, 2017

Variables	Seniors	Caregivers
Time as caregiver [n (%)]		
Up to 1 year	-	28 (23.1)
1–3 years	-	37 (30.6)
>3 years	-	56 (46.3)
Hours of work/day [n (%)]		
Up to 8h/day	-	38 (31.4)
8–12h/day	-	38 (31.4)
>12h/day	-	45 (37.2)
Days off [n (%)]		
None	-	104 (86.0)
1/week	-	8 (6.6)
2/week	-	5 (4.1)
>2/week	-	4 (3.3)
Risk for movement and transference [n (%)]		
Low risk	28 (23.1)	-
Moderate risk	69 (57.0)	-
High risk	24 (19.8)	-
Seniors' Katz Score [n (%)]		
A	0 (0)	-
B-C	28 (23.2)	-
D-E	20 (16.5)	-
F-G	49 (40.5)	-
Others	24 (19.8)	-

Table 3 – Prevalence of musculoskeletal symptoms for the grouped physical and emotional regions, São Carlos, São Paulo, Brazil, 2017

Region of the body	Physical n (%)
Spine	
Symptoms in the last 12 months	83 (68.6)
Symptoms in the last 7 days	47 (38.8)
Upper Limbs	
Symptoms in the last 12 months	57 (47.1)
Symptoms in the last 7 days	26 (21.5)
Lower Limbs	
Symptoms in the last 12 months	50 (41.3)
Symptoms in the last 7 days	49 (40.5)
SRQ-20 Score	Emotional n (%)
<8	81 (66.9)
≥8	40 (33.1)

SRQ-20 – Self-Reporting Questionnaire.

Table 4 shows that the increase in the symptoms of emotional discomfort (SRQ-20 score ≥8); specifically, always transferring the senior without assistance, increase in the perception of effort, high risk for movement and transfer, higher Katz score (more dependent seniors), are factors associated with an increase in musculoskeletal symptoms in the spine. For emotional symptoms, there was an association with insufficient guidance on caring for the elderly.

Table 4 – Spearman's correlation coefficient between overload factors and physical and emotional symptoms, São Carlos, São Paulo, Brazil, 2017

Variables	Symptoms in spine in the last 12 months	Symptoms in spine in the last 7 days	Emotional Symptoms
SRQ-20 score ≥8	0.21*	0.23*	
Always performs transfers without assistance	0.12*		
RPE score ≥13	0.34*		
Risk for movement and transfer	0.21*		
Katz score	0.30*	0.19*	
Insufficient guidelines on caregiving			0.18*

*SRQ-20 – Self-Reporting Questionnaire; RPE – Rating of Perceived Exertion; *p<0,05.*

The logistic regression analyses (Table 5) showed that the increase in Katz score (more dependent seniors) increases the chances of physical symptoms in the spine in the last 12 months and in the last seven days by 1.3 times, (p <0.01 and p= 0.02, respectively). Caregivers with greater perceived exertion are 3.3 times more likely (p= 0.01) to have symptoms in the spine in the last 12 months and caregivers with SRQ-20 score ≥8, 3.1 times more likely (0 <0.01) of presenting symptoms in the spine in the last seven days.

In the upper limbs, the chances of symptoms increased 4.2 times in caregivers with SRQ-20 score ≥8 (p <0.01) within the last 12 months. As per the lower limbs, the age of the caregiver increases 1.1 times the chances (p= 0.04) of symptoms in the last 12 months and in the last seven days (p <0.01), and the greater perception of effort 2.6 times (p= 0.02) in the last seven days. The symptoms of emotional discomfort, on the other hand, showed a 3.8 times greater chance of association (p= 0.02) in caregivers with an income of up to two minimum wages.

DISCUSSION

The demographic results obtained corroborate those of current literature, including when compared to groups of caregivers from different regions[15], revealing a group that is mostly female and of an older age. This age group, close to 60 years, validates the importance of better knowing the risk factors of caregiver activity, since it is a population that will soon also be aged.

When considering this age group, it is important to highlight the correlation of this factor with mental disorders and pain symptoms, since they are outcomes known to be linked to age[7] and which were also observed in our study. Flesch et al[16] found similar results when observing in middle age and over 60 year-old caregivers of an urban region a decrease in physical vitality and an increase in emotional symptoms.

Table 5 – Logistic regression results, São Carlos, São Paulo, Brazil, 2017

Outcome Variable	Independent Variable	Odds ratio (IC 95%)	*p* value
Symptoms in the last 12 months			
Spine	More dependent seniors	1.3 (1.1 – 1.6)	<0.01
	Greater perception of effort	3.3 (1.3 – 8.0)	0.01
Upper Limbs	SRQ-20 score ≥8	4.2 (1.9 – 9.6)	<0.01
Lower Limbs	Caregiver age	1.1 (1.0 – 1.1)	0.04
Symptoms in the last 7 days			
Spine	More dependent seniors	1.3 (1.0 – 1.5)	0.02
	SRQ-20 score ≥8	3.1 (1.3 – 7.0)	<0.01
Lower Limbs	Caregiver age	1.1 (1.0 – 1.1)	<0.01
	Greater perception of effort	2.6 (1.2 – 5.9)	0.02
Emotional symptoms			
	Caregiver income up to 2 minimum wages	3.8 (1.2 – 11.7)	0.02

SRQ-20 – Self-Reporting Questionnaire.

The urban region, where this study was developed, may also have interfered in this data since the study by Pavarini et al[17] showed that populations of elderly caregivers have differences in the prevalence of emotional symptoms according to the region in which they live, being higher in regions of high social vulnerability and in the urban area compared to populations living in rural regions.

Regarding the occupational factors of the care activity, the possible deleterious effects of the high workload and absence of breaks experienced by many caregivers are highlighted. The recognized damage can go beyond the physical and mental exhaustion reported in most studies on the topic[7]. Current studies have been able to correlate the high caregiver workload with the change in the concentration of cortisol hormone, which can also generate negative physiological effects[18].

We understand that the topic of high workload should be treated from aspects such as the need for support from health systems, relying on help from people who are close and family members, and the awareness of the caregiver, who often interprets the periods in which they do not provide care as a personal failure or weakness, denying their need for rest[3,7,19].

In addition to presenting a correlation between the symptoms in the spine, the transfers were perceived by the caregivers as the factor that most affects their physical health and, although there is extensive knowledge that dealing with weight can affect physical health, especially when this situation is highly frequent[20], studies that relate the caregiver's perception of burden to transfers are scarce. Darragh et al[8] reported very similar results in a sample with a smaller number of caregivers, reinforcing transfers as an important factor to be studied in the care activity. As within our study, these same authors found more physical than emotional symptoms in their group of caregivers, in addition to identifying that the main region of musculoskeletal symptoms was also the spine, with a prevalence of pain in 76% of caregivers.

When compared with a study by Morais et al[2], which used the same instruments to assess the impacts of caring activity on the symptoms of family caregivers, the results are also similar, revealing that physical symptoms are more present than emotional symptoms in this group, despite having been studied on a smaller scale.

The symptoms of emotional overload correlated with insufficient guidance on caring for the elderly. The systematic review conducted by Bernardo and Raymundo[21] identified that the training of caregivers of elderly with dementia favors less burden on the caregiver. Among the factors related to less overload, we highlight the better understanding of the evolution of the disease with consequent improvement in coping with deficiencies of the elderly, better relationship with them, and a greater feeling of competence of the caregiver.

This study was also able to demonstrate the association between low functional capacity of the elderly with increased physical symptoms of caregivers, especially in the spine. Studies that associate greater dependence of the elderly with increased physical symptoms are still recent. Bekdemir and Ílhan[22] correlated the caregiver's physical symptoms with the functional capacity of bedridden patients and Waters[20] related the increase in physical symptoms mainly to the need of constant transference of the most dependent elderly.

Considering that the functional capacity of seniors, in most cases, cannot be altered, it is suggested that environmental adaptations include ergonomic issues focused not only on seniors, but also on the caregiver. A recent study showed that both postural orientations and environmental adaptations significantly reduce the symptoms of physical burden on caregivers[23].

Age was also associated with symptoms of physical overload in the regression model. Recently, a study identified that caregivers in the age group between 50-59 years, interval in which the average age of our participants is found, was associated with musculoskeletal disorders, possibly triggered by age-related degenerative processes. This study also considered informal workers[24].

Regarding the perception of effort, the association was stronger in the region of the spine. It has already been shown that patient transfers generate scores of high perceived efforts. In our study, caregivers were instructed to complete this scale after the activity that caused them the greatest feeling of physical effort. The majority opted to complete it after they had transferred the patient, which possibly generated greater association with the region of the spine, as it is the area with highest physical demand during the action of transference[10].

The emotional discomfort associated with musculoskeletal symptoms is not new. There is currently no clear explanation of the mechanism by which emotional factors interfere with physical symptoms. However, the authors believe that the suffering caused by pain, by the element of affection towards the other, negative thoughts, and emotional exhaustion are the main routes of association[7].

Having an income of up to 2 minimum wages was the only factor associated with increased symptoms of emotional discomfort. The fact that some of the caregivers had some level of income leads us to believe that they had a job in addition to the care activity, thus possibly increasing the perceived overload and, consequently, the symptoms of emotional overload[25].

Limitations of the study

This study has limitations because the questionnaires are based on self-report, which can generate a bias in the answers, especially those that refer to long periods of time, since some questions refer to symptoms in the last 12 months. It is also known that there are several other factors involved with the overload in the care activity and that may have interfered with the results. The sample collected is also a limitation due to the non-probabilistic character, thus being a possible source of bias.

Contributions to the field of nursing, health, or public policies

This study contributes to a better understanding of the factors related to caregiver burden that generate both physical and emotional symptoms and it is expected that this data will trigger further discussions on the activity of caring for the elderly, based on the work and ergonomic view of this activity.

CONCLUSIONS

The perception of effort, the higher dependence of the elderly, the caregiver's age, and symptoms of emotional overload are involved with the symptoms of physical overload. Regarding the symptoms of emotional overload, there was an association with caregivers' low income. Actions aimed at a more laborious and ergonomic look can help to reduce these symptoms, since some factors, such as the functional capacity of the elderly and the age of the caregiver, are hardly altered.

SUPPLEMENTARY MATERIAL

https://repositorio.ufscar.br/handle/ufscar/11431

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