Perceptions of Cancer Patients about Oral Nutritional Therapy through Nutritional Supplements during Chemotherapy Treatment

ABSTRACT

Introduction: Treatment toxicity is often associated with anorexia and unintentional weight loss. Oral nutritional therapy (ONT) is a type of strategy carried out through oral nutritional supplements with the purpose of complementing nutritional needs, dependent on the adherence to therapy, mainly.

Objective: To analyze the perception and adherence of cancer patients to ONT and associate them with demographic factors.

Method: Qualitative field study with patients diagnosed with any type of cancer, aged between 18 and 59 years, undergoing chemotherapy treatment, at nutritional risk, certified by a nutritional screening instrument and utilizing ONT. A single interview was carried out, mediated by a semi-structured questionnaire. The data were transcribed, classified and analyzed using the method suggested by Laurence Bardin.

Results: The results revealed a diversity of responses, but there was a significant tendency to highlight difficulties in using and adherence, as well as emphasizing the importance of ONT. Among difficulties of adherence, financial difficulties were the most mentioned, followed by the sensory attributes of the supplements and gastrointestinal changes such as nausea, vomiting, dysgeusia and inappetence.

Conclusion: The perception of cancer patients about ONT interferes with adherence to therapy, and is influenced by education, guidance received by the prescribing professional, the sensory attributes of the nutritional supplements used and the importance they attribute to therapy, in addition to socioeconomic conditions.

Key words: Neoplasms/epidemiology; Drug Therapy; Malnutrition/therapy; Nutritional Therapy/instrumentation; Dietary Supplements.

RESUMEN

Introducción: La toxicidad del tratamiento a menudo se asocia con anorexia y pérdida de peso involuntaria. La terapia nutricional oral (TNO) es un tipo de estrategia que se realiza a través de suplementos nutricionales orales con el propósito de complementar las necesidades nutricionales, las cuales dependen principalmente de la adherencia a la terapia. Objetivo: Analizar la percepción y adherencia de los pacientes oncológicos sometidos a tratamiento de quimioterapia respecto a la TNO y asociarlas con factores demográficos.

Método: Se trata de una investigación de campo cualitativa, con pacientes diagnosticados con cualquier tipo de cáncer, entre 18 y 59 años, en tratamiento quimioterápico, en riesgo nutricional, certificado mediante instrumento de tamizaje nutricional y en uso TNO. Se realizó una única entrevista, mediada por un cuestionario semiestructurado. Los datos fueron transcritos, clasificados y analizados utilizando el método sugerido por Laurence Bardin.

Resultados: Los resultados revelaron diversidad de respuestas, pero hubo una tendencia significativa a resaltar dificultades en el uso y adherencia, además de enfatizar la importancia de la TNO. Entre las dificultades de adherencia, las financieras fueron las más mencionadas, seguidas de las características sensoriales de los suplementos y los cambios gastrointestinal como náuseas, vómitos, disgeusia e inapetencia.

Conclusión: La percepción de los pacientes con cáncer sobre la TNO interfere en la adherencia a la terapia, y está influenciada por la educación, la orientación recibida por el profesional prescriptor, las características sensoriales de los suplementos nutricionales utilizados y la importancia que le atribuyen a la terapia, además de las condiciones socioeconómicas.

Palabras clave: Neoplasias/epidemiología; Quimioterapia; Desnutrición/terapia; Terapia nutricional/instrumentación; Suplementación nutricional.
INTRODUCTION

Cancer is one of the main problems of public health worldwide, it is the first or second major cause of death and consequently one of the great obstacles to increase life expectancy of the world population. The estimates of Santos et al. indicate the incidence of 704,000 new cases of cancer in Brazil for each year of the triennium 2023-2025, requiring increased control of cancer in the country. Currently, the literature describes more than 100 types of cancer which have in common the abnormal, aggressive and uncontrolled growth of cells that eventually lead to the appearance of tumors. These tumors differ regarding the origin tissue, speed of cellular multiplication and capacity to reach adjacent or remote tissues or organs.

The development and growth of the tumor produce metabolic modifications as alterations in intracellular and extracellular metabolites that can accompany the cancer-associated metabolic reprogramming and have profound effects on gene expression, cellular differentiation and tumor microenvironment. Further to these impacts the tumor causes, chemotherapy treatment induces signs and symptoms that directly interfere in feeding and consequently on the nutritional status and prognosis of the patient.

Quite often, treatments’ toxicity is associated with anorexia and weight loss together with poor absorption of nutrients and limited oral intake which can also cause malnutrition and aggravate when associated with surgery which intensifies the catabolic state related to perioperative fasting, development of fistulae among others.

The loss of body tissues is common in patients with cancer because the literature shows that malnutrition occurs in 40% to 80% of the cases with variations depending on the tumor stage, histological type and therapeutic strategies utilized causing negative repercussions on several aspects involving poor efficacy of the treatment, clinical worsening, decline of the quality-of-life and increased mortality.

Early nutritional evaluation allows the estimate of nutritional risk, magnitude of malnutrition and definition of guidelines and applicable interventions. Nutritional diagnosis is influenced by the instrument utilized and periodicity of the evaluations since each method has advantages and disadvantages, reason for which subjective, objective parameters and the combination among them are required for an accurate diagnosis.

Nutritional strategies are essential for harm control that interfere on the nutritional status and clinical prognosis. Diet therapy attempts to mitigate the impacts of malnutrition through adequate intake orally when possible and trying to manage the symptoms, diet counselling and utilization of oral nutritional supplements.

Oral nutritional supplementation is a strategy applied through oral nutritional therapy (ONT) to complement the nutritional demands, indicated for patients in nutritional risk, malnutrition, insufficient conventional oral food intake as well as for patients in preoperative and postoperative period to avoid complications and reduce the length of hospitalization. Successful nutritional intervention through ONT hinges essentially on the therapeutic adherence, however, low adherence has been reported in the literature, associated with several factors as sensory attributes, gastrointestinal tolerance, dysgeusia, medications prescribed and efficacy of the guideline offered by the prescribing professional.

The objective of the study is to analyze the perceptions and adherence of patients with cancer to ONT in chemotherapy treatment and associate with demographics, and understand to what extent these perceptions influence the adherence and maintenance of this therapeutic approach.

METHOD

Descriptive-explanatory, cross-sectional, qualitative field study approved by the Institutional Review Board of Centro Universitário Tabosa de Almeida (Asces/Unita) (CAAE (submission for ethical review): 72948023.5.0000.5203), report number 6,308,122, in compliance with Ordinance 466/2012 of the National Health Council. The study was developed at an oncology outpatient unit associated with the National Health System – SUS in Pernambuco’s Agreste which offers chemotherapy treatment.

The study sample consisted of patients diagnosed with any type of histologically confirmed cancer, aged 18-59 years old in chemotherapy treatment, in nutritional risk classified by the Nutritional Risk Screening (NRS-2002, SCORE ≥ 3) and using ONT. Patients treated with other antineoplastic therapies, with cognitive impairment, in palliative care and concomitant use of enteral nutritional therapy (EN) were excluded after their electronic medical records were investigated.

Data were collected from September to October 2023. Demographics as age, sex, education and primary diagnosis have been collected from the electronic charts adopted at the oncology outpatient and analyzed through descriptive statistics in Excel.

At the routine nutritional consultation, the participants were briefed about the study and after signing the consent form, the participants agreed to their data be collected through descriptive statistics in Excel.
Informed Consent Form, a single interview mediated by semi-structured questionnaire was conducted with open questions presented verbally and simultaneously transcribed for further analysis according to the site’s biosafety norms.

Three thematic categories were defined according to the specific goals of the study related to the knowledge of ONT, experience in using ONT for chemotherapy treatment and adherence to this therapeutic.

The open questions semi-structured questionnaire addressed three thematic categories: "Knowledge about nutritional supplementation", “Experience in using nutritional supplements” and “Adherence to Oral Nutritional Therapy”.

**Chart 1.** Semi-structured questionnaire about the perception and adherence of patients with cancer in chemotherapy on ONT through nutritional supplements

<table>
<thead>
<tr>
<th>Questions about knowledge of nutritional supplements</th>
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<tbody>
<tr>
<td>1. Before the diagnosis, were you aware of what nutritional supplements meant?</td>
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<tr>
<td>2. And today, what do you know about nutritional supplements?</td>
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<tr>
<th>Questions related to the experience of using nutritional supplements</th>
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<tr>
<td>3. What is your opinion about the sensory attributes (taste, odor, texture) of the supplement(s) utilized?</td>
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<tr>
<td>4. Is nutritional supplementation meaningful to your treatment?</td>
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<tr>
<td>5. What changed after utilizing the nutritional supplements prescribed?</td>
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</table>

<table>
<thead>
<tr>
<th>Questions related to adherence to oral nutritional therapy</th>
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<tr>
<td>6. Was it difficult to utilize the nutritional supplements prescribed?</td>
</tr>
<tr>
<td>7. What are the obstacles to continue utilizing the nutritional supplements prescribed?</td>
</tr>
<tr>
<td>8. Have you suspended the nutritional supplements? Why? For how long?</td>
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</tbody>
</table>

All the applicable biosafety and ethical norms and Law 13,709/2018, the General Law of Protection of Personal Data were complied with. The anonymity of the interviewees was secured by assigning a number following the order of the interviews (Interviewee 1, Interviewee 2 successively).

Upon collection, the data were classified and analyzed by the method of content analysis suggested by Laurence Bardin, a set of techniques of communication analysis to obtain by systematic and objective procedures of description of the content, indicators (quantitative or not) that allow the inference of knowledge related to the conditions of production and reception of these messages.

The method is divided into three stages: preliminary analysis involving the organization of the information, exploration of the material during which the data were coded and the final stage of treatment and interpretation when the information were categorized to evaluate the results obtained.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) were applied to ensure the methodological quality of the study by markers of the rigor checklist.

### RESULTS AND DISCUSSION

According to the eligibility criteria, 29 patients met the inclusion criteria and after applying the exclusion criteria, 14 patients were interviewed: nine women and five men with a mean age of 45 years and a standard deviation of 9.49.

Half of the participants have not completed elementary school, only two completed university and the others completed high school as shown in Chart 2.
CATEGORY 1. KNOWLEDGE ABOUT NUTRITIONAL SUPPLEMENTS

Understanding what occurs in all phases of the treatment makes the patient the protagonist of his/her own care when affected by a chronic disease, in addition, the passivity and unfamiliarity aggravate beliefs supporting fear and insecurity. Little information about the disease and treatment can negatively interfere in the adherence to the treatment and accelerate the disease progression or induce low quality-of-life\textsuperscript{19}.

Studies with patients with different diagnoses show that those who know his/her disease, treatment and prognosis tend to present low rates of anxiety and depression and better adherence to the treatments\textsuperscript{19,20}, unlike those who are unaware of enough and correct data about the required care to prevent infections and other motives that leave them more exposed to this complication\textsuperscript{21}.

Given this, a deeper comprehension of what oral nutritional supplements mean and reasons why they are used in the perspective of the patient is essential to foster an effective and correct nutritional therapy to prevent malnutrition and ensure the good nutritional status throughout the whole course of the treatment\textsuperscript{22}. In this context, this study initially identified what the patients knew about the theme in two different moments of their lives: before and after the diagnosis of cancer.

When asked about their understanding on nutritional supplements before the diagnosis of cancer and treatment or whether they had already acquired some information about the theme, most of them (85.8\%) had ever had any contact or any information whatsoever, as the narratives below show:

I had never knew anything (Interviewee 1).

Knew nothing about supplements, had ever heard anything, at the beginning, I didn’t want to take (Interviewee 2).

Had heard about, a person from my family had taken but I had never wanted to know more. I knew only the basics, today, I know a little more (Interviewee 4).

Didn’t even know what it was all about (Interviewee 12).

Some of them had already taken, but barely knew anything about it, as the narratives portray:

I used to take, it is good for health. I believe they are vitamins (Interviewee 10).

Yes, I always used these supplements, my doctor told me it was good for my health, that I should take any medication they prescribed me (Interviewee 11).

Low-education persons tend to seek and understand health information less, therefore, the professionals should help the patients to try to get the required information, seeking health literacy strategies and value the autonomy of these individuals\textsuperscript{23}.

Only 14.2\% of the participants claimed they knew the subject, the interviewees who completed university showed more technical knowledge and familiarity as seen in their narratives:
I have already taken protein modules and creatinine for muscle mass gain, I did bodybuilding (Interviewee 7).

My husband went to the gym and I did too, I used to take those isolate proteins and pre-training (Interviewee 14).

When asked about their current understanding after the indication and use of some type of nutritional supplement, similar responses were found. The narratives showed different understanding compared to pre-diagnosis, it is evident they have been guided or attempted to know more, and now they hold some level of knowledge:

It is good to lose weight, to strengthen the body (Interviewee 1).

I think it is a type of vitamin, a fortifier that has been helping me so much, I feel well and safe of becoming more treatment-resistant (Interviewee 3).

I believe it will boost my system, regarding immunity or the whole body, can’t explain it right, but it is something to nourish us (Interviewee 4).

It is a substance that helps to gain muscle mass, I noticed that some supplements I have already used when I was training helped me to gain mass and some other vitamins the body stops producing with ageing (Interviewee 7).

I believe it helps the metabolism on a daily basis, but I believe it optimizes with physical activity (Interviewee 14).

Most of the studies about adherence to ONT are clinic-based, the patients’ perception is not well investigated and why the supplements have not been adhered to were not explored. Despite some sensory factors as acceptance of the taste are frequently quoted as a predictor of adherence, the reliability of the prescribing professional’s guidance is essential to ensure the patient gives the therapeutic the required attention.

The communication among all parties involved is critical (patient, family, health professionals), open dialogue, information and ideas exchange demystify the “monster”, as the disease and treatment are seen. Try to change the conception of “not knowing” is better or helps to not get worse is essential. Limited knowledge about sickening is connected to age and difficulties of communication team-patient that can be attributed to some factors as cognitive deficit, family issues, patient’s denial, among others.

**CATEGORY 2. EXPERIENCES IN USING NUTRITIONAL SUPPLEMENTS**

Many physiologic or psychologic factors contribute to inappropriate nutritional intake, very common in oncologic patients. Nutritional care with strategies to improve the intake should start even before the chemotherapy, so the patient is prepared and ensures therapeutic success.

When the patient fails to orally ingest enough food, oral, enteral or parenteral nutritional therapy is required, and the route should be determined according to the nutritional and clinical status of the patient, weighing the risks and benefits. ONT is the first option as long as the digestive system is able to be utilized, further to being the most physiological and easy-to-access pathway and prescribed whenever the conventional oral intake of the patient is < 70% of the nutritional needs concurrently with nutritional counseling.

ONT through nutritional supplements is widely utilized in the oncologic setting and patient’s experiences can offer invaluable information to build a better understanding of how the patients lived with ONT and translate into their daily lives, minimizing the challenges faced to adhere to the therapeutic.

In general, nutritional supplements are hypercaloric and high-protein content to minimize the energetic and protein catabolism, like arginine, nucleotides and omega-3 enriched immunomodulators mainly in patients with head and neck and gastrointestinal cancers in perioperative period, beginning from five to ten days before the surgery and discontinued on the day of the surgery and in the seventh day after at least from 500 ml to 1000 ml daily.

The proper utilization of nutritional supplements should be an integral part of malnutrition management as the evidences of efficacy of alternative strategies of oral nutrition are scarce, for instance, food fortification and nutritional counseling. Like other therapies, the adherence to and use of oral nutritional supplements need to be maximized and monitored.

The perceptions about sensory attributes (taste, odor and texture) of the supplements utilized were heterogeneous:

I don’t like the smell, or the texture (Interviewee 1).

Everything is fine, I use different flavors every other day, strawberry, chocolate... I like them all, it is my preferred milkshake (Interviewee 2).
I don’t like with flavor, get sick very fast, the flavorless is better (Interviewee 3).

Some flavors are strong, the smell gets me sick and the taste is sweet. I prefer bittersweet and milk chocolate, they are milder (Interviewee 14).

The sensory perception of nutritional supplements has been investigated in the current literature as some chemotherapy-related side effects as dysgeusia, xerostomia and even nausea and vomits directly interfere in food intake and hamper the adherence to the supplements commonly prescribed.27

Palatability varies highly among the patients, the supplements are more accepted when diluted with milk and less juices. In this case, they feel metal taste mainly during chemotherapy. A recent pilot cross-sectional clinical trial concluded that patients with cancer value positively the organoleptic characteristics as sweet flavors as brownie and fruity flavors as tropical and negatively evaluate the salty flavors or with salt addition.28,29

Some studies emphasize that the use of artisanal food supplements (AFS) is a promising strategy when compared to those industrialized because they offer good nutritional support when well-prepared and prescribed.26,30

AFS result from the combination and adjustment of ingredients that include a wide array of foods and nutrients as fruits, vegetables, proteins, vitamins, minerals, fibers and herbs. The manual approach grants more flexibility in the preparation because the patient can prepare them, however, because they are unregulated yet, the quality and safety vary significantly.30

The positive perception the oncologic patient has about what nutritional supplements means in cancer treatment is clear in the narratives, they used the terms “fundamental” and “very important” while referring to the treatment.

It is very important, a source of nutrients that makes me feel well (Interviewee 2).

Very important, fundamental, can’t live without it (Interviewee 3).

It is very important, if not, you would not prescribe us (laughs), I’m positive it is worth it (Interviewee 4).

It is very important, supplementation will help me to not lose muscle mass, possibly I won’t gain mass, but I’m not going to lose (Interviewee 7).

It is a great help, very important (Interviewee 9).

These aspects are corroborated when they report changes noticed after using the supplements prescribed, as the narratives demonstrate:

I gained weight, I feel stronger, the weakness I felt in the beginning went away before I began using (Interviewee 1).

I have more appetite, I’m more resilient and stronger, I noticed I stopped losing weight (Interviewee 3).

I felt charged, when I take it, my disposition boosted. My weight kept stable, I was losing too much weight, I’m recovering slowly (Interviewee 5).

It changed everything, in terms of food, 100%, I used to eat lots of junk food, snacks, then I started to use them with fruits, vitamins and facilitated my adjustment. Not to speak about the 4 kilos I gained, thanks to God because I was afraid to continue losing (Interviewee 8).

When I had mucositis, it was when I noticed the difference because I was unable to eat well and it helped me (Interviewee 14).

A recent study concluded that nutritional supplements were contingent upon taste acceptance and the priority given to daily feeding. The intake has risen when the nutrients were deemed as necessary for weight gain or recovery from diseases. Low adherence was noticed when the patients’ goals were not to increase the intake of nutrients or body weight, or when other activities were perceived as more important.21

### CATEGORY 3. ADHERENCE TO ORAL NUTRITIONAL THERAPY

The most reported difficulty was purchasing because the supplements were not offered by the outpatient unit, followed by sensory attributes and gastrointestinal alterations as nausea, vomits, dysgeusia and inappetence as the responses revealed:

The obstacle is the price, but I try to keep up (Interviewee 3).

Financial difficulty, still didn’t receive any support for the disease, everything is too expensive (Interviewee 6).

Cash, sometimes I have to diminish to last more (Interviewee 13).
Most of the times the smell made me retch, I was traumatized, felt bad just to see it (Interviewee 9).

Only the taste, it is tough to swallow down, but I'm going to buy another one to see if I can do better (Interviewee 4).

When asked what was the motive to interrupt using it, the financial issue was unanimous as most of the patients reported:

I stopped taking once because I got sick, couldn't even look at it (Interviewee 1).

No problem at all, only improvement and now that I'm going to do the surgery, I'm taking more lightly because I know it will help me much, the doctor told me to continue taking the one for immunity in the five days before the surgery. But it is costly, this is the hurdle (Interviewee 2).

The worst part is the money, it has risen quite a lot since I started, the price doubled (Interviewee 9).

No, none. I like the taste, but it is expensive (Interviewee 8).

It is just the money (Interviewee 14).

The patients should take the amount prescribed for the period to be more effective, being required a high investment. The economic burden together with the oncologic treatment restrains the access to many resources and reflects the lack of public policies to strengthen the continuity.

Although the supplements might outweigh the nutrients not taken or as part of a strategy of compensation, they are unable to reduce the burden of food changes. Nevertheless, despite the difficulties listed, it has been noticed an effort to keep the nutritional supplementation, given that they are necessary for a better response to the treatments:

I don't feel hungry, rarely when appetite is catching up, it is just close to the other session and then it all starts again... nausea, vomits and bad taste at the mouth, in these days I focus on the supplement, but even it is quite hard (Interviewee 2).

Only the flavor, but I try to take because I know it is important (Interviewee 4).

In the beginning, I was nauseated, could not take it right, but I managed to adapt slowly. Have to take it, chilled is much better (Interviewee 5).

Somewhat because of the price, but we manage, although the price has risen very much (Interviewee 6).

Finally, the participants were guided to mention if the use of supplements was suspended temporarily for any reason, the responses corroborate this thematic axle:

I quit for a few days, I was nauseated, but then I resumed because I thought they were doing me well and was afraid of losing weight (Interviewee 1).

I suspended only when I was admitted for surgery, but I didn't know whether the hospital has been prescribing, it was just for a few days and I resumed (Interviewee 3).

Due to nausea, I suspended for a few days and then I resumed (Interviewee 5).

Motive was not the issue, it was there, but I managed somehow, it is too expensive this treatment, transportation too, complicated (Interviewee 6).

Given that nutritional supplements are a mix of ingredients, their sensory attributes should be granted special attention. Actually, some substances as vitamins and some specific minerals can have an unpleasant or residual taste. The negative perception can lead to low use and reduce the efficacy of the treatment. Flavors are a strategy to disguise bitter or metal odd tastes of some components added to the formula of the supplements, potentially leading to rejection of the product or negative economic impact.

The alternative are AFS due to the difficulties of industrialized supplements because the flavors can be adjusted and help the customization of the treatment to the patient's taste. These are economically viable options with nutritional profile similar to the industrials and attempt to be more palatable and include food the patient is already familiarized. The definition of the macro nutritional composition is relevant and reduces the reproducibility of this strategy at home.

**CONCLUSION**

Expand the understanding of the meaning of oral nutritional supplements and reasons to adopt in the perspective of the patient is essential to allow proper and effective nutritional therapy to prevent malnutrition and
to ensure good nutritional status in the whole course of the treatment. Better understanding makes the patient the protagonist of his/her own care and is influenced by early contact with the theme, attributes and personal perceptions.

Education is a determinant aspect among demographic factors since participants who completed university are familiarized and hold technical knowledge, however, most of them claimed that before the diagnosis, they had barely if any knowledge about nutritional supplements.

In that line, the guidelines provided by the prescribing professionals about management of supplements and nutritional counseling are essential to increase the patient’s trust in the information offered. Communication among all the players, including the patient, family and health team is imperative and directly reflects on the adherence to the therapeutic.

The adherence is affected by the sensory attributes, mainly taste, followed by odor and texture, which, when connected to chemotherapy-related symptoms as nausea, vomits, among others, interferes in the quality and frequency of use. Socioeconomic status is a predictor of adherence, since difficulty to purchase was unanimous among the participants.

Notwithstanding the difficulties, the participants acknowledged the importance of the supplementation and endeavored to keep up with the use. The perception of the patients with cancer about ONT interferes in the adherence and depends on the education, guidance received from prescribing professionals, sensory attributes and importance they give to the therapy, in addition to socioeconomic conditions.

Several scenarios were noticed during the study, the opportunities that appear in face of the participants’ perceptions indicate the necessity of new qualitative studies able to deepen the theme, since the focus on the patient’s experiences can provide invaluable information about nutritional therapy for more effective and continuous approach.

CONTRIBUTIONS

All the authors contributed substantially to the study design, acquisition, analysis and interpretation of the data, wording and critical review. They approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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