

ORIGINAL ARTICLE

BURDEN OF FAMILY CAREGIVERS OF CANCER PATIENTS IN PALLIATIVE CARE*

HIGHLIGHTS

1. Most of the main caregivers are women.
2. Caregivers have health problems.
3. Moderate to severe overload.
4. Some illnesses increase the caregiver's burden.

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ABSTRACT

Objective: To analyze the correlation between the burden of family caregivers of cancer patients in Palliative Care and the variables gender, age, health problems, and length of care. **Method:** Descriptive correlational study with a non-probabilistic sample of 147 family caregivers at the Oncological Palliative Care Clinic in 2021 in Belém do Pará - Brazil. The Zarit Overload Scale was used to collect data, with descriptive and inferential statistical analysis. **Results:** 86 (58.5%) of the caregivers were female, 66 (44.9%) caregivers felt "Very overloaded", and 104 (70.7%) had Moderate to Severe overload. There was no consistency in concluding that the variables gender, age group, health problems, or length of care had a statistically significant relationship ($p > 0.05$). **Conclusion:** It is hoped that the results will contribute to increasing knowledge of the subject, supporting care practice, and formulating public policies to meet the needs of caregivers of family members who are ill with cancer.

KEYWORDS: Overload; Caregivers; Palliative Care; Oncology Nursing; Neoplasms.

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INTRODUCTION

Cancer is the second leading cause of death worldwide and is estimated to be responsible for 9.6 million deaths¹. In this way, more people are entering the field of Palliative Care, which aims to improve the quality of life of patients and their families who face associated life-threatening problems through early identification, correct assessment, and treatment of pain and other physical, psychosocial, and spiritual problems².

How a family faces the illness of a loved one with cancer is shrouded in a mixture of feelings. Care is a personal action taken by a person or someone else for the continuity of life. In prolonged illness, such as cancer, these actions are focused on the sick person, with a reduction in self-care and an intense burden on the family caregiver (FC)³.

Faced with the changes resulting from the illness, the family tends to reorganize itself to offer the care that the patient needs at this critical moment, which justifies the role of the FC. The FC is an informal care agent responsible for the care demands, usually mediated by relationships of affection and commitment, which unite the family member, friends, or neighbors with the sick/dependent person⁴.

FCs play a fundamental role in maintaining the lives of sick people who need care. However, the study reported that these caregivers may experience psychological problems such as anxiety or depression, a feeling of helplessness in the face of the situation, as well as difficulties sleeping; a worsening in their general quality of life, they may feel helpless and financial difficulties resulting from possible changes in employment and health expenses, in addition to a feeling of social isolation as a result of providing this care. They also suffered from reduced self-care due to physical, emotional, spiritual, and social overload⁵.

The FC of a patient in oncology palliative care needs to maintain their self-care so that caring favors them and their sick family member, as it is fundamental for the quality of life and well-being of the patient and is essential for decision-making. The overload of activities, decisions, and the definition of the therapeutic path for the sick person results in the physical and mental overload of the FC without them realizing or valuing their own needs, which could make them ill⁶.

Because of the above, the research question arose: what is the degree of burden on family caregivers? The hypothesis established was: The overload of family caregivers is influenced by the variables gender, age, health problems, and care time, and is expressed by null hypothesis (H_0) - There is no relationship between caregiver overload and the variables gender, age, health problems and care time, and alternative hypothesis (H_1) - There is a relationship between overload and the variables gender, age, health problems and care time.

Therefore, the objective was to analyze the correlation between the burden of family caregivers of cancer patients in Palliative Care and the variables gender, age, health problems, and length of care.

METHOD

This is a descriptive correlational study with a quantitative approach involving family caregivers of cancer patients admitted to the Oncology Palliative Care Clinic (CCPO) of a High Complexity Oncology Center (CACON) in the city of Belém, Pará. This institution works in teaching, research, and extension in health, as well as assisting in medical specialties and Radiotherapy and Nuclear Medicine Services.

The study sample consisted of 147 oncology patients, with sample calculation for finite populations and a non-probabilistic sampling technique for convenience, according to their turnover between admission and discharge, with people who were more easily accessible to participate. A 95% confidence interval was established, with a significance level of 1.96 and a maximum error (E) of 0.05 (5%).

The selection criteria were family members over 18 who declared themselves the main caregivers, even if they shared the care, or caregivers who stayed with the sick person in the hospital for at least 72 hours. The exclusion criteria were caregivers of patients attending their first appointment at the Palliative Care service or in outpatient care and caregivers with no family ties.

During data collection between August and November 2020, according to the availability of caregivers, preventive measures to combat the SARS-CoV-2 virus pandemic were maintained. The researcher checked with the caregivers present that they met the selection criteria for the study. In cases of eligibility and acceptance, they were informed about the research objectives, the benefits, and possible risks and were given and read the Informed Consent Form (ICF).

For data collection, a form was used to characterize the caregivers according to the Likert scale, divided into patient code and identification; sociodemographic information about the caregiver; care information; health conditions, and lifestyle habits, prepared by the researchers; and the Zarit Burden Scale - Burden Interview (ZBI) questionnaire. The Zarit Scale has been one of the most widely used in Brazil in studies assessing caregiver burden. It consists of 22 questions, with a Likert-type score from 0 to 4: 0 (Never), 1 (Rarely), 2 (Sometimes), 3 (Often) and 4 (Always). In the last item, the score has other names: 0 (Not at all), 1 (A little), 2 (Moderately), 3 (Very), and 4 (Extremely). The sum of the scores for all the items gives the final overload score. There is no overload for scores below 21, Moderate to Mild overload for scores between 21 and 40, Moderate to Severe overload for scores between 41 and 60 points, and Severe overload for scores between 61 and 88⁷.

The data was tabulated in Microsoft Excel® 2019 spreadsheets, processed, and analyzed using descriptive and inferential statistics in the Statistical Package for the Social Sciences (SPSS) software version 24.0, all in a Windows 10 environment.

The *Kolmogorov-Smirnov* test was used to analyze the normal distribution of the variables, and a significance level of $p\text{-value} < 0.05$ was adopted. In other words, if $p\text{-value} < 0.05$, H_1 is accepted = the observed frequencies differ significantly for the different groups. The results were analyzed using descriptive statistics, correlation, and comparison of means, using the Likert scale and the Analysis of Variance test to compare the average scores obtained in the evaluations.

This study was approved by the Research Ethics Committee of the Universidade Federal do Pará (UFPA), under opinion No. 4.059.404, and the Ophir Loyola Hospital (HOL), under opinion No. 4.115.162.

RESULTS

Among the caregivers in this study, 86 (58.5%) were female, with an average age of 40 years ($\mu = 39.76$), and 46 (94%) of them had been involved in informal care for between one and five years (Table 1).

Table 1 shows that 84 (57.1%) of the caregivers had some kind of health problem. Of these, 76 (51.7%) reported back pain and 16 (10.9%) were diagnosed with Systemic Arterial Hypertension.

After statistical analysis, it was found that the presence of health problems and the

occurrence of back pain showed no statistically significant difference ($p>0.05$). Thus, the null hypothesis (H_0) was not rejected, indicating that the health problem was not correlated with family burden (Table 1).

However, it was observed that problems such as shoulder pain, hypertension, hernias, claustrophobia, gastritis, depression, asthma, diabetes, HIV seropositivity, *Vogt-Koyanagi-Harada* Syndrome, polycystic ovaries, osteoporosis; medication use; and smoking showed statistically significant differences ($p<0.05$). Therefore, the null hypothesis (H_0) was rejected, showing that these variables influenced the burden of family caregivers, as shown in Table 1.

Table 1 - Distribution of family caregivers according to health. Belém, PA, Brazil, 2020.

Caregivers' health	n	%	p-Value
Do you have any health problems?			
Yes	84	57.1	0.099ns
No	63	42.9	
Shoulder Pain			
No	89	60.5	0.013*
Yes	58	39.5	
Coastal Pain			
Yes	76	51.7	0.741ns
No	71	48.3	
Systemic Arterial Hypertension			
No	131	89.1	0.000*
Yes	16	10.9	
Hernias			
No	145	98.6	0.000*
Yes	2	1.4	
Claustrophobia			
No	146	99.3	0.000*
Yes	1	0.7	
Gastritis			
No	146	99.3	0.000*
Yes	1	0.7	
Depression			
No	146	99.3	0.000*
Yes	1	0.7	
Asthma			
No	145	98.6	0.000*
Yes	2	1.4	
Diabetes			
No	139	94.6	0.000*

Yes	8	5.4	
HIV positive			
No	146	99.3	0.000*
Yes	1	0.7	
Vogt-Koyanagi-Harada syndrome			
No	146	99.3	0.000*
Yes	1	0.7	
Polycystic ovary			
No	146	99.3	0.000*
Yes	1	0.7	
Osteoporosis			
No	146	99.3	0.000*
Yes	1	0.7	

Source: Research protocol (2020).

Legend: ns: Not significant

Table 2 shows the overload assessment in family caregivers obtained using the ZBI questionnaire. There was a significant difference between the proportions of answers; in all the questions, the answer "often" by the caregivers stood out, with 95 (64.6%) of them in the question 'Do you feel you could take better care of your relative?'. To the question 'Do you feel you don't have enough money to take care of your family member, adding up your other expenses?', the majority, 137 (93.2%), answered 'almost always'. In addition, 66 (44.9%) caregivers said they felt "Very overburdened".

Concerning the general burden of caregivers, three (2%) presented an Absent burden, 35 (23.8%) as Moderate, 104 (70.7%) as Moderate to Severe, and five (3.4%) as Severe.

Table 2 - Distribution of family caregivers according to the score obtained in the ZBI questionnaire. Belém, PA, Brazil, 2020.

ZBI items	Answers					P-Value	
	N*	QN*	AV*	F*	QS*		
1. Do you feel your family member asks for more help than he/she needs?	n	123	20	1	1	2	0.000*
	%	83.7	13.6	0.7	0.7	1.4	
2. Do you feel you don't have enough time for yourself because of your time with your family members?	n	4	16	87	34	6	0.000*
	%	2.7	10.9	59.2	23.1	4.1	
3. Do you feel stressed between caring for your family member and your other responsibilities with family and work?	n	11	11	72	52	1	0.000*
	%	7.5	7.5	49.0	35.4	0.7	
4. Do you feel ashamed of your family member's behavior?	n	70	69	6	2	0	0.000*
	%	47.6	46.9	4.1	1.4	0.0	
5. Do you feel irritated when your family member is around?	n	64	41	41	1	0	0.000*
	%	43.5	27.9	27.9	0.7	0.0	

6. Do you feel your family member negatively affects your relationships with other family members or friends?	n	43	45	57	2	0	0.000*
	%	29.3	30.6	38.8	1.4	0.0	
7. Do you fear for your family member's future?	n	3	3	35	61	45	0.000*
	%	2.0	2.0	23.8	41.5	30.6	
8. Do you feel that your family member depends on you?	n	0	5	47	65	30	0.000*
	%	0.0	3.4	32.0	44.2	20.4	
9. Do you feel tense when your family member is around?	n	24	27	59	35	2	0.000*
	%	16.3	18.4	40.1	23.8	1.4	
10. Do you feel your health has been affected by your involvement with your relative?	n	4	9	33	78	23	0.000*
	%	2.7	6.1	22.4	53.1	15.6	
11. Do you feel you don't have as much privacy as you would like because of your family member?	n	5	16	51	68	7	0.000*
	%	3.4	10.9	34.7	46.3	4.8	
12. Do you feel that your social life has been impaired because you care for your family member?	n	4	10	35	66	32	0.000*
	%	2.7	6.8	23.8	44.9	21.8	
13. Do you feel uncomfortable having visitors at home because of your family member?	n	32	44	66	5	0	0.000*
	%	21.8	29.9	44.9	3.4	0.0	
14. Do you feel that your family member expects you to care for him/her as if you were the only person he/she could depend on?	n	5	5	38	73	26	0.000*
	%	3.4	3.4	25.9	49.7	17.7	
15. Do you feel you don't have enough money to care for your family members on top of your other expenses?	n	1	2	1	6	137	0.000*
	%	0.7	1.4	0.7	4.1	93.2	
16. Do you feel you cannot look after your family member for much longer?	n	12	19	61	49	6	0.000*
	%	8.2	12.9	41.5	33.3	4.1	
17. Have you lost control of your life since your family member's illness?	n	25	35	53	34	0	0.000*
	%	17.0	23.8	36.1	23.1	0.0	
18. Would you like to let someone else take care of your family member simply?	n	29	28	52	38	0	0.000*
	%	19.7	19.0	35.4	25.9	0.0	
19. Do you feel uncertain about what to do for your family member?	n	1	13	39	85	9	0.000*
	%	0.7	8.8	26.5	57.8	6.1	
20. Do you feel you should do more for your family member?	n	20	8	36	78	5	0.000*
	%	13.6	5.4	24.5	53.1	3.4	
21. Could you take better care of your family member?	n	8	4	35	95	5	0.000*
	%	5.4	2.7	23.8	64.6	3.4	
22. how burdened do you feel caring for your family member?	n	3	9	64	66	5	0.000*
	%	2.0	6.1	43.5	44.9	3.4	

Source: Research protocol (2020). Questionnaire: Burden Interview (Zarit & Zarit, 1987); SCAZUFCA, 2002).

*N: Never; QN: Rarely, AV: Sometimes; F: Often, QS: Almost Always

In the correlation analysis (Table 3), there was not enough consistency to conclude that the variables gender, age group, health problems, or length of time in care had a statistically significant relationship ($p>0.05$) with the ZBI score. Therefore, the null hypothesis (H_0) was not rejected.

Table 3 - Comparison of mean caregiver burden according to caregiver variables: gender, age, health problems, and length of care. Belém, PA, Brazil, 2020.

Variable	ZBI score		P-Value	
	Average	DP		
Sex	Female	46.2	9.3	0.496ns
	Male	45.1	10.4	
Age group	18 a 27	46.9	12.2	0.330ns
	28 a 37	44.5	10.1	
	38 a 47	43.7	8.9	
	48 a 57	48.3	7.6	
	58 a 67	46.4	10.0	
Do you have any health problems?	No	45.3	10.7	0.642ns
	Yes	46.1	9.1	
How many hours do you provide care?	More than 10 hours	46.2	8.8	0.637ns
	Full-time	45.4	10.4	

Source: Research protocol (2020).

DISCUSSION

Overload is conceptualized as the limit of an individual's physical and psychological state in the face of constant extreme stress, under which they cannot develop viable and effective coping solutions to change their condition and adapt better to the situation, which can reflect on their state of health and quality of life⁴. Another author describes overload as a multidimensional perspective on the caregiver's bodily and mental health, including their feelings, the individual's relevance, and social life, resulting from caring for their family member⁸.

In this study, three (2%) caregivers presented Absent overload, 35 (23.8%) as Moderate, 104 (70.7%) Moderate to Severe, five (3.4%) as Severe, and 66 (44.9%) felt "Very overloaded". These findings align with a study⁹, in which 40% of caregivers presented severe overload, and another study showed 42% with mild to moderate overload and 58% with moderate to severe overload¹⁰. Another study¹¹ found that Moderate and Moderate to Severe overload were the most common, with 35.59%. Caregivers also indicated weariness and a general overload related to caring for the patient¹².

However, the findings of other studies differ, as 53 (40.1%) of the family caregivers of cancer patients showed Mild to Moderate overload, and 12 (9.1%), Moderate to Severe overload⁴; Mild overload for 63.7% of the participants, Moderate for 18.15% and Severe for 18.15%¹³; absence of overload (50.8%), 53 (40.1%) with Mild to Moderate overload and 12 (9.1%) with Moderate to Severe overload, as well as another study, which found

overload in 31% of caregivers and 69% of caregivers with absence of overload^{4,14}.

Individuals begin to live better by understanding their process and the context surrounding them, and nurses can facilitate this process during their care practice with family caregivers. To this end, the self-care theory can be adopted, which considers the therapeutic needs of individuals, both objective and subjective, the longitudinality of care in nursing actions, and the preparation of these individuals for the future maintenance of self-care/care actions independently¹⁵.

On the other hand, the caregiver is immersed in the so-called "caregivers' loneliness", a feeling of solitude and abandonment, added to the lack of hospital facilities for the patient's companions. Despite the discussion about the overload of informal caregivers, few publications problematize this issue, especially for caregivers of hospitalized patients¹⁶.

The fact that 66% of the caregivers said that they should do more for their family members may be related to the caregivers' loneliness accentuates the burden due to their self-perception of responsibility for the situations surrounding them. This results in fear of facing the future¹⁷ and a high sense of overload due to the high demands of care¹⁰.

In the hospital environment, caregivers have their families assisted by the multi-professional team. Still, this environment can also generate overloads, such as wear and tear stress and even health problems. Another negative aspect of this environment is that these caregivers experience more social isolation, moving away from their belongings and routine, and short visiting hours¹⁶.

This discussion has become indispensable due to the social reality of the SARS-CoV-2 virus pandemic, which has drastically affected individuals' collective and individual lives. During the critical period of the pandemic, the patient remained hospitalized with the help of a caregiver, although it was not always possible to take turns with another companion. This further accentuated the physical and mental strain and health problems, which, if left untreated, could develop into serious psychiatric consequences. The whole is represented by the remoteness but also by the lack of comfort and sleep, the absence of a suitable place to sleep, and the lack of structure. Overload is, therefore, one of the most challenging factors for the caregiver^{16,18}.

Few studies have addressed the impact of these difficulties on the caregiver's life, but there is direct evidence that the accumulation of difficult situations throughout life affects the emotional state. And, consequently, they limit the ability to respond more effectively to adversity and health problems¹⁷.

Another study showed that their health situation influenced overload. Whether or not the caregiver had illnesses differed in the values obtained for four of the seven domains: emotional burden, implications for personal life, financial burden, satisfaction with the role and with the family member, and the total burden score, in all cases, the highest average burden was in the group with illnesses¹⁹.

Another finding from this survey was that 64.6% of caregivers said they often feel they could take better care of their family members. This can lead to losing control over their health, which is often suppressed to provide better quality informal care. Most of the time, these caregivers try to manage the whole situation independently and get lost along the way, which is especially noticeable for spouses or people who live with the sick person²⁰.

For women caregivers (mothers, spouses, or daughters), caring for their loved ones can give new meaning to their lives and social conditions. They use their time differently, dedicating an average of eighteen hours a day to this care, not counting household chores and childcare, characterizing social, work, relationship, and leisure fragility. Despite the intense overload and loneliness of caring, in this *ik-stant*, women can use their power to subvert time in their favor, transcending their existence and anguish by reconciling self-

care with caring for others²¹.

In this scenario, the nursing intervention with these caregivers is health education supported by the Nursing Support-Education System. It addresses specific problems for self-care and autonomy, with back-up and emotional support, as well as adapting to the new life situation, teaching management strategies that make it possible to reduce their burden¹⁵.

Financial burden was indicated by 93.2% of the caregivers, who felt that they didn't have enough money to take care of their family members, in addition to their other expenses. This burden is evidenced in scientific literature, as the costs of a person with cancer increase by 40% compared to other diseases. According to Medicare, the sick person's annual expenses range from approximately US\$2,000 to more than US\$8,000, and many continue to suffer the impact of the financial burden long after the patient's death²²⁻²³.

These caregivers have less time and resources to carry out the care. However, they don't talk about it in front of the patient; they end up sacrificing their own health and financial well-being to try to meet the financial and care demands of the sick family member²³.

There was no statistically significant relationship between the variables gender, age, health problems, or length of care with the ZBI score. However, another study found a statistically significant relationship between gender and care-related burden. This burden can be attributed to the difference between the sexes and, above all, due to different personal stresses, as women tend to be concerned with providing better care. Regression showed that gender is a highly significant predictor of overload⁴.

The gender of the patient was a significant predictor of caregiver burden, with male caregivers having a greater burden than female caregivers²⁴. In this study, the gender of the caregiver was not predictive of burden at the beginning, but over time, male caregivers reported less burden than female caregivers.

The male caregiver recognizes the lack of care skills and inexperience in this role, which were a major source of stress¹⁰. Care overload was strongly associated as a risk factor for emotional discomfort, characterized by headaches, insomnia, inappetence, sadness, and anxiety, among others¹¹.

There was a positive correlation between caregiver burden and age, with the higher the age, the greater the perception of burden¹³. This association permeated the result between pain and caregiver burden, with an r value of 0.321, with $p \leq 0.05$, showing a slightly positive correlation⁹.

Caregivers with longer periods of informal care reported greater overload; in other words, caregivers who spend more time caring experience greater work overload. Therefore, an average of 18 hours of care per day was associated with increased caregiver burden. A Taiwanese study measured caregiving hours as its unit of analysis (while our study measured costs). That study found that caregivers who reported more caregiving hours (13-24 hours per day) had a lower burden than those who reported less time (8-12 hours)^{24,25}.

Another study showed an association between caregiver burden and formal employment ($p=0.002$), financial support ($p=0.027$), and help with activities of daily living ($p<0.001$)²⁶. This condition is related to the time spent caring because after this caregiver was faced with the burden of care, in addition to other personal activities, including paid work, he found himself in a complex situation. Without the support of other family members, he felt helpless. Sometimes, he blamed the rest of the family for the physical and emotional overload, leading to disagreements in family relationships²⁷. Decreased leisure time and deterioration of emotional and physical health were the most common effects perceived among caregivers¹⁰.

Research has associated overload with quality of life and described overload as the accumulation of functions inherent in caring for the sick person, as well as the constant concern for the health and well-being of this family member who is under their care; a change in the personal/social/professional dimension of the HC; a feeling of heaviness and discomfort when carrying out certain functions¹¹. The caregiver's suffering intensified because they felt less prepared and less confident to manage cancer symptoms and provide the necessary complex care²⁸.

The study's limitations were that the research was carried out in a single specialized public service, focusing on the family caregiver of cancer patients, and the variables ethnicity or race, degree of dependence of the patients, and influence of the pandemic were not contemplated. In the pandemic, caregivers, in addition to worrying about the care and well-being of patients, faced the additional challenge of dealing with intensified security measures, visitation restrictions, and social isolation, which affected their ability to offer emotional and social support to patients.

FINAL CONSIDERATIONS

This study found that most caregivers are quite overburdened with informal care. However, no correlation was established between overburden and the variables gender, age, health problems, and length of time caring for this specific group, thus proving the null hypothesis. Despite the absence of a significant overall correlation with "health problems", there were statistically significant differences with diseases such as Systemic Arterial Hypertension, Hernias, Claustrophobia, Gastritis, Depression, Asthma, Diabetes, Seropositive, *Vogt-Koyanagi-Harada* Syndrome, Polycystic Ovary and Osteoporosis.

Future studies on burden could focus on the different types of cancer, hospital stay and care conditions, and intra-family relationships, as these factors become conditioning factors for the perception of quality of life and burden. Suffering is multifactorial/multidimensional, linked to complex structures and socio-cultural contexts, with its values and meanings.

It is hoped that the results of this study will contribute to the field of health and nursing, expanding knowledge of this subject, which has been little explored in the scientific literature. It also supports care practices to improve their quality and for formulating public policies to meet the needs of caregivers of family members who are ill with cancer.

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