

ORIGINAL ARTICLE

FACTORS RELATED TO BURDEN AND SELF-CARE FOR HYPERTENSION IN FAMILY CAREGIVERS

HIGHLIGHTS

1. Work overload is related to damage to the caregiver's self-care.
2. Caregivers in this study had inadequate self-care.
3. Living with the elderly and caring for them continuously is related to greater overload.
4. Building health strategies that favor the needs of the caregiver.

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ABSTRACT

Objective: To identify factors related to burden and self-care for hypertension in family caregivers. **Method:** an online, cross-sectional survey of 68 family caregivers of elderly people, carried out between December 2021 and February 2022 in Brazil. Questionnaires on caregiver activity, the Informal Caregiver Burden Assessment Questionnaire and the Hypertension Self-Care Scale were applied. Descriptive and analytical analyses were carried out. **Results:** caregivers who lived with the elderly ($p=0.0006$) and had no rest day ($p=0.0097$) showed greater burden. The longer the time as a caregiver ($p=0.0411$), the lower the score in the domain of self-care management measures during blood pressure decompensation. Caregivers who received help from someone else ($p=0.0379$) had a higher score in the domain of the patient's degree of confidence in self-care related to hypertension. **Conclusion:** This study contributes to a better understanding of the variables relating to caregiver activity related to burden and self-care for hypertension among caregivers of elderly people.

DESCRIPTORS: Caregivers; Hypertension; Elderly; Geriatric Nursing; Burnout, Professional.

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INTRODUCTION

According to the World Health Organization (WHO), the number of people aged over 60 in 2015 was 900 million, a figure that will reach two billion by 2050, with 434 million aged 80 or over¹. In Brazil, the fifth-largest elderly population in the world, there are around 28 million people aged 60 or over. It is estimated that, by 2030, this number will exceed that of children aged 0 to 14².

In recent decades, improvements in the quality of health care and the consequent increase in life expectancy have been associated with an increase in the elderly population and a reduction in late-life mortality. However, there has been an increase in multimorbidity due to the morphophysiological changes resulting from the aging process, with an increase in the prevalence of chronic diseases, which can contribute to causing or worsening the state of dependence of the elderly and imply a greater demand for long-term care³.

In 1999, the National Health Policy for the Elderly (PNSI, in Portuguese) defined a caregiver as a person who provides care for the elderly, sick or dependent in carrying out their daily activities⁴. In Brazil, the number of family members dedicated to caring for the elderly jumped from 3.7 million in 2016 to 5.1 million in 2019, according to the Continuous National Household Sample Survey (PNAD-C 2019)¹⁹.

Family caregivers generally help the elderly person and have various responsibilities, such as supervision, medication administration, mobilization, hygiene and psychological support³. The result of the caregiver's duties can generate stressful events, suffering and damage to their well-being and self-care. The burden of caring can include physical, psychological, and financial difficulties⁶.

Overload is defined as the effect of the individual's transformations in relation to the family, originating in the subsequent need for care and supervision⁷. When caring for elderly people, many caregivers experience restrictions in their personal and professional lives, with a reduction in leisure activities and a deficit in self-care, due to lack of time or motivation. This process can cause wear and tear, compromising the quality of care provided, family relationships and self-care⁷.

Self-care in health refers to the activities that individuals, families and society carry out to promote health, prevent disease, reduce health problems, and restore health⁸.

According to the WHO, hypertension affects 20-40% of the adult population and is one of the most prevalent public health problems, mainly due to the complexity of the resources needed to control it and the impact on the population's health⁹. It is considered one of the major risk factors for the development of cardiovascular and cerebrovascular diseases, which are important causes of morbidity and mortality, as well as having a high social cost. Despite the risks presented by hypertension, adherence to drug and non-drug therapy is inefficient, posing a challenge to health services and public policies, since most hypertensive patients do not keep their blood pressure under control due to low adherence to treatment¹⁰.

In Brazil, however, the relationship between burden and the domains of self-care for hypertension, with variables relating to the caregiver's sociodemographic and clinical activity, has not been fully clarified. Knowing this relationship could support the planning of multidisciplinary interventions aimed at controlling hypertension, avoiding health problems for the caregiver, and contributing to the continuity of care for the elderly.

The objective of this study was to identify factors related to burden and self-care for hypertension in family caregivers.

METHOD

Quantitative, online, cross-sectional survey. The Google Forms® tool was used to create online instruments, distributed through a public call via a link on social media (WhatsApp®, Facebook® and Instagram®). The process used to select the caregivers included in the sample was by convenience, during the data collection period from December 2021 to February 2022, thus composing the final sample of 68 hypertensive family caregivers. The Strengthening the Reporting of Observational studies in Epidemiology statement (STROBE)¹¹ recommendations were used.

Family members of the elderly people they were caring for were included if they had a diagnosis of hypertension and were taking antihypertensive medication, and if they had been working as caregivers for at least three months, which was considered an appropriate time to incorporate the guidelines and practice caregiving¹². Family caregivers who received remuneration for their caregiving activities and who were under the age of 18 were excluded.

A graduate student in nursing disseminated the instruments online via a public call via a link on social media (WhatsApp®, Facebook® and Instagram®), without the need to identify the study participants. When accessing the link, the caregiver would access the Free and Informed Consent Form; if accepted, they would be directed to answer the online survey.

The instruments used were structured forms with the variables age, gender, schooling, marital status, occupation, income, comorbidities, and medication, and on caregiver activity (hours per day dedicated to care, whether they are the sole caregiver, whether they live with the elderly person, whether they share care with other people and whether they feel overburdened). The Hypertension Self-Care Scale assessed self-care capacity for hypertension. The scale has 23 items, which analyze the self-care of people with hypertension in the domains of maintenance (section A), self-care management (section B) and confidence (section C). The answers were given using a Likert scale, and the scores were calculated individually between the domains. The basis of the calculation was the sum of the questions in the section, subtracting the total number of questions in the section multiplied by the constant, where for section A, the sum was (-11×3.03) , for section B, the sum was (-6×5.55) , and for section C, the sum was (-6×5.55) . In the self-care management domain (section B), there are two questions that are scored from 0 to 4; if the participant answers the equivalent of "0" in one or two of them, a total of five or four questions from this domain should be used, respectively. Self-care is considered adequate with scores equal to or greater than 70¹³⁻¹⁵.

Caregiver overload was assessed using the Informal Caregiver Overload Assessment Questionnaire (QASCI, in Portuguese), made up of 32 items covering seven domains (emotional overload; implications for personal life; financial overload; reactions to demands; perception of efficacy and control mechanisms; family support; and satisfaction with the role and the family member). The answers range from one to five (1= never; 2= rarely; 3= sometimes; 4= almost always; and 5= always). The total score ranges from 32 to 160 points. The higher the score, the greater the burden. To obtain the score, it is necessary to invert the values of the last three domains, as they are positive dimensions¹⁵. To check overload, a normative analysis of the QASCI was carried out: 0 points = no overload; 1 to 25 points = slight overload; 26 to 50 points = moderate overload; 51 to 75 points = severe overload; and >75 points = extremely severe overload¹⁶.

All the variables were stored in Microsoft Office Excel® 2016 spreadsheets for later statistical analysis. Descriptive analysis was used for categorical variables in terms of frequency and percentage. Mean, standard deviation, minimum, median, and maximum were used for continuous variables. The t-test (two categories) and ANOVA (three or more categories) were used to compare QASCI domain scores with categorical variables. If the

assumptions for the tests were not met, the Mann-Whitney test (two categories) and the Kruskal-Wallis test (three or more categories) were used.

Spearman's correlation coefficient was used to compare the scores of the QASCI domains with continuous variables. To compare the scores of the domains of the Hypertension Self-Care Scale with categorical variables, the t-test (two categories) and ANOVA (three or more categories) were used. If the assumptions for the tests were not met, the Mann-Whitney test (two categories) and the Kruskal-Wallis test (three or more categories) were used. Spearman's correlation coefficient was used to compare the scores of the domains of the Hypertension Self-Care Scale with continuous variables. Spearman's correlation coefficient was used to verify the relationship between the scores of the QASCI domains and the scores of the Hypertension Self-Care Scale domains with categorical variables. A significance level of 5% (p -value < 0.05) was used in all comparative analyses.

This study was approved by the Research Ethics Committee of the Federal University of São Paulo (UNIFESP), under Report No. 4.600.957. All participants had their names expressed by numbers and coded by acronym.

RESULTS

The sample consisted of 68 caregivers: mean age 52.72 years (SD=11.41); mean years of schooling 14.13 years (SD=3.98); caregiver activity performed for an average of 4.78 years (SD=5.42); time dedicated to care from 4 to 24 hours a day; female (n=58; 85.3%); lived with the elderly (n=44; 64.7%); mostly daughter or son (42; 61.8%); elderly people receiving care with a diagnosis of dementia (n=40; 58.8%); care provided daily (n=42; 61.8%); married caregivers (n=34; 50%); and retired or pensioners (n=21; 30.9%).

In the Hypertension Self-Care Scale (n=68 caregivers), only the self-care maintenance domain referring to routine care showed inadequate self-care (Table 1).

Table 1 - Scores of the domains of the hypertension self-care scale in caregivers of elderly people - São Paulo, SP, Brazil, 2022

Domains of the Hypertension Self-Care Scale	Mean (standard deviation)
Maintenance of self-care in relation to routine care	69.07 (14.05)
Self-care management measures during pressure decompensation	73.04 (17.95)
Patient's level of confidence regarding their condition	87.06 (13.80)

Source: The authors (2022).

Table 2 shows that the caregivers (n=68) presented extremely severe overload according to the QASCI total score, and the domain of implications for personal life indicated moderate overload.

Table 2 - Scores of the domains of the Informal Caregiver Overload Assessment Questionnaire

in caregivers of elderly people - São Paulo, SP, Brazil, 2022

Informal Caregiver Overload Assessment Questionnaire	Mean (standard deviation)
Total score	83.75 (28.97)
Emotional overload	11.79 (4.47)
Implications for personal life	31.43 (13.38)
Financial burden	5.50 (3.02)
Reactions to demands	11.62 (4.67)
Efficacy and control mechanism	6.84 (2.78)
Family support	5.94 (2.88)
Satisfaction with role and family members	10.68 (5.29)

Source: The authors (2022).

In Table 3, caregivers (n=68) who did not feel overburdened had a higher score in the patient confidence domain regarding their hypertensive condition, compared to those who felt very overburdened. Caregivers who were helped by someone else had a higher score in the domain of the patient's level of confidence regarding their hypertensive status, compared to those who were not helped. The longer the care provided, the lower the score in the domain of self-care management measures during pressure decompensation.

Table 3 - Association between the domains of the Hypertension Self-Care Scale and the variables related to the activity of caregiver of elderly people - São Paulo, SP, Brazil, 2022

Variables	Domains of the Hypertension Self-Care Scale		
	Maintenance of self-care, care routine - mean (standard deviation)	Self-care management measures during pressure decompensation - mean (standard deviation)	Patient's level of confidence regarding their condition - mean (standard deviation)
How do you feel being a caregiver?			
Very overwhelmed	64.71 (15.31)	68.62 (16.96)	82.76 (14.94)
Overloaded	71.37 (10.98)	75.69 (15.93)	91.18 (9.35)
Very little/not at all overloaded	67.78 (15.05)	69.26 (20.80)	79.63 (17.28)
I don't feel overloaded	76.67 (11.26)	82.05 (18.59)	96.41 (4.80)
p-value	0.0645 [†]	0.0937 [†]	0.0065 [‡]
Do you receive help from someone else for your care?			
Yes	69.67 (15.39)	76.33 (14.67)	92.67 (9.28)
No	68.82 (13.62)	71.67 (19.13)	84.72 (14.76)

p-value	0.8227 [§]	0.4743 ^{††}	0.0379 ^{††}
How long have you been a caregiver? (years)			
	R ^{††}	-0.12	-0.25
p-value	0.3330	0.0411	0.8952

†Kruskal-Wallis test; †ANOVA; §T test; ††Mann-Whitney test; ††Spearman correlation coefficient.

Source: The authors (2022).

Caregivers (n=68) without weekly rest scored higher on the QASCI in the domains of implications for personal life and satisfaction with the role and with the family member. Caregivers who provided daily care scored higher on the QASCI in the domain of implications for personal life than those who provided care for one to three days. Those who lived with the elderly had higher QASCI scores in the domains of personal life implications, financial burden and reactions to demands (Table 4).

Table 4 - Association between the domains of the Informal Caregiver Burden Assessment Questionnaire and the variables related to caregiver activity for the elderly - São Paulo, SP, Brazil, 2022

Informal Caregiver Overload Assessment Questionnaire	Have a rest day in the week		Days of the week you take care of			Lives with the elderly person	
	Yes	No	From 1 to 3 days	From 3 to 4 days	Every day	Yes	No
Mean	72.0 (21.5)	90.5 (30.7)	63.8 (24.2)	75.3 (25.5)	91.7 (28.5)	92.3 (28.5)	68.0 (22.7)
(standard deviation)	0.0097 [†]		0.0079 [§]			0.0006 [†]	
p-value							
Emotional overload	11.0 (3.5)	12.2 (4.9)	10.4 (4.9)	10.8 (3.9)	12.5 (4.5)	12.5 (4.3)	10.4 (4.4)
Mean	0.3192 [†]			0.0687 [†]			
Implications for personal life							
Mean	25.0 (10.5)	35.1 (13.5)	20.3 (9.5)	26.9 (12.5)	35.7 (12.5)	36.4 (12.0)	22.2 (10.5)
(standard deviation)	0.0041 [†]		0.0019 ^{††}			<0.0001 [†]	
p-value							
Financial burden	4.8 (2.1)	5.9 (3.3)	4.2 (2.7)	4.6 (2.0)	6.1 (3.2)	6.3 (3.0)	3.9 (2.2)
Mean	0.2515 [†]		0.1419 ^{††}			0.0026 [†]	
(standard deviation)							
p-value	10.3 (3.3)	12.3 (5.0)	10.0 (3.5)	10.5 (5.2)	12.4 (4.5)	12.5 (5.0)	9.8 (3.3)
Reactions to demands	0.1565 [†]		0.1455 ^{††}			0.0222 [†]	

Efficiency and control mechanism							
Mean	6.2 (1.9)	7.1 (3.1)	5.4 (1.2)	6.6 (3.0)	7.2 (2.8)	7.1 (2.7)	6.2 (2.8)
(standard deviation)	0.3757 [‡]		0.1158 ^{††}		0.0910 [‡]		
p-value							
Family support	5.6 (2.7)	6.1 (2.9)	4.7 (3.0)	6.5 (3.0)	6.0 (2.7)	6.1 (2.9)	5.5 (2.8)
Mean	0.5118 [‡]		0.2750 ^{††}		0.4754 [‡]		
(standard deviation)							
p-value	8.8 (3.6)	11.7 (5.8)	8.8 (4.0)	9.1 (5.7)	11.6 (5.2)	11.1 (5.3)	9.7 (5.1)
Satisfaction with role and family members	0.0372 [‡]		0.0556 ^{††}		0.1716 [‡]		

T-test; [‡]Mann-Whitney test; [§]ANOVA; ^{††}Kruskal-Wallis test.

Source: The authors (2022).

With regard to the caregivers in Table 5 (n=68), the higher the total score on the QASCI and the domains emotional overload, implications in personal life and reactions to demands, the lower the score in the domain maintenance of self-care, care routine of the Hypertension Self-Care Scale. The higher the total score of the QASCI and in the domains of implications for personal life and family support, the lower the score in the domain of self-care management measures during pressure decompensation of the Hypertension Self-Care Scale. The higher the total score on the QASCI and in the domains of implications for personal life and financial burden, the lower the score in the domain of the patient's level of confidence regarding their condition on the Hypertension Self-Care Scale.

Table 5 - Correlation between the domains of the Hypertension Self-Care Scale and the domains of the Informal Caregiver Burden Assessment Questionnaire. São Paulo, SP, Brazil, 2022

Informal Caregiver Overload Assessment Questionnaire	Hypertension Self-Care Scale			
		Maintenance of self-care, care routine	Self-care management measures during blood pressure decompensation	Patient's level of confidence in their condition
Emotional overload	R [†]	-0.26	-0.17	-0.21
	p-value	0.0321	0.1786	0.0824
Implications for personal life	R [†]	-0.33	-0.30	-0.32
	p-value	0.0060	0.0138	0.0071
Financial burden	R [†]	-0.10	-0.14	-0.28
	p-value	0.4057	0.2562	0.0190
Reactions to demands	R [†]	-0.31	-0.17	-0.08
	p-value	0.0114	0.1635	0.5101

Efficacy and control mechanism	R [†]	-0.16	-0.08	-0.14
	p-value	0.1919	0.5091	0.2413
Family support	R [†]	-0.15	-0.34	-0.22
	p-value	0.2094	0.0047	0.0686
Satisfaction with role and family members	R [†]	-0.17	-0.23	-0.14
	p-value	0.1741	0.0635	0.2643
Total score	R [†]	-0.26	-0.28	-0.28
	p-value	0.0294	0.0203	0.0230

†R= Pearson's correlation coefficient

Source: The authors (2022).

DISCUSSION

In this study, most hypertensive caregivers of the elderly were female, daughters or sons, married, retired or on a pension. In addition, most of them lived with the elderly person and provided care daily. These data corroborate a study carried out in Teresina, which assessed anxiety and depression in informal caregivers of dependent elderly people. Despite all the social changes and the new roles taken on by women, women are still expected to take on care duties in general¹⁷.

The caregivers in this study had inadequate self-care in the domain of maintaining self-care in relation to the care routine. Non-adherence to drug and non-drug therapy can lead to uncontrolled blood pressure, increased risk of complications and mortality in hypertensive individuals¹⁸.

The sample studied showed that the longer the caregiver had been providing care, the lower the score in the domain of self-care management measures during blood pressure decompensation. It is known that hypertension is associated with an increased risk of acute myocardial infarction, heart failure, peripheral arterial disease, stroke and chronic kidney disease. This association contributes to hypertension being one of the main causes of reduced quality of life and life expectancy, associated with premature death and disability¹⁹.

Caregivers who did not feel overburdened had a higher score in the domain of the patient's level of confidence in their condition. As the dependency of elderly people increases, care becomes more exhausting and stressful, with probable restrictions on their routine, generating overload. Overload can contribute to family caregivers neglecting self-care for their health due to the caregiving task²⁰. This may explain why the most overburdened caregivers in this study were less confident about their health.

Caregivers who received help from someone else in their care had a higher score in the domain of the patient's level of confidence in their condition. It is well known that the activity of caring is commonly taken on by family members and often carried out by just one member of the family, who accumulates, along with this new role, other functions that they already carried out. Therefore, informal, or formal support is essential so that the caregiver doesn't feel overwhelmed, can take care of their physical and mental health, and organize their personal life²¹.

Overload is significantly associated with being female, having a low level of education, living with the patient, spending long hours caring for them, being depressed, living in social isolation, and having financial restrictions²². Similar characteristics were found in this study. Caregivers who lived with the elderly person, who provided care every day of the week, without rest, had a higher total score on the QASCI and in the domains of implications for personal life, financial burden, reactions to demands, satisfaction with the role and with the

family member, when compared to those who did not.

Caregiver burden is associated with immune dysregulation, coronary artery disease and increased all-cause mortality²³. Caregivers often provide long-term care for loved ones in their roles as spouses, partners, and children. Conflicts between professional career, caregiving responsibilities and family needs contribute to the caregiver's feeling of greater burden.

Family, community, and social support is an important aspect in preventing or reducing this burden. Therefore, the caregiver's burden needs to be understood so that health professionals can identify the caregiver's needs, difficulties, and health conditions, enabling them to care efficiently, without harming their physical and mental health²².

This study found that the higher the total score of the QASCI and its domains emotional overload, implications for personal life and reactions to demands, the lower the score in the domain maintenance of self-care, care routine of the Hypertension Self-Care Scale. These results are in line with what is already well established in the literature in relation to informal caregivers who have a high risk of developing burnout and exhaustion, as care tasks are stressful with other duties²⁴. Caregivers who are more overburdened have less time to maintain their own health and well-being, which can be associated with worse health outcomes.

Poor adherence to antihypertensive medication is a critical component of hypertension self-care. Difficulty with medication adherence is often multifactorial, as the cost of medication, access to care and health beliefs about the safety and efficacy of medication and health literacy are associated with adherence. In addition to these factors, caregivers who experience a high level of burden with varied responsibilities may not prioritize medication adherence, especially if medications need to be taken at certain times of the day or if a regimen is complex²⁵.

They may also be less likely to prioritize attending their own medical appointments, and therefore opportunities to reinforce the need to adhere to medication may be missed²⁵. Another important aspect to highlight is that family caregivers, due to the difficulty of sharing the care of elderly people with other relatives, give up professional and existential projects. This abdication is often accompanied by negative impacts on the financial lives of these caregivers²⁶.

Public policies are still precarious, and many caregivers find themselves alone when carrying out this role, feeling helpless in the face of daily challenges. Family caregivers need psychological support and social support to find the conditions to build strategies that favor their quality of life²⁷.

This study had some limitations, such as the fact that caregiver burden can vary between caregivers who care for patients with different diseases or at different stages, the technique for data collection (online), since many family caregivers are also elderly people; therefore, they might have greater difficulty in this type of data collection (answering an electronic form, difficulty understanding questions, among others), and the sample of caregivers in this research was small, which does not allow the data to be generalized.

CONCLUSION

Hypertensive caregivers had inadequate self-care on the Hypertension Self-Care Scale. The self-care maintenance domain, referring to the care routine, indicated extremely severe overload, and the personal life implications domain showed moderate overload. The longer the caregiver had been providing care, the lower the score in the domain of self-care management measures during pressure decompensation. Those who did not receive

help from another person to provide care had a lower score in the domain of the patient's level of confidence in their condition.

The variables relating to the activity of caregiver that were related to impaired hypertension self-care were longer time as a caregiver, feeling overwhelmed and not having the help of another person for care. The variables relating to the activity of caregiver that were related to the burden of the informal caregiver of the elderly were caring every day of the week, living with the elderly person, and feeling overwhelmed.

This study made it possible to assess family caregiver burden using the QASCI and the Hypertension Self-Care Scale. The results indicated that the burden of caring has a negative impact on the emotional, physical, financial, and social well-being of the caregiver.

However, this study has contributed to a better understanding of the variables related to caregiver activity that are associated with burden and self-care for hypertension among caregivers of elderly people. Considering the aging population and the growing need for caregivers of elderly people, it is necessary to identify the work demands, difficulties and health conditions of caregivers to develop health strategies that address the needs of this population.

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