

# Overload and quality of life of caregivers of bedridden people at home

Sobrecarga e qualidade de vida dos cuidadores de pessoas acamadas em domicílio  
Sobrecarga y calidad de vida de los cuidadores de personas encamadas en domicilio

Marcela dos Santos Albuquerque Melo<sup>1</sup>  <https://orcid.org/0000-0003-3240-1864>

Alexandro Silva Coura<sup>1</sup>  <https://orcid.org/0000-0002-0628-648X>

Inacia Sátiro Xavier de França<sup>1</sup>  <https://orcid.org/0000-0002-2695-510X>

Alexandra Rodrigues Feijão<sup>2</sup>  <https://orcid.org/0000-0002-8686-9502>

Carla Carolina da Silva Leite Freitas<sup>3</sup>  <https://orcid.org/0000-0002-4780-7640>

Jamilly da Silva Aragão<sup>4</sup>  <https://orcid.org/0000-0002-8140-3180>

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## Corresponding author

Marcela dos Santos Albuquerque Melo  
Email: marcela.melo3@gmail.com

## Associate Editor (Peer review process):

Ana Lúcia de Moraes Horta  
(<https://orcid.org/0000-0001-5643-3321>)  
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil

## Abstract

**Objective:** To associate the sociodemographic profile with the work overload and the quality of life of caregivers of bedridden people.

**Methods:** Cross-sectional study, carried out in 2019, with a total of 240 caregivers who answered three instruments: sociodemographic questionnaire, Zarit Burden Interview and the WHOQOL-bref. For analysis, the Chi-square, Fisher and Binary Logistic Regression tests were used.

**Results:** Most caregivers (86.6%) were found to have moderate or severe overload and the overall quality of life score was 48.9 points. Caregivers that worked at home (OR=52.89), with health affected because of their involvement as a caregiver (OR=22.92) and who have lost control of their lives since the bedridden person's illness (OR=49.38), were more likely to have poor quality of life.

**Conclusion:** Occupation and period of care were significantly related to the quality of life of caregivers of bedridden people. The occupation "household" and overload factors are significant predictors of poor quality of life.

## Resumo

**Objetivo:** Relacionar o perfil sociodemográfico com a sobrecarga de trabalho e a qualidade de vida dos cuidadores de pessoas acamadas.

**Métodos:** Estudo transversal, realizado em 2019, com 240 cuidadores, os quais responderam três instrumentos: questionário sociodemográfico, *Zarit Burden Interview* e o *WHOQOL-bref*. Para análise foram utilizados os testes Qui-quadrado, Fisher e Regressão Logística Binária.

**Resultados:** Verificou-se que a maioria dos cuidadores (86,6%) apresentam sobrecarga moderada ou severa e o escore geral de qualidade de vida em 48,9 pontos. Cuidadores com ocupação Do Lar (OR=52,89), com a saúde afetada por causa do seu envolvimento como cuidador (OR=22,92) e que perderam o controle de sua vida desde a doença da pessoa acamada (OR=49,38), tiveram maior probabilidade de ter qualidade de vida ruim.

**Conclusão:** A ocupação e o período de cuidado relacionaram-se significativamente com a qualidade de vida dos cuidadores de pessoas acamadas, sendo, a ocupação "Do lar" e fatores da sobrecarga preditores significativos da qualidade de vida ruim.

## Resumen

**Objetivo:** Relacionar el perfil sociodemográfico con la sobrecarga de trabajo y la calidad de vida de los cuidadores de personas encamadas.

<sup>1</sup>Universidade Estadual da Paraíba, Campina Grande, PB, Brazil.

<sup>2</sup>Universidade Federal do Rio Grande do Norte, Natal, RN, Brazil.

<sup>3</sup>Universidade Federal da Paraíba, Campina Grande, PB, Brazil.

<sup>4</sup>Universidade de Pernambuco, Recife, PE, Brazil.

Conflicts of interest: none to declare.

**Métodos:** Estudio transversal, realizado en 2019, con 240 cuidadores, que respondieron a tres instrumentos: cuestionario sociodemográfico, *Zarit Burden Interview* y el *WHOQOL-bref*. Para el análisis se utilizaron las pruebas de ji cuadrado, Fisher y Regresión Logística Binaria.

**Resultados:** Se verificó que la mayoría de los cuidadores (86,6 %) presenta una sobrecarga moderada o severa y el puntaje general de calidad de vida es de 48,9 puntos. Cuidadores con ocupación "Amo/a de casa" (OR=52,89), con la salud afectada a causa de su implicación como cuidador (OR=22,92) y que perdieron el control de sus vidas desde la enfermedad de la persona encamada (OR=49,38) tuvieron más probabilidades de tener mala calidad de vida.

**Conclusión:** La ocupación y el período de atención se relacionaron de forma significativa con la calidad de vida de los cuidadores de personas encamadas. La ocupación "Amo/a de casa" y factores de la sobrecarga fueron predictores significativos de la mala calidad de vida.

## Introduction

The profile of morbidity and mortality has undergone changes over the last decade, factors such as the reduction of infant mortality and fertility rates contribute to the increase in life expectancy of the Brazilian population, and consequently favor the emergence of people with chronic non-communicable (NCDs) and degenerative diseases.<sup>(1)</sup> Sometimes, these people may have reduced mobility, which can make them bedridden, causing the need for a caregiver.

The limitations imposed by the appearance of CNCs are diverse, ranging from mild cognitive and functional damage to total dependence on basic daily activities, food, hygiene care, medication administration, dressings, among others. A stage of bed restriction requires home care, generating changes in the daily life of many families, requiring a specific routine of the caregiver, who in most cases are family members, in specific cases being close people or friends of the patient, who are providing care for long time periods, without having received any type of preparation.<sup>(2)</sup>

However, despite the work provided by the nursing team and other health professionals, the performance of tasks is centered on the lay caregiver causing, on several occasions, the overload and the requirement to perform them correctly are constant, generating anguish and insecurities about the care provided.<sup>(3)</sup>

Generally, caregivers who assume the home responsibility are not prepared to face the situation of an acute illness of a loved one full-time. The diagnosis is sometimes sudden and unexpected. Diseases such as diabetes, stroke, Alzheimer's, Parkinson's, sclerosis and muscular dystrophies, require specific care and require attention in the administration of

various medications. Life changes and routine reorganization are imposed, which lead, several times, to a behavior of reduction in social interaction, affective isolation and depression, leading to a decrease in the quality of life.<sup>(4)</sup>

Quality of life (QoL) is understood as a sign of society's health and its assessment is used to develop actions to promote health. QOL can be defined as "the individual's understanding of their reality in the cultural and social scenarios in which they are inserted and their perspectives and uncertainties", involving aspects of physical and psychological health, social relationships, environment and religiosity,<sup>(5)</sup> including the overload of activities.

The scenario of insecurity and caregiver overload is an indicator of negative impact that can interfere with the physical, psychological, social and financial state, causing physical and emotional problems in many cases, such as muscle pain, physical and emotional exhaustion, mental health, anxiety, insomnia and depression. Lay caregivers often do not have the technical and psychological preparation to take on all the responsibilities imposed on them without help and support, and may face unexpected situations that require guidance.<sup>(6)</sup>

Therefore, this scenario reaffirms the need for attention on the part of nurses, health professionals and public managers, requiring knowledge of the profile, degree of overload and activities related to care, since the actors involved in the care process, on average term, aged, which can cause difficulties in providing essential care and, consequently, influence the overload and generate implications for both the caregiver and the patient.<sup>(7)</sup>

In this context, the study is justified considering the importance of knowledge about the aspects, whether sociodemographic or overload, that influence the quality of life of lay caregivers, who in

most cases are a family member and do not have the skills and abilities to care. Thus, the study seeks to provide data that can support care focused on the caregiver-user, expanding the perspective of professionals who help families in the provision of actions aimed at health promotion, disease prevention, treatment and rehabilitation at home.

In this perspective, the following questions emerged: what is the relationship between the sociodemographic profile with the work overload and the quality of life of caregivers of bedridden people? Are sociodemographic and work overload factors predictors of quality of life? Thus, the objective was to relate the sociodemographic profile with the work overload and the quality of life of caregivers of bedridden people.

## Methods

This is a cross-sectional study, with a quantitative approach, carried out in 2019, in a small city in the Brazilian Northeast. Within the political-administrative organization, the city consists of 10 health districts, which have 109 teams from the Family Health Strategy, with a total of 1437 patients bedridden at home.

To estimate the sample size, so that it was representative, the following formula was used:  $n = \frac{Z^2 N P (1-P)}{e^2 (N-1) + Z^2 P (1-P)}$ , in which:  $n$  = sample value,  $Z$  = confidence interval (1.96),  $N$  = population (1437),  $P$  = prevalence (0.25)<sup>(8)</sup> and  $e$  = tolerated error (0.05). It results in a sample of 240 participants, considering that each patient has a main caregiver.

To ensure the representation of all health districts, the following were proportionally interviewed: District I (Total bedridden: 254; Respondents: 43 people), District II (Total: 181; Respondents: 30), District III (Total: 179; Respondents: 30), District IV (Total: 120; Respondents: 20), District V (Total: 120; Respondents: 20), District VI (Total: 107; Respondents: 18), District VII (Total: 63; Respondents: 11), District VIII (Total: 42; Respondents: 7), District IX (Total: 190; Respondents: 32) and District X (Total: 181; Respondents: 30).

The inclusion criteria of this research were to be of legal age and to act as the main caregiver of bedridden patients at home, regardless of the diagnosis that determined the restriction to the bed. The exclusion criteria were: to be a person with a disability, a health professional, have a diagnosis or signs of depression, and care for more than one bedridden patient.

Data collection was carried out in October and November 2019, using three instruments, which were applied by the researcher. A sociodemographic questionnaire was applied to the lay caregiver of the bedridden patient, which contained the following variables: sex, age group, religion, education, race, marital status, per capita income, occupation and period of care, which were considered as independent variables.

Along with this questionnaire, the validated Brazilian version of the Caregiver Overload Inventory (Zarit Burden Interview) was applied, which assesses caregiver overload, which has 22 questions, graded from 0 to 4 according to the presence and intensity of responses for each item. Caregiver overload is obtained by adding the total score of questions, which assesses the caregiver's health, social and personal life, financial situation, emotional well-being and interpersonal relationships and environment. Its score ranges from 0 to 88 and the higher the score, the greater the overload, with  $\leq 20$  = no overload, 21-40 = moderate overload, 41-60 = moderate to severe overload,  $\geq 61$  = severe overload.<sup>(9)</sup>

And to assess the caregiver's quality of life, the WHOQOL-bref was applied, in its validated Portuguese version, consisting of 26 questions. The first question analyzes the quality of life in general and the second one, the satisfaction with one's own health. The other 24 are divided into physical, psychological, social relationships and environment domains. The items are evaluated on a scale from 0 to 100, with higher averages suggesting a better perception of QoL. In addition to the cross-cultural character, the instrument values the person's individual perception, being able to assess the quality of life in different groups and situations.<sup>(10)</sup>

Data were stored in the SPSS program and, in the univariate analysis, descriptive measures, ab-

solute frequencies and percentages were calculated. Then, a bivariate analysis was performed using Pearson's chi-square test to verify the association between the dependent variables (overload and quality of life) and the independent variables, considering, at that moment,  $p < 0.05$ . In cases where the Chi-square requirements were not met, Fisher's exact test was used.

In the bivariate analysis, the variables related to caregiver overload were dichotomized into never/rarely and sometimes/often/always. The general overload score was dichotomized into caregivers with or without overload where the score up to 40 points represented individuals without overload and light overload, and above this value, individuals with overload. And the QOL was categorized into two levels: Poor quality of life (PQL) for caregivers whose answers were from 1 to 3 and good quality of life (GQL), from 4 to 5.

Binary logistic regression models were created, including only independent variables with statistical significance previously found in the association tests. The Backward Wald method was used to introduce the variables and the Hosmer Lemeshow test to measure the fit quality. For the analysis of the predictor variables, a  $p < 0.05$  was considered significant, as well as the calculation of the adjusted Odds Ratios (OR).

The project was submitted to the Research Ethics Committee of the Universidade Estadual da Paraíba and after opinion no. 3606124 (Certificate of Presentation of Ethical Appreciation: 19807219.7.0000.5187), favorable for its accomplishment, the data collection began, respecting all ethical precepts.

## Results

It was identified that the predominant religions were Catholic (48.3%) and Evangelical (40.8%). The age of caregivers ranged from 25 to 81 years old with an interval of 56 years, with a mean of 48.2 years old and a standard deviation of 1.59. The average income was 1.3 of the minimum wage. The sociodemographic characteristics can be seen in table 1.

**Table 1.** Sociodemographic characteristics of lay caregivers of bedridden people at home, in a small city in Northeast Brazil.

Variables	n(%)
Sex	
Female	236(98.3)
Male	4(1.7)
Religion	
Religious	234(97.5)
Not religious	6(2.5)
Age group	
18-50	138(57.5)
>50	102(42.5)
Race	
White	96(40)
Not white	144(60)
Education	
Up to 12 years of study	136(56.7)
>12 years of study	104(43.3)
Marital status	
With a partner	132(55)
No partner	108(45)
Occupation	
Household	221(92)
Others	19(8)
Period of care	
Full time	206(85.8)
Partial	34(14.2)
Per capita income	
< 1 minimum wage*	157(65.4)
> 1 minimum wage	83(34.6)

\*Minimum wage value = R\$: 998.00

When assessing the overload, it was found that the highest frequency was concentrated in the score from 41 to 60 ( $n=208$ ; 86.6%), a significant result of the overload from high to severe, followed by 21 to 40 ( $n=23$ ; 9.6%) and, finally,  $\leq 20$  ( $n=9$ ; 3.8%). In the analysis of the association between the sociodemographic profile and the burden score, no statistically significant relationships were identified, as seen in table 2.

Regarding QOL, the Physical domain resulted in 54 points (SD 0.7), Psychological 50.6 (SD 2.8), Social relationships 46.6 (SD 1.4), Environment 43.5 (SD 0.7). The overall QOL score was equivalent to 48.9 points (SD 0.8). In the analysis of the association between the sociodemographic profile and the categorization of the QOL score, there was an association with the occupation ( $p=0.001$ ) and period of care variables ( $p=0.039$ ), as shown in table 3.

The significant predictors corresponded to caregivers with occupation "Household" who were more

**Table 2.** Sociodemographic characteristics associated with the overload score of caregivers of bedridden people at home, in a small city in Northeast Brazil

Variables	Score		p-value
	No overload and light overload n(%)	Moderate and severe overload n(%)	
Sex			0.562**
Male	0(0)	4(1.7)	
Female	32(13.3)	204(85)	
Religion			0.420**
Religious	32 (13.3)	202(84.2)	
Not religious	0(0)	6(2.5)	
Age group			0.591
18-50	17(7.1)	121(50.4)	
>50	15(6.2)	87(36.3)	
Race			0.394
White	15(6.2)	81(33.8)	
Not white	17(7.1)	127(52.9)	
Education			0.664
< 12 years of study	17(7.1)	119(49.6)	
>12 years of study	15(6.2)	89(37.1)	
Marital status			0.819
With a partner	17(7.1)	115(47.9)	
No partner	15(6.2)	93(38.8)	
Occupation			0.479**
Household	29(12.1)	192(80)	
Others	3(1.2)	16(6.7)	
Period of care			0.424
Full time	26(10.8)	180(75)	
Partial	6(2.5)	28(11.7)	
Per capita income			0.242
< 1 minimum wage <sup>*</sup>	18(7.5)	139(57.9)	
> 1 minimum wage	14(5.8)	69(28.8)	

\*Minimum wage value in the collection period = R\$: 998.00; \*\*Fisher's test

likely (OR=52.89) to have poor QoL compared to caregivers with another occupation. Regarding work overload, “caregivers who feel that their health was, sometimes/often/always, affected because of their involvement as a caregiver” were more likely (OR=22.92) to have poor QoL compared to caregivers who reported never or rarely, and “caregivers who feel that they have lost, sometimes/often/always, control of life since the illness of the bedridden person” were more likely (OR=49.38) to have poor QoL compared to caregivers who reported never or rarely.

## Discussion

The condition of prolonged chronic illness often means a situation that generates stress and fragility in personal, family and social functioning.<sup>(11)</sup> This assumption is consistent with the results of this re-

**Table 3.** Sociodemographic characteristics associated with the Quality of Life of caregivers of bedridden people at home, in a small city in Northeast Brazil

Variables	Score		p-value
	Bad quality of life n(%)	Good quality of life n(%)	
Sex			0.903**
Male	4(1.7)	0(0)	
Female	230(95.8)	6(2.5)	
Religion			0.858**
Religious	228(95)	6(2.5)	
Not religious	6(2.5)	0(0)	
Age group			0.213**
18-50	136(56.7)	2(0.8)	
>50	98(40.8)	4(1.7)	
Race			0.544**
White	94(39.2)	2(0.8)	
Not white	140(58.3)	4(1.7)	
Education			0.226**
< 12 years of study	134(55.8)	2(0.8)	
>12 years of study	100(41.7)	4(1.7)	
Marital Status			0.253**
With a partner	130(54.2)	2(0.8)	
No partner	104(43.3)	4(1.7)	
Occupation			0.001**
Household	220(91.7)	1(0.4)	
Others	14(5.8)	5(2.1)	
Period of care			0.039**
Full time	203(84.6)	3(1.25)	
Partial	31(12.9)	3(1.25)	
Per capita income			0.343**
< 1 minimum wage <sup>*</sup>	154(64.2)	3(1.25)	
> 1 minimum wage	80(33.3)	3(1.25)	

\*Minimum wage value in the collection period = R\$: 998.00; \*\*Fisher's test

search, as the lay caregiver is mostly dedicated with exclusivity to the daily care of the bedridden patient. Most of the time, according to evidence, this lay caregiver is from the family cycle, such as daughter, neighbor or close friend.<sup>(6,11)</sup>

A cross-sectional study carried out in Turkey, with a total of 4500 caregivers of bedridden patients, showed that 71.8% took care of their parents or siblings. In addition, in relation to factors associated with caregiver overload, when compared with average scores of caregiver overload with Daily Living Activities (DLA) scores, it was found that the mean overload scores for caregivers of patients who were partially dependent for dressing, continence, and feeding issues were significantly higher than the mean scores for caregivers who cared for completely dependent patients. ( $p < 0.01$ ).<sup>(12)</sup>

In this context, the caregiver's overload, consistent with stress, means a negative response in the

provision of care. Caregivers who find it difficult to adapt to meet the demands of care can evolve into overload conditions, becoming vulnerable to physical illness, depression, weight loss and insomnia.<sup>(8)</sup> These characteristics are worrying and were indicated in this research by the high score of the overload, which is similar to another study developed in Sao Paulo, which identified a general overload score of 47.27 points and interference in all domains of the scale (general tension, isolation, disappointment, emotional involvement and environment).<sup>(11)</sup>

Regarding the finding that the largest number of caregivers are female, the feminization of care is revealed, within the scope of a patriarchal society, in which care is more often performed by women. This status of main caregiver was historically designed in the definition of social roles for men and women, mainly influenced by the period in which the male person developed activities outside the house and the woman was responsible for domestic activities, a characteristic currently reverberated on a smaller scale, but still present in society. Therefore, it is understood that the feminization of care is a culturally and socially accepted phenomenon due to gender asymmetries.<sup>(7,13)</sup>

With regard to age, the growth in the number of older adults, as a consequence of the increase in life expectancy, increases the possibility of caregivers of different age groups, specifically elderly and middle-aged. The mean age, 48.2 years old, is similar to a study carried out in the city of Goiania in the State of Goias, with 95 caregivers, which resulted in an average of 49.7 years old.<sup>(14)</sup>

These data must be considered by the health teams, because for there to be quality of care directed to the bedridden, the health of this caregiver must be considered, who, with advancing age, also becomes vulnerable due to functional limitations, high incidence of diseases and disabilities, with possible physical, cognitive and emotional damage and, consequently, a deficit in care.<sup>(15)</sup>

A study carried out with 121 caregivers in Campinas, Sao Paulo, identified that older adults provide care even with psychological problems, such as depression, or the need for extreme physical effort.<sup>(16)</sup> Another study carried out in Teresina,

Piaui, with 208 caregivers information, found that the older the caregiver, the greater the perceived overload.<sup>(2)</sup>

Regarding education, most have few years of study corroborating other evidence. A study with a quantitative-qualitative approach highlighted a higher percentage of caregivers from 1 to 4 years of study and showed a negative correlation between overload and education.<sup>(7)</sup> Overload is also related to the patient's education. A cross-sectional study carried out in Turkey showed a greater overload of care for caregivers of patients with higher levels of education. This may happen due to the increased care overload, as people with higher education have greater knowledge of the patient's needs and seek to provide more assertive care.<sup>(12)</sup>

It should be noted that a lower level of education is of great significance in the identification of contexts of greater social vulnerability, as low education is sometimes associated with lower access to consumer goods.<sup>(7,17)</sup> A study with 50 caregivers of hospitalized dependent patients pointed out that predominantly low education can make it difficult for these people to enter the formal job market, also contributing to a lower understanding of medical prescriptions and leading to a lower understanding of the importance of offering certain care, many of which are related to patient hygiene.<sup>(18)</sup>

When considering the time of care for the bedridden patient, most caregivers were fully dedicated for periods, corroborating a study carried out with 99 caregivers in the countryside of Sao Paulo, in which 67.6% of caregivers are fully dedicated to care.<sup>(19)</sup> This impacts on the overload and QOL of these people due to the need to interrupt a life project, abandon a job, give up social moments, be absent from health units to maintain their own health and difficulty in performing physical activities.

The low economic conditions of caregivers evidenced in this study may be related to the fact that the unpaid work to be carried out at home impairs the income of these people, who are often unable to perform extra domestic work due to the time available to care for the bedridden, and in some circumstances, not having anyone to take care of this person.<sup>(5)</sup>

A study carried out with 71 caregivers in the city of Manoel Vitorino, state of Bahia, found that they had low economic status, performed the role of the home and those who had an income received less than the minimum wage.<sup>(13)</sup>

From this perspective, in this study, the independent variables of the sociodemographic profile that were associated with quality of life were, precisely, the period dedicated to bedridden and occupation. Thus, the reduction of time in favor of care for the bedridden interferes with the performance of basic tasks and recreational activities, which usually end up being dispensed with to prioritize care.<sup>(20)</sup>

Therefore, female caregivers, middle-aged, married, with children, low socioeconomic level, low education and caring for bedridden people experienced greater overload, and consequently had a significant worsening of their quality of life,<sup>(7)</sup> according to the caregiver profile found in this research.

Regarding this profile of caregivers, these findings are similar to those found in other countries, such as Spain, in a study with a total of 829 participants, of which 82.8% were women, with a mean age of 63.3 years old, low education level, with 60% of caregivers having not completed elementary school and presenting an average of 17 hours per day dedicated to care,<sup>(21)</sup> as well as in France, the United Kingdom and Germany with 1322 participants, 64.5% of them were women, with an average age of 67 years old and 78.1% without income.<sup>(22)</sup>

The means of QOL found in the four domains and in the general score were, with a tendency towards dissatisfaction, similar to those identified in another study carried out in Campina Grande, Paraíba, with informal caregivers of octogenarians.<sup>(23)</sup> However, while in this study the greater satisfaction was with the Physical domain and the lowest with Social relations, in the investigation with caregivers of people over 80 years old these domains were, respectively, Environment and Physical.<sup>(23)</sup>

These distortions can be explained by the fact that octogenarians have greater motor dependence, including for mobilization in bed, requiring greater physical effort from caregivers and affecting facets such as daily safety and pain, which showed the highest correlations with QOL and health.<sup>(2,23)</sup>

From this perspective, when the interpretation of the results of this study was launched after the implementation of the logistic regression, it was noticed that the overload variables, in addition to the sociodemographic variables, which are influencing QOL, constitute the sensation of affected health and the loss of life control after the beginning of care for the bedridden person, that is, supporting the inference that the degree of limitation of the bedridden person may be interfering with the caregiver's QoL and, above all, that the level of dependence can directly affect their health.<sup>(2)</sup>

Therefore, considering that the frequency of lay caregivers has become more common, it is necessary to implement support strategies that strengthen the professional-caregiver-user link. From this perspective, this study highlights the importance of actions to reduce the overload and improve the QOL of users of Primary Health Care (PHC), to be promoted by nurses, other health professionals and public managers, who should plan their actions considering the variables associated and identified as predictors in this study. So, it is believed to have contributed to the practice by identifying the facets that should be highlighted in the development of care, educational and self-care activities for lay caregivers.

The limitations of the study, in addition to the impossibility of establishing consistent causal inferences due to the cross-sectional view, are revealed by the need to better investigate the interference of the degree of dependence of the bedridden, the types of care provided and the kinship of the caregiver in the investigated outcomes, variables and relationships not measured in this research.

## Conclusion

Lay caregivers of people bedridden at home have a high degree of overload and dissatisfaction with their quality of life. Occupation and period of care were significantly related to quality of life. In addition, the occupation "Housekeeper" and the overload variables "caregivers who feel that their health was sometimes/often/always affected because of involvement as a caregiver" and "caregivers who feel

they have lost, sometimes/often/always, the control of life since the illness of the bedridden person” were significant predictors of poor quality of life.

## Collaborations

Melo MSA, Coura AS, França ISX, Feijao AR, Freitas CCSL and Aragao JS contributed to the study design, data analysis, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

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