HUMAN AND SOCIAL SCIENCES
IN FOOD
DOI: 10.12957/demetra.2025.83061

DEMETRA
Alimentação, Nutrição & Saúde

e-ISSN:2238-913X

Gabriele Bentes de Aguiar[1]
Rosane de Souza Santos[2,3]
Vicente Sarubbi Junior[4]
Mariana Fernandes Costa[2,3]

[1] Instituto Nacional de Câncer, INCA Curso de Residência Multiprofissional em Oncologia. Rio de Janeiro, RJ, Brasil.

[2] Universidade do Estado do Rio de Janeiro, Programa de Pós-Graduação em Alimentação, Nutrição e Saúde. Rio de Janeiro, RJ, Brasil.

[3] Instituto Nacional de Câncer, INCA, Hospital do Câncer IV. Rio de Janeiro, RJ, Brasil.

[4] Universidade Estadual de Mato Grosso do Sul, Faculdade de Medicina. Mato Grosso do Sul, MS, Brasil.

Correspondence
Mariana Fernandes Costa
marifcosta@gmail.com

Assistant Editor
Renata Brum Martucci

Social representations of palliative care and nutrition in patients with advanced cancer

Representações sociais sobre cuidados paliativos e alimentação entre pacientes com câncer avançado

Abstract

Introduction: The transition from the curative care to palliative care can generate conflicts, and the study of social representations about palliative care and nutrition supports the considerations of our investigation. *Objective:* To understand the shared social representations about palliative care and nutrition among patients with advanced cancer. *Method*: This is a qualitative exploratory and descriptive research, adopting the Theory of Social Representations in which the Free Word Association Technique was used. The data were analyzed using the EVOC software, highlighting central and peripheral words. *Results*: The analysis of the evocations highlighted "symptom control" as the main evocation in palliative care, followed by "care" and "treatment"; "quality of life" was also mentioned, although by fewer patients. Regarding food, "healthy eating" and "health" were central, while "pleasure" and "good" reflected the participants' association with food. *Conclusion*: The limits in understanding the term “palliative care” reveal challenges in communication, when the transition of care is perceived as a unique moment, with the focus shifting from cure to symptom management, comfort and quality of life. At the same time, individualized nutritional care is essential to preserve the patient’s sociocultural identity.

Keywords: Social Representation. Palliative Care. Diet. Quality of Life. Health. Health.

Resumo

Introdução: A transição da modalidade de assistência para cuidados paliativos pode gerar conflitos, e o estudo das representações sociais sobre cuidados paliativos e alimentação embasa as considerações desta pesquisa. *Objetivo*: Compreender as representações sociais compartilhadas sobre cuidados paliativos e alimentação entre pacientes com câncer avançado. *Método*: Trata-se de uma pesquisa qualitativa do tipo exploratória e descritiva, adotando a Teoria das Representações Sociais em que foi utilizada a Técnica de Associação Livre de Palavras. Os dados foram analisados pelo *software* EVOC, destacando palavras centrais e periféricas. *Resultados*: A análise das evocações destacou "controle de sintomas" como principal evocação nos cuidados paliativos, seguida por "cuidado" e "tratamento"; “qualidade de vida" também foi mencionada, embora por menos pacientes. Sobre alimentação, "alimentação saudável" e "saúde" foram centrais, enquanto "prazer" e "boa” refletiram a relação dos participantes com a comida. ***Conclusão***: Os limites na compreensão sobre o termo “cuidados paliativos” revelam desafios na comunicação, quando a transição do cuidado é percebida como momento único, sendo o foco transferido da cura para o manejo de sintomas, conforto e qualidade de vida. Paralelamente, o cuidado alimentar individualizado é fundamental para preservar a identidade sociocultural do paciente.

Palavras-chave: Representação Social. Cuidados Paliativos. Dieta. Qualidade de Vida. Saúde.

INTRODUCTION

According to the World Health Organization,[1] palliative care comprises in-patients' assistance provided by a health multidisciplinary team, aiming at improvingthe quality of life of patients' and their families"that arefaced with a life-threatening illness, through prevention and relief of suffering, early identification and treatment of pain and of other physical, social, psychological and spiritual symptoms. Thus, the ideal scenario would involve the implementation of palliative care from the diagnosis of the illness, as defined in its concept, aiming to provide a better quality of life, free from anguish, focusing on the person and diverting the focus from the illness.[1,2]

In this study, we address the specific practice of offering exclusive palliative oncology care only after it has been determined that there is no longer any possibility of treatment that can modify the course of cancer disease. At this point, there is a transition from treatment care aimed at the cure of the disease to palliative care, which requires transfers between hospital units. This makes the connection between palliative care and the final course of the disease more evident. Could this transition from the treatment care to palliative care generate conflicts? It is worth noting that there are other possibilities for offering this type of integrated care.

In Brazil, attention to palliative care is increasing, which is reflected in the creation of specialized services. In addition, more recent movements in this field have strived to demystify the idea that palliative care should only be used when the patient is terminally ill, and should be offered earlyafter diagnosis. However, attention to quality at the end of life and the availability of services are still incipient, and therefore require recognition from the authorities and awareness in our society, in order to seek universal provision and improvements in this type of care.

The holistic approach makes an interprofessional team essential, involving doctors, nurses and nursing technicians, social workers, psychologists, nutritionists, physiotherapists, pharmacists, occupational therapists, spiritual assistants of an ecumenical nature or of the religion chosen by the patient.[3] Thus, the palliative approach to care seeks to improve the patients' quality of life, giving priority to pain management and symptom relief. It is also worth noting that although the implementation of palliative care can generate conflicts especially related to the change in the type of care provided and the active participation of the family,[4] when a well-managed transition is made, the risk of conflicts can be significantly reduced, and is even a target of this approach.

Dietary changes in patients with advanced cancer, due to pathophysiology or side effects, present challenges such as nausea and weight loss. In this sense, the goals of nutrition in palliative care are to provide comfort and maintain quality of life, often with cultural meanings for the patient, according to the clinical diagnosis and the time-point in which the patient stands in the trajectory of the disease process.[5]

Therefore, the philosophy of palliative care recognizes the complexity of the meanings of food and the impacts on patients and caregivers, since food issues in human finitude generate divergences, involving symbolic aspects, beliefs and rituals, since eating goes beyond nutrition, being also a social and cultural act.[6] Thus, the objective of this study was to understand the shared social representations about palliative care and food among patients with advanced cancer.

METHODS

This is a qualitative, exploratory and descriptive investigation, based on the Social Representations Theory (SRT), carried out in an exclusive oncology palliative care hospital in Rio de Janeiro.

All patients treated at the exclusive palliative care unit of the oncology institute are transferred from three other care units of the institution, based on care provided at the “ready to assist” health outpost. Thesehealth posts correspond to outpatient clinics located in the units of origin, coordinated by nurses specialized in oncology palliative care who will assess the patients referred to exclusive palliative care and choose the type of care in which they should continue (hospitalization, outpatient clinic or home care). Hospital admission is restricted to patients with advanced cancer, with no possibility of curative oncological treatment (surgery, radiotherapy, chemotherapy and hormone therapy) who are over 16 years of age, who accept the transfer and sign personally, or through a family member, the term of adhesion to palliative care.

After transfer between units, participants were recruited to participate in this study, with the sample consisting of adult patients with advanced cancer. Face-to-face and audio-recorded interviews were conducted from March to July 2023. The selection criteria included patients aged 18 years or older, of both genders, diagnosed with advanced-stage malignant tumors regardless of the tumor body site, who were alert and oriented, and able to communicate verbally. Patients with cognitive deficits, using enteral nutrition via catheter or ostomies, illiterate and with a reduced level of consciousness were excluded. The high number of participants excluded from the study was due to several factors such as disorientation, lethargy, mental confusion, already being followed up by the institution's home care or not being in-patients in the unit for the first time.

Data were collected using the Free Word Association Technique (FWAT). FWAT is a research instrument that relies on a conceptual repertoire regarding the type of open investigation, allowing the identification of semantic universes through the salience of common word universes in the face of different stimuli. The instrument is structured around evoking responses given based on induced stimuli. The inducing terms must be previously defined according to the representational object, also taking into account the characteristics of the sample or of the patients who will be interviewed.

Thus, the test consists of one or more inducing stimuli chosen according to the criteria of salience and coherence with the investigation objects. The standardized question for applying the technique consists of asking the interviewee: "If I say "X" to you, what comes to your mind? Give me "X" words that, for you, characterize "X".[7,8]

The inducing terms used were “palliative care” and “food”. After the introduction of the inducing term, the interviewee was asked to say three words or expressions that came to mind and to list each one according to an order of importance, as more recent studies suggest replacing the “ranking of appearance” criterion with the “ranking of importance” criterion, resulting from the hierarchization carried out by the subject.[9]

FWAT data were processed using the EVOC software, which performs statistical analyses to evaluate the frequency and position of words in the evoked sequence, resulting in the estimate of the Mean Order of Evocation (OME).[10,11]

The cumulative value of around 50% of the total number of words evoked was defined for the entry of evocations into the Vergès’ four-quadrant analysis framework. The four boxes highlight the peripheral zones (first and second peripheries), the contrast zone and the centrality zone, taking into account the combination of frequencies and each evoked term. The central tendency is expressed by the median of the evocations admitted into the framework, while the hierarchical value (range) of the AOE is calculated by the average of its weighted averages.[11]

Secondary data were filled out in the questionnaire for clinical and sociodemographic characterization of the patient (age, gender, functional capacity, diagnosis, previous treatments, metastases, symptoms and diet prescription). These data were analyzed by simple descriptive statistics, using the Microsoft Excel® program.

All patients voluntarily agreed to participate in the study and signed the Free and Informed Consent Form, after approval by the Research Ethics Committee of the institution, under CAAE number 66500223.3.0000.5274.

RESULTS

Out of the 91 patients transferred from the care units of origin to the exclusive palliative care unit during the period analyzed, 39 were excluded, according to the study criteria. Thus, 52 patients took part in the study.

Regarding the sample characterization, 59.6% of the patients were aged between 20 and 59 years; 67.3% were female. With regard to visits to the respective outpost, 61.5% of the patients were not visiting. Regarding the diagnosis, gynecological (25%) and gastrointestinal (25%) tumors were predominant. Approximately 50% of the patients had peritoneal or gastrointestinal metastasis. According to the Karnofsky Performance Status (KPS) scale for functional capacity, 42.3% had40% KPS and 38.4% had 30% KPS. Among the patients interviewed, 48.2% had three to four gastrointestinal symptoms and 34.6% were receiving a complete liquid oral diet (Table 1).

Table1. Profile of patients with advanced cancer interviewed (n=52). Rio de Janeiro-RJ, 2023

Variables	n (%)
Age (years)	
20 to 59 years	31 (59.6%)
≥ 60 years	21 (40.4%)
Gender	
Female	35 (67.3%)
Male	17 (32.7%)
Outpost carried out with patient	
Yes	20 (38.5%)
No	32 (61.5%)
Diagnosis	
Breast cancer	12 (23.0%)
Gastrointestinal cancer	13 (25.0%)
Gynecological cancer	13 (25.0%)
Prostate cancer	4 (7.7%)
Melanomas	3 (5.8%)
Other tumor sites (lung, bone-connective tissue, head and neck, neurological)	7 (13.5%)
Presence of peritoneal or GI metastasis	
Yes	26 (50.0%)
No	26 (50.0%)
Karnofsky performance status (KPS)	
30%	20 (38.4%)
40%	22 (42.3%)
50%	10 (19.3%)

Table1. Profile of patients with advanced cancer interviewed (n=52). Rio de Janeiro-RJ, 2023.(Continues)

Variables	n (%)
Number of gastrointestinal symptoms	
No symptoms	2 (3.8%)
1 to 2 symptoms	23 (44.2%)
3 to 4 symptoms	25 (48.2%)
5 or more symptoms	2 (3.8%)
Oral diet consistency	
Comfort diet	7 (13.5%)
Full liquid	18 (34.6%)
Semi-liquid	3 (5.8%)
Soft	8 (15.4%)
Soft or regular	16 (30.9%)

Source: Prepared by the authors

The analysis of the evocation of the inducing term “palliative care” generated the four-zone chart, in which its construction and representational organization can be observed. The concepts related to each zone are reported in Figure 1.

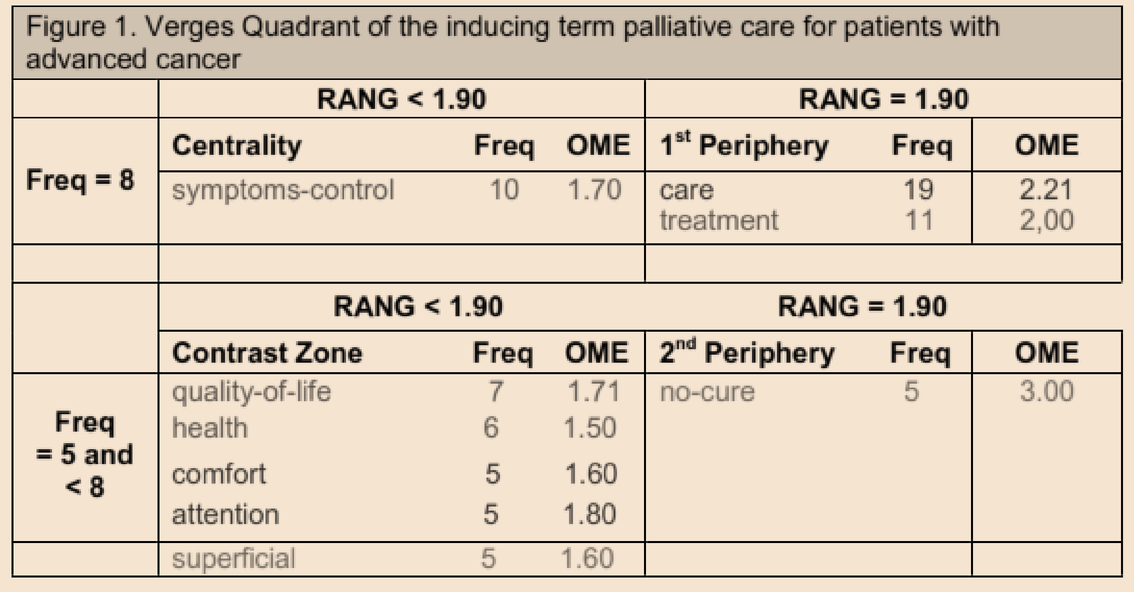

Figure 1. Verges Quadrant of the inducing term palliative care for patients with advanced cancer

	RANG < 1.90			RANG = 1.90		
Freq = 8	Centrality	Freq	OME	1st Periphery	Freq	OME
	symptoms-control	10	1.70	care treatment	19 11	2.21 2,00
	RANG < 1.90			RANG = 1.90		
	Contrast Zone	Freq	OME	2nd Periphery	Freq	OME
Freq = 5 and < 8	quality-of-life health comfort attention	7 6 5 5	1.71 1.50 1.60 1.80	no-cure	5	3.00
	superficial	5	1.60			

RANG: hierarchical value; AOE: average order of evocation.

The characterization of free evocations, according to Vergès' proposal (Figure 1) for the inducing term “palliative care”, highlights in the upper left quadrant the term “symptom control” as a central evocation, being understood as an element related to the basic meaning of palliative care for the interviewed subjects.

The most frequent evocations are located in the upper right quadrant (first periphery), and with a higher order of evocation as well, with the terms “care” cited 19 times (range 2.21) and “treatment” 11 times (range 2.00), referring to the idea of palliative care as a new form of care and treatment possible in advanced disease. These evocations were characterized as peripheral elements more pertinent to the representation.

The less frequent evocations and with a lower order of evocation are located in the third quadrant (bottom left); these are terms considered relevant for a smaller group of participants. In this study, the terms "quality of life", "health", "comfort", "attention" and "superficial" were observed in the contrast zone. Among these terms, "quality of life" was the most frequent.

Finally, in the fourth quadrant (bottom right), we find the less frequent evocations but which are considered relevant by the study participants, since they are evoked without hesitation, with a higher order of evocation. The highlighted term was "without cure", which contrasts with the first periphery.

When exploring the peripheries and the contrast zone according to the characteristics of palliative care, "superficial" and "incurable" were terms with conflicting evocations that characterize a specific subgroup of patients who diverged from a discourse that was quite reified by the majority of the interviewees.

The terms: "symptom control", "treatment", "quality of life" and "health" share semantic similarity (highlighted in blue).

Likewise, the terms "care", "comfort" and "attention" were emphasized as similar expressions (highlighted in red). Ultimately, the terms "incurable" and "superficial" were highlighted as being of equal importance (highlighted in green). Thus, all these words seek to characterize the concept that induces palliative care in patients with advanced cancer.

The analysis of the evocation of the inducing term "food" generated the four-zone chart, in which its construction and representational organization can be observed. The concepts related to each zone are displayed in Figure 2.

To characterize free evocations according to Vergès' proposal (Figure 2) for the inducing term "food", the terms "healthy food" and "health", in centrality,stand out in the first quadrant (top left), as being the words most frequently evoked by the interviewees.

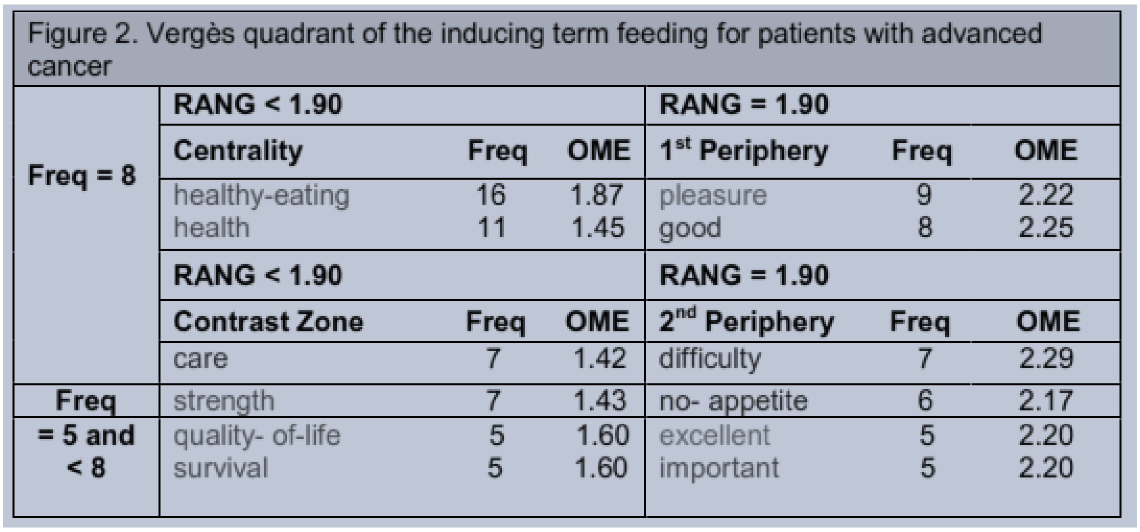

Figure 2. Vergès quadrant of the inducing term feeding for patients with advanced cancer

	RANG < 1.90			RANG = 1.90		
Freq = 8	**Centrality**	**Freq**	**OME**	**1^{st} Periphery**	**Freq**	**OME**
	healthy-eating	16	1.87	pleasure	9	2.22
	health	11	1.45	good	8	2.25
	RANG < 1.90			**RANG = 1.90**		
	Contrast Zone	**Freq**	**OME**	**2^{nd} Periphery**	**Freq**	**OME**
	care	7	1.42	difficulty	7	2.29
Freq = 5 and < 8	strength	7	1.43	no- appetite	6	2.17
	quality- of-life	5	1.60	excellent	5	2.20
	survival	5	1.60	important	5	2.20

RANG: hierarchical value; AOE: average order of evocation.

In the second quadrant (upper right), we find the first periphery evocations, with a higher order of evocation, with the most frequent terms being "pleasure" and "good", respectively, which refer to food with a positive positioning, with the objective of providing emotional comfort at this moment in life, being characterized as the peripheral element most pertinent to the representation.

In the third quadrant (bottom left), the less frequent evocations and with a lower order of evocation are located, highlighting the terms “care”, “strength”, “quality of life” and “survival”, which were considered important by a small number of individuals, with “care” being the most frequent in the contrast zone.

Therefore, in the fourth quadrant (bottom right), there are the evocations of lower frequency, but considered relevant by the study participants and with a higher order of evocation in which the highlighted term was “difficulty”, followed by “without appetite”, being contrasted with the centrality, the first periphery and the contrast zone. In addition to these, the terms “optimal” and “important” were configured”.

The terms share similarity in their semantic universe through the salience of common universes between words, such as “healthy eating”, “health”, “important”, “strength”, “quality of life” and “survival” (highlighted in blue). Likewise, the expressions “pleasure” and “great” were emphasized as similar terms (highlighted in green). Further, similar terms were identified, such as “good” and “care” (highlighted in pink). Finally, the terms “difficulty” and “no appetite” (highlighted in red) were indicated as being equally relevant. In this way, all these words seek to characterize the concept that induces feeding of patients with advanced cancer.

DISCUSSION

In this study, we addressed the social representations of palliative care and nutrition through word evocation in patients with advanced cancer. Thus, the social representation of palliative care and nutrition was organized based on the words “symptom control” and “healthy eating”, respectively. These were presented as central evocations in which a positive relationship is established between palliative care and the concept of treatment that controls the disease symptoms and nutrition as an important health resource, even when cancer cannot be “cured”. However, it is worth highlighting the difficulty encountered in understanding the inducing term “palliative care” that was adopted by the interviewees.

Palliative care aims at alleviating suffering at all the stages of the malignancy. The integration of curative and palliative treatment is possible and should be valued in earlier stages of the disease to facilitate this transition. This can be especially challenging when news of a poor prognosis is received, as it marks not only a change in medical care, but also a change in the patient's expectations, from cure to comfort and quality of life. This integration is possible and should be encouraged from the early stages of the disease. By giving to it early priority, the transition to the phase in which palliative care becomes exclusive will be less abrupt and more gentle, allowing the patient to continue to feel welcomed and supported throughout the process.[12-14]

In a qualitative study, the authors of this paper found that participants felt better prepared for the transition when information was provided by multiple sources, including the healthcare teams. Factors associated with a positive transition experience included clear and repeated communication between the patient, the healthcare team, and the family. However, some patients reported a less positive transition experience, as they reported feeling overwhelmed by the amount of information delivered to them.[15]

Information about palliative care should be communicated to patients and to their families, and should be introduced early and gradually by the health care team, with the support of palliative care specialists, during the course of disease-modifying treatment, as necessary adjustments are made to the care programs. In addition, recent efforts to create public policies that integrate palliative care at all levels of health care and ongoing training of health teams addressing this topic, including how to deal with difficult news, are measures that would allow more effective communication between the health teams, the patients, families and society.[16,17]

Returning to the main objective of ourinvestigation, after the classification process of the terms into categories according to their semantic similarity, we will discuss the shared social representations about palliative care and nutrition among patients with advanced cancer.

Social representations of palliative care

Symptom control, treatment, quality of life and health

In our study, the category "symptom control" stands out, encompassing terms such as "quality of life", "health" and "treatment". These concepts reflect the principles of palliative care, which aim to promote the patients' and their family's quality of life, preventing and alleviating suffering, and identifying and treating early physical, social, psychological and spiritual issues.[13]

Studies have highlighted the importance of providing quality of life to individuals through physical, psychological and spiritual comfort, while understanding that quality of life depends on the individual's satisfaction with preserving their autonomy, maintaining self-care and independence to carry out their daily activities.[18,19]

In Rothe's research,[20] the evocation "treatment" appeared in the first periphery, indicating a clear separation between curative and palliative treatments. The participants generally did not associate the two types of treatment. However, Sarradon-Eck et al.[21] described the social representations of oncologists about palliative care, emphasizing a "comprehensive treatment" approach, which gives priority to the patients' comfort and to the listening of their needs.[20,21]

"Health" was an important social representation, as it appears both in the term inducing palliative care as a contrasting evocation, and in the term "food" as a central evocation. In this sense, comprehensive health care in palliative care should focus on patients, as well as on the family's involvement for general well-being.[22]

Care, comfort and attention

In the first periphery, "care" was the most common evocation associated with palliative care, with a high association of AOE. This term encompasses two distinct aspects: the ideal care for patients, aiming at their well-being, comfort and pain relief; and the feeling of frustration associated with patients' care in the palliative stage. The care provided aims to improve quality of life, not to prolong suffering. The care offered by the palliative care health team stands out, based on the bond established with patients through reception, communication and attention, promoting a relationship of trust and better care.[23,24]

Incurable and superficial

On the other hand, some patients associated terms such as "incurable" and "superficial" in a conflicting way, indicating a negative view of palliative care. This perspective is supported by previous studies, such as that of Coelho de Britto et al.,[25] which highlighted terms such as "pain", "death" and "suffering" as central to the negative representation. Other studies, such as that of Sarradon-Eck et al.,[21] observed negative connotations associated with the term "palliative", suggesting a fear of being abandoned.[21,25] In the study by Lefaucheur et al.,[26] some emotions, such as "darkness", "sadness", "fear", "anxiety" and "loss of hope", also brought negative perceptions associated with the term palliative care.[26]

In the study by Fitaroni et al.,[27] the meanings attributed to death in palliative care were associated with the themes "unknown", "fear" and "denial", as observed in the respondents' statement: "I think that death is still a mystery to everyone, because when [we] talk about death, everyone is already shaken. So, death is an unknown entity. It is an unknown… imagine for the patients, so it is complicated".[27]

According to Reale,[28]the results found for the representation of palliative care revealed a negative positioning for patients, expressed by the ideas of "death", "terminality", "pain" and "suffering". For Matos et al.,[1] negative representations such as "suffering", "disabling disease", "dread" and "fear" were also associated. These words corroborate the semantic meaning of the terms "incurable" and "superficial" that appeared in this work.[1,28]

Social representations about food

Healthy eating, health, important, strength, quality of life and survival

If food acquires meanings, the act of eating takes on connotations related to interpretation in an imaginary and symbolic scenario, necessarily disconnected from rationality, but capable of generating individual and collective identities, social connections and bonds that transcend the conscious logic of communication.[29]

Regarding the quadrant for the term inducing food, the central word highlighted was "healthy eating". After a cancer diagnosis, patients generally seek a more balanced and natural diet, avoiding harmful foods, also known as "crazy foods". They opt for foods considered healthier, even during exclusive palliative care, as also observed in the statement of patients in the Daumas study:[30] "I tried to protect myself and eat better and healthier things, to reduce the junk food I ate a little. So, eat more greens, more broccoli, you know?".[30]

"Quality of life" is in the contrast zone of our study, corroborating the work of Daumas,[30] who demonstrated the direct relationship between diet and "quality of life", "symptomatology", "vital force" and "autonomy", as when the patient reports that he was able to eat a food that he could not eat before, giving him a feeling of encouragement and strength. Thus, diet in oncology palliative care is influenced by several variables, being associated with health and quality of life.[31]

The term "strength" was also found in the contrast zone. Costa and Soares[31] emphasize that an important aspect of nutrition for patients undergoing palliative care for oncology is to preserve the ability to perform basic routine activities such as going to the bathroom and taking a shower, without needing help from another person, and even more complex activities, such as being able to work. Thus, the authors identified as one of the meanings in this phase that "food is good, gives strength and preserves autonomy", demonstrating its importance in facing the challenges and losses in the process of disease progression. According to Daumas,[30] despite the critical situation in several aspects, patients are able to associate feeling pleasure eating food with feeling strong enough to live.

Regarding the term "survival", present in the contrast zone, the work of Caldeira & Fava[32] considers that food and drinks are seen as necessary to sustain the body, confirmed by the statement "food is something we eat to sustain ourselves, without food we cannot survive". In addition, the term "important" appears in the second periphery, indicating a change in the importance and value attributed to food with the emergence of a disease, as observed by Silva et al.[33] In situations of impossibility, such as difficulty in ingesting food or lack of food, food becomes even more essential.[32,33]

Pleasure and optimal

It is recognized that food plays a significant role in palliative care. In this context, the category "pleasure" is located in the first periphery, sharing its semantic field with the term "optimal", which is found in the second periphery. According to the study by Costa and Soares,[31] patients in oncology palliative care express a liking for eating and report that food can replace the pleasure of smoking and drinking. However, the perception of a worsening ability to eat is seen as a sign of disease progression.

The search for pleasure in food is a way to feel good and is valued as an opportunity to enjoy life. The representation of eating in palliative care was identified as "Eating is when you eat for desire, for pleasure, sometimes without taking into account the nutritional aspect, right? I didn't take that into account, but now I do. This doesn't bring me any more benefits, although I often eat anyway."[30] Therefore, eating during palliative care should not only nourish the body, but also provide emotional comfort and promote bonding with family members and caregivers.[31]

In Matos' study,[34] it was observed that food, in addition to being a means of subsistence, is characterized as a pleasurable experience that helps promote comfort, communication, social interaction and helps maintain autonomy.[34]

Be careful and good

The category "care", a term most frequently located in the contrast zone, shares its semantic field with the term "good", located in the first periphery. According to Costa and Soares,[35] offering food and drink is a significant human action of respect for the life and care for others. Another study found that, for the general population, food is interpreted as the act of "nourishing the individual for growth, development and maintenance", playing an essential role in their lives, conveying life, care and affection. Food was represented as "Good food! Food... is there anything better in the world than good food to keep you standing on your feet?"[35]

Diet can provide psychological comfort, as certain foods have the ability to evoke positive emotional memories or serve as a motivational stimulus in the battle against the disease, by providing a sense of control when still being able to eat, even if in reduced quantities.[36]

For Leonardo Boff,[37] care exists before human action, being present in all things and situations of human beings. Care is an attitude that generates multiple acts and expresses the essence of care itself. Care between human beings is what gives meaning to their existence. In this way, the relationship of care is not one of domination over, but of coexistence, and therefore it is not pure intervention, but rather interaction. Thus, food is perceived as a form of care, giving meaning to human existence.[37]

Difficulty and no appetite

Regarding the negative aspects of eating, the terms "difficulty" and "no appetite" were highlighted in the fourth quadrant. Faced with the challenge of dealing with advanced-stage cancer, individuals experience a series of losses throughout the natural progression of the disease.Those losses include discomfort and pain that permeate different spheres, from the physical aspects to the emotional and spiritual components. These changes, combined with the uncertainty of what is to come, instigate feelings of apprehension and hopelessness in the patients, potentially negatively influencing their psychosocial health.[38]

In the study by Santos,[38] the category "loss" appeared as the most significant dietary attribute in the group of patients, collaborating with different studies that address the losses faced by individuals in palliative care. This is directly related to the presence of dysphagia and the need for changes in oral feeding throughout the progression of cancer; therefore, patients are forced to make choices and adjustments in connection with their diet. As to family members, they are faced with the anguish of witnessing their loved one's difficulty in eating, while health professionals face the challenge of redefining this loss, focusing on promoting pleasure and comfort for the individual. Thus, changes in diet can cause several repercussions, characterized by decreased autonomy and, in some cases, imminent death. Therefore, as the disease progresses and health deteriorates, there is an increase in the incidence of complications related to swallowing. In these circumstances, food can become unsafe, contributing to complications and health risks.[38]

Therefore, González & Gusenko[39] argue that nutritional intervention in palliative care should focus primarily on controlling symptoms such as nausea, vomiting, early satiety, constipation, diarrhea, dysphagia, and xerostomia. According to Pinho-Reis,[40] effective symptom control is crucial, since these symptoms not only impact appetite and nutrient absorption, but also influence the pleasurable experience associated with the act of eating. It is common for patients to manifest symptoms such as lack of appetite, difficulty swallowing, and the need for assistance with eating, and it is crucial to offer a comfort diet, implementing adjustments in the texture, temperature, volume, and density of foods, in addition to considering food preferences.[36]

It is worth mentioning that this study had limitations such as performing the interviews in a single hospital unit, with a reduced number of participants. Due to the difficulty of the participants in finding terms or expressions that conveyed their thoughts and opinions due to their current clinical, emotional and cognitive state, a smaller number of evocations was also chosen. The report of the caregiver/family member was not taken into account, since the focus was on the patient.

However, as strengths of this study, it is worth highlighting the fact that the terms were considered exactly as they were uttered by the patients during the interview. In addition, it provided a comprehensive analysis of the social representations about palliative care and nutrition in patients with advanced cancer, exploring the semantic associations and the importance attributed to the different terms.

CONCLUSION

The study addressed social representations of palliative care and nutrition in patients with advanced cancer, highlighting the centrality of the terms "symptom control" and "healthy eating," respectively, which reveals the emphasis of the approach on symptom relief and focus on the quality of life of those patients and their family.

The limited understanding of the term "palliative care" by the study's participants indicates the existence of communication challenges. This difficulty may be related to the recent review of the terminology, as it is misinterpreted by many people due to several factors such as lack of information and prejudices, which distort the true purpose of palliative care. The transition to palliative care is perceived as a unique phase, marked by the change in focus from cure to symptom management, comfort, and quality of life. Thus, it is suggested that the lack of integration between curative treatment and palliative care becomes an obstacle, evidencing stigmas, when portrayed as "superficial" care, referring to the idea of "no cure."

Therefore, it is essential to make adjustments to the expectations of patients and caregivers in order to give new meaning to care during illness, based on effective communication.Thus, palliative care should be addressed earlier as part of the treatment, aiming at a more humanized transition based on a broader understanding of this care.

The segmentation of social representations about food evidenced in our study offers an insight into the complex associations between food and emotional, physical and social aspects, which directly impact health, quality of life and the patient's illness experience. On the other hand, “difficulty” and “lack of appetite” emerge as challenges, reflecting the losses and complications faced by patients with advanced cancer in palliative care.

Given the complexity of the aspects involving food, it is essential to understand the meaning attributed by the individual to the act of eating, so that the implementation of dietary adaptations, necessary due to complications inherent to the progression of the disease, are shared decisions between health professionals, patient and caregiver. Therefore, individualized dietary care must be offered in order to minimize the biographical ruptures that occur throughout the illness, considering that food choices and preferences are markers of sociocultural identity and give meaning to human existence.

ACKNOWLEDGMENTS

We are grateful for the support of librarian Fádia Carvalho Pacheco, of the Integrated Library System Center of the National Cancer Institute, for her bibliographic search strategies.

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Contributors

Aguiar GB participated in the ideation of the study design; data collection, analysis and interpretation, and writing of the article; Costa MF participated in the ideation of the study design, data interpretation, writing and review of the article; Santos RS participated in the ideation of the study, data interpretation, writing and review of the article; Sarubbi Junior V performed the analysis and interpretation of the data. All authors approved the final version of the article.

Conflict of Interest: The authors declare no conflict of interest.

Received: March 26, 2024
Accepted: October 1, 2024