When Nutrition is no Longer Necessary: Breaks and Continuities in Palliative Care For Patients With Head and Neck Cancer

Quando Nutrir Não é Necessário: Rupturas e Continuidades nos Cuidados Paliativos em Pacientes com Câncer de Cabeça e Pescoço

Cuando Nutrir ya no es Necesario: Rupturas y Continuidades en los Cuidados Paliativos en Pacientes con Cáncer de Cabeza y Cuello

RESUMO
Objetivo: Compreender o cuidado nutricional de pacientes com câncer de cabeça e pescoço nos cuidados paliativos sob a perspectiva da subjetividade. **Metodologia:** Trata-se de ensaio teórico crítico-reflexivo, com enfoque argumentativo lógico-analítico. Fundamentou-se em teóricos e autores, cujas publicações relacionam-se à assistência nutricional, cuidados paliativos, experiência alimentar e câncer de cabeça e pescoço, oriundos tanto das Ciências da Saúde como das Ciências Humanas e Sociais. **Resultados e Discussão:** Os pacientes com câncer em cuidados paliativos enfrentam perdas e mudanças nas práticas alimentares, afetando suas emoções e sentimentos. A alimentação torna-se um ato de humanização, visando conforto e qualidade de vida. Sentimentos como angústia, prazer e identidade reforçam a subjetividade durante a paliação, destacando a importância de reconhecer essas experiências, muitas vezes ocultas. **Conclusão:** É importante repensar o tratamento de pacientes com câncer terminal, destacando os cuidados paliativos para preservar a dignidade e o conforto, mesmo quando a cura não é possível.
DESCRITORES: Câncer de Cabeça e Pescoço; Subjetividade; Alimentação; Cuidados Paliativos.

ABSTRACT
Objective: To understand the nutritional care of patients with head and neck cancer in palliative care from the perspective of subjectivity. **Methodology:** This is a critical-reflective theoretical essay with a logical-analytical argumentative approach. It is based on theorists and authors whose publications are related to nutritional assistance, palliative care, eating experience, and head and neck cancer, originating from both Health Sciences and Human and Social Sciences. **Results and Discussion:** Patients with cancer in palliative care face losses and changes in eating practices, impacting their emotions and feelings. Nutrition becomes an act of humanization, aiming for comfort and quality of life. Feelings such as anguish, pleasure, and identity reinforce subjectivity during palliative care, highlighting the importance of recognizing these often hidden experiences. **Conclusion:** It is important to rethink the treatment of terminal cancer patients, emphasizing palliative care to preserve dignity and comfort, even when a cure is no longer possible.
DESCRIPTORS: Head and Neck Cancer; Subjectivity; Nutrition; Palliative Care.

RESUMEN
Objetivo: Comprender el cuidado nutricional de los pacientes con cáncer de cabeza y cuello en cuidados paliativos desde la perspectiva de la subjetividad. **Metodología:** Se trata de un ensayo teórico crítico-reflexivo, con un enfoque argumentativo lógico-analítico. Se fundamenta en teóricos y autores cuyas publicaciones están relacionadas con la asistencia nutricional, cuidados paliativos, experiencia alimentaria y cáncer de cabeza y cuello, provenientes tanto de las Ciencias de la Salud como de las Ciencias Humanas y Sociales. **Resultados y Discusión:** Los pacientes con cáncer en cuidados paliativos enfrentan pérdidas y cambios en las prácticas alimentarias, lo que afecta sus emociones y sentimientos. La alimentación se convierte en un acto de humanización, orientado al confort y la calidad de vida. Sentimientos como angustia, placer e identidad refuerzan la subjetividad durante la paliación, destacando la importancia de reconocer estas experiencias, muchas veces ocultas. **Conclusión:** Es importante repensar el tratamiento de los pacientes con cáncer terminal, destacando los cuidados paliativos para preservar la dignidad y el confort, incluso cuando la cura ya no es posible.
DESCRIPTORES: Cáncer de Cabeza y Cuello; Subjetividad; Alimentación; Cuidados Paliativos.

RECEIVED: 01/27/2025 **APPROVED:** 02/07/2025

How to cite this article: Fernandes HMA, Barbosa ES, Lopes GCB, Oliveira FM, Uchôa BO, Freire LFO, Walter VC, Andrade BKM. When Nutrition is no Longer Necessary: Breaks and Continuities in Palliative Care For Patients With Head and Neck Cancer. Saúde Coletiva (Edição Brasileira) [Internet]. 2025 [acesso ano mês dia];15(93):14515-14521. Disponível em: DOI: 10.36489/saudecoletiva.2025v15i93p14515-14521

DOI: 10.36489/saudecoletiva.2025v15i93p14515-14521

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INTRODUCTION

The World Health Organization (WHO) defines Palliative Care (PC) as assistance offered by a multidisciplinary team, with the aim of providing comfort, alleviating symptoms and suffering, in addition to listening, respecting, sharing, welcoming and accompanying the patient and their family members until the end of life. This approach seeks to promote quality of life for those facing life-threatening illnesses, especially in the case of cancer (1).

PC, through Ordinance GM/MS No. 3,681, of May 7, 2024, establishes the National Palliative Care Policy (PNCP - Política Nacional de Cuidados Paliativos), within the scope of the Unified Health System (SUS), aiming to provide a better quality of life for patients, family members and caregivers dealing with serious chronic diseases (2).

According to the Worldwide Hospice Palliative Care Alliance (WHPCA) and the WHO, it is estimated that 56 million people in the world need this type of care. The PNCP, established in May 2024, seeks to fill this gap, offering comprehensive support not only to patients, but also to their families and caregivers. For health professionals, especially nutritionists, this approach represents both an opportunity and a challenge, given the lack of training and specialization in the area on how to promote a dignified, humanized and welcoming diet in patients with Head and Neck Cancer (HNC) (2,3).

Considering the terminology of HNC, it refers to a group of heterogeneous tumors that affect the upper aerodigestive tract, including the anatomical regions of the oral cavity, pharynx, larynx and thyroid (4). Therefore, the main histological type is squamous cell carcinoma, responsible for approximately 90% of cases (5).

In this context, of the various types of HNC, approximately 40% correspond to oral cavity cancers, 15% to the pharynx and 25% to the larynx, with the remaining percentage distributions in the region of the salivary glands and thyroid (6). Its incidence has been increasing in recent decades due to the increased availability of its risk factors, that is, smoking, alcohol, obesity, family history, exposure to radiation and environmental factors (7).

When addressing nutritional care in the sphere of PCs, HNC subjects, numerous strategies are included in eating and commensality practices. These strategies involve changing the texture of food, adding recipes that aim to relieve symptoms in a pleasurable way, restoring dietary autonomy, since food has an expression in the form of social organization, in which food culture is associated with citizens' manifestations before society, thus constituting eating habits (8,9,10,11).

In addition to the sociocultural function of nutrition, it also involves psychological aspects related to the choice of food type and time of day. In addition, eating behavior is also linked to quality of life, since it is from this moment on that eating problems are constructed or reconstructed as a way of better relating to food (12).

In this context, the need for professional qualification of the nutritionist in the area of clinical oncology becomes extremely important, especially when he or she accompanies the subject in prevention, diagnosis, treatment, palliative care, end-of-life care and post-treatment, in a non-sequential manner, so that all nutritional needs are guaranteed, minimizing the impacts of treatment, promoting

DOI: 10.36489/saudecoletiva.2025v15i93p114515-14521

comfort through nutrition and preserving the reduction of progression during the therapeutic process of the oncological subject (11).

Thus, the objective of this article is to understand the nutritional care of patients with head and neck cancer in palliative care from the perspective of subjectivity.

METHOD

This is a critical-reflective theoretical essay, with a logical-analytical argumentative focus. The academic essay is a type of critical text, with great theoretical-scientific relevance, which exposes the author's ideas, subjectivities and points of view on a given theme, seeking originality, interpretations with other areas, focus, without, however, exploring the theme exhaustively. Therefore, the theoretical essay starts from the discussion of a previously established theme, following a delimited theoretical basis (13).

Therefore, during the methodological path, to discuss and problematize the idea in focus, a bibliographic search was carried out based on scientific articles (reviews and essays), books, dissertations and theses, with the purpose of approaching the paradigm of nutritional care and eating experience in subjects with Head and Neck Cancer, from a perspective of valuing subjectivity in the context of Palliative Care (13).

Furthermore, no temporal marker or language was defined, and the search was guided by theoretical/thematic proximity, using the following databases: Scientific Electronic Library Online (SciELO); PubMed®; Scopus and Web of Science. To systematize the findings, the Health Sciences Descriptors - DeCS, available on the respective platform, were used: "Head and Neck Neoplasms", "Subjectivity", "Palliative Care" and "Food, Diet and Nutrition".

To compose the corpus of this research, the theoretical basis was carried out with theorists and authors, whose publications are related to nutritional assistance, eating experience, Palliative Care, Comfort, Humanization and Head and Neck Cancer in dialogue with other Health Sciences, in addition to their subcategories, which include discussions and thoughts from the areas of Psychology, Anthropology, Sociology, Subjectivity and Applied Social Sciences.

In addition, a filter and selection of the main authors who address the proposed or related theme were carried out, who can dialogue with the Social and Human Sciences, so that discussions and reflections can be promoted and intersubjectivity can be understood within the context of the subject's appreciation of their eating experiences from the cultural, symbolic, representative, social, psychological and emotional perspective.

RESULT AND DISCUSSION

The selected bibliographic materials were subjected to reading as well as critical analysis and, subsequently, organized into a section, whose title and objective are presented below. **1) When nourishment is no longer necessary: ruptures and continuities in palliation.** This topic will address nutrition and feeding in the context of palliative care, in addition to its feeding routes (oral or enteral), discussing when feeding is no longer necessary or beneficial for the patient.

The complexities and subjectivities involved in decisions about the continuation or interruption of nutrition in palliative care will be explored, considering clinical, ethical and cultural aspects. In addition to understanding the perspectives of family members in this decision-making process.

When nourishment is no longer necessary: ruptures and continuities in palliation

The oncological trajectory involves different contexts and life experiences of individuals, and it could not be different for those who are terminally ill, receiving palliative care or at the end of life. PC is often associated with the end of life, but in reality, it should be initiated from the diagnosis of serious, progressive and potentially fatal diseases, regardless of the stage the patient is in.

Before death, there is still life, and, in diagnosis and treatment, this life manifests itself through other subjectivities, even when the end seems near after the diagnosis of cancer, since it is a life-threatening disease. Thus, this palliative care proposal must guarantee humanized and comprehensive care in its entirety, promoting well-being and maintaining dignity, respect and appreciation of the self, so that the being is not expropriated of his or her life (14).

When palliative care and end-of-life care are discussed, reference is usually made to the last days or 72 hours of the patient's life. Recognizing the value of the life of a patient with HNC is a difficult, delicate and complex process, but it is essential for planning care, in addition to being fundamental to preparing the patient and their family for loss, death and the subsequent grieving process (9).

These processes bring reflections on the principles of Bioethics, in which death cannot be anticipated, but rather respected. This table illustrates how the principles of Bioethics (autonomy, beneficence, non-maleficence and justice) apply to the nutritional care of cancer patients, ensuring respectful, beneficial and equitable decisions at all stages of treatment (15).

DOI: 10.36489/saudecoletiva.2025v15i93p14515-14521

Table 1 – Principles of Bioethics in applicability to nutritional care:

PRINCIPLES OF BIOETHICS		
	Conceito	Aplicabilidade
AUTONOMY	It refers to the patient's right to make decisions about his or her own life, including his or her dietary choices. It advocates that the freedom of every human being must be protected.	If a cancer patient expresses a preference for a certain type of food, even if it is not the most nutritious, this choice must be respected, as long as it does not put his or her health at immediate risk.
BENEFICENCE	It refers to the duty to help others, to do or promote good in their interests. It recognizes the moral value of others, taking into account that, by maximizing the good of others, it is possible to reduce harm.	Offer alternative foods that improve the patient's diet and quality of life, even if the patient has difficulty eating due to symptoms of the disease.

Source: Prepared by the Authors, adapted by Koerich; Machado; Costa (2005).

These principles must be applied in a balanced manner in the nutritional care of cancer patients to ensure that their physical, emotional and psychosocial needs are respected. This includes considering the patient's dietary preferences, offering options that alleviate symptoms and improve quality of life, while avoiding harm. In addition, it is essential to ensure that all patients have access to adequate nutritional care, taking into account their clinical conditions and individual values.

This holistic care promotes a more dignified and patient-centered approach throughout the disease. Thus, it is observed that, when the condition of the patient in palliative care is at an advanced stage, with no positive prospects for recovery, the nutritionist must adapt the dietary and nutritional approach, alternating between continuity, changes and dietary interruptions. These variations are common, unpredictable and often generate suffering and anguish in family members, since food also carries a symbolism of "life" or "living".

In this context, (16) highlights the importance of the act of eating, stating that "eating" and "drinking water" are essential conditions for human survival, in addition to representing respect for life and care for oneself and others, whether in relation to friends, family or relatives. Food and water are sources of life and, when they are deprived, human beings understand it as an "attack on life", even if involuntary, which is represented by the following authors:

> Food is associated with life, with a person "staying alive", because without eating "they cannot survive". Some expressions show this meaning, such as: "if a person does not eat, they cannot live, they cannot resist"; "we cannot live without eating"; "if we do not eat, we cannot live"; "if we do not eat, then we die"; "if we do not eat, we die". For subjects and caregivers, food represents "everything good"; "a large part"; "the basis"; "fundamental"; "essential"; "is part of life"; "main"; "the most important thing in life"; "primordial"; "essential good"; "the top". (16, p.221).

Despite the meanings that food carries, in some cases, it is observed that caregivers and family members insist that patients eat/nourish themselves even when the body has already adjusted its metabolic pathways to the specific conditions of the disease.

This insistence may reflect not only concern for the patient's physical health, but also emotional and psychological resistance to the process of loss of autonomy and the approaching end of life. Food, in this context, ceases to be just a biological necessity and begins to be seen as a symbol of continuity and resistance to death, which can generate a conflict between appropriate care for the patient's condition and the family's expectations regarding survival and well-being.

The human body has an incredible capacity for adaptation, being able to adjust its metabolic processes even during prolonged periods of fasting, lasting more than a week. Although caregivers may consider this fasting harmful, associating it with suffering, pain or even a threat to life, the body, in response, resorts to using ketone bodies derived from fat reserves as a primary source of energy, replacing glucose, which is no longer efficiently available. This adaptation mechanism is essential for survival in conditions of food deprivation, maintaining homeostasis and allowing the maintenance of vital functions for prolonged periods (17,18).

In addition, studies indicate that the state of ketosis can provide pain relief, probably due to the release of endogenous substances with an effect similar to that of opioids, in addition to reducing the sensation of hunger, mediated by the hormone ghrelin. Based on these biochemical, physiological and organic mechanisms of the body, in many cases, maintaining fasting in the last days of the patient's life does not represent an attack on life, but rather a strategy to alleviate suffering and promote well-being (17,19).

When caregivers do not understand this adaptation of the body, they end up insisting or even forcing it, causing a stressful, conflicting, uncomfortable and distressing situation for the patient, causing their quality of life and autonomy to be disrupted and disrespected (20).

This behavior by caregivers can be seen as an impulsive and emotional

DOI: 10.36489/saudecoletiva.2025v15i93p114515-14521

response, which reflects more resistance to the process of death and loss of autonomy than truly patient-centered care. Thus, the practice of forcing feeding not only compromises the patient's comfort, but also creates an ethical dilemma, by contradicting the principles of respect for the patient's dignity and autonomy in the context of palliative care.

In this context, the importance of training and qualification for caregivers becomes fundamental, as these educational processes are essential for a better understanding of the body's mechanisms in the face of death. Food, often seen as a form of "salvation", is commonly associated with the idea that nourishing the body prolongs life and improves health.

However, this view can be limiting and does not consider the biochemical and physiological aspects that indicate that, in terminal stages, food may no longer be beneficial, but rather a source of suffering. Therefore, training caregivers to understand the patient's real needs and the body's adaptations in the last days of life is essential so that they can offer respectful care focused on the patient's well-being, avoiding practices that may compromise their quality of life and autonomy.

Thus, eating becomes an act of humanization and respect for human dignity, without the intention of achieving specific nutritional goals, such as increasing nutrient intake or weight control. Diets focused on "weight control", "nutritional performance" or even "restricted" diets should be replaced by prescriptions for "Comfort Diets" or "Ludic Diets", in which the main objective is to stimulate eating, offering pleasure and comfort to the patient, instead of prioritizing purely quantitative or functional aspects (21).

When the comfort diet is combined with insufficient oral intake, Oral Nutritional Supplements (ONS) emerge as an option to increase the intake of proteins, calories and nutrients. However, it is important to highlight that, although the use of ONS is necessary, it may not improve nutritional status in advanced stages of the condition. In this context, supplements may offer psychological benefits to some individuals, due to their taste and palatability (22).

At the end of life, it is important to meet dietary preferences. Even foods considered carcinogenic, such as ice cream; processed meats (sausages, bacon and smoked meats); foods rich in saturated fats; soft drinks; among others, are considered null in palliative care, since the return of pleasure, comfort and memories that these preparations represent in the lives of individuals is marked by emotion and relief from suffering. In this context, offering the foods that the individual wants to eat, without restrictions, and respecting their preferences, is a way of valuing their dignity and dietary autonomy. Thus, when the family receives adequate guidance, their presence during meals can be essential to create a welcoming and comfortable environment, favoring the eating experience.

When reflecting on enteral nutrition (through a tube), it is undeniable that every human being needs nutrition and hydration to survive. However, does this premise apply to end-of-life care? Regarding this issue, it is known that nutritional therapies can be invasive, stressful, expensive and tiring, without guaranteeing the desired results for individuals in palliative care. Therefore, regardless of the therapeutic choice, it must consider both quality of life and the emotional aspect (18).

In the literature, there is a consensus that the indication and continuity of Enteral Nutrition Therapy (ENT) in cancer patients continues to be a controversial topic, and should be discussed jointly by the multidisciplinary team, by the patient himself – when possible, respecting his autonomy – and by his family members. In the context of the end of life (19,21).

In cases of certain types of cancer, especially those with HNC, they may be unable to communicate, falling into a coma, presenting a reduced level of consciousness or mental confusion. In these cases, the opinion of the main caregivers should be considered so that, together with the team, the best therapeutic approach can be defined (19,21).

In this discussion, (23) analyze that individuals with terminal cancer, using nutritional therapies (oral or enteral), did not present differences in survival and, probably, they did not provide them with a better quality of life in the last 48 hours of life, so the route of food choice is shown to be important, however this is not the main focus, but rather the presence of comfort and quality of life.

Another study conducted by (16) states that the use of nasogastric ENT did not improve nutritional status and contributed to reduced survival in these subjects due to increased clinical complications, including pneumonia.

Therefore, it is important to analyze in detail the indications for feeding routes in agreement with the subject, family and team, preserving autonomy and quality of life, as indicated by the American Dietetic Association (24) in the following excerpt:

> Nutrition for individuals with advanced disease should provide emotional comfort and pleasure, help reduce anxiety and increase self-esteem and independence, and allow for greater integrity and communication with family members. If the individual chooses not to receive nutrition, their decision must be respected by health professionals and their family members, since the autonomy of the individual is above any scientific evidence. This decision is not only technical, but also has a strong

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> moral component involved, since nutrition and hydration have a significant symbolic value in our society (24, p.319).

Thus, the main objective is to minimize suffering, anguish and alleviate symptoms, promoting a better quality of life and avoiding, whenever possible, interventions that prove futile.

These issues extend to the use of hydration, with studies indicating that, in terminally ill patients, hydration does not contribute to increased survival. However, given that water has a strong symbolism of life, many family members consider it more acceptable to continue hydration than to interrupt it, believing that the decision to suspend treatment would lead the patient to death. However, it is important to emphasize that suspending hydration does not accelerate death, with the underlying disease being the determining factor for the final course (25).

Furthermore, intravenous, artificial oral or enteral hydration should be administered according to the patient's survival expectation and symptoms, since dehydration or inadequate fluid intake can contribute to worsening mental confusion and increased discomfort. On the other hand, failure to provide hydration constitutes neglect of essential basic care for the patient (26).

The study by (27) demonstrated, in its results, that when hydration is suspended, in some types of cancer or comorbidities (such as dementia), there is an improvement in adverse events, such as dyspnea and agitation, since hydration was a factor in the high levels of discomfort in the population studied, and it is important to analyze whether to continue or suspend hydration.

When considering HNC, symptoms of dysphagia and odynophagia are often present during feeding, resulting in discomfort and, as a consequence, weight loss, which leads to malnutrition, often aggravated by chemotherapy and radiotherapy treatments. In this context, the introduction of Percutaneous Endoscopic Gastrostomy (PEG) can bring clinical benefits to patients (28).

Although the introduction of PEG can offer clinical benefits, as demonstrated in the study by (28), it is important to reflect on the real need for its use, especially considering the discomfort it can cause to patients.

When dealing with symptoms such as dysphagia and odynophagia, which in themselves cause suffering during feeding, the introduction of PEG can, in some cases, worsen the discomfort and negatively impact the quality of life. On the other hand, in certain situations, PEG can alleviate the symptoms of dysphagia and odynophagia, making the discomfort associated with the use of the tube more tolerable, although it still represents a source of discomfort for the patient.

In addition to improving symptoms, PEG can also contribute to improving nutritional status, as indicated by the study carried out by the Enteral Nutrition Study Group (GENE), with the collaboration of the authors (28). The study investigated adults and elderly people with inoperable esophageal cancer undergoing palliative chemotherapy and radiotherapy treatment after the introduction of PEG. The results were positive, showing stability in the mean values of the Body Mass Index (BMI) and in laboratory evaluations, in addition to an increase of 5.9 months in the survival of 12 patients.

Therefore, the decision to introduce a feeding tube must be carefully evaluated, taking into account not only the clinical benefits, but also the psychological impact and additional suffering that the patient and family members may experience with the procedure. In this sense, it is essential to consider whether the intervention really contributes to the patient's general well-being, or whether, often, continuing treatment may be more harmful than beneficial.

Given the lack of evidence on the interruption or continuity of feeding in terminal palliation and the influence of cultural factors on food choices, the decision to maintain feeding until the end of life must be supported by the multidisciplinary team and have the consent of the patient or, if the patient is unable to decide, of their family members.

CONCLUSION

Considering the aspects discussed throughout this text, it can be concluded that nutrition and feeding in the context of palliative care, especially in head and neck cancer situations, presents significant challenges and requires a careful and multidisciplinary approach. The decision about whether to continue or interrupt feeding, whether enteral or oral, must be based on a careful assessment of the patient's clinical condition, taking into account the effectiveness of the intervention, potential suffering and the preferences of the individual and their family.

To this end, the act of feeding and hydration must preserve the dignity, comfort and quality of life of the patient, even when a cure is no longer a possibility. Thus, by focusing on well-being and respecting the autonomy of the individual, palliative care contributes to a more dignified, respectful and humanized end of life.

In addition, cultural influences and family values play an important role in decision-making about nutritional care in palliative care, which makes effective communication and emotional support essential. Therefore, the decision-making process must involve the multidisciplinary team, with an emphasis on respecting the patient's autonomy, while taking into account the physical, emotional and psychosocial needs of the patient and their family members.

DOI: 10.36489/saudecoletiva.2025v15i93p114515-14521

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DOI: 10.36489/saudecoletiva.2025v15i93p14515-14521