

ORIGINAL ARTICLE

BURDEN OF CAREGIVERS OF PATIENTS UNDER HOME CARE*
SOBRECARGA DO CUIDADOR DE PACIENTES ATENDIDOS NA ATENÇÃO DOMICILIAR
SOBRECARGA DEL CUIDADOR DE PACIENTES TRATADOS EN ATENCIÓN DOMICILIARIA

Monique Évellin Alves Cruz¹, Daniel Vinícius Alves Silva², Júlia Rocha do Carmo³, Gabriel Dias de Araújo⁴, Luiza Rodrigues Camisasca⁵, Fabíola Afonso Fagundes Pereira⁶, Ricardo Otávio Maia Gusmão⁷, Diego Dias de Araújo⁸

ABSTRACT

Objective: to assess the burden of caregivers of patients treated by a public home care program. **Method:** this is a quantitative, descriptive, cross-sectional study, with 127 caregivers of patients treated by the Melhor em Casa Program. Sociodemographic and clinical data were collected, and the reduced Zarit Burden Interview Scale and the Beck Hopelessness Scale were also applied. Descriptive and bivariate data analyses were performed. **Results:** of the 127 caregivers, the majority was female (114=89.8%), pardos (81=63.8%); composed of unmarried (56=44.1%) and the mean age was 46.66 years. Importantly, 38.6% (49) had moderate to severe burden, 78.7% (110) stated the occurrence of changes in their daily routine, 59.8% (76) mentioned having suffered some change in emotional state after starting the care with the patients and 56.7% (72) have body ache. The bivariate analysis confirmed the statistical significance of 15 independent variables. **Conclusion:** the burden of caregivers of homebound patients is a common finding, requiring care actions for its prevention. **Descriptors:** Caregivers; Burnout, Psychological; Home Care Services; Home Nursing; Homebound Persons; Nursing.

RESUMO

Objetivo: avaliar a sobrecarga de cuidadores de pacientes atendidos por um programa de atenção domiciliar público. **Método:** trata-se de um estudo quantitativo, descritivo, transversal, com 127 cuidadores de pacientes atendidos pelo Programa Melhor em Casa. Coletaram-se dados sociodemográficos e clínicos e aplicaram-se também a Escala *Zarit Burden Interview* reduzida e a Escala de Desesperança de Beck. Realizou-se análise descritiva e bivariada de dados. **Resultados:** verificou-se que, dos 127 cuidadores, a maioria era do sexo feminino (114=89,8%), de cor parda (81=63,8%); composta por solteiros (56=44,1%) e a média de idade foi de 46,66 anos. Destaca-se que 38,6% (49) apresentaram sobrecarga de moderada a grave, 78,7% (110) afirmaram que houve mudanças em sua rotina diária, 59,8% (76) dizem ter sofrido alguma mudança no estado emocional após iniciar o cuidado do paciente e 56,7% (72) sentem dores no corpo. Confirmaram-se, na análise bivariada, 15 variáveis independentes que obtiveram significância estatística. **Conclusão:** conclui-se que a sobrecarga do cuidador de pacientes da atenção domiciliar é um achado comum e cuidados para a sua prevenção devem ser estabelecidos. **Descritores:** Cuidadores; Esgotamento Psicológico; Serviços de Assistência Domiciliar; Assistência Domiciliar; Pacientes Domiciliares; Enfermagem.

RESUMEN

Objetivo: evaluar la sobrecarga de los cuidadores de pacientes tratados mediante un programa de atención domiciliar público. **Método:** se trata de un estudio cuantitativo, descriptivo, transversal, con 127 cuidadores de pacientes tratados por el Programa Melhor em Casa. Recogieron datos sociodemográficos y clínicos y se aplicaron la escala *Zarit Burden Interview* reducida y la Escala de Desesperanza de Beck. Se realizó el análisis descriptivo y bivariado de los datos. **Resultados:** se constató que, de 127 cuidadores, la mayoría eran mujeres (114=89,8%), pardos (81=63,8%); compuesto de solteros (56=44,1%) y el promedio de edad fue de 46.66 años. Cabe destacar que el 38,6% (49) presentó sobrecarga moderada a severa, el 78,7% (110) declaró que ha habido cambios en su rutina diaria, el 59,8% (76) afirmó tener sufrido algún cambio en el estado emocional después de iniciar los cuidados del paciente, y el 56,7% (72) siente dolor en el cuerpo. Se confirman, en el análisis bivariado, 15 variables independientes que tuvieron significación estadística. **Conclusión:** se concluye que la sobrecarga de los cuidadores de pacientes en atención domiciliar es un hallazgo común y cuidados en su prevención deben ser establecidos. **Descritores:** Cuidadores; Agotamiento Psicológico; Servicios de Atención de Salud a Domicilio; Atención Domiciliar de Salud; Personas Imposibilitadas; Enfermería.

¹Public Health School of Florianópolis/ESP-FLORIPA. Florianópolis (SC), Brazil.  <https://orcid.org/0000-0002-7502-2744> ²Hospital Santa Casa de Montes Claros/SCMOC. Montes Claros (MG), Brasil. ³ <https://orcid.org/0000-0001-9280-9146> ^{3,5,6,7,8}State University of Montes Claros/UNIMONTES. Montes Claros (MG), Brazil. ⁴ <https://orcid.org/0000-0002-2144-8002> ⁵ <https://orcid.org/0000-0002-2185-7973> ⁶ <http://orcid.org/0000-0003-1804-619X> ⁷ <https://orcid.org/0000-0001-9941-1114> ⁸ <https://orcid.org/0000-0002-8927-6163> ⁴School of Odonatological Sciences. Montes Claros (MG), Brazil. ⁴ <https://orcid.org/0000-0003-0525-3085>

*Article extracted from the Course Completion Work << Assessment of indicators sensible to nursing practice in a home health care program >>. State University of Montes Claros/UNIMONTES. 2018

How to cite this article

Cruz MEA, Silva DVA, Carmo JR do, Araújo GD de, Camisasca LR, Pereira FAF, *et al.* Burden of caregivers of patients under home care. J Nurs UFPE on line. 2020;14:e244235 DOI: <https://doi.org/10.5205/1981-8963.2020.244235>

INTRODUCTION

Due to changes in the morbidity and mortality and fertility, Brazil has been undergoing, in recent decades, demographic and epidemiological transitions, whose consequence is the population aging, greater longevity, increased prevalence of chronic non-communicable diseases, hospitalizations and reduction or loss of functional capacity.¹⁻⁴

In this context, there is need to develop new health care strategies to ensure continuity of care processes for the population. Therefore, there arises the Home Care (HC) assistance modality, whose purpose is to rearrange the healthcare, ensuring an ongoing assistance contextualized to the user's reality, when providing the care at the client's home.⁵⁻⁶

Representing a milestone and a commitment that the HC is a priority, in November 2011, the Brazilian Federal Government launched the Program *Melhor em Casa* (PMC), which reaffirmed the HC as a strategy of technological incorporation of substitutive character to the low- and mid-complexity hospital intervention to the care initiated in the services of urgency and emergency and complementary to the primary care.⁷⁻⁹

In the HC context, the caregiver is an important figure, who can be defined as the person providing the care directly, continuously and/or regularly, at home, and may or may not be someone from the family, with or without remuneration. The caregiver has the following responsibilities: assist in body care; nutrition; mobility; change of decubitus, and comfort; serve as a link between the user, family and healthcare team; administer prescribed medications; give psychological support and communicate complications to the health team.¹⁰

The experiences as a caregiver vary between positive and negative aspects. The main positive aspects are the feelings of affection, solidarity, gratification, appreciation of his/her actions, commitment and well-being. As negative aspects, the abandonment of the work, difficulties in the affective life and social activities such as leisure, in addition to changes in the health-disease process. Those points minimize and maximize the caregiver's feeling of burden.¹¹⁻³

The caregiver's burden consists of a disturbance resulting from work in dealing with the physical or mental dependency of the person who needs care and attention.¹⁴⁻⁵ Furthermore, there is also the set of mental, physical and socioeconomic problems that affect the emotional balance, social relationships and daily activities of the caregivers.¹⁶

A previous study on caregivers' burden held in homes in the municipality of Manoel Vitorino-BA evidenced the mean score in the Zarit Scale of 47

points (moderate burden).¹⁷ Another study, also developed from the Zarit Scale with caregivers in the homes of users registered in a HC service in the municipality of Goiânia-GO, obtained a prevalence of 48.4% of moderate burden.¹⁶

Therefore, the caregiver's burden is a frequent event. The evaluation of the caregiver's burden grade through instruments enables health professionals to determine how the care task affects the lives of those individuals, assisting them in developing strategies for coping with the situation.¹⁸⁻⁹

Moreover, the nurse can play a vital role in the identification of burden and complicating factors in the caregiver's work, and thus, plan and implement actions to prevent or minimize that problem. Furthermore, there is a limitation of studies in the literature that specifically address the issue of the burden of caregivers of users linked to HC public services.

OBJECTIVE

- To assess the burden of caregivers of patients treated through a public home care program.

METHOD

This is a quantitative, descriptive, cross-sectional study, performed with caregivers of patients treated by the PMC in a city in northern Minas Gerais, Brazil, in the period from June 2017 to January 2018.

The municipality is enabled, by the Ministry of Health, since December 2013, to perform the PMC. This HC service is composed of multidisciplinary teams that aim to support the families of users of the Unified Health System (UHS). It offers home treatment for patients with motor rehabilitation needs, chronic diseases without worsening or in postoperative situation and with possibility of de-hospitalization.

This study included caregivers who met the following inclusion criteria: age greater than or equal to 18 years; taking care of patients registered and assisted by the PMC and consenting to participate in the study by signing the Informed Consent Form (ICF). Caregivers not found in the household in up to three attempts were excluded.

In the data collection period, 131 caregivers were identified. Of this population, four were excluded by not accepting to participate in the study. Therefore, after the application of inclusion and exclusion criteria, the final sample consisted of 127 caregivers.

A graduate student performed the data collection, from the seventh term of the Nursing course of a public university in Minas Gerais, duly qualified and under the supervision of the advising professor. Data collection used an adapted and systemized instrument containing variables of

socioeconomic and clinical characterization, namely: name; age; sex; color; marital status; profession; economic classification; characteristics of the street of residence; schooling; time as caregiver; hours daily used with the patient; formal or informal caregiver; degree of kinship in relation to the patient; housing arrangement; medical diagnosis; change in daily routine; altered leisure and social activities; burnout and tiredness; changes in the house routine; jeopardized attention to other family members; emotional state; body ache; fail to enjoy vacation; receives fewer people at home; works less or quit the job and retired earlier.

The reduced Zarit Burden Interview Scale (ZBI)²⁰ and the Beck Hopelessness Scale were also applied.²¹ The reduced ZBI scale score varies between 14 and 22 points, interpreted in the following way: mild burden, up to 14 points; moderate burden, from 15 to 21 points, and severe burden, above 22 points. The Beck Hopelessness Scale score varies from zero to 35 points, in the following way: minimum depression level, zero to 11 points; mild depression level, 12 to 19 points, and moderate depression level, 20 to 35 points.

The dependent variable of the study was the caregiver's burden (score on the scale of reduced ZBI \geq 15 points); the independent variables were divided into the caregiver's characterization and

clinical data. The data were analyzed after double entry in the program Statistical Package for Social Sciences (SPSS), version 20.0, checking their consistency. Subsequently, the descriptive analysis (simple frequency and percentages) was performed. The prevalence was established considering the number of caregivers who reported the outcome to be identified during the data collection period. Bivariate analysis was used for the studied variables, in order to evaluate the association with the caregiver's burden, from the chi-square test and Fisher's exact test.

The study is in accordance with Resolution n. 466/2012, which regulates researches with human beings. The project was previously sent to the Research Ethics Committee (REC) of the State University of Montes Claros and obtained a favorable opinion under the number 1.866.616 and CAAE 62123716.3.0000.5146.

RESULTS

Of the 127 caregivers, the majority was female (114=89.8%), with ages between 18 and 82 years. The average age was 46.66 years, median 48 years and standard deviation of 16.43 years; higher prevalence of *pardo* color (81=63.8%) and unmarried (56=44.1%) (Table 1).

Table 1. Sociodemographic and clinical profile of the caregivers. Montes Claros (MG), Brazil, 2017-2018

Variables	n	%
Sex		
Female	114	89.8
Male	13	10.2
Marital status		
Unmarried	56	44.1
Stable union	1	0.8
Married	50	39.4
Divorced	11	8.7
Widow(er)	9	7.1
Self-reported color		
White	21	16.5
<i>Pardo</i>	81	63.8
Black	24	18.9
Other	1	0.8
Family income		
Up to 1 minimum wage	37	29.1
1 - 3 minimum wages	83	65.4
3 - 5 minimum wages	6	4.7
Over 5 minimum wages	1	0.8
Medical diagnoses		
Vascular disease	39	30.7
Metabolic disease	16	12.6
Musculoskeletal disease	16	12.6
Other uncategorized diseases	9	7.1

In relation to the caregiver's burden, table 2 shows that the burden was moderate to severe in 38.6% (49) of the caregivers. In turn, regarding the

depression level, 40.2% (51) of the caregivers had mild to moderate depression.

Table 2. Prevalence of caregiver's burden and hopelessness identified by the reduced Zarit Scale and Beck's Hopelessness Scale. Montes Claros (MG), Brazil, 2017-2018.

Variables	n	%
Zarit Scale		
Mild burden	78	61.4
Moderate burden	25	19.7
Severe burden	24	18.9
Beck Hopelessness Scale		
Minimum depression level	76	59.8
Mild depression level	33	26
Moderate depression level	18	14.2

Most caregivers was composed of sons/daughters (36=28.3%), informal caregivers (96=75.5%), with time as caregiver ranging between one and 384 months, the mean time was 50.56 months and median of 18 months. The time used for the daily care with the patient ranged between one and 24 daily hours, the average was 16.20 hours and median of 16 hours. Concerning the housing arrangement, 18.9% (24) of the caregivers live only with the patient, 11% (14), with the spouse and 67.7% (86), with other arrangements.

For the variables related to the care act, 78.7% (110) of the caregivers stated the occurrence of changes in their daily routine and 70.9% (90) mentioned altered house routine; 59.8% (76)

reported having suffered some change in emotional state after initiating the care with the patient, 56.7% (72) have body ache and 63.8% (81) feel burnout or tiredness. Leisure and social activities also changed to 66.1% (84), 38.6% (49), because they no longer go on vacation, and 42.5% (54) work less or quit the formal employment.

Table 3 presents the association between sociodemographic and clinical characteristics of caregivers of patients treated by a home care program in northern Minas Gerais with the caregiver's burden evaluated by the reduced Zarit Scale.

Table 3. Association between the dependent variable, caregiver's burden and independent variables of caregivers of patients treated by a home care program. Montes Claros (MG), Brazil, 2017-2018.

Characteristics	Group	Caregiver's burden				P value
		Moderate to Severe		Mild		
		N	%	N	%	
Caregiver	Informal	48	50	48	50	<0.001
	Formal	1	3.2	30	96.8	
Color	Non-white	41	38.7	65	61.3	0.960
	White	8	38.1	13	61.9	
Income	1 minimum wage	15	40.5	22	59.5	0.773
	> 1 minimum wage	34	37.8	56	62.2	
Age	Elderly	17	53.1	15	46.9	0.063
	Adult	32	33.7	63	66.3	
Sex	Female	44	38.6	70	61.4	0.992
	Male	5	38.5	8	61.5	
Marital status	With partner	25	49	26	51	0.052
	Without partner	24	31.6	52	68.4	
Schooling	Illiterate	1	33.3	2	66.7	0.843*
	Literate	48	38.7	76	61.3	
Time as caregiver	≥ 25 months	18	35.3	33	64.7	0.433
	1 - 24 months	30	42.3	41	57.7	
Daily time as caregiver	≥ 17 hours	34	54	29	46	<0.001
	1 - 16 hours	15	23.4	49	76.6	
Degree of kinship	Relative	48	49.5	49	50.5	<0.001
	Non relative	1	3.3	78	61.4	
Beck Hopelessness Scale	Mild to moderate	35	68.6	16	31.4	<0.001
	Minimum	14	18.4	62	81.6	
Musculoskeletal disease	Yes	10	62.5	6	37.5	0.049
	No	39	35.1	72	64.9	
Vascular disease	Yes	24	61.5	15	38.5	<0.001
	No	25	28.4	63	71.6	
Metabolic disease	Yes	7	43.8	9	56.2	0.660
	No	42	37.8	68	62.2	
Change in daily routine	Yes	47	47	53	53	<0.001

	No	2	7.4	25	92.6	
Altered leisure and socialization	Yes	46	54.8	38	45.2	<0.001
	No	3	7	40	93	
Burnout or tiredness	Yes	47	58	34	42	<0.001
	No	2	4.3	44	95.7	
Altered out-of-home routine	Yes	47	52.2	43	47.8	<0.001
	No	2	5.4	35	94.6	
Change in emotional state	Yes	42	55.3	34	44.7	<0.001
	No	7	13.7	44	86.3	
Body aches	Yes	41	56.9	31	43.1	<0.001
	No	8	14.5	47	85.5	
Fail to enjoy vacation	Yes	34	69.4	15	30.6	<0.001
	No	15	19.2	63	80.8	
Fail to receive guests	Yes	18	75	6	25	<0.001
	No	31	30.1	72	69.9	
Quit the job	Yes	31	57.4	23	42.6	<0.001
	No	18	24.7	55	75.3	
Earlier retirement	Yes	2	40	3	60	0.978*
	No	47	38.5	75	61.5	

*Fisher's Test

DISCUSSION

According to the scores of the reduced Zarit Scale, there was prevalence of moderate to severe burden in caregivers of patients treated by a home care program of 38.6%.

Higher burden levels were identified by other studies that also evaluated the caregivers' burden through the Zarit Scale. In a study in Recife (PE), 87.2% of the caregivers showed presented burden; in Manoel Vitorino (BA), the average was 47 points (moderate burden); in Goiás (GO), 33.83 (moderate burden); in João Pessoa (PB), 77.2% of the caregivers presented work overload and, in Ribeirão Preto (SP), 40% of caregivers obtained scores equal to or greater than 44, demonstrating a moderate to high burden level.^{16-7,22,25-6}

In relation to the caregiver's profile, the data found in this study corroborate other studies^{16-7,19,22-4,27} in which middle-aged women and relatives of the patient normally exercise the function of caregiver. Such finding explains the woman's social activities as care provider, since culturally is associated with the role of mother. This confirms that taking care of the patient often becomes an assignment that the woman assumes in the domestic sphere.^{22,24-5} The marital status unmarried of caregivers in this study differs from the literature, since the greater prevalence is married caregivers.^{16,23,26}

The caregiver can be defined as informal or formal. The informal caregivers do not receive payment for the care provided and do not have professional training. Therefore, the informal caregivers are usually family members, friends or neighbors, while the formal caregiver is the qualified professional who provides services under remuneration.¹⁰ The type of caregiver was also associated with burden ($P<0.001$). Corroborating other studies,⁷ informal caregivers presented greater burden.

Informal caregivers can suffer from burden due to several factors, such as the severity of the patient's clinical status, level of functional disability, number of medications in use, presence of psychiatric, visual, auditory and/or cognitive disorders, low schooling, lack of social support and guidance.^{23,26} In this context, this population should be the focus of attention, and actions need to be implemented aiming to prevent or reduce situations that could result in increased burden.

The daily time spent with the care ranged between one and 24 daily hours, with an average of 16.20 hours. The bivariate analysis allowed inferring that the daily time as caregiver ≥ 17 hours can contribute to greater burden ($P<0.001$). This datum is corroborated by other studies.¹⁶⁻⁷ The prolonged dedication can expose the caregiver's health to risks, mainly due to the stress factors related to care, such as the lack of formal and informal support.¹⁷

Moreover, few people were or are prepared to assume this responsibility, which jeopardizes the quality of life of both the caregiver and the patient. The caregivers usually cannot keep out-of-home functions. Furthermore, they frequently leave the job, exercising full-time care, tending to put in second place their own lives, self-care activities, leisure and social activities.^{23,26}

It is necessary to understand that the care is a noble task, however, complex, which, in certain situations, makes this activity health-threatening for those who perform it, because the care routine may deprive the accomplishment of caregivers' basic needs.¹² The caregiver's surrender, coupled with the absence of leisure and confinement in the care environment, contributes to feelings of burden.¹¹

In relation to the presence of diseases, 30.7% of the caregivers reported the diagnosis of vascular diseases ($P<0.001$). Previous studies showed that caregivers reported diagnoses of hypertension

(41.4%) and varicose veins (37.9%).^{17,22} Furthermore, due to the time spent with care, caregivers reported reduced levels of regular physical activity and physical and psychological efforts, factors that can lead to an increased risk of cardiovascular changes.⁶

Similarly to other studies,^{11,14} 42.5% of the caregivers reported working less formally or quitting the job. Caregivers of productive age feel forced to reduce the working day, leave the paid work, undergo resignation process or obstacles to promotion and progression, alteration of routines and functions of the job, to adapt to the role of caregiver. Those aspects thus generate lower incomes, stress or fatigue, especially when the patient's clinical situation requires full-time dedication.⁷

The results revealed the association between the burden level and altered leisure and socialization ($P < 0.001$), fail to enjoy vacation ($P < 0.001$) or receive guests ($P < 0.001$). The social support and leisure are indispensable variables in the caregiver's life. The more the patient requires care, the more the caregiver tends to stay at home and, consequently, more distant from his/her family and social context, changing the opportunities of leisure and daily habits. Most caregivers were not part of groups and, even with advanced technological resources of communication such as internet, mobile phones, radios and TV, they do not fully meet the caregivers' leisure and socialization needs.^{12,14}

After starting the patient care, 59.8% of the caregivers reported some change in emotional state ($P < 0.001$), 56.7% have body ache ($P < 0.001$) and 63.78%, burnout or tiredness ($P < 0.001$). Therefore, health-related negative effects, with emphasis on physical, psychosomatic diseases, anxiety, depression and stress, can emerge over time. Nevertheless, not all caregivers develop diseases or become dissatisfied with the care task. The complexity of the care task often affects caregivers, who forget their needs. In that way, there may arise positive and negative feelings, psychological conflicts, distress, fear and insecurity. Those are believed to be common along the care experience, being considered as burden symptoms due to the continuous care.^{22,24,26}

The mild to moderate depression level, assessed by the Beck Hopelessness Scale, was another condition that was associated ($P < 0.001$) with increased burden among caregivers investigated. Anxiety and depression are highly related and comprise a process of psychological stress, commonly experienced by caregivers, and that directly influences their health status and increased burden.¹⁶ The work demands of family caregivers can cause stress and depressive symptoms. Therefore, it is essential to identify those groups in order to implement interventions.

Concerning the accumulation of activities, lack of support from other family members and from health services, the caregiver prioritizes the dependent's care at the expense of his/her care, which can contribute to the onset of burden, as well as other negative outcomes.¹¹⁻¹³

In this sense, this research is relevant, since it broadens the knowledge and visibility of issues related to the caregivers of patients of HC public services. It is believed to produce implications in nursing assistance, redirecting the view of those professionals for the multidimensional phenomenon that involves the dependent patient, the caregiver and the family, so that assistance focuses on the development of strategies, actions and interventions that shall minimize the impact of the caregiver's burden.

This study had some limitations, such as the lack of studies evaluating the burden of caregivers of homebound patients, regardless of the clinical profile or age, once the studies focus, mainly, on the burden of caregivers for the elderly. Importantly, there were also sample losses.

CONCLUSION

The results revealed that the burden overload of caregivers of homebound patients is a common finding, and they are exposed to a set of internal and external factors that may contribute to the emergence of the problem.

The bivariate analysis showed that, among the demographic and clinical factors identified, those associated to the phenomenon under study were: informal caregivers; daily time as caregiver ≥ 17 hours; being patient's relative; mild to moderate depression level through Beck Hopelessness Scale; vascular disease; change in daily routine; altered leisure and socialization; burnout and tiredness; altered out-of-home routine; change in emotional state; body aches; fail to enjoy vacation or receive guests and leaving the job.

Early recognizing the factors that contribute to the increased caregiver's burden of homebound patients and adopting preventive measures certainly will reduce the likelihood of this problem, in addition to other adverse events.

Further studies on the subject should be developed, as well as investigations that allow establishing the best Nursing actions to prevent the problem, in particular, to caregivers of homebound patients from public services.

REFERENCES

1. Feuerwerker LCM, Merhy EE. Home care's contribution to alternative health care networks: deinstitutionalization and transformation of practices. *Rev Panam Salud Publica*. 2008;24(3):180-8. DOI: [10.1590/s1020-49892008000900004](https://doi.org/10.1590/s1020-49892008000900004)

2. Miranda GDM, Mendes ACG, Silva ALA. Population aging in Brazil: current and future social challenges and consequences. *Rev Bras Geriatr Gerontol.* 2016 May/June;19(3):507-19. DOI: [10.1590/1809-98232016019.150140](https://doi.org/10.1590/1809-98232016019.150140)
3. Rebouças M, Coelho Filho JM, Veras RP, Lima-Costa MF, Ramos LR. Validity of questions about activities of daily living to screen for dependency in older adults. *Rev Saúde Pública.* 2017 Sept;51:84. DOI: [10.11606/s1518-8787.2017051006959](https://doi.org/10.11606/s1518-8787.2017051006959)
4. Kobayasi DY, Partezani RRA, Silva FJR, Silva LM, Souza AC, Campos CEMP. Overload, social support network and emotional stress on the caregiver of elderly. *Av enferm.* 2019 Aug;37(2):140-8. DOI: [10.15446/av.enferm.v37n2.73044](https://doi.org/10.15446/av.enferm.v37n2.73044)
5. Wachs LS, Nunes BP, Soares MU, Facchini LA, Thumé E. Prevalence of home care and associated factors in the Brazilian elderly population. *Cad Saúde Pública.* 2016 Mar; 32(3):e00048515. DOI: [10.1590/0102-311X00048515](https://doi.org/10.1590/0102-311X00048515)
6. Muniz EA, Freitas CASL, Oliveira EM, Lacerda MR. Overload degree of caregivers of elderly assisted at home by the Family Health Strategy. *Saúde Debate.* 2016 July/Sept;40(110):172-82. DOI: [10.1590/0103-1104201611013](https://doi.org/10.1590/0103-1104201611013)
7. Santos WJ, Albuquerque PC, Fittipaldi EOS. Analysis of the profile and burden of caregivers of three Family Health Units at Recife/PE. *Fisioter Bras [Internet].* 2016 Sept/Oct [cited 2018 Oct 26];17(5):464-71. Available from: <http://portalatlanticaeditora.com.br/index.php/fisioterapiabrasil/article/view/682/1500>
8. Bôas MLCV, Shimizu HE. Time spent by the multidisciplinary team in home care: subsidy for the sizing of staff. *Acta Paul Enferm.* 2015 Jan/Feb;28(1):32-40. DOI: [10.1590/1982-0194201500007](https://doi.org/10.1590/1982-0194201500007)
9. Silva KL, Castro EAB, Toledo ST, Gonçalves J, Ribeiro AD. Political pathway of home health care in Minas Gerais. *REME Rev Min Enferm.* 2019 Jan;23:e1155. DOI: [10.5935/1415-2762.20190002](https://doi.org/10.5935/1415-2762.20190002)
10. Valer DB, Aires M, Fengler FL, Paskulin LMG. Adaptation and validation of the Caregiver Burden Inventory for use with caregivers of elderly individuals. *Rev Latino-Am Enfermagem.* 2015 Jan/Feb;23(1):130-8. DOI: [10.1590/0104-1169.3357.2534](https://doi.org/10.1590/0104-1169.3357.2534)
11. Couto AM, Castro EAB, Caldas CP. Experiences to be a family caregiver of dependent elderly in the home environment. *Rev RENE.* 2016 Jan/Feb;17(1):76-85. DOI: [10.15253/2175-6783.2016000100011](https://doi.org/10.15253/2175-6783.2016000100011)
12. Oliveira SCC, Moura PRM. Reflective analysis of the self-care ability of home caregivers. *Rev Fac Cienc Med Sorocaba.* 2017 Mar;19(1):15-8. DOI: [10.5327/Z1984-4840201727022](https://doi.org/10.5327/Z1984-4840201727022)
13. Nunes DP, Brito TRP, Duarte YAO, Lebrão ML. Caregivers of elderly and excessive tension associated to care: evidence of the Sabe Study. *Rev Bras Epidemiol.* 2018 Feb;21(Suppl 2):e180020. DOI: [10.1590/1980-549720180020.supl.2](https://doi.org/10.1590/1980-549720180020.supl.2)
14. Santos MBS, Leite EP, Alfredo PP, Rodrigues JRA. Biopsychosocial overload and stress of the dependent elderly caregiver. *Rev Fac Cienc Med Sorocaba.* 2018 July;20(2):92-7. DOI: [10.23925/1984-4840.2018v20i2a7](https://doi.org/10.23925/1984-4840.2018v20i2a7)
15. Martins T, Peixoto MJ, Araújo F, Rodrigues M, Pires F. Development of the short version of the Informal Caregiver Burden Assessment Questionnaire. *Rev Esc Enferm USP.* 2015 Mar/Apr; 49(2):234-42. DOI: [10.1590/S0080-623420150000200008](https://doi.org/10.1590/S0080-623420150000200008)
16. Guerra HS, Almeida NAM, Souza MR, Minamisava R. The burden of home caregivers. *Rev Bras Promoç Saúde.* 2017 Apr/June; 30(2):179-86. DOI: [10.5020/18061230.2017.p179](https://doi.org/10.5020/18061230.2017.p179)
17. Anjos KF, Boery RNSO, Pereira R, Pedreira LC, Vilela ABA, Santos VC, et al. Association between social support and quality of life of relative caregivers of elderly dependents. *Ciênc Saúde Colet.* 2015 May; 20(5):1321-30. DOI: [10.1590/1413-81232015205.14192014](https://doi.org/10.1590/1413-81232015205.14192014)
18. Fuhrmann AC, Bierhals CCBK, Santos NO, Paskulin LMG. Association between the functional capacity of dependant elderly people and the burden of family caregivers. *Rev Gaúcha Enferm.* 2015 Jan/Mar;36(1):14-20. DOI: [10.1590/1983-1447.2015.01.49163](https://doi.org/10.1590/1983-1447.2015.01.49163)
19. Neves ACOJ, Seixas CT, Andrade AM, Castro EAB. Home care: care profile of a service linked to a teaching hospital. *Physis.* 2019 Sept;29(2):e290214. DOI: [10.1590/s0103-73312019290214](https://doi.org/10.1590/s0103-73312019290214)
20. Ministério da Saúde (BR), Secretaria de Atenção à Saúde, Departamento de Atenção Básica. Caderno de atenção domiciliar [Internet]. Brasília: Ministério da Saúde, 2013 [cited 2018 Nov 10]. Available from: http://bvsmms.saude.gov.br/bvs/publicacoes/caderno_atencao_domiciliar_melhor_casa.pdf
21. Sequeira CAC. Adaptation and validation of Zarit Burden Interview Scale. Referência [Internet]. 2010 Mar [cited 2018 Nov 15];2(12):9-16. Available from: <http://www.index-f.com/referencia/2010pdf/12-0916.pdf>
22. Brandão FSR, Costa BGS, Cavalcanti ZR, Bezerra MR, Alencar LCA, Leal MCC. Overload of elderly people caregivers assisted by a home care service. *J Nurs UFPE On Line.* 2017 Jan;11(Suppl 1):272-9. DOI: [10.5205/1981-8963-v11i1a11905p272-279-2017](https://doi.org/10.5205/1981-8963-v11i1a11905p272-279-2017)
23. Ballarin MLGS, Benedito AC, Krön CA, Christovam D. Sociodemographic profile and burden of informal caregivers of patients assisted in occupational therapy outpatient clinic. *Cad Ter*

Ocup UFSCar. 2016 Apr/June; 24(2):315-21. DOI: [10.4322/0104-4931.ctoA00607](https://doi.org/10.4322/0104-4931.ctoA00607)

24. Sampaio LS, Santana PS, Silva MV, Sampaio TSO, Reis LA. Quality of life and depression in caregivers of elderly dependents. Rev APS. 2018 Jan/Mar;21(1):112-21. DOI: [10.34019/1809-8363.2018.v21.16235](https://doi.org/10.34019/1809-8363.2018.v21.16235)

25. Silva IFG, Neves CFS, Vilela ACG, Bastos LMD, Henriques MILS. Living and caring after a stroke. Referência. 2016 Mar;4(8):103-11. DOI: [10.12707/RIV15047](https://doi.org/10.12707/RIV15047)

26. Costa TF, Costa KNFM, Martins KP, Fernandes MGM, Brito SS. Burden over family caregivers of elderly people with stroke. Esc Anna Nery Rev Enferm. 2015 Apr/June;19(2):350-5. DOI: [10.5935/1414-8145.20150048](https://doi.org/10.5935/1414-8145.20150048)

27. Fhon JRS, Janampa JTG, Huaman TM, Marques S, Rodrigues RAP. Overburden and quality of life of the primary elderly caregiver. Av Enferm. 2016;34(3):251-8. DOI: [10.15446/av.enferm.v34n3.58704](https://doi.org/10.15446/av.enferm.v34n3.58704)

Corresponding author

Diego Dias de Araújo

Email: diego.dias1508@gmail.com

Submission: 2020/02/12

Accepted: 2020/03/16

Copyright© 2019 Journal of Nursing UFPE on line/JNUOL.

 This is an Open Access article distributed under the terms of the [Creative Commons Attribution-ShareAlike 4.0 International License](https://creativecommons.org/licenses/by-sa/4.0/). This license lets others distribute, remix, tweak, and build upon your work, even commercially, as long as they credit you for the original creation. Recommended for maximum dissemination and use of licensed materials.