Cogitare Enfermagem

ORIGINAL ARTICLE

THE EXPERIENCE OF PATIENTS WITH HEAD AND NECK CANCER REGARDING SELF-CARE FOR RADIODERMATITIS*

HIGHLIGHTS

1. Lack of knowledge about self-care for radiodermatitis.
2. Nurses' guidance on self-care is fundamental.
3. Adverse effects exert an impact on patients' self-esteem and self-image.

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ABSTRACT

Objective: To analyze the experience of patients with head and neck cancer regarding self-care for radiodermatitis associated with sociodemographic and clinical-pathological factors. **Method:** A descriptive study with a qualitative approach, carried out at a High Complexity Oncology Reference Center in Belém - Pará - Brazil. It was conducted through interviews and analysis of medical records. The data were collected from February to April 2022 and processed using Bardin's content analysis supported by the IRAMUTEQ software. **Results:** Three subcategories emerged: The importance of the patient's knowledge about radiotherapy; Identification of adverse effects related to the treatment; and Nurses' guidance on self-care. **Final Considerations:** The patients' knowledge about the treatment was incipient, adverse effects were identified by the negative impact on their self-esteem and self-image, and self-care guidance was effective in reproducing care. The study provides an opportunity to develop an appropriate teaching strategy in future research.

DESCRIPTORS: Neoplasms, Head and neck neoplasms; Self-care; Radiodermatitis; Nursing.

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INTRODUCTION

Head and Neck Cancer (HNC) is the sixth most common cancer in the world and its most usual histological type is epidermoid carcinoma, which accounts for 90% of the cases. These tumors affect the oral cavity, oropharynx, hypopharynx and larynx, and their risk factors include exposure to chemical carcinogens from tobacco, alcohol and/or viruses such as the Human Papillomavirus (HPV), which is mainly associated with oropharyngeal tumors[1].

The HNC treatment is based on eradicating the disease, but cases of diagnosis in advanced stages are common, making it difficult to achieve a cure. The therapeutic plan for these patients should be based on clinical data and tumor classification and be carried out by means of surgery, chemotherapy and radiotherapy, whether associated or not[2].

Radiotherapy (RT) is based on the use of ionizing radiation that damages the genetic material of neoplastic cells, thus affecting their ability to multiply and leading to apoptosis[3]. It has individualized planning and delivery and is a deterministic event (dose-dependent effect), i.e., it has a relationship between the accumulated dose and the extent of the expected damage[4].

RT alters the cell maturation, proliferation and renewal stages and causes an inflammatory cascade culminating in tissue damage and a skin reaction called radiodermatitis. This adverse event exerts a negative impact on the patient's quality of life in terms of appearance of the skin, pain and discomfort, and treatment has to be interrupted in severe cases[5].

Radiodermatitis is classified according to the criteria defined by the Radiation Therapy Oncology Group (RTOG) , which developed the Acute Radiation Morbidity Scoring Criteria in grades, namely: 0: No alterations; I: Mild hyperemia, epilation, desquamation and reduced sweating; 2: Painful erythema, localized moist desquamation and moderate edema; 3: Confluent moist desquamation and significant edema; and 4: Hemorrhage, ulceration and necrosis[6].

Patients with HNC undergoing radiotherapy need to learn about self-care for radiodermatitis[7,8]. Orem's Self-Care Theory is pertinent, linking the theory of self-care deficit and that of Nursing systems. The main idea is that the patient's participation is important for their care and that Nursing should assist in this process[9].

Therefore, the objective of this study is to analyze the experience of patients with head and neck cancer in relation to self-care for radiodermatitis, associated with sociodemographic and clinical-pathological factors.

METHOD

This is a descriptive study with a qualitative approach, carried out from February to April 2022 at a High Complexity Oncology Reference Center (*Centro de Referência de Alta Complexidade em Oncologia*, CACON) located in Belém - Pará - Brazil, specifically in the Radiotherapy service, where there are three linear accelerators and a mean of 180 patients/month.

The following inclusion criteria were used to select the participants: patients diagnosed with head and neck cancer undergoing radiotherapy; over 18 years of age, regardless of gender, treatment fraction and whether or not it was concomitant with chemotherapy. Patients with incapacitating cognitive decline in terms of verbal communication were excluded, as well as those diagnosed with metastasis to the head and neck region, as they

had fewer treatment fractions than the standardized number.

Data collection took place from February to April 2022 in three stages, namely: in the 1st stage, a survey was carried out of the number of patients with HNC treated at the radiotherapy service, as well as the time at which they attended their sessions. Subsequently, the participants were invited (always after the treatment session) individually and with the possibility of making an appointment.

In the 2nd stage, after explaining and signing the Free and Informed Consent Form (FICF) and the authorization form for voice recording, interviews were conducted with the patients in a private room, in the presence of the companion/family member and using a semi-structured script prepared by the researchers, with questions related to the patient's sociodemographic profile, as well as knowledge about the treatment, adverse effects and care of the treated area. Alphanumeric codes were used to identify the participants, as follows: HNC (P1, P2, P3), where HNC stands for "Head and Neck Cancer" and P is "Patient".

In the 3rd stage, the patients' medical records were consulted and then double-checked, by consulting the technical files using a specific instrument to obtain diverse information on biopsy, surgery, diagnosis, tumor staging and concomitant chemotherapy, as well as the number of fractions planned, daily dose, total dose, treatment field and accessories used to optimize dose delivery, in compliance with the Commitment Form for the Use of Data and Medical Records (*Termo de Compromisso para Utilização de Dados e Prontuários*, TCUD).

The data obtained in the 2nd stage were transcribed and analyzed using the content analysis method grounded on Bardin (2011), which consists of three stages: Pre-analysis and exploration of the material; Data processing; and Inference and interpretation[10].

The IRAMUTEQ (*Interface de R pourles Analyses Multidimensionnalles de Textes et de Questionnaires*) software, version 0.7 alpha 2 for Windows, was used in the second stage of data analysis; this program uses functions from the R software and enables various forms of statistical text analysis[11].

Using this software allowed for a lexicographic analysis employing Descending Hierarchical Classification and similarity analysis, as both forms of coding organize the *corpus* and text segments, developing a graphic analysis based on the frequency of the most expressive words[12].

Words with a frequency equal to or greater than the mean frequency recorded (three) were considered relevant. The word classes were represented by the most significant words, using the Chi-squared test (p-value<0.001). The sociodemographic and clinical-pathological data obtained in the third stage were structured in spreadsheets using Microsoft Excel 2019 for descriptive analysis expressed as frequency and percentages.

This study was approved by the Ethics Committees for Research with Human Beings of the State University of Pará and the Pará State Oncology Reference Hospital, No. 5,150,428.

RESULTS

Of the 24 eligible patients, two were excluded for presenting a weak general condition that precluded oral communication. Thurs, the sample consisted of 22 participants. Their clinical and socioeconomic backgrounds are shown in Table 1.

Table 1 - Clinical and sociodemographic characteristics of the patients with head and neck cancer undergoing radiotherapy. Belém-PA, Brazil, 2022

Characteristics	n	(%)
Gender		
Male	18	82
Female	4	18
Age group		
20-40 years old	5	23
41-61 years old	11	50
62-82 years old	6	27
Race		
Black	3	14
Brown	15	68
White	4	18
Religion		
Catholic	14	64
Evangelical	6	27
Atheist	1	4
Umbandist	1	5
Schooling		
Incomplete Elementary School	12	54
Complete Elementary School	2	9
Incomplete High School	3	14
Complete High School	3	14
Incomplete Higher Education	1	5
Complete Higher Education	1	4
Diagnoses		
Oral cavity cancer	2	9
Laryngeal cancer	5	23
Nose/Skin cancer	1	4
Nasopharyngeal cancer	3	14
Ear/Skin cancer	1	4
Oropharyngeal cancer	8	36
Cervical lymphoma	1	5
Eye and orbit	1	5
Habits		
Only smoker	2	9
*Only alcoholic	6	27
Smoker and alcoholic	11	50
Non-alcoholic and non-smoker	3	14

**Family Income (minimum wages)		
1-2	20	91
2-4	1	4.5
4-6	1	4.5
Total	**22**	**100**

Source: Research data (2022).

*Alcoholism: men (14 or fewer alcohol shots per week and no more than 4 shots on any single occasion) and women (7 or fewer shots per week and no more than 3 shots on any single occasion)[13].

**Value of the current minimum wage: R$ 1,212.00.

It was identified that 82% (18) of the participants were male and that the mean age was 51.1 years old, varying from 41 to 61; the predominant race was brown with 68%, and the Catholic religion prevailed with 64%. In relation to schooling, 54% (12) of the participants had Incomplete Elementary School, whereas 4% (1) had Complete Higher Education. Regarding histological types, there was predominance of oropharyngeal cancer in eight (36%) participants, followed by laryngeal cancer in five (23%).

As for the drinking and smoking habits, it was observed that 86% (19) of the participants had them in isolation (six drinkers and two smokers) and in combination, totaling eight patients with these habits. The predominant family income of the participants was between 1 and 2 minimum wages, with 91%, whereas the study indicates one (4.5%) earning between 2 and 4 minimum wages and between 4 and 6 minimum wages, respectively, which corresponds to 9% of the participants.

The following categories emerged when analyzing the *corpus* using IRAMUTEQ: "Knowledge about the treatment and its adverse effect" and "Nurses' guidance for self-care", presented by means of Descending Hierarchical Classification (DHC) of words (Figure 1).

Based on the analysis of the dendrogram in Figure 1 and focusing on the most representative words, the following subcategories (classes) stand out: The importance of the patient's knowledge about radiotherapy (classes 2 and 7); Identification of treatment-related adverse effects (classes 3 and 6); and Nurses' guidance on self-care (classes 1, 4, 5 and 8).
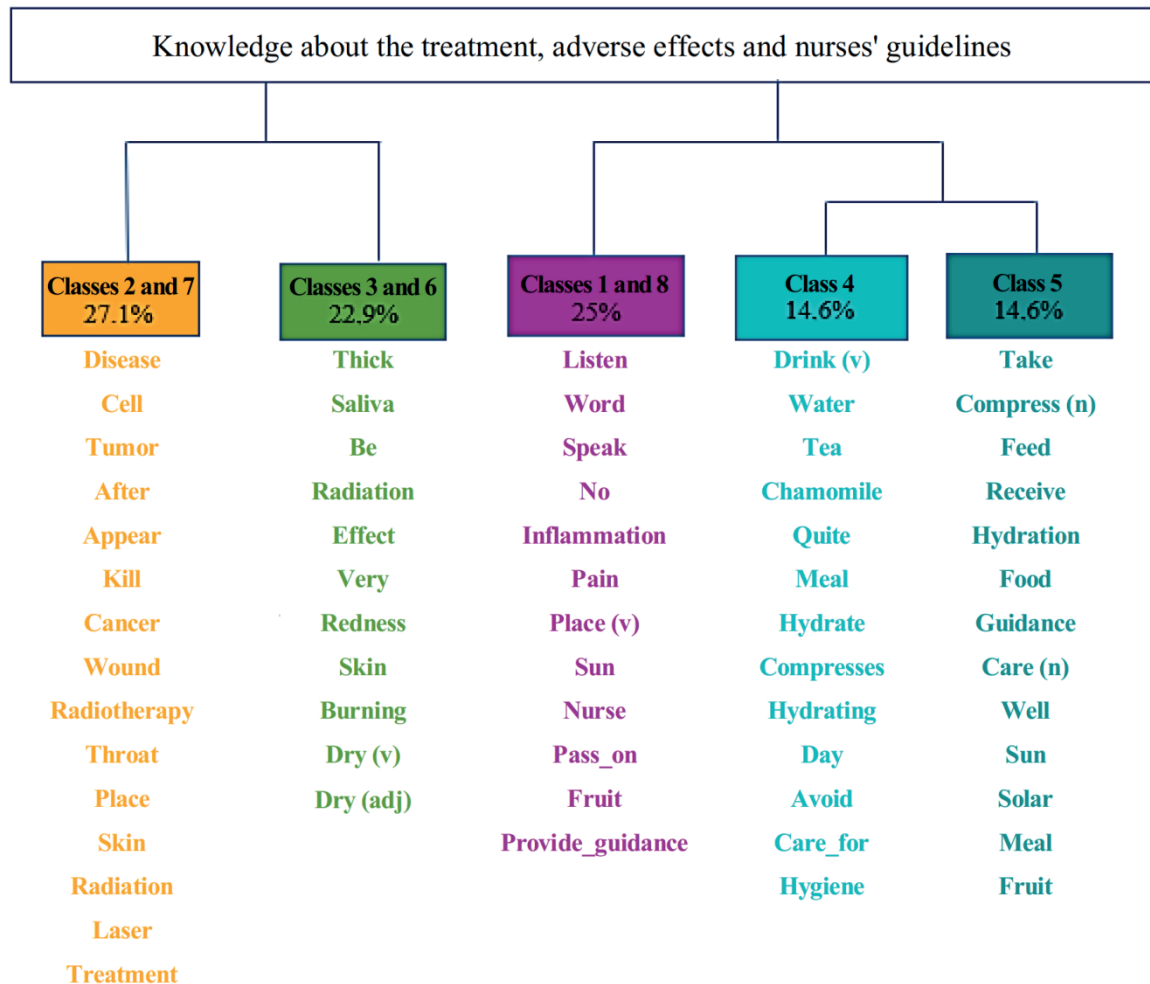
Figure 1 - Dendrogram corresponding to the Descending Hierarchical Classification of knowledge about treatment, adverse events and nurses' guidance. Belém, PA. Brazil, 2022
Source: Research data (2022)

The importance of the patient's knowledge about Radiotherapy - Classes 2 and 7

This subcategory represents one of the intermediate expression classes and which, when added together, had important significance. This category arose because of the need to identify the patient's minimum knowledge about radiotherapy in order to substantiate the emergence of adverse events, expected during and after treatment.

Treatment that uses radiation to destroy tumors or prevent cells from growing (HNCP1).

Applying radiation where the cancer was found (HCNP2).

Laser that penetrates the body, the skin and generates no pain (HCNP13).

It was observed that there was an association between the treatment and the adverse effects, a fact that goes back to the understanding of the last century (Henry Beckerel-1900), when he used the term "dose erythema", which was suggestive of effective treatment and is well-represented in the following transcript:

Radiotherapy is a burning sensation in the neck and on the sides of the lump, it is a quick thing for those who have the problem (HCN11).

Identification of the treatment-related adverse effects - Classes 3 and 6

There are positive and negative effects in any therapeutic modality, which emphasizes the importance of guidance as to what is expected from the treatment, so that the patient understands the benefits obtained. The most relevant point in the interviews was in this subcategory, as evidenced by the following report:

It's redness on the skin (HCNP1).

Burning and inflammation in the throat (HCN16).

Dry mouth and hot, red neck (HCNP17).

Saliva thickens and skin dries out (HCNP18), (HCNP19).

The aforementioned report shows how important the changes caused by the treatment and the patients' understanding are for a successful treatment, as well as the nurses' role in this process, as evidenced in the following transcript:

"The nurse told me that it can cause eye pain" (HCNP3)

It can cause dizziness, sores in the mouth and redness of the skin (HCNP4).

Of all the adverse effects that occurred during treatment, the one with the most obvious repercussions is radiodermatitis; however, in the interviews on this specific topic, the expression was unknown to the entire sample represented in the study, characterizing lack of knowledge.

Nurses' guidance on self-care - Classes 1, 4, 5 and 8

This subcategory was the most significant. The importance of the patient's understanding about out-of-hospital assistance was highlighted, characterizing self-care throughout the treatment.

Self-care is of utmost importance so that adverse effects do not take on drastic proportions and interrupt the patient's treatment. This is characterized by the expressions below:

Using compresses with chamomile tea, oral hygiene, not exposing yourself to the sun, drinking plenty of water (HCNP4).

The nurse said you can't sunbathe so that your skin doesn't dry out (HCNP7).

When it comes to hydration, you have to drink plenty of liquid, eat well and hydrate the area with moisturizer (HCNP9).

The nurse told me to make chamomile tea to help relieve the burning (HCNP10).

In the dendrogram shown in Figure 2, the *corpus* was divided into three blocks: the first showed classes 2 and 7, corresponding to 27.1%; the second block had classes 3 and 6, corresponding to 22.9%; and the third block included classes 1, 4, 5 and 8, corresponding to 54.2%. A list of words was computed for each class, generated using the chi-square test (X^2).
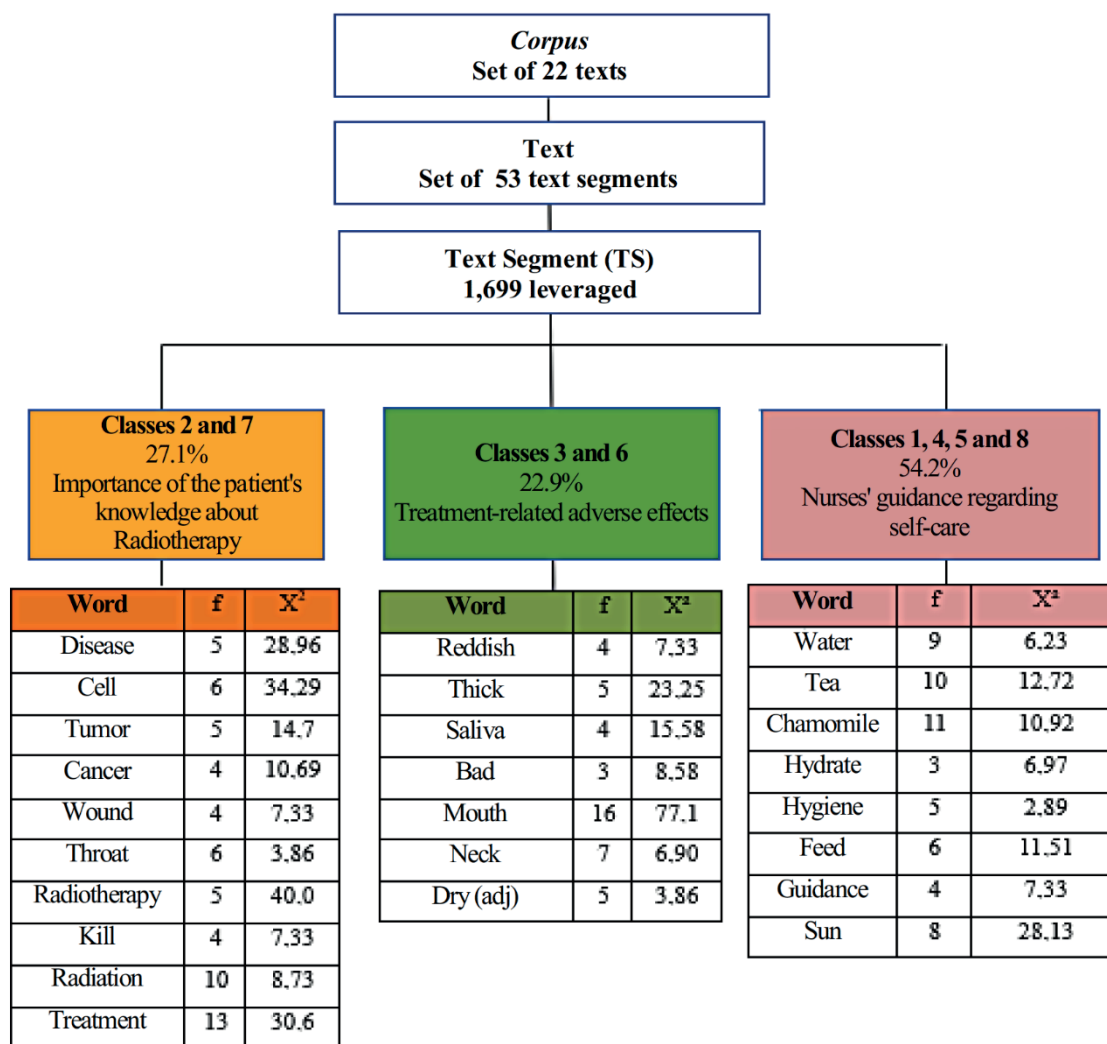
Corpus
Set of 22 texts

Text
Set of 53 text segments

Text Segment (TS)
1,699 leveraged

Classes 2 and 7
27.1%
Importance of the patient's knowledge about Radiotherapy

Word	f	X^2
Disease	5	28.96
Cell	6	34.29
Tumor	5	14.7
Cancer	4	10.69
Wound	4	7.33
Throat	6	3.86
Radiotherapy	5	40.0
Kill	4	7.33
Radiation	10	8.73
Treatment	13	30.6

Classes 3 and 6
22.9%
Treatment-related adverse effects

Word	f	X^2
Reddish	4	7.33
Thick	5	23.25
Saliva	4	15.58
Bad	3	8.58
Mouth	16	77.1
Neck	7	6.90
Dry (adj)	5	3.86

Classes 1, 4, 5 and 8
54.2%
Nurses' guidance regarding self-care

Word	f	X^2
Water	9	6.23
Tea	10	12.72
Chamomile	11	10.92
Hydrate	3	6.97
Hygiene	5	2.89
Feed	6	11.51
Guidance	4	7.33
Sun	8	28.13

Figure 2 - Descending Hierarchical Classification (DHC) dendrogram with frequency analysis and chi-square. Belém, PA, Brazil,
Key: f: Frequency; X^2: Chi-square.
Source: Research data (2022)

The similarity analysis (Figure 3) denotes the occurrence between words and the result in their connections was identified in a graphic representation. There were semantic interconnections between the most expressive words, such as mouth, skin, treatment, nurse, talk, effect, water and chamomile.
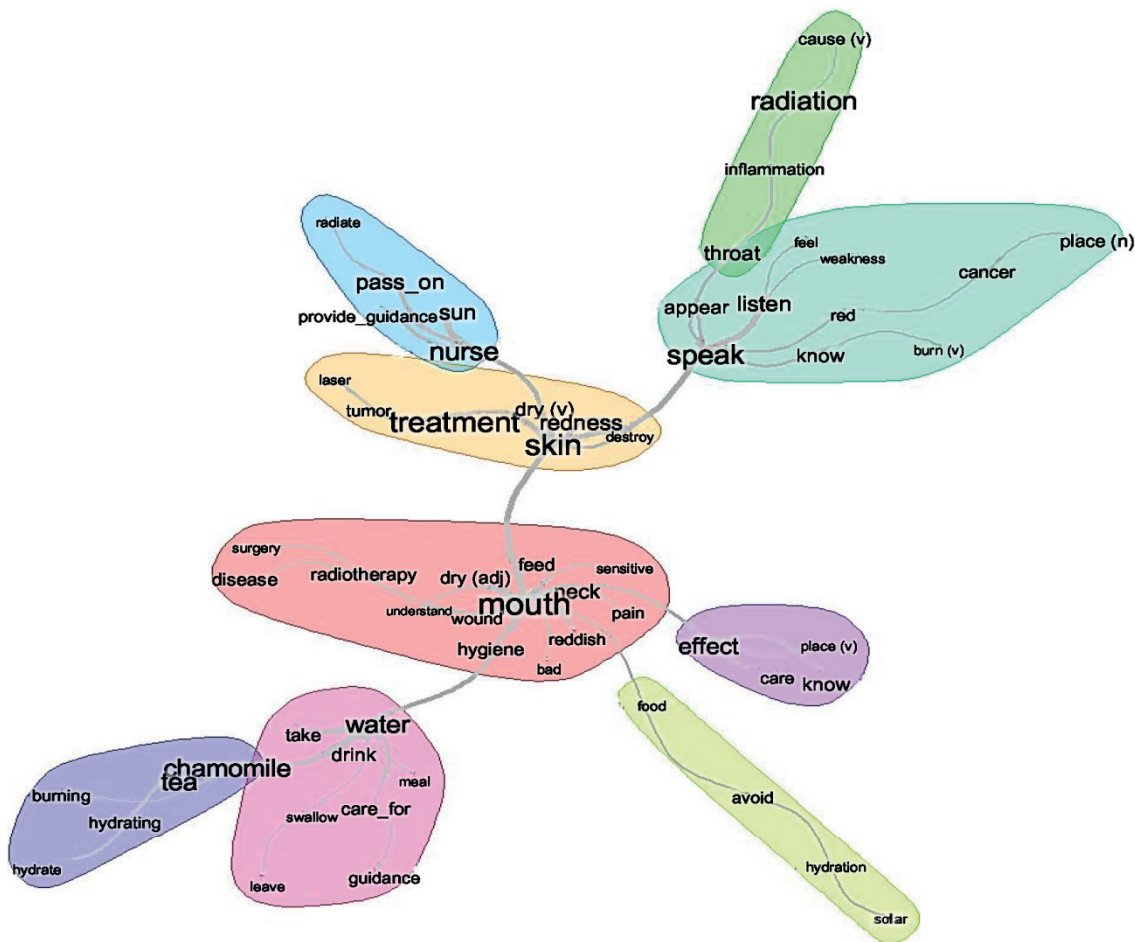
Figure 3 - Similarity Analysis on Knowledge about the Treatment, Adverse Effects and Self-Care Guidance. Belém, PA, Brazil, 2022
Source: Research data (2022)

With the generic analysis of the tree, some connections were established, such as:

The nurse advised me to wear soft clothes, stay out of the sun, apply sunscreen, clean my mouth, make compresses with chamomile tea so that my skin doesn't dry out and drink plenty of water to hydrate it (HCNP18).

Follow the care measures that nurses recommend, such as chamomile tea, as it takes longer for the effects to appear (HCNP20).

It's radiation treatment that penetrates my skin until it kills those cancer cells (HCNP21).

The nurse told me that it's the red skin that appears during the treatment (HCNP12).

The testimonies highlight the importance of knowledge and care, which must be provided to the study participants and the essence, as well as of the nurses' practice as educators in the learner's context throughout the radiotherapy treatment, reinforcing the idea that the patient is the study focus.

DISCUSSION

Head and neck cancer exerts an impact on all life aspects, as it compromises self-image, speech, breathing and swallowing[7]. Risk factors are decisive in the disease triggering process, with associated use of alcohol and tobacco among them[1]. This condition was observed in a significant percentage of participants in this study.

An educational weakness related to the participants' low schooling level was identified. This factor increases nurses' responsibility in terms of a safe and effective teaching-learning process for the self-care practice[14].

A study[15] carried out in Santa Catarina (southern Brazil) evidenced that, regardless of the Brazilian region, the patients affected by the disease have low schooling and family income levels. In the study in question, the main age group affected was from 41 to 61 years old, corroborating the findings of this research. The aforementioned study reinforces the importance of better strategies for providing diverse information throughout the treatment, from primary- to tertiary-level health care.

As for religion, it is linked to believing in recovery and a cure for the disease, as many people still consider cancer as an incurable disease that means the end of life. In this way, religiousness helps deal with cancer in its natural history process[16].

In relation to knowledge about the radiotherapy treatment, it was observed that the words most easily understood by the patients were the ones they heard the most during their treatment. However, there are still difficulties understanding the subject matter. A literature review[17] corroborates these findings, describing the understanding difficulties patients have regarding lack of information about their treatment.

Referring to the adverse effects, the target population was more emphatic in their reports because they are alterations that compromise the respiratory and digestive systems, and the chi-square test shows that the most important comments corresponded to the mouth, where saliva was changed, becoming thick.

A cross-sectional study[18] conducted in the Brazilian state of Sergipe analyzed 34 patients diagnosed with head and neck cancer regarding adverse events following radiotherapy and found that 94.1% of them had dry mouth (xerostomia). Consequently, this study highlights the negative repercussions on the patients' life as a result of the reactions that took place, as shown by the higher number of classes in the dendrogram and in the mouth reactions presented in the chi-square test.

Also regarding the treatment's effects, a relevant point is radiodermatitis, which is one of the main toxicities for radiotherapy patients. A documentary study[19] carried out in Rio de Janeiro (Brazil) analyzed 167 medical records of patients with HNC undergoing curative radiotherapy. In all, 99.4% of them had radiodermatitis, with 11.4% in its severe form (RTOG grade 3). Severe radiodermatitis was associated with type of device, treatment technique and presence of comorbidities. Of the patients affected by grade 3 radiodermatitis, 53% had their treatment temporarily suspended.

A case series study[20] was carried out in Brasília-DF (Brazil) with the objective of describing the impact of radiodermatitis on the body aesthetics of 10 patients with HNC undergoing radiotherapy. All the patients presented characteristic signs such as epilation (in men), hyperpigmentation and dry scaling, which affect body aesthetics. This analysis reinforces the fact that such alterations compromise the patients' physical and psychological well-being. As the head and neck region is always exposed, aesthetic alterations related to radiodermatitis negatively affect quality of life and can lead to social isolation.

In relation to the Nursing guidelines, the four classes selected in the dendrogram show how important the approach by these professionals is in terms of helping to identify

these effects and providing guidance on how to take care of them properly These findings, which are in line with other studies[7,8], show the need for nurses to possess the appropriate knowledge to provide safe care for patients with head and neck cancer. Nursing consultations are essential for minimizing severity of the adverse events and reducing treatment interruptions due to radiodermatitis[19].

The study limitation is linked to the small sample size due to the fact that data collection took place in the midst of the COVID-19 pandemic, as the affected patients were withdrawn from their treatment, making it impossible to carry out the interviews, as well as patients with metastases to the head and neck region that were not part of the sample due to the reduced number of fractions and increased therapeutic dose.

FINAL CONSIDERATIONS

This study evidenced that the patients' knowledge about the treatment was quite incipient, as their concept was restricted and correlated to the adverse effects due to the negative impact. The participants were able to identify the adverse effects because they are visible and exert an impact on self-esteem and self-image, significantly affecting the aerodigestive tract and causing changes in everyday life. In terms of self-care guidance, the teachings passed on by the nurses were assimilated, as self-care was assessed at each weekly visit through the patients' reproduction of those teachings.

The study provides an opportunity to develop appropriate teaching strategies in future research to meet the psychobiological and psychosocial needs of patients with head and neck cancer undergoing radiotherapy; it also contributes to nurses' knowledge and visibility in order to devise products that reach the patients' knowledge.

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