Cogitare Enfermagem

ORIGINAL ARTICLE

Work burden and quality of life of informal caregivers of palliative care patients*

HIGHLIGHTS

1. Preventive interventions can reduce informal caregiver burden.
2. Despite moderate burden, caregivers report high satisfaction with their role.
3. Family support positively impacts caregivers' social life.
4. Financial burden negatively impacts caregivers' psychological domain.

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ABSTRACT

Objective: To investigate the correlation between burden and quality of life of informal caregivers of palliative care patients. **Method:** Quantitative, analytical study with 70 caregivers of patients admitted to a hospital in northwestern São Paulo State who completed a sociodemographic questionnaire, the World Health Organization Quality of Life - Bref, and the Informal Caregiver Burden Assessment Questionnaire, from October 2023 to March 2024. Data were analyzed using descriptive statistics, the Shapiro-Wilk normality test, and Spearman's correlation. **Results:** 28 (40%) were children, 54 (77.1%) were women, who devoted more than 18 hours a day to care, with moderate burden for 38 (54%) of participants. Overall quality of life perception was good, despite weaknesses in specific domains such as the social domain. A significant negative correlation ($p<0.05$) was found between burden and quality of life across the different dimensions analyzed. **Conclusion:** These findings suggest the need to strengthen public policies aimed at preventing illness in informal caregivers in palliative care.

DESCRIPTORS: Nursing Care; Caregivers; Quality of Life; Family; Work.

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INTRODUCTION

Palliative care (PC) was first defined in the early 1990s, and its concept was updated by the International Association for Hospice and Palliative Care (IAHPC) in 2002 and revised in 2020. Currently, PC is understood as an active, holistic approach carried out by a multidisciplinary team, aimed at promoting the quality of life (QoL) of people of all ages facing suffering related to serious illness, as well as that of their families, through the prevention and relief of physical, psychosocial, and spiritual suffering[1].

The growing demand for PC is directly related to population aging and the increasing prevalence of chronic and degenerative diseases, as well as some communicable diseases. It is estimated that, annually, 56.8 million people worldwide need this care, of whom approximately 25.7 million are in the last year of life[2]. In this context, caregiver involvement becomes essential to ensure continuity of care and the support patients need.

Caregivers can be classified as formal, when they perform the activity for remuneration, or informal, when they provide care without a professional bond or financial compensation[3]. In PC, the informal caregiver is often a close family member, such as a spouse, children, parents, or siblings[3]. In addition to tasks related to health and hygiene, these individuals take on responsibilities associated with emotional and social support and the maintenance of the patient's daily activities[4].

As the disease progresses and care needs increase, caregivers are exposed to increasingly intense demands, which can result in physical, emotional, social, and financial burden[5-6]. Continuous care often leads to a reduction in time devoted to work, leisure, and self-care, compromising the caregiver's health and well-being. Evidence indicates that family caregivers often need to provide care that exceeds their resources, and they are at greater risk of illness, financial difficulties, and psychological burden compared with individuals without this responsibility[7].

QoL is defined by the World Health Organization (WHO) as an individual's perception of their position in life, taking into account cultural context, value systems, goals, expectations, and personal concerns[8]. It is a multidimensional construct encompassing physical, psychological, social, and emotional aspects[5]. In this sense, the burden resulting from caregiving can significantly compromise caregivers' QoL, producing negative repercussions both for their health and for the care provided to the patient[9-10].

Although the principles of PC recognize the family as the unit of care and recommend systematic support for caregivers, care practice remains predominantly patient-centered, especially in resource-limited settings such as the Brazilian Unified Health System (SUS). Consequently, the assessment and monitoring of caregivers' needs are not always incorporated in a structured way into health care plans.

Given this scenario, investigating the relationship between burden and QoL among informal caregivers can contribute to the development of care strategies aimed at the early identification of vulnerabilities, prevention of illness, and strengthening of the support provided by nurses and the multidisciplinary team to this population[11].

Thus, the objective of this study was to investigate the correlation between burden and quality of life of informal caregivers of patients in palliative care.

METHOD

This is an analytical, cross-sectional, quantitative study, reported according to the recommendations of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE), conducted with informal caregivers of patients admitted

under the care of the PC team, at a large teaching hospital in the interior of the state of São Paulo, Brazil, from October 2023 to March 2024.

The study population consisted of informal caregivers who were accompanying the hospitalized PC patient during the data collection period, forming a non-probabilistic convenience sample. It is worth noting that PC beds are distributed across all specialties of the hospital, with an average length of stay of 20 days and 150 admissions per month. Data were collected on Saturday afternoons, based on the daily list of patients admitted under the care of the PC team. A total of 96 PC patients were identified, of whom 20 had no caregiver, four declined to participate in the study, and two caregivers were paid workers. Thus, 70 informal caregivers took part in the research, who, after agreeing and signing the Informed Consent Form, answered the questionnaires provided by the researcher.

Caregivers aged 18 years or older, who had been informally caring for the patient for six months or more, who understood the information provided, and who expressed willingness to participate after being invited, were included in the study. Caregivers who did not have the clinical condition to understand the questions were excluded.

Three instruments were used for data collection, namely: 1) Sociodemographic data, comprising: sex, age, length of time caring for the patient, whether the caregiver was a family member of the patient, children's ages, monthly income, religion, education level, marital status, daily working hours, and whether the caregiver had another job; 2) the QoL instrument, World Health Organization Quality of Life-Bref (WHOQOL-bref)[12] and; 3) the Informal Caregiver Burden Assessment Questionnaire - QASCI-short version[13].

The WHOQOL-bref is an instrument made up of 26 questions divided into: overall QoL assessment - one question; satisfaction with health - one question. Each item is rated on a five-point Likert-type scale: 1= very poor, 2= poor, 3=neither poor nor good, 4= good and 5= very good. The other 24 questions are distributed across four domains: Physical- seven items, Psychological - six items, Social relationships - three items and Environment- eight items. The response scales for the items are also five-point Likert-type scales: 1= Not at all, 2= a little, 3=moderately, 4= very much and 5= extremely[12]. These scores were then converted to a 0 to 100 scale. The closer to 100, the better the individual's satisfaction or QoL[12].

The QASCI-short version was validated in Brazil in 2022. It comprises 14 items, distributed across seven dimensions: Emotional Burden (EB) - two items; Personal Life Implications (PLI) - two items; Financial Burden (FB) - two items; Reactions to Demands (RD) - two items; Perception of Effectiveness and Control Mechanisms (PECM) - two items; Family Support (FS) - two items; Satisfaction with the Family Role (SFR) - two items. The response scales for the items are also five-point scales:1= No/never, 2= Rarely, 3= Sometimes, 4= Almost always, 5=Always[14]. For the burden analysis, the scores of the items in the positive dimensions (PECM, FS and SFR) were initially reverse-scored. The mean score for each dimension (possible range 1 to 5) was then calculated, and the overall burden was the sum of all the means, ranging from 14 to 70. Higher scores correspond to greater burden[14].

Data were initially organized in Microsoft Excel spreadsheets and subsequently analyzed using the R programming language (R Foundation for Statistical Computing), version 4.4.1. Descriptive and inferential analyses were performed, adopting a significance level of 5% ($p < 0.05$).

The exploratory data analysis comprised the calculation of descriptive measures, including mean and standard deviation for continuous variables. The distribution of these variables was assessed using the Shapiro-Wilk normality test. Considering the analytical assumptions, the correlation between continuous variables was examined

using Spearman's correlation coefficient. Results were presented through correlation coefficients, their respective 95% confidence intervals, p-values, and coefficients of determination, used as a measure of the effect size of the correlation[15-17].

It should be noted that the QASCI analysis was based on the validation article for this instrument, which describes that, regarding the internal consistency parameters across the different models, both Cronbach's alpha and Composite Reliability for the dimensions showed adequate values (>0.7), with the exception of PECM (α =0.33)[14].

The project was approved by the Research Ethics Committee via Plataforma Brasil, under opinion No. 6,016,925, dated April 24, 2023.

RESULTS

Among study participants, 54 (77.1%) were female, with a mean age of 53 years (SD 13.5); 36 (51.4%) had more than eight years of education; 57 (81.4%) lived with a partner; 38 (66.7%) had children older than 21 years of age; 58 (82.8%) reported being a family member of the patient, such as a spouse, child, or sibling, while 12 (17.1%) were identified as other relationships (son-/daughter-in-law, brother-/sister-in-law, grandchild, friend). Time devoted to caregiving exceeded 18 hours per day for 48 (68.6%) caregivers. All reported following a religion, with 40 (57.1%) Catholic; 36 (51.4%) reported an income of R$1,000 to R$3,000 per month; 39 (55.7%) had up to 18 months of caregiving activity, 28 (40.0%) between 18 months and 10 years; 45 (64.3%) reported having no work activity.

WHOQOL-bref domain scores varied considerably across the physical, psychological, social, and environmental aspects, reflecting different QoL perceptions, with moderate perceived physical QoL, relatively positive perceived psychological well-being and living environment, but marked differences in perceived social QoL among participants (Table 1).

Table 1. Descriptive analysis of the quality of life of informal caregivers according to WHOQOL-bref domains. São José do Rio Preto, SP, Brazil, 2024

Variables	Mean	SD	p-value	Min	Percentile			Max
					P25	P50	P75	
Physical domain	60.75	12.74	0.07	32.14	50.00	62.50	70.54	82.14
Psychological domain	67.08	17.17	0.02	20.83	58.33	70.83	79.17	100.00
Social domain	60.36	24.05	0.00	0.00	50.00	66.67	75.00	100.00
Environmental domain	67.67	15.28	0.18	34.38	59.38	70.09	78.12	96.88

Legend: SD - Standard Deviation; Min - Minimum; P - Percentile; Max - Maximum; n=70.
Source: The authors (2024).

According to the QASCI-short version, the burden classification of most study participants was moderate (Table 2).

Table 2. Distribution and Classification of Burden (QASCI) among study participants (n=70). São José do Rio Preto, SP, Brazil, 2024

QASCI Classification	n	%
Severe burden (57 to 70 points)	0	0
High burden (43 to 56 points)	9	12.8
Moderate burden (29 to 42 points)	**38**	**54.3**
Low burden (14 to 28 points)	23	32.8

Source: The authors (2024).

The analysis of the QASCI-short version dimensions is presented in Table 3. The scores reflect moderate Financial Burden, but with significant variability, indicating that some caregivers face a higher financial burden. Caregivers, on average, perceive Reactions to Demands as relatively low, although there is individual variation. The mean family support score suggests that most caregivers perceive a moderate to high level of family support.

Despite the challenges, caregivers generally report high satisfaction with their role and with the family member they care for. (Table 3)

Table 3. Descriptive analysis of the burden of informal caregivers according to the dimensions of the QASCI-short version (n=70). São José do Rio Preto, SP, Brazil, 2024

Variables	Mean	SD	p-value	Min	Percentile			Max
					P25	P50	P75	
Financial Burden	2.39	1.41	0.00	1.00	1.00	2.00	3.50	5.00
Reactions to Demands	1.74	0.98	0.00	1.00	1.00	1.25	2.00	5.00
Family Support	3.79	1.34	0.00	1.00	3.00	4.00	5.00	5.00
Satisfaction with the Role and with the family member	4.64	0.83	0.00	1.50	5.00	5.00	5.00	5.00

Legend: SD - Standard Deviation; Min - Minimum; P - Percentile; Max - Maximum; n=70.
Source: The authors (2024).

Table 4 presents the Spearman correlation, revealing associations between the variables analyzed (Burden and QoL), indicating both the strength and direction of these relationships, which provide insight into the precision of the coefficients.

A significant negative correlation was observed between Emotional Burden and the Psychological domain ($p<0.05$), Social domain ($p<0.01$), and Environmental domain ($p<0.05$), and a non-significant correlation with the Physical domain. The variable Personal Life Implications also shows a negative correlation with all QoL domains (Physical, Social, and Environmental $p<0.01$; and Psychological $p<0.001$), reflecting a complex interaction between Personal Life Implications and the different aspects of well-being. Financial Burden shows a significant negative correlation with the Physical domain ($p<0.01$), environmental ($p<0.001$), psychological ($p<0.01$), and a non-significant correlation with the Social domain, suggesting that higher Financial Burden is associated with reduced values in these domains. (Table 4)

The Reactions to Demands dimension shows a non-significant association - negative with the Psychological, Social, and Environmental domains and positive with the Physical domain; Family Support shows a positive association with the QoL domains, but significant only with the Social ($p<0.01$) and Environmental ($p<0.001$) domains. Satisfaction with the Role and with the Family Member shows a non-significant positive association between the physical and environmental domains and negative between the psychological and social domains. (Table 4)

Table 4. Correlation between Quality of Life (WHOQOL-bref) and caregiver Burden (QASCI) of palliative care patients (n=70). São José do Rio Preto, SP, Brazil, 2024

Burden	Domains			
	Physical	Psychological	Social	Environmental
Emotional Burden	-0.12 r = [-0.35, 0.12]	-0.23 * r = [-0.44, 0.01]	-0.40 ** r = [-0.58, -0.18]	-0.26 * r = [-0.47, -0.03]
Personal Life Implications	0.29 ** r = [-0.49, -0.06]	-0.43 *** r = [-0.6 -0.22]	-0.34 ** r = [-0.53, -0.11]	-0.33 ** r = [-0.52, -0.10]
Financial Burden	-0.36 ** r = [-0.55, -0.14]	-0.36 ** r =[-0.55, -0.14]	-0.21 r = [-0.42, 0.03]	-0.47 *** r = [-0.63, -0.26]
Reactions to Demands	0.12 r = [-0.12, 0.35]	-0.25 r =[-0.46, -0.02]	-0.20 r = [-0.42, 0.04]	-0.15 r = [-0.37, 0.09]
Family Support	0.02 r = [-0.22, 0.25]	0.14 r = [-0.1, 0.36]	0.42 *** r = [0.21, 0.60]	0.32 ** r = [0.09, 0.52]
Satisfaction with the Role and with the Family Member	0.13 r = [-0.11, 0.35]	-0.02 r = [-0.25, 0.22]	-0.08 r = [-0.31, 0.16]	0.19 r = [-0.05, 0.41]

Legend: *indicates p < .05. ** indicates p < .01. *** indicates p < .001. Values in brackets indicate the 95% confidence interval for each correlation, and n=70.

Source: The authors (2024).

DISCUSSION

The complexity of providing uninterrupted care throughout the progressive course of a disease causes numerous insecurities, uncertainties, and vulnerabilities for the family caregiver, leading to burden during the caregiving responsibility and a consequent worsening of their QoL[11]. This is an aspect that should be considered by nurses and other PC team professionals when assessing the patient.

Other studies also point to a predominance of female caregivers, children, spouses, age over 21 years, Catholic religion, as well as monthly income[18-20].

From a feminine ethics perspective, the responsibility of caregiving is attributed to women, who provide care for others as an obligation: when young, they care for their children and husband; when adults and older adults, they care for their parents. This is attributed to women's receptive nature, but they often accumulate multiple roles and, in some cases, must also perform professional activities outside the home[19]. Having a partner and children older than 21 years is a factor that can favor and strengthen the ability to provide care, as they can share caregiving responsibilities and reduce burden in the caregiving process[21].

Although caregivers face significant demands, especially in the financial domain, and deal with continuous caregiving demands, they report perceiving adequate family support and largely demonstrate satisfaction with the role they perform. The heterogeneity of responses shows individual differences in how support and burden are perceived and experienced, signaling the need for multidisciplinary team interventions directed at the caregiver, with the potential to minimize the negative impacts of this disease process. Thus, it becomes essential to consider sociodemographic variables, such as age, ethnicity, and education level, as well as the type of relationship with the person being cared for (spouse/partner or adult children), since these factors can influence both the degree of involvement and the strategies adopted to reconcile caregiving demands with the caregiver's other daily activities[22].

Another study highlights that an unfavorable financial condition, as observed in this research, can influence the quality of care provided and generate more distress and anxiety in the family caregiver, given the expenses with medications, food, hygiene, as well as other products needed for patient care[23]. A study points out that adult child caregivers may offer fewer hours of care but experience higher levels of social/emotional and, especially, financial burden than spousal caregivers[7].

Often, caring for a family member requires leaving employment, resulting in loss of income, which, in turn, increases the risk of financial difficulty for caregivers/family members, especially younger ones, which influences the caregiver's physical, psychological, and environmental quality of life[24].

Belonging to a religious community offers caregivers not only spiritual support but also emotional support for daily practices, and can provide a network of people willing to help through prayers, visits, or even direct assistance with patient care activities. Faith and religious practice represent strength and resilience, helping caregivers cope with everyday challenges[25].

Most informal caregivers devote long hours to caregiving, and a significant proportion combines this role with other work activities. This overlap of responsibilities can negatively affect the QoL and health of these individuals. Furthermore, the diversity of family relationships and occupations reinforces the complexity inherent in the role of the informal caregiver, especially among those who accumulate multiple roles. The female predominance in this context stands out, reflecting sociocultural constructions that assign women the responsibility for family caregiving, often to the detriment of self-care and their own needs[19].

The absence of adequate planning of caregiving activities has direct implications for the caregiver's health. Evidence from a study conducted in the United States indicates that reconciling formal work with caregiving demands within the family environment constitutes a significant challenge for both men and women. This contributes to increased burden and stress levels, and it was observed that caregivers engaged in full-time work schedules had worse QoL compared with those who provide care part-time. In this sense, the implementation of public policies aimed at full-time caregivers is especially relevant for promoting these individuals' well-being. Such findings reinforce the perspective that work-related norms place additional pressure on caregivers who accumulate work and family responsibilities in the process of caring for a loved one[26].

Results from a study conducted in China showed that caregivers of PC patients present moderate levels of burden, manifested across different dimensions, including physical, emotional, social, and economic aspects. Emotional burden was the most prominent dimension, suggesting that psychological distress is one of the main challenges faced by caregivers. Based on these results, the authors advocate for the adoption of family-centered PC approaches and the promotion of educational actions that broaden the population's understanding of the principles and objectives of PC[27].

Another study, conducted in Australia, found that caregivers working part-time had better scores for satisfaction with work-life balance than those working full-time[28].

The study conducted in Maranhão, with family caregivers of chemotherapy patients, with characteristics similar to those of this research, found that certain caregiver conditions, such as sex, medication use, degree of kinship, work leave, health problems, and length of comorbidity, were directly associated with the level of burden, and that the assistance received and the division of responsibilities among family members were essential for reducing the level of burden[29].

A significant correlation between burden and QoL was also found in a study conducted in Santa Catarina with caregivers of post-stroke patients, which showed a lower index of satisfaction regarding the physical and environmental domains[30].

Caregivers of PC patients have, in practice, good caregiving capacity, but with weaknesses regarding the emotional and relational dimensions, as well as self-care, especially distress, anxiety, and fear of the family member's death, which can be addressed with the attention and support of a healthcare team qualified in the PC philosophy[22].

Caregivers who receive social support show better QoL and tend to use more effective coping strategies compared with those who have less social support; that is, there is a correlation among the various dimensions of social support, showing that positive social interaction and emotional support have a significant impact on caregiver burden. Another factor to be considered as a predictor of impasse for caregivers is the presence of comorbidities, which may already exist before the caregiving role begins or develop after caregiving activities start, a condition that is frequently associated with the caregiver's emotional health problems and QoL[11].

These findings can guide nurses' activities, with health education programs and support for informal caregivers, such as support groups, as a strategy to reduce the physical, social, and emotional impact on these caregivers, who are often not guided in coping with PC.

A limitation of this research regarding the generalization of the data is that it is a cross-sectional study conducted at a single institution, at one point during hospitalization, with a small number of participants, in addition to being a convenience sample dependent on the availability of caregivers during the data collection period. This type of selection may result in certain caregiver profiles being underrepresented or overrepresented in the sample, or lead participants to underestimate or overestimate aspects related to burden or QoL.

Thus, there is a need for further studies aimed at better understanding the needs of caregivers in the PC field, so that support actions and nursing interventions can be studied and provided, with a view to reducing the physical, mental, social, and spiritual impacts on both the caregiver and the patient.

CONCLUSION

The data indicate that, while the psychological and environmental domains are perceived more positively and consistently, the social domain shows greater disparity in ratings, possibly reflecting varied contextual and interpersonal influences. At the same time that caregivers experience financial burden and some demands, they perceive good family support and are largely satisfied with their role. The variability in responses reflects individual differences in perceptions of support and burden, indicating areas where interventions could be beneficial in relieving the burden on caregivers.

A significant negative correlation was observed between Emotional Burden and the Psychological, Social, and Environmental Domains of QoL; between Personal Life Implications and all QoL domains; between Financial Burden and the Physical, Psychological, and Environmental domains; and between Family Support and the Social and Environmental domains. The correlations were not significant between Satisfaction with the role and with the family and between Reactions to Demands and the QoL domains.

It is believed that this study can contribute to the development of future research with a larger number of participants, conducted in different care settings and with longitudinal designs, allowing for a deeper understanding of the relationships between burden, QoL, and social support among informal caregivers. In addition, it may contribute to strengthening public policies aimed at protecting and monitoring

caregivers of PC patients, considering the impact of burden on the health and well-being of these individuals.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - **Pinheiro BNA, Pinto MH.** Drafting the work or revising it critically for important intellectual content - **Pinheiro BNA, Pinto MH, Alves EA, Canille RMS.** Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - **Pinheiro BNA, Pinto MH.** All authors approved the final version of the text.

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