Evaluation of the Quality of Life of Oncological Patients in Palliative Care

Avaliação da Qualidade de Vida de Pacientes Oncológicos em Cuidados Paliativos
Evaluación de la Calidad de Vida de los Pacientes Oncológicos en Atención Paliativa

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ABSTRACT

Introduction: Palliative care for cancer patients aims to promote quality of life, by controlling signs and symptoms, improving physical, emotional, social and spiritual well-being. **Objective:** To evaluate the quality of life of cancer patients in palliative care. **Method:** Descriptive, cross-sectional, quantitative approach study, conducted with 21 patients admitted to a palliative care unit. Data on sociodemographic and clinical aspects were collected, using the *European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core15 PAL* (EORTC QLQ C-15) PAL scale to assess quality of life. **Results:** The average global health was 60.32, with quality of life considered satisfactory. In the symptom scale, the most affected domains were pain (52.38), constipation (46.03) and fatigue (42.86). Emotional function (37.30) was assessed worse than physical function (59.79). There was a significant relationship between the time of diagnosis with the general quality of life and dyspnea, of Karnofsky (KPS) performance status, with physical functioning, and presence of metastasis with dyspnea. **Conclusion:** Quality of life should be assessed daily, as palliative care considers, in addition to symptoms, the patient's own comfort during a life-threatening illness and effective care interventions, helping the multiprofessional team to focus their action.
Key words: Palliative Care; Quality of Life; Karnofsky Performance Status; Neoplasms.

RESUMO

Introdução: Os cuidados paliativos para pacientes oncológicos têm por finalidade promover a qualidade de vida por meio do controle de sinais e sintomas, melhoria do bem-estar físico, emocional, social e espiritual. **Objetivo**: Avaliar a qualidade de vida de pacientes oncológicos em cuidados paliativos. **Método**: Trata-se de uma pesquisa descritiva, transversal, de abordagem quantitativa, realizada com 21 pacientes internados em uma unidade de cuidados paliativos. Foram coletados dados sobre aspectos sociodemográficos e clínicos, e utilizada a escala do *European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core15 PAL* (EORTC QLQ C-15 PAL) para avaliação da qualidade de vida. **Resultados**: A média de saúde global foi de 60,32, sendo a qualidade de vida considerada satisfatória. Na escala de sintomas, os domínios mais afetados foram dor (52,38), constipação (46,03) e fadiga (42,86). A função emocional (37,30) mostrou-se pior do que a avaliação da função física (59,79). Houve relação significativa do tempo de diagnóstico com a qualidade de vida geral e a dispneia do *performance status* de Karnofsky (KPS) com o funcionamento físico, bem como da presença de metástase com dispneia. **Conclusão**: A qualidade de vida deve ser avaliada diariamente, visto que os cuidados paliativos consideram, além dos sintomas, o conforto do próprio paciente durante o estado de doença que ameaça à vida e as intervenções efetivas de cuidados, permitindo assim o direcionamento da atuação da equipe multiprofissional.
Palavras-chave: Cuidados Paliativos; Qualidade de Vida; Avaliação de Estado de Karnofsky; Neoplasias.

RESUMEN

Introducción: Los cuidados paliativos para pacientes con cáncer tienen como objetivo promover la calidad de vida, controlando los signos y síntomas, mejorando el bienestar físico, emocional, social y espiritual. **Objetivo:** evaluar la calidad de vida de los pacientes con cáncer en cuidados paliativos. **Método:** Este es un enfoque descriptivo, transversal y cuantitativo, realizado con 21 pacientes ingresados en una unidad de cuidados paliativos. Se recopilaron datos sobre aspectos sociodemográficos y clínicos, utilizando la escala del *European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core15 PAL* (EORTC QLQ C-15 PAL) para evaluar la calidad de vida. **Resultados:** La salud global promedio fue de 60.32, con calidad de vida considerada satisfactoria, en la escala de síntomas los dominios más afectados fueron dolor (52.38), estreñimiento (46.03) y fatiga (42.86). La función emocional (37.30) se evaluó peor que la función física (59.79). Hubo una relación significativa entre el momento del diagnóstico y la calidad de vida general y la disnea, del *performance status* de Karnofsky (KPS) con el funcionamiento físico, así como la presencia de metástasis con disnea. **Conclusión:** La calidad de vida debe evaluarse diariamente, como lo consideran los cuidados paliativos, además de los síntomas, así como la propia comodidad del paciente durante una enfermedad potencialmente mortal e intervenciones de atención efectivas, lo que permite la dirección del desempeño del equipo multiprofesional.
Palabras clave: Cuidados Paliativos; Calidad de Vida; Estado de Ejecución de Karnofsky; Neoplasias.

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INTRODUCTION

Non-communicable chronic diseases (NCDs) are the biggest causes of morbimortality in the world, causing 63% of the deaths[1]. Among the NCDs, are the cardiovascular, respiratory diseases, diabetes and cancer. These diseases reflect directly in the loss of quality of life, most of all cancer, leaving individuals with disabilities and limitations[2,3].

In this context, despite the technological advances in health, with better diagnostic and therapeutic resources and the broadening of monitoring, cancer diagnosis occurs still late in many cases. Thus, cure is related to the stage of the disease generally and as early the diagnosis, higher are the odds of cure[4,5].

In the moment of the diagnosis, it is essential to identify the cancer staging, which ensures proper definition of the treatment and evaluation of the prognosis. For the patients who were in stages III or IV, cancer is defined as advanced, and the indication is for palliative treatment to control the symptoms and increase survival, as palliative chemotherapy and radiotherapy and the possibilities of cure are reduced with the treatment[5-7].

Despite the improved effectiveness of the treatment help to increase the disease survival and control, mainly with the inclusion of new therapeutic as immune therapy and hormone therapy, the disease itself and the treatment cause too much suffering to the patients and family, in advanced cases, most of all[8].

For the patients who are out of curative therapeutic possibilities, the treatment needs to be focused to control signs and symptoms barely controllable, as pain, nausea, vomits, diarrhea, anorexia, fatigue, depression, anxiety, constipation, among others[9]. In this perspective, palliative care is the approach that aims to provide support to the patients and family, promoting the improvement of quality of life through the control of physical, psychological, social and spiritual symptoms[10,11].

The palliative care approach is indicated since the diagnosis for all the patients with incurable, progressive and severe diseases that threat the continuation of life. Therefore, the patients with cancer must have palliative care integrated to the antineoplastic treatment since the diagnosis and not only in the end of life. The palliative therapeutic attempts to promote survival as long as possible with preservation of the quality of life[12].

The World Health Organization (WHO) defines palliative care as:

> an approach that improves the quality of life of patients (adults and children) and that of their families who are facing challenges associated

with life-threatening illness. Prevents and relieves suffering through the early and correct identification and treatment of the pain and other physical, psychological, social, family or spiritual problems[13].

Quality of life is a subjective and wide concept. Several factors must be determined to evaluate the quality of life that goes beyond the disease and treatment related aspects, encompassing the physical, functioning, emotional, family, social and spiritual dimensions[9,14]. WHO defines quality of life "as an individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns"[15].

Considering the importance of palliative care to improve the quality of life of patients with cancer in advanced stage without possibility of disease modifying treatment and to control the symptoms that interfere in this quality of life, this study had as objective to evaluate the quality of life of oncologic patients in palliative care.

METHOD

Descriptive, cross-sectional, quantitative approach study of non-probabilistic sample by convenience. The study was conducted in the palliative care unit of a state reference hospital for cancer treatment in the city of São Luis, State of Maranhão which provides care through the National Health System (SUS). Patients diagnosed with cancer without possibilities of disease modifying treatment who were inpatients at the unit in exclusive palliative care, were conscious, lucid and able to verbalize, aged equal or above 18 years and who agreed to join the study were enrolled. The exclusion criteria were patients with no clinical conditions to fill in the questionnaire. 21 patients participated of the study.

Between June and December 2019 data were collected. After the confirmation of the inclusion and exclusion criteria, the inpatients were approached individually in their own rooms because of the physical limitations to ambulate with the purpose of collecting the data. The Informed Consent Form was given to them for reading and clarification of possible doubts. Upon agreeing in joining the study, the patients signed and authorized the use of information from charts and later, the application of the questionnaires. Data were collected in two moments. First, the interview with the application of a form and the charts were verified to collect sociodemographic and clinical data if necessary. Secondly, the application of the questionnaire European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Core15 PAL (EORTC QLQ C-15 PAL) to measure the

quality of life. It was requested to the group EORTC and accepted authorization to use the instrument in the study.

The sociodemographic and clinical variables were: age, gender, color, marital status, education, profession, religion, family income, municipality of residence, diagnosis, presence of metastases, clinical staging, Karnofsky performance status, type of treatment performed, time of diagnosis and inclusion in exclusive palliative care.

Karnofsy scale consists of 11 levels of performance, from 0 to 100 divided in intervals of 10, "0" indicating death and "100", normal performance without changes because of the disease[16].

The questionnaire EORTC QLQ-C15-PAL is an instrument with 15 items related to quality of life, the items 1 to 3 involve the physical functioning with questions about the difficulties of walking, if stays the whole day in the bed or chair and activities of the daily living; items 4 to 12 address some physical symptoms as dyspnea, pain, sleeping disorders, weakness, loss of appetite, nausea, constipation, tiredness; items 13 and 14, emotional status with questions about tension and depression and the last item is about quality of life in general. Each item has Likert-based scores from 1 to 4 (1 – not at all, 2 = a little, 3 = quite a bit, 4 = very much), excepting the last, where scores varies from 1 (poor) to 7 (excellent). Scores range from 0 to 100, and for physical and emotional functioning, higher scores mean better quality of life as well as in item 15 about quality of life in general; as a counterpart in the scale of symptoms in items 4 to 12, high score signified worse compromise of functioning and more symptoms[17,18].

The data were analyzed through the software Stata, version 14.0. Initially, a descriptive analysis of the data was conducted with distribution of frequencies, means and standard deviation for the numerical variables and proportions for categorial variables. The scores of the questionnaire EORTC QLQ-C15-PAL were calculated according to the formulas developed by the group that created the questionnaire and expressed through means and standard deviation. Later, the means of the scores obtained in EORTC QLQ-C15-PAL were compared with the sociodemographic and clinical variables. Those with normal distributions were verified through the Shapiro Wilk test. The test t of Student was utilized for the variables with two categories or the analysis of variance for those with more than two categories. If not in normal distribution, the tests utilized were Mann-Whitney for the variables with two categories or Kruskall-Wallis for more than two categories. For the analysis, it was considered the level of significance of 5% (p≤0.05) with level of confidence of 95%.

The Institutional Review Board of Hospital Carlos Macieira reviewed and approved the study, number CAAE: 05337218,3,0000,8907 and report 3,216,493, in compliance with the ethical norms of Resolution 466/202 and 510/2016 of the National Health Council (CNS).

RESULTS

21 patients who met the inclusion criteria and wished to participate were enrolled in the study. Of these, females were predominant (71.4%), in the age-range from 30 to 59 years (57.1%), Brown color (85.7%), complete elementary school (57.1%) and income of one to two minimum wages (71.4%). In relation to origin, most of the patients (52.4%) came from the rural area and were farmers (33.3%) (Table 1).

According to Table 2, the most prevalent cancers in the population studied were gynecologic (23.8%), gastrointestinal system (19.1%) and breast (14.3%); large part of the patients had remote metastasis (57.1%); most had diagnostic time higher than 12 months (52.4%) and time of admission in palliative care under six months (95.2%) and 47.6% of the patients presented KPS of 50%.

It is noticed that an expressive number of patients did not undergo any treatment (33.3%). Of those who submitted to any treatment, chemotherapy and radiotherapy (19.1%) were predominant and chemotherapy, radiotherapy and surgery (19.1%) as shown in Table 3.

In relation to the scores of the questionnaire EORTC QLQ-C15-PAL, the mean of global health was 60.32. Still, among the scales of symptoms, the most affected domain was pain (52.38), followed by constipation (46.03) and fatigue (42.86). In the functioning scales, the compromise of the emotional functioning (37.30) reached lower mean than physical functioning (59.79); however, both present one domain affected (Table 4).

Upon evaluating the relation of the domains of EORTC QLQ-C15-PAL with the sociodemographic and clinical characteristics of the patients (Table 5), it was observed significative correlation between the time of the diagnosis and presence of dyspnea (p=0.05) and with global health (p=0.01), showing that the time of diagnosis affects the quality of life of the patients and favors the presence of the symptom dyspnea. It was observed still a significant relation between KPS and physical functioning (p=0.01) and presence of symptoms as fatigue (p=0.02) proving that low KPS is related to harmed physical functioning and presence of symptoms like fatigue. In relation to metastases, a significant correlation occurred with the appearance of dyspnea (p=0.05), corroborating the fact that when cancer is at more advanced stage, it increases the incidence of symptoms hard to control as dyspnea, mainly in lung metastases that are very common.

Table 1. Distribution of the sociodemographic variables of patients with cancer in palliative care. São Luís-MA, Brazil, 2019

Variable	Category	N	%
Gender	Female	15	71.4
	Male	6	28.6
Age (years)	18 to 29 years	1	4.8
	30 to 59 years	12	57.1
	≥60 years	8	38.1
Color	Brown	18	85.7
	Black	3	14.3
Marital Status	Single	9	42.9
	Married	9	42.9
	Widower	3	14.2
Education	Illiterate	2	9.5
	Elementary School	12	57.1
	High school	6	28.6
	University	1	4.8
Religion	Catholic	8	38.1
	Evangelic	13	61.9
Income	<1 minimum wage	4	19.1
	1 to 2 minimum wages	15	71.4
	2 to 4 minimum wages	2	9.5
Origin	São Luís	9	42.9
	Rural area	11	52.4
	Other states	1	4.7
Profession/ occupation	Retired	4	19.1
	House activities	3	14.3
	Farmer	7	33.3
	Professor	2	9.5
	Others	5	23.8

Table 2. Distribution of the variables of clinical aspects of patients with cancer in palliative care. São Luís-MA, Brazil, 2019

Variable	Category	N	%
Diagnosis	Gynecologic	5	23.8
	Gastrointestinal	4	19.1
	Breast	3	14.3
	Others	9	42.9
Remote metastases	Yes	12	57.1
	No	9	42.9
Time of diagnosis	<6 months	8	38.1
	From 6 to 12 months	2	9.5
	>12 months	11	52.4
Time of admission in palliative care	<6 months	20	95.2
	From 6 to 12 months	1	4.8
Karnofsky Performance status	30%	3	14.3
	40%	6	28.6
	50%	10	47.6
	60%	2	9.5

Table 3. Distribution of the type of treatment patients with cancer in palliative care were submitted. São Luís-MA, Brazil, 2019

Treatment	N	%
No treatment	7	33.3
Chemotherapy	2	9.5
Surgery	1	4.8
Chemotherapy and radiotherapy	4	19.1
Chemotherapy; radiotherapy and surgery	4	19.1
Chemotherapy; hormone therapy and surgery	1	4.8
Radiotherapy and surgery	1	4.8
Chemotherapy; hormone therapy; surgery and radiotherapy	1	4.8

Table 4. Distribution of scores of the questionnaire EORTC QLQ-C15-PAL of patients with cancer in palliative care. São Luís-MA, Brazil, 2019

Scores QLQ C15 PAL	Mean	Standard-deviation
Physical functioning	59.79	39.20
Dyspnea	28.57	43.83
Pain	52.38	36.24
Insomnia	36.51	42.04
Fatigue	42.86	36.73
Appetite	23.81	36.73
Nausea	31.75	37.23
Constipation	46.03	48.85
Emotional functioning	37.30	38.70
Global health	60.32	32.26

DISCUSSION

In the past, tumoral regression was seen as a priority during the oncologic treatment. However, currently, the maintenance of the quality of life is assuming great emphasis during the whole treatment of these patients, mainly those in palliative care. In this context, the measurement of the quality of life, considering the several dimensions, is essential as well as the knowledge of clinical and sociodemographic factors that most interfere in the maintenance of the quality of life[14,19].

The study of Ribeiro et al.[20] in relation to the sociodemographic characteristics had the objective of comparing costs and quality of life of patients with cancer in palliative care in the hospital and at home. The subjects were adult oncologic inpatients at the palliative care infirmary and assisted in their houses and similar results

Table 5. Relation of the scores of the questionnaire EORTC QLQ-C15-PAL of patients with cancer in palliative care with the sociodemographic and clinic characteristics. São Luís-MA, Brazil, 2019

	p-value (≤0.05)					
	Gender	Age	Time of diagnosis	Karnofsky Performance status	Remote metastases	Time of admission in palliative care
Physical functioning	0.66	0.55	0.33	0.02*	0.58	0.86
Dyspnea	0.37	0.27	0.05*	0.57	0.05*	0.49
Pain	0.65	0.24	0.15	0.58	0.96	0.80
Insomnia	0.87	0.32	0.89	0.30	0.18	0.79
Fatigue	0.76	0.27	0.09	0.02*	0.54	0.80
Appetite	0.32	0.23	0.16	0.32	0.62	0.45
Nausea	0.47	0.11	0.60	0.92	0.18	0.33
Constipation	0.08	0.32	0.95	0.42	0.31	0.31
Emotional functioning	0.63	0.23	0.38	0.39	0.34	0.27
Global health	0.51	0.98	0.01*	0.25	0.75	0.93

Caption: *Presented significance.

in relation to gender were obtained, most of them were females, corresponding to 65.2% of the participants. In relation to color, the results were alike, most claimed they were black or brown (82.6%).

Regarding age-range, the study conducted by Freire et al.[9] indicated that the age-range of 60 years and older had the biggest percent, and in this study, in counterpart, the age range was predominantly with less than 60 years. In this same study, it was observed the level of education, corroborating the data found in the current study, where most of the patients in palliative care had completed only elementary school and still it was noticed that most were originated from the rural area of the State, portraying the lack of oncologic services out of the capital.

In relation to the time of the diagnosis, different results were found in the same study whose time of diagnosis most common was less than six months.

In the study of Figueiredo et al.[19], females also predominated (55.6%) with low education level, the highest degree was incomplete elementary school (33.3%).

In a study conducted by Silva et al.[21], whose objective was to evaluate the overall quality of life of patients with advanced cancer in palliative therapy or in palliative care, the most prevalent diagnosis was breast cancer (15.8%) in patients who were in palliative care, different from what was found in this study, where the most common were gynecologic cancers. This can be explained by the fact that, in the State of Maranhão, cervical cancer still remains as the most prevalent among the female population, the predominant gender in the present study. Regarding the treatment in this same study, there was prevalence of chemotherapy, radiotherapy and surgery, 5.1% did

not submit to any treatment; nevertheless, the data of this study indicated that great part of the patients did not undergo any treatment and, among the treatments, chemotherapy, radiotherapy and surgery were the most prevalent equally.

The study conducted by Ahlam et al.[22], in the Moroccan National Oncology Institute with the objective of evaluating the quality of life of patients with advanced cancer in palliative phase showed that like what was found in this study, most of the patients had KPS between 40 and 50, showing loss of functioning of these patients who needed assistance considerably and frequent medical care.

In reference to quality of life, the patients investigated considered satisfactory, demonstrated by the value of global health over 60 (above the mean). Similar results were encountered in a study that evaluated the health-related quality of life and spirituality of individuals with cancer[23]. Still in a study conducted by Cruz et al.[24] with oncologic patients in palliative care, it was found a mean score of 66.6 for global quality of life, similar results of this study.

In another study, it was found loss of physical and emotional functioning, being physical the most harmed, while in this study, the emotional was the most compromised. For the symptoms, the same study presented fatigue affecting the patients in palliative care mostly, followed by lack of appetite and pain. In this study, the most common was pain, followed by constipation and fatigue. Therefore, it is noticed that pain and fatigue are common symptoms affecting the quality of life of patients in palliative care[22].

The patients with advanced cancer receive better attention to their quality of life because of the great number of symptoms that can develop as a result of the disease itself or of the treatment performed that compromise the physical and emotional domains, mainly. Consequently, the early beginning of the palliative care in patients with advanced cancer ensures a better quality of life[7].

In addition, a study conducted by Krug et al.[25] with patients in palliative care in primary attention, reported fatigue and pain among the most predominant symptoms, corroborating the data of the present study.

Pain is considered one of the main symptoms impacting the quality of life of patients with cancer. In a study conducted with patients' caretakers with cancer in advanced stage, it was reported that 71% of the patients had pain[26].

Fatigue was one the most frequent symptoms in patients with cancer described among 50% and 90% of the patients, impacting the quality of life directly. It is a symptom generally persistent for long periods in individuals with cancer, does not improve fully with sleep and rest, it is not commensurate to the activities performed by the patient and damages its proper functioning, being a symptom of difficult treatment[27,28]. Likewise, constipation is a very common symptom in patients with advanced cancer, related to various causes, standing out the use of opioids to control the pain, causing important deterioration of the quality of life, its prevalence is estimated in 23% to 84% of the patients with advanced neoplasms[29].

Functional loss is frequent in patients with palliative care, reflecting in various aspects of their lives. Therefore, difficulties to perform daily tasks favor the development of psychological changes, especially because they relate to the patients' fear in becoming a burden to their family and caretakers[30].

Symptoms as anxiety and depression are present since the diagnosis of cancer is received because despite the scientific advances, cancer still appears to be associated to suffering and death, resulting in losses of the emotional functioning of these patients. Therefore, in the study of Costa et al.[31], anxiety was identified as the second domain most affected in the evaluation of the quality of life[31].

In the study of Freire et al.[9], significant results of the association of the variable extension of the disease and the scale of symptoms dyspnea were encountered. In this study, nevertheless, it was noticed association between metastasis and symptom dyspnea. Still in the same study, the association between time of diagnosis and the domains of the scale EORTC QLQ-C15-PAL presented statistically significant difference for the symptom constipation; however, it was verified in this study a relation of the time of diagnosis with the symptom dyspnea and with global health.

Dyspnea is one of the symptoms that most affect patients with cancer in advanced stage, with great impact in their lives and to their family. Its prevalence in patients with cancer is around 90%, aggravating with the progress of the disease, particularly in patients with lung cancer[32].

The relation found between KPS and physical functioning can be clarified by the fact that the patients in palliative care who are in advanced stage present low KPS indexes, reflecting in their functioning. A study developed by Golčić et al.[33] with patients in palliative care demonstrated that the patients with higher scores of palliative performance scale (PPS) presented significant better levels of physical functioning and global quality of life, similar to what was verified in the present study that found a relation between KPS and physical functioning.

The small number of participants is the main limitation of the study, because several patients were excluded for not having clinical conditions to respond to the questionnaire. Another limitation was the non-evaluation of factors related to spirituality and emotional, social and family support that can influence the quality of life. In despite of the limitations, nevertheless, the content was not damaged at all, since the results will contribute for the publicization of the theme and possibilities of new perspectives about the quality of life during the period of palliative care.

CONCLUSION

Quality of life is a complex phenomenon to be measured effectively for is mutable clinical aspects, it would be inflexible to consider fixed standards that guide its normality. Thus, some outcomes of this study could be concluded in relation only to the inpatients of the palliative care admission unit.

The EORTC QLQ-C15-PAL scores obtained in this study allowed to observe that emotional functioning was more affected than physical functioning, which is a relevant finding for the chronic ill during the life-threatening disease, since it is expected that physical limitations occur more, interfering in the quality of life.

While the symptoms scores of pain, constipation and fatigue were frequent, although expected during palliative care, it indicates the necessity of intensifying care in the most advanced phases of cancer and better conducts of assistance in order to reduce the impacts during the therapeutic of patients without possibilities of disease modifying treatment.

Based in the conclusions, it is being analyzed the possibility to improve the assessment of the quality of life

according to the current scales associated to the general health condition of the patient, utilizing broad criteria to evaluate the health of the ill, since the improvement of the quality of life during palliative care is essential for the patients.

CONTRIBUTIONS

All the authors contributed substantially for the conception and/or design of the study, gathering, analysis and interpretation of the data, wording and critical review. All the authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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