





Quality of life: overload and depression between caregivers of elderly people in home care

Qualidade de vida: sobrecarga e depressão entre cuidadores de idosos em atendimento domiciliar

Calidad de vida: sobrecarga y depresión en cuidadores de ancianos en atención domiciliar

Paula Afonso Rodrigues de Carvalho¹ , Julia Barbosa de Andrade¹ ,
Eonice Bárbara de Rezende¹ , Isabel Cristina Gonçalves Leite¹ 

¹Universidade Federal de Juiz de Fora. Juiz de Fora, Brazil; ²Prefeitura Municipal de Juiz de Fora. Juiz de Fora, Brazil

ABSTRACT

Objective: to evaluate the prevalence and impact of overload and depression on the quality of life of 102 caregivers of elderly people registered in the *Melhor em Casa* Program. **Method:** cross-sectional analytical study approved by the Research Ethics Committee. Carried out between June and November 2022, in Juiz de Fora (MG/Brazil), with a census sample and application of a sociodemographic form, the Zarit Scale, the Beck Depression Inventory and the World Health Organization's quality of life questionnaire (WHOQOL-bref). Student's t-test, Mann-Whitney test and multiple linear regression were used, with a significance level of 5%. **Results:** overload was observed in 69.6% of caregivers, in addition to the presence of symptoms suggestive of depression in 41.1% of the study population. **Conclusion:** overload was associated with worsening quality of life in the physical, psychological and social relationship domains, while depression was associated with worsening quality of life in the psychological and general evaluation domains. **Descriptors:** Quality of Life; Home Care Services; Caregivers; Workload; Depression.

RESUMO

Objetivo: avaliar prevalência e impacto da sobrecarga e da depressão na qualidade de vida de 102 cuidadores de idosos cadastrados no Programa Melhor em Casa. **Método:** estudo analítico transversal aprovado pelo Comitê de Ética e Pesquisa. Realizado entre junho e novembro 2022, em Juiz de Fora (MG/Brasil), com amostra censitária e aplicação de formulário sociodemográfico, da Escala de Zarit, do Inventário de Depressão de Beck e do questionário de qualidade de vida da Organização Mundial de Saúde (WHOQOL-bref). Foram utilizados Teste t de Student, Mann-Whitney e regressão linear múltipla, com nível de significância de 5%. **Resultados:** observou-se sobrecarga em 69,6% dos cuidadores, além da presença de sintomas sugestivos de depressão em 41,1% da população em estudo. **Conclusão:** a sobrecarga esteve associada a piora da qualidade de vida nos domínios físico, psicológico e de relação social, enquanto a depressão esteve associada a piora da qualidade de vida nos domínios psicológico e de avaliação geral. **Descritores:** Qualidade de Vida; Serviços de Assistência Domiciliar; Cuidadores; Carga de Trabalho; Depressão.

RESUMEN

Objetivo: evaluar la prevalencia y el impacto de la sobrecarga y la depresión en la calidad de vida de 102 cuidadores de ancianos registrados en el Programa *Melhor em Casa* (*Mejor en casa*). **Método:** estudio analítico transversal aprobado por el Comité de Ética en Investigación. Realizado entre junio y noviembre de 2022, en Juiz de Fora (MG/Brasil), con muestra censal y aplicación de un formulario sociodemográfico, la Escala de Zarit, el Inventario de Depresión de Beck y el cuestionario de calidad de vida de la Organización Mundial de la Salud (WHOQOL-bref). Se utilizó la prueba t de Student, la prueba de Mann-Whitney y la regresión lineal múltiple, con un nivel de significancia del 5%. **Resultados:** se observó que el 69,6% de los cuidadores sentían sobrecarga, además de algunos síntomas sugestivos de depresión en el 41,1% de la población de estudio. **Conclusión:** la sobrecarga se asoció con un empeoramiento de la calidad de vida en los dominios físico, psicológico y de relaciones sociales, mientras que la depresión se asoció con un empeoramiento de la calidad de vida en los dominios psicológico y de evaluación general. **Descriptor:** Calidad de Vida; Servicios de Atención de Salud a Domicilio; Cuidadores; Carga de Trabajo; Depresión.

INTRODUCTION

The global increase in human longevity and the consequent proportional growth of the aged population are considered important achievements of modern society. However, it should be noted that, in developed countries, this process took place gradually, along with constant improvements in older adults' quality of life; in turn, in developing countries, this transition happened was recent, fast, and mostly without proper planning¹.

It is known that the population aging process is associated with the emergence of chronic diseases characterized by gradual onset, usually uncertain prognoses and of long or indefinite duration, capable of causing disabilities in the patients². Thus, these conditions require the support from a caregiver, who may or may not be a family member and who presents themselves as the person responsible for providing care focused on the patient's basic, social and rehabilitation needs³.

This study was financed in part by the *Universidade Federal de Juiz de Fora – Brazil* (UFJF).
Corresponding author: Paula Afonso Rodrigues de Carvalho. E-mail: drapaulaafonso@gmail.com
Editor in chief: Cristiane Helena Gallasch; Editor Associate: Magda Guimarães de Araujo Faria

In Brazil, older adults' care is attributed to an informal, unpaid and untrained support network subjected to long working hours⁴. Consequently, all these difficulties can increase the caregiver's risk of suffering from functional incapacity, affecting their professional career, leisure and self-care and negatively impacting their physical and mental well-being⁵. To minimize such situation, it is believed that informal caregivers need training and guidance from health professionals to improve their task performance, in addition to promoting their well-being.

In this context, the participation of the multidisciplinary team belonging to the Better at Home (*Melhor em Casa*) program stands out, which includes physicians, nurses, nursing technicians and physiotherapists, with the possibility of incorporating other support professionals such as social workers, speech therapists, nutritionists, psychologists, dentists, pharmacists and occupational therapists, all responsible for monitoring patients in home care⁶.

Home Care has gradually advanced over the years, as it is known that the act of bringing multiprofessional teams to the homes of people who need assistance, inputs and equipment can reduce their hospitalization time, significantly contributing to a reduced risk of in-hospital infections, in addition to promoting closer contact with the family, a relevant factor for the recovery of patients who feel well-treated⁷. The Better at Home program serves patients with various comorbidities and needs, grouping them into three modalities based on the characteristics of these patients and on the type of care and procedures used to provide this assistance⁶. This variety of diseases and types of care provided renders home care even more complex, which can lead to burden and stress in caregivers.

The literature review contributes a wide variety of studies that, through different instruments used to assess Quality of Life, found some impairment in home caregivers' quality of life in Brazil⁸⁻¹⁰. On the other hand, lack of research focused on analyzing burden and depression in quality of life amongst caregivers of aged individuals in home care is noticed.

This study was carried out with the aim of better understanding the profile of caregivers of older adults who count on the support offered by the Unified Health System (*Sistema Único de Saúde*, SUS) through the Better at Home program, as well as other characteristics referring to personal aspects and inherent to the care provided that may eventually impact these caregivers' quality of life.

It is thus considered that it will be possible to propose and adapt specific actions that may be offered by the Home Care Service (HSC), in order to improve the quality and capacity with which caregiving services have been provided, thus being relevant to the quality of life of caregivers and aged patients in home care.

In this context, the objective of this study was to assess the prevalence and impact arising from burden and presence of symptoms suggestive of depression on quality of life amongst caregivers of aged individuals in home care in the city of Juiz de Fora.

METHOD

This is a cross-sectional, quantitative and analytical study conducted using a census survey, with data collection and analysis carried out between June and November 2022.

The inclusion criteria were as follows: being a caregiver over the age of 18, primarily responsible for the care provided to aged patients (60 or over) registered in the Better at Home program, a service provided by the Home Hospitalization Department (*Departamento de Internação Domiciliar*, DID) of the city of Juiz de Fora, state of Minas Gerais. Cognitive deficit in the caregivers was established as the exclusion criterion, according to the Mini-Mental State Examination¹¹. The sample group loss was due to an aged caregiver's refusal to take part in the research.

The personal data were obtained via a caregiver characterization form prepared by the researchers, with questions regarding the caregivers' profile: age, gender, race/skin color, marital status, schooling, employment status, remuneration, degree of kinship with the aged person, presence of training for the role, number of days and hours devoted to older adults' care and health care support provided by other people. It also contained questions about the type of care provided according to the type of disease suffered by the older adult that triggered the care need, as well as the aged individual's dependence degree and presence of elaborate care measures such as using home oxygen therapy, use of a feeding tube and/or urinary catheter, tracheostomy and presence of skin injuries.

To analyze the caregivers' burden, the translated version of the *Zarit Burden Interview* (ZBI) was used, previously validated in Brazil¹². The assessments respected the cutoff points recommended by international¹³ and national¹⁴ studies, namely: 0-20, no burden; 21-40, from mild to moderate burden; 41-60, from moderate to severe burden; and 61-88, severe burden.

To assess the presence and severity of depressive symptoms, the translated version of the second edition of the *Beck Depression Inventory* (BDI-II) was used, in which the following categories were adopted to assess the depression symptoms: scores from 0 to 13, “minimal depression” or “no depression”; from 14 to 19, “mild depression”; from 20 to 28, “moderate depression”; and values from 29 to 63, “severe depression”¹⁵.

Finally, the World Health Organization Quality of Life (WHOQOL) tool reduced and translated version was used. WHOQOL-bref consists of 26 facets. The first two comprise general Quality of Life aspects that respectively deal with the person's perception about their own quality of life and health. The other 24 are grouped into four domains: Physical, Psychological, Social Relations and Environment. The higher the scores, the more positive the Quality of Life perceptions¹⁶.

Approach to the caregivers was individual and in the house where each aged individual received health care, but in a distant room from the older adult, respecting the following: monthly acquisition of the list of older adults cared for by the Home Hospitalization Department (DID) in the municipality of Juiz de Fora; presentation of the research objectives; request to complete the consent form for carrying out the research; and application of the form and questionnaires to the caregivers with a physician as an intermediary.

To perform the statistical analysis, the variables were coded, the data were entered in Microsoft Excel® and a subsequent analysis was carried out using the *Statistical Package for the Social Sciences* (IBM-SPSS®), version 20.

In the sociodemographic characterization form, descriptive analyses were carried out using frequency, central tendency and dispersion measures. Normality of the variables was verified by means of the Kolmogorov-Smirnov test. To associate the independent variables with the Quality of Life scores, the Student's t or Mann-Whitney tests were used. All variables with p-values ≤ 0.10 were included in the multiple linear regression. The significance level adopted was 5%.

All research stages were conducted in accordance with Resolution No. 466/2012 of the National Health Council for research studies involving human beings. The research protocol was approved by the local Research Ethics Committee and by the respective participants who, after being duly informed about the study, signed the Free and Informed Consent Term (FICF).

RESULTS

The monthly review of the list of older adults registered in the Better at Home program and assisted by the DID in the municipality of Juiz de Fora identified 252 caregivers. Of these, 53 were removed from the original sample due to fact that the aged person to whom they provided care had died before they were even invited to participate in the research. A similar situation occurred with 95 caregivers, as the aged individuals under their care were discharged before the researchers' home visit. Only one caregiver refused to participate in the research and another one was excluded from the initial sample after undergoing the Mini-Mental State Examination. Therefore, we obtained the consent of 102 caregivers of older adults. Tables 1 and 2 present the characteristics of the care provided to the aged people.

Table 1: Characteristics of the care provided to the older adults assisted by the Home Hospitalization Department and of the caregivers' health and working conditions (n = 102). Juiz de Fora, MG, Brazil, 2022.

Caregiver's health and working conditions	n	%
Work-related burden		
None	31	30.4
Mild to moderate	59	57.8
Moderate to severe	10	9.8
Severe	2	2.0
Symptoms suggestive of depression		
None	60	58.9
Mild	18	17.6
Moderate	15	14.7
Severe	9	8.8

Table 2: Characteristics of the care provided to the older adults assisted by the Home Hospitalization Department and of the caregivers' health and working conditions (n = 102). Juiz de Fora, MG, Brazil, 2022.

Characteristics of home care for older adults	n	%
Older adult's disease that triggered the care need		
Nervous system	36	35.2
Circulatory system	25	24.5
Respiratory tract	21	20.6
Mental and behavioral disorders	7	6.9
Neoplasms	5	4.9
Infectious-parasitic diseases	4	3.9
Genitourinary system	1	1.0
Musculoskeletal system and connective tissue	1	1.0
Endocrine, nutritional and metabolic diseases	1	1.0
Injuries, poisoning, or other consequences of external causes	1	1.0
Days per week devoted to care		
1 - 3	2	2.0
4 - 6	21	20.6
7 (every day)	79	77.4
Hours per day devoted to care		
Up to 6	5	4.9
Up to 12	18	17.6
Up to 18	9	8.8
Up to 24	70	68.7
Support from others		
Yes	85	83.3
No	17	16.7
Katz index – Independence in basic activities of daily living		
Independent	11	10.8
Partially dependent	16	15.7
Totally dependent	75	73.5
Use of oxygen therapy		
Yes	42	41.2
No	60	58.8
Feeding		
Oral route	64	62.7
Gastrostomy	33	32.4
Nasoenteric tube	5	4.9
Tracheostomy care		
Yes	10	9.8
No	92	90.2
Indwelling urinary catheter care		
Yes	7	6.9
No	95	93.1
Care related to skin pressure injuries		
Yes	28	27.5
No	74	72.5
Home adaptations (adding grab bars, removing the shower area, and installing ramps in the house)		
Yes	48	47.1
No	54	52.9

It was verified that, among the 102 research participants, most of the caregivers were between 18 and 59 years old (59.8%), with a mean age of 55.7 (± 11.4), female (83.3%), self-declared as white-skinned (63.7%), married or in a stable union (61.8%), with High School level (34.3%), not actively working in any job other than caring for the aged individuals (76.5%), not receiving any remuneration for this activity (85.3%), having some degree of kinship with the aged person (90.2%) and not having attended any training course to provide home care (89.2%).

During the bivariate analysis, among the caregivers' characteristics and their influence on their quality of life, it is noted that age interfered in the Physical ($p=0.058$) and General ($p=0.066$) domains. Self-declared race/skin color influenced the Psychological ($p=0.030$), Environment ($p=0.089$) and General ($p=0.010$) domains. Marital status was capable of interfering in the Environment ($p=0.060$) domain and in the self-assessment ($p=0.030$), whereas schooling level only interfered in the Environment domain ($p=0.073$). Regarding remuneration, unpaid caregivers presented

unfavorable values in the Psychological domain when compared to their paid counterparts ($p=0.072$). Not having any degree of kinship with the aged person favored the caregivers' psychological conditions ($p=0.072$). Not having specific caregiver training was associated with worse conditions in the Physical ($p=0.049$), Psychological ($p=0.005$) and General ($p=0.010$) domains, as well as in the caregivers' self-assessment ($p=0.056$). Those who devoted seven days a week to caring for the older adults showed unfavorable quality of life in the Physical ($p=0.018$), Psychological ($p=0.030$), Environment ($p=0.065$) and General ($p=0.035$) domains. The number of hours per day devoted to care also interfered in the Physical ($p=0.027$) and Environment ($p=0.018$) domains. Having support from other people ($p=0.065$) and the older adults' ability for independence ($p=0.092$) exerted positive impacts on the caregivers' Psychological domain. Finally, both work-related burden and depression influenced almost all the quality of life domains.

The data related to the multiple analysis are presented in Tables 3 and 4.

Table 3: Coefficients and respective significance of the multiple linear regression models for the quality of life outcomes in the Physical, Psychological and Social Relations domains. Juiz de Fora, MG, Brazil, 2022.

Adjusted r^2 Variáveis	Physical 0.29			Psychological 0.48			Social Relations 0.15		
	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value
Age - Older adult	6.999	0.837; 13.161	*0.026						
Self-declared race/skin color:									
Afro-descendants. mixed-race and black-skinned				-2.596	-8.442; 3.251	0.380			
Marital status - Not married	-	-	-	-	-	-	-	-	-
Schooling - ≥ 9 years	-	-	-	-	-	-	-	-	-
Remuneration - Unpaid				-3.170	-14.467; 8.126	0.579			
Degree of kinship - Family member				-1.178	-15.841; 13.484	0.874			
Training - No course taken	-6.464	-16.815; 3.887	0.218	-0.927	-11.879; 10.024	0.867			
Days per week devoted to care – 7 days	-4.189	-12.139; 3.760	0.298	-9.566	-17.121; -2.011	*0.014			
Hours per day devoted to care – 18 – 24	-2.464	-9.881; 4.954	0.511						
Support from others - None				-5.931	-13.764; 1.902	0.136			
Katz index - Dependent				-0.919	-10.350; 8.512	0.847			
Oxygen therapy - Yes							2.825	-5.038; 10.689	0.478
Feeding – oral route							6.493	-1.571; 14.557	0.113
Work-related burden - Yes	-15.457	-22.090; -8.825	*< 0.001	-7.907	-14.971; 0.843	*0.029	-8.906	17.686; -0.126	*0.047
Symptoms suggestive of depression - Yes				-18.900	-25.567; 12.232	*<0.001	-6.712	14.948; 1.523	0.109

Table 4: Coefficients and respective significance of the multiple linear regression models for the quality of life outcomes in the Physical, Psychological and Social Relations domains. Juiz de Fora, MG, Brazil, 2022.

Adjusted r ²	Environment			β	Geral			Self-assessment		
	Variables	β	95% CI		p-value	β	95% CI	p-value	β	95% CI
	Age - Older adult				-6.397	-32.968; 20.175	0.634			
	Self-declared race/skin color Afro-descendants. mixed-race and black-skinned	-6.443	-12.869; -0.017	*0.049	13.658	-13.857; 41.174	0.327			
	Marital status - Not married	-5.933	-12.104; 0.238	0.059				-9.458	-17.096; -1.821	*0.016
	Schooling - ≥ 9 years	3.660	-2.779; 10.100	0.262						
	Remuneration - Unpaid	-	-	-	-	-	-	-	-	-
	Degree of kinship - Family member				-28.201	-81.766; 25.364	0.299			
	Training - No course taken				12.267	-38.252; 62.786	0.631	-9.232	-21.694; 3.230	0.145
	Days per week devoted to care - 7	-1.505	-9.406; 6.396	0.706	-46.036	-79.843; -12.229	*0.008			
	Hours per day devoted to care - 18 – 24	-3.193	-10.259; 3.873	0.372						
	Support from others - None	-	-	-	-	-	-	-	-	-
	Katz index - Dependent	-	-	-	-	-	-	-	-	-
	Oxygen therapy - yes	-	-	-	-	-	-	-	-	-
	Feeding – oral route	-	-	-	-	-	-	-	-	-
	Work-related burden - yes	2.112	-4.149; 8.374	0.505	8.538	-23.898; 40.975	0.602	-4.495	-13.628; 4.637	0.331
	Symptoms suggestive of depression - yes				-39.918	-70.727; -9.109	*0.012	-4.823	-13.412; 3.766	0.268

With the exception of the “age” variable, all the control and independent variables researched that presented significance had a negative association with the domains for which they were tested; in other words, through the stipulated coefficient (β), it was possible to demonstrate to which extent their presence decreased the predicted Quality of Life score for each domain.

DISCUSSION

Chronic diseases constitute a health problem of significant magnitude, accounting for 60% of the entire burden from diseases around the world². In the current study, the three main groups of diseases that required home care for the older adults were Nervous System, Circulatory System and Respiratory System diseases.

This study showed that most caregivers of older adults are women (83.3%), aged between 18 and 59 years old (59.8%), with a mean of 55.7 (± 11.4), married or in a stable union (61.8%), with High School level, and having some degree of kinship with the older adults (90.2%). In another study carried out with home caregivers¹⁷, a similar profile was found when characterizing the sample, with majority of females (85.4%), mean age of 61.1 (± 12.5) years old and belonging to the age group between 26 and 81 years old. In the same study, there was predominance of caregivers who had higher schooling levels (58.5%). It is possible to infer that this difference in educational levels is related to the country in which the study was carried out, the Netherlands, where the illiteracy rate is less than 1%, whereas it is nearly 7% in Brazil¹⁸.

Also regarding age, in the current study it is noted that caregivers over the age of 60 presented statistically favorable scores for Quality of Life in the Physical domain. This finding can be justified by the fact that most young people are responsible for carrying out a wide range of tasks such as caring for their children, spouse, household and work, in addition to the older adult they care for¹⁹. At the same time, when caregivers belong to the same generation as the aged people, despite having more limitations in their physical and cognitive skills, they present higher care commitment levels when compared to younger individuals, which “protects” them from unfavorable interferences in

their quality of life²⁰. It is valid to highlight that older caregivers have a high chance of having already been involved with the care process of their parents, children and other relatives, which can make them more prepared to deal with different aspects. People who have not yet played the caregiver role are rarely prepared to assume all the responsibilities assigned to them²¹.

Despite the predominance of women in the home caregiver role, it is noted that gender did not interfere with Quality of Life. However, a Brazilian study revealed that being a woman was one of the factors related to caregiver burden, which might thus exert a negative impact on their quality of life²². A German research study²³ also reported lower quality of life and higher stress levels among female caregivers. In a still sexist society, the responsibility of caring for a family member is usually attributed to the daughters, who, in addition to meeting the patient's needs, assume other duties within the family²⁴.

When the caregiver is single and an only child, the situation can be even more exhausting, as they have no one else to share this responsibility with²⁵. This corroborates the findings of the current study, in which marital status influenced the caregivers' self-assessment and the fact of not being married led to worse Quality of Life scores. A systematic review concluded that marital status was an aspect that produced contradictory results on the caregivers' quality of life due to significant cultural, family and individual differences in development of the relationship²⁶.

Black race/skin color was associated with lower quality of life in the Environment domain. The World Health Organization's Quality of Life group²⁷ advocates that the assessment of the environment for quality of life includes issues such as opportunities to acquire new information and skills, financial resources, and the home environment. In Brazil, the illiteracy rate among black-skinned people over 15 years of age is approximately 2.5 times higher than among white-skinned individuals²⁸. When observing the percentage distribution of the population according to income and skin color, 75.2% of the black-skinned people are among the 10% with the lowest incomes. In addition, 44.5% of the Afro-descendants or mixed-race subjects live in houses that have at least one deficit (lack of direct or indirect garbage collection, lack of a water supply general network or lack of sanitary sewage through collection systems or pluvial networks), whereas this rate drops to 27.9%²⁹ for white-skinned people. Given the aforementioned, it can be considered that living with an aged person with limitations is even more challenging for black- and brown-skinned people in Brazil if they live in households that cannot meet basic needs.

In relation to the variables referring to the characteristics of home care for aged people, it is observed that the act of devoting all seven days of the week to caring for the older adults presented a significant interference in the caregivers' Psychological and General domains. In the former domain, the World Health Organization's Quality of Life group²⁷ states that the interviewee's positive and negative feelings, spirituality/personal beliefs, learning process/memory/concentration, body and appearance acceptance and self-esteem should be considered. Lack of time for activities that enhance well-being and raise self-esteem such as practicing regular physical exercise or, more basically, sleeping enough hours, are examples of how the caregivers' Psychological domain can be drastically affected³⁰.

Most of the older adults included in the current study were totally dependent (73.5%) on their caregivers, according to the Katz index. Even so, this variable did not interfere in the caregivers' quality of life. This non-association may have been due to the fact that most of the aged individuals did not require any type of special care such as home oxygen therapy, tube feeding, tracheostomy, urinary catheter, care for skin injuries or structural adaptations in their homes. It is known that handling this type of care requires greater cognitive mastery from caregivers, making it indispensable, in these cases, to have the support of home care teams.

When assessing the households participating in this research, 52.9% did not have any structural home adaptation for the care to be provided; however, among those that did, the most common ones were fitting grab bars, removing the shower area and installing ramps in the house. It is known that the presence or absence of obstacles or facilitators for older adults can hinder or help the caregivers' actions. Even so, there was no statistical correlation between home adaptations and the caregivers' quality of life.

The current study identified some burden degree in 69.6% of the caregivers, which is strongly associated with worse quality of life in their Physical, Psychological and Social Relations domains. In this context, it is reinforced that this feeling of burden can be associated with losing control over one's own life⁵.

In a scenario in which caregivers, in most cases informal, start to dedicate themselves to caring for older adults, and adding the excessive days of work involved in care and the presence of burden, it is reasonable to think about some degree of harm to their mental health. Thus, presence of signs suggestive of depression can be seen in 41.1% of the population in the current study, strongly associated with worse quality of life in the Psychological and General assessment domains. These results are consistent with those reported in a review that indicated a 6%-64% variation in the prevalence

of depressive symptoms among caregivers³¹. As in the current study, a Polish survey³² reported that depression considerably affected quality of life in caregivers of older adults. In fact, the caregiver role was described as capable of leading to depression, psychological distress, deficient self-care and worse self-reported health perceptions³⁰.

Some studies present the “burden” and “depression” variables from a cause and consequence perspective. This finding might explain the striking significance of burden and depression in the quality of life of the caregivers participating in this study. A relevant study on caregivers of older adults³³ highlights this link by reporting that burden can affect the psychological sphere, leading to symptoms such as chronic sadness, stress, low self-esteem and depression.

Study limitations

This is a cross-sectional study and, therefore, does not contribute any causal connotation to the findings. In addition to that, it may not have explored some variables particularly linked to the caregivers, which might also have exerted impacts on their quality of life.

CONCLUSION

Burden was observed in 69.6% of the caregivers of aged people receiving home care, in addition to presence of symptoms suggestive of depression in 41.1% of this population. Burden was associated with worse quality of life in the Physical, Psychological and Social Relations domains; in turn, depression was associated with worse quality of life in the Psychological and General assessment domains.

Based on the data presented, it becomes possible to propose actions within the scope of the services provided by Multiprofessional Home Care Teams and Multiprofessional Support Teams to reduce burden – by systematically providing support and education with a view to the due training for assuming the caregiver role – and to improve the mental health of these caregivers, strengthening the valuable bond established by the health professional-caregiver-patient triad.

REFERENCES

1. Lima-Costa MF, Andrade FB, Souza PRB Jr, Neri AL, Duarte YAO, Castro-Costa E, Oliveira C. The Brazilian longitudinal study of aging (ELSI-Brazil): objectives and design. *Am J Epidemiol*. 2018 [cited 2022 May 18]; 187(7):1345-53. DOI: <https://doi.org/10.1093/aje/kwx387>.
2. Brasil. Ministério da Saúde. Diretrizes para o cuidado das pessoas com doenças crônicas nas redes de atenção à saúde e nas linhas de cuidado prioritárias. Brasília: Ministério da Saúde; 2013 [cited 2023 May 22]. Available from: https://bvsms.saude.gov.br/bvs/publicacoes/diretrizes%20_cuidado_pessoas%20_doencas_cronicas.pdf.
3. Kobayasi DY, Partezani Rodrigues RA, Silva Fhon JR, Silva LM, Souza AC, Campos Chayamiti EMP. Overload, social support network and emotional stress on the caregiver of elderly. *Av En Enferm*. 2019 [cited 2022 Jun 10]; 37(2):140-8. DOI: <https://doi.org/10.15446/av.enferm.v37n2.73044>.
4. Couto AMD, Caldas CP, Castro EAB. Home care for dependent elderly patients by caregivers with overload and stress. *Rev Pesqui Cuid É Fundam Online*. 2019 [cited 2022 May 18]; 11(4):944-50. DOI: <https://doi.org/10.9789/2175-5361.2019.v11i4.944-950>.
5. Mendes PN, Figueiredo MLF, Santos AMR, Fernandes MA, Fonseca RSB. Physical, emotional and social burden of elderly patients' informal caregivers. *Acta Paul Enferm*. 2019 [cited 2022 May 18]; 32:87-94. DOI: <https://doi.org/10.1590/1982-0194201900012>.
6. Ministério da Saúde (Br). Portaria no 2.527, de 27 de outubro de 2011. Redefine a atenção domiciliar no âmbito do Sistema Único de Saúde (SUS). Brasília: Ministério da Saúde; 2011 [cited 2023 May 25]. Available from: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2011/prt2527_27_10_2011_comp.html.
7. Nishimura F, Carrara AF, Freitas CE. Effect of the Melhor em Casa program on hospital costs. *Rev Saúde Pública*. 2019 [cited 2022 May 18]; 53:104. DOI: <https://doi.org/10.11606/s1518-8787.2019053000859>.
8. Sampaio LS, Santana PS, Silva MV, Sampaio TSO, Reis LAD. Quality of life and depression in caregivers of elderly dependents. *Rev APS*. 2018 [cited 2022 May 18]; 21(1):112-121. DOI: <https://doi.org/10.34019/1809-8363.2018.v21.16235>.
9. Silva AM, Nunes DP, Grazziano ES, Jesus ITM, Brito TRP, Santos-Orlandi AA. Relationship between burden and quality of life of informal caregivers of older adults: a cross-sectional study in outpatient care. *Online Braz J Nurs Online*. 2020 [cited 2022 Jun 10]; 19(1):e20206275. DOI: <https://doi.org/10.17665/1676-4285.20206275>.
10. Bierhals CCBK, Dal Pizzol FLF, Low G, Day CB, Santos NO, Paskulin LMG. Quality of life in caregivers of aged stroke survivors in southern Brazil: a randomized clinical trial. *Rev Lat Am Enfermagem*. 2023 [cited 2022 Jun 10]; 31:e3657. DOI: <https://doi.org/10.1590/1518-8345.5935.3657>.
11. Brucki SMD, Nitrini R, Caramelli P, Bertolucci PHF, Okamoto IH. Suggestions for utilization of the mini-mental state examination in Brazil. *Arq Neuropsiquiatr*. 2003 [cited 2022 May 18]; 61(3B):777-781. DOI: <https://doi.org/10.1590/S0004-282X2003000500014>.
12. Scazufca M. Brazilian version of the Burden Interview scale for the assessment of burden of care in carers of people with mental illnesses. *Braz J Psychiatry*. 2002 [cited 2022 May 18]; 24(1):12-7. DOI: <https://doi.org/10.1590/S1516-44462002000100006>.
13. Hébert R, Bravo G, Préville M. Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Can J Aging Rev Can Vieil*. 2000 [cited 2022 May 18]; 19(4):494-507. DOI: <https://doi.org/10.1017/S0714980800012484>.

14. Luzardo AR, Gorini MIPC, Silva APSS. Characteristics of elderly with Alzheimer's disease and their caregivers: a series of cases in a neurogeriatric service. *Texto Contexto - Enferm.* 2006 [cited 2022 May 18]; 15:587-594. DOI: <https://doi.org/10.1590/S0104-07072006000400006>.
15. Gomes-Oliveira MH, Gorenstein C, Lotufo Neto F, Andrade LH, Wang YP. Validation of the brazilian portuguese version of the Beck Depression Inventory-II in a community sample. *Braz J Psychiatry.* 2012 [cited 2022 May 18]; 34(4):389-94. DOI: <https://doi.org/10.1016/j.rbp.2012.03.005>.
16. Fleck MP, Louzada S, Xavier M, Chachamovich E, Vieira G, Santos L, Pinzon V. Application of the Portuguese version of the abbreviated instrument of quality life WHOQOL-bref. *Rev Saúde Pública.* 2000 [cited 2022 May 18]; 34(2):178-83. DOI: <https://doi.org/10.1590/s0034-89102000000200012>.
17. Bijnisdorp FM, Pasman HRW, Boot CRL, van Hooft SM, van Staa A, Francke AL. Profiles of family caregivers of patients at the end of life at home: a Q-methodological study into family caregiver' support needs. *BMC Palliat Care.* 2020 [cited 2023 Jan 16]; 19(1):51. DOI: <https://doi.org/10.1186/s12904-020-00560-x>.
18. Unesco. Netherlands. Education and literacy. General information. 2016 [cited 2023 May 22]. Available from: <https://uis.unesco.org/en/country/nl>.
19. Oliveira AS. Transition, epidemiological transition and population aging in Brazil. *Hygeia - Rev Bras Geogr Médica E Saúde.* 2019 [cited 2022 Sep 13]; 15(32):69-79. DOI: <http://dx.doi.org/10.14393/Hygeia153248614>.
20. Schulz R, Beach SR, Czaja SJ, Martire LM, Monin JK. Family caregiving for older adults. *Annu Rev Psychol.* 2020 [cited 2022 Dec 08]; 71:635-59. DOI: <https://doi.org/10.1146/annurev-psych-010419-050754>.
21. Jesus ITM, Orlandi AAS, Zazzetta MS. Burden, profile and care: caregivers of socially vulnerable elderly persons. *Rev Bras Geriatr E Gerontol.* 2018 [cited 2023 Dec 08]; 21(2):194-204. DOI: <https://doi.org/10.1590/1981-22562018021.170155>.
22. Silva ARF, Fhon JRS, Rodrigues RAP, Leite MTP. Caregiver overload and factors associated with care provided to patients under palliative care. *Investig Educ En Enfermeria.* 2021 [cited 2022 Dec 08]; 39(1):e10. DOI: <https://doi.org/10.17533/udea.iee.v39n1e10>.
23. Zwar L, König HH, Hajek A. Gender differences in mental health, quality of life, and caregiver burden among informal caregivers during the second wave of the covid-19 pandemic in Germany: a representative, population-based study. *Gerontology.* 2023 [cited 2023 Jan 16]; 69(2):149-62. DOI: <https://doi.org/10.1159/000523846>.
24. Meira EC, Reis LA, Gonçalves LHT, Rodrigues VP, Philipp RR. Women's experiences in terms of the care provided to dependent elderly: gender orientation for care. *Esc Anna Nery.* 2017 [cited 2023 May 22]; 21(2):e20170046. DOI: <https://doi.org/10.5935/1414-8145.20170046>.
25. Augusto FMF, Silva IP, Ventura MM. Child caregivers: choice, changes and challenges. *Rev Kairós-Gerontol.* 2009 [cited 2022 Dec 08]; 12(2):103-18. DOI: <http://dx.doi.org/10.14393/Hygeia153248614>.
26. Alshammari B, Noble H, McAneney H, Alshammari F, O'Halloran P. Factors associated with burden in caregivers of patients with end-stage kidney disease (a systematic review). *Healthc Basel Switz.* 2021 [cited 2023 Jan 16]; 9(9):1212. DOI: <https://doi.org/10.3390/healthcare9091212>.
27. Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. *Psychol Med.* 1998 [cited 2022 May 18]; 28(3):551-8. DOI: <https://doi.org/10.1017/s0033291798006667>.
28. Instituto Brasileiro de Geografia e Estatística. Tabela 7125: Taxa de analfabetismo das pessoas de 15 anos ou mais de idade, por cor ou raça e grupo de idade. 2019 [cited 2023 May 22]. Available from: <https://sidra.ibge.gov.br/tabela/7125#resultado>.
29. Instituto Brasileiro de Geografia e Estatística. Desigualdades sociais por cor ou raça no brasil. 2018 [cited 2023 May 22]. Available from: <https://www.ibge.gov.br/estatisticas/sociais/populacao/25844-desigualdades-sociais-por-cor-ou-raca.html?=&t=resultados>.
30. Aljuaid M, Ilyas N, Altuwajiri E, Albedawi H, Alanazi O, Shahid D, Alonazi W. Quality of life among caregivers of patients diagnosed with major chronic disease during COVID-19 in Saudi Arabia. *Healthcare (Basel).* 2022 [cited 2023 Jan 16]; 10(3):523. DOI: <https://doi.org/10.3390%2Fhealthcare10030523>.
31. Lacerda MS, Prado PR, Barros ALBL, Lopes JL. Depressive symptoms in the family caregivers of patients with heart failure: an integrative review. *Rev Gaúcha Enferm.* 2019 [cited 2023 Jan 22]; 40:e20180057. DOI: <https://doi.org/10.1590/1983-1447.2019.20180057>.
32. Ślusarska B, Bartoszek A, Kocka K, Deluga A, Chrzan-Rodak A, Nowicki G. Quality of life predictors in informal caregivers of seniors with a functional performance deficit - an example of home care in Poland. *Clin Interv Aging.* 2019 [cited 2023 Jan 22]; 14:889-903. DOI: <https://doi.org/10.2147/cia.s191984>.
33. Nah S, Martire LM, Zhaoyang R. Perceived gratitude, role overload, and mental health among spousal caregivers of older adults. *J Gerontol B Psychol Sci Soc Sci.* 2022 [cited 2020 Jan 22]; 77(2):295-99. DOI: <https://doi.org/10.1093/geronb/gbab086>.

Authors' contributions

Conceptualization, P.A.R.C. e I.C.G.L.; methodology, P.A.R.C., I.C.G.L., L.B.R.; software, P.A.R.C., I.C.G.L., J.B.A.; validation, P.A.R.C., I.C.G.L., L.B.R.; formal analysis, P.A.R.C. e I.C.G.L.; investigation, P.A.R.C., I.C.G.L. e J.B.A.; resources, I.C.G.L.; data curation, P.A.R.C. e I.C.G.L.; manuscript writing, P.A.R.C., I.C.G.L., J.B.A. e L.B.R.; manuscript review and editing, P.A.R.C., I.C.G.L., J.B.A. e L.B.R.; visualization, P.A.R.C., I.C.G.L., J.B.A. e L.B.R.; supervision, I.C.G.L.; project administration, P.A.R.C. e I.C.G.L.; financial aquisition, I.C.G.L. All authors have read and agreed to the published version of the manuscript.