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# Exploring oral health care for patients undergoing cancer therapy of the head and neck region: A case study in the eThekwini District, KwaZulu-Natal

**A dissertation submitted in fulfilment of the requirements for the degree of Masters in Medical Science (Dentistry) in the School of Health Sciences, University of KwaZulu-Natal**.

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**Date of submission: December 2017**

**Exploring oral health care for patients undergoing cancer therapy of the head and neck region: A case study in the eThekwini District, KwaZulu-Natal**

**BS Bauluck-Nujoo**

A dissertation submitted to the Discipline of Dentistry, School of Health Sciences, University of KwaZulu-Natal, Westville, for the degree of Masters in Medical Science (Dentistry) in the School of Health Sciences.

This dissertation is presented in manuscript format. The presentation comprises five chapters including the introduction, literature review, methodology, manuscript presentations (two articles) and finally the conclusion and recommendations.

This is to certify that the contents of this dissertation are the original research work of Dr Bibi Saleenna Bauluck-Nujoo, carried out under my supervision.

As the candidate's supervisor, I have approved this dissertation for submission for examination.

Dr Shenuka Singh

Supervisor

Date: 21 December 2017

## DECLARATION

I, ***Bibi Saleenna Bauluck-Nujoo***, hereby declare that:

1.The research reported in this dissertation, except where otherwise indicated, is my original work.

2. This dissertation has not been submitted for any degree or examination at any other university or college.

3. This dissertation does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.

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B.S.Bauluck-Nujoo

## DEDICATION

I dedicate this work to my Lord, The Almighty and the Best of Planners, without Whom this achievement would never have been possible and to the most beloved Messenger (Peace be upon him), the best of creation.

## ACKNOWLEDGEMENTS

I would like to extend a special vote of thanks to Dr Shenuka Singh, my supervisor, for all that I learnt from her and for her ongoing assistance, guidance, encouragement, patience and support throughout this study.

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## MANUSCRIPTS ARISING OUT OF THIS STUDY FOR PUBLICATION

Two manuscripts emanated from this study, namely:

1.Self-reported oral health status: Perspectives of patients undergoing therapy for cancer of the head and neck region, in the eTthekwini District, KZN

**Authors:** Bauluck-Nujoo B. Saleenna and Shenuka Singh

**Submission:** Submission to *South African Dental Journal*

2. Oral health promotion for patients undergoing therapy for head and neck cancer in KwaZulu-Natal – A qualitative study examining patients' perspectives

**Authors:** Bauluck-Nujoo B. Saleenna and Shenuka Singh

**Submission**: Submission to *Health SA Gesondheid*

## ABSTRACT

**Introduction:**

Oral health care is paramount for patients with head and neck cancer. There is currently no published evidence to ascertain these patients' access to oral health care. The extent to which oral health planning in the province takes into account the specific oral health needs of patients with head and neck cancer is not known so far.

**Aim:**

The aim of this study was to assess the perceptions and oral health practices of patients undergoing therapy for cancer of the head and neck region, in the Ethekwini District, KwaZulu-Natal, so as to inform oral health planning of the needs for this population.

**Method:**

This was a cross-sectional, descriptive and exploratory study using both quantitative and qualitative data to determine the perceptions and oral health practices of patients with head and neck cancer. The study population for the quantitative component of the study, consisted of purposively selected patients with head and neck cancer (n=235) from a public tertiary central referral hospital in the Ethekwini District, KwaZulu-Natal (KZN). Data collection included the use of two previously validated questionnaires that was combined, namely, The EORTC QLQ-C30 and the EORTC QLQ- H&N35. These combined questionnaires included both single and multiple item scales to assess self-reported treatment side effects and oral health–related symptoms (Aaronson *et al.*, 1993). There were eleven single item questions (such as mouth opening, dry mouth, sticky saliva, teeth problems, feeling ill, cough, pain killers, nutritional supplements, use of feeding tube, weight loss/gain) and seven multiple item questions on pain, swallowing, sexuality, social contact, social eating, speech and senses (Aaronson *et al.*, 1993; Sherman *et al.*, 2000; López-Jornet *et al.*, 2012).

The quantitative data collected was captured in Microsoft excel spreadsheet and imported onto Statistical Package for Social Sciences software (SPSS) version 24 for analysis. The demographic details for the participants were calculated using descriptive statistics (mean, frequency, percentages, standard deviation). Pearson Chi-Square test was used to assess

possible relationships between the independent and dependent variables. The p-value was set to less than 5% ($p < 0.05$) to be significant.

For the qualitative component of the study, structured interviews were conducted with twelve voluntary patients (n=12) undergoing cancer therapy for the head and neck region. The purpose of the interview was to gain a better understanding of oral health-related challenges and opportunities facing these patients. The interview schedule comprised demographic questions related to the date of diagnosis, duration and type of treatment and past and present habits. Other questions included participant's knowledge of oral health care in relation to one's overall well-being, oral health self-care practices, perceived barriers and opportunities to access oral health care, and familial support.

Another semi-structured interview was conducted with the Ethekwini oral health district coordinator using purposive sampling technique. The interview schedule comprised questions related to oral health strategies in place to support patients with head and neck cancer and the extent to which oral health care is covered in district health policy and planning for these patients. Other questions included the existent institutional support for oral health promotion activities such as risk factor intervention programmes or strategies to improve oral health awareness.

Data analysis of the qualitative data incuded content analysis using a thematic process by following the steps described by Braun and Clarke (2006). The audio-recorded interviews were first transcribed verbatim and a data clean-up process was applied (Braun and Clarke, 2006; Theron, 2015). The narrative from each interview transcript was then coded and analysed based on the conventional thematic content analysis approach (Braun and Clarke, 2006; Theron, 2015). A code guide was developed to guide and support the coding process. Open nodes were generated in the open coding phase (Pateman *et al.*, 2015). This form of coding thus allowed for inductive reasoning of the emergent themes (Theron, 2015).

**Results:**

The results from the quantitative component of the study indicated that head and neck cancer was most common among participants in the 61-70 (n=86; 36.6%) age group. Oral cavity cancer was most common type of cancer reported (n=91; 38.7%), followed by laryngeal cancer (n= 53; 22.6%). Males (n=50; 21.3%) were more affected by oral cavity cancer as compared to females (n=41; 17.4%). With regards to employment, 14.5% (n=34) of participants were

employed, while 46.4% (n=109) were unemployed because of cancer and 39.1% (n=92) were unemployed due to other reasons (old age, housewife). With respect to treatment, 20.4% of participants (n=48) were on radiotherapy, 28.5% (n=67) on chemotherapy and 9.8% (n=23) were on concurrent chemoradiotherapy, while 17.4% of participants (n=41) had already undergone surgery. Only 8.5% of participants (n=20) were recently diagnosed with cancer of the head and neck while 23.4% (n=55) were on follow up programme. There were noted differences in the self-reported severity and extent of oral complications in relation to the participants' perceived oral health status. Xerostomia was found to be more common with increasing age. Pain in the jaw was experienced by 46.8% of participants while the majority of participants (n=125; 53.2%) did not report any pain in the jaw. Among those who perceived intra-oral discomfort, 13.8% females (n=13) and 7.8% males (n=11) experienced severe intra-oral related pain and discomfort. More female participants (n=7; 7.4%) in the age group of 41-60 reported severe difficulty in swallowing liquids than males of the same age group. Male participants who perceived severe difficulty to swallow liquids were all in the age group of 51-70 years. Among those (n=100; 42.6%) who perceived difficulty to swallow pureed food, slightly more females (n=13; 13.8%) perceived severe difficulty in swallowing pureed foods than males (n=17; 12.1%, p=0.034). Most of the participants (n=148; 63.0%) had difficulty in swallowing solid foods. Similarly, the majority of participants experienced problems with their teeth (n=162; 69.0%) and reported xerostomia (n=159; 67.7%). A higher proportion of females (n=27; 28.7%) reported severe trismus as compared to male participants (n=33; 23.4%). Sticky saliva (increased viscosity in salivary flow) was reported by 34.0% (n=32) females and 29.8% males (n=42). Dysgeusia (altered sense of taste) was also reported by the majority of participants (n=131; 55.7%), among whom 22.3% females (n=21) reported severe dysgeusia as compared to 19.1% males (n=27). The majority of participants (n=138; 58.7%) perceived difficulty to eat, with 35.1% females among them (n=33) reporting of severe problem in eating as compared to 23.4% males (n=33).

With reference to the qualitative data, six themes emanated from both interviews namely, knowledge and practices in oral health care, barriers in accessing oral health care, support for oral health care (includes both familial and institutional support), perceived opportunities to access oral health care, perceived precautions for outdoor activity and identified shortcomings in oral health service delivery at district level. Participants generally agreed that oral health was important for their overall well-being, with the exception of one participant. The reported oral hygiene practices included toothbrushing, mouthwash and dental floss. With reference to the

perceived barriers, a lack of dental services in some areas of the province which consequently led to the need to travel long distances to access the nearest dental facility, was reiterated by some participants. The co-existence of other diseases in addition to cancer was perceived by one participant as being challenging to seek oral health services. The time taken by hospital staff to diagnose dental pathology was also seen as a barrier to access oral health care. Additionally, the fact that medical personnel fell short of informing patients about oral complications arising with chemotherapy was perceived as a shortcoming. Financial instability and failure of the local dental clinic to provide basic oral health care were reported to hamper access to oral health care. With regards to support, most participants reported that they had support, whether financially or morally from their families, with the exception of one participant who did not get any form of familial support. One interviewee reported that support was obtained through prayer. Participants also indicated the need to use protective clothing, hats and sunscreen.

As for professional support, the oral health district coordinator reported that there was no specific support for oral health promotion activities from a policy perspective for head and neck cancer patients. However, he narrated that the pathway of referral patterns to oral and maxillofacial surgeons, ENT or oncology in cases of suspected malignancies was a form of oral health-related support for patients. Furthermore, he indicated that the district has many dental facilities with good infrastructure to offer services, such as oral prophylactic treatment and prosthetic services. Some of the opportunities perceived by head and neck cancer participants for improving oral health self-care practice included access to a dental hygienist, comprehensive explanation of the benefits and complications of cancer therapy, and clear referral patterns for further oral health management. Among the shortcomings identified to deliver oral health services at the district level was the absence of a specific oral health policy formulated for head and neck cancer patients and risk factor intervention programs.

**Conclusion:**

The results indicate that patients with cancer of the head and neck region reported limited access to professional oral health care. Oral health promotion services in the district, should take into account the specific needs for patients with cancer of the head and neck cancer region. There is an urgent need to prioritise oral health care for this vulnerable population in district oral health planning efforts.

**TABLE OF CONTENTS**

## LIST OF TABLES



## LIST OF FIGURES

## LIST OF ABBREVIATIONS

ADA: American Dental Association

AIDS: Acquired Immuno Deficiency Syndrome

BREC: Biomedical Research Ethics Committee

CANSA: Cancer Association of South Africa

CCRT: Concurrent chemoradiotherapy

CPCR: Cytoskeletal protein-related coding regions genes

CPD: Continuing Professional Development

DC: Dental caries

DNA: Deoxyribonucleic acid

EBV: Epstein Barr Virus

EORTC: European Organisation for Research and Treatment of Cancer

E-cigarette: Electronic cigarette

FDA: Food and drug administration

Gy : Gray (International system of unit to measure the dose of ionising radiation)

HIV: Human Immunodeficiency Virus

HPV: Human papilloma virus

HSV: Herpes simplex virus

HHV: Human herpes virus

HPCA: Hospice Palliative Care Association of South Africa

ICD: International Classification of Disease

IARC: International Agency for Research on Cancer

NNN: N’-nitrosonornicotine

NNK: 4-(methylnitrosamino)-1-(3-pyridyl)-1-butanone

PREP: potential reduced exposure product

SD: Standard deviation

TB: Tuberculosis

TNF-α: Tumour necrosis factor alpha

TSNA tobacco-specific N-nitrosamines

UK: United Kingdom

WHO: World Health Organization

UV: Ultraviolet

# CHAPTER 1: INTRODUCTION

## 1.1 Introduction

Oral health care has a significant role in cancer patients as it contributes to overall well-being of the individual (Bueno *et al.*, 2015). Studies suggest that oral health complications could contribute to inferior emotional health, deficient physical functioning and poorer quality of life (Ingram *et al.*, 2005; Zucoloto, Maroco and Campos, 2016). Oral health is defined as " *multi-faceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex*" (FDI World Dental Federation, 2016, page 20). This broad definition of oral health implies that oral health care should be an integral component of the cancer therapy regimen (Mawardi, Al-Mohaya and Treister, 2013; Samim *et al.*, 2016). While poor oral health/hygiene is associated with various systemic diseases such as diabetes mellitus, myocardial infarction and ventilator-associated pneumonia (Jablonski, 2012), there is a paucity of literature on the impact of oral health care for patients undergoing cancer therapy, specifically cancer therapy for the head and neck region. Cancer of the head and neck region is defined as those anatomical structures that extend from the skull base to the clavicles and thus comprise the pharynx (including hypopharynx, nasopharynx and oropharynx), larynx, paranasal sinuses and nasal cavity, minor and major salivary glands, oral cavity (including lip, alveolar ridge, buccal mucosa, gingiva, oral tongue, retromolar trigone and floor of mouth), skin, ear, eye and neck (World Health Organization, 2005a; Argiris *et al.*, 2008; Chen *et al.*, 2008; Ouyang, 2010; Romesser *et al.*, 2012; Erovic *et al.*, 2013; Rettig and D'Souza, 2015). Hence, assessment of the oral health of patients with head and neck cancer is possibly one of the most important aspects in oral health care since the head and neck region comprises of vital organs serving for mastication, speech and deglutition, which when affected, unfavourably impact on the overall well-being (Wan Leung *et al.*, 2011; Bottomley *et al.*, 2014). The literature suggests that around 58-97% of patients diagnosed with cancer require some type of dental treatment before cancer therapy (Bertl *et al.*, 2016).

The impact of oral complications like oral mucositis, xerostomia amongst others, related to the multi modality treatment of head and neck cancer aggravates the quality of life of the

affected individual (Lawrence, Aleid and McKechnie, 2013). The motor functions like mastication, deglutition, speech and sensory functions like gustatory and olfaction are all severely impacted during the course of treatment (Jawad, Hodson and Nixon, 2015). Complications in the oral cavity which arise as a secondary effect to head and neck cancer treatments call for a professional approach and a combination of several specialisations for proper management (Samim *et al.*, 2016). This includes sufficiently trained dental health professionals in oral oncology and other health care providers like radiation and medical oncologists (Samim *et al.*, 2016). Oral health examination and care begins prior to cancer therapy and intensified during the treatment phase to decrease possible complications bound to worsen the quality of life, and continue even after (Mainali *et al.*, 2011). The post treatment phase is also a crucial segment which should not be neglected (Murphy and Deng, 2015). It is the time when intense rehabilitation is necessary to lessen late side effects and alleviate functional deficits related to trismus, dysphagia and impaired chewing by ongoing oral health assessment and maintenance (Murphy and Deng, 2015).

Globally, the number of cancer cases is drastically increasing (Tanaka, Tanaka and Tanaka, 2011). South Africa is by no means spared. According to the Globocan 2012 data, the estimated number of new cancer cases (non melanoma skin cancer not included) in South Africa was 77 440 in the year 2012 and 87 222 in 2015, showing an increase in two years (International Agency for Research on Cancer, 2012b). It is predicted that 94 267 new cases of cancer will be encountered in 2020 and it will hit the 103 157 by 2025 at the national level (International Agency for Research on Cancer, 2012a, 2012c). Breast cancer was the most common cancer at the national level among females in 2013 with an incidence of 32.60 per 100 000 followed by basal cell carcinoma having an ASR= 26.53 per 100 000 and cervical cancer with an ASR=22.06 per 100 000 (National Cancer Registry, 2013). Breast and cervical cancer are the two main causes of death among South African women (National Department of Health, 2017a). While basal cell carcinoma was the second most common cancer in females, it was the leading cancer among males with an age-standardised incidence rate of 56.24 per 100 000, followed by prostate cancer with an ASR of 44.30 per 100 000 and squamous cell carcinoma of skin with an ASR of 26.07 per 100 000 (National Cancer Registry, 2013).

Head and neck cancer alone accounts for 48% of cases and 90% of these are oral squamous cell carcinoma, with an incidence of more than 300,000 annually (Tanaka, Tanaka and Tanaka, 2011; Sousa *et al.*, 2014). The 2012 estimated age standardised incidence rate of head and neck cancer cases (comprising ICD 09, 10, 12 and 14 and discussed further in chapter 2) in the

Southern African region including South Africa was 3.9 per 100 000 (number of cases=784) in males and 1.5 per 100 000 (392 new cases) in females (World HPV Information Center, 2017a, p. 101). South Africa has experienced an increase of oral squamous cell carcinoma since 1995 (Davidson *et al.*, 2014). As an example, the number of new cases of cancer of the lip and oral cavity was 1686 in 2012 and was 1855 in 2015 (Globocan, 2012). Head and neck cancer is reported to be among the ten leading causes of mortality worldwide (Bakhtiari *et al.*, 2017). The study conducted by the National Burden of Disease has also identified cancer as being one of the commonest mortality causes in public institutions across South Africa in addition to tuberculosis, pneumonia, hypertension and gastroenteritis (KwaZulu-Natal Department of Health, 2016, p. 22). The mortality rate of cancer in public hospitals in the province accounts for 5.5% (KwaZulu-Natal Department of Health, 2016, p. 22). Cancer of the breast, oesophagus and cervix accounted for the highest proportion in KZN public health facilities (KwaZulu-Natal Department of Health, 2016, p. 28).

The most recent statistics for histologically diagnosed head and neck cancer cases were released in 2013 by the National Cancer Registry which is South Africa's exclusive source for data on cancer surveillance and incidence. The cancer rate provided, is for South Africa as a whole. The data is not seggregated by province. Therefore, data specific to head and neck cancer rate in KZN is very sparse. There are studies which were conducted on the epidemiology of head and neck cancer in the country (Ndui, 2011; Abram, 2013; Davidson *et al.*, 2014), however updated reporting on the actual incidence and prevalence of head and neck cancer specifically in KwaZulu-Natal is very scant. Despite this constraint, the data available from the National Cancer Registry and previous studies provide an interesting picture of the situation of cancer. The age standardised incidence rate (ASR) of mouth cancer (excluding cancer of lip, gingiva and tongue) in South Africa was 1.99 per 100 000 (number of new cases being 342), representing 0.95% of all cancers in male, while that in female was 0.79 per 100 000 with the number of new cases being 191, making up to 0.52% of all cancers (National Cancer Registry, 2013). The ASR for tongue cancer in males accounted for 1.65% with the incident number of cases being 299, representing 0.83% of all cancers (National Cancer Registry, 2013). With reference to females, the ASR of tongue cancer was 0.56 per 100 000 with the incident number of cases being 136, representing 0.37% of all cancers. With respect to laryngeal cancer, the incidence in males was 471 with an ASR of 2.82 per 100 000 or representative of 1.31% of all cancers while that in females was 101 with an ASR of 0.42 per 100 000 which represents 0.28% of all cancers (National Cancer Registry, 2013). The National Cancer Registry reports

incidence data of oropharyngeal and nasopharyngeal cancers as a combined group. The ASR of naso-oropharyngeal cancer grouped together in males was 1.51 per 100 000 with the number of new cases accounting for 275, representing 0.77% of all cancers. With reference to naso-oropharyngeal cancer cases in females, the ASR was 0.40 per 100 000 with the number of new cases being 100, which represents 0.27% of all cancers (National Cancer Registry, 2013).

Oral health services are delivered via the public and private sector in South Africa (Bhayat and Chikte, 2017). Dental specialists, dentists, oral hygienists and dental therapists who are registered with the Health Professional Council of South Africa (HPCSA) form part of the network of dental health care providers in the country (van Wyk and van Wyk, 2004; Bhayat and Chikte, 2017). While the private sector caters for around 20% of the population of South Africa, the public sector caters for the majority, accounting for 84-90% (Ramphoma, 2016; Bhayat and Chikte, 2017). The majority of dental health professionals operate in the private sector (van Wyk and van Wyk, 2004; Bhayat and Chikte, 2017). Delivery of oral health services in the public sector is based on the primary health care system (van Wyk and van Wyk, 2004; Bhayat and Chikte, 2017). Preventive and restorative care including extractions, restorations, sepsis control and pain relief are included in the package of care (Bhayat and Chikte, 2017). However, personnel working in these clinics are not as yet fully trained to face the challenges encountered in such settings (Dookie, Singh and Myburgh, 2017).

Among the priorities set by the KwaZulu-Natal Department of Health in the strategic plan for the province for the year 2015-2019, are implementation of healthy lifestyle, promotion of health and early screening and diagnosis of chronic diseases (including head and neck cancer) (KwaZulu-Natal Department of Health, 2015). Further, the Department emphasized that screening and counselling for cancer is among its top priorities and stated that strategic plans to promote equitable health and service delivery are in place to target underprivileged and poverty-striken areas (KwaZulu-Natal Department of Health, 2015). Despite the fact that the content of various oral health policy documents is powerful and persuasive towards improving oral health care at both the national and provincial levels, however, literature reports that oral health care in the province remain so disjointed from the health system that this poses a challenge in equitable access across many regions of the province and the country (Singh, Myburgh and Lalloo, 2010; Ramphoma, 2016; Dookie, Singh and Myburgh, 2017).

## 1.2 Problem Statement

Good oral health is of vital importance before, during and after treatment regimens of head and neck cancer (Samim *et al.*, 2016). The knowledge of oral health and compliance to its practices can lead to a better quality of life by surviving cancer patients both in terms of treatment costs and overall well-being. In addition, sufficient psychosocial support must be provided to those cancer patients in order that the quality of life is further enhanced. The literature reports that the oral health of this group of patients is affected in a number of ways including difficulty to eat, dysphagia (difficulty to swallow), odynophagia (painful swallowing) and gustatory and auditory disturbances due to a number of complications like oral mucositis, xerostomia (dry mouth), osteoradionecrosis, periodontal disease, trismus (reduced mouth opening), hypersensitivity and infections, thus compromising the quality of life (Schultz *et al.*, 2010; Frydrych *et al.*, 2012; McCaul, 2012; Mawardi, Al-Mohaya and Treister, 2013; Hartnett, 2015; Jawad, Hodson and Nixon, 2015). So far there is no information to ascertain the impact of head and neck cancer patients' access to oral health care in KwaZulu-Natal. There is no published evidence that oral health planning in the province takes into account the specific oral health needs of patients with head and neck cancer. Ineffective and inefficient oral health service delivery in underprivileged areas across South Africa and also in the province of KwaZulu-Natal is present due to poor infrastructure and shortage of oral health care providers (Thema and Singh, 2013; KwaZulu-Natal Department of Health, 2016; Ramphoma, 2016). Furthermore, reduced budgetary allocations in oral health care as a result of the increased burden of tuberculosis and HIV is also reported to contribute to inequitable distribution of oral health services (Ramphoma, 2016). Despite the fact that oral health has a significant place in head and neck cancer data regarding oral health service delivery for the head and neck cancer population is lacking in the current literature for KwaZulu-Natal. Hence the purpose of this study is to gain an understanding of the current situation of oral health care patterns in KwaZulu-Natal. This was fulfilled by exploring the perceived challenges which head and neck cancer patients encounter to access oral health services. Additionally, this study also intends to have an insight into the availability of oral health promotion strategies for this population group. By so doing, suitable educational framework can be suggested to health care providers to improve the quality of life of this vulnerable population.

## 1.3 Purpose of the study

The purpose of the present study is to contribute to oral planning by including cancer patients' perspectives on their needs for oral health care. Including cancer patients' perspectives in oral planning helps to build patient empowerment: empowering patients to identify their own needs**.** Thus, oral health planning for patients with head and neck cancer will be based on patients' needs and demands. Oral health planning would need to take into account the availability of oral health facilities for patients wanting to access oral health care. Planning also needs to take into account, oral health promotion requirements that are specifically tailored for patients with head and neck cancer. Furthermore, it will equally need to consider an integrated approach to take into account the other psychosocial needs of patients with head and neck cancer. This significant step consequently aims at making recommendations for improvement in the overall oral health and well-being of these individuals by reducing the burden of the patient in terms of early referral for assessment and management of the oral health to dental surgeons and dental health care providers prior to undergoing therapy for cancer of the head and neck region. The study is also designed to identify the barriers present in accessing oral health care as perceived by this category of patients. Consequently, this will help in suggesting suitable recommendations which may help in improving the oral health care system including oral health education for head and neck cancer patients in KwaZulu-Natal. To our knowledge, this is the first study in KZN to explicitly explore patients' as well as oral health management perspectives on oral health promotion needs for this vulnerable population.

## 1.4 Research Questions

1. What are the oral health practices of people undergoing therapy for cancer of the head and neck?
2. What is the perceived impact of oral health care on quality of life for patients undergoing treatment for head and neck cancer?
3. What are the barriers and opportunities for practicing optimal oral health self-care among these patients?

## 1.5 Aim and Objectives of the study

### Aim:

The aim of this study was to assess the perceptions and oral health practices of patients undergoing therapy for cancer of the head and neck region, in the eThekwini District, KwaZulu-Natal, so as to inform oral health planning of the needs for this population.

### Objectives:

1. To assess the perceived oral health status of patients undergoing therapy for head and neck cancer by means of a questionnaire.
2. To determine the level of oral health knowledge and attitudes of patients with head and neck cancer by means of structured face-to-face interviews.
3. To establish patients' perceived barriers and opportunities to accessing optimal support for oral health care by means of structured face-to-face interviews.
4. To determine the current delivery of oral health promotion services for patients with cancer of the head and neck region, by means of a semi-structured interview with the Ethekwini oral health district coordinator.

## 1.6 Chapter Outline (Format of the the dissertation)

The current study is presented in five chapters as outlined below.

### Chapter 1 Introduction

The first chapter of this research study is founded on the importance of oral health care in general and in head and neck malignancy as well. It gives a broad overview of the significance of incorporating head and neck cancer into national cancer management programs with a view to improve oral health. The existent shortfalls which need to be addressed is framed explicitly in the problem statement section. The purpose and research questions of the study which need to be answered are also described. Finally, the aim along with the different steps involved of how to achieve it are outlined.

**Chapter 2 Literature review**

This chapter is concerned with the description of the risk factors and mechanisms through which the latter contribute to the development of cancer of the head and neck region. It also describes the burden of head and neck cancer along with the magnitude of the adoption of some of these contributing factors in South Africa. The importance of palliative care as an integral component in the management of head and neck cancer besides the treatments provided at the clinical level is also highlighted in this chapter. Furthermore, it focuses on the undesirable effects that these treatments exert on the oral health and ultimately and indirectly on the self esteem, body image and overall well being of the individual. Lastly, it stresses upon the importance of assessing and managing the oral health timeously and the strategies identified by the KwaZulu-Natal Department of Health in promoting and achieving equitable distribution of oral health across the Province.

**Chapter 3 Methodology**

This chapter describes the steps involved in designing the study, by virtue of its location, study population, sample size, inclusion and exclusion criteria, data collection methods along with the required tools, the qualitative and quantitative data processing and finally the ethical aspects taken into due consideration in this study.

**Chapter 4 Manuscript presentations**

The fourth chapter is presented in a manuscript format consisting of two articles intended for submission to a peer-reviewed journal.

**Chapter 5 Conclusion and recommendaions**

The last chapter summarises the quantitative and qualitative results obtained from this study according to the aim, objectives and research questions. Finally, it provides useful recommendations which can be considered to improve oral health promotion services for the head and neck cancer patients in KwaZulu-Natal.

**1.7 Summary**

The first chapter stressed on the importance of oral health in head and neck cancer. The purpose of the study, the research questions together with the aim and objectives were clearly outlined. The outline of the dissertation with respect to the organisation of the contents of the chapters was also described**.**

# CHAPTER 2: LITERATURE REVIEW

## Preamble

The review of the literature was aimed at identifying the different possible etiologies for head and neck cancer and their related implications to the oral health deterioration. It gave an overview of the challenges facing the health care system, scope of oral health care, challenges in equitable delivery of oral health services, package of care, oral health promotion strategies the risk factors associated with cancer, the oral health assessment and management prior to initiation of cancer therapy the current treatment protocols and the side effects that the different treatment have in relation to the oral cavity and other regions of the head and neck and finally the perception of self-esteem and body image of head and neck cancer patients. A comprehensive and thorough search through PUB MED, Medscape Dentistry, other PDF search engines and dental journals was conducted to have a sound background and understanding of the subject matter.

## 2.1 Introduction

Head and neck cancer is a major burden in South Africa and many other African countries (Ayo-Yusuf, Lalloo and Johnson, 2013). There are more than one hundred types of cancer within this global epidemic that poses a threat to public health (Tanaka, Tanaka and Tanaka, 2011; World Health Organization, 2017). Worldwide, head and neck cancer is the sixth most common cancer (Tanaka, Tanaka and Tanaka, 2011; Joshi *et al.*, 2014). It is also the most prevalent cancer in developing countries and represent the eighth major cause of death (Peer, 2013; Joshi *et al.*, 2014). The global incidence is 670,000 with a mortality rate of 350,000 annually (Cognetti, Weber and Lai, 2008; Critchlow, Morgan and Leung, 2014). The pathogenesis contributing to this debilitating and life-threatening disease is multifactorial (World Health Organization, 2017). Tobacco smoking, alcohol consumption, paan chewing, viruses, genetics, immunity, diet devoid of fresh fruits and vegetables, ultraviolet radiation, and socioeconomic factors are some of the etiological factors responsible for the development of head and neck cancer (Zaraa *et al.*, 2013; Critchlow, Morgan and Leung, 2014; Baba, 2016; Marur and Forastiere, 2016; World Health Organization, 2017). Although excess alcohol consumption and tobacco smoking are the more frequently related to most cancers of the head and neck, a growing incidence of human papilloma virus-type 16 (HPV-16) are incriminated in cancers of the base of the tongue, tonsils and other sites of the oropharynx (World HPV Information Center, 2017b). It is reported that the risk of head and neck cancer is increased by 1.7-4.0 times in the presence of HIV infection (D'Souza *et al.*, 2014).

Cancer or malignancy is the uncontrolled and abnormal cell growth and division with a potential to invade tissues and spread to distant sites in the body via the circulation or lymph vessels (National Cancer Institute, 2015b; World Health Organization, 2017). Cancer is on the rise on a global aspect and notwithstanding the intensive efforts and advances in the field of oncology throughout the world, it still remains a global epidemic and poses a threat to public health (Tanaka, Tanaka and Tanaka, 2011). It is the second principal cause of mortality worldwide (World Health Organization, 2017). According to the World Health Organization, the incident cases of cancer over the next 20 years are expected to increase by around 70% (World Health Organization, 2017). Cancer is among the most common non-communicable diseases which require admissions in public hospitals of KwaZulu-natal (KwaZulu-Natal Department of Health, 2016). Worldwide, the incidence of all the cancers combined in 2012

was 14.1 million with a mortality of 8.2 million and 32.6 million cancer survivors (Ferlay *et al.*, 2015; International Agency for Research on Cancer, 2015). The incident cases of all cancers combined in South Africa is 100,000 every year (Cancer Association of South Africa, 2016).

The International Classification of Diseases which is published by the World Health Organization is the most widely used system for disease classification (World Health Organization, 2016b). It is used for monitoring the prevalence and incidence of diseases including malignancies of the head and neck region (World Health Organization, 2016b). The latest available version is the tenth iteration, ICD-10 (World Health Organization, 2016b). The 11$^{th}$ version is currently being developed and is due to be launched in 2018 after approval from the World Health Assembly (World Health Organization, 2016b). Cancers of the lip, oral cavity and pharynx, according to the International Classification of Disease, is categorised from C00 to C14 as shown in table 1. Cancer of other head and neck subsites like larynx, paranasal sinuses, nasal cavity are categorised separately.

**Table 1: Classification of cancer of the lip, oral cavity and pharynx. Adapted from the WHO International Classification of Diseases (World Health Organization, 2016a)**

| ICD Code | Anatomical site |
|---|---|
| C00 | Malignant neoplasm of lip |
| C01 | Malignant neoplasm of base of tongue |
| C02 | Malignant neoplasm of other and unspecified parts of tongue |
| C03 | Malignant neoplasm of gum |
| C04 | Malignant neoplasm of floor of mouth |
| C05 | Malignant neoplasm of palate |
| C06 | Malignant neoplasm of other and unspecified parts of mouth |
| C07 | Malignant neoplasm of parotid gland |
| C08 | Malignant neoplasm of other and unspecified major salivary gland |
| C09 | Malignant neoplasm of tonsil |
| C10 | Malignant neoplasm of oropharynx |
| C11 | Malignant neoplasm of nasopharynx |
| C12 | Malignant neoplasm of pyriform sinus |
| C13 | Malignant neoplasm of hypopharynx |

| | |
|---|---|
| C14 | Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx |

Treatment for head and neck cancer often means surgery, radiotherapy, chemotherapy and concurrent chemoradiotherapy (Cognetti, Weber and Lai, 2008; Tulunay-Ugur *et al.*, 2013; Varelas and Kukuruzinska, 2014). Treatment outcome in South Africa is often influenced by the socio economic status of the individual, infrastructure, availability of medical personnel and financial resources (Peer, 2013). Despite a lack of resources which can be experienced in South Africa, surgeries ranging from endoscopic skull-base interventions to cochlear implant are undertaken in head and neck cancers by devoted surgeons in order to improve the prognosis (Peer, 2013). The multimodality treatment of head and neck cancers however, have the potential to severely affect the oral health (Pateman *et al.*, 2015). Underestimating the role of oral health can consequently have a severe impact on the the overall well-being and quality of life in cancer (Sheiham, 2005; Bueno *et al.*, 2015).

The literature suggests that the sex predominance for head and neck cancer is male (Joshi *et al.*, 2014). Although male gender above 40 years old constitutes a stronger predisposition to acquiring it, a growing incidence of head and neck cancer among the younger population is also being noted (Bakhtiari *et al.*, 2017). The 5 year survival rate has not shown any improvement in the last 3 decades regardless of major scientific and clinical developments in this field, unlike that of cancers in other body parts where the survival rate has been seen progressing within the same time frame (Mighell and Gallagher, 2012; Alhazzazi and Alghamdi, 2016; Bakhtiari *et al.*, 2017). Alcohol consumption, tobacco smoking, infections, sedentary lifestyle and poor diet are responsible for 43% of cancer-related mortality (Petersen, 2009b).

According to the figures available (discussed in chapter 1) from the National Cancer Registry, head and neck cancer is more prevalent in males than in females (National Cancer Registry, 2013). The male predominance of head and neck cancer is not only observed in the local context but is in conformity with other studies conducted in other countries. A study conducted in Nigeria also observed a male predominance of 1.8:1 (Adeyemi *et al.*, 2008). Another study from Taiwan reported a male to female predominance in the ratio of 51:1 (Chen *et al.*, 2008). The study of Bakhtiari *et al* equally reported a higher male to female tendency in the ratio of 2.85:1 (Bakhtiari *et al.*, 2017).

On a global aspect, oral cavity cancer is reported to account for around 3% of all cancers (Cancela *et al.*, 2010). Cancer of the oral cavity can affect the structures by which it is bounded and this includes the lips, anterior two-thirds of tongue (oral tongue lying in front of sulcus terminalis), horseshoe-shaped floor of mouth, maxillary and mandibular gingivae, buccal mucosa and hard palate (World Health Organization, 2005a; National Cancer Institute, 2015a). Worldwide, oral and pharyngeal cancers together are the sixth most common cancer (Warnakulasuriya, 2009; Mahapatra *et al.*, 2015; El-Bayoumy *et al.*, 2017). The highest incidence of oral cavity and lip cancers worldwide was encountered in Melanesia with 22.9 per 100 000 in men and 16.0 per 100,000 in women (Ferlay *et al.*, 2015).

Laryngeal cancer is also reported to have a male preponderance where a previous study reported that laryngeal cancer was more prevalent in males than in females with a sex ratio of 7:1 on a global scale (Parkin *et al.*, 2005). It is rare in women from developed countries (Parkin *et al.*, 2005). The survival rate of laryngeal cancer patients is higher in Europe and North America as compared to developing countries (Parkin *et al.*, 2005). The prognosis is also poorer in regions with a high predominance of alcohol (Parkin *et al.*, 2005).

The pharynx is subdivided into three anatomical sites namely: nasopharynx, oropharynx and hypopharynx (Mittal, 2011). The nasopharynx is found behind the nasal cavity and originates from the skull base to the soft palate in the superior part of the pharynx (Mittal, 2011). The incidence for nasopharyngeal carcinoma accounts for 86,000 with a mortality of 50,000 annually on a global aspect (Hui and Chan, 2016). Oropharyngeal cancer occurs in the middle part of the pharynx involving either the soft palate or the tonsils or the base of tongue (Stepnick and Gilpin, 2010).

## 2.2 Contextual setting: Describing KwaZulu-Natal

KwaZulu-Natal (KZN) is a coastal province with an area of 92,100 square kilometres, located in the South East of South Africa (KwaZulu-Natal Department of Health, 2016, p. 13). The geography is divided in three parts where the central part consists of rolling planes while the northern and western parts consist of mountains. The lowland region is narrow in the south along the Indian Ocean. It has an array of mountains, rivers, game reserves and moist savannah. It is the second most densely populated province after Gauteng which shares the highest population density of South Africa (Statistics South Africa, 2017). It is comprised of 828 wards

and 11 districts among which 10 are district municipalities and the most populous one being the metropolitan municipality which is the Ethekwini metropolitan municipality (Kwazulu-Natal Department of Health, 2016, p. 13). The capital of KZN is Pietermaritzburg (located in UmGungundlovu district) and the largest city is Durban which is found in Ethekwini district. The majority of the KZN population comprises of Black accounting for 87.2% Black followed by 7.2% Indian/Asian, 4.2% White and 1.4% Coloured (Statistics South Africa, 2017). The majority of its residents speak IsiZulu followed by English, Xhosa and Afrikaans. It is bordered by Lesotho, Mozambique and Swaziland (KwaZulu-Natal Department of Health, 2016, p. 13).

According to the latest figure which was released in July this year, the KZN mid year population estimate is 11, 074, 800, representing 19.6% of the total South African population of 56,521,900 people (Statistics South Africa, 2017). Poverty is primarily present in the rural areas of KZN (KwaZulu-Natal Department of Health, 2016, p. 18). The poverty headcount for KwaZulu-Natal is estimated to be 7.7% and the intensity of poverty is 42.5% (Statistics South Africa, 2016). Extreme poverty was experienced by 28% while absolute poverty was present in 29% of the total KZN population in the year 2012 (KwaZulu-Natal Department of Health, 2016, p. 18). The lowest absolute level of poverty is found in Ethekwini and UmGungundlovu while the highest level of absolute poverty is in Harry Gwala, Zululand, Umzinyathi and Umkhanyakude districts (KwaZulu-Natal Department of Health, 2016, p. 18).

The tertiary central referral hospital, Inkosi Albert Luthuli Central Hospital, is located in the city of Durban in the Ethekwini metropolitan municipality with a population density of 3.5 million.

### 2.3 KwaZulu-Natal cancer crisis

KwaZulu-Natal is currently (at the time of writing up this dissertation) experiencing a severe crisis in oncology following the resignations of several oncologists from state hospitals owing to poor leadership at the DOH, lack of resources and excessive working conditions (PoliticsWeb, 2017). Further, the crisis was intensified with the breaking down of two life-saving, high-tech radiotherapy machines which were not considered for repair and further maintenance (Ndaliso, 2017a). This gave rise to the need for patients to be referred to the tertiary referral hospital for continuation of treatment (Ndaliso, 2017a). However, with the shortage of professionals in the hospital, the waiting time ranged from 4 to 8 months (Ndaliso,

2017a; PoliticsWeb, 2017). The long waiting period claimed the lives of several hundreds of cancer patients in KZN (Ndaliso, 2017a). According to an article written and published in July this year, 179 patients had not yet initiated cancer treatment and were still waiting amid the staff shortage and the dysfunctional machines (PoliticsWeb, 2017). The KZN Department of Health was blamed by one and all, including patients and also the South African Human Rights Commission for not undertaking regular maintenance of the machines, refusing to pay the company which had supplied these machines and violating cancer patients' rights to access cancer care facilities (Ndaliso, 2017a, 2017b).

### 2.4 Challenges facing health care

Disparity in accessing health care services is ever present in the province (Kwazulu-Natal Department of Health, 2016). Reduced budget allocations for the past five years is the primary challenge in delivering equitable health care (KwaZulu-Natal Department of Health, 2016). The growing number of patients due to increased disease burden demands a restructuring of the infrastructure in many health facilities of the province because they are judged as inadequate (restrained space and limited number of consultation and waiting rooms) to effectively serve the community (KwaZulu-Natal Department of Health, 2016). However, the South African health care system is overburdened with tuberculosis (TB), HIV, other sexually transmitted diseases (National Department of Health, 2017b). The leading cause of death in South Africa and also KZN is tuberculosis with an incidence of 834 per 100 000 population at the national level and 450 000 new cases of TB infections of which 63% were also infected with HIV for the year 2015 (KwaZulu-Natal Department of Health, 2016; National Department of Health, 2017b). A study reported that the primary manifestation of TB of the head and neck in KwaZulu-Natal is cervical lymphadenopathy (Khuzwayo and Naidu, 2014).

KwaZulu-Natal is the province carrying the highest HIV burden with a prevalence of 18% as compared to 6.6% in Western Cape (National Department of Health, 2017b). It is estimated that approximately 7.1 million of South Africans are currently infected with HIV (National Department of Health, 2017b). In 2016, 270 000 new HIV cases were diagnosed and the mortality rate was 27.9%, accounting for 150 375 deaths (National Department of Health, 2017b). Moreover, other sexually transmitted diseases like syphilis, gonorrhoea and HSV-2 infections increase the risk of HIV and equally represent a burden despite a decrease (from

11.2% to 1.6%) in the prevalence was noted between 1997 and 2011 (National Department of Health, 2017b). Thus, the high burden of all these diseases places an unequal demand on the South African health system (KwaZulu-Natal Department of Health, 2016). As a result of restricted budget, the construction of more public health facilities could not be accomplished (KwaZulu-Natal Department of Health, 2016).

## 2.5 Scope of oral health care and education

The Liverpool Declaration of the 8th World Congress in preventive dentistry stated that oral health is a fundamental right of every single individual and is an essential component of the general health and well-being (World Health Organization, 2005c). The oral health-related well-being of cancer survivors, as is the case for the general population as well, is impacted by the quality, efficacy and standard of oral health promotion policies which are in place. Despite great steps that have been and are still being taken in view of promoting oral health globally, problems associated with oral health and well-being still persists in developing and under privileged areas in developed countries (Petersen, 2009a). The same holds true when applied to the local context, South Africa, where oral diseases represent a significant burden in spite of substantial improvements in oral health-related technologies (Singh, Myburgh and Lalloo, 2010). These latter factors are further dictated by the resources available, budget required to implement such policies and efficacy of delivery of implemented strategies (Singh, 2012).

Patient education is mandatory to help them cope with cancer therapy side effects and adhere to treatment plan (Kav and Bostanci, 2006). Oral side effects are common in head and neck cancer. The importance of oral health care in this population group cannot be underemphasized since a range of oral complications such as oral mucositis, trismus and infections owing to the multimodality treatment, affecting oral hygiene maintenance may occur (Lalla, Sonis and Peterson, 2008; Rapidis *et al.*, 2015; Samim *et al.*, 2016). Oral health care of standard quality can be achieved when other health professionals, besides dental professionals, like nurses and doctors, are engaged in the oral health promotion network (Dolce, Haber and Shelley, 2012). Furthermore, providing comprehensive education to patients and motivation to seek treatment help to improve the outcome of any disease (Jin *et al.*, 2008).

The primary roles of nurses relate to educating cancer patients both in the active and follow up phase of cancer therapy (Kav and Bostanci, 2006). However, nurses should first be educated properly about the importance of oral health care so that they can subsequently educate patients (Kav *et al.*, 2008; Dolce, Haber and Shelley, 2012). Further, nurses can play a significant role in improving access to oral health care provided they are equipped with adequate education on oral health (Dolce, Haber and Shelley, 2012). They can also impact significantly on reducing oral health inequalities prevalent in socially marginalised and underdeveloped regions (Dolce, 2014). On the other hand, doctors also need to be educated of the value of oral health care (Dolce, Haber and Shelley, 2012). The process of effective management of head and neck cancer is also facilitated if doctors are educated on the importance of oral health and assessment of head and neck cancer patients before oncology treatment starts and of the role they have in timely referral of patients for oral health consultation and management (Lawrence, Aleid and McKechnie, 2013; Samim *et al.*, 2016). This aids to decrease or avoid where possible, oral complications and organ malfunctioning, which may cause interference or interruption of cancer therapy (Patel *et al.*, 2012; Sonis, 2013; Lang *et al.*, 2014; Saito *et al.*, 2014; Samim *et al.*, 2016).

## 2.6 Challenges in equitable oral health care distribution

Equitable delivery of oral health care is a cornerstone of oral health promotion. Growing inequality in oral health service delivery in South Africa is a reality, with the urban areas being prioritised over the rural counterpart (Ramphoma, 2016). The WHO Global Commission on Social Determinants of Health states that health inequalities exist as a result of, "*unequal distribution of power, income, goods, and services, globally and nationally, the consequent unfairness in the immediate, visible circumstances of peoples lives - their access to health care, schools, and education, their conditions of work and leisure, their homes, communities, towns or cities – and their chances of leading a flourishing life*" (Kamargo, 2011). Furthermore, amalgamation of "*poor social policies and programmes, unfair economic arrangements, and bad politics*" all contribute towards inequitable health within a country (Kamargo, 2011). The literature reports that the deficiencies to set up a rigorous oral health promotion program are probably present due to a lack of health care workers, poor health budget allocation, shortage

of equipment and transport problems, making it difficult to reach out to those whose needs are to be met (Reddy and Singh, 2015).

Despite the significant proportion of population who utilises the public health service in the country and also KZN, there is a lack of oral health care providers (Bhayat and Chikte, 2017; Dookie, Singh and Myburgh, 2017). Adequate workforce is critical for delivery of high quality dental care (Bhayat and Chikte, 2017). The reasons pertaining to this lack, might be attributed to an uneven distribution of oral health care workers across districts, reduced recruitment by the public service due to limited posts, and migration of oral health professionals to other countries due to improved financial stability and lifestyle choices (Thema and Singh, 2013; Bhayat and Chikte, 2017; Dookie, Singh and Myburgh, 2017). It is estimated that around 70-80% of the 6125 registered dentists in South Africa are in the private practice which roughly serves 20% of the country's population, while the rest is employed by the public sector to cater for the vast majority (Bhayat and Chikte, 2017). The dentist to population ratio is estimated to be in the order of 1:8900 countrywide, while it is around 1:2000 in developed countries (Bhayat and Chikte, 2017). This reflects the gap facing the oral health care system in terms of professionals being employed when compared to other countries. Similarly, oral health care has always been inadequate in the province (Dookie, Singh and Myburgh, 2017). The province has around 54% of its residents in rural areas where there is a severe disparity in oral health service delivery (Brindle *et al.*, 2000; KwaZulu-Natal Department of Health, 2016; Ramphoma, 2016). Distribution of oral health services is focused on urban regions (Brindle *et al.*, 2000; Ramphoma, 2016; Dookie, Singh and Myburgh, 2017). However, the pattern of oral health service delivery within rural areas is also unequal across the province (Dookie, Singh and Myburgh, 2017). Inadequate number and maldistribution of oral health care providers across the province impact on the availability and equitable delivery of oral health services (Dookie, Singh and Myburgh, 2017). KwaZulu-Natal has the most worrying dentist to population ratio when compared to Western Cape and Gauteng provinces (Bhayat and Chikte, 2017). The ratio of dentist to cater for the population is approximately 1:12 891 in the province as compared to 1:4536 in Western Cape and 1:5627 in Gauteng (Bhayat and Chikte, 2017). In 2012, the number of dentists employed by the public sector was 78, among whom 26 were based in the Ethekwini district (Dookie, Singh and Myburgh, 2017). Dental therapists accounted for 26 in total, of whom 8 were based in Ethekwini, while among the 32 oral hygienists who were employed, 12 were distributed across Ethekwini (Dookie, Singh and Myburgh, 2017). The reasons which might be attributed to the uneven distribution of oral

health care personnel include a deficiency of human resource planning and inadequate funded posts in the public sector (Dookie, Singh and Myburgh, 2017). Another challenge in achieving equitable delivery of oral health services is in relation to the reduced number and uneven distribution of oral health care facilities between the urban and rural divide, as well as within the rural setting (Dookie, Singh and Myburgh, 2017). The total number of fixed dental facilities in 2012 was 60, with 52% of them being integrated in district hospitals, while 13% were located in primary health care clinics and 22% in community health centres (Dookie, Singh and Myburgh, 2017). Ethekwini had 10 fixed dental facilities and is reported to be among the three districts that had the least number (10 facilities) of dental facilities when compared to other districts with a lower population density (Dookie, Singh and Myburgh, 2017).

Besides staff shortages, the location of oral health services with respect to habitation must also be considered to improve accessibility to oral health care. According to the norm in South Africa, the walking distance from the place of residence to the nearest primary health care facility should fall within 5 kilometres radius (KwaZulu-Natal Department of Health, 2016). However, a survey carried out in 2010 reported that 672 272 houses were outside the established norm (KwaZulu-Natal Department of Health, 2016). Moreover, dedicated funding contributes to equitable oral health distribution (Dookie, Singh and Myburgh, 2017). The HIV burden is highest in KwaZulu-Natal as compared to other provinces, while tuberculosis (TB), is the most common infection requiring hospital admissions in the province (KwaZulu-Natal Department of Health, 2016). Tuberculosis is the primary cause of death globally and the majority of TB cases coupled with HIV infections is reported to occur in developing countries like Sub Saharan Africa (Khuzwayo and Naidu, 2014). The rate of HIV-TB co-infection is around 70% (KwaZulu-Natal Department of Health, 2016). The high burden of HIV, other sexually transmitted diseases and TB represent a severe drain on the health system, affecting the financial priorities and reducing the budget allocated for oral health development and service delivery (KwaZulu-Natal Department of Health, 2016; Ramphoma, 2016). It is further reported that constant scrutiny of the outcome and effectiveness of oral health promotion program is lacking and therefore very little is known so that improvement in terms of resource allocation and oral health status is made in South Africa (Ramphoma, 2016).

The literature reports that HIV-positive/AIDS individuals have an elevated risk of squamous cell carcinoma of the head and neck region, mainly non-Hodgkin's lymphoma and Kaposi sarcoma (McLemore *et al.*, 2010; Purgina, Pantanowitz and Seethala, 2011; D'Souza *et al.*, 2014). A study carried out in KwaZulu-Natal and Western Cape provinces reported that,

patients were not given the necessary oral care needed, when dentists and oral health care workers became aware of the HIV-positive status of the patients (Turton and Naidoo, 2008). It is further reported that many patients are either denied care by their dentists or experience a feeling of discrimination and unwelcoming attitudes on the part of dental health care workers when their HIV status are revealed (Robinson and Croucher, 1993; Turton and Naidoo, 2008). This consequently acts as a challenge for patients with HIV-related head and neck cancer to access dental care.

## 2.7 Package of care and policy planning

The package of oral and dental health care services is administered via two main routes namely: 1) fixed health facilities (accounting for 60 in total as discussed above) including primary health care clinics, community health centres and district hospitals and 2) non-fixed facilities including outreach services and mobile units (KwaZulu-Natal Department of Health, 2016; Dookie, Singh and Myburgh, 2017). A greater fraction of the population (26.7%) who do not have medical insurance and utilise public health services live in Ethekwini as compared to Umgungundlovu and Uthungulu which comprise 8.4% and 7.7% of the uninsured popoulation (KwaZulu-Natal Department of Health, 2016). While primary health care clinics and community health centres are free, district hospitals charge a fee (Dookie, Singh and Myburgh, 2017). Delivery of oral health services is founded on an individual and curative approach rather than a population-based preventive and promotive approach (Ramphoma, 2016; Dookie, Singh and Myburgh, 2017).

Fixed facilities provide promotive, preventive and restorative care such as extractions, restorations, pit and fissure sealant application, dental consultations and prophylaxis (Singh, Myburgh and Lalloo, 2010; KwaZulu-Natal Department of Health, 2016; Dookie, Singh and Myburgh, 2017). The KwaZulu-Natal Oral Health Plan 2011-2015 did outline policies to reduce the magnitude of oral diseases through oral health screening, promotion, prevention and education (Dookie, Singh and Myburgh, 2017). The approach through which this would be undertaken include intensifying school health programs and fissure sealant application (Dookie, Singh and Myburgh, 2017). Further, control and relief of pain and sepsis, orthodontic and oral and maxillofacial facilities in different regions and prosthetic services in districts were also outlined as part of the strategies aimed towards reducing the oral disease burden (Dookie,

Singh and Myburgh, 2017). Additionally, reducing the extraction to filling ratio which has been fluctuating since 2005 was also drafted in the KwaZulu-Natal Oral Health Plan 2011-2015 (Dookie, Singh and Myburgh, 2017). However, the study by Dookie *et al* noted an increase in the number of extractions for the whole province relative to the number of restorations undertaken which is in contrast to the policy statement (Dookie, Singh and Myburgh, 2017). The study carried out by Singh *et al* also reported that persuasive oral health strategies have been proposed and do exist on paper in the health care system in South Africa but are not fully translated into actions and hence a lack in meaningful content is observed (Singh, Myburgh and Lalloo, 2010). Additionally, Dookie *et al* also observed a lack of implementation procedures of a number of stated policies (Dookie, Singh and Myburgh, 2017). Ramphoma reported that the current oral health system needs to be revised such that it is directed more towards the population in order to promote oral health and prevent oral diseases (hence including head and neck cancer) rather than being individually-oriented as is the actual case (Ramphoma, 2016).

Non-fixed facilities are provided by faith-based organizations, non-governmental organizations and community care givers and includes health promotion (school health programs), screening, education, referral services and support for patients who are on treatment (KwaZulu-Natal Department of Health, 2016). Mobile unit services are run during working hours and they contribute to the improvement of health care access for those who are in underpriviledged and remote places where there are no clinics and community health centres (KwaZulu-Natal Department of Health, 2016).

## 2.8 Philosophy of health promotion

### 2.8.1 Ottawa Charter

The Ottawa charter is a landmark document that was created in 1986 in the first International Conference on health promotion held by the World Health Organization in Ottawa, Canada (Flynn, 2015). Health promotion is defined in the Ottawa Charter as *"the process of enabling people to increase control over, and to improve their health"* (International Conference on Health Promotion 1986; Pg 1). Health promotion is an important concept which aims at equitable health for both men and women in a supportive environment (International

Conference on Health Promotion, 1986). It provides guidance to the goals and concepts of health promotion in public health (Flynn, 2015). The principles established in the charter are fundamental for health promotion activities (McPhail-Bell, Fredericks and Brough, 2013). Five action areas were identified in this charter with the aim of achieving "Health for All" by the year 2000 and beyond by collaboration of not only government sectors but also non-governmental organisations and other bodies (International Conference on Health Promotion, 1986). Building healthy public policy to protect the health of communities and individuals and to facilitate people to make healthy choices was the first action area set out in the charter (International Conference on Health Promotion, 1986). This is possible by a coordinated approach of legislative, organisational, regulatory and taxation changes (International Conference on Health Promotion, 1986). The second action area is creation of supportive environments so as to allow people to make health promoting choices in the places where they are living, working or learning (International Conference on Health Promotion, 1986) . The third action area was based on strengthening community action which enables people to collectively make efforts to improve their health by enabling access to information and financial support (International Conference on Health Promotion, 1986). Developing personal skills at both the individual and social level is the fourth action area established which encourages learning at all instances to have more control over one's health and also to cope with injuries and other illnesses (International Conference on Health Promotion, 1986). The charter also recommends a reorientation of health services as the fifth action area so that the concept of health promotion is distributed among health professionals, individuals, community, health service institutions and the State (International Conference on Health Promotion, 1986).

### 2.8.2 Jakarta Declaration

The Jakarta Declaration on Leading Health Promotion into the 21st Century was signed at the 4$^{th}$ International Conference on Health Promotion in 1997 in Jakarta, Indonesia (World Health Organization, 1997). The priorities set out in the Ottawa Charter were further stressed upon, along with the establishment of additional priority actions (World Health Organization, 1997). It has highlighted the role and importance of promotion of social responsibility, expansion of health developments by increased investments, consolidation and expansions of health

partnerships, empowerment of individual and community groups and secured health promotion infrastructure (World Health Organization, 1997).

### 2.8.3 Bangkok Charter

This came into existence in 2005 in the 6th Global Conference on Health Promotion of the WHO in Bangkok, Thailand (Mittelmark, 2008). As much as it recognises pledges, actions and commitments to address health determinants via health promotion (World Health Organization, 2005b), however, it has sparked much concern among health promotion experts who consider it to be *"an inadequate and timid document"* which does not focus adequately on the requirements to deal with health problems globally (Mittelmark, 2008).

## 2.9 Oral health promotion strategies in head and neck cancer

Good oral health is more than healthy teeth since the health of gingiva, periodontal ligaments, alveolar bone, hard palate, tongue, salivary glands, lips, mucosal linings of the mouth, floor of mouth, soft palate, muscles and nerves are dictated by proper oral hygiene (Benjamin, 2010). It also contributes to more favourable outcome of treatment and well being (Farquhar *et al.*, 2017). Dental caries (DC), hyposalivation (reduced salivary flow), xerostomia (dry mouth), trismus and osteoradionecrosis occurring as a side effect of chemotherapy and radiotherapy are common complications in head and neck cancer (Deng *et al.*, 2015). Some of these like DC may be decreased to some extent with effective oral health promotion strategies (Deng *et al.*, 2015; Needleman *et al.*, 2015).

The development of radiation caries occurs in the first year (more specifically within 3 months) after radiotherapy owing to the dramatic increase in colony counts of cariogenic bacterial species Streptococcus mutans and lactobacilli, but is preventable if effective strategies including topical fluoride application, toothbrushing, flossing, interdental aids, mouth rinse and restriction of high carbohydrate and sucrose diet are instructed to patients as part of the preventive regimen (Deng *et al.*, 2015; Gupta *et al.*, 2015).

Hyposalivation is mainly attributed to the effects of radiation which directly causes salivary gland damage at a minimum dose of 26 Gray within 1-2 weeks of commencement of radiotherapy (Papas *et al.*, 2008; Deng *et al.*, 2015). Irreversible damage occurs at 60 Gray (Papas *et al.*, 2008). The buffering actions and composition of protein are altered producing mucoid acidic fluid (Papas *et al.*, 2008). DC occurs as a result of xerostomia and hyposalivation (Papas *et al.*, 2008). High carbohydrate liquid supplements favouring the deposition of plaque equally contribute to DC in this segment of population (Deng *et al.*, 2015). DC may also occur due to difficulty to brush in between meals taken frequently in small portion in these patients (Deng *et al.*, 2015). The direct mechanism of action of radiation on teeth is not yet understood, but alteration in chemical composition and hardness of dentin and enamel, have been observed in in-vitro studies (Deng *et al.*, 2015).

### 2.9.1 Toothbrushing and fluoride toothpaste

Toothbrushing is an indispensable daily oral health self-care routine to effectively remove plaque and prevent halitosis and diseases (Poklepovic *et al.*, 2012; Oliveira, Slot and van der Weijden, 2014; Critchlow, 2017). A study conducted in Germany reported that daily toothbrushing and flossing along with regular dental visits contribute to prolonged overall survival in head and neck cancer patients (Friemel *et al.*, 2016). Soft-bristled toothbrush with small head and low abrasive tooth paste are recommended for effective plaque removal (Sultana and Sham, 2011; Critchlow, 2017). Toothbrush handles can be modified with putty impression material by dentists so that a better grip (customised to patients' finger impression) can be obtained for patients with reduced manual dexterity (Critchlow, 2017). Reduced manual dexterity, limited hand strength and decreased range of finger motion numbness and reduced sensation are often reported among head and neck cancer survivors (Orlik *et al.*, 2014). This is because surgical flaps of the forearm are often used for reconstruction purposes of damaged structures in the head and neck region (Orlik *et al.*, 2014). Electric toothbrushes are other alternatives for those having reduced dexterity of the hand since less skill is required as compared to manual toothbrushes (Critchlow, 2017).

Fluoride is the cornerstone for enhancement of remineralisation and prevention against irreversible demineralisation and also as a desensitising agent by preventing forward and backward movement of fluid within the dentinal tubules (Dholam *et al.*, 2013; Deng *et al.*,

2015). Fluoride toothpastes should have at least 1350 parts per million(ppm) fluoride for more effective and enhanced protection (Critchlow, 2017). Fluoride toothpaste in high risk population where xerostomia and caries are expected ( as in head and neck cancer patients) is recommended in a concentration of 2800 ppm which can be obtained without prescription (Critchlow, 2017). Higher doses of 5000 ppm where a prescription is mandatory is even better for prevention or reversal of caries (Critchlow, 2017). However, as much as high-fluoride toothpaste has its place in effective caries prevention protocol, toothpaste alone cannot prevent against radiation induced caries (Papas *et al.*, 2008). More advanced regimens in addition to high fluoride toothpaste, as described further, are required in this high-risk population.

### 2.9.2 Fluoride rinses

Many studies have supported the use of calcium phosphate either in the form of paste or rinse to protect against radiation caries progression (Papas *et al.*, 2008; Singh and Papas, 2009). A study conducted by Papas *et al* supported that remineralising toothpaste which contains calcium phosphate in addition to high concentration of fluoride is useful since calcium and phosphate ions are important for remineralisation to take place (Papas *et al.*, 2008) . These two ions, contained in saliva, are depleted following hyposalivation (Deng *et al.*, 2015). Remineralisation is restricted in the absence of these two ions even if fluoride ions are present (Papas *et al.*, 2008; Deng *et al.*, 2015). Another study conducted on head and neck radiotherapy and Sjogren's Syndrome patients found that remineralising rinse containing 1.1% sodium fluoride and hypersaturated with calcium phosphate is equally useful in preventing xerostomia and therefore progression of caries in high-risk group (Singh and Papas, 2009). Its findings reported that although it is costly in the long term preventive regimen, however, significant decrease in coronal surface caries, root caries and number of decayed tooth surfaces was observed in those using the hypersaturated calcium phosphate rinse more than once daily as compared to those who were not compliant (Singh and Papas, 2009).

### 2.9.3 Custom made fluoride trays

Construction of custom-made fluoride trays is one useful option to deliver fluoride to enamel and dentin (Deng *et al.*, 2015). Topical sodium fluoride liquid or gel with neutral pH in a concentration of 1% is poured onto the tray and inserted daily in the mouth for the recommended duration of 5 minutes (Walker *et al.*, 2011; Deng *et al.*, 2015; Gupta *et al.*, 2015).

### 2.9.4 Fluoride gels, varnishes and lacquers

Prescription of brush on fluoride gel or pastes, and fluoride rinses are also effective if trays are uncomfortable or too costly to afford (Deng *et al.*, 2015). Additionally, administration of in-office fluoride lacquers and varnishes is another way to administer fluoride. (Deng *et al.*, 2015). Fluoride varnishes usually contain 5% sodium fluoride which is equivalent of 22, 600 ppm fluoride ion and carries less discomfort to patients and takes less time to apply than fluoride gels (American Dental Association Council on Scientific Affairs, 2006). According to the recommendations issued by the American Dental Association, fluoride varnishes or gels should be applied every 3-6 months yearly for those at high risks of developing caries, including therefore head and neck cancer patients (American Dental Association Council on Scientific Affairs, 2006; Dholam *et al.*, 2013).

### 2.9.5 Interdental aids

Interdental aids, including dental floss, interdental toothbrushes and toothpicks, are more effective at removing dental plaque interproximally than toothbrushing alone since manual toothbrushes cannot penetrate in interproximal spaces (Poklepovic *et al.*, 2012; Muniz *et al.*, 2015). However, each one of them has got its own indication and potential at controlling interdental plaque as elaborated below.

Flossing, in addition to toothbrushing, is a daily recommended key strategy to prevent periodontal diseases and dental caries (Sambunjak *et al.*, 2011). A length of 18 inches is the ADA- recommended length of string floss to be used for cleaning interproximal surfaces (Jablonski, 2012). Flossing is indicated where proximal contacts between the teeth are small, while interdental toothbrushes are best for wider spaces (Critchlow, 2017). Interdental toothbrushes and floss holders are useful especially for those patients who are dependent on

care givers (Jablonski, 2012). Interdental toothbrushes are also useful adjuncts to toothbrushing (Tarannum *et al.*, 2012). A systematic review argued that interdental brushes are more effective at removing interdental plaque than dental floss or toothpicks (Slot, Dörfer and Van der Weijden, 2008). Another study reported that BrushPicks which resemble interdental toothbrush and toothpicks were better than dental floss as an interdental cleaning aid (Tarannum *et al.*, 2012).

### 2.9.6 Water fluoridation

Water fluoridation is considered as a relatively major cost-effective public health intervention by health professionals to control dental caries on buccal, lingual and proximal tooth surfaces (Kroon and Van Wyk, 2012; Iheozor-Ejiofor *et al.*, 2015). Water fluoridation is an effective strategy to prevent dental caries in populations living in remote areas where access to dental health care is restricted. It is also reported to be equally effective in persons having poor oral hygiene and those who have an increased risk of developing dental caries due to unhealthy eating lifestyle (high carbohydrate and sucrose diet). Based on this statement, it can be concluded that patients with cancer of the head and neck regions might as well benefit from water fluoridation since they present with poor oral hygiene very often (Critchlow, Morgan and Leung, 2014) and are also at higher risk of developing caries (Deng *et al.*, 2015).

#### 2.9.6.1 Situation in South Africa

Water fluoridation was first instigated in the USA in 1945 (Iheozor-Ejiofor *et al.*, 2015). It is currently implemented in roughly 25 countries around the globe including Spain, UK, Australia, USA and Ireland (Iheozor-Ejiofor *et al.*, 2015). Water fluoridation was considered as a public primary health intervention by the African National Congress (Kroon and Van Wyk, 2012). However, South Africa has no existing community water fluoridation system despite a national bill that has been voted in its favour in the year 2000 and was approved to be included in the Health Act No 63 of 1977 by the Minister of Health (Kroon and Van Wyk, 2012). According to this legislation, artificial fluoride was meant to be incorporated in all water supplies in Durban, East London, Cape Town and Port Elizabeth (Kroon and Van Wyk, 2012). This step has however, never been undertaken owing to a revision in its regulation in a new Health Act despite provision for its successful implementation were proposed (Kroon and Van

Wyk, 2012). A study recently conducted to determine the cost-effectiveness of controlled addition of fluoride in community water supplies in South Africa revealed that it is the cheapeast medium through which more than 50% of South Africans can have fluoride (Kroon and Van Wyk, 2012).

### 2.9.7 Diet instructions

Patients with head and neck cancer often complain of several symptoms like dry mouth, weight loss due to impaired nutritional intake amongst others. The severity of these symptoms can be reduced or corrected to a certain extent with specific approach.

Besides mechanical and chemical plaque control, the eating lifestyle plays an equally important role in xerostomia (Sultana and Sham, 2011). A rigorous anti-cariogenic diet is highly recommended to control caries in patients prone to developing xerostomia (Sultana and Sham, 2011). Reduction in sugar intake frequency is one of the foundations of oral health promotion (Solhi *et al.*, 2010). Increase in the intake of fluid is also vital for patients with xerostomia (Sultana and Sham, 2011). Nurses are critical to educate patients on diet change (Dolce, Haber and Shelley, 2012).

Malnutririon, which results in cachexia and poor outcome of treatment, is a commonly encountered complication in patients undergoing multi modality head and neck cancer therapy (Colasanto *et al.*, 2005; Bhattacharjee, Bahar and Saikia, 2015). Nutritional supplements are recommended for those who stand a high weight loss risk (Colasanto *et al.*, 2005; Bhattacharjee, Bahar and Saikia, 2015). The enteral or parenteral routes can be used for feeding where eating via the oral route is not possible (Colasanto *et al.*, 2005). Protein is the most important element in these patients, followed by carbohydrate, fat, vitamins, minerals and fluid (Colasanto *et al.*, 2005). Adherence to a diet specifically formulated for head and neck cancer patients is important to correct weight loss and metabolic stress (Colasanto *et al.*, 2005). A study conducted in India reported of an increase in weight and basal metabolic rate in head and neck cancer participants following administration of and adherence to a head and neck cancer -specific diet chart (Bhattacharjee, Bahar and Saikia, 2015).

## 2.10 Health promotion settings

### 2.10.1 Hospitals and clinics

The WHO came up with a global initiative in the early 1990s to encourage hospitals to incorporate health education, information and advice, disease prevention and rehabilitation services in addition to curative care (Groene and Jorgensen, 2005; World Health Organization, 2006). Hence, promotion of health in clincs and hospitals goes far beyond treating medical issues per se, it also takes into account the emotional and holistic well-being of the individual to improve health care quality (Gillam, 1992; Groene and Jorgensen, 2005; Bulotaitė *et al.*, 2017). Health care settings are promising strategies for sustained public health motivation and health promotion as they have a more profound impact on patients and families who tend to be more attentive and practice upon health advice during illness (World Health Organization, 2006). Considering this fact and based on the same principle, it can be said that the same can be applied to patients undergoing therapy for head and neck cancer, in relation to promoting oral health care in hospital settings. As an example, hospitals have to provide patients with adequate information of the impact that the multimodality treatment of head and neck cancer has on the oral health during and after therapy (Jawad, Hodson and Nixon, 2015). Furthermore, the importance of pretreatment dental assessment and management must also be stressed upon (Jawad, Hodson and Nixon, 2015). In this way, the patient would be better prepared psychologically to face the challenges about to come. Moreover, identifying the needs of patients with chronic conditions (including head and neck cancer patients as well) and providing advice of lifestyle risk factors help to empower them to modify the behaviour and guarantee sustained care (Groene and Jorgensen, 2005). Promotion of health incorporates a combination of medical, behavioural and socio-environmental approaches for it to be successful (World Health Organization, 2006). Medical approach is concerned with screening for physiological factors and performs individual risk assessment and immunization to promote health, while behavioural approach is concerned with educating and informing about lifestyle factors such as smoking by engaging the community (World Health Organization, 2006). Socio environmental approach addresses general conditions such as poverty and unemployment by engaging both society and environment (World Health Organization, 2006).

### 2.10.2 Hospices and homes

The Ottawa Charter advocates that strengthening community actions by support organisations (example can be hospices and cancer support groups) help to improve health (International Conference on Health Promotion, 1986). Maintenance and promotion of oral health care in cancer is a vital determinant for the improvement of overall health and well being in holistic settings (Simons, 2016). This helps to create a supportive environment as set out in the Ottawa Charter (International Conference on Health Promotion, 1986). However, this is very often neglected due to several barriers (Simons, 2016). These barriers include lack of know-how and quality oral health care training among caregivers, inability of the latter to recognize the oral health related needs of terminally ill cancer patients, psychological affliction by patients, inability of the patients themselves to address their oral problems to caregivers, functional impairment and transport problems (Chen and Kistler, 2015; Simons, 2016).

It is reported that more than 90% of cancer patients in hospices suffer from oral-related problems, with xerostomia being the most predominant complication (Chen and Kistler, 2015). Oral health in homes and hospices is underemphasised both by patients and nurses as a general fact (van der Putten *et al.*, 2013). Literature suggests that an effective way of giving oral health its place among residents of hospices is through the application and supervision of oral health care concepts which are backed by objective evidence (van der Putten *et al.*, 2013).

A study conducted in the Netherlands proved that the oral health of the patients in its intervention arm which made use of a Dutch-developed oral health guideline which encompasses important aspects of oral health skills needed by nurses to deliver care to residents in hospices, good oral health care and on-going supervision of the progress of the oral health of home residents was significantly better when compared to the control arm which did not follow any supervised concepts (van der Putten *et al.*, 2013). Another study carried out in England demonstrated how important it is to integrate oral health care assistance to cancer patients suffering from their mouth as a result of the cancer itself or cancer therapy side effects (Simons, 2016). It reported on a case of how a patient with metastatic lesions in the floor of the mouth and on the tongue experienced significant improvement in the oral health with continuous delivery and assistance of oral care by the hospice staff (Simons, 2016).

Hence from the cited studies it can be concluded that integrating oral health messages into a wider framework of management of cancer in hospices and homes helps to improve the quality

of life of cancer patients. It is worth noting that South Africa has several community cancer advocacy organisations like CANSA, Al Ansaar cancer support groups, Cancer Buddies amongst others which provide moral and psychosocial support to cancer patients so that they can again re-integrate the society and develop a genuine cancer survivorship approach after having had the disrupting news of suffering from this challenging and harrowing illness.

## 2.11 Oral health promotion in cancer

Oral health promotion and awareness programs to educate people of the importance of oral health during and even after cancer treatment are important requisites to improve the health related quality of life (Ohrn, 2004; Plemons, Rankin and Benton, 2013; McQuistan *et al.*, 2015; Samim *et al.*, 2016). The sixtieth World Health Assembly, held by the World Health Organisation in view of implementing new strategies towards improving the oral health policy from several aspects, directed numerous oral-health related approaches towards Member States with one of them being that cancer of the oral cavity should be an important component of a cancer control program held at the national level (Petersen, 2009a). The Assembly also urged that oral health workers including primary health care staff or health professionals with adequate training to make diagnoses and provide treatment at the initial stage of oral cancer be actively involved in national cancer control programs (Petersen, 2009a).

### 2.11.1 Life style and socio-economic risk factor intervention through educational campaigns in head and neck cancer

In order to achieve a standard level of oral health promotion policy, knowledge of the importance of oral health coupled with control of risk behaviours are vital pre-requisites (Blaggana *et al.*, 2016).

Intervention through campaigns (either TV/mass media or other forms) by informing and educating people at risk of the effects of tobacco and alcohol which are the most preventable dose-dependant etiological factors for head and neck cancer is of paramount importance if the incidence is to be reduced (Petersen, 2009b; Dwojak and Bhattacharyya, 2017). A study from Taiwaan reported that due to lack of knowledge, none of the participants in the survey carried out knew they were having signs of oral cancer since the lesions were painless and small and

did not therefore assume medical assistance was important (Hu, Cooke and McCarthy, 2009). They opted instead for over the counter ointment and traditional medicines (Hu, Cooke and McCarthy, 2009).

Hence, educational campaigns help to conscientise people to be in greater authority of their own health so that they are made aware that expert assistance need to be solicited if suspected lump is detected (Mighell and Gallagher, 2012). Education on the consequences of tobacco smoking, alcohol consumption, areca nut-chewing and the other various risk factors discussed above should be part of a properly structured oral health promotion programme in addition to routine toothbrushing and flossing methods. Education through a risk factor approach has to aggressively be an important component in campaigns against cancer of the head and neck region (Abdo *et al.*, 2007). In this regard, the cancer burden can hopefully show a decrease if people are instilled and properly educated and motivated of the life threatening consequences of these lifestyle risk factors, since hospitalised patients battling against oral cancer represents a huge drain on the health care system due to the exorbitant cost of care (Abreu, Kruger and Tennant, 2009). In this way, the severe financial burden on both the patient and the State can be avoided to some extent (Abdo *et al.*, 2007; Abreu, Kruger and Tennant, 2009; Joshi *et al.*, 2014).

A study conducted in Brazil reported that educational campaigns very often do not include the high-risk population who genuinely represent the originality of the problem being addressed (Nemoto *et al.*, 2015). The same author suggested that for such campaigns to show a positive outcome, the number of participants should be as big as possible and should target those at high risk for developing head and neck malignancy and the families of the latter as well (Nemoto *et al.*, 2015). This could be achieved by holding campaigns at different periods during the year and planning home visits to the at-risk and socioeconomically marginalised, instead of them travelling to participate in such campaigns (Nemoto *et al.*, 2015).

Intervening through lifestyle factors exclusively, however, has been reported to carry questionable chances to minimise exposure to etiological factors (Conway *et al.*, 2008). Elimination or reduction of alcohol consumption and tobacco cessation programmes coupled with actions to condense socioeconomic disparities and improve social and financial situations are important factors to consider while formulating oral health policies pertaining to head and neck cancer (Conway *et al.*, 2008; Torres-Pereira, 2010; Mighell and Gallagher, 2012). Those who are socially marginalised and live in underprivileged conditions are more exposed to risk

factors like infections, tobacco and alcohol which are associated with head and neck cancer (Petersen, 2009b; Auluck *et al.*, 2014). They are also those who are exposed to a more significant extent to lack of access to health care and health education (Petersen, 2009b; Auluck *et al.*, 2014). A study from Canada reported that the risk for oral cancer was higher in those with low socioeconomic status in terms of educational level and income (Johnson *et al.*, 2010). Another study carried out in Scotland also found that people residing in poor regions had increased chances for oral cancer (Conway *et al.*, 2010).

### 2.11.2 Education and training of oral health promoters

The Global Oral Health Programme declared in its World Oral Health Report 2003 that oral health promotion be a component of general health promotion and chronic disease prevention because the risks to health are linked (Petersen, 2008). A study carried out in Canada recommends that dental services be incorporated in cancer hospitals where treatment is being delivered so that oral complications arising during cancer therapy can be dealt with rapidly, without causing interruption in the treatment for malignancy (National Institute for Clinical Excellence, 2004). However, the initial step to incorporate oral health into general health requires quality training and education of oral health care workers, stakeholders and decision makers to communicate important oral health messages to the population (Horowitz *et al.*, 1996; Molete, Daly and Hlungwani, 2013). A study carried out in Gauteng, South Africa, reported that oral health promoters from 5 out of the 6 districts in the province had a poor background on oral health and consequently did not have the mastery required to promote oral health through a risk factor approach (Molete, Daly and Hlungwani, 2013).

Besides education of oral health promoters, prohibition of smoking in public places and private transport carrying children, outlawing the sale of alcohol and tobacco to minors and increasing taxes on tobacco products are some of the risk factor approaches to formulating public policies which have been considered in many countries including South Africa (Horowitz *et al.*, 1996; Baleta, 2010; Bhat *et al.*, 2015). Alcohol related cancers and consumption rate have not shown a decrease despite promotion, advertisement and sponsorship of alcoholic drinks are proscribed under Section 9 of the South African Liquor Act (Stefan *et al.*, 2013; Department of Trade and Industry, 2015). The South African Government is hereby encouraged to act more sternly in this respect so as a significant decrease in smoking and alcohol consumption rate is observed in the very near future.

### 2.11.3 Self examination of oral cavity

Besides risk factor intervention, mouth self examination (individual makes a self examination of the mouth for any suspicious lumps and refer himself to a doctor) which is cost-effective, simple, applicable to mass population and bearing no invasive procedures could be an important aspect of oral health promotion policy for curbing the incidence of head and neck cancer (Torres-Pereira, 2010). Although this has not gained much interest among governments and policy-makers owing to a lack of scientifically valid strategies for implementation, more in-depth works are necessary to judiciously study its effectiveness (Torres-Pereira, 2010).

### 2.11.4 Early screening and recognition of factors which delay diagnosis

The survival rate of early stage oral cancer is 80% while that of late stage is 20%, reflecting the need therefore to maximise the effort into striving to make an early diagnosis (Stahl, Meskin and Brown, 2004). The survival rate is equally linked to the country income (Farmer *et al.*, 2010). South Africa is classified as an upper-middle income country which is still developing and the fatality from cancer in relation to the proportion of incidence to mortality in developing countries is approximately 64% while that in high income countries is 46% (Farmer *et al.*, 2010; World Economic Situation and Prospects, 2014; World Bank, 2017). Recognising, reviewing and improving on the factors responsible for delay in diagnosis of head and neck cancer is another option of promoting oral health in head and neck malignancy (Torres-Pereira, 2010). The health system, health care providers who take long time to refer or simply the patient who takes time to present himself for treatment are some of the factors which delay the diagnosis of head and neck cancer (Torres-Pereira, 2010). Recognising these factors early can help in reducing the mortality and morbidity of cancer (Torres-Pereira, 2010; Mighell and Gallagher, 2012). Factors which compel the patient to present late for treatment include strong cultural beliefs that cancer “is a curse”, poor socio-economic status, illiteracy, reduced access to care, transport unavailability (Joshi *et al.*, 2014).

Recognising pre-malignant lesions early through screening programs and mass education is equally reported to be have significant favourable diagnostic and prognostic values (Dionne *et al.*, 2015). More research is however needed in order to achieve this level of recognition since the molecular pathways along with the diagnostic aids needed in these interventions need to be first understood (Dionne *et al.*, 2015). Significant importance should be given upon training

and involving primary health care workers and oral health professionals to screen, diagnose, refer and provide suitable treatment of premalignant and malignant lesions of the head and neck region in the early stage (Petersen, 2008). A study from Brazil also reported that the detection of oral cancer in the early stage at the primary health care level and referral via proper channels were included in its national oral health policy since 2004 so as to improve the cancer prognosis (Sousa *et al.*, 2014). This is important while formulating national strategic plans on promotion of health in cancer to also improve the accessibility to quality care for cancer sufferers who live far from tertiary care settings (Sousa *et al.*, 2014).

An oral cancer campaign held by the American Dental Association in the United States reported that the majority of the dentists who participated in its survey following the campaign reported that it definitely helped to highlight the importance of early diagnosis of oral cancer by being more particular about the presence of lumps and other lesions of the oral cavity and informing patients that oral examination for cancer will be undertaken (Stahl, Meskin and Brown, 2004). It is also reported of having had an impact on the public as well, in the way that more people requested for screening of existing lesions (Stahl, Meskin and Brown, 2004). The oral cancer campaign that Brazil held also proved to be of great benefit and had a positive impact on the oral health of the population (Martins *et al.*, 2012). It made use of strategies issued by the Brazilian Ministry of Health pertaining to printed guidelines to follow to develop the campaign, intensification in oral examination services, proper organisation of patient referral, training of primary health care workers with a specialist for reviewing oral cancer patients in the follow-up phase in primary health care centres for any soft tissue changes (Martins *et al.*, 2012).

Since these initiatives provided positive results in United States and Brazil, the South African Government, with the help of policy makers, is also fully encouraged to have such campaigns held.

### 2.11.5 Incorporating head and neck malignancy as a CPD topic

The General Dental Council of the United Kingdom passed a regulation subject to the increase in oral cancer cases stating that oral cancer be listed among Continuing Professional Development (CPD) topics for dental professionals within the United Kingdom so as to provide them with the insight required to manage and refer cases of oral cancer (Mighell and Gallagher, 2012). This is very important as skipping or missing out on a painless mass during dental

examination due to lack of knowledge on the part of the dentist can lead to aggravation of medical condition and subsequently results in inferior quality of life for the patient later (Hertrampf *et al.*, 2009). Hence professional educational updates in relation to head and neck malignancy are vital to improving treatment outcomes (Hertrampf *et al.*, 2009).

### 2.12 Palliative approach to promote health

The earlier a diagnosis of cancer is made the better is not only the symptomatic management but the holistic or palliative approach equally (Thompson et al. 2007; Blum & Schonfeld 2015). In order to address the issues of palliative care in different South African hospices, the non-profit organisation, Hospice Palliative Care Association of South Africa (HPCA), was founded in 1986 to form a united national body with the goal of integrating and creating awareness of the importance of palliative care into each and every health care framework (Southern African NGO Network, 2016). It is a registered national organisation with the Department of Social Development under section 21 of the Companies Act having its branches in all the nine provinces of South Africa (Southern African NGO Network, 2016).

The idea of modern palliative care dates back to 1959 by Dame Cicely Saunders who was initially a nurse and finally became a medical doctor (Blum and Schonfeld, 2015; Olver, 2015). Dame Cicely founded the first modern hospice named St Christopher's Hospice in South-East London in 1967 with the intent to emotionally, psychologically and socially support the dying patient and not merely providing medications to ease pain (Olver, 2015). She came up with the idea after seeing the degree of inadequate care at hospitals in terms of psychosocial support (Olver, 2015).

Palliative medicine was introduced as a speciality in 1987 by the Royal College of Physicians in the United Kingdom (Lo and Woo, 2000). Palliative or holistic care is a universal and vital part of any comprehensive treatment plan of not only head and neck cancer but other cancers and life threatening illnesses as well (Lo and Woo, 2000). It begins from the initial diagnosis of cancer and remains the focus of care even when the course of cancer therapies is over until the patient is alive (World Health Organization, 2002). It takes into account not only the relief of pain through medications but also the emotional, moral, social and physical needs which are mandatory to improving the quality of life (Lo and Woo, 2000; World Health Organization,

2002). Hence holistic management requires a multidisciplinary team approach consisting of doctors, nurses, social workers, dieticians and psychologist (Lo and Woo, 2000; National Cancer Institute, 2010).

Palliative care is based on the relief of suffering from cancer pain with the intention to accept life as it is and view death as the law of nature (World Health Organization, 2003). It also has the objective to help family members and cancer survivors cope with the hardships accompanied by the disease by providing counselling and encouragement through an organised team approach (Lo and Woo, 2000; World Health Organization, 2003). While doing so, it takes into consideration the spiritual and psychological aspects of the patient in a way as to uplift the essence of life (World Health Organization, 2003). In addition to psychological upliftment and counselling, palliative care is also based on compliance to medications to relieve pain (World Health Organization, 2003).

### 2.13 Risk factors of head and neck cancer

Cancer is a multifactorial non-communicable disease (Hernandez *et al.*, 2017). Early diagnosis of head and neck cancer or any other life threatening diseases leads to prompt intervention and treatment, resulting in a better quality of life and lower treatment costs for the patient (Goyal and Bhagawati, 2016). However, review of the risk factors is an ongoing requirement in research in order to highlight the avoidable causative influences which can help in curbing the growing incidence and damage related to cancer of the head and neck region.

Developing countries facing rapid economic growth have been impacted by changes in lifestyles including alcohol and tobacco (Fagan, Stannard and Dalvie, 2014). Most of the pharyngeal (oropharyngeal and hypopharyngeal) and oral cancers (66.7%) occur in developing countries (Fagan, Stannard and Dalvie, 2014). While oral cancer is mainly caused by betel quid and tobacco in chewable or smoked form, nasopharyngeal cancer, which is equally predomininant in developing countries, is associated with Epstein Barr virus infection (Maxwell *et al.*, 2010; Yoshizaki *et al.*, 2012; Fagan, Stannard and Dalvie, 2014).

### 2.13.1 Chemical and environmental factors

#### 2.13.1.1 Tobacco

Tobacco, in all its forms, whether smoked or smokeless, is hazardous to human health even though the degree of harm infliction varies greatly among the different products (O'Connor, 2012). Despite being the most preventable risk factor for cancer, tobacco smoking is still embraced by approximately 7 million people in South Africa (van Zyl-Smit *et al.*, 2013; De Almeida *et al.*, 2014). One of the reasons pertaining to this huge amount of smokers is the illegal trade of cigarettes which are sold at cheaper prices to potential buyers in South Africa (National Council Against Smoking, 2015). Cigarette smoking is a more common practice among South African males than in females whereby the study carried out by Reddy et al. confirmed this fact by reporting the prevalence of adult males smoking cigarette to be 29.2% in contrast to 7.2% of adult females, representing a four-fold prevalence in males than in the latter (Reddy *et al.*, 2015). This trend is consistent with the global report of the WHO which estimated the prevalence of smoking in South Africa to be 32% among males and 8% among females in 2010 (World Health Organization, 2015). However, it is not only a lifestyle habit of the adult population. A previous study conducted among students aged 13-15 years in ten African countries (including South Africa), reported a high prevalence (12.6%) of cigarette smoking in this age group for South Africa (Zhao *et al.*, 2015). The report of the South African National Youth Risk Behaviour Survey indicated that 15.3% of boys and 11% of girls aged 14 years were current smokers of cigarettes (World Health Organization, 2015). A possible reason to this shockingly high figure is the attraction to advertisements of cigarette brands on television (Zhao *et al.*, 2015). A study conducted in Australia reported that oral health therapists represent a promising strategy in delivering messages and counselling school children of the diseases and conditions related to smoking (Matias *et al.*, 2013). South African Government may also adopt this approach by recruiting more oral health therapists to educate the youngsters. Globally, the estimated proportion of regular adolescent smokers is no less than 15% with the highest prevalence of 25%-35% being in Europe, America and South Africa (Petti, 2009).

#### 2.13.1.1.1 Mechanisms of tobacco carcinogenicity

A number of studies has proved a strong relationship between tobacco smoking and head and neck cancer (Czerninski, Zini and Sgan-Cohen, 2010; Chen *et al.*, 2011). Simard *et al* reported that a pooled analysis from Europe, Latin America and North America found that 33% of cases related to cancer of the head and neck was associated to tobacco exposure, whether active or passive (Simard, Torre and Jemal, 2014). Furthermore, a case-control study from Taiwan, reported that smoking tobacco increases the chances of developing oral cancer by eighteen times (Chen *et al.*, 2016). Another study from Brazil reported that tobacco smokers stand 6 to 16 times more chances to develop cancer of the oral cavity than those who do not smoke (Nemoto *et al.*, 2015).

The compounds in tobacco exert their carcinogenic effects by causing irreversible mutation at the genetic level but the mechanism for such alterations of the protein-coded genes associated with tobacco smoke is not fully investigated and understood (Yavorski and Blanck, 2016). However, the mechanisms which have been put forth state that the constituents of the smoke cause adduction of DNA, mainly 6-methyl-guanine resulting in interference with the replication and damage to the cells of the immune system (Pezzuto *et al.*, 2015). The smoke also increases the number of cellular components namely antiapoptotic factors to prevent the normal apoptotic activity, which is primordial in cancer prevention, from taking place (Pezzuto *et al.*, 2015; Liu *et al.*, 2017). Chronic inflammation is promoted due to the activation of Interleukin-1 and Tumour Necrosis Factor α by reactive oxygen species produced by tobacco smoke (Pezzuto *et al.*, 2015). The smoke constituents are also blamed to decrease ciliary motility and increase mucosal secretion by inhibiting the production of antimicrobial peptide β defensin-2 by gingival cells (Pezzuto *et al.*, 2015). In a recently published study, the cytoskeletal protein-related coding regions genes (CPCR) were reported to be mostly affected by mutagens in the process of malignant formation in smoking-related head and neck cancer, although there are other genes which are affected but to a lesser degree (Yavorski and Blanck, 2016).

The risk of developing head and neck cancer is dropped by 30% following a tobacco cessation period of 1-4 years (Shaw and Beasley, 2016). Laryngeal cancer risk is reduced by 60% with 15 years of tobacco cessation while that of oral cavity is reduced to the level similar to a person who never smoked after 20 years (Shaw and Beasley, 2016). When the smoke is formed during

burning over four thousand different products are created and more than sixty of these are carcinogenic with nitrosamines being one of them (Slaughter *et al*. 2011; Hussain *et al*. 2008; Richter *et al*. 2008; El-Bayoumy *et al*. 2017). Tobacco smoking not only contributes to the formation of head and neck cancer but has unfavourable outcomes on the the success of treatment during radiation therapy if the patient continues to smoke after the cancer diagnosis (Shaw and Beasley, 2016).

The most potent carcinogens of tobacco in smoked or smokeless forms are N'-nitrosonornicotine(NNN),4-(methylnitrosamino)-1-(3-pyridyl)-1-butanone(NNK), benzene, acetyldehyde, acrolein, carbon monoxide and formaldehyde (Gorini, 2011; Biener *et al.*, 2014). The International Agency for Research on Cancer (IARC), has classified carcinogens into four groups as shown in the Table 1 (WHO-IARC, 2004).

**Table 2: Classifiaction of carcinogens by International Agency for Research on Cancer**

| | |
|---|---|
| **Group 1** | Agent or mixture carcinogenic to humans |
| **Group 2A** | Agent or mixture probably carcinogenic to humans |
| **Group 2B** | Agent or mixture possibly carcinogenic to humans |
| **Group 3** | Agent or mixture not classifiable as to its carcinogenicity to humans |
| **Group 4** | Agent or mixture probably not carcinogenic to humans |

NNN and NNK are the tobacco-specific N-nitrosamines (TSNA) which are harmful to the oral cavity and contribute to cancer formation of the same (Hatsukami *et al.*, 2015). The amount of NNN and NNK vary in proportion and harmfulness in smoked and smokeless tobacco across countries (WHO-IARC, 2004; Hatsukami *et al.*, 2015). The working group of the International Agency for Research on Cancer stated in its report that the concentration of NNK varies from an undetected level to 10 945 nanogram per cigarette and that of NNN from 45-58 000 nanogram per gram of cigarette across USA, Canada, UK, Italy, India and other countries with the last two containing the largest concentration of the carcinogenic TSNA (WHO-IARC, 2004).

Nicotine, besides being a highly addictive compound in tobacco, is also blamed for exerting carcinogenic effects by causing damage to genomic components, disrupting the metabolism at the cellular level and causing inactivation of tumour-suppressor genes favouring therefore the formation of cancer (Grando, 2014). The IARC working group reported about a wide variation

in the proportion of nicotine which ranges from 7.2 to 18.3 mg/cigarette among countries (WHO-IARC, 2004). Tobacco-related deaths account for 8% of the total deaths in South Africa (Ayo-Yusuf and Szymanski, 2010). Greater than 1 billion of the total 7.4 billion global population smoke tobacco and 8.4 million is expected to die by 2020 with the majority (70%) to occur in developing countries (World Health Organization, 2008; Joshi *et al.*, 2014; Population Reference Bureau, 2016). Tobacco smoking as well as alcohol consumption contribute to secondary cancers of the head and neck and other regions as well (De Almeida *et al.*, 2014; Massa *et al.*, 2017).

#### 2.13.1.1.2 Tobacco Variants

Apart from tobacco smoking, various other forms in which tobacco is used is waterpipe tobacco smoking, cigars, pipes, electronic cigarettes (e-cigarettes), and chewed tobacco as in betel quid, the combination being ghutka (Kasza *et al.*, 2014; Gupta and Jain, 2016; Hamadeh *et al.*, 2017).

Electronic cigarette is the latest alternative form of smoking whereby nicotine, along with a solution mixture of flavours, (strawberry, menthol, mint, cinnamon), propylene glycol/ glycerine base and other chemical constituents contained within a high-voltage lithium battery-powered device is heated by a filament to create a vapour which is inhaled by the smoker (Bourke *et al.*, 2017; Jiwani *et al.*, 2017; Shariat, 2017). Since its development in 2003 by a Chinese pharmacist and first entry on the market in 2004, it is incessantly gaining escalating fame worldwide in developed countries and South Africa as well (van Zyl-Smit, 2013; Bourke *et al.*, 2017). Sufficient data has been put forth to support the fact that potential risks of e-cigarette outweigh the benefits (van Zyl-Smit, 2013). It creates addiction and dependence to nicotine contrary to what manufacturers have claimed to market as a 'potential reduced exposure product'-PREP (Vansickel *et al.*, 2010; van Zyl-Smit, 2013). Further, Van Zyl-Smit reported that it can actually contribute to nicotine addiction and finally prompt the user to adopt cigarette smoking (van Zyl-Smit, 2013). Lethal amount of nicotine might be present in e-cigarettes cartridges (Callahan-Lyon, 2014). However there is much controversy surrounding this fact where some manufacturers argue that they can be used as an alternative way to stop cigarette smoking and smoke in a healthier, cleaner and safer way because of the fact that its

toxic chemical content is "apparently" low (Vansickel *et al.*, 2010; Grana, Benowitz and Glantz, 2014). It is relentlessly encouraged and fiercely promoted and marketed by the tobacco industry (Grana, Benowitz and Glantz, 2014). However, there is no evidence yet to scientifically support the claims from manufacturers (Grana, Benowitz and Glantz, 2014). Moreover, the FDA has not given its approval so far for the use of e-cigarettes as a means of stopping cigarette smoking (Callahan-Lyon, 2014). In addition, its safety in the long term in general and particularly in pregnancy has still not been established in larger researches. Since they form part of the newly born generation of electronic nicotine delivery systems (ENDS), the effects and "attractive" claims are still unclear and evidence-based clinical data are lacking to objectively support these claims (Vansickel *et al.*, 2010; van Zyl-Smit, 2013).

#### 2.13.1.2 Alcohol

Alcohol is another preventable chemical risk factor contributing to the pathogenesis of head and neck cancer (Pezzuto *et al.*, 2015; Bertl *et al.*, 2016). A wide amount of data has been and is still being analysed to emphasise the major role that alcohol has to play in the development of cancer especially those of the oral cavity and oropharynx (Turati *et al.*, 2013). According to a meta-analysis of about 18,000 oral and pharyngeal cancer cases and 49 publications, approximately more than 30% of cancers of the oral cavity and pharynx are due to consumption of alcohol globally (Turati *et al.*, 2013). A person who drinks more than 170g of whisky on a daily basis is ten times more prone to developing oral cancer than his fellow occasional drinker (Ram *et al.*, 2011). According to a study carried out on more than one million women in the United Kingdom, the risk of oral and pharyngeal cancers is increased by increasing consumption of alcohol per day (Allen *et al.*, 2009). Persons who consume alcohol without smoking cigarette are three times more prone to developing cancer of the oral cavity and pharynx than those who do not drink at all according to a study carried out in Italy (Goldstein *et al.*, 2010).

However, it is unfortunate to note that alcohol is heavily consumed by both South African males and females accounting for 5 billion litres of consumption per year (Kalichman *et al.*, 2006). Alcohol drinking in South Africa is not only a practice of the adult population but of the younger generation groups as well. The study carried out by Kalichman *et al* reported that South African children from as early as 10 years old have adopted this deleterious lifestyle habit, representing 39% males and 23% females in the age group of 10-21 years only

(Kalichman *et al.*, 2006). It is interesting to note that the consumption of alcohol is in bigger proportion in urban areas of South Africa as compared to rural counterparts (Kalichman *et al.*, 2006). The quality of life of people who continue to engage in the habit of excessive alcohol drinking in the post treatment phase for cancer of the head and neck is extensively poorer (Shaw and Beasley, 2016).

#### 2.13.1.2.1 Mechanism of carcinogenicity

Alcohol disrupts the metabolism of the cells found in the mucosa to aid the absorption of carcinogens into exposed cells (Ram *et al.*, 2011). It increases the permeability of the oral mucosa so that the carcinogens' penetration is facilitated (Wight and Ogden, 1998). This is achieved by removal of some of the lipids found in the lipid barrier in the superficial layers of the oral epithelium by alcohol (Ogden and Wight, 1998). Alcohol and its metabolite, mainly acetyldehyde, act on the exposed cells to produce cytochrome P4502E, cause a disregulation of the cell cycle and contribute to the development of reactive oxygen species (Pezzuto *et al.*, 2015). Acetyldehyde further reacts with DNA to cause chromosomal anomalies (Pezzuto *et al.*, 2015). Alternatively, another mechanism by which alcohol exerts its carcinogenic effects is by increasing the solubility of the carcinogens itself (Wight and Ogden, 1998).

### 2.13.1.3 Areca nut chewing

Apart from tobacco smoking and alcohol consumption, areca nut is another potent carcinogen since its practice is attributed to cancer of the head and neck region, mainly of the oral cavity (Sharan *et al.*, 2012; Garg, Chaturvedi and Gupta, 2014; Hernandez *et al.*, 2017). Areca nut is the seed of the palm tree, Areca catechu (Prabhu *et al.*, 2014). It is an integral ingredient used in the formulation of betel quid or synonymously known as paan (Prabhu *et al.*, 2014). Betel quid is prepared by brushing betel leaves with slaked lime and sprinkling ground areca nut. When tobacco is added to the mixture it is called ghutka and is flavour-enhanced with spices like cardamom, saffron and turmeric depending on the taste preferences of the individual (Prabhu *et al.*, 2014). Areca nut ranks at the fourth place after alcohol, nicotine and caffeine among the most frequently used psychostimulants worldwide (Quinn Griffin *et al.*, 2014; Goyal and Bhagawati, 2016). It is chewed for its psychostimulating and euphoria-inducing effects (Song, Wan and XU, 2013; Garg, Chaturvedi and Gupta, 2014; Prabhu *et al.*, 2014).

Its independent association with the formation of pre-malignant conditions having high malignant potential transformation like oral submucous fibrosis and leukoplakia as well as established cancers of the head and neck has been well reported in numerous studies (Kumar *et al.*, 2015). The International Agency for Research on Cancer has classified it as a Group 1 carcinogen, owing to its contribution to the development of oral cavity and pharyngeal cancers (Garg, Chaturvedi and Gupta, 2014; Chen *et al.*, 2016). Areca nut chewing is popular among the Indian migrants in South Africa (Bissessur and Naidoo, 2009). The South Africans have also ultimately adopted this serious lifestyle habit from the fellow areca nut chewers (Bissessur and Naidoo, 2009). In the study carried out in South Africa by Bissessur *et al*, it was reported that 60% of 101 participants did not know about the destructive effects of areca nut (Bissessur and Naidoo, 2009). The study carried out by Van-Wyk *et al* in KwaZulu-Natal revealed that 17% of men and 93% of women who participated in the study chewed areca nut (Van Wyk *et al.*, 1993). Further, another study in the 1980's in Durban reported a female predominance for chewing areca nut, with the ratio of women to men being 13:1 (Seedat and van Wyk, 1988).

Areca nut chewing is also incriminated in "de novo malignancies" (Chen *et al.*, 2016). In a recent study published in Taiwan, areca nut chewing was found to be a strong contributing factor for the development of head and neck cancer in patients who had undergone liver transplantation after acute liver failure or hepatocellular carcinoma (Chen *et al.*, 2016). It was further reported that the 68.7% of the research participants who developed head and neck cancer following liver transplantation were all chewers of betel quid (Chen *et al.*, 2016). The likelihood of developing oral cancer by the the use of betel quid alone is increased by 28 times while the probability by the simultaneous combination of tobacco smoking, alcohol consumption and areca nut chewing shoots up by 123 times (Chen *et al.*, 2016). Besides contributing to cancer, areca nut has also been blamed to playing a negative role on the treatment outcome for cancer of the head and neck where a recent retrospective study in Taiwan reported that the concomitant habits of betel nut chewing and cigarette smoking reduce the response of induction chemothereapy in patients with advanced stages of head and neck cancer, resulting in a poor prognosis (Su *et al.*, 2016).

Paan has taken its origin from South and South East Asian countries namely India, Pakistan, Bangladesh, Taiwan, Thailand and Cambodia (Song, Wan and Xu, 2013; Prabhu *et al.*, 2014). Some countries of the western pacific like Federated States of Micronesia, Marshall Islands and Mariana Islands are also famous for the use of paan (Song, Wan and Xu, 2013). In some of these countries chewing of betel quid holds a religious value (Prabhu *et al.*, 2014). South

Africa, Eastern Africa, Australia and UK are popular about this practice owing to the migrant population from some of the South Asian countries (Petti, 2009). However, its popularity is not only confined to Asians in South Africa but to the whole world. It is reported that around seven hundred million people on the globe practice the habit of areca nut chewing (Sharan *et al.*, 2012). Previously, a review from Italy reported that the chewing of areca nut is practiced by six hundred million to one thousand and two hundred million (1200 000 000) people worldwide including both developing and developed countries (Petti, 2009).

#### 2.13.1.3.1 Mechanisms of Areca Nut Carcinogenicity

A clear and in-depth work of the mechanisms involved in areca nut to induce carcinogenity at the genomic level has not yet been reported but ongoing research suggests that arecoline content in this seed is the most potent water soluble alkaloid blamed for exhibiting carcinogenic properties (Bhattacharjee and Sharan, 2008; Wang *et al.*, 2010). Arecoline constitutes the highest concentration followed by arecaidine which is another alkaloid present in areca nut (Sharan *et al.*, 2012). Several other alkaloids like arecholinine, guavacine and guavacoline are also present but in lesser percentage (Sharan *et al.*, 2012). Besides these, tannins, which are responsible for conversion of the genes and polyphenols, which upon auto-oxidation release reactive oxygen species, are other group of chemicals in areca nut that do not have definitive and confirmatory evidence of contributing to carcinogenesis of the oral cavity since polyphenols are strong antioxidants with lots of health benefits while tannins are reported in some literature to be carcinogenic only in the condensed form (polyflavanoid or condensed tannins) when they are associated with the compounds flavans and not on their own (Sharan *et al.*, 2012). Studies have reported that areca nut is toxic to and destroys the genetic information within the cells of the buccal epithelium and its extracts have been found to augment chromosomal abnormality and upsurge the formation of Howell-Jolly bodies (micronucleus), an indication of increased DNA damage (Wang *et al.*, 2010). Besides the production of micronuclei, formation of reactive oxygen species and cell death are important proceses that take place when keratinocytes are exposed to areca nut extracts (Chen *et al.*, 2008). Arecoline has also been reported in preventing DNA repair and degrading and suppressing p53 which is an important gene functioning as a tumour suppressor (Wang *et al.*,

2010). Further the same authors found that arecoline can contribute in the over expression of Aurora A which is a mitotic kinase documented in cancer of the head and neck (Wang *et al.*, 2010). Betel-specific nitrosamines are formed during nitrosation of arecoline (Bhattacharjee and Sharan, 2008). Experimental laboratory investigations on these nitrosamines have proved that they have a high affinity for DNA and subsequently DNA adducts might be produced if interaction between the two occurs (Bhattacharjee and Sharan, 2008). Sharan *et al* reported that an increase in mutation of mitochondrial DNA in the oral tissues leads to segregation of the cytoplasm in the course of cell division which contributes to the early formation of oral malignancy (Sharan *et al.*, 2012).

The exclusive component to betel quid, hydroxychavicol, increases the expression of cyclooxygenase-2 protein which is found early in the development of oral cancer (Sharan *et al.*, 2012). Experiments on cultured cells have revealed that hydroxychavicol is linked to the development of breaks in single stranded DNA and genesis of 8-hydroxydeoxyguanosine which is an sign of oxidative damage of DNA (Chen *et al.*, 2008).

Despite the fact that the chances of developing cancer is related to the consumption of areca nut, the genetic make-up is also largely responsible in determining the formation of malignancy in a particular individual (Sharan *et al.*, 2012). Malignancy may not occur in a strong areca nut chewer since the genetic predisposition is a robust factor to be considered in carcinogenesis (Hsiao *et al.*, 2013).

The susceptibility of a person to suffer from betel quid-induced oral cancer is also governed by several factors including the variances in metabolism which dictate the metabolic activity of the carcinogens in areca nut, the condition of genetic repair pathways, the state of nourishment of the individual, the way tumour suppressor genes and proto-oncogenes express themselves and the genetic polymorphism (Sharan *et al.*, 2012).

#### 2.13.1.4 Sun exposure and tanning beds

Prolonged and excessive exposure to ultraviolet radiation emitted by sunlight, tanning beds and sun lamps is the most advocated cause for lip cancer (Sivamani, Crane and Dellavalle, 2009; Zaraa *et al.*, 2013; O'Sullivan and Tait, 2014). The rate of lip cancer among South African males is higher with an incidence of 0.32 per 100 000 representing 0.17% of all cancers as compared to females with a rate of 0.09 per 100 000 which represents 0.06% of all cancers.

This corresponds to a previous study from Australia which also reported that lip cancer was mostly encounterd in men than in women with the most probable reason being that the men were exposed for longer hours under the sun and hardly wear any sunscreen lotions like women (Abreu, Kruger and Tennant, 2009).

Ultraviolet radiation from the sun are of two types namely UV-A, having a wavelength between 320-400 nm, and UV-B with a wavelength range of 290-320 nm, both of which being harmful to exposed skin including that of the lip as they contribute to cancer formation (Abreu, Kruger and Tennant, 2009). Exposure to the sun is an important environmental factor contributing to the development of squamous cell carcinoma, basal cell carcinoma and malignant melanoma of the skin (Sivamani, Crane and Dellavalle, 2009). Most carcinoma of the lip is of the squamous cell type and is common in people who are exposed to the harmful ultraviolet radiation from the sun for a long period of time as evidenced by a population-based case-control study from Denmark (Kenborg *et al.*, 2010).

There is an increased risk for cancer of the lip in those persons who had been doing outdoor works for more than 10 years (Kenborg *et al.*, 2010). Besides being predominant in the latter category of people, solar radiation-induced lip cancer is also encountered in fair-skinned individuals, most probably due to insufficient protection by melanin pigment (Abreu, Kruger and Tennant, 2009; Czerninski, Zini and Sgan-Cohen, 2010). According to a study from Israel, the lower lip was reported to be five times more at risk for squamous cell carcinoma than the upper lip which is seldom involved (Czerninski, Zini and Sgan-Cohen, 2010). A large number of surveys on lip cancer is consistent with this finding and this is evident in a previous investigation from Australia which also concluded that the lower lip is more inclined to malignancy than the upper counterpart (Abreu, Kruger and Tennant, 2009). In his study, Czerninski *et al* found that the part of the lip which was more likely to be affected by cancer was the dry portion, that is the external lip, in comparison to the inside of the lip, an interesting finding which might further prove the carcinogenic role of sun exposure (Czerninski, Zini and Sgan-Cohen, 2010).

Tanning beds can be as dangerous as the natural sun and in some cases they have been found to be more harmful, emitting ultraviolet radiation which is 10-15 times higher in intensity than that experienced at noon (International Agency for Research on Cancer Working Group on artificial ultraviolet (UV) light and skin cancer, 2007; O'Sullivan and Tait, 2014). They offer no protection against the harmful rays like some are supposedly marketed as being safe

(O'Sullivan and Tait, 2014). They equally emit harmful ultraviolet radiation responsible for the disruption of DNA and mutation and uncontrolled proliferation of cells (D'Orazio *et al.*, 2013).

### 2.13.2 Biological Factors

Cancer-causing viruses are gaining much interest among investigators since they represent an emerging area of research in the field of oncology (Javier and Butel, 2008). Human immunodeficiency virus (HIV), human papillomavirus (HPV), herpes simplex virus (HSV) and Epstein Barr virus (EBV) are recognized in the development of certain types of cancer including that of the head and neck region (Javier and Butel, 2008; Merten *et al.*, 2016). These viruses act by altering the structure of DNA and cause proliferative changes at the chromosomal level (Javier and Butel, 2008).

#### 2.13.2.1 Human immunodeficiency virus

With the effectiveness of antiretroviral therapy, the life expectancy of HIV-infected individuals has increased (Beachler and D'Souza, 2013). HIV increases the susceptibility of cancer-causing viruses like HPV, EBV and HSV (McLemore *et al.*, 2010). This implies that malignancies associated with viruses are on the increase (Beachler and D'Souza, 2013). South Africa carries the highest incidence (7.1 million) of HIV infected individuals globally (Hoek, 2012). Kaposi sarcoma and non-Hodgkin lymphoma of the head and neck are the most common malignancies in HIV positive patients followed by squamous cell carcinoma of the head and neck region (McLemore *et al.*, 2010; Hoek, 2012). Both Kaposi sarcoma and non-Hodgkin lymphoma are AIDS-defining malignancies while squamous cell and basal cell carcinomas of the head and neck and Hodgkin disease are not directly associated with HIV (Hoek, 2012). HIV infections also increase the risk of oral cavity, laryngeal and non-HPV-related cancers (Beachler and D'Souza, 2013). Oral manifestations of HIV infections are xerostomia, aphtous ulcres, gingival and periodontal diseases (Hoek, 2012). Other head and neck manifestations include nasal obstruction, neck mass and parotid gland disease (Hoek, 2012).

#### 2.13.2.2 Human papilloma virus

Human papilloma virus represents a serious concern to public health despite on-going development in vaccines and treatment approaches (Christensen, 2016). HPV exists in over one hundred and fifty fully sequenced genetically different types with fifteen among them being carcinogenic and includes HPV-16 and HPV-18 which have been mostly incriminated in malignancy of the head and neck, mainly that of the oropharynx (Chen *et al.*, 2008; Boscolo-Rizzo *et al.*, 2013; Christensen, 2016; Hernandez *et al.*, 2017). HPV type-16 is present in 80% of oropharyngeal cancers (Beachler and D'Souza, 2013). HPV has also been widely documented as an etiologic factor for cervical cancer (Cao *et al.*, 2011). HIV positive individuals are at increased risk of developing HPV infections of the oral cavity and HPV-associated head and neck malignancies (Beachler and D'Souza, 2013). The risk of developing cancer of the tonsils in HIV-infected individuals is approximately two to four times more than the non HIV-infected population (Beachler and D'Souza, 2013). Its association to the development of cancer of the oropharynx, especially in the base of the tongue and the tonsils is expected to exceed the number of new cervical cancer cases by 2020 (Ha and Califano, 2004; Mannarini *et al.*, 2009; Gross *et al.*, 2013; Marur and Forastiere, 2016; Dwojak and Bhattacharyya, 2017). Globally, its prevalence in head and neck cancer is 16% to 30% (McLemore *et al.*, 2010). It is an independent risk factor for cancer of the oral cavity and hence is not linked to any cancer-causing oral habits like betel nut chewing, tobacco smoking and alcohol consumption (Chen *et al.*, 2008; Galbiatti *et al.*, 2013).

HPV-associated oropharyngeal cancers have been shown to be have a wide geographical distribution worldwide with 56% in North America, followed by Japan with 52%, Australia with 45% and Europe with 39% (Marur and Forastiere, 2016). The incidence of oral squamous cell carcinoma in South Africa has been on the increase for the past 22 years and 90% of the cases were associated with type-16 human papilloma virus (Davidson *et al.*, 2014).

##### 2.13.2.2.1 Mechanism of Carcinogenicity of HPV

HPV, being a double stranded sexually transmitted DNA virus, is reported to be a high risk factor for malignancy in the mucosa of the head and neck region (Marur and Forastiere, 2016; Wang *et al.*, 2017). Infection with HPV is temporary, controlled and detected by the host immunity and clears within a short time, hence does not always progress to cancerous lesions

(Christensen, 2016; Maura *et al.*, 2017). However, persistent infection ensues when there is reduced or absence of immunity of the affected person to clear the virus resulting therefore in the latter being united into the host DNA to exert its oncogenic effects by altering the function of different tumour suppressor proteins namely p53 and retinoblastoma gene (Marur and Forastiere, 2016) . The oncoproteins which come into play in this process are E6 and E7 where E6 causes degradation of p53 while E7 integrates the retinoblastoma gene to disrupt the cell cycle mechanism by causing increased expression of p16 to give rise to malignant formation after accumulation of prolonged genetic damage (Marur and Forastiere, 2016; Wang *et al.*, 2017). HPV-associated oropharyngeal cancers are more responsive to chemoradiation than alcohol or tobacco associated malignancies (Marur and Forastiere, 2016).

#### 2.13.2.3 Herpes simplex and Epstein-Barr viruses

Herpes simplex virus (HSV), also known as human herpes virus (HHV), is associated with several malignancies, including that of the head and neck (McLemore *et al.*, 2010). HSV-1 was demonstrated to have an oncogenic relationship to squamous cell carcinoma of the oral cavity (Ha and Califano, 2004). Kaposi Sarcoma is mainly caused by HSV-8 (McLemore *et al.*, 2010). HSV-2 antibodies are predominantly incriminated in cervical cancer (Kreimer *et al.*, 2005). Epstein Barr virus, human papilloma virus and other oncogenic viruses, when co-existed, have demonstrated to playing an important role in the transformation of healthy epithelial cells to cancerous ones (Al Moustafa *et al.*, 2009). EBV is associated with cancer of the nasopharynx (Al Moustafa *et al.*, 2009). Epstein Barr virus have also shown positivity in lymphoma of the parotid gland (Plummer and Masterson, 1971).

#### 2.13.2.4 Syphilis

Syphilis is a sexually transmitted disease occurring as a result of unprotected sex with an infected individual, blood tranfusions, infected sharp object injury (Strieder *et al.*, 2015). It is characterised by a chancre (painless ulceration) on the lips, but the soft palate and tongue may also be affected depending on the disease evolution (Ficarra and Carlos, 2009; Strieder *et al.*, 2015). The syphilitic lesion on the lip may give rise to squamous cell carcinoma of the oral cavity (Strieder *et al.*, 2015). Previously, arsenic compounds were used to treat syphillis and this was contributing to tongue cancer since they are carcinogenic (Ficarra and Carlos, 2009).

Many cases of malignancies are preceded by pre-existing syphilitic glossitis and leukoplakia (Al Moustafa *et al.*, 2009).

### 2.13.3 Diet

A lack of fresh fruits and vegetables have been shown to contribute to 60% of oesophageal, oral and pharyngeal cancer formation in developing countries (Key *et al.*, 2004). Diets poor in raw vegetables and fruits have incessantly been mentioned in the literature with regards to cancer of the oral cavity (Baba, 2016). It is reported that incorporation of larger proportion of fresh fruits and vegatables is associated with decreased chances of oral cancers (Key *et al.*, 2004; Baba, 2016). However, some investigators have reported the fact that a high intake of fresh fruits and vegetables to having a protective role against cancer is not fully substantiated since evidence obtained so far was from case-control rather than from prospective studies (Key *et al.*, 2004).

## 2.14 Oral health assessment and management

Poor oral health has a severe impact on the general health and quality of life of the patient (Deng *et al.*, 2015). Assessment of the oral health and timely management, both clinically and radiographically, by a qualified dental team is one of the vital steps involved in the management of patients who are to undergo therapy for head and neck cancer (Samim *et al.*, 2016). This is of prime importance not only prior to treatment but also during and even after (Ray-Chaudhuri, Shah and Porter, 2013; Bueno *et al.*, 2015). The National Institute for Clinical Excellence has proclaimed, through issued guidelines, that restorative dentist and dental hygienist should be accessible for pre-treatment dental evaluation and also for follow up in the post treatment phase in order to improve the oral health outcome of patients both during and after treatment for cancer of the head and neck (National Institute for Clinical Excellence, 2004).

Hence, it is fundamental to refer all patients who need to undergo any cancer therapy of the head and neck region for a complete pre-treatment dental evaluation and timely management (Mawardi, Al-Mohaya and Treister, 2013; Ray-Chaudhuri, Shah and Porter, 2013). Pre treatment dental evaluation is critical since a great percentage of patients have existing dental problems and poor oral health prior to treatment (Lawrence, Aleid and McKechnie, 2013; Critchlow, Morgan and Leung, 2014).

In the case of radiotherapy, dental assessment and management should preferably be undertaken well in advance in relation to the first course so as to allow sufficient time for healing of the tissues, in cases of extraction, extensive scaling and curettage and construction of custom-made fluoride carriers (Samim *et al.*, 2016). Dentists with expertise in managing head and neck cancer cases should be in a position to identify and treat those areas which demand immediate attention since they are essential elements of the multidisciplinary team of oncology (Samim *et al.*, 2016). A study from Michigan reported that 10% of dentists and 25 % of radiation oncologists who participated in a survey did not have the necessary training required and 55% of dentists reported that they were not confident enough to treat head and neck cancer patients owing to insufficient training in this area (Patel *et al.*, 2012).

In addition to managing oral complications, it is the fundamental role of dentists to instruct patients on the maintenance of oral health care during and after treatment (Horowitz and Kleinman, 2008; Ray-Chaudhuri, Shah and Porter, 2013). The use of high-fluoride containing toothpastes, use of alcohol free fluoridated mouthwash and fluoride trays, smoking cessation, restriction of high-refined sugar containing foods and the use of interdental toothbrushing and flossing in addition to regular toothbrushing are some of the preventive home care instructions which dentists have to provide to patients (Ray-Chaudhuri, Shah and Porter, 2013).

The radiographic examination routinely undertaken include intraoral periapical, bitewing and panoramic radiographs (Deng *et al.*, 2015). Dental prophylaxis like scaling, polishing, root planing, curettage should be performed prior to radiotherapy to attain an acceptable level of oral hygiene status (Beech *et al.*, 2014). Subgingival scaling and curettage should be undertaken not later than three weeks of the first radiotherapy appointment to allow the gingiva and all the other components of the periodontium to heal properly. In order to prevent the occurrence of radiation caries, custom-made fluoride trays should be constructed (Gupta *et al.*, 2015). Fluoride trays are of paramount importance during radiotherapy and even after as they significantly decrease the chances of radiation-induced irreversible demineralisation and ultimately caries (Beech *et al.*, 2014). Neutral sodium fluoride gel in a concentration of 1% is poured into the tray and inserted daily into the mouth for 5 minutes (Deng *et al.*, 2015; Gupta *et al.*, 2015).

Teeth which are carious but without any complaint nor any pulpal involvement are treated with simple routine restorations. All overhanging restorations and sharp cusps should be smoothened to avoid trauma to the patient later (Beech *et al.*, 2014). Teeth which cannot be

restored as in the case of acute apical periodontitis with extensive periapical radiolucency, moderate to advanced periodontal involvement where pocket depth is greater than or equal to 6 mm along with grade I, II and III furcation involvement and mobility, and root stumps must be extracted regardless of the radiation field prior to radiation to prevent unwanted occurrence of osteonecrosis (Beech *et al.*, 2014; Bueno *et al.*, 2015). A period of least three weeks must be allowed before commencing radiation treatment to maximise the healing process of the wound and prevent the occurrence osteoradionecrosis (Marx and Johnson, 1987). The three weeks interval is based on experimental works which found that osteoid takes three weeks to form (Marx and Johnson, 1987). In cases where extraction is not feasible due to the rapid growth and size of the lesion, it should be deferred until four to six weeks after the radiotherapy sessions are over (Dental Oncology Education Program, 2008).

As for those non-vital teeth with absence of periapical radiolucency, conservative endodontic treatment should be the ideal choice. Apicoectomy is indicated in moderate periapical radiolucency without furcation defects or mobility (Jansma *et al.*, 1992).

In partially or completely edentulous patients, care should be taken to smooth out any bony spicules or sharp ridges in order that they do not interfere with the occlusion and denture wearing later on by piercing through the soft tissue. Furthermore, the patient should be advised to abstain from wearing denture during the active phase of radiotherapy.

### 2.15 Impact of head and neck cancer therapies on oral health

The earlier a cancer is diagnosed the better is the prognosis. About 40% of patients present in the early stage (Marur and Forastiere, 2016). Due to the continuous drastic increase in the incidence of cancer more aggressive treatments have been and are still being developed (Saito *et al.*, 2014). The basic treatment modalities for treating head and neck cancer are surgery, chemotherapy, radiotherapy and concurrent chemoradiotherapy depending on the stage, location and extension (Cognetti, Weber and Lai, 2008; Tulunay-Ugur *et al.*, 2013; Varelas and Kukuruzinska, 2014; Marur and Forastiere, 2016; El-Bayoumy *et al.*, 2017). Surgery and radiotherapy are indicated in early stages (1 and II) while concurrent chemotherapy and radiotherapy and in some cases induction chemotherapy (chemotherapy prior to other treatment) come into play in advanced stages (3 and 4) of head and neck cancer (Marur and

Forastiere, 2016). However, the therapies are not without risks and they can severely impact on the oral health and oro-facial region (Pateman *et al.*, 2015).

### 2.15.1 Surgery

Oncological surgical procedures of the head and neck have made major advancements to improve aesthetic impairment and functional disabilities of the oral cavity and other head and neck subsites (Kolokythas, 2010). In addition to trans oral resection, laser or robotic surgery are also done conditional to the extent and anatomical location of the malignant lesion (Cmelak *et al.*, 2013; Marur and Forastiere, 2016). Primary curative surgeries followed by adjuvant chemotherapy or radiotherapy are undertaken in the early stages where the functions of vital structures can be conserved (Cmelak *et al.*, 2013; Marur and Forastiere, 2016). Lingual release techniques and mandibular osteotomies are undertaken in more advanced malignancies followed by adjuvant radiotherapy or chemotherapy (Cmelak *et al.*, 2013). This has decreased the burden of survivors having to live with undesirable aesthetic and functional impairment which might affect the quality of life (Wong, 2014). Maxillectomy, mandibulectomy, glossectomy, laryngectomy, Mohs micrographic surgery and neck dissection are some of the surgeries undertaken for head and neck cancer (Leone *et al.*, 2016; Mazarro *et al.*, 2016; Patel *et al.*, 2016; Santamaria and de la Concha, 2016; Tanaka *et al.*, 2016; Nobis *et al.*, 2017).

#### 2.15.1.1 Complications of oncological surgery on oral health

Despite all the cutting-edge surgical innovations, complications do occur. Severe limitations or inability to masticate, swallow, and articulate properly are serious complications arising from surgery of the head and neck (Kolokythas, 2010). Additionally, fistula formation and disfigurement are other possible significant issues to which the patient are exposed (Wong, 2014).

Speech and proper articulation are affected by surgery of the anterior tongue while surgical resection of the posterior portion of the tongue affects the swallowing pattern primarily (Kolokythas, 2010; Wong, 2014). Speech and swallowing are further compromised due to fibrosis and scarring during the healing phase of the surgical site (Kolokythas, 2010). Surgical resections of the maxilla or mandible impact on the occlusion and alter the biting forces

resulting in inability for proper mastication to take place (Kolokythas, 2010). Weight loss becomes apparent due to inability to eat (Kolokythas, 2010). This might warrant the use of feeding tubes (Kolokythas, 2010).

Furthermore, mandibular nerve injury during surgery results in cosmetic alteration of the lower lip (Kolokythas, 2010). The movement of the lower lip is beyond the control of the patient and this also interferes with consumption of liquid (Kolokythas, 2010). Tongue deviation and loss of sensation to the tongue occur due to iatrogenic injury to lingual and hypoglossal nerve (Kolokythas, 2010). Injury to the lingual and hypoglossal nerves can further exacerbate existing mastication and swallowing problems (Kolokythas, 2010). Xerostomia is another complication which can occur due to adjuvant radiotherapy post surgery (Kolokythas, 2010).

Inability to open the mouth wide or trismus (interincisal distance less than required 35 mm) is a common complication reported by cancer survivors in the post surgical phase (Kolokythas, 2010; Ray-Chaudhuri, Shah and Porter, 2013). This condition can occur following maxillectomy where the medial and lateral pterygoid muscles of mastication are involved (Wong, 2014). Moreover, mandibulectomy where any of the masticatory muscles are involved can equally result in trismus (Wong, 2014). Tissue scarring and contraction of the masticatory muscles are responsible for trismus in the post surgical phase (Kolokythas, 2010). The severity of trismus induced by surgery can be further exacerbated by adjuvant radiotherapy (Kolokythas, 2010).

Reconstruction of the maxilla, mandible and tongue with osteocutaneous or fasciocutaneous flaps after surgical resection of advanced malignancies of the head and neck region is a must in order to restore the functional and cosmetic properties of these structures (Cmelak *et al.*, 2013).

### 2.15.2 Radiotherapy

Radiotherapy is one of the treatment modalities employed in head and neck cancer to destroy malignant cells (Beech *et al.*, 2014). It is also indicated, in a dose of 60-70 Gray, as an adjunct to surgery or simultaneously with chemotherapy in advanced cases of head and neck cancer where metastasis has not occurred (Marur and Forastiere, 2016). However, radiotherapy has the notorious reputation of impacting severely on the patient's oral and dental health when the oral mucosa, teeth, bone, salivary glands, taste buds, temporomandibular joints and masticatory

muscles are exposed to ionising radiation in a dose greater than 55 Gray (Ray-Chaudhuri, Shah and Porter, 2013; Beech *et al.*, 2014; Wong, 2014; Marur and Forastiere, 2016).

#### 2.15.2.1 Impact of radiotherapy on oral mucosa and taste buds

The mouth is that part of the head and neck region which is susceptible to the effects of radiation during treatment of head and neck cancer and caring for it before, during and even lifelong after cancer treatment is of vital importance for maintained well-being (Mainali *et al.*, 2011; Wan Leung *et al.*, 2011). The early undesirable complications of radiation on the head and neck subsites are evident shortly after treatment commences and they resolve around 15-21 days after the last fraction of radiotherapy is given (Wong, 2014). The occurrence of the late complications varies and can take weeks or years to become apparent after treatment (Wong, 2014).

Oral mucositis is often the first acute and prominent complication arising shortly after radiotherapy, affecting greater than 60% of patients (Ray-Chaudhuri, Shah and Porter, 2013; Beech *et al.*, 2014). It is manifested by seven to fifteen days of treatment initiation and clinically the oral mucosa is tender, erythematous and ulcerated due to damage to the basal cells of the epithelium (Lalla, Sonis and Peterson, 2008; Ray-Chaudhuri, Shah and Porter, 2013). The buccal and labial mucosa, soft palate and floor of mouth are often affected, but other sites of the oral cavity can equally be targeted (Ray-Chaudhuri, Shah and Porter, 2013; Wong, 2014). Eating and swallowing become compromised (Ray-Chaudhuri, Shah and Porter, 2013). The WHO oral mucositis grading scale is presented as follows (Lalla, Sonis and Peterson, 2008, page 67).

**Table 3: Grade of oral mucositis according to WHO classification**

| GRADE | SIGNIFICANCE |
|---|---|
| **Grade 0** | None |
| **Grade 1** | Soreness and erythema |
| **Grade 2** | Erythema and ulcers. Solid diets possible |
| **Grade 3** | Ulcers. Liquid diet only |
| **Grade 4** | Oral alimentation not possible |

Loss of taste sensation is another common complication arising due to radiation damage to the taste buds present on the tongue, lips, pharynx and upper oesophagus thereby affecting the sweet, salty, bitter and sour taste perceptions (Ray-Chaudhuri, Shah and Porter, 2013; Wong, 2014). The perceptions of salty and bitter tastes are most commonly reported to be reduced (Ray-Chaudhuri, Shah and Porter, 2013).Taste alterations are further aggravated due to xerostomia (Ray-Chaudhuri, Shah and Porter, 2013). Taste impairment develops early during radiation therapy and is most intense at 1-2 months (Ray-Chaudhuri, Shah and Porter, 2013). This, however, usually resolves completely after 2-4 months of treatment but can still linger on for more than a year in those who had high dose irradiation (Irune *et al.*, 2014; Wong, 2014).

#### 2.15.2.2 Impact of radiotherapy on the jaw bone

In the event of bone being exposed to radiation, the latter is subjected to a reduced blood supply, reduced number of cells and reduced oxygen supply leading consequently to its inability to remodel (Manimaran *et al.*, 2014). The bone becomes necrosed and non-vital (Manimaran *et al.*, 2014). Trauma or surgical interventions in the irradiated bone gives rise to osteoradionecrosis (Manimaran *et al.*, 2014). Osteoradionecrosis ia a late complication of radiotherapy and occurs in 95% of cases in the mandible because of the presence of compact bone and poor vascular supply (Ray-Chaudhuri, Shah and Porter, 2013; Beech *et al.*, 2014; Manimaran *et al.*, 2014). The field of radiation should be without infection foci before radiotherapy to reduce the risk of osteoradionecrosis (Bertl *et al.*, 2016). Extraction of teeth which are located in the field of radiation increases the chances of osteoradionecrosis (Beech *et al.*, 2014). It is recommended that teeth to be extracted should be ouside the radiation field or if it is in the radiation field the radiation dose should be less than 50 Gray (Beech *et al.*, 2014). In cases where extraction is required and the radiation dosage is over 50 Gy an experienced oral and maxillofacial surgeon is preferred to handle the case (Beech *et al.*, 2014). Osteoradionecrosis, if severe, is characterised by pain, swelling, mucosal fistula, reduced mouth opening and pathological bone fracture (Ray-Chaudhuri, Shah and Porter, 2013; Manimaran *et al.*, 2014).

#### 2.15.2.3 Salivary gland function and impact of radiotherapy on salivary glands

Salivary glands including the parotid, submandibular and sublingual glands are responsible for the production of saliva which contains about 99% of water and the rest being electrolytes,

mucopolysaccharides, enzymes, and immunoglobulins in various proportions (Redman, 2008; Carpenter, 2013; Deng *et al.*, 2015). Saliva has a complex role to play in the mouth (De Almeida *et al.*, 2008; Redman, 2008). Some of the functions of saliva include taste perception, helping in initial process of digestion due to its enzyme content, mostly alpha amylase and protection of oral tissues against irritation (De Almeida *et al.*, 2008; Redman, 2008; Deng *et al.*, 2015). Saliva also exhibits: a lubricating action to the food bolus to facilitate deglutition (swallowing), cleansing action by sweeping away food debris and non-adherent bacteria and buffering action by neutralising the pH of acids liberated by microorganisms to prevent demineralisation of teeth (De Almeida *et al.*, 2008; Redman, 2008; Deng *et al.*, 2015). Finally, it assists in removal of any surplus carbohydrates to minimise the amount of sugar available to the biofilm (De Almeida *et al.*, 2008; Redman, 2008; Deng *et al.*, 2015). As a result it prevents bacteria from colonising by depriving them from ambient environmental conditions (De Almeida *et al.*, 2008; Redman, 2008; Deng *et al.*, 2015).

When salivary glands are irradiated they can become partially functional or non-functional depending on the intensity and duration of radiation they are exposed to (Redman, 2008; Beech *et al.*, 2014; Wong, 2014). This leads to a reduction or absence in saliva production and flow rate (Redman, 2008; Beech *et al.*, 2014; Wong, 2014). As a result, xerostomia or sensation of dry mouth which is one of the most commonly reported complication in irradiated patients occurs (Wong, 2014). The literature indicates that radiotherapy affects around 90% of patients (Beech *et al.*, 2014). The saliva assumes a sticky and viscous consistency (Wong, 2014). Consequently, mastication, swallowing and denture wearing become painful (Vissink *et al.*, 2003; Wong, 2014). Unilateral exposure of salivary glands contribute to 60-70% reduction of saliva while bilateral exposure causes the salivary flow to drop by 80% (Wong, 2014). Xerostomia can be managed by the use of palifermin which is a keratinocyte growth factor (Ray-Chaudhuri, Shah and Porter, 2013). Caries development also occurs due to reduced salivary flow (Wong, 2014).

#### 2.15.2.4 Impact of radiotherapy on the oral cavity and teeth

Candida load is expected to rise during and after radiotherapy due to the altered oral flora caused by hyposalivation, thus giving rise to candidiasis (Ray-Chaudhuri, Shah and Porter, 2013; Beech *et al.*, 2014). The oral cavity, commissure of the lips and tongue are mostly affected by candidiasis (Beech *et al.*, 2014). The dentist will be able to assess the severity of

the candida infection and prescribe effective anti-fungal. Topical anti-fungal include nystatin, fluconazole or miconazole (Beech *et al.*, 2014). In severe oral candidiasis, systemic anti-fungal like amphotericin B or fluconazole are generally recommended. Regular dental visits during the radiotherapy phase is as important as the pre-treatment evaluation and should be stressed upon. Moreover, effective maintenance of oral hygiene is important to keep the candida load under control (Beech et al., 2014). Radiation causes degeneration of odontoblastic processes and collagen disruption in the pulp (Ray-Chaudhuri, Shah and Porter, 2013). This results in radiation caries which can appear after several months of treatment (Ray-Chaudhuri, Shah and Porter, 2013). Radiation caries can be aggressive and results in a non functioning dentition in less than one year (Ray-Chaudhuri, Shah and Porter, 2013).

### 2.15.3 Chemotherapy

Chemotherapy can be used before (neoadjuvant), after (adjuvant) or in conjunction with radiotherapy (Vokes, 2010). Chemotherapy is a cancer modality which uses drugs to destroy cancer cells and prevent their replication, but at the same time they also damage the healthy cells of the body (Wong, 2014).

#### 2.15.3.1 Impact of chemotherapy on oral health

Oral mucositis and xerostomia, as discussed previously above, also arise as a side effect of chemotherapy (Lalla, Sonis and Peterson, 2008; Wong, 2014). Oral mucositis can also occur on the ventral tongue in addition to the floor of mouth, soft palate and buccal and labial mucosa as mentioned above (Wong, 2014). The mouth becomes oversensitive to food intake due to tingling or burning sensation (Wong, 2014). Chemotherapy-induced oral mucositis develops at 1-2 weeks of initiation of therapy (Wong, 2014). Taste alterations, as also discussed further above,equally occur as a result of chemotherapy (Tsutsumi *et al.*, 2016). However, the perceptions of sweet and bitter taste are reduced with chemotherapy (Tsutsumi *et al.*, 2016). The sour and salty tastes are not affected (Tsutsumi *et al.*, 2016). Other toxicities associated with chemotherapeutic drugs include infections, haemorrhage, pain, nutritional and neurologic complications (Wong, 2014).

## 2.16 Socioeconomic impact of head and cancer

In addition to the side effects related to cancer treatment as discussed above, financial burden and unemployment have been reported to be severe outcomes in a cancer diagnosis (Carlsen *et al.*, 2008; O'Brien *et al.*, 2017).

In a study carried out in Denmark, 45,149 out of 236 993 cancer participants suffered unemployment after active treatment (Carlsen *et al.*, 2008). Unemployment in other words refer to the loss of productivity and negatively impacts on the country's economy. In many instances the rights of a person attained with any cancer might be violated by employers because of the functional and physical impairment that the patient may experience. The socio-economic status and the level of education are factors that can be linked to the risk of unemployment (Carlsen *et al.*, 2008). A study from Denmark reported that a low socioeconomic status and low educational level increase the risk for unemployment as compared to those with high income and a stable education (Carlsen *et al.*, 2008). A low socioeconomic status is also related to non-compliance to treatment and unprivileged quality of life and well-being (O'Brien *et al.*, 2017).

Besides unemployment and financial strain, malnutrition is another serious complication of cancer of the head and neck. In a study carried out in Spain, it was reported that 22.6% of the participants whose treatment for oral and oropharyngeal cancer was over 6 months or more, suffered from malnutrition which consequently affects the self image and quality of life of the patient (Barrios *et al.*, 2014). Cancer-related malnutrition may be attributed to the clinical side effects of chemoradiation and surgical resection causing inability to speak and eat properly (Barrios *et al.*, 2014).

## 2.17 Perception of self esteem and body image

The diagnosis of any cancer can be disrupting and poses a challenge to accept (Wong, 2014). It can induce dramatic and detrimental changes in a person's life (Leite, Nogueira and Terra, 2015). Such a diagnosis, in other words, means a recalibration and adjustment to integrate the cancer by dealing with the physical and emotional pain that is accompanied along in the daily routine (Leite, Nogueira and Terra, 2015). As a result, the self-esteem which is the confidence that one has of one's own worth and the body-image which is the insight and intuition that one has about one's own appearance, are affected (Kobayashi *et al.*, 2008; Leite, Nogueira and

Terra, 2015; Nayak, Pai and George, 2016). The literature reports that 20% to 50% of cancer patients in general have low self esteem (Kobayashi *et al.*, 2008)..

However, patients with cancer of the head and neck are more exposed to issues of body image and self-esteem as compared to those with cancers in other regions because of the easily noticeable or perceivable nature of the head and neck region (Kobayashi *et al.*, 2008; Nayak, Pai and George, 2016). It is also reported that head and neck cancer patients experience increased isolation, degrading relationship with their partners and more psychological distress and depression relative to other cancers (Gamba *et al.*, 1992; Kobayashi *et al.*, 2008). This can be attributed to the probable disfigurement and impaired functions due to teeth loss that may occur as a result of the nature and severity of the cancer and the sequelae of treatment (Fingeret *et al.*, 2010; Deng *et al.*, 2015).

## 2.18 Summary

This chapter described the challenges which the health care system faces in delivering equitable oral health services to patients. It also focused on the availability of oral health services in KwaZulu-Natal coupled with the provincial policy planning. Additionally, it highlighted the philosophy of health promotion and its application in different health promotion settings. The importance of oral health promotion and strategies in cancer was also covered. The risk factors associated with head and neck cancer were also covered. Furthermore, the impact that cancer therapy has on the oral health and the importance of dental referral and management were also discussed.

# CHAPTER 3: STUDY DESIGN AND METHODOLOGY

## 3.1 Introduction

The design and procedures involved in the research study are outlined in this chapter together with the study population, sampling, setting, data collection methods, data capture and processing.

## 3.2 Study design

This study was a cross sectional, descriptive and exploratory one. It is a cross sectional study since this investigation was carried out with a particular group of population, namely head and neck cancer patients, for a specific point in time. Data was sourced by a combination of quantitative and qualitative data to achieve its aims and objectives. The quantitative data was sourced to assess the perceived oral health status of patients undergoing therapy for head and neck cancer through standardised and validated questionnaires. The qualitative data explored oral health knowledge and practices of these patients towards oral health care and also the barriers and opportunities that exist for them to access oral health services. This was undertaken through structured face to face interviews with head and neck cancer participants. Furthermore, the qualitative component of the study also explored the support strategies that are in place and the extent to which oral health care for these patients is covered in the district health system through a semi-structured face to face interview with the oral health district coordinator.

## 3.3 Study site

The study was conducted in Durban-based tertiary cancer hospital, namely Inkosi Albert Luthuli Central hospital. This study location was chosen because histologically confirmed cases of head and neck cancers can only be obtained in hospitals. An attempt was made to include another private hospital in the study site but communication with the official led to the conclusion that consent for site permission would not be obtained since the oncologists work independently and book their own patients at different times.

### 3.4 Sample population

Data collection comprised of an administered questionnaire and interview phase. The study sample comprised of head and neck cancer patients attending Inkosi Albert Luthuli Central Hospital.

### 3.5 Selection of research participants (patients) for the questionnaire phase

#### 3.5.1 Inclusion criteria

All research participants were histologically proven cases of head and neck cancer (oral cavity, dorsum and ventral tongue, oropharynx, nasopharynx, hypopharynx, larynx, paranasal sinuses, nasal cavity, major and minor salivary gland, eyes and ear cancer) in any stage. This was confirmed with the treating oncologist through the patients' records.

Patients who were on active treatment or on follow up (full or partial remission) were included.

Those who had had a confirmed diagnosis of cancer of the head and neck, but treatment had not yet started were equally included.

The age range was between 20-70 years for all participants. This age range was chosen because the literature indicates that cancer of the head and neck region primarily occurs in the older age group of 40-59 years old (Elrefaey *et al.*, 2014). Higher age group of 65 years and above is also reported (VanderWalde *et al.*, 2013). However, it is also reported that the younger age group in the range 18-45 years old is increasingly being affected by cancer of the head and neck due to an increasing frequency of human papilloma virus (VanderWalde *et al.*, 2013; Majchrzak *et al.*, 2014).

Parental consent is not required for those who are aged 20 and above.

#### 3.5.2 Exclusion criteria

Patients who had cancer in other sites besides that of the head and neck region were excluded from the study since the study is concerned with head and neck cancer participants.

Patients who were still undergoing investigation and there was no confirmed diagnosis of cancer of the head and neck were not considered.

Those below the age of 20 were excluded from the study.

## 3.6 Sampling framework

### 3.6.1 Sampling technique

The sampling method used for participant selection was purposive sampling technique. Purposive sampling is a non-probablity sampling technique concerned with particular characteristics of a population for participant selection. This technique was chosen since this study is concerned specifically with patients undergoing head and neck cancer therapy.

### 3.6.2 Sample size

The sample size for the qualitative phase of the study was obtained after consultation with a statistician. The sample size was calculated by taking into consideration the proportion of population in KZN, using a uniform distribution to have an estimate of the head and neck cancer cases in KZN and assuming that 65% of head and neck cancer patients attend public hospitals. This is shown below.

#### 3.6.2.1 Sample size for the questionnaire phase

2011 histologically diagnosed head and neck cancer cases in South Africa= 1838

Population of South Africa=56,000,000

Population of KwaZulu-Natal=10,920,000

Proportion of population inKwaZuluNatal=10,920,000/56,000,000

=0.195

Assume uniform distribution of head and neck cancer

Therefore, estimate of head and neck cancer in KZN is: 0.195x1838

=358

Based on Formula $n=NZ^2pq/E^2(N-1)+Z^2pq$

Sample required for both private and public hospitals is 186.

Assume 65% of head and neck cancer are seen in public hospitals, then estimated cases

=0.65x358

=234

Thus, required sample size(n) for public hospital only, based on N of 234

= 147.

According to the calculation 186 patients were to form the sample size if consent was obtained from both private and public hospitals and 147 were to be included if consent was only obtained from the public hospital.

However, it was agreed that 250 participants would be included in the study instead of 147 so as to have more conclusive and accurate results and increase the statistical power. However, the final sample size was 235 because there was one withdrawal and fourteen patients did not give their consent to participate.

**Hence, the final sample size was 235.**

### 3.6.2.2 Sample size for the interview phase

Twelve voluntary participants (n=12) undergoing therapy for head and neck cancer were invited for the interview. Data saturation or redundancy occurred at the 12$^{th}$ interviewee.

The eTthekwini district coordinator (n=1) who is responsible for oral health planning in the district was also purposively selected and invited for an interview.

## 3.7 Data collection tools for the questionnaire phase

A combination of structured standardised and validated questionnaires (EORTC QLQ-C30 and EORTC QLQ-H&N35) from the European Organisation for Research and Treatment of Cancer was used as the data collection tool in addition to structured and semi-structured face to face interviews. The questionnaires were administered to two hundred and thirty-five participants undergoing therapy for head and neck cancer. The structured face-to-face interviews were conducted with twelve head and neck cancer participants. The semi-structured face to face interview was conducted with the eThekwini oral health district coordinator.

Permission from the EORTC Data Centre was obtained prior to using it in this research project by filling in a form containing details of the research project title, the institution in which the researcher is enrolled and the contact details followed by signing a user agreement form to be able to download this questionnaire.

The questionnaire used in this study has two main components. The EORTC QLQ-C30 and the EORTC QLQ- H&N35. This questionnaire was chosen because its reliability and validity have been researched and implemented using a modular and integrated approach for over a decade and is used in numerous international clinical trials and is reported to be accurate, valid and reliable (Aaronson *et al.*, 1993; Apolone *et al.*, 1998; Toth *et al.*, 2005; Wan Leung *et al.*, 2011). Its validity and reliability was first tested in a multicentre study from Sweden, Norway and Netherlands in 1993 (Bjordal *et al.*, 2000). The study carried out by Sherman *et al* also reported that it was reliable (Sherman *et al.*, 2000). It is available in English and ten other different translations (Bjordal *et al.*, 2000) including isiZulu. The English and IsiZulu versions were both downloaded from the EORTC Data Centre website.

The EORTC QLQ-C30 which was designed in 1986 by researchers from the European Organisation for Research and Treatment of Cancer, is specific for assessing the health-related quality of life of cancer patients (Aaronson *et al.*, 1993). The newer version, that is version 3.0 was used in this research as it was shown to be more reliable than previous versions based on the physical functioning scale (Bjordal *et al.*, 2000). EORTC QLQ-C30 is known as the core questionnaire and consists of thirty questions in a four-point likert type scale format with responses such as 1(Not at all), 2(A little), 3 (Quite a bit) and 4 (Very much) for all questions but 2 items related to global health status and quality of life where there is a scale of 1-7. Five items cover the functional scales (physical, role, cognitive, emotional and social), nine cover the symptom scales (pain, fatigue, nausea, vomiting, diarrhoea, constipation, loss of appetite,

financial difficulties and insomnia) and one scale being related to global health status and quality of life (Aaronson *et al.*, 1993).

EORTC QLQ- H&N35 is a specific module for head and neck cancer and has been field tested in more than ten countries and was found to possess robust psychometric validity, although some minor modifications were intended to be made (Aaronson *et al.*, 1993; Singer *et al.*, 2009, 2013). It must be used along with the core questionnaire regardless of the stage, treatment and site of head and neck cancer (Bjordal *et al.*, 2000). It is composed of 35 questions in a four-point likert type scale format with responses such as 1(Not at all), 2(A little), 3 (Quite a bit) and 4 (Very much) for all questions but five items where there is a choice between yes or no. It contains both single and multiple item scales to assess treatment side effects and symptoms (Aaronson *et al.*, 1993). There are eleven single item questions (like mouth opening, dry mouth, sticky saliva, teeth problems, feeling ill, cough, pain killers, nutritional supplements, use of feeding tube, weight loss/gain) and seven multiple item questions on pain, swallowing, sexuality, social contact, social eating, speech and senses (Aaronson *et al.*, 1993; Sherman *et al.*, 2000; López-Jornet *et al.*, 2012).

In addition to questionnaire administration, structured and semi-structured face-to-face interviews with the head and neck cancer participants and the Ethekwini oral health district coordinator who is responsible for oral health planning for Ethekwini District were also conducted respectively.

## 3.8 Interview schedules

### 3.8.1 Interview schedule for patient interviewees

The interview schedule for the head and neck cancer participants comprised of demographic questions related to the date of diagnosis, duration and type of treatment and past and present habits. Other questions included the participant's knowledge of oral health in relation to the overall well-being, oral health self-care practices, perceived barriers and opportunities that exist to access oral health care, and familial support that they receive.

### 3.8.2 Interview schedule for Ethekwini oral health district coordinator

The interview schedule for the oral health district coordinator comprised of questions related to the strategies that are in place to support patients with head and neck cancer and the extent to which oral health care is covered in district health policy and planning for these patients. Other questions included the existent institutional support for oral health promotion activities like risk factor intervention program and strategies to improve access to oral health promotion for these patients.

## 3.9 Data collection process

Prior to starting the data collection process, the researcher defended the research proposal in the presence of all the faculty members in the Discipline of Dentistry at the UKZN Westville Campus. Application for ethical clearance was consequently made to the Biomedical Research Ethics Committee. A provisional approval was granted following an expedited committee review of the research proposal. An official letter requesting permission to carry out the study in the hospital premises was then sent to the Head of Department of Oncology and the hospital's Chief Executive Officer (CEO). Gate-keeper permission from the KwaZulu-Natal Department of Health was then obtained (HRKM ref 107/17) by submitting the support letter received from the CEO. Following this, full ethics approval from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal was given (BREC REF: BE041/17).

The District Coordinator was approached through the Ethekwini Health District Office by submitting a formal letter requesting permission for a face to face interview. Explicit information about the purpose and objectives of the research was provided. The support letter from the hospital, approval letter from the KZN Department of Health and BREC final approval letter were all attached.

When the data collection process started, written informed consent was obtained from all participants wishing to participate in the study. Informed consents were available in English as well as in isiZulu for those who are not conversant in English. A total of two hundred and thirty-five participants were included for the questionnaire phase and twelve participants for

the interview phase. Additionnally, the eTthekwini oral health district coordinator was also interviewed.

A research assistant who is fluent in IsiZulu was recruited for the purpose of filling of questionnaires for participants who do not speak, read and understand English and for those who cannot read and write but understand isiZulu. The researcher was responsible for administering the questionnaires to English-speaking participants. All interviews were conducted in English by the researcher.

The signature of the subject on the consent form indicates that he/she was fully willing to form part of the study voluntarily without being subjected to compulsion from a second party, therefore minimising undue influence and coercion. For privacy purposes, each participant was interviewed and administered the questionnaires in a vacant room allocated to the researcher by the nurse in charge of the Oncology unit where other persons could not hear and see what was being said and written. This was done either when the patient was waiting for his/her turn to be seen by the oncologist or to go for their radiotherapy session or while they were receiving their chemotherapy session in which case a nurse would help to take the patient to the vacant room.

The study did not bear any clinical examination or intervention. Hence there was minimal risk of clinical adverse effects. The study neither carried any social nor economic risks to the patient.

The possibility of psychological risk is expected because the participant will have to recollect the phase he/she has gone/is going through since psychological distress is a frequent "unreported and untreated" condition characterised by unhappiness, nervousness, irritation, lack of ambition and terror in patients suffering from cancer (Faessler *et al.*, 2016; Milanti, Metsala and Hannula, 2016). Psychological risks in cancer patients are not to be ignored since it poses as a challenge always (Liu, Peh and Mahendran, 2017). This was taken into consideration by providing support with words of encouragement prior to starting the data collection session. Provision to refer to on-site social worker or psychologist at any time if distress and anxiety was anticipated, was made.

Further, the participants were allowed to be accompanied by a friend or relative or whoever has accompanied them to hospital during the interview and questionnaire filling sessions should they wish so. This was solely based on the participant's choice.

## 3.10 Data analysis

The data analysis was done in two parts: Quantitative data analysis and qualitative data analysis.

### 3.10.1 Data analysis for the quantitative phase

Demograhic details including gender, race, age, municipality, employment history, cancer site and treatment history were recorded. The cancer site was confirmed with the oncologist or the oncology nurse from the participants' medical files. The other details were obtained verbally from the participants. The quantitative data collected was captured in Microsoft excel spreadsheet and imported onto Statistical Package for Social Sciences software (SPSS) version 24 for analysis. The demographic details of the participants were calculated using descriptive statistics (mean, frequency, percentages, standard deviation). Pearson Chi-Square test was used to assess possible relationship between the independent and dependent variables. The p-value was set to less than 5% (< 0.05) to be significant.

### 3.10.2 Data analysis for the qualitative phase

The approach used for analysis of the qualitative data was content analysis using a thematic process by following the steps as described by Braun and Clarke (2006). The audio-recorded interviews were first transcribed verbatim and a data clean-up process was applied (Braun and Clarke, 2006; Theron, 2015). The narrative from each interview transcript was then coded and analysed based on the conventional thematic content analysis approach (Braun and Clarke, 2006; Theron, 2015). A code guide was developed to guide and support the coding process. Open nodes were generated in the open coding phase (Pateman *et al.*, 2015). This form of coding thus allows for inductive reasoning of the emergent themes (Theron, 2015). It also includes rules for the application of each code to ensure rigor and thoroughness (Whittemore, Chase and Mandle, 2001; Braun and Clarke, 2006; Elo and Kyngäs, 2008; Baillie, 2015; Brown *et al.*, 2015; Pateman *et al.*, 2015).

## 3.11 Ethical considerations

### 3.11.1 Ethical clearance and permission to conduct study

Prior to applying for and receiving Ethical clearance from the Biomedical Research Ethics Committee (BREC) of the University of KwaZulu-Natal and KwaZulu-Natal Department of Health, the researcher enrolled and qualified for compulsory certificates in "Research Ethics Evaluation" (Module 2.1) and "South Africa".

The participant information sheet, questionnaires, interview schedules, letter requesting permission to conduct study to the medical manager of the hospital and a letter to request consent of the oral health district coordinator to be interviewed were evaluated and approved by both BREC and KwaZulu-Natal Department of Health prior to the beginning of the study.

### 3.11.2 Confidentiality, beneficence and data storage

Patient anonymity and privacy is a primordial rule governing ethics and was therefore taken very seriously and upheld at all instances. Names were not asked during the questionnaire filling and interviewing. The questionnaire only required the initials of the participants. As soon as the research assistant completed the filling of questionnaires, they were handed over to the researcher and kept in an envelope.

The aspect of beneficence which is an important ethical aspect in Biomedicine was upheld at all instances and no harm in any way was caused to the participants (Kinsinger, 2009). The researcher ensured not to miss out on any signs of psychological distress and anxiety from the participants so as to refer them immediately to the on-site social worker for counselling and reassurance, but no such event occurred during the data collection process.

The filled questionnaires, voice recorder and transcripts were safely kept in a location where access to external parties were restricted. A locked cabinet in the Department of Dentistry at the University of KwaZulu-Natal was used for this purpose. The data was only accessible to the supervisor and the researcher.

The data which was entered on Microsoft Excel (raw data), was electronically stored in a secured/password-protected computer and used for the sole purpose of the study. All the data

was stored according to the rules and regulations specified by the University of KwaZulu-Natal which states that the data be stored for a minimum period of five years and thereafter destroyed.

### 3.11.3 Scientific validity and reliability in the quantitative data

Scientific validity is applicable in quantitative research and is concerned with the degree to which an assessment tool meaures what it is intended to measure (Watson, 2015). The questionnaires used in the study are standardised and validated (Bjordal *et al.*, 2000). The questionnaires (EORTC QLQ-C30 and EORTC QLQ-H&N35) used, were aligned to the aims and obectives of this study and this added to the internal validity. The findings are limited to the Ethekwini district but overall the shortcomings identified are consistent with that in other districts and provinces. This added to the external validity of the study.

Reliability in quantitative study design is the ability to reproduce the same results if a particular instrument is used at different times and by different researchers (Roberts, 2006; Watson, 2015). Reliability was maintained by double checking the data during data entry and eliminating all outliers. The data from the semi-structured interview was relatively reliable as the response was from a professional engaged in oral health service delivery.

### 3.11.4 Rigour and trustworthiness in the qualitative data

Credibility, confirmability, transferability and dependability were maintained as described below to guarantee rigour and trustworthiness in the qualitative component of this study (Hadi and José Closs, 2016).

#### 3.11.4.1 Credibility

Maintaining credibility is an important factor to guarantee trustworthiness in a study (Shenton, 2004; Hadi and José Closs, 2016). In order to maintain credibility, the research methodology was adopted by reviewing the literature of previously well established studies (Shenton, 2004).

The credibility was further intensified by becoming accustomed to the research setting prior to the data being collected (Baillie, 2015). The room to be used for interviewing head and neck

cancer patients and questionnaire filling, office of social worker on site, radiotherapy and chemotherapy departments were all spotted prior to collection of data.

Spending a long time with the participants allowed them to speak freely and honestly during the interview session and using the words of the participants in the report writing added to the credibility of the research (Thomas and Magilvy, 2011; Baillie, 2015). Engagement with the head and neck cancer patients before the first data collection process began was a way to develop mutual trust (Hadi and José Closs, 2016). Shenton reported that Lincoln and Guba recommended a "prolonged engagement between the two parties" help to establish trust (Shenton, 2004).

The third factor which helps to maintain credibility is the use of sampling so that confounding variables are distributed evenly within the sample and bias on the part of the researcher is eliminated (Shenton, 2004). This study made use of purposive sampling which focuses only on participants possessing characteristics pertinent to the study (Etikan, Musa and Alkassim, 2015). Hence, in this case it is concerned with head and neck cancer participants.

Triangulation is an equally important aspect of credibility (Bowen, 2008). The type of triangulation of interest in this study is data source triangulation as it involves structured face to face interviews in addition to administration of questionnaires. It consists of using more than one method of data collection to capture different dimensions on the same topic and also to cross validate the data (Carter *et al.*, 2014). Data source triangulation is concerned with collecting data from different sources like focus groups, individual interviews, community or families to have a broader dimension of the phenomenon being investigated (Carter *et al.*, 2014). Other types triangulation are method triangulation, theory triangulation and investigator triangulation (Carter *et al.*, 2014).

Voluntary participation of subjects and withdrawal at their own will without the need or compulsion to give clarification is primordial to maintaining credibility in the work (Shenton, 2004; Ryan *et al.*, 2005). This aspect was clearly emphasized in the consent form. In addition to that participants were encouraged to be genuine and feel free to speak since there are no right or wrong answers.

Debriefing workshops on a regular basis is another way to improve the rigour in a study (Baillie, 2015). It helps to probe the shortfalls present in the study right from the proposal level. Such a workshop was held in two instances in the Department of Dentistry of UKZN Westville

Campus, where the faculty members brought in their views and suggestions to improve the study. On-going communication with the supervisor throughout this research inevitably helped to refine the study process. Additionally, the researcher had presented an oral proposal defence of the study in the presence of members of the Faculty of Dentistry as part of a mandatory process before applying for ethical clearance.

#### 3.11.4.2 Confirmability

It is concerned with the extent to which the results could be confirmed by others and is present when dependability, credibility and transferability are existent (Thomas and Magilvy, 2011). Confirmability was maintained by doing an "audit trail" which takes into consideration the pathway from the data collection process to the data analysis where readers can track the course of the research by explicit descriptions of methodologies involved (Hadi and José Closs, 2016).

#### 3.11.4.3 Transferability

It is concerned with the degree to which the results of a study can be applied or generalised to other settings or situations (Graneheim and Lundman, 2004; Baillie, 2015). Transferability was maintained by providing a thick description of the data collection process, selection and characteristic of participants, study site and data analysis process (Hadi and José Closs, 2016). Transferability was further enhanced by elaborate demonstration of findings along with proper citations (Graneheim and Lundman, 2004).

#### 3.11.4.4 Dependability

Dependability in qualitative research refers to the reliability in quantitative study design (Shenton, 2004). It is concerned with the ability to reproduce the same results if a study is repeated with the same participants. Dependability was maintained by reporting elaborately of the processes involved in the study so that another researcher can have an in-depth understanding of the subject matter and use it as a guide to repeat a research (Shenton, 2004). It goes hand in hand with credibility where Shenton reported that Lincoln and Guba stressed on the fact that maintaining credibility ensures dependability (Shenton, 2004).

Given that the researcher was also involved in collecting the data (research assistant was recruited for IsiZulu-speaking participants), this might have led to observer bias although the researcher was careful not to ask leading questions to the research participants.

### 3.11.5 Respect for participants, participant information sheet and informed consent

As an invaluable element of any research, participant information sheet and informed consent forms were provided to those who potentially wished to engage in the study (Guraya, London and Guraya, 2014). Disclosure, understanding and voluntariness are essential components for an informed consent form to be valid (Cahana and Hurst, 2008; Kamuya, Marsh and Molyneux, 2011; Abaunza and Romero, 2014; Schofield, 2014). Detailed and adequate information regarding the study was fully disclosed to allow participants to make voluntary informed decisions before consenting (Abaunza and Romero, 2014). Information about the nature, purpose and any potential benefits and risks of the study in a simple, concise and easily understandable language, with no jargon terms, was provided (Moreno and Arteaga, 2012; Abaunza and Romero, 2014). Participants were also informed of their time commitments and the right to withdraw from the study at any time they wish so without incurring any penalty or loss of treatment benefits to which they are entitled to receive (Guraya, London and Guraya, 2014). English and Isizulu translated versions were both available since there are participants who are exclusively Isizulu speaking. Undue influence or coercion as specified in the Belmont report was not used in anyway and participation was entirely voluntary (Largent *et al.*, 2013). However, as a means of gratitude the participants were given refreshments after the session.

## 3.12 Work plan

The time frame in which the study was being completed is as follows

| **Activity** | **Deadline** |
|---|---|
| Submission of research proposal for Ethics approval and gatekeeper permission | 20 Aug 2016- January 2017 |

| | |
|---|---|
| Data Collection | April-August 2017 |
| Submission of first draft of dissertation excluding articles | May 2017 |
| Submission of second draft of dissertation excluding articles | August 2017 |
| Data Analysis | September 2017 |
| Report writing and submission of full dissertation including both articles | October-November 2017 |
| Submission of manuscript for examinations and journal publication. | December 2017 |

### 3.13 Dissemination of results

The results of the study will be made available to the KwaZulu-Natal Department of Health, The Head of the Discipline of Dentistry, UKZN, The Biomedical Research Ethics Committee of UKZN and the Medical Manager in charge of the hospital where data collection was undertaken. The results will also be disseminated via conference presentations and journal publications.

### 3.14 Summary

This chapter described the methodology involved in the study so as to achieve its aim and objectives and answer the research questions. It also discusses the extent to which the aspects of validity, reliability, rigour and thoroughness which are primordial for a study were established.

# CHAPTER 4: MANUSCRIPT PRESENTATION

## First manuscript: Preface

The purpose of the first manuscript entitled *Self-reported oral health status: Perspectives of patients undergoing therapy for cancer of the head and neck region, in the Ethekwini District, KZN,* was to have an insight into the perceived needs of patients based on the reported oral health status which can be included in oral health planning in the province.

This manuscript focused on the first objective of the study which was to assess the perceived oral health status of patients undergoing therapy for head and neck cancer. This manuscript explicitly examined patients' perspectives on perceived oral health status and complications associated with cancer treatment.

**Manuscript 1: Self-reported oral health status: Perspectives of patients undergoing therapy for cancer of the head and neck region, in the eThekwini District, KZN**

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**Both authors consent to publication and declare that there are no conflicting interests.**

## Abstract

### Background

There is a dearth of published evidence related to understanding oral health needs for patients undergoing therapy for cancer of the head and neck region.

### Aim and objectives

The aim and objectives of this study was to assess the perceived oral health status of patients undergoing therapy for cancer of the head and neck in the Ethekwini district, KwaZulu-Natal.

### Methods

This was a descriptive cross-sectional case study using quantitative data to determine patients' perspectives of oral health status and need. The study population comprised 235 voluntary patients (aged between 20-70 years old), undergoing treatment or follow up for cancer therapy of the head and neck region, in a public tertiary referral hospital in the Ethekwini district, KwaZulu-Natal. Purposive sampling technique was used for participant selection. The research instrument comprised a combination of two previously validated questionnaires: a core questionnaire (EORTC QLQ-C30, Version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35). Data was analysed using the statistical package for software sciences (SPSS), version 24.

### Results

The study population consisted of 235 patients, including 60% (n= 141) male and 40% (n=94) female, undergoing treatment for cancer of the head and neck. The mean age was 54.38 (SD= 12.30). The results indicate that 14.5% (n=34) were employed, 46.4% (n=109) were unemployed because of cancer and 39.1% (n=92) were unemployed due to other reasons (old age, housewife). Oral cavity cancer was the most common (n=91; 38.7%), followed by laryngeal cancer (n= 53; 22.6%) among all the other head and neck cancers. Males (n=50; 21.3%) were more affected by oral cavity cancer as compared to females (n=41; 17.4%). With reference to treatment, 20.4% (n=48) were on radiotherapy, 28.5% (n=67) were on chemotherapy and 9.8% (n=23) were on CCRT, 17.4% (n=41) had had surgery, 8.5% (n=20) were recently diagnosed with cancer of the head and neck and 23.4% (n=55) were on follow up. Oral health-related symptoms were experienced to varying degree by the participants. Pain

in the jaw was experienced by 46.8% (n=110) of participants while the majority of participants (n=125; 53.2%) did not report any pain. Among those who perceived intra-oral discomfort, 13.8% females (n=13) and 7.8% males (n=11) experienced severe intra-oral related pain and discomfort. More female participants (n=7; 7.4%) in the age group of 41-60 reported of severe difficulty in swallowing liquids than males of the same age group. Among those (n=100; 42.6%) who perceived difficulty to swallow pureed foods, slightly more females (n=13; 13.8%) perceived severe difficulty in swallowing pureed foods than males (n=17; 12.1%, p=0.034). Most of the participants (n=148; 63.0%) had difficulty in swallowing solid foods. Similarly, the majority of participants experienced problems with their teeth (n=162; 69.0%), reported xerostomia (n=159; 67.7%). With reference to trismus, a higher proportion of females (n=27; 28.7%) reported severe trismus compared to male participants (n=33; 23.4%). With reference to increased viscosity of saliva, 34.0% (n=32) of females reported extremely sticky saliva as compared to 29.8% males (n=42). The majority of participants (n=131; 55.7%) had varied responses to the severity of dysgeusia. Difficulty to eat was equally reported by the majority of participants (n=138; 58.7%).

**Conclusion**

It is apparent from the findings that oral health-related complications are present to varying degrees in head and neck cancer. It is important to educate patients to seek treatment for these complications. It is equally important that dentists and dental health care providers with special training assess and manage such complications efficiently and timely so that the quality of life of patients with head and neck cancer are not significantly affected. Further, education of life style risk factor of the general public needs to be emphasized. Oral health care support including patient counselling is strongly recommended as it is pivotal to psychologically prepare them to cope with any side effect.

## Introduction

The head and neck region is a complex anatomical structure (Sammut, Ward and Patel, 2014). This region and its physiological functions are both affected by cancer or its multimodality treatment (Sammut, Ward and Patel, 2014). Head and neck cancer (HNC) is a complex disease extending from the skull base to the clavicles, comprising different subsites namely, pharynx (including hypopharynx, nasopharynx and oropharynx), larynx, paranasal sinuses and nasal cavity, minor and major salivary glands, oral cavity (including lip, alveolar ridge, buccal mucosa, gingiva, oral tongue, retromolar trigone and floor of mouth), ear, skin and neck. (World Health Organization, 2005a; Argiris *et al.*, 2008; Chen *et al.*, 2008; Ouyang, 2010; Romesser *et al.*, 2012; Erovic *et al.*, 2013; Rettig and D'Souza, 2015). Cancer of the eye was also included besides that of oral cavity, pharynx, larynx, nasal cavity, paranasal sinuses and salivary glands since it is also found in the head and neck region (Shinde and Hashmi, 2013).

Radiotherapy (RT), chemotherapy (CT), concurrent chemoradiotherapy (CCRT), and surgery are the different treatment modalities employed in the management of head and neck cancer (Tulunay-Ugur *et al.*, 2013; Varelas and Kukuruzinska, 2014). The oral cavity, its subsites and dental hard tissues are some of the vital structures which get affected either directly or indirectly by effects of radiotherapy, chemotherapy, concurrent chemoradiotherapy and surgery of any head and neck cancer (Lieshout and Bots, 2014; Van Der Veldt *et al.*, 2014). Thus, oral health support and maintenance is of dynamic importance before, during and even after therapy since multimodal treatment-related oral complications like radiation caries, oral mucositis, xerostomia, osteoradionecrosis, periodontal disease , trismus, hypersensitivity and infections, pose a challenge for optimum oral health care (Frydrych *et al.*, 2012; McCaul, 2012; Mawardi, Al-Mohaya and Treister, 2013; Hartnett, 2015). The motor functions including mastication, deglutition, speech and sensory functions of the gustatory, olfactory and auditory systems are disturbed (Schultz *et al.*, 2010; Jawad, Hodson and Nixon, 2015). Disfigurement of the facial appearance is also a challenging complication because of the highly conspicuous nature of this region (Howren *et al.*, 2013; Shavi *et al.*, 2015).

Poor oral health is linked to poorer quality of life and increased mortality (Jablonski, 2012). Therefore, assessment of the oral health of patients with cancer of the head and neck is an important form of support in oral health care since the head and neck region comprise of vital

organs which, when affected, unfavourably impact on the overall well-being (Wan Leung *et al.*, 2011; Bottomley *et al.*, 2014).

Oral health services are delivered via the public and private sector in South Africa (Bhayat and Chikte, 2017). The public sector caters for 80% of the population of South Africa by providing primary preventive and restorative care (Bhayat and Chikte, 2017). The rural areas of KwaZulu-Natal comprise of almost 62% of the total population. However, an unequal distribution of services is present since the urban areas are more privileged in terms of oral health care access (Brindle *et al.*, 2000; Ramphoma, 2016). Inadequate and unequal distribution of dental health care providers and dental professionals is one of the reason contributing to this unequal trend in service delivery (Brindle *et al.*, 2000; Ramphoma, 2016; Bhayat and Chikte, 2017). Delivering oral health care through an integrated approach is incessantly and persuasively mentioned in policy planning documents but research demonstrated that this approach is not fully translated into actions and hence a lack in meaningful content is observed (Singh, Myburgh and Lalloo, 2010; Thema and Singh, 2013). A qualitative component of this present study also showed that there is a significant gap in service delivery for patients undergoing treatment for head and neck cancer since there is no specific oral health policy for this population group.

This study arose as a need to assess the perceived overall well-being and oral health status of patients undergoing therapy for cancer of the head and neck so as to empower patients to identify their own needs which will subsequently provide a contribution to provincial oral health planning.

For ease of analysis, cancer of the lip, buccal mucosa, anterior two thirds of tongue, floor of mouth, maxilla, mandible, hard palate, gingiva and retromolar trigone were grouped under oral cavity cancer (Shinde and Hashmi, 2013; Chi, Day and Neville, 2015; Matsuzaki *et al.*, 2017). Similarly, cancer of the base of the tongue, soft palate and tonsils were categorised under oropharyngeal cancer (Chi, Day and Neville, 2015). Salivary gland cancer consisted of only parotid and submandibular gland cancer. There were no other cancers of the salivary gland like sublingual gland and minor salivary gland cancer.

## Methods

This was a descriptive cross-sectional case study conducted between April to August 2017 to determine the perceptions of overall well-being and oral health status in patients undergoing treatment for head and neck cancer using quantitative methods. The study site was a public tertiary central referral hospital for the management of cancer, located in the Ethekwini Metropolitan Municipality within the province of KwaZulu-Natal. The sample population consisted of 235 voluntary adult patients of both sexes who were undergoing therapy exclusively for cancer of the head and neck region (active treatment, prior to treatment, or follow up). Purposive sampling technique was used for participant selection.

The sample size was calculated by taking into consideration the proportion of population in KZN, using a uniform distribution to have an estimate of the head and neck cancer cases in KZN and assuming that 65% of head and neck cancer patients attend public hospitals. The required sample size according to the calculation was 147. However, it was agreed that 250 participants would be included in the study instead of 147 so as to have more conclusive and accurate results and increase the statistical power. However, the final sample size was 235, given that fifteen patients did not consent. A total of 250 patients were approached either from the waiting room or radiotherapy or chemotherapy departments of the Oncology Unit of the hospital and explicit information about the study and time commitments were given verbally. All interested persons were given a participant information sheet to allow voluntary informed decisions to be made before consenting. The information sheets contained full details about the nature, purpose and any potential benefits and risks of the study in a simple, concise and easily understandable language (Cornejo-Moreno and Gómez-Arteaga, 2012; Abaunza and Romero, 2014). Participants were also informed of their right to withdraw from the study at any time they wish so without incurring any penalty or loss of treatment benefits to which they are entitled to receive (Guraya, London and Guraya, 2014). The inclusion criteria were histologically diagnosed head and neck cancer participants undergoing therapy, aged between 20-70 years old.

The research instrument comprised of a combination of two different validated questionnaires: A core questionnaire (EORTC QLQ-C30, Version 3.0) and the head and neck cancer specific module (EORTC QLQ-H&N35). A total of 30 and 35 questions respectively were answered in a four-point likert type scale format with responses such as 1(Not at all), 2(A little), 3 (Quite a

bit) and 4 (Very much) for all questions but 2 items related to global health and quality of life in EORTC QLQ-C30 where there is a scale of 1-7 and 5 items of EORTC QLQ-H&N35 where there is a choice between yes or no.

The EORTC QLQ-C30 is known as the core questionnaire and was chosen because its reliability and validity have been researched and implemented using a modular and integrated approach for over a decade and is used in numerous international clinical trials and is reported to be accurate, valid and reliable (Aaronson *et al.*, 1993; Apolone *et al.*, 1998; Toth *et al.*, 2005; Wan Leung *et al.*, 2011). The newer version, that is version 3.0, was used in this research as it was shown to be more reliable than previous versions based on the physical functioning scale (Bjordal *et al.*, 2000). This questionnaire consists of 30 questions with both single item and multi item scales, out of which 5 cover the functional scales (physical, role, cognitive, emotional and social), 9 cover the symptom scales (pain, fatigue, nausea, vomiting, diarrhoea, constipation, loss of appetite, financial difficulties and insomnia) and one scale being related to global health status and quality of life (Aaronson *et al.*, 1993).

EORTC QLQ- H&N35 is a specific module for head and neck cancer and has been field tested in more than ten countries and was found to possess robust psychometric validity, although some minor modifications were intended to be made (Aaronson *et al.*, 1993; Singer *et al.*, 2009, 2013). It has to be used together with the core questionnaire. It is composed of 35 questions containing both single and multiple item scales to assess treatment side effects and symptoms (Aaronson *et al.*, 1993). There are 11 single item questions (like mouth opening, dry mouth, sticky saliva, teeth problems, feeling ill, cough, pain killers, nutritional supplements, use of feeding tube, weight loss/gain) and 7 multiple item questions on pain, swallowing, sexuality, social contact, social eating, speech and senses (Aaronson *et al.*, 1993; Sherman *et al.*, 2000; López-Jornet *et al.*, 2012).

The English and IsiZulu versions of the questionnaires are both available. Permission from the EORTC Data Centre was obtained prior to using both questionnaires in both languages in this research project. The questionnaires were administered by the researcher (for English-speaking participants) and a research assistant (for IsiZulu-speaking participants).

Approval from the KwaZulu-Natal Department of Health and ethical clearance from the Biomedical Research Ethics Committee of the University of KwaZulu-Natal were given prior to the commencement of the study (BREC Ref: BE041/17). Ethical principles were strictly adhered to.

Demographic details including gender, race, age, municipality, employment history, cancer site and treatment history were recorded. The cancer site was confirmed with the oncologist or oncology nurse from the participants' medical files. The other details were obtained verbally from the participants prior to administering the questionnaires.

The data set was captured on Microsoft excel spreadsheet on a password-protected computer and imported onto IBM Statistical Package for Social Sciences (SPSS) Version 24. Demographic details of the participants were calculated using descriptive statistics (mean, frequency, percentages, standard deviation). Pearson Chi-Square test was used to assess possible relationship between the independent and dependent variables. The p-value was set to less than 5% (< 0.05) to be significant.

Both questionnaires have been validated in previous studies (Bjordal *et al.*, 2000). The questionnaires (EORTC QLQ-C30 and EORTC QLQ-H&N35) used were aligned to the aims and obectives of this study and this added to the internal validity. The generalisability of this study is limited to the study site which is a tertiary hospital. Reliability was maintained by double checking the data during data entry and eliminating all outliers.

**Results**

The study population consisted of 235 patients undergoing treatment for cancer of the head and neck. The sample population comprised of 60% (n= 141) male and 40% (n=94) female. The mean age was 54.38 (SD= 12.30). According to racial classification, the majority of the participants were Black, accounting for 60.9% (n=143), followed by 26.4% (n=62) Indian, 7.2% (n=17) White, and 5.5% (n=13) Coloured. The majority of the participants was from Ethekwini municipality (n=175; 74.5%). Amajuba district recorded the least number of participants (n=1; 0.4%). Concerning employment history, 14.5% (n=34) were employed, 46.4% (n=109) were unemployed because of cancer and 39.1% (n=92) were unemployed due to other reasons (old age, housewife). As for treatment history, currently (at the time of data collection) 20.4% (n=48) were on radiotherapy, 28.5 % (n=67) were on chemotherapy and 9.8% (n=23) were on CCRT. Participants who were recently diagnosed with cancer of the head and neck (treatment not yet started) accounted for 8.5% (n=20), while 23.4% (n=55) were on follow up.

The oral cavity cancer was found to be the most common (n=91; 38.7%), followed by laryngeal cancer (n= 53; 22.6%) among all the other head and neck cancer. Males (n=50; 21.3%) were mostly affected by oral cavity cancer as compared to females (n=41; 17.4%). Our study also showed that laryngeal cancer was three times more common in males (n=40; 17%) than in females (n=13; 5.5%). A significant relationship was found between laryngeal cancer and Coloured male and female, Indian male and female and White male. A significant statistical difference for Indian with cancer site variable was found ($p < 0.05$).

**Table 4: Demographic and clinical characteristics of all participants**

| **Variable** | **n** | **%** |
|---|---|---|
| **Gender** | | |
| Male | 141 | 60 |
| Female | 94 | 40 |
| **Race** | | |
| Black | 143 | 60.9 |
| White | 17 | 7.2 |
| Indian | 62 | 26.4 |
| Coloured | 13 | 5.5 |
| **Age range** | | |
| 20-30 | 13 | 5.5 |
| 31-40 | 24 | 10.2 |
| 41-50 | 38 | 16.0 |
| 51-60 | 74 | 31.5 |
| 61-70 | 86 | 36.6 |
| **Municipality** | | |
| Ethekwini | 175 | 74.5 |
| Amajuba | 1 | 0.4 |
| Ilembe | 5 | 2.1 |
| Ugu | 22 | 9.4 |
| Sisonke | 5 | 2.1 |
| Zululand | 6 | 2.6 |
| Uthungulu | 15 | 6.4 |
| UMkhanyakude | 3 | 1.3 |

| | | |
|---|---|---|
| UMgungundlovu | 3 | 1.3 |
| Uthukela | 0 | 0 |
| **Employment history** | | |
| Employed | 34 | 14.5 |
| Unemployed because of cancer | 109 | 46.4 |
| Unemployed because of other reasons (old age, housewife) | 92 | 39.1 |
| **Cancer site** | | |
| Oral cavity | 91 | 38.7 |
| Oropharynx | 22 | 9.4 |
| Nasopharynx | 5 | 2.1 |
| Hypopharynx | 12 | 5.1 |
| Larynx | 53 | 22.6 |
| Salivary gland | 15 | 6.4 |
| Nasal cavity | 16 | 6.8 |
| Paranasal sinuses | 2 | 0.9 |
| Eye | 13 | 5.5 |
| Ear | 6 | 2.6 |
| **Treatment history** | | |
| Treatment not yet started | 20 | 8.5 |
| Actively on radiotherapy** | 48 | 20.4 |
| Actively on chemotherapy** | 67 | 28.5 |
| Actively on CCRT** | 23 | 9.8 |
| Surgery | 41 | 17.4 |
| Follow up | 55 | 23.4 |

(** includes those who had undergone surgery also)

Different symptoms including soreness in the mouth, difficulty to swallow liquid, pureed and solid foods, dry mouth (xerostomia), sticky saliva, altered taste, teeth problems, difficulty to open the mouth wide and trouble to eat were perceived to different extent by the participants. We found that xerostomia was more commonly reported as the age went up (Figure 1) and was perceived by 67.7 % (n= 159) of the participants to varying degrees (Table 5). Soreness in the mouth, difficulty to swallow pureed and solid foods exhibited a significant relationship when tested with race (Table 5).

**Figure 1: Age distribution of patient-reported xerostomia**

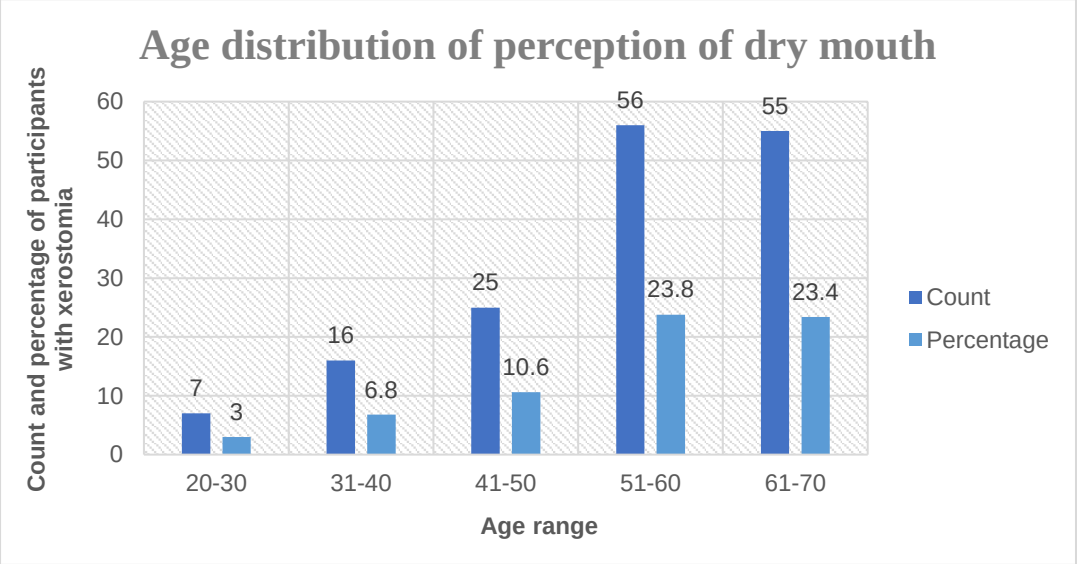

**Table 5. Respondents' reported oral health related symptoms**

| Questions | Responses | Black n (%) | Coloured n (%) | Indian n (%) | White n (%) | Total, n (%) | $\chi 2$ | p-values |
|---|---|---|---|---|---|---|---|---|
| Have you had pain in your jaw? | Not at all | 72 (50.3) | 7 (53.8) | 37 (59.7) | 9 (52.9) | 125 (53.2) | 0.389 | 0.424 |
| | A little | 20 (14.0) | 2 (15.4) | 8 (12.9) | 6 (35.3) | 36 (15.3) | | |
| | Quite a bit | 20 (14.0) | 2 (15.4) | 5 (8.1) | 1 (5.9) | 28 (11.9) | | |
| | Very much | 31 (21.7) | 2 (15.4) | 12 (19.4) | 1 (5.9) | 46 (19.6) | | |
| Have you had soreness in your mouth? | Not at all | 68(47.6) | 8 (61.5) | 46 (74.2) | 13 (76.4) | 135 (57.4) | 23.021 | 0.006* |
| | A little | 37 (25.9) | 2 (15.4) | 6 (9.7) | 0 (0) | 45 (19.1) | | |
| | Quite a bit | 18 (12.6) | 3 (23.1) | 7 (11.3) | 3 (17.6) | 31 (13.2) | | |
| | Very much | 20 (14.0) | 0 (0) | 3 (4.8) | 1 (5.9) | 24 (10.2) | | |
| Have you had problems swallowing liquids? | Not at all | 81 (56.6) | 10 (76.9) | 48 (77.4) | 12 (70.5) | 151 (64.3) | 11.303 | 2.55 |
| | A little | 30 (21.0) | 1 (7.7) | 7 (11.3) | 3 (17.6) | 41 (17.4) | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Quite a bit | 19 (13.3) | 1 (7.7) | 3 (4.8) | 2 (11.8) | 25 (10.6) | | |
| | Very much | 13 (9.1) | 1 (7.7) | 4 (6.5) | 0 (0) | 18 (7.7) | | |
| Have you had problems swallowing pureed food? | Not at all | 71 (49.7) | 7 (53.8) | 44 (71.0) | 13 (76.5) | 135 (57.4) | 18.059 | 0.034* |
| | A little | 33 (23.1) | 2 (15.4) | 8 (12.9) | 2 (11.8) | 45 (19.1) | | |
| | Quite a bit | 20 (14.0) | 0 (0) | 3 (4.8) | 2 (11.8) | 25 (10.6) | | |
| | Very much | 19 (3.3) | 4 (30.8) | 7 (11.3) | 0 (0) | 30 (12.8) | | |
| Have you had problems swallowing solid food? | Not at all | 44 (30.8) | 3 (23.1) | 32 (51.6) | 8 (47.1) | 87 (37.0) | 18.400 | 0.031* |
| | A little | 35 (24.5) | 3 (23.1) | 7 (11.3) | 4 (23.5) | 49 (20.9) | | |
| | Quite a bit | 21 (14.7) | 4 (30.8) | 5 (8.1) | 4 (23.5) | 34 (14.5) | | |
| | Very much | 43 (30.1) | 3 (23.1) | 18 (29.0) | 1 (5.9) | 65 (27.7) | | |
| Have you had problems with your teeth? | Not at all | 44 (30.8) | 4 (30.8) | 19 (30.6) | 6 (35.3) | 73 (31.1) | 7.778 | 0.557 |
| | A little | 29 (20.3) | 1 (7.7) | 9 (14.5) | 3 (17.6) | 42 (17.9) | | |
| | Quite a bit | 31 (21.7) | 6 (46.1) | 19 (30.6) | 6 (35.3) | 62 (26.4) | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Very much | 39 (27.3) | 2 (15.4) | 15 (24.2) | 2 (11.8) | 58 (24.7) | | |
| Have you had problems opening your mouth wide? | Not at all | 51 (35.7) | 5 (38.5) | 31 (50) | 7 (41.2) | 94 (40.0) | 14.428 | 0.108 |
| | A little | 27 (18.9) | 0 (0) | 6 (9.7) | 2 (11.8) | 35 (14.9) | | |
| | Quite a bit | 22 (15.4) | 4 (30.8) | 15 (24.2) | 5 (29.4) | 46 (19.6) | | |
| | Very much | 43 (30.1) | 4 (30.8) | 10 (16.2) | 3 (17.6) | 60 (25.5) | | |
| Have you had a dry mouth? | Not at all | 40 (28.0) | 4 (30.8) | 26 (41.9) | 6 (35.3) | 76 (32.3) | 9.679 | 0.377 |
| | A little | 32 (22.4) | 4 (30.8) | 9 (14.5) | 5 (29.4) | 50 (21.3) | | |
| | Quite a bit | 33 (23.1) | 2 (15.4) | 8 (12.9) | 1 (5.9) | 44 (18.7) | | |
| | Very much | 38 (26.6) | 3 (23.1) | 19 (30.6) | 5 (29.4) | 65 (27.7) | | |
| Have you had sticky saliva? | Not at all | 40 (28.0) | 2 (15.5) | 29 (46.8) | 7 (41.2) | 78 (33.2) | 13.180 | 0.155 |
| | A little | 29 (20.3) | 1 (7.7) | 8 (12.9) | 2 (11.8) | 40 (17.0) | | |
| | Quite a bit | 27 (18.9) | 5 (38.5) | 8 (12.9) | 3 (17.6) | 43 (18.3) | | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Very much | 47 (32.9) | 5 (38.5) | 17 (27.4) | 5 (29.4) | 74 (31.5) | | |
| Have you had problems with your sense of taste? | Not at all | 60 (42.0) | 7 (53.8) | 30 (48.4) | 7 (41.2) | 104 (44.3) | 6.251 | 0.715 |
| | A little | 37 (25.9) | 0 (0) | 9 (14.5) | 2 (11.8) | 38 (16.2) | | |
| | Quite a bit | 26 (18.2) | 4 (30.8) | 10 (16.1) | 5 (29.4) | 45 (19.1) | | |
| | Very much | 30 (21.0) | 2 (15.4) | 13 (21.0) | 3 (17.6) | 48 (20.4) | | |
| Have you had trouble eating? | Not at all | 54 (37.8) | 4 (30.8) | 29 (46.7) | 10 (58.8) | 97 (41.3) | 6.966 | 0.641 |
| | A little | 28 (19.6) | 3 (23.1) | 10 (16.1) | 0 (0) | 41 (17.4) | | |
| | Quite a bit | 19 (13.3) | 2 (15.4) | 7 (11.3) | 3 (17.6) | 31 (13.2) | | |
| | Very much | 42 (29.4) | 4 (30.8) | 16 (25.8) | 4 (23.5) | 66 (28.1) | | |

* means statistically significant, ($p<0.05$)

The findings (Table 5) indicate that the majority of participants (n=125; 53.2%) did not experience any pain in the jaw (maxillary and/or mandibular) while the rest of the participants (n=110; 46.8%) had varied responses to perceived pain. Among those who had pain in the jaw, a greater number of males (n=26; 18.4%) than females (n=10; 10.6%) reported minimal/negligible ("a little") pain in the jaw, while more females (n=24; 25.5%) reported severe ("very much") pain in the jaw than males (n=22; 15.6%). The results also demonstrated that perceived inta-oral discomfort ("soreness in the mouth") was statistically significant (p=0.006). The majority of participants (n=135; 57.4%) did not experience any intra-oral related pain and discomfort (soreness of the mouth). The results indicate that only 13.8% females (n=13) and 7.8% males (n=11) experienced severe intra-oral related pain and discomfort. With reference to swallowing liquids, 10.6% females (n=10) and 5.7% males (n=8) indicated severe difficulty in swallowing. The findings further demonstrate that more female participants (n=7; 7.4%) in the age group of 41-60 reported of severe difficulty in swallowing liquids than males of the same age group. Male participants who perceived severe difficulty to swallow liquids were all in the age group of 51-70. Only one female in the age group of 31-40 reported severe difficulty in swallowing liquids. The majority (=135; 57.4%) of participants did not experience any problem in swallowing pureed foods. Among those who did have difficulty (n=100; 42.6%) to swallow pureed food, equal proportion of males (n=27; 19.1%) and females (n=18; 19.1 %) experienced minimal difficulty to swallow pureed foods. However slightly more females (n=13; 13.8%) experienced severe difficulty in swallowing pureed foods than males (n=17; 12.1%, p=0.034). Most of the participants (n=148; 63.0%) experienced difficulty to swallow solid foods, among whom 65 participants (27.7%; p=0.031) comprising 26.2% (n=37) males and 30% (n=28) females reported severe difficulty in swallowing solid foods. The results indicate that the majority of participants experienced problems with their teeth (n=162; 69.0%). With reference to trismus (difficulty to open the mouth wide), the majority of participants (n=141; 60%) reported difficulty to open their mouth completely and there was a higher proportion of females (n=27; 28.7%) who reported severe trismus compared to male participants (n=33; 23.4%). A significant number of participants experienced xerostomia, ("dry mouth") (n=159; 67.7%). Almost 28% of participants (n=65) experienced severe xeroxtomia. More females (n=33; 35.1%) than males (n=32; 22.6%) experienced severe xerostomia. Increased viscosity of saliva ("sticky saliva") was also reported by the majority of participants (n=157; 66.8%). Thirty four percent (34.0%) of females (n=32) reported extremely sticky saliva as compared to 29.8% males (n=42). Futher, 44.3% (n=104) participants did not experience dysgeusia (taste alteration/taste distortion), while the majority of participants

(n=131; 55.7%) had varied responses to the severity dysgeusia. Among those who perceived dysgeusia, less females (n=13; 13.8%) reported negligible dysgeusia than males (n=25; 17.7%) while 22.3% females (n=21) reported severe dysgeusia as compared to 19.1% males (n=27). The findings also indicate that 41.3% participants (n=97) did not experience any difficulty to eat while the majority of participants (n=138; 58.7%) had varied reponses with respect to difficulty in eating. Among those who had difficulty to eat, 35.1% females (n=33) had severe problem in eating as compared to 23.4% males (n=33).

**Discussion**

This study examined the reported oral-health related symptoms among patients with cancer of the head and neck.

A higher percentage of men were found to be affected by head and neck cancer than women in the ratio of 1.5:1. This is consistent with the literature which reports that head and neck cancer is 2-5 times more prevalent in males than in females globally, depending on the geographical location (Rettig and D'Souza, 2015). The results indicate that head and neck cancer was most common in the 61-70 (n=86; 36.6%) age group followed by the 51-60 age group (n=74; 31.4%). This finding is in contrast with previous studies which reported of the commonest head and neck cancer cases in the age group 51-60 (Bhurgri *et al.*, 2006; Shinde and Hashmi, 2013; Alam, Siddiqui and Perween, 2017). The reason for a higher predominance in the 61-70 age group in this study might be due to illiteracy and lack of awareness among older people about the side effects of lifestyle risk factors (Joshi *et al.,* 2014). Strong cultural beliefs that cancer is a "curse" or a "punishment" might also be another reason for preventing people from seeking treatment and thus presenting late (Daher, 2012; Joshi *et al.,* 2014). Further, we found that cancer of the oral cavity was more predominant among all the other head and neck cancer subsites (larynx, pharynx, nasal cavity, paranasal sinuses, salivary gland, ear, eye). This finding is consistent with the literature (Chi, Day and Neville, 2015; Alam, Siddiqui and Perween, 2017). It was also the most common cancer among both gender, a finding which is equally consistent (Shinde and Hashmi, 2013; Joshi *et al.,* 2014). However, the results indicate that males were more affected by cancer of the oral cavity than females. This is in agreement with previous studies conducted among head and neck cancer patients which also found that cancer of the oral cavity was higher among males (Shinde and Hashmi, 2013; Shavi *et al.*, 2015).

However, the study by Shinde and Hashmi reported of a higher male to female ratio (1.9:1) of oral cavity cancers (Shinde and Hashmi, 2013), while the male to female ratio was lower (1.2:1) in our study.

Laryngeal cancer (n=53; 22.6%) was the second most prevalent cancer in our study and it was three times more common in males than in females (n=40 versus n=13 respectively). The National Cancer Registry in South Africa also reported of a higher male predominance for this cancer type (National Cancer Registry, 2013). Further, it is also reported to be more prevalent in males than in females globally but with a higher sex ratio of 7:1 (Parkin *et al.*, 2005).

Concerning unemployment, our study demonstrated that 46.4% of the participants were unemployed due to their present state of health as related by them. The majority of them originated from Ethekwini municipality. Added complication like unemployment is reported to be common in cancer (Carlsen *et al.*, 2008). A study reported that 45,149 out of 236 993 (19.1%) of cancer participants suffered unemployment after active treatment (Carlsen *et al.*, 2008). Our study however, indicated a much higher unemployment ratio.

Cancer of the head and neck or its multimodality treatment often leaves patients with several side effects and support needs (Chi, Day and Neville, 2015). The support needs are purely subjective (Moore, Ford and Farah, 2014b). The oral health of this population group is affected in a number of ways including difficulty to eat, dysphagia, odynophagia, gustatory and auditory disturbances due to a number of complications like oral mucositis, xerostomia, osteoradionecrosis, periodontal disease, trismus, hypersensitivity and infections, thus compromising the quality of life (Schultz *et al.*, 2010; Frydrych *et al.*, 2012; McCaul, 2012; Mawardi, Al-Mohaya and Treister, 2013; Hartnett, 2015; Jawad, Hodson and Nixon, 2015).

Soreness in the mouth, difficulty in swallowing and dry mouth are common perceived symptoms which patients often complain of (Chi, Day and Neville, 2015). Cancer therapy can directly affect teeth, tongue and other structures of the oral cavity which very often alter the eating and swallowing patterns (Moore, Ford and Farah, 2014b; Chi, Day and Neville, 2015). Soreness occurs due to oral mucositis which is characterised by atrophy of the oral mucosa resulting in ulceration and accompanied by dysphagia and pain (Stokman, Burlage and Spijkervet, 2012). It is a dose-dependent toxicity and developing in the first week after the initiation of radiotherapy and having the potential to last approximately up to 3 months (Maria, Eliopoulos and Muanza, 2017). Oral mucositis is one of the most common disturbing patient-

reported oral toxicity, accounting for an incidence of 85%-100% (Stokman, Burlage and Spijkervet, 2012; Sonis, 2013; Pattanayak *et al.*, 2016).

Dysphagia is characterised by fibrosis of the muscles of deglutition and is a major stressful and challenging treatment sequale which patients are concerned about and like to discuss with their doctors (Moore, Ford and Farah, 2014b; Starmer, 2014; Pateman *et al.*, 2015). A recent update suggests that the assessment of the swallowing pattern and swallowing therapy as a prophylaxis by a swallowing therapist prior to radiation exposure is essential (Starmer, 2014).

Trismus, as reported by the majority of participants, is evident when the interincisal distance is less than 35 mm due to contraction of the masticatory muscles after radiotherapy, chemotherapy or surgery of the head and neck region (Scott *et al.*, 2008; Johnson *et al.*, 2015; Rapidis *et al.*, 2015; Steiner *et al.*, 2015). The presence of temporomandibular joint, masseter and pterygoid muscles within the radiation field is a cause for trismus (Johnson *et al.*, 2015; Steiner *et al.*, 2015). Surgical intervention involving the retromolar trigone, buccal mucosa and tonsillar fossa is another etiological factor for trismus (Johnson *et al.*, 2015; Rapidis *et al.*, 2015; Steiner *et al.*, 2015). Varied responses with respect to the degree of trismus were reported among the participants. One factor which determines the varying degree of severity of trismus is the stage of the malignancy (Scott *et al.*, 2008). It is further reported that the difference in severity of trismus is also associated to the dose and field of radiation (Rapidis *et al.*, 2015; Steiner *et al.*, 2015). Higher radiation doses contribute to greater reduction of the interincisal distance (Steiner *et al.*, 2015). Trismus occurs at around two months after radiation, progresses rapidly over 9 months before it starts to resolve (Steiner *et al.*, 2015). Trismus is treated by initiating exercise therapy shortly after treatment is over (Rapidis *et al.*, 2015).

Sticky saliva and dry mouth (xerostomia) were perceived to different extent by the majority of the participants. Xerostomia is one of the most common reported side effect of radiotherapy (Beetz *et al.*, 2012). Xerostomia was perceived by more people from the older age group as compared to the younger counterpart. This observation corresponds to an earlier report which also found that the risk of xerostomia was greater as the age advances (Beetz *et al.*, 2012). Xerostomia occurs when the unstimulated and stimulated flow rate of saliva are reduced well below the normal level of 0.3-0.4 ml/min and 1.5-2.0 ml/min respectively (Villa, Connell and Abati, 2015). Reduction in the flow of saliva is significant in the first week of radiotherapy with 60-70 Gy irradiation (Sultana and Sham, 2011). Radiation doses above 52 Gy causes

severe dysfunction of the salivary gland while permanent salivary gland damage can occur with a minimum single radiation dosage of 20 Gy (Sultana and Sham, 2011).

Our study shows that more than half of the study population (55.7%) perceived an altered taste ranging from "a little" (16.2%), to "quite a bit" (19.1%) to "very much" (20.4%) while the rest (44.3%) did not perceive any taste impairment at all. This might be due to the fact that recent diagnosis was made and treatment had not yet started or they were on follow up and radiotherapy or chemotherapy which are both responsible for taste impairment were not being administered (Irune *et al.*, 2014). Taste alteration is also a significant patient-reported symptom in head and neck cancer (Najafizade *et al.*, 2013). It is, however, dependent on the stage of the cancer and the type of treatment that patients are undergoing (Murtaza *et al.*, 2017). Taste impairment is more evident by the 3$^{rd}$ or 4$^{th}$ week of radiotherapy with a minimal dose of 30 Gy (Irune *et al.*, 2014). Taste alteration usually resolves completely after 2-4 months of treatment but can still linger on for more than a year in those who had had high dose irradiation (Irune *et al.*, 2014; Wong, 2014).

**Limitations of the study**

This was a single site hence the results can only be generalised to the site. Moreover, there was no control group of patients with other cancers, while this could have helped to ascertain whether certain oral health-related conditions are unique to head and neck cancer patients. Despite these limitations, the study makes a substantive contribution to understanding patients' self-reported oral health status. The study can make important contributions to oral health planning in the province.

**Conclusion**

It is apparent from the findings that oral health-related complications are present to varying degrees in head and neck cancer. It is important to educate patients to seek treatment for these complications. Oral health care support including patient counselling is strongly recommended as it is pivotal to psychologically prepare them to cope with any side effect.

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**Second manuscript: Preface**

The second manuscript titled *Oral health promotion for patients undergoing therapy for head and neck cancer in KwaZulu-Natal – A qualitative study examining patients' perspectives*, made use of qualitative data from structured and semi-structured face-to-face interviews. Structured interviews were conducted with twelve participants (n=12) undergoing therapy for cancer of the head and neck region. A separate semi-structured interview was conducted with the Ethekwini oral health district coordinator (n=1).

The purpose of the second manuscript was to gain an understanding of the extent to which support for oral health care was available for patients with cancer of the head and neck region.

The second manuscript focused on three objectives of the study. Firstly, it aimed to determine the knowledge and attitudes of patients undergoing therapy for cancer of the head and neck towards oral health which was the second objective of the study. It also highlighted the reported challenges and opportunities which these patients faced in accessing optimal support for oral health care (objective three). Additionally, it focused on the fourth objective to provide insight into the current delivery of oral health promotion sevices for these patients.

**Manuscript 2: Oral health promotion for patients undergoing therapy for head and neck cancer in KwaZulu-Natal – A qualitative study examining patients' perspectives**

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**Both authors consent to publication and declare that there are no conflicting interests.**

## Abstract

### Background

There is no published evidence on access to oral health care for patients undergoing cancer therapy for the head and neck region.

### Aim and objectives

The aim and objectives of this study were to assess the oral health practices and perceptions of patients undergoing cancer therapy for the head and neck region, and explore opportunities and barriers in accessing oral health care.

### Methods

This was a descriptive case study in which a qualitative approach was used for data collection so as to explore patients' perspectives on oral health care. Structured face-to-face interviews were conducted with volunteers (n=12) undergoing therapy for cancer of the head and neck region. Purposive sampling was used to select the study participants, who were recruited from a public tertiary central referral hospital in KwaZulu-Natal. Additionally, a semi-structured interview was conducted with the Ethekwini oral health district coordinator to gain better insights into oral health service delivery and promotion for this population group.

### Results

The results indicated that the oral health in this vulnerable population was not prioritised. Some of the emergent themes included: lack of dental services in some areas of the province, failure of the local clinic to provide appropriate care and the lack of referral by oncology doctors to access dental care. Furthermore, the non-existence of a specific oral health policy and risk factor intervention program highlighted significant shortcomings for quality oral health service delivery for this population group.

### Conclusion

Support for oral health promotion is important for patients undergoing head and neck cancer therapy. There is an urgent need for oral health planning in the province to take into account the specific oral health needs of this vulnerable population.

## Introduction

Head and neck cancer represents a major burden in South Africa and many other African countries given its impact on oral health and quality of life (Ayo-Yusuf, Lalloo and Johnson, 2013; Melo Filho *et al.*, 2013; Samim *et al.*, 2016). Oral health, as per the new definition by the Federation Dentaire International is, *"multi-faceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex*" (FDI World Dental Federation, 2016, page 20).

The importance of oral health care in head and neck cancer cannot be underemphasized since a range of oral complications such as oral mucositis, trismus and infections owing to the multimodality treatment, affecting oral hygiene maintenance may occur (Lalla, Sonis and Peterson, 2008; Rapidis *et al.*, 2015; Samim *et al.*, 2016). Oral health examination and care begins prior to cancer therapy and intensified during the treatment phase to decrease possible complications bound to worsen the quality of life, and continues even after (Mainali *et al.*, 2011).

Radiotherapy and chemotherapy both contribute to oral mucositis which is uncomfortable and sometimes painful (Samim *et al.*, 2016). Micro-organisms overgrowth can give rise to bacterial pneumonia due to infections after surgery of head and neck cancer but with proper oral health care the load is reported to decrease (Sato *et al.*, 2011). The severity of these complications can be avoided to some extent if patients are educated about oral hygiene maintenance and the dental problems are properly managed by dental professionals with expertise in oral management of head and neck cancer since they are considered as key elements in the multidisciplinary team (MDT) of oncology (Samim *et al.*, 2016).

Besides dental professionals, the role of oncologists and nurses in the MDT is substantial in the chain of integrated oral health care to optimise outcome of head and neck cancer treatment (Rogers, Clifford and Lowe, 2011; Patel *et al.*, 2012). In order to provide effective oral health care, doctors and nurses should be educated about the importance of oral health for head and neck cancer patients (Dolce, Haber and Shelley, 2012). Nurses are considered integral elements to provide supportive care to these patients by delivering palliation through pain management of acute complications (Moore, Ford and Farah, 2014a). They are also critical in providing necessary information, emotional and psychological support to both patients and their families

or caregivers (Moore, Ford and Farah, 2014a; Dempsey *et al.*, 2016). On the other hand, doctors should be made aware through oral health education that dental assessment of head and neck cancer patients is vital before oncology treatment starts and thus they have to help in timely referral of patients for oral health consultation and management (Lawrence, Aleid and McKechnie, 2013; Samim *et al.*, 2016). In this way, the severity of oral complications and organ malfunctioning, which may cause interference or interruption of therapy, can be reduced or avoided as much as feasible (Patel *et al.*, 2012; Sonis, 2013; Lang *et al.*, 2014; Saito *et al.*, 2014; Samim *et al.*, 2016).

This study arose as a need to assess the perceptions of these patients towards oral health practices, explore the opportunities and barriers in accessing oral health care and determine the provision for oral health promotion services since there is no published evidence that oral health planning in KZN takes into account the specific oral health needs of these patients.

## Methods

This was a descriptive case study using qualitative data to explore head and neck cancer patients' perspectives on oral health care. Approval from the KwaZulu-Natal Department of Health and ethical clearance were obtained prior to initiation of the study by the Biomedical Research Ethics Committee of the University of KwaZulu-Natal (BREC Ref Number: BE 041/17). The study site was a public tertiary central referral hospital for the management of cancer, located in the Ethekwini Metropolitan Municipality within the province of KwaZulu-Natal. The study population comprised of 12 voluntary participants (n=12) undergoing active cancer therapy or follow-up sessions for maintenance therapy (those patients in remission). The volunteers were purposively selected from the waiting area in the Oncology unit after the purpose of the study was explained to all patients in the waiting area (to see oncologist or for radiotherapy or chemotherapy). Prior to the recruitment process, a participant information sheet was provided to explain the purpose of the study. Participation was entirely voluntary. Informed consent forms were obtained from all participants. The interview schedule comprised of demographic questions related to the date of diagnosis, duration of treatment and habits. Other questions included the participant's knowledge of oral health in relation to overall well-being, oral health self-care practices, perceived barriers and opportunities that exist to access oral health care, and social support that they receive. The participants' privacy was maintained

by conducting the interview in a vacant room in the oncology department. The duration of the interview was 15-20 minutes. Another semi structured face to face interview was conducted with the Ethekwini Oral Health District Coordinator, using purposive sampling technique. The interview schedule comprised of questions related to the strategies that are in place to support patients with head and neck cancer and the extent to which oral health care covered in district health policy and planning for these patients. Other questions included the existent institutional support for oral health promotion activities like risk factor intervention program for these patients and strategies to improve access to oral health promotion for these patients. The interview and venue were set up based on the availability and convenience of the district coordinator. The duration of the interview was 20-30 minutes. All the interviews were audio-recorded after explicit permission was obtained from the participants.

The audio-recordings were first transcribed verbatim by a transcriber and a data clean-up process was applied (Theron, 2015). The narrative from each interview transcript was then coded and analysed based on the conventional thematic content analysis approach by following the steps as described by Braun and Clarke (Braun and Clarke, 2006). A code guide was developed to guide and support the coding process. Open nodes were generated in the open coding phase (Pateman *et al.*, 2015). This form of coding thus allows for inductive reasoning of the emergent themes (Pateman *et al.*, 2015; Theron, 2015). It also includes rules for application of each code to ensure rigour and thoroughness (Whittemore, Chase and Mandle, 2001; Braun and Clarke, 2006; Elo and Kyngäs, 2008; Baillie, 2015; Brown *et al.*, 2015; Pateman *et al.*, 2015).

Credibility was maintained by ensuring that the researcher had prior engagement with the research participants to build trust and issues such as privacy, confidentiality and right to withdrawal from the study, were discussed before commencement with the interview (Baillie, 2015; Hadi and José Closs, 2016). Confirmability was maintained by doing an "audit trail" which takes into consideration the pathway from the data collection process to the data analysis where readers can track the course of the research by the descriptions of methodologies provided (Hadi and José Closs, 2016). Transferability was facilitated by providing a thick description of the data collection process, selection and characteristic of participants, setting and data analysis process (Hadi and José Closs, 2016). Dependability was achieved through a clear indication of the methods and processes used in the study so that the study could be replicated (Shenton, 2004). The results were validated by both the researcher and the qualitative analyst. The data was analysed by both and the results then compared. Member checks were

not done as it was difficult to again get hold of the patients after the data collection process was over since the treatment for a particular patient might have been over by the time the data was analysed.

**Results and Discussion**

The results of both interviews identified six main themes: Knowledge and practices in oral health care, barriers in accessing health and oral healthcare, support for oral health (Family and institution), opportunities available for oral health care, precautions when going outdoors and shortcomings identified in service delivery at the district level.

The demographic profile of the research participants undergoing cancer therapy is outlined in Table 1. The results indicate that half of the number of the respondents (n=6) engaged in smoking and alcohol consumption while only one reported chewing paan (betel nut and leaf).

**Table 6: Demographic data of participants**

| Participants | Date of Diagnosis | Duration of Treatment | Present Treatment Regime | | | Past Habits and Duration | | |
|---|---|---|---|---|---|---|---|---|
| | | | Radiotherapy | Chemotherapy | Surgery | Smoking & Duration (Years) | Alcohol &Duration (Years) | Paan Chewing & Duration (Years) |
| **P1** | Oct-16 | 3 months | | √ | | √ 18 | √ 10 | X |
| **P2** | Oct-16 | 1 month | √ | √ | | X | X | X |
| **P3** | 2013 | 30 days | √ | | | X | X | X |
| **P4** | Jan-17 | August | | √ | | √ - | √ Occasional | X |
| **P5** | Jan-16 | 31 days | | √ | | X | X | X |
| **P6** | Apr-17 | 26 days | √ | | | √ 10 | √ Occasional | X |
| **P7** | Jun-15 | Not yet started | | | | X | X | X |
| **P8** | Nov-16 | Does not know | | √ | | √ 5 | √ 6-7 | X |
| **P9** | 2014 | Forever | √ | √ | | √ 20 | √ 20 | √ 10 |
| **P10** | 2015 | Does not know | √ | | | X | X | X |
| **P11** | Nov-16 | Not been told | | | √ | X | X | X |
| **P12** | Apr-16 | Does not know | √ | √ | | √ 15 | √ 10 | X |

X: No √: Yes

**Theme 1: Knowledge and practices of oral health care**

Most of the participants, (n=11), acknowledged that oral health is important to their overall well-being with one narrating that his dentist disseminated the knowledge to him. The literature reports that dental professionals are key elements in educating people about oral hygiene before, during and after treatment and about effects of smoking and alcohol (Samim *et al.*, 2016). Only one participant responded negatively in the way that he did not acknowledge the importance of oral health to overall well-being (participant 7). Overall, their responses depicted the notion that good oral health is vital to prevent infections as presented in Table 2. Optimum oral health knowledge is crucial to achieve good oral health practice and consequently improved quality of life and well-being (Parker and Jamieson, 2010; Gao *et al.*, 2014).

Head and neck cancer patients, very often, present with poor oral health (Critchlow, Morgan and Leung, 2014). This is because of short term and long term oral complications associated to chemoradiation and surgery (Critchlow, Morgan and Leung, 2014; Hartnett, 2015). Optimum oral health care therefore is vital in these patients (Hartnett, 2015). Questions on oral health practices prompted various responses from the participants.

**Table 7: Participants' perceived knowledge on oral health and oral health practices**

| **Perceived knowledge of oral health and oral health practices** | **Responses** |
|---|---|
| 1.Do you think that oral health is important in relation to your well-being? How? | |
| Perceived knowledge of oral health: | *"Yes. Dentist said the health of the mouth is important and keep my teeth clean" (P1).*<br><br>*I think it is important my mouth must be clean so there are no germs. The doctor explained the benefits and complications and told me about the side effects that there is going to be dry mouth, dark skin, lose hair. (P3)* |
| 2. How do you keep your mouth clean? | |

| | |
|---|---|
| Oral health Practices: | *"I go to a private dentist. I brush in the morning and sometimes at night but I always gargle at night" (P1).*<br><br>*"brushing, flossing and mouthwash"* to maintain oral hygiene (P2)<br><br>*"The doctor told us that as soon as radiation will start some of these areas* (he was referring to the lips) *are going to be disturbed so I must boost myself". (P7)* |

**Theme 2: Barriers to accessing oral health care - The present socioeconomic landscape**

This theme addresses the barriers that exist to obtain oral health services. Many barriers, according to the participants' perceptions to access oral health care, have been identified in this study and are represented in figure 1.

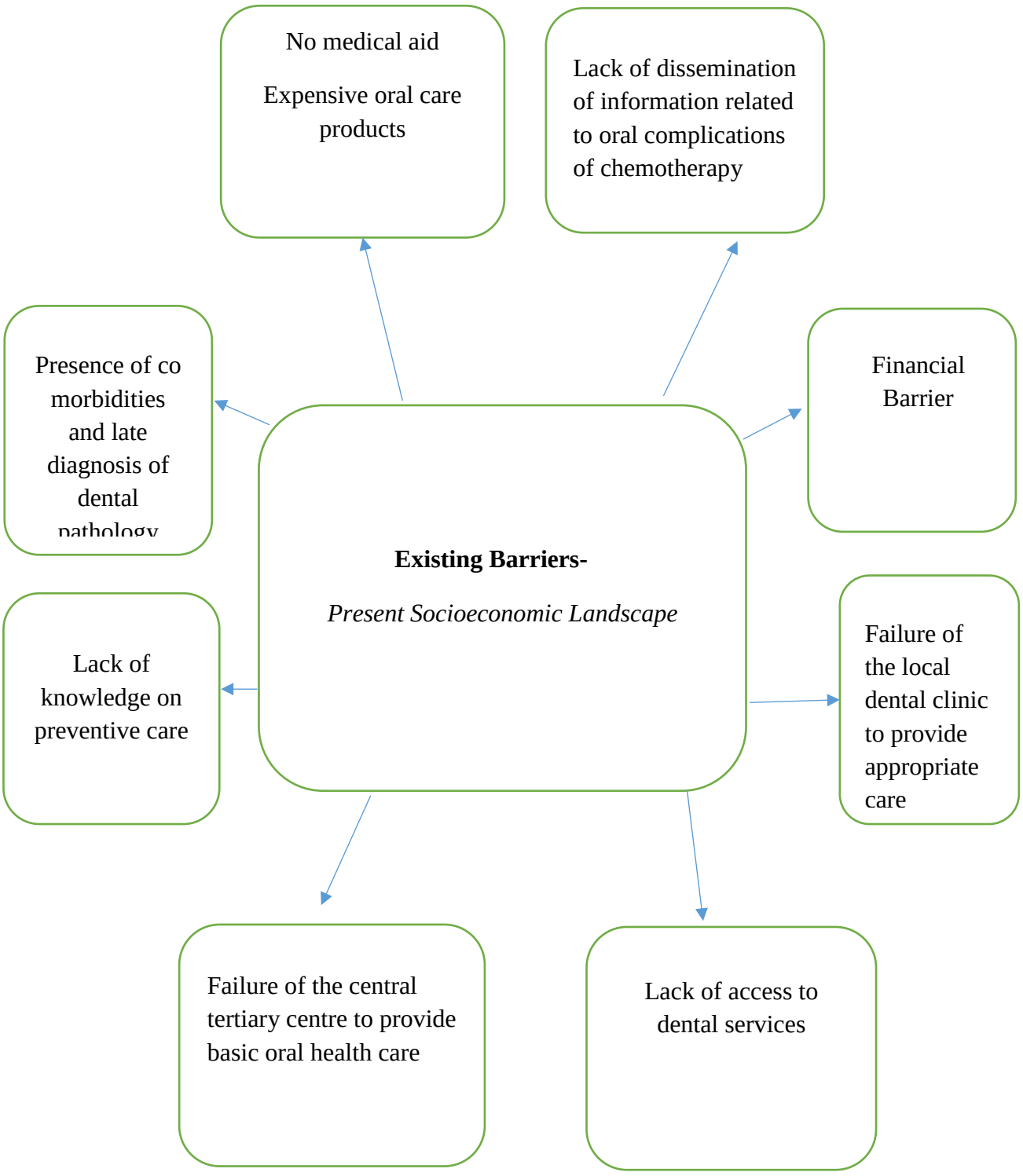


**Figure 2: Barriers perceived by participants to access oral health care**

Some participants living in underdeveloped areas in Empangeni and Oakford, narrated that it is difficult for them to access dental care since there are no nearby dentists around these regions. This observation is consistent with the literature which also reports that those living in socially marginalised regions in either developed or developing countries have reduced access to oral health care (Jin *et al.*, 2011; Ramphoma, 2016). Inequality in oral health service delivery is a reality in South Africa, with the urban areas being prioritised over the rural counterpart (Ramphoma, 2016). Disparity in the province is also present whereby the urban areas are more priviledged to oral health care services as compared to the rural areas which comprise of 54% of the total provincial population (KwaZulu-Natal Department of Health, 2016; Ramphoma, 2016). This inequitable distribution exists as a result of shortage of staff and lack of access to oral health services (Brindle *et al.*, 2000; Ramphoma, 2016).

Other participants narrated that it is difficult for them to access care due to other diseases that they are suffering from in addition to the cancer. The co-existence of other diseases like hypertension, diabetes, obesity, bone loss amongst others in cancer patients is a generally agreed fact although the prevalence varies significantly sometimes, owing to the type of cancer, study population and other factors (Edgington and Morgan, 2011; Sarfati, Koczwara and Jackson, 2016).

**Table 8: Existing barriers to oral health care**

| **Barriers at individual level** | **Responses** |
|---|---|
| Do you experience any difficulty to buy stuff to keep the mouth clean? Is it difficult for you to get to the dentist? | |
| No medical aid and expensive oral products | "because I did not have medical aid so they referred me. Yes I experience difficulty to buy stuff to keep the mouth clean because they are expensive" (P1). |
| Lack of dissemination of information related to oral complications of chemotherapy | *"They didn't say anything at all about importance (of oral health); they didn't mention it could have an effect on the teeth". (P2)* |
| Financial barrier | *"We do not receive things like toothpaste and toothbrushes, it is expensive because my dad collects a disability grant it is a financial strain because he wears diapers and all that has to be done with his pension" (P4)*<br>*"Yes since I started this treatment I have difficulty because the money is getting short* |

| | |
|---|---|
| | *we are using 96 rand a day it is difficult. We cannot afford to go to the dentist and doctors where you have to pay more than the government hospitals. Money, it is very expensive for us because he is no longer working I am not working. (P6)* |
| Failure of the local dental clinic to provide appropriate care | *"They see so many patients a day until after 12 they do not take any more patients. If after 12 you must come the next day. They do not do most of things they just do general extractions. the oncologist from here* (the tertiary cancer centre) *stated that my dad must have a fluoride treatment and he needed to be stitched as well where the teeth was removed and they do not do that. So we have to go to private dental practitioners". (P4)* |
| Lack of access to dental services | *"There are no dentists around where I live. It is like one hour's drive". (P5)* |
| Failure of the central tertiary centre to provide basic oral health care | *"Some teeth needed to be removed and I asked if the dentist can do it here* (that is the hospital) *and they said no". (P4)* |
| Lack of knowledge on preventive care | *"I am not sure about how the sun affects my mouth" (P8).* |
| Presence of co morbidities and late diagnosis of dental pathology | *"I have chronic pancreatitis and I am diabetic I do not know why I am still losing weight I am 50 kgs I was 80 kgs. It took the hospital about one and a half years to find out that I have cancer. The operation was done within a month because it was that serious". (P9)*<br>*"Yes now, before it wasn't difficult to go to the dentist although it was not too near but now not anymore because of weakness. (P6)."* |

**Theme 3: Support for oral health care**

This theme is concerned with the different forms of support that were provided to the participants by their families from the time of cancer diagnosis. It also focuses on the type of institutional support provided to them.

Moral and financial support are some of the forms of assistance that most of the participants obtained with the exception of one respondent who did not receive any support from his family. However, one unique interviewee narrated that he obtained support through prayers. Prayer is

recurrently used in chronic illness and is a popular form of "Complementary and Alternative Medicine" to obtain relief (Jors *et al.*, 2015). A study conducted in USA among cancer patients reported that prayer is a strong weapon as it helps to stabilise the heart rate and other vital signs of the anxious patients (Carvalho *et al.*, 2014).

As an institutional support strategy, the district coordinator describes that support is given by referring patients for further investigation to specialists if suspected lesions are reported during examination and advising against smoking and drinking. This statement is in line with the literature which reports that dentists may be in the first position to diagnose cancerous lesions of the head and neck and they are also important in lifestyle change behaviour like alcohol and smoking (Mol, 2010; Samim *et al.*, 2016).

**Table 9: Support for oral health care**

| **Familial and Professional Support** | **Responses** |
|---|---|
| **A. Familial Support:** | |
| How has your family supported you to obtain treatment? | |
| 1a. Lack of support | *"Basically, I have been doing everything myself from the day I came out I have been confident; I have been coming for treatment myself. I have no back up". (P9)* |
| 1b. Moral support | *"They were supportive and tried to help. They are always there for me". (P7)* |
| 2. Financial Support | *"They supported me a lot.financially and caring for me".( P11)*<br><br>*"They give me money to see a doctor." (P12)* |
| 3. Telephonic conversation | *"They support me by calling me asking me how I am doing." (P3)* |
| 4.Support through visit | *"They come to visit." (P6)* |
| 5.Prayer and advice | *"My family was also confused and they supported me through prayer and advice". (P8)* |
| **B. Professional Support** | |
| **Institutional Support from a policy perspective and Referral Mechanism** | |
| 1.Is there any institutional support for oral health promotion activities for patients with cancers of the head and neck region? What is your opinion about it? | |
| 1a. Institutional Support | *"We do not target a specific group of patients. We target all patients. For head and neck cancer patients, we have to make sure that their oral health is maintained to optimum level by cleaning and polishing twice or thrice a year. We do have oral hygienist to do the cleaning and polishing for all the patients who require cleaning. If cancer patients require dentures we got facilities for that".* |
| 1b. Referral Mechanism | *"While examining the patients we tell them what needs to be done and if we feel that the patient has got something which looks like squamous cell carcinoma, we refer them to ENT or Oncology for further investigation. We do small biopsy but anything major we refer to ENT or Max Fac".* |
| **2.Access to care** | |
| 2a. What are some of the challenges you think these patients encounter? | |
| Good infrastructure | *"I don't think there are because it is open for all. Ethekwini for example has got 17* |

| | |
|---|---|
| | *hospitals and clinics. We got 7 major hospitals and lots of CHC's".* |
| 2b. What can be done to improve access to oral health promotion activities for these patients? | |
| Poor resource allocation | "*Human resources and financial resources are the two most important things. If we can have more staffs and financial resources we will definitely improve access to oral health promotion for these patients*". |

**Theme 4: Perceived Opportunities**

This theme focuses on available opportunities as deemed by these patients to receive oral health services. One of the most pertinent and interesting factor is that they are given mouthwash for free at the hospital while at the same time when it runs out patients find it a challenge to buy, representing a barrier. Mouth washes containing diphenhydramine, sodium bicarbonate and saline or 5% morphine or 0.5% Doxepin are prescribed for patients suffering from oral mucositis occurring as a result of chemotherapy and radiotherapy or a combination of both (Caillot and Denis, 2012; Lalla, Saunders and Peterson, 2014; Majdaeen, Babaei and Rahimi, 2015). Oral mucositis is a painful condition characterised by inflamed mucosa and inability to eat compromising the quality of life and well-being of the individual (Lalla, Saunders and Peterson, 2014).

Access to dental hygienists was also deemed as an opportunity. Dental hygienists are considered as integral elements in providing dental care and preventative treatment plans suited to each individual patient's needs (Yi Mohammadi, Franks and Hines, 2015). It is also reported that their roles can be expanded to provide oral health care from a holistic approach (Yi Mohammadi, Franks and Hines, 2015).

Reflection also emerged as an opportunity for one of the participants to ponder over his present condition.

**Table 10: Perceived opportunities to oral health care**

| **Perceived Opportunities** | **Responses** |
|---|---|
| Access to dental hygienist | "*If there is a problem the dentist normally refers you to a hygienist" (P2).*<br><br>*"We receive mouth washes here and sometimes they do not have stock so we have to buy it (P4)".* |
| Good Referral | *"I go to the dentist around the area when I have problems with my teeth and he referred me to come here" (P8).* This patient had a swelling on the nose and deviation of the jaw and this might be the reason for the dentist to refer him<br><br>"*My teeth are cleaned"* which is a benefit when going to the dentist" *(P3).* |
| Comprehensive Explanation | *"The doctor explained the benefits as well as the complications and referred me to others"* (P9). |
| Self-reflection | *"That is why sometimes I get stressed I am not smoking I am not drinking why I get the cancer every time I am going to the church so why does the bad things go through to my life" (P10).* |

**Theme 5: Present precautions outdoors**

One participant related that as a precaution when going out she covers her mouth because she used to remain in the sun, doing gardening always and was consequently diagnosed with lip cancer. It is well known that prolonged and excessive exposure to ultraviolet radiation emitted by sunlight, tanning beds and sun lamps causes lip cancer which is a type of head and neck cancer (Sivamani, Crane and Dellavalle, 2009; Zaraa *et al.*, 2013; O'Sullivan and Tait, 2014).

The safety precautions to take when going outdoors as portrayed by most of the participants include protective clothing, hats and sunscreen. This is consistent with the literature which

also reports that wide brimmed hats, protective clothing, sunscreen and sunglasses are important when being exposed to the sun (Andersen *et al.*, 2010).

**Theme 6: Shortcomings identified in service delivery at district level**

This theme focuses on the deficiencies that are present at the district level to enhance access to oral health care for these patients. The interview with the district health coordinator suggested that oral health strategies remain isolated from general health interventions, as indicated in the following quotation:

*"We do not have a separate policy on oral health care for head and neck cancer patients. I have not seen one specifically for head and neck patients. But we got a specific policy in KZN as to decrease the filling to extraction ratio which at the moment is sitting at 1:20. By 2021/2022 we want to bring it down so that for every 10 extractions we do a filling".*

A similar response was obtained from the district coordinator on the availability of life-style induced health risk-related intervention programmes, highlighting therefore a gap in service delivery:

*"We do not have any (risk factor intervention program) but we do encourage all our patients not to smoke and drink." (oral health district coordinator).*

Oral health care has a significant role in cancer patients as it dictates the overall well-being of the individual (Bueno *et al.*, 2015). A study conducted in North Carolina on cancer patients reported that participants who had dental or oral problems were also those who experienced inferior emotional health, deficient physical functioning and poorer quality of life as compared to those who did not have any oral health-related issues (Ingram *et al.*, 2005). A risk factor intervention program is important to address common risk factors for non-communicable diseases (in this case head and neck cancer) as part of health determinants (Molete, Daly and Hlungwani, 2013).

Oral health is vital for the overall well-being in cancer of the head and neck (Pateman *et al.*, 2015). Thus, oral hygiene maintenance is of utmost importance in these patients (Samim *et al.*, 2016). Toothbrushing, flossing and mouth rinse are vital and effective strategies to this population group as part of an appropriate oral health care regimen (Deng *et al.*, 2015; Gupta *et al.*, 2015). In general, the participants were knowledgeable about the importance of oral

health with respect to their overall health and were practicing on at least one of these strategies. One unique interviewee however, denied that oral health is vital for the overall well-being. Hence, on-going oral health education about the importance of oral hygiene maintenance before, during and even after therapy and providing appropriate treatment are integral to improving oral health literacy and also quality of life (Plemons, Rankin and Benton, 2013; McQuistan *et al.*, 2015; Samim *et al.*, 2016). This forms part of the dental professionals' duty (Plemons, Rankin and Benton, 2013; Samim *et al.*, 2016). This is however not possible in the presence of factors preventing access to oral health care as observed in this study. Barriers at both the individual and district levels have been noted.

Low income, living in a socially deprived area where there is no dental facility and long distance to dental clinics, as expressed by the participants, were among the most striking factors related to inaccessibility to dental care. This is consistent with the literature which reports that socially marginalised and disadvantaged groups have reduced access to health services (Petersen, 2009b). The overflow of patients in local clinics resulting in long waiting hours was also expressed as a barrier to use dental public services. All these factors can be attributed to a lack of coordinated and integrated oral health planning which, when present, can eliminate inaccessibility to oral health care (Thema and Singh, 2013). Previous studies also reported of similar barriers to accessing effective oral health services (Vargas and Arevalo, 2009; Molete, Yengopal and Moorman, 2014; Almado, Kruger and Tennant, 2015). The lack of referral by the oncology doctors to obtain dental care in this tertiary centre was another significant barrier identified. This deficiency might be attributed to the fact that doctors are unaware of the importance of dental assessment and oral health care in this population group (Lawrence, Aleid and McKechnie, 2013).

Guidelines issued by the National Institute for Clinical Excellence recommend that all patients about to start head and neck cancer therapy should be referred to dental professionals by their service providers to decrease the incidence of oral complications related to the multimodality oncology treatment (Lawrence, Aleid and McKechnie, 2013; Samim *et al.*, 2016).

Another limitation identified is the lack of dissemination of information related to oral complications of chemotherapy to patients by other members of the MDT (Oncologists and nurses). Poor knowledge of oral health care on their part might be the likely reason. This observation is consistent with another study which also reported that nurses demonstrated weak oral health care knowledge of cancer patients (Pai and Ongole, 2015). Continuous inter-

professional oral health care education that incorporates evidence-based strategies of oral health care should be prioritised for improved patient outcome (Pai and Ongole, 2015). In this way the knowledge can be spread from professionals to patients. Developing and following oral health care recommendations to provide comprehensive care to patients undergoing therapy for cancer is equally meaningful (Kav *et al.*, 2008; Pai and Ongole, 2015).

Integrated planning is vital for oral health promotion activities (Thema and Singh, 2013), yet a substantial deficiency, as observed in this study, is the absence of a specific policy planning at the district level in the interest of these patients. Furthermore, the Common Risk Factor Approach is a means by which oral health promotion can be incorporated in general health so that risk factors which are similar for non communicable diseases (hence including head and neck cancer as well) can be addressed as part of health determinants (Molete, Daly and Hlungwani, 2013). This approach is supported by the South African Oral Health Promotion framework (Molete, Daly and Hlungwani, 2013). However, absence of a risk factor intervention program for promotion of oral health is another major gap that was identified in service delivery for this population group. Education on the consequences of tobacco smoking, alcohol consumption, areca nut chewing and other risk factors should be part of a properly structured oral health promotion programme in addition to routine toothbrushing and flossing methods. Education about life threatening consequences of lifestyle risk factors is important to decrease the severe financial burden on both patient and State (Abdo *et al.*, 2007; Abreu, Kruger and Tennant, 2009; Joshi *et al.*, 2014). Literature reports that educational campaigns can help to implement this type of approach (Nemoto *et al.*, 2015). However, very often campaigns do not include the high-risk population who genuinely represent the originality of the problem being addressed (Nemoto *et al.*, 2015). Thus the number of participants should be as big as possible and should target those at high risk for developing head and neck malignancy, especially those living in underdeveloped regions because they are the ones who have more exposure to tobacco, alcohol, carcinogenic viruses and other avoidable risk factors and also experience reduced access to education besides health services (Petersen, 2009b; Ford *et al.*, 2013; Nemoto *et al.*, 2015). Thus, holding campaigns at different periods during the year and planning home visits to the at-risk and socioeconomically marginalised, instead of them travelling to participate in such campaigns is one way through which this approach can be implemented (Nemoto *et al.*, 2015). Inadequate human and financial resources were blamed for this shortfall in oral health promotion strategies. Adequate workforce is critical for delivery of high quality dental care since 80% of the South African population utilises public dental

services (Bhayat and Chikte, 2017). The dentist to population ratio in SA was 1:8900 in 2015 according to the latest available data, while it is 1:2000 in developed countries (Bhayat and Chikte, 2017).

The support needs of the participants were largely met by their families. Moral and financial support were the most common forms of support that they received. Moral support is indispensable since it contributes to better handling of psychological and physical challenges to which head and neck cancer patients are confronted and results in improved well-being (O'Brien *et al.*, 2017). Financial support in cancer is crucial as it is reported to be accompanied by severe financial strain (Zaidi, Ansari and Khan, 2012). Prayer was another form of support provided by the family. Prayer/spirituality is recurrently used in chronic illnesses and helps to cope better with undesirable situations (Mesquita *et al.*, 2013; Jors *et al.*, 2015). Many studies also reported that prayer is a powerful and effective approach to cope with cancer (Mesquita *et al.*, 2013; Carvalho *et al.*, 2014).

**Limitations of the study**

This study cannot be generalised. The study participants were drawn from a single site and the results cannot be extrapolated to other provinces and districts. However, this study provides valuable data on access to oral health care given that no study so far has explored the oral health needs of head and neck cancer patients in the province of KwaZulu-Natal. Future research in this population group across all the provinces of South Africa would be helpful so that national policies can be formulated to better meet the oral health needs of this population group.

**Conclusion**

The results indicate that support for oral health promotion is important for patients undergoing head and neck cancer therapy, but there are substantive gaps and barriers in accessing oral health care. There is an urgent need for oral health planning in the province to take into account the specific oral health needs of this vulnerable population.

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# CHAPTER 5: CONCLUSION AND RECOMMENDATIONS

## 5.1 Introduction

Oral health care has a significant role in cancer patients as it dictates the overall well-being of the individual (Bueno *et al.*, 2015). Poor oral health is linked to poor quality of life and increased mortality (Jablonski, 2012). The study was conducted owing to a paucity of information to ascertain the impact of head and neck cancer patients' access to oral health care in KwaZulu-Natal. There is no published evidence so far, that oral health planning in the province takes into account the specific oral health needs of patients with head and neck cancer.

Three research questions were structured with respect to the aim and objectives. These were: 1) What are the oral health practices of people undergoing therapy for cancer of the head and neck? 2) What is the perceived impact of oral health care on health-related quality of life for patients undergoing treatment for head and neck cancer? and 3) What are the barriers and opportunities for practicing optimal oral health self-care among these patients?

The aim of the study was to assess the perceptions and oral health practices of people undergoing therapy for cancer of the head and neck region, in the Ethekwini District, KwaZulu-Natal, so as to inform oral health planning of the needs for this population. The study had four objectives to achieve its aim namely: 1) to assess the perceived oral health status of patients undergoing therapy for head and neck cancer by means of a questionnaire, 2) to determine the level of oral health knowledge and attitudes of patients with head and neck cancer by means of structured face-to-face interviews, 3) to establish patients' perceived barriers and opportunities to accessing optimal support for oral health care by means of structured face-to-face interviews and finally 4) to determine the current delivery of oral health promotion services for patients with cancer of the head and neck region, by means of a semi-structured interview with the Ethekwini oral health district coordinator.

The first objective which was to assess the perceived oral health status of patients undergoing therapy for head and neck cancer, was achieved by means of a combination of previously validated questionnaires. The sample population comprised of 60% (n= 141) male and 40% (n=94) female. Oral cavity cancer was the most common (n=91; 38.7%) among all the other

head and neck cancer sites. The oral health status was assessed based on the perceived complications present in the oral cavity. The severity of the complications varied from participant to participant. The findings indicated that the majority of participants (n=125; 53.2%) did not experience any pain in the jaw. Among those who did experience pain, more females (n=24; 25.5%) reported severe pain in the jaw than males (n=22; 15.6%). The majority of participants (n=135; 57.4%) did not experience any intra-oral related pain and discomfort while the rest of participants did report varied severity of oral pain and discomfort. Slightly more females (n=10; 10.6%) than males (n=8; 5.7%) reported of severe difficulty in swallowing liquids. Among those (n=100; 42.6%) who had difficulty to swallow pureed food, equal proportion of males (n=27; 19.1%) and females (n=18; 19.1 %) perceived minimal difficulty to swallow while slightly more females (n=13; 13.8%) perceived severe difficulty in swallowing pureed foods than males (n=17; 12.1%) However, the majority of participants reported difficulty to swallow solid foods (n=148; 63.0%), teeth problems (n=162; 69.0%), trismus (n=141; 60%), xerostomia (n=159; 67.7%), increased viscosity of saliva (n=157; 66.8%), dysgeusia (n=131; 55.7%) and eating difficulty (n=138; 58.7%) to varied extents. In general, more females perceived these symptoms as severe in relation to males.

The second and third objectives were both achieved by means of structured face-to-face interviews. The second objective was to determine the level of oral health knowledge and attitudes of patients with head and neck cancer. The third objective was to establish patients' perceived barriers and opportunities to accessing optimal support for oral health care. Most of the participants acknowledged that oral health was important for the overall well-being with the exception of only one who did not acknowledge its importance. This implies that educating people of the importance of oral hygiene maintenance before, during and even after therapy and providing appropriate treatment are integral to improving oral health literacy and quality of life (Plemons, Rankin and Benton, 2013; McQuistan *et al.*, 2015; Samim *et al.*, 2016). The oral hygiene practices included toothbrushing for all the participants, and mouthwash and dental floss for some of them. Few of the participants also indicated having a dental check up as part of oral hygiene maintenance. With reference to the perceived barriers, the findings indicated that there is a lack of coordinated and integrated oral health planning. Patients perceived many challenges which restrict access to oral health care. The absence of dental facilities in some areas (thus having to travel long distances to access nearest dental services), failure of the local clinic to provide appropriate care, financial barrier, failure of the tertiary centre to provide basic oral health care and late diagnosis of dental pathology were among

some of the perceived barriers identified. A lack of referral by the oncology doctors and dissemination of information related to the oral complications of head and cancer therapy were also highlighted by the participants. It is of utmost importance to start considering educating non-dental health professionals forming part of an oncology multidisciplinary team about the importance of oral health for head and neck cancer patients since doctors might be unaware of the importance of dental assessment and oral health care in this population group (Dolce, Haber and Shelley, 2012; Lawrence, Aleid and McKechnie, 2013).

The fourth objective of determining the current delivery of oral health promotion services for patients with cancer of the head and neck region, was achieved by means of a semi-structured interview with the Ethekwini oral health district coordinator. The interview revealed a major shortcoming in oral health service delivery for this population group and this was the absence of a specific oral health policy formulated in the interest of head and neck cancer patients. Further findings revealed another significant deficiency in relation to the absence of a risk factor intervention program. Risk factor intervention programs are important to educate high-risk population of the oral health related effects of lifestyle risk behavior. The literature reports that the risk factor intervention program is supported by the South African Oral Health Promotion Framework (Molete, Daly and Hlungwani, 2013). Moreover, the oral health district coordinator reported that if financial allocations and human workforce were adequate, access for oral health promotion strategies for this vulnerable population would have been improved. Hence, from this statement it can be concluded that promotion of oral health for this population group at the institutional level was not given the deserved importance.

With reference to the study's research questions: the first research question namely, "what are the oral health practices of people undergoing therapy for cancer of the head and neck?", was answered by making use of structured face to face interviews with the head and neck cancer participants. Toothbrushing and at least flossing or gargling were undertaken by all of the participants. The majority of the participants acknowledged the importance of oral health with respect to general health. Many of the participants were previously smoking, drinking or chewing betel nut. However, all of them reported to have given up these lifestyle-related habits. There could have been possible over-reporting with regards to the participants indicating reformed lifestyle practices.

With reference to the second research question namely: "What is the perceived impact of oral health care on health-related quality of life for patients undergoing treatment for head and neck

cancer?", the results indicate that the current delivery of oral health services was inadequate to support specific oral health needs of patients undergoing cancer therapy of the head and neck region. The study outlined challenges experienced by research participants in relation to transport, inadequate information on complications and support for oral health care, no medical insurance and oral health self care products being too costly to purchase. Thus, more research needs to be conducted to examine the specific challenges experienced by patients undergoing head and neck cancer therapy and identify measures to overcome these challenges.

The third research question, "what are the barriers and opportunities for practicing optimal oral health self-care among these patients?", was answered by conducting a structured face to face interview with the head and neck cancer participants. As indicated, the perceived barriers included among others, the lack of dental services in some regions of the province, failure of the local clinic to provide basic oral health care and late diagnosis of dental pathology. Some of the perceived opportunities for improving oral health self-care practice included access to a dental hygienist, comprehensive explanation of the benefits and complications of cancer therapy and clear referral pattern for further oral health management. More research is required to further explore barriers and opportunities for improved oral health care in this population.

The aim of this study was to assess the perceptions and oral health practices of people undergoing therapy for cancer of the head and neck region, in the Ethekwini District, KwaZulu-Natal, so as to inform oral health planning of the needs for this population. The aim was achieved through the use of quantitative and qualitative data collection methods. Participants provided insights into their perceived oral health status, practices, attitudes, familial support and access to oral health care. The oral health district coordinator was able to provide insights into institutional support, oral health promotion activities and service delivery for these patients. The findings and recommendations represent the collective participation and contribution of the head and neck cancer patients and the oral health district coordinator.

### 5.2 Significance of the study findings

The findings of this study revealed that:

- There is no specific policy and integrated planning for delivery of oral health services for patients with head and neck cancer.

- Oral health care is not incorporated in general health care in terms of lifestyle risk factors.
- Inadequate budgetary allocations and workforce are responsible for absence of effective oral health promotion activities.
- Provision of support either morally, financially or professionally is integral for head and neck cancer patients.
- The overall well-being and oral health status of patients (in terms of soresness, dysphagia, xerostomia, sticky saliva and trismus) with head and neck cancer are subjective and dictated by the stage of cancer and type of treatment.

### 5.3 Study limitations

The first limiting factor is related to the structured interviews carried out with the head and neck cancer participants. The structured interviews limit the amount of data gathered. Information which is deemed important by respondents but not foreseen by the investigator might have gone unrevealed.

The questionnaire used to assess the oral health related symptoms of the participants might have led to possible under-reporting of one item related to teeth problems, because the participants would not know of asymptomatic carious lesions and periodontal involvement unless being examined by a dentist. However, the questionnaire provided an interesting and useful picture into understanding the oral health status of the participants.

This was a single institution study. The results cannot be generalised. It was initially planned to include participants from private hospitals. However, this presented a challenge because the appointment scheduled for head and neck cancer patients were structured at different timings during the day. Furthermore, many of the patients from the private hospital were not willing to participate. Therefore, no data could be collected from the private hospitals. This would have given a broader picture of patients' reported access to oral health care. Despite all these constraints, this study provides valuable insights into patient reported access to oral health care and the way in which oral health services are delivered to this population group.

### 5.4 Recommendations

The following recommendations are made for this study:

- Further research is required to identify further mechanisms to improve oral health-related quality of life for people living with head and neck cancer.
- There is an urgent need to review the provincial oral health policy to ensure that specific oral health promotion activities are planned and implemented for people living with head and neck cancer.
- There is need for a dedicated oral health budget for oral health activities so that oral health promotion strategies for this vulnerable population could be implemented efficiently and effectively.
- There is urgent need to develop and implement lifestyle induced risk factor intervention programmes that could be aimed at educating and supporting at-risk populations.

## 5.5 Conclusion

In summary, the study indicated that participants did experience oral complications associated with cancer therapy of the head and neck region. The results further indicated that there is no dedicated oral health awareness or oral health support programme for patients undergoing cancer therapy. There is an urgent need for oral health planning to take into account the specific oral health needs for this population group.

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## ANNEXURES

## Annexure 1: BREC ethical clearance letter

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

27 March 2017

Dr BS Bauluck (216076204)
Discipline of Dentistry
School of Health Sciences
salinabauluck@yahoo.com

Dear Dr Bauluck

**Protocol: Oral Health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal.**
**Degree: MMedSc**
**BREC reference number: BE041/17**

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 20 January 2017.

The study was provisionally approved pending appropriate responses to queries raised. Your response received on 02 March 2017 to BREC letter dated 14 February 2017 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given **full ethics approval** and may begin as from 27 March 2017.

This approval is valid for one year from **27 March 2017.** To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be **RATIFIED** by a full Committee at its next meeting taking place on **11 April 2017.**

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

Professor Joyce Tsoka-Gwegweni
Chair: Biomedical Research Ethics Committee

cc supervisor: singhshen@ukzn.ac.za
cc postgraduate administrator: nenep1@ukzn.ac.za

**Biomedical Research Ethics Committee**
**Professor J Tsoka-Gwegweni (Chair)**
**Westville Campus, Govan Mbeki Building**
**Postal Address:** Private Bag X54001, Durban 4000
**Telephone:** +27 (0) 31 260 2486 **Facsimile:** +27 (0) 31 260 4609 **Email:** brec@ukzn.ac.za

## Annexure 2: BREC Approval for amendment of title

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI
RESEARCH OFFICE
Biomedical Research Ethics Administration
Westville Campus, Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za
Website: http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx

12 December 2017

Dr BS Bauluck (216076204)
Discipline of Dentistry
School of Health Sciences
salinabauluck@yahoo.com

Dear Dr Bauluck

**Protocol: Oral Health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal.**
**Degree: MMedSc**
**BREC reference number: BE041/17**

***NEW TITLE: Exploring oral health care for patients undergoing cancer therapy of the head and neck region: a case study in the eThekwini District, KwaZulu-Natal***

We wish to advise you that your Application for Amendments received on 06 December 2017 **to change the title to the above** has been noted and approved by a subcommittee of the Biomedical Research Ethics Committee.

This approval will be ratified at the next committee meeting to be held on 13 February 2018.

Yours sincerely

Mrs A Marimuthu
Senior Administrator: Biomedical Research Ethics

cc supervisor: singhshen@ukzn.ac.za
cc postgraduate administrator: nenep1@ukzn.ac.za

## Annexure 3: Approval letter from KZN Department of Health

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email:
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

HRKM Ref: 107/17
NHRD Ref: KZ_2016RP40_461

Date: 28 March 2017
Dear Dr BS Bauluck
UKZN

**Approval of research**

1. The research proposal titled **'Oral health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal'** was reviewed by the KwaZulu-Natal Department of Health.

   The proposal is hereby **approved** for research to be undertaken at Inkosi Albert Luthuli Central Hospital.

2. You are requested to take note of the following:
   a. Make the necessary arrangement with the identified facility before commencing with your research project.
   b. Provide an interim progress report and final report (electronic and hard copies) when your research is complete.

3. Your final report must be posted to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to hrkm@kznhealth.gov.za

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

**Dr E Lutge**
Chairperson, Health Research Committee
Date: 19/03/17.

Fighting Disease, Fighting Poverty, Giving Hope

**Annexure 4: Support letter from CEO of hospital**

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:
Office of The Medical Manager
IALCH

Physical Address: 800 Bellair Road, Mayville, 4058
Postal Address: Private Bag X08, Mayville, 4058
Tel: 0312401059 Fax: 0312401050 Email: ursulanun@ialch.co.za
www.kznhealth.gov.za

28 February 2017

Dr B S Bauluck
Discipline of Dentistry
School of Health Sciences

Dear Dr Patel

**Re: Approved Research: Ref No: BE 041/17: Oral Health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal.**

As per the policy of the Provincial Health Research Committee (PHRC), you are hereby granted permission to conduct the above mentioned research once all relevant documentation has been submitted to PHRC inclusive of Full Ethical Approval.

Kindly note the following.

1. The research should adhere to all policies, procedures, protocols and guidelines of the KwaZulu-Natal Department of Health.
2. Research will only commence once the PHRC has granted approval to the researcher.
3. The researcher must ensure that the Medical Manager is informed before the commencement of the research by means of the approval letter by the chairperson of the PHRC.
4. The Medical Manager expects to be provided feedback on the findings of the research.
5. Kindly submit your research to:

   The Secretariat
   Health Research & Knowledge Management
   330 Langaliballe Street, Pietermaritzburg, 3200
   Private Bag X9501, Pietermaritzburg, 3201
   Tel: 033395-3123, Fax 033394-3782
   Email: hrkm@kznhealth.gov.za

Yours faithfully

.....

**Dr L P Mtshali**
**Medical Manager**

Fighting Disease, Fighting Poverty, Giving Hope

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:

Physical Address: 800 Bellair Road, Mayville, 4058
Postal Address: Private Bag X08, Mayville, 4058
Tel: 0312401059 Fax: 0312401050 Email: ursulanun@ ialch.co.za
www.kznhealth.gov.za

Office of The Medical Manager
IALCH

Reference: BE041/17
Enquiries: Medical Management

28 February 2017

Dr B S Bauluck
Discipline of Neurology
School of Clinical Medicine

Dear Dr Bauluck

**RE: PERMISSION TO CONDUCT RESEARCH AT IALCH**

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **Oral Health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal.**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

Yours faithfully

.....

**Dr L P Mtshali**
**Medical Manager**

## PERMISSION TO CONDUCT A RESEARCH STUDY/TRIAL

This must be completed and submitted to the Medical Superintendent/s / Hospital Manager/s for signature.

For **King Edward VIII Hospital (KEH) and Inkosi Albert Luthuli Central Hospital (IALCH)** studies please submit the document together with the following:

1. Research proposal and protocol.
2. Letter giving provisional ethical approval.
3. Details of other research presently being performed by yourself if in the employ of KEH, (individually or as a collaborator).
4. Details of any financial or human resource implications to KEH, including all laboratory tests, EEGs, X-rays, use of nurses, etc. (See Addendum 1)
5. Declaration of all funding applications / grants, please supply substantiating documentation.
6. Complete the attached KEH Form - *"Research Details"*

Once the document has been signed it should be returned to **Mrs Patricia Ngwenya:** at the Biomedical Research Ethics Administration, Room N40, Govan Mbeki Building, Westville Campus, University of KwaZulu-Natal.

To: Chief Medical Superintendent / Hospital Manager

**Permission is requested to conduct the above research study at the hospital/s indicated below:**

Site 1 address:
IALCH
800 Bellair Rd, Mayville
Durban.

Investigator/s:
Principal: Dr Bibi Salaam Bawuck-Nujoo
Co-investigator: Dr Shenuka Singh.
Co-Investigator: _____

Signature of Chief Medical Superintendent/Hospital Manager:
_____ Date: 03 March 2017

Site 2 address:
_____
_____
_____

Investigator/s
Principal: _____
Co-investigator: _____
Co-Investigator: _____

Signature of Chief Medical Superintendent / Hospital Manager:
_____ Date: _____

**NB: Medical Superintendent/s / Hospital Manager/s to send a copy of this document to Natalia**

## Annexure 5: User agreement form

# EORTC USER AGREEMENT FOR ACADEMIC USE

This User Agreement License for Academic Use ("The Agreement") this made up by and between

**Dr B. Saleenna Bauluck-Nujoo - University of KwazuluNatal 70, Mallinson Road-Overport KwazuluNatal 4091 South Africa** (hereafter RECIPIENT)

AND

European Organisation for Research and Treatment of Cancer, with its principal executive offices located at Avenue E. Mounierlaan 83/11, Brussels 1200, Belgium, VAT BE 0408.292.992, represented by Julie Walker, Quality of Life Officer (hereinafter "EORTC"),

EORTC represents and warrants that it has all rights, title and interests, including without limitation all intellectual property rights, in and to the questionnaire and has full lawful authority to grant the license granted hereunder

**Protocol:** 1 research project entitled Oral health awareness and well-being in head and neck cancer patients in Durban

Use of the EORTC QLQ-C30 and modules in the above-mentioned investigation is subject to the following conditions:

1. **RECIPIENT** confirms that this study is being conducted without direct or indirect sponsorship or support from pharmaceutical, medical appliance or related, for-profit health care industries.

2. **RECIPIENT** will grant the EORTC Quality of Life Group limited access to the trial database. Access will be limited to the following: (a) the EORTC QLQ C30 and module data; and (b) additional data will be made available to the EORTC at the sole discretion of RECIPIENT as deemed appropriate for the purpose of validation of the EORTC QLQ C30.

3. **RECIPIENT** will not modify, abridge, condense, translate, adapt or transform the EORTC QLQ-C30 or the basic scoring algorithms in any manner or form, including but not limited to any minor or significant change in wording or organization of the EORTC QLQ-C30.

4. **RECIPIENT** will not reproduce the EORTC QLQ-C30 or the basic scoring algorithms except for the limited purpose of generating sufficient copies for its own use and shall in no event distribute copies of the QLQ-C30 to third parties by sale, rental, lease, lending, or any other means. Reproduction of the QLQ C30 as part of any publication is strictly prohibited.

5. Analysis and reporting of QLQ C30 data by **RECIPIENT** shall follow the written guidelines for scoring of the QLQ C30 as provided by the EORTC Group on Quality of Life.

6. This Agreement holds for the above-mentioned Study only. Use of the EORTC QLQ-C30 in any other studies supported by **RECIPIENT** will require separate agreements.

7. The EORTC Quality of Life Group will withdraw their permission for RECIPENT to use the EORTC QLQ-C30 if any of the above terms and conditions is breached

Melodie Cherton
Quality of Life Department
For EORTC Quality of Life Group
Avenue E. Mounier 83, B11
Brussels 1200
Belgium

I, the undersigned accept the above Terms and conditions by ticking the box "I've read and I accept the user's agreement"

**Dr B.Saleenna Bauluck-Nujoo - University of KwazuluNatal 70 Mallinson Road-Overport KwazuluNatal 4091 South Africa**

## Annexure 6: Questionnaires used in the study

## EORTC QLQ-C30- English version

ENGLISH

### EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:
Your birthdate (Day, Month, Year):
Today's date (Day, Month, Year): 31

| | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|
| 1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? | 1 | 2 | 3 | 4 |
| 2. Do you have any trouble taking a long walk? | 1 | 2 | 3 | 4 |
| 3. Do you have any trouble taking a short walk outside of the house? | 1 | 2 | 3 | 4 |
| 4. Do you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| 5. Do you need help with eating, dressing, washing yourself or using the toilet? | 1 | 2 | 3 | 4 |

| **During the past week:** | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|
| 6. Were you limited in doing either your work or other daily activities? | 1 | 2 | 3 | 4 |
| 7. Were you limited in pursuing your hobbies or other leisure time activities? | 1 | 2 | 3 | 4 |
| 8. Were you short of breath? | 1 | 2 | 3 | 4 |
| 9. Have you had pain? | 1 | 2 | 3 | 4 |
| 10. Did you need to rest? | 1 | 2 | 3 | 4 |
| 11. Have you had trouble sleeping? | 1 | 2 | 3 | 4 |
| 12. Have you felt weak? | 1 | 2 | 3 | 4 |
| 13. Have you lacked appetite? | 1 | 2 | 3 | 4 |
| 14. Have you felt nauseated? | 1 | 2 | 3 | 4 |
| 15. Have you vomited? | 1 | 2 | 3 | 4 |
| 16. Have you been constipated? | 1 | 2 | 3 | 4 |

Please go on to the next page

| **During the past week:** | **Not at All** | **A Little** | **Quite a Bit** | **Very Much** |
|---|---|---|---|---|
| 17. Have you had diarrhea? | 1 | 2 | 3 | 4 |
| 18. Were you tired? | 1 | 2 | 3 | 4 |
| 19. Did pain interfere with your daily activities? | 1 | 2 | 3 | 4 |
| 20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television? | 1 | 2 | 3 | 4 |
| 21. Did you feel tense? | 1 | 2 | 3 | 4 |
| 22. Did you worry? | 1 | 2 | 3 | 4 |
| 23. Did you feel irritable? | 1 | 2 | 3 | 4 |
| 24. Did you feel depressed? | 1 | 2 | 3 | 4 |
| 25. Have you had difficulty remembering things? | 1 | 2 | 3 | 4 |
| 26. Has your physical condition or medical treatment interfered with your family life? | 1 | 2 | 3 | 4 |
| 27. Has your physical condition or medical treatment interfered with your social activities? | 1 | 2 | 3 | 4 |
| 28. Has your physical condition or medical treatment caused you financial difficulties? | 1 | 2 | 3 | 4 |

**For the following questions please circle the number between 1 and 7 that best applies to you**

29. How would you rate your overall health during the past week?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very poor | | | | | | Excellent |

30. How would you rate your overall quality of life during the past week?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very poor | | | | | | Excellent |

## EORTC QLQ-H&N35- English Version

# EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

| **During the past week:** | | **Not at all** | **A little** | **Quite a bit** | **Very much** |
|---|---|---|---|---|---|
| 31. | Have you had pain in your mouth? | 1 | 2 | 3 | 4 |
| 32. | Have you had pain in your jaw? | 1 | 2 | 3 | 4 |
| 33. | Have you had soreness in your mouth? | 1 | 2 | 3 | 4 |
| 34. | Have you had a painful throat? | 1 | 2 | 3 | 4 |
| 35. | Have you had problems swallowing liquids? | 1 | 2 | 3 | 4 |
| 36. | Have you had problems swallowing pureed food? | 1 | 2 | 3 | 4 |
| 37. | Have you had problems swallowing solid food? | 1 | 2 | 3 | 4 |
| 38. | Have you choked when swallowing? | 1 | 2 | 3 | 4 |
| 39. | Have you had problems with your teeth? | 1 | 2 | 3 | 4 |
| 40. | Have you had problems opening your mouth wide? | 1 | 2 | 3 | 4 |
| 41. | Have you had a dry mouth? | 1 | 2 | 3 | 4 |
| 42. | Have you had sticky saliva? | 1 | 2 | 3 | 4 |
| 43. | Have you had problems with your sense of smell? | 1 | 2 | 3 | 4 |
| 44. | Have you had problems with your sense of taste? | 1 | 2 | 3 | 4 |
| 45. | Have you coughed? | 1 | 2 | 3 | 4 |
| 46. | Have you been hoarse? | 1 | 2 | 3 | 4 |
| 47. | Have you felt ill? | 1 | 2 | 3 | 4 |
| 48. | Has your appearance bothered you? | 1 | 2 | 3 | 4 |

Please go on to the next page

| During the past week: | | Not at all | A little | Quite a bit | Very much |
|---|---|---|---|---|---|
| 49. | Have you had trouble eating? | 1 | 2 | 3 | 4 |
| 50. | Have you had trouble eating in front of your family? | 1 | 2 | 3 | 4 |
| 51. | Have you had trouble eating in front of other people? | 1 | 2 | 3 | 4 |
| 52. | Have you had trouble enjoying your meals? | 1 | 2 | 3 | 4 |
| 53. | Have you had trouble talking to other people? | 1 | 2 | 3 | 4 |
| 54. | Have you had trouble talking on the telephone? | 1 | 2 | 3 | 4 |
| 55. | Have you had trouble having social contact with your family? | 1 | 2 | 3 | 4 |
| 56. | Have you had trouble having social contact with friends? | 1 | 2 | 3 | 4 |
| 57. | Have you had trouble going out in public? | 1 | 2 | 3 | 4 |
| 58. | Have you had trouble having physical contact with family or friends? | 1 | 2 | 3 | 4 |
| 59. | Have you felt less interest in sex? | 1 | 2 | 3 | 4 |
| 60. | Have you felt less sexual enjoyment? | 1 | 2 | 3 | 4 |

| During the past week: | | No | Yes |
|---|---|---|---|
| 61. | Have you used pain-killers? | 1 | 2 |
| 62. | Have you taken any nutritional supplements (excluding vitamins)? | 1 | 2 |
| 63. | Have you used a feeding tube? | 1 | 2 |
| 64. | Have you lost weight? | 1 | 2 |
| 65. | Have you gained weight? | 1 | 2 |

# EORTC QLQ-C30: IsiZulu version

ZULU

## EORTC QLQ-C30 (version 3)

Kunezinto ezithile esithanda ukuzazi ngawe nangempilo yakho. Sicela uphendule yonke imibuzo wena ngokwakho ngokuthi ukekelezele inombolo ehambisana kangcono nempendulo ngesimo sakho. Akukho zimpendulo "eziyizo" kumbe "ezingafanele". Ulwazi olunikile luyohlala luyimfihlo.

Bhala ama-enishiyali akho:

Usuku lwakho lokuzalwa (Usuku, Inyanga, Unyaka):

Ideyithi yanamuhla (Usuku, Inyanga, Unyaka) 31

| | Cha azange | Yebo kancane | Yebo kakhudlwana | Kakhulu impela |
|---|---|---|---|---|
| 1. Ngabe unenkinga ngemisebenzi edinga amandla njengokuthwala isikhwama esisindayo sezimpahla ozithengile noma ukuthwala ipotimende? | 1 | 2 | 3 | 4 |
| 2. Ngabe unenkinga yini ekuhambeni ibanga elide ngezinyawo? | 1 | 2 | 3 | 4 |
| 3. Ngabe unenkinga yini ekuhambahambeni ngaphandle kwendlu yakho? | 1 | 2 | 3 | 4 |
| 4. Kuyenzeka yini udinge ukuhlala embhedeni noma esitulweni ngesikhathi sasemini? | 1 | 2 | 3 | 4 |
| 5. Udinga usizo yini lapho udla, ugqoka, uzigeza noma usebenzisa indlu yangasese? | 1 | 2 | 3 | 4 |

### Esontweni eledlule:

| | Cha azange | Yebo kancane | Yebo kakhudlwana | Kakhulu impela |
|---|---|---|---|---|
| 6. Ngabe wake waphazamiseka emsebenzini wakho kumbe kweminye imisebenzi yansuku zonke? | 1 | 2 | 3 | 4 |
| 7. Waphazamiseka yini ekwenzeni lezo zinto ozijabulisa ngazo kumbe izinto oyaye uzenze ngesikhathi sakho sokungcebeleka? | 1 | 2 | 3 | 4 |
| 8. Waba nenkinga yini yokuphelelwa wumoya? | 1 | 2 | 3 | 4 |
| 9. Wake waba nobuhlungu? | 1 | 2 | 3 | 4 |
| 10. Ngabe kwaba nesidingo sokuba uphumule? | 1 | 2 | 3 | 4 |
| 11. Waba nenkinga yini yokulala? | 1 | 2 | 3 | 4 |
| 12. Waba nenkinga yini yokuzizwa ungenamandla? | 1 | 2 | 3 | 4 |
| 13. Waba nenkinga yini yokungakuthandi ukudla? | 1 | 2 | 3 | 4 |
| 14. Waba nenkinga yini yokunenkezela kwenhliziyo? | 1 | 2 | 3 | 4 |
| 15. Ngabe uke waphalaza? | 1 | 2 | 3 | 4 |

Sicela uqhubekele ephejini elilandelayo

| **Esontweni eledlule:** | **Cha azange** | **Yebo kancane** | **Yebo kakhudlwana** | **Kakhulu impela** |
|---|---|---|---|---|
| 16. Wake waqunjelwa? | 1 | 2 | 3 | 4 |
| 17. Wake wahanjiswa yisisu? | 1 | 2 | 3 | 4 |
| 18. Ngabe wazizwa ukhathele? | 1 | 2 | 3 | 4 |
| 19. Ngabe izinhlungu zaphazamisa umsebenzi wakho wansuku zonke? | 1 | 2 | 3 | 4 |
| 20. Ngabe waba nenkinga ekugxiliseni ingqondo yakho kokwenzayo njengokufunda iphephandaba noma ukubuka ithelevishini? | 1 | 2 | 3 | 4 |
| 21. Ngabe wazizwa ungakhululekile? | 1 | 2 | 3 | 4 |
| 22. Ngabe waba unokukhathazeka? | 1 | 2 | 3 | 4 |
| 23. Ngabe wazizwa unokucasuka kalula? | 1 | 2 | 3 | 4 |
| 24. Ngabe wazizwa uphansi emoyeni? | 1 | 2 | 3 | 4 |
| 25. Ngabe waba nenkinga yokukhumbula izinto? | 1 | 2 | 3 | 4 |
| 26. Ngabe isimo sempilo yakho kumbe ukwelashwa kwakho kuphazamisa impilo yomndeni wakho? | 1 | 2 | 3 | 4 |
| 27. Ngabe isimo sempilo yakho kumbe ukwelashwa kwakho kuphazamisa izinto ezithile ezikuhlanganisa nabanye abantu? | 1 | 2 | 3 | 4 |
| 28. Ngabe isimo sempilo yakho kumbe ukwelashwa kwakho kukwenze waba nezinkinga zemali? | 1 | 2 | 3 | 4 |

## Emibuzweni elandelayo ucelwa ukuba ukekelezele inombolo ukusuka ku-1 ukuya ku-7 kuye ngokuthi yiyiphi ehambisana ngcono nempendulo ngesimo sakho

29. Ngesonto eledlule ungathi yayikusiphi isimo impilo yakho nje iyonke?

1 2 3 4 5 6 7

Besisibi kakhulu Besisihle kakhulu

30. Ngesonto eledlule ungathi yayikuliphi izinga impilo yakho?

1 2 3 4 5 6 7

Beyiyimbi kakhulu Beyiyinhle kakhulu

## EORTC H&N35: IsiZulu version

ZULU

# EORTC QLQ - H&N35

Ngesinye isikhathi iziguli ziyaye zibike lezi mpawu kumbe izinkinga ezilandelayo. Sitshele ukuthi zikukhathaze kangakanani lezi zinkinga esontweni eledlule. Sicela ukekelezele inombolo ehambisana kangcono nempendulo ngesimo sakho.

| **Esontweni eledlule:** | **Cha azange** | **Yebo kancane** | **Yebo kakhudlwana** | **Kakhulu impela** |
|---|---|---|---|---|
| 31. Ngabe wake waba nezinhlungu emlonyeni wakho? | 1 | 2 | 3 | 4 |
| 32. Ngabe waba nezinhlungu emhlathini wakho? | 1 | 2 | 3 | 4 |
| 33. Ngabe waba nobuhlungu emlonyeni wakho? | 1 | 2 | 3 | 4 |
| 34. Ngabe wawunomphimbo obuhlungu? | 1 | 2 | 3 | 4 |
| 35. Ngabe waba nenkinga ekugwinyeni izinto eziwuketshezi? | 1 | 2 | 3 | 4 |
| 36. Ngabe waba nenkinga yokugwinya ukudla okucutshiwe? | 1 | 2 | 3 | 4 |
| 37. Ngabe waba nenkinga yokugwinya ukudla okuqinile? | 1 | 2 | 3 | 4 |
| 38. Ngabe wakhwinceka lapho ugwinya? | 1 | 2 | 3 | 4 |
| 39. Ngabe waba nenkinga ngamazinyo akho? | 1 | 2 | 3 | 4 |
| 40. Ngabe waba nobunzima bokuvula kakhulu umlomo wakho? | 1 | 2 | 3 | 4 |
| 41. Ngabe waba nenkinga yomlomo owomile? | 1 | 2 | 3 | 4 |
| 42. Ngabe waba nenkinga yamathe anamfuzelayo? | 1 | 2 | 3 | 4 |
| 43. Ngabe waba nenkinga yomuzwa wakho wokuhogela? | 1 | 2 | 3 | 4 |
| 44. Ngabe waba nenkinga yezinzwa zakho zokunambitha? | 1 | 2 | 3 | 4 |
| 45. Ngabe waba nenkinga yokukhwehlela? | 1 | 2 | 3 | 4 |
| 46. Ngabe waba nenkinga yokuhoshozela kwezwi? | 1 | 2 | 3 | 4 |
| 47. Ngabe wagula? | 1 | 2 | 3 | 4 |
| 48. Ngabe waba nokukhathazeka ngendlela obukeka ngayo? | 1 | 2 | 3 | 4 |

Sicela uqhubekele ephejini elilandelayo

| **Esontweni eledlule:** | **Cha azange** | **Yebo kancane** | **Yebo kakhudlwana** | **Kakhulu impela** |
|---|---|---|---|---|
| 49. Ngabe waba nenkinga yokungafuni ukudla? | 1 | 2 | 3 | 4 |
| 50. Ngabe waba nenkinga yokudla phambi komndeni wakho? | 1 | 2 | 3 | 4 |
| 51. Ngabe waba nenkinga yokudla phambi kwabanye abantu? | 1 | 2 | 3 | 4 |
| 52. Ngabe waba nenkinga yokuthokozela ukudla kwakho? | 1 | 2 | 3 | 4 |
| 53. Ngabe waba nenkinga ekuxoxeni nabanye abantu? | 1 | 2 | 3 | 4 |
| 54. Ngabe waba nenkinga yokukhuluma ocingweni? | 1 | 2 | 3 | 4 |
| 55. Ngabe waba nenkinga ekuxhumaneni ngokwenhlalo nomndeni wakho? | 1 | 2 | 3 | 4 |
| 56. Ngabe waba nenkinga ekuxhumaneni ngokwenhlalo nabangani bakho? | 1 | 2 | 3 | 4 |
| 57. Ngabe waba nenkinga ekuhlanganeni nabantu? | 1 | 2 | 3 | 4 |
| 58. Ngabe waba nenkinga ekubonaneni siqu nomndeni wakho kumbe nabangani bakho? | 1 | 2 | 3 | 4 |
| 59. Ngabe wancishelwa wuthando lokuya ocansini? | 1 | 2 | 3 | 4 |
| 60. Ngabe wachishelwa yintokozo ocansini? | 1 | 2 | 3 | 4 |

| **Esontweni eledlule:** | **Cha** | **Yebo** |
|---|---|---|
| 61. Ngabe wasebenzisa imithi ethile yokuqeda izinhlungu? | 1 | 2 |
| 62. Ngabe wasebenzisa okuthile kokwengeza izondlamzimba (ungakubali okwamavithamini)? | 1 | 2 |
| 63. Ngabe wasebenzisa ishubhu lokufunza ukudla? | 1 | 2 |
| 64. Ngabe waye wehla ngokwesisindo somzimba? | 1 | 2 |
| 65. Ngabe isisindo somzimba wakho senyukile? | 1 | 2 |

## Annexure 7: Interview schedule for oral health district coordinator

Interview Schedule for the District Manager

My name is Dr B. Saleenna Bauluck-Nujoo from the Department of Dentistry, College of Health Sciences, University of KwaZulu-Natal, Westville. I am currently doing a research project entitled "Oral health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal". It would be much appreciated if you could kindly spare some of your time to answer few questions related to the oral health policies and support strategies that are in place for patients with cancer of the head and neck region.

1. What strategies are in place to support patients with cancers of the head and neck region?
2. Is oral health care covered in district health policy and planning for patients with cancers?
3. Is there any institutional support for oral health promotion activities for patients with cancers of the head and neck region?
4. What can be done to improve access to oral health promotion activities for these patients?
5. Do you have any further comments?

Thank you so much for your time.

## Annexure 8: Interview schedule for patient interviewees

**Structured Interview Questions**

*I will be asking you a few more questions regarding the health of your mouth and the treatment which you are receiving. I know it must be tiring for you by now but it would be much appreciated if you could spare some few more minutes to answer these questions. If you feel you need a break we can stop and take up after a while.*

1. Tell me, from where do you come?
2. When were you diagnosed?
3. What was your reaction and that of your family when you learnt that you are suffering from this cancer? How has your family supported you to obtain treatment?
4. For how long will you be on treatment? Do you have any idea of what kind of treatment the doctor has prescribed for you? Has he explained you about the benefits as well as the complications that can occur?
5. Did your doctor refer you to other health professional before starting your course of treatment (eg. Radiotherapy)?

*I am now going to ask you some short questions on how you care for your mouth.*

6. Do you think oral health is important in relation to your overall wellbeing? How?
7. Have you ever been told about the importance of the health of your mouth? By whom?
8. When you have problems with your teeth, where do you go to receive treatment? Why you choose to go there? Are there any difficulties to get to the dentist or any other oral health care provider? What benefits do you get when you visit the dentist?
9. How do you keep your mouth clean? Do you experience difficulty in buying stuff to keep your mouth clean?
10. What has dentist/dental health worker advised you?
11. Do you have any of the following habits:
    a. -Tobacco smoking/chewing. If yes for how long have you been a smoker? Number of cigarettes per day?

b. -Alcohol consumption. If yes for how long have you been consuming alcohol? Frequency/ Number of glasses?

c. -Chewing of paan. If yes how frequently?

d. -Going out in the sun frequently. If yes, what precautions do you think are important while going out? How do you think can the sun affect your mouth?

12. Do you have any other comments?

Thank you so much for your time.

## Annexure 9: Letter requesting permission to conduct interview of oral health district coordinator

To
The District Manager
Ethekwini
Durban
09 January 2017

**RE: Request for permission to conduct interview of the District Manager regarding oral health policies for head and neck cancer patients**

Dear Sir

I, Dr B. Saleenna Bauluck-Nujoo, Dental Surgeon by profession and currently a Master's student in Medical Science in the Department of Dentistry at the University of KwaZulu-Natal, am hereby, writing to seek your consent to carry out an interview regarding the oral health policies and support strategies which are in place for patients with cancer of the head and neck region.

The study entitled **"ORAL HEALTH AWARENESS AND WELL-BEING AMONG HEAD AND NECK CANCER PATIENTS IN DURBAN, KWAZULU-NATAL"** is supervised by Dr Shenuka Singh, Acting Dean and Academic Leader in the Discipline of Dentistry.

It has for objectives the following:

1. To review the existing literature to identify risk factors associated with cancer of the head and neck region.
2. To determine the availability of oral health promotion services for patients with cancers of the head and neck region by means of an interview with the Ethekwini District Manager responsible for oral health planning.
3. To assess the perceived oral health status of people undergoing therapy for head and neck cancer by means of a questionnaire.
4. To assess the overall well-being of these identified individuals by means of a questionnaire.
5. To determine the level of oral health knowledge by means of structured face-to-face interviews.
6. To ascertain perceptions on the opportunities and barriers to accessing optimal support on oral health care by means of structured face-to-face interviews.

In order to assist you in your pronouncement, I have enclosed the following document:

-A copy of the Ethical Clearance Certificate issued to me by the University of KwaZulu-Natal.

Should you require any further details regarding this study, kindly feel free to get in touch with either me or my supervisor at the addresses given on the next page.

Dr B. Saleenna Bauluck-Nujoo (Research Student)

E-mail: salinabauluck@yahoo.com

Tel: 0813791369

Dr Shenuka Singh (Supervisor)

Email: singhshen@ukzn.ac.za

Tel:0738417384

Your willingness to consent for this study will provide a major contribution and will be much appreciated.

Respectfully Yours

Dr B. Saleenna Bauluck-Nujoo

Master's Student by Research

University of KwaZulu-Natal (Westville Campus)

## Annexure 10: Letter requesting permission to CEO of hospital to conduct study

To
The Chief Executive Officer
Inkosi Albert Luthuli Central Hospital
800 Bellair Road
Cato Manor
Durban,4138
KwaZulu-Natal
8 December 2016

**RE: Request for permission to conduct research in the Oncology Unit of Inkosi Albert Luthuli Central Hospital**

Dear Sir

I, Dr B. Saleenna Bauluck-Nujoo, Dental Surgeon by profession and currently a Master's student in Medical Science in the Department of Dentistry at the University of KwaZulu-Natal, am hereby, writing to seek your consent to carry out a research study in the Oncology unit at your institution.

The study entitled **"ORAL HEALTH AWARENESS AND WELL-BEING AMONG HEAD AND NECK CANCER PATIENTS IN DURBAN, KWAZULU-NATAL"** is supervised by Dr Shenuka Singh, Acting Dean and Academic Leader in the Discipline Of Dentistry.

It has for objectives the following:

1. To review the existing literature to identify risk factors associated with cancer of the head and neck region.
2. To determine the availability of oral health promotion services for patients with cancers of the head and neck region by means of an interview with the Ethekwini District Manager responsible for oral health planning.
3. To assess the perceived oral health status of people undergoing therapy for head and neck cancer by means of a questionnaire.
4. To assess the overall well-being of these identified individuals by means of a questionnaire.
5. To determine the level of oral health knowledge by means of structured face-to-face interviews.
6. To ascertain perceptions on the opportunities and barriers to accessing optimal support on oral health care by means of structured face-to-face interviews.

I am envisaging of recruiting 250 patients altogether with head and neck cancer in two more hospitals besides Albert Luthuli hospital to carry out this study. It will be conducted by means of questionnaires and interviews only and will not bear any clinical examinations or interventions.

In the case where approval is granted from your part, the participants will be required to sign an informed consent document to prove their voluntary participation in the study and they will have to answer a questionnaire specific for head and neck cancer consisting of 65 questions. A small face-to-face interview consisting of 12 questions will also be carried out. The questionnaire and interview questions will be available both in English and IsiZulu. I am expecting to perform this survey while the patients are waiting for their turns to see their oncologists in a location of the hospital where the privacy of the participants can be fully maintained and respected. A vacant room or a restricted area of the hospital could be the place of choice so that nobody can hear and see of what is being said and written as some of

the questions are sensitive and personal. A research assistant, fluent in IsiZulu, will be standing by to help those who cannot speak and write English. The survey should take no longer than 45 minutes to 1 hour.

Given that the possibility of psychological risk is expected in the study because the participant will have to recollect the phase he/she has gone/is going through, I kindly request you to include the details of the psychologist or on-site social worker to whom the participant might be referred in case where psychological problems arise. Further, in order to facilitate this task, I humbly request you for the assistance of a nurse also to make phone calls immediately after I have notified her in any such event so that the participant can spontaneously be rushed to the psychologist/ on-site social worker.

In order to assist you in your pronouncement, I have enclosed the following documents:

-A copy of the Ethical Clearance Certificate issued to me by the University of KwaZulu-Natal.

-A copy of the Informed Consent Document

-A copy of the questionnaire to be used in the study

-A copy of the interview questions

Should you require any further details regarding this study, kindly feel free to get in touch with either me or my supervisor at the addresses given below.

Dr B. Saleenna Bauluck-Nujoo (Research Student)

E-mail: salinabauluck@yahoo.com

Tel: 0813791369

Dr Shenuka Singh (Supervisor)

Email: singhshen@ukzn.ac.za

Tel:0738417384

Your willingness to consent for this study will provide a major contribution and will be much appreciated.

Respectfully Yours

Dr B. Saleenna Bauluck-Nujoo

Master's Student by Research

University of KwaZulu-Natal (Westville Campus)

## Annexure 11: Letter requesting permission of the HOD of Oncology

To
The Head of Department
Oncology Unit
Inkosi Albert Luthuli Central Hospital
800 Bellair Road
Cato Manor
Durban,4138
KwaZulu-Natal
22 February 2017

**RE: Request for permission to conduct research in the Oncology Department of Inkosi Albert Luthuli Central Hospital**

Dear Doctor

I, Dr B. Saleenna Bauluck-Nujoo, Dental Surgeon by profession and currently a Master's student in Medical Science in the Department of Dentistry at the University of KwaZulu-Natal, am hereby, writing to seek your consent to carry out a research study in the Oncology Departmen at your institution.

The study entitled **"ORAL HEALTH AWARENESS AND WELL-BEING AMONG HEAD AND NECK CANCER PATIENTS IN DURBAN, KWAZULU-NATAL"** is supervised by Dr Shenuka Singh, Acting Dean and Head of Department in the Discipline of Dentistry.

It has for objectives the following:

1. To identify the risk factors associated with cancer of the head and neck region through the review of existing literature.
2. To determine the availability of oral health promotion services for patients with cancers of the head and neck region by means of an interview with the Ethekwini District Manager responsible for oral health planning.
3. To determine the level of oral health knowledge of head and neck cancer patients by means of structured face-to-face interviews.
4. To assess the perceived oral health status of patients undergoing therapy for head and neck cancer by means of a questionnaire.
5. To assess the overall well-being of these identified head and neck cancer patients by means of a questionnaire.
6. To establish patients' perceived barriers and facilitators to accessing optimal support on oral health care by means of structured face-to-face interviews.

I am envisaging of recruiting 250 patients altogether with head and neck cancer in two more hospitals besides Albert Luthuli hospital to carry out this study. It will be conducted by means of questionnaires and interviews only and will not bear any clinical examinations or interventions. The survey should take no longer than 45 minutes to 1 hour and is expected to be carried out while the patients are waiting for their turns to be seen by the oncologist.

In order to assist you in your pronouncement, I have enclosed a summary of the research protocol and a copy of the provisional approval to conduct research issued by the Biomedical Research Ethics Committee of the University of KwaZulu-Natal.

.

Should you require any further details regarding this study, kindly feel free to get in touch with either me or my supervisor at the addresses given below.

Dr B. Saleenna Bauluck-Nujoo (Research Student)

E-mail: salinabauluck@yahoo.com

Tel: 0813791369

Dr Shenuka Singh (Supervisor)

Email: singhshen@ukzn.ac.za

Tel:0738417384

Your willingness to consent for this study will be much appreciated and will provide a major contribution so that this project can be accomplished timeously.

Respectfully Yours

Dr B. Saleenna Bauluck-Nujoo

Master's Student by Research

Department of Dentistry

Westville Campus

University of KwaZulu-Natal

## Annexure 12: Participant information sheet and consent form-English version

# UKZN BIOMEDICAL RESEARCH ETHICS COMMITTEE

**APPLICATION FOR ETHICS APPROVAL**
**For research with human participants (Biomedical)**

## INFORMED CONSENT RESOURCE TEMPLATE

Note to researchers: Notwithstanding the need for scientific and legal accuracy, every effort should be made to produce a consent document that is as linguistically clear and simple as possible, without omitting important details as outlined below. Certified translated versions will be required once the original version is approved.

There are specific circumstances where witnessed verbal consent might be acceptable, and circumstances where individual informed consent may be waived by BREC.

**Information Sheet and Consent to Participate in Research**

Date: 01 April 2017

Good day

My name is Dr B. Saleenna Bauluck-Nujoo from the Department of Dentistry, College of Health Sciences, University of KwaZulu-Natal, Westville. My contact details are as follows:
Tel: 0813791369
Email Address: salinabauluck@yahoo.com

You are being invited to consider participating in a study that involves the assessment of the oral health and well-being among patients with cancer of the head and neck in Durban, KwaZulu-Natal. The aim and purpose of this research is to assess the perceptions and oral health practices of people undergoing therapy for cancer of the head and neck. The study is expected to enroll 250 participants in total from two hospitals namely Inkosi Albert Luthuli Central Hospital and a private hospital. It will involve the following procedures:

A questionnaire to be filled in and a structured face to face interviewing. The questionnaire, consisting of two parts with 30 questions in the first part and 35 questions in the second part with regards to the different issues of the cancer and your overall health, will be required to be filled in by answering 'Not at all' or 'a little' or 'quite a bit' or 'very much' for the majority of questions besides the last two of the first part where you have to encircle a number from 1 to 7 and the last five of the second part where you will be required to answer with a 'yes' or a 'no'.
The face to face interview consists of 12 questions. They carry no options as in the questionnaire and each answer is your own formulated one. Please note that there are no right or wrong answers.
Please kindly note that in order to facilitate the task of analyzing your responses for the purpose of data analysis, the interview will be tape-recorded only if you give your full consent to do so. There is a section to consent to tape-record the survey further down.

There will be no clinical examination or intervention and therefore be assured that there is no fear of any physical discomfort or invasive procedures at all.
The duration of your participation if you choose to enroll and remain in the study is expected to be around 45 minutes to 1 hour. The study is funded by the College of Health Sciences-University of KwaZulu-Natal.

The study may involve the following discomfort:
Personal questions with regards to your sexual life and a flashback of the symptoms and discomfort that you experience with this illness. In this regard, you are allowed to be accompanied by your relative/whoever is close to you who has come with you to hospital today to keep your spirit high.

This survey in itself will be of no personal benefit to you but we hope that the study will create the following benefit to the community as a whole:
-To suggest suitable educational frameworks to health care workers in order to give more access to oral health care to those who live in underprivileged areas so that the health care delivery system is equitable between the urban and rural divide.

This study has been ethically reviewed and approved by the UKZN Biomedical Research Ethics Committee (approval number: BE041/17).

In the event of any problems or concerns/questions you may contact the researcher on 0813791369 or at salinabauluck@yahoo.com or the UKZN Biomedical Research Ethics Committee, contact details as follows:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Kindly note that your participation in this research is entirely voluntary and your rights as a participant will be upheld at all times. In other words, you have the right to withdraw from this study at any point without any negative consequences. This means that if you decide to withdraw from this study this will not impact on your medical care and you will not incur any penalty or loss of other treatment benefits to which you are entitled. I have attached the necessary contact details to assist you in case you have any further queries on this study or if you are unsure of anything related to this study.

Kindly note that no costs will be incurred by you for your participation in this study. As a matter of gratitude however, for having given your precious time by consenting to participate in this study you will be given refreshments when the questionnaire filling and interviewing sessions are over.

Confidentiality is a principle rule governing ethics. As a matter of fact, the following points will be observed to ensure that confidentiality and anonymity are maintained at all instances throughout the study and even 5 years after:

- Your Names will not be asked in the survey.
- Each participant will be handed out the questionnaire in a location where other persons will not hear and see of what is being said and written. For instance, it can be a room which is vacant or in a remote area of the hospital/institution. The interview session will be carried out in a similar location to maintain privacy.

- As soon as the questionnaire in the isiZulu version is filled in it will be handed over to me immediately by the research assistant.
- The data collected is intended to be used for the sole purpose of the study.
- The questionnaires will be safely kept in a location where access to external parties are restricted. A locked cabinet will be used for this purpose. The data will only be accessible to my supervisor and myself.
- The raw data will be converted electronically and stored in a secured/password-protected database. It will be stored for a period of 5 years and thereafter destroyed.

---

**CONSENT (Edit as required)**

I, _____ , have been informed about the study entitled

'Oral health and well-being among patients with cancer of the head and neck in Durban,

KwaZulu-Natal' by Dr B.Saleenna Bauluck-Nujoo.

I understand the purpose of the study is to assess the perceptions and oral health practices of people undergoing therapy for cancer of the head and neck and the procedures consist of filling in of questionnaires and structured face to face interviewing.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any treatment or care that I would usually be entitled to.

I have been informed that refreshments will be given to me when the procedures are over as a matter of gratitude for having given my time to answer the questions.

I have been informed that I am allowed to be accompanied by close relative/friend during the survey if I wish so.

I have been informed that the interview will be tape-recorded only if I wish so.

**Consent to tape-record interview:** (Please tick the appropriate box)

☐ I agree to have the interview tape-recorded.
☐ I do not agree to have the interview tape-recorded.

_____ _____
**Signature of Participant** **Date**

If I have any further questions/concerns or queries related to the study, I understand that I may contact the researcher at salinabauluck@yahoo.com or on 0813791369.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researcher then I may contact:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

| | |
|---|---|
| **Signature of Participant** | **Date** |
| **Signature of Witness (Where applicable)** | **Date** |
| **Signature of Translator (Where applicable)** | **Date** |

## Annexure 13: Participant information sheet and consent form-IsiZulu version

**IKOMINDI LOCWANINGO LEBIOMEDICAL NOKUZIPHATHA LASE UKZN**

Isaziso kubacwaningi: Ngenxa yesidingo sesayensi nezomthetho sokuqikekela, kumele kwenziwe yonke imizamo yokwenza amaphepha okuvumelana, asebenzise ulimi olucacisayo nolulula ngaphandle kokushiya okubalulekile.

Kunezimo ezithize lapho ukuvuma ngomlomo obunobufakazi bumukelekile, futhi kunezimo lapho ukuvuma komuntu obungeke bamukelwe iBREC.

**Iphepha lolwazi kanye nokuvuma ukuba ingxenye yocwaningo**

**Usuku: 01 April 2017**

**Sanibona**

Igama lami ngingu Dokotela B. Saleenna Bauluck-Nujoo womnyango wezamazinyo, kwiKolishi lezempilo nesayensi, eNyunivesithi yakwaZulu Natal, eWestiville. Izinombolo zami nazi ngezansi: 081 3791 369

iemail:salinabauluck@yahoo.com

Uyamenywa ukuba ube inxenye yesifundo socwaningo sempilo yomlomo kanye nendlela yokuphila yabantu abanomdlavuza wekhanda nentamo eThekwini, KwaZulu Natal. Inhloso yocwaningo ukuhlaziya izinkolelo-ze nendlela yokuphatha impilo yomlomo kubantu abathatha imithi yomdlavuza wekhanda nentamo. Lezizifundo kulindeleke ukuthi zibe nabafundi abangu 250 kwizibhedlela ezingu 2; okwiyi Albert Luthuli Central Hospital kanye nesisodwa esizimele. Ucwaningo luzohlanganisa lokhu okulandelayo:

Uhla lwemibuzo okumele liphendulwe kanye ne*ngxoxo ehleliwe phakathi komncwaningi nomfundi*. Uhla lwemibuzo lunezigaba ezimbili, isigaba sokuqala sinemibuzo engu 30, isigaba sesibili sinembuzo engu 35 ekhuluma ngezinto ezahlukahlukene eziphathelene nomdlavuza kanye nakho konke okuphathelene nempilo yakho, kuzomele uphendule ngokuthi 'Lutho sampela' noma 'kancane noma kancanyana' noma 'kakhulu' kwimbuzo eminingi ngaphandle kwemibili yokugcina yesigaba sokuqala lapho okumele uzungeze inombolo eqala ku 1 iya ku 7 kanye nembibuzo emihlanu yokugcina yesigaba sesibili lapho kumele uphendule ngokuthi 'Yebo' noma 'Cha'.

Ingxoxo inemibuzo engu 12. Ingxoxo ayinazimpendulo ezikhethiweyo njengohla lwemibuzo, impendulo isuka kuwena. Sicela uqaphele ukuthi lana akukho izimpendulo okungezona noma okuyizona.

Sicela ukukwazisa ukuthi ukuze sikwazi ukwenza umsebenzi wokuhlaziya izimpendulo zakho, ngenhloso yokuhlaziya ulwazi oselugqoqiwe, kuzomele siyiqophe ingxoxo kodwa uma usinika

imvumo yokwenzanjalo. Kunesigaba lapho ucelwa khona ukuthi usinike imvumo yokuqopha lolucwaningo ngasekugcineni.

Ngeke kubekhona ukuhlolwa ngesimo sempilo yakho noma ukungenelela ngakhoke sikunika isiqiniseko sokuthi ngeke sikwenze lutho emzimbeni wakho ezokuzwisa ubuhlungu. Isikhathi esizosithatha uma ukhethe ukuba yingxenye yalesisifundo sizoba phakathi kukwemizuzu engu 45 kuya kwihora elilodwa. Lesisifundo sikhokhelwe yiKolishi Lezempilo neSayensi kwiYunivesithi yKwaZulu Natal.

***Lesisifundo singaba nalokhu okungakwenza ungakhululeki:***

Imibuzo ephathelene nempilo yakho yocansi kanye nezimpawu ozikhumbulayo nokungakhululeki okuzwayo ngalesisifo. Ngenxa yalokhu uvumelekile ukuthi uphelekezelwe isihlobo sakho noma umuntu osondelene naye akuphelezele eze naye esibhedlela ukuze akuququzele.

Lolucwaningo ngeke lube usizo kuwena kodwa siyathemba ukuthi lizoba nalolusizo olulandelayo emphakathini wonke:

Ukuphakamisa umhlahlandlela wolwazi kubasebenzi bezempilo ukuze banike usizo olundingekayo kubantu abahlala ezindaweni ebezinganakekelwe, ukuze ukunakekelwa kwezempilo kulingane ezindaweni zasemadolobheni nalezo zasemakhaya.

Lolucwaningo lucutshunguliwe lwaphasiswa I UKZN Biomedical Research Ethics Committee (inombolo ephasiswe ngayo ithi: BE041/7).

Uma kwenzeka kuba nenkinga noma ukukhathazeka noma imibuzo ungafonela owenza ucwaningo kulenombolo 081 379 1369 noma ku salinabauluck@yahoo.com noma uthinte I UKZN Biomedical Research Ethics Committee kulelikheli: UKZN Biomedical Research Ethics Committee:

UKZN Biomedical Research Ethics Committee

Kwi hofisi Locwaningo, kwicampus yase Westiville

Govan Mbeki Building
Private bag x 54001
Durban
4000

KwaZulu Natal, Ningizimu Afrika

Nombolo: 27312604769 isikhahlamezi: 27312604609

Iemail:BREC@ukzn.ac.za

Sicela uqaphele ukuthi ukubamba kwakho iqhaza kulolucwaningo akusiyo impoqo futhi ilungelo lakho njengomuntu obambe iqhaza kuzohlale kuhlonishwa. Ngamanye amagama unelungelo lokungaqhubeki nocwaningo noma ingasiphi isikhathi futhi ngeke ujeziswe ngalokho. Lokhu kusho ukuthi uma ungasathandi ukuqhubeka nocwaningo lokho ngeke kube nomphumela omubi ekusizakaleni kwakho kwezempilo futhi ngeke ujeziswe noma uphucwe ilungelo lakho lokwelashwa. Ngifake imininigwane yami ukuze usizakale uma unemibuzo ngalolucwaningo noma kukhona ongakuzwisisi kahle ngalolucwaningo.

Sicela futhi uqaphele ukuthi akukho mali okumele uyikhokhe ngokuba ingxenye yalolucwaningo. Njengendlela yokukubonga ngokubamba iqhaza kulolucwaningo nokuchitha isikhathi sakho sizoba nokuya ngasethunjini uma sesiqedile ingxoxo yethu nembuzo yonke yaphenduleka

Imfihlo iwona mgomo obusa indlela yokuziphatha kulolucwaningo. Empeleni lamaphuzu alandelayo azonakekelwa ukuqinisekisa imfihlo kanye nokungavezi igama lomuntu kulolucwaningo ngisho emva kweminyaka emihlanu:

- Igama lakho ngeke libuzwe kulolucwaningo
- Umuntu obamba iqhaza kulolucwaningo uzonikwa uhla lwembuzo endaweni lapho khona abanye abantu bengeke bambone noma bezwe ukuthi kuthiwani futhi ngeke babone ukuthi ubhala ukuthini. Isibonela kungaba sekamelweni engenamuntu noma kube sendaweni eqhelile kubantu esesibhedlela noma esikhungweni esithile. Ingxoxo izokwenzelwa kulendawo ukuze kugcineke imfihlo.
- Emva kokuphendula uhla lwembuzo ngesiZulu iyobe isidluliselwa kimi ngumsizi wocwaningo
- Ulwazi oluqoqiwe luzosebenziswa kulolucwaningo kuphela
- Uhla lwemibuzo ephenduliwe luzogcinwa endaweni lapho kungavunyelwe khona ukungena abantu bangaphandle. Kuzosetshenziswa ikhabethe elikhiywayo. Lolulwazi luzogcinwa imina nomphathi wami kuphela
- Lolulwazi lizobe selifakwa kwikhomputha ezoba nenombolo eyimfihlo yokuyivula. Izogcinwa iminyaka emihlanu bese iyashabalaliswa emva kwalokho.

**Isivumelwano (*sihlelwe ngokwesidingo*)**

Mina ……., ngichazelwe ngalolucwaningo olubizwa ngokuthi 'Impilo yomlomo kanye nempilo yeziguli ezinomdlavuza wekhanda kanye nentamo eThekwini, KwaZulu Natal' ngu Dokotela B. Saleenna Bauluck-Nujoo.

Ngiyayiqonda inhloso yalolucwaningo ukuthi luhlaziya izinkoleloze kanye nendlela yokuphatha impilo yomlomo kubantu abadla imithi yomdlavuza wekhanda nentamo lolucwaningo luhlanganisa uhla lwemibuzo kanye nengxoxo.

Nginikiwe ithuba lokuphendula imibuzo yalolucwaningo ngayiphendula futhi ngendlela engigculisayo.

Ngiyafunga ukuthi ukuthatha kwami ingxenye kulolucwaningo angiphoqwanga futhi ngiyazi ukuthi ngingashiya kulolucwaningo noma ngasaphi isikhathi ngaphandle kokulahlekelwa ukwelashwa noma ukusizakala okumele ngikuthole mayelana nempilo yami.

Ngitsheliwe ukuthi ngizothola okuya ngasethunjini uma sekuphele ucwaningo njengendlela yokubonga ngesikhathi engisisebenzise ngiphendula imibuzo.

Ngitsheliwe ukuthi ngivumelekile ukuphelezelwa isihlobo sami noma umngani wami uma ngithanda ngesikhathi socwaningo.

Ngitsheliwe ukuthi ingxoxo izoqoshwa uma ngikuvuma lokho.

Ukuvuma ukuqoshwa kwengxoxo (uyacela ukuba ubeke uphawu ebhokisini)

☐ Ngiyavuma ukuba ingxoxo iqoshwe.

☐ Angivumi ukuba ingxoxo iqoshwe.

…….. ……

Ukusayina kobambe iqhaza usuku

Uma nginemibuzo noma ukukhathazeka ngiyaqonda ukuthi kumele ngithinte umcwaningi ku salinabauluck@yahoo.com noma ku 081 3791 369.

Uma nginemibuzo noma ukukhathazeka ngelungelo lami njengomuntu obambe iqhaza noma nginokukhathazeka nganoma yini ephathelene nocwaningo noma ngocwaningayo ngingaxhumana ne:

UKZN BIOMEDICAL RESEARCH ETHICS ADMINISTRATOR
Kwi hofisi Locwaningo, kwicampus yase Westiville
Govan Mbeki Building
Private bag x 54001
Durban
4000
KwaZulu Natal, Ningizimu Afrika
Nombolo: 27312604769 noma isikhahlamezi: 27312604609

| | |
|---|---|
| …….. | …… |
| Ukusayina kobambe iqhaza | usuku |
| ……... | …….. |
| Ukusayina kukafakazi | usuku |
| (uma kunesindingo) | |
| …… | …… |
| Ukusayina kukatolika | usuku |
| (uma kunesindingo) | |

**Annexure 14: Research Ethics Certificates**

**TRREE: Module 2.1**

TRREE

Zertifikat
Certificat
Certificado
Certificate

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Clinical Trials Centre
The University of Hong Kong

**Certificat de formation - Training Certificate**

Ce document atteste que - this document certifies that

Saleenna Bauluck-Nujoo

a complété avec succès - has successfully completed

Research Ethics Evaluation

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

January 5, 2017
CID : 09mGMjjtQ2m

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

FMH Continuing Education Program (5 Credits)
Programme de Formation continue (5 Crédits)

Foederatio Pharmaceutica Helvetiae FPH Programmes de formation continue
Continuing Education Programms
Programmes de formation continue

Ce programme est soutenu par - This program is supported by :
European and Developing Countries Clinical Trials Partnership (EDCTP) (www.edctp.org) - Swiss National Science Foundation (www.snf.ch) - Canadian Institutes of Health Research (http://www.cihr-irsc.gc.ca/e/2891.html) - Swiss Academy of Medical Science (SAMS/ASSM/SAMW) (www.samw.ch) - Commission for Research Partnerships with Developing Countries (www.kfpe.ch)

[REV : 20140328]

**TRREE: Module South Africa**

Zertifikat
Certificat
Certificado
Certificate

TRREE

Promouvoir les plus hauts standards éthiques dans la protection des participants à la recherche biomédicale
Promoting the highest ethical standards in the protection of biomedical research participants

Clinical Trials Centre
The University of Hong Kong

**Certificat de formation - Training Certificate**

Ce document atteste que - this document certifies that

Saleenna Bauluck-Nujoo

a complété avec succès - has successfully completed

South Africa

du programme de formation TRREE en évaluation éthique de la recherche
of the TRREE training programme in research ethics evaluation

December 24, 2016
CID : DSqFVbSB0Q

Professeur Dominique Sprumont
Coordinateur TRREE Coordinator

FMH Continuing Education Program (5 Credits)
Programme de Formation continue (5 Crédits)

Foederatio Pharmaceutica Helvetiae FPH Programmes de formation continue
Continuing Education Programms
Programmes de formation continue

Ce programme est soutenu par - This program is supported by :
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[REV : 20140328]

**National Institute of Health: Ethics certificate**

**Certificate of Completion**

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Bibi Saleenna Bauluck** successfully completed the NIH Web-based training course "Protecting Human Research Participants".

Date of completion: 08/24/2016.

Certification Number: 2128266.

**Annexure 15: Language Clearance Certificate**

25 Maple Crescent
Circle Park
KLOOF
3610

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0823757722
Fax 031 - 7110458
E-mail:
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sathsgovender4@gmail.com

# Dr Saths Govender

28 DECEMBER 2017

TO WHOM IT MAY CONCERN

## LANGUAGE CLEARANCE CERTIFICATE

This serves to inform that I have read the final version of the dissertation titled:

Exploring oral health care for patients undergoing cancer therapy of the head and neck region: A case study in the Ethekwini District, KwaZulu-Natal by Bibi Saleenna Bauluck-Nujoo, student no. 216076204.

To the best of my knowledge, all the proposed amendments have been effected and the work is free of spelling and grammatical errors. I am of the view that the quality of language used meets generally accepted academic standards.

Yours faithfully

*S. Govender (duly signed)*

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DR S. GOVENDER
B Paed. (Arts), B.A. (Hons), B Ed.
Cambridge Certificate for English Medium Teachers
MPA, D Admin.