

QUALITY OF LIFE OF PATIENTS TREATED FOR ORAL AND OROPHARYNGEAL
SQUAMOUS CELL CARCINOMA AT KENYATTA NATIONAL HOSPITAL AND
UNIVERSITY OF NAIROBI DENTAL HOSPITAL

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A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT FOR DEGREE OF
MASTER IN DENTAL SURGERY IN ORAL AND MAXILLOFACIAL SURGERY IN THE
UNIVERSITY OF NAIROBI

DECLARATION OF ORIGINALITY

I, Dr. Mutwiri Isaiah Muriuki, V60/77052/2015, of College of Health sciences, School of Dental Sciences, Department of Oral and Maxillofacial Surgery, declare that this research titled ‘Quality of Life of patients treated for oral and oropharyngeal carcinoma at Kenyatta National Hospital and University of Nairobi Dental Hospital’ is my original work

Where other people’s work has been used, it has been properly referenced and acknowledged according to University of Nairobi requirements.

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I understand that any false claim in respect to this report shall result in disciplinary action in accordance to University of Nairobi Plagiarism policy

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Date.....

APPROVAL

I, Dr. Mutwiri Isaiah Muriuki hereby submit my dissertation entitled ‘Quality of life of patients treated for oral squamous cell carcinoma at Kenyatta National Hospital and University of Nairobi Dental Hospital’ as of partial fulfillment for degree of masters in dental surgery in oral and maxillofacial surgery

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ACRONYMS

ENT	-Ear, Nose & Throat
EORTC QLQ	-European Organization for Research Quality of Life Questionnaire
HBO	-Hyperbaric Oxygen
HR-QoL	-Health Related Quality of Life
KNH	-Kenyatta National Hospital
ORN	-Osteoradionecrosis
QoL	-Quality of Life
SF-36	-36-Item Short Form Survey
TNF- α	-Tumour Necrotic Factor Alpha
TNM	-Tumour, Nodes & Metastasis
UoN	-University of Nairobi
UoN-DH	-University of Nairobi Dental Hospital
UW-QoL	-University of Washington Quality of Life Questionnaire
WHO	- World Health Organisation

ABSTRACT

Background: The number of patients treated for oral cancer continues to rise. Most of these patients have to live with debilitating complications which adversely affect their quality of life (QOL). Rarely do clinicians assess and record quality of life of these patients routinely. Evaluation and documentation of this subjective feedback will help provide a baseline against which evidence-based effectiveness of a treatment intervention can be measured.

Broad objective: To determine the quality of life of patients treated for oral and oropharyngeal carcinoma at Kenyatta National Hospital (KNH) and University of Nairobi Dental Hospital (UDH)

Materials and Method: This study was a descriptive prospective study conducted at Kenyatta National Hospital and University of Nairobi Dental hospital from August 2018 to August 2019 involving patients diagnosed with oral and oropharyngeal squamous cell carcinoma. University of Washington Quality of Life Questionnaire version 4 was used. QOL assessment was scheduled before starting treatment and 3 months after treatment. Scores for each question in every patient were tabulated and the means for all relevant variables were calculated mainly for comparison purposes

Results: Seventy-one patients were recruited in this study and most of them were presenting for treatment at advanced stage of cancer (98.6%). 37 were found suitable to participate in the second interview upon completing 3 months after treatment. 20 patients died within the course of this study and out of these 20 patients 6 had been interviewed 3 months after treatment. Nine patients were lost to follow up and the remaining eleven patients had not completed the required 3 months after treatment mainly due to treatment delays. The overall QOL mean score for the 71 patients before treatment was 61 points. The overall QOL mean score of the 37 patients who had been reviewed 3 months after treatment slightly improved from 68 points before treatment to 72 points after treatment although this change was not statistically significant (p value = 0.1645). There was significant improvement in emotional functions such as pain, mood and anxiety

following treatment. Patients presenting with base of the tongue lesions had the worst QOL scores (54 points) before treatment compared to others

Conclusion: There was overall slight improvement in QOL following treatment mainly due to better emotional functioning following treatment but this change was not statistically significant. Majority of the patients were presenting at advanced stage of cancer which translated to lower QOL as disease stage advanced. Patients treated at very advanced disease stage were more likely to get post-op complications and early mortality

CHAPTER 1

1.1 INTRODUCTION

It is estimated that the global annual incident of head and neck cancer is about 550,000 cases, with more than 380,000 deaths each year.^{1,2} Head and neck cancer is the sixth most common cancer worldwide and squamous cell carcinoma constitutes approximately 90% of these cancers.³ Modes of treatment for oral squamous cell carcinoma includes; surgery, radiotherapy, chemotherapy, or various combination of these. With advent of newer therapeutic regimens, It is expected that the survivors from oral cancer will be more but the length of survival alone is not an enough measure treatment success.² Many of these cancer patients have to live with post treatment morbidities such as, disfigurement, dysfunction and other limitations altering their quality of life, thus the need for evaluating the Quality of Life (QoL) of these patients as one of the treatment outcome parameters to adjunct the traditional clinical endpoints such as tumor response and disease free survival.^{4,5}

The World Health Organization defines Quality of Life as *'An individual's perceptions of their position in life taken in the context of their culture and value systems in which they live and in relation to the goals, standards and concerns.'*⁶ It can also be defined as the measure between age expectations or present experience, and the perceived and actual goals (Calman-gap theory).⁷ Quality of Life (QoL) is a comprehensive, multidimensional concept, further specified as health-related quality of life (HRQoL) in assessments addressing treatment side effects, physical function and performance.⁸

There is a tendency by clinicians to concentrate more on the objective clinical outcomes at the expense of the subjective feedback given by the patients.⁹ It is thus justifiable to use tools designed to capture the patient's perceptions regarding their status at any particular point during the period their cancer treatment. In 1994, the WHO came up with an elaborate questionnaire designed to assess the quality of life of patients.⁶ Subsequently there has been attempts to modify this questionnaire to adequately capture most of the domains affected in patients suffering from head and neck cancer. The most common are the University of Washington Quality of Life Questionnaire (UW-QoL) and the European Organization for Research Quality of Life Questionnaire (EORTC QLQ). In this study, UW-QoL questionnaire has been used as it is brief and self-administered, it is multifactorial with sufficient detail and it provides question specific

to head and neck cancers. To ensure that all our participants comprehensively understand all the questions being asked, the questionnaire was translated to Kiswahili and validated.

Several studies conducted in America, Europe and Asia, regarding the health related quality of life of patients treated for oral cancers, consistently find that advanced tumor stage, posteriorly located oral cancer and multimodal treatment contributes to a lower QoL than early stage cancer, anteriorly located oral cancer and single modal treatment respectively.^{4,9} There is not much difference in overall quality of life between male and female patients or in young and elderly patients.^{4,5,10,11} The most frequently reported 'influential quality' of life domain is chewing, difficulty in swallowing and pain.⁴ The most common trend in longitudinal changes in QoL is whereby the overall quality of life deeply slumps down to low levels up to the first three months and then slowly and gradually start to rise over time but rarely surpasses the pretreatment levels.^{5, 11, 12} There are very few published studies on QoL of oral cancer patients in Africa and none, to the investigator's knowledge, has been conducted in Kenya.

The aim of the study was to determine how disease specific variables such as tumor stage & site, type of treatment modality, age and gender influence quality of life outcome. The study also demonstrates how QoL changes three months after treatment and identified the most influential QoL domains reported by the cancer patients.

Information garnered from this study can be used in developing the most appropriate treatment protocols per the patients' prevailing circumstances. It can be used for pre-operative counseling of the patients to psychologically prepare them of the likely changes that might occur following treatment. It is also hoped that regular HR-QoL assessments will create a positive impact on patient doctor communication and better emotional functioning of the patients as well as challenge researchers to explore ways and means of improving QoL

1.2 LITERATURE REVIEW

Due to the complexity of assessing QoL holistically, the term health related quality of life has evolved and is restricted to those disease and treatment related factors that affect the physical, psychological and social wellbeing of an individual.^{13,14}

Quality of life has four core domains viz; physical function, psychological function, social interactions, diagnosis and disease related symptoms. The domains assessed for head and neck cancer in the UW QoL include; chewing, appearance, mood, anxiety, activity, pain, speech, swallowing, shoulder movements, saliva production and taste.¹⁴ The main Predictors modifying the QoL are; site of the lesion, disease TNM stage, treatment modality instituted and the phase in trajectory of illness.⁴ Various socio-demographic parameters that act as confounding factors in the QoL include age, gender, level of education, level of income and patient personality^{5,11,15}

1.2.1 FACTORS THAT AFFECT QOL

1.2.1.1 Disease stage at presentation

Many researchers have reported overall best results in QoL from lesions in early stages (TNM stage I & II) more so those not requiring reconstruction as compared to advanced stages.^{4,9,16} In a study by Andradel et al using the UW QoL, patients with T3 and T4 tumors ranked lower for chewing, swallowing, saliva production, pain, taste and speech than T1 & T2 tumours⁴

1.2.1.2 Site of the lesion

Posteriorly located lesions tend to have poorer quality of life as compared to anterior one.⁴ Rogers et al. described worse QoL in posterior oropharynx location, especially due to a worse deglutition.¹⁷ Worse prognosis in posterior tumors is attributed to delay in diagnosis due to the hidden location of the tumors. Posterior-based tumors also have poor accessibility during tumor resection and might require a mandibulectomy together with a cheilotomy. These may cause mastication, deglutition and speech problems.¹⁸ Carcinomas of the posterior oropharyngeal wall have the worst prognosis of all squamous cell affecting oral cavity and oropharyngeal region. These tumours spread both in a caudal direction into the hypopharynx as well as cranial direction into the nasopharynx.¹⁹

1.2.1.3 Treatment modality

Multimodal treatment regimens usually results in poorer quality of life compared to single treatment modality such as surgical resection alone.^{4,9} If treated by radiotherapy alone advanced stage lesions in the oropharynx, results in better quality of life with fewer difficulties with speech, feeding, less pain and slightly better emotional and social domains than when treated with combination of surgical resection and radiotherapy.²⁰

Campbell et al. evaluated the HR-QoL for 72 head and neck cancer patients with a 3-year disease free survival using the questionnaires of the UW-QoL. They found advanced cancer stage was significantly correlated with lower HR-QoL scores in the domains of disfigurement, chewing ability, speech and eating in public. Patients treated with radiotherapy alone had significantly better HR-QoL scores than those treated with combined surgery/radiotherapy in the pain, disfigurement, chewing and speech domains.²¹ It has been reported that surgery involving jaw resection appears to be the biggest contributor of poor QoL with or without reconstruction since the soft tissue parts that coordinate the complex process of mastication will be missing.²¹

Some predictor variables are interrelated and dependent on each other. An advanced stage malignancy is likely to be treated in a multimodal approach involving large tumor resections, reconstruction and radiotherapy. All these are known contributors to poor QoL(4,20) these confounding factors if recognized early can be controlled for at the study design level.²³

Patients who have undergone cervical dissection have poorer QoL than those who have not mainly because this category of patients are actually in an advanced disease stage. Other contributors to the poor QoL are reduced esthetic appearance from additional scars at the neck and possible impaired neck mobility due to tissue fibrosis, sacrifice of spinal accessory nerve and sternocleidomastoid muscle. Occasionally progressive fibrosis following neck dissection can lead to shoulder pain and QoL deteriorates further if radiotherapy is used in addition to the neck dissection as it provokes fibrosis of the neck tissues.^{11, 24}

It has been reported from several studies that use of adjuvant radiotherapy results in poorer scores in function parameters and in symptoms than treatment by surgery alone.^{4,7, 20, 63} It should also be understood that those patients requiring both surgery and radiotherapy are usually in advanced stage of disease and this could also contribute to low overall QoL and worse prognosis.

Long term complications of radiotherapy include; reduced saliva, sticky saliva and decrease in taste.²⁵

Osteoradionecrosis (ORN) mainly ORN of the mandible is another devastating complication of radiotherapy. ORN can be described as complication of radiotherapy in which the irradiated bone is rendered non-viable. ORN can also be defined as exposure of bone at a radiation field for at least two months in the absence of local neoplastic disease. The radiation injury site results in hypovascularity, hypocellularity, and local tissue hypoxia. Prior radiation exposure can injure the reserve reparative capacity of bone and cause it to be overwhelmed by apparently various forms of trauma such as denture-related injury, ulcers, or tooth extraction. ORN can also occur spontaneously following tissue irradiation with no identifiable provoking injury agent^{26, 27}

The incidence of mandibular ORN in head and neck cancer patients managed with radical or postoperative irradiation has varied widely in the literature from 0.4% to 56%. The risk of developing ORN is usually in the first three years after radiotherapy but patients remain at an indefinite risk thereafter and caution should always be observed to avoid unnecessary trauma to the tissues at risk. The diagnosis of ORN is principally based on the clinical picture of chronically exposed bone. Radiological symptoms include decreased bone density with fractures, cortical destruction and loss of spongiosa trabeculation. Numerous factors that may be associated with the risk of ORN include treatment-related variables (for example, total radiotherapy dose, combination of external beam irradiation and interstitial brachytherapy, type of radiotherapy given, field size, fraction size, volume of the mandible irradiated with a high dose), patient-related variables (like deep periodontitis, pre-irradiation bone surgery, bad oral hygiene, alcohol and tobacco abuse, bone inflammation, dental extraction after radiotherapy) and tumour-related factors (tumour size or stage, proximity of the tumour to bone and anatomic tumour site).²⁸

Primary management of post-radiation bone lesions include conservative modalities such as saline irrigations, antibiotics during infectious episodes, topically applied antiseptics, gentle sequestrectomy and removal of visibly loosened bone elements as well as treatment with hyperbaric oxygen (HBO). Surgery is reserved for persistent ORN and includes radical resection of the lesion (sequestrectomy, hemimandibulectomy etc.) with reconstruction. Another recent addition to the above treatment modalities is therapy with pentoxifylline and tocopherol. Pentoxifylline has been found to act against some inflammatory mediators including TNF- α .

Alpha-tocopherol, scavenges free radicals generated during oxidative stress and protects cell membranes against lipid peroxidation. Given these well-known antioxidant properties of tocopherol, these two drugs have recently been reported to be potent and synergistic antifibrotic agents.^{28,29}

In recent years the introduction of preventive oral hygiene measures and meticulous dental evaluations before and after irradiation, improvement in radiotherapy techniques and the development of reliable diagnostic and therapeutic procedures have resulted in a decreased incidence of ORN. Several studies have reported improved quality of life in patients with advanced osteoradionecrosis following surgical treatment and reconstruction^{30,31}

1.2.1.4 Socio-demographic factors (age, gender & socioeconomic status)

It is reported that patients younger than 60 years have lower quality of life especially on social and emotional functions than those over 60 years old who have quality of life comparable to their cancer free peers(4) This may be attributed to the fact that they usually have fewer social ambitions.²⁰ contrary to this a few other studies have reported patients older than 60 years to have more complaints than those younger than 60 years.^{4,5} This may be due to already compromised physical functions such as dry mouth and poor dentition from old age itself and from chronic conditions associated with advanced age¹¹

Socio-economic status is a well-known predictor of disease morbidity or mortality rates. Individuals lower in the socio-economic hierarchy suffer disproportionately more from almost every disease and have poorer prognosis than those with higher socio-economic status.⁵ Poor nutrition as well as lack of proper health care in this group makes them more vulnerable to these kinds of diseases. Sprangers et al. evaluated the HRQL of 15 000 patients with chronic diseases using the SF-36 (36-Item Short Form Survey). They found that patients who were older, with lower education levels and with at least one co-morbid condition generally had a lower level of HRQL.¹⁵

There are conflicting literatures about gender influence in QoL. Some studies on oral cancer and QoL report no difference, while others do.^{11,32,33} Bjordal et al noted pre-treatment QoL in women presents worse results than in men, although after a year these differences disappear, finding

more alterations, alcohol problems and bad nutrition in men. Women are more affected domain concerning mobility, recreation and functions related to food.¹¹

Patient personality also plays a significant role on the patient's perception of their wellbeing. Pessimists are known to report low QoL and are less able to cope and adjust to situation as compared to optimists. Strauss et al observed that pre-surgery psychological status led to a larger or smaller post-surgery adaptation.⁽³⁴⁾ Patients with strong negative perception about their condition are less likely adapt and cope following treatment thus making them more likely to score low QoL levels. Optimistic patients value better the cognitive function, role and overall assessment of QoL. Pessimist patients are more psychologically affected by the disease a year after diagnosis than optimist patients, independently from other clinical and socio-demographic variables.^(20,34)

1.2.2 QOL DOMAINS

1.2.2.1 Pain

Pain is a common symptom in head and neck cancer patients and may be attributed to the malignancy itself and/or cancer treatment.³⁵ Cancer pain causes reduced performance status, increased anxiety and depression, increased morbidity and diminished quality of life.³⁶ Management of head and neck pain may be particularly challenging due to the complex and rich innervation of the region and because oral intake, swallowing, speech and other motor functions of the head and neck and oropharynx are constant pain triggers³⁵

In a prospective longitudinal study conducted in India by Jaisani et al, they reported the proportion of patients with no pain increased from 16.7% at 6 months to 52.8% at 12 months post-treatment but the 2 out of the 36 patients participating in the study who presented with recurrence at 12-month follow-up interval reported excruciating pain. Smit et al observed that most patients with proven recurrent disease report pain complaints as the first symptom. They also concluded that each pain complaint after initial curative treatment should be regarded as a warning sign and may reflect survival rate.^{16,37}

It has been reported that combined surgery and radiotherapy treatment commonly results in higher level of pain compared to single treatment modalities. In addition to acute post-surgical

pain patients may experience pain as a result of post radiotherapy complications such oral mucositis and from radiation fibrosis syndrome and osteoradionecrosis

Ping-YI citing Farquhar-smith concluded that some common anti-cancer drugs can lead to a complication known as chemotherapy-induced peripheral neuropathy (CIPN) which is often under recognized and undertreated. Examples of such drugs include paclitaxel, carboplatin, cisplatin.³⁸

Infections, both local and systemic, may also play a role in exacerbating pain in the patient with head and neck cancer.³⁸

1.2.2.2 Chewing

In most of the studies assessing quality of life after treatment of oral cancer, chewing domain overall is invariably reported as the most significant problem these patients have to deal with post-operatively.^{4,9,39} The tongue, palate, maxilla and mandible with the adjacent tissues are vital structures used for mastication and their anatomic and functional integrity is altered during ablative surgery.⁴⁰ Mandibular or maxillary resection affects the masticatory ability either due to loss of stable and reproducible stomatognathic system relationships or due to loss of occlusion and diminished biting forces. In addition, loss of soft tissue bulk and altered sensation causes difficulties with the patient's ability to manipulate the food bolus to the occlusal table, retrieve the bolus, and then consolidate it prior to deglutition. This is more evident if the surgery involve resection of the mandible.⁴⁰

Some patients present with trismus especially in lesions involving the retromolar pad and extending to the retromolar pad and is deep enough to involve the pterygoid musculature.⁹ Tumor resection involving the pterygoids, masseter and temporalis muscle may lead to fibrosis and subsequent trismus that restricts mouth opening. Use of radiotherapy can worsen the trismus and result to limited range of jaw movements. Finally, disarticulation of the temporomandibular joint during tumor resection also occasionally results in limited jaw opening.⁴⁰

In the presence of these difficulties with trismus, mastication and swallowing along with utilization of bulky flaps or grafts for coverage of surgical defects that do not always address the functional needs of the patient all contribute to challenges when it comes to food intake. This

compromise on the nutritional status of patients usually has a huge impact on general well-being as well as poor wound healing postoperatively.⁴⁰

1.2.2.3 Swallowing

It is commonly known that most influential factors on functional outcomes after surgical treatment is the extent of the resection (determined by the size of the tumor) site and the type of reconstruction technique employed.⁴¹ Less extensive resections allowing primary surgical closure or use of laser resections results to in better speech and swallowing functions.⁴² Groher as cited by Caterina proposed that the removal of less than 50% of a structure involved with swallowing will not seriously impact swallowing function.⁴¹

Going by site pharyngeal tumors results in worse swallowing problems as they often result in total inability to ingest food orally, slowed and painful deglutition as well as aspiration. Surgeries involving submental resection and glossectomy lead to hindered tongue propulsion and loss of lip sensation. Total glossectomy with bilateral neck dissections has a poor swallowing outcome unless the superior laryngeal nerve, hyoid bone, and epiglottis remain intact. Nasal regurgitation of fluids may also occur due to defects created following resections of either hard or soft palate or if the surgical repair of the defects is ineffective.⁴²

The use of adjuvant radiotherapy with surgery, creates additional problems due to xerostomia and fibrosis that prolongs transit of food boluses. Post radiation fibrosis may result in reduced tongue mobility, pharyngeal strictures as well as trismus, all of which negatively alters the swallowing function. Pauloski et al observed that oral cancer patients who received post-operative radiotherapy demonstrated worse swallowing outcomes than those who received surgery alone.⁴¹

Chemotherapeutic agents for head and neck cancer can also cause side effects such nausea, vomiting, generalized weakness, and fatigue which have a negative impact on swallowing and nutrition resulting anorexia and weight loss. Mucositis from chemotherapy causes odynophagia and this worsens if both chemotherapy and radiotherapy are used together. The most common cytotoxic agents associated with these symptoms are antimetabolites such as methotrexate and fluorouracil.^{4,3}

Oral cancer Patients unable to feed orally following limitations from surgery and radiotherapy may utilize gastroscopy tubes for feeding. However, use of these devices are usually related to low quality of life to those using them and in long-term periods, they lead to more ingestion difficulties and a worse social function.²⁰

1.2.2.4 Speech

Sufficient control of lips, tongue, and soft palate is important for production of speech. Any impairment in the range of movement, strength, and adaptability of these dynamic articulators might influence the capacity to make exact individual speech movements and coarticulations required in connected speech.⁴⁴

Factors affecting speech outcomes in head and neck cancer patients include site and extent of the cancerous growth, quantity of tissue resected in surgical operation and frequency of speech therapy.⁴⁴ for tongue tumors residual tongue mobility after tumor resection is more important in terms of function such as speech and swallowing than the amount of preserved tongue.⁹

Lazurus as cited by Alison stated that speech intelligibility is largely influenced by the type of reconstruction used and this, in turn, is influenced by available sensation, bulk and mobility, if a flap is employed.⁴² Following floor of mouth resection, the oral tongue may be tethered as part of the surgical closure, thereby limiting its movement for speech and swallowing.⁴² Su WF et al reported the articulation intelligibility to be better in patients not receiving flap than in those receiving flap. Reconstruction with flaps, which may additionally interfere with the flexibility and mobility of the tongue, can contribute to articulatory impairment.⁴⁴

Patients with oropharyngeal deformities may produce altered speech with nasal reverberation due to velopharyngeal insufficiency. Air might also escape through the nose, making vowels sound nasal, and inadequate weight can be developed in the oral cavity to deliver stops and fricatives. Gomanthi et al reported buccal cancer patients, preoperatively to have no articulatory errors were found.⁴⁴

1.2.2.5 Saliva and Taste

Xerostomia is a common side effect following treatment by radiotherapy. This is due to glandular atrophy and fibrosis of salivary glands. Dry mouth can sequentially result in root caries, periodontal diseases, problems with speech and eating.^{4,5}

Since taste is associated with salivary functions, it is common to have complaints of taste loss in relation to xerostomia resulting from head and neck radiotherapy. Dysgeusia(altered taste) can occur at a rapid rate and be exacerbated at up to an accumulated dose of 30 Gy. In addition, radiation induced tongue microvilli damage may result in secondary taste loss.(32)Fortunately, this situation usually improves with loss of taste acuity reversing after one to four months following radiotherapy to near full recovery however in some patients subjective residual hypogeusia may occur.³²

Use of chemotherapy is also associated with disgeusia and hypogeusia. These Patients commonly reports bitter or metallic taste in the course of taking their medication. In a review of several articles on dysgeusia induced by cancer chemotherapy, Allan J. et al estimated that about 50% to 75% of the cancer patients receiving chemotherapy, radiotherapy, or both will suffer from distorted or impaired ability to taste.⁴⁵

1.2.2.6 Appearance

Unlike other sites in the body, defects following treatment forehead and neck cancer cannot be concealed by clothing and become too conspicuous making these patients vulnerable to distress, intimacy issues, social isolation, stigma, untoward behavior from other.⁴⁴ From a study of assessing the nature and extent of body image concerns among 280 surgically treated patients with head and neck cancer, Fingeret et al found out that 75% of the participants raised concerns or embarrassment about one or more types of bodily changes at some point during treatment.⁴⁶ A third of them reported dissatisfaction with their body image predicting worse HRQoL outcomes including emotional, functional, physical, and social well-being.⁴⁶ Ramsey et al also observed that a considerable proportion of patients with disfiguring conditions experienced psychosocial difficulties, displaying raised levels of anxiety, depression, social anxiety and social avoidance and reduced quality of life.⁴⁷ Contrary to this finding a few studies have reported significantly lower proportions of patients concerned about their appearance following surgical treatment.²³ Ramsey et al established that levels of psychosocial distress were not well predicted by the severity of disfigurement while Fingeret et al observed that age, gender, cancer type, time since surgery, and body image variables were significantly associated with psychosocial outcomes of patients with body image concerns.^{46,47}

1.2.2.7 Shoulder mobility

Surgery is the mainstay of treatment for cervical lymph node metastases and this may be combined with adjuvant radiotherapy. Modified and selective neck dissection are currently more preferred than radical neck dissection as this preserve function, especially in relation to the accessory nerve, which if sacrificed usually gives rise to a stiff and painful shoulder.⁴⁸

Injury to the spinal accessory nerve, which provides motor innervation to the sternocleidomastoid and trapezius, results in pain, loss of mobility and strength and deformity of the shoulder ipsilateral to the dissection. This collection of symptoms is referred to as neck dissection syndrome or spinal accessory nerve syndrome. Resection of sternocleidomastoid muscle in radical neck dissection also results to impaired neck movement and asymmetry.⁴⁹

If radiotherapy is administered after cervical dissection, morbidity is increased from side effects such as fibrosis in the neck.²⁰ Radiation pain may occur with fibrosis when the skin and underlying structures contract. An example is “dropped head syndrome”, described by Rowin et al. in 2006 as one potential complication of radiation of the mantle field (neck, axillary and mediastinal lymph nodes). This is a late complication of radiotherapy, characterised by fibrosis and contractures of the anterior cervical muscles and atrophy of the posterior neck and shoulder girdle.^{43,48}

1.2.2.8 Anxiety

Pre-treatment anxiety is, along with depression, a common clinical display which continues six months after surgery and minimizes in a year.³⁴ At diagnosis of cancer, most patients have a hard time coming to terms with their new condition. They are also usually very anxious about treatment outcome, whether there will be tumor recurrence or disease-free survival.⁴⁴ With time, patients learn to cope with the situation and anxiety levels go down.

Apart from fear of tumor recurrence, persistence anxiety is also associated with level of function. Hassanien et al in a 2001 study, concluded that patients who had worse functional domain were more likely to be associated with anxiety, depression and ineffective coping style, and better functional scores were weakly associated with fighting spirit, level of social support and satisfaction with that support.³³

1.2.3 LONGITUDINAL CHANGES IN QUALITY OF LIFE OF ORAL CANCER PATIENTS

Several prospective studies have demonstrated the longitudinal changes in HRQoL for head-and-neck cancer patients following treatments.^{4,5,11} In the series reported by Rogers et al., they found that at the time of presentation patients with oral cancer scored lower than the norms. At 3 months following surgery, there was a considerable deterioration in HR-QoL. One year after surgery, most of the scores approached the pre-treatment level but do not reach or exceed it. Bjordal et al. also prospectively assessed the HR-QoL of head-and-neck cancer patients using EORTC QLQ questionnaire after treatment by various modalities, at baseline and 1, 2, 3, 6 and 12 months later. They reported a general trend by which HR-QoL deteriorated profoundly during treatment, followed by a slow recovery until the 12 month follow-up, with a few exceptions of altered senses, dry mouth and sexuality.¹¹ This invariable drop in the overall quality of life after head and neck cancer treatment is consistent regardless of type of tool used to collect data. It is worth noting that coping and adaption as well as drop out survival effects has a role in the improved quality of life reflected as time goes by. With time many patients adapt to their current situation and perception of their hindrances is not as strong as it used to be¹⁰. Drop out from the inception cohort by severely ill patients might improve the overall QoL score of the remaining cohort.⁴

In long-term studies, some authors have found that QoL does not reestablish to normal levels until 3-5 years due to parameters that permanently stay diminished as an after-effect of the disease and its treatment.^{24,50} However, for other authors no differences exist between QoL at one year after treatment or years following treatment⁵¹⁻⁵³

Contrary to the findings of most QoL studies on head and neck cancer patients, a study conducted by Akinwale et al in Nigeria reported improved QoL after treatment instead of the usual drop postoperatively. The study involved a sample size of 24 patients who were treated with surgical means alone with no radical neck dissection.⁵⁴

1.2.4 MOST INFLUENTIAL QOL DOMAIN

Most of the researchers assessing quality of life in oral cancer patients have reported chewing, pain and difficulty in swallowing to be most significantly affected domains.⁴ Akinwale et al

reported that Appearance,' 'recreation,' and 'chewing' were rated as the most important determinants of postoperative QoL in patients with oral cancer.⁵⁴

1.3 RESEACH PROBLEM

1.3.1 Problem Statement

Patients diagnosed and treated for oral squamous cell carcinoma endure immense agony living and coping with various altered aspects of life. The number of patients diagnosed and treated for oral cancer continues to grow making up a sizeable group of people living in this condition. In most cases, clinicians attending to these patients are more concerned with quantitative outcomes such as disease-free survival, tumor recurrence, tumor regrowth and other complications that are clinically evident during post-treatment follow up. Less emphasis is put on assessing outcome based on patients' experience, symptoms, function and dysfunctions, satisfaction and overall perception of his or her quality of life. It is now known that health related quality of life is a major determinant of mortality and morbidity.

1.3.2 Justification of the Study

There is a knowledge gap on how patients in our local set up, within our cultural context, perceive their wellbeing after receiving treatment for oral cancer. Several studies on this subject, mostly from western and some Asian countries reports a wide array of post treatment complications that inevitably lower the quality of life of these oral cancer patients. The fact that actual cure for the disease remains elusive further subjects these patients to more anxiety and psychological stress. Documentation of the extent to which these complications impact on the quality of life is important as this provides the evidence-based information in care improvement including the preferable treatment protocol

1.4 Objectives

1.4.1 Broad objective

To determine the quality of life of patients treated for oral and oropharyngeal carcinoma at Kenyatta National Hospital (KNH) and University of Nairobi Dental Hospital (UDH)

1.4.2 Specific objectives

- i. To establish QoL at diagnosis prior to commencing treatment
- ii. To establish treatment modalities offered to oral cancer patients
- iii. To establish QoL 3 months after treatment

1.5 Hypothesis

- i. There is no difference in quality of life before and three months after completing treatment in patients with oral and oropharyngeal cancer.
- ii. There is no difference in quality of life in patients treated with multimodal treatment regimen and those treated with single treatment modality

1.6 Independent variables

Table 1: Independent variables

Independent variables	Measurement/Indicators
1. Age	Years
2. Gender	Male/Female
3. Disease stage	TNM classification
4. Disease site	Anatomical sites
5. Treatment modality	Codes; 1=surgery, 2=chemotherapy, 3=radiotherapy, 4=surgery & adjuvant radiotherapy

1.7 Dependent variables

Table 2: dependent variables

Dependent variables	Measurement
HRQOL	UW-QoL Questionnaire scores ⁶ (Appendix III)
1. Pain	
2. Appearance	
3. Activity	
4. Recreation	
5. Swallowing	
6. Chewing	
7. Shoulder mobility	
8. Speech	
9. Saliva production	
10. Taste	
11. Mood	
12. Anxiety	

2 CHAPTER 2: MATERIALS AND METHODOLOGY

2.1 Study area

The study took place at the University of Nairobi Dental Hospital and maxillofacial surgery and Ear Nose and Throat departments at the Kenyatta national hospital. Both institutions are located in Nairobi and are tertiary referral hospitals for patients from all over the country. Kenyatta national hospital is one of the oldest hospitals in Kenya and is classified as a level VI institution by the ministry of health. The hospital has a bed capacity of 1800 and 22 outpatient clinics. The university of Nairobi dental hospital located along Argwings Kodhek road has a well-established maxillofacial department which runs an outpatient clinic, a maxillofacial surgical theatre and an in-patient ward

2.2 Study Design

This study was a prospective longitudinal study of patients undergoing treatment for oral squamous cell carcinoma from august 2018 to august 2019.

2.3 Inclusion and exclusion criteria

2.3.1 Inclusion criteria

- i. All patients with histological diagnosis of oral squamous cell carcinoma during the period allocated for recruitment of study participants were eligible to participate in the research.
- ii. Eligible patients who consent to participate in the study.

2.3.2 Exclusion criteria

Patients with prior treatment for oral cancer.

2.4 Sampling and sample size determination

Convenience sampling method was used.

Sample size calculation

Sample size was calculated using Fischer's formula for a single mean.

$$n = \frac{Z_{\alpha}^2 \sigma^2}{E^2}$$

Where Z_{α} = statistic from standard normal distribution representing 95% level of confidence (so $Z = 1.96$)

σ = standard deviation around the mean composite score for QoL in patients treated for oral and oropharyngeal squamous cell carcinoma (estimated at 20)(56)

E = the desired margin of error around the mean composite score for QoL in patients treated for oral and oropharyngeal squamous cell carcinoma (set at 5 units)

$$n = \frac{1.96^2 \times 20^2}{5^2}$$

$n = 62$

2.5 Data collection

Data was collected using University of Washington Quality of Life Questionnaire version 4 which was later translated to Kiswahili to enable all participating patients adequately understand what was being assessed. The questionnaire was later validated before being used. It consisted of twelve single question domains, having between three and six response options, that were scaled evenly, using a Likert scale from 0 (worst) and 100 (best) according to hierarchy of response (appendix III).

Patients' details such as: age, gender, occupation, place of residency, telephone contacts, TNM stage of the disease, site of the lesion, type of treatment instituted and presence of habits were also recorded. Other details such as the kind of challenges they faced in the course of getting access to treatment were also recorded. The questionnaires were administered at diagnosis/initial presentation and three months following treatment

2.6 Data analysis and presentation

Data was recorded in Microsoft Excel spread sheet, cleaned and analysed. Data analysis to compare QoL scores before and after treatment was done using paired T – tests and Cohen’s d effect size. Results were presented mainly in form of tables and bar graphs.

2.7 Ethical consideration

The study was approved by KNH-UoN Ethics Research Committee in July 2018 and assigned research number P225/04/2018. (Appendix IV) Permission was also sought from the relevant authorities in the departments in which the study was being conducted.

There was no inducement or coercion to the patients to participate in the study and those patients who refused to participate in the study did not in any way influence quality of care available to patient. Patients were free to withdraw from the study at any point with no negative impact on their care. Data collected using the questionnaire had no patients’ identifiers and it was used only for the purposes of this study.

3 CHAPTER 3: RESULTS 1.19

3.1 DEMOGRAPHICS

There were 71 participants recruited and interviewed for this study at presentation to the clinic before treatment commenced. Forty-two (59.2%) of these patients were male and 29 (40.8%) females with a male to female ratio of 1.4:1. There was no statically significance difference between the genders using chi squared test. (p- value: 0.1229) The age range for this group was 25 to 88 years with a mean age of 56 years and median age of 55 years. Figure one shows age distribution for male and female patients

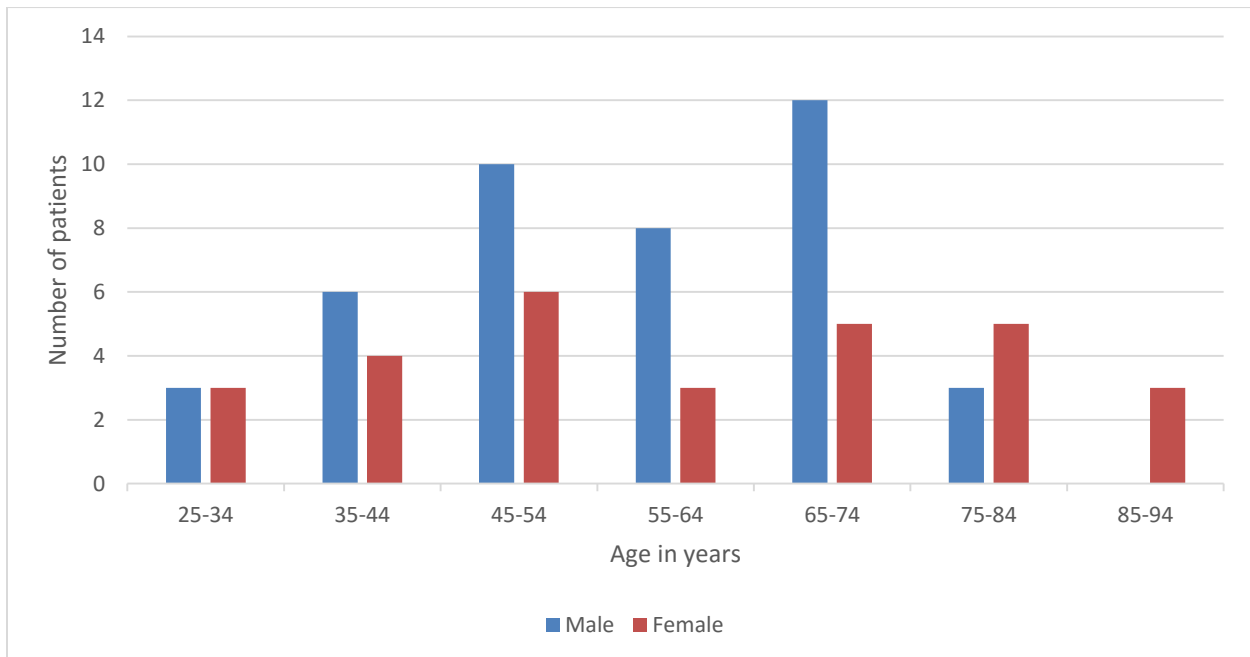


Figure 1: Age and gender distribution of the participants

3.1.1 Tumour stage

Majority of the participants presented at late stage of the disease and there was only one (1.4%) patient who presented at an early stage of disease (stage II). Seven (9.9%) patients presented with stage III disease, 13 (18.3%) patients at stage IVA, 47 (66.2%) patients at stage IVB and 3 (4.2%) patients at stage IVC.

When asked to report the challenges they faced that hindered timely access to cancer treatment, majority of the patients stated that they were unaware of the seriousness of the disease at an early stage and lack of financial resources to access appropriate medical attention. 31% of the patient reported to have been delayed by their primary clinician due to initial misdiagnosis at their nearest health centers.

3.1.2 Tumour site

Majority of the patients presented with anterior two thirds of the tongue lesion as well as mandibular lesions with 20 patients each as shown in table 3.

Table 3: patient distribution per tumour site

SITE	NUMBER OF PATIENTS
Anterior 2/3	20
cheek	5
Floor of the mouth	2
Lower lip	8
Mandible	20
Maxilla	6
oropharynx	1
Tongue base	9

3.1.3 Deceased patients

Out of the 71 patients, 13 (18%) died before they could complete the second survey three months after treatment. Majority of these patients who died were aged between 65 to 74 years old and the average age of these patients was 62 years. All these patients were at stage IV of the disease.

Four of the deceased patients died as a result of post-operative complications. Three from suspected pulmonary thrombo-embolism and one from airway obstruction. Seven patients died while undergoing radiotherapy. Three patients died as a result of residual tumour following treatment and the other six patients died before they could start treatment.

3.2 TREATMENT

Of the 71 patients who were recruited in this study 37 were interviewed three months after treatment. 13 patients died before completing the study, 7 patients were lost to follow up and the remaining 14 patients had delays in starting treatment mainly due to lack money for the treatment and delays at the radiation oncology department.

Twenty-three patients required adjuvant radiotherapy after surgery. At the time of this report, only four patients had completed adjuvant radiotherapy and out of which only one had completed 3 months upon completion of adjuvant radiotherapy. Four patients were still receiving adjuvant radiotherapy. Three patients declined adjuvant radiotherapy. Six patients got delays before they could start adjuvant radiotherapy due to the following reasons; three patients got post-operative complications that delayed radiotherapy and three other patients had residual tumour that required further surgery. Those patients who had completed three months after having surgery and were still waiting for adjuvant radiotherapy qualified to be interviewed for the second survey to assess their QoL at that point.

Out of the twenty-three patients who required adjuvant radiotherapy, fourteen patients had no post-operative complications or comorbidities or financial problems and on average, took 15 weeks before they started adjuvant radiotherapy after surgery. On average, patients who required radiotherapy with chemotherapy as their primary treatment took 10 weeks before starting radiotherapy upon booking at radiation oncology department.

3.3 QUALITY OF LIFE SCORES

3.3.1 Overall QoL scores

The overall QOL scores for the 71 as interviewed before treatment was 61 points (out of the possible 100 points)

3.3.2 Overall QoL scores before after treatment

For the 37 patients who were interviewed 3 months upon completion of treatment, their overall QoL slightly improved from 68 scores before treatment to 72 scores after treatment but paired t test showed no statistically difference between the two means (p-value = 0.1645)

A Cohen's d test showed a statistically significant small effect size of comparison between overall QOL before and Overall QOL after treatment, (Cohen's d = 0.37, p = 0.029).

3.3.3 Comparing QoL scores between younger and older patients

Overall, patients who were 54 years and below had a QoL mean score of 60 and those who were 55 years old and above had a mean score of 67 (Before treatment)

3.3.4 Comparing male vs female patients QoL mean scores

Females had a slightly better quality of life than their male counterparts. female patients had an overall QoL mean score of 65 while male patients had a mean score of 59 points. (Before treatment)

3.3.5 Tumour stage – QoL mean scores

QoL scores worsened with advancement of tumour stage (before treatment)

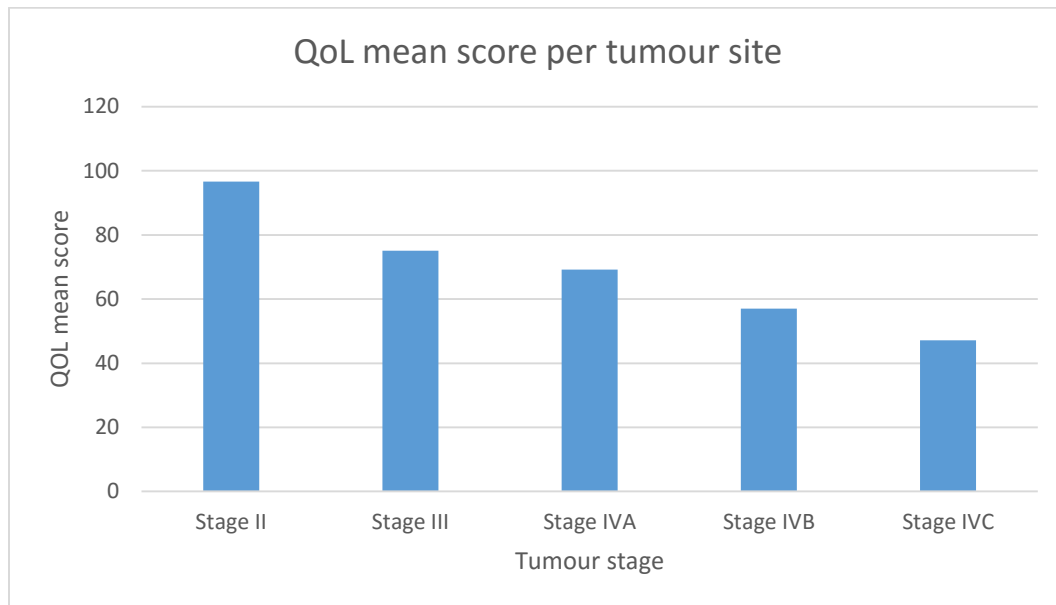


Figure 2: QoL per TNM tumour stage

3.3.6 QoL scores per site

Patients presenting with base of the tongue lesions had the worst overall QoL while patients with mandibular lesions had relatively better QoL than the rest as demonstrated in table 7. Patients with base of tongue lesions experienced more pain (mean score of 33) than patients presenting with lesions elsewhere while patients presenting with lower lip and cheek lesions had the lowest scores on how they rate their appearance. Patients with lesions in the mandible, maxilla and tongue had worse scores on chewing than the rest of the sites and patients with tongue lesions had worse scores on swallowing and speech than patients with lesions elsewhere. (table 7)

Table 4: Comparison between mean scores on various domains per site before treatment

SITE	NUMBER OF PATIENTS	OVERALL QOL MEAN SCORE	PAIN QOL MEAN SCORE	APPEARANCE MEAN SCORES	CHEWING MEAN SCORES	SWALLOWING MEAN SCORES	SPEECH MEAN SCORES
Anterior 2/3- tounge cheek	20 5	60 59	45 70	83 65	45 83	48 67	70 73
Floor of the mouth	2	57	38	63	75	67	84
Lower lip	8	64	59	53	75	96	88
Mandible	20	67	52	80	50	75	84
Maxilla	6	62	49	79	50	78	78
oropharynx	1	67	25	100	100	100	100
Tongue base	9	54	33	92	28	37	71

3.3.7 QoL scores per domain

The overall mean QoL score for each of the parameters assessed for the 71 patients before treatment is shown in table 5. Most of the patients had relatively worse scores on pain, chewing, mood and anxiety. On average most self-reported their QoL to be between poor and fair (where fair is 40 scores and poor is 20 scores using the Likert scale from the questionnaire)⁶

Table 5: QOL scores per domains

DOMAINS	SCORES (out of 100)
Pain	49
Appearance	78
Activity	75
Recreation	65
Swallowing	65
Chewing	49
Speech	78
Shoulder	96
Taste	87
Saliva	93
Mood	41
Anxiety	49
Patients own rating of their QOL	33

3.3.8 Frequency at which the HRQoL domains were indentified as the most bothersome

When asked to highlight at least three domains that they thought was bothering them more than the others, majority of the patients reported that chewing, pain and swallowing was the most bothersome items as displayed in table 6. Even though majority of the patients scored low on mood and anxiety question, they seemed not to regard them as the most important item that was adversely affecting their QoL.

Table 6: Ranking of the most frequently affected domains as reported by the patients

DOMAIN	OCCURENCE	PERCENTAGE
Chewing	38	22
Pain	33	19
Swallowing	25	15
Speech	16	9
Appearance	13	8
Activity	11	6
Anxiety	10	6
Mood	10	6
Taste	6	3
Saliva	5	3
Shoulder	3	2
Recreation	2	1
TOTAL	176	100%

3.3.9 Taste and saliva

There was significant reduction in saliva production and taste ability 3 months after radiotherapy. (table 10)

Table 7: taste & saliva before and after radiotherapy

	Before radiotherapy	After radiotherapy
Taste	89	33
Saliva	100	56

3.3.10 Pain

Overall 28 out the 71 patients (before treatment) reported to have severe pain..

The mean score for mood and anxiety of the patient who had severe pain was 33 points compared to an overall score 45 points for the 71 patients in general. (table 7)

In general, the overall mean score for pain improved from 58 points before treatment to 78 after treatment. Using a paired t test, there was a statistically significant differences between the two scores. (p-value = 0.002295)

Table 8: pain before and after treatment

	Number of patients	QOL mean score before treatment	QOL score after treatment	mean after	Cohen's <i>d</i>	<i>p</i> - value
Surgery	29	63	80		0.56	0.004**
Radiotherapy with or without chemotherapy	6	38	67		0.52	0.256
total	35	58	78		0.54	0.002**

Cohen's *d* (Effect size: 0.2 = small, 0.5 = medium, 0.8 = large) was used for effect size calculation.

** $p < 0.01$

3.3.11 Mood and anxiety

The overall average scores for mood and anxiety before treatment was 45 points and 76 points mood and anxiety scores following treatment. (p-value = 0.0000857)

3.3.12 Appearance

Generally, patients treated with surgery reported slight worsening of their appearance while patients treated with radiotherapy had a significant drop in how they perceived their appearance after treatment. (table 9) Overall there was no statistically significant difference in appearance before and after treatment. (p-value = 0.2027)

Table 9: patients' appearance before and after treatment

	NUMBER OF PATIENTS	SCORES BEFORE TREATMENT	SCORES AFTER TREATMENT	Cohen's <i>d</i>	<i>p</i> - value
Surgery	29	80	77	0.15	0.420
Radiotherapy	6	88	71	0.45	0.280
total	35	81	76	0.21	0.203

Cohen's *d* (Effect size: 0.2 = small, 0.5 = medium, 0.8 = large) was used for effect size calculation.

4 CHAPTER 4

4.1 DISCUSSION

This research involved evaluation of quality of life of oral squamous cell carcinoma patients before treatment and 3 months after treatment and it was also assessing various components that affect their QoL.

Majority of the respondents were male with a male to female ratio of 1.4 :1 a finding similar to a study by Onyango et al in 2004 where the male to female ratio was 1.3:1.⁵⁸ Majority of the patients in this study were in their 4th to the 8th decade of life with a mean age of 56 years. Studies from developed world report an average age of that is slightly above 60 years, which is comparable to local findings.^{4,5,20}

Majority of the patients presented with an advanced stage of disease. Only one out of the 71 interviewed patients presented with an early stage lesion and the rest presented with advanced stage tumour. It seems that this problem is unique in our population as most of the literature from the developed world has proportionately higher number of patients at lower stages of their disease.^{5,11,21,24} The reasons given by the patients for late presentation was lack of knowledge on the seriousness of the disease at early stage, financial obstacles in obtaining quality medical attention and delays by their primary clinicians in giving proper diagnosis and timely referral to the relevant medical authorities. A third of the interviewed patients reported to have had misdiagnosis by their primary clinician and initially being given inappropriate treatment that lead to worsening of their condition before being referred for proper management. Majority of the patients (82%) were from low socioeconomic status supporting the argument that insufficient economic resources could have hindered the patients to have access to appropriate treatment while the disease was at a lower stage or their low education level could have contributed to their ignorance on the seriousness of their disease when it was at lower stages

Anterior two thirds of the tongue and mandibular lesions were the commonest sites of these oral lesions with 20% prevalence each. Reports from previous study had similar findings.^{3,4} Lesions involving the mandible appeared to be many due to the fact that majority of these patients presented at very advanced disease stage and it was difficult to determine which of the mucosal

linings around the mandibular alveolus or the sites adjacent to mandible was the initial site of cancer development.

Out of the 71 patients, 37 qualified to have the second interview that was meant to be administered 3 months after treatment. Twenty-nine patients had surgery only, one had both surgery and radiotherapy and 6 had radiotherapy with chemotherapy. The main reason for low numbers in patients treated with irradiation was due to the fact that the radiation oncology department has a limited capacity to handle the large number of patients that present there. The average waiting period for patient requiring radiotherapy at KNH was 10 weeks. The other reason is that substantial number of the patients referred to this department are usually at a very advanced tumour stage with unstable physical condition that delays starting radiotherapy or delays in finishing radiotherapy. Out of the 23 patients that required adjuvant radiotherapy only 4 have completed the treatment. The average duration of time it takes for patients KNH to have adjuvant radiotherapy was 15 weeks again due to the limited capacity at the radiation oncology department. From the existing past studies, the optimum surgical operation to adjuvant radiotherapy duration should be less than 6 weeks. These patients tend to have a better 5-year survival rate than those who delay adjuvant radiotherapy.⁵⁷

Nineteen patients (28%) died within the first 6 months of follow up. The high number was mainly due to the high number of advanced stage of lesions in our set up that lowered the prognosis. Eleven patients (58% of the dead patients) died shortly after starting treatment. Nine out of these eleven patients died as a result of harsh side effects of the treatment worsening their already frail pre-treatment condition.

On average all the patients interviewed before treatment had an average overall QoL score of 62 which is satisfactory but when asked to rate their own quality of life, the average score for the same group was 33. The most probable reason for this is that the questionnaire had some questions which were structured to assess how certain functions are altered following treatment and compare the two. Functions such shoulder movements, taste and saliva which were being assessed in this questionnaire are rarely affected by the disease itself but rather get affected when they occur as a side effect of the treatment. Ideally when patients are asked to rate their quality of life, they tend to focus on the problems they have and rate themselves according to the severity

of the problems they are facing without necessarily taking into consideration areas or functions they are doing okay

Several studies have reported a baseline overall mean score higher than the overall mean of 62 and the main reason could be their study population and a higher proportion of patients with early stage tumours.^{4,5,8}

The overall QoL of the treated patients slightly improved from 68 scores before treatment to 72 scores 3 months after treatment. This is contrary to the findings from most of the past studies that demonstrate quality of life drastically declining within the first 3 months after treatment.^{8,20,22,25} These studies have also reported that although quality of life gradually improves as time goes on following treatment, these scores rarely reach the pretreatment quality of life scores. The only possible explanation is probably patients from our local set learn to quickly cope and adapt to their new situation after treatment despite the functional impairment that result following treatment. A study by Akinwale et al in in Nigeria in 2015 was able to demonstrate similar trends as in this study were patients QoL improves within the first three months of after treatment.⁵⁴

Patients with tongue lesions had the lowest overall QoL scores as well as low mean scores in pain. The tongue is richly innervated and highly mobile. It has a central location in the mouth and frequently engaged during oral functions such speech, chewing and swallowing. Any movements during these functions and stimuli from food creates constant triggers for pain and unfortunately some of these oral functions cannot be avoided and these patients have to endure this kind of agony. This is worse for patients without access to proper analgesia to help them cope.³⁵

This study has been able to demonstrate significant relief in pain three months following treatment with surgery or radiotherapy compared to pretreatment scores on pain, a finding that can be attributed to better overall scores in quality of life in this study.³⁵ Most of the patients presenting with moderate to severe pain three months or more after treatment had residual or recurrent tumour. Same observation was also made in a study by smit et al.³⁷

Portenoy et al was able to demonstrate a link between severe pain in patients and low physical and emotional functions in the same patients. From this study, a correlation between severe pain and low mood and anxiety scores were able to be demonstrated.³⁶

As expected, patients with tongue, maxillary and mandibular lesions had the lowest scores in chewing since all these structures are involved in mastication. Patients with tongue lesions, especially base of tongue lesions had the worst scores on swallowing and speech again due to role played by the tongue during this function.⁴⁰

The all the six patients who had completed radiotherapy three months ago reported drastic drop in saliva production and ability to taste and it was the commonest a side effect that was bothering these patients.

4.2 CONCLUSION

Ninety nine percent of the patients in this study presented at late stage (stage III and stage IV) and therefore had poorer prognosis and lower QoL scores as disease stage progressed

There was a general trend by which the QoL of these patients slightly improved after treatment even though these patients had to deal with some incapacitating side effects that altered their physical functions. One of the commonest item that these patients identified to have had adversely affected their QoL was pain. A third of these patients reported that had severe pain upon presentation for treatment and did not have proper analgesics.

This study has demonstrated that patients with oral squamous cell carcinoma present with high levels anxiety and depression with an average score of 45 points and unless these patients are given a platform to express themselves, they will not disclose these problems

There were delays before diagnosis and further delays occasioned by waiting for treatment between 10 to 15 weeks due to congestion in the treatment facilities and the fact that KNH is the sole public hospital offering radiotherapy currently in the country.

4.3 RECOMMENDATIONS

The following recommendations should be implemented to improve the care of oral cancer patients:

- I. Increase public awareness, improve primary health care resources to aid in early recognition and referrals of oral cancer patients and expansion of cancer care facilities to improve access to early treatment and recruitment of more trained personnel in orofacial cancer care and oncology in general.
- II. Patients planned for cancer treatment should have timely intervention as their overall QoL is projected to be better. Good patient selection for radical treatment should be done to avoid unnecessary post-operative complication and early mortality.

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APPENDICES

APPENDIX I: PATIENTS' INFORMATION

I, Dr. Mutwiri Muriuki of the University of Nairobi, School of Dental Sciences, am conducting a study titled 'quality of life of patients treated for oral and oropharyngeal squamous cell carcinoma at the Kenyatta National Hospital and Dental Hospital.'

Study purpose: The study seeks to determine the quality of life of oral cancer patients before and after treatment of the cancer and the establish factors that influence the quality of life in these patients

Benefits of participation: This study will help to understand better some of the challenges patients face when diagnosed and treated for oral cancer based on the patient's own experiences. This feedback will be used to adjunct the regular clinical outcomes such disease-free survival. All this can be used when determining the most appropriate treatment for the patients, treatment that results in the best possible quality of life outcome at a given tumor response level. This information will also help to improve patient doctor communication and help patients understand better on some of the expected outcomes

Risks of participation in the study: There is no expected risk of psychological or bodily harm to the participants.

Voluntariness of the participation: Participation is voluntary and one is at the liberty to decline to participate or withdraw at any stage.

Confidentiality: the information obtained will be treated with utmost confidentiality.

APPENDIX II: CONSENT CERTIFICATE

I (initials) having understood the purpose, benefits and risks of the study titled ‘quality of life of patients treated for oral and oropharyngeal squamous cell carcinoma at the Kenyatta National Hospital and University of Nairobi Dental Hospital’ willingly accept to participate. I understand there are no risks anticipated from this study and all information provided to the investigator will be handled with utmost confidentiality.

Signature of the participant date
.....

Investigator’s statement:

I certify that I have I have explained to the participant the nature and purpose of this study and potential benefits. I have answered any questions that have been raised. I have explained the above to the participant on the date on this consent certificate

Investigator date
.....

In case of any clarifications or concerns regarding the study you may contact the investigator, the lead supervisor or secretary KNH/UON ethics , research and standards committee using the following contacts:

- Dr. Mutwiri I. Muriuki (principle investigator) masters student in M.D.S oral and maxillofacial surgery in the university of Nairobi
- Dr. Wambeti Njiru
- Dr. Walter Odhiambo
- Prof. J.F. Onyango
- Prof. Anastasia N. Guantai, Professor of Pharmacology and Therapeutics Department of Pharmacology and Pharmacognosy University of Nairobi

APPENDIX III: DATA COLLECTION TOOL

University of Washington Quality of Life Questionnaire

(UW-QOL v4)

This questionnaire asks about your health and quality of life **over the past seven days**. Please answer all of the questions by ticking one box for each question.

1. **Pain.** (Tick one box:)

- a. I have no pain.
- b. There is mild pain not needing medication.
- c. I have moderate pain - requires regular medication (e.g. paracetamol).
- d. I have severe pain controlled only by prescription medicine (e.g. morphine).
- e. I have severe pain, not controlled by medication.

2. **Appearance.** (Tick one box:)

- a. There is no change in my appearance.
- b. The change in my appearance is minor.
- c. My appearance bothers me but I remain active.
- d. I feel significantly disfigured and limit my activities due to my appearance.
- e. I cannot be with people due to my appearance.

3. **Activity.** (Tick one box:)

- a. I am as active as I have ever been.
- b. There are times when I can't keep up my old pace, but not often.
- c. I am often tired and have slowed down my activities although I still get out.
- d. I don't go out because I don't have the strength.
- e. I am usually in bed or chair and don't leave home.

4. **Recreation.** (Tick one box:)

- a. There are no limitations to recreation at home or away from home.
- b. There are a few things I can't do but I still get out and enjoy life.
- c. There are many times when I wish I could get out more, but I'm not up to it.
- d. There are severe limitations to what I can do, mostly I stay at home and watch TV.
- e. I can't do anything enjoyable.

5. **Swallowing.** (Tick one box:)

- a. I can swallow as well as ever.
- b. I cannot swallow certain solid foods.
- c. I can only swallow liquid food.
- d. I cannot swallow because it "goes down the wrong way" and chokes me.

6. **Chewing.** (Tick one box:)

- a) I can chew as well as ever.
- b) I can eat soft solids but cannot chew some foods.
- c) I cannot even chew soft solids.

7. **Speech.** (Tick one box:)

- a. My speech is the same as always.
- b. I have difficulty saying some words but I can be understood over the phone.
- c. Only my family and friends can understand me.
- d. I cannot be understood.

8. **Shoulder.** (Tick one box:)

- a. I have no problem with my shoulder.
- b. My shoulder is stiff but it has not affected my activity or strength.
- c. Pain or weakness in my shoulder has caused me to change my work / hobbies.
- d. I cannot work or do my hobbies due to problems with my shoulder.

9. **Taste.** (Tick one box:)

- a. I can taste food normally.
- b. I can taste most foods normally.
- c. I can taste some foods.
- d. I cannot taste any foods.

10. **Saliva.** (Tick one box:)

- a. My saliva is of normal consistency.
- b. I have less saliva than normal, but it is enough.
- c. I have too little saliva.
- d. I have no saliva.

11. **Mood.** (Tick one box:)

- a. My mood is excellent and unaffected by my cancer.
- b. My mood is generally good and only occasionally affected by my cancer.
- c. I am neither in a good mood nor depressed about my cancer.
- d. I am somewhat depressed about my cancer.
- e. I am extremely depressed about my cancer.

12. **Anxiety.** (Tick one box:)

- a. I am not anxious about my cancer.
- b. I am a little anxious about my cancer.
- c. I am anxious about my cancer.
- d. I am very anxious about my cancer.

Which issues have been the most important to you during the past 7 days?

Tick **up to 3 boxes**.

Pain	Swallowing	Taste
Appearance	Chewing	Saliva
Activity	Speech	Mood
Recreation	Shoulder	
Anxiety		

GENERAL QUESTIONS

Compared to the month before you developed cancer, how would you rate your health-related quality of life? (Tick one box:)

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

In general, would you say your **health-related quality of life** during the past 7 days has been: (Tick one box:)

- a. Outstanding
- b. Very good
- c. Good
- d. Fair
- e. Poor
- f. Very poor

Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your **overall quality of life** during the past 7 days. (Tick one box:)

- a. Outstanding
- b. Very good
- c. Good
- d. Fair
- e. Poor
- f. Very poor

Please describe any other issues (medical or nonmedical) that are important to your quality of life and have not been adequately addressed by our questions

KIAMBATISHO

Jina langu ni Daktari Mutwiri Muriuki kutoka Chuo Kikuu cha Nairobi, Kitivo cha Sayansi ya meno. Kwa wakati huu ninafanya utafiti kuhusu 'Hali ya maisha ya wagonjwa wanaotibiwa kwa saratani ya mdomo na sehemu za koo katika Hospitali ya Kitaifa ya Kenyatta na Hospitali ya Meno, Chuo Kikuu cha Nairobi.

Madhumuni ya Utafiti: Utafiti huu unataka kubaini hali ya maisha ya wagonjwa wa saratani ya mdomo kabla na baada ya matibabu ya kansa na pia kubaini sababu ambazo huathiri ubora wa maisha ya wagonjwa hawa.

Faida za ushiriki: Utafiti huu utasaidia kufahamu vyema baadhi ya changamoto wagonjwa ukabidhi wakati wametambuliwa na kutibiwa kwa kansa ya mdomo kwa kutumia uzoefu wa mgonjwa mwenyewe. Majibu haya yatatumika pamoja na matokeo mengine ambayo hutumika kwa kawaida kuashiria mafanikio ya matibabu kama vile muda wa kuishi pasipo athari za saratani. Haya yote yanaweza kutumika wakati wa kuamua matibabu sahihi zaidi kwa wagonjwa, matibabu ambayo yanaweza kuboresha hali ya maisha kutokana na kiwango cha maumivu ya saratani. Habari hii pia yawezasaidia kuboresha mawasiliano kati ya mgonjwa na daktari na kusaidia wagonjwa kuelewa vizuri zaidi baadhi ya matokeo yanayotarajiwa.

Hatari ya kushiriki katika utafiti: Hatutaraji hatari au madhara ya kisaikolojia au kimwili kwa mgonjwa kutokana na kushiriki utafiti huu.

Ushiriki wa ihari: ushiriki ni wa hiari na mshiriki yuko huru, na kuamua kutoshiriki au kujiondoa katika muda wowote baada ya kujishajilisha.

Usiri: taarifa zilizopatikana zitachukuliwa kwa usiri mkubwa

KIAMBATISHO 2: CHETI CHA IDHINI

Mimi (herufi za jina la mshiriki) baada ya kuelewa kusudi, faida na hatari ya utafiti kuhusu 'Hali ya maisha ya wagonjwa wanaotibiwa kwa saratani ya mdomo na sehemu za koo katika Hospitali ya Kitaifa ya Kenyatta na Hospitali ya Meno, Chuo Kikuu cha Nairobi.' nimekubali kushiriki kwa hiari. Naelewa hakuna hatari zinazotarajiwa kutokana na utafiti huu na taarifa zote zinazotolewa kwa uchunguzi itachukuliwa kwa usiri mkubwa.

Sahihi ya mshiriki tarehe

Kauli ya Mtafiti:

Ninathibitisha kwamba nimeeleza mshiriki hali na lengo ya utafiti huu na faida za kushiriki. Nimemruhusu mshiriki kuuliza maswali na kutoa majibu kwa maswali ambayo yaliuluizwa. Nimeelezea mambo haya kwa mshiriki katika tarehe iliyoonyeshwa katika cheti idhini

Mtafiti tarehe

Iwapo pana hitaji ya ufafanuzi yoyote au wasiwasi kuhusu utafiti unaweza kuwasiliana na mtafiti, msimamizi wa mtafiti, au katibu wa kamati ya maadili, na utafiti, Hospitali ya Kitaifa ya Kenyatta/ Chuo Kikuu cha Nairobi kupitia:

- Dr. Mutwiri I. Muriuki (Mtafiti), Kitivo cha Sayansi ya Meno, Chuo Kikuu cha Nairobi
- Dr. Wambeti Njiru (Msimamizi), Kitivo cha Sayansi ya Meno, Chuo Kikuu cha Nairobi
- Dr. Walter Odhiambo (Msimamizi), Kitivo cha Sayansi ya Meno, Chuo Kikuu cha Nairobi
- Prof. J.F. Onyango (Msimamizi), Kitivo cha Sayansi ya Meno, Chuo Kikuu cha Nairobi
- Prof. Anastasia N. Guantai (katibu wa kamati ya maadili, na utafiti, Hospitali ya Kitaifa ya Kenyatta) kitivo cha sayansi ya madawa, chuo kikuu cha nairobi

CHUO KIKUU CHA WASHINGTON, DODOSO LA HALI YA MAISHA

Dodoso hii linauliza kuhusu afya yako na hali ya maisha katika kipindi cha siku saba.

Tafadhali jibu maswali yote kwa kuchagua sanduku moja kwa kila swali.

1. **Maumivu.** (Jibu kwa kuchagua sanduku moja:)

- Sina maumivu.
- Kuna maumivu kiasi yasiohitaji dawa.
- Nina maumivu ya wastani - inahitaji dawa mara kwa mara (mfano paracetamol).
- Nina maumivu makali kudhibitiwa tu na dawa (mfano morphine).
- Nina maumivu makali, yasiyo dhibitiwa na dawa.

2. **Sura.** (Jibu kwa kuchagua sanduku moja:)

- Hakuna mabadiliko katika muonekano wangu.
- Mabadiliko katika muonekano wangu ni madogo.
- Muonekano wangu unanisumbua lakini bado ninafanya shuguli za kawaida.
- Najisikia mabadiliko makubwa katika sura yangu na shughuli zangu zimeathirika kutokana na muonekano wangu.
- Siwezi kuwa na watu kwa sababu ya sura yangu.

3. **Shughuli.** (Jibu kwa kuchagua sanduku moja:)

- Mimi hufanya shughuli zangu jinsi ambavyo nilikuwa na fanya hapo awali.
- Kuna wakati siwezi kufanya shughuli zangu kwa kasi yangu ya zamani, lakini si mara kwa mara.
- Mimi huwa na uchovu mara nyingi na nimepunguza kasi ya shughuli zangu lakini bado hutoka nje.
- Siwezi kwenda nje kwa sababu sina nguvu.

Mimi kwa kawaida huwa katika kitanda au kiti na wala siondoki nyumbani.

4. **Burudani.** (Jibu kwa kuchagua sanduku moja:)

- Hakuna upungufu kwa burudani nyumbani au mbali na nyumbani.
- Kuna mambo machache Siwezi kufanya lakini bado hutoka nje na kufurahia Maisha.
- Kuna mara nyingi wakati ningependa kufanya mengi zaidi, lakini mimi hulemewa.
- Kuna upungufu kubwa kwa yale naweza kufanya, hasa mimi hukaa nyumbani na kutazama TV (runinga).
- Siwezi kufanya kitu chochote cha kufurahisha.

5. **Kumeza.** (Jibu kwa kuchagua sanduku moja:)

- Naweza kumeza kama kawaida.
- Siwezi kumeza baadhi ya vyakula vigumu.
- Naweza kumeza tu vyakula laini.
- Siwezi kumeza kwa sababu chakula huwa "inaenda njia isio sahihi" na kukwama kooni.

6. **Kutafuna.** (Jibu kwa kuchagua sanduku moja:)

- Naweza kutafuna kama kawaida.
- Naweza kula vyakula laini lakini siwezi kutafuna baadhi ya vyakula.
- Siwezi hata kutafuna vyakula laini.

7. **Mazungumzo.** (Jibu kwa kuchagua sanduku moja:)

- Mazungumzo yangu ni sawa kama kawaida.
- Nina shida kusema baadhi ya maneno lakini naweza kueleweka kwa simu.
- Familia yangu na marafiki ndio tu wanaweza kunielewa.
- Siwezi kueleweka.

8. **Bega.** (Jibu kwa kuchagua sanduku moja:)

- Sina tatizo na bega langu.
- Bega langu ni ngumu lakini bado halijaathiri shughuli zangu au nguvu.
- Maumivu au udhaifu kwenye bega imesababisha mabadiliko ya kazi yangu / burudani.
- Siwezi kufanya kazi yangu au burudani sababu ya shida na bega langu.

9. **Ladha ya vyakula.** (Jibu kwa kuchagua sanduku moja:)

- Naweza hisi ladha ya chakula kama kawaida.
- Naweza hisi ladha ya vyakula vingi kama kawaida.
- Naweza hisi ladha ya baadhi ya vyakula.
- Siwezi hisi ladha ya vyakula vyovyote.

10. **Mate.** (Jibu kwa kuchagua sanduku moja:)

- Mate yangu ni ya kawaida.
- Nina mate ndogo kuliko kawaida, lakini ni ya kutosha.
- Nina mate kidogo mno.
- Sina mate.

11. **Hisia.** (*mood*) (Jibu kwa kuchagua sanduku moja:)

- Hisia yangu ni bora na haijaathirika na saratani.
- Hisia yangu kwa ujumla ni nzuri na mara kwa mara tu ndipo huathirika na saratani.
- Sijafurahia wala wala kuhuzunika kuhusu saratani.
- Nina huzuni kiasi fulani kuhusu saratani.
- Nina huzuni sana kuhusu saratani.

12. **Wasiwasi.** (*anxiety*) (Jibu kwa kuchagua sanduku moja:)

- Sina wasiwasi kuhusu saratani.
- Nina wasiwasi kidogo kuhusu saratani.
- Nina wasiwasi kuhusu saratani.
- Nina wasiwasi sana kuhusu saratani.

Ni mambo ghani yamekuwa na umuhimu sana kwa hali yako ya Maisha katika muda wa siku saba zilizopita (unaweza kuchagua vipengele hadi tatu)

- Maumivu
- Muonekano wangu
- shughuli
- Burudani
- Kumeza
- Kutafuna
- Kuongea
- Mabega
- ladha
- mate
- hisia
- Wasiwasi

MASWALI KWA JUMLA

Ukilinganisha sasa na mwezi moja kabla ya kuanza kuugua ugonjwa wa saratani, hali ya Maisha yako iko vipi?

- Njema
- Njema kiasi
- Haijabadilika
- Mbaya kiasi
- Mbaya

Kwa jumla, ukitilia maanani afya yako, unaeza kusema nini kuhusu hali yako ya maisha katika kipindi cha siku saba zilizopita

- Bora zaidi
- Njema sana
- Njema
- Njema kiwango cha wastani
- Mbaya
- Mbaya sana

Hali yako ya maisha kwa jumla haichangiwi tu na ubora wa kimwili na kimawazo pekee yake, hila pia na mambo mengine kama familia, marafiki, dini au burudani mbali mbali kwa maisha yako. Ukitilia maanani mambo yote kwa Maisha yako yanayo changia kwa ubora wako wa kimaisha, unaweza sema nini kuhusu hali yako ya maisha katika kipindi cha siku saba zilizopita?

- Bora zaidi
- Njema sana
- Njema
- Njema kiwango cha wastani
- Mbaya
- Mbaya sana

Tafadhali elezea mambo mengine yoyote yanayo umuhimu kwa hali yako ya maisha ambayo hatujashughulikia vilivyo katika maswali yetu hapo awali