



**PSYCHOLOGICAL AND PSYCHOSOCIAL IMPACTS IN HEAD & NECK CANCER PATIENTS – A SYSTEMATIC REVIEW**

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**ABSTRACT**

Oral and or pharyngeal cancers so far have become a dreaded disease due to its considerably higher rate of occurrence associated with mortality and morbidity. The global overall five year survival is approximately 50% – 60% with varied geographic distribution. Apart from physical crippling, mental instability due to apprehension of death as well as inactivity plays a crucial role in the prognostication of head & neck cancer. Most of the cancer patients and survivors experience psychosocial distress during the course of their diagnosis and treatment. Psychosocial distress can be related to physical or psychological problems, family issues or social concerns. Issues and the level of distress vary between two individuals, and within an individual itself, over the course of diagnosis and treatment. This disruption of social well-being is cumulatively considered as diminution in quality of life (QoL). Unfortunately, assessment of psychosocial aspect is most often ignored among cancer patients and their care-givers. The aim of this review article is to highlight the prevalence of psychological and psychosocial distresses and its specific manifestations in the oral cancer population as well. Researchers have evolved scales to evaluate the status and level of anxiety and depression which is now-a-days mandatory to ensure appropriate management in these cases.

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**INTRODUCTION**

The global incidence of oral and oropharyngeal cancer is on the rise in many countries. Oral and oropharyngeal cancer, grouped together, is the sixth most common cancer worldwide, despite its geographical disparity [1]. In Indian scenario, oral cancer is one of the most commonly occurring cancers with an estimated amount of total 600,000–700,000 deaths in 2012 [2]. The International Agency for Research on Cancer (IARC) GLOBOCAN project [3] has predicted increase in India's cancer burden to be double in the next 20 years, from slightly over a million new cases in 2012 to more than 1.7 million in 2035. Five-year survival rates vary from 34 to 77%, depending on tumour type, staging and localization besides conventional treatment. Futility in prototype methods focuses on organ preservation and Quality Of Life (QoL) [4].

Patients diagnosed with oral and oropharyngeal cancer experience physiological impairment in terms of difficulty in swallowing, speech, verbal communication culminating into long-term psychological and psychosocial problems including anxiety, depression, loss of self-esteem. Management of oral and oropharyngeal cancer demands interdisciplinary approach hence there is a dynamic relationship in oncology between research, clinical and supportive care in assessing and meeting cancer patients' needs.

**Aim of this Review**

The aim of this review is to ascertain the prevalence of psychological and psychosocial distress and its specific manifestations in the oral cancer population.

Previous integrative reviews of the head and neck cancer literature tentatively suggested that psychosocial interventions improved quality of life, had a positive impact on emotional adjustment and improved coping skills, but many of these studies had methodological flaws (Semple 2004) [5]. In recent

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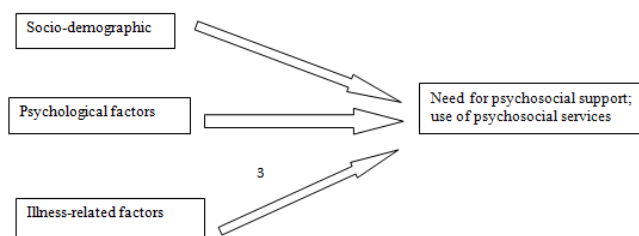
years there has been an increase in the number of studies that have developed and tested interventions to improve quality of life, reduce distress and enhance adjustment for patients with head and neck cancer; therefore it is reasonable to suggest that a higher standard of methodology and reporting should be evident in this systematic review.

### Psychological and Psychosocial Aspects

#### Assessment of Patients' Needs in Current Scenario

Defining "needs" is difficult due to the inherent complexity of the concept. Maslow's "Theory of Human Motivation", has distinguished between physiological, safety, love, esteem and self-realization of human needs, which are hierarchically arranged. That is to say, "the appearance of one need usually rests on the prior satisfaction of another more pre-potent need". [6] The basic aspect of human need is the health-care need which is defined as capacity to benefit from health care.

Those offers should be made to cancer patients as well as survivors, since distress and needs for supportive care might be significant up to 10 years post-cancer treatment. Since cancer patients facing life-threatening diagnoses often experience distress, screening tools for emotional distress have been developed to identify those patients who need psychosocial support and are being used in many countries. However, psychological distress cannot explain much of the variance of the need for psychosocial support, i.e. the severity of anxiety and depression cannot predict satisfactorily the perceived need for psychosocial support. A wider perspective is required for the investigation of determining factors. To address this issue, the research model underlying our review is the "Behavioral Model of Health Services Use" by Andersen. According to him, the need for a special health service determines the use of this service. In his original and revised model, the author assumes that the use of health services is part of the health behaviour of a subject and dependent on a range of factors [7]. There are predisposing characteristics (e.g. socio-demographic factors) which determine individual enabling resources (e.g. family) which in turn impact the need for a special health service. Given the situation that the identification of patients at need for psychosocial help is a crucial aspect of high quality oncological care, it is the aim of our study to (a) describe the proportion of patients needing help and (b) examine the socio-demographic, psychological and illness related variables as hypothesised determinants of the need for or the use of psychosocial services (Fig.1) [8].



**Figure 1** demonstrating interrelationship between psychosocial factors and need for psychosocial support.

Head and neck cancer has an enormous impact on QoL, because of problems with speech, dry mouth, swallowing, pain, anxiety, mood disorders, fatigue and depression. Information and support were found to positively influence rehabilitation. Rehabilitation outcomes were related to type of treatment, with no insight into long-term influence of

treatment [4]. Numerous concerns exist from a psychological perspective for the head and neck cancer patient, including the reaction to the cancer itself, the threat to one's mortality, body image issues, fears of treatment (surgery, radiation, and chemotherapy) and potential disfigurement, family, social and vocational issues, and normal psychological responses such as anxiety and depression. [8] It is currently recommended in UK government policy that all patients with a cancer diagnosis should "undergo systematic psychological assessment at key points and have access to appropriate psychological support" (NICE 2004) [9]. The National Cancer Comprehensive Network (NCCN) in the USA advocates that all cancer patients should be screened for psychological distress, with the premise that a number may benefit from further psychosocial interventions (Holland 2005) [10].

#### Difficulties with Speech

Verbal communication plays a major role in one's life style, and when it is distorted by surgical treatment of head and neck cancer, the patient often feels a very real sense of loss. Following surgery, artificial speech can be attained in the laryngectomy patient, and important predictors of successful speech rehabilitation relate to problem-solving behavior, age, and marital status/support system. When speech impairments result from reconstructive procedures, this deficit or loss of a primary means of expression can be devastating. Quality of speech is often compromised and vocal expression related to routine, special and emotional situations may be sacrificed. Understanding and patience are needed to assist the patient in overcoming this difficulty.

#### Difficulties with Deglutition

Changes in the ability to eat and drink in a socially acceptable fashion are often difficult issues for the patient. Many patients require an altered diet, which is often blended and relatively tasteless. Some patients will separate themselves entirely from the ritual family meal. Aside from the physical difficulties and embarrassment encountered in eating with radically altered and sometime insensate mouth structures, patients often experience altered taste sensation, which reduces the enjoyment formerly associated with eating and drinking. This is frequently a difficult loss for the patient physically, emotionally, and socially. Encouragement from friends and family can prove helpful to the patient facing these difficulties.

#### Psychological Distress and Depression

Depression may present as an early symptom of cancer, even developing prior to the diagnosis (Brown & Paraskevas, 1982) [11]. Davies, Davies, and Delo (1986) [12] attempted to ascertain levels of anxiety and depression in patients undergoing diagnostic investigations for head and neck cancers. Patients attending a regional head and neck oncology unit were evaluated for depression and anxiety before a diagnostic biopsy. Following the diagnosis of head and neck cancer, depression is a common manifestation which should be treated aggressively and appropriately (Telfer, 1993) [13]. Higher levels of fatigue are often reported, and the fact that depression and somatization may be issues for the head and neck cancer patient dictate that the psychological needs of the patient be carefully evaluated (Jones, Lund, Howard, Greenberg, McCarthy, 1992) [14].

Due to disfigurement, maintenance of the conjugal life often becomes difficult due to sexual impairment. Some additional

factors associated with human sexuality as they relate to head and neck cancer include alcohol, aging, depression, and facial appearance.

Higher levels of fatigue are often reported, and the fact that depression and somatization may be issues for the head and neck cancer patient dictate that the psychological needs of the patient be carefully evaluated [14]. The experience of psychological distress, particularly depression—whether as subclinical depressive symptomatology or clinical depressive disorder—is quite common among cancer patients and may occur throughout the course of illness, often persisting months beyond the conclusion of treatment in cancer survivors (Massie, 2004) [15]. The basis for this distress is likely multifaceted and may be a function of the diagnosis itself, the presence of burdensome disease and treatment sequelae, declines in Health Related QoL (HRQoL), and/or the possibility of disease progression, recurrence, or death. Notably, depression in HNC patients has been estimated to be more prevalent than in other types of cancer [15]. Estimates vary by assessment method (i.e., self-report measures vs. diagnostic interview), but indicate that between approximately fifteen and fifty percent of HNC patients suffer some degree of depression at any given point across the disease trajectory (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009) [16] and may affect immune competence, treatment adherence, self-care behaviors, re-socialization, and aspects of HRQoL (DiMatteo, Lepper & Croghan, 2000; Howren, Christensen, Karnell, & Funk, 2010; Spiegel & Giese-Davis, 2003) [17] [18] [19].

Numerous studies have evaluated the impact of depression on various global and HNC specific HRQoL domains. For example, Howren and colleagues (2010) [18] found that subclinical depressive affect present at diagnosis, before the initiation of treatment, was associated with poorer HRQoL one year later after adjusting for baseline HRQoL values as well as age, gender, marital status, disease site and stage, alcohol and tobacco use, and physical comorbidities. Specifically, those patients scoring 10 or above on the Beck Depression Inventory (BDI; Beck, Rush, Shaw, & Emery, 1979) [20] failed to regain normal functioning by one year post diagnosis across each of four HNC-specific domains including speech, eating, facial aesthetics, and social disruption as measured by the Head Neck Cancer Inventory (HNCI) (Funk *et al.*, 2003) [21]. Chen and colleagues (2010) compared 165 HNC inpatients, divided by caseness according to the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) [22], on several outcomes including disease impact, symptom distress, and supportive care needs. The authors found that patients with high levels of anxiety were more likely to report increased disease impact including disease-specific intrusion and avoidance, although the groups did not differ significantly relative to symptom distress and supportive care needs. More commonly, anxiety is considered only when measures such as the HADS are used to capture psychological distress, but depression and anxiety subscale scores are also evaluated as predictors or correlates of HRQoL and/or other clinical and psychosocial outcomes, sometimes as a secondary aim of the study (e.g., Kobayashi, Sugimoto, Matsuda, Matsushima, & Kishimoto, 2008) [23].

In a study of HNC patients with (versus without) persistent post treatment depressive symptomatology (i.e., patients with consistently elevated BDI scores for six months or more

beyond the conclusion of treatment), Karnell and colleagues (2006) [24] reported that patients experiencing persistent depressive affect were more likely to report worse HNC-specific HRQoL outcomes after adjusting for various clinical characteristics. Similar results have been found in other studies measuring depressive symptomatology and/or more general distress in HNC patients (Bornbaum, Fung, Franklin, Nichols, Yoo, & Doyle, 2011) [25]. Despite evidence of its presence at all stages of the disease trajectory, relatively few studies have primarily aimed to evaluate the association between anxiety and clinical or HRQoL outcomes in this population (Chu TL, Yu WP, Chen SC, Peng HL, Wu MJ; 2011) [26].

### **Quality of Life**

Costa, Azevedo and Vartanian (2008) [27] conducted a study on quality of life related to swallowing after tongue cancer treatment. Evaluating the quality of life related to these swallowing alterations is important to further our knowledge about the impact of such alterations from the patient's point of view. Our objective was to describe the quality of life related to swallowing in patients treated for tongue cancer, using specific questionnaires. Twenty-nine patients participated in the study for a minimum of one year after oncologic treatment. Patients with advanced disease who underwent radiotherapy had significantly worse scores in most domains. The aspects related to how to deal with deglutition problems, time taken for meal consumption, pleasure in eating, chewing problems, food sticking in throat and mouth, choking, and the knowledge of feeding restrictions, which were evaluated by different domains of QoL, were factors that contributed to a negative impact for patients with advanced-stage tumors who underwent radiotherapy. Recently, better methods for symptom assessment have been developed, including brief self-report tools for the assessment of multiple symptoms and interactive voice response systems for assessing symptoms at home. Symptom assessment can be linked to evidence-based or best practice guidelines to expedite optimal symptom treatment. Because patients with cancer receiving radiotherapy are seen in the clinic frequently, the radiation oncologist can play an integral role in a comprehensive approach that involves both the medical and radiotherapeutic treatment of cancer related symptoms. Borggreven, Verdonck and Muller (2007) [28] conducted a study on quality of life and functional status in 80 patients with cancer of the oral cavity and oropharynx. The results revealed a wide range of health related quality of life (HRQoL) and functional deficits before treatment.

Five main factors were associated with varying degrees with HRQoL, personality, social support, satisfaction with consultation and information, behavioural factors, such as consuming alcohol and smoking, and depressive symptoms. The major difficulty with synthesizing the findings was the amount of different indices of QoL that have been used. However, a number of psycho-social factors have been investigated in relation to HRQoL in head and neck cancer patients, some of which are potentially modifiable, such as those related to informational needs. Further research is needed to investigate other psychological factors which may influence aspects of HRQoL. By understanding the relationship between HRQoL and potentially modifiable variables, interventions can be designed with the aim of improving a patient's long-term well-being. Terrell, Ronis and Fowler (2004) [29] conducted a study on clinical predictors of

quality of life in 570 patients with head and neck cancer. A self-administered health survey was constructed to collect demographic, health, smoking, alcohol, depression symptom, and QoL information.

### **Body Disfigurement**

Van Doorne, Van Waas, and Bergsma (1994) [30] made several observations regarding the coping of cancer patients who suffered facial disfigurement. They observed that the patient's fear of dying of cancer was intense, often overshadowing the fear of facial disfigurement. As the fear of possible death diminished, the process of accepting the mutilation was able to begin. It also seemed important for the patient to establish a revised self-image. In essence, this refers to the fact that the best time to assist patients in returning to their careers or social activities is probably after they have accepted the facial disfigurement. Encountering relatives and friends poses special concerns for some patients. The immediate family frequently provides an important support system, usually reacting with compassion. The reaction of others may be varied, and conflicting reactions from others may confound the patient's coping process. Additionally, patients who experience facial disfigurement can find a medical setting frustrating, especially if they encounter delays, scheduling difficulties, or lack of empathy from the medical staff. Continuity and continuous exchange of information among team members may assist the patient in his recovery. Other studies have concluded that the process of adjustment to facial disfigurement is extremely difficult from a psychological perspective. The patient must cope first with the possibility of imminent and premature death and then must accept the fact that his or her face may be disfigured and people will respond differently. Facial disfigurement is a particularly difficult challenge to adjustment because the face is in a visually prominent area of the anatomy, it reflects animation, intellect, and emotion, and it serves as a means of communicating with others. Unfortunately, society's emphasis on physical attractiveness may impose additional burdens upon the individual who suffers facial disfigurement or dysfunction following surgery. Part of a complete recovery involves a complex process described as body image reintegration, which occurs gradually over time as the patient learns to accept and compensate for anatomic alterations (Dropkin & Scott, 1983) [31].

### **Continued tobacco and alcohol use**

Perhaps the most significant problem facing HNC patients and clinicians is the continued use of tobacco and alcohol beyond diagnosis, which negatively affects treatment efficacy, HRQoL, and survival (Mayne, Cartmel, Kirsch, & Goodwin, 2009) [32]. Continued smoking during and after treatment may worsen the severity of mucositis, a common side effect of chemotherapy and radiotherapy in which the cells lining the inside of the mouth become inflamed, leading to difficulties in eating and swallowing. Mucositis not only causes significant discomfort and compromised functioning, but as severity increases, so do breaks in treatment, patient hospitalizations, and possibly mortality (Trotti *et al.*, 2003) [33]. Similar results in patients who continue to use alcohol after diagnosis have been reported (Miller, Day & Ravenel 2006) [34].

## **DISCUSSION**

Due to the small number of studies, which are generally not of high quality, the main conclusion of this review relates to how future research in this area should be conducted. There is a clear need for future intervention trials, but the ongoing challenge with conducting such studies is the relatively small number of patients available for accrual at any one cancer centre. To overcome this, a collaborative, multicentric approach will be necessary. Furthermore, there is a need for a consensus on what type of intervention and delivery approach is most effective. Appraisal of the broader cancer literature to include systematic reviews on general or other site-specific cancer populations could help inform intervention design.

## **CONCLUSION**

Oral & Oropharyngeal carcinoma is a debilitating disease with many, often unique, physical and psychological sequelae. The process of treatment and recovery requires a multidisciplinary approach with surgeons, radiation and medical oncologists, onco-pathologist, dental surgeon, plastic surgeons, and rehabilitation specialists all involved. The evidence reviewed here supports the need for clinical health psychologists and behavioral medicine specialists at all phases of the disease trajectory, from diagnosis through treatment and recovery, a role previously advocated by others.

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