ORIGINAL ARTICLE

THE EXPERIENCES OF ORAL CANCER PATIENTS: A NARRATIVE REVIEW

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ABSTRACT

This is a critical review of the current evidence on patients' experiences with oral cancer. The impact on the quality of life and implications to clinical practice and research were also discussed. A comprehensive search of three databases, PubMed, Scopus, and Google Scholar was undertaken. The search was restricted to English-language primary research papers from 2009 till 2019. The following keywords were used: mouth neoplasms, patients, experiences, oral cancer, physical, social, psychological. A total of 173 studies were retrieved using the search strategy. After removing duplicate reports and scrutinising those based on title and abstract, 68 studies were shortlisted for full text review. Three major themes emerged from the literature: (1) physical experiences of oral cancer patients, (2) psychological experiences of oral cancer patients, and (3) social experiences of oral cancer patients. Experiences of oral cancer patients are complex and subjective, and phases of physical, psychological, and social experiences of oral cancer have not been explored in detail. However, there is evidence that experiences such as pain, facial alterations, body image disturbances, anxiety, depression, social avoidance, social support, and financial implications affect patients' quality of life. This review underlines the importance of further research to look into the type of support needed to address various experiences of oral cancer patients.

Keywords: Oral Cancer, Patients, Experiences, Physical, Psychological, Social

INTRODUCTION

Oral cancer refers to malignant neoplasms of the lips, oral cavity, salivary glands and oropharynx, which correspond to the codes C00-C10 of the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)¹. In 2018, there were an estimated 354,864 new cases of lip and oral cavity cancers, 52,799 new cases of salivary gland cancers, and 92,887 new cases of oropharyngeal cancers worldwide, and more than 250,000 deaths². The survival rate for oral cancer is at approximately 50%³. This poor rate has remained essentially unchanged since the past three decades despite the advances in therapeutic interventions⁴. Being among the 10 most common cancers in the world, oral cancer is considered a major public health problem⁴.

Treatment options for oral cancer include surgical resection, radiotherapy and chemotherapy, which can be administered alone or used in combination depending on location and stage of the tumour, as well as patient's overall health and personal preferences^{5,6}. Although there have been continuous improvements in the treatment modalities of oral cancer, collateral damages to the head and neck structures remain as the unwanted

consequences⁷. Debilitating side effects associated with cancer therapy encompass short term and long terms complications arising in various conditions and degrees of severity, depending on the individual and the type of treatment such as stomatitis, infection, bleeding, mucositis, pain, loss of function, and xerostomia⁷.

Apart from the physical suffering, oral cancer treatments and complications can cause significant psychological stress not only of the patients but also their families and caregivers⁸⁻¹¹. Following diagnosis of oral cancer, patients may express emotional and physiological traumatic experiences primarily as the oral region is a prominent part of the body¹². Additionally, studies have suggested that after getting treatment for oral cancer, patients may develop multifaceted social challenges that disturb their daily life style causing deviations in interpersonal communication, decrease in social activities and work related concerns^{13,14}.

Assessment of patient quality of life has therefore become an integral outcome measure for oral cancer treatment¹⁵. The World Health Organization (WHO) define quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards

and concerns”¹⁶. It is a complex multidimensional concept that measures the relationship of a person’s physical health, psychological state, personal beliefs, and social relations to the environment. There is a vast literature reporting the quality of life of oral cancer patients utilising generic and disease-specific instruments to quantitatively assess patients’ health status and the impact of therapeutic applications¹⁵. Additionally, there are numerous qualitative studies that explore the meaning and understandings of individual oral cancer patients’ personal life experiences^{17,18}.

This narrative literature review compiles available evidence of oral cancer patient experiences across the disease trajectory. This will help health care professionals and policy makers to better understand the experiences of oral cancer patients and facilitate the development of comprehensive patient-centred care and support for the patients.

METHODS

Three electronic databases (PubMed, Scopus, and Google Scholar) were searched using seven major keywords “mouth neoplasms”, “patients”, “experiences”, “oral cancer”, “physical”, “social”, and “psychological” in combination. The following restrictions were applied to the search: 1) papers published in English language from 2009 till 2019, and 2) primary research papers reporting oral cancer patients’ experiences. The online search was also supplemented by manual search and examination of the references listed in the identified research papers.

All primary studies reporting experiences of being diagnosed and treated for oral cancer published in English from 2009 till 2019 were identified. Titles and abstracts of the studies were screened. Duplicated studies and studies that were not related to oral cancer were removed. Any disagreement was resolved by discussion to achieve a consensus among all authors. Studies fulfilling the aims of this review were included for full review and exported to the reference managing software Mendeley version 1.19.4.

RESULTS

The search strategy and initial screening of abstracts and titles yielded 173 studies. After removing duplicates (n=3), 170 were scrutinized according to the pre-determined criteria and 108 were shortlisted for full text review. Following discussion and review, 68 studies were included in the final list.

The studies included in this review reported experiences of oral cancer patients from different cultural backgrounds living in 23 countries around the world. Except for the Antarctica and Africa, the remaining world continents were well represented with studies from Asia (China, India, Japan, Pakistan, and Taiwan), North America (Canada and

United States of America), South America (Brazil), Europe (Bosnia, Denmark, France, Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, Switzerland, and United Kingdom) and Australia/Oceania (Australia).

Three major themes emerged from the literature: (1) the physical experiences of oral cancer patients, (2) the psychological experiences of oral cancer patients (3) the social experiences of oral cancer patients. The findings of this review are presented in the light of these interrelated experiences.

The physical experiences of oral cancer patients

The intensity of the physical impact related to oral cancer, as reflected in quality-of-life measures, differs significantly depending on the site and size of tumour, disease progression and type of treatment¹⁹⁻²². Pain is a highly prevalent physical symptom experienced among oral cancer patients²³. Oral cancer patients reported experiencing pain irrespective of the disease stage although the pain often increases as the tumour progresses²⁴⁻²⁷. The features of oral cancer pain are unique. Besides experiencing pain at the primary tumour site¹⁰, pain is also generated from the constant need for oral cavity anatomical area to be functioning during the activities of daily living, particularly speaking, eating, chewing and swallowing^{20,28,29}. Pain will further reduce the function ability of the oral cavity^{19,26,30}. Pain is therefore reported as the worst symptom by oral cancer patients, exacerbated by the functional requirements and mechanical stimulation³¹.

Collateral damages to the head and neck structures such as mouth, teeth and salivary glands are frequently encountered as unwanted consequences following cancer therapy, particularly radiotherapy directed to the head and neck area and chemotherapy³²⁻³⁴. Oral complications of cancer and cancer therapy comprise of acute and chronic toxicities resulting in various oral symptoms and signs including pain, reduced saliva quality and quantity leading to feeling of dry mouth or xerostomia which can make it difficult for patients to eat and speak, neurosensory changes (taste alteration, taste loss), mucosal infection (candida, herpes etc.), acute exacerbation of dental caries, gum inflammation, and limited opening of the jaw (trismus) and tongue function^{31,35-37}. Oral cancer and its treatments can also result in facial disfigurement. The degree of facial disfigurement vary from mild to severe depending upon the tumour site, disease progression, and treatment type³⁸. Facial disfigurement may result in speech impairment, swallowing and chewing problems, difficulty in controlling oral secretions, pain and discomfort of neck and maxillofacial areas, and physical weakness due to poor nutrition³⁹⁻⁴¹.

Human faces are unique and contribute to individual identity⁴². The face is one of the most fundamental parts of the body for self-recognition, body image, communication and interpersonal

relationships⁴³. Despite considerable advances in treatment therapies, facial disfigurement resulting from the cancer itself or its treatments is usually very noticeable and oral cancer patients may encounter associated social stigmatisation^{26,38,44}. Facial disfigurement is also linked to experiences of anxiety and depression in both patients and caregivers^{45,46}. Most patients go through financial difficulties such that it is not feasible for them to go for facial reconstructive surgeries^{37,47}.

The psychological experiences of oral cancer patients

The impacts of oral cancer are beyond functional limitations^{46,48}. Oral cancer patients express the highest level of unmet needs in psychological domain⁴⁹. A cancer diagnosis can disrupt the life of almost any individual by threatening one's general sense of security and orderliness in life⁵⁰. Patients with oral cancer are prone to psychological distress that can happen immediately following diagnosis and during the treatment phase⁵¹. Psychological experiences related to oral cancer include depression, anxiety, stigma, distress, helplessness, and fear⁵²⁻⁵⁵. These psychological experiences were found to be related to disease progression, type of treatment and disease outcomes including body image disturbance⁵²⁻⁵⁵.

Body image disturbance is the perception of changes in body appearance including facial disfigurements, body function, or both^{40,56}. The relationship between body image disturbance and experiences of distress and anxiety is complex and multifaceted⁵⁷. Personal dissatisfaction, feelings of unattractiveness and concerns about changes in body appearance often lead to social avoidance^{56,58}. Additionally, patients may experience emotional and existential vulnerability arising from their feelings of being trapped in their body image⁵⁰. The severity of psychological experiences is influenced by the patient's pre-operative state of mind, social environment, coping strategies, and acceptance of illness⁵⁶.

As oral cancer progresses and treatment starts, the psychological experiences are commonly attributed to physical complications of the disease⁴⁶. These include impairments of the basic functions of the mouth such as chewing, swallowing and ability to speak which vary according to the course of disease (remission, recurrence, progression, and end of life) and phase of treatment^{19,26,30}. Different types of oral cancer treatment would have resulted in different degree of functional impairments and subsequent psychological outcomes⁵⁹. Patients treated with combined therapies, particularly involving radiotherapy and/or chemotherapy, were more likely to experience functional impairments than those who had surgical resection alone⁵⁹. Reciprocally, patients who underwent surgery alone have been shown to report more positive psychological change than those who had combined treatment of surgery and radiotherapy⁶⁰.

The rates of depression generally increase with the growing tumour or the treatment-related physical symptoms⁶¹. Evidence has also shown that the level of anxiety is highest at pre-operation period while depression is highest at post-operation period⁵¹. This is in accordance to the number of patients experiencing the psychological impact; the number of patients experiencing anxiety is highest before start of therapy while the number of patients experiencing depression is highest soon after therapy⁶¹.

Emotional distress can remain high even after one month post-therapy before improving slowly after three months²⁴. Additionally, upon discharge, many patients feel worried or anxious that the cancer will come back after therapy^{29,62}. The constant pattern of high level of uncertainty during and one month after treatment may hinder cancer survivor's adjustment to daily life²⁷. After three years, some patients are still worried about reoccurrence although the magnitude of the apprehensions does not impact their quality of life⁶³. Nevertheless, throughout the oral cancer trajectory, patients will commonly feel powerless, diminished and dependent, with damaged self-esteem and the need to struggle to build self-image^{64,65}.

The social experiences of oral cancer patients

Social avoidance, social isolation, social distress, lack of social support from family and friends, health care professionals and health care system, altered social interactions, financial constraints are among social experiences described by oral cancer patients^{22,66-70}. These social experiences do not occur in a vacuum. The social experiences are influenced by various levels of circumstantial events or conditions that disrupt patients' socio-ecology balance including symptoms and complications of oral cancer and the therapy such as xerostomia, taste disturbances, dietary restrictions, dysphagia and pain, and fatigue⁷¹⁻⁷⁴. Patients with altered sense of affiliation may report problems related to social interactions or intimacy with their partners⁷⁵.

Financial issues are related to the social experiences of oral cancer patients. The costs of oral cancer treatment and follow-up care can put patients and their families under great financial strain. Besides the cost of treatment, patients may face extra expenses for treating and/or managing symptoms and side effects of treatment and for travelling to and from the hospital^{11,20,26,69,73,76}. Worse still, a high proportion of oral cancer patients had to reduce their work capacity following diagnosis, and many were unable to return to work after therapy⁷⁶. Reduction of work hours and work loss, which are associated with employment status before diagnosis, cancer-related symptoms, tumour stage, presence of comorbidity, and treatment modalities, may lead to social isolation, reduced self-esteem, and impaired quality of life for survivors^{9,26,41,58,76-78}.

In addition to negative social experiences, patients with oral cancer also reported positive experiences in relation to their diseases, such as resilience, spiritual beliefs, and stronger family relationships^{11,79}. Social support from family members can help patients cope with the physical, emotional and social distress associated with the disease and deal with the stigma of the disease and the fear of recurrence⁶⁵. Social support is also positively associated with enhanced health-related quality of life. On the other hand, patients who experience less social support would be at greater risk for psychological symptoms and psychosocial dysfunction^{55,80}. Social support is linked to social inequality, and it is apparent in the case of late diagnosis which is more prevalent in patients who live alone and have low education level⁸¹.

DISCUSSION

A diagnosis of oral cancer can have a significant impact, not just on the patient, but on their spouse/partner, family, and broader social network. Patients with oral cancer experience tremendous physical, psychosocial, and social challenges. The experiences are unique to the individual as each patient will respond differently to the disease and its treatment. While disease interpretation, outcomes and experiences of patient may vary, the close interrelatedness amongst physical functionality, psychological suffering and social distress of oral cancer is unquestionable.

Pain is a significant factor influencing the daily living activities of oral cancer patients⁸². The unpleasant experience of intense pain can also have negative impact on the social-emotional wellbeing, and subsequent quality of life of patients^{19,26,30,82,83}. Impaired speech due to pain may also lead to changes in work and restriction of interpersonal relationships⁸⁴. Inability to accomplish essential activities of daily living and having to rely on others may lead to psychological impact as patients feel lessened or limited by the condition⁸⁵. Nevertheless, guided support by specialists has been shown to be helpful in enhancing patients' quality of life through development of positive coping strategies to deal with pain⁴¹. Pain often co-exist with fatigue^{10,23}, which was reported as the predominant physical symptom related with overall care and supportive needs²⁹. The literature also suggests that patients with psychological support may have decreased intensity of physical experiences⁸⁶.

Oral cancer and its therapy may result in permanent facial disfigurement that can cause not only oral dysfunctions, but is also associated with body image disturbances, anxiety and depression⁸⁷. Patient often have concerns regarding their appearance and need to learn to cope with the way people react when looking at their face^{42,88}. Patients may also encounter social stigmatisation associated with the facial disfigurement³⁸. Quality of health care received and the attitude of health care professionals have significant influence on patient's

narration of pain and the ability to self-govern life and cope with facial deformities⁸⁹.

The decline in oral functionality changes the social functioning atmosphere of patients which is linked to the psychological consequences such as depression and emotional imbalance⁸⁸. The state of anxiety and depression of oral cancer patients appears to reflect the general experience of anguish which relates to the state of psychological vulnerabilities at different disease stages and treatment phases. The issues of anxiety and depression found in oral cancer in this review is complex. The struggle arises as the relationship between depression, anxiety, functionality and quality of life is ill-defined⁸⁸. Depression and anxiety are reported to have significant implications on the quality of life of oral cancer patients, influencing their thoughts about confronting mortality and dealing with morbidity⁹⁰. Depression has marked effects on oral cancer patients because depressed patients are less likely to adhere to the recommended treatment; instead they are more likely to have extended hospital admissions and decreased ability for gaining normality after treatment⁹¹.

Disruptions in physiological functioning following oral cancer treatment may lead to social avoidance^{92,93}. Additionally, loss of employment may place greater financial burden on the patients which will further reduce their psychological and social functioning⁹⁴. Issues with employment are significantly associated with poor quality of life among patients as reflected by high levels of anxiety and social avoidance⁹⁵. Clearly, there is a need for health care providers to comprehend and explore the expressions of depression, anxiety and building self-management skills in oral cancer patients in order to provide better quality of life^{96,97}.

The support needed by oral cancer patients vary across the disease trajectory⁹⁸. Some patients reported a fulfilling life with satisfaction, despite considerable degree of physical disability as a result of treatment⁹⁹. Health care professionals should therefore pay careful attention to patient's perceptions of quality care and the specific needs of each patient¹⁰⁰. However, it was reported that most oral cancer patients were dissatisfied with the way health care providers are helping them to cope with body changes, indicating unmet health needs among the patients³⁹.

This narrative review identified physical, psychological, and social experiences of oral cancer patients. The review includes results from both quantitative and qualitative studies on heterogeneous samples of oral cancer patients from various cultural background using various quality of life instruments and interview topic guides respectively. However, the experiences presented in this review were derived, hence may not be the comprehensive narration of oral cancer experiences. Furthermore, none of the included studies reported

physical, psychological, and social experience of oral cancer patients all at once.

Additionally, oral cancer is a broad term referring to malignant neoplasms of lip, oral cavity, salivary glands, and oropharynx. Indistinctness exists in the literature associated with the term used to describe the disease as some studies used the term 'head and neck cancer' to refer to malignant neoplasms of the oral and oropharynx area. Nevertheless, we have made the attempt to reduce this ambiguity by including studies that met the criteria for inclusion and studies on 'head and neck cancer' besides 'oral cancer'.

CONCLUSION

The experiences expressed by oral cancer patients are of varying nature with high subjectivity, reflective of the complexity of disease progression. This review delivers an overview of the physical, psychological, and social experiences of oral cancer patients across the disease trajectory that vary according to the affected site, stage of disease, type of therapy and other personal and environmental factors. The physical, psychological, and social stressors are often intertwined, both resulting from and contributing to each other. This review highlights the need for further qualitative research on the broad experiences of oral cancer patients that can help inform a better understanding of the issues.

A comprehensive list of experiences and a good understanding of patients' experiences would provide a sound basis for development of patient-centred and individualised care. Considering that oral cancer experiences are unique to each patient; this information would enable health care providers to focus on individual patient support requirements and needs depending on the patient's specific issues or challenges in life.

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