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## Tube feeding and gastrostomy in advanced cancer: indication, experience, senses and meanings

### *Alimentação por sonda e gastrostomia no câncer avançado: indicação, vivências, sentidos e significados*

#### Abstract

**Introduction:** Patients with advanced cancer show symptoms and metabolic disorders that can make appropriate oral feeding impossible causing weight loss, with implications regarding functional capacity and quality of life; feeding tubes/ostomies are indicated in such cases. **Objectives:** To understand the senses and meanings of tube feeding/ostomies for patients with advanced cancer in exclusive palliative care and for caregivers. **Methods:** This is a qualitative, exploratory-descriptive investigation, carried out in a hospital in Rio de Janeiro, through semi-structured interviews with 12 patients and 12 caregivers, in the year 2021. After transcriptions, Laurence Bardin's content analysis was used. As theoretical references, the ideas of Elizabeth Kübler-Ross and perspectives of Social Psychology were used. **Results:** Three thematic dimensions were identified on indication, experiences and senses and meanings of tube feeding/ostomy, with respective categories. Most patients and caregivers addressed the evolution of the disease and their decision on the alternative food route. As meanings of food: quality of life, comfort, life and hope. **Conclusions:** In this way, artificial nutrition is resignified as the new possible feeding method; artificial nutrition also presents symbolic aspects besides the biological function.

**Keywords:** Palliative Care. Enteral Nutrition. Food. Cancer.

#### Resumo

**Introdução:** Pacientes com câncer avançado apresentam sintomas e distúrbios metabólicos que podem impossibilitar a alimentação oral adequada e levar à perda de peso, com implicações na capacidade funcional e na qualidade de vida, sendo indicadas sondas/ostomias para alimentação. **Objetivos:** Compreender os sentidos e significados da alimentação por sondas/ostomias para pacientes com câncer avançado em cuidados paliativos exclusivos e cuidadores. **Métodos:** Trata-se de uma pesquisa qualitativa, exploratório-descritiva, realizada em hospital do Rio de Janeiro, através de entrevistas semiestruturadas com 12 pacientes e 12 cuidadores, no ano de 2021. Após transcrições, utilizou-se a análise de conteúdo de Laurence Bardin. Como referenciais teóricos, as ideias de Elizabeth Kübler-Ross e perspectivas da Psicologia Social. **Resultados:** Três dimensões temáticas foram identificadas sobre indicação, vivências e sentidos e significados da alimentação por sonda/ostomias, com respectivas categorias. A maioria dos pacientes e cuidadores abordou a evolução da doença e a participação na decisão da via alimentar alternativa. Como sentidos da alimentação: qualidade de vida, conforto, vida e esperança. **Conclusões:** Dessa forma, a nutrição artificial é resignificada como a nova alimentação possível, apresentando também aspectos simbólicos, além da função biológica.

**Palavras-chave:** Cuidados Paliativos. Nutrição Enteral. Alimentação. Câncer.

## INTRODUCTION

Patients with advanced cancer present with symptoms and metabolic and nutritional disorders, such as: nausea, vomiting, xerostomia, dysphagia, odynophagia or lack of appetite. These interurrences make appropriate oral feeding impossible and lead to weight loss with considerable implications for the patient's nutritional status, functional capacity and quality of life.<sup>1,2</sup>

Enteral nutritional therapy is indicated for patients who cannot feed orally or when their food intake is less than 60% of their estimated nutritional requirements during two weeks.<sup>3</sup> Artificial nutrition can be administered by tubes (nasal/oral gastric/enteric) or ostomies (gastrostomy - GTT/ jejunostomy - JJT), the latter for extended use.<sup>4</sup> For patients with advanced cancer in exclusive palliative care, feeding goes beyond the supply of nutrients, having a central position in their lives, providing better quality of life and comfort.<sup>5</sup>

However, the indication and maintenance of artificial nutrition for those patients are controversial, and the role in the control and relief of symptoms is not well described, demanding a reflection from a sociological, clinical and bioethical perspective.<sup>5</sup> Thus, the objective of this study was to understand the senses and meanings of feeding through tubes or ostomies for patients with advanced cancer in exclusive palliative care and the involvement of their caregiver/cuidadores.

## METHODS

This is a qualitative, exploratory-descriptive survey, with an interpretative perspective, carried out in an exclusive cancer palliative care hospital in Rio de Janeiro.

The sample was selected for convenience; semi-structured, face-to-face, audio-recorded interviews were carried out from March to August 2021. The selection criteria included patients and caregivers aged 18 years or older, of both genders. Patients with preserved level of consciousness and speech, diagnosed with advanced stage malignant tumors regardless of location, hospitalized or in outpatient care, who had been feeding through tubes or ostomies for at least seven days, were selected. Exclusion criteria covered patients and caregivers with cognitive disorders.

The interview consisted of three guiding questions about: 1) process of indication of the accessory food route by the professional and participation in decision-making; 2) impact of this way of feeding as a life experience, with advantages and disadvantages; 3) senses and meanings of feeding through tubes/ostomies.

After transcribing the interviews, Laurence Bardin's content analysis technique was used,<sup>6</sup> organized into three stages: pre-analysis; exploration of the material; and treatment of results, inference and interpretation. The MaxQDA software<sup>7</sup> supported the mediation between empirical data and the analysis developed by the investigators, as described by Miles et al.,<sup>8</sup> generating word clouds and frequency graphs of categories in coded segments. Data interpretation was based on Elizabeth Kübler-Ross' theoretical frameworks on death and dying<sup>9</sup> and perspectives from the Social Psychology of Food.<sup>10</sup>

Additional patient data, such as age, gender, diagnosis, signs and symptoms, dietary route, reason for indication, time with the route, and current functional capacity on the Karnofsky Performance Status (KPS) scale were collected from the medical records. Caregivers informed during the interview: age, gender, profession and relationship with the patient. Descriptive analysis was presented in percentages for categorical variables and in mean and standard deviation for continuous variables. This work was approved by the Research Ethics Committee of the Institution and all participants signed the Free and Informed Consent Form.

## RESULTS AND DISCUSSION

A total of 12 patients and 12 caregivers were interviewed. Regarding the patients, 58% (n=7) were male and 83% (n=10) were hospitalized: the mean age was  $59.5 \pm 12$  years and 66.6% (n=8) had KPS between 40 and 50%. As for the location of the malignancy, the abdominal region was prevalent (41.6%; n=5). The alternative food route was indicated in the course of the disease, mostly due to dysphagia (33.3%; n=4). Only two patients (16.6%) were referred to the Palliative Care Unit. The length of stay with this route ranged from 9 to 180 days. Exclusive artificial nutrition was used for 33% (n=4) of these patients while the others used also the oral route for satisfaction (67%; n=8).

Regarding the caregivers, 91.7% (n=11) were female and the mean age was  $47 \pm 13$  years. All were family members, namely: wife (6); children (4); sister (1); and mother (1). Occupational activity was diversified (teacher, student, self-employed, housemaid, ironing maid, bakery cashier and housewife). Other characteristics are shown in Table 1..

**Table 1.** Clinical and pathological characteristics of tube feeding/ostomy patients with advanced cancer in exclusive palliative care. Rio de Janeiro-RJ, 2021.

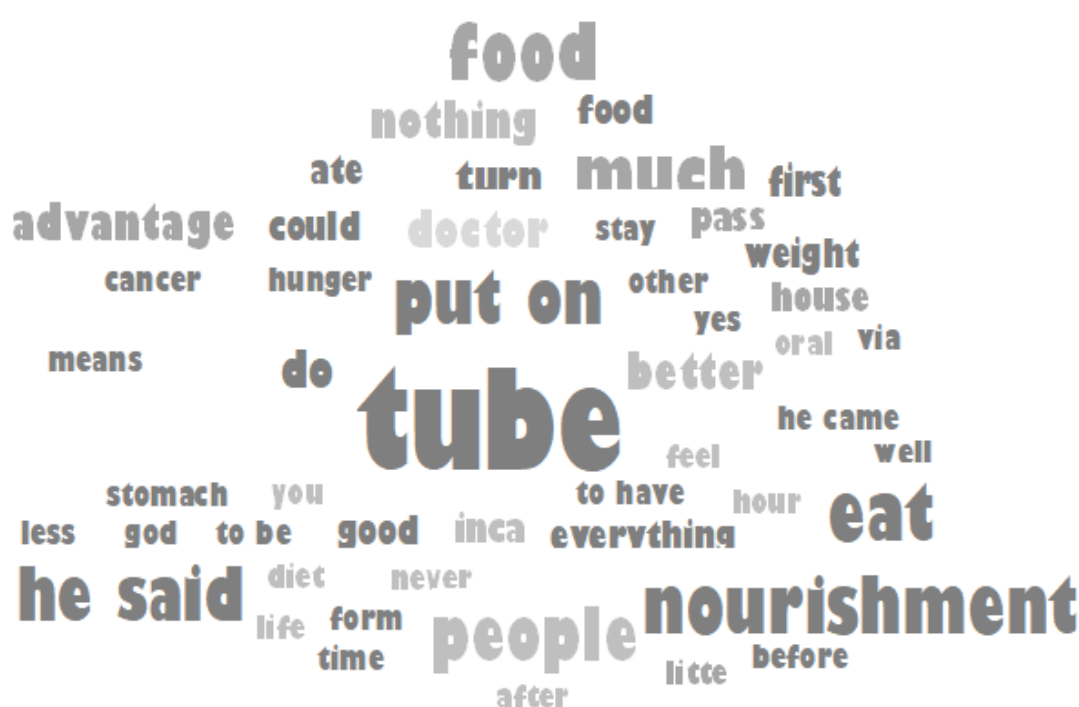
Variables	N (%)	Median (SD)
Gender		
Male	7(58.0)	
Female	5(42.0)	
Age		59.5(12)
Functional capacity (KPS)		
30%	2(16.5)	
40 %	5(42.0)	
50%	3(25.0)	
≥60%	2(16.5)	
Tumor Location		
Head and neck	3(25.0)	
Gastrointestinal Tract	5(42.0)	
Others (breast. gynecological. neurological. thoracic)	4(33.0)	
ENT indication		
Dysphagia	4(33.0)	
Oral intake ≤60% of nutritional needs	3(25.0)	
Weight loss	2(17.0)	
Others (Vomiting. trismus)	3(25.0)	
Food route		
Ostomies	5(42.0)	
Feeding tubes	7(58.0)	
Place of Indication		
Palliative care unit	2(16.5)	
Origin clinic	10(83.5)	
Associated oral route		
Yes	8(66.7)	
No	4(33.3)	
Time with the accessory alimentary pathway (days)		
1-30	7(58.0)	
31-60	1(9.0)	
> 60	4(33.0)	

Note: KPS: *Karnofsky Performance Status*.

The analysis of the words' cloud (Figure 1), "feeding tube" is in the center, representing the strongest word in connection with the interviews, followed by "feed" and "eat". These results point to the use of the

tube as a feeding route, being the main focus of the statements - an alternative to eating. Also noteworthy is the word “people” referring to the patient-caregiver binomial in decision-making in the face of the disease's evolution; “inserting” and “doing” as intervention measures in the care process; and “physician” as the professional who mostly “voiced” the procedure indication.

**Figure 1.** Word cloud based on the interviews with advanced cancer patients and caregivers



During the interview coding process, three thematic dimensions and respective categories were identified, namely:

- Indication process of the alternative food route: advanced disease, participation in the decision and failure in communication.
- Experiences with tube feeding/ostomy: desire for food, acceptance, device care, improvement of symptoms and discomfort.
- Senses and meanings of tube ostomies feedings: quality of life, comfort, life and hope.

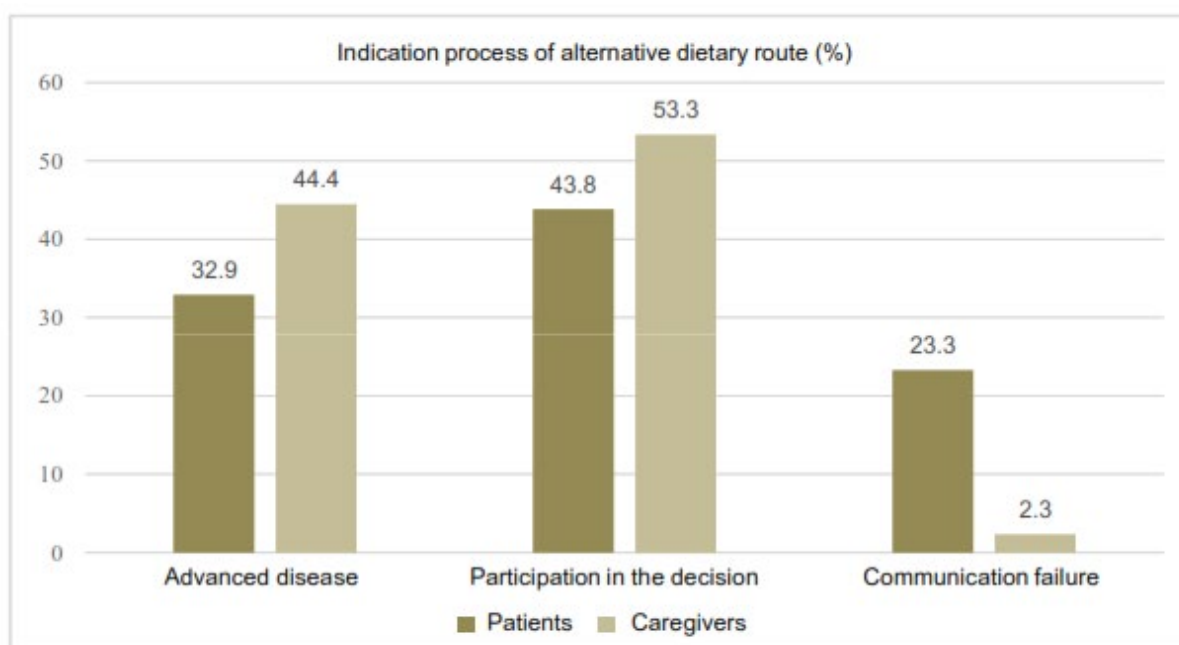
### Alternative dietary route indication process

The multidisciplinary team in palliative care faces situations in which the decision to provide artificial nutrition or not requires compliance with the patients' autonomy, in addition to assessing their expectations and those of their families.<sup>11</sup> If their desire is contrary to the beliefs and convictions of the health team regarding procedures and treatments, it is important to talk openly about this conflict and let the patient make the decision.<sup>9</sup>

Regarding the indication of an alternative food route, patients with advanced cancer and caregivers addressed the complications, limitations and suffering that accompany the advancement and progression of the disease, as a

way of contextualizing the process of indication by the professional and the participation of the patient and caregiver in the decision to insert the tube or to perform the gastrostomy, some pointing out the existence of communication failures (Figure 2).

**Figure 2.** Frequency of the categories of the alternative food route indication process in the interviews with patients with advanced cancer and caregivers.



## Advanced disease

The understanding of the disease evolution and consequent losses involving food intake are materialized in the narratives of patients and caregivers, as follows:

So we already knew that at some point in time he would have to put it on. Because as his cancer was, now it's on the tongue, advancing throughout the tongue, to the mouth, I knew that at some point in time he wasn't going to be able to eat anymore. (C1)

My belly was touching, it was touching, if looked as a gourd, my stomach, my abdomen, then I started to do... (P9)

Prognosis should include discussion of the expected progression of the disease to help patients and families prepare, program, and deal with the situation.<sup>12</sup> The lack of information about what was happening and what to expect in the future, including the stages of end-of-life, was reported by caregivers as a critical unmet need.<sup>13</sup> Thus, when the benefits of an intervention are not discussed and understood by patients in palliative care, this threatens not only their ability to participate in decision-making, but also the quality of decisions, if they participate.<sup>14</sup>

Therefore, decision-making depends on the person's understanding of the disease and their global beliefs, such as identity, health, general objectives and level of suffering associated with the disease and spirituality.<sup>15</sup> In this regard, nutrition and hydration are basic elements for maintaining life, and are considered signs of health in our

society.<sup>16</sup> The inability of adequate oral intake to meet nutritional needs can raise physical issues, such as weight loss, and psychosocial issues, such as anxiety and anguish,<sup>17</sup> influencing such decision-making.

## Participation in the decision

The patient has the right to participate directly in his treatment, with autonomy to question, decide, start or withdraw artificial nutrition, according to what seems best for his life.<sup>18,19</sup>

He was the one who decided on the use of both (tube and gastrostomy), because he has to be comfortable to eat better; the idea to pass on to him the decision, so it was super cool for him. (C4)

These choices can confront patients, family members and health professionals. Therefore, having a good knowledge of the benefits and harms of using the alternative feeding route is essential to reduce ethical conflicts and understand how this can influence the physical, psychological and spiritual domains and, therefore, the quality of life of patients.<sup>20</sup>

Kübler-Ross<sup>9</sup> drew the attention of health professionals and the lay public to the situation of people living with a life-threatening illness. She always insisted on the value of actively listening to them.

Then my father at first was against it, he said he didn't want to put it on, then we argued too, we chose not to put it on at first, then the doctor talked to him, saying it would be better for him, he then accepted to insert the probe, then we went there, they scheduled the procedure, and placed the probe. But it was all a conversation process anyway. (C1)

Perhaps the way to avoid ethical conflicts and dilemmas is the use of advance directives, an instrument for the patient to previously express his will and interests, after reflecting on future medical treatments or techniques.<sup>21</sup>

## Communication failure

The participation of both patients and caregivers in the decision-making process for the placement of an alternative food route was frequent. However, some narratives foster communication failures, probably originating from the offer of insufficient information by the health team for decision-making or by barriers of understanding or by denial regarding the progression of the disease and the need for an accessory diet route.

Denial acts as a buffer to bad news, allowing the patient to recover and, over time, mobilize other defenses.<sup>9</sup> Unfortunately, some caregivers seem to think of denial only as a bad reaction, leading them to encourage patients to move on to another stage. Appreciating how denial can work constructively avoids dismissing it as being a mere rejection of reality.

The importance of communication in healthcare is recognized in medical education as the foundation of good care, and reports continue to highlight the need for open and honest discussions with patients and families.<sup>12</sup> Many healthcare professionals, however, fail to completely verify if patients understand or misunderstand the information they provide, they do not explore what the patient already knows and what information is still needed, and rarely

discuss preferences for palliative or end-of-life care. Effective communication and attentive listening are necessary strategies to overcome this situation.<sup>22</sup>

They just picked it up and put it on (...) No, nobody said anything (...) I just got there, they laid me down, I didn't even know there was going an insertion of a tube. (P10)

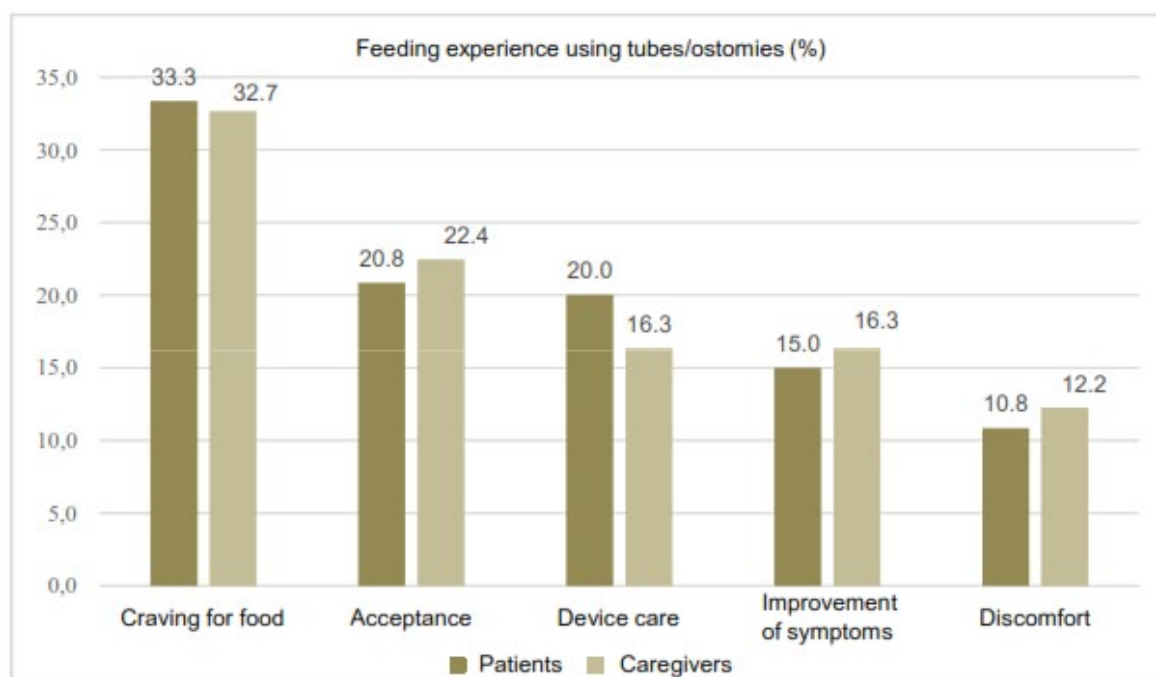
The doctor ordered. He never talked about it. To force the person to do things, you cannot force. (P6)

Although with good intentions, indications of an alternative diet, brief explanations, false expectations, lack of attentive listening or submission to medical knowledge are aspects that constitute barriers to communication that would support the choices of patients and family members.

### Experience with feeding tubes/ostomies

About the experience with feeding tubes/ostomies the interviewees talked about the impact of this experience in their lives, focusing advantages and disadvantages of this new way of feeding. Among these aspects, the desire for food materializes as a feeling of deprivation because they are no longer able to eat through their mouth as before. Acceptance corresponds to the understanding that the tube/ostomy was the feasible alternative in their lives for the time being. Still, they emphasize the care with the device as a new learning that involves the preparation and administration of food. The report of improvement of symptoms seems to enhance the decision of the interviewees for this food route, but, as a detriment, they point out the discomfort due to the presence of the device which they feel as something artificial - an element foreign to the nature of their bodies (Figure 3).

**Figure 3.** Frequency of experience categories with tube feeding/ostomies based on interviews with patients with advanced cancer and caregivers





## Craving for food

Food is associated with the language of eroticism, of intrasomatic libido, which can be characterized by the following sequence of prototypical scenes in everyday narrative: initial state of organic body harmony; balance disrupted by the desire to eat evoking food selection and quantity; attempt to consummate the desire in the very act of eating, leading to the pleasure resulting from the ingestion and the end of the discomfort (hunger, desire or both); with consequences both of organic euphoria, if the intake was satisfactory in the selection and quantity of food, or asthenia, if the choice was unsatisfactory (abundance or shortage); final state, which may be the recovery of organic balance, or lasting asthenia, or yet, another tension may emerge related to a body balance that has not been recovered.<sup>10,23</sup>

In the interviews, it is noticed that the desire to eat often cannot be satisfied, which contributes to the state of lasting asthenia or results in other tensions such as unpleasant sensations and negative emotions. The affective bond with food and the memories associated with the act of eating remain with people who will no longer have this void filled.

Oh, it's quite complicated. Just the other day, I was talking to the other girl who was here, in relation to the simple things that we eat on a daily basis; as I always loved eating fresh rice, fresh beans, a fried egg with tomato salad, which today there is no chance to get close, it's a simple thing... (P3)

It's bad, you want to eat something and you can't. At home everyone having lunch and I'm just watching. I feel like. (P11).

According to Rossio,<sup>24</sup> the relationship between motivation, pleasure of senses and food intake gives rise to an intricate chain: need, desire and pleasure.

## Acceptance

For Elizabeth Kübler-Ross, "the more they struggle to circumvent the inevitable death, the more they try to deny death, the more difficult it will be to reach the final stage of acceptance with peace and dignity"<sup>9</sup> (p.119), a stage in which they no longer will feel neither depression nor anger about their "fate". When seeking a parallel between dying and eating, it is common for patients to refuse the placement of a feeding tube/ostomy at first, deny the difficulties in eating, or wish to continue trying to eat, sometimes reaching the extreme limit of what they are able to eat or even not being able to eat anymore. With the use of tubes/ostomies for feeding, patients and caregivers experience a feeling of acceptance.

For me, this support from the team was very important, to clarify for us why it would be necessary; at first he did not understand very well that it was necessary to do the procedure preventively, to help in the future. (C8)

I mean, the human being is like a car, if a car doesn't feed itself, if you don't put fuel in it, how can a car that has wheels, a powerful engine, how can it drive people if it doesn't have a body to hold the people? People will sit there, they will fall like water on the road, and I was like that... I placed the tube and it was through this probe



that I started to feed.... Otherwise I would lose weight until I would be dry, then I started taking food through the tube. (P9)

This metaphor between the human body as a machine takes us back to the Cartesian proposition. In the same way that machines carry out automatic functions, the body breathes, digests and grows spontaneously, but for that purpose the car needs gasoline and the human being needs food. In this analogy, the patient compares the body of the car to the body mass that depends on food, fundamental for humans to be coming and going, and thus, living.

## Device care

In our study, most caregivers were female, a fact that is in line with other studies. Hopkinson<sup>25</sup> carried out a qualitative research with advanced cancer patients who had eating problems; their main caregivers were included, in order to describe their role. The caregiver was seen as an extension of the normal role of wife and mother in the family, showing the need to support family members. According to Alam et al.,<sup>26</sup> patients with advanced cancer are mostly taken care of by women, being their spouse or daughter.

The number of family members involved with patients' eating problems at home is growing<sup>25</sup> and there are signs of suffering of those who are unable to feed advanced cancer patients.<sup>27</sup> In the United States, more than 40 million adults are family caregivers, with cancer being one of the five main reasons for having a caregiver.<sup>26</sup>

Nutritional care provided at home by a family member is challenging for both the caregiver and the patient, as it causes feelings such as guilt for not knowing if they are feeding the patient properly; frustration due to the expectation of improving the patient's intake; or the feeling of failure in the role of nurturing - a moment when a harsh reality overwhelms expectations. What stands out to mitigate these sensations is the respect of the patient's autonomy allowing the caregiver's participation in the elaboration of an appropriate nutritional care program.<sup>25</sup>

She takes care of me. (P11)

At first it was difficult, because we didn't know what it was like, what care was like and everything; how his feeding was going to be, he was also a little scared, but over time, we adapted to his new feeding procedure. But it was quiet later. (C3)

It is essential that caregivers and patients have all the information about the disease, the treatment and the possible adverse effects in the short and long term.<sup>26</sup> For Kübler-Ross,<sup>9</sup> family members play a leading role and their reactions greatly contribute to the patient's own reaction during the illness. The family's needs vary from the onset of the disease and continue in different ways long after death.

## Symptoms improvement

In palliative care, it is more common to indicate tubes/ostomies due to the presence of dysphagia,<sup>28</sup> characterized by difficulty in swallowing, whether due to physiological changes caused by neurological diseases, traumas, among others, and also by obstructive processes, such as head, neck and esophagus

cancer.<sup>4</sup> Our study corroborated this finding, since dysphagia was the prevalent symptom and also the main reason for indicating the accessory pathway.

I wasn't able to eat. Everything I put in, I ate, I put it out, which burned everything, then it was fermenting, then I started doing the... I placed the tube and it was through this probe that I started to eat. (P9)

I was very weak. I weighed 60 kg, and I reached 64 kg with the tube, from April to May... I weighed 96 kg, and I went down to 57 kg. (P3)

According to Amano et al.,<sup>27</sup> family members and patients were apprehensive with regard to feeding, especially when dealing with cachectic or anorexic patients who experience alterations in the composition of body fluids, affecting different physiological functions.<sup>29</sup>

## Discomfort

Some palliative care practitioners do not indicate artificial nutrition and hydration because these procedures can cause complications and discomfort to the patient, affecting his/her quality of life,<sup>30</sup> outweighing the benefits, since studies have not evidenced a greater survival in patients with advanced disease.<sup>31</sup> However, often times it is the only feeding alternative, and the patient then has to live with this new reality. This discomfort is presented in some segments of the interviews as a disadvantage in the experience of feeding with tubes/ostomies.

I found it very uncomfortable. Very difficult. It's hard to swallow. It bothered the throat. (P2)

When I drank something cold, when I... felt everything cold, and you felt going through your stomach, you realized that there was something different inside you, and you know what it is, but you don't know how to explain it. (P8)

Furthermore, the use of a feeding tube is associated with fear in its different forms, such as the fear of pain, discomfort, the unknown, the strange, the abnormal.<sup>32</sup>

## Senses and meanings of feeding through tubes/ostomies

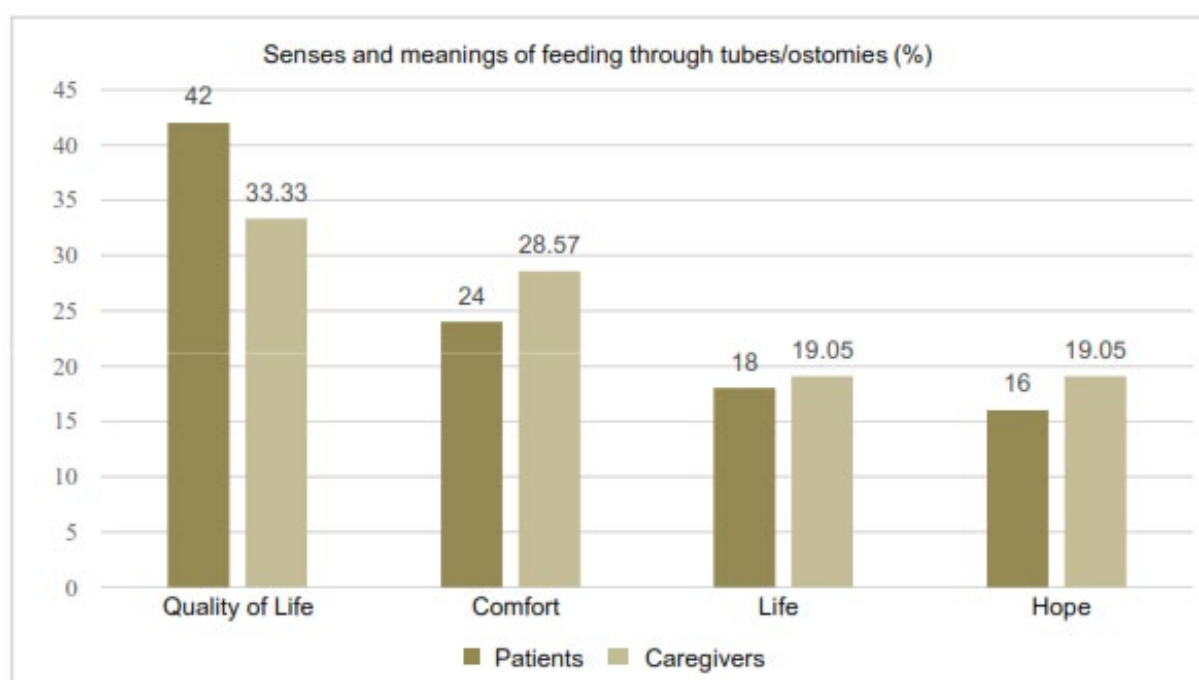
Food is anything that can be ingested to keep a person alive. Food is not just a substance; it is also a style and a way of eating. All human beings feed and thus nourish themselves and ensure the survival of the species. What you eat is food transformed by culture, since it is prepared in a certain way, offered by a certain person, with a specific presentation, discarded in a particular way, in a sociocultural context.<sup>33</sup>

In contrast, artificial nutrition is not included in the normative social component that food and drink have. A few decades ago, feeding tubes were called "forced feeding", considering that from a social point of view, artificial nutrition is not synonymous with feeding someone, nor eating or drinking. However, food and fluids, offered orally or artificially, represent a form of affection and support and, over time, concepts such as nutrition and artificial hydration began to be compared with food and drinks as an extension of care.<sup>30</sup> It is

worth mentioning that distinguishing the nature domain from the cultural domain in food implies accepting assumptions that are currently criticized, as the connection between the biological and social dimensions is profound.<sup>10</sup> In this way, food goes beyond the material and physical concept; it becomes a symbol, it becomes meaning and gives meaning to human experience.

Our reports indicated that artificial nutrition acquires the meaning of food for the human being at this point in life; artificial nutrition constitutes what is possible, and it also has specific preparation, presentation, supply and disposal, not being considered just a treatment or medical intervention that depends on prescription and invasion of the body. For our interviewees, artificial nutrition is the new way of feeding that translates into food. Therefore, among the senses and meanings of feeding through tubes/ostomies, the main categories identified were quality of life and comfort, consistent with the objectives of feeding in exclusive palliative care, followed by life and hope (Figure 4).

**Figure 4.** Frequency of categories of senses and meanings of tube ostomy feeding based on interviews with patients with advanced cancer and caregivers



## Quality of life

Advanced cancer is probably the factor that causes the greatest impact on the quality of life of individuals, enhanced by the decrease in functional capacity and the presence of symptoms caused by the disease or treatment. Functionality Impairment affects the ability to perform activities of daily living, social relationships and affects the financial situation.<sup>34</sup>

In the interviews with patients and caregivers, we found that feeding through tubes/ostomies refers to the sense of quality of life. Quality of life focused on physical, mental and social well-being, translated into autonomy, strength, endurance and health.

It means being able to improve. Even though I don't have that pleasure anymore, I'm getting better. Health, head, physically. I was thin, dry and today I weight 70Kg, thank God I'm getting better. (P4)

I see that it was what enabled him to continue the treatment, with better quality of life. It gave him quality of life, even though it is difficult for the patient to adapt. (C8)

This meaning of tube feeding/ostomy enhances some of the principles of palliative care, such as improving quality of life and positively influencing the course of life, offering a support system that helps the patient to live as actively as possible.

## Comfort

Food is not just ingested. Before taking it to the mouth, it is prepared and thought out in detail. The preparation of food is a mediation between nature and culture. Nature stands out and shows its strength when there is a lack of food and when there is a dramatic need to avoid hunger, which leads to putting aside rites and customs,<sup>24</sup> as it occurs with the use of artificial nutrition.

For patients with reduced life expectancy, the relief of symptoms of nutritional impact can mitigate the suffering with the disease, and when artificial nutrition is maintained, it can be used as a comfort measure, and no longer as nutritional support.<sup>35</sup>

Patients and caregivers highlight comfort as a meaning for tube feeding/ostomy in their lives. This achievement of comfort is associated with a care resource, as discussed in the following two talking segments.

I think it is better. It is more comfortable. (P1)

It's complicated to say this, the meaning. Perhaps, I would say a resource. I think it's a necessary resource, we think about everything, at the time we think: two months ago I was doing everything, suddenly like this, you're here for palliative care because there really isn't another way to care. (C10)

Consequently, it is critical to explain the objectives and communicate the pros and cons of the ongoing nutritional program by patients, families, and staff. In this sense, the suspension of tube feeding/ostomy in cancer patients undergoing palliative care should be evaluated, especially in the presence of complications and in the finitude process. Kübler-Ross<sup>9</sup> points out that the way of communicating bad news is an extremely important factor and what would give the most comfort to patients is the feeling of empathy, which is stronger than the immediate tragic news.

## Life

The act of eating is part of the construction of cultural and social identities and involves emotion, memory and feelings, which reflect the symbolic value of food in all stages of life.<sup>36</sup> However, whatever the set of meanings and practices related to food, there is a continuous social representation linked to the organic quality of nutrition, that is, food is concretely related to the substance of life. There is a sense of permanence, of survival associated with eating, and this sense has the density of a social representation.<sup>10</sup>

Thus, for patients with advanced stage cancer, eating can take on the meaning of energy to stay alive, with patients eating out of obligation, in the hope of preventing weight loss and death, summing up to a task performed without pleasure, hunger or appetite, just for the sake of survival.<sup>37</sup>

The central idea “if you don't eat, you can't live”, identified in the talk of patients with advanced cancer who ate orally and their caregivers, demonstrates that the primordial meaning of food is in its conditional association with life, highlighting its cultural and social value, full of symbolic meaning and great emotional load.<sup>38</sup> In our study, the respondents also indicated the same meaning for life with the tube feeding/ostomy.

I'm not ready to die yet. Enteral nutrition was life. Because if I hadn't been fed through the tube, I would have died, because everything I swallowed came back out, I threw it all out. So, it is life. (P8)

Meaning of keeping him fed, nourished. If it weren't for the tube, he wouldn't be eating. As much as it is a diet that is not what he is used to eat, beans, rice, meat, vegetables. But, it is something that nourishes the body that keeps it alive, nourished. (C1)

## Hope

According to Kübler-Ross,<sup>9</sup> when faced with tragic news, people go through different stages (denial, anger, bargaining, depression and acceptance) that vary in duration, one will replace the other or they will sometimes be side by side. Generally, the only feeling that persists through all stages is hope, a feeling that serves as comfort. Even the most realistic and resigned patient left open the possibility of a cure, as something that supports the patients in the face of suffering.

Depending on the way of acting and communicating about the indication of passing a tube or performing a gastrostomy, patients perceive that they are being treated, despite the progression of the disease. Feeding through tubes/ostomies has a sense of hope for the patients and caregivers interviewed, when food is hope! According to Kübler-Ross,<sup>9</sup> the reaffirmation that everything possible would be done, that they would not be abandoned, that there would always be a ray of hope was fundamental, even in the most advanced cases. However, when a patient no longer gives any sign of hope, it can be a harbinger of imminent death, as the fear of dying stems from hopelessness, helplessness, and the isolation that accompanies death.

In this survey, being able to eat and gain weight from tube feeding/ostomy means hope, bringing cheer to life.

I feel like I'm coming back to life, because I was hopeless, I couldn't feed myself. I think it's good, it will bring new directions, new hope. Now I have a bigger project to gain some weight. (P9)

Yes, because at home I kept looking at myself, every day that passed I just saw, I felt that I was drying up. And now, when I look at it like this, I get more drive to get well. (P11)

The limitation of the study lies in the approach to patients who had an indication of the alternative dietary route at different stages of cancer treatment and had this experience for a different period of time. However, this allowed for a greater scope of the experience and meanings of feeding through tubes/ostomies in the disease process.

## FINAL CONSIDERATIONS

With the progression of the disease and the patients clinical worsening, diet is frequently revised, when dietary guidelines are aimed at quality of life, minimizing discomfort, and maintaining food and cultural preferences. The importance of symptom management is highlighted as a fundamental issue that involves nutrition and artificial hydration, because, in many cases, even before receiving the news of the impossibility of feeding by mouth, the patient perceives it and experiences this loss, often in a progressive way, with adaptations in the consistency of the food preparations and reduction in the food volume.

The professional's approach indicating the alternative dietary route should include the advantages and disadvantages, based on empathetic communication so that patients and caregivers feel safe in participating in the decision-making process. Despite experiencing the desire for food and the discomfort of the presence of the device, the improvement of symptoms is perceived significantly, which favors the acceptance process and care. Thus artificial nutrition is resignified as the new possible feeding method, also presenting symbolic aspects without disregarding its biological function.

Thus, feeding through tubes/ostomies for patients with advanced cancer and caregivers has senses and meanings - quality of life, comfort, life and hope- that serve as support for coping with the disease with dignity, adding "life to everyday", within what is possible to control, recognizing the limits and being present in the scope of care until the last day.

## REFERENCES

1. Baracos VE, Martin L, Korc M, Guttridge DC, Fearon KCH. Cancer-associated cachexia. *Nat Rev Dis Primers* 2018;4:17105.
2. Fearon K, Strasser F, Anker SD, Bosaeus I, Bruera E, Fainsinger RL, Jatoi A, Loprinzi C, MacDonald N, Mantovani G, Davis M, Muscaritoli M, Ottery F, Radbruch L, Ravasco P, Walsh D, Wilcock A, Kaasa S, Baracos VE. Definition and classification of cancer cachexia: an international consensus. *Lancet Oncol* 2011;12(5):489-95.
3. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, Fearon K, Hütterer E, Isenring E, Kaasa S, Krznaric Z, Laird B, Larsson M, Laviano A, Mühlebach S, Muscaritoli M, Oldervoll L, Ravasco P, Solheim T, Strasser F, de van der Schueren M, Preiser JC. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 2017;36(1):11-48.
4. Minicucci MF, Silva GF, Matsui M, Inque RMT, Zornoff LAM, Matsubara LS, Paiva SAR. O uso da gastrostomia percutânea endoscópica. *Rev. Nutr* 2005;18(4):553-559.
5. Loyolla VCL, Pessini L, Bottoni A, Serrano SC, Teodoro AL, Bottoni A. Terapia nutricional enteral em pacientes oncológicos sob cuidados paliativos: Uma análise da bioética. *Saúde, Ética & Justiça* 2011;16(1):47-59.
6. Bardin L. *Análise de Conteúdo*. São Paulo: Edições 70, 2011.
7. MAXQDA. Software for qualitative data analysis. Version Analytics Pro 2020. Berlin: VERBI Software – Consult – Sozialforschung GmbH, 2020.
8. Miles M, Huberman AM, Saldaña J. *Qualitative Data Analysis - A Methods Sourcebook*. 3. ed. Thousand Oaks: Sage, 2013.
9. Kübler-ross E. *Sobre a morte e o morrer: o que os doentes terminais têm para ensinar a médicos, enfermeiras, religiosos e a seus próprios parentes*. 9ªed. São Paulo: Editora WMF Martins Fontes, 2008.
10. Amon D. *Psicologia Social da Comida*. Petrópolis, Rio de Janeiro: Vozes, 2014.

11. Fuhrman MP, Herrmann VM. Bridging the continuum: nutrition support in palliative and hospice care. *Nutr Clin Pract* 2006;21(2):134-41.
12. Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med* 2016 J ;92(1090):466-70.
13. Grbich C, Parker D, Maddocks J. Communication and information needs of care-givers of adult family members at diagnosis and during treatment of terminal cancer. *Prog Palliat Care* 2000;8:345-5.
14. Bélanger E, Rodríguez C, Groleau D. Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat Med* 2011;25(3):242-61.
15. Rego F, Gonçalves F, Moutinho S, Castro L, Nunes R. The influence of spirituality on decision-making in palliative care outpatients: a cross-sectional study. *BMC Palliat Care* 2020;19(1):22.
16. Henry B. Evolving ethical and legal implications for feeding at the end of life. *Ann. Palliat. Med* 2017;6(1):87-90.
17. Reid J, McKenna H, Fitzsimons D, McCance T. Fighting over food: patient and family understanding of cancer cachexia. *Oncol Nurs Forum* 2009;36(4):439-45.
18. Baillie J, Anagnostou D, Sivell S, Van Godwin J, Byrne A, Nelson A. Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions. *BMC Palliat Care* 2018;17(1):60.
19. Benarroz MO, Faillace GBD, Barbosa LA. Bioética e nutrição em cuidados paliativos oncológicos em adultos. *Cad Saúde Pública* 2009;25(9):1875-82. 7.
20. Sánchez-Sánchez E, Ruano-Álvarez MA, Díaz-Jiménez J, Díaz AJ, Ordonez FJ. Enteral Nutrition by Nasogastric Tube in Adult Patients under Palliative Care: A Systematic Review. *Nutrients* 2021;13(5):1562.
21. Kurella Tamura M, Montez-Rath ME, Hall YN, Katz R, O'Hare AM. Advance Directives and End-of-Life Care among Nursing Home Residents Receiving Maintenance Dialysis. *Clin J Am Soc Nephrol* 2017;12(3):435-442.
22. Noordman J, van Vliet L, Kaunang M, van den Muijsenbergh M, Boland G, van Dulmen S. Towards appropriate information provision for and decision-making with patients with limited health literacy in hospital-based palliative care in Western countries: a scoping review into available communication strategies and tools for healthcare providers. *BMC Palliat Care* 2019;18(1):37.
23. Maldavsky D. A contribution to the development of a psychoanalytical methodology for research into language. A systematic study of narration as an expression of sexuality. *Int. J. Psycho-anal.* 2003;84 (3), 607-635.
24. Rossi P. 1923. Comer: necessidade, desejo, obsessão/Paolo Rossi; tradução Ivan Esperança Rocha. 1ª ed. São Paulo: Editora Unesp, 2014.
25. Hopkinson JB. The Nourishing Role. *Cancer Nursing*. [ serial on the internet]. 2018 Mar. [cited 2021 June 04]; 41 (2); 131-138p. Available from: <http://dx.doi.org/10.1097/ncc.0000000000000474>
26. Alam S, Hannon B, Zimmermann C. Palliative Care for Family Caregivers. *J Clin Oncol* 2020;38(9):926-936.
27. Amano K, Morita T, Koshimoto S, Uno T, Katayama H, Tatara R. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Support Care Cancer* 2019;27(8):2869-2876.
28. Gonçalves F, Mozes M, Saraiva I, Ramos C. Gastrostomies in palliative care. *Support Care Cancer* 2006;14(11):1147-51.
29. Sadeghi M, Keshavarz-Fathi M, Baracos V, Arends J, Mahmoudi M, Rezaei N. Cancer cachexia: Diagnosis, assessment, and treatment. *Crit Rev Oncol Hematol* 2018;127:91-104.



30. Pinho-Reis C, Sarmiento A, Capeles ML. Nutrição e hidratação nos cuidados de fim de vida: questões éticas . Acta Portuguesa De Nutrição 2018;15:36–40.
31. Reiriz AB, Motter C, Buffon VR; Scatola R P, Fay A S; Manzini M. Cuidados paliativos: há benefícios na nutrição do paciente em fase terminal? Rev Soc Bras Clín Méd 2008;6(4):150-5.
32. Barbosa JAG, Freitas MIF. Representações sociais sobre a alimentação por sonda obtidas de pacientes adultos hospitalizados. Rev Latino-am Enfermagem 2005;13(2):235-42.
33. Da Matta, R. O que faz o brasil, Brasil? Rio de Janeiro: Rocco. 1986.
34. Freire ME M, Costa SFGD, Lima RAGD, Sawada NO. Qualidade de vida relacionada à saúde de pacientes com câncer em cuidados paliativos Texto Contexto Enferm 2018; 27(2):e5420016
35. Weimann A, Braga M, Carli F, Higashiguchi T, Hübner M, Klek S, Laviano A, Ljungqvist O, N Lobo D, Martindale R, Waitzberg DL, Bischoff SC, Singer P. ESPEN guideline: Clinical nutrition in surgery. Clin Nutr 2017 Jun;36(3):623-650
36. Poulain, JP, Proença RPDC. Reflexões metodológicas para o estudo das práticas alimentares. Rev. Nutr. 2003;16:365-386.
37. Strasser F, Binswanger J, Cerny T, Kesselring A. Fighting a losing battle: eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. Palliat Med 2007;21(2):129-37.
38. Costa MF, Soares JC. Alimentar e Nutrir: Sentidos e Significados em Cuidados Paliativos Oncológicos. Rev. Bras. Cancerol. [Internet]. 30º de setembro de 2016 [citado 5º de fevereiro de 2022];62(3):215-24. Disponível em: [https://rbc.inca.gov.br/revista/index.php/revista/article/view/163\\_](https://rbc.inca.gov.br/revista/index.php/revista/article/view/163_)

### Contributors

Nascimento SB participated in the idealization of the study design; collection, analysis and interpretation of data; study writing. Santos RS participated in the analysis and interpretation of data; study writing and review. Costa MF participated in the idealization of the study design; data analysis and interpretation; study writing and review. All authors approved the final version of the study.

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