







Caregivers of older adults in palliative care: level of burden and depressive symptoms

Cuidadores de idosos em cuidados paliativos: nível de sobrecarga e sintomas depressivos

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Abstract

Introduction: The burden perceived by informal caregivers of older adult cancer patients in palliative care is an incessant daily repetitiveness, and can negatively affect their physical and mental health, as well as their social and family life. **Objective:** To assess the level of burden and the intensity of depressive symptoms in caregivers, and the dependence of the older adults for basic and instrumental activities of daily living. **Methods:** This was a cross-sectional and descriptive study, composed of 20 caregivers and 20 older adults with cancer in palliative care. Caregivers and older adults were administered the socio-economic and demographic profile assessment. For the caregivers, the International Physical Activity Questionnaire - IPAQ, the Zarit Burden Interview (ZBI), and the Beck Depression Inventory (BDI) were used. For the older adults, the Katz Index of Independence in Activities of Daily Living (Katz Index ADL) and the Lawton and Brody Instrumental Activities of Daily Living scales (Lawton and Brody IADL scales) were used. Data were represented in absolute and percentage values. **Results:** Caregivers were predominantly female, mostly daughters of the older adults, married or with a partner, with elementary school education, income of 1 to 3 times the minimum wage, and had a sedentary lifestyle. A moderate level of burden was verified in 75% of the caregivers, and mild to moderate depressive symptoms in 45%. The assessment of ADL in older adults found that 55% were independent in all six functions, with greater dependence (75%) in ADL for housekeeping such as laundry (85%) and driving vehicles (90%). **Conclusion:** Caregivers of older adults cancer patients in palliative care show moderate level of burden, and mild to moderate depressive symptoms.

Keywords: Caregivers. Depression. Elderly. Palliative care.

Resumo

Introdução: A sobrecarga vivenciada por cuidadores informais de idosos com câncer em cuidados paliativos em uma repetitividade diária incessante pode afetar negativamente a saúde física e mental, bem como a vida social e familiar do cuidador. **Objetivo:** Avaliar o nível de sobrecarga e a intensidade de sintomas depressivos nos cuidadores e a dependência para as atividades básicas e instrumentais de vida diária dos idosos.

Métodos: Estudo transversal e descritivo, composto por 20 cuidadores e 20 idosos com câncer em cuidados paliativos. Os cuidadores e os idosos foram submetidos à avaliação do perfil socioeconômico e demográfico. Quanto à avaliação dos cuidadores, utilizaram-se o Questionário Internacional de Atividade Física- IPAQ, a escala Zarit Burden Interview e o Inventário de Depressão de Beck. Para a avaliação dos idosos, o índice de Katz para as atividades básicas da vida diária (ABVD) e a escala de Lawton e Brody para atividades instrumentais de vida diária (AIVD). Os dados foram representados em valores absolutos e percentuais. **Resultados:** Houve predomínio de cuidadores do sexo feminino, a maioria filha dos idosos, casadas ou com companheiro, com ensino fundamental I, renda de 1 a 3 salários mínimos e sedentárias, sendo constatado nível de sobrecarga moderado em 75% dos cuidadores e sintomas depressivos de leves a moderados em 45%. Quanto à avaliação das ABVD nos idosos, constatou-se que 55% eram independentes nas seis funções, com maior dependência (75%) em AIVD para trabalhos domésticos como lavar roupas (85%) e condução de veículos (90%). **Conclusão:** Os cuidadores de idosos com câncer em cuidados paliativos apresentam nível de sobrecarga moderado e sintomas depressivos de leves a moderados.

Palavras-chave: Cuidadores. Depressão. Idoso. Cuidados paliativos.

Introduction

Caregivers of older adults are people who assume the responsibility of caring, offering support and relief. The "informal caregiver" is someone who provides unpaid assistance for activities undertaken, usually a family member; the "formal caregiver" is one who has professional preparation and training, and has assured remuneration.¹

Changes in the population demographic profile have increased chronic and/or degenerative illnesses, along

with a decline in organic functions. According to the Brazilian Institute of Geography and Statistics (IBGE), the number of people aged 65 and over is expected to almost triple, reaching 58.2 million by 2060, equivalent to 25.5% of the population.² Some older adults may be affected by pathological conditions, such as cancer, which is considered a global public health problem, and an estimated 27 million new cases could appear worldwide by 2030.³

Patients who cannot respond to treatment require palliative care. Palliative care is a sphere of care that has emerged with the objective of supplying a growing demand for patients beyond the possibility of therapeutic cure. The term palliative care, introduced in 1974 by Canadian Balfour Mount, comes from the pallium, a Latin word ("cloak"), and refers to the idea of protecting or supporting.⁴

Palliative care aims to offer patients better care, such as control of pain and other symptoms, prevention of injuries and disabilities, promotion of autonomy, comfort, and welcoming, ensuring a better quality of life, instead of simply waiting for the end of life.⁵ However, the burden experienced by caregivers of the older adults with cancer is an incessant daily repetitiveness, sometimes for years, which is exhausting. The older adult's caregiver often prioritizes the needs of the other and, pressured by immediate needs, neglects herself. Constant caregiving consumes practically all of the caregiver's time, strength, leisure, and even emotions, which negatively affects the caregiver's physical and mental health, as well as his or her social and family life.⁶

The clinical deterioration of the patient's condition, the particularities related to the reality of home care, especially in the case of advanced disease, and the possibility of the older adult's death can intensify the caregiver's burden.⁶

The present study intended to identify the characteristics of informal caregivers of older adult patients with cancer in palliative care, and to evaluate their level of burden and the intensity of depressive symptoms, as well as to analyze the degree of dependence of the older adults for basic and instrumental activities of daily living. Therefore, the results obtained in this research may favor the planning of strategies that contribute to the identification of changes that aim toward health promotion, improved quality of life, and paying more attention to the real needs of informal caregivers of older adults with cancer in palliative care.

Methods

This was a quantitative field, cross-sectional, descriptive study, conducted in the palliative care outpatient clinic of the Hospital de Clínicas da Universidade Federal do Triângulo Mineiro (HC-UFTM), city of Uberaba, Minas Gerais, from May to October of 2019.

The study population involved caregivers of the older adults assisted by the HC-UFTM Palliative Care Outpatient Clinic, aged over 18 years, formal or informal, who were available to complete the assessment instruments, able to understand the purpose of the study, and provided written informed consent. The exclusion criteria were caregivers of the older adults who did not provide all the information related to the instruments proposed in this study, and who were not in fact caregivers of the older adults, but rather companions.

A group of 22 caregivers and 22 older adults in ambulatory palliative care at HC-UFTM were identified; two caregivers and two older adults were excluded from the study because one of the companions was not the older adult's caregiver, and one of them died due to disease complications. The final sample was composed of 20 caregivers and 20 older adults in palliative care.

The participants were identified by numbers to preserve their identities. Those who agreed to participate in the research signed the Terms of Free and Informed Consent Form, after receiving explanations about the objective of the study. This research began after the approval by the UFTM Research Ethics Committee (opinion CAAE: 13800319.2.0000.5154).

The caregivers were administered the assessments without the presence of the older adults, to ensure that the interviewee would not be embarrassed to answer any questions and would not embarrass the one he/she cared for; however, the caregivers were present when the assessment was performed with the older adults. The caregivers and the older adults were administered the socioeconomic and demographic profile evaluation.

The caregivers were evaluated by means of the International Physical Activity Questionnaire - IPAQ, proposed by the World Health Organization, and used to estimate the level of habitual physical activity practice, validated in Brazil by Matsudo et al.;⁷ the Zarit Burden Interview (ZBI) scale, which evaluates the perceived overload,⁸ validated in Brazil by Scazufca et al.;⁹ and

the Beck Depression Inventory (BDI), to measure the behavioral manifestations and the intensity of depression.¹⁰ The instruments used to evaluate the older adults were the Katz Index of Independence in Activities of Daily Living (Katz Index ADL),¹¹ and the Lawton and Brody Instrumental Activities of Daily Living scales (Lawton and Brody IADL scales).¹²

The data were processed and analyzed in SPSS software, version 11.5 for Windows. All variables were analyzed descriptively and the data obtained were presented in tables with absolute values and percentages. Spearman's correlation test was performed, but no associations were found between the variables studied.

Results

Twenty caregivers and 20 older adults in palliative care participated in this study. The caregivers group was formed by 11 women (55%), with a mean age of 55.36 years (40-69) and nine men (45%), with a mean age of 49.18 years (28-72) (Table 1).

Results from the Zarit Burden Interview data showed 15 (75%) of the 20 caregivers with moderate burden, and three (15%) with moderate to severe burden, as shown in Table 2. According to the Beck Depression Inventory, seven (35%) caregivers presented mild depressive symptoms and two (10%) moderate depression, therefore 45% of the caregivers presented mental disorders (Table 2).

The older adults in palliative care were 12 (60%) males, with 10 (50%) between 60-69 years old, and seven (35%) with only elementary school education. The diagnoses of the older adults were: skin cancer (n = 1; 5%); bowel cancer (n = 2; 10%); liver cancer (n = 4; 20%); prostate cancer (n = 5; 25%); head cancer (n = 2; 10%); stomach cancer (n = 1; 5%); lung cancer (n = 3; 15%); bladder cancer (n = 2; 10%). All the patients had satisfactory scores on the Mini-Mental State Examination (MMSE), which is a rapid assessment of a person's cognitive function.

Regarding the assessment of functional independence (IADL), 11 (55%) were independent in the six functions (bathing, dressing, eating, toileting, transferring the patient from one place to another, and continence) and only one (5%) was dependent for all functions (Table 3).

Table 1 - Distribution of the older adult caregivers (n = 20) in palliative care, according to sociodemographic data, individual factors (IPAQ), and anthropometric variable (BMI)

Variables	n (%)
Sex	
Female	11 (55)
Male	9 (45)
Age group (years)	
< 35	1 (5)
36 - 50	9 (45)
51 - 65	6 (30)
> 65	4 (20)
Marital status	
Never married or lived with a partner	6 (30)
Lives with a wife or partner	10 (50)
Widow/Widower	1 (5)
Separated/Divorced	3 (15)
Level of relationship with the patient	
Spouse/Partner	6 (30)
Brother/Sister	2 (10)
Child	9 (45)
Nephew/Niece	1 (5)
Close family member	2 (10)
Level of education	
No education	1 (5)
Elementary school I	7 (35)
Elementary school II	4 (20)
Complete high school	3 (15)
Incomplete higher education	2 (10)
Complete higher education	3 (15)
Income (minimal wages)	
No income	4 (20)
< 1	3 (15)
1	3 (15)
1 - 3	10 (50)
Source of financial resources	
No personal income	7 (35)
Retirement	5 (25)
Pension	2 (10)
Welfare benefit/Family allowance - Child benefit	4 (20)
Savings/Rent	2 (10)
Physical activity level (IPAQ)	
Sedentary	10 (50)
Insufficiently active	7 (35)
Active	2 (10)
Very active	1 (5)
Body mass index	
Eutrophic	8 (40)
Overweight	8 (40)
Obesity	4 (20)

Table 2 - Distribution of frequency (n) and percentage (%) of caregivers (n = 20) according to the level of burden scale (ZaritBurden Interview) and Beck Depression Inventory

Variables	n (%)
Zarit Burden Interview	
No burden	2 (10)
Moderate burden	15 (75)
Moderate to severe burden	3 (15)
Beck Depression Inventory	
No burden	11 (55)
Moderate burden	7 (35)
Moderate to severe burden	2 (10)

Table 3 - Distribution of frequency (n) and percentage (%) of the older adults (n = 20) according to the Katz Index of Independence in Activities of Daily Living (Katz Index-ADL)

Variables	n (%)
Independent in the six functions of bathing, dressing, toileting, transferring, continence, and feeding	11 (55)
Independent in five functions and dependent in one function	1 (5)
Independent in four functions and dependent in two functions	1 (5)
Independent in three functions and dependent in three functions	2 (10)
Independent in one function and dependent in five functions	4 (20)
Dependent in all functions	1 (5)

As for the IADL, which demonstrate the interaction of the older adults with the social environment, involving information related to personal care (home care; work and recreation; shopping and money; locomotion; communication and social relations), a classification was established to identify the levels of independence of the older adults (Table 4).

No associations were found between burden and depressive symptoms with the assessment of functional independence (ADL and IADL).

Discussion

The support for chronic patients has prioritized the home model, which determines a greater investment of time and responsibility from the caregiver. Different from other chronic diseases, the representation of cancer assumes great proportions related to hopelessness, anxiety, pain, and prediction of a death with suffering.¹³

Table 4 - Distribution of mean and standard deviation (SD) of the older adults according to Lawton and Brody Instrumental Activities of Daily Living scales (IADL scales)

Information	Mean	SD	IADL scales n (%)		
			0 - 1	2	3
Food preparation, cooking	2.20	1.20	6 (30)	1 (5)	13 (65)
Setting the table	1.45	1.47	11 (55)	0 (0)	9 (45)
Housekeeping	2.45	1.10	3 (15)	2 (10)	15 (75)
House repairs	2.30	1.13	4 (20)	3 (15)	13 (65)
Laundry	2.70	0.73	3 (15)	0 (0)	17 (85)
Working	3.00	0.00	0 (0)	0 (0)	20 (100)
Recreation	1.50	1.15	12 (60)	2 (10)	6 (30)
Organizations	1.55	1.19	12 (60)	1 (5)	7 (35)
Traveling	2.40	1.10	5 (25)	0 (0)	15 (75)
Buying food (shopping)	1.05	1.39	13 (65)	1 (5)	6 (30)
Handling money	0.50	1.10	17 (85)	0 (0)	3 (15)
Managing financial matters	1.95	1.47	7 (35)	0 (0)	13 (65)
Public transportation	2.40	1.23	4 (20)	0 (0)	16 (80)
Driving a car	2.75	0.79	2 (10)	0 (0)	18 (90)
Moving around the neighborhood	0.90	1.29	15 (75)	0 (0)	5 (25)
Getting around outside familiar places	0.60	1.23	16 (80)	0 (0)	4 (20)
Operates telephone	0.25	0.79	18 (90)	1 (5)	1 (5)
Conversation	0.00	0.00	20 (100)	0 (0)	0 (0)
Understanding	0.20	0.52	19 (95)	1 (5)	0 (0)
Reading	1.05	1.23	13 (65)	3 (15)	4 (20)
Writing	0.85	1.09	14 (70)	4 (20)	2 (10)
Family relationships	0.80	1.32	15 (75)	0 (0)	5 (25)
Family relations (children)	1.35	1.53	11 (55)	0 (0)	9 (45)
Friends	1.00	0.65	18 (90)	1 (5)	1 (5)

Note: Scale of 0-1 = independent patients; 2 = patients with partial dependence; 3 = patients with total dependence.

In the present study, all caregivers were informal and provided assistance to the older adults in palliative care. When the caregiver is a family member, the care task can be perceived as more exhausting due to the greater time spent, the readjustment of daily occupations, besides the pain of witnessing the suffering of the loved one.¹⁴

The predominance of female caregivers was verified in this study. Araújo et al.¹⁵ state that these data reflect the condition associated with gender and historical construction, representing a reality in the care process, as caring involves tasks considered feminine, which were learned by women throughout life.

A study carried out in the United Kingdom found that in the group under 75 years of age, between 55% and 62% of the caregivers were women. However, with

increasing age, the proportions changed. For those aged 75 to 84, the proportion of male and female caregivers was about identical, with 50.4% of caregivers being male. The gender balance was reversed for caregivers older than 85, with 59% of caregivers being male.¹⁶

The age range of 36 to 50 years old was the majority of the caregivers; however, informal caregivers older than 65 years represented 20% of the total. The advanced age of the older adult caregivers can interfere in their health, as well as in the quality of the service provided, considering that these individuals are less capable of the physical efforts required for the function, and, more vulnerable to health problems.¹⁷ As presented in the work by Santos et al.,¹⁸ the concessions and efforts made by an older adult caregiver will have

negative repercussions, such as the worsening of existing diseases, the onset of physical pain, and fatigue that can affect him/her during the caregiving action. The restrictions on social life due to the activities developed by the older adult caregivers without the support of other family members, resignations, burden, and physical and emotional exhaustion can progress to possible illness.

In our study, 50% of the caregivers lived with their spouse or partner. The presence of a partner can offer help and emotional support to informal caregivers, however, the increasing requirements of caring can lead to biopsychosocial burden, and compromise marital relationships.¹⁹

With regard to the degree of family relationship, most (45%) of the caregivers were children of the older adults. This can be considered a moral responsibility of the children, as a form of rewarding the care received from their parents, prevailing the assignment of caregiver adopted by people who live in the same house and that usually are the children or spouses.²⁰

The predominant education level was Elementary School I, which reinforces the findings of Almeida et al.,²¹ who found that most caregivers had low education levels. These elements can imply in the caregiver a difficulty in understanding information and knowledge about the disease, a factor that generates physical and emotional burden. In addition, a greater vulnerability in the formal labor market exists for those who present low schooling and professional qualification. This lack of opportunity in obtaining a formal job due to their low level of education can contribute to increased number of informal caregivers.

The individual income of 50% of the informal caregivers, participants of this study, ranged from one to three minimum wages, however, 20% of the caregivers claimed no any income. These data confirm the findings of Amaral et al.,²² who demonstrated that the task accepted as caregiver by a family member can be due to the lack of resources to hire a formal caregiver. This economic vulnerability can cause stress, imbalance, and physical, social, and mental burden to the caregiver, as well as jeopardize the care provided, as it limits the purchase of inputs necessary for the provision of care.²²

The assessment of physical activity level showed that 50% of the informal caregivers stated that they were sedentary, and 35% were insufficiently active, which is consistent with another study in which a great part of the caregivers of the older adults denied any physical

activity.²³ The lack of physical activities increases the caregivers' propensity to non-transmissible chronic diseases and to several illnesses that can favor situations of dependence, and make them more predisposed to the development of anxious or depressive syndromes.²⁴ In the evaluation of the informal caregivers' burden by the Zarit scale, the results obtained showed that the majority (75%) presented moderate burden, followed by 15% with moderate to severe burden. These data show that a longer time dedicated to caregiving, due to an indefinite workload, may favor an increase in burden, and cause states of physical and mental fatigue, stress, depression, and anxiety. According to Sousa et al.,²⁵ the process of caring for an older person in palliative care demands full-time dedication from the informal caregiver, because both the care and the responsibilities tend to increase according to the evolution of the disease and the degree of dependence presented. In addition, in the terminal care stage, the patients' symptoms become more intense and demand more attention, which increases the caregiver's burden and stress.

Providing uninterrupted palliative care for cancer patients carries an emotional, physical, and social burden, resulting in psychosomatic changes for the caregiver, compromising their quality of life and health.²⁶

This study revealed that informal caregivers of the older adults in palliative care had mild (35%) and moderate (10%) depressive symptoms. Thus, almost half of the caregivers (45%) had mental illnesses. These data reveal that these caregivers can present a depressed mood, reduced interest or loss of pleasure in almost all activities, fatigue or loss of energy, among others, which can cause impairment of social functions and other activities of daily living.²⁶ Usually the main responsibility for care lies with a single family member, which makes the caregiver's physical and emotional exhaustion irremediable, favoring the increase of depressive symptoms. Schrank et al.²⁷ reported that informal caregivers motivated by obligation and not by feelings of affection or closeness tend to present higher rates of depression.

Caregivers of patients receiving home palliative care, very often experience physical and emotional exhaustion, sleep disturbances, somatization, social isolation, financial problems, post-traumatic stress disorder, emotional problems such as uncertainty and hopelessness, high levels of anxiety, distress and depression.²⁸

By means of the assessment of the basic activities of daily living, this study showed that 55% of the older adults were independent in functions such as bathing, dressing, feeding, toileting, transferring the patient from one place to another, and continence; 20% were independent in one function and dependent in five. The level of independence of most older adults with cancer in palliative care did not attenuate the psychological distress, perceived burden, and depression of family caregivers. According to Duimering et al.,²⁹ emotional distress causes more suffering than physical care, and as the disease progresses, disability, symptom progression, and anticipatory grief cause a significant burden for caregivers.

Regarding the IADL that support the basic ADL at home or in the community, the present study identified that the older adults were more dependent in the following tasks: housekeeping (75%), home repairs (65%), laundry (85%), financial management (65%), public transportation (80%), and driving vehicles (90%). In the study by Pereira et al.,³⁰ the authors reported that the older adults showed the least independence to move around, using some transportation device to do manual tasks, and to wash and iron clothes, which is in agreement with the present study. The execution of IADL requires higher cognitive and physical integrity, which are the first to be compromised by the disease, consequently affecting the autonomy of the older adults.³⁰

The present study found that most caregivers were family members and presented a level of burden and depressive symptoms, which highlights the relevance of care for the caregiver as well. Although associations between burden and depressive symptoms (ADL and IADL) were not observed, the authors intend to continue this study by means of an exclusive outpatient clinic with multiprofessional care, offering care to informal caregivers of the older adults in palliative care.

The reduced flow in the outpatient clinic prevented an assessment involving a larger number of patients and their caregivers and can be considered a limitation of the study. Also, the prevalence of informal caregivers made a comparative analysis with formal caregivers of older adults in palliative care infeasible.

Conclusion

The data found allowed for the identification of illnesses, difficulties, and challenges experienced by informal caregivers of the older adults with cancer in

palliative care. Full time care can cause psychological, physical, and emotional exhaustion due to the stressful routine and cause severe consequences in the lives of these caregivers. The knowledge of the findings presented may contribute to a multiprofessional intervention that promotes strategies to prevent the negative impacts of palliative care, and also the development of health promotion strategies with interventions that seek self-care, social support, and well-being for these informal caregivers.

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Authors' contribution

LAT, MCB, DPHA, KBR and LJPM were responsible for the study design, LAT and KBR for data collection, LAT and LJPM for data analysis and interpretation. LAT, MCB, LJPM conducted the discussion of the results, writing and critical review of the content. MCB, SGNS and LJPM reviewed and approved the final version.

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