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LIVING WITH CANCER OF THE HEAD AND NECK: A QUALITATIVE INQUIRY INTO THE EXPERIENCES OF PATIENTS TREATED AT AN ACADEMIC HOSPITAL IN GAUTENG

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A research report submitted to the Faculty of Health Science, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Nursing.

Johannesburg, 2018

DECLARATION

I Samuel Alloss Mbale Bingo declare that this research report is my own, unaided work.it is being submitted for the degree of Masters of Science in Nursing at the University of the Witwatersrand, Johannesburg. It has not been previously submitted for any degree or examination at any other university.

SIGNATURE..S.A.M. Bingo.....

SAMUEL ALLOSS MBALE BINGO

Date....31st..... day of...May..... 2018

DEDICATION

To my late father, Mr. Charles Solium Bingo and my uncle, Mr Oliver Chilowe Mkandawire. I hope I am on the right tract to fulfil the dreams that you wanted me to be. Your words are still fresh in my mind and I work to fulfil them.

ACKNOWLEDGEMENTS

No man is an island, I therefore show my appreciation to the following people for their support and encouragement.

- Professor JE Maree and Dr Kotie Jansen Van Rensburg for supervision, encouragement and support
- The Government Malawi for the scholarship and financial support throughout the program.
- All participants who spared their time to take part in my study and be able to share their experiences even though it was tough.
- My friends and colleagues at the research site, for their support and encouragement.
- The management of an academic hospital where research was conducted for giving me the opportunity to conduct this study.
- Above all I am so grateful to God for giving me life, energy and opportunity to do this work.

ABSTRACT

Background: Head and neck cancer is the collective name for cancers that affect the lips, oral cavity, nasal cavity, para-nasal sinuses, pharynx, larynx and parotid glands. South Africa, as one of the developing countries, is highly affected by the head and neck cancer due to lifestyle causes such as smoking and alcohol use. Patients with head and neck cancer experience more problems and severe symptoms as a result of the diagnosis and treatment as compared to patients diagnosed with other types of cancer. This is due to the fact that head and neck cancer affects critical parts of the body which are important for nutrition, breathing and communication. Despite the severe consequences of the disease, little is known about the experiences of patients living with this disease in South Africa.

Aim of the study: The study aimed to describe the experiences of patients living with head and neck cancer treated at an academic hospital in Gauteng.

Design and Methods: A descriptive qualitative design was used. The accessible population comprised all head and neck cancer patients treated at the study setting. Purposive sampling was used to select the sample and the sample size was informed by data saturation. The inclusion criteria were 18 years and older, ability to speak basic English and willingness to participate. General information was gathered using a demographic data sheet and in-depth interviews were conducted to gather the data. The data were analysed by means of qualitative content analysis.

Findings: Eighteen people (n=18), of which more than half were males (14 of 18), took part in the study. The participants were from four major population groups, with the majority from the black population (13 of 18). Their ages ranged from 26 to 73, with an average age of 50.8 years. Five subthemes arose from the data: the emotional effects of the head and neck cancer, the physical consequences of the disease and treatment, the socioeconomic implications of the disease and treatment, the importance of psychosocial support and the importance of hope and spirituality which were categorised into two themes: living with the consequences of the disease and treatment and coping with the changed life.

Conclusion: Living with cancer of the head and neck is not easy. The lives the participants knew before they became sick changed and became a living hell. They had to live the effects of the disease and treatment, which had a devastating effect on their financial burden. Eating became a major challenge and some of the participants struggled to communicate, whilst others had to live with facial disfigurement. Some were ridiculed and some isolated themselves from social contact. However, receiving support from family and friends and their faith in God assisted them to live this changed life.

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CHAPTER 1

AN ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Understanding the experiences of patients during the trajectory of a disease is one of the pillars of patient-centred care in cancer patients. Experiences of patients suffering from head and neck cancer have been given little attention in South Africa, and Africa as a whole, as indicated by the dearth of information available (Maree et al. 2017). Although this matter has been given attention in studies done overseas, it is argued that experiences and challenges of patients in South Africa are not the same due to different factors such as economic status, health systems, geographical factors, the burden of HIV and AIDs (Joshi et al. 2014) and poverty (Maree et al. 2017). This study was therefore designed to gather baseline information regarding the experiences of patients with head and neck cancer in the South African setting.

Chapter 1 gives an orientation for the study by presenting the background, the problem statement and significance of the study, the research question and objective, and an overview of the research design and methods.

1.2 BACKGROUND

Head and neck cancer is the collective name for cancers that affect the lips, oral cavity, nasal cavity, para-nasal sinuses, pharynx, larynx and parotid glands (Mehanna et al. 2011). Statistically, head and neck cancer is the sixth leading cancer and number eight in the cause of cancer-related deaths in the world. Worldwide, approximately 640 000 people are newly diagnosed with head and neck cancer annually, whist causing 350 000 deaths each year (Jemal et al. 2011).

South Africa, as one of the developing countries, is highly affected by head and neck cancer due to lifestyle causes, such as smoking and alcohol use (Fagan et al. 2014). According to the National Institute for Occupational Health (2011), 4.7% of all males newly diagnosed with cancer have head and neck cancer compared to 2% in females. Head and neck cancer has the highest incidence among males and is responsible for 7.75% of all cancers in Black males, 6.21% in Coloured males, 4.46 % in Asian males and 2.77% in White males. In females, the Coloured population has the highest incidence (3.31%) (Singh et al. 2013). Head and neck cancer affects people of all age groups, however it is more prevalent among

women who are 80 years and above and in men between 60 and 64 years old (Ndui 2011; Abram 2013).

In sub-Saharan Africa, 90% of head and neck cancers affect the oral pharyngeal area (Faggons et al. 2015). Tobacco and alcohol use are the main risk factors, however recent studies have shown that head and neck cancer is also associated with Human Papilloma Virus infection, primarily HPV 16 and 18 (Fagan et al. 2014), which is also responsible for most cervical cancers (World Health Organization 2006). However, head and neck cancer has some common signs and symptoms, including swelling or a sore in the mouth or nasal cavity that does not heal, a red or white patch in the mouth, a mass in the mouth with or without pain, hoarseness or change in voice, nasal obstruction or persistent nasal congestion, painful or difficulty chewing, ear and/or jaw pain, and loosening of teeth (Galbiatti et al. 2013).

The primary treatments for head and neck cancer are surgery and radiotherapy; chemotherapy is mostly added as an adjuvant treatment for patients with advanced disease. A multidisciplinary approach is required to be successful in the provision of care and treatment of these patients (Galbiatti et al. 2013). The prognosis of patients with head and neck cancer is good in the early stages of the disease, whilst advanced stages are associated with a poor prognosis (Nekhlyudov et al. 2017).

According to Farhangfar et al. (2014), patients with head and neck cancer experience more problems and severe symptoms as a result of the diagnosis and treatment compared to those diagnosed with other types of cancer. This is due to the fact that head and neck cancer affects critical parts of the body which are important for nutrition, breathing and communication (Itano et al. 2015). Patients with head and neck cancer experience eating-related problems, such as dysphagia, difficulty chewing, loss of appetite, loss of taste and other minor symptoms such as pain, salivation, dry mouth and thick saliva, which result in low dietary intake and weight loss (Farhangfar et al. 2014). In addition, these patients experience low self-esteem, poor self-image, self-despise, stigma, terror and trauma caused by the diagnosis and treatment (Hoole et al. 2015; Isaksson et al. 2016; Threader and McCormack 2016). Fear of recurrence is also common (Kanatas et al. 2015).

1.3 PROBLEM STATEMENT

The research problem for the study relates to patients living with head and neck cancer. Due to cancer of the head and neck affecting nutrition, breathing and communication (Lang et al. 2013; Farhangfar et al. 2014), patients experience unique problems and despite the severe consequences of the disease, little is known about the experiences of patients living with this

disease in South Africa (Maree and Schmollgruber 2014; Maree et al. 2017). This study would provide descriptive summary in its attempt to address the existing knowledge gap.

1.4 RESEARCH QUESTION AND AIM

The research question for this study was 'What are the experiences of patients living with head and neck cancer treated at an academic hospital in Gauteng?'

The study aimed to describe the experiences of patients living with head and neck cancer treated at an academic hospital in Gauteng.

1.5 SETTING, RESEARCH DESIGN AND METHODS

The study was conducted at an academic hospital in Gauteng. A descriptive qualitative design (Sandelowski 2000) was used. The target population was all patients treated for cancer of the head and neck, whilst the accessible population comprised all head and neck cancer patients treated at the study setting. Purposive sampling (Burns and Grove 2010) was used to select the sample and the sample size was informed by data saturation(Jolley 2013). The inclusion criteria were 18 years and older, ability to speak basic English and willingness to participate. General information was gathered using a demographic data sheet (Annexure B) and in-depth interviews (Polit and Beck 2014) were conducted to gather the data. The data were analysed by means of qualitative content analysis (Sandelowski 2000).

1.6 DEFINITION OF CONCEPTS

Experience refers to conscious knowledge of physical, emotional, psychosocial and spiritual occurrences that are gained through an encounter with an event or disease process (Venes 2017). It is the process that influences the entire life of an individual or group and usually leads to change of behaviour and way of thinking toward life (Boud et al. 2013).

Head and neck cancer is a collective name for cancers that affect the lips, oral cavity, nasal cavity, para-nasal sinuses, pharynx, larynx and parotid glands (Mehanna et al. 2011).

Anti-cancer treatment refers to any preventative or curative interventions for cancer and its associated symptoms (Siegel et al. 2012). For the sake of this study, anti-cancer treatment included chemotherapy, radiotherapy, surgery and treatment to control symptoms and side effects of the disease and the main treatment.

Patient-centred care is an approach that demands the organisation and delivery of healthcare based on the patients' needs by listening to and involving the patient (Rickert 2012).

Radiotherapy is a local treatment that involves the use of high energy ionising x-rays to kill cancer cells while causing minimal damage to the normal cells (Itano et al. 2015). Radiotherapy does not only target cancer cells, hence it causes damage to normal cells, resulting in several side effects. The severity of the side effects depends on the site and structures involved (Sourati et al. 2017). Radiotherapy can be given as external beam, meaning from a distance, or brachytherapy, meaning the radioactive source is placed close to the tumour or inside the tumour (Devlin 2015).

Biotherapy is the use of substances produced from living organisms to modify or augment biologic mechanisms against tumour cells (Itano et al. 2015). This is the only treatment modality that targets the cancer cells only (Chabner and Longo 2011).

Palliative treatment refers to the interventions given to cancer patients in order to relieve symptoms and improve quality of life without curing the disease (Pennbrant et al. 2015). These interventions may include pain control medication, control of tumours to restore structural functioning and supportive medication to reduce the effects of the disease on a patient's life (Dunlop 2012).

1.7 OUTLINE OF THE STUDY

Chapter 1 : Orientation to the study
Chapter 2 : Literature review
Chapter 3 : Research methods
Chapter 4 : Findings and discussion
Chapter 5 : Justification, limitations and recommendations

1.8 SUMMARY

Chapter 1 gave an overview for the study, including an introduction, background, the problem statement and research question. Furthermore, the research methods, the definition of the concepts and an outline of the study were presented. Chapter 2 provides a review of the relevant literature related to the study.

CHAPTER 2:

LITERATURE REVIEW

2.1 INTRODUCTION

Chapter 2 presents a review of literature related to the study. The review included cancer as a global burden and an overview of head and neck cancers. With regards to cancer as global burden, the focus was on epidemiology, treatment and side effects and survivorship, while the overview of head and neck cancer included global and local statics, the anatomy of the head and neck, the functions of the structures of the head and neck, etiological factors, clinical presentation, histological types and staging, the complications of the disease and treatment.

A search of evidence was done in the following databases and search engines: Science Direct, CINHAL, MEDLINE, Google scholar, ProQuest Nursing and Allied Health Source and PubMed. The search was limited to articles published between 2010 and 2017, as there was a large amount of literature related to research done overseas. The most recent findings were reviewed in order to have current understanding of the context of the study.

A combination of the search terms such as head and neck, cancer, tumours, aero digestive region, squamous cell carcinoma, oral, cancer burden, global burden, treatment, signs and symptoms, and malignancies were used to search the data bases.

2.2 CANCER AS A GLOBAL BURDEN

Cancer is a global health problem, and is one of the leading causes of morbidity and death globally (Jemal et al. 2011).

2.2.1 The incidence of cancer

In 2012, more than 14 million people were newly diagnosed with cancer while over 8 million people died from the disease. This is an increase in the global burden of cancer compared to the 2008 statistics, when approximately 12.7 million people were newly diagnosed and 7.1 million deaths occurred due to cancer (Torre et al. 2015). The trend shows that the incidence of cancer has remained the highest in the developed world, while the mortality rate is the highest in the developing world (Siegel et al. 2013). According to Siegel et al. (2013), more than 5 million of the 8.1 million cancer related deaths were from the developing world, indicating a high cancer mortality in the developing world compared to the developed world. The high mortality rate of cancer patients in the developing world is attributed to under-

developed health systems, a lack of resources (both human and material), high poverty levels and the increased burden of HIV and AIDS (Joshi et al. 2014). According to Torre et al. (2015), the five-year survival rate of all cancers worldwide is estimated in the range of 40 to 67%. People of all age groups are equally affected by different types of malignancies.

Sub-Saharan Africa, as part of the developing world, is hard hit by the burden of cancer. Sub-Saharan African women are mostly affected by malignancies of the breast and cervix, accounting for approximately 50% of all cancers in women, whilst men are mostly diagnosed with cancers of the prostate, Kaposi' sarcoma and liver cancer, representing more than 45% of all malignancies diagnosed in men (Ferlay et al. 2014; Olaleye and Ekrikpo 2017). Approximately 3% of Sub-Saharan African women will develop cancer of the cervix and breast, whilst more than 2% of those diagnosed will die. Conversely, approximately 3% of men develop prostate cancer in their life time, with a case fatality ratio of 1:50 (Ferlay et al. 2014; Parkin et al. 2014).

The Republic of South Africa is one of the countries where lifestyle factors such as smoking and drinking alcohol contribute to an increase in the prevalence of cancer in the population. According to the Cancer Association of South Africa (2017), more than 14% of South African men are at risk of developing cancer, while nearly 12% of women are likely to develop cancer. The risk of developing cancer is the highest among Coloured and White men (25% each group) compared to the rest of the racial groups, while in women, the risk is highest among White women (20%) followed by Asian and Coloured women, with life time risk of approximately 14% in each group (National Institute for Occupational Health 2011). Prostate cancer is the number one cancer in South African men, accounting for approximately three in every 20 men with cancer, while breast cancer is responsible for more than 20% of all cancers in women (Cancer Association of South Africa 2017). In all racial groups, cancer of the prostate is the most prevalent in men, whilst women are mostly affected by breast cancer, except for Black women who suffer most commonly from cervical cancer (Cancer Association of South Africa 2017). According to the Cancer Association of South Africa (2017), an estimated 46% of all cancer deaths in the general population are caused by malignancies of the lung, oesophagus, cervix and breast. Lung, oesophageal and prostate cancers are the main causes of cancer-related deaths in men, accounting for an estimated 50%. Most of the cancer-related deaths in South African women are caused by cervix, breast, lung, oesophagus and colorectal cancers, accounting for more than 60% of all cancer deaths.

2.2.2 Causative factors

A number of studies have reported three major causes of cancer worldwide, tobacco, alcohol and infection by viruses (Bravi et al. 2014; Pytynia et al. 2014; Shingler et al. 2017).

Tobacco is the main cause of several cancers in the world and is attributed to an increased percentage of cancer-related death. Almost all patients diagnosed with lung cancer have a history of tobacco use of some kind, or have had exposure to secondary smoking. Approximately seven in every 10 lung cancer deaths in the developing world are attributed to tobacco and around 20% of the world cancer deaths are caused by tobacco (Torre et al. 2015). In addition, cancers of the head and neck and oesophagus have been highly associated with cigarette smoking or exposure to it (Shingler et al. 2017). Chiaffarino et al. (2016) also reported a strong association between tobacco use and an increased risk for gynaecological cancers such as uterine myoma and cervical cancer. Furthermore, the risk of developing oesophageal cancer is high among smokers compared to non-smokers (Oze et al. 2011). According to the review and meta-analysis conducted by Leonardi-Bee et al. (2012), smokers are at a greater risk for the development of cutaneous squamous cell skin cancer than their counterparts. Another systemic review of cohort and case control studies regarding the major risk factors for pancreatic cancer also singled out tobacco as the predominant risk factor (Matsuo et al. 2011).

Alcohol on its own is carcinogenic in nature and is associated with different anatomic site-specific malignancies. Alcohol use is responsible for approximately 4% of global cancer-related deaths (Nelson et al. 2013). People who drink alcohol heavily are more than three times at risk of developing cancers of the head and neck, especially the malignancies of the oral cavity, larynx and pharynx (Bagnardi et al. 2015). Alcohol on its own is the number one cause of tumours of the oesophagus and a standalone causative factor of cancer of the liver (Grewal and Viswanathen 2012; Bagnardi et al. 2015). In a number of studies related to alcohol as the causative factor for breast cancer, researchers have reported an increased risk of breast cancer amongst women who drink compared to non-drinkers (Bagnardi et al. 2015). Fedirko et al. (2011), in a meta-analysis, also reported a direct proportional increase of risk for colorectal cancer associated with the increase in alcohol intake.

Approximately 20% of all cancers diagnosed in the world are caused by infections, such as viruses (Jacqueline et al. 2017). There are a number of viruses that cause different human cancers including hepatitis B and C virus, human papilloma virus (HPV), Epstein-Barr virus (EBV), Kaposi's sarcoma-associated herpes virus (KSHV) and Merkel cell polyoma virus (Jacqueline et al. 2017). Shiels et al. (2011) reported a number of cancers that are directly associated with Human Immunodeficiency Virus infection, mainly Kaposi’s sarcoma and non-Hodgkin’s lymphoma. Human papilloma virus is an established cause of several gynaecological cancers, such as cervix, vulva and vagina, as well as penis cancer. Pytynia et al. (2014) reported an increased incidence of oropharyngeal cancers among patients who were infected by human papilloma virus, which concurs with the research results reported by Vokes et al. (2015).

2.2.3 Treatment modalities

The goals of cancer treatment are cure, control, palliative and supportive care (Siegel et al. 2012). A number of treatment modalities are used to treat the disease, including radiotherapy, surgery, biotherapy and chemotherapy (Itano et al. 2015).

More than 60% of cancer patients are treated with radiotherapy along their disease continuum (Miller et al. 2016). According to Itano et al. (2015), cancer patients can receive radiotherapy as either primary therapy, neoadjuvant or adjuvant therapy. Early stages of cancer have been associated with a high cure rate when treated with radiotherapy, while the late stages require more than one treatment modality to produce successful results (Miller et al. 2016).

In certain types of cancers, and in advanced stages of cancer where cure may not be possible, radiotherapy can be administered to control tumour growth, thereby controlling disease progression for a duration of time from months to years. The use of brachytherapy along with external beam radiation has been associated with good patient outcome in patients with cancer of the breast, prostate and the head and neck (Itano et al. 2015).

Although radiotherapy is intended to kill cancer cells, it has lethal effects on normal cells, which may be acute or late. Nearly all patients who receive radiotherapy will report general acute side effects, such as fatigue and skin reactions, which compromise their quality of life (Itano et al. 2015; Bray et al. 2016). These undesirable effects can be distressing and incapacitating to the patients, depending on the severity. In addition, research has reported severe acute and late site-specific side effects of radiotherapy, such as alopecia in relation to brain irradiation, oral mucositis in relation to the head and neck, and vaginal dryness, diarrhoea and cystitis related to pelvic irradiation (Radvansky et al. 2013; Bray et al. 2016; Kole et al. 2017).

Amongst the interventions that have been developed, none have proven effective in completely preventing these distressing side effects, only lessening the severity (Di Franco et al. 2013). The knowledge of the relationship between the dose of radiotherapy and the severity of the side effects has resulted in the discovery of fractionation of the dose to reduce the lethal impact on the normal cells (Modesto et al. 2012). In addition, patients are generally advised on skin care practices, which only help in lessening the severity and preventing complications (Itano et al. 2015). Clinical experiments have revealed that fractionated radiotherapy is associated with reduced damage to the normal tissue and more damage to the tumour cells, hence less side effects with increased cure rate (Wong et al. 2013). The other measure to reduce the fatal outcomes of radiotherapy is pre-treatment assessment to rule out the risk factors that may aggravate radiotherapy-induced side effects, such as poor

performance status and comorbidities (Modesto et al. 2012). Scientific investigations have shown that patients with poor performance status and who have a comorbidity often do not respond well to treatment compared to those with good performance status (Chan et al. 2014).

Radiotherapy in combination with chemotherapy or surgery has proven effective in treating many cancers with a good cure rate, however in many scientific investigations, patients have reported multiple severe acute and late side effects compared to radiotherapy alone (Kole et al. 2017).

Chemotherapy is the most common treatment modality widely used globally to treat different cancers. Unlike radiotherapy and surgery, which are localised treatments, chemotherapeutic agents are administered through the cardiovascular system to reach the tumour site, hence the name 'systemic treatment' (Siegel et al. 2012). Chemotherapy can be used as primary treatment as a single treatment modality, or in combination with other treatment modalities as an adjuvant or neoadjuvant treatment (Chabner and Longo 2011). The use of more than one chemotherapeutic agent with different modes of action in combination to treat cancer is an effective way of killing many cancer cells at different stages of the cell cycle (Miller et al. 2016). Apart from cure, some patients receive this treatment just to control the growth of tumour or to relieve the cancer-related symptoms, such as pain, depending on the stage of the disease (Mañós et al. 2017).

The fact chemotherapy does not only target cancer cells but also the normal rapidly dividing cells, results in a number of associated problems ranging from acute to late side effects, such as mucositis, cystitis, alopecia, myelosuppression and hand-foot syndrome (Itano et al. 2015). Side effects resulting from chemotherapy are not tumour site-specific for the reason that it is a systemic treatment (Siegel et al. 2012).

If the tumour is localised to a small area and can be removed without causing major complications, surgery can be utilised. Oncological uses of surgery, based on the purpose of the procedure, are treatment of the disease, diagnosis and staging, relief of symptoms, reconstruction and rehabilitation (Itano et al. 2015). Like any other treatment modality, surgery causes undesirable side effects, such as disfigurement, acute or chronic pain, loss of function of body parts, lymphoedema, organ damage and loss of body image (Galbiatti et al. 2013).

Laboratory research regarding the chemical processes within the tumour cells has led to the discovery of yet another treatment modality known as targeted therapies and biotherapies, which target the specific processes within the tumour cells and augment the immune system against cancer cells (Miller et al. 2016). Kawalec et al. (2012) in a systemic review reported

an increased survival rate and reduced side effects among the patients treated with targeted therapy. According to the American Cancer Society (2016), targeted therapy and biotherapy are effective treatments for a number of malignancies. Many of these therapies have been approved by the Food and Drug Administration for diagnosis, treatment and supportive therapy in cancer patients. Targeted therapy and biotherapy can be used as primary treatment in combination with other modalities, or as a single agent (Miller et al. 2016).

2.2.4 Survivorship in cancer patients

The term survivorship is used for the ability to meet bio-psychosocial needs in order to maintain health and quality of life beyond the diagnosis of cancer, to the end of life (Ringash 2015). According to the National Cancer Institute's dictionaries, cancer survivorship is concerned with how healthy life is lived after diagnosis and treatment of cancer including the impact of cancer on the psychosocial, economic and physiological domains of life (National Cancer Institute 2016). Cancer survivorship is also defined as the life experiences of cancer patients from diagnosis of the disease, throughout treatment and beyond the disease (Cancer. Net 2016) and includes follow-up treatment and healthcare, quality and quantity of life issues and late side effects of treatment. Itano et al. (2015) grouped these survivors into three main categories, which includes those who have just begun the treatment, those who are recovering and adapting to a new normal and those who are living with lifelong needs. Patients present with different and unique needs at each phase of survivorship. The current focus of survivorship is on the quality of life through management of disease and the treatment related side effects, and early detection of recurrent disease, while psychosocial and socio-economic needs of the patients are usually overlooked.

Around 12 million cancer patients survive over five years globally (Jacobs and Shulman 2017). Cancer survivors still live with the aftermaths of cancer and its aggressive treatments, which may result in increased survivorship needs (Siegel et al. 2012). The major concerns of cancer survivors are the fear that cancer might come back, late side effects of treatment and the challenge of facing a new life following the incapacitation caused by cancer and treatment (Ghazali et al. 2013). Conversely, the partners and family members of cancer survivors are concerned with life changes in their partners, which influences the way they relate to them, yet survivorship support is mainly focused on the patients (Turner et al. 2013). Young cancer survivors are mostly affected by psychosocial and fertility issues (Watson et al. 2016) and Howard-Anderson et al. (2012) reported the need to address fertility issues and physical inactivity, as they are major concerns among young cancer survivors. Psychosocial needs of cancer survivors are mostly neglected, yet they are the major determinants of quality of life among cancer survivors (Watson et al. 2016).

Health and quality of life during the survivorship period depends on the patient's related factors. Survivors who engage in health-promoting behaviour, such as physical activities, live a healthier life compared to those who live a sedentary life, however the level of activity is related to level of individual ability (Garcia and Thomson 2014). According to Becker et al. (2012), comorbidities negatively influence the outcomes of survivorship as cancer survivors with comorbidities live with poor quality of life and shortened life expectancy.

Survivorship care for cancer survivors has been in place since 1986 however, there are still challenges to meet the needs of the cancer survivors. Jacobs and Shulman (2017) identified care coordination, shortage of health professionals, lack of knowledge by practitioners and quality and cost of care as some of the challenges to meet the needs of cancers survivors.

2.3 AN OVERVIEW OF HEAD AND NECK CANCER

Head and neck cancers are the notorious cancers of the aero digestive region, which includes the pharynx, nasal cavity, paranasal sinuses, oral cavity, saliva gland and the larynx (Jemal et al. 2011). These cancers affect the vital anatomical parts, which are responsible for life-supporting physiological processes such as breathing, nutrition and verbal communication.

2.3.1 Incidence of head and neck cancer

Head and neck cancer is in sixth position on the list of leading cancers worldwide, but it is one of the deadliest cancers due to the importance of the anatomical structures involved (Bose et al. 2013). Approximately 650,000 people are newly diagnosed, while 350,000 people die of head and neck cancer each year globally (Gupta et al. 2016). Cancer of the head and neck constitutes 4% of all cancers worldwide and the burden of the disease is three times more common in males than in females (Jain et al. 2013). Bose et al. (2013) described the most common sites affected by head and neck cancer as the oral cavity, larynx and oropharynx, and 90% of these cancers start from squamous cells, hence they are commonly known as squamous cell carcinoma of the head and neck. The disease is at its peak among people between 50 and 70 years of age. Approximately, 4% (27,953) of all cancers in Africa are head and neck cancers, whilst more than 65% (18,835) of these patients die each year. The ratio of male to female remains close to that of the world, ranging from 0.5:1 to 1:4.

South Africa, as one of the developing countries, is highly affected by head and neck cancer due to life style factors, such as smoking and alcohol use (Fagan, Stannard and Dalvie, 2014). Tumours of the head and neck constitute more than 5% (4,045) of all cancers in the South African population, causing 1815 deaths each year. The most common sub-anatomic

site for the disease remains the oral cavity, followed by the larynx and the nasopharynx. According to the National Institute for Occupational Health (2011), 4.7% of all males newly diagnosed with cancer have head and neck cancer, compared to 2% in females. The disease has the highest incidence among males and is responsible for 7.75% of all cancers in Black males, 6.21% in Coloured males, 4.46 % in Asian males and 2.77% in White males. In females, the Coloured population has the highest incidence (3.31%) (National Institute for Occupational Health 2011; Singh et al. 2013). Head and neck malignancies affect people of all age groups, however it is more prevalent among women who are 80 years and older and among men between 60 and 64 years old (Ndui 2011; Abram 2013).

2.3.2 The structures of the Head and neck

The region of the head and neck comprises the oral cavity, pharynx, nasal cavity, paranasal sinuses, larynx, salivary gland and the tongue (Bose et al. 2013), as shown in the Figure 1 below.

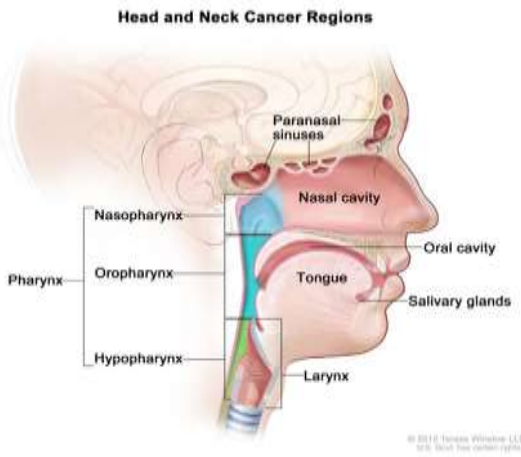

Figure 1: **The head and neck cancer anatomical sites.**
Source: National Cancer Institute (2017)

The oral cavity encompasses the lips, oral mucosa, anterior two thirds of the tongue, upper and lower alveoli, hard palate, floor of the mouth and retro molar trigone (Galbiatti et al. 2013) and also includes four pairs of the salivary glands, which are located in the different anatomical sites. The parotid glands are situated between the jaw and ear, submandibular glands are under the mandible or jaw bone, the sublingual glands are found on the floor of the mouth under the tongue and the buccal glands are found in the mucous membrane covering the oral cavity (Bose et al. 2013). The nasal cavity and paranasal sinuses encompasses the inner walls of the nostrils, the nasal vestibule, ethmoid and frontal sinuses, single sphenoid sinus and frontal sinuses (Gupta et al. 2016).

The pharynx is made up of three main anatomical sites, the nasopharynx, oropharynx and hypopharynx (Bose et al. 2013). The nasopharynx is the posterior wall behind the nasal cavity, while the oropharynx includes the base of the tongue, soft palate, posterior pharyngeal wall and tonsils. The inferior part of the pharynx is the hypopharynx, which makes up the posterior wall of the larynx.

The larynx, which is shielded by the thyroid cartilage, is from the epiglottis to the cricoid cartilage (Itano et al. 2015) and includes the supra-glottis, the glottis and sub-glottis (Gupta et al. 2016).

There are other vital anatomical structures around this area, but they are not categorised as part of the head and neck. These include the oesophagus, thyroid gland, parathyroid glands, the ears, bones and the eyes, which are likely to be affected by either cancer of the head and neck or the treatment (Gupta et al. 2016). The head and neck is also drained by a number of lymph nodes, including the pre- and post-auricular nodes, submandibular, submental, deep and superficial cervical chains, the tonsillar nodes and the occipital nodes. These lymph nodes become the first victims of head and neck cancer (Bose et al. 2013).

2.3.3 The life supporting functions of the head and neck region

The structures of the head and neck form the upper part of the respiratory system, which provides access to the external environment (Itano et al. 2015). These structures are responsible for removing dust and other particles from the inhaled air, providing warmth and moisture to the air before it reaches the lungs (Bose et al. 2013) and protecting the lungs from microorganisms and foreign bodies by trapping them using mucus and hair present in the nasal cavity and nasopharynx.

The olfactory nerves insert on the mucosa of the nasopharynx, which communicates with the olfactory cells within the mucosa, serves as the receptor for smell; this function helps to differentiate and classify different kinds of smells (Bose et al. 2013). The tumours of the nasopharynx or paranasal sinuses or associated treatment to these areas result in alterations or loss of sense of smell.

Speech is another important process that is a product of coordinated functions of the larynx, pharynx, mouth, nose and paranasal sinuses. These structures coordinate to form speech in three phases - phonation, articulation and resonation. Any cancer affecting these structures causes speech problems, or sometimes a complete loss of speech especially in malignancies of the larynx (Heijnen et al. 2016).

The anatomical structures of the head and neck also serve a nutritional function, whereby the oral cavity and oropharynx are the important structures for mastication and deglutination of

food (Itano et al. 2015). These processes cannot be possible if the structures are diseased, making it difficult for the person to ingest food via the mouth, resulting in malnutrition (Farhangfar et al. 2014).

The tongue is the only anatomical site where a sense of taste is accomplished. This function is achieved through the presence of taste buds on the tongue and other sites within the mouth, which are enervated by the trigeminal nerve (Bose et al. 2013). The trigeminal nerve is responsible for transmitting taste sensation to the gustatory cortex in the brain from the taste buds present on the tongue, roof of the mouth, sides of the mouth and in the throat (Itano et al. 2015). The most common causes of taste alteration or loss include malignancies of the tongue and treatment-related side effects such as surgery and radiotherapy to the head and neck (Isaksson et al. 2016).

The salivary glands, as described by Bose et al. (2013), are responsible for the production of saliva which serves to keep the mouth moist, to moisten dry food and to cool hot food. The saliva also contains the enzyme called saliva amylase, which is important for breaking down carbohydrates. Cancer of salivary glands or the treatment, such as radiation to the head and neck, can compromise the function of the glands resulting in xerostomia (Radvansky et al. 2013).

The thyroid and parathyroid glands are located in the area of the head and neck, as described earlier, and these glands produce thyroxine, calcitonin and parathyroid hormones (Bose et al. 2013). Thyroxine controls metabolism and acts as a growth factor for bone growth, while calcitonin and parathyroid hormones are responsible for regulation of calcium in the body (Itano et al. 2015). Either the head and neck tumours or the treatment's side effects can affect normal functioning of the above mentioned glands, resulting in disruption in hormonal regulation and electrolyte imbalance (Farhangfar et al. 2014).

2.3.4 Clinical Presentation

Patients experience signs and symptoms of head and neck cancer differently depending on the anatomical site from which the cancer arises (Itano et al. 2015). However, the common clinical signs and symptoms reported by patients are a lump or sore in the mouth that refuses to heal, difficulty with breathing, difficulty with swallowing, nasal bleeding, persistent nasal congestion, change of taste and unexplained change in voice (Galbiatti et al. 2013).

2.3.5 Histological classification of the disease

Histologically, the most common type of head and neck cancer is squamous cell carcinoma, which begins in the epithelial cells of the mucosa lining region (Bose et al. 2013).

Approximately 90% of patients are diagnosed with squamous cell cancer, while 10% present with adenocarcinoma or sarcoma (Jemal et al. 2011).

2.3.6 Staging of the disease

Like other tumours, staging of the head and neck cancers is based on the tumour size, number of lymph nodes involved and metastasis (TNM) (Gupta et al. 2016). Once the tumour is found, measurements are taken and the size is denoted by T followed by a number between 1 and 4 to represent the size of the tumour (D'cruz et al. 2013). Estimating the size of the tumour can be done clinically and a more accurate description can be done through computerised scans.

The cancers of the head and neck are likely to spread to the lymph nodes around the neck and the lungs. The number of lymph nodes involved influences the staging of the disease and is represented by N and a number between 1 and 4 to indicate how many nodes are involved. Patients who have had metastasis to the cervical nodes are more likely to develop another head and neck cancer after treatment (Deschler et al. 2014). Patients who have metastasis to the cervical nodes, compared to those who do not, have a reduced five-year survival rate, a reduction of approximately half (Huang and O'Sullivan 2017).

The staging for the disease is also measured by metastasis, whereby the presence of distant metastasis is denoted by M1, while its absence is represented by M0 (Galbiatti et al. 2013). Commonly, patients are diagnosed with the disease as a result of metastasis of cancers from other sites, such as breast, lung or the bowels, and it is recommended that head and neck cancer patients should be examined for the possibility of primary cancers from other sites (Bose et al. 2013). However, the disease has a common trend of metastasis and the most common anatomical regions that are affected are the lungs, breasts and the brain (Itano et al. 2015).

2.3.7 Etiological factors

A number of investigations have pointed out that tobacco and alcohol remain the major causes of head and neck cancer. Approximately 75% of head and neck cancers are caused by alcohol and tobacco use (Galbiatti et al. 2013). Different forms of tobacco use are attributed to different cancers of the specific anatomical sites in the head and neck area (Shingler et al. 2017). People who sniff or chew tobacco are prone to cancers of the nasopharyngeal and oral cavity areas respectively, while those who smoke tobacco are at high risk of developing cancer of the larynx, lips, oral cavity and oropharynx (Koyanagi et al. 2016). People who use tobacco are 25 times more likely to develop the disease compared to those who do not and those who consume excessive alcohol are nine times more at risk compared to those who do not drink alcohol (Bagnardi et al. 2015). According to Galbiatti et

al. (2013), a combination of these two risk factors poses a greater risk for the disease compared to one risk factor alone; people who use both tobacco and alcohol are at greater risk of developing this disease than those who use one or the other.

The increase in prevalence of head and neck cancer among non-smokers and young people has attracted the attention of researchers to discover viral infections as the cause of the disease. Recent studies have shown that infection with the human papilloma virus, especially types 16 and 18, increases the risk of developing malignancies of the head and neck area (Vokes et al. 2015). In a genetic study regarding the differences between HPV positive and HPV negative head and neck tumours, Seiwert et al. (2015) reported significant differences in the genetic mutations and the genes that are involved, which clearly indicates that HPV is an important risk factor. Globally, the incidence of HPV positive oropharyngeal cancers has roughly increased 20-fold, with an alarming increase of approximately 65% in North America (Gupta et al. 2016). Pytynia et al. (2014) reported that HPV is commonly the cause of specific cancers of the oropharynx, which include the base of the tongue, soft palate and the tonsils. According to Forte et al. (2012), the clear trends of HPV- associated oropharyngeal tumours can be understood when cancers of the oropharynx are examined separately from the rest of the head and neck cancers. According to Dayyani et al. (2010), HPV- associated carcinomas of the head and neck are more sensitive to chemo-radiation with good prognosis and increased survivor rate compared to tobacco and alcohol associated disease.

Rettig et al. (2015) and Shah et al. (2017) reported that the practices of oral-genital sex and multiple sex partners are high among patients with HPV-related oropharyngeal cancers, which denotes that these behaviours increase the infection rate of HPV resulting in increased prevalence of HPV related disease. However, researchers have observed that more than 60% of HPV positive oropharyngeal cancer patients are either exposed to tobacco or are previous smokers, and the trend of HPV-related disease among men and women is 3:1, which is no different to the trend in tobacco and alcohol-related disease suggesting that HPV is not fully understood as a risk factor for head and neck carcinomas (Forte et al. 2012).

2.3.8 Treatment of head and neck cancer

Depending on the stage of the disease at the time of diagnosis, head and neck cancers are curable. The important treatment options available for the disease include surgery, radiotherapy and chemotherapy. To make a decision regarding the best treatment modality to use depends on factors such as the location of the tumour, stage and type of the disease, and the anticipated side effects of the disease (Galbiatti et al. 2013). According to Gupta et al. (2016), more than 60% of patients diagnosed in the early stages of head and neck cancer respond well to local treatment while those diagnosed in the late stages require combined treatment modalities. The treatment decisions for carcinomas of the head and neck require a

multidisciplinary approach to minimise treatment-related side effects and improve the patient's quality of life after treatment (Mañós et al. 2017).

2.3.9 Complications of the disease and associated treatment

Head and neck cancer and its treatment are associated with a number of complications which may be life threatening and lifelong. Nearly all patients who are affected by tumours of the pharynx will experience airway obstruction requiring lifelong tracheostomy (Galbiatti et al. 2013). Most of these patients with cancers of other sites of the head and neck, other than the larynx, also lose the ability to articulate words properly and eventually they lose speech as the disease progresses (Heijnen et al. 2016). Usually, cancers of the oral cavity, nasopharynx, pharynx and nasal cavity interfere with patient's ability to chew and swallow, resulting in patients surviving with a gastric tube (Paccagnella et al. 2010).

Patients who undergo surgery are likely to live with the aftermath. During surgical procedures, nerves and lymph vessels may be destroyed or cut, resulting in numbness and oedema around the neck and throat, which may affect swallowing (Gupta et al. 2016). According to Galbiatti et al. (2013), major surgery for tumours of the head and neck causes disfigurement, resulting in a change of appearance. Laryngectomy, which is surgical removal of the larynx for treatment of cancer of the larynx, usually causes the patients to permanently lose their voices, which is a big challenge to human interaction (D'cruz et al. 2013). Some major operations involving the ear or eye can result in a loss of function of these organs, which may be temporary or permanent (Deschler et al. 2014). Cooper et al. (2012) reported that surgery to the head and neck area often results in a patient having lifelong or acute difficulties in chewing and dysphagia, and eventually they live with a gastric tube for feeding for the rest of their lives. Nearly all patients who undergo a total laryngectomy will develop serious metabolic problems, such as hypothyroidism and calcium imbalance, due to the involvement of the thyroid and parathyroid glands (Cooper et al. 2012).

Patients who are treated with radiotherapy usually present with severe specific side effects due to the delicacy of the anatomical structures involved. According to Radvansky et al. (2013), patients who receive radiotherapy for tumours of the aero-digestive region often report taste changes, dysphagia or voice changes due to the lethal effects of radiation on normal cells in this region. Often patients complain of xerostomia and mucositis, which are very distressing symptoms, resulting in reduced oral intake (Radvansky et al. 2013). Usually patients who are treated for cancer of the paranasal sinuses, nasopharynx and nasal cavity will complain of earache, or loss of hearing and sight due to the involvement of the ear and eye in the field of radiation (Reyes–Gibby et al. 2017), which results in the death of normal cells within these organs. Studies have also shown that patients receiving radiotherapy for cancer of the larynx are likely to develop hypothyroidism three to four weeks post treatment,

related to the damage of the thyroid gland by radiotherapy (Gupta et al. 2016). Heijnen et al. (2016) also reported trismus as one of the serious late side effects of radiotherapy caused by scarring of muscles of mastication due to the effects of radiotherapy.

2.3.10 Survivorship Issues

Current statics have shown that the number of survivors from head and neck cancers has increased worldwide due to improvements in treatment modalities (Ringash 2015). Survivors from malignancies of the head and neck area are a unique group with complex needs due to the complications associated with the disease and treatment (Becker et al. 2012). Simcock and Simo (2016) reported the uniqueness of these survivors is that most live with artificial life-supporting structures, such as tracheostomy or feeding tubes, resulting in changes in lifestyle that affect all spheres of their life.

Approximately, 68% of head and neck cancer survivors live with needs that require attention from health professionals and the most common identified needs are related to psychological and physical domains (Nekhlyudov et al. 2017). In another survey regarding unmet needs among head and neck cancer survivors, more than half of the patients reported at least one need that required attention (Ringash 2015). Simcock and Simo (2016) identified the most common needs presented by head and neck cancer survivors as psychosocial and physiological, which persist from diagnosis to beyond treatment. Siegel et al. (2012) reported most psychosocial and physical needs among survivors of head and neck malignancies are due to disease and treatment-related complications, such as permanent hearing loss, loss of speech, fatigue, disfigurement and financial costs. Mostly, the psychosocial and physiological domains are highly rated attributes of quality of life among survivors of tumours of the head and neck, with most of the needs arising from the psychosocial domain (Cohen et al. 2016). However, evidence has shown that health professionals prioritise physical problems and disease control as most important issues while patients' psychosocial needs remain unmet (Becker et al. 2012).

In a literature review, Pulte and Brenner (2010) reported that the overall five-year survival rate for head and neck cancer improved by more than 10% in the 14-year period from 1992 to 2006. However, most patients who continue drinking and smoking during and after treatment will not live for five years (Becker et al. 2012). Continued drinking and smoking during and after treatment have also been associated with high risk for recurrence of the disease and poor prognosis (Simcock and Simo 2016). In a study to compare five-year survival rates, Dayyani et al. (2010) reported a good prognosis and an increased survival rate in HPV-associated tumours compared to those related to tobacco and alcohol.

2.4 SUMMARY

Chapter 2 presented a literature review regarding cancer as a global, sub-Saharan and South African problem, with the focus on head and neck cancer. The focus on head and neck cancer included statistics, anatomical site and function, the predisposing factors, staging and treatment, the side effects of the disease and treatment and survivorship. Chapter 3 will discuss the research design and methods.

CHAPTER 3:

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

Chapter 3 will discuss the research design and methods that were used to answer the research question. Research methods are a framework for data gathering, management and analysis of data including trustworthiness and ethical considerations (Smith 2015). Therefore, this chapter presented the research design, population and sampling, data gathering process, data analysis, ethical considerations and trustworthiness.

3.2 RESEARCH SETTING

The study setting is defined as a description of the location or the environment in which the study is done (Burns and Grove 2010). The study setting was an academic hospital in the Gauteng Province, which provides highly specialised services and serves as referral hospital for regional hospitals, neighbouring hospitals and patients from the rest of Africa. According to South African Doctors (2017), the hospital has a capacity of 1088 beds and over 4,000 professionals and support staff. The hospital has 18 clinical departments and allied medical departments. The hospital provides specialised services for Oncology, Nephrology, Trauma, Cardiology, Intensive Care, Surgery, Obstetrics and Gynaecology. Various departments, including the Adult and Paediatric Oncology Departments are centres of excellence(Gauteng Provincial Government 2014). The hospital is a training institution for both undergraduate and postgraduate students from the University of Witwatersrand, Faculty of Health Sciences and other universities and colleges in the Gauteng Province. According to the Gauteng Provincial Government (2014), the Radiation Oncology Department is the largest oncology facility in South Africa and treats approximately 3,500 cancer patients per year. The hospital provides brachytherapy, external beam therapy, chemotherapy and surgery for cancer patients.

3.3 RESEARCH DESIGN

The research design is the main framework that guides the selection of suitable research methods to answer the research question in a study (Wahyuni 2012). It helps the researcher choose the suitable sample and sampling method, data gathering tools, data analysis method and methods of ensuring trustworthiness in a study (Yin 2013). In this study, a descriptive qualitative design was used to answer the research question. According to

Sandelowski (2000) and Polit and Beck (2012), qualitative description is a method that aims at giving a comprehensive summary of events surrounding a phenomenon with no intention of interpretation. Sandelowski (2010) recommends the use of qualitative description in situations where little is known about a phenomenon, in order to gather baseline data for further research.

Sandelowski (2000) considers qualitative description as the “least theoretical in the spectrum of qualitative approaches” [p. 337], as this approach is the least burdened by pre-existing theories such as philosophies. Qualitative descriptive studies support the beliefs of naturalistic enquiry where there is no pre-selection or manipulation of variables and no prior commitment to any theoretical or philosophical view. Using a descriptive qualitative design allowed the researcher to provide baseline data pertaining to the experiences of patients living with cancer of the head and neck without the influence of a pre-existing theoretical framework.

3.4 POPULATION AND SAMPLING

A research population refers to a group of individuals or objects with similar characteristics on which the study is focused (Polit and Beck 2012). The population is described in terms of a target and an accessible population. The target population is a group of individuals with characteristics to which the study conclusions are inferred, while the accessible population is a group of individuals which meet the selection criteria and are accessible to the researcher (Banerjee and Chaudhury 2010). The target population for this study comprised all patients diagnosed with cancer of the head and neck, while the accessible population were all head and neck cancer patients who were treated at the hospital where the study was conducted. The inclusion criteria were being treated and completed treatment for head and neck cancer, 18 years and older, the ability to speak basic (simple) English and willing to participate in the study.

A sample is defined as a manageable portion of the population that is used in a study to describe the characteristics of interest to represent the whole population. A sample size refers to the number of participants required for the sample. The sample for this study was determined by data saturation, a point where adding more participants would result in redundancy of information (Polit and Beck 2012). Data saturation defines the sample limit in qualitative studies because adding more participants after data saturation does not add any value to the research results (Fusch and Ness 2015). Data saturation was reached after 18 interviews and the sample size was therefore 18 (n=18).

Sampling is a method used to recruit participants for the study, selected based on suitability to the design of the study (Suri 2011). Purposive sampling, which is a non-probability sampling technique in which the participants are selected by the researcher based on the characteristics of the population and the objective of the study (Polit and Beck 2014), was used to select the sample for this study. Etikan et al. (2016) described purposive sampling as one of the cardinal features of descriptive qualitative studies and as the recommended sampling technique for descriptive qualitative design. The goal of purposive sampling is to include participants who are rich in information for the purpose of the study (Sandelowski 2000; Lambert and Lambert 2012).

3.5 DATA GATHERING

Data gathering is about processes and instruments used to gather information from the participants for a study (Polit and Beck 2014). After obtaining ethical clearance from the university (No: M170469) (Annexure C) and permission from the hospital to conduct the study (Annexure D), the researcher recruited the participants. The patients' files were reviewed at the head and neck cancer clinic to identify eligible participants based on the inclusion criteria and patients who met the inclusion criteria and waited for transport provided by Cancer Association of South Africa after their scheduled doctors' review, were approached and invited to participate in the study. Participation was voluntary. Nineteen patients were approached; one patient was not comfortable with the recording of the interview and refused participation. An information sheet (Annexure A) was handed to those who were willing to participate and the study was explained to them, thereafter informed consent was obtained. Eighteen patients were included in the study (n=18).

Once informed consent was obtained, general information was gathered (Annexure F) followed by unstructured interviews. Unstructured interviews are interviews in which questions are not prearranged and is the suitable method of data gathering in a study whereby little is known about the subject under study (Doody and Noonan 2013), as was the case in this study. One opening question was posed: *Please tell me what is it like for you to live with cancer of the head and neck* (Annexure G). Probes and prompting questions followed, based on the participant's answer, in order to clarify issues and enhance an in-depth description of the participant's experiences (Polit and Beck 2014). The first interview pre-tested the question. Hurst et al. (2015) defined pre-test interview as an interview designed to determine if the question is clear to the respondents and their understanding of the question. The purpose of pre-test interviews is to refine the question with regard to the length of interviews, language clarity and cultural acceptability of language used (Doody and

Noonan 2013). The participant understood the question well and no changes were made to the question. The data gathered during this interview was included in the analysis.

The interviews were conducted in a private room to ensure comfortability, privacy and confidentiality (Health Profession Council of South Africa 2015), allowing the participants to feel free to give honest information regarding their experiences. The interviews were recorded using a digital voice recorder, which is one of the recommended tools for capturing information from informants during interviews (Doody and Noonan 2013).

The researcher, a male registered nurse and a Master's student in the field of Oncology and Palliative Care nursing, was practicing in the Oncology Unit before and during the data gathering. The data were gathered by the researcher between 1st November 2017 and 21 December 2017 and the interviews lasted on average 45 minutes.

3.6 DATA ANALYSIS

Data analysis is the process of creating meanings from data, and in qualitative research it involves building themes from ideas and making conclusions about the themes (Bazeley and Jackson 2013). Qualitative content analyses, the preferred method of analysing descriptive qualitative data (Sandelowski 2000; Vaismoradi et al. 2013) was used to analyse the data. An inductive approach was used due to the lack of knowledge about the topic (Elo and Kyngäs 2008). The data were analysed following the six steps as described by Smith and Firth (2011).

Step 1: Verbatim transcription

Transcription began by listening to the recorded information repeatedly. The voice recorder was paused to allow for transcribing the information word for word, as it was heard. After the transcription, the process was repeated in order to capture any possible missing information during the initial process. Each transcript was identified by the same number as the one assigned to the recorded information for easy identification.

Step 2: Understanding the data

The transcripts were read and re-read until the data were clear to the researcher before an attempt to identify main ideas was made to gain familiarity with the data (Jolley 2013). Transcripts needing clarity were given clarity by listening to the corresponding recorded information again and re-reading the transcript, whereafter changes were made on the transcript where necessary to make complete sense of ideas.

Step 3: Identifying the main idea

The main ideas were noted by using highlighters of different colours, while headings and notes were written in the margins of the transcript. This process of reading and identifying ideas was done repeatedly to ensure that no headings describing all aspects of the content were missed.

Step 4: Grouping the ideas into sub themes

Headings and ideas from the different transcripts were recorded on separate sheets of paper. The ideas were carefully studied to identify relationships among them and those that fell under the same category were grouped to form a sub-theme. The list of ideas was read repeatedly to make sure the ideas were grouped into meaningful sub-themes and to ensure no ideas were misplaced.

Step 5: Building main themes

The sub-themes were critically examined to identify those that were communicating the same sense and similar sub-themes were combined to form main themes. Unrelated sub-themes were carefully re-examined to look for a possible relationship among them so that they could be grouped into one group and represented by one theme. The process was revisited repeatedly until all the sub-themes were built into main categories.

Step 6: Identifying main themes

The grouped sub-themes and supporting ideas were scrutinised carefully to identify higher order headings that fit each category of the sub-themes. Each category was then represented by higher order headings as the main theme.

The researcher analysed the data with the assistance of the supervisors. The researcher used reflexivity to ensure the results of the study were not affected by his personal beliefs and pre-conception. Reflexivity is the process of understanding oneself as a researcher in relation to the study, in that beliefs, preconceptions and assumptions of the researcher are examined in relation to the study (Haynes 2012). According to Palaganas et al. (2017), reflexivity involves paying systematic attention to the details of knowledge construction at each stage of the research process.

3.7 TRUSTWORTHINESS

Trustworthiness refers to the exposition of the true value of the research results and the strong relationship between the data and the conclusions made (Elo et al. 2014). In order to enhance trustworthiness in this study, Guba’s constructs of ensuring trustworthiness,

credibility, transferability, dependability and confirmability were used (Shenton 2004; Thomas and Magilvy 2011).

3.7.1 Credibility

Burns and Grove (2010) described credibility as the correctness or accuracy of the research findings in the eyes of other experts in research. In order to address credibility, the research methods used in this study were adopted from previous methods, which had been used successfully in previous studies with similar research questions. The sample for this study composed of participants from different racial and cultural backgrounds and age groups to ensure triangulation of data sources. Polit and Beck (2014) defined data source triangulation as using data gathered from multiple sources based on space, person and time. Person triangulation which involves gathering data from different types of people for the purpose of ensuring credible data through multiple perspectives as guided by Shenton (2004) was used in the current study as described above.

The proposal of this study was peer reviewed. Frequent discussion sessions between the researcher and the supervisor, who is an expert in research, were conducted throughout the study to review the progress of the study and for advice.

The participants were purposefully selected based on specific inclusion criteria and participation was voluntary, allowing the gathering of true data from participants who were genuinely willing to share their story. Probes and follow up questions were asked after the open-ended question in order to gather comprehensive data. To ensure familiarisation with the research setting, the researcher practiced at the research setting for more than three months prior to the data gathering process. Data gathering proceeded until saturation was reached so that important data regarding the research question were gathered. During the interviews, a summary of the information obtained was repeated and the participants were asked whether this was a true reflection of their story so that only the participants' views of the experiences were gathered.

3.7.2 Transferability

According to Polit and Beck (2012), transferability is the extent to which the research results can still hold true in other settings or contexts. In the current study, the research setting, research methods and the participants' characteristics were described in detail, which allows the readers to judge the conclusions and make a decision as to whether or not to use the results in their setting (Thomas and Magilvy 2011).

3.7.3 Dependability

Dependability refers to the consistency and repeatability of the research findings under the same conditions (Jolley 2013). To enhance dependability, a full description of the research method, and how the conclusions were reached, were included in this research report so that interested parties could easily follow the source of the conclusions. The same open-ended question was asked to all participants, to ensure consistency, and probes and follow up questions were asked depending on the participants' answers to ensure rich data were gathered.

3.7.4 Confirmability

Confirmability is the evidence that the research findings are the true reflection of the data gathered (Thomas and Magilvy 2011). An audit trail was developed through a full description of the study's steps to allow other researchers to judge the conclusions made from the research data.

3.8 ETHICAL CONSIDERATIONS

Research ethics refers to considerations that the researcher undertakes to ensure protection of human participants from harm, respect for their rights and maintenance of their personal privacy and confidentiality. In order for this study to be conducted in an ethical manner, the researcher followed the Health Professions Council of South Africa's general ethical guidelines (Health Profession Council of South Africa 2015), which include ethical values, standards and principles.

3.8.1 Procedural ethics

In order to ensure formality of this study, the research proposal was presented to the Department of Nursing Education for peer review to assist with clarification of ethical issues. The proposal was also approved by the University of Witwatersrand Postgraduate Committee, the Human Research Ethics Committee and the authorities at the research site. Data in the form of written records are kept in a double locked cabinet and data in soft copy are kept in a password protected hard drive to prevent unauthorised access to participants' information. Data is to be kept for a minimum of two years after publication of an article and no data will be taken out of South Africa (Britz and le Roux-Kemp 2012).

3.8.2 The research field ethics

The principle of respect for persons demands respect for participants' autonomy and confidentiality throughout the study. The information regarding the purpose of the study, risks and benefits of the study and the procedure of data gathering were given to the participants

in order for them to make informed decisions about participation. The participants were informed that they were free to ask questions, which would be answered, regarding participation in the study.

Written informed consent for participation and for recording data by means of a voice recorder was obtained from the participants (Annexures B and D). The participants were informed of their freedom to withdraw their participation at any time without any punishment or denial of their privileges as patients and no participant was coerced to take part in the study. Anonymity of the participants was observed by assigning pseudonyms to the participants, which were used throughout data gathering and reporting. Data are kept in password protected hard drive and the transcripts are kept in double locked cabinet to prevent unauthorised access The principle of best interest demands the protection of research participants from harm and the researcher must act in a way that promotes good for the participants. No physical harm was anticipated, however sharing of experiences could have led to emotional distress therefore, arrangements were made with a specialist mental health nurse to counsel patients if the participant wanted to referred at any point during or at the end of the interviews. Five participants broke into tears during interviews and the researcher allowed them time to expend their emotion and later asked if they wanted to be referred to someone and if it was okay to continue with the interviews. However, none of the affected participants wanted to be referred for counselling and allowed the interviews to continue to the end. At the end of the interview, the affected participants were asked if they wanted to be counselled and all of them responded that it was not serious and they did not want to be referred for counselling.

The principle of justice in research demands fair treatment of participants during the study period and equal benefits and burden of the research. Justice was achieved through selection of participants based on the inclusion criteria which did not segregate patients based on their social status or vulnerability. Patients who declined to participate or withdrew their participation were treated the same way as those who participated without segregation or prejudice. It was anticipated that the findings would help health practitioners to have an insight of the experiences of patients with head and neck cancer, which would enable them to provide evidence-based care to all patients suffering from the disease.

3.9 SUMMARY

In summary, Chapter 3 presented the research design and methods, which included the population and sampling, data gathering, data analysis, trustworthiness and ethical considerations. Chapter 4 will present the research findings and discussion.

CHAPTER 4:

RESULTS AND DISCUSSION

4.1 INTRODUCTION

Chapter 3 presented the study design and methods, measures to ensure trustworthiness and the ethical considerations. This chapter will be centred on the findings of the study and the discussion. The findings will include participant characteristics, a description of major themes, the discussion and a summary.

4.2 THE PARTICIPANTS

Eighteen people (n=18), of which more than half were males (14 of 18), consented to take part in the study. The participants were from four major population groups, with the majority from the black population (13 of 18). Their ages ranged from 26 to 73, with an average age of 50.8 and a standard deviation of ± 13.6 years; the median age was 51.8 and the modal age classes were (40-49) and (50-59). The largest number of participants were married and unemployed (10 of 18); half had an income of less than the breadline indication of R779 (Business Report 2015). More than half of the participants had at least attended high school (11 of 18). Some participants had gastric tubes for feeding (3 of 18), while others had tracheostomies (2 of 18), and their duration of sickness ranged from 3 months to 72 months with an average of 18 months; most (11 of 18) had lived with cancer of the head and neck for 24 months. Half of the participants were treated with radiotherapy and chemotherapy, while the rest were treated with other treatment modalities such as surgery alone, radiotherapy alone, chemotherapy alone or combination of the three (Table 4.1). Some participants were still on treatment (8 of 18) while the rest completed the treatment (10 of 18).

Table 4.1 Participants' demographic data

Pseudo name	Age	Gender	Level of education	Marital status	Diagnosis	Treatment	Monthly income level versus breadline
Alex	72	Male	Grade 12	Married	Ca oral cavity	Radiotherapy	Above
Allan	55	Male	Grade 8	Single	Ca oral cavity	Radiotherapy	Below
Anna	63	Female	Grade 8	Married	Ca palate and sinus	Chemotherapy Radiotherapy	Below
Arimedin	68	Male	Grade 4	Married	Ca larynx	Chemotherapy Radiotherapy	Above
Austin	68	Male	Grade 8	Married	Ca soft palate	Chemotherapy Radiotherapy	Above
Ben	54	Male	Grade 9	Single	Ca oropharynx	Chemotherapy Radiotherapy	Below
Dan	43	Male	Grade 12	Married	Ca nasopharynx	Chemotherapy Radiotherapy	Below
Esther	35	Female	Grade 10	Married	Ca buccal	Surgery	Above
Evans	28	Male	Grade 4	Married	Ca oral cavity	Surgery Radiotherapy	Below
Jack	61	Male	Grade 12	Married	Ca nasopharynx	Radiotherapy Chemotherapy	Above
James	29	Male	Grade 12	Single	Ca nasopharynx	Chemotherapy Radiotherapy	Above
Leah	54	Female	Grade 11	Married	Ca nasopharynx	Chemotherapy Radiotherapy	Below
Liam	42	Male	Grade 8	widower	Ca oral cavity	Radiotherapy	Below
Max	43	Male	Grade 12	Married	Ca larynx	Surgery Chemotherapy Radiotherapy	Above
Mc duff	59	Male	Grade 12	single	Ca tongue	Chemotherapy Radiotherapy	Above
Mercy	26	Female	Grade 10	Single	Ca oral cavity	Chemotherapy Surgery Radiotherapy	Below
Norman	43	Male	Grade 12	Single	Ca nasopharynx	Surgery Radiotherapy	Below
Xolan	56	Male	Grade 7	Married	Ca tongue	Radiotherapy	Above

*** Above the breadline = more that R799 per month** (Business Report 2015)

4.3 THEMES ARISING FROM DATA

Two themes and five subthemes arose from the data and are summarised in Table 4.2

Table 4.2 Themes and subthemes arising from the data

Theme	Subtheme
Living with the consequences of the disease and treatment.	Emotional effects of the head and neck cancer. Physical consequences of the disease and treatment. Socioeconomic implications.
Coping with a changed life.	The importance of psychosocial support. The importance of hope and spirituality.

4.3.1 Living with the consequences of the disease and treatment *"My life has undergone a horrible twist…"*

Subtheme 1: The emotional effects of the head and neck cancer

Most of the participants agreed that learning their diagnosis was a shocking experience, which led to negative emotional responses such as fear, uncertainty, isolation and even thoughts of suicide. Allan explained, "*When I was told that I have this disease, ijoh! it was painful my brother. I was thinking to make a suicide…I was always alone thinking of this thing and I was isolating myself from the family but now I am okay.*" James added, "*To me, I was surprised because no one at home has got cancer or anything related to it, I am the first person at home… so eeeh! … so everyone is busy asking me if no one had cancer before whether I took it from them or what but there is no one at home, I was the first one to have cancer so I was surprised…*"

Experiencing the distressing symptoms of the disease and not knowing the cause, made learning about the diagnosis easier for some participants and gave them hope. Ester explained, "*They told me that it was buccal cancer… I just appreciated it because there are some other diseases that are worse than this…Umm, I just took it like you know, if they see it, I was happy because before, for this sickness, I didn't know what was happening with me, so I was happy about that. So far I am happy because I know that what is happening inside is cancer and I am happy because I know that if something is seen and the doctor know that it is cancer then it can be treated and so on and so on."* In addition, having previously suffered from cancer also made learning the diagnoses easier. Anna said, "… *the result*

came out and they said that it was cancer of the sinus. But after that, aahmm… you go on living, you understand what I mean, because when I had breast cancer it was a shock because I was told that when you got cancer then you are going to die but after that I am still alive up to five years after treatment now and then I got this sinus cancer..."

Living with the disease was not easy. The lives participants knew before they became ill changed and they experienced their lives as a "living hell," "difficult," and "something is lost." Alex said, *"It's very painful…Sometimes it makes me very low, down, and you think, why does it happen to me because I was a person that was very health, I had no troubles and now all over sudden why all this…"* Dan agreed and said, "*It is painful, my life is no longer the same….it is difficult to live with this cancer because every time when you are happy you get pain so difficult to live with it. It is affecting me more because enjoy my life the way I used to do… life is like a living hell and I feel like I have lost everything."* Arimedin added, "*[sobbing] You know, you can't feel good, you can't feel good because you can't do things that you used to do, you know, it is so worrisome."* However, participants were also pragmatic about their illness and experienced it as merely another illness and part of life. Esther said, "*Aah, you just get used on it and you just tell yourself that it is part of life… there is no any other thing you can do, it's just part of life, it's another sickness that you can be with."*

Receiving treatment did not console all the participants, some felt uncertain about the treatment, and if it would result in a positive outcome. They also feared disease recurrence despite the fact they received treatment. Even the slightest discomfort in their head and neck region created fear that the disease had recurred. Alex explained, "*Yeah I was very much concerned, I was very much worried… there was always at the back of my mind, whether I am gonna make it or I am not gonna make it…whether this treatment is gonna be successful thus what makes me worried."* Austin said, "*It makes you worried, it does make you worried. When you get a little pain in the throat during radiation, you think it is coming back but it does a bit does affect the mind…"* Norman added, "*So it affects you, you see, because there is this thing what they call it recurrence after the treatment… even if when you ask the doctors, there is no guarantee that the disease won't come back, you see... So cancer affects you, knowing that even cancer has been treated but it is very much possible that it can come back that is one thing really that affects, hmm I mean one's psychological."*

Subtheme 2: The physical consequences of the disease and treatment

The participants agreed the cancer and its treatment resulted in severe suffering. Chronic pain was one of the most distressing symptoms the participants experienced. Esther said, "*Well, like when this thing started, it was just like a small pimple then… when I opened my*

mouth I just saw there was very reddish veins… the thing was very painful like fire, I couldn't even sleep on my left cheek and I used to sleep on my right hand only…" Allan said, "*Hmm it's painful, you can't stand it… every time you must drink tablets in order to be free from pain.*" James agreed saying, "… *for me it was only this disease like I was feeling pain like daily, the whole day so like I was drinking pills almost like every time..."*

Participants who received radiotherapy developed mucositis, which was responsible for severe pain in the mouth and throat. The participants described it as having a "sore mouth," "ulcers" and "swelling tongue." Pain in the mouth and throat resulted in severe eating problems such as dysphagia, anorexia and difficulty with chewing. Alex said, "…*it's very painful… I can't eat properly and I have completely lost my appetite… I eat only soft food, I can't drink coffee as I used to...*" Dan also added, "*It is painful… during the treatment I was sick, I could not eat properly…I had mouth sores and they were very painful…Yes, my food is always soft… I mustn't drink cold drinks and all food that contain acids I don't eat it…it was difficult to eat anything."*

The participants experienced other complications because of the radiotherapy, such as xerostomia and trismus. Jack explained, "*I think my saliva is becoming thicker and I don't know if I will be able to cough as treatment goes on*…" Ben added, "…*though physically I am not hundred percent as before. I am still encountering minor problems such as dry mouth, heartburn, cramps, stiffness of the neck, you know, uncomfortable. These are things that I encountered after I had undergone this kind of treatment*." Anna said, "*I took my radiation; after treatment I am not on any medication because I don't have any pain…. it's just that I can't open my mouth here and there…"*

Eating was a major problem for the participants and having to remove their teeth prior to radiotherapy caused emotional distress. Not only did the absence of teeth affected chewing, they were also not able to eat some foods. Evans said, "… *so I can't eat properly…I am affected because I am not eating nicely…all my teeth are removed before treatment because the doctor said so and there is a hole in the roof of my mouth… hmmm, because of the disease and radiation."* McDuff added, *"They also removed all my teeth because of radiation… and I don't know whether they are going to put false teeth for me or not."*

Some participants had to live with feeding tubes, which added to their suffering. Participants described living with a tube as "eating without satisfaction," "selective eating" and "admiring nice food that I cannot eat." Evans said, "…*I eat with the tube…I am affected because I am not eating nicely, yeah my stomach is not full…It affects me… it affects me because my stomach does not get full…. Sometimes this tube can block and I cannot feed properly. Hhmm I don't eat any food like I used to do before the sickness...*" Liam added, "*I can't do*

nothing in the mouth and the doctor put the tube for me to eat…You see, what food I am eating, only liquid. This bread I want to crush it, crush it, it must be liquid. I am taking meal like this in morning, lunch and in evening."

Not being able to eat caused persistent fatigue expressed as "weakness" and "tiredness." In addition, participants experienced severe weight loss described as "*I have remained with bones only," "I am not strong as I was" and "all my flesh is gone."* Severe weakness and weight loss had negative influence on participants' emotions and added to their emotional distress. Alex described his experiences, "*Well, it's very painful, the thing is that I am losing weight, I can't eat properly…"* Jack added, "*I feel pain in my heart…I feel troubled because I have lost weight, I am not strong anymore because I don't eat enough. I admire when I see others eating well but there is nothing I can do…You know, I used weigh more than 80 kilos but now I am weighing less than 65 and all my good looking self is gone because my flesh is gone and I have remained with bones only as you can see. All this is because I am not eating enough…"*

The physical consequences of the disease and treatment also caused severe communication problems for the participants. Some of the participants could not pronounce certain words, some lost their voices and some lost their speech completely. Evans explained, "*You know my voice cannot come out nicely, I can't say some words nicely and other peoples cannot hear what I speak. I have to repeat many time before someone can hear me…hmmm when I am with my friends I cannot chat properly because they cannot hear me and hmmm there is nothing I do to help it..."*

The facial disfigurement some participants experienced had severe negative consequences on participants' body image. Some participants covered the disfigured part with a mask or cloths and some wished they could just die. Mercy said, "*Mmm sometimes, when I finished the operation, I wish I could die… this thing is in my face and people look at me, some judge me calling me that I am HIV, you see it is not easy…"* Max explained, "…*so the whole area of radiation is now hard like a rock, it will never come right, the doctor said it will never come right…because my operation my eye is not on the straight position and my mouth in skewed to one side like this…you see my mouth is going this way… and then also it's nerve and all those stuff were cut off in order to take off this thing."* Dan added, "…*they took it away, my nose, because of the disease and you see I have been putting on the mask, just to cover up… shame, so that other people should not see what has happened to my face."*

Subtheme 3: The socioeconomic implications of the disease and treatment

The emotional and physical implications of head and neck cancer had a negative influence on the participants' relationship with other people. The participants were stigmatised,

rejected by their friends out of fear of being infected with cancer and even mocked because they were unable to speak clearly. James said, "…*at the start they were surprised, but like there is one thing that keeps making me laugh because my friends are telling me that I could give them because this cancer can be passed on from one person to the other. So they think that they could get it from me, yeah, thus the only thing they talk about*." Dan added, "*Hmmm when I am with my friends I cannot chat properly because they cannot hear me and hmmm there is nothing I do to help it…They tell me that I just have to keep quiet because they can't hear me and some them feel bad it and some do understand my problems. But it is difficult live among friends with this problem…Sometimes I just walk away because I feel that it is all my fault, sometimes I just stay with them while feeling bad just to keep company with them..."*

The weakness, pain and facial disfigurement the participants experienced led to relationship problems. They agreed that pain and persistent fatigue negatively affected their ability to indulge in sexual activities with their partners. Jack said, "*First of all, I no longer have sex with my wife because of the pains I feel…but it difficult to have sex with my wife because of the pains I feel most of the times. Sometimes I feel very weak that cannot do sex with my wife…I don't have power to have sex with my wife anymore. I cannot think of sex with my wife because of the pains I feel most of the times."* Some participants even lost their life partners because of their facial disfigurements and their partners' lack of understanding of the disease. Mercy said, "*…I am not married but I was in relationship and it ended because this sickness. I think I was not looking good to him anymore and he decided to leave me for other women."* James added, "*Eeh that girlfriend, actually thus the problem now, the girlfriend because like since I got sick everything has changed, to me it is like she is cheating on me, the way I see it because she doesn't understand anything about cancer…so to her it like from now on I am just wasting her time so I broke up with her because she doesn't understand my situation…"*

The participants agreed that the persistent fatigue, weakness, pain and social stigma they experienced rendered them unable to work, which resulted in serious financial difficulties. In addition, participants said that despite having had treatment and recovering to the extent they could resume work, they were regarded as still sick and not fit to work by other people. Xolan said, "…*I cannot do anything because I am weak ne … like I can't go to work, bathing myself at home…The problem is that I used to work and bring salary home but now I cannot all that and now it's my wife alone, so her salary cannot take care all of us.*" Norman explained, "*You see, the stigma of this disease cancer… even now I myself I feel strong now but they are still regarding me as someone who is sick. They say hey you mustn't do this, you know you got cancer and I don't feel okay with that."* The participants also agreed that travelling to the hospital and the special food they needed added to their financial burden. Jack said, "…*ehh… now my family is suffering and my relatives because now they have to*

see that I have a money to come to the hospital, they have to see that may be pap or rice doesn't taste well in my mouth, so they make sure that they buy something that I can eat well..."

Being diagnosed with cancer of the head and neck was a shock. It created fear, uncertainty isolation and even thoughts of suicide. For some participants, experiencing the distressing symptoms of the disease and not knowing the cause made learning the diagnosis easier and gave hope. The lives participants knew before they became ill changed and they experienced their lives as a living hell. Receiving treatment did not console all the participants, as some felt uncertain about the treatment and whether or not it would result in a positive outcome; some feared that the disease would return. The distressing symptoms of the disease and treatment, such as pain and mucositis, and the complications, such as xerostomia and trismus, resulted in eating becoming a major problem. Not being able to eat caused persistent fatigue and severe weight loss, which had a negative impact on relationships and work. In addition, the facial disfigurement and the communication problems the participants experienced also had a negative influence on social interactions and financial activities, which caused serious financial problems.

4.3.2 Theme 2: Coping with a changed life: *"You have to learn to live with it"*

Subtheme 1: The importance of psychosocial support

Having supportive family, friends and relatives helped the participants cope with the negative consequences of the disease and treatment. The participants agreed their family members were there for them, to encourage them and provide material and financial support. They believed that without family, life would be even more difficult. Dan said, "*I have got all the support…any support, finance, treatment, yeah, when I am asking for something they give me and they also encourage me…I feel good, I feel relieved and I feel like I am in safe hands. Without my family, I don't know what I would do and I think things could have been difficult without them."* Max added, "…*and my wife works in the hospital…so you see she has a lot of knowledge about this stuff because they see a lot of cancer patients. And my cancer in comparison with those people is nothing because some had very bad cancer…my wife is my source of hope…"*

Being accepted and supported by friends also assisted the participants in coping with their challenges. The encouragement of friends and being able to be with them was very important and brought hope. Ben said, "*Oh well, friends have been coming like to give me, you know, like support, you know, spiritual support to say okay, get well soon. They are happy that I am still alive because you know cancer is a very severe disease but fortunately, you have managed to overcome it by being consistent with your treatment."* Not having

support and friendship from relatives and friends added to the burden of the participants. Liam said, "*I am alone…everything that was happening I was just doing myself, no one was coming to help about me…it was hard my friend, but I did because there was no choice I have to do it. No one came and help me; I was myself to doing everything*…"

Participants agreed that sharing information and experiences with other patients who also has cancer decreased their emotional distress and gave them hope. James explained, "*The most fear I had was that I thought it is gonna kill me same time, you see, I was gonna die that was the most thing that was scaring me but when I was always talking to people about me and stuff, they told me, no, this disease is curable, radiation could help you a lot. So thus, when I started to believe that you know was there cure or solution for me to get better for cancer. So I wasn't scared to that extent…Most the people I was talking with about this cancer were patients…and I got more information from them...As of now there is a lot of hope."* The doctors who treated the patients also gave them hope by giving them information and advice. Leah said, *"The doctors told me that if you see this on, let's say pain, don't worry about this, just focus on treatment… so I followed the things that doctor told me…When I came back to the doctor to complain that I can't eat and I can't swallow, they gave me things to wash my mouth and they told me that it is gonna be fine but it is going to take long…Yeah it helped me a lot…the doctors gave me hope."*

Receiving a social grant relieved the financial pressure some of the participants experienced. Receiving the grant helped them to buy food and other basic commodities during the time that they could not work However, the grant was not sufficient to meet all the needs of the participants and their families. Xolan said, "*Yeah, It's only the money from SASSA that come to our rescue us, yeah, trying to feed my children, anything."* However, some participants still had financial difficulties regardless of the government grant and they said the grant was not enough to meet their financial needs. Jack added, "…*I applied for the government grant and they gave me and it is the one that is assisting me up to now…before this cancer, it was enough to help me and my family but now it is not enough to help with issues of transport to the hospital, pay for treatment and also to help at home*…"

Subtheme 2: The importance of hope and spirituality

The participants agreed that having hope, being positive and having faith in God and prayer support helped them to cope with their cancer journey. Hope was a key factor that helped them to cope emotionally. Ben said, "*Oh well, I didn't feel that bad knowing that one day I am going to recovered fully, I will be okay and physically, I will regain weight, facially I will be okay again…*" Alex said, "…*the thing is I have to stay positive, I have to stay focused and I have to think that this medical treatment is gonna help me*."

Having trust and faith in God also facilitated coping. The participants believed God was in control of their situation and trusted God to heal them. Anna said, "*God is the one who does the healing with the help of doctors…I believe and trust the Lord to be caring through just difficult times."* Alex added, "*I read my bible and sometime I play some music and yeah it helps a lot, it soothes me…the holy spirit helps you a lot, it comforts you."*

Some participants were of the opinion that God gave them a second chance by means of their cancer diagnosis. Dan said, "*Eeh God helped me a lot yeah, I often pray while I am still living…previously my relationship with God was too small, I did not have time to pray because I was a criminal, let me tell you straight, yeah, so now since I became sick I am working with God…My life changed after the sickness."* Ben added, "*I feel so loved and I mean to be given another chance in life is so exciting…God just gave me another chance for me to do my work and I am thanking him for that."* In contrast, some participants doubted the existence of God because they felt their prayers were not answered. Mercy said, "*Sometimes I feel God is not there because you pray asking for things and not happening…"*

Having a supportive family, friends and relatives helped the participants cope with the negative consequences of the disease and treatment. Being accepted and supported by friends also assisted the participants to cope with their challenges. Participants agreed that sharing information and experiences with other patients who also have cancer, decreased their emotional distress and gave them hope. Receiving a social grant relieved the financial pressure some of the participants experienced. In addition, participants agreed that having hope, being positive and having faith in God and prayer support helped them cope with their cancer journey. Some participants were of the opinion that God gave them a second chance by means of their cancer diagnosis however others doubted the existence of God because they felt their prayers were not answered.

4.4 DISCUSSION

This study provided evidence that being diagnosed with cancer of the head and neck was a shock and created fear, isolation and even thoughts of suicide. Experiencing these emotions is not new among these patients. Jagannathan and Juvva (2016), in a study related to emotions and coping among head and neck cancer patients, found shock and fear as the most distressing emotional reactions experienced. The evidence shows that patients experience these emotions when they are not sufficiently prepared prior to the disclosure of the diagnosis and also when they lack emotional support after the diagnosis (Singer et al. 2012). Whether the participants in the current study received emotional support after learning

the diagnosis is not clear. However, for those who found answers to the distressing symptoms they experienced, made learning the diagnosis easier.

Similar to people living with other types of cancer, the participants feared the treatment they received would not be successful and their disease would return. Kanatas et al. (2015), in a study conducted in the United Kingdom, found fear and uncertainty are important emotional problems for the patients living with head and neck cancer. In addition, Hulbert-Williams et al. (2014) said that fear of recurrence is the most distressing psychological problem for patients with aero digestive tumours and it persists even after treatment. Fear of recurrence affects the patients' psychological health and relates to poor quality of life among head and neck cancer survivors. In a study about the relationship between fear of recurrence and quality of life conducted in United States of America, Van Liew et al. (2014) found that more than 60% of the head and neck cancer patients experienced fear of recurrence and poor quality of life. Similar findings were reflected in a systemic review of literature, conducted in Ireland by Dunne et al. (2017), which described the relationship between psychological factors and quality of life.

Living with cancer of the head and neck was not easy. The lives participants knew before they became ill changed and they experienced their lives as a living hell. The distressing effects of the disease and treatment, such as pain, mucositis, xerostomia and trismus, added to their suffering and made eating a major problem. Unfortunately, these distressing symptoms and complications are common for patients living with this type of cancer. Molassiotis and Rogers (2012) support this finding by means of a qualitative study done in the UK, on experiencing the symptoms of head and neck cancer and treatment, and found the oral symptoms these patients experienced made eating a major problem. In a study to describe the eating experiences of these patients conducted in Sweden, Ottosson et al. (2013) reported that eating problems persist even after treatment of the disease. In addition, feeding tubes as a temporary or permanent intervention also have negative effects on eating. The current study has provided evidence that participants experienced feeding tubes as eating without satisfaction, selective eating and undesirable. In support of these findings, in a literature review on eating-related consequences of the disease and treatment, Ganzer et al. (2015), found lack of satisfaction and limited feeding as important problems associated with feeding tubes and which caused poor quality of life for patients with head and neck cancer.

Not being able to eat caused severe weight loss and added to the persistent fatigue the participants experienced. Some participants were unable to work, whilst others lost their paid employment. Larsson et al. (2005) support these finding and state that being unable to eat causes severe weight loss for head and neck cancer patients. With regard to the fatigue, Nautiyal et al. (2015) found the fatigue that patients diagnosed with head and neck cancer

experience, starts before radiotherapy and persists afterwards. It is well known that the persistent fatigue these patients experience negatively influences their daily activities and work life. In the current study, persistent fatigue rendered the participants unable to work, which resulted in serious financial problems. In support of these findings, Nautiyal et al. (2015) reported a strong negative association between persistent fatigue and work life of patients living with the head and neck cancer, resulting in serious financial consequences.

As with any other cancer, fatigue causes sexual problems. In a literature review focusing on the effects of fatigue on sexuality of the patients living with cancer of the head and neck, Rhoten (2016) reported fatigue as a significant cause of sexual problems among these patients. In confirmation of the aforementioned, the current study has provided evidence that fatigue resulted in participants' sexuality problems, to the extent that they failed to indulge in sexual activities with their partners.

Some of the participants experienced facial disfigurements, which had a negative effect on their self-image. Nayak et al. (2015), in a systematic review of the literature focusing on the relationship between facial disfigurement and self-image in head and neck cancer patients, found facial disfigurements caused negative changes in self-image. In response to disfigured faces, some participants in the current study covered their faces with masks or cloths and some felt a negative change in their appearance, which Henry et al. (2014) described as disrupted self-image.

The facial disfigurement problems resulted in the participants being stigmatised and rejected by their friends. According Threader and McCormack (2016), facial disfigurements are a major causing factor for social stigma and rejection experienced by patients living with cancer of the head and neck. In a study conducted in Canada on the consequences of social stigma on the patients' psychosocial life, Lebel et al. (2013) found the stigma and rejection experienced by these patients had devastating consequences on their psychosocial lives and negatively affected quality of life. In agreement to the above evidence, in the current study, participants mentioned similar stigma-related psychosocial problems and some participants were even ridiculed by their friends.

In addition, the communication problems participants experienced made social interactions difficult. Unfortunately, these communication problems, such as impaired speech and voice, are well known issues of concern for patients with the head and neck cancer. In a study conducted in the Netherlands, on the communication problems associated with head and neck cancer and treatment, Jacobi et al. (2010) found speech and voice impairments as major problems experienced by these patients. The current study found some participants experienced rejection and humiliation due to the inability to communicate with their friends

and they felt unwanted by their friends. In line with these findings, Kraaijenga et al. (2016) found that the communication problems these patients experience have a devastating effect on their daily interaction with their friends and it negatively affected the patients psychologically. Similarly, the above findings were reflected in an Australian study focusing on communication changes and their influence on a patients' life (Nund et al. 2015).

The current study also provided evidence that living with tracheostomies made patients' lives difficult. A study conducted in Korea on tracheostomy related morbidities, revealed that head and neck cancer patients with tracheostomies experienced bleeding, leaking and blockage of the tracheostomy, which was distressing to them and their guardians (Lee et al. 2016). As confirmation to the findings reported in Korean study, the participants in the current study also mentioned similar problems associated with tracheostomy and added that their voice and speech were impaired due to this intervention. Two studies conducted in the United Kingdom on tracheostomy experiences of the head and neck cancer patients, also reported physical problems, such as impaired voice and speech, chocking and discomfort, which caused fear for the patients (Coyle et al. 2017; Rogers et al. 2017).

Having supportive families, friends and relatives helped the participants to cope with the negative consequences of the disease and treatment. In addition, being accepted and supported by friends buffered participants' emotional trauma caused by adverse effects of the disease and treatment. According to Deno et al. (2012), social support and being accepted by friends reduces both emotional and social burden of the disease and treatment. Isaksson et al. (2016) also found that social support was crucial for patients with head and neck cancer to cope with consequences of the disease and treatment. Participants agreed that sharing information and experiences with other cancer patients decreased their emotional distress and gave them hope. In addition, receiving a social grant relieved the financial pressure some of the participants experienced. In support of these findings, Lang et al. (2013), in a systematic literature review focusing on psychosocial experiences of the head and neck cancer, stated that sharing experiences of the disease and treatment reduced patients' emotional suffering. Although receiving a social grant relieved participants of their financial burden caused by the disease and treatment, no evidence was found in literature to support the findings.

The participants agreed that having hope, being positive and having faith in God and prayer support helped them to cope with their cancer journey. According to Garssen and Visser (2016), spirituality plays an important role in mental well-being for patients with head and neck cancer and it has a positive influence on quality of life. Being positive and having hope reduces the emotional burden for cancer patients (Deno et al. 2012). Having faith in God is known to have a positive influence on patients' experiences of disease and treatment. An

Indian study, on coping with diagnosis and treatment of head and neck cancer, showed that hope and belief in God was an important coping mechanism for these patients (Jagannathan and Juvva 2016). In contrast, some participants in the current study experienced spiritual distress, to the extent that some doubted the existence of God because they felt that their prayers were not being answered. Unfortunately, no evidence from literature was found to support the findings.

4.5 SUMMARY

This chapter focused on the findings and discussion of the study. Chapter 5 will justify and conclude the study including the recommendations, limitations and a reflection of the researchers.

CHAPTER 5:

JUSTIFICATION, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

The previous chapter contained the findings and discussion. This chapter will focus on the justification of the study, limitations, recommendations and conclusion, with the aim of presenting an evaluation of the study by outlining the justification and limitations. Finally, the recommendations, researcher reflection and the conclusion will be provided.

5.2 JUSTIFICATION

The justification of the study will be based on the initial purpose of the study, which was to describe the experiences of patients living with head and neck cancer treated at an academic hospital in Gauteng.

Chapter 3 detailed the methods and design for the study and Chapter 4 presented the findings and discussion of the experiences of patients living with cancer of the head and neck. The experiences of head and neck cancer patients treated at an academic hospital were established and the feature was presented in terms of two themes: living with the consequences of disease and treatment and coping with changed life. Therefore, the purpose of the study has been achieved and it can be concluded that the study is justified.

5.3 LIMITATIONS OF THE STUDY

The findings of qualitative studies cannot be extended to a wider population. The study was a qualitative study and such studies do not reflect only the truth about a phenomenon, as there could be multiple interpretations of the raw data.

5.4 RECOMMENDATIONS

A holistic and individualised patient need assessment for head and neck cancer patients would assist nurses in identifying patients' needs and an individualised plan of care would help these patients to cope with symptoms and complications of the disease and treatment. Nurses should also develop educational materials, such as patients' information leaflets and brochures, focusing on self-care management to assist these patients to cope with physical, emotional and social consequences of the disease and treatment. Routine health education and pre-treatment counselling of patients focussing on the treatment related side effects and

their management would also help these patients to cope with the emotional and physical challenges caused by the disease and treatment. A study on experiences of caregivers and significant others would add more information in order to clarify the phenomenon investigated. The nursing education syllabus for oncology students should include the development and implementation of patients' education tools regarding self-care management of complications and side effects the head and neck cancer and treatment.

5.5 INVESTIGATOR'S REFLECTION ON HIS EXPERIENCE

Reflection is a process of revisiting one's thoughts, feeling and actions after an encounter with an event with the purpose of making sense of the experience, and it is an important part of experiential learning (Boud et al. 2013). Therefore, I would like to take this chance to share my experience of this study with the reader.

Despite the fact I worked with head and neck cancer patients and I knew some physical consequences of the disease and treatment, I did not know how the patients felt about the side effects or how they experienced life in their communities with these consequences. I felt awful seeing participants struggling to speak and having their faces covered with masks due to disfigurement. I felt deeply sorry for the participants as they narrated their traumatic experiences, such as loss of their beloved ones, loss of their body parts and living with tracheostomies and feeding tubes. I shared their emotion as they vented their feelings by crying and shedding tears.

Some participants had to cry while reflecting on their experiences during the interview and I allowed them to cry for some time. After crying I asked them whether they wanted to be referred to someone in order to help them with their emotional concerns and all affected participants said that the emotions were for the moment and it was okay for them to continue with the interview.

I met all the 18 participants on their follow up visits and an initial trust relationship was embellished during the time they were completing their radiotherapy hence the participants were free to entrust me with their experiences. Nineteen patients were contacted to consider participation in the study, but one patient refused to be audio recorded and cancelled the consent to participate. I felt humiliated, but later I realised the patient was exercising her autonomy and I was not prepared emotionally for the refusal. Given a similar situation in future, I realise that psychological preparation prior to data gathering is the tool to handle such situations.

5.6 CONCLUSION

Living with cancer of the head and neck is not easy. The lives the participants knew before they became sick changed and became a living hell. They had to live the effects of the disease and treatment, which had a devastating effect on their financial burden. Eating became a major challenge and some of the participants struggled to communicate, whilst others had to live with facial disfigurement. Some were ridiculed and some isolated themselves from social contact. However, receiving support from family and friends and their faith in God assisted them to live this changed life.

REFERENCES

Abram, M. H. (2013) *The incidence of oral and oropharyngeal cancer in South Africa for the five year period 1997-2001*.

American Cancer Society (2016) *What Is Targeted Cancer Therapy?* 6 June, 2016. USA: www.cancer.org/treatment/treatments-and-side-effects/treatment-types/targeted-therapy/what-is.html Accessed 24 December, 2017.

Bagnardi, V., Rota, M., Botteri, E., Tramacere, I., Islami, F., Fedirko, V., Scotti, L., Jenab, M., Turati, F. and Pasquali, E. (2015) Alcohol consumption and site-specific cancer risk: a comprehensive dose–response meta-analysis. *British journal of cancer* 112 (3), 580.

Banerjee, A. and Chaudhury, S. (2010) Statistics without tears: Populations and samples. *Industrial psychiatry journal* 19 (1), 60.

Bazeley, P. and Jackson, K. (2013) *Qualitative data analysis with NVivo.* Sage Publications Limited.

Becker, H., Kang, S. J. and Stuifbergen, A. (2012) Predictors of quality of life for long-term cancer survivors with pre-existing disabling conditions. *Oncology nursing forum.* Vol. 39. NIH Public Access.

Bose, P., Brockton, N. T. and Dort, J. C. (2013) Head and neck cancer: from anatomy to biology. *International journal of cancer* 133 (9).

Boud, D., Keogh, R. and Walker, D. (2013) *Reflection: Turning experience into learning.* Routledge.

Bravi, F., Parazzini, F., Cipriani, S., Chiaffarino, F., Ricci, E., Chiantera, V., Viganò, P. and La Vecchia, C. (2014) Tobacco smoking and risk of endometriosis: a systematic review and meta-analysis. *BMJ open* 4 (12), e006325.

Bray, F. N., Simmons, B. J., Wolfson, A. H. and Nouri, K. (2016) Acute and chronic cutaneous reactions to ionizing radiation therapy. *Dermatology and therapy* 6 (2), 185-206.

Britz, R. and le Roux-Kemp, A. (2012) Voluntary informed consent and good clinical practice for clinical research in South Africa: Ethical and legal perspectives. *SAMJ: South African Medical Journal* 102 (9), 746-748.

Burns, N. and Grove, S. K. (2010) *Understanding nursing research: Building an evidence-based practice.* Elsevier Health Sciences.

Business Report (2015) *More people living below breadline-Stats SA.* South Africa: Stats SA.

Cancer Association of South Africa (2017) *Fact Sheet on Top Ten Cancer per Population group.* 1st February, 2017. South Africa: CANSA. Accessed September.

Cancer. Net (2016) *About Survivorship.* 2016. www.cancer.net/survivorship/about-survivorship Accessed 24, August, 2017

Chabner, B. A. and Longo, D. L. (2011) *Cancer chemotherapy and biotherapy: principles and practice.* Lippincott Williams & Wilkins.

Chan, R. J., Webster, J., Chung, B., Marquart, L., Ahmed, M. and Garantziotis, S. (2014) Prevention and treatment of acute radiation-induced skin reactions: a systematic review and meta-analysis of randomized controlled trials. *BMC cancer* 14 (1), 53.

Chiaffarino, F., Ricci, E., Cipriani, S., Chiantera, V. and Parazzini, F. (2016) Cigarette smoking and risk of uterine myoma: Systematic review and meta-analysis. *European Journal of Obstetrics & Gynecology and Reproductive Biology* 197, 63-71.

Cohen, E. E., LaMonte, S. J., Erb, N. L., Beckman, K. L., Sadeghi, N., Hutcheson, K. A., Stubblefield, M. D., Abbott, D. M., Fisher, P. S. and Stein, K. D. (2016) American cancer society head and neck cancer survivorship care guideline. *CA: a cancer journal for clinicians* 66 (3), 203-239.

Cooper, J. S., Zhang, Q., Pajak, T. F., Forastiere, A. A., Jacobs, J., Saxman, S. B., Kish, J. A., Kim, H. E., Cmelak, A. J. and Rotman, M. (2012) Long-term follow-up of the RTOG 9501/intergroup phase III trial: postoperative concurrent radiation therapy and chemotherapy in high-risk squamous cell carcinoma of the head and neck. *International Journal of Radiation Oncology* Biology* Physics* 84 (5), 1198-1205.

Coyle, M., Main, B. and Godden, D. (2017) Re: Patients' experience of temporary tracheostomy after microvascular reconstruction for cancer of the head and neck. *British Journal of Oral and Maxillofacial Surgery* 55 (5), 568.

D'cruz, A., Lin, T., Anand, A., Atmakusuma, D., Calaguas, M., Chitapanarux, I., Cho, B., Goh, B., Guo, Y. and Hsieh, W. (2013) Consensus recommendations for management of head and neck cancer in Asian countries: a review of international guidelines. *Oral oncology* 49 (9), 872-877.

Dayyani, F., Etzel, C. J., Liu, M., Ho, C.-H., Lippman, S. M. and Tsao, A. S. (2010) Meta-analysis of the impact of human papillomavirus (HPV) on cancer risk and overall survival in head and neck squamous cell carcinomas (HNSCC). *Head & neck oncology* 2 (1), 15.

Deno, M., Tashiro, M., Miyashita, M., Asakage, T., Takahashi, K., Saito, K., Busujima, Y., Mori, Y., Saito, H. and Ichikawa, Y. (2012) The mediating effects of social support and self-efficacy on the relationship between social distress and emotional distress in head and neck cancer outpatients with facial disfigurement. *Psycho-Oncology* 21 (2), 144-152.

Deschler, D. G., Moore, M. and Smith, R. V. (2014) Quick reference guide to TNM staging of head and neck cancer and neck dissection classification. *American Academy of Otolaryngology-Head and Neck Surgery Foundation, Alexandria, VA Google Scholar*.

Devlin, P. M. (2015) *Brachytherapy: applications and techniques.* Springer Publishing Company.

Di Franco, R., Sammarco, E., Calvanese, M. G., De Natale, F., Falivene, S., DiLecce, A., Giugliano, F. M., Murino, P., Manzo, R. and Cappabianca, S. (2013) Preventing the acute skin side effects in patients treated with radiotherapy for breast cancer: the use of corneometry in order to evaluate the protective effect of moisturizing creams. *Radiation Oncology* 8 (1), 57.

Doody, O. and Noonan, M. (2013) Preparing and conducting interviews to collect data. *Nurse researcher* 20 (5), 28-32.

Dunlop, R. (2012) *Cancer: palliative care.* Springer Science & Business Media.

Dunne, S., Mooney, O., Coffey, L., Sharp, L., Desmond, D., Timon, C., O'sullivan, E. and Gallagher, P. (2017) Psychological variables associated with quality of life following primary treatment for head and neck cancer: a systematic review of the literature from 2004 to 2015. *Psycho-oncology* 26 (2), 149-160.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. and Kyngäs, H. (2014) Qualitative content analysis: A focus on trustworthiness. *Sage Open* 4 (1), 2158244014522633.

Elo, S. and Kyngäs, H. (2008) The qualitative content analysis process. *Journal of advanced nursing* 62 (1), 107-115.

Etikan, I., Musa, S. A. and Alkassim, R. S. (2016) Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics* 5 (1), 1-4.

Fagan, J., Stannard, C. and Dalvie, S. (2014) Management principles/guidelines for Head and Neck cancer in Developing Countries. *Open access atlas of otolaryngology, head & neck operative surgery.*, 1-13.

Faggons, C., Mabedi, C., Shores, C. and Gopal, S. (2015) Review: Head and neck squamous cell carcinoma in sub-Saharan Africa. *Malawi Medical Journal* 27 (3), 79-87.

Farhangfar, A., Makarewicz, M., Ghosh, S., Jha, N., Scrimger, R., Gramlich, L. and Baracos, V. (2014) Nutrition impact symptoms in a population cohort of head and neck cancer patients: multivariate regression analysis of symptoms on oral intake, weight loss and survival. *Oral oncology* 50 (9), 877-883.

Fedirko, V., Tramacere, I., Bagnardi, V., Rota, M., Scotti, L., Islami, F., Negri, E., Straif, K., Romieu, I. and La Vecchia, C. (2011) Alcohol drinking and colorectal cancer risk: an overall and dose–response meta-analysis of published studies. *Annals of oncology* 22 (9), 1958-1972.

Ferlay, J., Soerjomataram, I., Ervik, M., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., Parkin, D., Forman, D. and Bray, F. (2014) GLOBOCAN 2012 v1. 0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [Internet]. 2013; Lyon, France: International Agency for Research on Cancer. *globocan. iarc. fr/Default. aspx*.

Forte, T., Niu, J., Lockwood, G. A. and Bryant, H. E. (2012) Incidence trends in head and neck cancers and human papillomavirus (HPV)-associated oropharyngeal cancer in Canada, 1992–2009. *Cancer Causes & Control* 23 (8), 1343-1348.

Fusch, P. I. and Ness, L. R. (2015) Are we there yet? Data saturation in qualitative research. *The Qualitative Report* 20 (9), 1408.

Galbiatti, A. L. S., Padovani-Junior, J. A., Maníglia, J. V., Rodrigues, C. D. S., Pavarino, É. C. and Goloni-Bertollo, E. M. (2013) Head and neck cancer: causes, prevention and treatment. *Brazilian journal of otorhinolaryngology* 79 (2), 239-247.

Ganzer, H., Touger-Decker, R., Byham-Gray, L., Murphy, B. A. and Epstein, J. B. (2015) The eating experience after treatment for head and neck cancer: a review of the literature. *Oral oncology* 51 (7), 634-642.

Garcia, D. O. and Thomson, C. A. (2014) Physical activity and cancer survivorship. *Nutrition in Clinical Practice* 29 (6), 768-779.

Garssen, B. and Visser, A. (2016) The association between religion/spirituality and mental health in cancer. *Cancer* 122 (15), 2440-2440.

Gauteng Provincial Government (2014) *SA: Statement by the Gauteng Provincial Government, Gauteng Health MEC commends Charlotte Maxeke Johannesburg Academic hospital al for leading in cancer treatment (04/02/014)*. South Africa.

Ghazali, N., Cadwallader, E., Lowe, D., Humphris, G., Ozakinci, G. and Rogers, S. N. (2013) Fear of recurrence among head and neck cancer survivors: longitudinal trends. *Psycho-Oncology* 22 (4), 807-813.

Grewal, P. and Viswanathen, V. A. (2012) Liver cancer and alcohol. *Clinics in liver disease* 16 (4), 839-850.

Gupta, B., Johnson, N. W. and Kumar, N. (2016) Global Epidemiology of Head and Neck Cancers: A Continuing Challenge. *Oncology* 91 (1), 13-23.

Haynes, K. (2012) Reflexivity in qualitative research. *Qualitative organizational research: Core methods and current challenges*, 72-89.

Health Profession Council of South Africa (2015) *Ethics in health research: Principles, processes and structures*. Department of Health Pretoria.

Heijnen, B. J., Speyer, R., Kertscher, B., Cordier, R., Koetsenruijter, K. W. J., Swan, K. and Bogaardt, H. (2016) Dysphagia, Speech, Voice, and Trismus following Radiotherapy and/or Chemotherapy in Patients with Head and Neck Carcinoma: Review of the Literature. *BioMed Research International* 2016, 24.

Henry, M., Ho, A., Lambert, S. D., Carnevale, F. A., Greenfield, B., MacDonald, C., Mlynarek, A., Zeitouni, A., Rosberger, Z. and Hier, M. (2014) Looking beyond disfigurement: The experience of patients with head and neck cancer. *Journal of palliative care* 30 (1), 5.

Hoole, J., Kanatas, A. and Mitchell, D. (2015) Psychosexual therapy and education in patients treated for cancer of the head and neck. *British Journal of Oral and Maxillofacial Surgery* 53 (7), 601-606.

Howard-Anderson, J., Ganz, P. A., Bower, J. E. and Stanton, A. L. (2012) Quality of life, fertility concerns, and behavioral health outcomes in younger breast cancer survivors: a systematic review. *Journal of the National Cancer Institute* 104 (5), 386-405.

Huang, S. H. and O'Sullivan, B. (2017) Overview of the 8th Edition TNM Classification for Head and Neck Cancer. *Current Treatment Options in Oncology* 18 (7), 40.

Hulbert-Williams, N., Swash, B., Ozakinci, G., Fenemore, J., Humphris, G. and Rogers, S. (2014) Fear of recurrence in head and neck cancer patients. *Pscyho-oncology* 23, 5.

Hurst, S., Arulogun, O. S., Owolabi, M. O., Akinyemi, R., Uvere, E., Warth, S. and Ovbiagele, B. (2015) Pretesting qualitative data collection procedures to facilitate methodological adherence and team building in Nigeria. *International journal of qualitative methods* 14 (1), 53-64.

Isaksson, J., Salander, P., Lilliehorn, S. and Laurell, G. (2016) Living an everyday life with head and neck cancer 2–2.5 years post-diagnosis–A qualitative prospective study of 56 patients. *Social Science & Medicine* 154, 54-61.

Itano, J. K., Brant, J., Conde, F. and Saria, M. (2015) *Core curriculum for oncology nursing.* Elsevier Health Sciences.

Jacobi, I., van der Molen, L., Huiskens, H., Van Rossum, M. A. and Hilgers, F. J. (2010) Voice and speech outcomes of chemoradiation for advanced head and neck cancer: a systematic review. *European Archives of Oto-Rhino-Laryngology* 267 (10), 1495-1505.

Jacobs, L. A. and Shulman, L. N. (2017) Follow-up care of cancer survivors: challenges and solutions. *The Lancet Oncology* 18 (1), e19-e29.

Jacqueline, C., Tasiemski, A., Sorci, G., Ujvari, B., Maachi, F., Missé, D., Renaud, F., Ewald, P., Thomas, F. and Roche, B. (2017) Infections and cancer: the “fifty shades of immunity” hypothesis. *BMC cancer* 17 (1), 257.

Jagannathan, A. and Juvva, S. (2016) Emotions and coping of patients with head and neck cancers after diagnosis: A qualitative content analysis. *Journal of postgraduate medicine* 62 (3), 143.

Jain, K. S., Sikora, A. G., Baxi, S. S. and Morris, L. G. (2013) Synchronous cancers in patients with head and neck cancer. *Cancer* 119 (10), 1832-1837.

Jemal, A., Bray, F., Center, M. M., Ferlay, J., Ward, E. and Forman, D. (2011) Global cancer statistics. *CA Cancer J Clin* 61 (2), 69-90.

Jolley, J. (2013) *Introducing research and evidence-based practice for nurses*.

Joshi, P., Dutta, S., Chaturvedi, P. and Nair, S. (2014) Head and neck cancers in developing countries. *Rambam Maimonides medical journal* 5 (2).

Kanatas, A., Humphris, G., Lowe, D. and Rogers, S. N. (2015) Further analysis of the emotional consequences of head and neck cancer as reflected by the Patients' Concerns Inventory. *Br J Oral Maxillofac Surg* 53 (8), 711-8.

Kawalec, P., Paszulewicz, A., Holko, P. and Pilc, A. (2012) Sipuleucel-T immunotherapy for castration-resistant prostate cancer. A systematic review and meta-analysis. *Archives of medical science: AMS* 8 (5), 767.

Kole, A. J., Kole, L. and Moran, M. S. (2017) Acute radiation dermatitis in breast cancer patients: challenges and solutions. *Breast Cancer: Targets and Therapy* 9, 313.

Koyanagi, Y. N., Matsuo, K., Ito, H., Wakai, K., Nagata, C., Nakayama, T., Sadakane, A., Tanaka, K., Tamakoshi, A. and Sugawara, Y. (2016) Cigarette smoking and the risk of head and neck cancer in the Japanese population: a systematic review and meta-analysis. *Japanese journal of clinical oncology* 46 (6), 580-595.

Kraaijenga, S., Oskam, I., van Son, R., Hamming-Vrieze, O., Hilgers, F., van den Brekel, M. and van der Molen, L. (2016) Assessment of voice, speech, and related quality of life in advanced head and neck cancer patients 10-years+ after chemoradiotherapy. *Oral oncology* 55, 24-30.

Lambert, V. A. and Lambert, C. E. (2012) Qualitative descriptive research: an acceptable design. *Pacific Rim International Journal of Nursing Research* 16 (4), 255-256.

Lang, H., France, E., Williams, B., Humphris, G. and Wells, M. (2013) The psychological experience of living with head and neck cancer: a systematic review and meta-synthesis. *Psycho-Oncology* 22 (12), 2648-2663.

Larsson, M., Hedelin, B., Johansson, I. and Athlin, E. (2005) Eating problems and weight loss for patients with head and neck cancer: a chart review from diagnosis until one year after treatment. *Cancer nursing* 28 (6), 425-435.

Lebel, S., Castonguay, M., Mackness, G., Irish, J., Bezjak, A. and Devins, G. M. (2013) The psychosocial impact of stigma in people with head and neck or lung cancer. *Psycho-oncology* 22 (1), 140-152.

Lee, S. T., Kim, M. G., Jeon, J. H., Jeong, J. H., Min, S. K., Park, J. Y. and Choi, S. W. (2016) Analysis of morbidity, mortality, and risk factors of tracheostomy-related complications in patients with oral and maxillofacial cancer. *Maxillofacial plastic and reconstructive surgery* 38 (1), 32.

Leonardi-Bee, J., Ellison, T. and Bath-Hextall, F. (2012) Smoking and the risk of nonmelanoma skin cancer: systematic review and meta-analysis. *Archives of dermatology* 148 (8), 939-946.

Mañós, M., Giralt, J., Rueda, A., Cabrera, J., Martinez-Trufero, J., Marruecos, J., Lopez-Pousa, A., Rodrigo, J., Castelo, B. and Martínez-Galán, J. (2017) Multidisciplinary management of head and neck cancer: First expert consensus using Delphi methodology from the Spanish Society for Head and Neck Cancer (part 1). *Oral Oncology*.

Maree, J. and Schmollgruber, S. (2014) An integrative review of South African cancer nursing research published from 2002-2012. *curationis* 37 (1), 01-10.

Maree, J. E., Moshima, D., Ngubeni, M. and Zondi, L. (2017) On being a caregiver: The experiences of South African family caregivers caring for cancer patients. *European Journal of Cancer Care*, e12801-n/a.

Matsuo, K., Ito, H., Wakai, K., Nagata, C., Mizoue, T., Tanaka, K., Tsuji, I., Tamakoshi, A., Sasazuki, S. and Inoue, M. (2011) Cigarette smoking and pancreas cancer risk: an evaluation based on a systematic review of epidemiologic evidence in the Japanese population. *Japanese journal of clinical oncology* 41 (11), 1292-1302.

Mehanna, H., Paleri, V., West, C. M. L. and Nutting, C. (2011) Head and neck cancer—Part 1: Epidemiology, presentation, and preservation. *Clinical Otolaryngology* 36 (1), 65-68.

Miller, K. D., Siegel, R. L., Lin, C. C., Mariotto, A. B., Kramer, J. L., Rowland, J. H., Stein, K. D., Alteri, R. and Jemal, A. (2016) Cancer treatment and survivorship statistics, 2016. *CA: a cancer journal for clinicians* 66 (4), 271-289.

Modesto, A., Faivre, J., Granel-Brocard, F., Tao, Y. and Pointreau, Y. (2012) Evaluation and management of acute radiation dermatitis. *Cancer radiotherapie: journal de la Societe francaise de radiotherapie oncologique* 16 (5-6), 456-461.

Molassiotis, A. and Rogers, M. (2012) Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: a qualitative longitudinal study. *Palliative & supportive care* 10 (3), 197-204.

National Cancer Institute (2016) Definition of survivorship - NCI Dictionary of Cancer Terms - National Cancer Institute.

National Cancer Institute (2017) *Head and Neck Cancers fact sheet.* 29 March, 2017. USA: www.cancer.gov/types/head-and-neck/head-neck-fact-sheet Accessed 24 February, 2017.

National Institute for Occupational Health (2011) Summary Statistics of Cancer Diagnosed Histologically in 2011. Johannesburg.

Nautiyal, V., Lal, P., Verma, M., Yadav, R., Singh, N. and Kumar, S. (2015) Evaluation of fatigue in head and neck cancer patients undergoing (intensity modulated radiation therapy) radiotherapy: A prospective study. *Asian Journal of Oncology* 1 (1), 44.

Nayak, S. G., Shivananda, M. and George, L. S. (2015) Self concept of Head and Neck cancer patients-A systematic review of qualitative studies. *Health* 4 (2).

Ndui, M. K. (2011) Epidemiology of oral cancer in South Africa 1996-2002.

Nekhlyudov, L., Lacchetti, C., Davis, N. B., Garvey, T. Q., Goldstein, D. P., Nunnink, J. C., Ninfea, J. I. R., Salner, A. L., Salz, T. and Siu, L. L. (2017) Head and Neck Cancer Survivorship Care Guideline: American Society of Clinical Oncology Clinical Practice Guideline Endorsement of the American Cancer Society Guideline. *Journal of Clinical Oncology* 35 (14), 1606-1621.

Nelson, D. E., Jarman, D. W., Rehm, J., Greenfield, T. K., Rey, G., Kerr, W. C., Miller, P., Shield, K. D., Ye, Y. and Naimi, T. S. (2013) Alcohol-attributable cancer deaths and years of potential life lost in the United States. *American Journal of Public Health* 103 (4), 641-648.

Nund, R. L., Rumbach, A. F., Debattista, B. C., Goodrow, M. N., Johnson, K. A., Tupling, L. N., Scarinci, N. A., Cartmill, B., Ward, E. C. and Porceddu, S. V. (2015) Communication changes following non-glottic head and neck cancer management: The perspectives of survivors and carers. *International journal of speech-language pathology* 17 (3), 263-272.

Olaleye, O. and Ekrikpo, U. (2017) Epidemiology of Cancers in Sub-Saharan Africa. *Cancer in Sub-Saharan Africa.* Springer. 3-19.

Ottosson, S., Laurell, G. and Olsson, C. (2013) The experience of food, eating and meals following radiotherapy for head and neck cancer: a qualitative study. *Journal of clinical nursing* 22 (7-8), 1034-1043.

Oze, I., Matsuo, K., Ito, H., Wakai, K., Nagata, C., Mizoue, T., Tanaka, K., Tsuji, I., Tamakoshi, A. and Sasazuki, S. (2011) Cigarette smoking and esophageal cancer risk: an evaluation based on a systematic review of epidemiologic evidence among the Japanese population. *Japanese journal of clinical oncology* 42 (1), 63-73.

Paccagnella, A., Morello, M., Da Mosto, M. C., Baruffi, C., Marcon, M. L., Gava, A., Baggio, V., Lamon, S., Babare, R. and Rosti, G. (2010) Early nutritional intervention improves treatment

tolerance and outcomes in head and neck cancer patients undergoing concurrent chemoradiotherapy. *Supportive care in cancer* 18 (7), 837-845.
Palaganas, E. C., Sanchez, M. C., Molintas, M., Visitacion, P. and Caricativo, R. D. (2017) Reflexivity in Qualitative Research: A Journey of Learning. *The Qualitative Report* 22 (2), 426-438.
Parkin, D. M., Bray, F., Ferlay, J. and Jemal, A. (2014) Cancer in africa 2012. *Cancer Epidemiology and Prevention Biomarkers* 23 (6), 953-966.
Pennbrant, S., Tomaszewska, M. and Penttilä, G. L. (2015) Nurses' experience of caring for palliative-stage patients in a hospital setting in Sweden. *Clinical Nursing Studies* 3 (2), 97.
Polit, D. and Beck, C. (2012) *NURSING RESEARCH; Generating and Assessing Evidence for Nursing Practice.* Ninth edition. Wolters Kluwer Health|Lippincott Williams and Wilkins.
Polit, D. F. and Beck, C. T. (2014) *Essentials of Nursing Research; Appraising Evidence for Nursing.* 8th ed. edition. United States: Philadelphia : Wolters Kluwer/Lippincott/Williams & Wilkins Health.
Pulte, D. and Brenner, H. (2010) Changes in survival in head and neck cancers in the late 20th and early 21st century: a period analysis. *The oncologist* 15 (9), 994-1001.
Pytynia, K. B., Dahlstrom, K. R. and Sturgis, E. M. (2014) Epidemiology of HPV-associated oropharyngeal cancer. *Oral Oncology* 50 (5), 380-386.
Radvansky, L. J., Pace, M. B. and Siddiqui, A. (2013) Prevention and management of radiation-induced dermatitis, mucositis, and xerostomia. *American Journal of Health-System Pharmacy* 70 (12).
Rettig, E., Kiess, A. P. and Fakhry, C. (2015) The role of sexual behavior in head and neck cancer: implications for prevention and therapy. *Expert review of anticancer therapy* 15 (1), 35-49.
Reyes–Gibby, C. C., Melkonian, S. C., Hanna, E. Y., Yeung, S. c. J., Lu, C., Chambers, M. S., Banala, S. R., Gunn, G. B. and Shete, S. S. (2017) Cohort study of oncologic emergencies in patients with head and neck cancer. *Head & Neck* 39 (6), 1195-1204.
Rhoten, B. A. (2016) Head and neck cancer and sexuality: A review of the literature. *Cancer nursing* 39 (4), 313-320.
Rickert, J. (2012) Patient-centered care: What it means and how to get there. *Health Affairs Blog* 24.
Ringash, J. (2015) Survivorship and quality of life in head and neck cancer. *Journal of Clinical Oncology* 33 (29), 3322-3327.
Rogers, S. N., Russell, L. and Lowe, D. (2017) Patients' experience of temporary tracheostomy after microvascular reconstruction for cancer of the head and neck. *British Journal of Oral and Maxillofacial Surgery* 55 (1), 10-16.
Sandelowski, M. (2000) Focus on research methods-whatever happened to qualitative description? *Research in nursing and health* 23 (4), 334-340.
Sandelowski, M. (2010) What's in a name? Qualitative description revisited. *Research in nursing & health* 33 (1), 77-84.
Seiwert, T. Y., Zuo, Z., Keck, M. K., Khattri, A., Pedamallu, C. S., Stricker, T., Brown, C., Pugh, T. J., Stojanov, P. and Cho, J. (2015) Integrative and comparative genomic analysis of HPV-positive and HPV-negative head and neck squamous cell carcinomas. *Clinical cancer research* 21 (3), 632-641.
Shah, A., Malik, A., Garg, A., Mair, M., Nair, S. and Chaturvedi, P. (2017) Oral sex and human papilloma virus-related head and neck squamous cell cancer: a review of the literature. *Postgraduate Medical Journal*, postgradmedj-2016-134603.
Shenton, A. K. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for information* 22 (2), 63-75.
Shiels, M. S., Pfeiffer, R. M., Gail, M. H., Hall, H. I., Li, J., Chaturvedi, A. K., Bhatia, K., Uldrick, T. S., Yarchoan, R. and Goedert, J. J. (2011) Cancer burden in the HIV-infected population in the United States. *Journal of the National Cancer Institute* 103 (9), 753-762.
Shingler, E., Robles, L. A., Perry, R., Penfold, C., Ness, A., Thomas, S., Lane, J. A. and Martin, R. M. (2017) Tobacco and alcohol cessation or reduction interventions in people with oral dysplasia and head and neck cancer: systematic review protocol. *Systematic Reviews* 6 (1), 161.

Siegel, R., DeSantis, C., Virgo, K., Stein, K., Mariotto, A., Smith, T., Cooper, D., Gansler, T., Lerro, C. and Fedewa, S. (2012) Cancer treatment and survivorship statistics, 2012. *CA: a cancer journal for clinicians* 62 (4), 220-241.

Siegel, R., Naishadham, D. and Jemal, A. (2013) Cancer statistics, 2013. *CA: a cancer journal for clinicians* 63 (1), 11-30.

Simcock, R. and Simo, R. (2016) Follow-up and survivorship in head and neck cancer. *Clinical Oncology* 28 (7), 451-458.

Singer, S., Krauß, O., Keszte, J., Siegl, G., Papsdorf, K., Severi, E., Hauss, J., Briest, S., Dietz, A. and Brähler, E. (2012) Predictors of emotional distress in patients with head and neck cancer. *Head & neck* 34 (2), 180-187.

Singh, E., Sengayi, M., Urban, M., Babb, C., Kellett, P. and Ruff, P. (2013) The South African National Cancer Registry: an update. *Health*.

Smith, J. and Firth, J. (2011) Qualitative data analysis: the framework approach. *Nurse researcher* 18 (2), 52-62.

Smith, J. A. (2015) *Qualitative psychology: A practical guide to research methods.* Sage.

Sourati, A., Ameri, A. and Malekzadeh, M. (2017) *Acute Side Effects of Radiation Therapy: A Guide to Management.* Springer.

South African Doctors (2017) *State Public Hospitals and Clinics in Gauteng, South Africa; Charlotte Maxeke Academic hospital.* Accessed 11 December.

Suri, H. (2011) Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal* 11 (2), 63-75.

Thomas, E. and Magilvy, J. K. (2011) Qualitative rigor or research validity in qualitative research. *Journal for specialists in pediatric nursing* 16 (2), 151-155.

Threader, J. and McCormack, L. (2016) Cancer-related trauma, stigma and growth: the 'lived'experience of head and neck cancer. *European journal of cancer care* 25 (1), 157-169.

Torre, L. A., Bray, F., Siegel, R. L., Ferlay, J., Lortet-Tieulent, J. and Jemal, A. (2015) Global cancer statistics, 2012. *CA: a cancer journal for clinicians* 65 (2), 87-108.

Turner, D., Adams, E., Boulton, M., Harrison, S., Khan, N., Rose, P., Ward, A. and Watson, E. K. (2013) Partners and close family members of long-term cancer survivors: health status, psychosocial well-being and unmet supportive care needs. *Psycho-Oncology* 22 (1), 12-19.

Vaismoradi, M., Turunen, H. and Bondas, T. (2013) Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nursing & health sciences* 15 (3), 398-405.

Van Liew, J. R., Christensen, A. J., Howren, M. B., Hynds Karnell, L. and Funk, G. F. (2014) Fear of recurrence impacts health-related quality of life and continued tobacco use in head and neck cancer survivors. *Health Psychology* 33 (4), 373.

Venes, D. (2017) *Taber's cyclopedic medical dictionary.* FA Davis.

Vokes, E. E., Agrawal, N. and Seiwert, T. Y. (2015) HPV-Associated Head and Neck Cancer. *JNCI: Journal of the National Cancer Institute* 107 (12), djv344-djv344.

Wahyuni, D. (2012) The research design maze: Understanding paradigms, cases, methods and methodologies.

Watson, E., Shinkins, B., Frith, E., Neal, D., Hamdy, F., Walter, F., Weller, D., Wilkinson, C., Faithfull, S. and Wolstenholme, J. (2016) Symptoms, unmet needs, psychological well-being and health status in survivors of prostate cancer: implications for redesigning follow-up. *BJU international* 117 (6B).

Wong, R. K., Bensadoun, R.-J., Boers-Doets, C. B., Bryce, J., Chan, A., Epstein, J. B., Eaby-Sandy, B. and Lacouture, M. E. (2013) Clinical practice guidelines for the prevention and treatment of acute and late radiation reactions from the MASCC Skin Toxicity Study Group. *Supportive Care in Cancer* 21 (10), 2933-2948.

World Health Organization (2006) *Comprehensive cervical cancer control: a guide to essential practice.* World Health Organization.

Yin, R. K. (2013) *Case study research: Design and methods.* Sage publications.

ANNEXURE A: PREGIARISM DECLARATION FORM

Faculty of Health Sciences, Postgraduate Office
Phillip V Tobias Building, 2nd Floor
Cnr York & Princess of Wales Terrace, Parktown 2193
Tel: (011) 717 2745 | Fax: (011) 717 2119
Email: Mathoto.senamela@wits.ac.za



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Samuel Alloss Mbale Bingo (Student number: 1440355) am a student

registered for the degree of Masters of Science in Nursing (Oncology and Palliative care) in the academic year 2018.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: S-A-M Bingo Date: 31 May, 2018

S

ANNEXURE B: INFORMATION LEAFLET

Good day,

My name is Samuel Bingo, I am a postgraduate student for masters of science in Nursing (Oncology and Palliative Care) in the Department of Nursing Education, at the University of the Witwatersrand. I write to invite you to consider participating in a research study entitled **'**Living with the cancer of head and neck: experiences of patients with head and neck cancer treated an academic hospital in Gauteng.' It is very necessary for you to understand the explanations below regarding the purpose of the study, risks, benefits and your rights before you agree to participate. Should you have any question, you are free to ask me in person. You should agree to participate only if you are satisfied about procedures involved. Please do not agree to participate if you are engaged in another study at present. Should you decide to take part in this study, you will be required to sign this document as a proof of agreement and you will get a copy.

Purpose

As a patient who is being treated for head and neck cancer, you are asked to consider taking part in this study. The purpose of the study is to describe the experiences of patients living with head and neck cancer in order to gather information which will help the health care workers to provide the best care to the patients with head and neck cancer.

Procedures

If you agree to participate in this study, you will be required to attend a 30-45 minutes in-depth interview, where you will be asked to tell a story about your life after the diagnosis of head and neck cancer. You will be asked some more questions to clarify your story where necessary. The interviews will be done in a private room to ensure that no one will hear your story apart the interviewer.

Your rights

You have the right to self-determination, therefore, participation in this study is voluntarily and your decision not to participate will not attract any penalty or denial of any privileges. You will be given a number which will be used instead of your name throughout the interview and in the report in order to maintain your right to privacy and confidentiality. Your information will be treated with high level of confidentiality. However, your information might be inspected by the Supervisor and the University of the Witwatersrand, Human Research Ethics Committee (HREC).

Benefits of the study

This study may not have direct benefit for you as a participant, however the information will help health workers in planning of care for other patient with head and neck cancer.

Risks

In my opinion, there should be no risk to you as a participant in narrating your life story after the diagnosis of head and neck cancer. However, should you have any discomfort regarding sharing your story at any point, do not hesitate to inform me and you will be referred to appropriate people for further care.

Ethical approval

This study protocol has been submitted to the University of the Witwatersrand, Human Research Ethics Committee (HREC) and written approval has been granted by that committee. An approval was also sort from the research site and an approval was granted. This study is partly sponsored by the government of Malawi and partly by the researcher himself. There is no influence from the sponsor that may bias my actions in this study.

Reimbursement for the study participation

You will not be paid for participating in this study, however your transport may be reimbursed when necessary.

Sources of information

If you need further clarification or question about the participating this study, you are free to contact me (Samuel Bingo) at 0613410071 or write email to josephbingo26@gmail.com at any time. If you want any information regarding your rights as a research participant, or complaints regarding this research study, you may contact Prof. Cleaton-Jones, Chairperson of the University of the Witwatersrand, Human Research Ethics Committee (HREC), which is an independent committee established to help protect the rights of research participants at (011) 717 2301.

Yours faithfully

Samuel Bingo

Date_____

ANNEXURE C: INFORMED CONSENT FOR PARTICIPATION

I hereby confirm that I have been informed by the researcher, ...(name of the researcher) about the nature, conduct, benefits and risks of study entitled **'**Living with the cancer of head and neck: experiences of patients with head and neck cancer treated an academic hospital in Gauteng.

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the research study.

I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.

In view of the requirements of research, I agree that the data gathered during this study can be accessed by the supervisor and other Authorities.

I may, at any stage, without prejudice, withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

Participant:

Printed Name Signature / Mark or Thumbprint Date and Time

I, ...(Name of the researcher) herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Researcher:

Printed Name Signature Date and Time

WITNESS (If applicable)**:**

Printed Name Signature Date and Time

ANNEXURE D: INFORMATION LEFLET FOR VOICE RECORDING

Good day,

My name is Samuel Bingo, a postgraduate student in the department of nursing education at the University of Witwatersrand. I would like to inform you that this study involves the audio recording of your interview with the researcher. Neither your name nor any other identifying information will be associated with the audio recording or the transcript. Only the research and the supervisor will be able to listen to the recordings. The recording will be treated with high level of confidentiality.

The recordings will be transcribed by the researcher and erased once the transcriptions are checked for accuracy. Transcripts of your interview may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither your name nor any other identifying information such as your voice will be used in presentations or in written products resulting from the study.

You have the right to refuse the audio recording of this interview for any reason without being penalised.

If you have any question regarding recording of your interview with the researcher, please ask me (Samuel Bingo) now or you are free to contact me at 0613410071.

It is important that you understand the information on this leaflet before you agree by signing the consent form.

Yours faithfully

Samuel Bingo

ANNEXURE E: INFORMED CONSENT FOR AUDIO RECORDING

I hereby confirm that I have been informed by the researcher, ...(name of the researcher) about the audio recording of the interview between the me (the participant) and the researcher.

I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the audio recording of the interview.

I am aware that my name or any other identifying information will not be associated with the audio recording or the transcript.

In view of the requirements of research, I agree that the audio recordings recorded during this interview can be accessed by the supervisor and the researcher.

I may, without prejudice, deny the audio recording withdraw my consent and participation in the study.

I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to be recorded during this interview.

Participant:

Printed Name Signature / Mark or Thumbprint Date and Time

I, ...(Name of the researcher) herewith confirm that the above participant has been fully informed about the audio recording of the interview between the above participant and the researcher.

Researcher:

Printed Name Signature Date and Time

Witness:

Printed Name Signature Date and Time

ANNEXURE F: DEMOGRAPHIC DATA QUESTIONAIRE

LING WITH CANCER OF HEAD AND NECK: A QUALITATIVE INQUIRY INTO EXPERIENCES OF PATIENTS TREATED AT AN ACADEMIC HOSPITAL IN GAUTENG.

1. Participant number……
2. Diagnosis……
3. Duration of sickness……
4. Treatment received

Surgery	
Radiotherapy	
chemotherapy	

Others specify……

5. Age:

18-25	
26-33	
34-41	
42-49	
50-57	
58-65	
65-72	
72-79	

6. Gender:

Male	
Female	
Transgender	

7. Population group:
8.

White	
Asian	
Black	
Coloured	

Others, specify……

9. Marital status:

Single	
Married	
Divorced	
Widowed	
Separated	

10. Highest Level of education

Grade 1-4	
Grade 5-8	
High school	
Degree	
Postgraduate	

11. Employment

Full time	
Part time	
unemployed	
Retired	

12. Income:

Above R779	
Less than R779	

ANNEXURE G: POSTGRADUATE COMMITEE TITLE APPROVAL LETTER

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

10 January 2018
Person No: 1440355
PAG

Mr SAM Bingo
Kamuzu Central Hospital, P.O.Box 149,
3
Malawi

Dear Mr Bingo

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *Living with cancer of the head and neck: A qualitative inquiry into the experiences of patients treated at an academic hospital in Gauteng* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

ANNEXURE H: HUMAN RESEARCH ETHEICS CLEARANCE CERTIFICATE

R14/49 Mr Samuel Bingo

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M170469

NAME: (Principal Investigator)	Mr Samuel Bingo
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Living with Cancer of Head and Neck: A Qualitative Inquiry into the Experiences of Patients Treated at an Academic Hospital in Gauteng
DATE CONSIDERED:	05/05/2017
DECISION:	Approved
CONDITIONS:	Following GDoH Circular 10 of 2015 to GDoH Staff. It is the responsibility of the applicant to obtain written permission to to do the study from the study site CEO and Provincial Authorities.
SUPERVISOR:	Prof Lize Maree
APPROVED BY:	Prof P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	10/07/2017

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in April and will therefore be due in the month of April each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

ANNEXURE I: RESEARCH SITE APPROVAL

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. G. Ngwenya
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
24 JULY 2017

Mr. Samuel Bingo
University of the Witwatersrand
Department of Nursing Education
Faculty of the Health Sciences
NHRD REF : GP_2017RP48_881

Dear. Mr. Samuel Bingo

RE: "Living with Cancer of Head and Neck: A Qualitative Inquiry into the Experiences of Patients Treated at an Academic Hospital in Gauteng"

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.
5.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / ~~not supported~~

Ms. M.M Pule
Nursing Director
Date: 2017/07/24

Approved / not approved

Ms. G. Bogoshi
Chief Executive Officer
26.07.2017

ANNEXURE J: LANGUAGE EDIT CERTIFICATE

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Prof L. Maree, RN DCUR (Pret)
Address	Wits Dept of Nursing Education
Date	20/02/2018
Subject	LIVING WITH CANCER OF THE HEAD AND NECK: A QUALITATIVE INQUIRY INTO THE EXPERIENCES OF PATIENTS TREATED AT AN ACADEMIC HOSPITAL IN GAUTENG
Ref	LM/GS/058

I, Gill Smithies, certify that I have edited the following for language and style,

Research Study – Living with cancer of the head and neck: a qualitative inquiry into the experiences of patients treated at an academic hospital in Gauteng,

to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies

Work Certificate