

# Palliative Care and Social Representations for Caregivers of Cancer Patients in Exclusive Palliative Care: an Exploratory Analysis

<https://doi.org/10.32635/2176-9745.RBC.2024v70n2.4640>

*Cuidados Paliativos e Representações Sociais para Cuidadores de Pacientes Oncológicos em Cuidados Paliativos Exclusivos: uma Análise Exploratória*

Cuidados Paliativos y Representaciones Sociales para Cuidadores de Pacientes Oncológicos en Cuidados Paliativos Exclusivos: un Análisis Exploratorio

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## ABSTRACT

**Introduction:** The informal care of the cancer patient without curative possibility comprehends important physical, emotional and spiritual demands in the course of the disease still little addressed. **Objective:** To analyze the structure of social representations of palliative care in the perspective of the caregiver of cancer patients in exclusive palliative care. **Method:** Qualitative, descriptive and exploratory nature study, based on the Theory of Social Representations. Data collection was carried out between July and September 2023 in an oncology reference federal hospital in the city of Rio de Janeiro, with 100 primary or secondary caregivers, without work relationship to perform this role. The free evocations to the term "palliative care" were collected and the questionnaire was applied to characterize the caregivers, mostly women (75%) and considered as primary caregivers (52%) and later analyzed with the software IRAMUTEq, version 0.7. **Results:** Probable central nucleus: "no treatment" (Mean Evocation Order – MEO 2, frequency 41), "comfort" (MEO 2, frequency 25), "symptomatic control" (MEO 1.8, frequency 25) and "terminality" (MEO 2, frequency 21). It was identified the predominance of ideas related to the disease, and in contrast, the relevance of subjective aspects that can fragilize patients and caregivers was revealed. **Conclusion:** The social representations of caregivers are anchored in the terminality, absence of treatment, comfort and control of symptoms, which involve subjective aspects of coping and confirm the idea of finitude, but acknowledge that the well-being of the patient can be favored by technical and assistance actions associated with hospitalization.

**Key words:** Neoplasms/psychology; Integrative Palliative Care; Caregivers/psychology; Psychology, Social.

## RESUMO

**Introdução:** O cuidado informal do paciente oncológico sem possibilidade curativa abrange demandas físicas, emocionais e espirituais importantes no decorrer da doença, sendo pouco abordadas. **Objetivo:** Analisar a estrutura das representações sociais dos cuidadores paliativos sob a ótica do cuidador do paciente oncológico em cuidado paliativo exclusivo. **Método:** Natureza qualitativa, descritiva e exploratória embasada na teoria das representações sociais. A coleta de dados foi realizada entre julho e setembro de 2023 em um hospital federal referência em oncologia, no município do Rio de Janeiro, com 100 cuidadores principais ou secundários, sem vínculo de trabalho para exercer tal papel. Foram coletadas as evocações livres ao termo indutor "cuidados paliativos" e aplicado o questionário para caracterização dos cuidadores majoritariamente do sexo feminino (75%) e considerados cuidadores de 1º grau (52%), posteriormente, foram analisadas com o software IRAMUTEq, versão 0.7. **Resultados:** Provável núcleo central: "sem tratamento" (Ordem Média de Evocação – OME 2, frequência 41), "conforto" (OME 2, frequência 25), "controle sintomático" (OME 1,8, frequência 25) e "terminalidade" (OME 2, frequência 21). Identificou-se o predomínio de ideias relativas à doença. Em contrapartida, foi evidenciada a relevância de aspectos subjetivos que podem fragilizar paciente e cuidador. **Conclusão:** As representações sociais dos cuidadores estão ancoradas na terminalidade, ausência de tratamento, conforto e controle de sintomas, cuja ótica do cuidador envolve aspectos subjetivos de enfrentamento e confirma a ideia de finitude, porém compreendem que o bem-estar do paciente pode ser favorecido por ações técnicas e assistenciais vinculadas à hospitalização. **Palavras-chave:** Neoplasias/psicologia; Cuidados Paliativos Integrativos; Cuidadores/psicologia; Psicologia social.

## RESUMEN

**Introducción:** El cuidado informal del paciente oncológico sin posibilidad curativa abarca demandas físicas, emocionales y espirituales importantes en el transcurso de la enfermedad aún poco abordadas. **Objetivo:** Analizar la estructura de las representaciones sociales de los cuidadores paliativos para el cuidador del paciente oncológico en cuidado paliativo exclusivo. **Método:** Estudio de naturaleza cualitativa, descriptiva y exploratoria, basado en la Teoría de las Representaciones Sociales. La obtención de datos se realizó entre julio y septiembre de 2023 en un hospital federal de referencia en oncología, en el municipio de Río de Janeiro, con 100 cuidadores principales o secundarios, sin vínculo de trabajo para ejercer tal papel. Fueron recogidas las evocaciones libres al término inductor "cuidados paliativos" y se aplicó el cuestionario para la caracterización de los cuidadores. Posteriormente, estos datos fueron analizados en el software IRAMUTEq, versión 0.7. **Resultados:** Cuidadores mayoritariamente mujeres (75%), con vínculo de primer grado (52%). Probable núcleo central: "sin tratamiento" (Orden Promedio de Evocación – OPE 2, frecuencia 41), "confort" (OPE 2, frecuencia 25), "control sintomático" (OPE 1,8, frecuencia 25) y "terminalidad" (OPE 2, frecuencia 21). Se identificó el predominio de ideas relativas a la enfermedad, en contrapartida existe la relevancia de aspectos subjetivos que pueden fragilizar paciente y cuidador. **Conclusión:** Las Representaciones Sociales de los cuidadores están ancladas en la terminalidad, ausencia de tratamiento, confort y control de síntomas, que involucran aspectos subjetivos de enfrentamiento y confirman la idea de finitud, pero comprenden que el bienestar del paciente puede ser favorecido por acciones técnicas y asistenciales vinculadas a la hospitalización. **Palabras clave:** Neoplasias/psicología; Cuidados Paliativos Integrativos; Cuidadores/psicología; Psicología Social.

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## INTRODUCTION

Cancer consists of a set of diseases of multicausal origins, characterized by disordered patterns of cell proliferation, which contributes for a diversity of treatments and prognoses. Though the pathological process is harmful to the patient, there is the spectrum of agreed responsibilities to help patients and their support network through physical, emotional, social, cultural, and spiritual approaches<sup>1</sup>.

With the growth of case notifications, the disease has become an obstacle for increasing life expectancy and one of the main causes of death around the world. According to estimates by the Global Cancer Observatory (Globocan), there are 20 million new cancer cases around the world (18.1 million, if non-melanoma skin cancer cases are disregarded)<sup>2</sup>.

In Brazil, for each year of the 2023-2025 period, it is estimated that 704,000 new cancer cases will be reported (483,000 if non-melanoma skin cancer are disregarded). The distribution of cancer incidence does not reflect just quantitative characteristics, but also great variety in the magnitude of the disease depending on the social and economic profile of the analyzed regions<sup>3,4</sup>.

Having cancer, be it in acute or chronic conditions, is an eligibility criterion for palliative care, since the person is affected by a life-threatening disease. According to some authors, a few variables contribute to the increase in the well-being of patients and their recovery, such as family support, good income, access to treatment and having a good caregiver<sup>4-6</sup>.

Palliative care is increasingly being recognized in the health system as intrinsic to the process of health and sickness. It is important to understand that assistance in this context is promoted by a multidisciplinary team that aims to improve the quality of life of patients and their families by preventing and alleviating suffering, and through early identification, assessment and treatment of pain and other physical, social, psychological, and spiritual symptoms<sup>4</sup>.

When assessing the overload of the caregiver<sup>7</sup>, physical and emotional issues were reported by the interviewees due to the repercussion of signals and symptoms that are bad for the performance of daily life activities, such as, for instance, excessive tiredness, breaking relationship ties, pain claims, difficulties in sleeping, among other emotional and physical issues.

Understanding the care scenario, therefore, is part of the context that should be considered and integrated to the Health Care Network. Another finding is that, when there are doubts about following the prescribed health orientations, the pursuance and adhesion to the care plan

may be harmed, which can negatively impact the work of the health team<sup>8,9</sup>.

Thus, a reflection on palliative care, the object of this research, will search for actual considerations that relate to the studied environment with the goal of establishing communications and behaviors that actually happen systematically<sup>10</sup>. In view of this, the present study aims to analyze the structure of social representations of palliative care in the perspective of the caregiver of cancer patients in exclusive palliative care since this is a broad, subjective, and little discussed theme in the line of care planning.

## METHOD

Exploratory research with a qualitative approach. This method transcends traditional approaches based on the biomedical model and allows the researcher a better interpretation of the facts, though not detached from the scientific complexity, that validates the complexity of human relations, which cannot be dissociated from the cross-sectional character of the sciences and social context it is immersed<sup>11</sup>.

To understand and/or explain the set of phenomena and processes, the Theory of Social Representations (TSR)<sup>12,13</sup> elaborated by Serge Moscovici in 1961 was chosen. In its structural approach proposed by Jean-Claude Abric, its conceptions on experience or knowledge about something are not reduced to isolated components – names, images, concepts –, but also depend on the inference of communication forms where they circulate.

According to the mentioned theory, the organization of a social representation involves a central nucleus, composed of one or more elements that give meaning to the representation. The core is established by type and nature of the represented object, by the relationships defined between the group and the object of study and by the system of values and social norms that form the ideological environment<sup>12,13</sup>.

The studied environments were the outpatient and hospitalization sectors of the oncological palliative care unit of a federal institute that functions as a High-Complexity Oncology Center (Cacon) located in the city of Rio de Janeiro, Brazil. The data collection occurred from July to September 2023.

A hundred caregivers of patients who were in the institute during the collection period participated voluntarily by signing the Informed Consent Form (ICF). The inclusion criteria were companions, blood-related or not, whose self-declared function was being a secondary (occasionally care for patients) or primary (care for patients for the most part of the day) caregiver; and caregivers with no work relationship to perform this

activity. The exclusion criteria were those who were not in their functional cognitive capacity during the approach due to emotional or health-related reasons. It is worth mentioning that the focus was not on sectors, such as outpatient or hospitalization, but on caregiver profile. The number of participants followed recommendations from studies based on structural approach of social representations<sup>12, 13</sup>, and only one caregiver per patient was chosen.

The data collection was performed in a calm and reserved space, with data filled in by the researcher in an electronic form when the patient was not being submitted to procedures, appointments, or situations in which they were uncomfortable due to their symptoms or that required the caregiver to remain on the location. A semi-structured questionnaire was used, divided in two parts: the first part formed a profile of the participants (sex, age, official marital status and actual marital status, and daily patient care workload); the second part consisted of the free word association technique using the term “palliative care” as inductor. This technique<sup>13</sup> consists of associating the first words and/or expressions that come to the subject’s mind from hearing the inductive term. The subject should list a minimum of three words.

The data obtained from the sociodemographic profile and free word evocations coming from the electronic form exclusively filled out by the main researcher were organized in a Microsoft Excel for Windows file. The evoked words were later analyzed through the four-house board technique, generated by the IRAMUTEq, version 0.7 software<sup>14</sup>.

The responses evoked by the participants have two calculated coordinates, according to the method for analyzing TSR structural approach<sup>13</sup>; the frequency of the group *corpus* and the mean evocation order (MEO), that is, the value from the evocation mean, where 1 (one) is attributed to the most frequent answer and 2 (two) to the second most frequent, and so forth.

To identify the probable central nucleus, the frequency and position are important, that is, the terms mentioned in the beginning are the most important and the more frequently evoked or that have a lower MEO. Chart 1 was created as follows: in the upper left quadrant, are the elements of the central nucleus – high frequency and low MEO; in the lower left quadrant, is the contrast zone – low frequency and MEO; on the upper and lower right quadrants are the elements that compose first and second peripheries, respectively. These peripheries are related to the context, though they have a more practical and adaptable nature<sup>12,13</sup>.

Still regarding the first analysis, it is possible to determine an index of similitude among the words that

form the board. The similitude analysis is an analytical search mode that, despite complying to a mathematical foundation, respects the qualitative nature of the data representation and consists of identifying possible central nuclei for determining proximity liaisons among them. For calculation purposes, the order of evocation is not considered, but the frequency of terms, by dividing the number of repeated occurrences for the number of subjects and the continuity of the connection of these occurrences with the central term until the totality of elements are represented in it<sup>10</sup>.

In compliance with the ethical principles of the Resolution number 466/2012<sup>15</sup> of the National Health Council, this research was approved by the Research Ethics Committee (CEP), approval number 6.095.349 (CAAE (submission for ethical review): 69105323.8.0000.5274).

## RESULTS

A hundred caregivers, mostly female (75%) participated in the study. The mean age was 46 years-old, with 19 and 84 being the minimum and maximum ages, respectively, with a standard deviation of 15.8. Regarding marital status, there was a predominance of married (47%) and single (44%) individuals, followed by widowed (7%) and divorced (2%).

Regarding relationship with the patient<sup>16</sup>, blood or not, most of them had a first-degree kinship (52%), followed by spouse (19%), second-degree kinship (15%), third-degree kinship (6%) and other relationships (4%) – such as friend, former in-law, or godmother of the patient’s children. Of those, 55% of the participants reported that the assistance workload with interventions performed by direct or indirect interaction (activities that can be carried out at a distance, but that benefit the cared person) was greater than 12 hours a day, 33% reported from 6 to 12 hours a day, and only 12% performed 5 hours or less of daily assistance.

As to the free word association, the inductive term was “palliative care”. A total of 344 words were evoked, comprising 54 unique words after treating and grouping responses by creating a dictionary. The mean frequency was 17 and minimum 7, MEO mean was 2.1, in a scale of 1 to 5 (Table 1).

Regarding the board composition, the evoked terms were organized in four quadrants. In the possible central nucleus, that is, the quadrant where the responses were more promptly and frequently evoked, there is a contrast in the evocations by the group in which “no treatment” is shown as tied to “terminality” in a negative way, while “comfort” comes associated to “symptom control”, being both positive elements. The “no treatment” term was



**Table 1.** Four-house board related to the social representation of palliative care for caregivers of oncological patients in exclusive palliative care in a High-Complexity Oncology Center. Rio de Janeiro/RJ, 2023 (n = 100 subjects)

Mean frequency	MEO ≤ 2.1			≥ 2.3		
	Evoked term	Frequency	MEO	Evoked term	Frequency	MEO
≥ 17	No treatment	41	2	No pain	30	2.8
	Comfort	25	2			
	Symptom control	25	1.8			
	Terminality	21	2			
< 17	Care	17	1.9	Quality of life	16	2.9
	Love	10	1.8	Medication	15	2.3
	Fear	8	2	Hospitalization	13	3
	Attention	8	2.1	Death	11	2.6
				Decrease suffering	9	2.9
				Affection	8	2.4

**Caption:** MEO = mean evocation order.

the most evoked by the group, presenting the highest frequency of the chart (41), which suggests distinct perspectives of the representation that either include therapeutic propositions with no curative purpose, or disregard due to the impossibility of curing the disease. The lack of common-sense information about palliative care must be considered, as the concept is stigmatized regarding finitude. However, it is worth mentioning that the following terms “comfort” and “symptom control” reinforce the idea that caregivers act according to the principles of palliative care, which aims to control physical, emotional, and spiritual symptoms, offering comfort to the patient in the context of a disease with no healing perspective<sup>8</sup>. Additionally, considering the comfort element, the presence of a caregiver is important, so the patient does not feel lonely in this difficult process.

In the contrast zone there are words with low frequency and more promptly evoked in speech: “care”, “love”, “fear”, and “attention”, elements that reinforce the evocations present in the possible central nucleus and that are subjective to the interviewee. This can evidence the existence of a subgroup that consistently values inclusion of their feelings and attitudes throughout the assistance actions from the evocation of terms “love” and “fear”, for example.

The other quadrants refer to the peripheral zones. In the first peripheral zone (upper right quadrant) were included the most frequent answers in high order of evocation, that are, however, below the cutoff (MEO). Highlights in this quadrant include the “no pain” term, which can transcend physical aspects, much present in oncological patients, and include soul and collective-related pain, with significant negative impact to the caregiver and their ways of coping with it.

By analyzing the second periphery, the idea of complementing the central nucleus is reinforced, however,

it is worth mentioning that the exposed is about particular realities due to the dimension of evoked answers. The “quality of life” term associated to the other terms in the quadrant reinforces a contradictory representation about palliative care whose role is mixed up with the mistaken idea of exaggerated health intervention or futile therapeutic or end of life phase, due to the “medication”, “hospitalization”, and “death” terms.

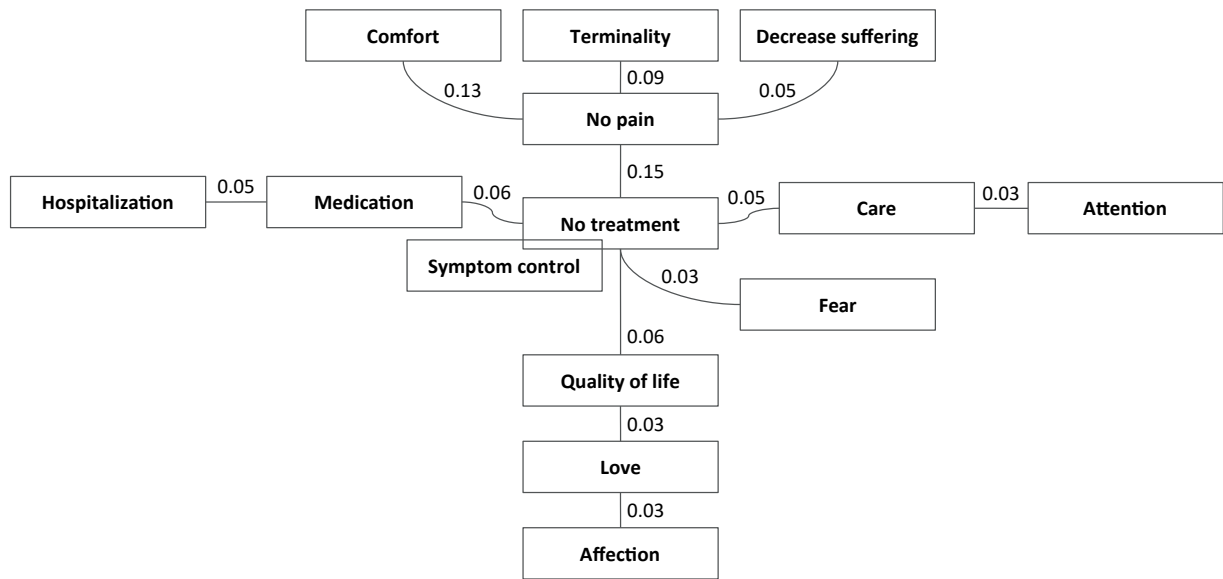
Aiming to understand the internal relations and the number of connections established by the words in Chart 1, the process of similitude analysis was carried out, throughout which a maximum tree was built. This representation (Figure 1) was elaborated using the 15 most representative words evoked by the interviewees and a similitude index of 0.05 was adopted as cutoff.

The analysis (Figure 1) is a graphic representation that identifies the occurrences between words, that is, enables to verify the connection (or ties) between the social representation elements, as well as the strong connection between them<sup>17</sup>.

It was possible to identify (Figure 1) that the term “no treatment” holds the more connections, which reinforces the possibility of centrality in comparison to the other terms due to the number of connections (6).

Thus, according to analysis criteria<sup>13</sup>, through hypothesis, the same element belongs to the central nucleus of social representation of palliative care for caregivers. The identified theoretical hypothesis is that the central terms are configured as an objectification of social representation, which will demand further studies to confirm it.

Among the other elements in connection with the term “no treatment” are “medication”, “symptom control”, “quality of life”, “fear”, “care” and “no pain”, the strongest connection being the one between “no treatment” and



**Figure 1.** Similarity tree related to the social representation of palliative care for caregivers of oncological patients in exclusive palliative care in a High-Complexity Oncology Center. Rio de Janeiro/RJ, 2023 (n = 100 subjects)

“no pain” (0.15). This strong correlation shows that the absence of pain is one of the main factors for this social group, confirming one of the main objectives of the assistance offered to people who live with cancer. These correlations may suggest that the establishment of the care flow for caregivers aims to promote the absence of pain, quality of life, symptom control via medications interrelated to care, even if with a weaker connection, the actions are permeated out of fear.

Hence, considering the impossibility of a treatment that modifies the course of the disease, the improvement of symptoms is given through the words “quality of life”, “medication”, and “care”. In this context, attention is drawn to the fact that correlations to “quality of life” are feelings of a personal nature, which does not reinforce the idea of the use of inputs justified only by pharmaceutical efficacy.

Other connections that are worth highlighting include “comfort” and “no pain”, “quality of life” and “love”, “love” and “affection”, “care” and “attention”, which reinforce the caring dimension offered by the support network to make this moment of life less difficult.

## DISCUSSION

As mentioned in the possible central nucleus, the repercussions of cancer and the impossibility of curative treatment for the disease include scenarios beyond care and technical activities, and include aspects related to the subject’s perception. Though both patient and support network – not necessarily blood-related – share negative elements given the process of sickness and death,

there are less painful ways of coping when it comes to deconstructing antagonistic concepts through care<sup>18</sup>.

Currently, due to the disqualification of the term “palliate”, a study conducted by the Lancet Commission Global Access to Palliative Care and Pain Relief aimed to establish a new consensus whose definition actively and holistically encompasses individuals of all ages diagnosed with diseases that have a high risk of mortality<sup>19</sup>. To consider oncological palliative care, in this perspective, involves offering applicable health management in all complexity levels and phases of the disease.

According to the orientations for palliative care<sup>20</sup>, though Medicine is essentially palliative in its origin, the acquisition of new technologies and, consequently, the use of every possible technological resource exceed the objective of improving quality (and functionality) of life justified by the efficacy outcomes. Thus, understanding the curative impossibility of cancer does precede best practices in health.

Regarding the profile of interviewees, the results of this study are in line with another study<sup>21</sup> that characterized the main caregiver as being female, having a family tie or significant relationship with the patient.

The predominance of women as providers of care and the poor social recognition they receive as to the responsibility inherent to their sex is a known historical fact. An analysis on the performance of female figures in these roles infers that such dynamic results in a routine in which women execute the most intense part of the work and other family members act as a secondary support network<sup>22</sup>.

In the course of the illness, by associating feelings and experiences of the family caregiver of the oncological



patient, interviewees reported an expectation of resolution based on the will to “do more”, despite being aware of the natural progression of the illness. However, when analyzed in the long-term, these discourses may suggest difficulties in managing life outside the home environment, health issues, a lack of future perspectives, resulting in a high level of overload<sup>23</sup>.

Amidst the lonely activity of care, the project Compassionate Communities stands out as a possibility of creating support networks to people in palliative care and their family members. In summary, it is a community activity conducted in the slums of Rio de Janeiro, Brazil, that trains volunteer residents and health professionals to offer care to their fellow community members. In a way, the help provided is positive, however, when considering the magnitude of cancer, it is an additional resource and does not compensate the obstacles in access to health<sup>24</sup>.

Another issue with coping that goes beyond the lack of social support for practical issues can be added in this context: emotional helplessness. As a result, when it comes to postmodern societies, groups look for ways to reduce their suffering in order to simultaneously deal with finitude and rescue the meaning of existence linked to spirituality. In this way, the appreciation of matter due to the spiritual plane tends to generate discussions regarding the meaning of life, as the existence of a new reality in which the soul is immortal can bring comfort to the fear of non-existence<sup>20,25</sup>.

These aspects are part of the context of care to be considered and integrated in supporting caregivers. However, factors such as understanding the workload, the profile of correlations to outcomes in health, the knowledge level of the professional for making a qualified approach are needed to determine solutions that will help patient and/or family caregiver in finding themselves and reasons to reaffirm life<sup>8</sup>.

Another issue is that, though they are treated as synonyms, spirituality and religion are distinct terms, despite being usually confounded. The job of spirituality is not to marginalize religions, but encompass greater motivations, ideas, utopias, passions, and the mystique for which people live and struggle, in a way that favors all. Thus, exercising spirituality is the possibility of living life fully, or, in a way, facilitating coping with the idea of finitude<sup>26,27</sup>.

Following the course of evocations, the first periphery of this study obtained the term “no pain”. Due to the localization of the quadrant, it is possible to assume this term is relevant to the probable central nucleus, although it appears later in the interviewees’ answers. For a technical understanding, pain can be defined as an unpleasant sensory and emotional experience associated

to an actual or potential tissue lesion. However, in the context of palliative care, the painful experience is seen as multidimensional and, though a physical assessment is important, psychological, social, and spiritual well-being may compromise the effective symptom control<sup>28</sup>.

The control of this event substantiates the first evocation of the second periphery “quality of life” and corresponds to a correlation mentioned in the literature<sup>20,29</sup>. That means, especially, that the presence of ill-managed pain generates a negative impact in the quality of life of patients and their family members or caregivers, resulting in a greater incidence of bad sleep quality, cognitive system disturbances, and survival decrease<sup>19</sup>.

In this way, not far from reality, it became evident, from the following terms “medication” and “hospitalization”, that the concept of controlling the symptom in an essentially pharmacological way, in search of relieving it through analgesia, is also shared in the context of caregivers. However, though the medication treatment is important and necessary, other undertreated aspects may suggest the continuity of suffering<sup>29,30</sup>. In this sense, it is imperative to contextualize the cultural scenario of Brazil, whose model of health care is still based on curative and hospital-centered actions, as well as a shortage or total lack of open communication about the process of death and dying, which is very characteristic of western culture. Considering that palliative care still has its main design rooted in terminality, patients are admitted to palliative care late, as highlighted in national studies on the subject<sup>31</sup>.

Situations, such as the previously described, of therapeutic stubbornness or ineffective symptom control are negatively highlighted and promptly evidenced in the routine of caregivers. By living a deficient health support, the representation of the experience becomes charged with bad emotions and impacts that trigger suffering and behavior changes<sup>32</sup>.

Palliative care, a recent specialty when compared to other health fields, though it should be enforced in the beginning of treating a potentially life-threatening disease, is usually applied only in the last stage of life. Thus, the evocation of words such as “death”, “decrease suffering”, and “affection”, though featured in the second periphery, implies a gradual and irreversible worsening of the patient and the subjective desire to ensure good conditions for dying<sup>33</sup>.

The mentioned transition to care – the active process of death –, despite being part of humanity, is a source of suffering in many cultures. In this context, in a study conducted with family members in the first moments of an oncological diagnosis, though early, the disease evokes ideas that range from negative perspectives to the hope of dignified care conditions, thus highlighting

the importance and possible reality of transforming the ideology that still stigmatizes palliative care and that, therefore, weakens the people involved in this process<sup>34</sup>.

## CONCLUSION

From the data analysis, it is possible to note that the social representations of the investigated group are anchored in terminality, absence of treatment, comfort, and symptom control. The point of view of the caregiver involves subjective coping aspects and confirms the idea of finitude; however, there is also an understanding that the patient's well-being can be favored by technical and assistance actions related to hospitalization.

In the course of palliative care, the disease is expected to progress and, consequently, trigger symptoms that negatively impact the quality of life of patients and family members. That way, though the interviewees shared concepts and objectives that follow technical orientation, the outcomes revealed a scenario in which the late referral to palliative approaches is the norm, even though it is recommended from the moment of diagnosing life-threatening diseases.

The early inclusion, in addition to the development of assistance approaches already carried out by the health team, therefore, contributes to a less painful coping for the caregiver, understanding that a greater knowledge of the situation plays an important role in their cooperation with activities that may influence the reduction of complications due to the natural progression of cancer.

Moreover, a limitation of the present study is the impossibility of generalizing its outcomes due to, firstly, the need for conducting this research in other treatment centers, contemplating the different life and access to health experiences, and, secondly, the difficulty of carrying out word association without other type of trigger – images, concepts, among others – assuming that the technical term is of common knowledge.

The multiple dimensions of the analyzed field of study meet the interdisciplinary demand of the caregiver during the developed activities. Thus, to insert them in the context of healthy living, as far as possible, it is important that their needs are actually considered by specialized professionals depending on the specificity.

That way, this study also suggests that the acknowledgment of the theme, despite the obstacles to health access, is positive. In other words, the health literacy of the interviewed population is a reality at the aforementioned institute. However, the location where the study was conducted is a limitation, for not being a care reality that is shared at a national level, which, therefore, demands further studies in other health centers.

## CONTRIBUTIONS

Izaura Jacob Gonçalves and Raquel de Souza Ramos have substantially contributed to the study design, acquisition, analysis and interpretation of the data. Antonio Marcos Tosoli Gomes has substantially contributed to the acquisition, analysis and interpretation of the data. Luciana Aparecida Faria de Oliveira and Rachel Verdan Dib have contributed to the wording and critical review. Margarida Maria Rocha Bernardes has contributed to the critical review. All the authors approved the final version for publication.

## DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interest to declare.

## FUNDING SOURCES

None.

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Recebido em 25/3/2024  
Aprovado em 4/6/2024

