



Relationship between burden and quality of life of informal caregivers of older adults: a cross-sectional study in outpatient care

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ABSTRACT

Objective: To analyze the relationship between burden and quality of life of informal caregivers of older adults cared for in a medium complexity outpatient clinic. **Method:** A descriptive, cross-sectional and correlational study conducted with 20 caregivers of older adults cared for in a medium complexity Health Unit in the city of São Carlos-SP. The following instruments were applied: questionnaire for socio-demographic characterization, Zarit Burden Inventory, and Ferrans and Powers Quality of Life Scale. The interviews were conducted at the Health Unit, during the care procedures with the older adults. All ethical issues have been respected. In the data analysis, the T-test, ANOVA, Pearson and Spearman Correlation Coefficient were used, with a significance level of 5%. **Results:** There was a negative correlation between burden and quality of life ($\rho=0.63$; $p=0.003$). **Conclusion:** Caregivers with high burden scores may present worse quality of life scores.

Descriptors: Family Caregiver; Quality of Life; Secondary Care; Geriatric Nursing.

INTRODUCTION

With aging, the older person may present a compromise in performing their daily life activities, thus demanding the need for a caregiver to help them with the activities taking care of the well-being, health, nutrition, personal hygiene, education, culture, recreation, and leisure of the assisted person⁽¹⁾.

A caregiver is a person responsible for helping an individual, facilitating the performing of their daily life activities, such as nutrition, hygiene, support in taking them to the health services, and offering medications, among others that the individual is limited to do so and needs assistance⁽¹⁾.

In the Brazilian context, most of the time the family is responsible for assuming this role of caring, which occurs in the home setting. This caregiver is usually informal, represented by a family member, a friend, or a neighbor, who carries out the task of caring voluntarily and receives no remuneration⁽²⁾.

Both the national and international gerontological literatures show that the profile of informal caregivers is characterized by female individuals, most of whom are middle-aged or older spouses or married daughters, who live with the older individual, with low schoolings and incomes⁽³⁻⁵⁾.

Some authors state that there are positive and negative aspects in the care process. On the positive side, love in caring for one's neighbor stands out, together with satisfaction with life and well-being by satisfying the needs of the dependent. However, family members are not always prepared to

assume such responsibility, and thus, negative aspects emerge, such as anxiety, stress, depression, and burden, which can negatively impact the quality of life of those involved^(2-3,6).

Recent research studies that analyzed the relationship between burden and quality of life of caregivers of older patients have been found in the literature, in the context of basic care⁽⁷⁾ and in high complexity hospital settings, which have shown that burdened caregivers presented worse perceptions about quality of life⁽⁸⁾. However, research studies of this nature carried out with caregivers of older individuals cared for in medium complexity outpatient clinics are scarce in the national scenario. In addition, other scholars point out that there is no relationship between burden and quality of life of these caregivers⁽⁹⁾.

Given the inconsistency identified in the literature and the scarcity of studies in outpatient settings, it seems important and pertinent to study the existing relationship between burden and quality of life of caregivers of older adults, especially in the context of developing countries like Brazil, where access to resources may be limited. It is worth noting that care in these conditions can be impaired in the face of high levels of burden⁽³⁾ and the low perception of quality of life.

Faced with this scenario, the study aimed to analyze the relationship between burden and quality of life of informal caregivers of older individuals cared for in a medium complexity outpatient clinic of.

METHOD

This is a descriptive, cross-sectional, and correlational study based on research quantitative assumptions. Its structure followed the guidelines present in the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) Declaration.

It was conducted in the city of São Carlos (SP), in the context of a Health School Unit (*Unidade Saúde Escola, USE*), that is, a multidisciplinary academic medium complexity outpatient clinic inserted in the Federal University of São Carlos (*Universidade Federal de São Carlos, UFSCar*). For the older people, this clinic offers care in cardiorespiratory care, neurological, musculoskeletal, and mental health, or in integrative and complementary practices.

The population was composed of caregivers of older individuals who resort to the USE in the UFSCar campus. Caregivers who met the following inclusion criteria were interviewed: being a relative of the older person cared for; receiving no remuneration for performing this care; being 18 years of age or older; being literate; having one hour available during the care provided for the older adult in the referred Unit. Caregivers with cognitive problems, with hearing and/or vision deficits which may hinder communication; and those with less than 12 months as caregivers were excluded.

Initially, the researcher conducted a registration survey to identify the older individuals who were seen at the aforementioned outpatient clinic. Subsequently, a survey was carried out on which of these individuals went to the outpatient clinic

accompanied by their caregivers. On the day that this older person would attend the outpatient clinic, the researcher approached these caregivers to explain the project and invite them to participate in the research during the time they were waiting for the older person in the care procedure. From August to December 2018, 20 interviews were conducted with the caregivers who agreed to participate in the survey when approached. If there was agreement, data collection would start after reading and signing the FICF and it would occur in a single session. The caregivers were submitted to socio-demographic and health characterization and to measures of burden and quality of life. The interviews were conducted by a student of the Undergraduate Nursing Course and lasted a mean of approximately 60 minutes.

Sociodemographic and health data were collected through a questionnaire previously built by the researchers, asking information about gender, age, race/ethnicity, marital status, religious belief, years of study, retirement, family income, smoking, alcoholism, number of diseases, degree of kinship with the older person cared for, how long they have been carrying out the task of caring for this older individual, how many hours a day, if they receive some kind of help, if they took a caregiver course, if they have time to relax, if they carry out leisure activities, and about anxiety, psychological well-being, and self-perception of health.

To evaluate burden, the Zarit Burden Inventory was used. This is a scale made up of 22 questions that evaluate the domains of health, psychological and socioeconomic

well-being of the family caregivers, as well as their relationship with the person being cared for. In the end, all the scores of the questions answered are added up and the result ranges from 0 to 88 points. Thus, burden can be classified as "No Burden" (0 - 20); "Mild to Moderate Burden" (21 - 40); "Moderate to Severe Burden" (41 - 60) and "Intense Burden" (61 - 88)⁽¹⁰⁾.

To assess quality of life, the Ferrans and Powers Quality of Life Scale was used. Composed of two scales with 33 questions, it evaluates the satisfaction and importance given to various aspects of life related to four domains: health/functioning; psychological/spiritual; socioeconomic; and family. The scores are calculated by recoding all the items answered in the "satisfaction" part and weighted by those obtained from the "importance" part. In the end, these quality of life scores range as follows: from 0 to 5 (very bad), 6 to 11 (bad), 12 to 17 (regular), 18 to 23 (good), and 24 to 30 (very good)⁽¹¹⁾.

In the descriptive analysis of the data, frequency distributions, means, and standard deviations were estimated for the study's

continuous variables. Proportions were estimated for the categorical variables. The Kolmogorov-Smirnov test was used to check the normality of the variables. The T-test and ANOVA were used for comparisons of means. Pearson's and Spearman's coefficients were used for correlation analysis. A significance level of 5% was adopted. The data obtained were coded and typed into a spreadsheet and analyzed with the support of the Stata statistical package, version 13. All ethical issues in Resolution 466/2012 that govern research with human beings were observed and respected, as regulated by the National Health Council. This study was approved by the Research Ethics Committee of the Federal University of São Carlos, under opinion number 2,655,483, on 05/15/2018, CAAE 85914418.9.0000.5504.

RESULTS

The sample of this study consisted of 20 informal caregivers of older individuals. Table 1 presents the mean caregiver burden and quality of life scores according to sociodemographic, health, and care condition characteristics.

Table 1 - Mean scores of caregiver burden and quality of life according to sociodemographic, health, and care characteristics. São Carlos, SP, Brazil, 2018 (n=20)

Variables	Total	Zarit Score	P	QoL Score	P
	n (%)	Mean (sd)		Mean (sd)	
Gender					
Female	13(65.0)	34.3(3.9)	0.466 ¹	24.7(1.0)	0.823 ¹
Male	7(35.0)	29.4(5.1)		24.4(0.9)	
Age - Mean (sd)	63.1(8.1)	-0.15*	0.521	0.36*	0.115
Race/Ethnicity					

White	11(55.0)	28.9(14.1)	0.344 ²	25.5(2.0)	0.041²
Brown/Mulatto/ <i>Caboclo</i>	5(25.0)	34.2(15.0)		25.4(3.0)	
Black	4(20.0)	40.8(10.5)		21.2(4.0)	
Marital Status					
Single	2(10.0)	30.0(8.4)	0.916 ²	23.3(0.2)	0.585 ²
Married or lives with a partner	13(65.0)	33.9(14.5)		24.4(3.4)	
Separated/Divorced	3(15.0)	32.7(15.0)		24.4(3.3)	
Widow/Widower	2(10.0)	26.5(21.9)		27.4(0.3)	
Religious belief					
Catholic	13(65.0)	30.1(12.9)	0.504 ²	24.8(2.5)	0.462 ²
Spiritist	4(20.0)	33.0(19.4)		23.0(5.1)	
Evangelical	2(10.0)	46.5(6.4)		27.2(0.0)	
Umbanda	1(5.0)	36.0(0.0)		23.1(0.0)	
Years of study – Mean (sd)	8.5(5.8)	0.13;	0.572	-0.18**	0.436
Retirement					
Yes	13(65.0)	31.6(14.3)	0.676 ¹	25.4(2.7)	0.140 ¹
No	7(35.0)	34.4(13.7)		23.2(3.5)	
Monthly family income					
From 1.0 to 2.9 MWs	14(70.0)	31.2(12.6)	0.025²	24.6(3.0)	0.165 ²
From 3.0 to 4.9 MWs	4(20.0)	45.7(6.8)		22.9(3.1)	
From 5.0 to 10.0 MWs	2(10.0)	16.0(12.7)		28.0(0.3)	
Smoking					
Yes	6(30.0)	34.2(12.8)	0.749 ¹	24.8(3.1)	0.884 ¹
No	14(70.0)	31.9(14.6)		24.5(3.2)	
Alcoholism					
Yes	8(40.0)	29.0(12.8)	0.355 ¹	24.4(2.3)	0.818 ¹
No	12(60.0)	35.0(14.5)		24.7(3.6)	
Number of diseases					
None	7(35.0)	38.1(10.7)	0.400 ²	22.5(3.6)	0.066 ²
One	4(20.0)	32.2(18.4)		25.1(2.9)	
Two or more	9(45.0)	28.4(14.0)		26.0(1.8)	
Self-perception of health					
Very good	1(5.0)	7.0(0.0)	0.104 ²	28.2(0.0)	0.214 ²
Good	12(60.0)	31.7(12.4)		25.1(2.3)	
Regular	7(35.0)	37.7(13.5)		23.2(3.9)	
Anxiety					
Yes	16(80.0)	35.5(12.1)	0.058. ¹	23.7(2.8)	0.007¹
No	4(20.0)	21.0(16.1)		28.1(0.8)	
Psychological well-being					
Yes	16(80.0)	28.6(12.3)	0.006¹	25.3(2.3)	0.045¹
No	4(20.0)	48.5(5.8)		21.9(4.6)	
Kinship with the older adult					

Spouse	10(50.0)	32.1(3.9)	0.876 ¹	24.2(1.0)	0.605 ¹
Son/Daughter	10(50.0)	33.1(5.0)		25.0(0.9)	
Care time					
Less than 1 year	12(60.0)	35.1(14.0)	0.433 ²	24.3(3.5)	0.398 ²
1 to 3 years	6(30.0)	26.3(12.3)		25.9(1.9)	
4 to 7 years	2(10.0)	36.5(19.1)		22.7(2.1)	
Daily hours of care – Mean(sd)	19.7(7.8)	-0.01**	0.953	0.17**	0.455
Receives financial aid					
Yes	8(40.0)	25.0(4.4)	0.041 ¹	25.3(0.8)	0.455 ¹
No	12(60.0)	37.7(3.7)		24.2(1.0)	
Gets help with the care					
Yes	6(30.0)	37.0(3.8)	0.365 ¹	24.6(0.9)	0.964 ¹
No	14(70.0)	30.7(4.1)		24.6(0.9)	
Gets another type of help					
Yes	2(10.0)	41.5(9.5)	0.351 ¹	25.6(1.6)	0.640 ¹
No	18(90.0)	31.6(3.2)		24.5(0.7)	
Took a caregiver course					
Yes	0(0.0)	-	-	-	-
No	20(100.0)	32.6(13.8)		24.6(3.1)	
Takes breaks to relax					
Yes	17(85.0)	30.3(3.2)	0.083 ¹	25.0(0.6)	0.194 ¹
No	3(15.0)	45.3(6.7)		22.4(3.2)	
Performs leisure activities					
Yes	9(45.0)	26.2(4.2)	0.059 ¹	26.2(0.7)	0.034 ¹
No	11(55.0)	37.8(3.9)		23.3(0.9)	

QoL=quality of life; sd=standard deviation; MW=Minimum Wage (the MW at the period of data collection was R\$954.00); *Pearson's Correlation Coefficient; **Spearman's Correlation Coefficient; ¹T-test; ²ANOVA.

Source: Elaborated by the authors, 2018.

Regarding burden, the caregivers of older individuals obtained a mean score of 32.6 points (sd=13.8). They showed mild to moderate burden (50.0%, n=10), followed by moderate to severe burden (30.0%, n=6) and by no burden (20.0%, n=4). The results showed that there was a statistically significant correlation between burden and the following aspects: family income (p=0.025), financial support (p=0.041), and psychological well-being (p=0.006).

Caregivers with a monthly family income from 3 to 4.9 minimum wages, who do not receive financial help and who do not have a feeling of psychological well-being, presented higher burden scores.

In relation to quality of life, the caregivers of older individuals obtained a score of 24.6 points on the mean (sd=3.1). The majority had very good quality of life (70.0%, n=14), followed by good quality of life (25.0%, n=5) and by regular quality of life

(5.0%, n=1). There was a statistically significant correlation between quality of life and the following aspects: leisure activities ($p=0.034$), race/ethnicity ($p=0.041$), anxiety ($p=0.007$), and psychological well-being ($p=0.045$). Caregivers who do not practice leisure activities, who are of the black race/ethnicity, who report anxiety,

and who do not have a feeling of psychological well-being demonstrated lower quality of life scores.

There was a negative correlation between burden and quality of life ($\rho=-0.63$; $p=0.003$) (Figure 1). Caregivers with high burden scores may have worse quality of life scores.

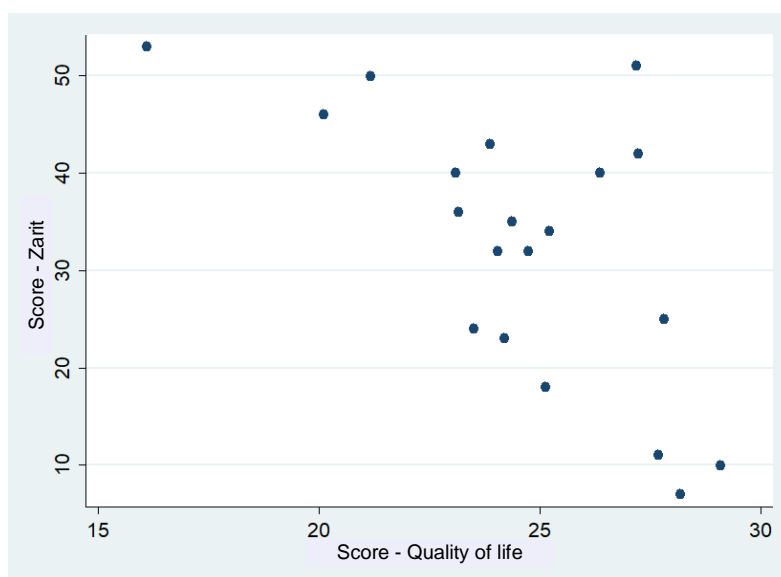


Figure 1 - Dispersion diagram according to caregiver burden and quality of life. São Carlos, SP, Brazil, 2018 (n=20)

Source: Elaborated by the authors, 2018.

DISCUSSION

In the present study, there was a predominance of female, middle-aged or old-aged caregivers, who were spouses or married daughters of the older individuals; with low income, who had been caring for them for less than a year, who did not take courses, and who do not receive help to perform the task of caring, findings similar to those found in national⁽³⁾ and international⁽⁵⁾ studies.

Regarding burden, most of the caregivers presented mild to moderate burden, corroborating the literature^(1,6,12). Most of the

time, the informal caregiver takes on the task of caring for the older person almost suddenly, without prior training, lacking information, and psychologically unprepared⁽³⁾.

In this context, burden may arise as a result of insufficient or no social support, excessive demand from the older person receiving the care, and absence of leisure activities, as well as intense changes in their daily routine and social roles. Such circumstances may cause the caregivers to ignore their own self-care and needs, and may result in them falling ill⁽³⁾.

In terms of family income, 70.0% of the caregivers earned between 1.0 and 2.9 minimum wages per month. However, those who were more burdened had a monthly family income between 3.0 and 4.9 minimum wages. These data differ from the literature, which points out that caregivers with low family income are more exposed to higher levels of burden⁽¹³⁾.

A number of researchers claim that low income can interfere with care for the older individuals, and thus generate financial stress and burden for the caregivers. In the absence of other family members to carry out the task of caring, many caregivers leave their job duties to perform full-time care. In this sense, the source of income of the family can only be the retirement wage of this older adult. In many cases, these resources are not sufficient to supply the needs of that family, which can lead to higher levels of burden on the caregivers⁽⁶⁾. The results showed that caregivers who did not receive financial support had higher burden scores when compared to those who had this kind of support. When the retirement wage of the older person cannot meet all the needs, many caregivers resort to their savings, which can compromise spending on personal or family items and interfere with family dynamics, culminating in higher levels of burden⁽¹²⁾.

Caregivers who do not have a feeling of psychological well-being obtained higher burden scores, a phenomenon found by a European⁽¹⁴⁾ survey. Factors like overlapping roles, self-isolation, lack of family support, and increased intensity of care for the older individuals may burden informal

caregivers and compromise their perception of psychological well-being⁽¹⁵⁾.

Regarding quality of life, 70% of the caregivers in this study presented a very good quality of life. Divergent results were identified in most of the research studies found in the literature⁽¹⁶⁻¹⁷⁾. A possible explanation for this is that the caregivers in this study did not care for older individuals with a high degree of physical dependence and severe cognitive decline.

A survey conducted in Switzerland with 277 informal caregivers of older individuals sought to identify variations in quality of life among members of two distinct groups: caregivers with intense demands, and caregivers who needed low-intensity care. As a result, they found that quality of life differed considerably between the two groups of family caregivers. High-intensity caregivers presented lower quality of life levels ($p < 0.001$) when compared to low-intensity caregivers. The authors concluded that the intensity of care provided by the caregiver can negatively affect quality of life⁽¹⁷⁾.

A number of studies show that the negative perception of quality of life stems from intense care given to highly physically dependent older adults, who are bedridden or who have significant cognitive impairment. Physical exhaustion, stress, low self-esteem, and self-isolation are factors that contribute to the caregivers' negative assessment of their own quality of life⁽¹⁶⁾.

In terms of race/ethnicity, this study showed that black caregivers had lower quality of life scores, which can be explained from the perspective of racism, racial discrimination, and social inequalities

to which they are exposed. However, scholars point out that black caregivers have greater resilience to deal with the stressors associated with the task of caring. Kin proximity to the patient, black ethnicity, good quality of life, healthy life habits, optimism, and satisfaction with life seem to have an influence on increasing resilience in the caregivers⁽¹⁸⁾.

There was a significant correlation between quality of life and anxiety, that is, the greater the caregivers' perception of their anxiety, the lower their quality of life. The literature corroborates these findings and state that unpreparedness in the face of unexpected situations and lack of family support raise anxiety and consequently reduce quality of life⁽¹⁹⁾.

Caregivers without psychological well-being had lower quality of life scores. Similar data were identified in the literature⁽¹⁴⁾. Faced with the exclusive dedication to the care of older individuals, with less time for themselves, scarcity of financial resources and support from other people, and constriction of social life, these informal caregivers can present psychological burden, which tends to reflect negatively on quality of life. In addition, a number of researchers point out that, when informal caregivers neglect their own health, physical symptoms can arise, which will impact on psychological well-being⁽¹⁵⁾.

Regarding leisure activities, this study showed that caregivers who engage in them have higher quality of life scores. Scholars point out that caregivers who take the time to entertain, relax, and participate in group activities demonstrate an increase in life

satisfaction and a reduction in stress levels, which has a positive impact on quality of life⁽²⁰⁾.

There was a negative correlation between burden and quality of life, that is, caregivers with high burden had a worse perception of quality of life. Similar data were identified in the literature^(8,15). Several research studies point out that this relationship may be associated with intense and sudden changes in their daily routine and in their social roles.

The responsibility imposed on the family caregivers may have negative implications on their quality of life, since they often take on this task without adequate guidance, and without the support of other family members, of society, and of health institutions. In addition, the absence of leisure activities and neglecting their own health can result in health harms, with a consequent negative impact on quality of life⁽²⁻³⁾.

The results of this study can provide helpful resources to the health professionals, particularly nurses, on the need for early identification of burden and its relationship with quality of life. With this information, adequate strategies aimed at caregivers of older individuals should be taken into consideration, especially when it comes to caregivers who are also old-aged individuals themselves.

The results showed that there was a negative correlation between burden and quality of life in informal caregivers of older individuals cared for in a medium complexity outpatient clinic. Caregivers with high burden scores may have worse quality of life scores.

Early identification of burden among these caregivers and the development of strategic actions to reverse this situation are fundamental for the maintenance or improvement of their quality of life. Health professionals, and especially geriatric nurses, are responsible for providing guidance, assistance, and social support to the caregivers in order to perform assertive interventions, such as support groups, to accompany these individuals and to welcome their demands, seeking to improve quality of life.

The findings of this study reveal contributions to the management of medium complexity services. Turning attention to the caregivers while they are in the waiting room allows us to understand the potential and challenges in the act of caring. It is imperative that medium complexity services elaborate assertive strategies to support the caregiver based on the understanding of the physical, social or emotional burden involved in the management of care. We encourage future research studies to investigate what the caregiver's need is in order to achieve satisfaction of care, with a view to relieving burden and improving quality of life.

Regarding the limitations of this study, we point out its cross-sectional design and its convenience sample, which do not allow establishing a cause-effect relationship or the generalization of information, respectively. However, these limitations do not invalidate the importance of the results found and encourage the development of new research studies with more robust methodologies for deepening the subject.

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