

Challenges Faced by Patients Undergoing Radiotherapy for Oral Cancer: A Qualitative Study

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Abstract

Background: Oral cancer is one of the most common types of cancers in India. Radiotherapy is one of the treatment options frequently resulting in complications. These complications affect the patient's quality of life, nutritional intake, and consequently undermine the treatment outcomes. Patients' verbal accounts of experiences regarding their overall oral health during radiotherapy have not been described sufficiently. **Aim:** The aim of the current study was to identify and analyze the issues experienced by patients while undergoing radiotherapy for oral cancer treatment. **Materials and Methods:** A phenomenology study design was chosen, with in-depth interviews as the selected strategy for data collection. A literature search was conducted based on which an interview guide in English was prepared and modified according to inputs from subject matter experts. The interview guide comprised nine questions, including opening, key, and closing questions, and was also translated into Telugu and Kannada – the two languages predominantly spoken by the patients visiting the hospital. Interviews were conducted with each patient separately, with each interview lasting for 60 min each. The interviews were audio-recorded, transcribed, coded, and categorized, following which themes were derived from the analysis. **Results:** The key theme that emerged from the study was the “Multifaceted experience of patients undergoing radiotherapy.” **Conclusion:** Understanding the specific issues faced by oral cancer patients undergoing radiotherapy drew our attention to the dire need for interprofessional collaboration, which could enable health professionals to share their expertise and perspectives toward achieving the common goal of restoring patients' health and improving health outcomes.

Keywords: Complications, oral cancer, qualitative research, radiotherapy

INTRODUCTION

Oral cancer is a significant component of the global burden of cancer.^[1] It affects 300,000 people worldwide annually, which accounts for 2.1% of the total world population, with two-thirds of the occurrence seen in men.^[2] Oral cancer ranks among the three most common cancers in India, and in some areas, it accounts for almost 40% of all cancer deaths. In most of the regions in India, oral cancer is the second-most common malignancy diagnosed in men and the fourth-most common in women.^[3] It results in severe disabilities and has a profound impact on the most fundamental activities of daily life.

Although various treatment modalities exist for oral cancer, surgery and/or radiotherapy remain the gold standards.^[4,5] A majority of the patients with oral cancer receive radiotherapy on an outpatient basis every day for up to 6 weeks, following which the adverse effects of radiotherapy can be observed in cells that divide rapidly such as the mucous membranes.^[6] These

adverse effects result in various side effects such as pain, stress, difficulty in eating, dryness of the mouth, and xerostomia. Radiotherapy also complicates further surgery since the endarteritis, in particular, impoverishes healing.^[7] Radiotherapy is a complex and dynamic pathobiological process that hampers the quality of life and leads to physiological and psychological distress in a patient.^[8]

Studies have been conducted to understand the experience of pain along with other implications for patients in terms of quality of life, nutrition, and ultimately treatment outcomes, thus marking a long and excruciating journey laden with problems affecting physical, psychological, and social aspects.^[9,10] However, there is a lack of evidence focused on

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patients' verbal accounts of their overall experience during radiotherapy, which has not been described sufficiently despite being of great importance. Therefore, the current study was undertaken to gain a deeper understanding of the issues experienced by such patients and to leverage these findings to formulate a treatment plan for them. The aim of the current study was to describe the experiences related to the oral health of patients with oral cancer during radiotherapy.

MATERIALS AND METHODS

Research approach

A phenomenological approach was adopted to gain a deeper insight into the everyday "lived" experiences of patients undergoing radiotherapy.^[11]

Epistemologically, phenomenological approaches are based on a paradigm of personal knowledge and subjectivity and emphasize the importance of personal perspective and interpretation.^[12]

Study setting

The study was conducted in the cancer ward of the Centre of Oncology, M. S. Ramaiah Teaching Hospital, Bengaluru, Karnataka, India.

Participants

Patients suffering from oral cancer and undergoing radiotherapy for the past 2 months were selected as the participants for the study.

The sampling strategy chosen for the present study was purposive sampling, through which patients capable of providing relevant and meaningful information regarding their experiences during radiotherapy were selected and recruited. The age of the patients ranged between 35 and 72 years. The participants provided written consents for their participation, following which the study was approved by the Institutional Review Board of M. S. Ramaiah University of Applied Sciences.

Research instrument

Interviews were conducted based on an interview guide [Table 1], prepared in English, which was developed using the literature search and was later modified according to the inputs from the subject matter experts. The interview guide was also translated into Kannada and Telugu – the two predominantly spoken languages in that community. It consisted of nine questions, including opening, key, and closing questions, of which six were related to experiences of pain, chewing, and swallowing during radiotherapy [Table 1].

Data collection process

The interviews were conducted by the first author with the patients admitted to the cancer ward, as they were comfortable with interaction there. Data were collected until data saturation was observed. After interviewing 16 participants, it was observed that no additional information was likely to be gained. A preliminary interview with a few opening questions was conducted to develop the rapport between the researcher

and the participant. Each interview lasted for 60–90 min. All interviews were audiorecorded using a mobile phone in the Adaptive Multi-Rate (.amr) audio codec format, following which they were transcribed verbatim by the investigator. Social cues of the participant, such as voice, intonation and body language were noted, as they are capable of providing a substantial amount of additional information that can be used to strengthen the verbal answer provided by the participant.

Data analysis

The codes were then reanalyzed and grouped into patterned categories that were derived from the in-depth interviews.^[13] Subsequently, a theme was derived from the data, using the concept thematic analysis framework. In this manner, analysis of the data was repeated until no further themes emerged, and all the relevant text was coded.

RESULTS

Sixteen in-depth interviews were conducted for the patients undergoing radiotherapy. The participants included 10 female and 6 male patients, with a mean age of 58.4 years ranging from 35 to 72 years.

Analysis of the data generated two types of codes, i.e., deductive codes and inductive codes, resulting in the emergence of four main categories – "Pain," "Nutritional Consequence," "Barriers in Communication" from deductive codes, and "Support system" from inductive codes. These categories helped in deriving the theme "Multifaceted experience of patients undergoing radiotherapy" as shown in Table 2.

a. Pain: Almost all of the participants reported pain in the oral cavity. The effect of this severe pain was two-fold, as it also contributed to fatigue – already a significant issue faced by all the participants. One of the patients described it as "Any side it is; the pain is always there." "Yes, there is pain. They gave some tablets for the pain, and hence, the pain has reduced a bit." All the patients were taking medications to reduce the pain.

Sores and boils in the patient's oral cavity were labeled as painful. A 72-year-old woman stated: "When they give the radiation there are heat-boils formed, which become a wound and cause pain."

b. Nutritional disturbance: Some of the common side effects experienced by the patients were weight loss, dysphagia, and poor nutritional intake. Many respondents described their experience of radiotherapy as "a struggle to eat." During the initial phase of radiotherapy, the respondents could eat sufficiently. However, all the modifications that had to be made to the diet resulted in a lesser variety of food choices, and the respondents were, therefore, unable to find anything new and exciting to eat.

A 65-year-old male patient said: "I was eating well in the beginning. But after a few days, I find it difficult to eat food. I only drink Rice Porridge."

Table 1: Interview guide

S no.	Type of questions	Questions
1	Opening questions	How would you describe your experience and what are the major problems you are facing due to radiotherapy in your mouth? Probe: Stressful, unsatisfactory, coping
2	Key question	What are the painful experiences you have had in your mouth while the therapy was ongoing? Probe: Treatment, coping What measures have you taken to avoid that pain? Probe: Medication, any other measure What all difficulties do you face during speaking, chewing, and swallowing? Probe: Slurring, not being able to pronounce some words Who all motivate you to stay strong and eat healthy? How? Probe: Doctor, family, friends How do you cope with the difficulties you face with respect to eating, chewing, and swallowing food? Whom do you feel the most comfortable to talk to? Why? Probe: Doctor, nurse, family, friends
3	Closing questions	How do you see your future? Probe: Positive, hopeful, negative What are your expectations from the people around you? Probe: Doctor, family

Table 2: Structure of codes, categories, and theme

Codes	Categories	Theme	
Deductive codes			
Frustrated	Pain	Multifaceted experience of patients undergoing radiotherapy	
Depressed			
Hurting			
Go back home			
Persistent pain			
Tablets			
Chemo			
Medicines reduce pain			
Painful chewing			Nutritional disturbance
Unable to eat			
Rice porridge			
Reduction in food intake			
Painful swallowing			
Loss of meals	Barriers in communication		
Unclear words			
Difficult to talk			
Unable to move tongue			
Slurring of speech			
Speak little			
Unable to convey feelings			
Inductive codes	Support system		
Get better			
Feel positive			
Don't worry			
Take care			
Everything fine			
Visit from relatives			
Get cured			

- c. **Barriers in Communication:** Patients' communications skills were compromised due to the oral symptoms, as the boils in the mouth aggravated speech difficulties.

One of the respondents explained his difficulty in communicating his problems. He said, "Words are not clear when I speak."

"Yes, I only speak only a little. When I speak a phrase/sentence it starts to hurt, so then I stop talking."

- d. **Support system:** Support from immediate family and friends emerged as an important finding during the treatment and rehabilitation periods. Respondents highlighted that emotional support significantly contributed toward helping them to get through the long and arduous journey. The encouragement provided by family, friends, and doctors motivated them to undergo painful treatment. Patients mentioned "They keep telling me that it will get better," "I will be able to speak properly and eat well." "Everyone takes care of me very well." and "Doctor says that it is all ok, and everything will be fine."

DISCUSSION

The current study explored several aspects of oral health and the issues experienced by oral cancer patients undergoing radiotherapy. The theme of the study highlights all the facets of experiences faced by the patients. It was observed that the major issues cited by the patients were those related to pain and coping with it, apart from their communication skills and nutritional status also being compromised. The study led to the emergence of an important category called "Support system." The motivation that enabled the patients to comply for and persevere the painful treatment was provided by their families, fellow patients, and health-care providers.

Similar results were obtained from the studies showing that patients with head-and-neck cancer (HNC) have complex pain issues that have a significant impact on their treatment, general well-being, and recovery.^[9,14] The studies also concluded that HNC patients did not report that their severe physical pain influenced their psychological suffering, although it did impact their social lives.^[15] Furthermore, nutritional consequences were reported to have a detrimental impact on the patients'

daily routines. Studies have also captured eating problems experienced by HNC patients in two interrelated main themes: “Ability to chew and swallow” and “Will and desire to eat.”^[6,16] Patients reported that they were willing to eat but were unable to do so.^[17] Similar observations made in previous studies show that the eating problems altered the psychological and social dimensions of food for the respondents. Restricted food choices and diminished taste changed the respondents’ overall satisfaction levels achieved through food.^[10]

It is, however, important to note that despite the participants facing several difficulties such as “Pain,” “Barriers in communication,” and “Nutritional consequences,” their ability to cope with such difficulties was substantially enhanced by the emotional and psychological support available to them from their families in the form of a “Support System.” Most participants generally agreed that their families were the essential source of support for them. Further, fellow cancer patients also provided their valuable support to each other by sharing their experiences and exchanging knowledge related to self-care.

The use of a phenomenological approach was one of the major strengths of the current study, allowing a rich description of the participants’ experiences of pain, difficulty in eating, and speech during radiotherapy.

Although this study provides meaningful insights, some limitations have been identified in its findings. One such limitation was that the participants were recruited from one setting could limit the transferability of the study’s findings.

CONCLUSION

The study demonstrates that the patients have complex health needs, requiring intervention from more than one discipline to fulfill them. Thus, an interprofessional collaborative approach is likely to enable health professionals to share their expertise and perspectives toward achieving the common goal of restoring patients’ health and improving health outcomes. A multisectoral approach, through a team comprising a nutritionist, a speech therapist, and a psychologist, is of utmost importance for providing these patients the best care possible. Public health dentists could be the key professionals who are in a position to drive such initiatives, as they possess the knowledge and skills required to enable effective interprofessional collaboration and improve health outcomes.

Suggestions for future work

Future studies can be aimed at understanding the need for interdisciplinary collaboration to help patients facing the challenge of managing chronic and complex diseases. These studies can help in designing a protocol, which can be applied in hospitals, that leverages interprofessional collaboration for providing a better supportive environment for oral cancer patients.

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Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form the patients have given their consent for their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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Conflicts of interest

There are no conflicts of interest.

REFERENCES

- Petersen PE. Oral cancer prevention and control – the approach of the World Health Organization. *Oral Oncol* 2009;45:454-60.
- Ferlay J, Soerjomataram I, Dikshit R, Eser S, Mathers C, Rebelo M, *et al.* Cancer incidence and mortality worldwide: Sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer* 2015;136:E359-86.
- Gupta B, Ariyawardana A, Johnson NW. Oral cancer in India continues in epidemic proportions: Evidence base and policy initiatives. *Int Dent J* 2013;63:12-25.
- Krug E, Varghese C. *Guide To Cancer Early Diagnosis*. Geneva: World Health Organization; 2017. p. 1-48.
- Neville BW, Day TA. Oral cancer and precancerous lesions. *CA Cancer J Clin* 2002;52:195-215.
- Larsson M, Hedelin B, Athlin E. Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *J Clin Nurs* 2003;12:562-70.
- Scully C, Epstein JB. Oral health care for the cancer patient. *Eur J Cancer B Oral Oncol* 1996;32B: 281-92.
- Thanvi J, Bumb D. Impact of dental considerations on the quality of life of oral cancer patients. *Indian J Med Paediatr Oncol* 2014;35:66-70.
- Pattison N, Brown MR, Gubbay A, Peacock J, Ross JR, Chapman S, *et al.* Towards a pain free hospital: An in-depth qualitative analysis of the pain experiences of head and neck cancer patients undergoing radiotherapy. *Br J Pain* 2016;10:29-37.
- Ottosson S, Laurell G, Olsson C. The experience of food, eating and meals following radiotherapy for head and neck cancer: A qualitative study. *J Clin Nurs* 2013;22:1034-43.
- Monique H, Inge H, Ajay B. *Qualitative Research Methods*. New Delhi: SAGE Publication; 2011.
- Lester S. An introduction to phenomenological research. Stan Lester Dev 1999;18:1-4. Available from: <http://www.sld.demon.co.uk/resmethy.pdf>. [Last accessed on 2016 Jun 21].
- Carol G. *Qualitative Data Analysis-An introduction*. 1st ed. New Delhi: SAGE Publication; 2007.
- Schaller A, Larsson B, Lindblad M, Liedberg GM. Experiences of pain: A longitudinal, qualitative study of patients with head and neck cancer recently treated with radiotherapy. *Pain Manag Nurs* 2015;16:336-45.
- Petr S, Berthelsen CB. Lived experiences of everyday life during curative radiotherapy in patients with non-small-cell lung cancer: A phenomenological study. *International J Qualitative Studies on Health and Well-being* 2015;10:1.
- Marin Caro MM, Laviano A, Pichard C. Impact of nutrition on quality of life during cancer. *Curr Opin Clin Nutr Metab Care* 2007;10:480-7.
- Orrevall Y, Tishelman C, Herrington MK, Permert J. The path from oral nutrition to home parenteral nutrition: A qualitative interview study of the experiences of advanced cancer patients and their families. *Clin Nutr* 2004;23:1280-7.