Indicators and factors associated with burden in informal caregivers of patients undergoing radiotherapy

Indicadores e fatores associados à sobrecarga em cuidadores informais de pacientes em radioterapia

Indicadores y factores asociados a la sobrecarga de cuidadores informales de pacientes sometidos a radioterapia

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Abstract

Objective: To analyze the indicators and factors associated with burden in informal caregivers of patients undergoing radiotherapy.

Methods: Analytical cross-sectional study conducted with 209 informal caregivers of patients undergoing radiotherapy. Age over 18 years old, having a family, affective, coexistence or cohabitation relationship and providing care for at least 30 days were considered as inclusion criteria. Caregivers who were absent during the interview for accompanying the patient were excluded, thereby resulting in incomplete completion of collection instruments. Data were collected with use of forms for characterization of caregivers and patients and assessment of the care demand. The burden was measured by means of the Informal Caregiver Burden Assessment Questionnaire. The Student's t-test was used to compare the mean burden scores, and the ANOVA, Mann-Whitney, Kruskal-Wallis and Spearman's correlation coefficient were used to assess the relationships between variables.

Results: The mean scores showed moderate burden with a greater impact on the "implications for personal life", "emotional burden" and "reactions to demands" domains. The determining factors for the highest level were associated with the care demand, degree of kinship and the patients' clinical and therapeutic conditions, including age, number of prescribed radiotherapy sessions, presence of comorbidities and physical symptoms.

Conclusion: Informal care in radiotherapy generated physical, emotional and social burden on caregivers and had implications for personal life and emotional instabilities. Aspects related to the care demand and the characteristics of patients were decisive for the increase in global scores.

Resumo

Objetivo: Analisar os indicadores e fatores associados à sobrecarga em cuidadores informais de pacientes em radioterapia.

Métodos: Estudo transversal analítico, realizado com 209 cuidadores informais de pacientes em tratamento radioterápico. Para inclusão considerou-se ter idade superior a 18 anos, apresentar vínculo familiar, afetivo, relação de convivência ou coabitação e exercer cuidados há no mínimo 30 dias. Foram excluídos os cuidadores que durante a entrevista ausentaram-se para fins de acompanhamento do paciente, resultando no preenchimento incompleto dos instrumentos de coleta. Os dados foram coletados mediante formulários para caracterização dos cuidadores e pacientes, bem como avaliação da demanda de cuidados. A mensuração da sobrecarga foi realizada por meio do Questionário de Avaliação da Sobrecarga do Cuidador Informal. Utilizaram-se os testes t de *Student* para comparação dos escores médios de sobrecarga, ANOVA, *Mann-Whitney, Kruskal-Wallis* e Coeficiente de Correlação de *Spearman* para verificar relações entre as variáveis.

Resultados: Os escores médios demonstraram sobrecarga moderada, com maior impacto nos domínios "implicações na vida pessoal", "sobrecarga emocional" e "reações às exigências". Os fatores determinantes para o maior nível estiveram associados à demanda do cuidado, ao grau de parentesco e às condições clínicas e terapêuticas dos pacientes, dentre elas, idade, número de sessões de radioterapia prescritas, presença de comorbidades e sintomas físicos.

Conclusão: O cuidado informal na radioterapia gerou sobrecarga física, emocional e social nos cuidadores, acarretando implicações na vida pessoal e instabilidades emocionais. Aspectos relacionados à demanda de cuidados e às características dos pacientes foram determinantes para elevação dos escores globais.

Resumen

Objetivo: Analizar los indicadores y factores asociados a la sobrecarga de cuidadores informales de pacientes sometidos a radioterapia.

Métodos: Estudio transversal analítico, realizado con 209 cuidadores informales de pacientes en tratamiento radioterápico. Para su inclusión, se consideraron las siguientes variables: tener edad superior a 18 años, presentar vínculo familiar, afectivo, relación de convivencia o cohabitación y ejercer cuidados durante 30 días como mínimo. Se excluyeron los cuidadores que, durante la entrevista, se ausentaron por motivos de atención al paciente, por lo que los instrumentos de recopilación quedaron incompletos. Los datos se recopilaron mediante formularios para la caracterización de los cuidadores y pacientes, así como también la evaluación de demandas de cuidados. La medición de la sobrecarga fue realizada mediante el Cuestionario de Evaluación de la Sobrecarga del Cuidador Informal. Se utilizó el test-T de *Student* para la comparación de la puntuación promedio de sobrecarga, ANOVA, *Mann-Whitney, Kruskal-Wallis* y Coeficiente de Correlación de *Spearman* para verificar relaciones entre las variables.

Resultados: Los puntajes promedio demostraron sobrecarga moderada, con mayor impacto en los dominios "consecuencias en la vida personal", "sobrecarga emocional" y "reacciones a las exigencias". Los factores determinantes del mayor nivel están relacionados con la demanda del cuidado, el nivel de parentesco y las condiciones clínicas y terapéuticas de los pacientes, entre ellas la edad, el número de sesiones de radioterapia prescriptas, la presencia de comorbilidades y los síntomas físicos.

Conclusión: El cuidado informal en la radioterapia generó sobrecarga física, emocional y social en los cuidadores, lo que conlleva consecuencias en la vida personal e inestabilidad emocional. Los aspectos relacionados con la demanda de cuidados y las características de los pacientes fueron determinantes para el aumento de la puntuación global.

Introduction

Changes in the age structure and pattern of morbidity and mortality are complex phenomena of great epidemiological, economic and social magnitude that directly reflect on the population's health conditions and result in a significant increase in chronic degenerative diseases, such as cancer, which has a high incidence and is one of the causes of disability and dependence.[1]

Chemotherapy, surgical intervention and radiotherapy are among the therapeutic resources, and require support, reorganization and restructuring at the family, social and health levels, since treatment can take place on an outpatient basis, require specialized care at different levels and generate burden for the caregivers involved.[2,3]

Despite the evident repercussions of care in different therapeutic modalities, investigations aimed at radiotherapy are incipient. Even though such a therapy is effective, it can be accompanied by immediate and late adverse events. These events compromise patients' degree of independence, lead to functional limitation, intensification of physical symptoms, emotional reactions and financial difficulties that require knowledge, availability of time and dedication for the management of home care.[3-5]

In this perspective, even without professional or technical training, family members assume responsibilities as caregivers, thereby constituting an informal support network to manage disabilities, symptoms and adverse events. An informal caregiver is a person who provides assistance in an unpaid manner and takes on care by the initiative or denomination of the family group, whether through kinship, gender, physical or emotional ties, thus representing one of the main strategies to cope with the disease.[6]

In the literature, informal care for patients undergoing radiotherapy treatment represents a condition that generates morbidity and is directly associated with physical, social, psychological and financial burden.[7] Burden is a multidimensional biophysical reaction resulting from the imbalance of care demands in relation to personal time, social roles, physical, emotional and financial status. It can be enhanced by deficiencies in its recognition and its focus is often ignored or neglected.[8,9]

The measurement of levels of burden and identification of its determinants is widely referenced. It can be performed using instruments, question-

naires and measurement scales for determining the limitations imposed on caregivers' life, marital conflicts, permanent tiredness, perception of worsened health, in addition to illness, social exclusion, psychopathological comorbidities, impaired self-care and quality of life.[10]

Considering the importance of understanding the predictors of burden, as well as the need for care strategies that strengthen the bond between caregiver, health team and patient, the objective of the study was to analyze the indicators and factors associated with burden in informal caregivers of patients undergoing radiotherapy.

Methods

Observational, cross-sectional, analytical study conducted in the radiotherapy sector of a referral hospital for cancer treatment in Teresina, Piauí, between January and July 2018.

The population of interest were the informal caregivers of patients undergoing radiotherapy. For the sample design, epidemiological indicators made available for public access in the Portal-INCA were consulted. The last estimates identified for the study site were from 2014, corresponding to 457 patients who underwent radiotherapy.[11]

The simple random sampling technique without replacement was used, considering a 95% confidence interval and a sampling error of 5%, resulting in the selection of 209 caregivers and their respective patients.

The following inclusion criteria were considered: 18 years of age or older, being a caregiver for at least 30 days and having a family bond, bonds of affection, coexistence or cohabitation with the person undergoing radiotherapy. Caregivers who were absent during the interview because they were accompanying the patient were excluded, resulting in incomplete completion of the collection instruments.

The sociodemographic and care demand characterization, as well as clinical and therapeutic evaluation of patients were performed with use of two forms prepared after a literature review and submitted to the appreciation of specialists for adaptation to the proposed objectives.

In this perspective, variables related to both the caregiver and the patient were investigated. Those related to the caregiver were: sex, age, marital status, degree of kinship, race, education, origin. The care demand was characterized by the following variables: work shift, weekly workload and time allocated to care. The variables related to patients were: presence of comorbidities, location of cancer, time of diagnosis and treatment, number of prescribed radiotherapy sessions and adjuvant therapies.

The Informal Caregiver Burden Assessment Questionnaire (QASCI) was used to measure the levels of burden. This tool was developed in Portugal, translated and validated for Brazil.[10]

It consists of 32 items evaluated by an ordinal frequency scale that varies in five categories of responses ("No/never", "Rarely", "Sometimes", "Almost always", "Always"), thus integrating seven dimensions: "implications for personal life" (11 items), "satisfaction with the role and the family member" (5 items), "reactions to demands" (5 items), "emotional burden" (4 items), "family support" (2 items), "financial burden" (2 items) and "perception of efficacy and control mechanisms" (3 items).[10,12]

The total score varies from 32 to 160 points and is calculated by adding the 32 items, after reversing the scores corresponding to the three positive dimensions ("perception of efficacy and control mechanisms", "family support" and "satisfaction with the role and the family member"). Thus, higher values correspond to situations of greater burden and the mean total score is obtained in the group of participants.[10]

Data were collected in a private environment made available by the participating institution, after surveying the people who met the inclusion and selection criteria of the sample. An individual interview was conducted with caregivers and patients, and medical and clinical records were analyzed. The mean time of the evaluation was 30 minutes.

Data were inserted in a double spreadsheet in Microsoft Excel® for validation purposes and transferred to the Statistical Package for the Social Sciences (SPSS) aiming at statistical analysis based on descriptive and inferential principles. The sociodemographic characterization of caregivers and clinical characterization of patients was expressed in measures of central tendency (mean and median), variability (standard deviation) and in absolute and relative frequencies.

In inferential analysis, the evaluation of the normal distribution of continuous variables was performed using the Kolmogorov-Smirnov test. To check the association between burden scores and the caregivers' sociodemographic variables, the care demand and the patients' demographic, clinical and therapeutic aspects, the Kruskal-Wallis and Mann-Whitney tests were applied to non-normal continuous variables and the Analysis of Variance (ANOVA) and Student's t test to normal variables. The Spearman's correlation coefficient was used to assess the correlation between the burden scores and the global QASCI. The p-value<0.05 was adopted as a significant level for all tests.

For interpretation of the correlation force, the following classification was considered: 0.00 to 0.20 - very low; 0.21 to 0.39 - low; 0.40 to 0.69 - moderate; 0.70 to 0.89 - high; 0.90 to 1.00 - very high; and equal to 1 - perfect.[13] All analyzes were performed at a significance level of 5%, in which results with p-value equal to or less than 0.05 were considered positive correlations.

The study was approved and a favorable opinion for its performance was issued by the Research Ethics Committee of the Universidade Federal do Piauí under process number 2.379.697. Participation was conditioned to the signing of the Informed Consent Form.

Results

Table 1 shows the characterization of participants and the description of the care demand. Female caregivers predominated (n = 165, 78.9%), mean age of 39.7 years, married (n = 114, 54.5%), with complete secondary education (n = 98, 46.9%), unemployed (n = 105, 50.2%) and from Teresina (n = 84, 40.2%). In relation to informal care, fraternal relationships of children were evidenced (n = 86, 41.1%), who had exercised this function for more than six months (n = 62, 44.0%) in a period of more than 12 hours per day (n = 129, 61.7%).

The patients assisted by the caregiver had the following characteristics: mean age of 58.5 years, female sex (n = 128, 61.2%), with head and neck cancer (n = 46, 22.0%), diagnosed more than six months earlier (n = 94, 44.9%), undergoing concurrent radiotherapy and chemotherapy (n = 80, 38.3%), with 21 to 30 prescribed sessions (n = 76, 36.4%) and family history of the disease (n = 107, 51.2%).

Patients referred pain as the main symptom presented during treatment (n = 120, 57.4%) and reported skin changes (n = 57, 27.3%) as an adverse event to radiotherapy that involved the need for daily dressing changes (n = 25, 12.0%). The following stood out as associated comorbidities: systemic arterial hypertension (n = 79, 37.8%), diabetes mellitus (n = 50, 23.9%), as well as habits of physical inactivity (n = 77, 36.8%), smoking (n = 70, 33.5%) and alcoholism (n = 47, 22.5%).

The results expressed in table 2 demonstrate the mean burden scores and the correlation between the seven dimensions and the total QASCI. The greatest commitments were concentrated in the domains "implications for personal life" (31.50 ± 13.57), "emotional burden" (11.0 ± 5.1) and "reactions to demands" (11.0 ± 6.2), and were considered the main indicators of care-related levels of burden (p<0.001).

Table 3 shows the comparison between the sociodemographic characteristics of caregivers and the care demand with the global scores. Among the associations, variables of age, family income, work situation, weekly workload and work shift, degree of kinship, origin and time devoted to care contributed directly to greater burden (p<0.05), specifically in "implications for personal life", "emotional burden" and "financial burden" domains.

Table 1. Variables for characterizing participants and the care demand

Variable	Caregiver		Patient	
	n(%)	Mean(SD)	n(%)	Mean(SD)
Sex				
Male	44(21.1)		81(38.8)	
Female	165(78.9)		128(61.2)	
Age		39.7(13.9)		58.5(15.2)
Martital status				
Married	114(54.5)			
Single	68(32.5)			
Separated	18(8.6)			
Widowed	9(4.4)			
Education				
Illiterate	4(1.9)			
Incomplete primary education	33(15.8)			
Complete primary education	49(23.5)			
Complete secondary education	98(46.9)			
Complete higher education	25(11.9)			
Work situation				
Formal work	48(23.0)			
Informal work	43(20.6)			
Unemployed	105(50.2)			
Retired	13(6.2)			
Degree of kinship				
Brother	36(17.2)			
Son	86(41.1)			
Father or mother	16(7.6)			
Spouse	34(16.3)			
Grandchild	5(2.4)			
Niece/nephew	29(13.9)			
Uncle/aunt	1(0.5)			
Friend	1(0.5)			
Brother/sister-in-law	1(0.5)			
Work shift				
Morning	28(13.4)			
Evening	4(1.9)			
Night	1(0.5)			
Double shift	50(23.9)			
Triple shift	8(3.8)			
Not applicable	118(56.5)			
Weekly workload				
Up to 20 hours per week	33(15.8)			
Up to 30 hours per week	34(16.3)			
Up to 40 hours per week	20(9.6)			
More than 40 hours per week	4(1.9)			
Not applicable	118(56.4)			
Time allocated to care				
Up to 4 hours a day	34(16.3)			
Up to 8 hours a day	34(16.3)			
Up to 12 hours a day	12(5.7)			
More than 12 hours a day	129(61.7)			
Time as a caregiver				
From 1 to 3 months	61(29.2)			
From 4 to 6 months	56(26.8)			
More than 6 months	92(44.0)			
Cancer location#				
Head and neck			46(22.0)	
Breast			34(16.3)	
Lung			12(5.7)	
Prostate			38(18.2)	

Continue...

Continuation.

Variable	Caregiver		Patient	
	n(%)	Mean(SD)	n(%)	Mean(SD)
Pancreas			1(0.48)	
Cervix			45(21.5)	
Colorectal			14(6.7)	
Skin			19(9.1)	
Time since diagnosis				
Up to 3 months			57(27.3)	
4 to 6 months			58(27.8)	
More than 6 months			94(44.9)	
Treatment performed#				
Radiotherapy			35(16.7)	
Radiotherapy and chemotherapy			80(38.3)	
Radiotherapy and surgery			52(24.9)	
Radiotherapy, surgery and chemotherapy			42(20.1)	
Presence of skin lesions*			57(27.3)	
Comorbidities and risk factors#				
Diabetic*			50(23.9)	
Hipertensive*			79(37.8)	
Smoker*			70(33.5)	
Alcoholic*			47(22.5)	
Sedentary lifestyle*			77(36.8)	
Family history of the patient*			107(51.2)	
Symptoms				
Pain*			120(57.4)	
Nausea*			48(23.0)	
Vomiting*			32(15.3)	
Fatigue*			98(46.9)	
Anxiety*			32(15.3)	
Other symptoms*			15(7.2)	

Caption: SD - Standard Deviation; #The sum of frequencies is greater than 100% since the participant may have presented more than one associated condition; *Only affirmative responses were considered.

Table 2. Mean scores for burden and correlation between domains and global QASCI score.

Dimensions	Mean ± SD	Spearman's ρ	p-value
QASCI	74.6 ± 25.5		
Emotional burden	11.0 ± 5.1	0.737	<0.001
Implications for personal life	31.5 ± 13.5	0.906	<0.001
Financial burden	5.7 ± 3.1	0.671	<0.001
Reactions to demands	11.0 ± 6.2	0.800	<0.001
Perception of efficacy and control mechanisms	5.58 ± 2.8	0.183	0.008
Family support	3.3 ± 2.2	0.305	<0.001
Satisfaction with the role and the family member	6.4 ± 2.9	0.358	<0.001

QASCI - Informal Caregiver Burden Assessment Questionnaire; p-value was obtained through the Spearman's ρ correlation test.

Table 4 shows that patients' clinical and therapeutic variables such as time of diagnosis, number of radiotherapy sessions, being hypertensive or diabetic and experiencing pain or vomiting were associated with higher global scores and greater impairment in "emotional burden", "financial burden", "implications for personal life", "reactions to demands" and "satisfaction with the role and the family member" domains.

Table 3. Relationship between burden scores with caregivers' sociodemographic variables and care demand.

Sociodemographic aspects of caregivers	QASCI Total	EB	IPL	FB	RD	PECM	FS	SRF
	p-value							
Sex	0.591[2]	0.450[1]	0.984[1]	0.370[1]	0.402[1]	0.666[1]	0.511[1]	0.164[1]
Age	0.047[5]	0.253[5]	0.019[5]	0.357[5]	0.028[5]	0.002[5]	0.053[5]	0.325[5]
Marital status	0.231[3]	0.133[3]	0.198[3]	0.020[3]	0.084[3]	0.465[3]	0.182[3]	0.113[3]
Education	0.404[3]	0.990[3]	0.137[3]	0.170[3]	0.432[3]	0.624[3]	0.105[3]	0.478[3]
Race or color	0.223[3]	0.400[3]	0.133[3]	0.020[3]	0.165[3]	0.727[3]	0.648[3]	0.261[3]
Work situation	0.016[3]	0.417[3]	0.004[3]	0.259[3]	0.031[3]	0.309[3]	0.833[3]	0.102[3]
Work shift	0.002[3]	0.100[3]	0.005[3]	0.021[3]	0.035[3]	0.095[3]	0.373[3]	0.169[3]
Weekly workload	0.001[3]	0.030[3]	0.001[3]	0.045[3]	0.001[3]	0.698[3]	0.696[3]	0.152[3]
Family income	0.006[3]	0.010[3]	0.122[3]	0.005[3]	0.004[3]	0.745[3]	0.048[3]	0.513[3]
Origin	0.004[4]	<0.001[3]	0.055[3]	0.432[3]	0.004[3]	0.388[3]	0.836[3]	0.366[3]
Time allocated to care	<0.001[3]	<0.001[3]	<0.001[3]	0.002[3]	<0.001[3]	0.047[3]	0.041[3]	0.003[3]
Degree of kinship	<0.001[3]	0.003[3]	0.001[3]	0.148[3]	<0.001[3]	0.153[3]	0.676[3]	0.247[3]
Time as caregiver	0.001[4]	0.160[3]	<0.001[3]	0.082[3]	<0.001[3]	0.126[3]	0.295[3]	0.015[3]

EB - Emotional Burden; IPL - Implications for Personal Life; FB - Financial Burden; RD - Reactions to Demands; PECM - Perception of Efficacy and Control Mechanisms; FS - Family Support; SRF - Satisfaction with the Role and the Family member; 1 - Mann-Whitney; 2 – Student's t; 3 - Kruskall-Wallis; 4 - ANOVA; 5 – Spearmann's Correlation Coefficient

Table 4. Association between burden scores and patients' demographic and clinical aspects.

Demographic and clinical aspects of cancer patients	QASCI Total	EB	IPL	FB	RD	PECM	FS	SRF
	p-value							
Sex	0.087[1]	0.225[1]	0.038[1]	0.809[1]	0.495[1]	0.418[1]	0.307[1]	0.318[1]
Age	0.047[5]	0.253[5]	0.019[5]	0.357[5]	0.028[5]	0.002[5]	0.053[5]	0.325[5]
Time of diagnosis	<0.001[4]	0.253[3]	0.002[3]	0.039[3]	0.002[3]	0.125[3]	0.026[3]	0.004[3]
Treatment performed	0.057[4]	0.012[3]	0.025[3]	0.355[3]	0.647[3]	0.435[3]	0.764[3]	0.853[3]
Number of sessions prescribed	<0.001[3]	0.002[3]	<0.001[3]	<0.001[3]	<0.001[3]	0.620[3]	0.537[3]	0.345[3]
Presence of skin lesions	0.991[1]	0.045[1]	0.747[1]	0.991[1]	0.762[1]	0.387[1]	0.657[1]	0.368[1]
Diabetic	<0.001[2]	0.002[1]	<0.001[1]	0.002[1]	<0.001[1]	0.954[1]	0.312[1]	0.005[1]
Hypertensive	0.001[1]	0.002[1]	<0.001[1]	0.291[1]	0.008[1]	0.926[1]	0.750[1]	0.525[1]
Smoker	0.172[2]	0.141[1]	0.136[1]	0.785[1]	0.094[1]	0.181[1]	0.114[1]	0.662[1]
Alcoholic	0.002[1]	0.034[1]	0.003[1]	0.056[1]	0.005[1]	0.577[1]	0.132[1]	0.553[1]
Sedentary lifestyle	0.008[1]	0.013[1]	0.035[1]	0.275[1]	0.098[1]	0.100[1]	0.186[1]	0.394[1]
Presence of pain	<0.001[2]	0.176[1]	0.005[1]	0.005[1]	0.007[1]	0.160[1]	0.015[1]	0.033[1]
Vomiting	0.031[1]	0.070[1]	0.095[1]	0.001[1]	0.315[1]	0.122[1]	0.696[1]	0.125[1]
Fatigue	<0.001[2]	0.021[1]	<0.001[1]	0.189[1]	<0.001[1]	0.712[1]	0.962[1]	0.812[1]
Anxiety	0.014[1]	0.116[1]	0.022[1]	0.524[1]	0.047[1]	0.226[1]	0.174[1]	0.084[1]
Metastasis	0.720[1]	0.885[1]	0.270[1]	0.911[1]	0.389[1]	0.976[1]	0.027[1]	0.812[1]

EB - Emotional Burden; IPL - Implications for Personal Life; FB - Financial Burden; RD - Reactions to Demands; PECM - Perception of Efficacy and Control Mechanisms; FS - Family Support; SRF - Satisfaction with the Role and the Family member; 1 - Mann-Whitney; 2 – Student's t; 3 - Kruskall-Wallis; 4 - ANOVA; 5 – Spearmann's Correlation Coefficient

Discussion

Informal care, as evidenced in this study, was a complex phenomenon associated with different factors involving both the care demand and clinical and therapeutic aspects of patients, which contributed to the increase in global burden scores and the establishment of impacts on the physical, mental and social wellbeing and on personal, family and financial functioning.

The burden experienced by caregivers is an indicator of negative impacts and results from the unpreparedness to assume all responsibilities placed on them, without knowledge, support or base to manage unexpected situations or adverse conditions. It may also be associated with contexts of vulnerabilities, in which multiple factors lead to exhaustion, changes in lifestyle, physical manifestations and emotional reactions such as disabilities, functional limitations and psychopathological comorbidities.[14-18]

Implications for personal life and emotional compromises were considered as indicators of burden and decisive for the increase in global scores. The associated factors that influenced the level of burden referred by caregivers included aspects related to both the care demand and clinical and therapeutic characteristics of patients, such as time spent

with care, degree of kinship, presence of comorbidities and physical symptoms.

In this context, impact on the "implications for personal life" domain prevailed, showing a worse perception of health conditions, greater physical effort, neglect of self-care, abandonment of work activities and interruption of future plans, thereby negatively reflecting on the quality of care provided, favoring the increase in disabilities and hindering the rehabilitation process.[10]

As in other studies, the "emotional burden" and "reactions to demands" domains also influenced the global scores, indicating greater caregiver burden.[15,19,20] The emotional impacts reported by caregivers correspond to the set of emotions and negative feelings, symptoms of anxiety and depression, feeling of tiredness, exhaustion and hopelessness, desire to escape and internal conflicts, most of the time enhanced by the unpreparedness for the provision of care.[14,10]

The "financial burden" experienced by participants may reflect the Brazilian reality in the social, educational and economic segment, in which states of dependence limit the access to education and generate work and family instability.

These difficulties can be justified by the abandonment of work activities to prioritize the patient's needs, the contemporary neoliberal context that requires the multifunctionality of workers, and the lack of specialized centers that generates changes in the life routine and family distancing, and requires investments in accommodation, transportation, consultations, diagnostic and therapeutic procedures and resources.[21,22]

The lowest burden scores were concentrated in the "family support" dimension, considered the main strategy for coping with cancer and the adverse events resulting from the treatment adopted. The formation and strengthening of social support networks in the face of chronic and disabling conditions minimizes the clinical manifestations and repercussions of care, such as physical, depressive and anxious symptoms, since responsibility is shared between different family members.[17,23]

Regarding the factors associated with the level of burden reported, the degree of kinship variable was significant, confirming a greater demand for the care provided by children, a role historically determined by social and cultural values. The affective relationship between patient and caregiver can contribute to the burden because of the accumulation of roles, when seen as an obligation. However, most of the time, maintaining this bond can favor insertion and adaptation to the care routine, reducing the scores of burden and negative feelings.[24]

A positive association was also observed between marital status and the "financial burden" domain. The predominance of married people, mentioned as home providers, contributed to the burden, given the need to reduce the workload or abandon work activities for the provision of family care and search for resources to finance treatment costs.[25-27]

In most cases, the unemployment resulting from the need to leave work for dedication to informal care was considered an important indicator of vulnerability and determinant for the "implications in personal life" and "reactions to demands" dimensions. This result can be justified by the chronic condition of the disease that demands time from the caregiver, thereby limiting social and economic growth, and making access to health services, information and therapeutic resources difficult.[24,28]

Regarding the demand for informal care, being a caregiver for more than six months and dedicating more than 12 daily hours to the management of the patient's needs are aspects that favor greater physical, emotional and social burden. This may be the result of limitations in personal life and the development of emotional reactions, since specific care may arise during radiotherapy, for example, daily dressing changes in radiation-induced dermatitis that cause a high degree of tissue destruction.[29]

However, in a study, it was found that the prolonged time dedicated by the caregiver to assist the sick family member and manage their needs can favor the emotional adaptation and establishment of strategies that strengthen the bond between family members, patients and the health team.[30]

Variables related to patients' clinical and therapeutic characteristics, such as time of diagnosis, number of radiotherapy sessions, and having comorbidities or physical symptoms were also as-

sociated with the mean burden scores. The presence of clinical complications, functional impairments, inabilities to maintain the necessary skills for self-care, independent and autonomous life resulted in greater dependence on the caregiver, impacts on family functioning, difficulties in care management, and the search and access to specialized services.[31,32]

Concurrent radiotherapy and chemotherapy were associated with emotional reactions, greater implications of the personal life and financial difficulties for the caregiver because of the greater need for locomotion to perform therapeutic sessions and intensification of adverse reactions constantly associated with pain, skin lesions, nausea and vomiting.[29]

In addition, the presence of comorbidities, risk factors and lifestyle habits such as diabetes, hypertension, metastasis, alcoholism and physical inactivity reflected on a higher level of burden in different dimensions of the QASCI. The level of burden of the caregiver of a family member with cancer may vary depending on the stage of the disease and associated clinical conditions, since these characteristics can contribute to a higher degree of dependence, thereby requiring more time, dedication and specific care.[33]

We expect to contribute to the production of knowledge about burden indicators, associated factors, repercussions and clinical manifestations arising from care, to know the determinants related to the caregiver's health and subsidize support strategies and public health policies that address the integration of services and home care with quality, effectiveness and safety.

The limitation of the study is related to the scarcity of national and international evidence for comparison of results and the design used, since the cross-sectional method does not allow the establishment of cause and effect relationships. We suggest the performance of new investigations aimed at determining the predictors of burden and establishing action strategies that seek to humanize and qualify care and minimize the impacts by including the caregiver in the therapeutic plan.

Conclusion

Informal care for patients undergoing radiotherapy treatment proved to be a complex phenomenon that can generate moderate physical, emotional and social burden on caregivers. The implications of personal life and emotional compromises represented the main indicators of burden and determined the increase in global scores. Aspects related to the care demand and to the clinical and therapeutic characteristics of patients, such as the time spent with care, degree of kinship, comorbidities and physical symptoms showed positive relationships and represented the main factors associated with the level of burden reported by caregivers.

Collaborations

Pedrosa AO, Rocha DM, and Oliveira AC contributed to the design of the project, analysis and interpretation of data and writing of the article. Santos AMR, Figueiredo MLF, Tolstenko LN contributed to the critical review of intellectual content and final approval of the version to be published.

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