Radiotherapy Experiences from the Perspective of Head and Neck Cancer Patients: Integrative Literature Review

Experiência Da Radioterapia Na Perspectiva Do Paciente Com Côncer De Cabeça E Pescoço: Revisão Integrativa

Experiencia deLa Radioterapia en la Perspectiva del Paciente con Câncer de Cabeza y Cuello: Revisión Integrativa

Dhiancarlo Rocha Macedo1*; Ryquelle Rhibna Neris2; Anna Claudia Yokoyama dos Anjos3

How to quote this article:

ABSTRACT

Objective: The study’s purpose has been to summarize the knowledge about primary studies that investigated radiotherapy experiences from the perspective of head and neck cancer patients. Methods: It is an integrative literature review. Results: The final sample consisted of 13 studies that were published from 1998 to 2015. Through the studies thematic analysis were identified four major themes, as follows: “physical consequences of radiotherapy”, “psychological and emotional repercussions of radiotherapy”, “lack of information about the treatment and posture of the health professional regarding the treatment adverse effects” and “support networks”. Conclusion: The studies showed that the radiotherapy treatment had important negative repercussions in the patients’ life regarding the reactions and readjustments, and also the roles played familywise, all due to the treatment. There was also an important knowledge gap on the subject, then demonstrating the need for new studies with a qualitative approach, aiming to better understand this experience, therefore, producing care improvement.

Descriptors: Head and Neck Neoplasms, Radiotherapy, Review.

1 Dentistry Graduate by the UFU, MSc in Health Sciences by the UFU, PhD in Nursing by the Universidade Federal do Rio de Janeiro (UFRJ), Specialist’s Degree in Hospital Dentistry by the Conselho Federal de Odontologia [Brazilian Federal Council of Dentistry], Universidade Federal de Uberlândia (UFU), Brazil.

2 Nursing Graduate by the UFU, Multiprofessional Residency in Health focused on Oncology Nursing by the UFU, MSc student enrolled in Nursing Postgraduate Program at the USP, Universidade de São Paulo (USP), Brazil.

3 Nursing Graduate by the Universidade Federal do Triângulo Mineiro (UFTM), MSc in Nursing by the USP, PhD in Sciences by the USP, Professor of the Nursing Graduation Course at UFU, Universidade Federal de Uberlândia (UFU), Brazil.
RESUMO


Descritores: Neoplasias de Cabeça e Pescoço, Radioterapia, Revisão.

RESUMEN

Objetivo: Sintetizar el conocimiento de estudios primarios que investigaron la experiencia de la radioterapia, en la perspectiva del paciente con cáncer de cabeza y cuello. Método: Revisión integrativa de la literatura. Resultados: La muestra final consistió en 13 estudios publicados entre 1998 y 2015. En el análisis temático de los estudios se identificaron cuatro temas más grandes: “repercusiones físicas de la radioterapia”, “repercusiones psicológicas y emocionales de la radioterapia”, “falta de información sobre el tratamiento y la la postura del profesional de la salud ante los efectos adversos del tratamiento y las redes de apoyo. Conclusión: Los estudios evidenciaron que el tratamiento radioterápico trajo repercusiones negativas importantes en la vida de los pacientes frente a las reacciones y reajustes en la vida y en los papeles desempeñados dentro de la familia, derivados del tratamiento. Se verificó también una laguna importante de conocimiento sobre la temática, demostrando la necesidad de nuevos estudios, con abordaje cualitativo, para una mejor comprensión de esta experiencia, reflejando en el perfeccionamiento de la asistencia.

Descritores: Neoplasias de Cabeza y Cuello, Radioterapia, Revisión.

INTRODUCTION

Cancer located in the head and neck region accounts for about 10% of malignant tumors, with approximately 50% of these cancers being located in the oral cavity. Patients bearing head and neck cancer have long-lasting and complex physical and psychosocial needs.

Malignant tumors of the head and neck are treated primarily by radiation therapy. During the radiotherapy treatment in the head and neck region, several adverse reactions such as mucositis, xerostomia, dysgeusia, odynophagia and opportunistic infections, which affect significantly the life of the patients, are common, resulting in difficulties in phonation, chewing, swallowing, sucking and breathing, which negatively affect the personal, professional, social and affective dimension.

In those kind of patients, high rates of depression symptoms are found when compared to other patients with different types of tumors. Anxiety, depression, uncertainties, and hopelessness are the most frequent psychological problems reported.

Qualitative studies have been conducted with the objective of investigating the experience of treatments from the perspective of the patient, being relevant to expand the knowledge about this trajectory. Accessing the patient experience can provide broad understanding of the phenomenon, bringing new possibilities for care quality improvement and, consequently, improving life quality.

Given the aforementioned aspects, we consider relevant the development of an integrative literature review, aiming to broaden and deepen the knowledge, summarizing results of primary studies that investigated radiotherapy experiences from the perspective of head and neck cancer patients, therefore, looking for scientific basis towards better care practice.

METHODS

It is an integrative literature review. A research method that makes it possible to gather and synthesize the current state of knowledge about a given topic in a systematic and orderly manner, as well as to identify knowledge gaps, which need to be met with new studies.

The searches were carried out from May to July 2016 with an update in April and May 2017, in the databases PUBMED, CINHAL, VHL, COCHRANE, and SciELO. The crosses used the Descriptors in Health Sciences (DECS) and terms of the Medical Subject Headings (MESH): head and neck neoplasms, radiotherapy, qualitative research/qualitative studies, in the VHL and SciELO databases; were also used: head and neck neoplasms, radiotherapy and qualitative research, interconnected by the Boolean operator AND. It was decided not to establish a publication period of the studies, being a historical understanding of this experience.

Inclusion criteria were, as follows: qualitative primary research, available in full, online, exclusively in the article format, published in the following languages: Portuguese, English or Spanish, focusing on the patient's experience with head and neck cancer in radiotherapy treatment; as exclusion criteria: articles not related to the proposed theme or that addressed other forms of treatment such as surgery and chemotherapy; articles not available in full and studies of a quantitative nature.

The following steps were followed: (1) identification of the theme and establishment of the guiding question; (2) search of scientific literature in the databases and selection of studies, observing the inclusion and exclusion criteria previously established; (3) categorization and organization of found articles; (4) analysis of the articles included; (5) evaluation of the results found and comparison with other studies; (6) presentation of the review with the synthesis of knowledge.
Bearing in mind that this study is a review of qualitative studies, we adopted the strategy named Population, Context, and Outcome (PCO)\(^\text{11}\) (Table 1), which refers to the population, context, and results, to construct the review question and search strategy performed. The guiding question was: “What has been published in the scientific literature with regards to the experience of radiotherapy from the perspective of head and neck cancer patients?\(^\text{12}\)

Table 1: Modified strategy: Population, Context, and Outcome (PCO). Uberlândia city, Minas Gerais State, 2017.

<table>
<thead>
<tr>
<th>Population</th>
<th>Context</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients bearing head and neck cancer</td>
<td>Radiotherapy</td>
<td>Experience, viewpoints</td>
</tr>
</tbody>
</table>

The data collection and quality evaluation of the studies were performed using the following instrument: Consolidated Criteria for Reporting Qualitative Research (COREQ),\(^\text{12}\) which is specific for the assessment of qualitative studies. 119 articles were found in the searched databases; after reading the titles and abstracts and observing the inclusion criteria, the final sample consisted of 13 articles.

RESULTS AND DISCUSSION

In Table 2 are presented the articles included in this integrative literature review well-arranged by sequential numbers, study objectives, journal in which they were published, and also their authors.

Table 2 – Study objectives, journals and authors. Uberlândia city, Minas Gerais State, 2017.

<table>
<thead>
<tr>
<th>Study objectives</th>
<th>Journal</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1</td>
<td>European Journal of Oncology</td>
<td>Olayeke, m. E.</td>
</tr>
<tr>
<td>S2</td>
<td>European Journal of Cancer Care</td>
<td>EGRIAT, D.</td>
</tr>
<tr>
<td>S3</td>
<td>International Journal Language &amp; Communication Disorders</td>
<td>Mung, R. L.</td>
</tr>
<tr>
<td>S4</td>
<td>Journal of Clinical Nursing</td>
<td>OTTISON, S.</td>
</tr>
<tr>
<td>S5</td>
<td>Danish Medical Journal</td>
<td>HÖRSMANN, O.; RAHBE, K. E.</td>
</tr>
<tr>
<td>S6</td>
<td>Journal of Oncology Nursing</td>
<td>MÜLLER, M. E.; MÜLLER, O. B.; KILIAN, A.; SCHRÖDER, U.</td>
</tr>
<tr>
<td>S7</td>
<td>European Journal of Oncology</td>
<td>LANDERMANN, U.; MEDRIN, B.; ATTEN, E.</td>
</tr>
</tbody>
</table>

The period of publication of the articles was from 1998 to 2015. No limitation was established as to the time period, in order to gather the largest number of publications. The studies (S1, S7, S8, S9, S10, S11) are of nursing and (S2, S3, S4, S5, S6, S12, and S13) of medicine.

The theoretical reference adopted in seven (7) of the studies was phenomenology (S1, S2, S3, S4, S8, S9, and S11); one (1) study adopted medical anthropology (S6), one (1) used the uncertainty theory in Mishel’s disease (S7) and four (4) studies did not mention theoretical reference (S5, S10, S12, and S13).

As data collection feature, the thirteen studies included in the review, five (5) (S1, S2, S3, S10, and S11) described the in-depth interview and six articles (S5, S6, S7, S8, S9 and S12) used the semi-structured interview. It was also verified that one (1) study (S13) did not describe the type of interview, and the study (S4) reported the use of an in-depth semi-structured interview.

After thematic analysis of the results of the studies, they were categorized. An analysis was then made to understand and integrate the results. Subjects and subtopics were built, which were distinguished by the homogeneity with which they appeared between the studies, making it possible to synthesize and integrate the experience of the study participants, with head and neck cancer, in treatment with radiotherapy (Table 3).

Table 3: Summary and integrated themes and subthemes of the review articles. Uberlândia city, Minas Gerais State, 2017.

<table>
<thead>
<tr>
<th>Themes/subthemes</th>
<th>Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Physical consequences of radiotherapy</td>
<td>1, 5, 6, 7, 8, 10, 11, 12 and 13</td>
</tr>
<tr>
<td>- Mouth alterations</td>
<td>1, 4, 5, 6, 7, 8, 9, 10, 11, 12 and 13</td>
</tr>
<tr>
<td>- Fatigue</td>
<td>1, 5, 6, 7, 8, 10, 11 and 12</td>
</tr>
<tr>
<td>- Speech Impairment</td>
<td>1, 2, 4, 5, 7, 8, 9, 10, 11 and 12</td>
</tr>
<tr>
<td>2: Psychological and emotional repercussions of radiotherapy</td>
<td>1, 2, 4, 5, 7, 8, 9, 10, 11 and 12</td>
</tr>
<tr>
<td>3: Lack of information about the treatment and posture of the health professional regarding the treatment adverse effects</td>
<td>1, 4, 5, 8 and 10</td>
</tr>
<tr>
<td>4: Support networks</td>
<td>3 and 4</td>
</tr>
<tr>
<td>- Other patients</td>
<td>2, 4, 5, 7, 11, 12</td>
</tr>
<tr>
<td>- Family</td>
<td>2, 4, 5, 7, 11, 12</td>
</tr>
</tbody>
</table>

Physical consequences of radiotherapy

Except for the studies (S2 and S3), the others showed that radiotherapy brought side effects, specifically in the oral cavity of the participants, such as: pain, xerostomia, mouth ulcers, palate alteration, and dysphagia; causing difficulty in
simple functions such as speech, chewing, swallowing, and even impairing the social interaction of the participants. The participants also described fatigue with the radiotherapy treatment, presenting fatigue, weakness and sleep disorders.

Psychological and emotional repercussions of radiotherapy

The studies (S1, S2, S4, S5, S7, S8, S9, S10, S11, and S12) showed psychological and emotional repercussions of the patients in relation to the disease and to the radiotherapy treatment, being these negative and positive.

Concerning the negative repercussions, according to the studies (S1, S2, S4, S9), the participants experienced a set of symptoms that revealed feelings of hopelessness, anxiety and other depressive symptoms. The results also showed that the patients were anxious and worried about the future and the effectiveness of the treatment. Radiation therapy has been associated with many difficulties and uncertainties.

In the studies (S5, S7, S8, S10, S11, S12) were pointed out positive feelings like hope and desire to return to the daily routine, adopted by patients to face disease and treatment reactions.

Lack of information about the treatment and posture of the health professional regarding the treatment adverse effects

This theme was evidenced in the studies (S1, S4, S5, S8, and S1) that brought the importance and need for information and an adequate posture by health professionals regarding the treatment and potential side effects of radiotherapy, including physical, emotional and psychological aspects.

For many participants, the information and guidance offered by the professionals were not specific or sufficient to address their doubts and assist them in the treatment, as well as the differences between the roles of each professional was not very clear.

A matter of concern for the participants was that their situation was not recognized in the real dimension by the health professional; the participants saw their situation deteriorate, despite the various treatments to which they were subjected. When they tried to express to the health professional the discomfort caused by the treatment, they received either little or no attention.

Support networks

The semi-structured interview has a script, previously established, with guiding questions; where the interviewer can ask supplementary questions to better understand the investigated phenomenon.7

Bearing in mind that the main focus of the studies was to recognize the person as being in constant interaction with their social environment, to interpret their impressions and to attribute personal meanings to the experience of the phenomenon, which was the radiotherapy treatment, we believe that the choice of methodology for the development of the studies was adequate. The qualitative methodology has given participants the opportunity to express their experiences, perceptions and the meanings they attribute to the process of illness and treatment.

Considering the current panorama, where cancer has been occupying increasingly high places among world statistics, being considered today an important public health problem. We highlight in this review that only one study on the experience of radiotherapy from the perspective of the patient with head and neck cancer was found before 2000 (S10), with most studies (60%) being published as of 2012. Although there has been an increase in the number of researches in general, there is still a low production on the subject. No other literature review was found, addressing this theme, reaffirming the relevance of this and new studies. It is also worth noting the lack of studies in the national scenario.

Considering the theoretical references adopted in the studies, this subject. Regarding clinical practice, it is important that the dentist professional broaden his/her vision about his/her patient, seeking to understand the different facets of the cancer patient’s trajectory during his/her treatment.

The studies focused on knowing/understanding and/or describing the patients’ experience vis-à-vis radiotherapy, adverse reactions and its consequences in their quality of life. The qualitative methodology, with its different theoretical references, data collection, and analysis techniques, allows the participants to express their experiences, perceptions, and senses attributed by them to the process of illness and treatments.26 It was verified that seven (53.8%) studies used the semi-structured interview for data collection, which confirms that this is one of the main strategies of the qualitative methodology, which provides an understanding of the experience lived by the participants of studies of this nature.

The studies (S4, S5, S7, S11, and S12) the family support stood out. Family members were identified as a significant source of support, mainly in dealing with side effects, among these, eating disorders.

In the studies (S4, S5, S7, S11, and S12) the family support stood out. Family members were identified as a significant source of support, mainly in dealing with side effects, among these, eating disorders.
Phenomenology, which indicates the interest of researchers in studying phenomena experienced by the participants. Phenomenology provides ways of providing insight into an individual experience, in other words, how individuals attribute meanings to social phenomena in their everyday lives.  

As for the data analysis, the thematic analysis technique was the most used by the authors, followed by content analysis. These are the two most frequently used forms for analyzing qualitative data, considering that they are techniques that provide an accessible and flexible approach, seeking to identify, analyze and report patterns from the data collected.  

For the theme “Physical repercussions”, it was verified that the malignant tumors of the head and neck region are treated mainly by radiotherapy, which acts in a localized way, using ionizing radiation; however, this modality of treatment is not selective, since it is incapable of differentiating normal tissues from what is malignant, which generates local and regional toxic effects for the organism.  

Except in the studies (S2 and S3), the others demonstrated side effects of radiotherapy such as: pain, xerostomia, dysgeusia, and dysphagia, leading to negative repercussions on participants’ lives, making it impossible to perform important functions such as talking, chewing and swallowing; so they needed to adapt to the new reality, whether in social, family and social life in general.  

The analysis of the studies (S1, S2, S4, S5, S7, S8, S9, S10, S11 and S12 showed that radiotherapy causes not only physical problems to the patient but also frequent psychological and emotional repercussions mixed with feelings of depression, uncertainties, hopelessness, anxiety, anguish, and suffering, as well as desire and hope to return to the daily life routine, interrupted by illness and radiotherapy.  

Evidence from the literature corroborates the results of this review showing that radiotherapy arouses a feeling of fear, including concerns about the efficacy of treatment and adverse reactions.  

Another important topic derived from the analysis of the results of the studies was the “lack of information about the treatment and posture of the health professional regarding the treatment adverse effects”. Considered inadequate by participants undergoing treatment, such attitudes increased patient insecurity and distress. It is important that educational actions and adequate treatment guidelines are carried out by professionals, both for patients and for family members and caregivers; therefore, it will contribute to the effective prevention, management, and treatment of possible adverse reactions.  

Only the study (S2) has led to the establishment of important positive links between patients and the radiotherapist. It should be noted that the patient’s trust with the radiotherapist as well as with the entire health team, transmitted calmness and confidence to the patients, in the face of unwanted reactions and other difficulties resulting from the treatment.  

The dedication of the health professional to his patient is of paramount importance for the success in the conduction and end of the treatment. In clinical practice, there must be empathy for the patient, offering individualized assistance, attentive and comprehensive listening, as well as an educational and professional orientation to the patient and family, seeking to understand their needs and attending effectively in a timely and qualified manner.  

The last issue identified as “support networks” showed that during illness and treatment family support as well as obtaining information from other patients who also experienced radiotherapy were instrumental in dealing with the adverse effects of treatment and the difficulties that have arisen. The family has been identified by patients as the most important source of support and assistance throughout the process of illness and cancer treatment.  

Family support is very important during treatment and convalescence, dealing with both the emotional support and the adaptation of family members to the patient’s new routine and needs.  

CONCLUSIONS  

The results of this review provide a scientific basis for the improvement of the humanized and individualized professional practice, as well as the deepening of knowledge and a better understanding of the subjective issues of the experience of patients with head and neck cancer submitted to radiotherapy oncological treatment.  

The great majority of the published and scientifically published studies related to the patient with head and neck cancer have been of a quantitative nature, making this comprehensive perspective impossible for all trajectory of the experience and repercussions of the treatment from the perspective of those who experience the phenomenon. As the main limitation of this review, we pointed out the lack of discussion of the results in the light of the theoretical references used, a fact that was due to the absence of this record in several studies and the diversity of theoretical references in the others, which would require great space for registration.  

This review also revealed an important gap in national knowledge and also low international production on the subject, emphasizing the importance, especially in the field of dentistry, since no study was found. The aforementioned poses challenges for the development of other studies that use the methodology qualitative targeting to explore in a broader and deeper way many aspects of the addressed thematic. Nonetheless, by using the aforesaid approach, it may be possible to provide a better understanding of the experience, in different socio-cultural and professional contexts, as well as adopting strategies that aim at the improvement of integral care offered to this population.  

REFERENCES  

Radiotherapy Experiences from the...
Radiotherapy Experiences from the...