# Assessing the burden of family caregivers of cancer patients: a cross-sectional study

Evaluación de la carga de los cuidadores familiares de pacientes con cáncer

Avaliação da sobrecarga de familiares cuidadores de pacientes com câncer: estudo transversal

Ana Luiza Rodrigues Lins[1] [ID], Érica Toledo de Mendonça [2] [ID], Tiago Ricardo Moreira[2] [ID], João Vitor Andrade[3] [ID], Diego Henrique Silveira Ramos[2] [ID], Pedro Alexandre Henriques Pedretti[2] [ID].

## ABSTRACT

**Objective:** Evaluate the burden of family caregivers of cancer patients in a Brazilian oncology hospital. **Method:** Quantitative, descriptive, and cross-sectional research conducted in a Brazilian oncology hospital, located in Minas Gerais. Data collection occurred through the application of a questionnaire containing sociodemographic questions, and the Zarit scale, which assesses the degree of burden of caregivers, was used. Inclusion criteria were family caregivers over 18, whose family member had a diagnosis of cancer, and who was involved in caregiving. The association between burden and the explanatory variables was performed from the multiple linear regression model. The program SPSS version 20 was used to perform the analyses. **Results:** Among the 125 individuals interviewed, the majority were under 38 years old, 66.4% were female, 45.6% were children, and 22.4% were spouses. The time of care varied from six months (39.2%) to two years (21.6%), and 80% of the interviewed individuals acted directly in the care of the ill person; 97.6% did not present overload. **Conclusions:** The caregivers, in general, did not present overload; however, it was verified reduction in the quality of life of these caregivers when the questions of the Zarit scale referring to the psychological and social relations domains, separately, were analyzed.

**Descriptors:** Caregivers, Neoplasms, Nursing, Family relations.

## RESUMEN

**Objetivo:** Evaluar la carga de los cuidadores familiares de pacientes con cáncer en un hospital oncológico brasileño. **Método:** Investigación cuantitativa, descriptiva y transversal, realizada en un hospital oncológico brasileño, ubicado en Minas Gerais. La recogida de datos se realizó mediante la aplicación de un cuestionario con preguntas sociodemográficas y se utilizó la escala de Zarit, que evalúa el grado de carga de los cuidadores. Los criterios de inclusión fueron los cuidadores familiares mayores de 18 años, cuyo miembro de la familia había sido diagnosticado de cáncer y estaba involucrado en el cuidado. La asociación entre la carga y las variables explicativas se realizó a partir del modelo de regresión lineal múltiple. Se utilizó el programa SPSS versión 20 para realizar los análisis. **Resultados:** Entre las 125 personas entrevistadas, la mayoría tenía menos de 38 años, el 66,4% eran mujeres, el 45,6% eran hijos y el 22,4% cónyuges. El tiempo de atención varió de seis meses (39,2%) a dos años (21,6%) y el 80% de los entrevistados actuó directamente en el cuidado del enfermo, el 97,6% no presentó sobrecarga. **Conclusiones:** Los cuidadores, en general, no presentaron sobrecarga, sin embargo, se verificó una reducción en la calidad de vida de estos cuidadores cuando se analizaron las preguntas de la escala de Zarit referidas a los dominios psicológico y de relaciones sociales, por separado.

**Descriptores:** Cuidadores, Neoplasias, Enfermería, Relaciones familiares.

## RESUMO

**Objetivo**: Avaliar a sobrecarga dos familiares cuidadores de pacientes com câncer num hospital oncológico brasileiro. **Método:** Pesquisa quantitativa, descritiva e transversal, realizada em um hospital oncológico brasileiro, localizado em Minas Gerais. A coleta de dados ocorreu por meio da aplicação de um questionário contendo perguntas socio-demográficas e foi utilizada a escala de Zarit, que avalia o grau de sobrecarga dos cuidadores. Os critérios de inclusão foram familiares cuidadores acima de 18 anos, cujo membro da família tivesse o diagnóstico de câncer

1    Instituto Nacional do Câncer, Rio de Janeiro, (RJ), Brasil.
2    Universidade Federal de Viçosa, Viçosa, (MG), Brasil.
3    Universidade Federal de Alfenas, Alfenas, (MG), Brasil.

e que estivesse envolvido no cuidado. A associação entre sobrecarga e as variáveis explicativas foi realizada a partir do modelo de regressão linear múltipla. O programa SPSS versão 20 foi utilizado para a realização das análises. **Resultados:** Dentre os 125 indivíduos entrevistados, a maioria possuía menos de 38 anos, 66,4% eram do sexo feminino, 45,6% eram filhos e 22,4% cônjuges. O tempo de prestação de cuidados variou de seis meses (39,2%) a dois anos (21,6%) e 80% dos entrevistados atuavam diretamente nos cuidados, 80% atuavam diretamente nos cuidados do ente adoecido, 97,6% não apresentaram sobrecarga. **Conclusões:** Os cuidadores, de uma forma geral, não apresentaram sobrecarga, porém, constatou-se uma redução na qualidade de vida destes cuidadores, quando analisadas as questões da escala Zarit referentes aos domínios psicológico e de relações sociais, isoladamente.

**Descritores:** Cuidadores, Neoplasias, Enfermagem, Relações familiares.

## INTRODUCTION

In the last century, Brazil underwent a relevant transfiguration in its epidemiological profile. The triple burden of diseases is present, referred to as chronic, infectious, and external causes, configuring new challenges for the Unified Health System[1].

Regarding chronic diseases, non-communicable diseases affect a large part of the population, with emphasis on neoplasms, which are characterized as one of the main causes of morbidity and mortality in the world population[2-3]. According to the National Cancer Institute, in 2018, the global burden of new cancer cases was 18 million people, and in Brazil, the estimates for the 2020-2022 triennium are 625,000 new cases per year[4].

Tørring et al.[5] show in their study that despite the achievements in cancer diagnosis and treatment methods, health services still face a high percentage of cancer patients with late diagnosis or even in advanced stages of the disease, which can be justified either by the lack of knowledge of health professionals about the methods of prevention and early diagnosis, fear of the diagnosis on the part of patients and/or even lack of information. Such factors imply lower survival rates and higher expenses by health systems[2].

The occurrence of cancer in the family nucleus changes the family dynamics and implies a reorganization, with a redefinition of roles and tasks, so that the family becomes able to assist the individual in the satisfaction of their basic human needs, such as hygiene, food, rest, and still offering emotional and financial support[3]. In this way, the daily demands of care from the patient to the caregiver promote a great responsibility to the individual who cares, causing them to omit often their own needs from the patient's, resulting in physical, social, psychological, and spiritual overload[6-7].

Overload is closely related to states of physical and mental fatigue, stress, anxiety, depression, social isolation, and lower quality of life in general, or even as a situation in which family members are unable to provide an adequate response to multiple patient needs[8].

Studies that assess the burden of family caregivers are important because once the factors that cause the burden and the needs of the caregivers are analyzed, it will be possible, on the part of the health services, to plan actions in order to provide support to the sick family nucleus and that prevent changes in the health status of caregivers[3,7].

Based on these considerations, the following questions were developed to guide this research: Do family caregivers of patients diagnosed with cancer feel overwhelmed in care? What is the degree of burden presented by family caregivers of cancer patients?

This study aims to evaluate the burden of family caregivers of cancer patients in a Brazilian oncology hospital.

## METHOD

Quantitative, descriptive, cross-sectional research. According to Esperón[9], quantitative research makes it possible to evidence the strength of association or correlation among variables, the generalization, and objectification of results through a sample that refers to a population. Descriptive research, on the other hand, makes it possible to study the characteristics of a particular group, such as gender, education, age, income,

among others, and discover the relationships between these variables, making it possible, sometimes, to determine their origin[10]. The use of the international guide Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)[11] was adopted in the preparation of the present study.

The research occurred in a Brazilian oncology hospital in Minas Gerais. This hospital is accredited by the Ministry of Health as a Center for High Complexity in Oncology. It provides care in Oncology to an area of coverage of 6 health macro-regions and 18 micro-regions, making a total of 260 municipalities in Minas Gerais and other states covering a population of more than five million inhabitants[12].

The research participants were family caregivers over 18 years whose family member had been diagnosed with cancer and who was directly or indirectly involved in care, either at home and/or in follow-up for treatment or hospitalization, who agreed to participate in the research upon prior signature of the Free and Informed Consent Term. To preserve the anonymity of the participants, the interviews were identified by numbers based on the order in which they were carried out.

Contact with family members was carried out at the medical and palliative care clinic of the aforementioned hospital, where the participants were invited to go to a comfortable place that guaranteed privacy to answer the research questions. This sector performs an average of 150 admissions per month. The clinical profile of patients hospitalized in this clinic is made up of people with varying degrees of dependence for care, including people with clinical complications arising from the cancer treatment process, who required hospitalization for antibiotic therapy, blood transfusion, hydration, among others, the people with more advanced disease, in the process of finitude.

Research participants were selected in a non-probabilistic way; the interviews were carried out for 3 months (February to April), totaling 125 interviews. All caregivers accompanying their family members during hospitalization were invited to participate in the study during the data collection period, and there were 12 refusals, justified by the family member's concern about leaving the ward to answer the questionnaire and leave the patient alone.

Data collection was carried out from February to April 2018 through the application of the "The Zarit Burden Interview" Scale or the Zarit Scale to assess the degree of caregiver burden. The Zarit Scale is an internationally validated instrument that measures the health, psychological and socioeconomic well-being of the main caregiver and their relationship with the patient, allowing an assessment of the degree of overload of informal caregivers13. The scale consists of 22 questions, whose answers are given according to a Likert-type scale from 0 to 4 (Never/Rarely/Sometimes/Often/Always), on which the maximum and the minimum score is determined for each assertion[13-14].

The level of caregiver burden considered in this study was based on the criteria defined by the study by Trindade et al.[14], classified by the sum of the points for each question, with a score above 56 as a severe burden; between 46 and 56 as a moderate burden; and below of 46, no overload. To determine the profile of family caregivers, the following questions were included in the interview: age; age of the sick family member; type of cancer of the sick family member; sex; marital status; degree of kinship; period of care; participation in care; previous experience as a caregiver; schooling.

The World Health Organization (WHO) concept of Quality of Life was adopted as a theoretical framework. By this definition, quality of life is inscribed in a broader view, in the transcultural perspective. It can be defined as the "individual's perception of their position in life in the context of the culture and value system in which they live and concerning their goals, expectations, standards, and concerns"[15].

This concept encompasses items divided into six domains, which were organized on the internationally recognized WHOQOL-100 scale, as follows: I: Physical domain: pain and discomfort, energy and fatigue and sleep and rest; II: Psychological Domain: positive feelings, thinking, learning, memory and concentration, self-esteem, body image and appearance and negative feelings; III: Level of Independence: mobility, activities of daily living, dependence on medication or treatments, ability to work;

IV: Social relationships: personal relationships, social support, sexual activity; V: Environment: physical safety and security, home environment, financial resources, health and social care (availability and quality), opportunities to acquire new information and skills, participation and opportunities for recreation/leisure, physical environment (pollution/noise/traffic/climate) and transport; VI: Spiritual Aspects/Religion/Personal Beliefs: Spirituality/Religion/Personal Beliefs[15].

Thus, to assess caregiver burden, items from the Zarit Scale were analyzed in light of the WHO Quality of Life concept.

For data analysis, initially, descriptive analyses were performed, estimation of frequencies, means, medians, standard deviations, and interquartile intervals to characterize the studied population regarding the variables under study. Then, inferential (analytical) analysis was conducted to identify factors associated with the outcome studied (overload) or Pearson's chi-square.

The normality of the distribution of the variable "overload" was tested using the Kolmogorov-Smirnov test. To verify the associations between overload and categorical variables, Student's t-test was used. For all tests, the significance level was set at 95%. The association between burden and explanatory variables was performed using the multiple linear regression model.

Considering the objectives of this research, for the selection of the final model of linear regression, the backward elimination method by Likelihood Ratio (LR) was used. This method starts with the inclusion of all significant explanatory variables in the model (p<0.20) in the bivariate analysis. The variables are then removed one at a time, starting with the one that reduces LR by the least amount. The equation is evaluated at each step and the procedure is repeated until each variable in the model explains a significant portion of the variation observed in the response[16]. In the multivariable model, variables with p<0.05 were considered significant. All analyses were performed using SPSS version 20.

This study was developed respecting the ethical aspects and was approved by the Ethics Committee in Research with Human Beings of the federal public university proponent of the research, opinion No. 2.449.293.

## RESULTS

A total of 125 participants were interviewed, of which 66.4% were female (n=83), ages ranging between 38 and 52 years or older, with the vast majority under 38 (n=45). Education ranged from 10 to 15 years of study (n=62); concerning the degree of kinship, 45.6% were children, and 22.4% were spouses. The time of providing care ranged from six months (39.2%) to two years (21.6%) and 80% of respondents worked directly in care. These data are described in Table 1.

**Table 1**

Descriptive Analysis of the Sociodemographic Data of the Population.

| VARIABLES | Nº | % |
|---|---|---|
| Sex | | |
| Female | 83 | 66.4% |
| Male | 42 | 33.6% |
| Age | | |
| <= 38.00 | 45 | 36.0% |
| 39.00 - 51.00 | 41 | 32.8% |
| 52.00+ | 39 | 31.2% |
| Education | | |
| <= 9.00 | 45 | 36.0% |
| 10.00 - 15.00 | 62 | 49.6% |
| 16.00+ | 18 | 14.4% |
| Marital status | | |
| Single | 39 | 31.2% |
| Married | 86 | 68.8% |
| Kinship | | |
| Son | 57 | 45.6% |
| Brother | 22 | 17.6% |
| Wife | 28 | 22.4% |
| Niece | 9 | 7.2% |
| Others | 9 | 7.2% |
| Participation in Care | | |
| Directly | 100 | 80.0% |
| indirectly | 15 | 12.0% |
| Sometimes | 10 | 8.0% |
| Experience | | |
| Yes | 34 | 27.2% |
| No | 91 | 72.8% |
| Care Period | | |
| <= 180.00 | 49 | 39.2% |
| 181.00 - 730.00 | 49 | 39.2% |
| 731.00+ | 27 | 21.6% |

The degree of overload of the interviewees is shown in Table 2, and presented a minimum score of 5.0 and a maximum of 69.00, with an average of 20.75%, and 96.7% of the participants did not present overload.

Regarding the average score of the questions present in the Zarit scale, only the questions "Are you afraid about what might happen to your family member in the future?"; "Do you feel that your relative is dependent on you?" showed a significant mean value of 2.13 and 2.48, respectively (Table 2).

In this analysis, no variable presented p<0.05, but the variables Gender, Period of care, Marital status, and Age of the family member were included in the multivariate model because they presented p<0.20 (Table 3).

Table 4 presents the adjusted and unadjusted linear regression models. In the unadjusted model, only the variable period of care was associated with the Zarit scale score. In the multivariate model adjusted for sex, marital status, period of care, and family age, only the variables sex and period of care remained in the final model, with the variable period of care showing a positive relationship with the Zarit scale score. Therefore, the increase in the care period is directly related to the risk of overload, increasing by 3.5 (95%CI=0.834-6.165) points in the scale score.

**Table 2**

Analysis of the results referring to the Zarit Scale.

|  | Mean | Standard deviation | Average | 25th percentile | 75th percentile |
|---|---|---|---|---|---|
| N1 | .77 | 1.17 | .00 | .00 | 1.00 |
| N2 | 1.20 | 1.43 | 1.00 | .00 | 2.00 |
| N3 | 1.12 | 1.39 | .00 | .00 | 2.00 |
| N4 | .38 | .86 | .00 | .00 | .00 |
| N5 | .17 | .55 | .00 | .00 | .00 |
| N6 | .26 | .76 | .00 | .00 | .00 |
| N7 | 2.13 | 1.56 | 2.00 | 1.00 | 4.00 |
| N8 | 2.48 | 1.46 | 3.00 | 2.00 | 4.00 |
| N9 | .28 | .77 | .00 | .00 | .00 |
| N10 | .68 | 1.17 | .00 | .00 | 1.00 |
| N11 | .56 | 1.01 | .00 | .00 | 1.00 |
| N12 | .87 | 1.29 | .00 | .00 | 2.00 |
| N13 | .34 | .92 | .00 | .00 | .00 |
| N14 | 1.74 | 1.64 | 2.00 | .00 | 3.00 |
| N15 | 1.32 | 1.36 | 1.00 | .00 | 2.00 |
| N16 | .30 | .89 | .00 | .00 | .00 |
| N17 | .59 | 1.14 | .00 | .00 | .00 |
| N18 | .26 | .78 | .00 | .00 | .00 |
| N19 | 1.18 | 1.20 | 1.00 | .00 | 2.00 |
| N20 | 1.60 | 1.39 | 2.00 | .00 | 2.00 |
| N21 | 1.62 | 1.50 | 2.00 | .00 | 2.00 |
| N22 | .93 | 1.34 | .00 | .00 | 2.00 |

**Table 3**

Univariate analysis referring to sociodemographic data.

| Variable | Score | | | | | |
|---|---|---|---|---|---|---|
|  | Average | Standard Deviation | Median | 25th percentile | Percent 75 | P-value |
| Sex |  |  |  |  |  |  |
| 1.00 | 21.84 | 11.69 | 19.00 | 12.00 | 30.00 | 0.140 |
| 2.00 | 18.60 | 11.24 | 16.50 | 12.00 | 22.00 |  |
| Age |  |  |  |  |  |  |
| <= 38.00 | 21.16 | 12.56 | 19.00 | 12.00 | 28.00 |  |
| 39.00 - 51.00 | 19.51 | 10.07 | 18.00 | 11.00 | 27.00 | 0.699 |
| 52.00+ | 21.59 | 12.12 | 18.00 | 13.00 | 29.00 |  |

**Table 3**

*(continuação)*

| Variable | Score | | | | | |
|---|---|---|---|---|---|---|
| | Average | Standard Deviation | Median | 25th percentile | Percent 75 | P-value |
| Education | | | | | | |
| <= 9.00 | 20.42 | 9.68 | 19.00 | 12.00 | 28.00 | |
| 10.00 - 15.00 | 20.79 | 13.11 | 18.00 | 12.00 | 27.00 | 0.951 |
| 16.00+ | 21.44 | 10.99 | 20.00 | 12.00 | 29.00 | |
| Marital status | | | | | | |
| Single | 18.64 | 9.70 | 17.00 | 11.00 | 22.00 | |
| Married | 21.71 | 12.29 | 19.00 | 12.00 | 29.00 | 0.171 |
| Kinship | | | | | | |
| Son | 20.72 | 9.32 | 21.00 | 13.00 | 28.00 | |
| Brother | 19.09 | 11.21 | 17.50 | 10.00 | 22.00 | |
| Wife | 23.25 | 13.42 | 19.00 | 13.00 | 29.50 | 0.707 |
| Niece | 18.56 | 12.50 | 13.00 | 11.00 | 17.00 | |
| Others | 19.44 | 18.56 | 12.00 | 10.00 | 19.00 | |
| Participation in care | | | | | | |
| Directly | 21.56 | 12.12 | 19.00 | 12.00 | 29.00 | |
| indirectly | 18.47 | 10.58 | 15.00 | 10.00 | 27.00 | 0.264 |
| Sometimes | 16.10 | 4.79 | 17.50 | 12.00 | 19.00 | |
| Experience | | | | | | |
| Yea | 22.12 | 11.00 | 21.00 | 13.00 | 30.00 | |
| No | 20.24 | 11.83 | 18.00 | 12.00 | 26.00 | 0.423 |
| Care period | | | | | | |
| <= 180.00 | 18.63 | 9.62 | 16.00 | 12.00 | 22.00 | |
| 181.00 - 730.00 | 20.47 | 9.64 | 19.00 | 13.00 | 28.00 | 0.063 |
| 731.00+ | 25.11 | 16.45 | 23.00 | 12.00 | 33.00 | |
| Age of the family member | | | | | | |
| <= 58.00 | 20.78 | 12.44 | 18.00 | 11.00 | 27.00 | |
| 59.00 - 69.00 | 23.63 | 13.05 | 20.00 | 12.50 | 32.50 | 0.083 |
| 70.00+ | 17.85 | 8.08 | 18.00 | 12.00 | 23.50 | |

**Table 4**

Multivariate analysis of the variables Gender, Marital Status, Care Period, and Age of the Family Member.

| Model | Variables | Beta | p-value | 95%CI | |
|---|---|---|---|---|---|
| | | | | Bottom | Higher |
| not adjusted | | | | | |
| | Sex | -3.248 | 0.140 | -7.573 | 1.077 |
| | Marital status | 3.068 | 0.171 | -1.347 | 7.483 |
| | Care period | 3.072 | 0.024 | 0.414 | 5.729 |
| | Age of the family member | -1.383 | 0.274 | -3.873 | 1.108 |
| 1 | | | | | |
| | Sex | -4.236 | 0.057 | -8.594 | 0.123 |
| | Marital status | 1.943 | 0.380 | -2.423 | 6.309 |
| | Care period | 3.496 | 0.011 | 0.823 | 6.170 |
| | Age of the family member | -1.741 | 0.160 | -4.179 | 0.697 |
| two | | | | | |
| | Sex | -4.550 | 0.038 | -8.847 | -0.254 |
| | Care period | 3.616 | 0.008 | 0.958 | 6.273 |
| | Age of the family member | -1.801 | 0.145 | -4.233 | 0.631 |
| Final | | | | | |
| | Sex | -4.176 | 0.056 | -8.462 | 0.111 |
| | Care period | 3.499 | 0.010 | 0.834 | 6.165 |

## DISCUSSION

In this study, it was found that most caregivers (66.4%) were female. Other studies with family caregivers of people with cancer also indicate that they mainly comprise women[17-19]. This fact can be attributed to the historical context in which women are primarily responsible for domestic care, as shown in another study[20]. Of the total, 22.4% of caregivers were spouses, a situation that is in line with the study carried out by Souza et al.[21], by portraying the woman as the most affectionate figure in the family, and, therefore, in charge of carrying out the daily care of her loved ones. On the other hand, these are more susceptible to a greater degree of overload, resulting in stress, insecurity, and suffering.

It is known that the diagnosis of cancer has a great impact on the patient and also on their family. In this way, some authors consider cancer as a family disease not only from a genetic point of view, since, from the aforementioned diagnosis, it is expected that significant changes in family dynamics will occur[22-23].

A British study showed that a cancer diagnosis in a family member is, for family members, often a catastrophic, stressful and traumatic event in the life of the whole family, with the power to change family dynamics[24]. These questions strengthen the findings of this study, since it was identified that the period of care influences the increase in caregiver burden, and this fact can have an impact on a change in family dynamics, requiring a reorganization of the daily routine, which may lead these caregivers to abandon occupational and leisure activities, in addition to a reduction in the quality of life, evidenced by the impact on social relationships and the environment, when analyzed in the light of the WHO[15].

During the questions on the scale, it was noticed that many interviewees cried and showed fear and insecurity when asked about the future of their family member, especially when answered question number 7 of the scale - "Are you afraid about what might happen to your family member in the future?". It is important to note that this question had a high average score of 2.13 points. This finding corroborates the findings of the literature since

a study carried out by Figueiredo et al.[23] shows that one of the main difficulties experienced by caregivers is related to death, which is associated with insecurity and lack of emotional support, increasing the vulnerability of the caregiver. These questions point to the weakening of spiritual aspects and personal beliefs of caregivers, in addition to negative feelings represented in the psychological domain, which contributes to the reduction of the caregiver's personal well-being[15].

These observations are similar to those in the literature, which shows that cancer treatment is permeated by various feelings such as insecurity, helplessness, sadness, fear about the future of loved ones, fear of chemotherapy and its adverse effects, mainly in the face of the suffering of the other[23]. Linked to these feelings, the stigmas associated with the disease generate perplexity, seen as a battle, death sentence, or even a state of intense pain and suffering[25-28].

In the context of cancer illness, it is common for the family caregiver to be a member of the same household and, in most cases, to have a significant relationship with the patient. The care offered by the family member can benefit if they receive emotional support, affection and gratitude not only from the patient but also from other family members, making the act of caring lighter and resulting in smaller drops in quality of life[15,29-30].

The present study confirms these precepts by noting that 45.6% of caregivers were children and 22.4% were wives, in line with Rosas & Neri[29], when they bring in their study that 27.7% of caregivers of elderly people were children and 62.1% were spouses. Also, this caregiver has several responsibilities, from care that involves basic needs, including emotional and financial ones. Therefore, due to the excess of functions, it is expected that, at some point, the caregiver will present some level of overload since they tend to neglect their health[7]. In this sense, the search for the caregiver's quality of life assumes a central position in care, as it brings with it the improvement of their functional capacity, in addition to the alignment of their value system with their goals and expectations, maintaining physical, social, psychic and spiritual health.

Furthermore, it is important to emphasize the existence of factors that contribute to the

reduction of the overload, such as the capacity of the caregiver to seek meaning in the care of the loved ones, the feeling of hope and religiosity[31-32], aspects contemplated in the concept of quality of life adopted in this study. Other studies also supply the family caregivers with resources, information, and support that propitiate the maintenance of their health and care, a psychoeducational approach with educational resources and guidance to perform low-impact physical exercises[33-34].

Regarding the age group presented in the study, the vast majority, between 18 and 38 years old (36%), is justified by the degree of kinship since the patients' children were predominant caregivers, in line with the aforementioned study, a work carried out by Santos et al.[35], where they show that the decision to take care of the parents is part of the transformations that are happening in the life of the person cared for, whether due to aging, frailty, fatigue, limitations and comorbidities that these people present, compromising physical and psychological integrity, thus leading to dependence on care.

According to the present study, the period of caregiving is directly related to the increase in burden by 3.5 points, as shown in Table 3. According to Rezende et al.[36], with the progression of the disease, the demand for care tends to increase, consequently increasing the deprivations and leading to the social isolation of the caregiver, which impacts social relationships[15]. Added to this aspect, caring requires commitment and time to be spent with the ill family member, directly affecting the caregivers' quality of life. Therefore, these findings legitimize the results found in this research.

In this context, a factor that contributes to increased overload is related to the patient's level of dependence, increasing care demands and promoting the development of anxiety, depression, psychological suffering and even Burnout syndrome[36]. In this perspective, when analyzing the age group of patients in the present study, which ranged from 28 to 90 years, with 45 people under 58, 40 people between 59 and 69, and 40 patients over 70, it can be seen that, as they are mostly elderly, it can lead to an increase in care demands.

Regarding this question, a higher score was identified in the question "Do you feel that your family member is dependent on you?", with an average of 2.48 points, and such dependence can be further reinforced by the fact that all respondents prefer to perform the interview in the corridor of the medical ward, a place where they could see their family members, as they were afraid to leave them alone, even for short periods.

Finally, confirming what is indicated in the literature, it was evidenced that 80% of the interviewees participated directly in the care of the sick family member, corroborating with Dinis et al.[37], when they report that informal caregivers, in this case, an individual in the family or close, present levels of emotional distress when compared to formal caregivers, who are those trained and who receive remuneration for such activity, which may be related to the existence of an affective bond.

In this study, only 1.6% of respondents had the expected burden, contrary to the findings in the literature. It is worth mentioning that the finding of this study, which identified that 97.6% of the interviewees did not have overload, a result that differs from those found in the literature, can be attributed to the fact that, in the hospital setting, caregivers have the support of the multiprofessional health team, people who provide religious shelter, such as chaplains and representatives of different religions, in addition to volunteers who provide other forms of social support, which contributes to minimizing the burden on family caregivers.

As limitations of the present research, the assessment of the burden of family caregivers has taken place in a formal care environment (hospital), whose care routine involves the continuous support of the health team, which contributes to minimizing the caregiver's burden, in addition to the non-classification of the clinical condition/dependence or capacity for self-care of the patients being cared for, influences the level of caregiver burden.

Finally, it is highlighted that the health team has a leading role in identifying the domains of quality of life affected by the relationship of care to the family member[15], and in the feasibility of strategies that seek a balance between

the care process and the preservation of life and well-being of caregivers. Such professionals are essential actors in providing comprehensive care to patients and their families, providing emotional support, offering clarifications about the treatment and other issues that may arise.

In line with these issues, the principles of the Palliative Care Model proposed by the WHO point out that the inclusion of the family member in the care process is fundamental. Palliative care is, in this perspective, conceptualized as curative or palliative actions developed by the multidisciplinary team in a multidimensional perspective, aimed at meeting the patient-family needs (symptom control, psychological, spiritual and social support care), implemented in any evolutionary stage of the disease or treatment to alleviate suffering[38]. In the meantime, providing support to the family caregiver is part of the care and contributes to maintaining the quality of life of the caregiver and the sick family member.

## CONCLUSION

The present study found that the caregivers interviewed were mostly women with a degree of kinship, daughters or spouses, who provided care for a period longer than six months, and who, in general, did not present an overload by the parameters of the applied scale. This fact can be attributed to the fact that the research was carried out in a formal care environment, whose support from the health team contributes to minimizing the family's effort to provide care, in addition to the affective dimension involved in the act of caring, since the family caregiver commonly shares with their loved one a relationship composed of feelings such as love, empathy, and compassion, thus facilitating the care.

However, a reduction in the quality of life of these caregivers was found when the Zarit scale questions referring to the psychological and social relations domains of the WHO quality of life were analyzed separately, which points to the need for actions by health professionals to preserve the functional capacity and well-being of caregivers in the hospital setting.

It signals the importance of actions that enhance the caregiver's coping capacity during the family member's oncologic treatment, with strategies that empower the caregiver and also help them to maintain their quality of life, reducing feelings of insecurity and fear. Further studies are necessary to investigate which care actions of the health team contribute to reducing the overload of family caregivers in the hospital setting.

## REFERENCES

1.  Marinho FP, Valéria MA, França EB. Novo século, novos desafios: mudança no perfil da carga de doença no Brasil de 1990 a 2010. Epidemiol. Serv. Saúde. 2016;25(4):713-24. https://doi.org/10.5123/S1679-49742016000400005

2.  Malta DC, Andrade SSCA, Oliveira TP, Moura L, Prado RR, Souza MFM. Probabilidade de morte prematura por doenças crônicas não transmissíveis, Brasil e regiões, projeções para 2025. Rev. bras. epidemiol. 2019; 22: E190030. https://doi.org/10.1590/1980-549720190030

3.  Milagres MAS, Mafra SCT, Silva EP. Repercussões do câncer sobre o cotidiano da mulher no núcleo familiar. Ciência, Cuidado e Saúde. 2016;15(4):738-45. https://doi.org/10.4025/ciencuidsaude.v15i4.29893

4.  INCA - Instituto Nacional de Câncer José Alencar Gomes da Silva. Brasil. Estimativa 2020: incidência de câncer no Brasil. Rio de Janeiro: INCA, 2019. Disponível em: https://www.inca.gov.br/publicacoes/livros/estimativa-2020-incidencia-de-cancer-no-brasil

5.  Tørring ML, Falborg AZ, Jensen H, Neal RD, Weller D, Reguilon I et al. Advanced-stage cancer and time to diagnosis: An International Cancer Benchmarking Partnership (ICBP) cross-sectional study. Eur J Cancer Care. 2019;28(5). https://doi.org/10.1111/ecc.13100

6.  Johansen S, Cvancarova M, Ruland C. The Effect of Cancer Patients' and Their Family Caregivers' Physical and Emotional Symptoms on Caregiver Burden. Cancer Nurs. 2018;41(2):91-9. https://doi.org/10.1097/ncc.0000000000000493

7.  Borges EL, Franceschini J, Costa LHD, Fernandes ALG, Jamnik S, Santoro IL. Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. J Bras Pneumol. 2017;43(1):18-23. https://doi.org/10.1590/s1806-37562016000000177

8.  Yavo IS, Campos EMP. Cuidador e cuidado: o sujeito e suas relações no contexto da assistência domiciliar. Psicol. teor. prat. 2016;8(1):20-32. http://dx.doi.org/10.15348/1980-6906/psicologia.v18n1p20-32

9.  Esperon JMT. Pesquisa Quantitativa na Ciência da Enfermagem. Esc. Anna Nery. 2017;21(1). https://doi.org/10.5935/1414-8145.20170027

10. Carrapato P, Correia P, Garcia B. Determinante da saúde no Brasil: a procura da equidade na saúde. Saude soc. 2017;26(3): 676-89. https://doi.org/10.1590/S0104-12902017170304

11. Cuschieri S. The STROBE guidelines. Saudi journal of anaesthesia. 2019;13(1):S31. https://doi.org/10.4103/sja.sja_543_18

12. FCV: FUNDAÇÃO CRISTIANO VARELLA. [Internet]. História. 2019. Disponível em: https://www.fcv.org.br/site/conteudo/detalhe/87

13. Coppetti LC, Girardon-Perlini NMO, Andolhe R, Silva LMC, Dapper SN, Noro E. Habilidade de cuidado, sobrecarga, estresse e coping de cuidadores familiares de pessoas em tratamento oncológico. Rev. Bras. Enferm. 2019;72(6):1541-46. https://doi.org/10.1590/0034-7167-2018-0605

14. Trindade I, Almeida D, Romão M, Rocha S, Fernandes S, Varela V, et al. Caracterização do grau de sobrecarga dos cuidadores de utentes dependentes da Unidade de Saúde Familiar USF Descobertas. Rev Port Med Geral Fam. 2017;33(3):178-86. https://doi.org/10.32385/rpmgf.v33i3.12160

15. Fleck MPA, Leal OF, Louzada S, Xavier M, Chachamovich E, Vieira G et al. Desenvolvimento da versão em português do instrumento de avaliação de qualidade de vida da OMS (WHOQOL-100). Rev Bras Psiquiatr. 1999;21(1). https://doi.org/10.1590/S1516-44461999000100006

16. Pagano, M, Gauvreau, K. Princípios de Bioestatística. São Paulo: Cengage Learning, 2010.

17. Xavier ECL, Júnior AJSC, Carvalho MMC, Lima FR, Santana ME. Diagnósticos de enfermagem em cuidados paliativos oncológicos segundo diagrama de abordagem multidimensional. Enferm. Foco. 2019;10(3): 152-157. https://doi.org/10.21675/2357-707X.2019.v10.n3.2109

18. Cardoso AC, Noguez PT, Oliveira SG, Porto AR, Perboni JS, Farias TA. Rede de apoio e sustentação dos cuidadores familiares de pacientes em cuidados paliativos no domicílio. Enferm. Foco. 2019;10(3): 34-39. https://doi.org/10.21675/2357-707X.2019.v10.n3.1792

19. Loh KP, Soto-Perez-de-Celis E, Duberstein PR, Culakova E, Epstein RM, Xu H et al. Patient and caregiver agreement on prognosis estimates for older adults with advanced cancer. Cancer. 2020. https://doi.org/10.1002/cncr.33259

20. Ferreira CR, Isaac L, Ximenes VS. Cuidar de idosos: um assunto de mulher? Est. Inter. Psicol. 2018;9(1):108-25. http://dx.doi.org/10.5433/2236-6407.2018v9n1p108

21. Souza ID, Pereira JA, Silva EM. Entre o Estado, a sociedade e a família: o care das mulheres cuidadoras. Rev. Bras. Enferm. 2018;71(6): 2720-27. https://doi.org/10.1590/0034-7167-2018-0111

22. Freitas JAL, Oliveira, BLG. Aspectos Psicológicos Envolvidos Na Sobrevivência do Câncer Infantil. Revista UNINGÁ. 2018;55(2):1-13.

23. Figueiredo T, Silva AP, Silva RMR, Silva JJ, Silva CSO, Alcântara DDF et al. How can I help? Feelings and experiences of the familiar caregiver of cancer patients. ABCS Health Sciences. 2017;42(1): 34-9. https://doi.org/10.7322/abcshs.v42i1.947

24. Lavallée JF, Grogan S, Austin CA. Cancer patients' family members' experiences of the information and support provided by healthcare professionals. Health Education Journal. 2018;1-12. https://doi.org/10.1177%2F0017896918812511

25. Wakiuchi J, Marcon SS, Oliveira DC, Sales CA. Reconstruindo a subjetividade a partir da experiência do câncer e seu tratamento. Rev. Bras. Enferm. 2019;72(1):125-33. https://doi.org/10.1590/0034-7167-2018-0332

26. Costa DT, Silva DMR, Cavalcanti IDL, Gomes ET, Vasconcelos JLA, Carvalho MVG. Coping religioso/espiritual e nível de esperança em pacientes com câncer em quimioterapia. Rev. Bras. Enferm. 2019;72(3): 640-45. https://doi.org/10.1590/0034-7167-2018-0358

27. Nakash O, Granek L, Cohen M, David MB. Association Between Cancer Stigma, Pain and Quality of Life in Breast Cancer. Psychology, Community & Health. 2019;8(1): 275–87. https://doi.org/10.5964/pch.v8i1.310

28. Kumar A, Bhagabaty SM, Tripathy JP, Selvaraj K, Purkayastha J, Singh R. Delays in Diagnosis and Treatment of Breast Cancer and the Pathways of Care: A Mixed Methods Study from a Tertiary Cancer Centre in North East India. Asian Pac J Cancer Prev. 2019;20(12):3711-21. https://doi.org/10.31557/apjcp.2019.20.12.3711

29. Rosas C, Neri AL. Qualidade de vida, sobrecarga, apoio emocional familiar: um modelo em idosos cuidadores. Rev. Bras. Enferm. 2019;72(2):169-76. https://doi.org/10.1590/0034-7167-2018-0439

30. Vale JMM, Neto ACM, Santos LMS, Santana ME. Self-care of the caregiver of the sick in adequate palliative oncological home care. J Nurs UFPE. 2019;13. https://doi.org/10.5205/1981-8963.2019.238381

31. Rocha RCNP, Pereira ER, Silva RMCRA, Medeiros AYBBV, Refrande SM, Refrande NA. Necessidades espirituais vivenciadas pelo cuidador familiar de paciente em atenção paliativa oncológica. Rev. Bras. Enferm. 2018;71(6): 2635-42. https://doi.org/10.1590/0034-7167-2017-0873

32. Lalani N, Duggleby W, Olson J. Spirituality among family caregivers in palliative care: an integrative literature review. Int J Palliat Nurs. 2018;24(2):80-91. https://doi.org/10.12968/ijpn.2018.24.2.80

33. Aubin M, Vézina L, Verreault R, Simard S, Desbiens JF, Tremblay L et al. Effectiveness of an intervention to improve supportive care for family caregivers of patients with lung cancer: study protocol for a randomized controlled trial. Trials. 2017;18(1):304. https://dx.doi.org/10.1186%2Fs13063-017-2044-y

34. Mazanec SR, Miano S, Baer L, Campagnaro EL, Sattar A, Daly BJ. A family-centered intervention for the transition to living with multiple myeloma as a chronic illness: A pilot study. Appl Nurs Res. 2017;35:86-9. https://doi.org/10.1016/j.apnr.2017.03.003

35. Santos D, Pereira FJR, Bitencourt MLS, Queiroz D, Nascimento LB. Cuidados de saúde prestados pelos filhos homens aos pais idosos. Saúde Coletiva (Barueri). 2020; 10(56):3102-11. https://doi.org/10.36489/saudecoletiva.2020v10i56p3102-3111

36. Rezende G, Gomes CA, Rugno FC, Carvalho RC, De Carlo MMRP. Sobrecarga de cuidadores de pessoas em cuidados paliativos: revisão integrativa da literatura. Rev.Medicina de Ribeirão Preto. 2016;49(4):344-5. https://doi.org/10.11606/issn.2176-7262.v49i4p344-354

37. Diniz MAA, Melo BRS, Neri KH, Casemiro FG, Figueiredo LC, Gaioli CCLO et al. Estudo comparativo entre cuidadores formais e informais de idosos. Ciênc. saúde coletiva. 2018;23(11):3789-98. https://doi.org/10.1590/1413-812320182311.16932016

38 International Association for Hospice e Palliative Care - Palliative Care Definition. Available from: https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/

**Author contributions**

All authors participated in the following stages of manuscript development: a) study conception and/or design; b) data collection, analysis, and interpretation; c) writing and/or critical revision of the manuscript; d) approval of the final version to be published.

**Conflict of interests**

The authors declare that there were no conflicts of interest during the conduct of this study.

Corresponding Author:
João Vitor Andrade
jvma100@gmail.com

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