ORIGINAL ARTICLE

QUALITY OF LIFE FACTORS AMONG SENIOR CAREGIVERS OF OTHER OLDER PEOPLE: A CROSS-SECTIONAL STUDY

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Highlights: (1) Caregivers with low burden, without depressive symptoms and pre-frail predominated. (2) Lower burden, depression, and frailty were associated with quality of life.

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QUALITY OF LIFE FACTORS AMONG SENIOR CAREGIVERS OF OTHER OLDER PEOPLE: A CROSS-SECTIONAL STUDY

ABSTRACT

Objective: To assess the factors associated with the quality of life of 282 senior caregivers who care for older family members. *Method*: A quantitative, cross-sectional study conducted through data collection in 2014, using a protocol consisting of the following instruments: sociodemographic questionnaire, Katz Index, Lawton and Brody Scale, CASP-19, Zarit Burden Inventory, Geriatric Depression Scale, Frailty Assessment (based on a five-component phenotype), Spirituality Scale, and Coping Strategies Inventory. *Results*: The majority of participants were married women who had been caring for their spouses for an average of 9.6 years. It was observed that older caregivers with lower burden levels were 246% more likely to report better quality of life, and for those without depressive symptoms, this likelihood increased to 527%. Non-frail individuals had a 154% higher chance of perceiving better quality of life, as did those with higher levels of spirituality and stronger coping strategies, who showed 65% and 9% greater likelihood, respectively. *Conclusion*: The findings highlight that a better quality of life is associated with key factors such as lower frailty and caregiver burden, especially in the absence of depressive symptoms. This underscores the importance of evaluating, identifying, preventing, and implementing when necessary through targeted interventions addressing these factors.

Keywords: Caregivers. Qualidade de Vida. Older adult. Elderly Health. Health Policy.

INTRODUCTION

The increasing number of older adults in need of care presents challenges not only to governments, particularly in terms of public health care costs, but also to families, who are often responsible for providing care without financial compensation[1]. These older individuals may have chronic illnesses, requiring assistance with daily living activities—ranging from basic tasks (such as bathing and eating) to instrumental tasks (such as managing finances). Such care can be long-term, leading family members to take on the role of caregiver for many years, devoting a significant portion of their day to assisting an older relative[2].

The caregiving role, also referred to as informal caregiving, is most commonly undertaken by adult children and spouses. Due to cultural factors, caregiving is predominantly performed by women[3]. Among spouses, it is common for one older adult to care for another, and the number of people in this situation is increasing worldwide. It is important to note that fulfilling this role can have negative consequences for both physical and mental health, particularly when the caregiver is an aging person[4-5].

In addition to stress and anxiety symptoms, depressive symptoms may arise, negatively impacting the mental health of the senior caregiver. This can, in turn, affect the caregiver-patient relationship and lead to negative outcomes[6]. Another major factor is the physical and emotional burden of caregiving. It is common for primary informal caregivers to receive little to no assistance from other family members, or only financial or material support that does not involve direct care for the elderly relative[7]. As a result, many caregivers manage caregiving responsibilities alone, which can lead to overload, contributing to or worsening health problems. For senior caregivers, these challenges may be further exacerbated, as they coincide with the aging process, which naturally brings biopsychosocial changes[4].

However, it is also important to highlight that caregiving has positive aspects, particularly in terms of the caregiver's ability to adapt. Spirituality, for instance, can play a crucial role in this process.

Through their beliefs, caregivers may find meaning in their role, gain strength to face challenges, renew their sense of hope, and maintain motivation to continue providing care[8]. The caregiver may use this and other coping strategies.

However, it is important to consider that both negative and positive factors directly impact the quality of life of caregivers. Quality of life can be defined as "*an individual's perception of their position in life, within the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns.*"[9] Thus, factors related to caregiving can influence this perception, leading caregivers to consider their quality of life as either better or worse.

Research exploring quality of life among older caregivers and the factors associated with it is necessary, as the number of aging people assuming this role has increased, yet there is still limited research focused on this topic. A study by Rosas and Neri investigated the relationship between quality of life, age, gender, caregiver burden, and emotional support among older adults caring for family members. One of the key findings was the significant negative association between quality of life and caregiver burden. Senior caregivers who had lower burden levels also reported higher perceived quality of life. Therefore, it is evident that a negative perception of quality of life is influenced by multiple factors and may compromise both the caregiver's physical and mental health[10].

Given the importance of understanding what affects quality of life in this population, this study examines the factors linked to the well-being of a sample of older adult informal caregivers. As study hypotheses, it is believed that there is an association between quality of life and the sociodemographic and psychosocial factors of older caregivers.

MATERIALS AND METHODS

This is a quantitative, cross-sectional study conducted with senior caregivers of older adults living within the coverage area of Family Health Units (FHU) in an inland municipality of São Paulo state. The study followed the recommendations outlined in the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement. Data collection took place between April and November 2014.

The inclusion criteria were: being the caregiver of an older person residing in the same household (characterizing an informal caregiving relationship); being 60 years old or older; being registered in an FHU; and providing care to an older adult who required assistance with at least one Basic Activity of Daily Living (BADL), assessed using the Katz Index[11], or with an Instrumental Activity of Daily Living (IADL), assessed using the Lawton and Brody Scale[12]. The aforementioned instruments were applied to both the care recipient and the older caregiver, with the latter needing to be more independent than the person receiving care. Exclusion criteria included: households where all older residents were deemed independent in BADLs and IADLs; individuals who could not be reached after three visits on different days and times; a change of address; the passing of an older resident; or refusal to participate in the study.

The sample was selected from a total of 594 households, where two or more older adults resided, as identified through data provided by health teams from 18 FHUs, representing each micro-area of the municipality. All households were visited, with the following exclusions: 69 households where no one was found after three attempts; 28 households due to change of address; 26 cases due to the death of one of the older resident; 84 refusals to participate; 36 cases where all aging people in the household were evaluated as independent for BADLs and IADLs. This resulted in a total of 351 older caregivers assessed.

Of these, 69 participants were excluded for not having completed the full evaluation of the variables used in data analysis, leading to a final sample of 282 senior caregivers.

Data collection was conducted by trained researchers in the participant's home during a single session, lasting approximately one hour and thirty minutes. The assessment protocol included the following variables, duly adapted and validated for the population:

- Sociodemographic characteristics: sex (female and male), age (in years), schooling level (in years), marital status (married, single, divorced, or widowed), religiosity (Catholic, Evangelical, Christian Congregation, Spiritist, Adventist, other, or none), whether they were practicing (yes or no), and for how long (in years).
- Caregiving context characterization: degree of kinship with the care-dependent older adult (spouse, parent, sibling, in-law, or other), duration of caregiving (years), and hours of caregiving per day.
- Quality of life: assessed using CASP-19, an acronym referring to the psychological constructs analyzed (control, autonomy, self-realization, and pleasure). Through this instrument, participants evaluate the extent to which each item reflects their own feelings about life. The scale consists of 19 Likert-type items (ranging from 0 = never to 3 = always), with scores ranging from 0 to 57[13], here higher scores indicate better quality of life. For data analysis, scores above or below the median threshold of 45.5 points were considered.
- Caregiver burden: measured using the Zarit Burden Inventory (ZBI)[14], consisting of 22 items that assess the perceived impact of caregiving on physical and emotional health, social activities, and financial well-being. The total score is obtained by summing all items and ranges from zero to 88, with higher scores indicating greater caregiver burden. For analysis, older caregivers were classified into two groups based on the sample median (median = 15): classifying them into the groups "Low burden" or "Moderate to severe burden".
- Indicators of depressive symptoms: assessed using the 15-item version of the Geriatric Depression Scale (GDS)[15]. Based on the total score, participants were classified as having: No depressive symptoms; Mild depressive symptoms; Severe depressive symptoms For this study, participants who scored between 0 and 4 were classified as having no depressive symptoms, while those scoring between 5 and 15 were classified as having depressive symptom[16].

- Frailty: assessed according to the five-component phenotype – unintentional weight loss (evaluated by the question: “In the last 12 months, do you think you have lost weight without dieting?” with an affirmative response if the loss exceeded 4.5 kg or 5% of body weight); fatigue (assessed by two questions from the Center for Epidemiological Studies – Depression, CES-D: “1) How often in the past week did you feel that everything you did required great effort?” and “2) How often in the past week did you feel that you could not keep going with your activities?” with an affirmative response if the answer was “always” or “most of the time” for at least one question); low grip strength (assessed by the average of three consecutive handgrip strength measurements of the dominant hand, in kgf, using a Jamar hydraulic dynamometer, Model SH5001, manufactured by SAEHAN®. Older adults in the lowest quintile of strength adjusted for sex and Body Mass Index (BMI) were classified as having low grip strength); slow gait speed (assessed by the average of three measurements of the time taken (in seconds) to walk 4.6 meters in a straight line at a usual pace, allowing the use of a cane or walker. To accommodate acceleration and deceleration, two additional meters were included before and after the walking distance, totaling 8.6 meters. The slowest 20%, based on sex and average height, were classified as having slow gait speed; and low physical activity level (determined by an affirmative response to the question: “Do you think you engage in fewer physical activities than you did 12 months ago?”). The presence of three or more components characterizes the individual as frail; one or two components as pre-frail; and none as non-frail[17]. For the analysis, the sample was classified into frail older adults and non-frail/pre-frail older adults.
- Spirituality: assessed using the Spirituality Scale[18], consisting of five items focused on two dimensions: belief and hope/optimism, aspects that give meaning to life through relationships with oneself, others, and the environment. Responses are based on a four-point Likert scale, ranging from "strongly disagree" to "strongly agree". The score is obtained through elementary statistical procedures, where the midpoint is 2.5 per item. Thus, as long as the scores exceed this point, it can be considered relevant to the dimension of spirituality.
- Coping strategies: assessed using the Coping Strategies Inventory[19], an instrument composed of 19 items rated on a four-point Likert scale (0 = never to 3 = always), representing the frequency with which caregivers use these strategies. The items are grouped into five orthogonal factors: negative emotions, behavioral excesses, and risk behaviors;

control over the immediate environment; religiosity; avoidance; and inhibition of emotions. For data analysis, the total sum of the instrument's items was considered, meaning that higher scores indicate greater use of these strategies.

The data were entered and validated using double-blind data entry in Epidata 3.1 software, then exported to the Statistical Package for the Social Sciences (SPSS for Windows), version 21.0 (IBM Inc., Chicago, IL, USA). Basic descriptive statistics were calculated for all studied variables (frequency, means, medians, and standard deviations). Multiple logistic regression using a stepwise forward selection method was applied to identify factors associated with quality of life[20]. The dependent variable was quality of life, based on CASP-19 scores, categorized as above or below the median threshold (45.5 points). The continuous independent variables were: age (in years), schooling level (in years), spirituality levels (total scores), and coping strategy levels (total scores). The dichotomous independent variables were caregiver burden: 1 = Low burden and 2 = Moderate to severe burden; Depressive symptoms: 1 = With symptoms and 2 = Without symptoms; Frailty: 1 = Frail and 2 = Non-frail. A p-threshold of <0.20 was used for variable selection in univariate analyses. To ensure good model performance, a variable selection criterion was adopted, applying a p-threshold of <0.20 in univariate analyses. For multivariate analysis, a p-threshold of <0.05 was applied.

All ethical principles governing research involving human subjects were upheld, in accordance with Resolution 466/2012 and Resolution No. 510/2016, regulated by the National Health Council. The 2014 study project was approved by the Research Ethics Committee of the Federal University of São Carlos, under opinion No. 416.467/2013. The follow-up study project was approved under opinion No. 4.804.872/2021. All participants agreed to take part in the study by signing the Informed Consent Form.

RESULTS

A predominance of female senior caregivers was observed (75.2%), with most being married (90.4%), having an average age of 69.8 (±7.2) years old, and an average schooling level of 3.8 (±3.7) years. The majority of participants identified as Catholic (62.8%), with 77% practicing their faith, and 73.8% having done so for 10 years or more. It is noteworthy that a low educational level was prevalent among caregivers, with 19.8% being illiterate and

59.6% having up to 4 years of schooling. Regarding caregiving characteristics, most caregivers provided care to their spouse (85.1%), for an average of 9.6 (±12.7) years and 5.8 (±4.6) hours per day. Table 1 presents these findings related to the sociodemographic profile and caregiving context of senior caregivers.

Table 1: Sociodemographic Characteristics and Caregiving Context of Senior Caregivers. N= 282. São Carlos, SP, 2014.

Variables	Category	Mean (SD) / N (%)
Gender		
	Male	70 (24.8%)
	Female	212 (75.2%)
Age		69.8 (±7.2)
	60-69 years old	157 (55.7%)
	70-79 years old	90 (31.9%)
	80+ years old	35 (12.4%)
Schooling		3.8 (±3.7)
	Illiterate	56 (19.8%)
	1-4 years	168 (59.6%)
	5-8 years	29 (10.3%)
	9-11 years	11 (3.9%)
	12+ years	18 (6.4%)
Marital status		
	Married	255 (90.4%)
	Widowed	12 (4.3%)
	Single	10 (3.5%)
	Divorced	5 (1.8%)
Religion		
	Catholic	177 (62.8%)
	Evangelical	67 (23.8%)

	Christian Congregation	14 (5%)
	Spiritist	10 (3.5%)
	Adventist	5 (1.7%)
	Others	3 (1.1%)
	No	6 (2.1%)
Practicing		
	Yes	217 (77%)
	No	62 (22%)
	Missing	3 (1%)
Years as a Practitioner		
	10 years or more	208 (73.8%)
	1 - 9 years	11 (3.9%)
	Less than 1 year	5 (1.7%)
	Missing	58 (20.6%)
Care Recipient		
	Spouse	240 (85.1%)
	Father/Mother	21 (7.4%)
	Brother/Sister	10 (3.5%)
	Father-in-law / Mother-in-law	7 (2.5%)
	Others	4 (1.5%)
Duration of Care (years)		9.6 (±12.7)
Hours of Care per Day		5.8 (±4.6)

SD= standard deviation.

Regarding the quality of life of senior caregivers, the average CASP-19 score was 43.9 (±9.6) points. The highest mean score was observed in the "self-actualization" domain, with 13.2 (±2.5) points, while the lowest mean score was in the "control" domain, with 8.5 (±2.9) points. Regarding caregiver burden, the mean score was 18 points (±14.6), with most caregivers (n=187) classified as experiencing low burden. In terms of depressive symptoms, the majority of the sample (77.7%) fell into the "no symptoms" category. It is noteworthy that 55.7% of caregivers were classified as pre-frail. For spirituality, the mean scores in the "belief" and "hope/optimism" dimensions were 3.8 and 3.3, respectively, indicating the importance of spirituality within the sample. The use of coping strategies among participants was considerable, with a mean score of 58.6. Table 2 provides a detailed description of the health-related variables of the participants.

Table 2: Description of Quality of Life and Health-Related Variables of Senior Caregivers N= 282. São Carlos, SP, 2014.

Variables	Category	Mean (SD) / N (%)
Quality of life		43.9 (±9.6)
	Control	8.5 (±2.9)
	Autonomy	10.6 (±3.4)
	Self-Actualization	13.2 (±2.5)
	Pleasure	11.5 (±3.3)
Burden		18.0 (±14.6)
	Little influence	187 (66.3%)
	Moderate to Severe	95 (33.7%)
Depressive symptoms		3.7 (±2.8)
	No symptoms	219 (77.7%)
	With symptoms	62 (21.9%)
	Missing	1 (0.4%)
Frailty		
	Not frail	59 (20.9%)
	Pre-frail	157 (55.7%)
	Frail	66 (23.4%)
Spirituality		17.8 (±2.5)
	Beliefs	3.8 (±0.4)
	Hope / Optimism	3.3 (±0.7)
Coping strategies		58.6 (±7.1)

SD: standard deviation.

Table 3 Presents the multivariate logistic regression model between quality of life and sociodemographic and psychosocial factors Senior caregivers with low levels of burden were 246% more likely to report a better quality of life. This percentage increased to 527% among caregivers without indicators of depressive symptoms. Additionally, non-frail senior caregivers had a 154% higher likelihood of experiencing better quality of life.

Table 3: Multivariate Logistic Regression Analysis of Quality of Life in Senior Caregivers N= 282. São Carlos, SP, 2014.

Variables	Category	*p* value	OR	CI 95%
Age	Continuous	0.657	1.014	0.955-1.076
Years of schooling	Continuous	0.190	1.071	0.967-1.185
Burden	Moderate to severe	Ref.	-	-
	Little influence	0.002	3.466	1.578-7.614
Depressive symptoms	With symptoms	Ref.	-	-
	No symptoms	0.002	6.277	1.975-19.944
Frailty	Frail	Ref.	-	-
	Not frail	0.029	2.542	1.097-5.888
Spirituality	Continuous	0.000	1.650	1.352-2.013
Coping strategies	Continuous	0.003	1.094	1.031-1.160

OR (Odds Ratio) = Factors associated with quality of life;
95% CI = 95% confidence Interval for the risk ratio; Ref.: Reference level.

DISCUSSION

The results indicate a sample predominantly composed of older women, with an average age of 69.8 years old, low education levels, and practicing Catholics, who have been caring for their spouses for an average of 9.6 years. The highest quality of life scores were observed in the “self-fulfillment” domain, while the lowest were in the “control” domain. Most of the sample was classified as having a low burden, no signs of depressive symptoms, and being pre-frail. The average scores in the belief and hope/optimism categories highlighted the significance of spirituality among the participants, and coping strategies were widely utilized. Non-frail participants and those with lower levels of burden had a higher likelihood of reporting better quality of life, with these chances increasing further among those without depressive symptoms.

The caregiver profile in this study aligns with findings from other published studies[1,4-6,9]. The predominance of older women, with an average age of 69.8 years and married, is a common trend in research on informal caregivers across various care-related topics. In one such study, Lemos et al.[21] tested a model of perceived control among older caregivers, considering factors such as burden, frailty, and quality of life. Their caregiver profile similarly showed a predominance of women, with an average age of 70 years, and 68% of caregivers being spouses of the care recipients. The prevalence of women as caregivers is primarily attributed to cultural factors and the traditional role of protection and care assigned to them.

Regarding schooling, the average in this study was 3.8 years. A considerable number of caregivers had little to no formal education. A study by Flesch et al.[22] conducted with 145 older caregivers, reported an average education level of 5.6 (±4.2) years, slightly higher than in the present study. However, 60% (n=87) of their sample had up to four years of schooling, which is consistent with the findings of this study. These data are relevant as they highlight that illiterate or low-educated older adults are taking on caregiving roles, making it necessary to assess whether (and how) this factor impacts the care provided, their understanding of the dependent older adult’s pathology, and other related aspects.

Regarding the time dedicated to caregiving (an average of 9.6 years and 5.8 hours per day), this finding is similar to the study by Souza et al.[23], which analyzed spirituality and hope among older caregivers, concluding that there is a relationship between levels of hope and spirituality. In that study, conducted with 301 caregivers over 60 years old, 42.6% (n=128) had been caring for a family member for more than five years, and 63.7% (n=192) spent up to five hours daily on caregiving. The duration of caregiving is also a crucial factor to consider, as spouses who cohabit with the care recipient often provide care continuously. Moreover, functional losses may increase over time as the disease progresses.

Studies on religiosity and spirituality are particularly important in older caregivers, as both factors are considered coping strategies used to overcome the challenges of caregiving. Regarding religiosity, most participants were Catholic, and only six caregivers reported having no religious affiliation. The predominance of Catholic older adults was also observed in the study by Brigola et al.[24], where 66.7% (n=66) of the sample identified as Catholic. The authors analyzed health complaints and identified characteristics of caregiving that were associated with them. Another study on spirituality, conducted by Silva et al.[25], aimed to investigate the coping mechanisms caregivers use to alleviate stress. It also found that among the 10 participating caregivers, six were Catholic. The results showed that participants used coping mechanisms to face challenges and attributed their strength to continue caregiving to their faith. The study concluded that spirituality was the primary coping strategy adopted by these caregivers.

Research suggests a higher prevalence of frailty among older caregivers with poorer quality of life, showing significantly lower scores in the physical dimension of quality of life compared to non-frail individuals[26]. There is an expected negative association between quality of life and frailty, as physical health can promote greater autonomy, which is one of the dimensions assessed in quality of life[22].

This association between caregiver burden and quality of life, measured through psychological constructs, has already been verified in other studies[22]. The study by Flesch et al.[4] observes that, for older caregivers, physical health aspects (such as chronic diseases, signs and symptoms, and perceived poorer health) combined with caregiver burden are the most influential factors in their quality of life. It is also important to consider other potentially stressful situations that can further increase the caregiver's perception of burden, such as overlapping roles, household chores, work-related issues, childcare responsibilities, among others[27-28]. The association found in this study, supported by other research, highlights the significance of perceived caregiver burden in their quality of life.

Data from the Frailty in Brazilian Older Adults (FIBRA) study not only demonstrate a relationship between quality of life and depressive symptoms but also indicate that older adults without depression are 5.6 times more likely to achieve higher levels of quality of life than their counterparts[29]. These findings suggest that the negative effects of informal caregiving may lead to emotional or mental strain during its provision, directly impacting the caregiver's quality of life[30]. This underscores the significant impact of depressive symptoms on the health of older caregivers, emphasizing the need for investments in strategies and interventions that contribute to early diagnosis and treatment of depression.

The literature indicates that coping strategies frequently used by older caregivers, such as spirituality, play a crucial role in caregiver stress. Their practice is associated with reduced caregiver burden and psychological benefits, directly influencing quality of life[21].

Some limitations must be considered in this study. Its cross-sectional nature does not allow for establishing a cause-and-effect relationship between outcomes. As it focuses on a specific sample of older caregivers, the findings cannot be generalized. Certain variables that, according to the literature, could be related to quality of life in a sample of older caregivers were assessed. However, additional sociodemographic aspects and caregiving support factors should be explored in future research.

CONCLUSION

The results reflect a predominantly elderly female sample of caregivers for their spouses, with low educational attainment and active religious engagement. Regarding quality of life, the "self-fulfillment" domain stood out, while in spirituality, the categories of belief and hope/optimism demonstrated relevance. Participants also made considerable use of coping strategies. Most of the sample was classified as experiencing low burden, with no indications of depressive symptoms and classified as pre-frail.

Burden, depressive symptoms, frailty, spirituality, and coping strategies were all associated with quality of life in this study, highlighting that elderly caregivers with lower levels of burden and no depressive symptoms are significantly more likely to have a better quality of life than overburdened caregivers with depressive symptoms. Frailty was also a determining factor in the perception of quality of life, as non-frail caregivers rated it more positively.

Taking on the responsibility of caring for an elderly family member can lead to various consequences that negatively impact the caregiver's quality of life. Factors such as burden and depressive symptoms can be detrimental both to the caregiver's health and to their relationship with the care recipient. However, positive factors, such as strengthened family bonds, can also emerge. Spirituality, considered one of the coping strategies, may help caregivers face the challenges brought by the dependency of the elderly person, making them more resilient.

Assessing quality of life and its associated factors is crucial, as it aids in identifying the physical and mental health needs of elderly caregivers. This assessment enables the development of interventions aimed at mitigating negative outcomes, empowering caregivers, encouraging the development of coping strategies, and fostering the exchange of experiences. Therefore, these interventions must take into account that caregivers themselves are also aging and face the demands inherent to this stage of life.

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