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ORIGINAL ARTICLE

Evaluation of the Burden of Family Caregivers of Patients in Chemotherapy

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Highlights:
(1) Identifying levels of family caregiver burden improves quality of life.
(2) Family caregivers may feel physically and emotionally overwhelmed.
(3) Social, economic, and clinical aspects are associated with family caregiver burden.

ABSTRACT

Objective: To evaluate the burden of family caregivers of cancer patients undergoing chemotherapy and to associate the burden of the caregiver with the sociodemographic, socioeconomic and clinical characteristics. *Methods*: Analytical study, conducted with 134 family caregivers. Caregivers over 18 years of age and whose patients were more than 12 months in treatment were included. Sociodemographic and clinical data were investigated and the Zarit Burden Interview Scale was used. For analysis, the mean and standard deviation were used, and the burden of work used Mann Whitney and Kruskall Wallis tests. *Results*: The survey involved 134 caregivers, mostly family members, female, between 30 and 39 years old, married, children of patients, with full elementary school, no formal employment, average income of 1 to 2 minimum wages, the time spent for care 1 to 3 months. The burden was evaluated in absent (44.8%), mild and moderate (41.8%), moderate to severe (12.7%) and intense (0.7%). *Conclusion*: Some family caregivers presented burden, mild to moderate, moderate to severe and intense. Gender, degree of kinship, absence from work activities, health problem, use of medications and time of illness were associated with the burden. The support and distribution of tasks among family members were fundamental to reduce the level of burden.

Keywords: Burden; Caregivers; Family caregiver; Cancer

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INTRODUCTION

Cancer is the second leading cause of death in the Americas, after cardiovascular disease[1]. The incidence and mortality from cancer have been increasing in part due to aging, population growth, distribution and prevalence of risk factors, especially those associated with socioeconomic development, as sedentary and inadequate eating[2].

The latest global estimate, in 2018, showed that there were 18 million new cases of cancer and 9.6 million deaths worldwide. The document produced by the World Health Organization (WHO), estimates that, in the coming decades, the impact of cancer on the world population will correspond to 80% of the more than 20 million new cases estimated for the year 2025[3].

In Brazil, the National Cancer Institute (Inca – *Instituto Nacional do Câncer*) and the Ministry of Health (MH) reported that for each year of the three-year period 2023-2025, there will be 704 thousand new cases of cancer. The distribution of incidence by geographical region shows that the Southeast region concentrates (345,230) new cases, followed by the Northeast (152,930), South (129,120), Midwest (51,340) and North (25,460)[4].

When the diagnosis of neoplasm is established, the family caregiver experiences several changes in the daily life, which include emotional burden and the possibility of becoming ill. Therefore, it is understood that suffering affects not only the person affected by cancer, but also every family system, and especially the caregiver, who often does not understand how he/she arrived in this function, because there was no question about the acceptance of tasks and, due to family ties, automatically took on the challenge of care[5].

The family caregiver is defined as a member of the family who provides care to the person with functional dependence, accompanying him/her in daily activities, helping with food, personal hygiene, medication use and contributing to the improvement in the quality of life of these patients[6].

Family caregivers have positive aspects when caring for the patient, however, several times, they present physical and psychological disorders, directly related to the responsibility and burden of care, as well as the condition of death of the loved one. This caregiver often experiences a considerable burden of activities, which causes burden and influences his/her physical, mental, spiritual and social well-being. The caregiver's suffering is the somatization of everything that he/she lives with the patient. The greater the burden on care, the greater the physical and psychological consequences generated by it[7].

Burden has been defined specifically as a resistance to the provision of care caused by the inclusion or expansion of activities performed by the caregiver[8], and comprises two dimensions: objective and subjective. The subjective variable refers to the burden derived from the reactions, emotions and behaviors of the caregiver before the care, thus related to the lived experience. The objective burden has been associated with the presentation of activities directed to care, time spent in its execution and changes suffered in the context of life and routine of the caregiver in the development of physical problems, of fatigue, loss of financial balance and family and occupational relations[9].

One of the ways to evaluate caregiver burden is the use of the Zarit Burden Interview Scale, translated and validated in 2002 for the Brazilian culture. The Zarit caregiver burden scale is a reliable instrument with good psychometric characteristics to evaluate the associated burden during care. The use of the burden scale in terms of research allows the assessment of the perceived impact on the physical and emotional health, social aspects and financial situation of the family caregiver[10].

This research assumes that the work performed by the caregiver has an attention, somewhat as fragile in the health system, because the main focus of the actions of professionals is directed to the care of the person with oncological conditions, in the hospital and at home. This fragility in the evaluation of the burden of family caregivers ends up compromising their health and, therefore, the quality of care to patients they care for.

The early identification of the levels of burden of the family caregiver can contribute to improve their quality of life, as well as that of the cancer patient, focus of care, whose results may contribute to broaden knowledge on the subject and subsidize health professionals, families and managers to implement measures aimed at promoting the health of this public that is so often neglected, and enabling the planning of strategies to minimize this problem.

Considering that the caregiver is the one who assumes responsibility for care, this study aimed to evaluate the burden of family caregivers of cancer patients on chemotherapy, and associate the caregiver's burden with his/her sociodemographic, socioeconomic and clinical characteristics.

METHODS

Design, Scenario and Period

Analytical study with family caregivers of patients undergoing chemotherapy at the Dr. Tarquínio Lopes Filho Cancer Hospital in São Luis – MA, (Brazil), a state unit under the management of the State Department of Health, from October 2021 to August 2022.

Sample and selection criteria

The sample selection was performed by the non-probabilistic method and all caregivers who met the inclusion criteria were invited to participate in the study. The inclusion criteria for selection of participants were: family caregivers of both sexes, aged 18 years or older, whose oncologic patients hospitalized and outpatients have been under their care during chemotherapy treatment for at least 1 month ago. The study did not include people with some difficulty of communicating that hindered answering the questionnaires.

Research instrument

The data collection was carried out by the authors in a reserved room. A questionnaire of sociodemographic, socioeconomic and clinical characteristics was used and to evaluate the caregiver burden, the Zarit Burden Interview Scale was used. The first questionnaire addressed the sociodemographic, socioeconomic and clinical characteristics of caregivers, as well as the following variables: name (initial), age, sex, race/color, marital status, degree of kinship, education level, paid employment, employment relationship, family income in the last month, if not working, has left professional activities to be a caregiver, period (in months) in the role of caregiver, workload intended to care for the patient, division of the activities performed to the patient with another person, health problems, time of these problems, regular use of medicines.

The Zarit Burden Interview Scale allows the assessment of the objective and subjective burden of informal caregiver and includes information about health, social life, personal life, financial situation, emotional situation and type of relationship, is a self-applicable scale of the Likert type. This scale has 22 questions and aims to evaluate the impact caused by the care in physical, emotional and social aspects. Each item on the scale is scored from 0 to 4, with 0 = never, 1 = rarely, 2 = sometimes, 3 = very often, 4 = almost always. The score varies from 0 to 88. The determination of the burden rating score is done as follows: < 21 = little or absent burden, 21 to 40 = mild to moderate burden, 41 to 60 = moderate to severe burden, > 61= severe burden. The higher the score, the higher the burden[11].

Data Analysis

All data were analyzed using the statistical program IBM SPSS Statistics 22 (2013). Initially, to obtain a profile of the sample of family caregivers, it was performed the analysis of descriptive statistics of sociodemographic, socioeconomic and clinical variables (Zarit Burden Interview Scale), with analysis of graphs and frequency tables. From the numerical variables, the average, standard deviation, maximum and minimum will be estimated.

The questions regarding the burden of caregivers were evaluated by the non-parametric tests of Mann Whitney and Kruskall Wallis, considering that there was no normality in the tested variables. The significance level to reject the hypothesis of nullity was 5%, that is, a value of $p \leq 0.05$ was considered as statistically significant.

Ethical aspects

This research is part of a project entitled “Health Care Complexity in the Hospital and Outpatient Environment”, approved by the Research Ethics Committee of the University Hospital of the Federal University of Maranhão, with opinion number 5.501.263. The adopted behaviors followed the ethical norms of the National Health Council (Resolution 466/2012), which deals with the guidelines and norms of research involving human beings.

The caregivers received information about the objectives, risks and benefits of the research. Those who agreed to participate, in order to follow the ethical principles, signed the Informed Consent Form in two copies, remaining one with the participant and another with the researcher. The confidentiality of the information obtained will be preserved, thus maintaining the individual privacy of each caregiver.

RESULTS

The study included 134 family caregivers of cancer patients undergoing chemotherapy. Table 1 shows that the majority were women 77.6% (104), aged between 30 and 39 years 32.1% (43), self-declared as brown 53% (71), married 56% (75) and referred to as children of patients 49.9% (67), having completed elementary school education 34.3% (46). Regarding the socioeconomic aspects, of the caregivers who exercise some paid activity, 48.5% (65) had no employment. The individual income of family caregivers, 39.6% (53), is between 1 and 2 minimum wages. It is important to mention that 56.7% (76) of the caregivers do not perform any type of paid work, of 43.3% (58) who were economically active, 23.1% (31) did not leave their work activities.

Table 1 – Sociodemographic aspects of family caregivers of patients undergoing chemotherapy treatment at the Dr. Tarquínio Lopes Filho Cancer Hospital, São Luís-MA, Brazil, 2022

Sociodemographic		**n**	**%**
Sex	Female	104	77.6
	Male	30	22.4
Age group (years)	< 20	03	2.2
	20-29	23	17.2
	30-39	43	32.1
	40-49	35	26.1
	50-59	18	13.4
	60 or more	12	9.0

Race/Color	Brown	71	53.0
	Black	35	26.1
	White	25	18.7
	Indigenous	02	1.5
	Yellow	01	0.7
Marital status	Married	75	56.0
	Single	52	39.0
	Divorced	05	3.7
	Widowed	02	1.5
Kinship degree in relation to the patient	Son/Daughter	67	49.9
	Spouse	35	26.1
	Brother/Sister	16	11.9
	Father/Mother	12	9.0
	Nephew/Niece	02	1.5
	Grandson/Granddaughter	01	0.7
	Uncle/Aunt	01	0.7
Education	Complete High School	46	34.3
	Incomplete High School	30	22.4
	Incomplete Elementary School	14	10.4
	Complete Elementary School	13	9.7
	Complete Higher Education	12	9.0
	Latu Sensu Post-Graduation	09	6.7
	Incomplete Higher Education	08	6.0
	Can read and write	02	1.5
Current paid work	Yes, exercising activity	58	43.3
	No, unemployed	45	36.6
	No, housekeeper	18	13.4
	No, Retiree or pensioner/social security	09	6.7
	No, student	03	2.2
	Yes, leave over 15 days	01	0.7
Employment	No employment	65	48.5
	Own-account worker	48	35.8
	Government professional	13	9.7
	CLL	08	5.6
Individual income of the family caregiver (minimum wages)	No income	44	32.8
	< 1	18	13.4
	1 - 2	53	39.6
	2 - 3	07	5.2
	3 - 5	07	5.2
	5 - 10	04	3.0
	10 - 20	01	0.7

Currently away from professional activities	Had no professional activity	76	56.6
	No	31	23.1
	Yes	27	20.1

Source: Created by the authors, 2022.

Table 2 identifies the occupational aspects of the family caregiver in terms of care provided to the patient during chemotherapy treatment, 38.8% (52) performed the role of caregiver between 1 and 3 months, 38.8% (52) devoted more than 12 (twelve) hours a day to care and 56% (75) were not exclusive to the patient and counted on another person to share the task of care.

Table 2 – Occupational aspects regarding the care provided by family caregivers of patients undergoing chemotherapy treatment at the Dr. Tarquínio Lopes Filho Cancer Hospital, São Luís – MA, Brazil, 2022

Variables of the care provided		**n**	**%**
Time spent caring for the patient on chemotherapy (months)	< 1	03	2.2
	1-3	52	38.8
	4-6	23	17.2
	7-9	09	6.7
	10-12	15	11.2
	16-18	06	4.5
	19-21	02	1.5
	22-24	08	6.0
	> 24	16	11.9
Time spent per day to care for the patient (hours)	1-3	10	7.5
	3-6	39	29.1
	7-9	11	8.2
	10-12	22	16.4
	> 12	52	38.8
The activities are divided with another person	Yes	75	56.0
	No	59	44.0

Source: Created by the authors, 2022.

Table 3 shows the health status of the family caregiver, 65.7% (88) of caregivers reported no health problems. 72.4% (97) did not use continuous use drugs. Among the caregivers who reported having health problems, the most frequent were: Systemic arterial hypertension (SAH) and diabetes, with 36.9% (17) and 21.7% (10) of cases, respectively. When the duration of the family caregiver's health problem was evaluated, 76.1% (35) reported that these diseases existed before they exercised the role of caregiver.

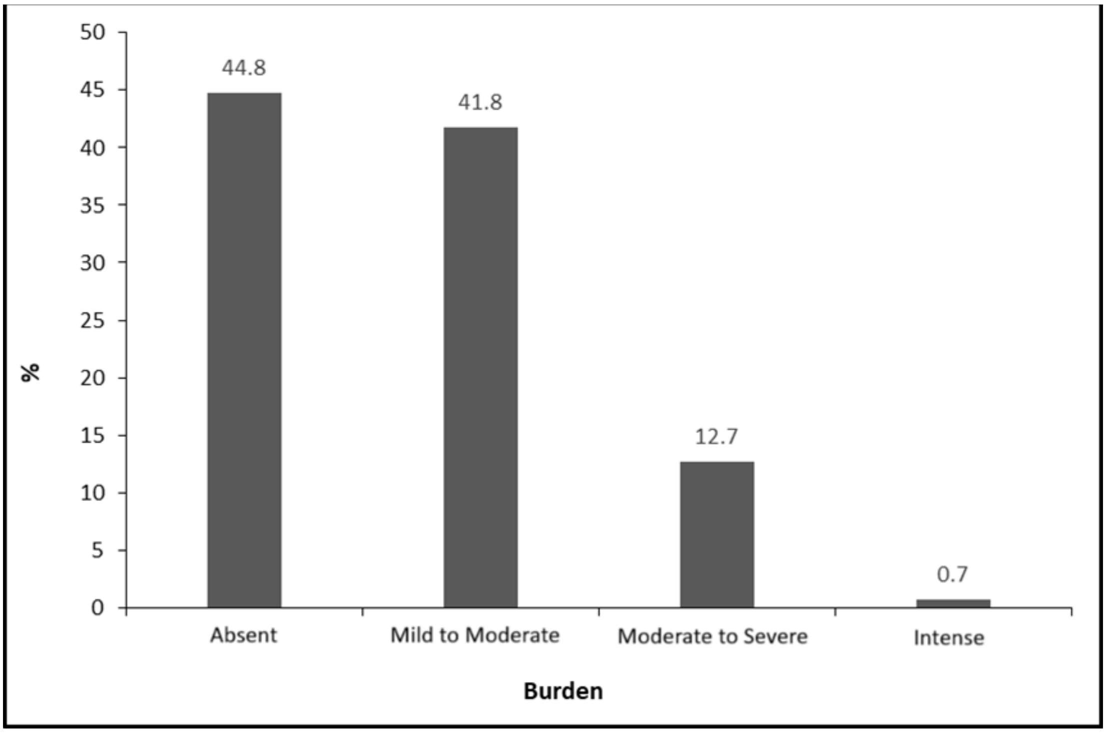
Table 3 – Clinical aspects of family caregivers of patients on chemotherapy at the Dr. Tarquínio Lopes Filho Cancer Hospital, São Luís-MA, Brazil, 2022

Clinical variables		**n**	**%**
Presence of any health problem	Yes	46	34.3
	No	88	65.7
Use of continuous use drugs	Yes	37	27.6
	No	97	72.4

Associated morbidity (n=46)	SAH	17	36.9
	Diabetes	10	21.7
	Anxiety and Depression	06	13.0
	Spine	04	8.7
	Gastritis	03	6.5
	Renal	02	4.3
	High cholesterol	02	4.3
	Cardiac	01	2.2
	Osteoarthritis	01	2.2
Presence of health problem for how long? (n=46)	Before being caregiver	35	76.1
	After being caregiver	11	23.9

Source: Created by the authors, 2022.

The level of variable burden was absent to intense among family caregivers, with the absence of burden being the most identified among the interviewed caregivers, with a percentage of 44.8% (60), followed by mild to moderate burden 41.8% (56) (Graph 1).



Graph 1 – Burden of family caregivers of patients on chemotherapy according to the degree of burden in the ZBI. Dr. Tarquínio Lopes Filho Cancer Hospital, São Luís-MA, Brazil, 2022.

Source: Created by the authors, 2022.

Table 4 shows the association between caregiver burden and sociodemographic, socioeconomic and clinical variables. Among the independent variables that presented a significant association ($p<0.05$), female caregivers showed greater burden than male caregivers. The caregivers who are grandchildren presented moderate burden, the children presented absent level of burden. Family caregivers who left work to perform the task of care expressed greater burden.

Table 4 – Relationship between burden and sociodemographic and socioeconomic aspects of caregivers of patients on chemotherapy. Dr. Tarquínio Lopes Filho Cancer Hospital São Luís-MA, Brazil, 2022

Independent variable		**Burden**			**Test**	***p***
		Median	**P25**	**P75**		
Sex *	Male	Absent	Absent	Mild	-2.47	**0.013**
	Female	Mild	Absent	Mild		
Age group	< 20	Mild	Mild	Mild	2.36	0.797
	20-29	Mild	Absent	Mild		
	30-39	Mild	Absent	Continuous Mild		
	40-49	Mild	Absent	Mild		
	50-59	Absent	Absent	Mild		
	60 or more	Mild	Absent	Mild		
Race/Color	Black	Absent	Absent	Mild	2.28	0.685
	White	Mild	Absent	Mild		
	Yellow	Absent	Absent	Mild		
	Brown	Mild	Absent	Mild		
	Indigenous	Mild	Mild	Mild		
Marital status	Married	Absent	Absent	Mild	4.81	0.307
	Stable union	Moderate	Moderate	Moderate		
	Single	Mild	Absent	Mild		
	Widowed	Mild	Mild	Mild		
	Divorced	Mild	Mild	Mild		
Kinship degree in relation to the patient?	Son/Daughter	Absent [b]	Absent	Mild	15.54	**0.030**
	Spouse	Mild [ab]	Mild	Moderate		
	Father/Mother	Mild [ab]	Absent	Mild		
	Brother/Sister	Mild [ab]	Absent	Mild		
	Uncle/Aunt	Mild [ab]	Mild	Mild		
	Grandson/ Granddaughter	Moderate [a]	Moderate	Moderate		
	Nephew/Niece	Mild [ab]	Absent	Moderate		
N. of people	1 – 2	Absent	Absent	Mild	4.50	0.212
	3 – 4	Absent/ Mild	Absent	Mild		
	5 – 6	Mild	Absent	Mild		
	> 6	Mild	Absent	Mild		
House	Owned	Mild	Absent	Mild	5.46	0.141
	Financed	Absent	Absent	Absent		
	Rented	Mild	Absent	Moderate		
	Others	Mild/ Moderate	Absent/ Mild	Moderate		

Education	Can read	Absent/ Mild	Absent	Mild	3.79	0.705
	Incomplete ES.	Mild	Absent	Mild		
	Complete ES.	Mild	Absent	Mild		
	Incomplete HS.	Mild	Absent	Mild		
	Complete HS.	Absent	Absent	Mild		
	Incomplete HE.	Absent/ Mild	Absent	Mild		
	Complete HE.	Absent/ Mild	Absent	Mild		
	Incomplete PG.	Mild	Mild	Mild		
	Complete PG.	Absent/ Mild	Absent	Mild		
	Ignored	Absent/ Mild	Absent	Mild		
Employment	CLL	Absent	Absent	Absent	5.88	0.118
	Government professional	Mild	Absent	Moderate		
	Own-account worker	Absent	Absent	Mild		
Currently away from professional activities to be caregiver?	Yes	Mild [a]	Mild	Moderate	8.61	**0.014**
	No	Mild [ab]	Absent	Mild		
N. of people at home	1-2	Absent	Absent	Mild	4.50	0.212
	3-4	Absent/ Mild	Absent	Mild		
	5-6	Mild	Absent	Mild		
	> 6	Mild	Absent	Mild		

[a,b] Different letters mean $p < 0.05$ by Dunn's test. *Mann Whitney and Kruskall Wallis tests.

Source: Created by the authors, 2022.

DISCUSSION

In the present study, when analyzing the sociodemographic profile of family caregivers, it was noticed that the task of caring is still linked to the female sex, with age between 30 and 39 years, most of the caregivers were married, children of patients undergoing chemotherapy, which may be related to the higher incidence of neoplasms in older people, thus, in the reorganization of family roles and functions, the children assume the position of caregivers of their parents. These data corroborate the study by Millani et al.[11], in which caregivers were mainly female, married and children of patients, however with age range between 38 and 57 years, higher than that observed in our study. Normally, the family member chosen to take care of a cancer patient is someone who has influence on decisions made in light of the treatment particularities[12]. It was observed that the fact that women are the main family caregivers is common, even with changes in labor market patterns and continuity of family responsibilities.

The caregivers of this research, in their majority self-declared themselves as brown. The self-declaration of color/race identified in this study is in agreement with the National Household Sample Survey (PNAD – *Pesquisa Nacional por Amostra de Domicílios*), in which almost half of Brazilians (46.8%) defined themselves as brown[13].

When analyzing the level of education of these caregivers, the survey showed that the largest number of respondents had completed high school, followed by caregivers with incomplete high school. Santos[14], when analyzing the same variable of caregivers, observed that 40% had incomplete/

complete high school education. The level of education is an important factor to be analyzed, since more educated caregivers tend to seek information from different sources, which contributes to the improvement of care provided[15]. In addition, in their daily activities, caregivers need to know how to read, interpret and know the mathematical operations to administer medicines correctly[16].

Regarding the socioeconomic profile of family caregivers, most respondents reported some kind of paid work, however few with employment in the CLL regime. It is worth noting that 56.7% of family caregivers do not have a paid activity. It is noteworthy that a significant number of caregivers left professional activities to perform the task of caring. The study conducted by Ladeira and Grincenkov[17] identified that 36% of caregivers worked at the time of family illness, and that only 4% reported formal employment. Among the caregivers, 64% did not exercise professional activity and 20% were away from work in the given period.

The result obtained shows that, due to the need to accompany the family member in consultations and hospitalizations, the caregiver ends up being constantly absent from formal work, which leads to anxiety about losing the job. In addition to the emotional health of the caregiver, he/she fails to promote the stable support of the family. These facts constitute relevant indicators, as they directly affect the quality of life of this individual[18].

The average salary income of caregivers in this study ranged between 1 and 2 minimum wages, which can be classified as low, taking into account the value of the minimum wage of 1,212.00 BRL[19]. When adding to this variable the 32.8% of the participants in the survey who do not have income, it is noticed that in the performance of care, there is a tendency for the family caregiver to move away from paid work activities in favor of exclusive dedication to the care demands at home, leaving the family income even more lagged. Rangel et al.[20] show that 65.1% of the caregivers interviewed receive between 1 and 2 minimum wages. As verified in our study, many caregivers abandon their jobs to dedicate themselves to care, starting to live with the income of the person cared for, which is insufficient to maintain basic needs.

When we analyzed the variables time given to care and assistance for care, it was observed that most family caregivers had been exercising the function for between 1 and 3 months. In turn, daily dedication in hours showed that most caregivers dedicated more than 12 hours a day to providing care and counted on the help of another person to share the care provided to the family member. Data that corroborate the study by Arias-Rojas et al.[21], which shows as an important result the fact that 75.8% of participants had support from other people for care activities, i.e., they had a secondary caregiver and exercised the function of caring for the patient, on average, 18 hours per day, indicating that their perception of burden is different from when the act of care is exercised by a single caregiver, because, according to Alves[22], the attention to the patient involves follow-up to medical services, as well as personal hygiene, food, medication, among other tasks that require direct attention from the caregiver, showing the need for a secondary caregiver.

The simple act of caring, by itself, is already a factor that can result in physical and/or mental illness. In this study, however, most of the caregivers interviewed indicated that they did not develop any health problem after starting their journey as a caregiver and consequently did not use continuous use drugs. The most common health problems found in caregivers were systemic arterial hypertension followed by diabetes mellitus, anxiety, depression and spine problems. Acute and chronic diseases can be an indication of increased caregiver burden, since associated with the task of caring directly interfere with their health.

These results show that, as the caregiver centralizes his/her attention in the sick family member, he/she begins to experience moments of loneliness with the reduction of the social interaction and low esteem. The absence of social interactions may be related to depression, because there is a decrease in social interaction, which means that they interact only with other caregivers in hostile environments such as hospitals, which directly interferes with their mood[23]. Scientific research shows that the work and attention of the caregivers result in symptoms that impact their physical and mental health, which can result in pathologies such as SAH, diabetes mellitus and low back pain, favoring the use of various mediations[14].

The burden occurs due to the association between patient care and the health status of the caregiver. The greater the dependency of the family member, the greater the caregiver's burden, thus requiring an attentive look at the caregiver in order to identify early signs of physical and mental difficulty or strain, providing care and attention to carergivers[9].

The results indicate that most of the family caregivers interviewed showed no burden. The absence of burden identified may be associated with the presence of aids in the care of the patient on chemotherapy and the ability of the patient to self-care. The mild to moderate or moderate to severe burden, even affecting in a lesser proportion the family caregivers, should be considered, because, besides influencing the performance and the ability of care delivery, added to the high responsibilities, may indicate incipient evidence of a process of exhaustion, which requires an intervention in advance with a view to improving the quality of life of these caregivers. Coppetti et al.,[24] identified the absence of even greater burden (50.8%) than that observed in this study, emphasizing that constant care responsibilities can lead to an exhaustion process. Similar results were found in the research of Millani *et al*.[12], identifying that most family caregivers do not present burden, followed by those who expose mild to moderate burden.

The results showed that the level of family caregiver burden is directly associated with socio-demographic characteristics, such as sex and degree of kinship, socioeconomic, regarding the need to leave their professional activities.

The role of women in caring for relatives on chemotherapy is quite present and, therefore, were the individuals who presented greater work burden, because, besides accumulating domestic activities, must be available to accompany the family member in examinations, procedures and other care provided to the patient on chemotherapy. Historically, the role of men is associated with work outside the home to provide for the family. Double working hours are likely to be the cause of overwork[23]. Jesus, Orlandi and Zazzetta[8] highlight in their study that men are rarely caregivers, because care involves tasks that are culturally characterized as feminine and that have been learned by women since childhood.

As for the degree of kinship, it was identified absent burden for children, low for spouses, father/mother, brothers and uncle and moderate burden for grandchildren. The absent burden in children evidenced may be associated with the affective bond and time spent on care, from 1 to 3 months, in addition to being patients in the initial phase of chemotherapy treatment and not palliative state, which demands lighter care. On the other hand, the burden observed in grandchildren may be related to changes in routine, since they end up taking on tasks aimed at the demands arising from care. Data that differ from those of Pedrosa et al.[25], who verified greater burden for children, however, evaluating burden in informal caregivers of patients undergoing radiotherapy.

In this study, the association between leaving work activities to be a caregiver and the level of burden was observed. It is known that diseases cause financial losses due to the costs of medicines and treatments, added to the expenses of the domestic routine, causing financial burden. The loss of formal work as well as the reduction of informal working hours of some family member to the care of the family with cancer reveal a significant and relevant level of burden after treatment. Unemployment due, in most cases, to the need for work absence for informal care was considered an important indicator of burden[25].

In view of the above, it can be inferred that it is essential to know the sociodemographic, socioeconomic and clinical profile of family caregivers of cancer patients under chemotherapy treatment, as well as the levels of burden caused by the act of caring and thus be able to contribute to mitigating it.

The limitations of this study concern the research period, which occurred during the Covid-19 pandemic, making it impossible to collect data in more cancer hospitals, which could provide a larger and more diverse sample. This pandemic period also contributed to increase the time of data collection, due to the reduction in the number of patients and consequently family caregivers who often did not feel comfortable answering the questionnaire. Seeking to minimize these difficulties despite all the care taken by the researcher regarding the use of mask, alcohol in gel and distance. The study's design and the evaluation of the burden on family caregivers of people undergoing chemotherapy also demonstrate that all health care for patients is provided by family caregivers.

CONCLUSIONS

The results showed that most family caregivers of cancer patients on chemotherapy were female, aged between 30 and 39 years, married and referred to as children of patients, self-declared brown, having as level of education complete elementary school, without formal employment, with average income of 1 to 2 minimum wages. The time given to care was from 1 to 3 months, devoting more than 12 hours a day and received assistance from other family members for care.

The present study identified that some of the family caregivers presented burden, mild to moderate, moderate to severe and intense. Sex, degree of kinship, leave from work activities, health problem, use of medications and time of illness were associated with burden. The support and distribution of tasks among family members were fundamental to reduce the level of burden.

This study is expected to contribute to health professionals, especially nursing, which, in addition to managing, planning and performing care actions, has a fundamental role in the development of educational practices, thus providing interventions aimed at the support and development of skills of family caregivers, always seeking the improvement of effective strategies that contemplate the caregiver, the patient/caregiver and the family. It is important to make caregivers a priority group of continuous care, thus contributing to the reduction of burden and enabling them to take care of their family without forgetting their own care, culminating in the maintenance of the health of the caregiver and the patient.

The care provided to caregivers is a warning to health teams, in order to build possibilities for intervention with the family caregiver, reducing risks of illness and improving life within the family.

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