DOI 10.18471/rbe.v.39.58501

EPIDEMIOLOGICAL PROFILE OF CAREGIVERS OF CANCER PATIENTS IN PALLIATIVE CARE

PERFIL EPIDEMIOLÓGICO DE CUIDADORES DE ADOECIDOS PELO CÂNCER EM CUIDADOS PALIATIVOS

PERFIL EPIDEMIOLÓGICO DE LOS CUIDADORES DE PACIENTES CON CÁNCER EN CUIDADOS PALIATIVOS

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How to cite this article: Vale JMM, Santana ME, Lima VLA, Parente AT, Sonobe HM, Ferreira IP. Epidemiological profile of caregivers of cancer patients in palliative care. Rev baiana enferm. 2025;39: e58501.

Objective: to analyze the profile of family caregivers linked to a specialized oncology center. Method: descriptive correlational study with a quantitative approach, with 147 family caregivers at the Oncology Palliative Care Clinic in a city in the North of the country. Data collection was through a Likert scale form and analyzed through descriptive and inferential statistics. Results: most caregivers are children (45.6%), female (58.5%), living in cities in the countryside (57.8%), with complete high school education (42.9%), married (50.3%), housewives (38.8%), Catholic (48.3%), they have no income (55.1%), and have health problems (57.1%). Final considerations: Regarding the health profile of caregivers, most had some type of health problem, with emphasis on pain, systemic arterial hypertension, and diabetes. The use of polypharmacy focused on antihypertensive and hypoglycemic drugs. These findings demonstrate that caregivers are in a situation of health and social vulnerability.

Keywords: Family. Caregivers. Neoplasms. Palliative Care. Epidemiology.

Objetivo: analisar o perfil dos cuidadores familiares vinculados a um centro especializado em oncologia. Método: estudo descritivo correlacional de abordagem quantitativa, com 147 familiares cuidadores na Clínica de Cuidados Paliativos Oncológicos numa cidade do Norte do país. A coleta de dados foi por meio de formulário conforme escala

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Likert e analisados por meio da estatística descritiva e inferencial. Resultados: a maioria dos cuidadores são os filhos (45,6%), sexo feminino (58,5%), residentes em cidades do interior (57,8%), com ensino médio completo (42,9%), casados (50,3%), do lar (38,8%), católico (48,3%), não possuem renda (55,1%), com problema de saúde (57,1%). Considerações finais: Quanto ao perfil de saúde dos cuidadores, a maioria possuía algum tipo de problema de saúde tendo destaque a dor, hipertensão arterial sistêmica e a diabetes. O uso de polifarmácia voltou-se para anti-hipertensivo e hipoglicemiantes. Estes achados demonstram que os cuidadores estão em situação de vulnerabilidade de saúde e social.

Descritores: Família. Cuidadores. Neoplasias. Cuidados Paliativos. Epidemiologia.

Objetivo: analizar el perfil de los cuidadores familiares vinculados a un centro oncológico especializado. Método: estudio descriptivo correlacional con enfoque cuantitativo, con 147 cuidadores familiares de la Clínica de Cuidados Paliativos Oncológicos de una ciudad del Norte del país. La recolección de datos se realizó mediante un formulario de escala Likert y se analizaron mediante estadística descriptiva e inferencial. Resultados: la mayoría de los cuidadores son hijos (45,6%), mujeres (58,5%), residentes en ciudades del interior (57,8%), con secundaria completa (42,9%), casados (50,3%), amas de casa (38,8%), católicos (48,3%), sin ingresos (55,1%), con problemas de salud (57,1%). Consideraciones finales: Respecto al perfil de salud de los cuidadores, la mayoría presentó algún tipo de problema de salud, con énfasis en dolor, hipertensión arterial sistémica y diabetes. El uso de polifarmacia se dirigió hacia antihipertensivos e hipoglucemiantes. Estos hallazgos demuestran que los cuidadores se encuentran en una situación de vulnerabilidad sanitaria y social.

Descriptores: Familia. Cuidadores. Neoplasias. Cuidados paliativos. Epidemiología.

Introduction

Cancer is one of the diseases that most affects individuals, being one of the main causes of death in the world, with approximately 9.6 million. In Brazil, in the three-year period 2023-2025, 704 thousand new cases of cancer are expected to occur each year. Therefore, palliative care can and should be implemented continuously, from diagnosis to end-of-life care, concomitantly with oncological treatment(1-2).

In this sense, according to the World Health Organization (WHO), palliative care is defined as an approach that aims to improve the quality of life of patients facing problems associated with diseases that threaten their lives and those of their families, through the prevention of suffering, early identification and impeccable assessment of pain and other physical, psychosocial and spiritual problems(3).

In this way, the more the disease progresses irreversibly, the more complex the care becomes. Thus, such care responsibilities fall on caregivers, who are usually family members (parents, spouse, children, etc.) and have a high degree of commitment to the health and well-being of patients. These family caregivers assume multiple responsibilities regarding the biological, social, and psychological aspects of the patient, suffering from stress due to physical and psychological limitations in providing care, which leads to a feeling of overload, reducing their quality of life(4-5).

Family caregiver (FC) overload is the result of a set of attitudes and emotional reactions brought about by the experience of care, which involves a significant amount of time, energy, and support, which can be physical, emotional, social, spiritual, or financial(4-6).

FCs end up assuming this role suddenly, not being prepared to assume the burden of care, making care a physical and emotional challenge. Thus, in this context, it is common for these caregivers to suffer both from the illness of their loved one and from health problems, such as anxiety and depression, sleep and mood disorders, lack of self-care, and practical problems in caring for the patient, which make them secondary victims of cancer. At the same time, FCs, in many cases, receive insufficient guidance and support from the health system, and their psychological, physical, and social issues are not considered during the course of their family members' cancer, leading to more severe emotional reactions. In the literature(6-8), there is also little research on the experiences of caregivers that would allow for the development of training programs for palliative care caregivers.

It is known that the relationship between caregivers and patients is very close, and unmet problems of caregivers will adversely affect them and reduce their quality of life, as well as having consequences for the patient, given that evidence in the literature indicates that their unmet needs are reflected in the increased care needs of their sick family members(3).

In view of all these aspects mentioned, it is clear that the family caregiver is neglected and becomes unknown. Therefore, this study aimed to analyze the profile of family caregivers linked to a specialized oncology center

Method

This is a descriptive correlational study with a quantitative approach, carried out in a Palliative Oncology Care Clinic (POCC), a reference in cancer treatment, in a capital city in the North of Brazil. The hospital is accredited as a High Complexity Oncology Center (CACON), and its functions include teaching, research and outreach in health and, in addition to serving 17 other medical specialties, it also offers outpatient services and Home Care Services.

The sample, selected by convenience, consisted of 147 family caregivers, drawn from a population of 236 patients, considering the admission and discharge flow. The inclusion criteria selected were family caregivers of patients in palliative oncology care; over 18 years of age; who declared themselves to be the main caregivers, even if they shared the care; or caregivers who remained with the patient in the hospital for at least 72 hours. Caregivers of patients who were in their first consultation with the Palliative Care service or in outpatient care were excluded.

Data collection was performed with the consent of the participant, by signing the Informed Consent Form (ICF). A form was used to characterize the caregivers, organized according to the Likert scale. The study variables related to the family caregiver were: sociodemographic; caregiving (Option to be a caregiver; Length of time providing care; sharing care with someone); health conditions (Health problem; Use of medication); and lifestyle habits (Smoking; Alcoholism).

The data collected were tabulated, interpreted, processed, and analyzed using descriptive and inferential statistics in Microsoft Excel® 2019 spreadsheets, in order to consolidate the information from the data collected. The database was organized and analyzed using the Statistical Package for the Social Sciences (SPSS) software, version 24.0, all in a Windows 10 environment, with the results presented in tables and discussed based on the scientific literature.

In accordance with Resolution 466/12 of the National Health Council, this study was approved by the Research Ethics Committee (REC) of the Federal University of Pará (UFPA), under Opinion number 4,059,404, and also by the Ophir Loyola Hospital (HOL), Opinion number 4,115,162.

Results

Regarding the caregiver variables, the analyzed data showed that the majority of caregivers are children (67 - 45.6%), female (86 - 58.5%), living in municipalities in the countryside or metropolitan region (85 - 57.8%), have completed high school (63 - 42.9%), are married (74 - 50.3%), are mostly housewives (57 - 38.8%) and self-employed (45 - 30.6%), Catholic (71 - 48.3%) and have no income (81 - 55.1%) (Table 1).

Table 1 – Distribution of family caregivers according to sociodemographic variables Belém, Pará, Brazil – 2021. (N=147)

Sociodemographic Characterization	n	%	Mean (µ)	± Standard-Deviation	P-Value(1)
Kinship					
Children	67	45.6			0.000*
Brother/sister	25	17.0			
Nephew	23	15.6			
Spouse	16	10.9			
Mother	5	3.4			
Uncle/aunt	4	2.7			
Grandson/granddaughter	3	2.0			
Cousin	3	2.0			
Father	1	0.7			
Sex					0.048*
Female	86	58.5			
Male	61	41.5			
Age			39.76	± 11.98	
Locality					
Outside Belém or the Metropolitan Region	85	57.8			0.000*
Belém	38	25.9			
Belém Metropolitan Region	24	16.3			
Education					
Complete High school	63	42.9			0.000*
Incomplete elementary education	27	18.4			
Incomplete High school	27	18.4			
Complete University education	16	10.9			
Complete Elementary education	8	5.4			
Incomplete University Education	6	4.1			
Marital status					
Married	74	50.3			0.000*
Single	52	35.4			
Stable Union	17	11.6			
Divorced	3	2.0			
Widowed	1	0.7			
Profession					
Housewife	57	38.8			0.000*
Self-employed	45	30.6			
Student	12	8.2			
Teacher	6	4.1			
Farmer	3	2.0			
Administrator	2	1.4			
Retired	2	1.4			
Accountant	2	1.4			
Farmer	2	1.4			
General Services	2	1.4			
Architect	1	0.7			
Librarian	1	0.7			
Hairdresser	1	0.7			
Carpenter	1	0.7			
Computer Science	1	0.7			

Table 1 – Distribution of family caregivers according to sociodemographic variables Belém, Pará, Brazil – 2021. (N=147)

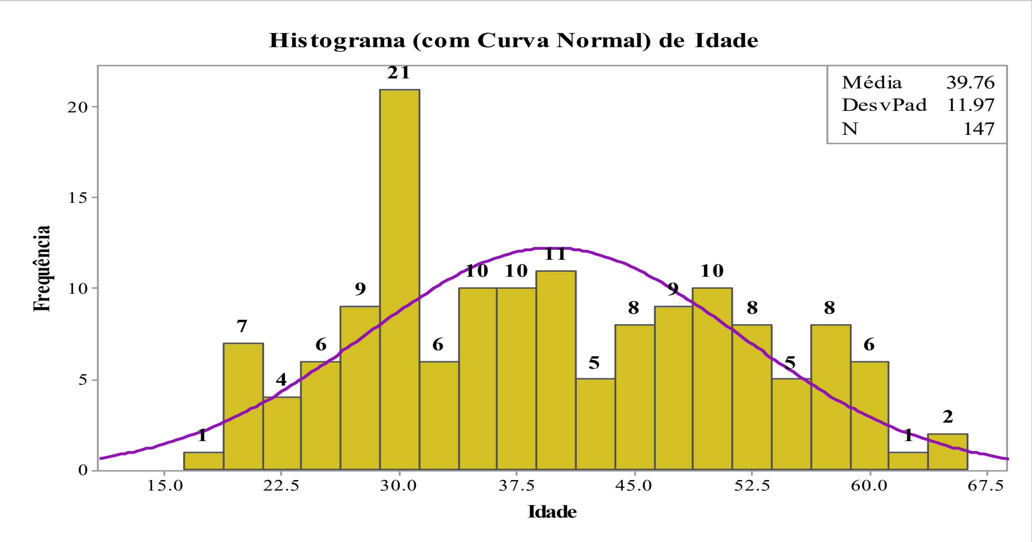
Sociodemographic Characterization	**n**	**%**	**Mean (μ)**	**± Standard-Deviation**	**P-Value**(1)
Composer	1	0.7			
Cook	1	0.7			
Housekeeper	1	0.7			
Statistician	1	0.7			
Metalworker	1	0.7			
Cashier	1	0.7			
Computer Technician	1	0.7			
Electronics Technician	1	0.7			
Watchman	1	0.7			
Religion					
Catholic	71	48.3			0.000*
Evangelical	65	44.2			
No religion	7	4.8			
Christian	3	2.0			
Adventist	1	0.7			
Family income					
No income	81	55.1			0.000*
1 to 3 minimum wages	53	36.1			
3 to 5 minimum wages	12	8.2			
Greater than 5 minimum wages	1	0.7			

Source: Own elaboration.

(1)Pearson's Chi-square test (Wilks' G^2) for independence (p-value<0.05).

The mean age of caregivers is 40 years (μ = 39.76), with a standard deviation of ± 12 years (σ = ± 11.97) (Graph 1).

Graph 1 – Distribution of family caregivers according to mean age. Belém, Pará, Brazil – 2020. (N=147).



Source: Own elaboration.

Tradução da figura

Histogram (with Normal Curve) of Age
Frequency
Age
Mean
Standard Deviation
N
Histograma (com Curva Normal) de Idade
Frequência
Idade
Média
Desvio padrão
N

The survey shows that, for most caregivers, becoming a caregiver was a family decision (65 - 44.2%), they are full-time caregivers (89 - 60.5%), within a period of 1 to 5 years (46 - 94%), they share the care with someone (89 - 60.5%), and 58 (39.5%) caregivers share the care with a sibling. It was also found that 80 (54.4%) caregivers work outside the home, 15 (10.2%) work in sales, the majority have children (108 - 73.5%) and 53 (36.1%) caregivers have more than two children.

In the assessment of the health of caregivers, it was observed that 84 (57.1%) have some health problem. The most common complaints include shoulder pain (58 - 39.5%) and back pain (76 - 51.7%). In addition, cases of hypertension (16 - 10.9%), hernias (2 - 1.4%), diabetes (8 - 5.4%), asthma (2 - 1.4%), depression, gastritis, osteoporosis, polycystic ovary, Vogt-Koyanagi-Harada syndrome and HIV (1 - 0.7% each) were reported. Regarding the use of medications, 15 (10.2%) used Losartan, 7 (4.8%) Metformin and Glibenclamide, while 1 caregiver (0.7%) used Haloperidol and another, antiretrovirals. Regarding lifestyle habits, 25 (17%) caregivers were smokers and 77 (52.4%) consumed alcoholic beverages.

Among the scores obtained, having a health problem did not present statistically significant differences, as well as problems of back pain and use of alcoholic beverages.

For problems of shoulder pain, systemic arterial hypertension, hernias, claustrophobia, gastritis, depression, asthma, diabetes, HIV status, Vogt-Koyanagi-Harada syndrome, polycystic ovary, osteoporosis, taking medication and smoking showed statistically significant differences.

Discussion

Regarding the sociodemographic characteristics of caregivers, a predominance of female children with a mean age of 40 years, married and working as housewives, was identified. These findings are corroborated by other studies(9-12). The image of the child as the primary caregiver appears to be anchored in research(9), which indicates that culture and ethnicity influence the forms of care, therefore filial responsibility is a social and moral attitude of children towards their parents, that is, it appears as a desire, obligation and affection to return care previously received. Results showed that the caregiver's burden intensifies when there are emotional and consanguinity bonds between them and the patient, so that the caregiver feels as if every advance and every setback or worsening of the disease is his/hers(12).

Studies also indicate the care attributed to the female image, as a characteristic inherent to their delicacy and also to their work at home, these being the representatives of caregivers in most cases. Given this, the large number of activities assigned to women creates an overload, since, in addition to the activities performed daily at home, they also take on the full responsibility of caring for the loved one who is sick with cancer(10).

Socially, women are expected to take care of others and not neglect their existential responsibility for self-care, which is characterized as the action aimed at preserving and maintaining their existence. In the experience of the women in the study, it was noted how much self-care is neglected, reflecting on the personal issues of being a woman as well as on their own health(13).

In the face of a situation of advanced cancer, they put self-care and their personal needs in the background and establish the health and well-being of those they care for as a priority. They miss appointments, miss exams, see their health problems worsen because they choose to care for their loved one, and place themselves entirely in the care of others, without taking any care of themselves(13).

So, once again, it is the female figure who ends up prioritizing total dedication to care, sacrificing self-care. The caregiver, immersed in his/her context, believes that his/her priority is the health of his/her loved one, causing him/her to give up his/her activities to subsidize the needs of the sick person, even dispensing with care for his/her own health and other needs(14).

A study states that 78.2% of caregivers give up sports, cultural or recreational activities to dedicate themselves more to care, although only 5% of female caregivers receive some financial incentive or compensation for dedicating themselves exclusively to providing care(15).

Regarding religion, the majority declared themselves to be Catholic and had completed high school, similar to findings in another study(16), in which 73.3% of the caregivers were married, 43.3% were Catholic and the majority (65%) of the participants had completed at least high school.

Regarding economic conditions, the majority was self-employed and did not have a fixed income. This shows the social vulnerability in which caregivers find themselves, since, due to the degree of need of the sick person, they have to choose to reduce or completely give up their academic or professional activities, to dedicate themselves entirely to caring for the needs of the sick person. (16)

In Brazil, family members often have to take on the role of caregivers, however, this is done without assistance and without the support of government programs that provide subsidies for their subsistence. Another study also indicates that the situation of these caregivers and of the family in general, worsens even more when they cannot count on a specific government support system for their peculiarities, stating that, probably, in the near future, the health system will have a new patient. A study indicates that caregivers who have completed high school or who have an annual family income of less than R$20,000.00 (twenty thousand reais) spend more hours per day providing care than those who have a higher level of education and financial income(12,17-18).

It is important to confirm that the level of education and income are in agreement with other international studies, and these factors act to construct the socioeconomic condition of the caregivers, which serves as an explanation for how such social conditions are implicated in the increase in their overload, resulting in their low quality of life(19).

Regarding religion, it is closely intertwined with the specificities presented by caregivers, characterizing the need for subjective and spiritual attention of each one, which are composed of perceptions, assumptions and feelings that need to be adjusted to their own transcendence(20).

The feeling of being alone may come from the fact that the decision to become a caregiver was a family decision and not an internal motivation, since most of these caregivers provide care full-time, within a period of one to five years, and receive help from a family member, who is usually a sibling. An integrative review(21) showed that caregivers in the hospital environment did not choose to be caregivers, but ended up becoming caregivers out of family necessity. This fact can be attributed to the increased burden of the caregivers, due to spending a lot of time in the hospital accompanying the family member.

Regarding support for care, it is worth noting that caregivers reported that they were only receiving support due to the hospitalization of the family member, but that, at home, care would be their responsibility. The mean length of care was 10.9 months(21). In another study(10), its findings are similar to those of this study, as most caregivers reported having cared for their family member for a period of 1 to 5 years, and only one reported a period of 11 years. In another study(11), this period was longer, ranging from 6 months to 15 years, and another study(16) found that 31.7% had been caring for the patient for more than two years and 48.3% dedicated more than 16 hours of their daily time to care, with a journey resulting in more than 8 hours of daily care or 12.5 hours daily. In this study, family caregivers are taking care of the sick for more than 24.4 hours/week, which is more than that reported by the National Alliance for Caregivers(10,11,14,16,19).

Another important fact raised in this study was the exercise of work outside the home and that most of these caregivers have more than two children. Research shows that 17.1% of caregivers had 1 to 3 children and 32.6% had 4 or more children. Regarding work outside the home, research showed that 82.9% dedicate themselves exclusively to domestic work and do not have another job, and 68 (73.1%) of the caregivers were unemployed. Corroborating the findings of this research, the study identified that 58 caregivers in its sample had formal employment, 68 had children and only 41.7% of the caregivers were workers. Patients from racial and ethnic minorities and low-income patients are more vulnerable to financial and job losses compared to their wealthier and white counterparts(9,11,16,18).

With regard to place of origin, one study(22), although showing results similar to those of this study in terms of profile, coinciding with family caregivers with a predominance of females, age group and occupation of activities linked to the home, the region of origin was an urban area, which contradicts the profile of those surveyed in this study. The region also shows vulnerability, as the further away from the capital, the more difficult it is to access specialized health resources.

Regarding health problems, the present study identified that most caregivers had some health problem, corroborating the findings of another study(23), in which 77.9% of caregivers had some body pain, and 66.7%, specifically back pain. In an international study, caregivers reported several other complications in addition to the pain already addressed in this study, such as the presence of heart problems, insomnia, dyspnea, agitation and feelings of guilt and anxiety as forms of physical and mental suffering(24). Other problems that could also be identified in the literature point to diseases of the circulatory system (30.38%), nutritional and metabolic endocrine diseases (18.99%) and mental and behavioral diseases (16.46%), in addition to emotional problems, anxiety, depression and stress(25).

Likewise, other problems related to the health of caregivers were identified and are related to chronic cardiovascular diseases, hypertension and diabetes mellitus. These are diseases that are increasing globally in the adult population and are present in the lives of caregivers, whether due to lifestyle or genetic factors, who, over time, may also need a caregiver.

The study had limitations such as the fact that it did not consider some variables, such as ethnicity or race, degree of dependency of patients, in addition to the influence of the pandemic within different contexts. Such facts may limit the possibility of generalizing the results.

The contribution to the nursing field involves identifying the epidemiological profile and health conditions of caregivers, which will enable the systematization of nursing care, as well as expanding such care to caregivers and improving preventive and support measures, aiming to understand their peculiarities and favoring quality of life. Furthermore, this study contributes to the promotion of more public policies that aim at the expansion, inclusion and specific support for caregivers.

Final considerations

It was concluded that, in relation to the degree of kinship, the majority were children, predominantly female, with a mean age of 40 years, married, with more than two children, Catholic, housewives, with a high school education, living outside the capital or metropolitan region.

Most caregivers worked outside the home, were self-employed, worked in sales and had no fixed income. The decision to become a caregiver was made by the family, and they provided care full-time, for a period of 1 to 5 years, with help from other family members, usually their siblings.

Regarding the health profile of caregivers, most had some type of health problem, with pain, systemic arterial hypertension and diabetes standing out. The use of polypharmacy was focused on antihypertensive and hypoglycemic drugs.

These findings demonstrate that caregivers are in a situation of health and social vulnerability. In this way, it is hoped that this research will encourage further discussions on the points raised, and other health professionals will be encouraged to seek to better understand the peculiarities of these users, who until now have remained marginalized in the context of health and care.

Collaborations:

1 – Project design and planning: Jamil Michel Miranda do Vale, Mary Elizabeth de Santana and Vera Lúcia de Azevedo Lima;

2 – Data analysis and interpretation: Jamil Michel Miranda do Vale;

3 – Writing and/or critical review: Jamil Michel Miranda do Vale, Mary Elizabeth de Santana, Vera Lúcia de Azevedo Lima, Andressa Tavares Parente, Helena Megumi Sonobe and Ilma Pastana Ferreira;

4 – Approval of the final version: Jamil Michel Miranda do Vale, Mary Elizabeth de Santana, Vera Lúcia de Azevedo Lima, Andressa Tavares Parente, Helena Megumi Sonobe and Ilma Pastana Ferreira.

Conflicts of interest

There are no conflicts of interest.

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Received: December 13, 2023

Approved: April 4, 2025

Published: July 23, 2025