

ORIGINAL ARTICLE

OVERBURDEN ON THE CAREGIVERS OF ONCOLOGICAL PATIENTS IN PALLIATIVE CARE*
SOBRECARGA DO CUIDADOR DE PACIENTES ONCOLÓGICOS EM CUIDADOS PALIATIVOS
SOBRECARGA DE LA ATENCIÓN DE PACIENTES ONCOLÓGICOS EN CUIDADOS PALIATIVOS

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ABSTRACT

Objective: to correlate the impact of caregiver burden on the quality of life of cancer patients in palliative care. **Method:** this is a quantitative, descriptive, observational, cross-sectional study with 50 cancer patients in palliative care and 50 caregivers. A sociodemographic questionnaire was applied for caregivers and family members, the Zarit Burden Interview Scale, the EORT QLQ -C15-PAL Questionnaire, the Wagnild & Young Adapted Resilience Scale and the Catastrophic Pain Thinking Scale, using the t Test, Spearman's correlation, Pearson's correlation and linear regression. The SPSS program, version 20.0, was used for data analysis. **Results:** it is reported that the domains of quality of life that showed an independent association with caregiver burden were fatigue, lack of appetite, constipation and the global impact. An independent association was maintained due to the catastrophism of the patient's pain with the burden of the caregiver, there was no association between the patient's resilience and the burden of the caregiver and 40% of the caregivers presented severe burden. **Conclusion:** it is noted that the increase in caregiver burden reduces the quality of life of cancer patients in palliative care. **Descriptors:** Caregivers Burden; Quality of Life; Palliative Care; Oncology; Cancer Pain; Resiliencia.

RESUMO

Objetivo: correlacionar o impacto da sobrecarga do cuidador na qualidade de vida do paciente oncológico em cuidados paliativos **Método:** trata-se de um estudo quantitativo, descritivo, observacional, transversal, com 50 pacientes oncológicos em cuidados paliativos e 50 cuidadores. Aplicou-se um questionário sociodemográfico para os cuidadores e familiares, a Escala *Zarit Burden Interview*, o Questionário EORT QLQ -C15-PAL, a Escala de Resiliência Adaptada de *Wagnild & Young* e a Escala de Pensamento Catastrófico da Dor, uso do Teste *t*, Correlação de *Spearman*, Correlação de *Pearson* e regressão linear. Utilizou-se o Programa SPSS, versão 20.0 para a análise dos dados. **Resultados:** informa-se que os domínios da qualidade de vida que mostraram associação independente com a sobrecarga do cuidador foram a fadiga, a falta de apetite, a constipação e o impacto global. Manteve-se associação independente pelo catastrofismo da dor do paciente com a sobrecarga do cuidador, não houve associação entre a resiliência do paciente e a sobrecarga do cuidador e 40% dos cuidadores apresentaram sobrecarga severa. **Conclusão:** nota-se que o aumento da sobrecarga do cuidador diminui a qualidade de vida do paciente oncológico em cuidados paliativos. **Descritores:** Sobrecarga de Cuidadores; Qualidade de Vida; Cuidados Paliativos; Oncologia; Dor do Câncer, Resiliência.

RESUMEN

Objetivo: correlacionar el impacto de la carga del cuidador en la calidad de vida de los pacientes oncológicos en cuidados paliativos **Método:** este es un estudio cuantitativo, descriptivo, observacional, transversal con 50 pacientes oncológicos en cuidados paliativos y 50 cuidadores. Se aplicó un cuestionario sociodemográfico para cuidadores y miembros de la familia, la Escala *Zarit Burden Interview*, el Cuestionario EORT QLQ-C15-PAL, la Escala de Resiliencia Adaptada *Wagnild & Young* y la Escala de Pensamiento de Dolor Catastrófico, usando la Prueba *t*, Correlación de *Spearman*, la Correlación de *Pearson* y regresión lineal. El programa SPSS, versión 20.0, se utilizó para el análisis de datos. Resultados: se informa que los dominios de calidad de vida que mostraron una asociación independiente con la carga del cuidador fueron fatiga, falta de apetito, estreñimiento y el impacto global. Se mantuvo una asociación independiente debido al catastrofismo del dolor del paciente con la sobrecarga del cuidador, no hubo asociación entre la resistencia del paciente y la sobrecarga del cuidador y el 40% de los cuidadores presentaron una sobrecarga severa. **Conclusión:** se observa que el aumento de la sobrecarga del cuidador reduce la calidad de vida de los pacientes oncológicos en cuidados paliativos. **Descriptor:** Carga del Cuidador; Calidad de Vida; Cuidados Paliativos; Oncología; Dolor de Câncer, Resiliencia.

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INTRODUCTION

The concern with the concept of Quality of Life (QOL) is aimed at valuing broader parameters than symptom control, decreased mortality or increased life expectancy.¹ The available resources of the public health area are directed towards curative medicine, when, too, they should be aimed at promoting health through Preventive Medicine.²

QOL has been used in several lines of research and in wide areas of activity. QOL was defined by the World Health Organization (WHO),³ as "the individual's perception of their position in life in the context of the culture and value system in which they live and is inserted and in relation to their goals, expectations, standards and concerns".⁴

The concept of QOL changes and transformations will suffer when the diagnosis of cancer is confirmed. Feelings and reactions related to changes in their daily routine and the search for new adaptations will be faced by the patient.⁵

In this approach, resilience can be the way found by patients when diagnosed with cancer, in order to accept the challenges caused by treatments, or even comfort themselves in the face of the possibility of death, thus achieving alleviate their suffering, using coping strategies to accept the diagnosis and having greater hope in the possibility of a cure. All these factors will contribute to a better understanding of the healing process and, consequently, a better QOL.⁶

It is noted, even in the face of the development of new technologies and the growth of the pharmaceutical industry, that there are patients who are resistant and incurable to treatment.⁷ This clinical condition is characterized by presenting psychological, spiritual, physical and social limitations and weaknesses to the patient. Thus, this patient is referred to the Palliative Care (PC) services.

Palliative care was defined by the WHO as active and total care for patients whose disease no longer has the possibility of a cure and no longer responds to curative treatment, promoting the improvement of the QOL of the patient and his family, through the prevention and relief of suffering, prioritizing pain control and other physical, social, psychological and spiritual symptoms.⁸

It is emphasized that patients in palliative care need special attention with regard to control, suffering and the psychological impacts caused by pain. It also provides, due to pain, a characteristic of somatization and catastrophism, which can increase the patient's pathological condition. This phenomenon of catastrophism is determined by a

negative mental condition caused by ruminative thoughts, of magnification and helplessness, in addition to the excess and exaggeration of the painful perception, the concern with its possible consequences, which will cause a greater functional disability. It is important, therefore, to investigate the catastrophism of pain, with regard to patients in palliative care, as these catastrophic thoughts are contrary to the acceptance of pain and, thus, delay their adaptation to the painful condition, leading to a decrease in your QOL.

There is the offer of care offered by a caregiver, who is responsible for dedicating himself for long periods, including meeting the patient's physical, emotional and social needs.⁹ Over time, the provision of such uninterrupted care to the sick patient can generate an emotional burden, financial and social restrictions, as well as psychosomatic changes to the caregiver, thus causing a compromise in the QOL offered to cancer patients undergoing Palliative Care.

Please be informed that the term "overload" is a translation of the English term "burden". It is defined as a set of consequences that occurs when there is close contact with a person who is sick. This term is seen from a negative point of view, as a "weight", "burden", when referring to caring for someone.¹⁰

It is noticeable that the negative consequences associated with this aspect, as confirmed in previous studies, lead to the implementation of preventive strategies; on the other hand, overload will negatively influence the caregiver's QOL, where the identification of this process will be relevant for effective prevention.¹¹ It was reinforced, by some authors that the burden, in addition to impacting the provision of care to cancer patients, affecting their QOL, can extend to the elaboration of a complicated mourning.¹²

It was led, by the responsibility that caregivers have, to the realization that they need support to provide a better QOL to their patients. Therefore, it appears that the caregivers report that they do not have adequate support for their needs, which, consequently, this will reflect on the care process for cancer patients, interfering in their QOL.¹³

This burden on the caregiver can bring considerable changes to the entire family and personal dynamics, with regard to the process of caring for a patient in palliative care, and its impacts will have an impact on the QOL of the person receiving the care, in this case, the cancer patient under palliative care.¹⁴

From the perspective of the oncological patient in palliative care, a scenario of uncertainty arises from the end of life stage, due to the fact that they do not know the unknown, generating, in addition to stressful and distressing factors, most of the time, pain symptoms, respiratory failure,

mental confusion, followed by anxiety and depression.¹⁵

It is recommended, given the perceptions observed in cancer patients, that the caregiver should work in the sense that these physical and psychological impacts of the disease are covered with less suffering and anguish, thus providing a better QOL in the final phase of life when cancer patient.¹⁶

OBJECTIVE

- To correlate the impact of caregiver burden on the Quality of Life of cancer patients in palliative care.

METHOD

This is a quantitative, descriptive, observational, cross-sectional study, carried out with 50 cancer patients in palliative care and 50 caregivers. Methods and results are reported according to STROBE guidelines. An observational and cross-sectional study was carried out to assess the correlation between caregiver burden and the impact on oncological patient's QOL in palliative care. Patient-caregiver dyads were recruited through contact with the cancer patients themselves at the Palliative Care Service of Hospital Santa Rita - Hospital Complex Santa Casa de Misericórdia of Porto Alegre (RS).

For the calculation of the sample size, the fact that a study reported that a significant correlation between the QOL of patients and the burden of caregivers of children with cancer was taken into account, using these data from the aforementioned study, which, in order to reach 99% power ($\beta = 0.01$), maintaining a level of classical statistical significance $\alpha = 0.05$, 43 subjects would be needed. It was estimated, considering a loss of up to 15%, the final sample size of 50 patients and their respective caregivers.

The study included the group of patients diagnosed with cancer and palliative care seen at the Institution's Palliative Care Service; for the group of caregivers, the companions of these patients were included, as long as they describe themselves as the main caregivers. It is explained that, in order to participate in the research, cancer patients and their caregivers were over 18 years old and were aware and that the research participant understood and signed the term. Study participants were excluded when patients and caregivers who did not have clinical conditions to complete the instrument that could make the understanding of the tests unfeasible.

All patients signed the Free and Informed Consent Term (FICT) before participating in this observational study, which was approved by the Research Ethics Committee of the Hospital Santa Casa de Misericórdia of Porto Alegre (RS)

(Research Ethics Committee - Opinion: 2,324,325 - CAAE: 76871617.9.0000.5335.), Carried out in accordance with the Declaration of Helsinki (Resolution No. 466/12 of the National Health Council). Informed consent was obtained from all individual participants included in the study.

The results were divided into parts, to assist in the understanding of the study, as well as in the interpretation and discussion of these, referred to in instruments I, II and III.

◆ Instrument I - Sociodemographic characteristics

A structured form was filled out addressing sociodemographic characteristics for patients and their caregivers. Characteristics related to patients include name, sex, age, relationship, race, marital status, diagnosis, time in palliative care and cancer treatment received, and caregiver characteristics included name, sex, age, time of care with this patient, daily time dedicated to this patient and the patient's degree of dependence. Questions were answered by the research participants in order to collect clinical and sociodemographic data.

◆ Instrument II - Evaluation of the patient in palliative care

It is detailed that the patients answered the following questionnaires: QOL EORTC QLQ-C15-PAL; Catastrophism Scale and the Resilience Scale for Patients in Palliative Care. The QOL of patients was assessed using the QOL questionnaire EORTC QLQ-C15-PAL, which has already been translated into Portuguese and validated in Brazil. This questionnaire is composed of 15 questions with domain of attention, assessing your QOL, such as pain, sleep, tiredness, among others, in the period of the last weeks. The degree of thoughts and feelings related to the pain, magnification, rumination and hopelessness of patients were assessed using the catastrophic pain scale Pain Catastrophizing Scale (PCS), validated for use in Brazil. It is an instrument composed of 13 questions that assess symptoms of intense pain-related concern¹⁷. The Wagnild and Young Adapted Resilience Scale, in Brazil, are composed of 25 questions to gauge patients' resilience levels.

◆ Instrument III - Caregiver Evaluation

It is added that the caregivers answered the following questionnaires: Zarit Burden scale, to assess the caregiver's burden, opting, for the assessment of the burden experienced by caregivers during the palliative phase, to use the Zarit Burden Interview (ZARIT Scale). The objective is, mainly, by the ZARIT Scale, to evaluate the factors that lead the caregiver to exhaustion to later provide more appropriate care. This scale is composed of 22 items that measure care domains such as: health; social and personal life; financial and emotional situations; well-being

and interpersonal relationships. It should be answered by the caregiver himself or in the form of an interview by the researcher. The last item on the scale is considered a general assessment in which the caregiver places how he feels in caring for that patient.

The patient-caregiver dyads were stratified for statistical analysis, when descriptive analyses were performed for each group in order to explore the relationships between all demographic variables. Data was analyzed according to the characteristics of the variables. Continuous variables with normal distribution using mean and standard deviation were described, while those with non-normal distribution were described using median and interquartile range. Categorical variables were described using frequencies. Comparison between groups was performed using t test for independent samples. Exploratory analyzes will be used to study the probable associations between the characteristics of patients and caregivers in non-parametric (Spearman's correlation) and parametric (Pearson's correlation) tests. It is detailed that the levels of statistical significance for the established alpha error was a two-tailed P <0.05 and the data were

analyzed using the SPSS program, version 20.0 (SPSS, Chicago, IL).

RESULTS

The study presents the final result of the research analysis, which took place between January 2018 and June 2018, totaling 100 participants who composed this research, 50 of which were cancer patients and diagnosed with Palliative Care and 50 were caregivers of these patients, as long as they describe themselves as primary caregivers. It is noteworthy that, in the analysis of these data, there was a predominance of females (27 = 54%); the average age of patients at diagnosis was 57.6 years; there was a prevalence of white race (43 = 86%) and the educational level was characterized by a significant number of patients with incomplete primary education (30 = 60%); of the neoplasms presented, there was a predominance of gynecological neoplasms (nine = 18%); with regard to treatment, there was a greater incidence in the combination of chemotherapy, radiotherapy and surgery (26 = 52%) and the longest time since cancer diagnosis was 29.54 + 52.02, with 10.80 + 66.00 being treated for palliative care.

Table 1. Sociodemographic characteristics of patients in palliative care. Porto Alegre (RS), Brazil. 2018. n=50.

Variable	Category	Patient
Sex biological	Female	27(54%)
	Male	23(46%)
Caregiver	Spouse	15(30%)
	Father/Mother	2(4%)
	Son/Daughter	16(32%)
	Sibling	5(10%)
	Others	12(24%)
Ethnicity	White	43(86%)
	Black	2(4%)
	Brown	5(10%)
Education	Illiterate	3(6%)
	Incomplete elementary school	30(60%)
	Complete elementary school	3(6%)
	Incomplete highschool	3(6%)
	Complete highschool	6(12%)
	Complete higher education	4(8%)
	Incomplete higher education	1(2%)
Religion	Catholic	34(68%)
	Evangelical	11(22%)
	Spiritist	4(8%)
	Others	1(2%)
Diagnostic	Neo lung	9(18%)
	Neo gynecological	9(18%)
	Neo breast	7(14%)
	Neo hematological	6(12%)
	Neo gastrointestinal	5(10%)
	Neo urinary	4(8%)
	Neo head and neck	5(10%)

Treatment	Neo melanoma	3(6%)
	Neo neurological	2(4%)
	None	4(8%)
	Chemotherapy (CT)	8(16%)
	Radiotherapy (RDT)	3(6%)
	Surgery	9(18%)
Diagnostic time	CT+RDT+ surgery	26(52%)
		29.54±52.0
Palliative care time		2
		10.80±66.0
		0

It is pointed out, in relation to caregivers, as shown in table 2, that most caregivers were female (35 = 70%); the average age of the caregivers was 42.02; regarding the degree of kinship, there was a predominance of other (36=72%); in the time of care, the prevalence of

the one-year period occurred (28 = 56%), with a daily time of care characterized in an interval of 18 to 24 hours (26=52%). Finally, the patient's degree of dependence on the caregiver was 31 (62%), that is, depending on more than four Daily Life Activities (ADLs).

Table 2. Distribution of caregivers according to sex, degree of kinship, length of care, time of daily care and degree of dependence. Porto Alegre (RS), Brazil. 2018.

Variable	Category	Caregiver
Sex	Female	35(70%)
	Male	15 (30%)
Kinship	Father	2(4%)
	Mother	2(4%)
	Sibling	6(12%)
	Uncle	2(4%)
	Grandparent	1(2%)
	Niece/Nephew	1(2%)
	Others	36(72%)
	Care time	1 year
From 1 year to 2 years		3(6%)
From 2 years to 3 years		7(14%)
More than 3 years		7(14%)
More than 5 years		5(10%)
Daily care time		6 hours
	6 to 12 hours	3(6%)
	From 12 to 18 hours	7(14%)
	18 to 24 hours	26(52%)
	More than 24 hours	1(2%)
	Degree of Dependence	Independent ADLs
Dependent more than 2 ADLs		7(14%)
Dependent more than 4 ADLs		31(62%)

However, it is evident in the multivariate analysis, that only fatigue, loss of appetite, constipation and the overall maintained an

independent association with the caregiver burden (Table 3).

Table 3. Multivariate linear regression for the caregiver burden and the patient's QOL domains. Porto Alegre (RS), Brazil. 2018.

Characteristics	B	R ²	CI Inferior	Superior	P
Physical functioning	-0.203	0.067	-0.430	0.023	0.077
Fatigue	-0.255	0.116	-0.489	-0.022	0.033*
Nausea and vomiting	-0.270	0.040	-0.699	0.160	0.213
Emotional functioning	-0.119	0.054	-0.434	0.160	0.449
Dyspnea	-0.190	0.016	-0.668	0.289	0.429
Pain	0.169	0.060	-0.041	0.380	0.113
Loss of appetite	-0.400	0.200	-0.758	-0.042	0.033*
Cold	-0.493	0.194	-0.863	-0.124	0.010*
Insomnia	-0.221	0.082	-0.599	-0.157	0.246
Global	-0.463	0.192	-0.783	-0.144	0.005**

*p< 0.05. ** p< 0.01.

It should be noted that there was an independent association between pain catastrophism and caregiver burden and there was

no significant association in the aspect related to resilience (Table 4).

Table 4. Multivariate linear regression of caregiver burden for pain catastrophism and patient resilience. Porto Alegre (RS), Brazil. 2018.

Characteristics	B	R ²	CI Inferior	Superior	P
Pain Catastrophism	0.182	0.209	0.054	0.310	0.006*
Resilience	-0.174	0.110	-0.465	0.118	0.236

**p< 0.05.

It was observed, according to the Zarit Burden Scale, of an n = 50 caregivers, that 20 caregivers presented (40%) severe overload.

Table 5. Assessment of caregiver burden according to the Zarit Burden Interview Scale. Porto Alegre (RS), Brazil, 2018. n=50

Category	Score	n	%
Little	>21	1	2.0
Light	21-40	17	34.0
Moderate	41-60	12	24.0
Severe	61-88	20	40.0

DISCUSSION

In this study, it was found that a greater burden on the caregiver presents a lower QOL of the cancer patient in palliative care and that the greater the catastrophism of the patient's pain, the greater the burden on the caregiver.

A negative association was found between the patient's QOL domain, fatigue and caregiver burden (p, 0.033), because the greater the fatigue, the greater the caregiver burden. Regarding the loss of appetite domain, it was found that the greater the loss of appetite, the greater the caregiver burden. It was found, in the constipation domain, that the greater the constipation, the greater the caregiver burden. Finally, one can also mention the global domain, that is, the greater the impact on the QOL of the oncology patient in palliative care, the greater the caregiver burden.

Family members who are caregivers are characterized, despite the existence of many patients with impaired QOL, as they have difficulties and limitations in performing tasks for which they are unaware of the magnitude of the problem, which leads to the compromise of the

patient's QOL and to increasing their dependence.¹⁸

In that study, it was found that there is a predominance of patients with incomplete primary education (30 = 60%). However, in other findings, the predominance of cancer in palliative care was observed in individuals who have a higher educational level.¹⁹

It is pointed out that in the relationship with the fatigue domain of the patient's QOL, the caregiver's burden has a negative correlation, given that the caregiver's burden is often conceptualized based on the impact that the tasks performed have on the caregiver, while fatigue is an important measurement reference in the empathic relationship between the caregiver and the care receiver. This assertion is confirmed in this context, in this study, because it identifies that the degree of kinship, other children, husband, wife, grandson, is the most expressive among caregivers (36 = 72%). It was also reported in this regard, due to other findings, that fatigue can represent a significant burden on the QOL of caregivers of patients in palliative care, especially when this care already occurs in an advanced time. It was proved, in the mentioned study, that the time destined to the care of patients in

palliative care is one year (28 = 56%) and the daily care time is from 18h to 24h, (26 = 52%), a fact this which corroborates this finding.

It is noted, in the domain lack of appetite of the patient's QOL and its relationship with the caregiver overload, also, that there is a negative association, as it is one of the most common symptoms in patients in palliative care, reaching 90% of this public, thus causing a significant impact for the caregiver.²⁰ It was identified, corroborating this assertion, in other studies, that the lack of appetite may be related to psychobiological changes and environmental factors, making it more complicated in the case of oncological diseases. However, this lack of appetite may be linked to other components, such as age, dysfunction of appetite hormones and the fragility of the patient's health status.²¹

It is relevant to report, under the analysis of the global domain of the patient's QOL associated with the caregiver's burden, which is a negative association, due to the fact that there is a reduction in the physical and mental health of the caregivers, thus bringing a low QOL.²² It was also evident that the demands of the caregiver's role can result in stress, tension, overload, increased anxiety and depression, factors that will directly reflect on their QOL. It is noteworthy that such findings are in line with the results described in this study and, in view of this scenario, the caregiver should assess their permanence in this care or seek additional help, with the aim of preserving their health and offering adequate assistance to the patient. in palliative care, thus interfering with your QOL.²³

When mentioning the positive association of pain catastrophism with caregiver overload, pain catastrophism is a marker of pain anticipation and this can affect caregivers' perceptions about the excess and exaggeration of the painful perception and concern about their possible consequences.²⁴ It has been suggested, in studies, to explain the relationship between catastrophic pain and pain intensity, that these individuals showed greater fear in relation to pain than it can cause, resulting in more negative outcomes, such as more severe pain.²⁵ It is added that, while caregivers are expected to show support and care responses to cancer patients' pain, caregivers may differ in their skills, resources and motives, therefore, patients' expression of pain does not necessarily result in positive and the caregiver's solicitations and can sometimes even result in negative responses.²⁶

It has been suggested in the literature that supportive responses from family caregivers, such as helpful responses, convey the notion to patients that their condition is serious. In other words, it is described that patients who have catastrophism and show pain behaviors can be confirmed in their

notion that pain is serious, which, in turn, can stimulate their perception of pain. Therefore, it is postulated that the relationship between pain behaviors and pain intensity is likely to be stronger in patients who receive highly solicitous responses compared to patients who receive less solicitous responses. It is verified, in view of this scenario, that this type of behavior will cause an overload on the caregiver, reflecting negatively on the care offered to cancer patients in palliative care.²⁷

Finally, the assessment of the caregiver burden is highlighted according to the Zarit Burden Scale, where it was observed that, out of a total of 50 caregivers, 20 caregivers presented (40%) severe burden, confirming the study hypothesis.

Some limitations of this study were identified that must be taken into account: first, it was a cross-sectional study and, therefore, the results should be interpreted with caution. Data was collected in just one interview with the family member and the caregiver, which did not allow determining the stability of the family caregiver's involvement over time. More studies are needed to investigate the long-term effect of caregiver burden on the patient's QOL. The study was developed, secondly, in a single hospital and with a relatively small sample, making it difficult to generalize the results. One seeks to carry out future research on theoretical and practical skills, behavioral and self-care so that patients and caregivers can deal with palliative care more easily. It is crucial that efforts are made to alleviate caregiver burden by creating a framework to help promote supportive relationships that will improve the QOL of oncology patients in palliative care. In summary, it is suggested by the results of this study that the patient's QOL is more affected by the caregiver's burden.

CONCLUSION

It was found, when carrying out the analysis of caregiver burden according to the Zarit Burden Scale, that 2% of caregivers (n = 1) have little burden, that 34% of caregivers (n = 17) have mild burden, that 24% of caregivers (n = 12) have moderate burden and that 40% of caregivers (n = 20) have severe burden.

In this study, it was observed that the highest rates of burden were perceived in female caregivers; thus, family members who assume the role of caregiver of these cancer patients in palliative care with advanced disease and without the possibility of a cure have a higher risk of overload and, thus, compromise the patient's QOL.

Further studies are needed in order to better understand the needs in the area of palliative care so that support measures and interventions can be studied and provided, aiming to reduce the physical, mental, social and spiritual impacts,

both on the caregiver and on the patient. As this study is cross-sectional, there is an extreme need for future studies that would be responsible for conducting longitudinal research, accompanying these caregivers during the patient's illness and in the grieving phase, to better understand the consequences of caring.

Despite an intense bibliographic search, studies on the burden of caregivers that reflect on their QOL were found, however, there were no studies on how the impact of this burden on caregivers can interfere in the QOL of oncology patients in palliative care.

The need to conduct more research that addresses this issue is highlighted, in addition to the development of public policies aimed at populations in palliative care. Thus, there would be a better targeting of health strategies in order to reduce the impact caused by illness, as well as the preservation of health and its QOL, both for caregivers and patients in palliative care.

Finally, it is noteworthy that this study brings relevant contributions to public health, considering that the results obtained will provide a better understanding of the burden involved in the task of caring for cancer patients in palliative care and in their QOL. It is hoped, therefore, that the results presented here can contribute to the implementation and expansion of services and health professionals trained to serve this population, aiming to establish priorities and improvements in the level of assistance for better QOL of cancer patients in palliative care.

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