

**UNIVERSITY OF GHANA  
COLLEGE OF HUMANITIES  
SCHOOL OF SOCIAL SCIENCES**

**PSYCHOLOGICAL DISTRESS AND HEALTH-SEEKING BEHAVIOUR  
AMONG PATIENTS WITH OROFACIAL TUMOUR: EXAMINING THE  
ROLES OF SPIRITUALITY, HEALTH BELIEF AND STIGMATIZATION.**

**A THESIS SUBMITTED TO THE DEPARTMENT OF PSYCHOLOGY OF THE  
UNIVERSITY OF GHANA**

**BY  
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DOCTOR OF PHILOSOPHY DEGREE IN PSYCHOLOGY**

## DECLARATION

I hereby declare that this thesis is the result of research undertaken by me Alfred Dickson Dai-Kosi towards the award of the Doctor of Philosophy in Psychology in the department of Psychology, University of Ghana. This thesis was carried out under the supervision of Dr. Adote Anum, Prof. Charity Sylvia Akotia and Dr. Maxwell Asumeng, and that no part has been presented either in part or in whole for the award of a degree in this University or elsewhere. Where views and ideas of others have been used, they have been duly acknowledged.

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## **DEDICATION**

To God Almighty for His guidance, my wife Mrs. Georgina Ogbo Dai-Kosi and my daughter Mary-Anne Esenam Dickson Dai-Kosi who sacrificed in all aspects of their lives to support this course.

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## **ABBREVIATIONS**

OSCC-Oral Squamous Cell Carcinoma

GSI- Global Severity Index

WHO - World Health Organization

MRI - Magnetic Resonance Imaging

HBM- Health Belief Model

HSB-Health-seeking behaviour

3 H, BMSEST-Head, Heart and Hand-Body, Mind, Spirit, Environment, Social and

Transcendental

TNM- Tumour Node Metasis

HBS – Health Belief Scale

SWB-Spirituality Well-being Scale

EWB – Existential well-being

RWB – Religious Well-being

HADS-Hospital Anxiety and Depression Scale

CFMP- Chronic Facial Musculoskeletal Pain.

PST-Positive Symptom Total

PSDI – Positive Symptom Distress Index

QoL- Quality of Life

DSM - Diagnostic and Statistical Manual for Mental Disorders

ICD- 10 - International Classification of Diseases, 10<sup>th</sup> edition

BSI -Brief Symptom Inventory

SOM - Somatization

O-C - Obsessive-Compulsive

I-S - Interpersonal Sensitivity

DEP - Depression

ANX - Anxiety

HOS - Hostility

PHOB - Phobic Anxiety

PAR - Paranoid Ideation

PSY - Psychoticism

BSI – Brief Symptom Inventory

PST – Positive Symptom Total

PSDI – Positive Symptom Distress Index

SPSS- Statistical Package for Social sciences

MANOVA –Multivariate Analysis of Variance

VIF- Variance Inflation Factor.

## ABSTRACT

The level of psychological distress and health-seeking behaviour (HSB) among patients with orofacial tumours (OFT) were assessed using explanatory sequential mixed methods designed in a two-component study. A sample of 272 comprising 143 patients with OFT and 129 patients with general periodontal diseases who served as a comparison group aged between 18 and 83 years were purposively selected from the Oral and Maxillofacial Units of the Korle-Bu Teaching hospital, 37 Military hospital and the Ridge hospital in Accra. Study one was a cross-sectional quantitative study with data collected via self-administered structured questionnaires. Study two was a qualitative study using a sample of 20 patients drawn from the original sample used in study one, with data collected through in-depth interviews to further explore HSB among patients. The results of Study one using regression analyses indicated that the type of condition, patients' perceptions of body image and stigmatization significantly predicted psychological distress among patients. The result also showed that the level of psychological distress among patients with OFT was significantly higher than that of the patients with periodontal diseases. Additionally, spirituality and perception of stigmatization were found to be the most significant predictors of HSB. The results showed a significant positive relationship between perception of stigmatization and health-seeking behaviour. Mediation analyses were done with the process procedures for SPSS (2.12.3) by Hayes (2013) and the result indicated that spirituality mediated the effect of the condition and health-seeking behaviour. Results from moderation analyses also indicated that spirituality and stigmatization moderated the type of condition and levels of psychological distress among patients. The findings from study 2 revealed five themes including conceptualization of cause of the condition, physical trauma, self-stigmatization and spiritual coping. In sum, spirituality emerged as one of the key determinants of health-seeking behaviour and also a major coping tool for the patients. This study provides knowledge about the role of spirituality as an additional factor to what has been provided in the health belief model as predictor of HSB. The study proffers a number of recommendations for the improvement of healthcare for patients with OFT in Ghana.

**Key words:** Orofacial tumour, psychological distress, spirituality, health-seeking behaviour, health belief, social support and Ghana.

# CHAPTER ONE

## INTRODUCTION

### 1.1 Background to the Thesis

Orofacial tumours (OFT) are emerging as one of the leading health concerns in Ghana. Orofacial tumours are tumours that affect the soft tissues of the mouth, face and neck of an individual which may develop into benign or malignant growth leading to severe pains and distress (Akinbami, Omitola, & Akadiri, 2013). The threat of the disease is much more pronounced as patients report to the health facilities at an advanced stage of the disease. This late reporting is mainly due to the health-seeking behaviour of patients (Afolabi, Daropole, Irinoye & Agegoke, 2013). The issue of health-seeking behaviour becomes much more crucial because the disease grows gradually in the form of a swelling and develops into an enlargement with a lot of psychological distress to the patients due to late reporting for treatment. Health-seeking then becomes a determinant in ensuring early diagnoses and treatment. The factors that influence health-seeking behaviour including spirituality, health belief, perceptions of stigmatization and body image and also level of psychological distress of patients are the focus of this study

Orofacial tumour (OFT) affects the face, head and the neck regions of the patients and may impair speaking and swallowing because of their special locations (Geirdal, Saltnes, Storhaug, Asten, Nordgarden & Jansen, 2014). The maxilla and the mandible form some of the most important and delicate parts of the human body. These parts of the body also act as a suitable host for the growth of both malignant and benign tumours (Theodorou, Havenetidis, Zanker, King, & Cooke, 2003).

The origin of some of these tumours, according to Baddoo and Parkins (2008), may be from the remnants of the development of teeth and their supporting and surrounding tissues. Parkins, Armah and Tettey (2008), reported that tumours and tumour-like lesions in many cases may start as a swelling but could lead to enlargement of the jaws and facial region and causes significant disfigurement, severe pain and psychological distress.

Some of the symptoms of psychological distress include anxiety, depression and somatization. Psychological distress is one of the feelings which an individual may experience due to severe physical or painful conditions. Mirowsky and Ross (2002) define psychological distress as a state of emotional suffering that is characterized by symptoms of depression including loss of interest; sadness; hopelessness and anxiety which covers restlessness; and feeling tense. The level of psychological distress can also be largely influenced by health belief and spirituality of the patients. Thus the interpretation and perception of threat of the disease largely determined by the health belief and the level of spirituality can result in more or less psychological distress. The health belief and spirituality equally may lead to health-seeking behaviour among patients (Bello & Satwinder, 2014).

The health belief of the patients does not only influence their psychological distress but may also result in the perception of stigmatization due to their body image challenges. The disease comes with significant disfigurement which many patients relate to public stigmatization. According to Aromaa, Tolvanen, Tuulari and Wahlbeck (2011), stigmatization is one of the factors that can increase the level of psychological distress experienced by patients and also a major determinant of health-seeking behaviour.

They explained that if patients perceive high levels of stigmatization from the public they suffer low self-esteem and consequently can get depressed. In addition, the level of psychological distress and health-seeking behaviour can be influenced by many factors including spirituality, health belief, perceptions of stigmatization and body image and self-esteem. The level of psychological distress is found to affect the quality of life and wellbeing of patients and in some cases their caregivers (Howren, Christensen, Karnell & Funk 2013). The disease which causes so much physical and psychological challenges is also widespread and wreaking havoc globally. According to Andisheh, Mehrabani and Heydari (2008), orofacial malignant tumours are the sixth most common malignancy in the world and, with pharyngeal malignancies, the third most common one in the developing world.

Tumour and tumour-like conditions within the orofacial region form 4% of all tumours while oral cancer represents 1%-4% of all cancers of the body in the Western countries and forms up to 40% of cases on the Asian subcontinent (Johnson, 1990). The incidence of OFT is also significantly high among Asians. For instance, Chen, Liao, and Chang (2011), reported that it is the fourth leading form of cancer among Taiwanese men in 2010. Bassey, Osunde and Anyanechi (2014) indicated that OFT cases are on the rise in most of the Nigerian states that were studied.

The most widely reported cases include odontogenic and non-odontogenic tumours. Other forms reported are odontogenic cysts and salivary gland tumours. The studies showed that cases of the tumours and tumour-like lesions were mostly from the northern and southwestern regions of Nigeria (Arotiba, Adebola, Ajike, Adeola & Ladeinde, 2003). In East Africa, reports indicated that very few studies were carried out into OFT (Kamulegeya & Kalyanyama, 2008).

For instance, Kamulegeya and Kalyanyama (2008) revealed that Tanzania recorded a little over (50.53%) of malignant neoplasm while Uganda had Kaposi sarcoma (37.78%) as the commonest followed by Burkitts lymphoma (30.78%). Kamulegeya and Kalyanyama (2008), further explained that there was significant incidence of benign tumours in Tanzania and Uganda. The commonest of the benign tumours is the ameloblastoma (35.61%) while in Uganda, the most popular was fibromas (26.67%). The situation in Kenya is not much different. Wakiaga and Awange in (1997) reported ameloblastoma, Burkitt's lymphoma, ossifying fibroma and osteogenic sarcoma respectively as the most common OFT. In Sudan, OFT are the fifth leading malignancies and more males are affected compared to females (Osman, Satti, Boe, Yang, Ibrahim and Suleiman, 2015)

### **1.1.1 Age distribution of OFT**

OFT, may affect both the young and the aged. Even though it is globally confirmed that the disease may occur at any age, it is mostly a condition that affects the elderly. It is said that it can be found among persons older than 40 years of age (Johnson, 1991 cited in Lawal, Kolude & Adeyemi. 2013). Lawal et al. (2013) cited two reasons why the OFT condition increases with age. Firstly, it is believed that there is increased level of free radical activities with age. Secondly, an individual's immune system reduces with age and becomes much more tolerant with tumour and carcinoma cells.

Omoriegie, and Akpata (2014) also confirmed the fact that OFT is not limited only to adults when they revealed that paediatric OFT rates were rising considerably in Nigeria. They indicated that in previous studies, incidence of such tumours was relatively low, with benign tumours recording (9.1% to 10.7%) while malignant tumours had a rate of (2.9% to 9%).

However, recent reports from Nigerian studies indicated that both benign and malignant tumour cases were on the increase among children. That of benign tumours was (24% to 28%) and that of malignant tumours went up (13.3% to 22.5%). On the incidence of paediatric OFT in Ghana, Abdulai, Nuamah and Gyasi (2012), stated that the condition is low and limited to mainly benign tumours. However, they complained of lack of studies about paediatric tumours in Ghana. One of the key challenges of the condition is the manner in which it disfigures patients. The disfigurements mostly affect the orofacial regions of the individuals affecting their socio-economic lives.

### **1.1.2 *Body Image/Disfigurement***

Many diseases are often concealed at particular locations or in particular organs of the body. In such cases, the patient decides to willfully reveal it to another person. The case of OFT is completely different. This is due to the fact that the disease cannot be easily concealed. The locations and nature of the disease make concealment virtually impossible since it affects the oral and facial regions of the body. This makes those suffering from OFT experience significant facial disfigurement, vulnerability to psychological distress, social isolation and stigmatization (Fingeret, Hutcheson, Jensen, Yuan, Urbauer, & Lewin, 2013).

The disfigurement and body image issues may cause significant change in appearance, disruptions to the social lives of the patients in terms of intimacy issues, stigmatization and isolation (Callahan 2005; Fingeret. Yuan, Urbauer, Weston, Nipomnick & Weber, 2014). Fingeret et al (2014), explained that for many of the patients, their main concern is whether the treatment could relieve them of their disfigurement and subsequent poor body image perceptions.

This apprehension is understandable because the appearance of such patients greatly affects their self-esteem and general wellbeing.

Howren, Christensen, Karnell and Funk (2013), stressed that OFT patients experienced high levels of social isolation which results in some of them withdrawing from public view and consequently seeking healthcare. The new appearance of the patients due to the disease may also cause majority of them to have significant levels of psychological distress (Masie, 2004; Pirl, 2004).

### **1.1.3. *Psychological distress and OFT Patients***

OFT brings about many challenges to patients including psychological distress. According to Geirdal et al (2014) psychological distress is one of the most pronounced impact of OFT. The psychological distress is brought about mainly as result of the severe pains and discomfort patients experienced. Psychological distress is termed as a state of emotional suffering that is characterized by symptoms of depression and anxiety (Mirowsky & Ross (2002). The symptoms of psychological distress are varied and may depend on the perceptions of persons involved. Some of the common symptoms include loss of interest; sadness; hopelessness, restlessness; and feeling tense (Lebel, Castonquay, Mackness, Irish, Bezjak & Devins, 2011).

Psychological distress can be experienced at different stages of stressful condition. In the case of OFT the experience of distress comes mostly at the start of the disease, pre and post-surgical stages. Llewellyn, Weinman, Mc Gurk and Humphris (2008), explained that at the time of diagnoses many patients become very anxious about the new and sudden onset of the

disease. Patients also get much more worried about the uncertainty regarding the cause of the disease and a successful treatment.

As the disease progresses, many of the patients with OFT's level of anxiety turns into depression. This is due to the fact that most of them have come to the realization that their lives have changed and perceive the full impacts of the disease including chances of recovery (Llewellyn et al; 2008). Humphris and Ozakinci (2006), stressed that the time of diagnoses becomes a crucial moment for the patients as they become very anxious about the disease. Massie (2004) stated that depression whether as subclinical symptoms or clinical depressive disorder is a widespread condition among OFT patient.

It is estimated that depression was more prevalent among OFT patients than patients suffering from other categories of cancer (Massie, 2004; Pirl, 2004). Depression is said to affect a significant percentage of patients with OFT in different proportions depending on the individual's perception of the disease (Lydiatt, Moran & Burke, 2009). Additionally, Humphris and Ozakinci (2006), explained that the process of depression takes about three months to get to its peak and majority of the OFT patients experience that phase.

In some cases, the issue of psychological distress stems from the fact that some patients fear for a possible recurrence of the disease (Hodges & Humphris, 2009). Hodges and Humphris (2009), indicated that the fears and associated worries mostly lead to mood challenges and could eventually result in depression among such patients. Amelung, Mulder, Verheijen, Draaisma, Siersema, & Consten (2015) also noted that often, depression and other forms of psychological distress escape the attention of primary care physicians.

The failure to identify and diagnose such depressive conditions may result in further decline in their quality of life (Amelung et al, 2015). Lydiatt, Moran and Burke (2009) revealed

further that depression has a number of negative repercussions for the patients. These effects include weakened immune system, poor adherence and compliance to treatment, self-care behaviour and reintegration into societal activities. Lydiatt et al, (2009) emphasized that the level of psychological distress also sometimes results from fear of recurrence and uncertainties of the malignant type of the tumours.

Following diagnosis and notification of the condition as well as treatment of the malignant tumours, some patients entertain significant levels of fear of recurrence and possible failure of treatment (Hodges & Humphris, 2009). In most cases, fear is associated with the fact that the disease could become unmanageable and completely affects their livelihood and their quality of life (Verdorick-de-leeuw, Eirenstein, Vad der Linden, Kuik, de Bree & Leemans, 2007).

Psychological distress also affects the general wellbeing and quality of life of patients since their livelihood may have been abruptly disrupted by the disease. In some cases pain, financial burden and fear of the future become the main concerns of the patients (Mellon, Kershaw, Northouse & Freeman-Gibb, 2015). The level of distress in many cases positively correlates with the quality of life of patients. Indicating that when patients experience high levels of psychological distress it also leads to poor quality of life (Silva, Grando, Fabro, & de Mello, 2015).

#### **1.1.4** *Relationship between Psychological Distress and Quality of Life.*

Quality of life of patients with OFT can be affected by the level of psychological distress they experience. WHO cited in Silva et al, (2015) defines quality of life as the perception an individual has about his or her position in life, situated within the cultural context

and value system he or she lives in, and evaluated in relation to his or her goals, expectations, parameters and social relations.

The concept of quality of health is influenced by many factors including physical and psychological health, socio-economic status access to healthcare and education (Griffiths, Humphris, Gerry, Skirrow & Simon, 2008). People's perception of quality of life is determined by their health status psychological wellbeing and state of their daily life. The quality of life of patients covers wide range of issues affecting the patients' life and their general perceptions of state of life (Efunkoya, Adebola, Omeje, Amole, Akhiwu & Osunde, 2015).

The main domains covered include the physical and psychological functioning of the patients. Efunkoya et al, (2015) explained further that quality of life also relates to patients' ability to perform social functions prior to the onset of a particular disease and how others also relate to them. In addition, quality of life concerns patients' perception of relief from most of the symptoms of the disease during their post-operative assessment of their health status. In that regard, patients look at the level of improvement in their current health as compared to the pre-surgery symptoms and make determination of their quality of life (Efunkoya et al, 2015).

Patients measure their quality of life from many activities in their lives. For instance, many patients with OFT suffer high levels of social isolation and embarrassment as the result of the changes in aesthetic appearance of their facial structures (Griffiths, Humphris, Gerry, Skirrow & Simon, 2008). The social isolation usually develops after patients perceive that people in their society show negative attitudes towards them due to their appearance Griffiths et al., (2008) explained further that patients with OFT initially go through a lot of emotional reaction immediately after diagnoses of the tumour or cancerous conditions.

The emotional reactions come about as patients reevaluate their situations, couple with the fear and uncertainty about their future with such a disease. Griffiths et. al., (2008), concluded that patients who experience such emotional reactions, shame and fear, also suffer from low self-esteem and may consequently prefer to keep away from the public. The level of shame experienced by OFT patients was evident in the manner in which many patients demonstrated great relief after successful surgeries.

Mochizuk, Omura, Harada, Marukawa, Shimamoto and Tomioka (2014), stated that improvement in the ability of patients to eat, chew and perform other important functions after surgery brings satisfactions and improvement in their health status. The surgery helps correct the disfigurement associated with ridicule and stigmatization from the public and gives them new life with hope. The more worrying aspect of OFT is that aside the disfigurement and psychological distress patients suffer, it also leads to high mortality among patients (Mochizuk et al, 2014). Apart from the perceptions and evaluations given by patients in determining the distress level of the disease their spirituality and health belief also greatly influence their level of psychological distress. Ill health, especially chronic conditions tend to change the patient's life in many ways (Puchahski, 2012). Some of changes include disruption to the economic, psychosocial and spiritual lives immensely (Puchahski, 2012).

The level of spirituality of patients can also play an important role in their perception of quality of life. This has become much more crucial because from the causes of the disease through to how patients cope, the influence of spirituality is real. This important factor was pointed out by Puchalski and McSkimming, (2006) when they stated that chronic health conditions of which causes are not readily known, patients often adduce spirituality as the main cause.

### ***1.1.5: Spirituality and Healthcare delivery***

Spirituality plays an important role as one of the antecedents in health-seeking. In that light, Mansfield and Mitchell (2002), examined the extent to which African Americans evaluate spirituality in health-seeking behaviour. They observed that African Americans had the perception or beliefs that God acts through physicians compared to whites. Spirituality relates to many aspects of the lives of people and can be a determinant factor in many actions they carry out and therefore needs to be clearly defined.

The concept of spirituality can be defined as “the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship to the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community” (Koenig, McCullough & Larson, 2001:p.18). Spirituality can also be defined to mean “A quality that goes beyond religious affiliation, that strives for inspirations, reverence, awe, meaning and purpose even in those who do not believe in any good (god). The spiritual dimension tries to be in harmony with the universe, strives for answers about the infinite, and comes into focus when the person faces emotional stress, physical illness or death” (Murray & Zentner, 1989; p 259).

According to Bouma (2006), spirituality refers to an experiential encounter and relationship with otherness, with powers, forces and beings beyond the scope of the material world. The other might be God, nature, land, sea or some other person or being. Spirituality has also come to be associated with movements or groups that are not always religious in nature, such as groups concerned with protecting nature who see a spiritual dimension to this activity.

The fundamental aspects of spirituality comprise hope in life, existentialism which covers the meaning and purpose of life as well as how fulfilled life becomes for an individual.

Spirituality also covers forgiveness, beliefs and values, spiritual care, relationship, belief in a God or deity, morality and conduct and creativity and self-expression (McSherry, 2006).

Spirituality and religion are sometimes used interchangeably. It is important to draw the distinction clearly. According to Koenig (2008), religion involves beliefs, practices and rituals related to the 'sacred' whereas spirituality is considered to be more personal relationship with object of belief and worship.

As indicated by Mansfield and Mitchell (2002) spirituality is very relevant in health-seeking among many patients. The relevance of spirituality is often demonstrated by some patients who opt for spiritual means to attend to their diseases. The fact that such diseases usually present in physical forms indicate that patients have different perceptions of their causes and therefore seek spiritual solutions. This type of spiritual belief was expressed in a pilot study by Bowie, Sydnor and Granot (2003) in which they revealed that two-thirds of African American men with prostate cancer wanted their physician to be in contact with their clergy to offer them prayers. In addition, qualitative interviews with eleven prostate cancer patients described three categories of spirituality important to these men: praying, receiving support, and coping with cancer (Walton & Sullivan, 2004).

#### **1. 1.6: *Spirituality, Culture and Transcendental in Health-seeking***

The place of spirituality among African American culture is very special. This is not different from other Africans on the continent. Spirituality forms an integral part of all aspects of life, including beliefs about their health and diseases (Polzer, 2005). Fisher (2011), noted that for individuals who are highly spiritual, there are four domains they engage in leading to healthcare. These four domains permeate and influence their health-seeking behaviour.

The first is the personal domain, where individuals think and appraise health and wellbeing within themselves. Therefore any decision is dependent on personal views and perceptions. The second domain is communal, in which people engage with in-depth interpersonal relationships relating to other important persons involved in their lives. The third is environmental domain where the relationship covers the environment within which such persons live and how that affects their spiritual wellbeing and health-seeking.

The fourth and final of the domains is transcendental domain. This domain, Fisher pointed out involves relating to something or someone beyond the human level. How much individuals believe and relate to such Super natural forces determine their perception and world view about general health, wellbeing and eventual health-seeking (Fisher, 2011). The domain on communality, it is very evident among Africans where most decisions taken are in consultation with immediate and extended family. This assertion was confirmed by Gyekye (2003) when he stated that Africans often come together and take a common decision in matters of ill health, distress and unpleasant news.

According to Gyekye (2003), Africans live highly communal lives and relate to family and friends in relations to issues affecting them. He gave example that Africans come together in times of challenges and joy and therefore share in each other's pains, difficulties and successes. He further opined that African's beliefs and perceptions of diseases are largely influenced by their cultural connectivity. It can thus be concluded that these cultural beliefs and collective decisions can significantly determine the health-seeking behaviour among Africans and may also influence patients with OFT.

There is a strongly held view that Africans are highly spiritual. This view has been corroborated by Mbiti (1990), when he indicated that many Africans interpret health conditions

that are difficult to infer their causes to mystical forces. The main cause often cited is mystical or spiritual forces that have vented their anger against such people either for offending them or going contrary to their traditions. Others believe that it is a punishment from their enemies or those who hate them (Mbiti, 1990).

To Mbiti (1990), typical examples of events include suffering, misfortune, disease and accidents which are cited as happenings from mystical forces and thereby confirming the beliefs of the people leading largely to suspicions and stigmatization from the society. It is this strong belief in the potency and relevance of spiritual forces in the etiology of many diseases that provides the powerful position of traditional healers, priests and priestesses who often intervene for the people. The interventions usually take the form of rituals and other forms of elaborate practices all geared towards pacifying the offended deity in order to restore health and wellbeing. This is again a strong indication of the level and position of spirituality in the affairs of the traditional African.

This issue of spirituality therefore is at the core; both individually and communally in determining health-seeking among the people. The fact that many patients are turning to spiritual means to solve their health problems might be indicative that healthcare providers may not be given adequate training concerning spiritual needs of the patients. According to McSherry (2006), 79.3% of nurses in a study on spirituality and quality of health delivery felt that they were not receiving enough education on spiritual needs of patients. The study further revealed that 79.9% of the nurses indicated that there was the need for further training in spiritual issues concerning patients and how to be able to handle such issues more competently.

### *1.1.7 Health beliefs and Health-seeking behaviour*

Health-seeking behaviour is determined by many factors. The key issues include patients' perception and appraisal of their health conditions and other antecedent factors such as barriers to access to health facility, knowledge of the condition, and vulnerability to the disease (Afolabi, Daropale, Irinoye & Adegoke, 2013). Health-seeking behaviour has been defined primarily as any activity carried out by individuals who think they have a health challenge or perceive themselves to be ill in order to find an appropriate treatment or remedy (Mackian, 2003).

A patient seeks a particular line of help relating to health issues as a result of a number of factors including health belief, socio-cultural background of the patients and other key determinants. These other factors include financial ability, knowledge about the etiology and severity of the disease (Young, 2004). Lack of or inadequate knowledge also serves as a major influence in the direction of health-seeking (Bello & Satwinder, 2014). Bello et. al., (2014), argued that even though spirituality and other factors are major antecedents in health-seeking, the level of awareness of the causes and effects of a particular disease is crucial in health-seeking. They concluded that poverty, illiteracy and ignorance are very essential determinants in a patient's decision on a particular healthcare.

According to Aromaa, Tolvanen, Tuulari and Wahlbeck (2011), perceived stigmatization and negative societal attitudes influence an individual's intentions towards health-seeking. In other words if a patient believes that others in the society have negative perception about his condition that is a major determinant to affect the health-seeking and may lead the person to stay away from attending orthodox health facilities since others may see him.

Patients with chronic health conditions experience a lot of complex psychological phenomena which affect them in many ways and therefore need to be thoroughly investigated (Klemenc-Ketis & Kersnik, 2014). Harding and Taylor (2002), argued that socio-demographic factors such as age, gender and education play important roles in influencing health-seeking. But impact of lay advice is equally very important. Harding and Taylor (2002), explained lay advice as emanating from the patient's social network. Lay advice is seeking referral for diseases from relatives, friends and individual's perception about the severity of the disease.

It is based on the individual's appraisal of the situation coupled with advice from the lay advisors that subsequently lead to a collective choice of healthcare. In addition, Kazaura, Kombe, Yuma, Mitiro and Mlawa (2007), identified certain specific cultural factors including taboos and myths surrounding the etiology of diseases as other major antecedents of health-seeking. It is only if patients understand the cause of the disease and are not influenced by some age old taboos that they will seek orthodox healthcare (Kazaura, Kombe, Yuma, Mitiro & Mlawa (2007),

Health beliefs also play an important role in an individual's decision on seeking healthcare. It is important to note that whether an individual resorts to orthodox healthcare or other means depends largely on the beliefs of such a person coupled with previous experiences. According to Fisher (2011), the cultural and societal background of the individual patient significantly influences the way the person perceives diseases and consequently the type of healthcare attention to seek.

A disease is first recognized, defined, labeled, and explained by lay members of a society in the course of their everyday life. On the basis of this initial assessment, the individual decides on the steps to seek healthcare. These include all the treatment options available to them

informally without payment and without consulting folk healers or medical practitioners (Helman, 1994; Fisher 2011). In such a situation some of the patients may resort to the use of herbal applications and self-medications.

The individual's final decision to seek orthodox healthcare, to a large extent, depends on information about the health facilities available, the cost of treatment and the waiting period before one is attended to by a dentist or a physician. Another important determinant is previous experience the patients might have had with a physician and the general disposition of doctors and other healthcare providers (Fisher, 2011).

All cultures have systems of health beliefs to explain what causes a particular disease, how it can be cured or treated, and who should be involved in the process. The extent to which patients perceive health education as having cultural relevance for them can have a profound effect on their reception of the information provided and their willingness to use it. For instance in Ghana and many African cultures the above factors play significant roles in health-seeking behaviour among patients.

According to Sarfo, (2015) health-seeking behaviour in the Ghanaian socio-cultural context is influenced by cognitive, social, behavioural and material factors. These factors he explains can be directed by predisposing influences such as the individual's level of education, age, gender, religious beliefs and socio-economic status. There are also the enabling factors which usually facilitate health-seeking behaviour such as financial status, availability of health-facilities, social support, affordability, accessibility and acceptance of health insurance.

The needs factor such as perception of severity of the condition, total number of sick days and support available also play very important role in health-seeking. Finally, the health service response includes ready accessibility of orthodox centres, traditional healers/herbalists,

drug stores/pharmacy , prayer and spritual camps. Sarfo (2015) concludes that these factors together determine health-seeking behaviour of patients and form an integral part of healthcare. Apart from the above discussed factors, there is evidence that support the idea that spirituality and health beliefs are just as important determinants of health-seeking behaviour (Sulmasy 2009; Bello et. al., 2014).

The difficulty is the recognitions that spirituality and health beliefs are crucial in giving a comprehensive healthcare to patients. The determination of which of the factors actually predict health-seeking has always been difficult. Afolabi et al, (2013) indicate that barriers to healthcare are much more important determinants to healthcare as compared to spirituality and health belief. This study examined the influence of spirituality and health belief on health-seeking behaviour among patients with orofacial tumour in Ghana.

## **1.2: Statement of the problem**

Orofacial tumours are increasingly becoming one of the leading causes of death globally and among Ghanaians (Howren, 2013). Reports on the prevalence of the disease indicate that it is now affecting children even though it is said to be a disease that mostly affects the adults (Abdulai et al, 2012). The rate at which the disease is growing makes it imperative for the public to become abreast with its causes, impact and how to cope with it. It is however unfortunate that most patients with OFT are ignorant about the causes of the disease. The situation is more serious considering the fact that the disease, according to Parkins et al (2008) starts as a little swelling and grows into enlargement of the maxillae and mandibular structures. The critical challenge is what factors determine health-seeking behaviour among the patients leading to their delayed reporting to the health centres.

Some of the factors identified to influence health-seeking behaviour among patients are spirituality and health belief (Bello et. al., 2014). Other factors including perceptions of stigmatization and body image also play very important roles in health-seeking and can become major determinant in decisions of healthcare by patients with OFT (Aromaa et al, 2011). The first problem the study seeks to investigate is what factors specifically influence their health-seeking behaviour and the type of healthcare they embark on in their quest to get treatment for the disease.

Also, there have been a number of studies (Aregbesola, et al 2005; Andisheh-Tadbir et al. 2008; Abdulai et al 2012; Dereje et al 2016) that looked at the prevalence, trend and epidemiology of orofacial tumours but the psychological factors including spirituality, health belief, perceptions of stigmatization and body image have not been explored. There are also other psychological impacts such as distress brought about as a result of the disease (Geirdal et al 2014). The gap in the level of studies regarding psychological variables is another problem the study aims at exploring in order to find psychological solutions to them.

The culture of an individual can also significantly influence his or her health belief and subsequently health-seeking behaviour. This is confirmed by Fisher (2011), when he indicated that the cultural and societal background of the individual patient significantly influence the way the person perceives diseases and consequently the type of healthcare attention to seek.

The various models investigating psychological challenges affecting patients with OFT concentrated heavily on the Western society. This study looked at health-seeking behaviour from the Ghanaian cultural background. Understanding the health-seeking behaviour from the background of the patients gives a better platform to proffer lasting solutions to the issues. The

issue of spirituality is not only limited to Africans but other parts of the world where people have varying levels of spiritual and health beliefs which could greatly influence their health-seeking behaviour.

When an individual is overly concerned about appraising most of his or her health conditions in terms of spirituality, he or she may decide to seek orthodox care only as a last resort. This is due to the fact that such a person might have sought treatment from other sources in the hope of getting remedy. They only resort to the orthodox health facilities when they feel that the spiritual basis of treatment was no longer efficacious, therefore there was the need to access orthodox healthcare. According to Clegg-Lamprey and Hodasi (2008), when patients delay in reporting to the hospital, their conditions and treatment become difficult and complex since the delay is likely to aggravate the disease. It is thus very crucial to encourage patients with orofacial tumours to promptly seek medical attention where their diseases could be scientifically investigated and treated.

Available literature shows that there are not enough studies to show the influence of spirituality, health beliefs perceptions of stigmatization and body image on health-seeking behaviour among patients with OFT. This study therefore sought to empirically examine the factors that influence health-seeking behaviour including spirituality and health beliefs among patients with OFT.

### **1.3. General aims and Objectives of the Study**

The main objective of the study is to examine to what extent spirituality, health beliefs, perceptions of stigmatization and body image influence health-seeking behaviour of patients and

the effects of orofacial tumours on the patients. The study will take into consideration such variables as age, sex, educational levels, and socio-economic background of respondents.

### **1.3.1 Specific Objectives of the Study**

A number of specific objectives were postulated to investigate the various variables in the study.

These specific objectives are to:

1. determine whether the level of spirituality influences Health-seeking (HSB) of patients.
2. examine the relationship between Health belief (HB) and stigmatization on HSB
3. ascertain if patients with malignant OFT perceive higher levels of stigmatization from the public than patients with benign orofacial tumours.
4. compare the level of psychological distress of patients with malignant tumour and benign tumour.
5. investigate the influence of stigmatization on HSB
6. ascertain the impact of spirituality on coping among patients
7. evaluate whether the perceived level of stigmatization will predict patients' level of distress.
8. find out if OFT patients' level of spirituality will (a) directly influence their HB
9. examine moderation roles of spirituality and health beliefs on the disease and level of distress.
10. assess whether stigmatization will moderate the level of distress and the disease.
11. ascertain whether OFT patients' health beliefs will mediate the relationship between OFTC and their health seeking-behaviour.
12. evaluate how respondents' demographic characteristics (age, sex, educational levels, and socio-economic background) influence their HSB.

#### **1.4. Relevance of the Study**

According to Griffiths et. al., (2008) patients with OFT experience physical and psychological challenges. The psychological distress in particular, comes at different stages of the illness. For instance at the time of diagnoses patients go through a phase of distress where they engage in initial assessment of the condition and how it may affect their lives. They also experience other forms of distress at the pre-and post-operative stages. At this stage the psychological distress comes as a result of the anxiety about the outcome of the surgery and attendant disfigurement and pans.

The study will further enhance the understanding of psychological challenges of patients and how to handle them at each stage of the disease. The findings from the study will help in contributing to the knowledge of patients and thus help in educating patients why they need to change their attitude towards health-seeking. In other words, identifying patients' level of spirituality and health beliefs can improve the quality of therapy because there will be more fruitful interactions between caregivers and patients. Further, knowing the cultural and spiritual background of patients also makes it easy to plan appropriate therapy for their conditions.

The study will also create a good collaborative relationship between religious and traditional healers who provide healthcare services to patients. The collaboration can help enlighten other caregivers about the scientific causes of the disease and the need to allow patients to access orthodox care alongside their treatment under control condition and supervision from medical specialists. Finally, information and knowledge on coping would be of great benefit to patients with OFT and other related chronic health conditions and improvement of healthcare delivery in Ghana.

## **1.5. Research Approach**

This study adopted the sequential explanatory mixed methods approach in order to combine the findings from both the quantitative and qualitative studies to draw credible conclusions (Creswell, 2010). Chapter three presents the quantitative methodology while chapter four comprises methodological strategies for the qualitative study. The study used the sequential explanatory mixed methods using both quantitative and qualitative research approaches to examine the relationships between spirituality, health beliefs, perceptions of stigmatization and body image and health-seeking behaviour among patients with orofacial tumours in Ghana. The research was carried out in two stages.

The quantitative research, study 1 was first carried out using survey and five standardized sets of instrument to collect data on the variables under study. The second phase of the study. Study 2, used qualitative approach to seek further explanations to key findings in study one and also to confirm certain aspects of the findings from the quantitative study. One-on-one in-depth interviews were conducted to elicit information from patients in study two and to allow for further probing for confirmation of answers provided in study one.

### **A Case for Mixed Method**

In dealing with spirituality, health beliefs, perceptions of stigmatization and body image, psychological distress and health-seeking behaviour was an interesting area of study. This was due to the fact that the various variables posed the challenges of assessing the subjective and objective experiences of the patients.

The sequential explanatory mixed methods was adopted in order to complement findings from the two approaches and draw empirical and objective conclusions on the health-seeking behaviour among patients with orofacial tumours in Ghana. The need for the complimentary

roles was stressed by Johnson and Onwuegbuzie (2006) when they indicated that mixed methods research was suitable if the combination of the quantitative and qualitative approaches provided superior research findings.

The sequential explanatory mixed method design was used because it has the ability to equally attend to the subjective and personal experiences of the patients with OFT. In addition, the approach also allowed for objective investigation with standardized scales measuring psychological variables such as spirituality, stigmatization, health beliefs and health-seeking behaviour.

One other key advantage of using the mixed method was that it provided diverse means of seeking information concerning a particular social phenomenon (Cameron, 2011). In this study, the quantitative research method was used first to mainly collect initial data while the qualitative method was used for more and explanatory information.

Another key reason why mixed method was adopted in this study was that it helped in the development of a conceptual framework and also helped build a strong linkage between information gathered from the quantitative method and eventually enrich the study (Madey, 1982). Further, employing the mixed methods approach as opined by Onwuegbuzie (2003 a) allowed the researcher to combine empirical precision with descriptive precision. In this case both objective and subjective views of the subjects with orofacial tumours were adequately addressed by the adoption of studies one and two which appropriately covered both the quantitative and the qualitative information from patients.

Even though the mixed methods approach helped enrich the quality of the study, a key disadvantage worth noting was the need to have experience from diverse methodological

background. In many cases it needs a research team as it is multi-tasked (research team with different methodological backgrounds). This situation was dealt with effectively because of the broad training given to the researcher and sound supervision enjoyed from his team of supervisors

The mixed methods thus became an appropriate technique for a topic that investigated variables such as Spirituality, health beliefs perceptions of stigmatization, body image and health-seeking behaviour and their effects on patients with OFT.

## **1.6. Organization of the Thesis**

The sequential two-part study is organized into five chapters. Chapter one is the introduction of the study which covers the background to the study, problem statement, objectives and relevance of the study. Chapter two of the study comprises theoretical and empirical literature reviews. The chapter also contains conceptual framework, statement of hypotheses, research questions and operational definitions of the various terms used in the study. It further, covers the general methodology of the thesis, epistemological basis of the study and the rationale for the choice of a mixed method of research. Chapter three presents the methodology, results and discussion pertaining to study one. Chapter four reports methodology, results and discussion specific to the study two, in which qualitative results are used to expatiate and confirm the findings from the study. Chapter five is presented in the following order: general discussions of the two findings. The qualitative results are used to throw more light on the findings of the quantitative studies one. The chapter further reports implications of the findings, limitations and recommendations of the study.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This study firstly examines the states of psychological distress of patients with orofacial tumours (OFT). It also evaluates the influences of spirituality and health beliefs on OFT patients' health-seeking behaviour. The study will specifically seek the roles of variables such as age, sex, educational levels, and socio-economic background of respondents in determining their health-seeking behaviour and state of distress of patients.

This chapter discusses relevant theoretical frameworks that help in explaining the variables under study. The theories employed in this study comprise the Health belief model by Hochbaum, Kegeles, Leventhal, and Rosenstock (1958), the 3 H and BMSEST, Spirituality model (Anandaraian, 2008), and the theory of biographical disruption (Bury, 1982).

The three theories that were selected and used in the study were mainly to play supplementary roles in providing explanations to the various variables under study. For instance the health belief model was used to point out some of the factors that influence health-seeking from the theoretical perspective. In the like manner, individual's spirituality in relations to health-seeking and coping were explored with the 3 H and BMSEST, Spirituality model. In addition, the extent to which the disease suddenly disrupts the life of the individual patient was also explained using the theory of biographical disruption model.

The chapter also includes the conceptual framework that guided the current study, the rationale and hypotheses that were tested. The final section of the chapter covers the research questions addressed in the study and operational definitions of key terms. The literature review is divided into various themes appropriate for the various variables in the study.

## **2.2 Theoretical Frameworks**

The position that healthcare should be encompassing in terms of exploring not only the biomedical western healthcare but also the psychosocial and spiritual dimensions are much more relevant today. The aim of such healthcare is to cover every aspects of the disease condition in order to give the patient a much more comprehensive treatment (Anim, 2015).

This type of healthcare has expanded the biomedical treatment to cover bi-psycho-social-spiritual concept of treatment which was found to reduce psychological distress significantly (Hurtig, 2008). Many professionals in the health sector have recognized the importance of bi-psychosocial approach to healthcare and expanding the concept to link this with spiritual becomes imperative in modern healthcare.

People's perception, appraisal and world view of diseases greatly influence how they deal with their health conditions. These include their health beliefs and health-seeking and subsequently moderating their psychological distress (Nobles, 2006; Bediako & Neblett, 2011). This study aims to integrate these important factors such as health beliefs, and health-seeking in order to explore diseases from multiple dimensions.

This is because as revealed by Bhugra (2005), patients with a reliable psychological and social support had their depressive levels significantly reduced. This study uses a number of

theoretical frameworks to explain this integrative and holistic approach to health perception (health beliefs), health-seeking and how to reduce psychological distress among patients with OFT.

The three theories include: The Health belief model by Hochbaum, Kegeles, Leventhal, and Rosenstock (1958), the 3 H and BMSEST, Spirituality model (Anandaraian, 2008), and the theory of biographical disruption (Bury, 1982).

### **2.2.1 *The Health Belief Model.***

The Health belief model was developed by: Hochbaum, Kegeles, Leventhal, and Rosenstock (1958) over fifty years ago to understand American citizens' lack of interest in participating in a free tuberculosis screening programme. It is a psychological health behaviour change model that aims to explain and predicts health-related behaviour particularly in relations to the acceptance of available health service (Sohler, Jerant & Franks, 2015). The health belief model is the most widely and frequently used theoretical model in health education, promotion and disease prevention (Jones & Bartlett, 2010).

The original model has four psychological constructs that influence patients' health-seeking behaviour. The first is the perceived susceptibility which describes the person's belief of the likelihood of contracting a condition. The second is the perception of the severity of the disease and explains the individual's view or opinion of the danger posed by the disease. The third, perceived benefits comprise the thoughts of the effectiveness of the recommended measures to deal with the threat. Perceived barriers are the negative aspects of a specific health action to be undertaken by the individual. In addition, a cue to action acts as the springboard on

which health decisions are often made by patients (Rawlett, 2011). Other key variables are modifying factors including demographic influence and likelihood of health action- which is classified under need factors.

The model has an important aspect which is based on the fact that it is relevant to behaviours that are under the control of an individual patient. That means that the disease goes through stages and levels of severity and the actions of the patient play a crucial role in the course of the disease (Lewis & Merched, 2014). The patient's health seeking behaviour therefore, largely depends on the interplay among the factors he or she considers important and relevant to the treatment of the disease. For instance, the perceived level of stigmatization, may lead to a number of patients withdrawing from the public view and subsequently deciding to stay away from healthcare (Andisheh-Tadyir & Heydari, 2008).

The perception of the level of threat the disease poses to the patient comprises the thoughts and views of individual patient about the danger the disease poses to him or her. This determination largely depends on the appraisal and conclusion arrived at by such a patient. This perceived threat may signal such a patient to review the risk associated with the disease and therefore takes appropriate steps to address the threat and consequently the approach to treatment.

In addition, perceived susceptibility is another core component of the model. If a person perceives that he or she is highly susceptible to a disease; that he is at risk of being affected by the disease, such a patient may take immediate steps if the susceptibility is higher,

and engages in behaviour that would reduce the risk associated with the disease (Glanz, Rimer, & Lewis, 2002).

When an individual is unwell, he or she takes action to remedy the situation. This action depends on the appraisal and conclusion reached by the person on the need to eventually take a particular line of action in terms of treatment. This process usually can be a complex one judging from all the factors that come into play such as HB, and HSB (Tomison, 2013). It is still difficult to comprehend how people perceive diseases based on their HB and eventually acceptance of a particular treatment available.

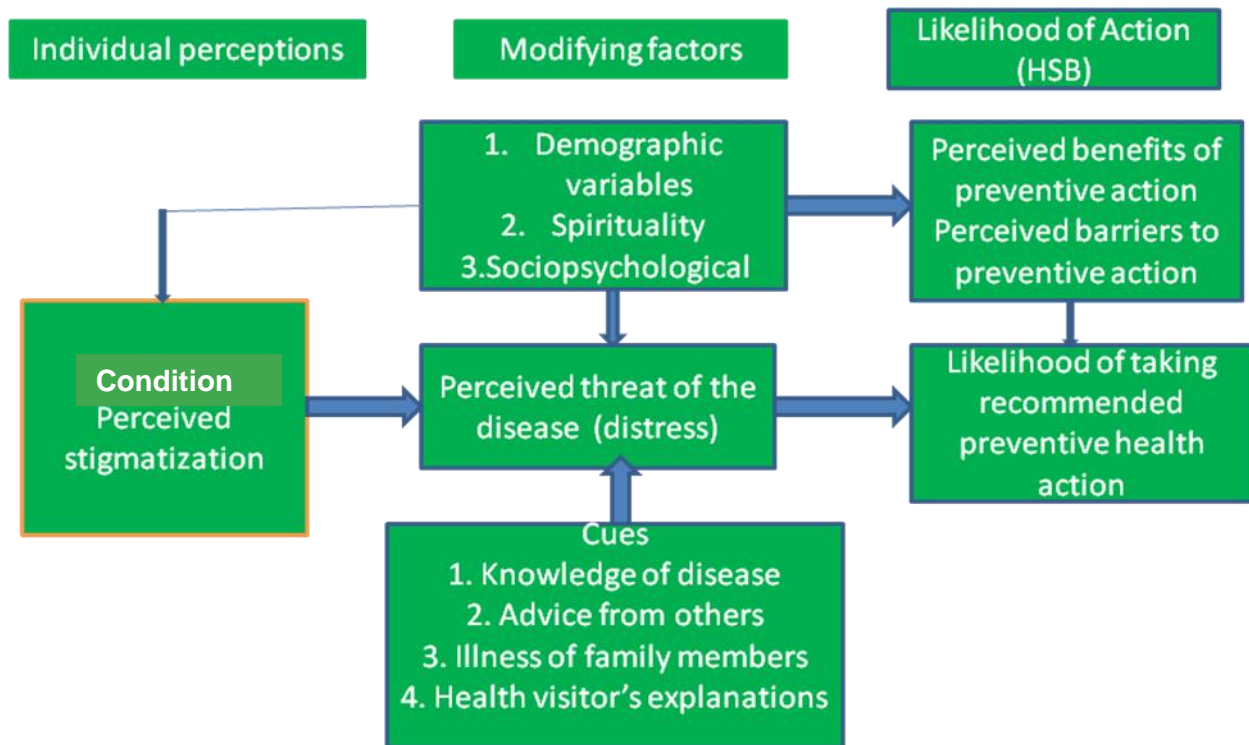
For instance in the USA this situation occurred in the 1950s when screening programmes especially for tuberculosis were not very successful because of the citizens' perceptions about the screening (Hochbaum, 1958 cited in Rimer & Lewis, 2002). In addition, HB of the people of Northern Uganda influenced them to reject a mass immunization campaign geared at controlling schistosomiasis and soil-transmitted helminth (Parker, Allen & Hasting, 2008). Parker et. al (2008) explained that just as the unsuccessful tuberculosis screening in the USA, the local people's perception in Uganda regarding the immunization process led to rejection of the programme at an estimated cost of \$36 million in 2010 alone. The issue of perception or the HB of the individual is even much more crucial judging from the fact that HB is one of the strongest factors determining HSB.

Relating health belief model to this study, OFT principally manifests as a physical or biogenic illness but the manner in which it develops makes a lot of patients appraise it from different perspectives. Most patients assess the possible cause, effect, access to treatment and

effect on their social and economic lives in deciding on the action for treatment. It is in this direction that the model aptly seeks to explain OFT patients' beliefs in dealing with such a disease.

Some other important determinants of HSB are the barriers to healthcare. These barriers include access to healthcare where patients are eager to seek healthcare but due to unavailability or long distances to the facilities patients could not access such care. Secondly, another important barrier is cost of services provided by such facilities. Many patients find it difficult to afford the financial burden placed on them in terms of getting good quality healthcare.

In Ghana, even though National Health Insurance is supposed to help bring some relief to patients most of the costs involved in treatment of OFT are borne by the patients. In addition, long waiting period at health facilities serves as another barrier to HSB. High costs of prescribed drugs, negative attitudes from health staff and unavailability of health information affect HSB (Afolabi et. al; 2013). Demographic factors also play important roles in explaining patient's HSB. The basic demographic factors include age, sex, and race. In addition, socio-demographic factors such as educational level, income, social class, and peer reference groups are also very essential in the final HSB. The demographic and other structural factors mainly comprising knowledge of the disease and past experience tend to indirectly influence HSB through other components of the model.



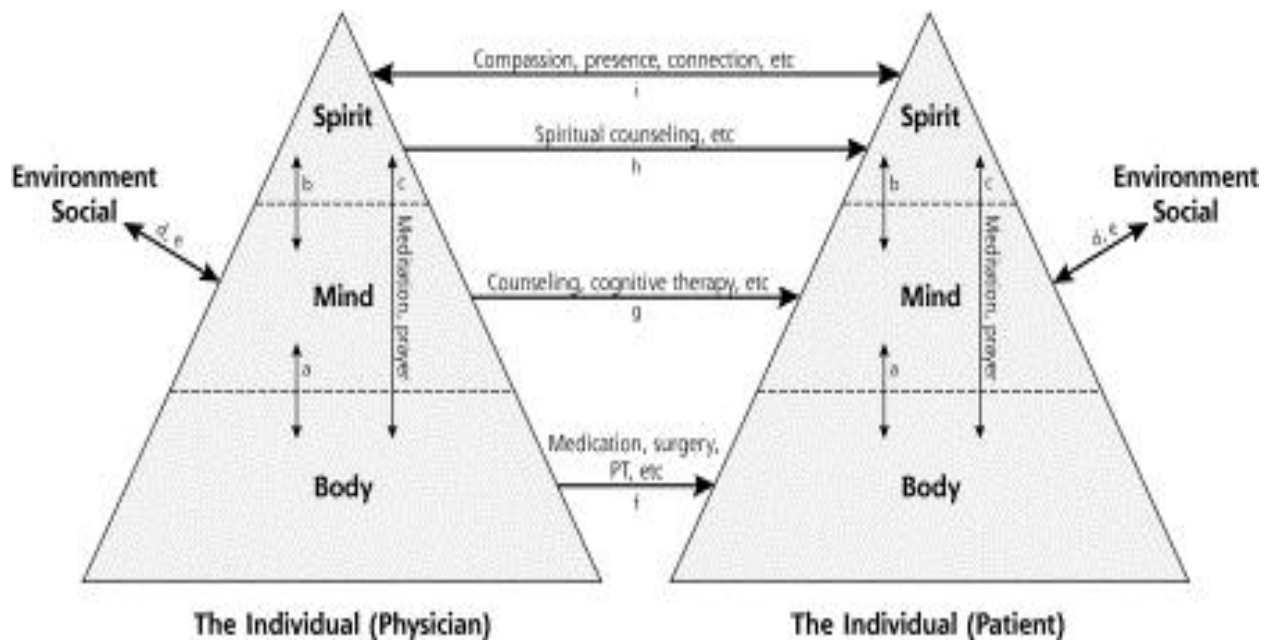
**Figure 1: Health Belief Model of Health-seeking behaviour among Patients**

*Source: Adapted from (Hochbaum, Kegeles, Leventhal, & Rosenstock, 1958)*

### 2.2.2 The 3 H dimensions of spirituality model

The 3 H model (head, heart, hands) and the BMSEST model (the body, mind, spirit, environment, social factors and transcendent) was developed by Anandarajah, (2008). It is a bio-psychosocial-spiritual model that integrates spirituality into health models. It seeks to explain the influences of the body, mind, spirit, social, environment and transcendental on the health of individual. According to Bhandari, Goyal and Parthi (2012), spirituality forms an integral part of a person's relationship with transcendental hence holistic health needs to encompass spirituality. Sulmasy (2009) and Anandarajah (2008) identified the need to provide treatment regime that caters for the spiritual, social and physiological needs of patients.

The search for an appropriate approach in dealing with spirituality and orthodox western medicine has led to a number of models (Sulmasy, 2009). Sulmasy (2009) revealed that George Engel's (1977) biopsychosocial model and Wilite, Williams and Greenberg's (1996) ecological model sought to explain a more holistic view of treatment. However, there are other components that are still not covered especially the spiritual aspect. Sulmasy (2002) proposed the Biopsychosocial-spiritual model. Other models such as Fitchett's 7x7 models for pastoral assessment and care and Wilber's 4-quadrant integral model have some limitations in fully providing explanations to integrate spirituality to fit into a whole-person healthcare (Astin & Astin, 2002)



**Figure 2: Spirituality and Health-seeking Model among Patients**

*Source: Adapted from Spirituality Model (Anandarajah, 2008)*

The 3 H and BMSEST model aims to provide a conceptual basis for approaching spirituality as universal human phenomenon. This is critical to understanding whole-person

medical care (Anandarajah, 2008). The 3 H dimensions of spirituality model (head, heart, hands) looks at the influence of the head (cognitive) domain in appraising diseases. Secondly, heart (affective) domain explains the process and influence of the heart on health-seeking. This deals with the feeling attached to the health status of the individual and how that affects the life of the person and significant others. The third 'H' represents hands which basically stand for the behaviour the person decides to carry out in health-seeking.

The second component of the model covers the body, mind, spirit, environment, social issues, transcendent (BMSEST). It focuses on the inclusion of spirituality and how it affects the patient in appraising the body, mind, spirit, environment, social setting and the transcendent. If the patient appraises the disease as a result of unnatural cause, then the line of treatment to seek is determined accordingly. The key factor is how the individual perceives the disease, reaction from the body, spirit and mind in reacting to a course of action-HSB

### **2.2.3 *The biographical disruption model***

The theory of biographical disruption was developed by (Bury, 1982) with further contributions from Charmaz (1983, 1994, 1995, 2002). The model primarily describes people's experiences of chronic illness and also seeks to explain how patients react to such ill condition as they attempt to adapt to the new life (Bury, 1982). The key theoretical perspective of the model is to explain how a patient's life is virtually affected in a very disruptive manner as a result of the disease.

Bury's emphasis was on the disruption that the illness brings to the patient especially at the onset of diagnosis mostly within the first year (Hubbard, Kidd & Kearney, 2010). In support

of the disruption to the lives of the patients Charmaz (1994) also came out with an interesting revelation. She indicated that people with chronic diseases suffer disruption to their identity. This is because some of them get worried and distressed particularly if they perceive that they were too young to die. In the case of the OFT patients Geirdal et. al (2014) clearly explained that the tumour impairs the ability to swallow, chew and generally affect their appearance.

In some cases it hampers the individual's lifestyle in terms of work and general wellbeing. Unfortunately, many of the patients ignorantly take it for granted and allow the disease to grow to an advance stage which makes success during surgery a difficult task (Parkins et. al, 2008). An interesting aspect of the model which looks at the disruption caused to the patients as a result of the sudden onset of the condition might not be the case in many patients who were already aging (Williams 2000). This is due to the fact that for such patients, they were already experiencing ill health and the OFT may only be an addition. For them according to Williams (2000) it is a normal health challenge but not necessarily a disruption to their lives.

Literature, especially that of Hubbard et al, (2010) also indicated that the OFT affects people across the age groups so even though Williams argument might apply to the aged there are younger patients who could be said to fall directly under the perspective of the theory. The best approach to elicit responses from the patients to identify the effect of the OFT on their lives is to engage them in a qualitative phase of the study for their personal views. It is believed that through the qualitative phase of the study, OFT patients will be able to share their "live" experiences of the tumour (2001; Shaha & Cox, 2003). This could become a vital source of information to aid in mapping out strategies for the treatment of such a disease.

### **2.3 Criticisms and Relevance of the Theories**

The three theories used in the study are found to be appropriate in delving into the key determinants of HSB among OFT patients. The theories form a strong basis for explaining the perceptions of causes, appraisal of the condition and consequent actions regarding HSB. The theories, though are very appropriate for the study, are not bereft of criticisms.

The HBM has been used to explain and predict behaviours that are related to health decisions especially in relations to HSB. It has over the years been used to predict health behaviour among different groups of patients (Rawlett, 2011). The original HBM considers health behaviour as what an individual appraises and appreciates to cause a potentially harmful health concerns that can be avoided or minimized (Weld, Padden, Ramsey & Bibb, 2008). Looking critically at certain aspects of the model, it can be seen that in some cases it lacks the ability to measure all the constructs being assessed (Rawlett, 2011). In the light of assessing the effectiveness of the model to accurately predict HSB, Smith and Lier (2008) used the vulnerable population conceptual model to explain access to resources and facilities.

Smith and Liehr (2008), scrutinize the HBM in terms of its substantive foundation, structural integrity and functional adequacy. They compared that with the vulnerable population conceptual model which measures interrelationship between resource availability, relative risk and health status of individuals. The core scope of the HBM is heavily framed on nursing. This can be inferred from its initial task of immunization against tuberculosis. The cardinal beliefs of nursing are: health promotion and disease prevention.

The HBM aims greatly at reducing or avoiding a particular disease or ill condition with its objective to explain and predict health behaviour (Jones & Bartlett, 2011). The underlying assumption of the HBM is that people will act in case they feel that their individual health is under some form of threat and they perceived that the benefit of the health promotion surpasses the risk of following through with the HSB. Pender, Murdaugh and Parsons (2011) concluded that the assumption is noted supported by the model's core aim of promoting health and preventing diseases.

The key issues the HBM discussed focused on an individual's likelihood of embracing a health action. But the critical action of that likelihood is strongly influenced by the person's awareness of personal susceptibility and the seriousness of the disease compared to the perceived benefits and barriers (Bartholomew, Parcel, Kok & Gottlieb, 2006). Equally, there is no doubt about the foundations of the HBM. It is well established in practice and research. The foundational idea of the model was from a direct clinical observation of lack of population's participation in screening process for tuberculosis. The fundamental factor identified by Social Psychologists at the time was non-participation. Some of the shortcomings of the HBM are that: of inconsistency and lack of guides for future action. Researchers have pointed out the inability of the model to accurately measure some of the important constructs; perceived susceptibility, perceived severity, and perceived benefits. The relationships between the constructs of the HBM have been questioned as not been clear, difficult to confirm, and construct validity (Weld, Padden, Ramsey & Bibb, 2008)

Another important theory in predicting behaviour is the social learning theory by (Rotter, 1954; Bandura, 1977). Major aspects of the social learning theories such as expectancy

and self-efficacy play very important roles in determining behaviour of individuals under different conditions including diseases. An individual's subjective expectations due to self-efficacy and value expectancy also serve as major predictors for behaviour. It is not surprising that Rotter's (1954) and Bandura's (1977) social learning theories have been used to predict behaviour including health among people.

In this regards the individual's subjective expectations and general expectancy can greatly influence the direction of action. On the issue of expectancy, Rotter explained generalized expectancy to include the measures of locus of control (Lewis, 2006). This concept of locus of control indicates that an individual's own behaviour or external forces determine behaviour outcomes. Rotter measured the concept on uni-dimensional scale of (internal – external) but other researchers notably Levenson (1973) expanded it to include beliefs in internality, powerful others and chance locus of control.

It is predicted that a person will most likely participate in a particular action if that person has the belief in internal locus of control and low belief in external locus of control. People are expected to make the best use of resources especially healthcare a result of their 'beliefs in such control'. This aspect of individual behaviour determinism shows that it is not always that the various constructs in the HBM automatically lead to a particular health-seeking behaviour since subjective views and expectancy can significantly influence a person's HSB.

### **2.3.1 Criticism of the 3 H and the BMSEST model**

There has been overwhelming endorsement among researchers for spirituality to be incorporated into the mainstream health care system (Anandarajah, 2008; van Rensburg, 2012). This obvious need to integrate spirituality into prognosis and treatment protocol among health services resulted in the development of a number of theoretical models to explain spirituality in relation to health challenges.

Some of the key models that were developed include: White, Williams and Greenberg's (1996) ecological model which sought to explain a more holistic view of treatment. Secondly, there was also Sulmasy (2002) who proposed the Biopsychosocial-spiritual model. Other important models worth noting are Fitchett's 7x7 models for pastoral assessment and care and Wilber's 4-quadrant integral model. The rest are systems of belief inventory by (Holland, Kash, Passik, Gonert, Sison, Lederberg et al., 1998) and spiritual well-being scale (Ellison, 1983).

According to Anandarajah (2008), there were certain shortcomings associated with most of the models that were previously developed. The key challenge identified was providing a comprehensive explanation about diseases and how spirituality either moderate or aggravates such diseases. This realization and concern led to the development of the 3 H and BMSEST model. The primary aim of the 3 H and BMSEST model is to provide a more holistic care for patients. This became much more important especially, looking at the influence of the body, mind, spirit, environment, social, and transcendent and that can help improve the treatment and recovery of diseases (Anandarajah, 2008).

Notwithstanding the useful roles of the model it also faces a few challenges. One of such challenges is culture. Cultural differences among different groups of people professing

different spiritual aspirations can pose a major difficulty in determining their levels of spirituality (Twumasi, 1975). That is according to Twumasi (1975) spirituality is interwoven with culture and each group of people practice it in unique manner and consequently perceive diseases and other conditions with the same understanding.

In addition, communal interconnectedness among Ghanaians and just as other Africans can help reduce the impact of diseases on the OFT patients. This communal living as pointed out by Gyekye (2003), provides social support for each other especially in times of difficulty. Since this communal practice forms part of the spiritual growth and life of the people, it can significantly influence their perception and behaviour in relation to healthcare and HSB. Interestingly, there are some Ghanaians who take their sick relatives from hospitals and seek spiritual and traditional treatment (Ewusi-Mensah, 1996).

Many people may not understand this practice but Twumasi (1975) provides two theories to explain that practice. In the first place culturally, people believe that there is the (Sunsum mu yadee) which translates as “disease in the spirit”. This means that the cause of such diseases is spiritual. The causes of such diseases are clearly assigned to witchcraft powers, magical and evil forces and wrath of gods and other spiritual sources. Most chronic diseases and unexplained diseases are often classified under this category.

The second explanation of the theory is the fact that some diseases are caused by physical factors usually called “Honam mu yadee”. This category of diseases is not attributable to supernatural forces and therefore they seek treatment along the line of orthodox medical care. Health challenges such as malaria waist pain headache fall into this domain. Twumasi revealed that an individual is made of a mortal component also known as the “Onipadua” (body), which

forms the spiritual aspect of the person. The second part is the spiritual “sunsum” referred to as the personality and the third part called a life force known as the “okra” (soul).

According to Twumasi an individual needs to have a harmony among the three and ensuring that they all function well to be described to be in good health. The belief that certain diseases are caused by spiritual forces and therefore cure for such diseases can be effectively found from the traditional sources has been strongly accepted by many Africans (Tsumasi, 1975; de Graft Aikins, 2005). A much more progressive means of changing the perceptions of such patients is to convince them of the need to collaborate and integrate both biomedical and traditional methods into solving their health conditions (Amegbor, 2014).

Another important challenge of the model is the difficulty delineating spirituality from religiosity. The two terms are often used interchangeably in many contexts. The fact is that though both terms are closely related, they apply differently to determine HSB among people. Salmasy (2009) confirms that spirituality and religion are related, but conceptually different. Spirituality has been captioned as the regular or daily activities which a group or community carries out in relations to the question of transcendence.

Religion on the other hand comprises a set of beliefs, reading materials, songs, rituals and other forms of practices that a group or community adopts in relationship with reaching out to the transcendence. In view of the similarity between the two terms, researchers sometimes mixed up their terms and concepts in relations to seeking answers from the respondents. Sometimes it is difficult for the respondents to clearly see the differences in the questions put before them and respond accordingly without interchanging responses for one another (Koenig 2008).

The model therefore faces the challenge of clearly identifying and also making participants understand the various construct that are truly measuring spiritually from both the point of view of researchers and respondents.

### **2.3.2 Criticism of the Biographical disruption model**

The model was propounded by Bury (1982) with further work by Chamaz (1994). The core aims of the model focused firstly on the description of individual's experiences as a result of a sudden onset of a chronic disease. Secondly, the model also provides explanation on how people interpret diseases, respond to them and attempt to adapt to the new situation (Bury, 1982; 1991; 2001). Though the model has and continues to provide great understanding about how people with chronic diseases such as OFT adapt to their diseases, it also has some short comings. The model emphasizes that chronic diseases usually present with pain, suffering and death. The model explains further that these diseases are perceived by many people as situations that are far from them. It therefore, becomes a sudden and abrupt state of health for such people to deal with when they are afflicted with such diseases (Bury, 2001; Chamaz, 2002).

This perspective of the model does not take into account individual's level of understanding of such diseases. Also, there are people who as a result of education, past experiences and personality, guide their lives with the fact that such events can befall anyone at any stage of live. The key issue involved is how the individual perceived such situations as part of his preparation and stage in life (Richardson, Ong & Sim, 2006). In addition, on the assertion that chronic diseases upset individuals as abrupt complications resulting in significant loss of functional abilities was found to be similar to the finding of Bury (1982). Bury (1992)

demonstrates that the onset of such diseases and loss of financial resources are so sudden that make it difficult for the individual to recover from the situation,

Larsson and Jeppsson-Grassman, (2012) discovered that even though the onset of chronic diseases and associated complications were similar to Bury's finding there are marked differences in the two situations. Larsson et al., (2012) stressed that the onset of the disease could not be entirely unexpected to the patients as found in their study. Equally, the categorical suggestion that the disruption comes as a single episode at the beginning of the disease cannot be accepted as the truth. Larsson et al (2012) concluded that the biographical disruption model should be used to explain and also explore much more complex and wider experiences of patients suffering from chronic diseases. Williams (2000) suggested that when chronic diseases affect individuals at a certain age in their lives, it much more have devastating impact on them because it has disrupted the normal flow of life's journey. However, in Larsson et al (2012), it was revealed that people who suffer from chronic diseases from birth equally experience a lot of painful complications and loss of functional abilities similar to those described by Williams (2000). In reality, the impact of the onset of OFT cannot easily be measured and differentiated among various groups of people or the stage of attack of the disease. There is one important factor which can moderate the impact. That is the level of social support available to the patient. This is whether the patient has the disease from infancy or at a later stage in life.

## **2.4 Related Literature Review**

In this review, major issues associated with the study that have been researched were summarized and critically assessed. The main areas researched include psychological distress,

health-seeking behaviour, spirituality, health belief, perceptions of stigmatization and body image in relation to OFT.

Literature indicates that OFT vary in terms of their prevalence based on geographical area of the victims, cultural influences, social and occupational differences (Arotiba et al, 2003; Aregbesola, 2005). The disease can also be influenced by socioeconomic levels of individuals as well as other demographic factors including education and gender (Arotiba et al, 2003; Aregbesola, Ugboko, Akinuande, Arole & Fagade, 2005). The disease, according to Luna and Wenig 2005 in Bahra et al., (2012) has been classified under specific categories by the World Health Organization (WHO). They indicated that WHO classified OFT into 5 groups namely: benign and malignant epithelial tumours, soft tissue, hemato-lymphoid tumours, and secondary tumours. The two types that this study looks at include the malignant and benign tumours.

The OFT is a worldwide condition affecting people across various regions of the world (Bassey et. al 2014). For instance it is the most common type of oral cancer among the Taiwanese population (Scully & Began, 2009). Taiwan cancer registry reported that there are more men who experience the condition than women. The most prevalence type of OFT is the oral squamous cell carcinoma (oscc) (Shah. & Young 2009). Chen, Liao, and Chang (2010) also confirmed that OFT specifically the Oral squamous cell carcinoma is the most common oral cancer in Taiwan.

Other countries which experience different rates of OFT include India, Hong Kong, Sri-Lanka, South Vietnam, Papua New Guinea and the Philippines. The high rates among these countries are attributed to widespread use of tobacco in different forms (Garewal, 1991).

Garewal, (1990) reported that in the United States of America, the condition forms about 2-4% of cases while it is 1% in Britain and Australia, respectively (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011). In addition, the prevalent rate is not limited to any geographical location.

The widespread nature of the condition was expressed by Jing, Xuan, Lin, Wu, Liu et. al (2007) when they indicated that odontogenic lesions which also affects the jaws are commonly frequently reported clinical cases in China and Malaysia. In Malaysia for instance, there have been more researches carried out into malignant lesions of the orofacial regions most specifically squamous cells carcinoma.

The higher interest in the squamous cell carcinoma can be explained as the fact that there are higher morbidity and mortality associated with it (Rahman, 2014). In the case of Sri-Lanka, Okada, Yamamoto and Tilakaratne (2007) revealed that the highest reported cases of OFT is the ameloblastoma. The cases of odontogenic tumours were lower as evidence in a retrospective study over 6 years period (1996-2002). In that study for over 6 years, 226 cases of odontogenic tumours were recorded. Buchner, Merrell and Carpenter (2006) found from various studies that odontogenic and ameloblastoma are the most common neoplasms among Northern California population.

There have been significant reports on OFT reported in Nigeria. For instance, studies from Nigeria notably by Arotiab et al (2003) showed that the condition affected many regions and states of the country. This finding was confirmed by other researchers including (Lawal, Kolude & Adeyemi 2013; Adeyemo, Ladeinde, Ogunlewe & James, 2005). Generally, reports of the condition from other parts of Africa are few. It may be due to lack of studies into the disease

and its impacts on the people. There were reported cases from Kenya, Tanzania, Uganda and Zimbabwe where prevalence rates ranged from 2.8% to 10% of all head and neck tumours (Mohammed, Singh, Raubenheimer, & Bouckaert, 2010; Vuhahula, 2004; Chidzonga, Lopez, Perez & Portilla-Alvarez, 1995; Silas, Echejoh, Manasseh & Mandong, 2009). Kamulegeya and Kalyanyama (2008) pointed out that though there is paucity of research reports on OFT in many parts of Africa, a few of such reports can be traced to 1956 when Pritam and Cook reported of sarcomas, odontoma and carcinomas as the commonest form of maxillofacial neoplasm in Uganda (Singh, & Cook, 1956).

In 1965, Dodge reported the incidence of odontogenic in a high percentage in Ugandan (Dodge, 1965). The high incidence of the condition was discovered by Slavin and Cameron to be as a result of a season of harvest in both Uganda and Tanzania (Slavin & Cameron, 1969). In Kenya, the category of OFT included mainly Ameloblastoma, Burkitts lymphoma, ossifying fibroma and osteogenic sarcoma. Another African country with recent record of the OFT is Ethiopia. The results from Ethiopia also showed that the incidence of the condition is similar to other African countries in terms of male female ratio and the type of tumours.

Firstly, more males than females were affected (52.76) with ratio of 1.21 with majority of patients between the ages of 21 and 30 years. Ameloblastoma, pleomorphic and squamous cell carcinoma were the most common types of OFT (Dereje, Treshome, Tolosa & Mulata, 2016).

Other African countries also recorded significant cases of OFT notably in Ghana, where (Parkins et al 2008; Abdulai et al 2012) indicated that the condition is the sixth leading killer in the country. Parkins, Armah and Tettey, (2009), revealed that ameloblastoma is the most common odontogenic tumours in Ghana forming (80%) of all cases. This finding is in line with other preceding studies carried out in Ghana and Nigeria which showed that ameloblastoma and other odontogenic tumours are common benign tumours in the West African Sub-region (Lawal et al., 2013). Studies that have reported on ameloblastoma as the most common type of tumour, cut across countries and continents. For instance, the findings in West Africa are similar to that of Zimbabwe and Turkey (Chidzonga, 1996).

In terms of paediatric pathology, Chidzonga 1996 in Parkins et al., (2009) found that benign tumours are more common among the younger age group whereas the older patients experienced more cases of malignant tumours. Glickman and Karlis, (2015) also confirmed that there are different types of pathologic lesions found in infants and children. But the most widespread and common types are the benign soft tissue lesions.

In further confirmation that malignancies are not common among children compared to benign tumours, Basse, Osunde, and Anyanechi, (2014) indicated that head and neck malignancies are rare in paediatric patients and represented 12% of all paediatric cases.

#### *2.4.1 The effects of the OFT on patients*

The OFT have a devastating impact on the patients mainly due to the delicate site and the associated pains, disfigurement and inability to use some of the vital organs such as the mouth, mandible and maxillae (Scully & Bagan, 2009). OFT, just like other chronic health

conditions affects the normal daily functions of the individual patients and also places significant limitations on the patients (Scully & Bagan, 2009).

According to Penner (2008), because most of the patients present to the health facilities with OFT late they require aggressive forms of treatment which mainly include surgery and radiation radiotherapy. Orofacial tumour, poses challenges for the patients on two fronts; as both disease and also the adverse effects of treatment. Firstly, patients have to content with psychological and physical side effects of treatment. Also, physical and psychological symptoms such as dysphagia (difficulty swallowing) disfigurement, anxiety and depression are commonly associated with such treatment (Devlin & Sherman, 2003).

Treatment of advanced malignant OFT, has evolved to encompass organ preservation protocols which include concurrent chemo radiation therapy (Devlin et al., 2005). Hanna, Alexiou and Morgan (2004) revealed that the main objective of the treatment is to help the treated organs to function better and also be preserved in order to reduce the incidence of morbidity associated with surgery and postoperative radiation.

Hanna et al., (2004) lamented that despite the fact that such therapies and care help create disease free-intervals between surgery and recovery for patients, organ-preserving treatments still pose severe side effects. In this regards, even though patients have survival rates of 5 years and are living meaningful lives, the disease and its side effects present them with a lot of physical and psychological challenges (Jemal, Murray, Ward et al., 2008). In a number of studies tracking the survival rates among patients it was realized that less than 45% of patients survived the 5 years period (Hanna et al., 2004).

The main reason adduced was the late reporting to health facilities. It was also noted in the studies that more than 70% of patients reported for treatment three months after the onset of the disease. Most of these studies were carried in the Western world where there are better facilities and better response rate. (Hanna et al., 2004). It is therefore a matter of concern that some of the patients reported late to seek healthcare and also the survival rate was low. Indeed if the survival rate and time of reporting in the developed countries are issues of concern, then it may become a much more challenging issue in the developing countries including Ghana. In addition, to late reporting, another important factor to consider in reducing the impact of the OFT and treatment is the availability and type of facilities for the treatment. In terms of such facilities both pre-surgical procedures and postoperative care are extremely essential (Bassey et. al., 2014). In countries where there is a lot of strain on the health facilities, adequate provision of both pre and postoperative treatments may have major challenges and are likely to lead to poor treatment outcomes (Bassey et. al., 2014)

#### **2.4.2 *Physical Manifestations of OFT***

Remarkable changes in the individual patient's ability to chew, swallow and drink in the manner acceptable to society becomes a major problem (Pauloski, Rademaker, & Logemann, 2000). According to the researchers, more than 50% of all patients diagnosed with OFT experience severe challenge swallowing prior to treatment. It becomes much more severe with advanced stage of the cancer. In many cases, treatment does not alleviate the plight of patients as often, the difficulty in swallowing is exacerbated with a long and enduring pain long after completion of treatment (Hanna et al.2004).

The effects of dysphagia on patients and their close relations are severe and permeated all aspects of their lives (Penner, 2008). The difficulty in swallowing and eating usually result in altered life of the individual. These effects cover physical, emotional, social and cultural components of the lives of patients. Changes in their diets, eating time and duration of eating are all altered as a result of the condition. Some of the patients experience drastic change in taste, texture and overall enjoyment of foods that were previously their favourite (McQuestion, 2006).

Granell, Garrido, Millas and Gutierrez-Fonseca. (2012) explained that in many cases, patients suffering from dysphagia have to be introduced to tube-feeding in order to maintain their nutritional needs. In a study of 75 patients the researchers above found that more than half of the patients with OFT have to go through tube-feeding which placed additional stress on patients and their care givers (Granell et al, 2012)). In addition, patients with OFT suffer immense distortion in their social interactions and interpersonal relationships. They also feel embarrassed and isolated due to the disease (Larsson, Hedelin & Athlin, 2003).

Furthermore, quality of life of patients who suffer from moderate-to-severe form of dysphagia has been found to be significantly affected negatively compared with patients with no or mild dysphagia (Lang, 2009). Not much research has been done into psychosocial impact of difficulties associated with eating and drinking. What is available however, indicated that individuals with such difficulties also experience a lot of negative impacts in terms of their psychosocial functioning (Kulberth et al., 2006).

The eating and swallowing functions are so affected that such patients need rehabilitation in that direction to help them regain their social functions. In such cases speech and language pathologists play a vital role in restoring the normal functions of swallowing among patients. But the key challenge is that in many countries speech pathologists are very few and difficult to get access to them in rural communities which makes it difficult for such patients to get the needed help.

### **2.4.3 *Psychological Distress in Relation to OFT.***

Psychological distress is common with OFT patients especially those with head and neck cancer. The psychological distress comes as both the result of the disease and its treatment. The key areas of distress stem from the fact that the patients suffer physical disfigurement, impaired communication, and inability to function as much as they used to previously which may lead to the feelings of vulnerability, sadness, and also about their future prospects. As has been indicated by Geirdal et. al., (2014) the disease affects the oral, face and neck regions of the patients and inflicts pain and discomforts. The disease can be malignant or benign with many sub classifications under each group (Geirdal et al., 2014). The following page presents samples of malignant and benign types of the tumours. Reader discretion is very important.



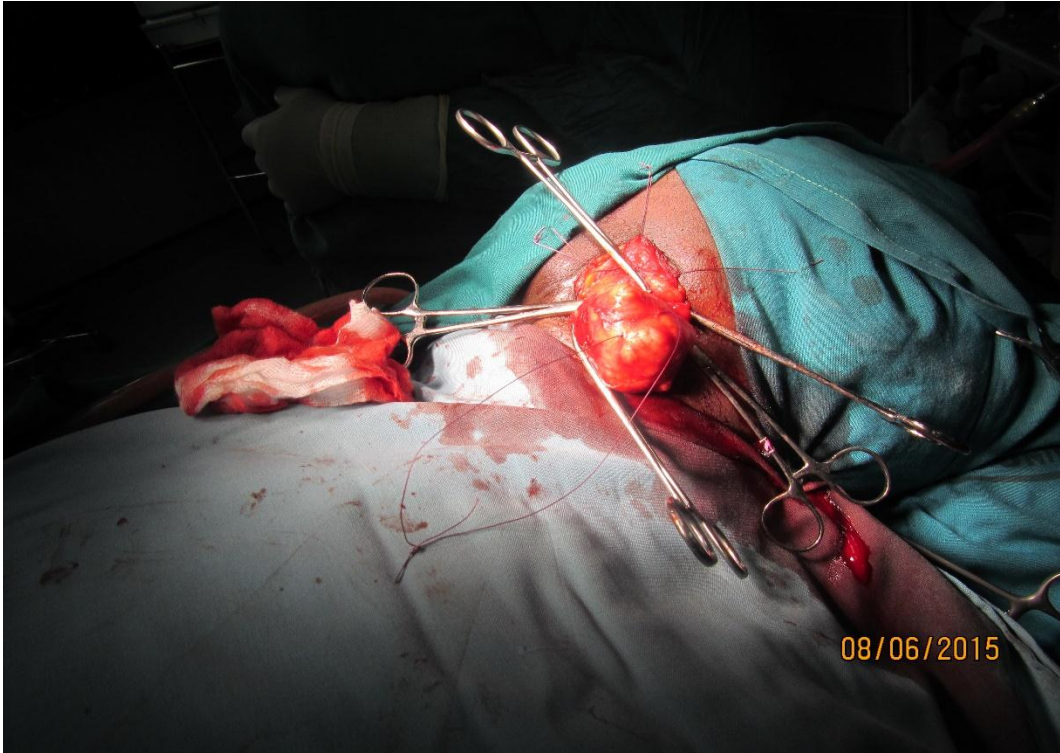
**Figure 3: Benign tumour affecting the maxillae and mandible of the patient**

Source: Maxillofacial Unit of the Korle-Bu Teaching hospital Library, (2015)



**Figure 4:: Benign tumour covering one half of the patient's face.**

Source: Maxillofacial Unit of the Korle-Bu Teaching hospital Library, (2015)



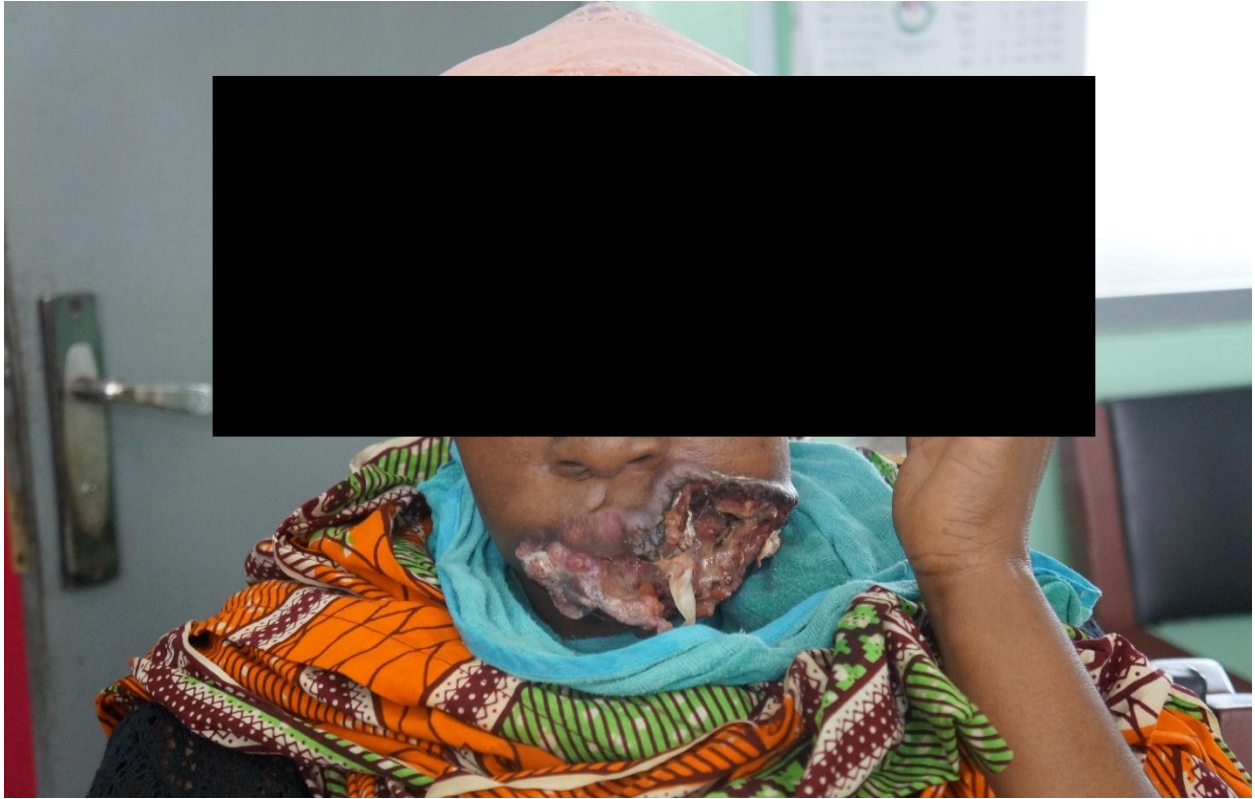
**Figure 5: Surgical procedure to remove benign tumour from a patient.**

Source: Maxillofacial Unit of the Korle-Bu Teaching hospital Library, (2015)



**Figure 6: Malignant tumour affecting the maxillae and mandible of the patient**

Source: Maxillofacial Unit of the Korle-Bu Teaching hospital Library, (2015)



**Figure 7: Malignant tumour affecting the maxillae and mandible of the patient**

Source: Maxillofacial Unit of the Korle-Bu Teaching hospital Library, (2015)

In addition to the distress reported, a lot of the patients have apprehension about a possible cancer recurrence (Semple, Dunwoody, Kernohan & McCaughan 2009; Gotay & Pagano, 2007). Fears and apprehensions of patients concerning possible recurrences are justified since Kissun, Magennis, and Lowe, (2006) revealed in a study on survival rate among cancer survivors that approximately 20% of all of them suffering from head and neck cancer are likely to experience a recurrence, with 90% of the recurrence cases found in the first two years following initial treatments.

Another major issue that predisposes patients to high levels of distress is the 5-year survival rate for patients with advanced form of the malignancy. The survival rate is considered by many researchers as poor (< 50%), after several researches into treatment procedures in order to improve the survival rate, it still virtually remained unchanged over the past few decades (Jemal et al., 2008). On quality of life as a result of the ailment, recent studies suggest that fear of recurrence lowers the quality of life in patients and significantly impacts the psychological morbidity of these individuals and their families (Mello, Northouse & Weiss, 2006; Hodges & Humphris, 2008).

The identification and diagnosis of psychological distress can be misleading as often, significant levels of under diagnoses are recorded. This usually happens if distress is viewed and considered as a normal part of such diseases and therefore inevitable and acceptable. It is important to note that psychological distress varies from patient to patient. In that regard, while most patients are able to cope with their distress and adapt to any changes that occur, others are not able to adapt. Those other patients suffer much more debilitating psychological distress such as anxiety and depression which can render them dysfunctional in many ways (Haman, 2008; Acher, Hutchison & Korszun, 2008).

Studies by a number of researchers notably Massie (2004) and Zabora, Brntzenhofeszoc and Curbow (2001), showed that anxiety and depression are reported to be higher in patients with head and neck cancer compared with other cancer diagnoses (Massie, 2004), The high levels of anxiety and depression among OFT patients were confirmed by Verdonck-de Leeuw et al., (2009). In a study which indicated that depressive symptoms were reported in 86% of patients with head and neck cancer. Symptoms of depression prior to surgery have been outlined as potential risk for developing major cases of depression among such patients after treatment (Karnell, Funk, & Christeinsen, 2006).

Karnell et al., (2006) explained further that although anxiety and depressive scores tend to improve after the initial 6 months, 80% of patients report persistent symptoms up to 3 years later. Some correlates of depression in patients with OFT have been identified and include the following: Patients who are younger, being male, unmarried, having a lower level of education, smoking, a lower level of physical functioning, and having larger tumors at diagnosis (Haisfield, 2009). In addition, anxiety and depression also adversely affect quality of life (Karnell et al., 2006)) and may interfere with the treatment and rehabilitation of patients.

#### *2.4.4 Employment Challenges faced by OFT patients*

Taylor, Terrell and Ronis, et al. (2004) pointed out that OFT renders a lot of individuals unemployable and unproductive due to physical and psychological changes they suffer. This situation in turn affects their families and their dependents. OFT often requires long and complex treatment processes which ultimately interferes with the daily chores and other activities of such individual patients and consequently their families.

Challenges of this nature also pose immense financial burdens on the patients in terms of what they earn from their employment and also the fact that they spend much more on their treatments. In many cases treatments for OFT mainly the malignant types may lead to a lot of pains and result in the patient's inability to function as properly especially in terms of work. In a cross-sectional study that assessed work-related disability among patients with head and neck cancer who were in active employment at the time of diagnosis, 52% of them were unable to return to work even after completion of treatments (Taylor, Terrell & Ronis, et al. 2004). In a few cases those who were able to return to work after treatment had to change their jobs of physical discomfort and poor health following their cancer treatment (Liu, Luan, Mu & Ji, 2010.).

Liu et al, (210) further stated that patients who suffer from OFT in comparison to other types of cancer, survivors experience the highest risk of disability or the incidence of job quitting (Taylor, Terrell & Ronis, et al. 2004). It is believed that because the orofacial region forms part of the window to the individual's life and very delicate, tumours and cancers within such parts of the body greatly affect the occupational and other functions of the individual far more than other tumours and cancers affecting other parts of the body.

#### *2.4.5 Psychosocial Impacts of OFT on Family Caregivers*

The effects of OFT extend beyond the patients and pose significant challenges to their caregivers (Stajduhar & Davies, 2005). Families of patients diagnosed with cancer are severely affected in two main ways. Firstly, by the emotional response to the disease that has afflicted a member of the family and secondly, family members often assume the roles of caregivers who

take up the difficult task of all responsibilities associated with caring for patients with chronic diseases (Goldstein, Concato & Fried, 2004; Winterling, Wasteson & Glimelius, 2004).

Winterling, Wasteson and Glimelius, (2004) stressed that providing care for an ill family member elicits enormous practical changes in the lives of both patients and their families which can result in emotional challenges for both parties involved. It may also have significant and enduring effects on their mental and financial wellbeing of family caregivers (Braun, Hales, Gilad, Mikulincer, Rydall, & Rodin. 2012; Cameron, Franche & Cheung, 2002; Dumont, Turgeon & Allord, 2006) and (Kim, Baker & Spillers, 2006) physical (Derje et al., 2016) Furthermore, caregivers engage in multiple roles that are simultaneously carried out as a result of the disease.

These roles are likely to compete with other functions of the caregivers considering caregiver's limited psychological resources, leading to the caregiver feeling over-burdened and stressed due to the new roles brought about by the disease (Kim, Baker & Spillers, 2006). As a result, family caregivers encounter considerable levels of psychological and emotional distress as they are faced with the new and demanding responsibilities associated with taking care of their ill member (Braun et al. 2012; Cameron, Franche & Cheung, 2002; Dumont, Turgeon & Allord, 2006). Cameron, Franche and Cheung, (2002) revealed that care giving responsibilities also cause a disruption in caregivers' routines.

This disruption may affect their ability to participate in activities that are very important to them including their jobs (Cameron, Franche & Cheung, 2002; Dumont, Turgeon & Allord, 2006). The disruptions to their important routine activities couple with multiple tasking result in

increased emotional distress and greater depressive symptoms among the caregivers (Cameron, Franche & Cheung, 2002). Caring for a family member who is having difficulty eating and drinking or is dependent on tube feeds dramatically changes mealtimes and diminishes the social life of patients and family caregivers (Penner, 2009; Stajduhar, 2003; Brotherton, Abbott & Agget, 2003; Larsson, Hedelin & Johansson, 2003). Penner, (2009) stressed that the family's pattern of cooking and eating also change drastically because they need to cook special meals for the member with OFT and separate for other members. In some cases the caregiver may have to eat alone which brings about different feelings from what they used to prior to the OFT due to the family member's change in feeding. Even if the family member is present during the meal, the dining experience is different in that the caregivers and patients may not enjoy a meal together. Caregivers frequently choose not to attend social functions if their partner/family member cannot eat because they do not want to leave the person alone or explain their absence to others (Penner, 2009).

Both the patient and the family caregivers experience negative psychological effects when they are unable to attend important social events because of reactions from the public and in some cases also because of the patients' inability to eat any type of food (Brotherton, Abbott & Agget, 2003; Liley & Manthorpe, 2003).

There is a paucity of empirical studies on family caregivers and the impact on both caregivers and patients with OFT. The dearth of studies into the impacts of caregiving on caregivers was pointed out by Vickery, Latchford and Hewison, (2003) when they stressed the need for such studies into caregiving roles of caregivers of patients with OFT. They stated further that caregiving roles significantly impacted negatively on the lives of caregivers. Vickery,

Latchford and Hewison, (2003) confirmed this findings in a comparative study by caregivers of patients with OFT.

The findings were that the levels of anxiety among the caregivers were significantly higher than those of the patients ( $P = .001$ ). The result also showed levels of anxiety that exceeded that of the general population. There was also a similar study by Verdonck-de Leeuw, Eerenstein, and Van der Liden (2007) to find correlation between the levels of psychological distress between spouses and patients of OTF receiving treatment. The result of that study also indicated that (20%) of spouses of patients who were receiving different forms of treatment for head and neck cancer experienced clinically significant levels of emotional distress. The result of their study thus corroborated that of Vickery et al, (2003) that caregivers experience high levels of psychological distress. Emotional distress was measured using the Hospital Anxiety and Depression Scale (HADS).

The main reasons for the high levels of emotional distress among spouses were due primarily to the new type of feeding; which was the use of tube for patients, a coping method focused mainly on pessimism or high degree of apprehension, having negative outlook for recovery and a drastic disruption to their routine daily schedule of work due to caregiving roles (Verdonck-de Leeuw, Eerenstein, & Van der Liden, 2007).

One critical factor that is virtually neglected is the levels of anxiety among caregivers. Looking at the amount of anxiety brought on the caregivers due to the burden of taking care of the family member it is not surprising that many caregivers experience equal or higher levels of psychological distress compared to those of the patients (Bergendal, Ahlborg, Knudsen et al,

2011). In addition, many family caregivers and other informal caregivers solicit for psychological support from healthcare providers in order to reduce the level of distress on them.

This is clear evidence that the psychological distress experienced by these caregivers is enormous. The distress is mostly due to the presence of multiple ongoing roles placed on them as part of caring for the ill relatives (Baghi, Wagenblast & Hambek, 2007). Baghi, Wagenblast and Hambek, (2007) stressed as a further confirmation of the need for psychological support for the caregivers that some caring relatives desire to have contact with self-help groups and also more helpful information about the necessary skills needed to be able to accomplish their roles as effective caregivers (Penner, 2009).

#### **2.4.6 *Body Image/Disfigurement and Impact on Patients with OFT***

Fernandes, Costa, Nogueira, de Sousa Lima and Mendonca (2014) stated that, surgical treatment of OFT mostly with the malignant type, frequently requires extensive resection of the surrounding (buccofacial) structures. This treatment may lead to various degrees of facial disfigurements which consequently, need restoration of parts of /or facial tissues. The disfigurements extensively affect the general looks of the patients and quality of life. These effects include negative self-appeal (aesthetic) value, social and work relationships and alterations in the person's life due to the disease (Martino & Ringath, 2008; Fingeret, Yuan, Urbauer, Weston, Nipomnick & Weber, 2012).

Apart from the life-threatening characteristics of the OFT, there is also the issue of permanent reminder of the disfigurement. The impact of the disfigurement becomes more evidence judging from the very sensitive parts of the body involved. The effect of this on the

individual includes reduced self-worth, poor interpersonal relationships and communication (Katz, Irish, Devins, Rodin & Gullane, 2003; Fingeret, Vidrine, Reece, Gillenwater & Gritz, 2010). Fingeret, Hutcheson, Jensen, Yuan, Urbauer & Lewin (2012) in a series of studies found that the body image challenge faced by patients with OFT after surgery can be affected by a number of body related experiences that warrant a well-organized psychosocial care.

Some of these body related experiences include anxiety about strained relationships with partners, social isolation and risk of depression (Katz, Irish, Devins, Rodin & Gullane, 2003; Vallente, 2009). This psychosocial care should be clearly factored into the functional rehabilitation processes for patients. Fernandes, et al., (2014) asserted that the process of surgery and its aftermath become a pensive and silent battle for patients in terms of physical, emotional, and spiritual moments in the lives of patients.

The researchers explained that patients' survival and adjustment to life thereafter depends on their perception and experiences following surgery and the level of side effects and information available to them. A more detailed, comprehensive and accurate assessment of patients' perceptions and experiences as regard surgery may be very helpful in providing more useful information on the outcome and side effects of treatment of OFT.

This information could go a long way in designing intervention strategies, rehabilitation and appropriate orientations needed by patients in their postoperative lives (Fernandes, et al., 2014). Fernandes, et al., (2014) carried out a qualitative study to explore patients' perceptions and experiences about their disfigurement following maxillofacial surgery. The result revealed

three major areas of concern to the OFT patients. Firstly, it is the concept of “becoming disfigured”. This includes the psychological impacts following diagnosis of OFT.

The main concern of patients at this stage was how they would cope and live with such conditions considering all the complications the disease could pose to their health (Konradsen, Kirkvold, Mc Callin, Caye-Thomasen & Zoffmann, 2012). The second phase is termed as being a “disfigured person”. This phase deals with social avoidance and individuals’ attempt to silence their emotions. Thirdly, the concept of “becoming a person with a disfigurement”

According to Katz et al., (2003), this third stage represents the point at which the patient realizes the gradual and challenging phase of returning to begin life after surgery. The key issue here is the changes in their everyday routine and schedule. Konradsen et al., (2012) identified that the initial stage is characterized by personal feelings including fear, escapism, denial, self-blame, stigma and psychological distress. In order to moderate the effect of this drastic change in their lives it was suggested that patients sharing their emotional reactions and expectations with family members play moderating roles in reducing their levels of psychological distress. This assertion was confirmed by O’ Brien et al., (2012) that social support buffers the effects of disfigurement and helps in psychological adjustment and wellbeing of patients (Vallente, 2009).

#### **2.4.7 *The Role of Stigmatization on Health-seeking and recovery among Patients with OFT.***

Perception of stigma and discrimination is one of the widely held views by patients with many diseases. Stigma depends to a large extent on the understanding of the public or individuals about a particular disease condition. Goffman defines stigma as “an attribute that

links a person to an undesirable stereotype, leading other people to reduce the bearer from a whole and usual person to a tainted, discounted one (p. 11)” (cited in Stuber, Meyer & Link, 2008). Stigma generally acts in two forms. First, as a psychological stressor which is different from stressor induced by interpersonal discriminations. This type of stigma classified as a stressor refers to the anticipation of negative treatments by members of the general group or in most cases the public against a marginalized group (Meyer, 2003b). In this type of stigmatization, the reaction comes from the external environment against the patients or the stigmatized members.

The second form of stressor associated with stigma relates to the negative societal attitudes towards the self or internalized stigma (Stuber & Schlesinger, 2006). To the researchers, both self-perception and public perception of stigmatization greatly affect patients especially in their health-seeking decisions. The perception of stigmatization and discrimination increases when the etiology and knowledge about a particular disease is not readily known (Islam, Scott & Minichiello, 2016). The internalized form of the stigma mainly leads to self-stigmatization which was found to be significantly high among patients with OFT.

The issue of stigmatization is not limited to OFT, but as indicated earlier it relates mostly to diseases of which their causes are not readily known. This assertion was evident when perception of stigmatization was assessed among the parents and caregivers of HIV/AIDS patients in Bangladesh by Islam, et al., (2016). The result from their qualitative study into this important factor revealed that parental experiences of stigmatization while living with their HIV children was high. The study indicated that the HIV/AIDS patients held the view that they were highly stigmatized in many forms. These included limited social interaction with HIV

positive patients, derogatory remarks, isolation, negative thoughts and general negative attitudes towards them. As in the case of HIV/AIDS and other diseases, the level of stigma among patients with orofacial tumours is high as reported in literature. For instance, Kazaura', Kombe, Yuma, Mtiro and Mlawa (2006) reported that many patients with various cancers including OFT reported late for treatments.

The sad aspect is that one of the main reasons for the late report is stigmatization. The fact that patients perceived that they were stigmatized by the public may make some of them stay away from the public view and thereby avoid treatment. According the researchers some other patients decided to seek treatment from herbal and other traditional sources until the disease got to advance stage before they were compelled to visit the orthodox facilities for care.

#### **2.4.8 *Influence of Spirituality and Health on health-seeking***

Spirituality plays an important moderating role in the HSB and also the psychological distress experienced by patients with OFT. This is because depending on the individual's level of spirituality the disease may be worsen or improved (Sarfo, 2015; Anim, 2015). Health belief also greatly determines choice of healthcare. Adewuya and Makanjuola (2008) revealed that depending on the patient's perception of the causes of the OFT, spirituality was found to play significant roles in both HSB and moderating psychological distress ((Delgado-Guay, Hui., Parsons, Govan, De la Cruz, Thorney & Bruera, 2011).

Powell, Shahabi and Thoresen (2003) added that spirituality has been shown to be medically important in the prevention of physical and mental illness, as well as in the coping and

recuperation from illness, in adult populations. Spirituality buffers the level of anxiety and depression that are often associated with negative and drastic life events such as being diagnosed of OFT (McCoubrie & Davies, 2006). Generally, spirituality has been found to be associated with the overall and emotional wellbeing of patients (Sulmasy, 2009).

Lago-Rizzardi, de Siqueira, and de Siqueira (2014) conducted a study to investigate spirituality and blood parameters associated with stress in patients with (OFT) specifically facial musculoskeletal pain. They sampled twenty-four women with chronic facial musculoskeletal pain (CFMP) and 24 healthy women for the study. The subjects were necessarily evaluated to meet certain criteria for OFT which included orofacial characteristics, research diagnostic criteria for temporomandibular disorders and also spirituality dimension. Blood samples were collected to analyze blood count, cortisol, ACTH, C3, C4, thyroid hormones, total immunoglobulin, C-reactive protein and rheumatoid factor. The study group was more spiritualized than control group. The result of the study indicated that individuals with a high score of spirituality had less myofascial pain, less bruxism and fewer complaints. They also had lower levels of ACTH and IgE. Spirituality was higher in the study group and can be considered an important tool for coping with CFMP.

Powell, Shahabi & Thoresen (2003) concluded that indeed spirituality plays an important role in the prevention or moderating the impact of diseases on patients. It significantly positively affects patients suffering from physical and mental illness. Patients with OFT have also been found to suffer psychological distress and associated physical pains. Spirituality was found to moderate the level of psychological distress including anxiety and depression that often characterize the impact of such diseases (McCoubrie & Davies, 2006)

Balboni et al. (2007) studied patients with advanced stage cancer and their caregivers in Boston in the USA. Patients were asked to rate the extent to which either religious community or medical system helped their healing and coping process on a scale of 1 (not at all) to 5 (completely supported). The findings showed that 88% of the patients indicated that religion was quite important to their wellbeing. However, 47% indicated that their spiritual needs were either minimally or not at all met by their religious community; furthermore, 72% indicated that their spiritual needs were less strongly or not at all met by the medical system. Those patients who reported significantly higher quality of life showed that either the religious community or the medical system was providing spiritual support. Among the nine variables studied, level of spiritual support was the next most powerful indicator of quality of life. This was especially true for individuals with African and Spanish origin.

Another study was conducted by Rama, Kanatas, Herzberg and Rana (2015) to investigate the influence of certain key coping strategies, such as social support, locus of control, spirituality, compared with quality of life (QoL) and severity of symptoms on how patients cope with oral squamous cell carcinoma (SCC) and coping in other chronic conditions. The comparison was based on quality of life (QoL), severity of symptoms, coping strategies, and factors that influence coping between patients with oral SCC and those with oral lichen planus (which is a less threatening condition).

The study comprised 104 patients with oral SCC and 51 with oral lichen planus who were asked to complete questionnaires about their coping strategies including social support, locus of control and spirituality. The outcome was that patients with oral SCC were far more likely to resort to coping strategies such as depressive coping, distraction, and self-motivation. The groups also differed regarding QoL and severity of symptoms. Patients with oral SCC had a poorer QoL

and higher depression scores, whereas patients with oral lichen planus had better scores in the social support and spirituality categories.

Patients with oral SCC generally had more distress than those with oral lichen planus. Not only did the former resort to depressive coping strategies, but they also had poorer QoL and higher values for depression. For the patients with oral lichen planus, social support and spirituality were protective, whereas they were associated with distress by patients with oral SCC. The result revealed that even though many studies have demonstrated that spirituality moderates the level of distress on patients the perception regarding the potential danger posed by the condition and complications associated with such conditions may be strong determinant as to whether spirituality moderates positively or not. The study was also carried out in the western society with more individualistic culture compared to Africans who are much more collective. These factors such as culture and type of socialization can also influence the outcome of the study.

## **2.5 Summary, Critique and Implications of the Literature Review**

A number of studies have been reviewed on psychological distress and impact on patients with OFT. The roles of spirituality, stigmatization, and health belief in determining HSB have also been explored. The various studies reviewed demonstrate that there are some challenges and gaps as regards conduct of studies into the influence of spirituality, health belief and stigmatization on HSB. These challenges become more compounded in the African context where multiple health-seeking behaviours are common (Amegbokor, 2015).

Spirituality, though has been widely confirmed to moderate psychological distress and also influence HSB, it is also sometimes a poor predictor in both health-seeking and reducing

psychological distress. A study by Afolabi et al., (2014) investigating health-seeking behaviour among OFT patients in Nigeria has revealed that in many cases, even though Africans are said to be highly spiritual, there are other factors including access and resource availability that actually determined health-seeking among OFT patients. Afolabi et al., (2014) therefore recommended that many more studies are carried out into spirituality and HSB.

Globally, patients with OFT report late for healthcare. The reasons differ depending on the culture and location of persons with such a disease. It is incumbent on researchers to identify specific factors responsible for the delay. This is in line with the advice by Parkins et al., (2008) that successes in treatment could be greatly enhanced with early reporting of patients to the health facilities.

The findings from literature reviewed indicated that patients with OFT rely largely on psychological variables such as social support and spirituality in their perception of the causes and appraisal of the disease and the course of action. Also the factors mentioned above significantly moderate the impact of the disease and influence HSB among patients with OFT. Most of the studies also were carried out in the Western culture. Literature showed that the prevalence and manifestation of OFT largely are influenced by geographical, occupational, cultural and social context of the individual patients (Arotiba et al, 2003; Aregbesola, 2005; Afolabi et al, 2014).

Western cultures have their own ontological, epistemological and philosophical underpinnings guided by methodological approaches unique to them. These factors greatly

influence research findings. It is therefore important to investigate variables such as HB, spirituality, stigmatization and HSB in the African and in particular Ghanaian contextual milieu.

Another important challenge is that most of the studies reviewed on OFT and other cancers of the neck and head region were retrospective. They were mainly carried out by medical experts in their fields of specializations looking at the trend. They heavily looked at the etiology, prognoses, epidemiology, treatment and survival rates among such patients. They did not delve much into the core psychological factors affecting patients. The studies that looked at such variables were mostly limited to psychological distress and its impact on quality of life of patients and in few cases caregivers (Martino et al, 2008; Fingeret, et al, 2012).

Many aspects of the disease such as HB in terms of patient's perception in appraising the disease have crucial roles in HSB. Further studies into HSB as well as early screening for vulnerable groups are all very important steps to help manage the disease. The steps stated above can reduce the prevalence of cancer and its related challenges for both patients and family members. It may in the final analysis reduce the burden on the medical and other health personnel.

Methodological approaches to studies play very important roles as regards the effects the results of such studies have on the public. As noted in the summary, most of the studies carried in the Western culture relied heavily on the quantitative approach in the investigations. Quantitative studies have their advantages but they equally have their obvious limitations especially as they are used to generalize in cultural context different from where they were

carried out. There is wide disparity in terms of culture, attitudes and perceptions between Africans for instance and the Western cultural world view.

As captured by Gyekye (2003) that Africans are highly communal and share in each other's burden and therefore decisions on health-seeking could be perceived and decided collectively as opposed to the individualistic perspective of the Western culture. Utsey, Bolden, Lanier & Williams (2007), also noted the importance of African philosophical world view and the role it plays in the choices made and coping strategies among Africans. It is obvious that with the minimal attention given to the cultural differences in generalizing results of studies from the Western world the impact may not be the same for the African.

There are appreciable numbers of the studies that also have completely employed the qualitative approach in reviewing the various variables of interests. These studies that use exclusively qualitative approaches cannot be generalized or used in jurisdictions beyond which the studies were carried out. Limiting a study to either qualitative or quantitative is mostly influenced by time and resource constraints. In addition, it was realized that many of the studies that used qualitative approaches also used small sample sizes of figures less than one hundred respondents. In such cases the statistical power of the study may be significantly affected.

There exist gaps on spirituality, HB, stigmatization and HSB. There is virtually no baseline study in Ghana specifically targeting the variables examined and their relationships among chronic health patients most importantly cancer patients. Adegbola (2005) recommended specifically that studies should target the relationship between spirituality and QoL since that could have a major impact on the level of psychological and overall wellbeing of patients.

Finally, a lot of the studies reviewed tried to establish correlations between and among various variables understudy. The approach did not make enough room for causes to be attributed to many of the factors under study. This current study aims to combine both quantitative and qualitative methods employing a sequential explanatory approach to unravel both relationships between variables and causes of the disease from ‘lived’ experience of patients.

## **2.6 Rationale for Study one and Study two**

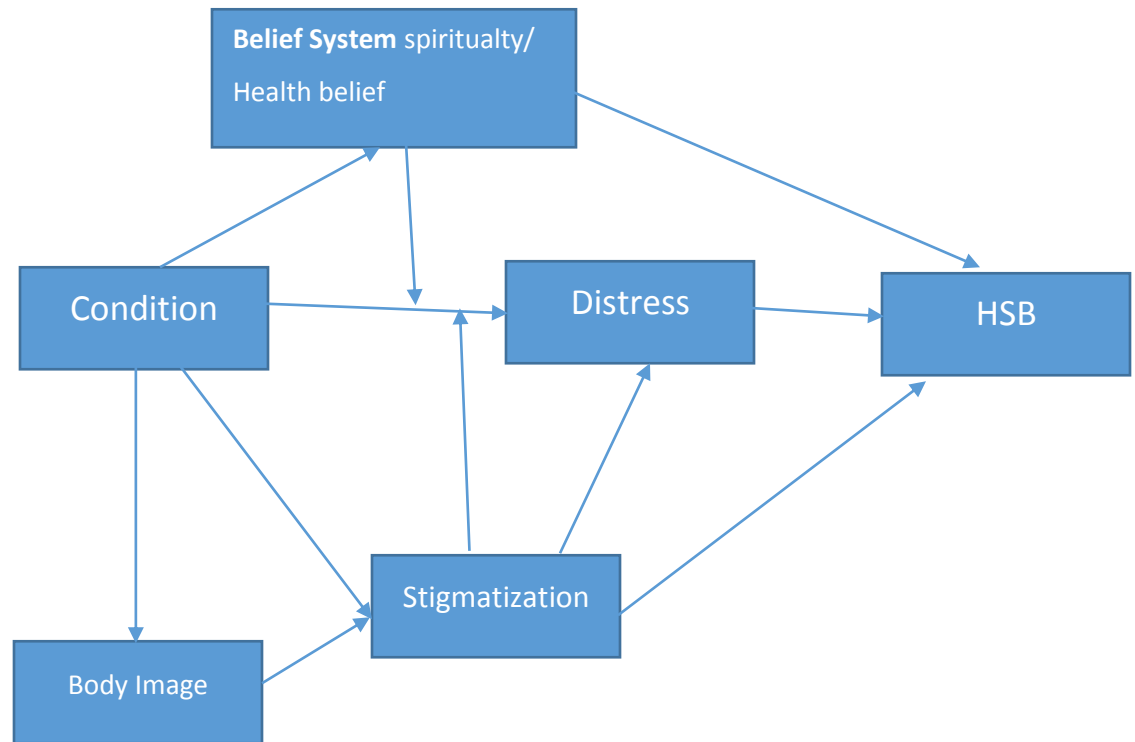
The study focuses on the roles of spirituality, HB, and stigmatization in determining HSB among patients with OFT. It also evaluates the level of psychological distress experienced by patients. The rationale of the study is to develop a theory purported to explain the relationship between spirituality, HB, stigmatization, body image perception and HSB. Several studies have been reviewed but there are certain gaps in terms of theory, methodology and conceptual issues that need to be filled. The main gap identified is investigating the relationship between spirituality HB, stigmatization and how they influence HSB in the Ghanaian context. Additional knowledge would be generated by studying these concepts in the African and Ghanaian culture so as to have a comparative basis for studies conducted in the Western world.

There are several factors responsible for the level of psychological distress among patients with OFT. In some cases it is as a result of the pain trauma, stigma attached to the disease. Other factors include fear of recurrence, disruption to their daily lives, challenges with eating and disfigurement. The factors responsible for distress and the relationships between spirituality and other key variables would also be established in the study one and have a strong basis to be compared with what happens elsewhere.

In study two (qualitative) the health-seeking experiences of patients and further information to throw more light on what has been provided from the quantitative study would be sought. This opportunity helps to get answers to questions from the study one and thus enrich the findings of the study by triangulating the outcome of the studies and drawing much more credible results.

## 2.7 Conceptual Framework for the Study showing hypothesized relations

Based on literature review, the following conceptual framework has been developed to explore the various variables and concepts in the study



**Figure 8: Conceptual Framework for the Study**

Source: Author's Constructs (2017)

Figure 8 shows the conceptual framework that this study is adopting to explain the various variables and their possible outcome in the study. The effect of OFT on the patients is profound and complicated with far reaching implications. The disease comes with shock at the onset of the diagnosis and may lead to anxiety, depression, stigma and psychological distresses. The level of distress is likely to negatively affect the quality of life of the individual and sometimes their

families. Spirituality and the level of stigmatization could significantly moderate the psychological distress of the patient. Equally very important is the fact that the disease can lead to body image perception. The patient's level of spirituality and health belief may also influence the appraisal of the disease and health-seeking behaviour. More importantly also the HSB is of paramount important in determining success of treatment and rehabilitation. This depends on the type of healthcare sought and the time.

## 2.8 Operational Definition of Terms

- ***Spirituality***: the level of an individual's understanding, belief and acceptance and subsequent walk with a supernatural being such as God. It has more to do with a relationship between the individual and that revered powerful being.
- **Early or late reporting**: determined by using the tumour, node, metastasis (TNM)-by the specialist surgeons.
- ***Health belief***: is the appraisal and evaluation assigned to the causes and state of health condition based on an individual's perception of the condition.
- ***Health seeking behaviour***: viewed as the response of individuals to states of ill-health, depending on their knowledge and perception of health, socioeconomic constraints, adequacy of available health services and attitudes of healthcare providers
- **Psychological health**: It is labeled as a person's Global Severity Index (GSI) score recorded on the Brief Symptoms Inventory (BSI). The index indicates whether the

individual is distressed or not. The person is described as psychologically distressed if GSI mean score is  $\geq 1.0$

- **Demographic variables:** comprises information such as age, sex, marital status and educational levels of OFT patients
- **Orofacial Tumour Patients (OFT):** Covers the category of adult patients (18 years and above) with cancer, tumour or lesions in the mouth, neck, face or head regions.

## 2.9 Statement of Hypotheses for Study one (Quantitative)

The following hypotheses were tested in the quantitative study (Study 1)

1. There would be significant difference in the level of psychological distress experienced by Patients with OFT and patients with general dental conditions.
2. There would be positive relationship between the OFT and general dental patient's level of (a) spirituality and (b) health belief and (c) HSB
3. Stigmatization will predict patients' level of distress.
4. There would be negative correlation between body image perception, level of psychological distress of patients and stigmatization
5. There would be positive relationship between the level -of psychological distress, spirituality, health belief, body image perception, stigmatization and health-seeking behaviour
6. Stigmatization would mediate the effect of OFT and general dental condition on psychological distress and HSB,
7. Stigmatization would mediate the effect of BODI on psychological distress and HSB,

8. Psychological distress would mediate the relationship between OFT/dental conditions and HSB
9. Psychological distress would mediate the effect STG on BODI and HSB
10. Patients' perception of stigmatization would moderate the effects of conditions on psychological distress.
11. Belief system (a). Spirituality and (b) health belief) of the patients with OFT and general dental condition would moderate the effects of health conditions on psychological distress.
12. The patients' levels of a) psychological distress and b) HSB, would significantly differ in relationship to their (a) educational level, (b) gender and (c) type of condition.

#### **2.10 Research Questions for Study Two (qualitative)**

The research questions that were used to explore the qualitative aspect of the study include:

1. What does the condition mean to the OFT patients?
2. What do OFT patients perceive as the causes of their condition;
3. How has living with OFT been for the patients?
4. What impact has OFT had on patients (physically, emotionally, and socially)?
5. How have patients of OFT coped with the condition?

## **CHAPTER THREE**

### **STUDY ONE (QUANTITATIVE)**

#### **3.1 Introduction**

This chapter presents the first empirical research report of study one, the quantitative study. It covers each specific and detailed methodological approach employed by the researcher during the study. The chapter is divided into two main parts with part one presenting specific objectives, research design for the quantitative study and the rationale for the choice of the research design. It also presents the methodological procedures adopted to attain the objectives set out in the study. These include: the research setting, population, sample, sample size, and sampling techniques, inclusion and exclusion criteria, research instruments, pretesting, administration of instruments and data analysis techniques used in the study. The second part of the chapter, reports on the research hypotheses postulated for the study one, the results, analyses and discussions of results. The chapter concludes with the limitations and recommendations for further research for the study. This study employs explanatory sequential mixed methods in order to combine the findings of both studies one and two and draw credible conclusions (Creswell, 2010). This chapter presents the quantitative methodology while chapter four comprises methodological strategies for the qualitative study.

#### **3.2 Specific Objectives of the study**

A number of specific objectives were postulated to investigate the various variables in the study.

These specific objectives are to:

1. determine whether the level of spirituality influences Health-seeking (HSB) of patients.

2. examine the relationship between Health belief (HB) and stigmatization on HSB
3. ascertain if patients with malignant OFT perceive higher levels of stigmatization from the public than patients with benign orofacial tumours.
4. compare the levels of psychological distress of patients with malignant tumour and benign tumour and that of general dental conditions.
5. investigate the influence of stigmatization on HSB
6. ascertain the impact of spirituality on coping among patients
7. evaluate whether the perceived level of stigmatization will predict patients' level of distress.
8. find out if OFT patients' level of spirituality will (a) directly influence their HB (b) moderate the effect of stigmatization on their level of distress.
9. ascertain whether OFT patients' health beliefs will mediate the relationship between OFTC and their health seeking-behaviour.
10. evaluate how respondents' demographic characteristics (age, gender and educational levels) can influence HSB and PDI.

### **3.3 Research Design for study one**

The cross-sectional survey method was adopted for the study one. Cross-sectional survey is a type of design in which data on a sample of respondents selected to represent a particular target population are collected at one point in time (Singleton & Straits, 2010). Smith and Davies, (2004) also explained that surveys are usually used to collect views and opinions of people regarding how they feel about some or a particular issue under study. Based on the explanations by Smith and Davies (2004) this study used the survey method to seek opinions and feelings of patients with OFT concerning health-seeking behaviour and psychological distress.

The views about spirituality, health belief, and stigmatization were also examined. Also, one of the key elements of cross-sectional survey is that it allows for the collection of data in a non-experimental method from participants during same limited time focusing on some topic or issues of interest to the investigator (Smith & Davies, 2004).

### **3.4 Rationale for the research Design**

The cross-sectional survey was considered the most appropriate design for the study. The characteristic attribute of it is the ability to gather information regarding beliefs, views, opinions and attitudes on certain issues (Ahmad, Marwat & Khan, 2013). The cross-sectional approach also helps to investigate phenomena that have not had extensive studies conducted in the areas such as assessing attitudes, behaviour, health and belief. Other areas include personal attributes notably thoughts, family history, environmental factors, current and previous health conditions (Carretero-Dios, & Pérez, 2007). The cross-sectional method is also suitable when the researcher intended to collect one-time data from a representative sample rather than every member of the population (Mc Millan & Schumacher, 2006).

The cross-sectional survey method is appropriate in establishing the relationships between and among health belief, spirituality, and stigmatization in health-seeking behaviour and the level of psychological distress of patients with OFT. By the adoption of the quantitative method, the researcher aimed to ensure objectivity of the findings which can be replicated and generalized (Lincoln & Guba, 1985). The study also compared associations among spirituality, health belief from Ghanaian perspective in relations to the various psychological variables. The use of quantitative method also helped to reveal limitations and strengths in established findings and the conclusions to be anticipated.

### **3.5 Study Area/ Setting:**

The study setting covered selected health facilities in Accra, Ghana. Participants were sampled from three health facilities in Accra that handle OFT cases. These hospitals included the oral and maxillofacial units of the Korle-Bu Teaching hospital, 37 Military hospital and Ridge hospital. The three health facilities were purposively selected since they are specialized health institutions dealing with a particular health condition. The oral and maxillofacial unit of the Korle-Bu Teaching hospital was selected because it is the facility that handles the highest number OFT cases. For instance, in 2014/15 there were 1284 orofacial tumour cases reported at the unit (Annual Medical Report, 2015).

In addition, 37 Military hospital also has a specialized department for oral and maxillofacial care which also serves as one of the key referral facilities and a Teaching hospital in the country. The 37 Military hospital also attends to health cases including both civilians and army officers. The choice for it was to create an opportunity to provide a good balance between civilian and military patients. Ridge hospital has a well-equipped dental department which also houses the oral and maxillofacial unit. It serves as the main referral hospital for oral and maxillofacial cases in the Greater Accra region and also a Teaching facility. The hospital treats patients from both rural and urban areas from Greater Accra region and therefore provided an appropriate environment to select participants from virtually all strata of society.

### **3.6 Population**

The study population included all patients with orofacial tumours (OFT) at the Korle Bu Teaching hospital, 37 Military hospital and Ridge hospital all in Accra, Ghana.

### **3.7: Sampling Techniques**

The purposive sampling technique was adopted to select participants for the study. This method was used because of the characteristics of patients; there were a few of such patients who reported to the hospitals and some of them were in very distressed states that did not make it possible for them to participate in the study. They also have designated days for attending to exclusive tumour cases in the various facilities.

### **3.8: Sample Size Determination**

The decision as to how many respondents to select for a study is very crucial to the success or failure of the study, especially the accuracy of the findings (Smith, 2013). The important role of sample size cannot be over emphasized. Cohen, (1988) recommended that in order to accurately determine the appropriate sample size for a study, there was the need to use analysis. The use of Power analysis is able to detect the risk of committing type II error in order to achieve statistically significant differences that exist in the population under study. Cluver et al. (2007) argue whether power calculations can be applicable directly to studies involving multiple regressions.

This study looks at the relationship between spirituality, health belief and stigmatization and health-seeking behavior among OFT patients. It also compares the relationship between OFT and the level of psychological distress of patients. In all, even though the study has one

group, there are four (4) predictors in this study. In order to determine the sample size, the G-Power was used. The sample size determination is also considered using the minimum sample size determinant proposed by Field (2009), which looks at the effect size compared to statistical power and level at which the effect could be realized. In determining the sample size, it is crucial to evaluate the level of significant and the anticipated statistical analysis to be used, which generally applies to the use of multiple linear regression analyses.

In order to identify the parameters with which to operate, the minimum values for the sample sizes are presented as follow: To calculate a medium effect size with high level of statistical power of (.80) looking at ten (10) predictors, a minimum sample size of 150 sample size is appropriate. When considering a medium effect with a statistical power of (.80) a minimum sample size of 200 is required with (20) predictors. In addition, considering six or less predictors, a minimum sample size of 100 is appropriate (Field, 2009).

Based on these principles and the sample size determination formulae, a sample size of 120 is selected for this study for the performance of multiple regression analyses at a statistical power of (.80). The sample size of 120 is deemed adequate judging from the fact that the study used clinical subjects as respondents who were difficult to select due to their conditions. The sample of 120 also serves as one of the highest of a study of this nature which mostly registered sample sizes of less than 100 (Basse et al 2014).

### ***Characteristics of OFT patients***

The sample characteristics of patients are illustrated in Table 1.

**Table 1: Socio-demographic and Disease-related Characteristics of the Sample**

Variable	OFT Benign		OFT Malignant		Dental patients	
	n= 88	(%)	n=55	(%)	n=129	(%)
<b>Age</b>						
18-28	7	(35.0)	1	(5.0)	12	(60.0)
29-39	2	(35.7)	12	(15.6)	38	(48.7)
40-50	10	(21.3)	6	(12.8)	31	(66.0)
51-61	6	(25.0)	4	(16.7)	14	(58.3)
62-72	15	(42.9)	11	(31.4)	9	(25.7)
73-83	7	(38.9)	7	(38.9)	4	(22.2)
Age of first diagnosis	40.93	(12.78)	43.77	(24.93)	26	(32.4)
Time since diagnosis(Mths)	19.02	(11.29)	24.74	(18.89)	6	26.7
<b>Educational level:</b>						
No education	11	(64.7)	6	(35.3)	0	(0.0)
JHS	17	(42.5)	16	(40.0)	7	(17.0)
Secondary	11	(28.9)	5	(13.2)	22	(52.0)
Tech/Voc,	19	(52.8)	15	(41.7)	2	(5.6)
HND	6	(37.5)	1	(6.3)	9	(56.3)
1 <sup>st</sup> Degree	9	(12.0)	9	(12.0)	57	(76.0)
2 <sup>nd</sup> Degree	0	(0)	0	(0)	10	(100)
PhD	0	(0)	0	(0)	4	(100)
<b>Marital status</b>						
Single	34	(29.1)	18	(15.4)	65	(55.6)
Married/cohabit.	41	(34.2)	20	(16.7)	59	(49.2)
Widowed	8	(72.7)	3	(27.3)	0	(0)
Divorced	5	(20.8)	14	(58.3)	5	(20.8)

The average age at first diagnosis of malignant tumour among the patients was 43.77 and that of patients with benign tumour was (M=40.93). The average age at first diagnosis among dental patients was 24. 93. The age group of patients with benign tumour which recorded the

highest participant is 62-72 years (15, 43%), while the age group with the highest malignant cases is 29-39 (12, 16%). The age group with the highest attendance among the dental patients was 40-50 years (31, 66%). Patients with malignant tumour recorded 24.74 months since the disease was reported while those of the benign and dental patients were 19.02 months and 6months respectively.

On education, 12% of patients with benign tumour and 11% of patients with malignant tumour respectively had no formal education. Among the dental patients, more 45% of them had different types of degrees and that represented the highest group of patients. For the patients with benign tumour the educational qualification with the highest participants is the technical and vocational which recorded 21% while that of the patients with malignant tumour had JHS 29% representing the group with the highest number of patients.

About 46% of dental patients were married while 47% of the benign groups were also married. The number of married patients with malignant tumour was 36%. The patients with dental challenge had 50% of them as single with that of benign and malignant also recording 39% and 33% single on marital status respectively. Patients with malignant tumour had the highest number of divorced participants 58% of the total patients (See Table 1)

***Inclusion Criteria for OFT patients:***

The study covered adult patients with OFT. Hence only participants who were between 18 years and 83 years qualified for selection and participation. Also, patients who have been clinically diagnosed and admitted as either an outpatients or inpatient qualified for participation. In addition, patients who were well oriented and not in extreme distress so as to be able to complete the questionnaires and participate in interviews were those selected for study. Language used in

both completion of the questionnaire and interview were English Language and Twi. Finally, only patients who gave consent were recruited for the study.

### ***Exclusion Criteria for OFT patients***

Patients who were acutely ill or had other life threatening co-morbidities were exempted from the study. Secondly, patients whose illnesses were related to infections in the orofacial regions were not included in the study since it was limited to tumour patients. In additions, those who were in too much pain to engage with interviewer despite support did not take part in the study.

### **Research instruments used in the study-characteristics and psychometric properties**

Data collection was carried out using different types of questionnaires to measure the relationship between spirituality, health beliefs, and stigmatization and health-seeking behaviour among patients with orofacial tumours. Other important variables measured include the level of psychological distress of patients, body image perception and coping mechanisms of patients. Below are the descriptive features and psychometric properties of the various instruments used.

The following are standardized tests which were modified and adapted to suit the cultural context of the participants:

### ***Brief symptoms Inventory by Derogatis L (1993)***

It was developed purposely to assess psychological distress together with the 28-item Brief COPE (Carver, 1997) to measure psychological coping strategies. The focus of BSI was identifying self-reported clinically significant and important psychological symptoms among adolescents and adults. It was designed to capture various psychological symptoms: Psychiatric indicators and symptoms in medical and non-medical respondents. The scale contains 53 items

within nine symptoms domains such as Somatization (SOM), Obsessive-Compulsive (O-C), Interpersonal Sensitivity (I-S), Depression (DEP), Anxiety (ANX), Hostility (HOS), Phobic Anxiety (PHOB), Paranoid Ideation (PAR), and Psychoticism (PSY). The global indices are Global Severity Index (GSI), Positive Symptom Total (PST) and Positive Symptom Distress Index (PSDI). Cronbach's alpha score was found to be between .71 and .85 for its 9 subscales. The test- retest reliability score ranged between .68 (Somatization) and .91 (Phobic anxiety) (Derogatis, 1993). The internal consistency of the current study was found to be fairly high with Cronbach alpha coefficients for the subscales being .79, .83, .76, .77, .73, .70, .67, .62, and .73 respectively. In this study the subscales on anxiety and depression were mainly used in assessing depression and anxiety for both groups.

### ***Scoring***

The BSI subscales are scored by summing the answers on the items under each subscale and then dividing the total by the number of items. That is Dimension scores are computed by adding the values for the items included in that dimension and dividing by the number of items in that dimension.

The Global severity index (the total score on the scale) is attained by summing all the items under all the subscales and divided it by 53 (the total number of items on the scale).

Subscales:

The items comprising each of the 9 primary symptom dimensions are as follows:

Somatization: Items 2, 7, 23, 29, 30, 33, 37

Obsessive-Compulsive: Items 5, 15, 26, 27, 32, 36

Interpersonal Sensitivity: Items 20, 21, 22, 42

Depression: Items 9, 16, 17, 18, 35, 50

Anxiety: Items 1, 12, 19, 38, 45, 49

Hostility: Items 6, 13, 40, 41, 46

Phobic Anxiety: Items 8, 28, 31, 43, 47

Paranoid Ideation: Items 4, 10, 24, 48, 51

Psychoticism: Items 3, 14, 34, 44, 53.

Items 11, 25, 39, and 52 do not factor into any of the dimensions, but are added because they are clinically important. These items are included when calculating Grand Total Scores (the global severity index)

Calculating scores for the three global indices is done as follows:

Global Severity Index (GSI). The GSI is computed using the summation of the nine symptom dimensions plus the four extra items not part of any of the dimension scores, and dividing by the total number of items to which the individual answered. If no items were left out the GSI will be the average for all 53 items.

Positive Symptom Total (PST). The PST is a count of all the items with non-zero responses and shows the number of symptoms the respondent reports to be experiencing.

Positive Symptom Distress Index (PSDI). The PSDI is the total of the values of the items receiving non-zero responses divided by the PST. This index offers information about the average level of distress the respondent experiences.

Health Belief Scale (Champion, 1984; Okraku et al., 2009)

This instrument is made up of 20 items. It was developed by Champion (1984). The scale is sub divided into four constructs namely perceived susceptibility, severity, benefits and

perceived barriers. It is a five-point scale and respondents are asked to indicate their level of agreement with particular statements on the four constructs. A section that deals with African constructs has been developed to modify each of the subscales. This was to enable the researcher elicit information on African health beliefs. The health belief scale has good internal consistency with Cronbach's alpha above .70. The internal consistency of the Health Belief Model was also high in the current study with Cronbach's alpha of .78 (Adapted from Okraku et al., 2009)

Items are scored from 1 indicating "strongly disagree" to 5 indicating "strongly agree". A score of 5 indicates high perception while 1 gives an indication of low perception as recommended by Champion (1984).

The Health Belief Model has been widely used in studies of health behaviours. These include preventive health behaviours, sick role behaviours, clinic use and physician visits for wide varying reasons (Conner & Norman, 1996).

### ***The Spiritual Well-being Scale (Paloutzian & Ellison 1983)***

The scale contains 20 items, purposely designed to measure spiritual wellbeing and covers both religious (RWB) and existential (EWB) dimensions. The scale is self-administered and there are two subscales including RWB which has 10 items comprising religious domain: reference to God and 2. It has EWB covering ten items with no reference to God. Half of the items from each subscales has been worded in positive and negative order to control for the challenge of response- set.

The SWB scale has three scores, namely 1. a total score 2. A summary of scores representing that of existential wellbeing items 3. It also has summary of scores on religious wellbeing items. The scale has Cronbach's alpha coefficient for internal consistency of 0.89 (SWB) 0.87 (RWB), and 0.78 (EWB).

**Stigmatization:** stigma scale by King, (2007) 28 items, 3 sub scales-concerns discrimination, potential effects of illness, disclosures. Cronbach  $\alpha$  0.84

**Health-seeking Scale (Afolabi et. al, 2013)**

Health-seeking scale was used to measure health-seeking behaviour among participants. The scale has 20 items in all, measuring different aspects of health-seeking behaviour among patients. The scale is divided into three subscales including. The type of health services preferred and patronised by patients which formed the first components of the scale.

The second subscale of the instrument measures barriers to seeking medical care from the health facilities available to the public. Thirdly, the last subscale comprised patients' perception of the type of services provided to them by the healthcare providers, barriers to access to healthcare and quality of healthcare. The scale has a Cronbach  $\alpha$  0.82

***Personal Appearance Billings Test*** developed by Butters and Cash (1987) and revised by Geremia and Neziroglu (2001). There are 15 items with subscales comprising how people perceive their appearance to be unattractive, activities carried out to conceal perceived defects of appearance and how much worries they experience for the perception of unattractive appearance. The scale has Cronbach  $\alpha$  0.78. The reliability information concerning the various instruments used for the study including number of items, and overall reliability coefficient is presented in Table 2.

**Table 2. Instruments and characteristics features: reliability values and number of items.**

<b>Variable</b>	<b>Mean</b>	<b>Std. Dev.</b>	<b>No. of items</b>	<b>Reliability coefficients</b>
<b>Global score -BSI</b>	63.75	4.53	53	<b>.83</b>
Anxiety	12.23	7.39	6	.73
Depression	11.92	7.82	6	.77
Interpersonal	8.22	5.19	4	.77
OCD	8.16	7.60	6	.83
Somatization	13.57	8.16	7	.80
Hostility	6.77	6.33	5	.71
Phobic anxiety	10.26	6.50	5	.67
Paranoid	6.89	6.23	5	.62
Psychoticism	6.95	6.20	5	.74
<b>Health belief</b>	54.16	10.48	20	<b>.72</b>
Subs-severity	13.82	3.24	4	.82
Susceptibility	12.17	4.73	6	.75
Barriers	13.77	3.53	5	.71
Benefits	13.67	3.46	5	.69
Body image –overall	22.98	13.89	15	<b>.75</b>
<b>Sp. Well-being scale</b>	72.89	13.96	20	<b>.78</b>
Existential	35.65	7.33	10	.72
Religious	37.24	7.35	10	.85
<b>Stigmatization score</b>	75.46	16.96	28	<b>.81</b>
Disclosure	28.85	8.170	11	.78
Discrimination	31.68	8.45	12	.83
Positive perception	14.93	3.48	5	.81
<b>Health-seeking scale</b>	32.22	7.67	20	<b>.79</b>

### **3.9. Quantitative Analysis:**

- Analyses of the data were done using SPSS version 20.0. The analysis for each hypothesis is as follows: Hypothesis 1, Analysis of Variance (ANOVA).
- Hypotheses 2, 3, 4 and 5, : Standard Multiple regressions
- Hypotheses 6-9: Mediation analyses using SPSS (2.12.3) developed by Hayes, (2013). The bootstrapping approach by Pritchard and Hayes (2013) was used with 5000 resampling to test the significance of the indirect effect.
- Hypotheses 10 and 11 were moderation analyses also using the process procedures for SPSS (2.12.3) developed by Hayes, (2013).
- Hypothesis 12: In addition, Multivariate analysis was carried out into the differences between the mean scores on the type of condition in relation to the health-seeking behaviour and the psychological distress of patient.

#### **3.9.1 Ethical Considerations**

The initial ethical clearance was sought from the Ethical Committee of the College of Humanities, University of Ghana. Institutional Review Board clearance was also sought from the three institutions (Korle-Bu Teaching Hospital, 37 Military Hospital and Ridge hospital) from where participants were recruited following a permission letter to carry out the study in the selected facilities and an introduction letter from the Department of Psychology, University of Ghana. The ethical clearance that was approved covered both study one and study two. This

was due to the fact that the participants for both studies were drawn from the same population and sample.

### **3.10 Results (Study One)**

#### **3.10.1 Introduction**

The result section for study one was divided into two. The first comprised the results of the preliminary analyses of the descriptive statistics and the second involved testing various hypotheses formulated for study one using appropriate statistical methods.

#### **3.10.2 Descriptive Analysis**

The next stage of the analysis of data was to explore the distributive characteristics of the various instruments used in the study. The summary of means, standard deviation, skewness, kurtosis and features of instruments used in the study is presented in Table 2.

The nine components of the BSI, four for health beliefs and health-seeking, two for spirituality well-being, three for stigmatization, and body image perception scales were examined and their characteristics presented.

These characteristics presented on Table 2 include: BSI, the scale showed a mean of 63.75 (S.D. =4.53). Health beliefs has a mean of 54.17 (SD= 10.42), with spirituality well-being scale recording (mean=72.89, S.D =13.96), health-seeking behaviour (mean= 36.71, S.D =9.02). The next scale is stigmatization which has (mean=75.46, S.D=16.93) and body image perception (mean=22.98, S.D =13.90). The result of skewness and kurtosis showed that the distribution of scores for all the variables were normal as none of the skewness and kurtosis statistics was above -2 to +2 (Tabachnick & Fidel 1996). The results are presented in Table 3.

**Table 3: Mean, SD, Skewness, Kurtosis and Item properties of the various Instruments and their Subscales**

Variable	Mean	Std. Dev.	No. of items	Maximum	Minimum	Skewness	Kurtosis
Global score -BSI	63.75	4.53	53	0	212	.473	-.867
Anxiety	12.23	7.39	6	0	30	-.309	-1.401
Depression	11.92	7.82	6	0	30	-.326	-1.460
Interpersonal	8.22	5.19	4	0	20	-.283	-1.434
OCD	8.16	7.60	6	0	30	.706	-.908
Somatization	13.57	8.16	7	0	35	-.225	-1.226
Hostility	6.77	6.33	5	0	25	.800	-.705
Phobic anxiety	10.26	6.50	5	0	25	-.342	-1.365
Paranoid	6.89	6.23	5	0	25	.755	-.871
Psychoticism	6.95	6.20	5	0	25	.704	-.916
Health belief	54.16	10.42	20	20	100	-.237	.797
Subs-severity	13.82	3.24	4	4	20	-.764	.599
Superstition	12.17	4.73	6	6	30	.862	.123
Barriers	13.77	3.53	5	5	25	-.443	-.267
Benefits	13.67	3.46	5	5	25	-.432	-.246
Body image –overall	22.98	13.89	15	0	60	.458	-.365
Sp. Well-being scale	72.89	13.96	20	20	120	-1.068	2.244
Existential	35.65	7.34	10	10	60	-1.002	1.925
Religious	37.24	7.35	10	10	60	-.919	1.639
Health-seeking	36.71	9.02	14	0	56	-.251	-.603
Stigmatization score	75.45	16.96	28	28	140	.137	-.550
Disclosure	28.85	8.170	11	11	55	-.014	-1.019
Discrimination	31.68	8.45	12	12	60	.279	-.703
Positive perception	14.93	3.48	5	5	25	-.418	-.236
Health-seeking type	32.22	7.67	20	0	100	.376	1.301

### 3.10.3 Tests of Normality and Multi-collinearity

All of the results of the calculations carried out to examine the normality of scores suggest that the residuals are normally distributed - the skewness and kurtosis were near 0 especially for the overall scores, Based on these results, the residuals from this regression appear to conform. Using *Tolerance* and *VIF* (Variance Inflation Factor), it was found that all variables were within acceptable levels of above .300 and below 3.00 respectively. Thus, Brief symptoms inventory and health belief were not related multi-collinearly as predictors of psychological outcomes. In the same way, health-seeking scale and other scales were not multi-collinearly related. The values are presented in Table 4.

**Table 4: Collinearity Indices for the Key Study Variables**

<b>Variable</b>	<b>Tolerance</b>	<b>VIF</b>
Brief Symptoms Inventory	.461	2.169
Health belief scale	.956	1.046
Spirituality Well-being	.945	1.059
Stigmatization scale	.521	1.920
Body image perception	.565	1.768
Health-seeking behaviour	.864	1.476

The mean and standard deviation values were assessed for the main instruments used in measuring the various study variables. The results of the analysis are presented in Table 5.

**Table 5: Means and Standard deviations among Variables**

	Mean	S D
HSBP	31.55	6.51
SWB	64.41	13.55
BSI	105.37	12.41
Stg	69.68	7.31
HBS	55.53	11.37
BODI	25.07	9.06

1. Health-seeking behaviour
2. Spirituality wellbeing scale
3. Brief symptoms inventory
4. Stigmatization scale
5. Health belief scale
6. Body image perception

The inter-correlations among the variables are presented in Table 6. The results showed significant negative relationship between spirituality and health seeking behavior among the patient with orofacial tumours. Spirituality again had a significant relationship with psychological distress. Perception of stigma also negatively related with health-seeking behavior and psychological distress, but had positive relationship with health beliefs. Body image perception related significantly and positively with health-seeking behavior, psychological distress and health beliefs.

**Table 6: Correlations among Key Study Variables (Brief Symptom Inventory, Body Image Perception, Spirituality Well-being and Health-seeking)**

Variables	HSBP	SWB	BSI	Stg	HBS	OFT.	BODI
HSBP	1.000						
SWB	-.211**	1.000					
BSI	.118	-.244**	1.000				
Stg	.145*	.170	-.172*	1.000			
HBS	-.037	.163	-.016	.426**	1.000		
Cond	.028	.085	.094	-.020	-.032	1.000	
BODI	.311**	.057	.274**	.054	.173*	-.067	1.000

\*significant at .05

\*\* Significant at 0.01

1. Health-seeking behaviour
2. Spirituality wellbeing scale
3. Brief symptoms inventory
4. Stigmatization scale
5. Health belief scale
6. Condition of the tumour
7. Body image perception

### 3.10.4 Testing Hypotheses

The various hypotheses postulated in the study were analysed and the results of the analyses are presented in this section. Analysis of Variance (ANOVA) was used to analyse the differences in the level of psychological distress experienced by Patients with OFT and patients with general dental conditions. The Standard Multiple Regression analyses were carried on hypotheses two to five to find the relationships among the various variables. A number of mediation and moderation analyses were also carried out to evaluate the mediating and moderating roles of some of the variables on the main dependent variables in the study. The process procedures for SPSS (2.12.3) developed by Hayes, (2013) was used for the mediation and moderation analyses. In addition, Multivariate analysis was also carried out into the differences between the mean

scores on the type of condition in relation to the health-seeking behaviour and the psychological distress of patient. The results of the analyses are presented on Tables 7 to 21.

Hypothesis one states that: There would be significant differences in the level of psychological distress experienced by Patients with OFT and patients with general dental conditions.

**Table 7: Analysis of Variance on level of Psychological distress among Patients**

Condition	M	SD	df	F	Sig	Bonferroni
Benign	100.88	17.48				
Malignant	181.05	5.67				
Control	46.62	7.91				
Total	91.36	38.28	2,269	49.88	.000	2>1,>,3

Mdf-1 and 2= 80.18\*, p < .000); Mdf-2 and 3= 134.43\*, p < .000); Mdf-1 and 3= 54.25\*, p < .000). Partial Eta squared =.770, 1=Benign, 2= Malignant, 3=Control

**\*Summary of Bonferroni Post hoc analysis**

The post hoc test, using the Bonferroni showed significant differences between the malignant and benign (mean difference = 80.18, p < .000); between malignant and general dental patients (mean difference = 134.43, p < .000); and also between benign and general dental patients (Mean difference = 54.25, p < .000). Thus, the nature of the condition has a significant effect on the level of distress experienced by the patients with malignant recording the highest psychological distress (mean = 181.0545), benign (mean = 100.88), and control group (mean = 46.62). The (Partial Eta squared =.770) demonstrating that the condition accounted for 77 % of the variance in .the experience of psychological distress. The result indicated that the hypothesis is supported.

Hypothesis two states that: There would be positive relationship between the OFT and general dental patient's level of (a) spirituality and (b) health belief and (c) HSB

**Table 8: Correlation between Spirituality, Health belief and Health-seeking behaviour among Patients**

<b>OFT and dental Patients (n=272)</b>			
<b>Variables</b>	<b>1</b>	<b>2</b>	<b>3</b>
1. Health Seeking Behavior			
2. Health belief	.054		
3. Spirituality	.286**	-.065	

\*significant at .05

\*\* Significant at 0.01

As depicted in Table 8, a significant correlation exists between spirituality and health seeking-behavior [ $r = .286^{**}$ ]. Health belief also correlates positively with HSB [ $r = .054$ ] though this was not significant, multiple regression was conducted based on Hayes (2013) recommendation that so far as some relationship exists whether it is significant or not a multiple regression can be carried out for the analysis. The analysis helps to determine the effect of the third variable on the relationship.

Further, the two variables (spirituality and health belief, control (.087) 9% variability in health-seeking behavior ( $R^2 = .087$ ,  $p < .000$ ).

Results from Standard Multiple Regression Analysis following the above observations are presented in Table 9.

**Table 9: Standard Multiple Regression Analysis of Health-seeking behaviour on the Relationship between Health belief and Spirituality among Patients.**

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**OFT and Dental Patients (n=272)**

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<b>Variables</b>	<b>B</b>	<i>SE</i>	$\beta$	<i>p</i>
Spirituality	.188	.038	.290	<.005
Health belief	.063	.051	.073	.212

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Dependent variable: Health Seeking Behavior ( $R^2 = .087$ ,  $p < .000$ )

Results in Table 9, showed that spirituality significantly predicted health-seeking behaviour ( $\beta = .290$ ,  $p < .000$ ). Results further indicated that health belief did not significantly predict health-seeking behavior. This implies that the above hypothesis was partially supported.

Hypothesis three states that: Stigmatization will predict patients' level of distress.

Table 10: Correlation between Psychological distress, Health belief, Health-seeking behaviour, Stigmatization, and Body Image Perception among patients

**Table 10: Correlation between Psychological distress, Health belief, Health-seeking behaviour, Stigmatization and Body Image Perception among Patients**

OFT and dental Patients (n=272)						
Variables	1	2	3	4	5	6
Psychological distress						
Spirituality	.071					
Health-seeking behavior	.402**	.286**				
Health belief	.138*	-.065	.054			
Stigmatization	.668**	.057	.171**	.187**		
Body image perception	.615**	.205**	.210**	.137	.537*	

\*significant at .05

\*\* Significant at 0.01

As depicted in Table 10, a significant correlation exists between stigmatization and psychological distress ( $r = .668^{**}$ ). Health belief also correlates positively with psychological distress ( $r = .138^*$ ). Other variables including body image perception also significantly correlated with psychological distress ( $r = .615^{**}$ ). Though spirituality also correlated with psychological distress, the level of the correlation was not significant [ $r = .071$ ], multiple regression was still conducted based on Hayes (2013) recommendation that so far as some relationship exists whether it is significant or not a multiple regression can be carried out for the analysis. The analysis helps to determine the effect of the third variable on the relationship.

Further, body image, stigmatization, health beliefs and spirituality, control (.539) 54% variability in the level of psychological distress ( $R^2 = .539, p < .000$ ).

**Table 11: Standard Multiple Regression Analysis on Relationship between Health belief, Spirituality, Stigmatization, Body Image Perception, Health-seeking behaviour and Distress among Patients**

<b>OFT and Dental Patients (n=272)</b>				
<b>Variables</b>	<b>B</b>	<b>SE</b>	<b><math>\beta</math></b>	<b><i>p</i></b>
Health belief	-.016	.238	-.003	.945
Spirituality	-.132	.178	-.032	.461
Stigmatization	1.622	.171	.472	<.005
Body image perception	1.544	.212	.368	<.005

**Dependent Variable: (PDI  $R^2 = (5.39, P < .001)$ )**

Hypothesis 3: that Stigmatization would predict patients' level of distress. The results of standard multiple regression of level of psychological distress, body image, stigmatization, health beliefs and spirituality indicated that the model was significant ( $R^2 = .539, p < .001$ ). Stigmatization ( $\beta = .472, p < .001$ ) and body image perception ( $\beta = .368, p < .001$ ) significantly predicted the level of psychological distress of the patients. Health beliefs and spirituality did not predict the level of psychological distress of the patients. The hypothesis was therefore confirmed with two of the variables.

Hypothesis four that: There would be negative correlation between body image perception, level of psychological distress of patients and stigmatization.

**Table 12: Correlation between Stigmatization, Body Image Perception and Psychological distress among Patients**

OFT and dental Patients (n=272)			
Variables	1	2	3
Stigmatization			
Body image perception	.537**		
Psychological distress	.668**	.615**	

\*significant at .05

\*\* Significant at 0.01

As demonstrated in Table 12, a significant correlation exists between body image perception and stigmatization ( $r = .537^{**}$ ). Also, psychological distress correlated with stigmatization ( $r = .615^{**}$ ).

In addition, the two variables (body image perception and psychological distress) control (.687) 69% variability in health seeking behavior ( $R^2 = .687$ ,  $p < .000$ ).

Results from Standard Multiple Regression Analysis following the above observations are presented in Table 13.

**Table 13: Standard Multiple Regression Analysis on Stigmatization, Body Image Perception and Psychological distress among Patients**

**OFT and Dental Patients (n=272)**

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<b>Variables</b>	<b>B</b>	<b>SE</b>	<b><math>\beta</math></b>	<b>p</b>
Body image perception	.249	.069	.204	<.005
Psychological distress	.158	.016	.542	<.005

---

**Dependent Variable: STG ( $R^2 = (0.472, P < .001)$ )**

Hypothesis four that: There would be negative correlation between body image perception, level of psychological distress of patients and stigmatization.

The results of standard multiple regression of correlation between body image perception, level of psychological distress of patients and stigmatization indicated that the model was significant ( $R^2 = .472, p < .001$ ). Psychological distress ( $\beta = .542, p < .001$ ), and body image perception ( $\beta = .204, p < .001$ ) significantly predicted stigmatization of the patients. Therefore, the hypothesis is fully supported.

Hypothesis 5 There would be positive relationship between the level -of psychological distress, spirituality, health belief body image perception, stigmatization and health-seeking behaviour

**Table 14: Correlation between Spirituality, Health belief and Health-seeking behaviour among Patients**

OFT and dental Patients (n=272)			
Variables	1	2	3
1. Health Seeking Behavior			
2. Health belief	.054		
3. Spirituality	.286**	-.065	

\*significant at .05      Dependent Variable-Health-seeking behaviour

\*\* Significant at 0.01

As shown in Table 14, a significant correlation exists between spirituality and health seeking-behavior [ $r = .286^{**}$ ]. Health belief also correlates positively with HSB [ $r = .054$ ] though this was not significant, multiple regression was conducted based on Hayes (2013) recommendation that so far as some relationship exists whether it is significant or not a multiple regression can be carried out for the analysis. The analysis helps to determine the effect of the third variable on the relationship.

Further, the two variables (spirituality and health belief, accounted for (.087) 9% variability in health seeking behavior ( $R^2 = .087, p < .000$ ).

Results from Standard Multiple Regression Analysis following the above observations are presented in Table 15.

**Table 15: Standard Multiple Regression Analysis of Health-seeking behaviour on Health belief, Spirituality, Stigmatization, Body Image Perception, and Psychological distress among OFT and Dental Patients**

OFT and Dental Patients (n=272)				
Variables	B	SE	$\beta$	p
Psychological distress	.085	.012	.548	< .005
Health belief	.036	.047	.041	.446
Stigmatization	-.087	.039	-.164	< .05
Body image perception	-.066	.046	-.102	.151
Spirituality	.181	.035	.280	< .005

Dependent Variable: (HSB,  $R^2 = (.539, P < .001)$ )

Hypothesis 5: that There would be positive relationship between the level -of psychological distress, spirituality, health, belief, body image perception, stigmatization and health-seeking behaviour. The results of standard multiple regression of health-seeking behaviour on the level of psychological distress, spirituality, health belief, body image and stigmatization indicated that the model was significant ( $R^2 = .253, p < .001$ ). Psychological distress ( $\beta = .548, p < .001$ ), spirituality ( $\beta = .280, p < .001$ ) and stigmatization ( $\beta = -.164, p < .05$ ) significantly predicted health-seeking behaviour. However, health belief and body image perception were not significant in predicting the health- seeking behaviour of the patients.

## **Mediation analyses**

A number of mediation analyses were also carried out to evaluate the mediating roles of some of the variables on the main dependent variables in the study. The bootstrapping approach by Pritchard and Hayes (2013) was used with 5000 resampling to test the significance of the indirect effect. These mediation analyses were done with the process procedures for SPSS (2.12.3) developed by Hayes, (2013) mainly for mediation analyses. The bootstrapping approach was used because Sobel test was criticized on the ground that it is based on parametric assumption but the indirect effect has been proven to be not normally distributed.

For mediation to be established, the indirect effect has to be significant (Garson, 2016; Hair et al, 2016). Full mediation takes place when the independent variable does not have direct effect on the dependent variable except through an intervening variable. In partial mediation, the independent variable on its own can affect the dependent variable as well as through a mediator.

### **The hypotheses that were tested include:**

H 6: Stigmatization would mediate the effect of OFT and general dental condition on psychological distress and HSB,

H 7: Stigmatization would mediate the effect of BODI on psychological distress and HSB,

H 8: Psychological distress would mediate the relationship between OFT/dental conditions and HSB

H 9: Psychological distress would mediate the effect STG on BODI and HSB

The results of these mediation analyses are presented in tables 16 & 17:

**Table 16: Mediation Analysis of Body Image and Stigmatization on Psychological distress and Health-seeking behaviour**

Path(relationship)	Direct effect	Indirect	Total effect	VAF	Boot.LLCI	Boot. ULCI	Remarks
BODI on PDI (STG)	1.5110***	1.0684***	2.5795***	.4142	.8459	1.3212	Full Med.
BODI on HSB (STG)	.1081*	.0285	.1366***	.2026	-.0196	.0821	No med
STG on HSB (PDI)	-.0932*	.1842**	.0910**	2.0233	.1387	.2316	Med, partial.

\*Sig at .05; \*\*Sig at .01; \*\*\*Sig at .001

**Table 17: Mediation Analysis of type of Condition on Psychological distress and Health-seeking behaviour.**

Path(Relationship)	Direct Effect	Indirect Effect	Total Effect	VAF	Boot.LLCI	Boot. ULCI	Remarks
Con on PDI (STG)	.3362***	.2749***	.7698***	.3571	.1380	.4130	Med. Partial
Cond on HSB (STG)	.4426***	.0081	.4715***	.0172	-.0289	.0491	No med.

\*Sig at .05; \*\*Sig at .01; \*\*\*Sig at .001

The results of the mediation analyses illustrated in Tables 16 and 17 showed that the effect of body image perception on psychological distress was mediated by perception of stigmatization. This mediation result shows that the way the patients perceived their body image, had effect on whether they were stigmatized or not. Also, the level of psychological distress mediated the effect of stigmatization on health-seeking behaviour. In this mediation, it indicates that stigmatization on its own, did not influence health-seeking behaviour among the patients. The health-seeking behaviour was indirectly influenced by the level of psychological distress experienced by the patients. In addition, the effect of the type of condition on psychological distress was partially mediated by stigmatization. Thus the condition on its own did not directly

cause the psychological distress. The psychological distress was mainly caused by the feeling of stigmatization by the patients. However, stigmatization did not successfully mediate the relationship between the type of condition and psychological distress and also body image perception and health-seeking behaviour.

The study also assessed the moderating effects of some of the variables such as spirituality on the level of psychological distress experienced by patients. The results are presented in Tables 18 to 20.

**Table 18: Moderation Effect of Stigmatization on the type of Condition on Psychological distress**

R	R-sq	MSE	F	df1	df2	p
.8907	.7933	715.2985	204.1858	5.00	266.00	.0000
Model						
	coeff	Se	T	p	LLCI	ULCI
Constant	87.68	22.29	3.93	.0001	43.79	131.57
Stg	.1581	.2648	.597	.5511	-.3634	.6795
D1	97.70	33.18	2.94	.0035	32.37	163.04
D2	-110.41	25.76	-4.28	.0000	-161.13	-59.68
Int_1	-.2053	.3748	-.548	.5843	-.9432	.5326
Int_2	.9416	.3327	2.83	.0050	.2865	1.60

R-square increase due to interaction:

R2-chng	F	df1	df2	p
.0114	7.3535	2.0000	266.0000	.0008

Hypothesis 10: that Patients' perception of stigmatization would moderate the effects of the conditions on their level of psychological distress. The moderation effect of stigmatization on the

effect of the condition on PDI was tested with the process macro Hayes (2013)). The result showed that the overall model was significant ( $R = .89$ ,  $R^2 = .79$ ,  $P < .001$ ). Since the condition was measured on a nominal scale, with three categories, dummy variables were first created and used to run the regression analysis. The interaction effect of stigmatization and the condition was significant ( $R^2$  change = .0114,  $P < .001$ ). This means that stigmatization significantly moderated the relationship as predicted.

**Table 19: Moderation Effect of Health belief on the type of Condition on Psychological distress**

R	R-sq	MSE	F	df1	df2	p
.8792	.7729	785.84	181.08	5.00	266.00	.0000
Model						
	Coeff	Se	t	p	LICI	ULCI
Constant	87.11	15.68	5.55	.0000	56.23	117.99
HB	.247	.276	.894	.3721	-.297	.7902
D1	90.34	23.59	3.83	.0002	43.89	136.80
D2	-64.49	21.44	-3.01	.0029	-106.70	-22.27
Int_1	-.181	.417	-.435	.6636	-1.00	.6391
Int_2	.209	.389	.538	.5912	-.556	.9743

R-square increase due to interaction:

R2-chng	F	df1	df2	p
.0008	.4488	2.0000	266.0000	.6389

Hypothesis 11a: that Belief system (health belief) of the patients with OFT and general dental condition would moderate the effects of health conditions on psychological distress

The moderation effect of health belief on the effect of the condition on psychological distress was tested with the process macro, Hayes (2013). The result showed that the overall model was significant ( $R = .88$ ,  $R^2 = .77$ ,  $P < .001$ ). However, the interaction effect of health belief and the

condition was not significant ( $R^2$  change = .0008,  $P > .05$ ). This means that health belief did not moderate the relationship as predicted.

**Table 20: Moderation effect of Spirituality on the type of Condition on Psychological distress**

R	R-sq	MSE	F	df1	df2	p
.8822	.7782	767.52	186.67	5.00	266.00	.0000
Model						

	Coeff	Se	t	P	LLCI
Constant	88.09	12.12	7.27	.0000	64.23
SWB	.2042	.1876	1.08	.2775	-.1652
D1	93.86	24.79	3.79	.0002	45.06
D2	-123.41	30.17	-4.09	.0001	-182.81
int_1	-.2153	.3252	-.6620	.5086	-.8555
int_2	.8632	.4046	2.13	.0338	0666

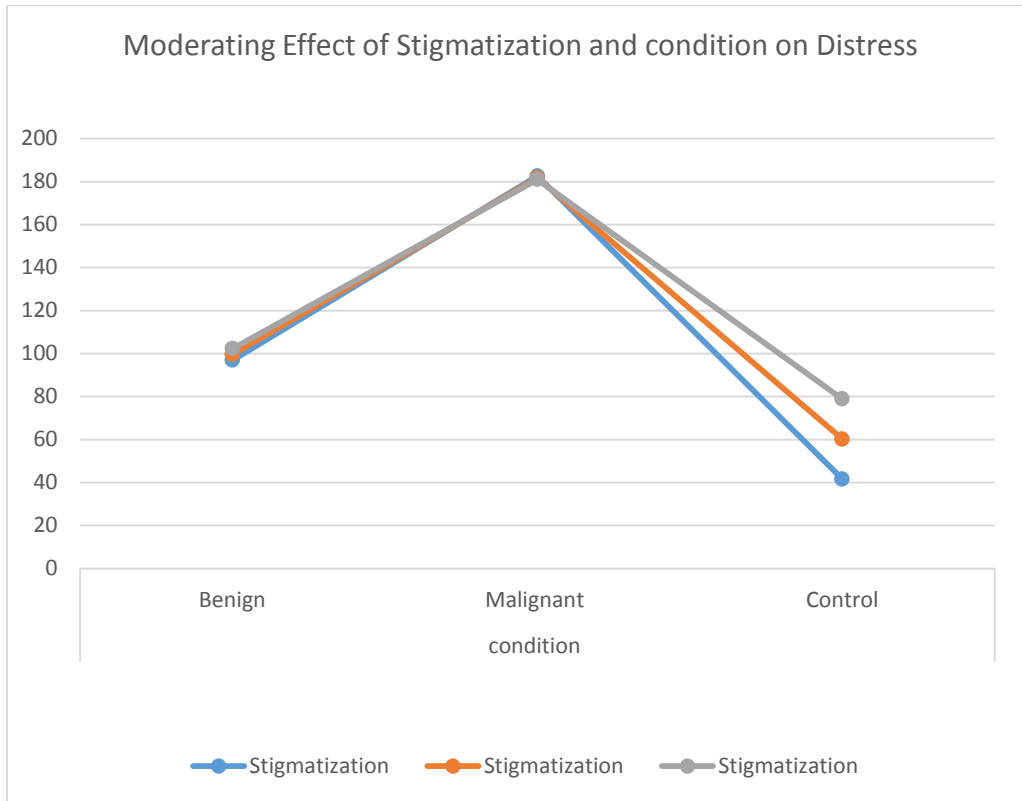
R-square increase due to interaction:

R2-chng	F	df1	df2	p
.0052	3.0949	2.0000	266.0000	.0469

Hypothesis 11b: that Belief system (spirituality) of the patients with OFT and general dental condition would moderate the effects of health conditions on psychological distress

The moderation effect of spirituality and the condition on PDI distress was assessed using the process macro. The result showed that the overall model was significant ( $R=.882$ ,  $R^2 = .778$ ,  $P < .001$ ). The interaction effect of spirituality and the condition was significant ( $R^2$  change = .0052,  $P < .05$ ). This means that spirituality moderated the relationship as predicted.

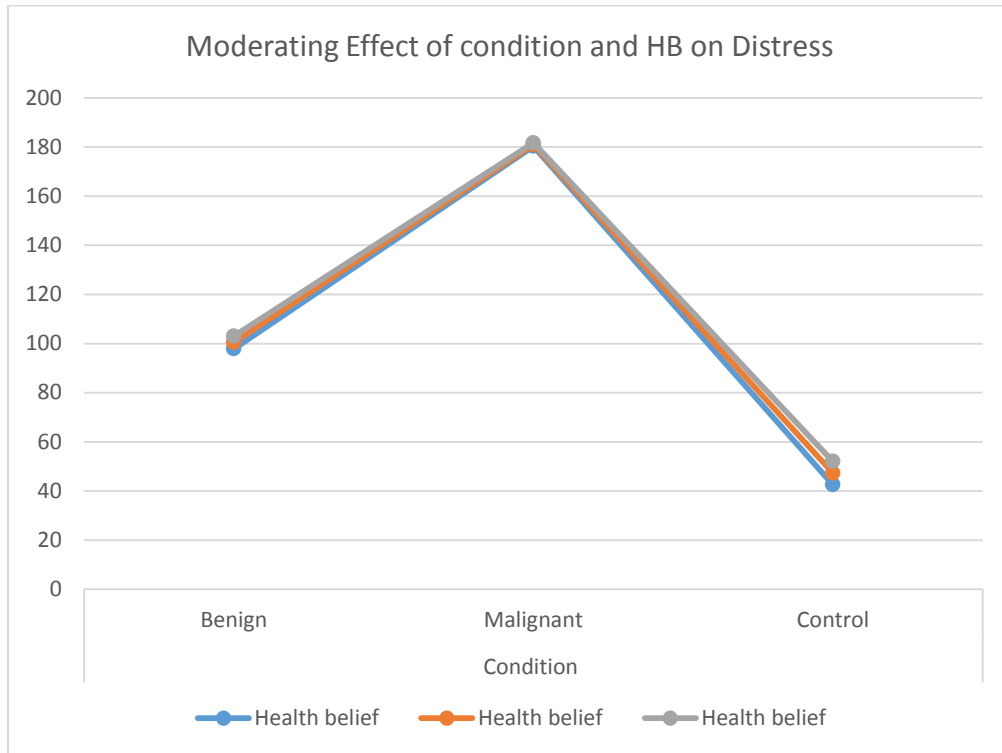
The graphs illustrating the moderation effects are presented in Figs: 9 to 11



**Figure 9: Result of Moderating Effect of Stigmatization and Condition on Psychological distress**

The result as can be observed from Figure 9: showed that at all levels of stigmatization, the level of psychological distress is similar for patients with both malignant and benign tumours.

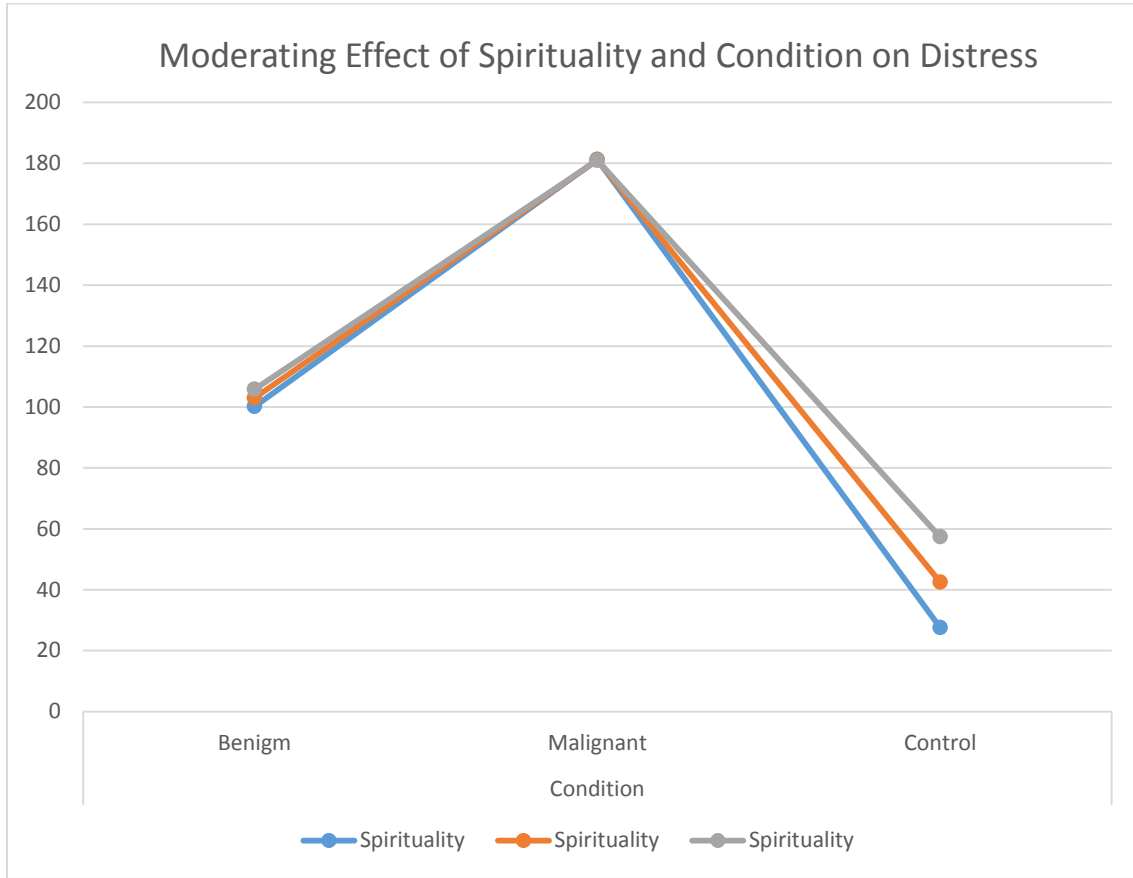
However, the levels of psychological distress differed significantly for the control group at all levels of stigmatization. Thus the level of distress is highest for the patients with malignant tumour while for the patients with periodontal conditions the level of stigmatization increases with the level of psychological distress.



**Figure 10: Result of the Moderating Effect of Condition and Health belief on Psychological distress**

The result as demonstrated on Fig. 10: showed that health belief did not significantly moderate the levels of psychological distress experienced by patients with OFT and dental conditions.

From the graph, the level of psychological distress was not affected by the level of health belief of patients.



**Figure 11: Result of the Moderating Effect of Spirituality on Condition and Psychological distress**

Similar to the results observed in Fig. 9: the result as demonstrated in Fig 11: on the graph showed that at all levels of spirituality, the level of psychological distress is similar for patients with both malignant and benign tumours. However, the levels of psychological distress differed significantly for the control group at all levels of spirituality. Thus the level of distress is highest for the patients with malignant tumour while for the patients with periodontal conditions the level of spirituality increases with the level of psychological distress.

Hypothesis 12 states: The patients' levels of a) psychological distress and b) HSB, would significantly differ in relationship to their (a) educational level, (b) gender and (c) type of condition.

**Table 21: Multivariate Analysis of Effect of Condition, Education and Gender on Health-seeking behaviour and Psychological distress**

Health-Seeking behavior						Psychological Distress				
Variables	M	SD	df	F	Sig	M	SD	df	F	Sig
Condition	110.46	10.51	2	62.88	<.000	181.19	12.31	2	194.09	<.005
Gender	86.33	10.23	1	2.08	.151	79.47	8.18	1	.162	<.005
Education	89.43	9.23	8	2.02	.048	86.43	8.78	8	.816	.590

Results in Table 21, showed that the mean score for the type of condition experienced by patients was (mean = 110.46) with a standard deviation of (SD = 10.51). The mean value of (mean = 181.19) and (SD=12.31) were recorded for health-seeking and psychological distress respectively. Multivariate analysis of these means revealed that a significant difference exist between the mean scores on the type of condition in relation to the health-seeking behavior and the psychological distress of patients [ $F_{(2,169)} = 62.88, P < .000$ ] commitment [ $F_{(2,169)} = 194.09, P < .000$ ] respectively. The result of the analysis further indicated that the level of education and gender did not record significant differences in the patients' level of distress and health-seeking behaviour. This means that hypotheses eleven as stated above was partially supported by the results of the analysis.

### **3.11 Summary of Quantitative Findings**

There were significant differences between the types of conditions in relation to the experience of psychological distress. Thus the type of condition: malignant, benign OFT and general dental conditions significantly predicted psychological distress among patients.

Spirituality and health-seeking behaviour correlated positively. Thus spirituality and health beliefs were regressed on health-seeking behaviour. Though spirituality positively predicted health-seeking behaviour health belief did not predict health-seeking behaviour.

There was positive relationship between stigmatization and psychological distress. Thus stigmatization positively predicted the level of psychological distress however, health belief did not predict psychological distress among patients.

There were negative correlations between body image perception, stigmatization and psychological distress. Thus both body image perception and stigmatization negatively correlated with the level of psychological distress experienced by patients.

Positive correlations existed between spirituality, stigmatization and psychological distress and they all predicted health-seeking behavior but health belief and body image perceptions of the patients did not predict their health-seeking behavior.

Psychological distress partially mediated the relationship between stigmatization and body image perceptions however; stigmatization did not mediate the relationship between the types of condition and level of psychological distress among patients.

Stigmatization successfully moderated the effect of the type of condition of patients on the level of psychological distress experienced by them.

In addition, spirituality also moderated the effect of the type of the condition on the level of psychological distress of patients but health belief of patients did not moderate the effect on the level of psychological distress.

On the demographic variables, differences existed between the types of condition, health-seeking behavior and psychological distress however, gender and education yielded no difference.

### **3.11.1 Discussion of Quantitative Results**

The results of the study assessing health-seeking behaviour among patients with OFT in relations to the roles of spirituality, health belief, stigmatization and body image perception and also the level of psychological distress were presented in the previous section. This section discusses the results as presented in the previous section in quantitative study one.

### **3.11.2 Influence of Socio-Demographic Factors on Key Study Variables**

Socio-demographic factors play very important roles in determining health-seeking behaviour and also the level of psychological distress among patients with OFT. The appraisal and final decisions an individual patient arrives at in health-seeking can be very much influenced by many socio-demographic variables including gender, age, level of education, time since the disease affects the patients and many other factors.

Literature demonstrate extensive instances where socio-demographic factors including gender, personality factors, psychosocial support, time of onset of illness and the time of report to seek healthcare and other factors such as the level of psychological distress of patients. In

addition, coping mechanisms that patients employ in dealing with the condition is also heavily influenced by the socio-demographic background of the patients (Lawal et al. 2013).

A number of socio-demographic factors have been examined in this study. The key among them include age of patients, age at diagnosis, educational levels time between onset the disease and health-seeking were all analysed in the study. The result showed that the time between the onset of the condition and health-seeking is very crucial for effective diagnoses and success of treatment. Since literature continues to emphasize that many of the patients report lately to health facilities for treatment, the analysis looks at the time it takes patients to report to the health facilities. The result shows that it takes 19.6 months for patients to report to the health facilities. Even though many of them cite ignorance as one of the major reasons for allowing the tumour to grow into uncontrollable structures from a simple swelling the waiting period is unacceptable and a major reason for poor outcome of treatment.

In this study, type of the condition significantly predicted the level of psychological distress of patients. This finding is also very significant in educating the public of the need to seek-early healthcare. The patients with malignant tumour demonstrate the highest levels of distress followed by benign and general dental patients. Since it is difficult to identify the type of condition from the onset of the disease it is of paramount importance that patients seek healthcare as soon as they detect any anomaly on their faces or neck and head regions (Parkins et. al 2008).

As tests are conducted and the appropriate diagnoses made the success rate and postoperative challenges are minimised. Literature attest to the fact that more people experience tumour and cancerous conditions in the Western world compared to Africa but the mortality

rate among Africans is higher because of the late health-seeking and unavailability of facilities to deal with such cases in Africa.

In this study, age, gender and educational levels of patients did not significantly predict psychological distress and health-seeking behaviour among patients. In this regard whether the individual patient is a male or female does not necessarily influence their levels of distress or health-seeking. Even though individually none of the factors predicts health-seeking and psychological distress, when gender, age and educational levels were put together, they significantly predicted the level of psychological distress. A situation which shows that these factors have influence on the distress level of patients a clear case of the important roles of socio-demographic variables on the outcome of health conditions.

In addition, it is clear from the findings of the study that social support plays an important role in moderating the level of psychological distress among patients. Greater majority of participants confirm that the main sources of social support in the family can be linked to children and spouses. This implies that those patients who have children and are also married may stand better chances of enjoying social support from the immediate family members. It is true that other forms of social support come from extended family members but that of children and spouses can be handy and much more reliable.

### **3.11.3 Differences in the level of psychological distress experienced by patients from the types of condition (malignant, benign and control).**

Hypothesis 1 states that “There would be significant difference in the level of psychological distress experienced by Patients with OFT and patients with general dental conditions”.

The various groups of patients were compared in terms of which type of the condition may result in more psychological distress among them. The result of the analysis indicated that there were significant differences between the types of conditions. Thus the type of condition: malignant, benign OFT and general dental conditions significantly predicted psychological distress among patients.

The three types of the conditions include malignant which results in the cancerous type of the tumour, benign which also has the tumour but only the disfigured structure appears whereas the control group has general dental problems. The fact that there were significant differences in the conditions in predicting levels of psychological distress among patients is very revealing. In considering the level of severity and devastation the conditions pose to their patients Fingeret et al. (2008) posit that patients with OFT face challenges of swallowing, and have other forms of pains associated with the disease. Though both benign and malignant patients experience similar symptoms that of the malignant patients certainly outweigh that of the benign patients. Also as demonstrated by Leeuw et al., (2009) that even the receipt of the news of cancer diagnoses can trigger high levels of anxiety and possible depression may explain the reason for the malignant patients experiencing the highest levels of psychological distress.

The fear of the outcome of cancer treatment and other myths surrounding it can also be a factor in influencing the rise in their levels of distress. The fear of surgery as the main treatment mode, concern about possible postoperative complications including recurrence and body image issues combine to evoke a lot of anxiety among patients with malignant tumour. In addition, though those with benign tumours also are saddled with pains and sometimes bleeding

from the mouth, the assurance that their success rate after surgery is high can act as a major moderating factor.

There is also the opportunity for them to get their facial feature virtually back to their original form through plastic and cosmetic surgery. In comparing the control group with the group with the tumour, it is understandable that most of the dental patients went to the hospital for routine dental procedures including restoration, extractions and scaling and polishing. These procedures are generally not very invasive and therefore do not evoke a lot of dental phobia among patients. Another interesting finding is that majority of the patients who visited the dental facility have high educational levels and might be well abreast with issues relating to health and dental challenges.

#### **3.11.4 Relationship between Spirituality, health belief and health-seeking behaviour**

Hypothesis 2 predicts that there would be positive relationship between the OFT and general dental patient's level of (a) spirituality and (b) health belief and (c) HSB

The results of study one showed that spirituality and health-seeking behaviour correlated positively. Thus patients' levels of spirituality significantly predicted their health-seeking behaviour however, health belief did not predict health-seeking behaviour. The determinants of health-seeking are many and varied. Some of the factors that influence health-seeking include spirituality and health belief. In this study however, health belief did not predict health-seeking behaviour. The result is not entirely surprising that health belief did not predict health-seeking behaviour.

The reason is that health belief has many factors that are closely related to those of spirituality such as belief in the aetiology of the condition. The two variables are also related in

terms of perception about the threat of the disease and benefits of a particular health-seeking as well as barriers to access to health-seeking. Since majority of patients agree that they are ignorant as to the cause of the condition, their perception and appraisal of the beliefs associated with the condition may also be affected in the same direction. The issue of awareness plays enormous role in deciding what sort of healthcare one seeks as aptly captured by Bello et. al., (2014), who argue that even though spirituality and other factors are major antecedents in health-seeking, the level of awareness of the causes and effects of a particular health condition are crucial in health-seeking.

They concluded that poverty, illiteracy and ignorance are very essential determinants in a patient's decision on a choice of a particular healthcare. Also, some of the health beliefs are very much embedded in the religious and spiritual culture of the individuals. Cultural background, spiritual and religious inclinations greatly influence the health belief of patients (Puchalski, 2012; Vivien & Noor, 2013). It is very much likely that their appraisal and thoughts are very much influenced by their spirituality hence the result indicating that spirituality had predicted both psychological distress and health-seeking behaviour.

In that regard they may tend to connect with their spirituality to find solace in the supernatural powers and how to help in taking action to solve the problem. As explicitly illustrated by Mansfield and Mitchell (2002) that African Americans and for that matter Africans and Ghanaians hold a strong belief that God acts through physicians in treating them. African Americans and other blacks generally have a strong belief that their ill conditions could be addressed by God but they can accomplish that through God's healing and miraculous powers through the doctors. This assertion may apply strongly among the patients noting that most of them indicated multiple sources of treatment and their trust and belief in God helping them in

their moment of ill health. It is on this basis that it can be inferred that most of the patients turned to spirituality as one of the sources of treatment and combine that with their orthodox protocols for treatment. This is because they are well aware that they can receive prayers and other spiritual practices while they are going through the orthodox treatment at the various health facilities.

### **3.11.5 Relationship between Stigmatization and Psychological distress.**

Hypothesis 3: states that Stigmatization will predict patients' level of psychological distress. There was positive relationship between stigmatization and psychological distress. Thus stigmatization positively predicted the level of psychological distress however; health belief and spirituality did not predict psychological distress among patients. The result of the study also indicated that majority of patients experience stigmatization. The result of the study thus confirmed the hypothesis on stigmatization as an important factor that influences the level of psychological distress of patients with OFT (Islam, Scott & Minichiello, 2016).

Stigmatization though did not occur openly most of the instances were perceived to be very significant by the patients. It is seldom to see a member of the society overtly attacking another person because of a particular disease but the non-verbal and other forms of attitudes may imply a clear sign of stigmatization to the patients (Stuber & Schlesinger, 2006). This form of stigmatization in many cases extends to other members of the patient's family and can pose high levels of psychological distress (Islam, et al., 2016). As demonstrated from the results it is stigmatization that increases the level of psychological distress among patients.

The significant influence of the perception of stigmatization on patients' level of distress was demonstrated in the analyses in study one. It was indicated that it is how much the patients with OFT perceived the public to stigmatize them that resulted in the upsurge in their

level of psychological distress. In some instances, the perception of stigmatization may not be real but as far as the patients think and appraise actions from the public as stigmatization and discriminations against them the effect on them can be very distressful (Meyer, 2003b). It therefore falls in line with the strong perception that the patients hold about society concerning such diseases (Kinnear, Link, Ballan & Fischbach, 2016). Society thus has to take a critical view of how members react to patients with OF. If members of the society relate to them positively just as they relate to other people without such diseases the perception of stigmatization may considerably reduce.

Further, on the issue of stigmatization, some of the patients use their dresses, hair and other objects to conceal the obvious presence of the tumour. These acts also may lend further credence to the fact that they feel highly stigmatized and may on their own want to prevent other people from identifying them with such a disease. It is glad to note that majority of them attest to the fact that society does not openly refuse to offer them opportunities such as jobs and admissions to schools and other institutions.

Those actions of society show that people may not be hostile to them but may also be wondering what sort of diseases they are suffering from but in showing those concerns the patients may interpret it as stigmatization. The result of the study and the sort of reactions that patients with OFT usually display confirm the fact that the change in appearance due to the location of the tumour leads to high levels of stigmatization and also psychological distress (Pirl, 2014). It therefore implies that the perception of the disease alone can trigger significant levels of self-stigmatization among patients. A situation officials who handle such patients and society need to be aware of in order to know how to relate to patients with OFT.

### **3.11.6 Relationship between Body image perceptions, Stigmatization and Psychological distress.**

Hypothesis 4 indicates that: there would be negative correlation between body image perception, levels of psychological distress of patients and stigmatization. There were negative correlations between body image perception, stigmatization and psychological distress. Both body image perception and stigmatization negatively correlated with levels of psychological distress experienced by patients. Many of the patients with orofacial tumours experience changes on their orofacial regions.

The changes in the appearance as reported by a number of studies may lead to the patients feeling very uncomfortable and can result in stigmatization. There is therefore a strong negative correlation between the body image perception and stigmatization which could result in high levels of psychological distress among patients with OFT. This assertion was confirmed by Geirdal et. al, (2014) who further explained that the tumour impairs the ability to swallow, chew and generally affect their appearance and body image perception. The resultant psychological distress is usually brought about as a result of change in appearance, disruptions to the social lives of the patients in terms of intimacy issues, stigmatization and isolation (Callahan 2005; Fingerret, Yuan, Urbauer, Weston, Nipomnick & Weber, 2012). Apart from the worries of the change in their appearance Fingerret (2011), explained that for many of the patients, their main concern goes beyond the issue of appearance to whether the treatment could relieve them of their disfigurement.

Many of the patients understand that the disease has come to disfigure them. But they are more concerned whether the sacrifice of going through surgery can restore them to their original looks and state of health. It is clear from the result and literature that the patients are

much more concerned about their postoperative state of health and looks because that is where they seem to have some level of assurance that they may get back to their original personalities.

The critical question is how many post-surgery facilities do we have in terms of restoring them to their original appearances? The cosmetic and plastic surgeries provide some reliefs in that regard but most of the patients may not be able to afford such cost and in addition, our premier hospital is not adequately equipped to provide such services to patients. Some who have such unfortunate appearance challenges may have to live with that for the rest of their lives creating so much psychological distress and social inhibitions for them.

### **3.11.7 Relationship between Body image perceptions, Stigmatization, Psychological distress, Belief systems and health-seeking behaviour.**

Hypothesis 5 predicts that there would be positive relationship between the level of psychological distress, spirituality, health belief body image perception, stigmatization and health-seeking behavior. Positive correlations existed between spirituality, stigmatization and psychological distress and they all predicted health-seeking behavior but health belief and body image perceptions of the patients did not predict their health-seeking behaviour. Spirituality, stigmatization and psychological distress correlated in the study and they also consequently predicted health-seeking behavior.

From the conceptual model and literature, stigmatization has a direct correlation on psychological distress. It is understandable that patients who get highly stigmatized experience high levels of psychological distress. This is due to the fact that patients' perception of stigmatization is very high because of the pain, disfigurement and worries about recurrence. This linkage between stigmatization and psychological distress has been stressed in many studies

reviewed in the study notably Geirdal et. al, (2014). They explained the fact that patients' perception of stigmatization is one of the factors that clearly determines how much psychological distress they are likely to suffer in the course of the disease.

The result also indicated that stigmatization and psychological distress also predicted health-seeking behaviour. This finding also falls in line with literature that the more distressed an individual patient and the level of vulnerability to the effect of the condition can lead the patients to seek a particular type of treatment. There are other factors that determine health-seeking behaviour among patients. The most important factor is that if patients have the feeling and understanding that there is much threat from the disease, they are likely to act quickly in health-seeking behavior compared to a situation whereby they appraise the threat as low and not of a major concern for action. In such cases patients may not be proactive in taking action to remedy the situation including seeking treatment.

Health-seeking can also be influenced by the level of spirituality of the individual patient. Spirituality in this study predicted health-seeking behaviour but health belief did not predict health-seeking behaviour. One may be tempted to conclude that since spirituality predicted health-seeking behaviour in the study health belief should have also yielded positive relationship and predicted health-seeking behaviour. The plausible reason is that people's belief system could play a very significant role in determining their perception and interpretation of diseases that they suffer from (Danquah, 2008). But in explaining this belief system, their spiritual beliefs are invariably interrelated with their health beliefs.

In addition, majority of patients also believe that their treatment in the hospitals and other orthodox facilities can be aided by the miraculous hand of God and that explains the

reasons behind many of them seeking multiple healthcare for their diseases. It is therefore important to understand the cultural contexts from which the Ghanaian operates and relates to the world view in determining their health-seeking options in case of ill health.

### **3.11.8 Mediating roles of STG, BODI, PDI and OFT condition on PDI, HSB and BODI.**

Hypotheses 6-9, mediation analyses. The results of the mediation analyses showed that the effect of body image perception on psychological distress was mediated by patients' perception of stigmatization while psychological distress also mediated the effect of stigmatization on health-seeking behaviour. In addition, psychological distress partially mediated the relationship between stigmatization and perception of body image and health-seeking behaviour of patients. Further, the effect of the type of condition on psychological distress was partially mediated by stigmatization. However, stigmatization did not successfully mediate the relationship between the type of condition and psychological distress and also body image perception and health-seeking behaviour.

The effect of body image perception on the level of psychological distress experienced by the patients was mediated by their perception of stigmatization. This finding supports the hypothesis and confirms literature on the impact of body image which includes how a patient appraises his or her body to be disfigured as a result of the OFT (Fernandes, et al., 2014). Fernandes, et al., (2014) lamented that both pre and post- surgery periods pose some of the most depressive times for patients with OFT.

The main reason cited is that most of the patients experience moments of uncertainties as to what may eventually become the outcome of their surgeries and whether that could solve their body image challenges. Since many of the patients also perceive the public to stigmatize them as a result of their disease it is not surprising that stigmatization mediated the effect of body

image perception on the level of psychological distress. It is thus very critical to look at body image issues when dealing with diseases such as OFT because that is what the patients perceive as a source of stigmatization which consequently affects their levels of anxiety and depression. In many cases patients get depressed due to the fact that some experience strained relationships with partners, social isolation and even job loss (Katz, Irish, Devins, Rodin & Gullane, 2003; Vallente, 2009).

The finding on the effect of psychological distress mediating the effect of stigmatization on health-seeking behaviour makes very interesting reading. Stigmatization directly did not predict health-seeking behaviour. However, the mediatory role of psychological distress leads to its prediction of health-seeking behaviour. It follows that as patients get much more distressed that may inform their decision to seek healthcare.

The results of study one also revealed that the issue of stigmatization is of paramount concern to patients so anything that may lead to vulnerability to stigmatization can result in them taking prompt actions. That assertion can signal a strong desire on the part of patients seeking healthcare in order to have the disease treated which can eventually lead to reduction or possible elimination of stigmatization from the public. This finding also explains the fact that stigmatization cannot directly predict HSB without another variable which becomes a precursor to the situation. It further reflected in the mediation analysis which showed that stigmatization did not successfully mediate the relationship between the type of condition and psychological distress and also body image perception and health-seeking behaviour.

The effect of the type of condition on psychological distress was partially mediated by stigmatization. There are basically three types of conditions namely malignant, benign, and control group. The result showed that the patients with malignant tumour experience the severest

levels of psychological distress. The other type of condition that also experience high levels of distress is the group with benign tumour. It is obvious that judging from literature the two groups may also have high perceptions of stigmatization and therefore stigmatization partially mediating the effect of the condition on the levels of psychological distress they experience.

### **3.11.9 Moderation effects of Stigmatization, Health belief and Spirituality on Psychological distress.**

Hypotheses 10-11 Stigmatization moderated the effect of the type of condition of patients on the level of psychological distress experienced by them. In addition, spirituality also moderated the effect of the type of the condition on the level of psychological distress of patients but health belief of patients did not moderate the effect on the level of distress. Cognitive appraisal of health conditions play an important role in how the individual reacts and copes with the disease. In perceiving that people stigmatize them because of the OFT, the patients may get much more worried and this can aggravate the disease.

Normally as the patients get worried about their appearances they may become anxious about the outcome of the disease and that can lead to increase levels of psychological distress. It is in line with the findings of this study that if perception of high stigmatization can lead to higher psychological distress then it is expedient to say that lower perception of stigmatization can lead to reduction in the levels of psychological distress and thereby improving the health condition of patients.

Spirituality also moderated the effect of the condition on the level of psychological distress among patients however health belief did not moderate the effect of the condition on the level of psychological distress of the patients. The result of the moderation analysis followed

that of the mediating analysis and the main correlation between health belief, psychological distress and health-seeking behaviour. In all these results health belief did not relate significantly to the health-seeking or level of psychological distress.

One major factor as explained above could be the level of spirituality among the patients who participated in the study. As Mbiti (1991) explains that Africans are very spiritual. It may be that their level of spirituality which influenced their responses in the instruments used in measuring the levels of spirituality and health belief. In assessing the two constructs respondents displayed strong relationships between certain similar items on both scales as demonstrated on their factor analysis. It therefore shows the closeness with which Ghanaians perceive spirituality and health belief.

The role of spirituality in moderating the level of psychological distress and alleviating all types of painful situations has been documented extensively in literature. This is evident when Utsey et al. (2007) examines culture-specific coping among 281 African Americans on spiritual wellbeing as a mediator of the relationship between culture specific coping and quality of life. The influence of spirituality in moderating the effect of distress was seen when the construct was measured by the Spiritual Wellbeing Scale (SWBS).

The result shows that it partially moderated the relation between culture-specific coping including religious coping, and quality of life as seen in physical health, psychological wellbeing, quality of social relationships, and environmental wellbeing. In addition, considering the spirituality model by Anandarajah, (2008) the concept of spirituality was clearly explained as involving whole-person medical care. The conceptualization comprises the dimensions of individual spirituality which looks at the (head, heart, hands) in appraising diseases.

That is the cognitive, affective and behavior aspects of individual's appraisal of diseases. It also takes into account the spirit, environment, social, transcendent. Spirituality in this concept looks at how a chronic disease condition affects the patient in appraising the body, mind, spirit, environment, social setting and the transcendent. The thought behind chronic disease condition involves many aspects of the patient's life. These include perception of the condition, cultural background and how others perceive the situation (de-Graft Aikins, 2013). The interpretation assigned each of this stages helps the individual cope positively and improves his or her health condition or negatively and aggravates the condition. Spirituality moderating the level of psychological distress in this study thus confirms what is in the model and literature. If one considers what Mbiti (1991) says about Africans and their spirituality, then in this case most of the patients may have used it in the positive way and thus moderating their distress levels.

### **3.12 Conclusion and future direction of thesis**

The discussion focuses on the differences among the three groups of participants namely those with malignant tumour, benign tumour and general dental conditions. The results of the analyses indicated that the patients with malignant tumour experienced the highest levels of psychological distress followed by those with benign tumour. The general dental patients had the lowest levels of psychological distress. This could be due to the severity and the fear surrounding cancer and how patients perceived their levels of vulnerability with such a deadly disease.

The level of psychological distress, stigmatization and spirituality predicted health-seeking behaviour among patients. In addition, stigmatization and body image perception

significantly predicted the level of psychological distress among the patients. Spirituality which plays an important role in moderating psychological distress predicted both health-seeking behaviour and also moderated the level of psychological distress. Body image perception did not mediate the health-seeking behaviour of patients but mediated psychological distress. Stigmatization also mediated the level of psychological distress while the type of condition mediated the level of distress among patients. Interestingly, health belief did not predict health-seeking and also did not moderate the level of psychological distress among patients

## CHAPTER FOUR

### STUDY TWO (QUALITATIVE)

#### 4.1 Introduction

This study was a follow-up to Study One and it was a qualitative study involving in-depth interviews (IDI). It was to complement and confirm the findings of study one. The result of study one showed that there was significant difference between patients with OFT and the general dental patients (control group) in relations to how they experienced the level of psychological distress. The result also indicated that OFT condition, perceptions of stigmatization and body image significantly predicted psychological distress of the patients. There were other findings concerning psychological distress, stigmatization and body image perception in relations to health-seeking behaviour.

Study two further, explored the experiences of patients and the determinants of health-seeking. The study also explored the reason why health belief did not predict health-seeking behavior. This chapter therefore presents the methodology used for data collection, transcription and analysis of the qualitative phase of the research, conclusions and limitations. The findings for the IDI are presented using the thematic approach format which are interpreted with the various extracts from participants. Thematic analysis is a technique used in qualitative research to analyze textual data leading to the development of themes (Vaismorad, Jones, Turunen, & Snelgrove, 2016).

## **4.2 Rationale for the choice of Study 2**

Study 2 sought to explore various aspects of some of the constructs that were already covered in the quantitative phase of the study. These include health beliefs, spirituality, health-seeking behaviour and stigmatization. The main aim of study 2 was to seek explanations to certain aspects of the empirical study one in study two, specifically in the Ghanaian cultural context and from perspective of patients with OFT. The further exploration of certain aspects of the constructs studied in the quantitative study one could be better understood and much more accurate conclusions drawn based on the findings from study two.

The results from the empirical study one showed that health belief did not predict HSB contrary to what was held in literature. A major reason that could produce the contrary results as illustrative from the study is the cultural variations between the countries from which the instruments were developed compared to the Ghanaian culture. Since the instruments used were developed and mostly used in the Western culture. It was important to explore the possible reasons for the differences in some of the findings by the use of qualitative approach. Further, the qualitative approach was employed to understand a phenomenon from the original or natural background of the patients.

In this case the phenomenon is the thought behind health-seeking experience of patients with OFT. This additional explanatory study was necessary because the various instruments used recorded good Cronbach alpha reliability Coefficient of .7 and above indicating that they were reliable. However, cultural differences could make an instrument that was reliable not to be valid in measuring the various constructs accurately compared to the population on which it was developed and used. In such a situation the use of the qualitative methodology

serves as a good approach to data validation or triangulation in order for new findings to strengthen and also fill in the gaps in the findings of the empirical study one.

### **4.3 Specific Objectives of Study Two**

1. What accounts for the higher levels of psychological distress among patients with OFT compared to patients with general dental condition?
2. What do patients with OFT perceive as the causes of their condition?
3. How has living with OFT been for the patients?
4. What impact has OFT had on patients (physically, emotionally, and socially)?
5. How have patients of OFT coped with the condition?

### **4.4 Study Design**

The study adopted the qualitative approach in this research by using One-on-one interviews format to evaluate health-seeking behaviour among patients with OFT in Ghana. Braun and Clarke (2006) indicated that qualitative approach with ID and thematic analysis provides the grounds for gathering detailed and varied information and allows the interview to go into novel areas.

The choice of in-depth One-on-one approach was to help elicit more information from the respondents. The purpose, firstly is to corroborate the information that was collected and analyzed in study one. Secondly, to investigate spiritual and cultural issues relating to the variables under study that provided valuable explanations of data (Ekblad & Bäärnhielm, 2002; Greenhalgh, 2001).

Clarke and Kitzinger, (2004) stressed that qualitative methods provide better understanding and relationships between phenomena by posing questions to unravel the unknown. By the use of the qualitative method the researcher explores the thoughts, attitudes, mind sets and behaviour of participants in relation to health-seeking (Willing, 2008). The OFT experience of patients were elicited in the form of narrations. The researcher used themes and narratives to present natural experiences, feelings, attitudes and thoughts from the patients.

## **4.5. Methodology**

### **4.5.1 Research Setting**

The study was conducted at the Oral and Maxillofacial Units of Korle Bu Teaching hospital, 37 Military hospital and the Ridge hospital all in Accra, Ghana. The interviews were conducted in the offices of some of the medical officers while they were not on duty for the participants to have privacy needed for such exercise. The participants came from some of the suburbs of Accra and attended listed referral hospitals. These suburbs include: Mamprobi, Korle-Bu, Korle Gonno, Dansoman, Tesano, Alajo and Odowna and attended Korle-Bu teaching hospital. Those who also visited the Ridge and 37 Military hospital included La, Osu, Burma camp, Lapaz, and its environs, Nii Boi town, Madina, Adenta, East and North Legon, Dodowa and their surrounding settlements. There were also some participants who came from other towns mainly in southern Ghana.

### **4.5.2 Target Population**

The target population comprised all the adult OFT patients officially admitted as in or out patients at the various facilities sampled for the study. In all, there were 1,240 Patients registered

over the 2015/16 from which the sample for study one was recruited. The accessible population covered all the OFT patients who participated in the study one (n=143) excluding patients with general dental conditions (n=129).

#### **4.5.3 Inclusion Criteria for OFT patients:**

The study covered adult patients with OFT from 18 years and above who were registered as patients in any of the facilities. Hence only participants who were between 18 years and 83 years as was in the study one qualified for selection and participation. Also patients who have been clinically diagnosed and admitted as either an outpatient or inpatient qualified for participation. In addition, patients who were well oriented and not in extreme distress so as to be able to communicate without much difficulty during the interviews were those selected for the study. Languages used in eliciting information during the interview were English Language and Twi. In order to ensure validity of the instrument, there was back to back translation of the interview guide into Twi and responses translated back into English Language by a language expert from the department of Languages University of Ghana. Twi was chosen because almost all the respondents were either comfortable in Twi or English. Finally, only patients who gave consent were recruited for the study.

#### **4.5.4 Exclusion Criteria for OFT patients**

Patients who were acutely ill or had other life threatening co-morbidities were exempted from the study. Secondly, patients whose illnesses were related to infections in the orofacial regions but not tumours were not included in the study since it was limited to tumour patients. In additions, those who were in too much pain to engage with interviewer despite support did not take part in the study.

#### **4.5.5 Technique for Participant Selection and Sample size.**

Purposive sampling technique was used to select all participants into the study. This is a non-probability sampling technique in which the researcher carried out selection of sample based on personal judgement or reason in which a particular sample would be best suited (Polit, Beek & Hungler, 2005).

In the qualitative study 2, the researcher selected participants to provide information on health-seeking, health beliefs, spirituality, stigmatization and psychological distress. The study also took into consideration the type of condition and strategies patients used to cope with the disease. The researcher selected patients who met the inclusion criteria and had the ability to provide the most reliable responses. The selection was done based on the two main groups (malignant and benign).

The selection of participants into each group went on until eight and twelve patients were selected from the malignant and benign groups respectively. After that point, the researcher noted that no new responses were forthcoming from the interview questions. The researcher then decided to set the sample size at 20 participants. The 20 participants were thus determined after the data had reached saturation point.

#### **4.5.6 Data Collection Instrument**

The data collection instrument used was semi-structured interview guide. In order to allow participants to express themselves effectively on the themes they have to be given opportunity to express their personal views without much restrictions. In this regard, the questions were open-ended in order to enable participants to provide detailed responses (Creswell, 2009). The questions were designed and self-developed by the researcher under the supervision of the supervisors. The interview guide comprised 12 items, seeking patient's

perceptions on the causes of the disease, health beliefs, spirituality, experience with the condition and general level of distress.

The open-ended nature of the interview guide also facilitated further probing of responses provided by participants. The researcher used stationery items such as pens and pencils to record observations and other important information from the field. The researcher also used scientific audio recorder to record responses provided by patients.

#### **4.5.7 Data Collection Procedure**

The initial ethical clearance was obtained from the School of Social Sciences under the Institute of Statistical, Social and Economic Research (ISSER) (IRB), University of Ghana. The ethical clearance certificate from the University of Ghana was presented together with a copy of the proposal to the Head of the Ridge hospital and Director of research of the 37 Military hospital for permission to use their facilities for the data collection.

Similar set of information was presented to the Research Review Committee of the Korle-Bu Teaching hospital where permission was granted for data collection in both studies one and two.

The interview mainly investigated the patients' understanding of the causes and other important information about the disease. It also explored factors that determined their health-seeking behaviours including, the distress level of the disease, health beliefs, spirituality and their experience with body image and stigmatization. Their coping strategies since the onset of the disease were also investigated from the perspectives of the patients. The languages for the interview were English and Twi languages.

The interviews were semi-structured and mainly conducted by the researcher. The researcher was assisted by a Research Assistant (RA). The questions and probings were done by the

researcher while the RA audio recorded the voice information of the responses and also wrote down other important information and observations on the field.

The participants were all debriefed after the initial interview. This session gave them the opportunity to express their impressions and sentiments about the interview exercise and their views about the interview. Most of the participants also were happy to have participated in the exercise and expressed the hope that the findings of the study would be made available to help improve their conditions and the general health delivery system in the country.

#### **4.5.8 Field Notes**

During the interview session, a number of verbal and non-verbal responses were expressed by participants. Field notes were also taken which helped in further strengthening the research questions and guides into the development and interpreting of the original data provided by the patients.

#### **4.5.9 Data Management**

In order to maintain the security of the data, the researcher kept the audio tapes, field notes and other field materials under strict supervision. The researcher also ensured that vital information was not lost by transcribing the audio recordings verbatim. The transcribing helped to keep information relevant and accurate to the study objectives and aims. The audio tape information served as a temporal source of data. To ensure that the data was safe, recorded data were transferred at short interval on to a laptop computer to keep adequate space on the audio recorder and also safe keeping of data.

#### **4.6 Ensuring Methodological Rigour in the Study.**

Guba and Lincoln as cited in Henry, (2015) referred to the accuracy and trustworthiness of research finding as rigour. Even though other researchers had outlined a number of criteria for rigour, the four criteria suggested by Guba and Lincoln still run through most of them. The four criteria to ensure rigour suggested by Guba and Lincoln (1985) included: credibility, fittingness, auditability and confirmability.

In this study, there were many steps taken to ensure credibility. Firstly, there was a pilot interview, which was carefully reviewed by the researcher. Secondly, the research committee headed by the supervisors also reviewed the report submitted by the researcher in line with the research questions and responses from the pilot interviews. In addition, the supervisory committee identified a number of challenges that could affect the credibility of the findings.

The first was that because the researcher is a clinical psychologist there was a strong temptation to give therapy to the patients as well as demonstrating personal sentiments during the interviews. The researcher was cautioned to detach himself from the process and also be open minded with his style of interviewing. Another set of pilot interviews were conducted and reviewed by the supervisors. After the supervisors were satisfied the researcher was permitted to proceed with the main data collection.

In view of the temptation to get influenced by the researcher's professional background, the concept of reflexivity became very important in ensuring methodological rigour in the study. Reflexivity is the process of identifying various constructs that implicitly and explicitly influence the research process (Guba & Lincoln 2005). The researcher declared his professional identity which could affect his objectivity in line with the advice by Guillemin and Gillam (2004) that researchers need to declare their stance concerning issues that can affect their neutrality.

As Guillemin and Gillam (2004) pointed out, controlling for reflexivity has to span the entire research and not only at a particular stage. Alvesson and Skolberg (2009) proposed a four phase approach in effectively managing reflexivity. The first major step was during the data collection stage, which dealt with how data were generated. The researcher ensured that the research instruments were subjected to pretest and also scrutiny by the supervisory team for reliability and validity.

Interviews were started with open-ended or general questions for rapport building and narrowed down to specific with the researcher taking the middle line not to influence the views of the patients (Holstein & Gubrium 2000). Also, field notes and memos were used to assist the researcher to stay on course about his line of questions and direction of the interviews.

The second phase was the interpretative phase. In this phase the researcher avoided the temptation of leading the narrations by the participants and rather took the middle course so as to be very neutral in his interpreting of the data. There was also a cross interpretation by other clinical psychologist in order to arrive at an objective conclusion. The supervisory team also reviewed the coding and interpretations of the data to ensure that the researcher's sentiments did not bias the data collected. Charmaz (2006), emphasized that the codes in such studies had to be done rapidly and as close as possible to the data. This was done in this study to ensure that the codes generated were as similar to the original data as possible. In this regard the audio interviews were transcribed and listened to carefully to be certain that only what was required to be included in the codes were applicable.

The critical interpretation of the context was the third stage. This was an important phase of the research process because the researcher's stance and values can affect his professional and socio-cultural position (Hammersley & Atkinson, 1995). At this point the

researcher depended a lot on his professional insight into the study and strict directives from his supervisors to ensure the interpretations were the actual narrations from participants (Sandelowski & Leeman, 2012). Finally, the professional guide and cross examination by others including supervisors and other colleagues ensured that the final presentation truly reflected what the participants presented devoid of the sentiments of the researcher. The researcher also kept a prologue of the purpose and objectives of the study to guide together with the effective measures throughout the study so that the objectivity of the data was upheld.

Auditability of the method refers to the ability of another researcher to understand and follow the methods and conclusions arrived at by the original researcher (Chiovitti, 2003). In this study, auditory trail, methods of coding, identifying and naming of themes and field observation notes were kept and presented to the research supervisory committee for scrutiny.

The aim was to ascertain whether they could arrive at the same conclusions. Peer reviewers and field assistants were also given the opportunity to review the process in the same manner and arrive at the same conclusion as the principal researcher.

Fittingness or transferability according to Lietz and Zayas (2010) refers to the degree to which findings of a study fit situations outside of the study and are found meaningful. Chiovitti, (2003) explains fittingness further as the extent to which the study working propositions generated could be applicable to other settings similar to that of the study setting which they were generated. In this study, notes about participants' conducts, direct quotes and vivid description of the setting were presented to help ensure fittingness. In this study the setting was the hospitals and the consulting rooms where interviews were held.

Confirmability is the extent of accuracy which others confirm or corroborate the result of a study (Lincoln & Guba cited in Lietz & Zayas, 2010). Peer debriefing, member checking and the use of audit trail are some of the strategies that were used to ensure confirmability of this study. In addition, research assistants were also given the opportunity to independently code and identify themes from the data as part of analysis to compare their independent findings with those of the researcher.

Further, the initial findings were made available to two participants (one woman and one man) during their routine hospital visits to familiarize and identify the results of the study as a true reflection of their responses during the interviews. The two participants were selected after giving their consent to participate in that review process. They both agreed to a large extent on all the findings but for the finding that indicated that OFT patients did not apply a lot of health beliefs in their health-seeking. The statement was appropriately amended to reflect the accurate statement and meaning as presented by participants in the study.

#### **4.7 Ethical Clearance**

Ethical clearance was sought from the Ethical Committee of the College of Humanities, University of Ghana before the study began. Institutional Review Board clearance was sought from the sampled health institutions following the presentation of the ethical clearance certificate from the University of Ghana together with a copy of the proposal for the study. After reviewing the application and some procedural measures permission was granted for data collection for both studies one and two.

The issues of human rights were very much adhered to throughout the study and the interviews. Participants who volunteered to take part in the study were informed about the

objectives of the study and given opportunity to ask any questions that they may not understand. Informed consent was verbally agreed on and all the participants were assured of the right to enter to participate and freedom to withdraw from the study without any form of coercion. Participants were informed that only their identification numbers they used in the hospital were being used since their identities were protected and to ensure their privacy. The interviews were held in selected consulting rooms of the doctors who had willingly agreed to that request. The interviews were held in those offices when the doctors were either not in office or on other assignments outside their offices. The participants were also informed that their responses were to be audio recorded but would not be identified by names. The recorded version and private information about the participants were all kept under lock and might be made available only to the supervisory committee members on request

#### **4.8 Method of Data Analysis**

Using thematic analysis requires flexibility and open mindedness on the part of the researcher in order to accurately capture participants' views from their perspectives (Holloway & Todres, 2003). On the basis of that the data was analyzed using direct narratives and presentations from the perspectives of the participants. The analysis was carried out in line with six guidelines proposed by Braun and Clarke (2006) to ensure credibility and reliability of the findings.

Getting familiar with the data: The first phase of the analysis demands that the researcher gets very familiar with the data. The verbatim transcribed data from the One-on-one interviews were read repeatedly together with the RA in order to be better understanding and familiarity together. This reading together was important even though the researcher was much more familiar with the data as a result of personally transcribing them it helped for team work. In order

to ensure accuracy of the process, the transcriptions were repeatedly checked against the original tape recordings together with the RA. The repeated reading also helped the researcher to search for and identify meanings of language used, ideas and patterns of thoughts expressed by participants and marked them down for subsequent coding.

Generation of codes: The second phase of the analysis involved generating of initial codes. According to Braun and Clarke (2006) the data has to be organized into meaningful groups that could enhance generation of theory. Using this advice, the researcher manually organized the data into meaningful groupings. This was done by first producing the initial codes from the data by the use of different coloured pens to identify potential patterns. The researcher then matched each of the codes with their appropriate data extract. During the process, any information or accounts which deviated from the dominant story captured in the analysis were noted and marked out.

Searching for themes: At this third phase of the data analysis, the various codes were sorted and put into potential themes. Each potentially identified theme was written out on a separate sheet of paper with different colours of fonts for easy identification. There was careful reading of each of the codes in order to assign appropriate names for the emerging themes and sub-themes. The various themes and sub-themes were typed with their corresponding data extracts.

Reviewing themes: The various themes were reviewed at this phase of the data analysis. This involved refining all the themes that were initially extracted from the data. At this stage some of the initial themes were collapsed and merged into one when it was obvious that such themes could not stand on their own as major themes. There was further reading to ensure that all the themes retained had enough data to support them and make them distinct from each other

(Braun & Clarke, 2006). At this point all the themes were compared against the data set to evaluate the validity in line with their representation in the original data set. Any overlooked data which was not added to the themes were included in the coded themes for accuracy and reliability of the data analysis.

Definition and naming of themes: Next phase, was for defining and naming of the themes for data analysis. The researcher went through another phase of reading to get each of the collated data extracts of the themes organized into coherent and consistent narratives corresponding to the exact representation in the main data. At this stage each theme was considered against other related ones. They were also assessed whether there were sub-themes under any of the main themes. It was at this stage that names were assigned to the various themes. Any changes in the names of themes to reflect the changes in the data set were also carried out. Also, the final thematic map representing each major topic or issues from the participants' perspectives were finalized.

Turning out report: This phase concluded the steps from phases 1 to 5 which culminated in producing the report (Braun & Clarke, 2006). The researcher organized the report reflecting the steps outlined by Braun and Clarke, (2006) as follows in the sections on results, interpretations and discussions.

#### **4.9 Findings**

The responses of the participants were analyzed and are presented below. The analyses were done using the audio transcribed responses from the participants. Interpretations based on the various themes were presented in line with the objectives, research questions and the theoretical underpinnings of the study. The findings are presented in line with the various themes and their

subthemes. The findings are presented following the demographic characteristics of respondents in Tables 22 and 23 respectively.

**Table 22: Demographic Characteristics of One-on-one Interview for Patients with OFT**

<b>Code</b>	<b>Age</b>	<b>Educational Level</b>	<b>Marital Status</b>	
1	50	No formal Education	Married	Malignant
2	52	Junior High School	Widowed	Benign
3	51	No formal Education	Prev. Married	Benign
4	27	First Degree	Single	Benign
5	30	Secondary Education	Single	Malignant
6	40	Junior High School	Married	Benign
7	41	Vocational/Technical	Married	Malignant
8	31	Junior High School	Married	Benign
9	54	Diploma	Widowed	Malignant
10	55	Junior High School	Divorced	Malignant
11	42	Junior High School	Single	Malignant
12	56	First Degree	Married	Benign
13	57	First Degree	Prev. Married	Benign
14	32	Diploma	Divorced	Malignant
15	33	Vocational/Technical	Divorced	Malignant
16	43	Secondary Education	Married	Benign
17	71	Secondary Education	Prev. Married	Benign
18	43	Secondary Education	Divorced	Benign
19	57	Secondary Education	Single	Benign
20	44	Secondary Education	Prev. Married	Benign

There was a One-on-one interview session which covered 20 participants made up of 8 patients with malignant and 12 with benign tumour respectively. The ages of participants who took part in the interview ranged from 27 – 71 with a mean age of 46.47. Two of the participants had no formal education, 5 had basic education, 6 had obtained West Africa Senior Certificate (WASSCE) and 5 had obtained diploma and first degree. Six subjects were married, 4 previously married, 3 widowed and 4 were never married 3 of the subjects were divorced. The participants were identified as F1, F2, F3, F4, F5, F6, F7, F8, F9, F10, F11 and F12 for the female while the males were M1, M2, M3, M4, M5, M6, M7 and M8 respectively for anonymity.

The researcher identified five themes and their related subthemes from the qualitative data. These are presented in Table 23.

**Table 23: Themes and Subthemes that emerged from the Study**

Theme	Subthemes/ Explanation	No	% response
Conceptualizing of causes of OFT	Spiritual/supernatural, biogenic, ignorance	18/20	90
Physical trauma	Intermittent bleeding, pain/discomfort, and weakness.	17/20	85
Self-stigmatization	Appearance and recurrent issues, self-esteem,	18/20	90
Economic challenges	Low income, expenditure on medical services, transport/accommodation costs.	14/20	70
Methods of coping	Hope in the healing power of Spiritual coping, Social support and Home.	20/20	100

The researcher extracted narratives from the personal experiences of the participants. The narratives are expressed in the following order.

Samples of Extracts

#### 4.9.1 Conceptualizing causes

Participants identified the cause of the disease as spiritual or due to supernatural sources. Most of the participants recounted a number of incidences in their lives leading to the onset of the disease to support the supernatural and spiritual causes of the disease. Others stated that they were ignorant about the cause of the disease but some believed that it was due to biogenic factors. In the case of those who alluded to ignorance as the cause of the disease, they did not seem to understand the circumstances surrounding the growth of a little swelling into such enlarged tumour.

For those who thought that the disease was spiritual or due to supernatural sources, the mystery about the onset of the disease was what gave them the strong basis for that belief as expressed by many of them as follow:

Spiritual/supernatural causes

*“The cause of this condition, hmmmmmm..I don’t seem to know exactly but it looks more as if there can be spirits behind it. I sometimes wonder if I have done something against someone that led to this condition. Because the way the boil turned into this big and painful thing on my face, still surprises me, if it was not some African magic then what else do you think?” (M2)*

In the case of this participant, the growth of the disease from the swelling into the large tumour surprised him. This form of mystery surrounding the disease makes it very difficult for such a patient to accept that it was a normal growth of his soft tissues around the oral and facial regions. The interpretation of this situation in relations to a spiritual attack lends credence to what

Dzokoto and Adams (2003) stated that some Africans easily blame the enemy for diseases or situations they find difficult to understand.

Another patient summed up her understanding of the cause of the condition in the words:

*“The causes of this disease, I think it’s more mysterious to believe that it is normal. I am pretty certain that it’s spiritual but I don’t think God is punishing me but it is spiritual from any other source. You know sometimes you can lead very good life but you don’t know what someone may be thinking and wishing for you. Somebody may just hate you for no reason. You see if you think about how this condition turned from a little swelling to what you see on my face now the only reason is spiritual” (F7).*

From the presentations of the participants who believed in the spiritual or supernatural cause of the condition, the main belief they hold is the element of mystery surrounding the disease. They could not understand how the disease which they had witnessed grow from start into an enlarged tumour on the mandibular and maxillae structures. It confirms the fact that some Africans easily assign spiritual cause to disease conditions they do not know the origin.

#### **4.9.2 Biogenic**

As indicated above, some of the patients believed the cause as physical. Even though they identified the cause as biological or physical, doubts regarding the growth of the condition still linger on among them. Their sentiments were aptly represented in the following words:

*“I was actually prompted by one of my children that there is something happening on my face. So I went and examined my face in the mirror. And I noticed that there was some*

*swelling somewhere and if not attended to it will disfigure my face. So I quickly went to the hospital to see how they can help me. I did not think about any spiritual cause because I in particular I don't think too much about spiritual things because everything that the body develops comes through the blood system. It was good I went to the hospital. "My brother, hmmm...the early reporting to the hospital is what has saved me (M3).*

Another patient who also believed that the disease was caused by physical ill health stated that since they carried out the surgery his condition had improved and he was recuperating so it could not have been caused by any spiritual means. His narratives are illustrated as follows:

*"For the cause of this disease, eerrrrh..... Though I 'm not too sure I can tell you that it's not from any supernatural forces or curses placed on me. I don't think I have wronged anyone. Even look at me, after the surgery I 'm looking fine and the scares are also going. You think if it's due to supernatural forces they will allow me to recover like that?. It can be some problem in my blood or any other issue concerning my physical condition" (M 8)*

The responses from the patients who identified biogenic cause for the condition show that they were concerned about their physical healing processes. They explained how diseases can attack the physical body due to weakness and aging process and therefore did not assign other causes for the disease. They also demonstrated knowledge about the need for prompt response to seek treatments for such diseases.

### 4.9.3 Ignorance about the origin of the etiology

The subtheme of ignorance seems to run through the thoughts of many of the patients. Careful analysis of their responses indicates that they were unaware about many aspects of the disease including the cause and its development. Some of them just could not specifically identify a particular reason for the aggravation of the disease to the present stage. Their views are presented below:

*“When it started I thought it was a toothache then it started swelling. Some people have been saying that the condition is as a result of punishment from God or a curse from some spirit. But for me personally I don’t know. All that I know is I have this swelling here accompanied by persistent toothache and later the swelling became bigger up to what you are seeing now.. I still get confused about how that little swelling has developed into this big thing on my jaw. If I knew and had come to the hospital early, it wouldn’t have resulted in this condition”. (M 6)*

It is very obvious that the participant in this case was totally oblivious of what was happening to him. He virtually underestimated the danger of what he was experiencing and thus did not take any immediate health-seeking action. In his case apart from the toothache which was his concern, he did not assess the swelling as a threat because it was a very gradual growth. The gradual nature of its growth could be one of the dangers associated with the disease. The fact that the disease does not present immediate symptoms of a serious disease, misleads some of the patients to delay in health -seeking.

## **Ignorance about the origin of the etiology**

*“If I had known earlier it wouldn’t have gotten to this stage, so what I will tell anybody is that when you are sick, and you don’t know what is wrong with you, the first thing is to go to the hospital and check. Because it might be a small problem that can be treated at the early stage. But if you wait for a longer period....if I had known...hmmm .... I feel very sad that things would have been far better than now and it could not have turned this way all this while I thought it was a dental problem and using mouthwash. I” (F2)*

The views expressed by the two participants reflect the danger inherent in delays before reporting for orthodox healthcare. They lamented that the delay had resulted in the disease becoming worse and difficult to treat. One other issue that was very explicit in their presentation is the fact that they were never aware of the type of disease that plagued them but unfortunately they underestimated the threat leading to the advance presentation of the condition.

### **4.9.4 Self-stigmatization**

Change in Appearance:

Guledgud, Patil, Saikrishna, Madhavan and Yelamali (2014) have emphasized that patients with OFT are very much concerned about the drastic change in their appearances and whether the surgery could correct such disfigurement. This concern about their looks reflected in the findings in both study one and two. Participants expressed deep feelings about their appearance. Their feelings usually lead to high levels of self-stigmatization among them. One interesting aspect of the self-stigmatization is that it is more a reflection of the mindset of patients than reality. They

often interpret the reactions of the public as a sign of stigmatization. These thoughts unfortunately results in psychological distress among them. The key sub theme of the stigmatization is the Change in Appearance and some of the narratives of their findings are presented as follow:

*'My looks have changed seriously since the condition. I feel strongly that people no longer see me attractive and I'm in doubt whether I can get good job and husband in the future. I don't believe I can ever get back to my charming looks even after the surgery'*  
(F3)

Another participant who also expressed the sentiments about how the condition makes him stigmatized is presented below:

*"You know, I sometimes felt very miserable because I never thought that tumour could lead me to a state where people will be shying away from me..... because they might think they could contract it from getting close to me. Sir, sometimes I think that way because of the behaviour of friends and other family members. If it were you how will you react knowing that people close to you no longer didn't want to get close to you again for no reason. It makes me very depressed because of the condition, you are also losing your close relations?"(M4)*

Another participant also expressed the self-stigmatization as the main issue that confront them as a result of the condition. His views are expressed as

*'How the condition has affected my life? You just take a good look at me and see whether you like what you see. My entire life has just turned upside down, I can't work very well*

*again and my customers don't want to offer me jobs any more. I m a carpenter so how do I survive. It has been a major shock to me finding myself in this state'.*(M5)

Similar feelings were expressed by a teacher in the following lines:

*“The condition has greatly affected me because as a teacher, you have to be on your feet and you have to be very active in class but the condition does not allow me especially when the pain is severe. More importantly is the reaction from the students where you can see surprises on their faces and some even asked you about the disease. And you can't explain to them. In actual fact you don't meet people openly laughing at you but their reactions and looks alone can put you in hiding from the public. Hmmmmm.....you see the difficulty in my case is that I need to go to the classroom and interact with the students and other stakeholders who are always wondering about what is this huge thing on the face”* (F5).

Perception of stigmatization was the main issue participants demonstrated in their justification for feeling stigmatized. It can be deduced from the sentiments they expressed that reactions from the public have become great worries to them. Majority of their evaluations seem to be based on their interpretation of people's attitudes towards them. Though some of them have clearly indicated that the public does not openly ridicule them their perception of stigmatization continues to grow.

#### **4.9.5 Fear of Recurrence, Pain and Appearance**

Another area of major concern to patients is the anxiety over the outcome of the surgery. The outcome of surgery evokes fears and a lot of uncertainties. In the case of patients with OFT, the

level of anxiety becomes more pronounced because of the fear that the disease may recur. In other words the issue of recurrence is of central concern to many of the patients with OFT (Llewellyn et al. 2008), Aside that there is also the worry about their post-operative appearance. They wonder whether the surgery can correct the tumour and restores them to their original looks. The worries concerning recurrence and body image issues are presented in the following:

*“I believe the pain is the major aspect am thinking about and how successful it will be. How my looks will be, errmm.... yes, that’s also my worry. Maybe after it I will have some scars on my face that people will recognize. You know people say the thing will come back if they don’t do it very well. It scares me to go through this surgery” (M1)*

*“With this tumour you go out and people will be looking at you and asking questions. You don’t feel comfortable. As the time for the surgery draws near I feel anxious. Because there are others who had the surgery and the problem came back so I don’t know how mine will become. If it comes back how will I face the public who always continue to ask many questions? I am praying that my face will be free of this condition so that I can also look decent once again in life. You see sometimes you feel a little bit..... sad that is why I have designed my hair to partly cover my tumor in order to hide it?” (F6)*

The effect of OFT regarding the appearance of patients continues to be a major worry to them as demonstrated in this study. The responses have shown that recurrence of the disease is a dreadful thought for most of the patients. Patients often have high hopes of reversing their

deformities through surgery hence the issue of recurrence comes to dash their hopes. The fear of recurrence therefore results in higher levels of anxiety among patients because the success of the surgery and aftermath are moments of high uncertainty. Most of the patients associate the disfigurement with stigmatization which results in psychological distress among them. In view of the unpleasant experience of stigmatization the desire to get over their deformities was well understood.

#### **4.9.6 Stigmatization and Self-esteem**

Self-esteem is the view that an individual has about himself or herself (Freire & Tavares, 2011). This view of the individual can be greatly affected by the perception of stigmatization due to the body image challenges. This view was identified as one of the key issues of concern to the patients in the study. Self-esteem was identified as one of the psychological challenges that persons suffering from chronic diseases such as OFT experience. This assertion was confirmed in the qualitative phase of this study. The views of some of these patients are summed up as follow:

*“My self-esteem went down because I saw myself as a partially deformed person and if not checked on time I could have been traumatized. People will shy away from me and try to avoid my associations. Initially I felt very bad when I compared my former face in a picture to the current” (F4).*

The problem of stigmatization and how it affected the patients was also expressed by another participant who consistently had to answer people concerning the disease. His sentiments are expressed below:

*“Hmmm.....my brother confidence as a person and how I see myself have gone down very much. You see some people have been making some remarks about the condition but I always try to ignore them. Some of them I know it’s out of sincere hearts they want to know what the problem is about but others cast insinuations or give insulting remarks which I consider to be abusive but I keep all that to myself. It affects how I feel about myself. Those who are close to me try to find out exactly what is happening to me but since I don’t know much about it, all that I know is this thing that started as a small swelling on my mouth has grown into this big structure. So I don’t give them any specific answers. But when I’m alone I feel very sad about such attitude and why it’s happening to me” (F9).*

From the narrations given by the patients above, it can be deduced that self-esteem has not only affected their self-image and confidence but also immense psychological distress. The patients expressed feelings of not ‘being their old personalities’ such statements demonstrate the depth of their feelings and views about themselves. The experience of psychological distress was also evident in their expressions such as ‘I feel very sad...and I could be traumatized’.

#### **4.9.7 Physical trauma**

There are number of physical challenges patients go through due to the condition. Some of them include pain and discomfort which are some of the severe physical symptoms associated with OFT. The pains affect their normal functioning including eating and speaking. These physical challenges also lead to psychological problems. Patients in study two have demonstrated these problems in their responses to the interview granted them. A number of other subthemes also emerged as a result of the conditions. The first is bleeding. Some of the patients revealed that in

addition to the pain, bleeding from their mouths and other orofacial regions was another problem that confronted them. The second subtheme is weakness experienced by some of the patients. They explained the weakness resulted in their inability to engage in any meaningful work or activities they previously participated in to make a living. Their views are presented below:

The patients who suffer from pain and intermittent bleeding expressed their sentiments in the following:

*“The condition has resulted in a lot of pain, bleeding and untold discomfort in my life. Aside that I am sometimes weak so it affects my ability to carry out my work and chores at home. The bleeding in particular makes it difficult for me to go to work and with persistent headaches and other challenges I can’t understand. . I ‘m told the cure mainly is through surgery and that gives me another form of worries since I have never had one in my life before”.* (M10)

*‘My brother it is not easy at all living with this condition, the pain when eating is so much that you don’t feel like eating at all. I only eat to survive, lest I die otherwise no need to eat because of the bleeding and pain from my mouth’.*

*(M7)*

Participant who also experienced a lot of pains as a result of the condition narrated their feelings as follows:

*“The pain issues are very worrying. You know I was having pains whenever I tried brushing. It comes and goes. When that was happening...initially I thought it was just toothache. So I just took it to be a normal thing. I went to the pharmacy and they gave me painkillers and I just took it. I don’t know but just around last year the pain became*

*serious. As at now the pain can be so much that I can't do anything meaningful on my own. The doctors gave me some medicines but they relieve the pain just a little but it comes back and can really be that bad". (F10).*

The pain narrative of another patient was put in the following way:

*In my case the pain comes a while and can be very severe and unbearable. When it happens like that I can't even work efficiently. The condition really affects me in all aspects of my life. From eating to speaking and working it's all suffering. When it gets very severe, I have to hold or just keep myself away from people and apply pressure on it. When it happens to me I don't want anybody to ask me what's wrong with you. So I just want to be indoors and nurse my problem". (F1).*

#### **4.9.8 Financial Challenges**

One of the main determinants of health-seeking is financial problem. Afolabi, (2013) emphasized that financial difficulty and other barriers to accessing healthcare are some of the major bottlenecks to health-seeking in Africa. Majority of patients identified these as some of the key factors that influence their health-seeking behaviour. The subthemes of disruption to their source of income due to ill health and costs of medical services including laboratory examinations and drugs dominated their concerns. The views of the patients are presented below:

*I have two children. The condition has affected me a lot. The time I didn't have the disease anytime I am going home I had a lot of money on me, but right now because of the sickness, I used my money for prayer camps and other expenses concerning the*

*condition. Nowadays it is my wife who is supporting me because my job is down. The pressure now is on my wife so she is complaining about the money and my sickness and how they have used all money to do a lot of things and still no improvement” (M6)*

### ***Disruption to work and financial difficulty***

*“The disease has affected my daily life. At times I don’t even feel like going to church because some people have been asking a whole lot of questions and I find it difficult to answer most of them. Even money to feed myself and my wife is a problem. People’s attitude also makes it difficult for me to go out freely and interact with other people. At work also even my colleagues don’t want to deal with me on business line” (M2)*

The financial difficulty brought about as a result of the condition was also expressed by another participant in the following narrative

*“How has the condition affected my financial fortunes? In fact it hasn’t been easy at all for me. It has greatly changed my economic standing in many ways. You .....see in the first place, initially I was able to work but at the moment I can’t go to work regularly and because of that my salary has been reduced significantly This makes my earning to become very small. Secondly, I need to spend a lot of money on the various tests recommended by the doctors and medicines to help improve the condition. The medicines and the tests are expensive and put a lot of pressure on me”. (F4)*

The effect of the condition on another patient’s economic life is illustrated below:

*“Now as I have told you my main concern about the condition and its effect is that my ability to work being affected, and economic life has been affected seriously by the*

*disease. Some time ago when the sickness was not serious I used to go to work regularly, but right now when am going to work then am feeling shy. So no am not going to work anymore" (M7)*

From the analysis of views presented by patients concerning financial problems, it can be observed that the first main concern is their inability to engage in gainful employment either as a self-employed or private sector worker. From the patients, customers no longer patronize their services due to the condition and those in private sector employment risks losing jobs or have been laid off. Most of the patients also have challenge of meeting the costs of services such as medical laboratory tests, drugs and other medical related expenses. These also partly explain the long delay of patients in going through treatment and eventually leading to the aggravation of the disease.

#### **4.9.9 Coping Strategies used by Patients.**

Participants identified some subthemes as strategies for coping. These include: hope, prayer, and social support. Patients demonstrated the importance of coping in moderating the impact of psychological distress on their condition. Some of them use hope in the healing power of God and others believed that prayer was the key strategy that helped them cope with the condition. Social support was another coping strategy confirmed by patients as effective in moderating the effect of the disease. It was in the form of help from the immediate family, friends, work colleagues and the church. The views of patients on the various subthemes are presented in the following narrations.

**Hope:** This is the subtheme that demonstrates the role and efficacy of the healing power of God.

Their views are as follow:

*'For me my hope in the Lord is what keeps sustaining me. Especially about a disease that the causes are not clear only trust and hope in the Lord can help me. Since the causes of the disease are not very clear I prefer to get treatment from the hospital and still other ways especially prayer and hope in God's healing powers. I trust it shall be fine even though I get sad many times God is in control'.(F8)*

Another patient who also demonstrated hope in God's healing power captions it as:

*"The role of the power of God in this process is wonderful. You see ....I don't even know what to say, it's been God ooooo. With my belief in God? I know that one day one day God will make it and help me to go through. As I go through the surgery, my hope is that God has a hand in the surgery and that it is God who will help the surgery to be successful" (M5)*

The issue of hope and belief in God as coping mechanisms continue to emerge in dealing with diseases among Ghanaians and for that matter Africans. The assertion by Mbiti (1991) that Africans are highly spiritual comes into focus judging from the narrations given by the two patients. The strong hope that their diseases could be cured by God provided them with a strong form of support and their ability to cope with the disease.

#### **4.9.10 Belief in God and prayer**

Some of the participants also indicated that prayer was the most powerful means by which they were able to cope with the disease. Those who used prayer have their results expressed in the following words:

*“With prayer, anytime my spirit is down and I pray, I know that there is hope and surely this thing will go and I will one day find a solution. I have a strong faith that we can use prayer to solve every problem so once I pray I know God will deliver me. I know the doctors are good but God heals through them. I know in this case it’s going to be surgery and for surgery you need the hand of God at work to be successful. All the specialist doctors can do their best but if God does not come into it you can fail. I don’t know how the surgery will be but with the assembly of all the specialist it will be a complex and difficult one but God is in control (F5)”*

Another patient also narrated the following sentiments:

*“I know they are going to carry out a major surgery on me but as I have mentioned to you early on my belief in God and spirituality are my strong factors which will help me get out of this successfully. I also trust the ability of the specialist doctors because if they were not to be very good I would not have been referred to them. I know they are good but my prayer is that God works his miracles through them” (F2)*

A postoperative patient recounted his experience and trust in prayers during and after his surgery. The following are his narratives:

*“The success of my surgery was largely due to the intense prayers before during and after. Myself, family and pastors supported me a lot in prayer. Even while the surgery was going on some of them were still praying for me. The prayers were very helpful especially some of the anticipated complications were avoided, like blood transfusion and possible dangers that could have happened to me after the surgery too”.*(M4)

#### **4.9.11 Social support**

Social support as indicated above is one of the coping strategies that worked for many of the patients. Their views are presented as follow:

*“My support comes from different sources: family, friends and work colleagues. For instance one of the female leaders in the community she has been talking to me and trying to make me understand that everything happens for a reason and that everything will be fine. She tells me not to be scared about the outcome of the surgery. She even used herself as example who has had multiple surgical procedures and she is still very fine. Generally, family members and friends have also been very kind to me”.*(F10)

Another presentation on social support by a patient demonstrates the influence of positive thoughts individually and as a collective factor in moderating a distressing condition.

*“For me about how I handle the situation, You, know it’s not been easy but I am just always looking at things positively and do what I need to do and relax. I don’t want it to affect me too much, so I need to relax and stay positive and remain hopeful that everything will be alright. My family in particular also gives me the necessary encouragement and other forms of support. I know I will have a successful surgery”* (F1)

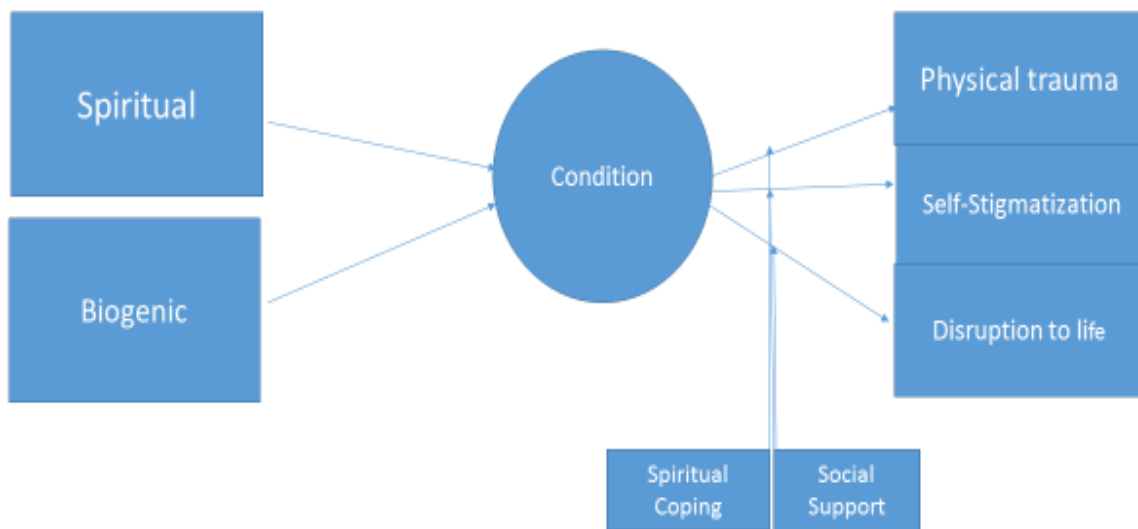
Participants' identification of social support as one of their coping strategies confirms widely held view in literature of the effectiveness of social support in moderating distressed situations (Howren, Christensen, Karnell & Funk, 2013). The social support in the form of help from spouses, parents and siblings play important roles in moderating psychological distress experienced by patients. In addition, supports from friends, work colleagues and members of society also provide good measure of help to patients. These forms of help also confirm the communal nature of Ghanaians and for that matter the African. Other forms of coping strategies patients alluded to include hope in the healing power of God and prayer. Majority of participants believed that their problems could be divinely solved and they employed prayer as a tool for God's intervention.

#### **4.10 Summary of Findings**

The qualitative research explored the health-seeking behaviour, spirituality, effects of the disease, influence of perceptions of body image and stigmatization on patients and how they coped with OFT. Also the 'lived' experience of patients with OFT was further assessed from the patient's point of view. Significant number of participants reported of the intense pains and self-stigmatization they experience due to the disease. Hope and spiritual coping were used by many of the participants to moderate the impact of the OFT.

Conceptualization the cause of the condition remains one of the most challenging issues to address in future judging from the responses provided by patients in study 2. Knowledge about the cause of a particular disease helps in health-seeking behaviour among patients. That also informs patients about the threats and other factors that facilitate health-seeking. A model

of conceptualizing OFT and the impacts on patients has been developed by the researcher to explain the behaviour of participants. The findings indicated that patients identified two causes of the condition namely supernatural and biogenic. The perception of the cause of the disease, determines to a large extent the health-seeking and other actions to deal with the disease. In this study, apart from the cause it has been found that patients experience high levels of physical distress, self-stigmatization and disruption to their lives. The model shows that they mainly used spiritual coping and also benefit from social support to buffer the level of the distress associated with the disease.



**Figure 12: Conceptualization of the causes of orofacial tumours**

Source: Qualitative data.

#### **4.11 Discussion of Qualitative Study Findings**

This qualitative study two investigated the role of spirituality, health belief and stigmatization in determining health-seeking behavior among patients with OFT. The level of patients' psychological distress was also explored. The final discussion was done in line with the specific research questions set for the study. Research participants were drawn from the sample that participated in study one. In-depth interviews were conducted to collect data for the qualitative study. Thematic analysis was used to analyze the data (Braun & Clarke, 2006). The study employed the four steps recommended by Lincoln and Guba cited in Lietz and Zayas, (2010) for ensuring credibility of findings in a qualitative study. Five themes and their subthemes were extracted from the data collected from the participants. The themes included conceptualizing the causes of OFT, physical trauma, self-stigmatization, financial challenges and methods of coping. The general research question that guided the qualitative study is:

How does the qualitative finding explain the roles of spirituality and health belief and reasons why health belief did not predict HSB as realized in the quantitative study one. It also, explores the influence of body image and stigmatization on HSB and psychological distress among patients with OFT. The specific research questions that were formulated to explore the qualitative aspect of the study include:

1. What accounts for the higher levels of psychological distress among patients with OFT compared to general dental patients?
2. What do patients with OFT perceive as the causes of their disease?
3. How has living with OFT been for the patients?
4. What impact has OFT had on patients (physically, emotionally, and socially)?

## 5. How have patients of OFT coped with the disease?

The first research question states: What factors account for the higher levels of psychological distress among patients with OFT compared to general dental patients?

This discussion follows the finding in the study which investigated the levels of psychological distress among the three groups of participants. The result indicated that the patients with malignant tumour have the highest levels of psychological distress followed by those with benign tumour and general dental patients. The discussion first looks at why patients with OFT experience higher levels of psychological distress compared to the patients with general dental conditions from the perspective of the qualitative study.

The themes and subthemes that emerged from the qualitative study explain to a large extent the reasons for the higher levels of psychological distress. In considering a subtheme on pain and discomfort it is clear that patients who experience certain levels of pain for a considerable period of time also tend to suffer more psychological distress. This point is extensively supported by Geirdal et al. (2014) who indicate that because the disease affects the face, head and the neck regions of the patients, it often results in extreme physical and psychological distress to them.

In explaining further the reasons for the differences in the levels of psychological distress, Jaafari-Ashkavandi and Ashraf (2011) stress that the tumour condition may impair speaking and swallowing because of their peculiar locations. Dental care in general evokes some level of anxiety among some patients. Chadwick as cited in Huda, Baig, Kamal and Khalid (2015) support this assertion but the reasons that account for the low levels of anxiety among dental patients in the study stem from the fact that majority of those patients have higher

levels of education and are much more familiar with the processes in the dental treatment. They were also mainly in the hospital for less invasive treatment such as extractions and restorative procedures, situations which evoke reduced levels of anxiety. These treatments usually do not pose much of a challenge to the patients. It is therefore not very surprising that the patients with malignant tumour have the highest levels of psychological distress.

The fact that some of them were informed that their disease was cancerous is in itself a major factor that can result in shock and sadness. That according to Fingeret, et al. (2012) is due to the fact that the locations and nature of the disease make it difficult to hide and also patients have a strong concern for recurrence and disfigurement. The disfigurement may subsequently lead to severe psychological distress among patients (Lebel, Castonquay, Mackness, Irish, Bezjak & Devins, 2011).

The result also indicates that patients with both malignant and benign tumours have more psychological distress compared to the control group. In both groups the condition presents with disfigurement which could be clearly seen on their faces. Since majority of them identify self-stigmatization as one of the key issues that greatly affect them that might have significantly contributed to the increased psychological distress among them. As they feel stigmatized they also become more anxious about the disease. They are also often worried about how people usually react to them and some of them can end up depressed; a finding that is in line with that of Lebel, (2011).

The second research question: “What do patients with OFT perceive as the cause of their condition? The appraisal given to a health condition plays a major role in how the individual reacts and deals with the situation including health –seeking behaviour. The way Ghanaians and for that matter many Africans perceive causes of diseases differ markedly from

that of the views held by many people from the Western societies. The result from the qualitative analysis confirms that assertion. The theme on spirituality clearly shows that cultural factors explain views held by many of the patients as was stressed by (Gyekye, 2003; Danquah, 2008). Cultural and health beliefs are major influences on how a patient interprets and views the cause of the OFT conditions.

The result further indicates that majority of the patients with OFT trace the cause of the disease to supernatural forces including superstitious beliefs, and other evil curses. Mbiti (1990) investigates the African's interpretation of strange diseases and concludes that in Africa many people attribute different forms of spiritual and other supernatural factors as causes of diseases they consider as strange.

There is also the belief in "enemyship" among many Africans and for that matter Ghanaians. In this belief, the African interprets ill health in terms of personal relationship with others characterized by hatred, malice, and sabotage (Adams, 2000). In this case some Africans believe that the diseases they suffer are from an enemy even though they cannot identify clearly any such sources.

Notwithstanding the overwhelming endorsement of supernatural cause for their diseases a greater minority of patients allude to the fact that their diseases are brought about as a result of biological or physical factors. Some of the patients cannot identify any cause of the disease and feel that the only error they committed is delays in seeking healthcare which normally aggravates the situation. For such patients they do not see the "small swelling" that started on their faces as any form of threat and therefore did not act quickly.

This particular factor is strongly stressed by Parkins et al. (2008) that tumours and tumour-like conditions in many cases may start as a swelling but can lead to enlargement of the jaws and facial region and cause significant disfigurement and severe pain. This revelation together with the findings from the patients make the disease more delicate that calls for urgency in health-seeking. In the sense that ignorantly, patients may just wait for a disease that can be quickly dealt with to deteriorate into an unbearable disfigured structure with so much pain and psychological distress.

The interpretation and appraisal given by a patient to the causes of the disease could lead to the determination of level of threat or distress and consequently the type of health-seeking behavior to be engaged in for treatment. Tomison, (2013) confirms this assertion that health-seeking is mediated by many factors some of which are still complex and not very clear. Ignorance seems to have a strong influence in the late reporting of patients to seek healthcare. However, it is not conclusive as to other reasons why a lot of the patients with OFT report late to the hospital to seek orthodox care. Some possible reasons are put forward. According to Afolabi et al. (2013), they include barriers to access to health facility, knowledge and vulnerability of the disease.

The difficulty in understanding the determinant factors for late reporting to seek orthodox healthcare is made clearer by Adams and Dzokoto, (2003) when they explain that among Africans, chronic health conditions evoke different types of interpretations and actions from patient as well as family members and community at large (Adams & Dzokoto, 2003). It is based on the finality of decision by all the stakeholders that the individual seeks a particular line of healthcare. As to where to seek healthcare and the type of care are determined by the type of interpretation for the etiology of the disease. Others also engage in multiple choice of treatments

(de-Graft Aikins, 2013). Those who engage in multiple sources of treatment may do so with the view that at least one of such approaches to treatment could work to alleviate them of the pains associated with the disease.

In the case of patients who interpret the condition as emanating from spiritual and other supernatural forces, the tendency to seek healthcare from other spiritual sources is very high leading to late reporting to the health facilities, to seek orthodox treatment. In some cases some of them abandon treatment and return to the hospitals afterwards with a much worse condition mostly in an advanced and untreatable stage. Clegg-Lamprey et al. (2009) observe a similar attitude among breast cancer patients and the level of frustration that poses for effective treatment of the condition.

It is therefore an indication that diseases that are chronic and their etiology not readily known patients interpret them differently and decide on their approach to treatment. It is very crucial for society to understand that certain diseases are best handled at the hospitals hence they report to the orthodox facilities first for treatment to be effective and also to reduce mortality and complications in such treatment.

On the research question “How has living with OFT been for the patients?” the finding reveals many themes based on how living with the disease has been. Majority of the participants stated that their lives have been greatly disrupted by the disease as explicitly explained by the biographical disruption model.

The model explains the extent to which the lives of people with such diseases are disrupted in terms of their normal lives and they also have to reappraise their lives in the reality of the disease and how to align their lives to face the new situation. From the experiencing of

extreme pain during swallowing to disruption in their economic lives the disease has a major toll on the lives of the patients. As narrated by one of the distressed participant:

*“How has the condition affected my financial fortunes? In fact it hasn’t been easy at all for me. It has greatly changed my economic standing in many ways. You see in the first place, initially I was able to work but at the moment I can’t go to work regularly and because of that my salary has been reduced significantly. I’m even lucky that my employers haven’t sacked me as of now. This makes my earning to become very small. Secondly, I need to spend a lot of money on the various tests recommended by the doctors and medicines to help improve the condition which worsen my financial situation (F4).*

The emotional and psychological challenges patients with such chronic disease go through have been expressed clearly in this study. Patients’ emotional and other psychological distress stem from the fact that majority of them experience a lot of anxiety as they are informed about the condition due to the uncertainty surrounding the causes and successful treatment. These assertions are confirmed by Llewellyn et al. (2008) when they revealed that many patients become very anxious about the new and sudden disease and even get much more worried about the issues of recurrence and general disruption to their lives.

Another major area that the disease has a lot of distressing moments for the participants is the level of pain and discomfort they have to contend with. A condition that in many cases starts as swelling which many consider as part of toothache and its transformation into painful and a big structure on the face of the patient causes much emotional and psychological challenges to the patients. Most of the patients cited ignorance as the principal

reason for not reporting early to seek orthodox treatment. They also report that they use different types of herbal medicines, mouthwash and other unorthodox methods to reduce the pain.

Unfortunately, the delay together with the unhygienic methods used in treating the disease often worsen the condition and thereby making treatment much more difficult and costly for both patients and the medical team.

Some of the patients experience bleeding from their mouths from time to time making it very difficult for them to eat. As one of such patient says that he finds it very distressing to eat and has to eat only because of survival. His narrative is presented to support the level of pain they had to contend with.

*'My brother it is not easy at all living with this condition, the pain when eating is so much that you don't feel like eating at all. I only eat to survive, lest I die otherwise no need to eat because of the bleeding and pain from my mouth'. (M7)*

The level of the pain and its attendant discomfort may result in high levels of anxiety and eventual depression. The anxiety and depression mostly come about due to what Verdorick-de-leeuw, et al. (2007) describe as fear associated with the fact that the disease can become unmanageable and completely affect their livelihood and their appearance.

Some emotional impacts of the pain are also reported by patients when they come to the realization that the routine processes of eating have become such difficult duties characterized with turmoil and great discomfort. As one patient puts it that he has to eat in order to survive otherwise he may not eat at all because of the unbearable pain and associated bleeding the emotional feelings. The patients also complained about other psychological challenges that make life difficult for them. These sentiments from the patients are understandable judging from

the fact that pain can drive individuals to become very lonely, sad, and generally worried about how to contend with the situation.

From the results of the study, a lot of participants also spoke about the perceived disfigurement caused to the once beautiful or handsome faces of the individuals and their worries about the uncertainty of returning to their original appearances. The expression of those strong emotional feelings are supported by Pritchard (2009) when he emphasizes that the fear of surgery, appearance issues and pain result in extreme psychological distress among patients.

There are also very interesting findings on the research question: “What influence has OFT had on patients (physically, emotionally, and socially)? Physically, patients go through several physical challenges which also trigger off some psychological problems. The fact that patients experience physical deformity in terms of their body image and associated perceived stigmatization mean that they may have a lot of challenges to contend with.

The effect of OFT on the patients becomes much more pronounced and devastating due to the delicate site and the associated pains, disfigurement and inability to use some of the vital organs such as the mouth, mandible and maxillae (Scully & Bagan, 2009). For instance as high as about 50% of all patients with OFT experience problems with swallowing as indicated by Pauloski et al. (2000). The impact of the challenges on patients in many cases becomes much more severe with advanced stage of the cancer. Some of the patients have to be assisted by tube feeding and in some cases such treatments do not alleviate the plight of patients making life extremely uncomfortable. Newman et al. (1998) explain that the difficulty and challenges associated with tube-feeding put extra burden on the caregivers not to mention the pain and agony the patients go through with such long and painful process of cure and treatment.

Indeed the site of the disease makes it very difficult to hide and the resultant disfigurement attracts a lot of attention on to the patients which heightened their perception of stigmatization from the public. The stigma associated with the disease also leads to body image challenges which can make some of the patients to experience low self-image. Body image problems subsequently could result in worries, sadness and generally high levels of anxiety and depression as some patients withdraw from friends and activities they previously were involved in. The anxiety about whether the postoperative recovery will be successful poses another major problem to the patients and affects their treatment and rehabilitation process.

Socially, the disease has a measure of negative toll on some marriages. Even though many of the respondents indicated that they enjoy social support from family members and other relations, some of them also suffer in the hands of their partners as a result of the disease. For instance some women are abandoned by their husbands because of the disease and left to care for themselves at very crucial times of the disease.

There cannot be any more painful experience at such a time in the life of a wife when the husband abandons her to her fate. Such women face much more challenging times due to lack of financial support from their husbands and other family members. A 29 year old mother of two children who narrates her difficult and painful ordeal in the hands of her husband is presented below:

*“For me when you talk about social support hmmm.....it’s been very difficult for me because the man I have married for more than five years with two children has sent the drinks back to my family that he was not interested any longer in the marriage. Both families tried to make him change his mind but he refused saying that I have grown too*

*lean and that he could not understand that. I became very devastated and sad because I don't know what to do at the moment. I 'm only praying to God to help me. A few family members and friends also help me but with two children and no longer working just image what life has been to me and the children” (F7)*

The nature and the effects of the disease on patients differ markedly. For instance, the effect on the lady whose marriage ends is not limited to her alone but the children also are affected since their father no longer takes care of the family. In addition to the unfortunate situation, the mother also lost her job due to the same reasons. Every effort should be made to intensify education for the public to understand and identify the initial symptoms of the disease. That can lead to early diagnosis and treatment in order to help reduce such challenging circumstances that some patients endured.

The effect of the disease on the economic life of the patients is also very severe. Many of the patients have to stop work completely or have to engage in limited work since the onset of the disease. Those of them who are self-employed or work as artisans, do not get enough job offers from their customers. Some of the customers feel that the patients are not healthy enough to work any longer because they are perceived to be too weak to work and hence are not given jobs to carry out for them.

The unwillingness of customers to offer them work makes most of them to experience harsh economic situations and the economic challenges become much more difficult due to the fact that they spend a lot of money on their medical bills and other cost including transportation. In addition, majority of patients with OFT cannot return to work even after their treatment in order to restart their lives successfully.

This assertion is supported by Taylor et al. (2004) from their cross-sectional study which shows that 52% of patients with head and neck cancer who were in active employment at the time of diagnosis were unable to return to work even after completion of treatment. A clear testimony of how devastating the disease has affected the economic fortunes of the patients. In a few cases those who are able to return to work after treatment have to change their jobs because of physical discomfort and poor health following their cancer treatment (Liu, 2008).

The research question on “How have patients of OFT coped with the condition”? From the result of the qualitative analysis, majority of patients indicated that they employ spiritual coping extensively in dealing with the disease. The main areas of the spirituality they often concentrate on are: hope in the efficacy of God’s healing power, prayer and belief in the power of other spiritual forces.

They also have strong belief in God’s power and the preparation and competence of the medical expert in delivering effectively during the surgery. Hope emerges as one of the most effective methods of spiritual coping in dealing with difficult situations. When individuals are confronted with challenging circumstances those with strong faith and hope in a particular supernatural power depend on that in moderating the impact of the condition.

The finding of the study is not very surprising because it is a strongly held perception and belief that the Ghanaian society is highly spiritual and also that religiosity plays vital roles in determining individual’s approach to dealing with challenges that confront them on daily basis. A good number of Ghanaians use prayer as a major tool to strengthen their ability to deal with difficult situations. They pray during major functions, pastors pray for patients while at various hospitals and have a strong belief that for the doctors to be successful there is the need for God to guide the process.

The role of positive spiritual coping in moderating such conditions is consistent with literature in which there are many studies that demonstrate the power and efficacy of reducing psychological distress among patients with OFT. On the other hand patients who use negative spiritual coping strategy have higher levels of psychological distress including anxiety and depression which can result in poor quality of life as demonstrated by (Bosworth et al., 2003).

Another important coping mechanism that many of the participants use is social support. Social support is extensively cited as one of the strongest mechanisms in coping with the level of psychological distress and other challenges patients experience as a result of the disease. Social support in the form of assistance from family members, friends, church members, colleagues at work and other community members. Though minority of patients complain that they do not enjoy good social support in dealing with the condition, mostly from their spouses greater majority attest to the enormous benefits of social support.

The extensive display of social support in this study can be identified with the traditional communal lifestyle of many Ghanaians. As confirmed by Gyekye (2003) when he explains that because Africans live communally they come together on many occasions when their services are needed. He cites instances when Africans come together in times of challenges and joy and therefore share in each other's predicaments and successes. The result of the study that indicates that social support forms an integral part of life among the people can be related to the traditional characteristics of Ghanaians which virtually mandates them to come together to help one another in times of need and trying moments.

#### **4.12 Summary of Discussion for Study Two findings**

The discussion highlights reasons why there are some differences in the groups of patients in study1. In that result patients with malignant OFT followed by those with benign OFT and the general dental patients experienced psychological distress respectively in order of severity. The discussion on the qualitative study 2, comprises themes and subthemes. The key themes in study 2 include: the patients' conceptualization of causes of OFT, physical trauma (pain or discomfort) associated with the disease, self-stigmatization, economic challenges and methods of coping. The results of the study as discussed demonstrate that majority of the patients identify supernatural forces, superstitious beliefs and other spiritual forces as the cause of OFT.

They explained that since they cannot readily identify certain sources of the condition the best explanation is that they could only be spiritual factors. Minority of the patients however believed that OFT is caused by biogenic or hereditary factors while the others indicated clearly they are ignorant about what might be responsible for the disease that has plagued and devastated their lives. From the discussions one can say that majority of the patients do not actually know the precise cause of OFT and are only conjecturing what they consider as the causes based on their perceptions.

Pain/discomfort, self-stigmatization, financial challenges and coping strategies are some of the other factors that influence the health-seeking behavior and levels of psychological distress among the participants. In addition, body image issues, and fear of recurrence of the tumour after surgery are some of the other key apprehensions of patients. The results also indicate that positive coping is mainly in the form of social support, hope, prayer and other forms

of spiritual practices. It is revealed that those who practice negative spiritual coping do not benefit from the coping strategies discussed

The level of psychological distress among the patients with malignant OFT is the highest followed by benign. The forms of the distress are mainly anxiety and depression associated with the disease and surgery. The main concerns of patients are predominantly the success of the surgery and body image challenges.

## **CHAPTER FIVE**

### **GENERAL DISCUSSION**

#### **5.1 Introduction**

This chapter comprises the discussion of the key findings of both empirical studies one (Quantitative) and two (qualitative). Findings from the two studies were linked to the objectives of the study. The relatedness of the findings to the theoretical framework was discussed. Limitations and recommendations of the study were also proffered by the researcher. Finally conclusions were drawn from the findings.

#### **5.2 Brief Overview of the Thesis**

The main objective which guided this study was to examine the relationships among spirituality, stigmatization, body image perception, health belief and health-seeking behaviour of patients with OFT and also assess their level of psychological distress. In study one, six sets of questionnaires were administered to patients with OFT and general dental conditions to elicit information on their level of psychological distress, spirituality, health belief, body image perception, stigmatization and health-seeking behaviour. The participants in study 2 were selected from those who took part in study 1 and engaged in one-on-one in-depth interview to further explore their views on the roles of spirituality, health belief and other psychological variables in their health-seeking behaviour. Study 2 also examined the influence of stigmatization and body image perception on the levels of psychological distress and coping mechanisms adopted by patients. The main aim of study two was to examine the health-seeking behaviour from the perspectives of the patients and also to confirm responses from the quantitative data.

### **5.3 Discussions of Findings from Studies One and Two**

The discussion highlights the psycho-spiritual and social determinants in health-seeking and also ascertains the influence of spiritual and other psychological factors in moderating the effects of OFT on patients. In addition, the discussion also assesses the influences of stigmatization, and body image perception on psychological distress.

#### **5.3.1 *Physical Manifestations and Psychological factors in OFT***

The conceptualizations of the causes of OFT are varied and interesting. Majority of patients with OFT considered the disease to emanate from spiritual or supernatural forces while significant number of them also believed that the disease was due to biogenic factors. There was a minority of them who expressed total ignorance as to what causes the disease.

The difficulty over the causes of OFT is not very surprising because the manner in which the disease develops from a little swelling to an enlargement of the jaw and other facial structures poses a lot of mystery to many of the patients. The mystery surrounding the origin of the disease was explained by Baddoo and Parkins (2008) that the disease may be from the remnants of the development of teeth and their surrounding tissues. Many of the patients and members of the general public may not have such information and therefore they might be tempted to provide their versions of the causes of the disease.

The findings from both studies one and two revealed that some participants were not sure about the causes of the disease. However, those who believed that there was physical basis felt that since it was around the orofacial regions of the face there might be some deformities that led to such conditions. They therefore supported the need for orthodox approach to treatment whereas those who felt that the cause was due to spiritual or supernatural forces sought treatment

from spiritual means. The key challenge is that since the disease develops from small swellings and other structures in a gradual manner, an early diagnosis helps a lot in the success rate of treatment. A main concern of the medical experts in this field is the late arrival of many of the patients to the health facilities which hinders successful diagnoses and treatment of such a disease (Parkins, Armah & Tettey 2008).

The other wrong interpretation of the causes of the disease lead to delay in seeking healthcare. The delay in seeking treatment also allows the tumour to develop and according to Jaafari-Ashkavandi et al, (2011) may impair speaking and swallowing. This is because of their special locations and the level of pain and discomfort they inflict on patients as was overwhelmingly alluded to by patients in this study. Some of the patients confirmed their feelings of pain and discomfort when they explained that they experienced bleeding from their mouths and could not eat and live their normal lives. They expressed uncertainties about the success of the surgeries and alleviation of their pains and discomfort. The extreme pain and discomfort patients go through also result in high levels of psychological distress that can lead to many challenges which may affect the recovery of such patients during their process of diagnoses and treatment (Geirdal, et al, 2014).

### **5.3.2** *OFT and Psychological Distress*

The results of study one indicated that there were differences in the experience of psychological distress as illustrated by the mean differences in empirical study one. The patients with malignant tumour had the highest levels of psychological distress compared to those with benign tumours. The patients with general dental diseases recorded the lowest levels of psychological distress. One of the key factors in the experience of such distress is the level of

pain associated with the disease. As explained by Geirdal, et al, (2014) the location of the tumour is so delicate that it virtually disrupts the individual's normal functioning and pains in such regions can be very unbearable. Patients with malignant and benign tumours have similar growth on their faces and may experience bleeding which was one of their chief complaints.

The result indicating that both groups experienced considerable levels of psychological distress clearly explained the similarities of symptoms both types of tumours pose to patients. The fact that in each case patients' ability to speak, eat, even drink water and perform other basic functions are impaired make the pain and discomfort very difficult for them. The symptoms of the patients with malignant tumour are much more debilitating. But a more important reason why the patients with malignant tumour may have the highest levels of psychological distress has been explained by Hodges and Humphris, (2009). They stressed the influence of the fear of recurrence as a key factor that leads to the high levels of psychological distress among patients with malignant OFT. It was further explained that on diagnosis of cancer many of the patients receive the news with shock and that coupled with the interpretation that the condition poses a major challenge to their health, can lead to higher levels of psychological distress.

Cancer itself evokes a lot of fear among sufferers and the fact that the survival rates is five years in advanced countries makes it more dreadful. But the survival rates can be far lower in Ghana and for that matter other African countries. This information may trigger another form of anxiety and other forms of psychological distress among patients. The finding brings to the fore the fact that many of the patients were showing symptoms of advanced cancer because of late reporting to the health facilities. Some of them reported to the health facilities at the district and other regional capitals where the process of diagnoses took long to discover. Partly due to

the fact that some of the patients often delay in completing the various recommended medical examinations because of lack of money. For others, it was due to ignorance that the disease may not pose much threat. Therefore most of the patients in the study had waited for a long period before reporting at the referral facilities. In this study, the mean period from the onset of the disease to the time of reporting to the referral hospital was 19.3 months which is relatively a long time. Internationally, three months from the time of the disease is considered a long time hence over 19 months can result in very advanced stage of cancer with attendant severe symptoms. As the patients also perceive the condition as deadly, that is likely to inform their reactions to the disease and may go a long way to increase the level of psychological distress they experience. The appraisal given about the disease is very much influenced by the health belief and spirituality of the individual patients and in some cases together with their families and other close relations.

### **5.3.3** *Spirituality, Health belief, Psychological distress and Health-seeking behaviour*

The roles of spirituality and health belief in the levels of psychological distress experienced by patients cannot be over emphasized. The two factors are also major determinants in health-seeking behaviour as exhibited by patients. In this study the results showed that spirituality significantly predicted and also moderated psychological distress and health-seeking behaviour of the patients. However, health belief did not predict and neither did it moderate psychological distress and health-seeking behavior of the patients with OFT and general dental conditions. In study one, health belief did not influence psychological distress which is very much contrary to literature.

There are a number of studies that illustrated the important roles of health belief in terms of health-seeking and moderating diseases (Adewuya et al 2008). Thus the patients' health belief greatly determines their decision on what action to embark on in terms of health-seeking, perception of the risks and vulnerability of the disease. According to the health belief model, the interpretation and appraisal a patient gives to a particular disease influences his line of health-seeking. If the person appraises that the condition is dangerous and makes him or her vulnerable then the likelihood of seeking quick healthcare is also high. On the other hand if the person perceives the threat and his or her level of vulnerability to be low and does not pose much danger then he or she may not take immediate action in health-seeking. In this study, significant number of participants expressed ignorance about the danger the disease poses especially at the onset.

Many of them who witnessed the development of the little swelling did not predict that it was going to grow and become such enlarged structures virtually disfiguring their orofacial features and resulting in so much pain and discomfort. The responses from the qualitative study two very much explained this line of thinking of the patients in this study. Though study one result pointed to the fact that health belief did not predict health-seeking and also psychological distress it could not provide reasons for that but that was explored further in study two. In study two patients lamented that if they had known that the little swellings they experienced formed the start of such a serious and dangerous disease they could have acted much swiftly and prevented the disease from getting to the point at which they got to the health facilities.

Some of the patients expressed regret and hoped that the public gets to know about the facts surrounding OFT so that they take appropriate actions to save lives and avoid pain and

discomfort associated with the disease. The findings on spirituality confirm the hypothesis and also literature on the effect of spirituality in moderating psychological distress and also health-seeking. Spirituality plays an important moderating role in the psychological distress OFT patients experience and also predicts their HSB. This is because depending on the individual's level of spirituality the condition may be worsen or improved (Sarfo, 2015; Anim, 2015). Spirituality buffers the level of anxiety and depression that are often associated with negative and tragic life events such as being diagnosed of OFT (McCoubrie & Davies, 2006). Generally, spirituality has been found to be associated with the emotional wellbeing of patients (Sulmasy, 2009). The fact that spirituality moderated the disease among the patients demonstrates the power and influence it has in determining the cause of the disease and subsequent level of psychological distress associated with OFT.

When an individual patient perceives the cause of the disease as spiritual or supernatural and evil forces, one of the sure approaches at tackling the problem is to turn to supernatural methods in dealing with the challenge. In tackling the disease from the spiritual sources some of the patients decide to seek healthcare elsewhere outside the orthodox health facilities which are the recommended approaches to treating OFT.

The delay and multiple sources of health-seeking in many cases aggravate the disease and make the treatment difficult and complicated (Clegg-Lampsey & Hodasi, 2008). Though spirituality has been found to buffer psychological distress, in many cases the situation depends on the level of spirituality patients profess and how that guides their thoughts which can be negative and result in poor coping techniques or positive which helps to actually reduce the level of distress.

#### **5.3.4 Stigmatization, Psychological distress and HSB.**

The perception of stigmatization is another important factor that influences a patient's level of psychological distress. In study one, the result showed that stigmatization predicted the level of psychological distress and health-seeking behaviour. From the themes that emerged from the study two, patients expressed deep sentiments about how much they feel stigmatized by the public. In many of the instances, patients could not provide enough evidence for the stigmatization but they perceived verbal and non-verbal reactions from friends, family members, colleague workers and others they come into contact with as part of the stigmatization. Since the public was not involved in the study to find out about the veracity of this allegation, it stands that the perception continues to affect patients with OFT and invariably influences their levels of psychological distress.

A number of studies have confirmed the fact that people suffering from OFT are highly stigmatized. Fingerret et al, (2012), explained that the main concerns of many patients are the challenges of disfigurement and worries of success of the treatment. The perception of stigmatization can emanate from different sources in our society. In Ghana and Africa where the citizens exhibit communal lifestyle to a large extent, many people may show their concerns about the disease.

These concerns may come in the form of visits and questions about the nature of the disease which the patients in some cases consider as demonstrated in the qualitative study as intrusion into their privacy. Some even think that by asking questions regarding the disease more information can be spread about their disease and many more people will get to know leading to more people laughing at them or taunting them. In some cases the actions of the public

may be borne out of genuine concern for them but the patients also misunderstand such acts as stigmatization.

Stigmatization is also another factor that can lead to health-seeking. As the patients consider that people continue to laugh at them or gossip about them as a result of the disease they may seek healthcare in order to have the condition rectified so as to avoid the source of the stigma. It looks as if both the patients and the general public seem to be very ignorant about the disease and therefore continue to marvel at what actually is the situation about. In this regard the public interest in knowing what the disease is about will always be high. Unfortunately, most people do not know that the enlarged growth they see on the maxillae and mandible of patients started as little swellings and develops gradually.

The key factor that needs to be considered seriously is the issue of public education. Both the patients and members of the public need extensive education about the disease and how to tackle situations surrounding the disease. The education can lead to reduction in the level of ignorance and also help patients with the disease to respond early for treatment and thereby reduce the complications associated with the disease. In that case the concerns of specialists including Clegg-Lamprey and Hodasi, (2008), Parkins and Tettey, (2009) who advised that if patients reported early, there will be better surgical outcome for patients with all types of cancer including OFT could be addressed.

### **5.3.5 *Body Image Challenges and Psychological distress in Relation to HSB.***

Orofacial tumour affects the soft tissues of the maxillae and the mandible regions of the sufferer. These areas of the patients are some of the most sensitive and delicate parts of the human body. Any injury or deformity caused to those regions becomes a major problem for the

patient. Body dysmorphic challenges worry many people including patients with OFT. In this study also responses from patients signify that majority of them consider the body image issues as a major concern to them due to the impact it has on their appearances. It is therefore not surprising that both body image perception and stigmatization correlated significantly with both psychological distress and health-seeking behaviour. The result showed that reaction to the disease confirms a number of findings in literature that the level of disfigurement on the orofacial regions of patients exposes them to a lot of perceptions of stigmatization whether real or imaginary.

The disfigurement subsequently leads to severe psychological distress among patients (Lebel et al, 2011). Appearance continues to be an important issue to many patients and that when they think that their looks have been compromised as a result of a disease they become extremely worried. It is said that the onset of the disease especially the malignant tumour evokes a lot of fear at the time of diagnoses because of the fear associated with cancer and its related problems. Apart from the initial fear the next major concerns of patients are about scars, recurrence and other forms of disfigurement.

Many a time, surgery also comes with its attendant challenges. In some cases as Fernandes et al. (2014) stated part of surgical treatment of OFT, frequently requires extensive resection of the surrounding structures. This further treatment leads to various degrees of facial disfigurement which consequently, needs restoration of parts of /or facial tissues. The disfigurement extensively affects the general looks of the patients and quality of life. These effects include negative self-appeal (aesthetic) value, social and work relationships and alterations in the person's life due to the disease (Martino et al, 2008; Fingeret et al, 2012). Post-

surgical care of patients with OFT is very crucial in ensuring that the level of psychological distress experienced by patients can be minimized. Psychological therapy needs to be incorporated into the various approaches of restoration after surgery in order to take care of the postoperative stressors for a complete and thorough rehabilitation to the patients.

**5.3.6** *Spirituality, Health belief, Stigmatization, Body image perception, Psychological distress in relation to Health-seeking behaviour.*

Spirituality and health belief are two important factors that determine to a large extent the direction of health-seeking among many patients including those with OFT. Spirituality and health belief form some of the most influential factors in the appraisal and final decision taken by patients in health-seeking. Health belief in particular significantly informs the patients about what they perceive as the cause of the disease and the determination about the vulnerability and barriers associated with health-seeking.

Based on the type of appraisal and understanding reached by a patient, the issue of spirituality also comes into play. In many cases if the disease is deemed to have been caused by any supernatural forces then the spiritual approaches to health-seeking are activated by patients and in many cases their families. If on the other hand, the disease is perceived to be caused by physical factors, the most appropriate place to seek healthcare is the orthodox health centre. Though health belief did not correlate positively with psychological distress and health-seeking behaviour its importance was expressed by respondents in the qualitative study two.

Some of the patients demonstrated the effect of health belief on their psychological states when they expressed the fact that the interpretation given to the danger and risks associated with the disease resulted in a number of them exhibiting symptoms such as mood

disorder, insomnia, restlessness and other psychological challenges. They explained that as they come to terms with the fact that the disease they perceived from the initial stages as harmless has now turned out to be cancerous or other major growth they experience self-guilt for not being proactive in their health-seeking behaviour. Some of them lamented the lack of action on their part at the initial stages of the disease and questioned why they failed to act decisively from the onset of the disease.

The experience of these patients attests to the influence of health belief in patients' reactions to life threatening chronic diseases such as OFT. It also shows that health belief does not only lead to a particular health-seeking behaviour, but also determines how patients physically and psychologically tune themselves to the disease (Sarfo, 2015). Sarfo, (2015) also explains that health belief greatly determines choice of health care and the level of psychological distress of patients.

Explaining the reason why health belief did not predict health-seeking in study one can be linked to the issue of cultural influences. The participants in the study may not have understood some of the questions in relations to their actual meanings in the Ghanaian culture. That explains why the participants gave responses in the qualitative study 2 which did not exactly reflect the finding of study one regarding health belief. From the results of the study it is clear that the roles of spirituality and health belief are very important in dealing with patients and their health conditions.

It is true that Ghanaians are very spiritual and that greatly influences their decisions regarding health-seeking attitudes. There is a need to create a form of synergy between their belief system and health-seeking habits so that both can work to the benefits of patients. In this

case, spiritual approaches and orthodox methods can be integrated in treatment. If that is done, patients may no longer report so late to the health facilities in order to have better and more successful outcomes of treatment.

### *5.3.7 Age, Gender Educational levels, and Socio-Economic background in relation to PDI and HSB.*

Socio-demographic background of patients is also very important in determining how they handle health challenges that confront them. In this study, age, gender and the level of education individually did not show any significant differences in the levels of psychological distress and health-seeking behaviour. However, interaction effects between them yielded significant result. From literature, the condition is more prevalent among adults than children even though Nuamah and Abdulai (2012) reported that OFT cases among children are increasing and should be of concern to all.

The level of psychological distress did not differ significantly among the various age groups. The study covers adults from 18 years up to 83 years and the fact that all the groups experience similar symptoms and impacts may have explained the reason for not recording any significant differences. The effects on the young adults and the old adults may be similar but their perceptions of the disease can differ. One important factor is that their perception of public reactions may influence their levels of psychological distress and health-seeking behaviour.

On the issue of age in relation to the disease, the fact is that it affects more people as they age. This finding was confirmed in this study as the mean age was 46.4 reflecting what Johnson, 1991 cited in Lawal et al.(2013) said that the disease can be found more among persons older than 40 years of age. Lawal et al. (2013) gave two reasons that account for higher prevalence of OFT with increased age. They explained further that firstly, it is believed that

there are increased levels of free radical activities with age. Secondly, an individual's immune system reduces with age and becomes much more tolerant with tumour and carcinoma cells. The educational levels of participants also usually affect their interpretation of disease but in this study, participants' psychological levels and health-seeking did not significantly differ.

It can be observed from the study that majority of the patients with OFT ended their education at the pre-tertiary level. On the other hand majority of the general dental patients have tertiary level education. The influence of education on the patients could not reflect in their perception of the effects of the disease which is very interesting judging from what pertains in literature.

The key reason may be due to the nature of the disease which affects all sufferers in a particular manner. This is much more intriguing to note that the type of disease that patients have registered significant differences on their health-seeking and also the experience of psychological distress.

The differences in the level of psychological distress and health-seeking point to the fact that it is rather the impact of the type of condition that actually affects patients' perception of the disease, appraisal of the threat and consequently the level of psychological distress they experience. Harding and Taylor (2002), argued that socio-demographic factors such as age, gender and education play important roles in influencing health-seeking. But the effect of the patient's perception together with lay advice is equally very important in health-seeking. It therefore shows that the interpretation and perceptions play very important roles in determining the reactions and impact of OFT on patients.

The fact that patients with malignant tumour recorded the highest levels of psychological distress indicates that the severity and perception of threat may have over shadowed the

influence of gender, education and age in determining health-seeking and psychological state of individual patients. When patients interpret that cancerous type of the disease poses more risk and that they are much more vulnerable, their reactions may differ markedly from the knowledge than that of the benign and other general dental diseases.

As literature explain that on the reception of the news of contracting cancer, the shock of patients can increase their distress levels. Further, appraisal of the threat and thoughts about the long term effects including the issue of surgery and post-surgery challenges can eventually lead to anxiety and depression among patients (Semple et al.2008).

### **5.3.8 Barriers to healthcare and relations with Health-seeking behaviour**

There are a number of factors that directly influence health-seeking behaviour among patients. In both studies one and two, some of these factors have been identified including socioeconomic background and geographical locations of patients. The socioeconomic levels of majority of patients indicate that their monthly income is low.

More than 50% of respondents fall below the World Health Organisation's classification for low income or poor category. The WHO classification indicates that an individual who earns less than US\$ 2 a day is considered poor or low income earner (WHO, 2014). World health Organization also draws a very strong link between socioeconomic level and vulnerability to diseases. It explains that people with low income are highly prone to diseases and ill health in general. This finding in study one was corroborated in study two when one of the main themes of the patients' narrative is on financial challenge as one of the key barriers to healthcare and that consequently affected their health-seeking.

Majority of patients in study two expressed frustration about how difficult it is for them to have transportation to the major referral hospitals such as Korle-Bu teaching hospital.

Interestingly, most of the patients come from rural areas and have to travel long distances to the capital city or Kumasi where the centres that deal with these referral cases are located. They also grapple with the challenge of accommodation in Accra when there is the need to stay for a couple of days to complete their medical examinations.

Some of these challenges were cited during interview with them as key problems that militate against health-seeking among them. This finding confirms what Afolabi et al. (2014) found in a study on health-seeking in Nigeria that it was not spirituality that delayed health-seeking behaviour among patients but it was barriers to healthcare especially accessibility to the health centres and money.

Finance and accessibility therefore are major obstacles to health-seeking in Ghana as much as was found in Nigeria. The situation becomes much more delicate when dealing with disease that grows by the day and gets more complicated to treat. Whereas, early detection and treatment records high success rate late reporting and advanced stage of the disease leads to poor treatment outcomes.

Another very important finding worth emphasizing in the study is the fact that significant numbers of patients come from mining communities or work as miners. Many patients reported from different parts of the country to the referral centres. But those who reported from regions noted for mining including Eastern and Western were appreciably higher than those from other regions. The study did not delve into geographical locations and relationship with prevalence of OFT but it is worthy to understand the correlation between locations of patients and spread of this disease.

It may be coincidental but a further study to ascertain any linkage between the disease and mining environment will be appropriate and timely. The National strategy for cancer control

(2011) reveals that geographical locations and the type of occupational environment play a major role in the prevalence of cancer including OFT. It indicates that there is a high level of radon gas identified in some regions of the country. It also reveals that other forms of risks of contracting the disease include exposure to radiations that can be found in the medical and mining industries (National strategy for cancer, 2011). Since there is documented evidence of the link between cancer and geographical location or environment, it stands to reason that conscious effort should be made to carry out a study into the extent of the prevalence of cancer causing agents in the mining communities in order to take appropriate measures to curb massive outbreak of this deadly disease among those communities.

### **5.3.9** *The moderating roles of Stigmatization in relation to Psychological distress*

Indeed perceptions of patients in relation to a particular disease condition greatly influence their reactions to the disease and health-seeking behaviour. The fact that type of the condition significantly predicted their levels of psychological distress was very interesting. It also demonstrates that apart from the severity of the disease, patients' assessment of how the condition might affect them also has an important role in determining their levels of psychological distress.

The patients in this study considered stigmatization as a major concern and it subsequently predicted their level of psychological distress. This finding informed test of moderation to ascertain its role in moderating their psychological distress. Predictably, stigmatization moderated the level of psychological distress among the patients. This is a very significant finding in the sense that knowing that stigmatization both predicted and moderated psychological distress.

It behoves that every effort is made to reduce the level of stigmatization among patients. If they perceive their appearance to be very much affected by the disease, and that they no longer look attractive they are likely to feel much more stigmatized. In the same manner if they are assured that their looks are not much affected by the disease then they may feel confident enough and this can influence their psychological distress. It can even improve treatment outcome and recovery rate as alluded to by (Katz et al, 2003). Fingeret et al (2012) found that the body image challenge faced by OFT patients after surgery does not only lead to stigmatization but also results in low self-worth reduced confidence and can affect the individual in many other psychological ways that warrant a well-organized psychosocial care.

#### **5.3.10. *The moderating roles of Spirituality in relation to Psychological distress***

Spirituality can improve or aggravate the state of a disease depending on how each individual patient appraises the cause of the disease and the type of mechanisms to deal with it. Spirituality is one of the constructs that moderates disease conditions and other distressing situations among people. Patients in this study are no exception and the result of the moderation analysis also demonstrates that patient's level of distress was significantly moderated by their level of spirituality. Significant number of patients shows that they are highly spiritual and use different approaches rooted in spiritual and other forms of beliefs in deciding on what actions to embark on in dealing with personal challenges.

In evaluating the possible cause of the disease, some of the patients employed their spirituality in terms of health-seeking behaviour. Depending on the patient's determination of the cause of the disease and cultural beliefs, an action can be taken in health-seeking. An interesting point to note is that spirituality predicted both psychological distress and health-seeking behaviour. It also moderated the level of psychological distress among the patients.

Since it can moderate the level of distress, it shows the important role it plays in dealing with diseases including the OFT. Patients who adopt positive spiritual approaches in handling the effect of the disease are very much likely to be relieved of some of the symptoms. But those who also perceive and use negative spiritual methods may worsen their health condition. The positive integration of the patient's spirituality into the health-seeking and also dealing with the psychological distress levels among patients should be the focus of a holistic healthcare.

### **5.3.11 *Social support and coping with the impact of OFT***

Social support comes in different forms and helps in alleviating the impact of psychological challenges and other forms of difficult situations on individuals. This important supportive role abounds in literature where help from spouses, children, family members and others has been confirmed to aid patients' recovery from diseases (Howren, Christensen, Karnell, & Funk 2013; Derje et al 2016). Howren et al (2013) indicated that social support in dealing with the effect of OFT on patients comes in different forms and stages.

The form of the support comes virtually at the onset, diagnoses, pre-surgery, during surgery, post-surgery and other related periods of the disease. The importance of social support was extensively expressed in the sentiments of patients with OFT. They demonstrated that in citing the various sources including spouses, children, family, friends, church and community members, and colleagues from offices.

The form of social support in this study significantly reduced their levels of psychological distress in most of the diseases reported by patients. In very few cases patients complained that they did not enjoy good social support from their relations especially some of the women revealed that their husbands even threatened divorce which made them very depressed. Patients confirmed that social support come in all forms including counselling,

financial, material and other forms. The study also reveals that patients also benefited from other forms of coping strategies including spiritual coping approaches. Hope and prayer have significantly aided many of the patients in their attempts to cope with the psychological distress they experienced as a result of the OFT.

The issue of prayer, hope and other spiritual coping methods also buttress the fact that spirituality plays a major role in moderating psychological distress. The main concern about the strategies using spirituality is whether the individual uses it in the positive and proactive way or in the negative way. If a patient uses the negative approach it may not yield the desired moderating effect and therefore the benefit of spirituality is lost on such patients (Princhar, 2009). Spirituality is one of the key factors that can be used for pre-surgical stage of patients and helps considerably in reducing their psychological problems especially those associated with surgery and its aftermath.

#### **5.4 Summary of General Findings**

From studies one and two there were a lot of interesting findings. The results of the findings especially in the quantitative study one showed that there were significant differences among patients with malignant and benign tumours compared to those with general dental problems. Patients with malignant tumours recorded the highest levels of psychological distress and those with general dental problems had the lowest levels of psychological distress. The results of the study also revealed that spirituality predicted both the level of psychological distress and health-seeking behaviour of patients. But health belief did not correlate significantly the relationship between the type of the disease and health-seeking behaviour as well as psychological distress. In addition, stigmatization and body image perception both correlated

with the levels of psychological distress and health-seeking behaviour. Further, the type of condition positively predicted health-seeking behaviour and psychological distress of patients.

Study one also revealed that psychological distress mediated the effect of the condition and health-seeking behaviour. Similarly, stigmatization mediated the effect of the condition on the level of psychological distress. The results from study one also showed that stigmatization and spirituality moderated the effect of the type of condition on psychological distress among patients but health belief did not moderate the relation.

On the causes of the disease majority of the patients in study two cited spiritual forces including supernatural and evil forces as the cause but minority of them stated that it was due to biological and other physical factors.

The results from study two also indicated that spirituality significantly influenced health-seeking behaviour and level of psychological distress among patients with OFT.

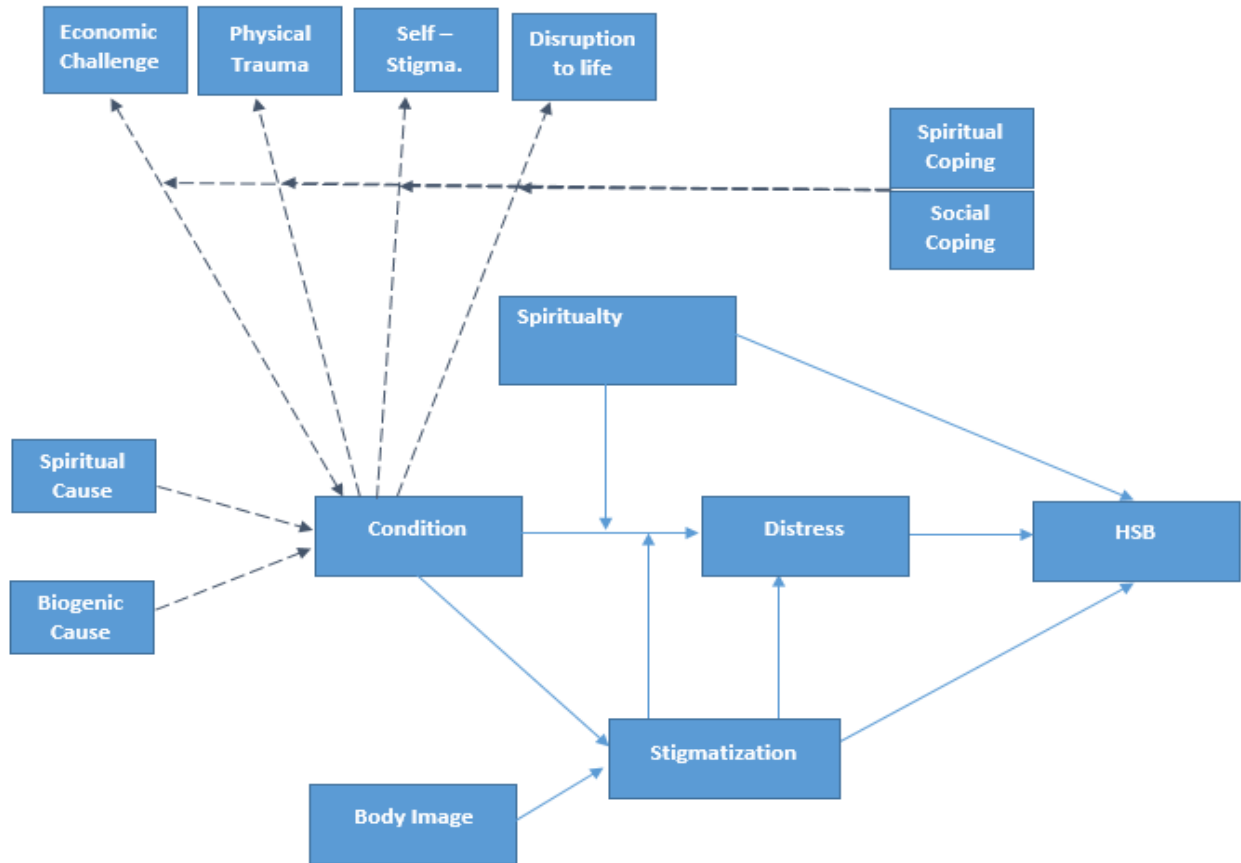
Additionally, in study two, perceptions of body image and stigmatization were among the factors that affected the level of psychological distress among patients.

Pain and discomfort associated with the OFT was cited as one of the most challenging issues patients have to contend with since it affects their speech, eating, normal daily functions and presents with extreme psychological problems.

Financial challenges in the form of transportation costs, costs of drugs, medical examinations and accommodation negatively affected patients' psychological distress and health-seeking behaviour.

The study also demonstrated that positive social support also helped participants cope with the psychological distress. Coping strategies mainly used by participants include hope, prayer positive thoughts and supports from family friends and others in the community. Thus

spirituality plays very important roles in the patients' experience of psychological distress and health-seeking and features at all levels of the disease and how patients relate to the disease.



**Figure 13: Revised Hypothesized Model of Health-seeking behaviour, Spirituality and Psychological distress**

A conceptual model evaluating health-seeking behaviour among patients in relations to spirituality, health belief, stigmatization and body image perception. Based on the results of the analyses from the study, a revised model of health-seeking behaviour in relations with other spiritual and psycho-cultural determinants was developed. The model presents the effects of the

disease on patients as extracted mainly from their responses in the qualitative study two and quantitative study one.

The effects include: physical trauma, economic challenges, self-stigmatization and disruption to life among the patients. The model in Figure 13, also demonstrates that patients identified spiritual and biogenic sources as the major causes of the disease. Stigmatization predicted the disease and led to health-seeking behaviour, whereas the type of condition also affected their levels of psychological distress.

In addition, spiritual coping and social support are two of the key strategies used in coping with the disease. Further, spirituality both moderated the level of the disease and also predicted health-seeking behaviour among patients. The main difference in this model and that of the original conceptual framework in Figure 3 is that health belief did not directly influence the disease and was thus removed from the model. The model has been updated significantly too.

For the patients with OFT and dental problems, the type of condition which each patient experiences predicts the level of psychological distress and health-seeking behaviour. From the model, the type of condition whether malignant, benign or general dental illness relates directly to the level of psychological distress of patients. In the study, the various sub-symptom domains of the Brief symptoms inventory the scale used for measuring psychological distress predicted the condition with depression and anxiety recording the highest scores. This shows that based on the severity or the perception of risks associated with the condition that leads to the experience of psychological distress among patients.

Perceptions of psychological distress and associated discomforts caused by the disease lead to a particular type of health-seeking behaviour. In this case patients who perceive that they were vulnerable to the disease and appraise the threat to be imminent engaged in positive health-

seeking behaviour but those who perceive the disease as not posing enough threat to them may not take action to seek healthcare or engage in negative healthcare. Stigmatization also affects Psychological distress directly as well as mediating the effects of the condition on psychological distress and health-seeking behaviour. The effect of stigmatization as explained in the model is in line with that when patients feel highly stigmatized they may experience psychological distress which can also lead to both negative and positive health-seeking behaviour.

The issue of stigmatization is closely related to body image perceptions. From the model, body image perception leads to stigmatization and consequently psychological distress and health-seeking behaviour.

Spirituality affects the Health-seeking behaviour directly (McSherry, 2006). Thus the level of spirituality of the patients leads to whether he or she seeks healthcare and what type of healthcare is what the model depicts. From the model, spirituality also moderates the relationship between the condition and the level of psychological distress of patients. Spirituality can therefore serve as positive or negative source of moderation on the type of condition of patients.

Stigmatization also plays a moderating role in terms of the effect of the condition on the level of psychological distress of patients. Perception of stigmatization is a very strong influence on how patients see themselves after the disease and this is associated with their body image and appearance. The moderating role of stigmatization is thus crucial in how patients react and deal with the condition.

## **5.5 Discussion and relatedness of findings to the Theoretical Framework and Conclusion**

The study investigated health-seeking behaviour and the level of psychological distress among patients with orofacial tumours. The roles of spirituality, health belief, stigmatizations

and body image perception were examined in the study to ascertain their influences on health-seeking and psychological distress among patients with OFT and dental conditions. The study adopted a number of theoretical frameworks to throw more lights on and explain major variables in the study. Three theories were selected and used in the study because of their international acceptance. The selected theories included: the health belief model, The 3 H dimensions of spirituality model and the biographical disruption model. The three theories were used to explain and draw linkages among the various factors that determine health-seeking behaviour among patients. The relationships among variables such as spirituality, health belief and stigmatization were also explained using the theories.

The theories much as they were used to explain various factors related to the study, they have some limitations. The key among them is the cultural variation between the societies where they were standardized and Africa (White, 2013). White (2013) complained that the conceptualization of God, disease, medicine and healing are different from the Western world so theories from the Western societies may not be most appropriate for explaining concepts of health and related issues among Africans.

In this study, the appraisal and perceptions of patients in relations to diseases in particular OFT and how that influence their health-seeking behaviour have been explained taking into consideration African concepts of spirituality, health belief, perceptions of stigmatization and body image. The conceptualization of etiology of the disease and how they view the vulnerability of such a disease and their experience of psychological distress and health-seeking behaviour were also investigated in the study.

The 3 H dimensions of spirituality model used in this study presents much insight into spirituality among patients looking at religious and transcendental issues in relations to the

patient's environment. This gives a broader interpretation and understanding of the spiritual factors that patients consider in health-seeking decisions.

The biographical model also delves into how patients view the sudden changes brought into their lives due to the disease and how to adjust to the situation and cope with the disease. In study one patients with OFT and general dental conditions were administered with different sets of questionnaires to examine their health-seeking behaviour and level of psychological distress. Their spirituality, health belief, perceptions of stigmatization and body image were also elicited with another sets of questionnaires. A subset of the sample was also recruited for study two which was the qualitative phase of the study. A one-on-one in-depth interview was used to collect information to confirm and validate the findings from study one and explain the phenomenon under study.

## **5.6 Originality and Contribution of the Study**

This study presents certain peculiar uniqueness and makes it original in terms of contribution to the field of Clinical Psychology, health and psycho-cultural issues in healthcare as well as research literature and methodology.

Firstly, the contribution of current study is in the introduction of spirituality, health belief and other psycho-cultural variables to investigate health-seeking behaviour among patients with OFT and general dental diseases. To the knowledge of the researcher, there is currently no research conducted on the relationship between these psychological variables in understanding health-seeking behaviour. Majority of studies carried out in the field were retrospective and on the epidemiology of the disease and doctors continue to ponder over the reasons for late reporting to the health facilities with advanced conditions.

Secondly, creating the link between maxillofacial condition and psychological factors makes the study a novelty. In most cases, medical conditions are generally treated on the basis of biomedical model of regimen and psychological factors are not considered very high in addressing such diseases. The introduction of psychological variables into investigating purely maxillofacial diseases provides a good opportunity to better understand certain conducts of patients in relations to health-seeking at such referral facilities. It will also create different levels of awareness and appreciation of integrating psychological methods into a holistic medical care for patients.

### **5.7 Methodological Contribution**

The study employed the explanatory sequential mixed methods design, comprising quantitative followed by qualitative study. Mixed methods approach was used to objectively investigate the health-seeking experiences of patients and also qualitatively delve deeper into the experiences from the perspectives of patients. In addition, the design incorporated a case control approach to compare the experiences of general dental patients to that of patients with OFT so as to come out with a valid conclusion. The qualitative phase of the study provided opportunity for the use of in-depth one-on-one interviews and observations to thoroughly investigate the phenomenon under study.

Also, the confirmatory factor analyses revealed that some of the items on the instruments used for data collections needed to be re-worded to reflect the understanding and cultural background of patients. This was done in order to reflect the Ghanaian context and elicit much more credible responses from respondents. This was a good contribution to methodological

aspects of the study. It also reflects the fact that eliciting African world view has always been problematic due to the differences in the instruments used in measuring the various constructs.

Additionally, the focus on key psycho-cultural constructs including health belief, spirituality in determining health-seeking behaviour among patients introduces another dimension into the study of maxillofacial conditions. Such studies often look at the trend, prevalence and other areas of interest to the medical specialists without consideration to the psychological issues that affect such patients.

The introduction of spirituality into the study and its influence on health-seeking behaviour reveal that Africans and for that matter patients in the study used spiritual coping strategies to alleviate the psychological distress that they experience. Spirituality in the African context is markedly different from that of the Western society and the impact is equally different. This special role of spirituality among Africans was strongly brought to the fore in the study emphasizing the role of spirituality in predicting both health-seeking behaviour and also coping with psychological distress thus indicating strong coping strategy (Belgrave & Allison, 2006; Koenig, 2010; White, 2013).

## **5.8 Implications for Health Service Delivery**

The results of the analyses from the study have illustrated some key determinants of health-seeking among patients. These important factors hold valuable lessons and experience to be integrated into providing a very effective and reliable healthcare in the country. The study reveals the importance of understanding the psycho-cultural background of patients in order to know how to deal with them. The knowledge about the psycho-cultural background of patients helps especially in dealing with their health-seeking behaviour. Many studies have shown that

the delay in reporting to the health facilities as lamented by Clegg-Lampsey et al (2009) is one of the most challenging issues for effective and successful treatment for many of the cancerous diseases including OFT. As the medical team understands the psychological and cultural issues at play they can design treatment programmes that ensure that the interest of the patients is taken on board and the issues of absconding from the hospitals to other places for treatment may end or be minimized.

Another important finding from the study that can aid the delivery of a more practical and result oriented health service is the level of spirituality exhibited by patients in the study. Spirituality was found to have significantly predicted health-seeking behaviour and psychological distress among patients. Patients' spirituality was identified by Belgrave et al (2010) and White (2013) as one of the basis on which they appraise diseases and also decide on the choice of healthcare. It is thus very crucial to understand the spiritual inclination of patients in dealing with their health challenges in order to accurately diagnose and map out treatment protocols for successful treatments. The coping mechanisms used by patients also are highly influenced by their religious and spiritual orientations.

When patients use their spirituality in employing positive coping strategies the results have been found to be very helpful in alleviating diseases. However, if they use spirituality in the negative sense and therefore apply it negatively in coping with distressing situations it yields poor outcomes (Princhard, 2009). This revelation even makes it much more important that healthcare providers including doctors, clinical psychologists, social welfare workers and other allied staff appreciate the need to incorporate spirituality in all healthcare services and at all levels of treatment.

It is recommended that support service providers such as health and social care professionals are brought on board from the start of the service so that they can provide appropriate care at the right time. This is very important because it was reported that in instances where other healthcare personnel were on hand to provide spiritual support to patients, it was found to be a useful means of coping with their diseases (Simon et al, 2007).

From the study it has been emphasized by Baddoo et al (2008), that the OFT may be from the remnants of the development of teeth and their supporting and surrounding tissues. Parkins, et al (2008), also explained that tumours and tumour-like conditions in many cases may start as a swelling but could lead to enlargement of the jaws and facial region and causes significant disfigurement and severe pain. This revelation from experts in the field of oral and maxillofacial surgery makes it an urgent call on policy makers and healthcare providers in the field to put in place an effective educational programme for the public for early detection and diagnoses. This recommendation is very timely judging from the fact that majority of patients in the study indicated that they were ignorant about the cause of the disease. The issue of ignorance also seems to have played a significant role in patients' appraisal and perception of the threat posed by the disease and subsequent health-seeking behaviour. If patients were well informed about the threat and risk of the disease, they may act with dispatch in seeking healthcare.

The study has also demonstrated the extent to which psychological distress affects patients with OFT at virtually all levels of treatment. Orofacial tumour poses challenges for the patients on two fronts; as both a disease and also the adverse effects of treatment. In many of such instances patients have to contend with psychological and physical side effects of treatment. Some of the physical and psychological symptoms include dysphagia (difficulty swallowing) and

disfigurement. In addition, anxiety and depression are commonly associated with such treatment (Devlin & Sherman, 2003).

Treatment of advanced malignant OFT, also poses a different level of challenges. Such treatments have evolved to encompass organ preservation protocols which include concurrent chemo radiation therapy (Devlin et al., 2005). Hanna et al (2004) revealed that because of the delicate nature of cases the main objective of the treatment is to help the treated organs to function better and also be preserved in order to reduce the incidence of morbidity associated with surgery and postoperative radiation.

Hanna et al., (2004) lamented that despite the fact that such therapies and care help create disease free-intervals between surgery and recovery for patients organ-preserving treatments still pose severe side effects. In this regards, even though patients have survival rates of 5 years and are living meaningful lives, the disease and its side effects present them with a lot of physical and psychological challenges (Jemal et al., 2008). In many cases the psychological trauma the patient goes through is what even aggravates the situation and affects the recovery process. But Hanna et al., (2004).lament that in many health facilities provisions for effective psychological services are only at initial stages or none at all for patients. It is therefore recommended that psychological services are provided at all stages of the treatment of OFT and should be integrated into the regiments of a holistic health strategy for better results.

The findings from the study further highlighted the important roles of social support in moderating the level of psychological distress among patients. The results showed that this important roles come from spouses, children, family members and people in the community and

has been confirmed to aid patients' recovery from illnesses (Howren, Christensen, Karnell, & Funk 2013; Derje et al 2016). Howren et al (2013) indicate that social support in dealing with the effect of OFT on patients comes in different forms and stages for it to have full impact on the patients of OFT since each stage poses its own challenges.

Another important findings relating to the provision of social support is the effect of providing such services to a close relation on the caregiver. This is because according to Kim, et al (2006) the caregiving roles are likely to compete with other functions of the caregivers considering caregiver's limited psychological resources, leading to the caregiver feeling overburdened and stressed due to the new roles brought about by the disease. As a result, family caregivers encounter considerable levels of psychological and emotional distress as they are faced with the new and demanding responsibilities associated with taking care of their ill member (Braun et al 2007). It is therefore recommended that a more formalized approach is adopted for the provision of social support. In many jurisdictions, professional support service providers are on hand to render such services in order to take away the burden on family members many of whom are already saddled with financial and other challenges in caring for their loved ones. In addition, regular counselling services and training for the family care providers on how to go about their duties and handle their ill person also helps in reducing the psychological distress they experience. The professional caregivers also need to identify the various groups and individuals who are in the network of people providing such services to their family members so that they can collaborate and provide better services to patients.

Further, some of the barriers to health-seeking identified in the study included: financial challenges and inaccessibility of referral hospitals. Majority of patients especially in

the qualitative study two complained of lack of funds to go through all the medical examinations required of them for accurate diagnoses and purchase of medications and other expenditures. Others have to travel long distances to the few referral facilities mainly in Accra and Kumasi to access healthcare. It is thus recommended that if National Health Insurance service can absorb treatment of OFT as one of the conditions so that patients can benefit from its services. This can also eliminate delays in reporting to the health facilities for early treatment. Provision and equipping of one referral hospital in each region to provide care for OFT in terms of surgery and other services would help save many lives in the country and also alleviate the suffering of many patients with OFT.

## **5.9 Directions for Future Research**

The study has covered a number of important issues relating to health-seeking among patients with emphasis on spirituality, health beliefs, stigmatization and body image perception. There are still some important areas that future studies should be directed at including investigating similar constructs among patients with OFT from the Northern sector of the country. Even though some of the participants in this study come from Northern regions of Ghana, it would be more useful and revealing if a study that covers that geographical part of the country is carried out.

An investigation into the psychological states of family and other members who provide social support would also be very timely since it has been revealed from this study that those social support providers experience high levels of psychological distress (Braun et al 2007). A study in that direction should adequately bring out what the caregivers go through and also provide means to improve their well-being.

In addition, a study into the quality of life of patients with OFT will be very appropriate. This is due to the fact that as literature confirmed the challenges of the condition span a long period and even beyond surgery. The survival of a patient after a surgery does not end his or her misery but a lot of psychological and physical challenges in terms of dealing with disfigurement and recurrence problems pose a great deal of issues worth studying.

Spirituality and health belief are some of the core psychological constructs that influence health-seeking and other related health matters. There is the need for assessment tools that can be considered more culture friendly to the Ghanaian context. Modifications of some of the models such as the health belief and spirituality models to include more local cultural friendly features will further enhance reliability of information elicited from Ghanaian and for that matter African participant.

### **5.10 Limitations of the Study**

The study has many strengths that provide a platform for it to contribute to the body of knowledge and research. However, there are a number of limitations that need to be outlined for consideration in future studies. The study was limited to only the referral hospitals in Accra. This is due the time and financial constraints. Though apart from Kumasi all the other referral hospitals are in Accra the addition of those from the northern parts of the country would have enriched the data collected and the findings of the study. But the personal information of patients shows that they spread across the length and breadth of the country.

The participants in both studies one and two were selected using purposive sampling method. In this regard, they might not present the entirety of information on spirituality, health beliefs and psychological symptoms that could be representative of the general population of

patients with OFT. In the light of this limitation, just as majority of studies especially clinical that investigated similar variables among patients, it may have issues of generalization but it presents a very reliable basis for further studies looking at its limitations.

In addition, there may be some level of sampling bias in the selection of patients. Since the patients sampling was confined to three referral hospitals in Accra some of the patients who perhaps did not have transportation and could not make it to Accra may not be captured in the study. It is mostly those who have the ability to afford the cost of healthcare who often report to the referral centres in Accra hence some of the patients may be out of the sample. In such a situation, the sample might not be the true representation of patients with OFT in the general populace in Ghana.

### **5.11 Implications of the Study**

The roles of spirituality, health belief, perceptions of stigmatization and body image have been investigated in line with health-seeking behaviour among patients with OFT and general dentals conditions. The level of psychological distress of patients was also assessed in the study. The findings of the study would provide a good platform of knowledge about the roles of spirituality and other variables in health-seeking behaviour among patients. Introduction of psychological variables into the field dominated by epidemiological studies, would also be a valuable contributions in the healthcare in the country.

Also, the study of live experience of the patients with OFT provides a novelty which will guide in understanding their experiences from their own perspectives. This is a major addition to what retrospective studies have provided over the years.

In addition, the crucial roles of spirituality in both predicting health-seeking and moderating the effects of the disease on the psychological distress of patients have been a major revelation. The result shows that if spirituality is handled very carefully and scientifically, it can be very helpful in enhancing health delivery. Identifying when to apply spirituality in a positive manner and incorporating it effectively would help patients stay on course with their orthodox treatments and also augment that with their spiritual supports. Equally integrating it professionally can help as a major coping mechanism for patients in reducing their distress levels.

### **5.12 Summary and Conclusion of the Study**

There has been a paucity of research into psychological variables such as spirituality and health-seeking behaviour among patients with orofacial tumours. Though studies have shown that patients with orofacial tumours experience high degrees of psychological distress, studies have not been targeted at understanding that phenomenon. In the face of increasing cases of orofacial tumours this study examined the health-seeking behaviour and the level of psychological distress among patients. The explanatory ability of the study into spirituality and health beliefs of patients as they appraise, perceive and react to the disease over its course provides a useful guide about the disease and how to chat appropriate intervention measures. This understanding provides a greater leverage for healthcare providers including doctors, clinical psychologists, nurses and social workers to deliver quality and much more reliable service to patients.

The level of psychological distress and health-seeking behaviour were assessed among patients with orofacial tumours (OFT) using explanatory sequential mixed methods. A sample of

143 patients aged between 18 and 83 years with orofacial tumours were purposively selected from the Oral and Maxillofacial Units of the Korle-Bu Teaching hospital and the Ridge and the 37 Military hospitals in Accra. The control group has a sample of 129 persons with general periodontal diseases making up a sample of 272 for study one. A subsample of 20 patients with orofacial tumour interviewees was also recruited for the qualitative study<sup>2</sup>. Study one was a cross-sectional quantitative study with data collected via self-administered structured questionnaires. Study two was a qualitative study with data collected through in-depth interviews. The data collection instruments which were administered to participants, examined psychological distress, spirituality, health beliefs, health-seeking behaviour, perceptions of stigmatization and body image. The results of Study one using regression analyses indicated that there was significant differences among patients with OFT and general dental conditions. The result also showed that perceptions of body image and stigmatization predicted psychological distress among patients with OFT. Additionally, perception of stigmatisation was found to be one of the most significant predictors of health-seeking behaviour. The results showed a significant positive relationship between perception of stigmatisation and health-seeking behaviour. The mediation analyses were done with the process procedures for SPSS (2.12.3) by Hayes (2013) and the results indicated that stigmatisation had a full mediation effect on body image perception and health-seeking behaviour. Further, stigmatization and spirituality moderated the effect of the condition on psychological distress of patients.

The results from study 2 showed a number of themes in participants' spirituality, health beliefs and perceptions of body image and stigmatization that are consistent with prominent descriptions of African culture. Patients with OFT felt that the condition has brought significant levels of psychological distress and disruption to their daily lives. Body image perception was a

major concern to them and the disfigurement caused to their appearance as a result of the OFT. Spirituality emerged as one of the key themes on coping, most patients believed in the power of healing through supernatural means and through prayer. This study generates knowledge about the relations among health-seeking behaviour, spirituality, health beliefs and psychological distress among patients with OFT in Ghana. The study suggests that extensive education on health-seeking behaviour among patients would help with early diagnoses and prognoses of the disease.

In conclusion, health-seeking behaviour is influenced by many factors including spirituality, health belief, perceptions of stigmatization and body image. The concern of health experts that patients with orofacial tumours report late to health facilities are highly influenced by their health-seeking behaviour. As emphasized by Afolabi et al (2014) that patients consider a lot of factors in arriving at a particular health-seeking act. Spirituality, stigmatization and body image have come out strongly as the key determinants of health-seeking and also predicted psychological distress among patients.

Any meaningful policies and measures to tackle the challenges of late reporting of patients should start with these key determinants. The understanding of the manner in which patients appraise and deal with OFT is the springboard on which to address the problem of late reporting and other negative health-seeking behaviour in order to provide the best of care to ensure high rate of success in the care of OFT patients.

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# APPENDICES

## Appendix A: Departmental Introductory Letter



### UNIVERSITY OF GHANA DEPARTMENT OF PSYCHOLOGY

Tel.: (233-0302) 500381 Ext. 3754/3310 P. O. Box LG 84, Legon - Ghana E-mail: psychology@ug.edu.gh  
028 955 04 63

Our Ref. No. ....

PSYC 2/33/01

January 19, 2016

The Administrator  
Ethics Committee for Humanities  
Institute of Statistical, Social and Economic Research (ISSER)  
University of Ghana  
Legon

Dear Sir/Madam,

#### **LETTER OF INTRODUCTION** **ALFRED DICKSON DAI-KOSI – ID NUMBER 10097644**

The above-named is a PhD student in the Department of Psychology, University of Ghana, Legon.

As part of the requirement, Alfred Dickson Dai-Kosi has to write and submit an original thesis. The title of his thesis is **“Psychological distress and health-seeking behaviour among orofacial tumor patients: Exploring the roles of spirituality, health belief and stigmatization”**. He is planning to conduct his study at Oral and Maxillofacial Departments, Korle-Bu Teaching Hospital, Ridge and 37 Military Hospitals.

He is applying to your Board for institutional approval/clearance to enable him carry on with his thesis. He has received approval from our department. Your assistance in reviewing his proposal is appreciated.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'C.C. Mate-Kole'.

Prof. C.C. Mate-Kole  
(Head of Department)

## Appendix B: Ethical Submission Form

UNIVERSITY OF GHANA



Official Use only  
Protocol number

OFFICE OF RESEARCH, INNOVATION AND DEVELOPMENT

**Ethics Committee for Humanities (ECH)**

### NEW PROTOCOL SUBMISSION FORM

#### Requirements:

- i. A new protocol must be submitted to the ECH at least five weeks before the proposed commencement date of the research.
- ii. All sections of the form must be completed before protocol can be considered for review.
- iii. 11 hard copies of proposal must be submitted to the ECH in addition to other documentations as spelt out in the SOP. A soft copy of proposal and other documentations should also be emailed to [ech@isser.edu.gh](mailto:ech@isser.edu.gh) / [ech@ug.edu.gh](mailto:ech@ug.edu.gh)

#### Section A – Background Information

1. Project Title: Psychological distress and health-seeking behaviour among orofacial tumour patients: Examining the roles of spirituality, health belief and stigmatization

2. Proposed Date of Commencement: 22<sup>nd</sup> February, 2016

3. Principal Investigator (Name, Title, Qualifications, Postal Address, Institution/Department, Phone number, Email address)

4. Co-Investigator(s) (Name; Title; Qualifications; Postal Address; Institution/Department; Phone number; Email address)

**Section B – Project Information**

5. Student Investigator(s) (Name; Title; Qualifications; Postal Address; Institution/Department; Phone number; Email address; Supervisors name, Title and Contact)  
Mr. Dai-Kosi Alfred Dickson, PhD candidate, [daikosi@yahoo.com](mailto:daikosi@yahoo.com), Department of Psychology, University of Ghana, Prof. Charity Akotia-The Dean of Social Sciences, UG.

1. Proposed Project Duration - From: (dd/mm/yy) 02/02/16\_\_\_\_\_ To:(31/05/17)\_\_\_\_\_

2. Collaborating Institution (if applicable)

3. Funding Status of Project?

Funding pending

Funded

Not funded

Other

4. Source of funding (Name and Address)  
Self sponsorship

5. Research Location(s)  
Oral and Maxillofacial department, Korle-Bu, 37 Military and Ridge hospitals

6. Data Collection Instruments (ie. Interview, questionnaire, observation et cetera)  
Interview and questionnaire

7. Consent Process (Circle all that applies):

- (i) Written
- (ii) Oral
- (iii) English language
- (iv) Local language
- (v) Other

9. Work Plan (Attach Work Plan)

**Section C – Ethical Survey**

1. Will the study involve participants who are particularly vulnerable or unable to give informed consent? (eg people under the age of 18, people with learning disabilities, students you teach or assess, etc.)

Yes  No

If Yes, state the category of persons?

2. Will it be necessary for participants to take part in the study without their knowledge and consent at the time?

Yes  No

If Yes, state why?

3. Will the study involve any audio or visual recording of people in public places?

Yes  No

If Yes, State which type? Audio recorder

4. Will the study involve the discussion of sensitive topics? (e.g. sexual activity, illegal drug use, illegal activities, death, whistleblowing)

Yes  No

If Yes, state the topic type?

5. Will the study involve invasive, intrusive or potentially harmful procedures of any kind?

Yes  No

If Yes, State procedures?

6. Is physical pain or psychological stress from the proposed project likely to cause harm or negative consequences beyond the risks in normal life?

Yes  No

If Yes, State how? Some of them may experience sadness and worries that would need psychological attention. I will provide them first aid and refer them to the official clinical psychologists in the hospitals concerned for further psychological therapy.

7. Will financial inducements (other than expenses) be offered to any of the participants?

Yes  No

**Section D – Signature**

Name of person completing the form:

Dai-Kosi Alfred Dickson \_\_\_\_\_

Role on the study:

Student Investigator \_\_\_\_\_

Signature: \_\_\_\_\_



For all student projects:

For Thesis Supervisor(s)

I the undersigned supervisor have read through the proposal thoroughly (Scientific Review of the proposal) and reviewed the research instrument(s).

\_\_\_\_\_  
Super visors Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Supervisors Signature

\_\_\_\_\_  
Date

**Note:**

As the **Principal Investigator/Student Investigator** on this project, my signature confirms that:

- (i) I will ensure that all procedures performed under the study will be conducted in accordance with UG – wide policy statement on ethical conduct of research involving human subjects as well as the Standard Operating Procedure of ECH.
- (ii) I understand that if there is any change from the project as originally approved, I must submit an amendment to the ECH for review and approval prior to its implementation. Where I fail to do so, the amended aspect of the study is invalid.
- (iii) I understand that I will report all serious adverse events associated with the study within seven days verbally and fourteen days in writing.
- (iv) I understand that I will submit progress reports each year for review and renewal. Where I fail to do so, the ECH is mandated to terminate the study upon expiry.
- (v) I agree that I will submit a final report to the ECH at the end of the study.

## Appendix C: Informed Consent Form and Ethical Approval Letter



UNIVERSITY OF GHANA



Official Use only  
Protocol number

**Ethics Committee for Humanities (ECH)**

PROTOCOL CONSENTFORM

Section A- BACKGROUND INFORMATION

Title of Study:	<b>Psychological distress and Health-seeking behaviour among orofacial tumour patients: Exploring the roles of spirituality, health belief and stigmatization.</b>
Principal Investigator:	DAI-KOSI ALFRED DICKSON
Assigned Protocol number	

Section B-CONSENT TO PARTICIPATE IN RESEARCH

### General Information about Research

The purpose of this study is to investigate whether spirituality, stigmatization and health beliefs of orofacial tumour (OFT) patients influence their health-seeking behaviour. The study also aims to find out the psychological effects of orofacial tumours on the patients. Three health facilities including: the oral and maxillofacial departments of the University of Ghana Dental hospital/oral surgery of the Korle-Bu teaching hospital, 37 Military hospital and Ridge hospital have been sampled for the study. This sequential exploratory mixed method design will be adopted for the study. The data collection will involve the use of one-on-one interviews and completion of quantitative questionnaire by patients. The completion of the questionnaire is expected to take between 40 minutes to 1 hour, while the interview will take between 30 and 40 minutes to complete.



**UNIVERSITY OF GHANA**  
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

*P. O. Box LG 74, Legon, Accra, Ghana*

My Ref. No.....

17<sup>th</sup> March, 2016

Mr. Alfred Dickson Dai-Kosi  
Department of Psychology  
University of Ghana  
Legon

Dear Mr. Dai-Kosi,

**ECH 078/15-16: PSYCHOLOGICAL DISTRESS AND HEALTH-SEEKING BEHAVIOUR AMONG OROFACIAL TUMOUR PATIENTS: EXPLORING THE ROLES OF SPIRITUALITY, HEALTH BELIEF AND STIGMATIZATION**

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

Expiry Date: 8/03/17  
On Agenda for: Initial Submission  
Date of Submission: 18/02/16  
ECH Action: Approved  
Reporting: Bi-Annually



Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y. Mante

CC: Prof. C. C Mate- Kole, Department of Psychology

## Appendix D: Letter of introduction to the health facilities used in the study



### UNIVERSITY OF GHANA DEPARTMENT OF PSYCHOLOGY

Tel.: (233-0302) 500381 Ext. 3754/3310 P. O. Box LG 84, Legon - Ghana E-mail: psychology@ug.edu.gh  
028 955 04 63

Our Ref. No.....  
PSYC 2/33/01

March 31, 2016

The Director  
Oral and Maxillofacial Depts.  
37 Military Hospital  
Accra

Dear Sir/Madam,

#### **LETTER OF INTRODUCTION** **MR. ALFRED DICKSON DAI-KOSI**

The above-named is a PhD student at the Department of Psychology, University of Ghana, Legon.

In partial fulfillment of the requirement for the awards of the PhD degree, **Mr. Alfred Dickson Dai-Kosi** has to write and submit an original thesis.

He has selected the topic: **“Psychological Distress and Health-Seeking Behaviour among Orofacial Tumour Patients: Exploring the Roles of Spirituality, Health Belief and Stigmatization”**.

To enable him collect data for his work, he would need to administer questionnaires and conduct interviews. He has selected your hospital as suitable for his data collection.

Your assistance is appreciated.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'C.C. Mate-Kole'.

Prof. C.C. Mate-Kole  
(Head of Department)



**UNIVERSITY OF GHANA**  
**DEPARTMENT OF PSYCHOLOGY**

Tel.: (233-0302) 500381 Ext. 3754/3310 P. O. Box LG 84, Legon - Ghana E-mail: psychology@ug.edu.gh  
028 955 04 63

Our Ref. No.....

March 31, 2016

PSYC 2/33/01

The Head  
Oral and Maxillofacial Depts.  
Ridge Hospital  
Accra

Dear Sir/Madam,

**LETTER OF INTRODUCTION**  
**MR. ALFRED DICKSON DAI-KOSI**

The above-named is a PhD student at the Department of Psychology, University of Ghana, Legon.

In partial fulfillment of the requirement for the awards of the PhD degree, **Mr. Alfred Dickson Dai-Kosi** has to write and submit an original thesis.

He has selected the topic: **“Psychological Distress and Health-Seeking Behaviour among Orofacial Tumour Patients: Exploring the Roles of Spirituality, Health Belief and Stigmatization”**.

To enable him collect data for his work, he would need to administer questionnaires and conduct interviews. He has selected your hospital as suitable for his data collection.

Your assistance is appreciated.

Yours sincerely,

Prof. C.C. Mate-Kole  
**(Head of Department)**



**UNIVERSITY OF GHANA**  
**DEPARTMENT OF PSYCHOLOGY**

Tel.: (233-0302) 500381 Ext. 3754/3310 P. O. Box LG 84, Legon - Ghana E-mail: psychology@ug.edu.gh  
028 955 04 63

Our Ref. No.....

PSYC 2/33/01

March 31, 2016

The Head  
Oral and Maxillofacial Depts.  
Korle-Bu

Dear Sir/Madam,

**LETTER OF INTRODUCTION**  
**MR. ALFRED DICKSON DAI-KOSI**

The above-named is a PhD student at the Department of Psychology, University of Ghana, Legon.

In partial fulfillment of the requirement for the awards of the PhD degree, **Mr. Alfred Dickson Dai-Kosi** has to write and submit an original thesis.

He has selected the topic: **“Psychological Distress and Health-Seeking Behaviour among Orofacial Tumour Patients: Exploring the Roles of Spirituality, Health Belief and Stigmatization”**.

To enable him collect data for his work, he would need to administer questionnaires and conduct interviews. He has selected your hospital as suitable for his data collection.

Your assistance is appreciated.

Yours sincerely,

Prof. C.C. Mate-Kole  
**(Head of Department)**



10. Do you take in alcoholic drinks? Yes..... No.....

If Yes, how long? .....

These following questions are about your personal health

11. Do you have any other chronic disease condition such as diabetes? Yes....No.....

If Yes, Please specify.....

12. Are you on medication for any other condition? Yes ..... No.....

If Yes, Please indicate the type of medicines .....

13. How old were you when the disease was first detected? .....

14. Length of time since diagnosis. .... Months/ Year(s)

**Questions about your current health condition (OFT)**

15. How much are you aware of your current health condition?

Very much [ ] much [ ] little [ ] very little [ ]

16. Were you informed of the stage of your tumour by the health care givers at the time of diagnosis? Yes ...No...

If your response is Yes, please indicate the stage:

[ ] Stage I [ ] Stage II [ ] Stage III

17. What is the current stage of your tumour?

[ ] Stage I [ ] Stage II [ ] Stage III

18. Have you been informed about the type of tumour? Yes.... No.....

If Yes, which type were you told? .....

19. Are you on chemotherapy for your illness? Yes..... No.....

If Yes, how long? .....

20. Have you been scheduled for surgical treatment? Yes..... No.....
21. Is this your first time of being diagnosed with OFT? Yes..... No.....
22. Have you been diagnosed with any other cancer? Yes..... No.....

If Yes, how many? .....

List them .....

23. Has anyone in your immediate family (mother, father, siblings, child) been diagnosed with OFT? Yes..... No.....

24. If Yes, kindly state the number and relation(s) to you. ....

### SECTION B:-Helath-belief Scale

These are questions that ask about your health belief in relations to your health-seeking behaviour.

Please rate your level of agreement or disagreement with each of the following statements on a 5-piont scale with a tick against each of the option.

**1** = Strongly disagree    **2** = Disagree    **3** = Neither disagree/agree    **4** = Agree    **5** = Strongly agree

	<b>Statements</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	OFT is a serious disease					
2	Living with OFT is very scary					
3	Medical procedure for testing is very painful					
4	OFT is a chronic disease					
5	OFT is caused by God to punish us from our sins					
6	It is very likely that I will develop infections					
7	It is very likely my children are at risk for OFT					
8	It is very likely to be at risk due to generational curses					
9	It is very likely to be at risk because of my clan					
10	It is very likely to be at risk due to my sex (Male or Female)					
11	Complying with routine medication is a good way of reducing frequent crises					
12	Attending or visiting a doctor for regular reviews is a good way of preventing future crises					
13	The use of herbs (traditional medicine) is a good way of reducing symptoms and crises					
14	Visiting the shrine for guidance is a good way of curing OFT					
15	Attending Church regularly and praying is a good way of curing OFT					
16	It is difficult to get information about OFT from health professionals					
17	It is difficult to get adequate finances for transport					
18	It is difficult to obtain finances for medication					
19	It is difficult to find a good herbalist for treatment					
20	It is difficult to find a shrine for treatment					

### SECTION C:-Spirituality Well-being Scale

**These questions seek information about how your relationship with God any supernatural power impacts your health and well being.**

Please circle a choice that best describes how much you agree with each statement. Circle only one answer for each statement. There is no correct or wrong answer.

6=Strongly Agree; 5=Moderately Agree; 4=Agree; 3=Disagree; 2=Moderately Disagree; 1=Strongly Disagree

		<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
1	I don't find much satisfaction in private prayer with God.	SA	MA	A	D	MD	SD
2	I don't know who I am, where I come from or where I am going	SA	MA	A	D	MD	SD
3	I believe that God loves me and cares about me.	SA	MA	A	D	MD	SD
4	I feel that life is a positive experience	SA	MA	A	D	MD	SD
5	I believe that God is impersonal and not interested in my daily situations.	SA	MA	A	D	MD	SD
6	I feel unsettled/unsure about my future.	SA	MA	A	D	MD	SD
7	I have a meaningful relationship with God.	SA	MA	A	D	MD	SD
8	I feel very fulfilled and satisfied with life	SA	MA	A	D	MD	SD
9	I don't get much personal strength and support from my God	SA	MA	A	D	MD	SD
10	I feel a sense of well-being about the direction of my life.	SA	MA	A	D	MD	SD
11	I believe that God is concerned about my problems.	SA	MA	A	D	MD	SD
12	I don't enjoy much about life	SA	MA	A	D	MD	SD
13	I don't have a satisfying relationship with God.	SA	MA	A	D	MD	SD
14	I feel good about my future	SA	MA	A	D	MD	SD
15	My relationship with God helps me not to feel lonely.	SA	MA	A	D	MD	SD
16	I feel that life is full of conflict and unhappiness.	SA	MA	A	D	MD	SD
17	I feel most fulfilled when I'm in close communion with God.	SA	MA	A	D	MD	SD
18	Life doesn't have much meaning for me	SA	MA	A	D	MD	SD
19	My relation with God contributes to my sense of well-being.	SA	MA	A	D	MD	SD
20	I believe there is some real purpose for my life.	SA	MA	A	D	MD	SD

### SECTION D: Stigmatization Scale

**The following are questions on your thoughts about how people see and react to you due to your condition.**

Please rate your level of agreement with each of the following statements on a 5-point scale with a tick under the rating figures.

**1** = Strongly disagree    **2** = Disagree    **3** = Neither disagree/agree    **4** = Agree    **5** = Strongly agree

	<b>Statements</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	I have been denied admission to schools because of my OFT					
2	Sometimes I feel that I am being negatively discussed because of my OFT					
3	Having had OFT has made me a more understanding person					
4	I do not feel bad about having had OFT					
5	I worry about telling people I receive treatment for OFT					
6	Some people with OFT problems are dangerous					
7	People have been understanding of my OFT problems					
8	I have been discriminated against by police because of my OFT					
9	I have been refused employment opportunities by employers because of my OFT					
10	My OFT problems have made me more accepting of other people					
11	Very often I feel alone because of my OFT					
12	I am scared of how other people will react if they find out about my OFT					
13	I would have had better chances in life if I had not had OFT					
14	I do not mind people in my neighbourhood knowing I have had OFT					
15	I would readily disclose that I have had OFT if I was applying for a job					
16	I worry about telling people that I take medicines/tablets for OFT					
17	People's reactions to my OFT make me keep to myself					
18	I am angry with the way people have reacted to my OFT condition					
19	I have not had any trouble from people because of my OFT					
20	I have been discriminated against by health professionals because of my OFT					
21	People have avoided me because of my OFT problems					
22	People have insulted me because of my OFT					
23	Having had OFT has made me a stronger person					
24	I do not feel embarrassed because of my OFT					
25	I avoid telling people about my OFT condition					
26	Having had OFT makes me feel that life is unfair					
27	I feel the need to hide my OFT from my friends					
28	I find it hard telling people I have OFT condition					

### SECTION E:-Health-Seeking behaviour

**These questions are concerned about your health-seeking behaviour.**

The first part of the questionnaire covers types of healthcare services available and your preferred services. The second half deals with barriers to healthcare services as you experience anytime you seek health care services listed against the options: (Every time=4; Very often=3; Often =2; Rarely=1 and Never=0). Kindly indicate your responses with a tick against the options for both services and barriers to health care

	<b>Types of Health care and perception about satisfaction of such services</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1	Hospitals superintendent by doctors					
2	Clinics not up to the standard of hospitals					
3	Pharmacy					
4	Chemical shops					
5	Medicine vendors					
6	Traditional practitioners					
7	Spiritual healers					
8	Prayer camps					
9	Others					
10	Cost of care is affordable					
11	Waiting time before attended to by a doctor is acceptable					
12	Lack of sufficient information on your condition					
13	Accessibility (distance) to the health facility is too far.					
14	Attitude of health workers is good enough.					
15	Medicine mostly out of stock					
16	Retrieval of medical records of individual patients takes too long					
17	Few doctors available for consultation leading to delays.					
18	Pharmacy services are slow and take a long time.					
19	Diagnostic laboratory services can take a long process virtually the whole day					
20	Nursing services available are inadequate delays					

### SECTION F-Body Image Perception Scale:

**These questions ask about changes that you have observed about yourself since the onset of the condition.**

Please rate each of the activities in the table which you might engage in because of the way you feel about your orofacial tumour. Rate each of the activity and frequency with which you carry it out with the options from: 0=Never, 1=occasionally, 2=Often, 3=Frequently to 4=Always

	<b>Behaviour</b>	<b>Frequency</b>
1	I check my facial features in the mirror	
2	I use a particular light to check my tumour in a mirror	
3	I check my tumour in other reflective surface e.g windows	
4	I check my face directly by looking at it without a mirror	
5	I check my face by taking photograph of myself	
6	I check my facial features by feeling it with my finger	
7	I compare my facial features with others in magazine, television and films	
8	I compare my facial features with other people I meet	
9	I compare my facial features with old pictures of myself	
10	I wear something to distract attention from my features e.g. jewellery, tattoo	
11	I change my posture to avoid my tumour being seen at a certain angle	
12	I hide my facial tumour with something for my hand, hat, scarf. Please specify	
13	I use padding in my clothes to camouflage or disguise my features	
14	I tried to convince others about how unattractive my face is	
15	I ask others to confirm the existence defect in my face	

## SECTION G: Brief Symptoms Inventory (BSI)

The following are questions on your how distressed or worried you have been over the past 7 days including today due to your condition.

Please rate how each of the symptoms applies to you on a 5-point scale. Blacken each of the corresponding figure below the rating figures: **0**= Not at all **1** = A little bit **2** = Moderately **3** = Quite a bit **4** = Extremely

	<b>HOW MUCH WERE YOU DISTRESSED BY:</b>	<b>NOT AT ALL</b>	<b>A LITTLE BIT</b>	<b>MODERATELY</b>	<b>QUITE A BIT</b>	<b>EXTREMELY</b>
1	Nervousness or shakiness inside	0	1	2	3	4
2	Faintness or dizziness	0	1	2	3	4
3	The idea that someone else can control your thoughts	0	1	2	3	4
4	Feeling others are to blame for most of your troubles	0	1	2	3	4
5	Trouble remembering things	0	1	2	3	4
6	Feeling easily annoyed or irritated	0	1	2	3	4
7	Pains in heart or chest	0	1	2	3	4
8	Feeling afraid in open space or in the streets	0	1	2	3	4
9	Thoughts of ending your life	0	1	2	3	4
10	Feeling that most people cannot be trusted	0	1	2	3	4
11	Poor appetite	0	1	2	3	4
12	Suddenly scared for no reason	0	1	2	3	4
13	Temper outbursts that you could not control	0	1	2	3	4
14	Feeling lonely even when you are with people	0	1	2	3	4
15	Feeling blocked in getting things done	0	1	2	3	4
16	Feeling lonely	0	1	2	3	4
17	Feeling very down	0	1	2	3	4
18	Feeling no interest in things	0	1	2	3	4
19	Feeling fearful	0	1	2	3	4
20	Your feeling being easily hurt	0	1	2	3	4
21	Feeling that people are unfriendly or dislike you	0	1	2	3	4
22	Feeling inferior to others	0	1	2	3	4
23	Nausea or upset stomach	0	1	2	3	4
24	Feeling that you are watched or talked about by others	0	1	2	3	4
25	Trouble falling asleep	0	1	2	3	4
26	Having to check and double check what you do	0	1	2	3	4
27	Difficulty making decision	0	1	2	3	4
28	Feeling afraid to travel on buses, trotros, or trains	0	1	2	3	4
29	Trouble getting your breath	0	1	2	3	4
30	Hot or cold spells	0	1	2	3	4
31	Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4

32	Your mind going blank	0	1	2	3	4
33	Numbness or tingling in parts of your body	0	1	2	3	4
34	The idea that you should be punished for your sins	0	1	2	3	4
35	Feeling hopeless about the future	0	1	2	3	4
36	Trouble concentrating	0	1	2	3	4
37	Feeling weak in parts of your body	0	1	2	3	4
38	Feeling worried or tensed up	0	1	2	3	4
39	Thoughts of death or dying	0	1	2	3	4
40	Having urges to beat, injure, or harm someone	0	1	2	3	4
41	Having urges to break or smash things	0	1	2	3	4
42	Feeling very self-conscious with others	0	1	2	3	4
43	Feeling uneasy in crowds, such as shopping or at a movie	0	1	2	3	4
44	Never feeling close to another person	0	1	2	3	4
45	Spells of terror or panic	0	1	2	3	4
46	Getting into frequent arguments	0	1	2	3	4
47	Feeling nervous when you are left alone	0	1	2	3	4
48	Others not giving you credit for your achievements	0	1	2	3	4
49	Feeling so restless you couldn't sit still	0	1	2	3	4
50	Feeling worthlessness	0	1	2	3	4
51	Feeling that people will take advantage of you if you let them	0	1	2	3	4
52	Feeling of guilt	0	1	2	3	4
53	The idea that something is wrong with your mind	0	1	2	3	4

## **SECTION H: Interview guide**

I would like to ask you a few questions concerning how you feel and perceive your disease. The information provided is for data analysis and academic purposes only. Your responses will in no way be used to identify you as an individual and you are assured of complete confidentiality. Your frank responses will help very much and there is no correct or wrong answers provided it depends on what you think. I will now like to seek your permission to ask you about your health.

1. Could you please tell me how you felt when you were told you had tumour?
2. What do you consider to be responsible for your illness?
3. What are your concerns about your illness?
4. Tell me, what kind of treatment was recommended by your doctor?
5. What keeps you going day after day since the diagnosis of your illness?
6. Could you discuss with me how much the tumour has affected your spiritual life?
7. What has been the impact of the condition on your work and social life since it started?
8. What will you say about the impact of social support on your current state?
9. In what ways has your belief in God helped you in coping with the illness? Probe.
10. How much has the condition changed your appearance and relations with others?
11. What roles do you consider that you can play in order to help the recovery process?
12. Is there anything else that you think I should know about your experiences with the tumour?

**Appendix F: Demographic Information and Questionnaires for patients with Dental Condition.**

Please fill in or indicate your choice by a tick for the appropriate response for each question.

I would like to ask you a few personal questions

1. What is your age? .....years
2. Gender  Male  Female
3. Please indicate your highest level of education with a tick against it.  
 PhD  Masters Degree  First Degree  H.N.D  
 Diploma  SHS  JHS  
 Others (Please specify).....
4. Marital status  Single  Married/cohabiting  Widowed  Previously married
5. Do you have children? Yes..... No.....

If your response is Yes, to question 4, how many? .....

6. Do you have other people who take care of you at home? Yes..... No.....

If your response is Yes, kindly state the number and relation to you .....

7. What is your occupation?  
 artisan  Trader  Farmer/fisherman  Student  
 Unemployed  Others (please specify) .....

8. Please indicate your monthly salary range  
 GHS 100 to 500  GHS 501 to 1000  GHS 1000 to 1500  
 GHS 1500+

The following questions seek information about your personal habit.

9. Do you smoke? Yes..... No.....

If Yes, how long? .....

10. Do you take in alcoholic drinks? Yes..... No.....

If Yes, how long? .....

These following questions are about your personal health

11. Do you have any chronic disease condition such as diabetes? Yes....No.....

If Yes, Please specify.....

12. Are you on medication for any other condition? Yes ..... No.....

If Yes, Please indicate the type of medicines .....

Questions about your current health condition

13. How much are you aware of your current health condition?

Very much [ ] much [ ] little [ ] very little [ ]

14. Were you informed of the type of dental condition you have by the health care givers at the time of diagnosis? Yes ...No...

If your response is Yes, please indicate the type of condition:

[ ] periodontal [ ] restoration [ ] orthodontic [ ] extraction [ ] other

15. Have you been scheduled for surgical treatment? Yes..... No.....

16. Have you been diagnosed with any other dental problem? Yes..... No.....

If Yes, how many? .....

List them .....

17. Has anyone in your immediate family (mother, father, siblings, child) been diagnosed with the same dental condition? Yes..... No.....

18. If Yes, kindly state the number and relation(s) to you. ....

### SECTION B:- Health Belief Scale

These are questions that ask about your health belief in relations to your health-seeking behaviour.

Please rate your level of agreement or disagreement with each of the following statements on a 5-point scale with a tick against each of the option.

**1** = Strongly disagree    **2** = Disagree    **3** = Neither disagree/agree    **4** = Agree    **5** = Strongly agree

	<b>Statements</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	Dental sickness is a serious disease					
2	Living with dental sickness is scary					
3	Medical procedure for testing is very painful					
4	Dental conditions are considered as chronic diseases					
5	Dental conditions are caused by God to punish us from our sins					
6	It is very likely that I will develop infections					
7	It is very likely my children are at risk for such a condition					
8	It is very likely to be at risk due to generational curses					
9	It is very likely to be at risk because of my clan					
10	It is very likely to be at risk due to my sex (Male or Female)					
11	Complying with routine medication is a good way of reducing frequent crises					
12	Attending or visiting a doctor for regular reviews is a good way of preventing future crises					
13	The use of herbs (traditional medicine) is a good way of reducing symptoms and crises					
14	Visiting the shrine for guidance is a good way of curing such conditions					
15	Attending Church regularly and praying is a good way of curing my disease					
16	It is difficult to get information about my condition from health professionals					
17	It is difficult to get adequate finances for transport					
18	It is difficult to obtain finances for medication					
19	It is difficult to find a good herbalist for treatment					
20	It is difficult to find a shrine for treatment					

### SECTION C: Spirituality Well-being Scale

**These questions seek information about how your relationship with God or any supernatural power impacts your health and well being.**

Please circle a choice that best describes how much you agree with each statement. Circle only one answer for each statement. There is no correct or wrong answer.

6=Strongly Agree; 5=Moderately Agree; 4=Agree; 3=Disagree; 2=Moderately Disagree; 1=Strongly Disagree

		<b>6</b>	<b>5</b>	<b>4</b>	<b>3</b>	<b>2</b>	<b>1</b>
1	I don't find much satisfaction in private prayer with God.	SA	MA	A	D	MD	SD
2	I don't know who I am, where I come from or where I am going	SA	MA	A	D	MD	SD
3	I believe that God loves me and cares about me.	SA	MA	A	D	MD	SD
4	I feel that life is a positive experience	SA	MA	A	D	MD	SD
5	I believe that God is impersonal and not interested in my daily situations.	SA	MA	A	D	MD	SD
6	I feel unsettled/unsure about my future.	SA	MA	A	D	MD	SD
7	I have a meaningful relationship with God.	SA	MA	A	D	MD	SD
8	I feel very fulfilled and satisfied with life	SA	MA	A	D	MD	SD
9	I don't get much personal strength and support from my God	SA	MA	A	D	MD	SD
10	I feel a sense of well-being about the direction of my life.	SA	MA	A	D	MD	SD
11	I believe that God is concerned about my problems.	SA	MA	A	D	MD	SD
12	I don't enjoy much about life	SA	MA	A	D	MD	SD
13	I don't have a satisfying relationship with God.	SA	MA	A	D	MD	SD
14	I feel good about my future	SA	MA	A	D	MD	SD
15	My relationship with God helps me not to feel lonely.	SA	MA	A	D	MD	SD
16	I feel that life is full of conflict and unhappiness.	SA	MA	A	D	MD	SD
17	I feel most fulfilled when I'm in close communion with God.	SA	MA	A	D	MD	SD
18	Life doesn't have much meaning for me	SA	MA	A	D	MD	SD
19	My relation with God contributes to my sense of well-being.	SA	MA	A	D	MD	SD
20	I believe there is some real purpose for my life.	SA	MA	A	D	MD	SD

### SECTION D:-Stigmatization Scale

**The following are questions on your thoughts about how people see and react to you due to your condition.**

Please rate your level of agreement with each of the following statements on a 5-point scale with a tick under the rating figures.

**1** = Strongly disagree    **2** = Disagree    **3** = Neither disagree/agree    **4** = Agree    **5** = Strongly agree

	<b>Statements</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	I have been denied admission to schools because of my dental condition					
2	Sometimes I feel that I am being negatively discussed because of my dental condition					
3	Having had this dental problem has made me a more understanding person					
4	I do not feel bad about having had a dental problem					
5	I worry about telling people I receive treatment for a particular dental problem					
6	Some people with sicknesses problems are dangerous					
7	People have been understanding of my dental problems					
8	I have been discriminated against by police because of my dental condition					
9	I have been refused employment opportunities by employers because of my dental condition					
10	My dental problems have made me more accepting of other people					
11	Very often I feel alone because of my dental condition					
12	I am scared of how other people will react if they find out about my dental condition					
13	I would have had better chances in life if I had not had this dental condition					
14	I do not mind people in my neighbourhood knowing I have had a dental sickness					
15	I would readily disclose that I have had a dental problem if I was applying for a job					
16	I worry about telling people that I take medicines/tablets for my condition					
17	People's reactions to my dental condition make me keep to myself					
18	I am angry with the way people have reacted to my dental condition					
19	I have not had any trouble from people because of my dental condition					
20	I have been discriminated against by health professionals because of my dental condition					
21	People have avoided me because of my dental problems					
22	People have insulted me because of my dental condition					
23	Having had such a dental sickness has made me a stronger person					
24	I do not feel embarrassed because of my dental condition					
25	I avoid telling people about my dental condition					
26	Having had dental sickness makes me feel that life is unfair					
27	I feel the need to hide my dental sickness from my friends					
28	I find it hard telling people I have a dental problem.					

### SECTION E:-Health-Seeking.

**These questions are concerned about your health-seeking behaviour.**

The first part of the questionnaire covers types of healthcare services available and your preferred services. The second half deals with barriers to healthcare services as you experience anytime you seek health care services listed against the options: (Every time=4; Very often=3; Often =2; Rarely=1 and Never=0). Kindly indicate your responses with a tick against the options for both services and barriers to health care

	<b>Types of Health care and perception about satisfaction of such services</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>
1	Hospitals superintendent by doctors					
2	Clinics not up to the standard of hospitals					
3	Pharmacy					
4	Chemical shops					
5	Medicine vendors					
6	Traditional practitioners					
7	Spiritual healers					
8	Prayer camps					
9	Others					
10	Cost of care is affordable					
11	Waiting time before attended to by a doctor is acceptable					
12	Lack of sufficient information on your condition					
13	Accessibility (distance) to the health facility is too far.					
14	Attitude of health workers is good enough.					
15	Medicine mostly out of stock					
16	Retrieval of medical records of individual patients takes too long					
17	Few doctors available for consultation leading to delays.					
18	Pharmacy services are slow and take a long time.					
19	Diagnostic laboratory services can take a long process virtually the whole day					
20	Nursing services available are inadequate delays					

## SECTION F: Body Image Perception Scale

**These questions ask about changes that you have observed about yourself since the onset of the condition.**

Please rate each of the activities in the table which you might engage in because of the way you feel about your orofacial tumour. Rate each of the activity and frequency with which you carry it out with the options from: 0=Never, 1=occasionally, 2=Often, 3=Frequently to 4=Always

	<b>Behaviour</b>	<b>Frequency</b>
1	I check my facial features in the mirror	
2	I use a particular light to check my face in a mirror	
3	I check my face and mouth in other reflective surface e.g windows	
4	I check my face directly by looking at it without a mirror	
5	I check my face by taking photograph of myself	
6	I check my facial features by feeling it with my finger	
7	I compare my facial features with others in magazine, television and films	
8	I compare my facial features with other people I meet	
9	I compare my facial features with old pictures of myself	
10	I wear something to distract attention from my features e.g. jewelry, tattoo	
11	I change my posture to avoid people noticing any change on my face by turning at a certain angle	
12	I hide my facial features with something such as my hand, hat, and scarf. Please specify	
13	I use pudding in my clothes to camouflage or disguise my features	
14	I tried to convince others about how unattractive my face is	
15	I ask others to confirm the existence defect in my face	

## SECTION G: Brief Symptoms Inventory (BSI)

The following are questions on your how distressed or worried you have been over the past 7 days including today due to your condition.

Please rate how each of the symptoms applies to you on a 5-point scale. Blacken each of the corresponding figure below the rating figures: **0**= Not at all **1** = A little bit **2** = Moderately **3** = Quite a bit **4** = Extremely

	HOW MUCH WERE YOU DISTRESSED BY:	NOT AT ALL	A LITTLE BIT	MODERATELY	QUITE A BIT	EXTREMELY
1	Nervousness or shakiness inside	0	1	2	3	4
2	Faintness or dizziness	0	1	2	3	4
3	The idea that someone else can control your thoughts	0	1	2	3	4
4	Feeling others are to blame for most of your troubles	0	1	2	3	4
5	Trouble remembering things	0	1	2	3	4
6	Feeling easily annoyed or irritated	0	1	2	3	4
7	Pains in heart or chest	0	1	2	3	4
8	Feeling afraid in open space or in the streets	0	1	2	3	4
9	Thoughts of ending your life	0	1	2	3	4
10	Feeling that most people cannot be trusted	0	1	2	3	4
11	Poor appetite	0	1	2	3	4
12	Suddenly scared for no reason	0	1	2	3	4
13	Temper outbursts that you could not control	0	1	2	3	4
14	Feeling lonely even when you are with people	0	1	2	3	4
15	Feeling blocked in getting things done	0	1	2	3	4
16	Feeling lonely	0	1	2	3	4
17	Feeling very down	0	1	2	3	4
18	Feeling no interest in things	0	1	2	3	4
19	Feeling fearful	0	1	2	3	4
20	Your feeling being easily hurt	0	1	2	3	4
21	Feeling that people are unfriendly or dislike you	0	1	2	3	4
22	Feeling inferior to others	0	1	2	3	4
23	Nausea or upset stomach	0	1	2	3	4
24	Feeling that you are watched or talked about by others	0	1	2	3	4
25	Trouble falling asleep	0	1	2	3	4
26	Having to check and double check what you do	0	1	2	3	4
27	Difficulty making decision	0	1	2	3	4
28	Feeling afraid to travel on buses, trotros, or trains	0	1	2	3	4
29	Trouble getting your breath	0	1	2	3	4
30	Hot or cold spells	0	1	2	3	4
31	Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4

32	Your mind going blank	0	1	2	3	4
33	Numbness or tingling in parts of your body	0	1	2	3	4
34	The idea that you should be punished for your sins	0	1	2	3	4
35	Feeling hopeless about the future	0	1	2	3	4
36	Trouble concentrating	0	1	2	3	4
37	Feeling weak in parts of your body	0	1	2	3	4
38	Feeling worried or tensed up	0	1	2	3	4
39	Thoughts of death or dying	0	1	2	3	4
40	Having urges to beat, injure, or harm someone	0	1	2	3	4
41	Having urges to break or smash things	0	1	2	3	4
42	Feeling very self-conscious with others	0	1	2	3	4
43	Feeling uneasy in crowds, such as shopping or at a movie	0	1	2	3	4
44	Never feeling close to another person	0	1	2	3	4
45	Spells of terror or panic	0	1	2	3	4
46	Getting into frequent arguments	0	1	2	3	4
47	Feeling nervous when you are left alone	0	1	2	3	4
48	Others not giving you credit for your achievements	0	1	2	3	4
49	Feeling so restless you couldn't sit still	0	1	2	3	4
50	Feeling worthlessness	0	1	2	3	4
51	Feeling that people will take advantage of you if you let them	0	1	2	3	4
52	Feeling of guilt	0	1	2	3	4
53	The idea that something is wrong with your mind	0	1	2	3	4

## Appendix G: Mediation Analysis

Stg mediating effect of body image on Bsi. It was significant Partial  
Run MATRIX procedure:

\*\*\*\*\* PROCESS Procedure for SPSS Release 2.16.3 \*\*\*\*\*

Written by Andrew F. Hayes, Ph.D. www.afhayes.com  
Documentation available in Hayes (2013). www.guilford.com/p/hayes3

\*\*\*\*\*

Model = 4  
Y = BSI  
X = bODi  
M = Stg

Sample size  
272

\*\*\*\*\*

Outcome: Stg

Model Summary

R	R-sq	MSE	F	df1	df2	p
.5374	.2888	205.4103	109.6376	1.0000	270.0000	.0000

Model

coeff	se	t	p	LLCI	ULCI
constant	60.3808	1.6817	35.9053	.0000	57.0699 63.6916
bODi	.6561	.0627	10.4708	.0000	.5327 .7794

\*\*\*\*\*

Outcome: BSI

Model Summary

R	R-sq	MSE	F	df1	df2	p
.7335	.5380	1581.0968	156.6075	2.0000	269.0000	.0000

Model

coeff	se	t	p	LLCI	ULCI
constant	-66.2479	11.2118	-5.9088	.0000	-88.3220 -44.1739
Stg	1.6286	.1688	9.6454	.0000	1.2961 1.9610
bODi	1.5110	.2061	7.3304	.0000	1.1052 1.9168

\*\*\*\*\* TOTAL EFFECT MODEL \*\*\*\*\*

Outcome: BSI

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6150	.3782	2120.0335	164.2094	1.0000	270.0000	.0000

Model

coeff	se	t	p	LLCI	ULCI
constant	32.0859	5.4026	5.9390	.0000	21.4494 42.7225
bODi	2.5795	.2013	12.8144	.0000	2.1832 2.9758

\*\*\*\*\* TOTAL, DIRECT, AND INDIRECT EFFECTS \*\*\*\*\*

Total effect of X on Y						
	Effect	SE	t	p	LLCI	ULCI
	2.5795	.2013	12.8144	.0000	2.1832	2.9758

Direct effect of X on Y						
	Effect	SE	t	p	LLCI	ULCI
	1.5110	.2061	7.3304	.0000	1.1052	1.9168

Indirect effect of X on Y						
	Effect	Boot SE	BootLLCI	BootULCI		
Stg	1.0684	.1215	.8459	1.3212		

Partially standardized indirect effect of X on Y						
	Effect	Boot SE	BootLLCI	BootULCI		
Stg	.0183	.0018	.0149	.0221		

Completely standardized indirect effect of X on Y						
	Effect	Boot SE	BootLLCI	BootULCI		
Stg	.2547	.0283	.2020	.3122		

Ratio of indirect to total effect of X on Y						
	Effect	Boot SE	BootLLCI	BootULCI		
Stg	.4142	.0538	.3179	.5259		

Ratio of indirect to direct effect of X on Y						
	Effect	Boot SE	BootLLCI	BootULCI		
Stg	.7071	.1682	.4660	1.1092		

R-squared mediation effect size (R-sq_med)						
	Effect	Boot SE	BootLLCI	BootULCI		
Stg	.2859	.0410	.2062	.3671		

\*\*\*\*\* ANALYSIS NOTES AND WARNINGS \*\*\*\*\*

Number of bootstrap samples for bias corrected bootstrap confidence intervals:  
5000

Level of confidence for all confidence intervals in output:  
95.00

NOTE: Kappa-squared is disabled from output as of version 2.16.

----- END MATRIX -----

**bSI mediating the effect of stigmatization on HSP. There was mediation**  
Partial mediation

Run MATRIX procedure:

Written by Andrew F. Hayes, Ph.D. [www.afhayes.com](http://www.afhayes.com)  
 Documentation available in Hayes (2013). [www.guilford.com/p/hayes3](http://www.guilford.com/p/hayes3)

\*\*\*\*\*

Model = 4  
 Y = HSBP  
 X = Stg  
 M = BSI

Sample size  
 272

\*\*\*\*\*

Outcome: BSI

Model Summary

	R	R-sq	MSE	F	df1	df2	p
	.6676	.4457	1889.9063	217.0815	1.0000	270.0000	.0000

Model

coeff	se	t	p	LLCI	ULCI
constant	-81.7162	12.0389	-6.7877	.0000	-105.4182 -58.0142
Stg	2.2937	.1557	14.7337	.0000	1.9872 2.6002

\*\*\*\*\*

Outcome: HSBP

Model Summary

	R	R-sq	MSE	F	df1	df2	p
	.4225	.1785	67.3575	29.2239	2.0000	269.0000	.0000

Model

coeff	se	t	p	LLCI	ULCI
constant	36.4026	2.4591	14.8034	.0000	31.5612 41.2441
BSI	.0803	.0115	6.9895	.0000	.0577 .1029
Stg	-.0932	.0395	-2.3600	.0190	-.1709 -.0154

\*\*\*\*\* TOTAL EFFECT MODEL \*\*\*\*\*

Outcome: HSBP

Model Summary

	R	R-sq	MSE	F	df1	df2	p
	.1712	.0293	79.2956	8.1500	1.0000	270.0000	.0046

Model

coeff	se	t	p	LLCI	ULCI
constant	29.8405	2.4660	12.1008	.0000	24.9855 34.6955
Stg	.0910	.0319	2.8548	.0046	.0283 .1538

\*\*\*\*\* TOTAL, DIRECT, AND INDIRECT EFFECTS \*\*\*\*\*

Total effect of X on Y

Effect	SE	t	p	LLCI	ULCI
.0910	.0319	2.8548	.0046	.0283	.1538

Direct effect of X on Y						
	Effect	SE	t	p	LLCI	ULCI
	-.0932	.0395	-2.3600	.0190	-.1709	-.0154

Indirect effect of X on Y				
	Effect	Boot SE	BootLLCI	BootULCI
BSI	.1842	.0239	.1387	.2316

Partially standardized indirect effect of X on Y				
	Effect	Boot SE	BootLLCI	BootULCI
BSI	.0204	.0025	.0154	.0253

Completely standardized indirect effect of X on Y				
	Effect	Boot SE	BootLLCI	BootULCI
BSI	.3463	.0440	.2613	.4351

Ratio of indirect to total effect of X on Y				
	Effect	Boot SE	BootLLCI	BootULCI
BSI	2.0233	79.8198	1.1928	6.2000

Ratio of indirect to direct effect of X on Y				
	Effect	Boot SE	BootLLCI	BootULCI
BSI	-1.9772	12.9709	-5.8130	-1.1767

R-squared mediation effect size (R-sq_med)				
	Effect	Boot SE	BootLLCI	BootULCI
BSI	.0123	.0311	-.0472	.0736

\*\*\*\*\* ANALYSIS NOTES AND WARNINGS \*\*\*\*\*

Number of bootstrap samples for bias corrected bootstrap confidence intervals:  
5000

Level of confidence for all confidence intervals in output:  
95.00

NOTE: Kappa-squared is disabled from output as of version 2.16.

----- END MATRIX -----

**Stigmatization mediating the effect of Body on HSP-no mediation**

Run MATRIX procedure:

\*\*\*\*\* PROCESS Procedure for SPSS Release 2.16.3 \*\*\*\*\*

Written by Andrew F. Hayes, Ph.D. [www.afhayes.com](http://www.afhayes.com)  
 Documentation available in Hayes (2013). [www.guilford.com/p/hayes3](http://www.guilford.com/p/hayes3)

\*\*\*\*\*

Model = 4  
 Y = HSBP  
 X = bODi  
 M = Stg

Sample size  
 272

\*\*\*\*\*

Outcome: Stg

Model Summary

	R	R-sq	MSE	F	df1	df2	p
	.5374	.2888	205.4103	109.6376	1.0000	270.0000	.0000

Model

coeff	se	t	p	LLCI	ULCI	
constant	60.3808	1.6817	35.9053	.0000	57.0699	63.6916
bODi	.6561	.0627	10.4708	.0000	.5327	.7794

\*\*\*\*\*

Outcome: HSBP

Model Summary

	R	R-sq	MSE	F	df1	df2	p
	.2214	.0490	77.9732	6.9335	2.0000	269.0000	.0012

Model

coeff	se	t	p	LLCI	ULCI	
constant	30.9473	2.4898	12.4295	.0000	26.0453	35.8493
Stg	.0434	.0375	1.1586	.2477	-.0304	.1173
bODi	.1081	.0458	2.3620	.0189	.0180	.1982

\*\*\*\*\* TOTAL, DIRECT, AND INDIRECT EFFECTS \*\*\*\*\*

Total effect of X on Y

Effect	SE	t	p	LLCI	ULCI
.1366	.0386	3.5368	.0005	.0606	.2127

Direct effect of X on Y

Effect	SE	t	p	LLCI	ULCI
.1081	.0458	2.3620	.0189	.0180	.1982

Indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
Stg	.0285	.0258	-.0196	.0821

Partially standardized indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
Stg	.0032	.0028	-.0023	.0089

Completely standardized indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
Stg	.0439	.0395	-.0310	.1250

Ratio of indirect to total effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
Stg	.2086	.2658	-.1573	.7650

Ratio of indirect to direct effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
Stg	.2636	1519.0187	-.1503	2.6215

R-squared mediation effect size (R-sq\_med)

	Effect	Boot SE	BootLLCI	BootULCI
Stg	.0246	.0143	.0033	.0614