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THE BURDEN OF HOME CAREGIVERS

A sobrecarga do cuidador domiciliar

La sobrecarga del cuidador domiciliario

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ABSTRACT

Objective: To evaluate the work overload of caregivers of users of a public home care service and to know the factors associated with this condition. **Methods:** This is an analytical cross-sectional study conducted in 2013 with caregivers working in the households of users of the home care service of the municipality of Goiânia, Goiâs. Eligible participants were literate caregivers aged 18 years or older working as a primary caregiver for at least two months. Data were collected through interviews with application of instruments for the characterization of the caregiver and burden was evaluated using the Zarit Burden Interview (ZBI). The data were analyzed using SPSS version 15.0, with calculation of mean and standard deviation and a 95% confidence interval. Bivariate analysis and multiple linear regression were used with p-value set at<0.05. **Results:** The mean age of the 95 interviewees was 49.7 years (±13,0); 93 of them (97.9%) were women and 53 (57.9%) were married. The mean score in the burden evaluation was 33.8. Higher ZBI scores were associated with not having a weekly day off (p=0.002), problems in the back (p=0.039) and depression (p=0.016). **Conclusion:** The caregivers' work overload results from the caring task and the main factors associated with it are the lack of a weekly day off, problems in the back and depression.

Descriptors: Caregivers; Home Nursing; Primary Health Care.

RESUMO

Objetivo: Avaliar a sobrecarga de trabalho dos cuidadores de usuários vinculados a um serviço público de atenção domiciliar e conhecer os fatores associados a essa condição. Métodos: Trata-se de um estudo transversal analítico, realizado com cuidadores nos domicilios dos usuários cadastrados pelo serviço de atenção domiciliar do município de Goiânia - Goiás, no ano de 2013. Selecionaram-se cuidadores com idade igual ou superior a 18 anos, alfabetizados e em exercício da função como cuidador principal há pelo menos dois meses. Os dados foram coletados por meio de entrevista com aplicação dos instrumentos de caracterização do cuidador e de avaliação de sobrecarga pela Zarit Burden Interview (ZBI) e analisados pelo SPSS, com cálculo da média, desvio padrão, intervalo de 95% de confiança, análise bivariada e regressão linear múltipla com valor de p<0,05. Resultados: Dentre os 95 cuidadores entrevistados, a idade média foi de 49,7 anos (±13,0), sendo que 93 (97,9%) eram do sexo feminino e 53 (57,9%) casados. Na avaliação da sobrecarga, a média obtida foi de 33,8 pontos. Maiores níveis de sobrecarga foram associadas ao fato de o cuidador não possuir folgas semanais (p=0,002), apresentar problemas de coluna (p=0,0039) e depressão (p=0,016). Conclusão: Conclui-se que os cuidadores apresentam sobrecarga de trabalho decorrente da tarefa de cuidar e os principais fatores associados são a falta de folga semanal, problemas de coluna e depressão.

Descritores: Cuidadores; Assistência Domiciliar; Atenção Primária à Saúde.



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RESUMEN

Objetivo: Evaluar la sobrecarga de trabajo de cuidadores de usuarios vinculados de un servicio público de atención domiciliaria y conocer los factores asociados con esa condición. Métodos: Se trata de un estudio transversal y analítico realizado con cuidadores en los domicilios de usuarios con registro realizado por el servicio de atención domiciliaria del municipio de Goiânia - Goiás, en el año de 2013. Fueron seleccionados los cuidadores con 18 años o más, alfabetizados y actuando en la función de cuidador principal desde hace dos meses. Se recogieron los datos a través de entrevista con la aplicación de los instrumentos de caracterización del cuidador y de evaluación de la sobrecarga por la Zarit Burden Interview (ZBI). Los datos fueron analizados por el SPSS versión 15.0 con el cálculo de la media, la desviación típica, el intervalo de confianza del 95%, el análisis bivariado y la regresión linear múltiple con el valor de p < 0.05. Resultados: La media de edad entre los 95 cuidadores entrevistados fue de 49,7 años (± 13.0), siendo 93 (97,9%) del sexo femenino y 53 (57,9%) casados. La media de la puntuación de la evaluación de la sobrecarga fue de 33,8. Niveles más elevados de sobrecarga se asociaron al hecho del cuidador no tener descansos semanales (p = 0.002) y tener problemas en la columna (p = 0.0039) y depresión (p = 0.016). Conclusión: Se concluye que los cuidadores tienen sobrecarga de trabajo decurrente de la tarea de cuidar y que los principales factores asociados son la ausencia de descanso semanal, los problemas de columna y la depresión.

Descriptores: Cuidadores; Atención Domiciliaria de Salud; Atención Primaria de Salud.

INTRODUCTION

Advances in health care, improvements in the living conditions of the population and the decrease in fertility and mortality rates are very important factors for understanding the aging process worldwide. Both developed and developing countries have been experiencing this reality, which is one of the biggest public health challenges^(1,2).

Aging is accompanied by foreseeable changes in nearly all the organs and systems of the body and a potential reduction of functional reserve. The physiological changes are gradual but progressive, and there is an increase in the prevalence of acute and chronic diseases⁽³⁾.

The transformations that have occurred in Brazil since 1960 changed the morbidity and mortality profiles of Brazilians. Infectious and parasitic diseases, the leading causes of death at the beginning of the last century, have given way to chronic noncommunicable diseases (NCDs). These diseases, typical of aging, are defined as a health condition that accompanies the individual over a long period of time, alternating moments of worsening (acute) or sensible improvement⁽⁴⁾.

In addition to the deaths, many of which are preventable and premature, NCDs lead to sequelae and disability, generating suffering and a high number of years of life lost⁽⁵⁾. These sequelae or disabilities can put individuals in a situation of dependence in which they need the help of other people to perform basic activities, such as feeding, hygiene, and transferring.

There is a strong tendency to encourage community involvement in issues related to long-term care, and this is due to several reasons – for instance, the cost reduction of hospital and institutional care. Thus, the indication for disabled older people to stay in their homes is increasingly common, with some family member being responsible for becoming a caregiver⁽⁶⁾.

The most common activities carried out by caregivers are related to feeding, hygiene, elimination, therapy, locomotion, moving the patient, preparation of meals, housekeeping, washing and ironing, and tasks other than household chores⁽⁷⁾.

Caring is usually nonstop, i.e., without any rest. Caregivers work long hours, which lead them to experience stressful situations and work overload⁽⁸⁾.

Caregivers' work overload is a multidimensional phenomenon involving physical and emotional changes, imbalance between activity and rest, and compromised individual coping⁽⁹⁾. The caregiver often sees his/her health and well-being being affected and feels unable to face this reality, becoming a patient unknown to the health service, which requires an early diagnosis and immediate intervention⁽¹⁰⁾.

After taking responsibility for caring, caregivers tend to value the needs of the person under their care first, leaving their own needs behind⁽¹¹⁾. In addition, this situation is exacerbated by the lack of information about the disease, the treatment used and the most appropriate strategies to handle patients' problematic behaviors and crisis management, which can have a negative impact on the family, social and work contexts⁽¹²⁾.

When they are encouraged to speak out, caregivers reveal that the experience of caring is full of antagonistic feelings: love and anger, patience and intolerance, affection, sadness, irritation, discouragement, pity, revolt, insecurity, negativism, solitude, doubt regarding care, guilt, fear of being sick too, and fear related to their patients' suffering and death⁽¹³⁾.

Health promotion and disease prevention actions are reportedly rare in the daily life of caregivers, either because of lack of time or because of the lack of other people to share the task of caring. The recognition that caregivers play a key role in health care, especially with regard to chronic and long-term conditions, has encouraged the investigation of the problems presented by them. This knowledge could support health professionals so as to tailor the care provided to the needs of caregivers, thus

contributing to the improvement of their quality of life. Given that, this study aimed to evaluate the work overload of caregivers of users of a public home care service and to know the factors associated with this condition.

METHODS

This is a quantitative analytical cross-sectional study carried out in 2013 with caregivers of users of the Home Care Service (*Serviço de Atenção Domiciliar – SAD*) of the municipality of Goiânia, Goiás, Brazil.

SAD is a service composed of a multidisciplinary team that aims to support the families of users of Brazil's Unified Health System ($Sistema\ \'Unico\ de\ Sa\'ude-SUS$) who are carriers of chronic diseases and are bedridden or have difficulty locomotion and that require a greater frequency of care through continuous monitoring. However, enrollment in the program requires, in addition to the clinical profile, the presence of a caregiver previously identified and who is able to carry out the actions agreed between the SAD team and the user's family⁽¹⁴⁾.

Study participants were the formal and informal caregivers of users enrolled in and served by SAD who were selected according to the following inclusion criteria: literate individuals aged 18 years and older who were primary caregivers of the user for at least two months. Illiterate caregivers and those with communication difficulties that precluded the interview were excluded.

Data were collected at the user's household registered in the SAD after previous telephone contact, through which the caregiver was explained about the study and then invited to participate voluntarily in the research. If the user agreed to participate, the visit was scheduled. Data were collected using two instruments: one for the characterization of the caregivers, consisting of 17 items, and the Zarit Burden Interview (ZBI) to evaluate the burden.

The questionnaire on the characterization of caregivers was adapted and contained questions on gender, age, marital status, degree of kinship, education, previous or no experience in caregiving, number of hours dedicated to care, and presence of any disease, among others – caregivers' diseases were self-reported^(15,16).

The Zarit Burden Interview (ZBI) is an instrument containing 22 questions that evaluate the caregiver's objective and subjective burden. Scale scores range from 0 to 88 points and the total score is obtained from the sum of the scores of the 22 questions, which range from 0 to 4 points each. The higher the score, the greater the burden, and the classification adopted by this study was as follows: absence of burden for scores lower than 21 points, moderate burden for scores of 21-40 points, moderate to severe burden for 41-60 points, and severe burden for scores between 61-88 points⁽¹⁷⁾.

This instrument was adapted and validated for Brazil and can be used in the study of the impact of mental and physical illness on caregivers. In addition, the Zarit Burden Interview is a reliable instrument with good psychometric characteristics to assess the burden associated with the caring process^(17,18).

The dependent variable of the study was the caregiver's work burden. The independent variables were divided into data on the characterization of the caregiver, caregiver's clinical data and data on the users of the SAD.

The data were analyzed in the Statistical Package for the Social Sciences (SPSS version 15.0). The burden in the ZBI was determined by the sum of all the answers of the 22 questions, obtaining a total score ranging from 0 to 88 points. Means and standard deviations were calculated and confidence interval was 95%. The internal consistency of the instrument was verified using Cronbach's α , and simple linear regression analysis identified the potential factors associated with ZBI scores. The explanatory variables with biological plausibility for each outcome and with p value <0.01 were included in the multiple linear regression model. The backward selection method was used and the coefficient of determination (r^2) was used to measure the accuracy of the model. Values of p≤0.05 were considered significant for all analyses.

The study was approved by the Research Ethics Committee of the *Hospital das Clínicas* of the Federal University of Goiás (*Universidade Federal de Goiás*), with Approval No. 86.194/12.

RESULTS

Table I depicts the characteristics of the caregivers outlined in the current and in the following paragraphs. Most of the caregivers were women (93 - 97.9%), with age ranging from 19 to 82 years and mean age of 49.7 years (± 13.0) . The analyses also showed that the majority were married (44 - 57.9%) and had eight years of study or less (50 - 52.6%). In all, 61 (64.2%) caregivers had a household income of more than one minimum wage per month. Regarding the degree of kinship to the SAD user, 71 (74.7%) caregivers reported being first-degree relatives or spouses.

A total of 58 (61.1%) participants who were primary caregivers shared this task with other people while 37 (38.9%) were exclusively responsible for the care of the patient. Even so, 66 (69.5%) caregivers spent more than 12 hours a day on this task, and the other 29 (30.5%) spent up to 12 hours. As a result, 92 (98.8%) caregivers reported not performing other work activities besides caring, while 3 (3.2%) had other work activities.

Of the total sample, 80 (84.2%) caregivers reported providing care continuously, without any weekly rest days. In all, 93 (97.9%) caregivers reported informally caring for the patient without receiving any type of remuneration and 2 (2.1%)

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confirmed a formal paid work. The median time caregivers had spent on the care of their relatives was 36 months. The minimum time reported by them was four months and the maximum time was 408 months.

Regarding the health problems reported by caregivers, back problems and anxiety were the most prevalent, with 73 (76.8%) and 64 (67.4%) cases, respectively. Other diseases reported were systemic arterial hypertension (24.2%), depression (23.2%) and diabetes mellitus (10.5%).

Table I - Distribution of the characteristics of the caregivers of the Home Care Service. Goiânia, Goiás, Brazil, 2013 (n=95).

Caregivers' characteristics	n	(%)
Gender		
Women	93	97.9
Men	02	2.1
Age		
<50 years	43	45.3
≥ 50 years	52	54.7
Marital Status		
Single	21	22.1
Married	53	55.8
Widowed	06	6.3
Separated	13	13.7
Other	02	2.1
Years of study		
≤9 years	50	52.6
> 9 years	45	47.4
Household income		
≤ 1 minimum wage	34	35.8
2 to 5 minimum wages	58	61.0
> 5 minimum wages	03	3.2
Degree of kinship		
1 st degree relative or spouse	71	74.7
Other	24	25.3
Previous experience in caregiving		
Yes	15	15.8
No	80	84.2
Caregiving shift		
Only one shift	10	10.5
More than one shift	85	89.5
Health problems		
Yes	82	86.3
No	13	13.7
Total	95	100

The ZBI scores ranged from 1 to 63 points, with a mean score of 33.83 (95%CI 31.00 - 36.66), indicating a moderate burden among caregivers. Table II presents the distribution of caregivers by degree of burden, indicating a higher prevalence of moderate and moderate to severe burden.

Table II - Distribution of caregivers according to the degree of burden in the ZBI (Zarit Burden Interview). Goiânia, Goiás, Brazil, 2013 (n=95).

Burden	Score	n	Prevalence (95%CI)
None	0-20 points	15	15.8 (9.5-24.2)
Moderate	21-40 points	46	48.4 (38.5-58.4)
Moderate to severe	41-60 points	32	33.7 (24.7-43.6)
Severe	61-88 points	2	2.1 (0.4-6.8)
Total	•	95	100.0

Higher ZBI scores were associated with the lack of weekly rest days, back problems and depression (Tables III and IV). The Cronbach's alpha value found for ZBI was 0.85, indicating a good internal consistency of the scale.

Table III - Results of the simple linear regression for factors potentially associated with the ZBI (Zarit Burden Interview) scores of the caregivers of the Home Care Service. Goiânia, Goiás, Brazil, 2013 (n=95).

Caregivers' characteristics	ZBI Mean (SD) of the scores	p-value	
Gender	, ,		
Men	31.0(12.73)	0.758	
Women	34.1(13.9)		
Age			
≤50 years	31.0(14.7)	0.052	
50 years and older	36.5(12.6)		
Married	` '		
Yes	35.7(13.9)	0.168	
No	31.7(13.5)		
Household income	` '		
≤ 1minimum wage	37.5(14.1)	0.067	
> 1 minimum wage	32.1(13.4)		
Education	,		
≤ 8 years	34.5(14.0)	0.513	
> 8 years	33.4(13.8)		
Previous experience	` '		
Yes	31.4(18.0)	0.430	
No	34.5(13.0)		
Shared caregiving	,		
Yes	32.3(14.1)	0.129	
No	36.7(13.1)		
Daily working hours	(,		
Up to 12 hours	30.4(14.1)	0.094	
More than 12 hours	35.6(13.5)		
Rest days	()		
Yes	22.0(10.7)	0.000*	
No	36.3(13.2)		
Has another job	(,		
Yes	33.6(13.8)	0.117	
No	46.3(9.8)		
Time as a caregiver	()		
≤ 36 months	30.9(14.3)	0.034	
36 months and more	36.9(12.8)		
Back problems	,		
Yes	35.5(12.9)	0.062	
No	29.2 (15.8)		
Anxiety	()		
Yes	36.3 (14.1)	0.018*	
No	29.2 (12.1)		
Depression	()		
Yes	42.2 (13.3)	0.001*	
No	31.5 (13.1)		

Table IV - Multivariate analysis of the factors associated with the ZBI^a scores of the caregivers of the Home Care Service. Goiânia, Goiás, Brazil, 2013 (n=95).

Outcomes	Explanatory variables	β	95%CI		p-value*
ZBIb	Lack of rest days	0.29	4.14	17.72	0.002^{*}
	Time as a caregiver	0.16	-0.00	0.07	0.075
	Back problems	-0.18	-11.73	-0.30	0.039^{*}
	Depression	-0.22	-13.00	-1.38	0.016^{*}
	Patient's degree of dependence	0.16	-0.86	13.20	0.085
	Patient's CVA	-0.17	-9.89	0.43	0.075

^a = Zarit Burden Interview; ^b= R² 0.289 adjusted for gender, age, household income, daily working hours, anxiety, patient's age; CVA: cerebrovascular accident; * p≤0.05

DISCUSSION

The data found in the present study corroborate those found by several authors in the literature, which report that caregivers are mainly women, married individuals, first-degree relatives or spouses of the patient undergoing treatment, with a mean age of 50 years⁽¹⁹⁻²¹⁾.

Not having previous experience in caregiving, dedicating more than 12 hours a day to the task of caring, not having weekly rest days and presenting at least one health problem were common characteristics among the majority of the SAD caregivers in the present study. Likewise, studies conducted in Odivelas - Portugal and in Porto Alegre - Brazil also identified caregivers with no prior experience in caregiving^(18,22). The inexperience in caring can lead to problems – such as frequent hospitalization of the individual being cared for – and generate anxiety and greater physical exhaustion in the caregiver⁽²³⁾.

The long hours dedicated to caregiving and the lack of weekly rest days may be due to financial matters, since most caregivers of SAD users have low income and cannot hire a professional to share this task.

The work burden of SAD caregivers was mainly moderate and moderate to severe, which are similar to the burden indicated by other studies that used the same scale^(16,24-26). The work burden is a major problem experienced by the caregiver and is characterized by a decrease in the sense of well-being and occurrence of health problems, with objective and subjective manifestations⁽²⁷⁾.

Most of the caregivers in the present study reported at least one health problem, with back problems being the main complaint. The same has been highlighted by other studies, in which 44.4% and 63.8% of the caregivers, respectively, reported having back disorders^(15,28). Caregiving has adverse effects on physical and emotional health, and the resulting burden can lead to the development of acute and chronic diseases⁽²⁶⁾.

Among the health problems reported by the SAD caregivers, back problems may be related to the use of muscle strength, repetition of movements, prolonged and inadequate static postures, improper handling of the patient and improper furniture. It is known that muscle and postural activities are constantly required in the caregiver's work, both in simple tasks and in tasks considered more difficult, such as assisting in the bath, helping the patient to stand, changing position and assisting in locomotion. In addition to requiring strength, these activities are possibly the main causes of the muscular pain reported by caregivers^(29,30).

Depression was another condition that was associated with increased burden among the SAD caregivers analyzed. Anxiety and depression are highly related and constitute a process of psychological stress, commonly experienced by caregivers, that influence their health status, increase their work burden and decrease their quality of life^(31,32).

As demonstrated in the present study, the continuous exercise of the caregiving task, without rest and leisure days, interferes in the life of caregivers, increasing their burden and generating physical, psychological and social problems. The caregiver's fatigue and exhaustion, added to the symptomatology of those who feel overloaded, can be the result of the uninterrupted dedication and the effort in the caring task. This usually leads the caregiver to disregard their own needs, generating a psychosocial problem⁽¹⁶⁾.

In Brazil, the vast majority of informal caregivers are still without the necessary information and support from the Health System for the promotion of care. Initiatives such as the Better at Home program (*Programa Melhor em Casa*), in which SAD is included, help to change this reality. They are aimed at providing the caregiver with guidance, empowering them and accepting their doubts in an attempt to increase their skills and optimize the care provided to the user.

Some limitations of the present study should be considered, such as the fact that it was carried out in a specific service with a reduced sample, which restricts the generalization of the findings. Because it is a cross-sectional study, there is the possibility of memory bias and limited conclusions about the direction or causality of the associations observed.

It is important to raise health professionals' awareness – at all levels of care – of the repercussions of providing care to the caregiver so as to identify situations of exposure to risk factors early and to collaborate in the planning of actions to promote the care of this specific public in order to improve the quality of life of the caregiver and decrease the impact of care on their health.

CONCLUSION

The caregivers present moderate burden related to the task of caring and the main factors associated with it are the lack of weekly rest days, back problems, and depression.

The findings draw attention to the situation in which caregivers are found and pose challenges to professionals working in home care and to the service managers.

CONFLICTS OF INTEREST

The authors of the present study have no conflicts of interest to declare.

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