**Oral Feeding in Oncologic Palliative Care**

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**Resumo**

**Introdução:** A alimentação oral é carregada de sentidos e significados, em especial, naqueles indivíduos em cuidados paliativos. As dificuldades de deglutição presentes em decorrência de uma doença ameaçadora da vida impactam diretamente na vida do paciente e de todos os envolvidos em seu cuidado. **Objetivo:** Identificar, na percepção de cada grupo de participantes, os valores e as crenças relacionados à alimentação oral diante das modificações alimentares vivenciadas por pacientes disfágicos com câncer avançado em cuidados paliativos exclusivos. **Método:** Pesquisa de caráter exploratório-descritivo com a participação de profissionais de saúde, cuidadores e pacientes em entrevistas semiestruturadas que responderam a perguntas para análise de suas crenças e de seus valores com relação às modificações necessárias na alimentação de pacientes com disfagia, acompanhados em um hospital de referência em oncologia na unidade de cuidados paliativos exclusivos. **Resultados:** A pergunta norteadora feita a todos os participantes “O que a alimentação significa para você?” possibilitou a criação da dimensão temática: valores e crenças relacionados à alimentação oral. A partir da análise dos dados, as seguintes categorias foram identificadas: vida, prazer, qualidade de vida, modos de cuidar e perda. **Conclusão:** A compreensão sobre o impacto das alterações de deglutição vivenciadas por esses indivíduos permite uma melhor abordagem visando à qualidade de vida do paciente em cuidados paliativos oncológicos.

**Palavras-chave:** Cuidados Paliativos; Transtornos de Deglutição; Pessoal de Saúde; Neoplasias/epidemiologia; Educação em Saúde.

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**Abstract**

**Introduction:** Oral nutrition is full of senses and meanings, especially in those individuals in palliative care. Swallowing difficulties resulting from a life-threatening disease will directly impact the life of the patient and everyone involved in its care. **Objective:** To identify, in the perception of each group of participants, the values and beliefs related to oral nutrition in face of dietary changes experienced by dysphagic patients with advanced cancer receiving exclusive palliative care. **Method:** Exploratory-descriptive research with the participation of health professionals, caregivers and patients with semi-structured interviews who answered questions to analyze their beliefs and values regarding the necessary changes in the diet of patients with dysphagia, monitored in a reference hospital in oncology in the exclusive palliative care unit. **Results:** The guiding question asked to all participants “What does food mean to you?” enabled the creation of the thematic dimension: values and beliefs related to oral nutrition. From data analysis, the following categories were identified: life, pleasure, quality of life, fear, care and loss. **Conclusion:** Understanding the impact of swallowing changes experienced by these individuals allows a better approach aimed to improve the patient’s quality of life in oncological palliative care.

**Key words:** Palliative Care; Deglutition Disorders; Health Personnel; Neoplasms/epidemiology; Health Education.
INTRODUCTION

Biotechnoscientific advances of the last decades have fostered therapeutics that increasingly promote the maintenance of life of patients carriers of infirmities then seen as fatal but that now became chronic diseases. The possibility of utilizing all this technological asset that sometimes leaves apart what is more important, the sick individual and attempting to cure him at any cost, eventually submits him/her to futile treatments without changes in the natural course of the disease and instead, causes pain and suffering.

Palliative care within this scenario is the therapy of choice to manage life-threatening diseases whose focus is to prevent and control the symptoms, maintenance of the dignity and improvement of the quality of life, seeing this individual as a unique human being immersed in biopsychosocial and spiritual issues and ensuring an integral care.

The basic functions in advanced cancer as mastication and deglutition quite often can change, impacting and compromising not only the nutritional condition and hydration, but also the patient's food security, further to pleasure and autonomy. These obstacles affect all the sociocultural experiences that feeding may warrant to the individual.

Health professionals dealing with swallowing disorders due to advanced disease have to manage ethical issues emerging from dichotomies among what is culturally understood as food together with food preferences and incompatibilities of ensuring both a safe feeding and amenable to the patient like before getting ill. The issues are related to existing complex connections among feeding, identity and social living. Food preferences and habits can function as different markers of personal identity and belonging to a certain group of the society and must be respected and kept whenever possible.

The meaning of food can assume distinct feelings, depending on the context of the individual and its history. Considering the symbology involving feeding, food and feeding habits of an individual with life-threatening disease as cancer is important. The construction of the concept of feeding for patients in palliative care quite often is based in different values and beliefs as pleasure, care, spirituality, losses lived through the sickening process or quality of life.

The objective of the present article is to identify how each group of the study participants (health professionals, caregivers and patients) perceive the values and beliefs related to oral feeding in face of the modifications dysphagic patients with advanced cancer in exclusive palliative care live.

METHOD

Exploratory-descriptive qualitative study. The data were collected through semi-structured interviews with questions which could ensure the analysis of beliefs and values of health professionals, caregivers and patients regarding the required modifications of dysphagic patients feeding followed-up at a palliative care unit of a reference oncology hospital and who were in speech therapy. The interviews were individual, standardized for each group needing only one encounter to be concluded.

Twenty-one participants were enrolled in the study: seven healthcare professionals of different categories who provided care directly to inpatients, seven caregivers who were attending to the patients for at least three months, a period considered satisfactory to know the routine, possible changes and limitations caused by the evolution of the disease and seven patients, adults and/or older adults admitted to the palliative care unit in speech therapy due to dysphagia with preserved autonomy, communicating verbally, orally fed exclusively or associated with alternative feeding route (nasogastric, nasoenteral tube, gastrostomy or jejunostomy).

The Karnofsky Performance Status (KPS ≥ 30%) was applied to evaluate the functionality of the patients and to measure the level of functionality of deglutition, the scale American Speech-Language-Hearing Association National Outcome Measurement System (ASHA-NOMS ≥ 2) divided in seven levels from 1 to 7 was utilized.

The research question to all the participants “What does food mean to you?” warranted the creation of the thematic dimension: values and beliefs related to oral feeding.

The responses to the interviews were organized and analyzed following the content analysis proposed by Laurence Bardin, grounded in the theoretical backbone of ethical principles based in the Principism proposed by Beauchamp and Childress.

The software MaxQDA (version 2020) was utilized to mediate empirical data and the analysis developed by the investigators as described by Miles et al., creating clouds of codes from the frequencies of the categories of the coded segments according to the groups interviewed.

The Institutional Review Board of Escola Nacional de Saúde Pública Sergio Arouca and of the National Cancer Institute (INCA) approved the study, reports number 4,635,951 (CAAE (submission for ethical review): 44588921.7.0000.5240) and 4,701,686 (CAAE (submission for ethical review): 44588921.7.3001.5274), respectively in compliance with Ordinance 466/2012 of the National Health Council. All the participants signed the Informed Consent Form.
RESULTS AND DISCUSSION

Twenty-one individuals participated in the study: seven health professionals, seven caregivers and seven adult patients, to whom were attributed the codes HP, C and P respectively. The female health professionals included one speech therapist, two nurses, two psychologists and two nutritionists. The reduced number of participants may have been impacted by the COVID-19 pandemic during which the study was conducted with restrictions of circulation of caregivers and family members and even health professionals; this scenario has also reduced the participation of other professionals as physicians, social workers and physiotherapists.

The caregivers were females, only one with institutional relationship earning a salary, all the others held some sort of family bond with the patient.

Five male patients and two female patients were interviewed. The KPS of the patients ranged between 30% and 60%, the level of deglutition measured by ASHA-NOMS varied between 3 and 5. Five patients fed orally exclusively and two, oral feeding associated with one nutritional feeding (both with gastrostomy).

Based in the analysis of the data extracted from the participants’ narratives, the following categories were identified: life, pleasure, quality of life, fear, care and loss (Chart 1). During the discussion of each category, portions of the narratives able to portray the analytic categories in questions were transcribed.

The discussion of the present article was based in clouds of the codes generated from the frequencies of the analytical categories related to the thematic dimension. Chart 2 shows the cloud of all the participants together and each group separately referred to the thematic dimension – values and beliefs related to oral feeding. As some categories stood out for all the participants, it was necessary to reflect about the specificities of each group who expresses values and beliefs related to feeding according to their role and experience in advanced cancer. Therefore, each group has a different perception of what oral feeding means to them.
In face of the complexity of feelings and meanings involving oral feeding, it is necessary to know the values and beliefs related to the feeding of individuals coping with a life-threatening disease as cancer, further to health professionals and caregivers. It is believed that this is the best way to help patients respecting their eating preferences and wishes considering what they understand as food and minimizing possible ethical conflicts arising from dysphagia in a setting of advanced disease. Therefore, the conducts should be shared among all the players to avoid suffering and aiming the maintenance of the dignity of the individual always in respect to their biography and principles of palliative care.

CARE

While analyzing the cloud of codes of this thematic domain, it was noticed that in the group of healthcare professionals (Chart 2), care stands out compared to other categories, corroborating the analysis that care is the essence of the human being, especially for these interviewees who work in an exclusive oncological palliative care unit. They see death as a natural process of every human being unlike other healthcare professionals who understand care as the final outcome of their intervention, and death becomes a failure. Their conduct, therefore, follows the principles of palliative care, attempting to improve the quality of life, ensuring the control of symptoms, promoting the dignity and respecting the patient’s autonomy.

It means affection, care, a form to show love, it is, ... The autonomy of the patient is his EATING, it is a thing, it is ON US, if he eats, it is a process of autonomy, this is it, I think (HP1).

Food is much more than nourishing the patient, isn’t it? There is the symbolism, involves the meaning, affection, so... there is this whole question BESIDES nourishing the human being. (HP3).

For me, I think it means affection and memories as well, right? (HP4).

Caring is not a mere moment, it goes beyond, it assumes there is an affectionate engagement with the other, some concerns, a way of being as the individual fits into the world, how it relates with things and with other human beings. It is an attitude that allows to recognize the other as a subject.

Care is the ground itself of the most primitive human relations. In the womb, a construction of a relation with that human being who grows and develops begins. The binomial care and feeding strengthens throughout the whole life when the baby comes to live, calling for special care for its survival and unfolds into feeding choices the parents make as a form of expressing affection and love to ensure health and well-being. As life evolves, feeding musters feelings and meaning bound to care with the other, a way of expressing love, sympathy and zeal.

He stays more at home with her, he tends to her, he likes cooking too (C4).

Mother gives what the son wants and the son does the same... pities her, then I take a bite and I’m happy (P3).

For me, feeding is more than giving food, when you think of home feeding, it goes since the beginning of the process of what I’m going to do to feed myself, the preparation, and then comes the moment of feeding, eating that food and the ensuing feeling. And it does not stop there, the feeling food brings, the flavor, how it was done, the family around the table to talk, get together, enjoying the relations during the meal (HP6).

I see food in a way because of a family relation, the women of my house, my mother, mainly, saw food with affection. For me, food has this face of affection beyond nourishment (HP7).

Ensure an impeccable and humanized care seems to be the moto of the relations, allowing the acknowledgment of the other as a unique subject with its singularities and differences.

LIFE

According to the clouds of the thematic codes of values and beliefs related to oral feeding (Chart 2), the category “life” does not appear for health professionals perhaps due to the specialization and profile of assistance, fully palliativist where the expected outcome is death seen as a natural process.

The focus of the assistance is based on care and comfort to the patient, the cure is not the end anticipated. For the group of patients, feeding meaning life was noticed only in the narrative of one participant, so, it is possible to conclude that the focus of the patient living his/her finitude is not on the category “life”, with intent-to-cure, of returning to pre-disease times, but as a resignification where the patient is attempting to understand and deal with the process of dying.

You can’t live without food. It is the basic, So ... food is all (C5).

Because without food nobody can live. How? Then, in few words, this is it (C7).
Very important. We are sort of... We are nothing without food. You have to have a meal, if I don’t eat, I feel weak, if I eat well, then... my life gets better (P3).

The current biomedical formation is cure-driven, sees death as a failure and utilizes the entire biotechnoscientific array to maintain the biological life and leaves apart the life that actually matters, the biographical life\(^9\). On it, values and beliefs of the individual are actually considered, attempting to maintain the dignity and quality of life, understanding that life is worth only when the personal history, its singularity are respected and that in face of an advanced disease with poor curative prognosis, the attempt to maintain life at all cost is refuted and technology aims to ensure the control of pain and symptoms.

One of the many feelings and meanings of food is life. Costa and Soares\(^20\), in a study with caregivers and patients with advanced cancer in Brazil and Portugal, noticed that feeding holds a very close relation with category “life” for the study participants because while someone eats, life is there, it is a form of care and source of life and deny food to a patient with advance disease is the definition of disrespect, is a violence against life.

**QUALITY OF LIFE**

The meaning of feeding related to quality of life was expressed in every narrative of all the groups interviewed, which reaffirms the complexity of nuances the theme has and what is aligned with the principles of palliative care, being relevant to see feeding as a determinant to ensure better quality of life to the patient.

The definition of the concept of quality-of-life is but accurate and unanimous as it is multidimensional, subjective and dynamic because it is bound to the perception of each individual, it yields from his/her experiences\(^9,19\).

The discussion of this category and relating it with food within the conception of those involved in palliative care demands problematization, a characteristic of modern societies associated with two human life-related ethical principles quite present in the biomedical practice: the principle of sanctity of life and the principle of quality-of-life\(^21\).

Every life is sacred, says the first principle, should be kept no matter what, even if keeping it, means to leave the individual apart from that life, which can cause pain and suffering. In that line, invasive procedures that do not open the possibility of changing the course of the disease are justifiable, for the sake of maintenance of the biological life, which is the opposite of the philosophy of palliative care. The second principle understands that life is worth only if dignifies the individual of that specific life, legitimating any intervention that abates avoidable suffering, ensuring better well-being. In fact, it aligns with what palliative care dictates, respecting the autonomy of the patient and minimizing symptoms\(^21\).

The model of health prevailing until mid-20th century was disease-centered and disregarded the patients with advanced diseases without any possibility of curative treatment. Diverse bioethical questions emerged from the necessity of ensuring the individual living the proximity of death a comfort-driven therapeutic for his/her dignified comfort, based in full care to improve the quality of life\(^22\).

Feeding has a strong meaning connected to health and well-being, it is essential for human survival, imbued with multiple meanings bound to quality of life as the narrative of the participants show.

Nutritional conduct is not the main aspect of this case, it is the well-being and quality of life of the patient instead (HP3).

What eating means to me? Well-being, health, regeneration of our bodies, this is what food means to me (C2).

I think is the base of good health, isn’t it? In addition to physical exercises, feeding. Feeding in first place and then, physical exercises, visit to the doctor but is the base for a good quality-of-life (C4).

The relation eating well and healthy has always been connected to the concept of quality of life to prevent diseases. However, this relation seems paradoxical in the context of advanced disease that eventually leads to functional decline, which prompts the reflection on the complexity of feelings and meanings closely tied to feeding and the power this belief holds when a progressive and incurable disease appears.

That food is not... Some persons say that eating well, food is not to, is to prevent. If I eat some meal, what is going to happen to me? It will bring me health, my health will be back, it will be back what I very much lost, I’m skinny like a tic, gotcha? All this is coming back to me again, for sure (P2).

If there is no food, you don’t eat, you get weak, you don’t think, you don’t work, you can’t do anything (C5).

I’m worried she is not going to eat, she gets weak, debilitated... (C5).

Dysphagia is a frequent symptom in advanced diseases that significantly impacts the quality of life of these patients, potentially compromising the nutritional status and hydration further to social isolation, constant...
admissions and even speeding up the process of dying. It is essential that the interventions on swallowing disorders in palliative oncologic patients begin as soon as the patient is diagnosed. With this, it is possible to maintain oral feeding as long as possible to align the patient’s wishes (respect to autonomy) to prevention/reduction of risks from potential clinical complications (non-maleficence) and reduce the impact on quality of life.

PLEASURE

The category “pleasure” related to food appeared in the narrative of all the study groups (Chart 2), it is believed that in face of so many losses and suffering, feeding the patient in palliative care with meals that actually represent and identify him/her is an act of humanity, means care with someone you love and care, even in a near-death scenario because food is this, brings comfort and closeness.

Eating is not a mere biological act, it is a social act altogether involving the other. Sharing food is being close to the other at that moment, after all it involves affection, care, memories and a form of pleasure. Being with someone you love, whom you identify with. Food and the ritual involving commensalism as a form of pleasure and celebration, demanding the society to share of what is eaten and its codes.

Nobody eats only with the mouth, all five senses are engaged in eating, therefore, presentation of the food is paramount. Dysphagic patients due to swallowing disorders require changes in food and drink consistency, which may even make the patient reject food, a repulsion to what is ingested, contributing to social isolation and unpleasantness in eating. It is necessary to align food security, proper nourishment and pleasure, ensuring the dignity of the individual.

I put myself in their shoes because as I had this thing very strong with food and I love eating, I enjoy eating, then I figure out how tough it is for someone stopping to eat what she likes (HP5).

Feeding in advanced cancer should prioritize the holistic perspective attempting to adhere to the patient’s wishes and preferences, even in situations when nourishing is not possible anymore and feeding is bound only to pleasure and comfort.

LOSS

According to the clouds of codes in Chart 2, the category “loss” was the value associated with feeding that appeared at the most for the group of patients, corroborating several studies that address losses patients in palliative care face, considering the presence of dysphagia and necessity of significant changes in oral feeding during the evolution of cancer. The patient has to make choices and changes related to his/her feeding. The family needs to learn to deal with the suffering and see the difficulty the beloved one has in eating, like health professionals that also need to resignify this loss and target the comfort and pleasure for the individual in a safe manner.

While coping with an incurable disease as advanced cancer, the patient experiences losses along the natural trajectory of the disease and discomfort and pain that permeate diverse dimensions as physical, emotional and spiritual pain. Changes of family, financial and social dynamics in the scenario of the disease concomitantly with the regular routine the family lives, affects the patient like the uncertain future that lies ahead, bringing fears, hopelessness and impacts on the psychosocial health.

Oral feeding involves different values and for being there since birth, the baseline meaning bound to vitality is quite strong. For many patients, maintenance of oral feeding represents the continuity of their history, the certainty it is still there, controlling the life, hope and sometimes, the ultimate or sole source of joy. Changes of food consistency and/or suspension of oral feeding could be an additional loss the patient has to live, causing great suffering to everyone involved in care.

This is the difficulty I see with her because of the disease because so far, she ate EVERYTHING (C1).

For me, it is tough, because she was a person who ate well, then the doctor prescribed pasty good, liquid and she couldn’t eat (C3).

She is beginning to have difficulties swallowing, masticate, because she could not keep the denture (C4).
I feel completely DEVASTATED. I figure what he LIKES to eat and he says ‘Oh God, I wanted to eat this”, then I stopped bringing home things so he could not smell them (C7).

I sat at the table with everybody to lunch and when my children sat at the table, I had almost finished eating. Today I don’t... (P2).

I have to change because I know that this type of food makes me choke... My niece brought me some food, I ate, don’t know, I was very anxious, I ate it all but I choked and almost died there, trying to get back and failing. I could have died (P3).

Could not eat that regular food, I would rather eat some watery food through my mouth (P4).

Sometimes, a simple thing, a coffee, a piece of cake, so common and he can have it, I think, this is hard, eating by a probe, you can’t taste coffee, ice cream, you can’t have a chocolate and I’m sad with all this (HP5).

FEAR

The category “fear” appeared related to feeding as a risk factor for the development of cancer, which is seems paradoxical, having in mind that the participants are the patients with advanced cancer or are involved in caring to patients in exclusive palliative treatment. It also appeared in the narratives of caregivers, possibly the participants of this group were aware that inadequate feeding can be a risk factor for the development of cancer and probably lived this with their relatives who are ill and do not want to go through this too. Only one patient associated “fear” with feeding, actually it is not a concern to them, because allegedly they have been diagnosed with cancer and there is nothing to prevent from. According to this line of thought, this category did not appear for health professionals as in palliative care, the focus of the team is caring, symptoms control and ensure improved quality of life and not prevention of an existing disease.

The adherence to non-healthy food – low intake and poor variation of vegetables and high intake of salt, sugar and saturated fat, present in many ultra-processed food – are, actually, risk factors for cancer30,31. However, in advanced cancer, no food can cure it and special diets, quite restrictive, attempting to reverse the disease, can cause, further to nutritional risks, more suffering to the patient while not respecting the choices and preferences in this moment of the disease32.

Azevedo33 affirms that the concept of healthy food starts when changes of the concept health and its construction is culturally defined for each group according to the moment they live. For individuals with advanced disease, most of the times the food eaten eventually is similar to the food of healthy individuals, not considering the specificities imposed by the disease guided by a desire to prevent or control cancer, which can be frustrating to the patient and his/her family since the needs are not the same because of the symptoms resulting from the progress of the disease32. I have more restrictions, sort of … at my house, me and my daughter quit eating crackers. I’m eating now because I’m very anxious but it is not … we hardly buy it, no more soda for some years now, no crackers, no cookies. Jars of sweets, we don’t buy anymore (C1).

She ate EVERYTHING, everything, I think this was not good for her (C1).

At home we ate lots of canned food (C1).

And she is a person who does not eat anything, the food has to be WELL seasoned (C4).

She likes chips... It is being hard to offer different and healthy food, with vegetables and legumes (C4).

She likes UNHEALTHY food (C5).

Currently, I can’t have spicy food, it busts my organism (P2).

CONCLUSION

No living being in the nature holds so many ties related to eat and drink as the human being. The symbology these acts bear constructs the history of everyone and bridges the relations among his/her pairs. Therefore, the relation of food is not merely physiologic and becomes an action involving pleasure, affection through memories and creates the cultural and social identity25.

The power of feeding and its multiple dimensions and nuances was the motive to attempt to understand how the players involved (health professionals and caregivers) in providing care to a patient with advanced cancer in palliative care, in addition to the patient him/herself, see and cope with beliefs and values related to food as death nears his/her life. The results showed that all the groups identified the category “loss” as an important meaning chained to oral feeding, for health professionals, the category “care” appeared quite bluntly in the narrative.

The study calls for reflection about how health professionals behave in face of so many complexities of oral feeding to dysphagic patients, and actions grounded in respect and autonomy of the patient, further to shared decision-taking regarding choices and food changes.
Understand the impact of swallowing disorders lived by these individuals warrants a better approach and improved quality of life of oncologic patients in palliative care.

CONTRIBUTIONS

Christiane Gouvêa dos Santos and Fermin Roland Schramm contributed to the study design, analysis and interpretation of the data, wording and critical review. Ernani Costa Mendes and Mariana Fernandes Costa contributed to the analysis and interpretation of the data, wording and critical review. All the authors approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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