

## Quality of Life and Maintenance of Human Dignity in the Last Phase of the Life Cycle

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### Abstract

The research assessed the quality of life of cancer patients in palliative care. For data collection, a sociodemographic questionnaire, the Karnofsky Performance Status Scale and the Palliative Outcome Scale were used. An average age of 20 to 59 years was observed, 60.0% were female, 87.5% had a companion during hospitalization and the highest occurrence was breast cancer (30%). Of the patients, 75% have been in palliative care for more than a month, 42.5% have been diagnosed for between one and five years (42.5%) and 85% were satisfied with the care received at the unit. The average score score of the Palliative Outcome Scale was 18.75 (6.25), with greater impairment in the time spent in consultations and anxiety of family members and the patient himself.

**Keywords:** Cancer; Palliative Care; Quality of Life; Oncology; Attention to Cancer

### Introduction

The global health-disease pattern has been changing due to the process of industrialization, urbanization and advances in science and technology. This change, known as the epidemiological transition, brought about a change in the profile of morbidity and mortality, such as a reduction in the rates of infectious diseases and an increase in the rates of chronic non-communicable diseases [1,2].

In this scenario, cancer is one of the most complex public health problems, given its epidemiological, social and economic magnitude. Traditionally, cancer control prioritizes cancer treatment. However, in the past two decades, the inclusion of the perception of well-being and quality of life in the treatment of patients has been increasingly valued.

In the initial stages, the treatment is usually aggressive, aiming at the cure or remission of the condition. This objective is shared with the subject being treated and with his family through an optimistic perspective of the prognosis. The evolution of the disease may, however, lead to a prognosis that does not offer conditions for the cure or for the remission of the underlying oncological condition. For all the treatment of this individual, the control of signs and symptoms and the promotion of quality of life should be the main strategies adopted by the multidisciplinary team, especially in the phase without possibility of cure for the oncological condition and in the terminal phase.

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This care strategy centered on the individual's symptoms, uniqueness and complexity is understood as palliative care. The World Health Organization (WHO) [3] defines palliative care as an approach that promotes the quality of life of patients and their families, when facing an active and progressive disease that threatens the continuity of life. They include active and total care when the disease does not respond to curative treatments, through the prevention and relief of suffering, prioritizing symptom control and patient comfort.

Palliative care requires early identification, assessment and treatment of pain and other problems of a physical, psychological, social and spiritual nature. They stand out as a humanized and specialized care for patients and their families to support quality of life and maintenance of human dignity in the course of the disease, in the end of life, in death and in the period of mourning [1].

On the other hand, the traditional model of care, curative and hospital-centered, still prevails, with an emphasis on technological advances and medicalization of death. Precious and unique time is lost in the search for a cure and in prolonging the patient's life, to the detriment of care that can bring comfort and quality of life in this, which is the last phase of its life cycle [4,5].

In Brazil, the dying process continues to occur massively in the hospital environment. There are still few services provided for palliative care, as well as national publications on this topic [2]. In this context, the present study sought to assess the quality of life of cancer patients in palliative care attended at a University Hospital.

### Method

Study of a quantitative and qualitative approach, elaborated based on the guidelines of the Equator Network<sup>6</sup>. Intentional saturation sampling was performed, considering patients admitted at the time of the research that met the inclusion criteria: patients of both sexes, aged 18 years or over, diagnosed with malignancy, under palliative care, oriented and contact persons at the time of the interview, having agreed to participate in the research, with the signature of the Free and Informed Consent Form. Those without clinical conditions to participate in the research, with progression of imminent death or with severe cognitive or auditory impairments, and those who died during the research were excluded.

Sociodemographic and clinical data were collected from the participants' medical records. The data regarding the perception in relation to the quality of life and the care received were collected from the application of a questionnaire with open questions and the Palliative Outcome Scale - Brazil (POS-Br). It is a multidimensional quality of life assessment scale, consisting of ten questions that reflect the main domains of palliative care, considering a time window referring to the three days preceding its application [6].

Responses are given on a five-point Likert scale, with the exception of one item with three points. The scale also has an open question regarding the main problems experienced by the patient. The total score of the POS-Br is given by the sum of the points of the ten questions, which can vary from zero to 40 points, with zero representing the best quality of life and 40 corresponding to the worst evaluation [7].

To investigate the clinical condition of the participants, the Functional Assessment Scale or Karnofsky Performance Status Scale (KPS) was used. This scale provides a general measure of the individual's independence in exercising self-care and daily activities, on a scale from zero (death) to 100 (without evidence of illness). The lower the score, the lower the patient's functional capacity and the expectation of his recovery or return to normal activities [8].

The collected data were entered into a Microsoft Excel 2016 spreadsheet. The statistical analysis was used using the IBM SPSS Statistics for Windows 22.0 program. To compare quality of life according to sociodemographic and clinical characteristics of patients, Student's t test and ANOVA were used. In all analyzes, a significance level of 5% was considered.

The answers to the open questions were analyzed according to the method of content analysis by Bardin<sup>9</sup>, comprising the pre-analysis, the exploration of the material and the treatment of the results, with inference and interpretation of the findings. In this way, units of meaning were extracted from the interviews, which enabled the analysis of the collected content.

The conduct of the study followed the ethical recommendations with research involving human beings, respecting the resolutions of the National Health Council 466 of 2012 and 510 of 2016, with approval in all institutional instances and by the Research Ethics Committee (CEP), through of opinion number 2,768,583.

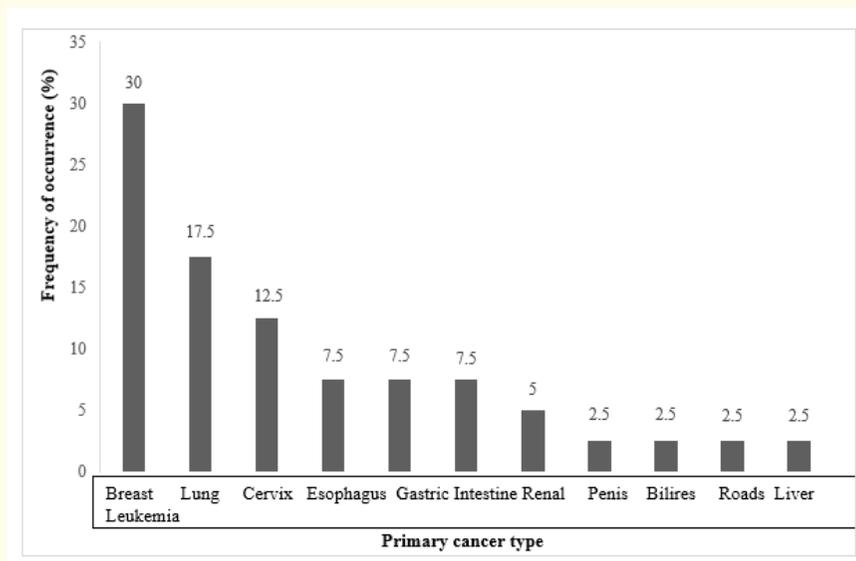
### Results

Of the 40 study participants, the majority were female, married, with a practicing religion and of low socioeconomic status (Table 1). With regard to origin, 72.5% (n = 29) reported residing in the Federal District (DF), with the remainder coming from municipalities in the state of Goiás located around the DF.

Variables	Frequency Number (%)	Total score POS-Br* Mean (± SD)**	P value
<b>Age</b>			
20 to 59 years	21 (52.5)	20.00 (5.79)	0.359
60 years or older	19 (47.5)	17.36 (6.59)	
<b>Sex</b>			
Female	24 (60.0)	18.95 (6.13)	0.852
Male	16 (40.0)	18.43 (6.61)	
<b>Race/color</b>			
Brown	31 (77.5)	18.19 (6.09)	0.573
black	5 (12.5)	20.20 (5.26)	
White	4 (10.0)	21.25 (9.21)	
<b>Marital status</b>			
Married	23 (57.5)	18.78 (6.27)	0.480
Not married	9 (22.5)	16.55 (5.36)	
Widower	5 (12.5)	20.20 (8.70)	
Separated/divorced	3 (7.5)	22.66 (3.51)	
<b>Education level</b>			
No elementary school	24 (60.0)	17.79 (5.54)	0.252
Complete primary education	12 (30.0)	21.25 (7.52)	
Complete high school	4 (10.0)	17.00 (5.35)	
<b>Retirement or social benefit</b>			
Yea	25 (62.5)	18.00 (6.33)	0.512
No	15 (37.5)	20.00 (6.10)	
<b>Income</b>			
< 1 Minimum Wage	22 (55.0)	19.50 (5.85)	0.550
≥ 1 Minimum Wage	18 (45.0)	17.83 (6.75)	
<b>Religion</b>			
Practitioner	36 (90.0)	19.00 (6.78)	0.811
Non-Practitioner	4 (10.0)	18.72 (6.29)	
Total	40 (100)	18.75 (6.25)	-

**Table 1:** Distribution of study participants according to sociodemographic characteristics and scores obtained on the Palliative Outcome Scale (POS-Br) (n = 40). Brasilia, DF, Brazil, 2018.

Regarding primary cancer, the highest occurrence of breast cancer (30.0%) stands out, followed by lung cancer (17.5%) and cervix (12.5%) (Figure 1).



**Figure 1:** Percentage and types of cancers of cancer patients in palliative care participating in the study for (n = 40). Brasilia, DF, Brazil, 2018.

As for the other investigated clinical characteristics (Table 2), the initial diagnosis time was from one to five years for 42.5% of the participants (n = 17), while 75% (n = 30) was one month or less under palliative care. Most participants (85%; n = 34) reported being satisfied with the care provided by the health team. Although all research participants needed hospital care, only 27.5% (n = 11) were weakened and required supportive measures or treatment (KPS = 20%).

Variables	Frequency Number (%)	Total score POS-Br* Mean (± SD)**	P value
<b>Diagnosis Time</b>			
≤ 1 year	15 (37.5)	20.40 (6.41)	0.281
1 to 5 years	17 (42.5)	16.94 (6.04)	
≥ 5 years	8 (20.0)	19.50 (6.11)	
<b>Weather in Palliative Care</b>			
≤ 1 month	30 (75.0)	18.56 (6.62)	
> 1 month	10 (25.0)	19.30 (5.25)	
<b>Satisfaction with health care</b>			
Pleased	34 (85.0)	17.44 (5.42)	0.857
Dissatisfied	6 (15.0)	26.16 (5.74)	
<b>Has companion</b>			

Yea	35 (87.5)	18.31 (6.32)	0.277
No	5 (12.5)	21.80 (5.26)	
<b>Functional Capacity (KPS)***</b>			
50%	2 (5.0)	14.00 (7.07)	0.54
40%	16 (40.0)	16.93 (4.98)	
30%	11 (27.5)	20.36 (5.50)	
20%	11 (27.5)	20.63 (7.95)	
Total	40 (100)	18.75 (6.25)	-
*: Palliative Outcome Scale - Brazil			
*: Standard deviation			
***: Karnofsky Performance Status Scale - 50%: requires considerable assistance and frequent medical care; 40%: incapable requires special care and assistance; 30%: very incapable, indicated hospitalization, although death is not imminent; 20%: very weak requires hospitalization, measures or supportive treatment.			

**Table 2:** Distribution of study participants according to clinical characteristics and scores obtained on the palliative outcome scale (POS-Br) (n = 40). Brasilia, DF, Brazil, 2018.

The average the total score of the POS-Br was 18.75 ( $\pm$  6.25), showing the impairment of the patients' QoL, regardless of their socio-demographic and clinical characteristics ( $p > 0.05$ ) (Table 1 and 2). On the other hand, there were differences between the QoL scores verified for the symptoms and concerns investigated in the POS-Br ( $p < 0.001$ ). Worse scores were found for the perception of lost time due to consultations related to their health care. On the other hand, having received all the information intended for you, family or friends, positively influenced the patients' QoL.

The analysis of the interviews revealed multidimensional aspects considered important by the patients, related to the assistance, physical, psychological, social and spiritual dimensions.

The assistance dimension is sensitive to the relationship with the team that assists the subjects in palliative care during hospitalization. The statements raised in the study indicate that the research participants were satisfied, especially with the medical team. However, there are reports of some patients who, even considering the assistance as good, would prefer to be at home:

- “There is quality here, doctors are very intelligent and polite, they answer all the questions I ask. The nurses are attentive and the nutritionist tries to find a way for me to eat” (CRS).
- “The people are all very good, the food is good, but my house is better” (CRS).

Still in this dimension, there is a pattern in the statements regarding assistance at the unit. The subjects demonstrated a similar perception when they expressed that they felt well assisted and comfortable and that their pain was controlled:

- “The assistance is good, the nurses do the dressing very carefully so as not to feel pain and when they take me to bathe in the chair they are also good, they give medicine before (morphine) to hurt less, it still hurts, but it is less” (CHC).
- “The psychologist comes to talk to me every day and physiotherapy too, helps me to move my legs, arm and eat alone” (JJS).

The physical dimension aims to raise indicators about how patients assess their quality of life in the face of physical symptoms. In the statements of the study, it was found that the perception of physical symptoms associated with the pathological condition directly affects

quality of life. Pain stands out among these symptoms because it has a great impact on the subject's daily life, with tiredness being the second most reported symptom by the interviewees:

- "Tired, back pain, left leg radiating to the back. Ending the pain and this tiredness, everything is fine. I just don't like to talk when I'm in pain" (JFS).
- "I feel very short of breath, I get tired just getting out of bed, and oxygen doesn't help much, this tube in the nose is bad" (LM).

When assessing the psychological aspects, the presence of signs and symptoms of another nature was observed, such as anxiety, concern about the disease or treatment, in addition to the subjective perceptions of these individuals regarding the feeling that their lives were important and how good they felt about themselves and as people. Various emotions are observed in the speeches, such as fears/fears, sadness, anguish and family concerns:

- "(...) but I want my house, my little girl, she is so small and I miss her, I don't like to stay in the hospital, it's depressing, it's sad, a lot of people die here. My problem is to go back to my house and stay with my daughter" (JJS).
- "Depressed, saddened by this disease, having to be hospitalized, away from grandchildren and without working, very bad" (ANCP).

It was also observed the perception and verbalization of loneliness experienced by these individuals in the course of their illness:

- "Scared and lonely, my partner is at work and I stay here alone with strangers" (VMS).
- "I have already achieved retirement, but I wanted my husband to be with me, accompanying and visiting, I feel alone" (CRS).

The social dimension was also present in the speeches of the individuals participating in the study, when asked about the existence of any practical, financial or personal setbacks associated with the disease. In the statements, financial problems caused by hospitalization and absence from work were observed. There were also reports of concerns related to retirement by the National Institute of Social Security (INSS) or by the Continuous Payment Benefit (BPC):

- "Financial problems, a lot of expenses for exams and I only had my husband's pension" (JFSS).
- "Financial problem because the son ends up not working when he comes to accompany me at the appointments, that's why they pay a caregiver (and the family has qualified for it) which is expensive" (EFA).

As for the spiritual dimension, although 90% of the interviewees are practitioners of some type of religion, hopelessness was marked in the speeches of the individuals:

- "The disease has not been cured, I am going to die" (EMA).
- "And the drugs are not helping, I think the disease is in my head and in my lung" (MSS).

When considering the place where this research was carried out, humanized and comprehensive care stands out, attention to suffering and human dignity, especially with regard to the patient in palliative care. This is assisted by an interdisciplinary team, consisting of doctors, nurses and technicians, psychologist, social worker, nutritionist, speech therapist, occupational therapist, physiotherapist, dentist and pharmacist, in addition to volunteers and chaplains. This assistance even favors an environment for the fulfillment of some wishes (such as weddings and birthdays), farewells from family and friends, strengthening the care provided to the patient in his individuality and his family nucleus. The attention offered contemplates the person in all its dimensions as a subject of action.

## Discussion

The provision of care mediated by the principles of Palliative Care represents a commitment to the consolidation of the doctrinal principles of the Unified Health System. The care provided to subjects who experience a life-threatening diagnosis, such as cancer, requires that all individuals, regardless of their geographic location, access, stage of the disease, prognosis and subjective understanding about their treatment, are welcomed.

The data observed in the sociodemographic characterization are suggestive of the heterogeneity of the population that uses the assistance services of the Unified Health System. The suggestive social vulnerability highlights several indicators that permeate the present study, such as social and financial issues, the granting of benefits as protective in their Quality of Life, bringing as a determining factor to the discussion of the importance of Social Security - Health, Social Security and Social Assistance - while essential for the promotion of comprehensive health care and committed to equity in an intersectoral perspective [11,12].

The perception of individuals about the quality of care provided by the health unit is also a sensitive factor to the functioning of the Unified Health System. The university hospital that sets up the present research, integrated to SUS through agreements, is responsible not only for the teaching, research and extension, as they offer assistance aligned with the integrality of the individual's care, in addition to respecting fundamental principles of palliative care, as observed in the subjects' perceptions, especially regarding symptom control [3,13].

Advanced cancer patients usually experience multiple signs and symptoms associated with their health condition. These manifestations range from physical and psychological discomfort to their social implications and existential concerns due to illness or treatment. These manifestations can impair the functionality of these individuals, negatively impacting their quality of life [14].

Among the aforementioned physical discomforts, understanding of total pain is essential in assisting subjects who have a cancer diagnosis. In the present research, this question presents itself in a curious way when comparing different collection instruments. While, at POS-Br, pain does not present itself as the main domains related to impacting palliative care in their day-to-day lives, the perception of pain suggested in the reports shows how their control is undoubtedly important for greater comfort and well-being of the subject with advanced disease and without the possibility of a cure [15].

The quality of life of people after the diagnosis of cancer and repeated hospitalizations leads the individual to undergo changes of different natures in their daily lives. Among these changes, those related to home routine, work, leisure, physical and psychological integrity emerge. These changes bring challenges to be experienced by the individual, causing him and his family to undergo profound changes in their lives [13]. These changes, perceived within the subjectivity of the subject who suffers with the course of his treatment, can lead him to feelings such as loneliness, as observed in the statements of the studied group.

These perceptions about physical, psychological and social challenges lead these individuals to seek different support networks. The meanings and the search for support in the spiritual dimension were revealed in a peculiar way for each one. This search is shown to be fully anchored in the sixth principle of Palliative Care, which includes the "integration of psychological and spiritual aspects in patient care". Spirituality, as a vital dimension of the human being, should be considered an issue to be addressed in the treatment like any other medical demand [13].

The analysis of the interviews revealed aspects of relevance in the lives of people living with cancer. It is undoubtedly to point out that, despite the protective points observed and discussed, the quality of life of these individuals is compromised. Although physical pain is controlled and most subjects in palliative care have a companion during hospitalization, the main difficulties experienced are in relation to lost time and personal and family anxiety, highlighting the need to strengthen strategies aimed at "promoting relief of pain and other physical symptoms, psychosocial, spiritual and existential suffering, including appropriate care for family members and caregivers", understood as a principle of the philosophy experienced by Palliative Care [13].

### Final Considerations

Assessing the quality of life of patients in palliative care allows the identification of their overall condition. The applied evaluations prove to be useful in clinical practice, since they allow to know and prioritize problems, establish better communication, monitor changes in the pattern of the disease evolution or in the health level, and allow the sharing of clinical decisions.

The study enabled a relevant finding: the importance of the presence of the companion with the patient. The inpatient unit where the research participants met and were interviewed guarantees cancer patients the right to remain with companions during the entire hospitalization, thus reinforcing comprehensive care, supported by the pillars of citizenship and autonomy and committed to the quality of life of individuals.

The knowledge of factors related to the quality of life of cancer patients provided evidence for an area with a lack of local studies. Therefore, it is expected, with this study, a contribution in the field of scientific evidence in the area of knowledge, enabling useful data for the planning of services, aiming at improving the quality of life of patients.

In the search for Brazilian regulatory frameworks, the country presents significant government legislation that includes the theme of palliative care and quality of life. Resolution No. 41/2018 “provides for guidelines for the organization of palliative care in the Unified Health System (SUS)” [16]. In view of the legal context, this study also intends to offer subsidies that contribute to the formulation of effective public health policies in the field of Palliative Care, capable of transcending the centrality of the discussion of the theme in the area of cancer care. , reached all individuals who have diagnoses of life threatening diseases.

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