# VOICE DISORDERS AND PSYCHOSOCIAL IMPACT ON LARYNGEAL CANCER PATIENTS AND FAMILIES: CASE OF KENYATTA NATIONAL HOSPITAL, NAIROBI CITY COUNTY– KENYA.

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**E55/CE/26221/2014**

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**JUNE, 2021**

## DECLARATION

I declare that this thesis is my original work and has not been presented in any other institution for consideration of any certification. This thesis has been complemented by references duly acknowledged. Text, data, pictures and graphics which have been borrowed from other sources including the internet have been specifically accredited and references cited using current APA system and in accordance with anti-plagiarism regulations.

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## ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| **(C)RT** | Chemotherapy with Radiotherapy |
| **ENT** | Ear Nose and Throat |
| **EORTC** | European Organization for Research and Treatment of Cancer |
| **HNC** | Head and Neck Cancer |
| **HRQL** | Health Related Quality of Life |
| **HRQOL** | Health Related Quality of Life |
| **KNH** | Kenyatta National Hospital |
| **NACOSTI** | National Commission for Science, Technology and Innovation |
| **NCI** | National Cancer Institute |
| **PWCD** | People with Communication Disorders |
| **RT** | Radiotherapy |
| **SF-36** | Short Form 36 |
| **SLP** | Speech and Language Pathologist |
| **S-SECEL** | Swedish-Self Evaluation of Communication Experiences after |
| **TL** | Total Laryngectomy |
| **VHI** | Voice Handicap Index |
| **WHO** | World Health Organization |

## ABSTRACT

Voice disorders after treatment of laryngeal cancer are usually high ranging from dysphonia to alaryngeal voice. Presence of these disorders pose myriad challenges in communication contributing to the patients' emotional distress which can create psychological and social problems. This study sought to establish the psychological and social impact of the voice disorders on laryngeal cancer patients and families at the Ear, Nose and Throat clinic; Kenyatta National Hospital – Nairobi City County-Kenya. The objectives of this study were: to analyze the social impact of the voice disorders on the laryngeal cancer patients and families; to establish the psychological impact of the voice disorders on the laryngeal cancer patients and families; to find out coping behaviors developed by the laryngeal cancer patients and families in verbal communication at the ENT clinic of Kenyatta National Hospital. This study was anchored on Psychological Impact Theory and Social Impacts based on the estimation of the social and psychological consequences of an action on individual or specific social units. The research used a case study design adopting qualitative research methods. A sample size of thirty respondents including fifteen adult laryngeal cancer patients and fifteen family members/caregivers were purposively sampled from the ENT clinic of Kenyatta National Hospital, Nairobi City County- Kenya. Piloting was done at a facility with the same characteristics as KNH. Data was collected using interview schedules which were administered to the patients, observation checklists administered to both patients and family members and focus group discussions with family members/caregivers. The data was transcribed, organized, edited, coded and sorted for thematic analysis. Patterns across data sets consistent with the theoretical tradition of the study were pinpointed, examined and recorded to answer specific research questions. The key study findings were that the voice disorders led to limited social interactions among the patients and their families. The patients lost friends, had unusually quiet families, over-depended on family members to aid in verbal communication and had limited verbal engagements. The family members were not happy with the patients' condition as they struggled to communicate. Worry and fear among the patients as well as family members increased. There were reduced levels of confidence hence low self-esteem among the patients. Negative coping strategies were adopted by both patients and family members. In conclusion, voice disorders after laryngeal cancer treatment are a source of social limitations and psychological challenges thus the need for early intervention involving both patients and family members for effective results. The study recommends increased public awareness on voice disorders and availability of speech therapy services for effective rehabilitation for both patients and family members/caregivers after laryngeal cancer treatment.

# CHAPTER ONE

# INTRODUCTION

## 1.0 Introduction

This chapter entails background to the study, statement of the problem, purpose of the study, research objectives, research questions, significance of the study, assumptions of the study, limitations, delimitations, theoretical framework, conceptual framework and the operational definition of terms.

## 1.1 Background to the Study

Communication disorder is an impairment affecting the reception, sending, processing and even comprehending concepts (Howard, Abberton & Fourcin, 2012). The concepts can be presented verbally, non-verbally or in graphic symbol systems. This disorder can manifest in an individual's speech, language and/or hearing. Howard, Abberton and Fourcin (2012) define speech as the utterance of language verbally and consider it disordered when voice, articulation or fluency is affected. Voice disorders are inappropriate variance in quality, pitch and loudness contrary to the expectations in terms of gender, age, cultural background and geographical location (Aronson & Bless, 2009). Therefore, individuals suffering voice disorders may be troubled in the way their voices sound whereas their listeners may be troubled in understanding them. It is important to highlight the fact that voice is not just a tool for communication, but also a feature for identification that allows expression of personality (Starmer, Tippett &Webster, 2008) hence the presence of a voice disorder can affect an individual's personality and subject one to negative social impact.

World Health Organization and World Bank (2011) report on disability raised a genuine concern in available studies on communication disorders focusing more on the primary pathologies under-pinning voice disorders and focusing less on specific communication impairments. To confirm this, studies have focused on the impact of laryngeal cancer on patients and families (Offerman, Pruyn, Boer, Busschbach, & Jong, 2015) and the effect of laryngectomy on cancer patients (Bergstrom, Ward & Finizia, 2016). Many studies have not focused on the effect of the voice disorder as a result of laryngeal cancer treatment on the patient. Moreover, tools that have been developed in different cultural backgrounds predominantly minority world cultures and different social settings have been used to measure the impact of voice disorders on patients. Caution is therefore recommended in the process of importing these models for PWCD in majority world settings (WHO and World Bank, 2011). This study seeks to fill this gap by focusing on voice disorders and their psychosocial impact on laryngeal cancer patients and their families. In addition, this study does not use the standard tools available to measure the impact of voice disorders on laryngeal cancer patients and families/caregivers but uses qualitative methods of data collection to enable the researcher get rich in-depth knowledge of the patients' experiences,

Noonan and Hegarty (2010) carried out a study in Ireland- Europe sampling twelve laryngectomees. The study revealed that various patients face functional difficulties as measured by quality–of–life instruments. These functional difficulties include challenges in voice production and quality, eating, drinking, breathing and kissing (Deleyiannis, Weymuller, Coltrera, & Futran, 1999). The challenges thus cause significant changes in the psychological, social and emotional domains for the patient and family. Whereas Noonan and Hegarty (2010) have addressed general functional difficulties including challenges in voice production, this study narrows down and

seeks in-depth knowledge specifically on the voice disorders and their psychosocial impact on laryngeal cancer patients and their families.

Another study was done in Sweden by Bergstrom, Ward and Finizia (2016) involving one hundred and sixty three patients with Tis- T4 laryngeal cancer treated with (chemo) radiotherapy at Sahlgrenska University Hospital. They used Hospital Anxiety and Depression Scale and confirmed prevalence of distress after laryngeal cancer treatment specifically regarding voice rehabilitation after laryngeal cancer and the associated effects on psychological well-being of the patient. Bergstrom, Ward and Finizia (2016) based their findings on a quality of life instrument (Hospital Anxiety and Depression Scale) whereas this study bases its findings on qualitative data giving in-depth knowledge and reflection of patients' feelings.

Ma and Yiu (2001) conducted another study in China to analyze the effect voice disorders have on everyday activities. The study involved 40 respondents suffering partial voice loss (dysphonia) and 40 respondents with normal voices (control respondents). It was evident from this study that dysphonic patients significantly demonstrated serious limitations due to the voice problems in their daily activities. The study further proved that the dysphonic subjects' perception of a voice problem positively correlated with their perception of restricted participation and limitation in voice activities. It is therefore clear that patients suffering voice disorders risk social malfunctioning. Such individuals can have both serious psychological and physical complications due to inability to exercise, enjoy a family outing or participate in any social activity without restriction. Ma and Yiu (2001) used quantitative data collection methods whereas this study uses purely qualitative data collection methods.

In Nigeria, a study was carried out by Lam, Ayres and Sadhra (2014) on voice disorders among Nigerian primary school teachers. A total of 496 respondents were sampled and VHI tool administered to them. The study revealed that physical aspects of voice problems had the greatest impact on psychosocial functioning. It was noted that the voice symptoms had affected the respondents' ability to communicate. The study was a quantitative study using the VHI tool and administered to primary school teachers, this study is purely qualitative using qualitative data collection methods and administered to laryngeal cancer patients.

In East Africa, disability is still linked with stigma. Families with disabled members especially those with communication disorders face serious challenges socially. Some of these patients are hidden simply because neighbors will not tolerate them (Jochmann & Ossietzky, 2005). Most families consider communication disorders a curse hence unbearable reflection on them (Mwihaki, 2003). This state of affairs has been fueled by ignorance and a feeling of helplessness. It is therefore a fact that psychological and emotional stress result from presence of disabilities hence the need for more research in this area, a gap this study sought to fill.

In Kenya, laryngeal cancer is the third most common cancer at the Ear, Nose and Throat-Head and Neck Surgery Unit of the Kenyatta National Hospital (Obura, 2010) resulting in voice disorders after treatment. Alcohol ingestion and cigarette smoking have been identified as strong risk factors for development of not only late stage but also poor differentiation of laryngeal squamous cell carcinoma in Kenyan population (Menach, Patel & Oburra, 2014). Kenya Medical Research Institute (KEMRI) report 70% of Kenyan families as alcohol abusers with ages ranging between 15 to 65 years. In addition, 17% of men smoke tobacco with a worrying median age of first use as

low as 10years. This means a higher percentage of the active population is at risk of laryngeal cancer exposing them to organic voice disorders.

Although available data on voice disorders in Kenya is sparse, Mbogo (2017) acknowledges increase in the number of laryngectomees to a total of 60 by the year 2017. Combined with the steady rise in cancer cases as expressed by Pyeko and Ouma (2014) pointing to probable increase in laryngeal cancer cases, many patients continually struggle with voice disorders posing myriad social and psychological challenges that impact not only on them but their families as well.

Surprisingly, barely any study has been conducted not only in Kenya but the whole of East Africa hence the need for this study on voice disorders and their psychosocial impact on laryngeal cancer patients and their families at the ENT clinic of Kenyatta National Hospital-Nairobi, Kenya.

### 1.2 Statement of the Problem

A total number of 210,606 new cases of laryngeal cancer have been diagnosed in 2017 alone translating to 2.76 new cases per 100,000 inhabitants worldwide (Nocini R., Molteni G., Mattiuzzi C. & Lippi G. 2020). In Kenya, laryngeal cancer is the third most common cancer at the Ear, Nose and Throat-Head and Neck Surgery Unit of the Kenyatta National Hospital, (Obura, 2010). Alcohol ingestion and cigarette smoking have been identified as strong risk factors for development of not only late stage but also poor differentiation of laryngeal squamous cell carcinoma in Kenyan population (Menach, Patel & Oburra, 2014). It's reported that 70% of Kenyan families are alcohol abusers with ages ranging between 15 to 65 years. In addition, 17% of men smoke tobacco with a worrying median age of first use as low as 10years (KEMRI).

This means a higher percentage of the active population is at risk of laryngeal cancer exposing them to organic voice disorders.

Presence of these voice disorders contributes to the patients' emotional distress most likely creating psychological problems and personality effects. Emotional distress affects social interactions and poses challenges not only to the patient but also to family members who closely interact with the patient on a daily basis. Unfortunately, in Kenya, many people are seemingly ignorant of the impact of the voice disorders on the laryngeal cancer patients hence some get scared of them, laugh at them or make derogatory comments concerning their condition. In addition, family members may fail to give necessary support such patients need in the process of verbal communication. Such experiences may hamper the patients' social interactions and cause negative psychological effect.

In consideration of the great need for comprehensive understanding of the voice challenges impacting patients post laryngeal cancer treatment in Kenya, this study seeks to establish the psychological and social impact of voice disorders on these patients and their families as an essential guide to effective rehabilitation, optimizing patient psychological health and general function.

### 1. 3 Purpose of the Study

The purpose of this study was to establish the psychological and social impact of voice disorders on laryngeal cancer patients and their families at KNH (ENT clinic).

## 1.4 Objectives of the Study

The following objectives guided the study:

i. To determine the social impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic).
ii. To establish the psychological impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic).
iii. To find out coping behavior developed by the laryngeal cancer patients and their families in verbal communication at Kenyatta National Hospital (ENT clinic).

## 1.5 Research Questions

i. What is the social impact of the voice disorder on the laryngeal cancer patient and family interactions at Kenyatta National Hospital (ENT clinic)?
ii. What is the psychological impact of the voice disorder on the laryngeal cancer patient and family at Kenyatta National Hospital (ENT clinic)?
iii. What changes in behavior have been developed by laryngeal cancer patients and families to cope with the voice disorder at Kenyatta National Hospital (ENT clinic)?

## 1.6 Significance of the Study

The findings of this study on voice disorders and their psychosocial impact on laryngeal cancer patients and their families at Kenyatta National Hospital (ENT clinic) may:

- Benefit policy makers, speech therapists, psychologists, otolaryngologists, laryngeal cancer patients and their family members.
- Be a source of awareness to the general public on the impact of voice disorders hence need to avoid risk factors.
- Be an essential guide for optimal and effective rehabilitation.
- Contribute significant literature for scholarly work in this area of study for global comparison.

## 17 Limitations and Delimitations

### 1.7.1 Limitations

Limitations are aspects of a research that may influence the outcome over which the researcher has no influence over (Bogdan & Biklen, 2003). This study was limited by the fact that it cannot be generalized to include children since it sampled adult population. The researcher created awareness on the significance of the study and conducted individualized interviews and observations to minimize peer influence. The study was also limited by time due to the intensive nature of data collection and analysis processes.

### 1.8.2 Delimitations

According to Mugenda and Mugenda (2013), delimitations refer to boundaries the researcher has set for the study. This study was restricted to laryngeal cancer patients and therefore did not include other HNC patients. The study did not include laryngeal cancer patients with an earlier psychological diagnosis as these would influence the findings of the study.

### 1.9 Assumptions of the Study

The researcher assumed that the respondent answered the interview questions honestly and candidly.

### 1. 10 Theoretical and Conceptual Framework

#### 1.10.1 Theoretical Framework

This study was anchored on psychological impact theory and social impacts by Finsterbusch (1984). This theory mainly focuses on the estimation of the social and psychological consequences of an action on individual or specific social units. It functions on two strands: stress theory and life satisfaction theory.

**Stress theory** focuses on the environmental forces or events threatening an individual's well-being and how the individual responds. The threatening event is the stressor while the response is the coping behavior. If the stressor is not eliminated over a period of time, it can lead to development of physical and mental disorders. The threatening event in this study is the presence of a voice disorder and the myriad challenges it poses in verbal communication. This becomes the stressor. In the vent of using the disordered voice, the patient may develop negative coping behavior which over time may lead to the development of physical and mental disorders.

**Life satisfaction theory** on the other hand positively correlates an individual's well-being to happiness. Therefore, psychological well-being is highly correlated to the excess one has of positive against negative effect. Presence of a voice disorder increases negative effect on an individual hence reducing happiness. This in the long run has negative effect on the individual's life. Negative social impact has significant negative psychological impact as seen in strain and frustrations. Presence of a voice

disorder is likely to elicit negative social impact due to limitations and unprecedented reactions from listeners. This may subject the patient and family to strain in the process of communication. Unsuccessful attempts in communicating might lead to frustrations which may eventually lead to strain in family relationships.

### 1.10.2 Conceptual Framework

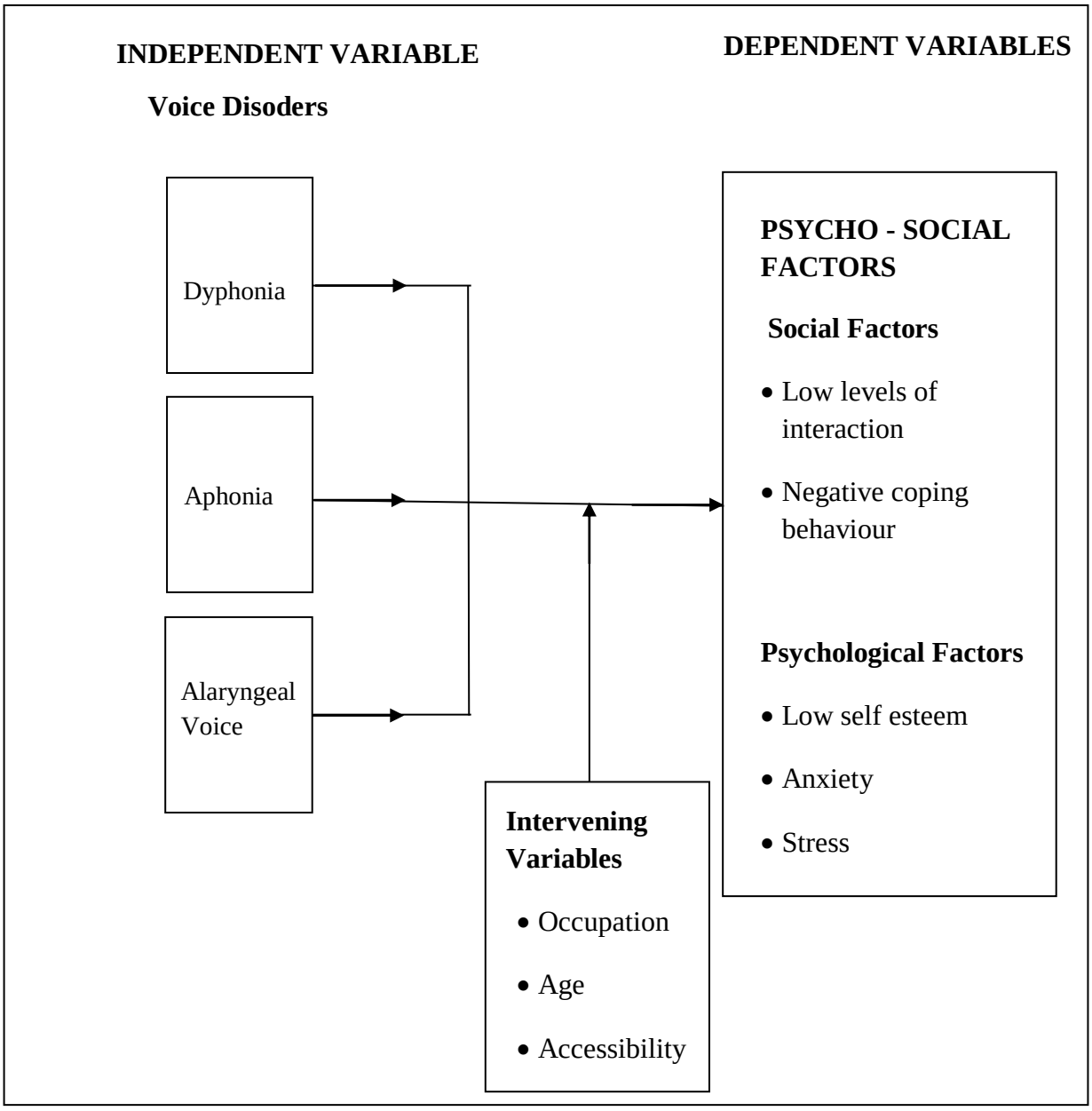


**Figure 1. 1: Conceptual Framework**

**Source: Researcher, 2018.**

The diagrammatic representation of conceptual framework above shows how the voice disorders affect a patient's social interactions and psychological state as influenced by age, occupation and accessibility of SLP services with the end result being negative psychological and social impact. The framework illustrates the relationships between the independent, dependent and intervening variables and their effects on the patient's day to day interactions with family. The independent variable which will be under focus is voice disorders while the dependent variables under focus are the social and psychological impact on patient and family. The intervening variables under focus will be the patient's age, occupation and accessibility of SLP services.

### 1.11 Operational Definition of Terms

**Adult** - The term means a person who is fully grown or developed but in this study it means a patient at 20 years of age and above.

**Aphonia** - It means inability to speak through disease damaging the larynx or mouth but in this study it means a condition where one experiences complete loss of voice.

**Disability** - This term means physical or mental condition that limits a person's movement, senses or activities but in this study, it means a permanent or temporary paralysis hampering normal operations.

**Dysphonia** - It means difficulty speaking due to a physical disorder of the mouth, tongue, throat or vocal cords but in this study, it refers to partial loss of voice commonly referred to as hoarse voice.

**Family** - This means a group consisting two parents and their children living together as a unit but in this study, it means the basic social unit involving blood relations with the patient and caregivers.

**Patient** - This means a person receiving or registered to receive medical treatment, but in this study, it refers to an individual who comes to the ENT clinic for health care services following an earlier diagnosis and treatment of laryngeal cancer.

**Peer** - This means a person of the same age, status or ability as another specified person but in this study, it implies other participants who are respondents in data collection.

**Psychosocial** - It refers to the interrelation of social factors and individual thought and behavior but in this study it refers to factors involving the state of mind (psychological) and those involving inter-personal relationships (social).

**Stressors** - It means something causing a state of strain or tension but in this study, it refers to factors/things that make one worried or anxious.

**Voice** - It refers to sound produced in the larynx and uttered through the mouth as speech but in this study, it implies reverberating quality of sound which is heard as one speaks.

**Voice disorder**- Refers to a problem with pitch, volume, tone and other qualities of voice but in this study, it refers to a distortion to the quality of voice affecting pitch, volume or resonance.

# CHAPTER TWO

# LITERATURE REVIEW

## 2.1 Introduction

Literature in this chapter is reviewed based on the study objectives from international to local perspectives. Basically, the review centers on, laryngeal cancer and voice production, social impact of voice disorders, psychological impact of voice disorders and effect on family/caregivers. The review also elaborated on the theoretical rationale upon which this study was based.

## 2.2 Laryngeal Cancer,Voice Production and Voice Disorders

According to WHO (2016), voice is classified as one of the major body functions hence any disease affecting its function can lead to disturbed function in daily life. Laryngeal cancer forms in the tissues of the larynx also known as the voice box**.** The larynx is divided into three major regions being: supraglottic, glottis and subglottic regions. The glottis contains the true vocal cords (NCI, 2017).

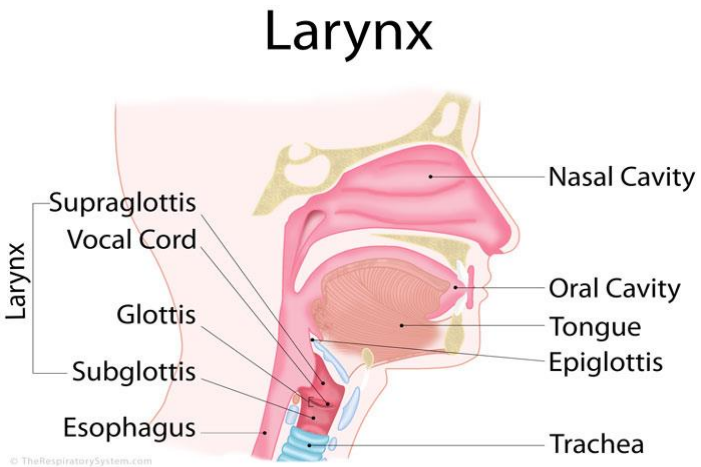


**Figure 2. 1: Anatomy of the Larynx**

**Source: (NCI, 2017)**

Various modes can be adopted in the treatment of laryngeal cancer as dictated by location of the tumor, stage of the disease, organ preservation measures and recurrence of the cancer (NCI, 2017). These models include: radiotherapy (RT), concomitant chemotherapy, surgery (laryngectomy) with adjuvant RT with or without chemotherapy.

According to National Cancer Institute (2017), laryngeal cancer which is a type of Head and Neck Cancer (HNC) forms in tissues of the larynx traditionally referred to as the voice box. This is the area of the throat containing the vocal cords and coordinates voice production, swallowing and breathing. Crowe (2013) confirms the fact that head and neck region supports many fundamental physiologic functions such as voice production among others hence presence of cancer in this area impact critical structures and functions. In addition, there is effect on patients' psychological, social and physical well-being by the severe limitations that various treatment options impact on the functions of the affected organs. One such impact is alteration in the function of vocal cords necessary for phonation and verbal speech due to (chemo) radiotherapy [(C) RT] (Bergstrom, Ward & Finizia, 2016) and laryngectomy as modes of treatment. Bergstrom, Ward and Finzia (2016) express the fact that although there is confirmed improvement in health related quality of life of patients following improved voice function post treatment, there is severe limitation on the number of studies specifically on the associated impact of voice disorders on the psychological well-being of patients post laryngeal cancer treatment. This study therefore seeks to fill this gap by focusing on voice disorders and their psychosocial impact on laryngeal cancer patients and their families.

## Voice Disorders

Voice means production of recognizable speech sounds through the coordination of the lungs (breathing for speech), larynx, vocal chords and the nasal passage (Ndung'u & Kinyua, 2009). According to ASHA (2004), the abnormal production of these speech sounds or absence of vocal quality, pitch, resonation, loudness and duration which is not suitable for an individual's age or sex indicates presence of a voice disorder. Aronson and Bless (2009) concur with this view by observing that an individual has a voice disorder when the quality, loudness and pitch of voice have a significant difference or are not appropriate for the gender, age, cultural background or geographical location.

According to Lee, Stemple, Glaze and Kelchner (2004), voice disorders can be classified as organic, functional or psychogenic. This study focused on organic voice disorders which are further divided into structural or neurogenic disorders (Satterfield, 2015). Focusing on laryngeal cancer patients narrows the scope further to structural voice disorders due to physical changes in the voice mechanism due to the various modes of treatment adopted to cure the laryngeal cancer hence impacting vocal fold function or results in total removal of the voice box referred to as total laryngectomy (TL). Development of a voice disorder is secondary to a primary pathology which may be medical as in the case of laryngeal cancer or a change in the structure of laryngeal anatomy. World Health Organization and World Bank (2011) have raised a genuine concern in available studies on communication disorders focusing more on the primary pathologies under-pinning voice disorders and focusing less on specific communication impairments hence a gap this study sought to fill as it focuses on the voice disorders as a consequence of laryngeal cancer treatment.

In addition, World Health Organization (2011) acknowledges the significance of communication as a human right and raises concern that the needs of people with communication disorders may not be met in low and middle-income countries due to varied limitations and barriers. Voice disorders after treatment of laryngeal cancer are usually high ranging from dysphonia to alaryngeal voice. According to Nocini R., Molteni G., Mattiuzzi C. and Lippi G. (2020), laryngeal cancers are listed as the 22nd in incidence of all cancers worldwide with 5.1 percent of the patients surviving with laryngectomy hence alaryngeal voice in communication. For comprehensive care of these patients, more studies are therefore needed especially in majority world cultures hence the need for this study.

A study was carried out in Sweden by Bergstrom, Ward and Finizia, (2016) on voice rehabilitation after laryngeal cancer treatment and the associated effects on psychological well-being of the patient at Sahlgrenska University hospital. The study involved 63 patients randomized to either voice rehabilitation or control group. The findings indicated that laryngeal cancer patients usually experience vocal dysfunction varying from mild to severe in nature after treatment. These changes present as complex dysphonia with voice post chemotherapy combined with radiotherapy (C)RT being harsh, rough, strained and breathy. The study further revealed that after treatment of laryngeal cancer, patients reported poor vocal quality, dysphonia, aphonia and general vocal fatigue. It's therefore clear that treatment options for laryngeal cancer interrupt normal physiologic functions including voice production. A further study done by Stoekli, Guidicelli and Schneider (2001) indicated no difference in voice quality in patients who were treated with radiotherapy and those who underwent surgery thus illustrating the magnitude of voice dysfunction that laryngeal cancer treatment subject patients to. The above studies confirm existence of voice

disorders after laryngeal cancer treatment but do not shed light on the impact of these voice disorders on the patients and family members. Therefore, there is need to further establish the psychological and social impact of these voice disorders on laryngeal cancer patients and their families, a gap this study sought to fill.

Siupsinskiene, Vaitkus, Grebliauskaite, Engelmanaite and Sumskiene (2008) conducted another study on quality of life and voice in patients successfully treated for early laryngeal cancer in the department of otolaryngology in Siauliai Hospital at Kaunas University of Medicine. The study sampled 49 patients diagnosed with Tis-$T_2$NO laryngeal carcinoma. Voice quality measured by Voice Handicap Index (VHI) indicated hoarseness (dysphonia) as the most frequent complain among the patients. One interesting thing about this study is that majority of patients rated their voices as normal according to VHI data with slight to moderate dysfunction but the general finding of the study revealed quality of life of patients previously treated for laryngeal cancer as worse than healthy subjects. This raises the fact that voice quality must be having a significant contribution to the general quality of life of individuals hence need for further research on the psychological and social impact of these voice disorders on laryngeal cancer patients and their families.

In addition, Siupsinskiene, Vaitkus, Grebliauskaite, Engelmanaite and Sumskiene (2008) acknowledge the grim fact that very few studies have focused on the contribution of voice handicap to the general well-being in patients treated for laryngeal cancer hence need for further research; a gap this study sought to fill. Siupsinskiene, Vaitkus, Grebliauskaite, Engelmanaite and Sumskiene (2008) in their finding contradict an earlier study done by Farrand and Duncan (2007) on health related quality of life among patients with three different voice restoration methods after total laryngectomy.

Farrand and Duncan (2007) indicate in their findings that improved voice quality does not result in widespread benefits to quality of life. This conclusion definitely calls for more research as Mbogo (2017) reveals how people in Kenya react to laryngectomees by being scared of them, making comments like 'You talk like a robot' and some basically wanting to run away as he removes his electrolarynx machine to talk. Such reactions must definitely affect the patients' social interactions and in the long run, if not checked, result in negative psychological and social effects. These effects contribute to general quality of life. This study therefore sought to find out the effect of voice disorders on psychological and social well-being of laryngeal cancer patients post-treatment.

### 2.3 Social Impact of Voice Disorders

How people behave in social environments is largely a reflection of what they have learnt. It is unfortunate that dysphonia affects not only personal perceptions, but can negatively affect social interactions as well. Negative perceptions of individuals with voice or resonance disorders are generalized by listeners hence creating negative impressions of the individuals' intelligence, appearance and kindness (Lallh & Rochet, 2000). This simply means that people are bound to make wrong conclusions about individuals with voice disorders attaching negative traits by judging from the impression of the voice.

Stow and Dodd (2003) state that the direct effect the voice disorder has on speech puts many patients at risk of being ignored, feared, pitied, mimicked, laughed at, considered helpless, rejected or denied opportunities by being hidden. Consequently, such patients may become depressed, anxious and develop low- self-esteem. This may

lead to poor self-perception and consequent development of maladjusted behavior. This normally comes as a result of increased difficulty in communicating with others.

Such patients may develop unresolved conflicts which may not come as a result of psychopathological problems but a manifestation of failures, annoyances, injuries, daily anxieties, disappointments, non-fulfilment of desires, lack of self-confidence and general feelings of inadequacy (Stow & Dodd, 2003). Unfortunately, Farrand and Duncan (2007) regret the fact that there is very little evidence supporting the relationship between voice quality and general quality of life hence need for more studies focusing on specific contribution of voice disorder on social and psychological aspects of patients' lives and families as social units thus the need for this study.

Zraik, Risner, Smith-Olinde, Gregg, Johnson and Mcweeny (2007) carried out a study comparing patients' versus partners' perception of voice handicap using Health Related Quality of Life (HRQOL) and Short Form 36(SF-36). The study revealed patients having lower SF-36 than those with normal voice in terms of physical functioning, vitality, emotional role, social functioning and mental health. Their partners were also in agreement with this observation as reflected in VHI-partners' scale. As illustrated in this study, the findings are based on quality of life instruments such as HRQOL and ST-36 (Zraik et al, 2007) in measuring impact of voice disorders on patients.

The concern is that these tools have been developed in different cultural backgrounds predominantly minority world cultures and different social settings. Caution is recommended in the process of importing these models for PWCD in majority world settings (WHO and World Bank, 2011). Therefore, this study adopted qualitative methods of data collection delving deep into patient and family experiences, feelings

and observation regarding impact of voice disorders on their social and psychological well-being.

### 2.4 Psychological Impact of Voice Disorders

Bouwers and Dikkers (2007) emphasize the need to acknowledge the impact of voice problems on daily life. The psychological impact of the voice problems differs from person to person and there has been a growing understanding of the same. Additionally, Roy and Bless (2000) observe that certain disorders impact psychological processes leading to changes in personality consequently changing temperamental characteristics. According to Aronson and Bless (2009), verbal communication is a tool for social interaction, expression of affection and leisure engagements hence presence of a voice disorder is a trigger for considerable emotional and functional restrictions. These give rise to psychological difficulties with those who professionally rely on their voices likely to perceive their condition as more paralyzing than others (Behrman, Sulica, & He, 2004). Yet studies on communication disorders are focusing more on the primary pathologies under-pinning voice disorders and focusing less on specific communication impairments (World Health Organization and Wossrld Bank, 2011). This study therefore focused on the psychological effect of voice disorders on laryngeal cancer patients post-treatment.

Psychological studies have shown that severity of dysphonia can be linked to psychological and social distress. According to study done by Deary , Wilson, Carding, and Mackenzie (2003), individuals who reported more severely dysphonic voices also had: higher neuroticism (emotional disturbance) and alexithymia (the inability to express oneself); more emotional coping strategies and increased stress hence lowering the life quality resulting in unexplained medical symptoms. Deary,

Wilson, Carding, and Mackenzie (2003), however, admit that there is still lack of evidence of the precise relationship between voice disorders and psychological variables hence need for further studies investigating the same.

Tuomi, Johansson, Andréll, and Finizia (2015) carried out a study basing their finding on Health Related Quality of Life (HRQL) measured by European Organization for Research and Treatment of Cancer (EORTC), Core 30 (C-30), Head and Neck 35(H&N35) and communication function as measured by Swedish Self Evaluation of Communication Experiences after Laryngeal Cancer (S-SECEL). It demonstrated that voice rehabilitation after laryngeal cancer treatment greatly improved communication, boosted social function, social contact and general quality of life of patients and vice versa. As earlier highlighted, these tools have been developed in different cultural backgrounds predominantly minority world cultures and different social settings. Caution is therefore recommended in the process of importing these models for PWCD in majority world settings (WHO and World Bank, 2011). This study adopted qualitative methods of data collection delving deep into laryngeal cancer patients' and families' experiences, feelings and opinions regarding impact of voice disorders on their social and psychological aspects of life.

### 2.5 Impact of Voice Disorders on Family/Caregivers

Focusing on social impact on the family, Zerbeto and Chun (2012) conducted a research in Brazil focusing on caregivers of children and adolescents with communication disorders on their quality of life targeting a total of 40 participants. The study demonstrated that a patient requiring special care such as those with voice disorders have a higher probability of influencing the environmental and emotional aspects of others in the family. While Zerbeto and Chun (2012) focused on caregivers

of children and adolescents, this study focused on caregivers of adult laryngeal cancer patients ranging 20 years and above.

Offerman, Pruyn, Boer, Busschbach, and Jong (2015) on the other hand carried out a study on psychosocial consequences for partners of Total Laryngectomy (TL) patients sampling 151 laryngectomees and 144 partners. The study revealed negative change in the relationship with special reference to communication. This led to negative effects on the social life of partners. In addition, a third of the sampled population of partners attended fewer social occasions and didn't enjoy leisure as before. This is because they felt irritated by the neglect their laryngectomized companions faced in social settings. Since it's clear that a TL affects many other aspects of a patient's life, there is need to establish other effects that might also affect patients and their partners. The above study does not single out the psychosocial impact of alaryngeal voice as a result of a TL hence the need for a more specific focus on social and psychological effects of voice disorders on laryngeal cancer patients post-treatment.

According to psychological impact theory and social impacts (Finsterbusch, 1984) upon which this study is based, negative social impact has significant negative psychological impact as seen in strain and frustrations. Presence of a voice disorder is likely to elicit negative social impact due to limitations and unprecedented reactions from listeners. This may subject the patient and family to strain in the process of communication. Unsuccessful attempts in communicating might lead to frustrations which may eventually reflect in strained family relationships. Mbogo (2017) for instance, acknowledges his son's confession that it was too hard for him to have a father who couldn't speak. His daughter too confessed not knowing how to adjust to her father's alaryngeal voice;

In light of the limited studies in this area especially in Kenya, there's need for further investigation into the psychological and social impact of voice disorders on laryngeal cancer patients and their families hence the need for this study.

## 2.6 Summary of Literature Review

World Health Organization and World Bank (2011) have raised a genuine concern in available studies on communication disorders focusing more on the primary pathologies under-pinning voice disorders and focusing less on specific communication impairments. To confirm this, studies have focused on the impact of laryngeal cancer on patients and families (Offerman, Pruyn, Boer, Busschbach, & Jong, 2015) and the effect of laryngectomy on cancer patients (Bergstrom, Ward & Finizia, 2016). This study sought to fill this gap by focusing on voice disorders and their psychosocial impact on laryngeal cancer patients and their families.

As much as we appreciate work done in this area by other scholars, it is important to note that a number of research findings are based on quality of life instruments such as VHI (Siupsinskiene, Vaitkus, Grebliauskaite, Engelmanaite and Sumskiene, 2008)), HRQOL and ST-36 (Zraik et al, 2007) in measuring impact of voice disorders on patients. The concern is that these tools have been developed in different cultural backgrounds predominantly minority world cultures and different social settings. Consequently, this study adopts qualitative methods of data collection delving deep into patient and family experiences, feelings and observation regarding impact of voice disorders on their social and psychological well-being.

A sharp contradiction is arising from Siupsinskiene, Vaitkus, Grebliauskaite, Engelmanaite and Sumskiene (2008) study postulating quality of life of patients earlier treated for laryngeal cancer as worse with slight to moderate voice dysfunction compared to normal subjects. On the other hand Farrand and Duncan (2007) indicate in their findings that voice quality does not result in widespread benefits to quality of life.

In Kenya, Mbogo (2017) reveals how people react to laryngectomees. Some people get scared of him while others make comments like 'You talk like a robot'. Such reactions may affect the patients' social interactions and in the long run, if not checked, result in negative psychological and social effects. This study sought to find out the effect of voice disorders on psychological and social well-being of laryngeal cancer patients and their families to facilitate a more comprehensive intervention.

Since most studies in this area as seen above have either used a tool to measure the impact of voice disorders or are quantitative in nature, this study has used qualitative data collection methods for in-depth knowledge of patients' experiences and opinions. Moreover, barely any study has been conducted in the area of voice disorders and their psychosocial impact on laryngeal cancer patients in Kenya, a gap this study sought to fill.

# CHAPTER THREE

# METHODOLOGY

## 3.0 Introduction

A description of the methodology that was used in this study is contained in this chapter. It includes the research design, study variables, location of the study, target population, proposed sample and sampling procedures, research instruments, pilot study, procedures for data collection, data analysis and ethical considerations.

## 3.1 Research Design

This study adopted a case study research design. This design suits this study because it involves study in real life setting in line with Yin (2009) recommending case study research designs for real life context studies. Due to reliance on respondents sharing their personal experiences, the researcher used qualitative research methods of direct observation, focus group discussions and interviews to collect data from respondents. Direct observation, focus group discussions and interviews enabled the researcher attain in-depth knowledge on the concept.

Qualitative research is recommended especially when collecting data on people's attitudes, opinions, habits or social issues (Yin, 2009). This study explored attitudes, personal opinions, habits and consequent impact on both parties, that is, the patient with the voice disorder and the family.

## 3.2 Variables

### 3.2.1 Independent Variable

A characteristic that affects an outcome but remains stable in it as proposed by Creswell (2015) is referred to as an independent variable. In this study, the independent variable is the voice disorder.

### 3.2.2 Dependent Variable

This is the variable that is influenced by the independent variable (Creswell, 2015).In this study; the dependent variable is the psychological and social state of the patients and family members.

### 3.2.3 Intervening Variable

An intervening variable is a mediating variable that is hypothesized to clarify the causal links between the independent and the dependent variables (Creswell, 2015). In this study, the intervening variables are age, occupation and accessibility of SLP services.

## 3.3 Study Locale

This study was carried out at the ENT clinic of Kenyatta National Hospital in Nairobi County, Kenya. It's a referral hospital with equipped Ear, Nose and Throat (ENT) clinic for diagnosis and treatment of laryngeal cancer. This study focused on adult laryngeal cancer patients with voice disorders who come for post-treatment clinical monitoring and support. The researcher found the hospital appropriate for the study being the largest teaching and referral hospital in Kenya. In addition, the hospital has the largest number of laryngeal cancer patients in Kenya.

### 3.4 Target Population

The total target population was sixty (60) comprising fifteen (30) adult laryngeal cancer patients and fifteen (30) family members. These patients were targeted from the out-patient ENT clinic. The clinic is scheduled twice per week. Each clinic serves approximately 20 patients hence a target of three clinics. The laryngeal cancer patients with voice disorders at least three months post-treatment from KNH – Kenya-ENT clinic were selected. These comprised of those who underwent laryngectome as well as those who opted for organ preservation modes of treatment hence having aphonia or dysphonia. One family member who was either a spouse, off-spring or caregiver for each laryngeal cancer patient was included. The patients were targeted as they were the ones directly affected by the voice disorder hence provided relevant data to establish psychological and social impact of the condition on them. The family members/caregivers were targeted because they were the closest to the patients interacting on a daily basis.

### 3.5 Sampling Technique and Size

#### 3.5.1 Sampling Technique

The study used purposive sampling to enable the researcher get the fifteen laryngeal cancer patients and fifteen family members who provided the relevant data at Kenyatta National Hospital- Kenya – ENT clinic. Inclusion criteria involved laryngeal cancer patients at least three months post treatment and having aphonia, dysphonia or using alaryngeal voice in communication. The patients sampled were adults of 20 years and above. Family members included spouses, off-springs or caregivers of the patients. Exclusion criteria involved other HNC cases that may result in voice disorders. The sample also excluded laryngeal cancer patients with an earlier

psychological diagnosis as this may have influenced the findings of the study. The respondents were expected to provide rich data for this study.

### 3.5.2 Sample Size

The sample comprised fifteen laryngeal cancer patients with voice disorders at least three months after treatment from Kenyatta National Hospital (ENT clinic) and fifteen family members hence a total of thirty respondents giving 25% sample size. This in line with Mugenda and Mugenda (2013) who stated that when a study population is less than 10,000, a sample size between 10% and 30% is a good representation of the target population.

## 3.6 Research Instruments

### 3.6.1 Interview schedules

This was used to collect data from key informants (the laryngeal cancer patients) at the ENT clinic at Kenyatta National Hospital. The researcher sought to establish the social and psychological impact of the voice disorder on the patients as well as coping strategies developed by the patients in verbal communication. This instrument was used to:

i. Facilitate high response quality as it allows the researcher to clarify to the patient the questions for better understanding.
ii. Enable the researcher to collect rich data as it allows recording of non-verbal cues such as patients' nervousness, eye contact and posture among others (Creswell, 2015).

The interview schedule has three sections. The first and second sections cover background and general information while the third section elicited data in line with

the research objectives. The interview schedule has twelve items. Data was recorded through writing.

### 3.6.2 Observation checklist

This was filled as the researcher interacted with the patient and family member or caregiver at the ENT clinic at Kenyatta National Hospital. Observation involves systematic description of events and behaviors in the social setting through watching and recording as they occur (Creswell, 2015). This instrument sought to establish the social and psychological impact of the voice disorders as well as the coping behavior adopted by the patient and family. This instrument was used:

i. Enhance collection of richly detailed data through viewing and recording relevant unscheduled events.
ii. Enable the researcher explains existing situations using senses (Creswell, 2015).

The instrument has two sections. The first section covers background information whereas the second section has six items. Data was recorded through writing.

### 3.6.3 Focus Group Discussions

This was used to collect data from family members (spouses, off-springs or caregivers). The researcher divided the 15 family members into two groups; one having 7 and the other 8 members. The researcher believed that a group of 7-10 participants was effective for efficient communication (De Walt & De Walt, 2002). This instrument sought to establish the social and psychological impact of the voice disorders and the coping behavior adopted by the patients and family members at the KNH (ENT clinic). This instrument enabled the researcher to:

i. Solicit in-depth information from personal and group feelings of family members.

ii. Interact with participants and allow multiple narratives to be voiced in one session (De Walt & De Walt, 2002).

Data was recorded through writing.

### 3.7 Pilot Study

Before the actual collection of data, a pilot study was carried out with four laryngeal cancer patients and four family members picked from a facility with the same characteristics as that of the main study locale. These were purposively selected on suitability to give relevant data for the study. They were not involved in the main study. Interview schedules were administered by the researcher as a trained assistant administered the observation checklists. The researcher conducted the focus group discussions and recorded data. Analysis was done to ascertain whether the instruments efficiently gathered necessary data for the study. Evaluation of the relevance of the instruments to determine ability to cover all aspects of the study was done after piloting. The pilot study also helped the researcher to identify and correct ambiguities and inadequacies of the instruments. Necessary adjustments were therefore made after consultation with the supervisors.

### 3.8 Validity and Reliability

#### 3.8.1 Validity

Through piloting the study with eight of the sampled respondents, the validity of the instruments was established by analyzing the extent of agreement of the items in the instruments and judgment made regarding Content Validity Index (CVI). The

researcher also held discussions with the university supervisors from the Special Needs Department then implemented synchronized comments and suggestions (Creswell, 2015).

### 3.8.2 Reliability

After a purposive selection, a pre–test was held using eight correspondents, which involved four laryngeal cancer patients (at least three months post treatment) and four family members. The researcher used a test-retest method to establish stability of the instruments (Creswell, 2015). Ambiguities noted were then corrected before the final data collection process took place.

## 3.9 Data Collection Procedures

After obtaining relevant permissions for data collection, the researcher visited the ENT clinic at KNH-Kenya and purposively sampled laryngeal cancer patients from the available patient records who come for clinical services at least three months post-treatment. The researcher booked for the first meeting at the clinic where the patient consented to participate in the study and signed the consent form. Family members who were to participate in the study were proposed by the patient. A second meeting was scheduled at the patient's convenience for interview and observation at the ENT clinic at KNH. Two separate meetings were scheduled at the agreed time with family members where the researcher conducted focus group discussions at the ENT clinic at KNH.

### 3.10 Data Analysis

Data was analyzed qualitatively in this study (Creswell, 2015). The data collected from observation check lists, interview schedules and focus group discussions was transcribed, organized, edited, coded and sorted for thematic analysis. Patterns across data sets consistent with the theoretical tradition of the study were pinpointed, examined and recorded to answer specific research questions.

### 3.11 Logical and Ethical considerations

Clearance from the university was first sought by the researcher after which permission from National Commission for Science, Technology and Innovation (NACOSTI) was obtained in order to carry out the research and collect data. Introductory letters were obtained from relevant ministries, that is, Ministries of Education and Ministry of Health, Graduate School and Department of Special Needs Education confirming permission to go out and collect data. Clearance was also sought from the Nairobi-County office, County Health Officer and KNH superintendent.

The patients' confidentially was guaranteed as dictated by law (Kenya National Health Policy 2016-2030). The information provided was assigned a code number. Any list attaching true identity to the data collected was kept under lock in the supervisor's office. Upon completion of this study and analysis of data collected, the list was destroyed and patients' names not used in any publication. Consent was confirmed through signing of a consent form before any recording was done as this is an essential aspect of ethical consideration in attaining validity of research findings.

# CHAPTER FOUR

# FINDINGS, INTERPRETATION AND ANALYSIS

## 4.0 Introduction

In this chapter the researcher starts by presenting an analysis of the background characteristics of the laryngeal cancer patients and independent variables, before addressing each of the study objectives namely: the social impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic); the psychological effect of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic); and coping behavior developed by the laryngeal cancer patients and their families in verbal communication at Kenyatta National Hospital (ENT clinic).

## 4.1 Background characteristics of the laryngeal cancer patients

The patient's background characteristics included sex, age, marital status and occupation.

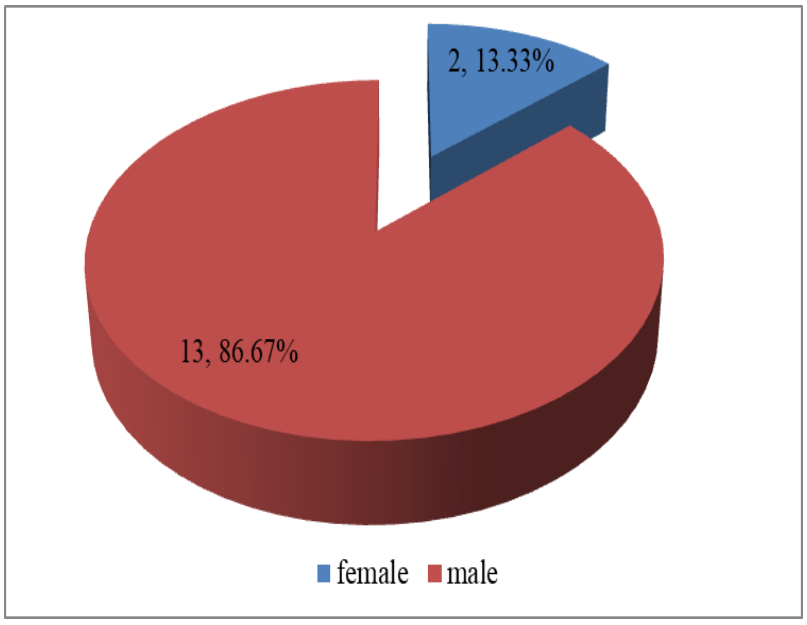

**Figure 4. 1: Sex of the Patients**

Figure 4.1 above shows that out of the 15 patients interviewed and observed 13 (86.67%) were males while only two (13.33%) were females. Thus most of the patients were males.

**Table 4. 1: Age of the Patients**

| Variable | Obs | Mean | Std. Dev. | Min | Max |
|---|---|---|---|---|---|
| Age | 15 | 62.06667 | 6.83966 | 46 | 71 |

Table 4.1 above gives the age of the patients and shows that the mean age of the patients was 62 years, with the youngest being 46 years and the oldest was 71 years. Hence, all the patients interviewed and observed were adults.

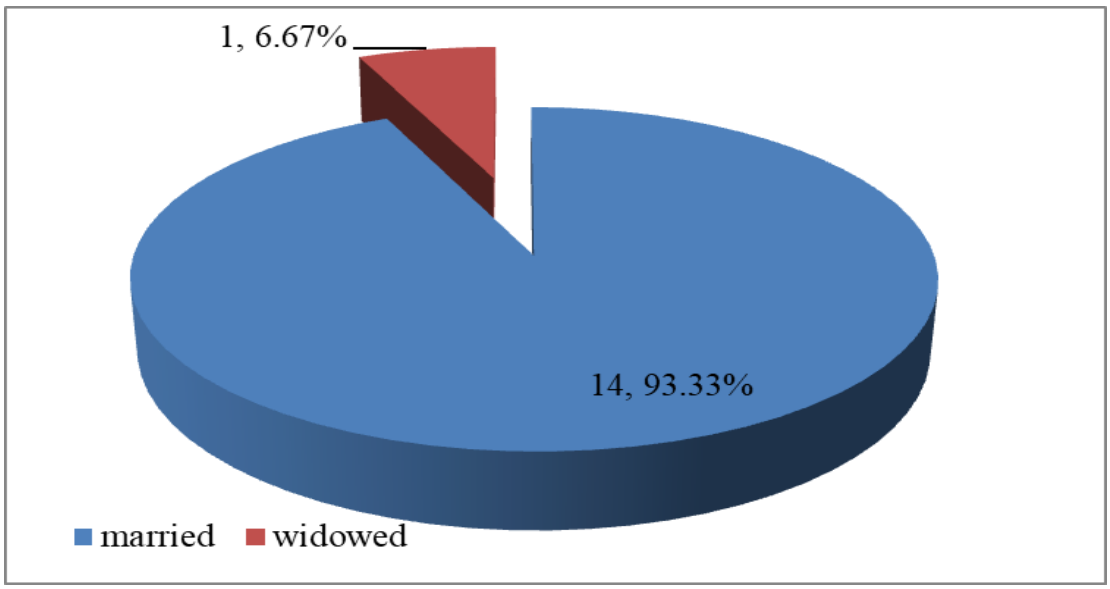

**Figure 4. 2: Marital status of the patients**

Figure 4.2 above on the marital status of the patients, shows that 14 (93.33%) of the patients were married while only one (6.67%) was widowed. Thus majority of the patients are married.

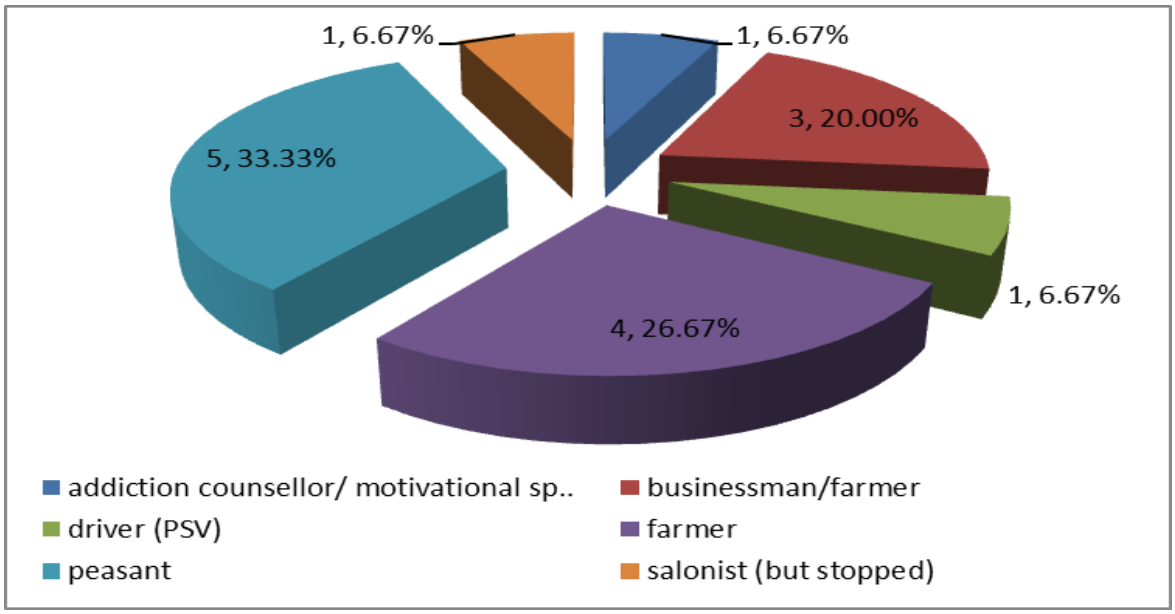


**Figure 4. 3: Occupation of the patients**

The occupation of the patients is illustrated in figure 4.3 above. The patients who were into peasant farming were five (33.33%), while four (26.67%) were into farming only with three (20.00%) practicing business and farming. Hence, most 12 (80.00%) of the patients were into farming either in isolation or with other activities irrespective of the extent of their farming activities be it peasant or large scale.

### 4.3 Types of voice disorders among the patients (Independent variable)

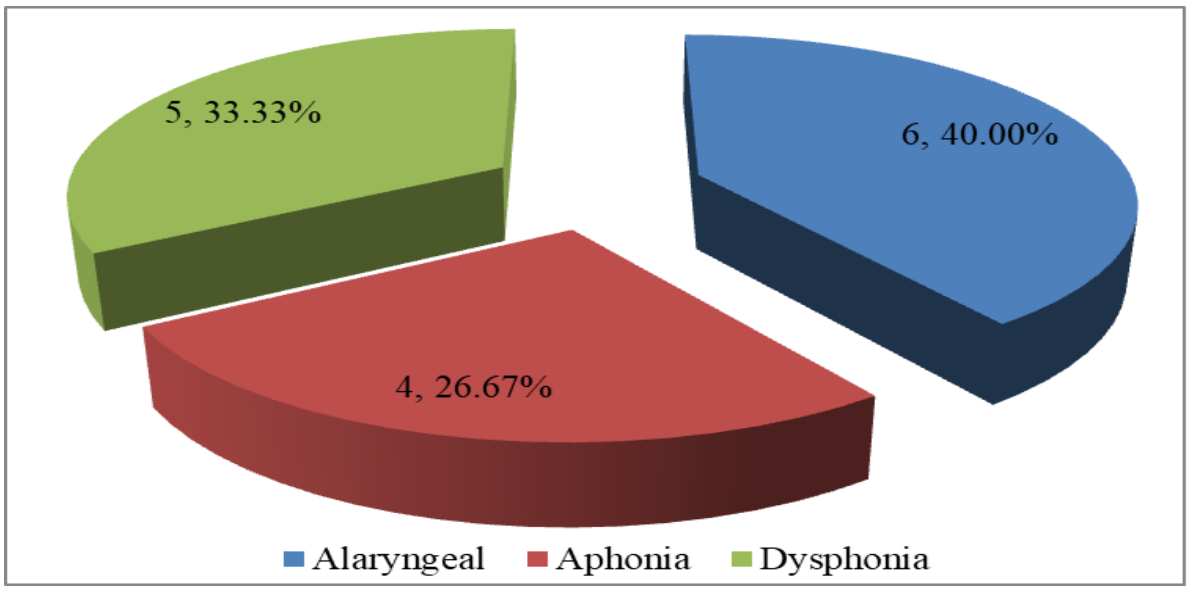


**Figure 4. 4:Voice disorders among the interviewed patients**

The different voice disorders among the interviewed patients at KNH ENT department are illustrated in figure 4.4. Six (40.00%) of the patients had alaryngeal, five (33.33%) had dysphonia, while four (26.67%) had aphonia.

### 4.4 Social impact of the voice disorders on the laryngeal cancer patients and families

Based on the researchers' observation of the social factors and the corresponding mean; table 4.2 shows that as a result of the voice disorders 80% of the patients fumble in the process of initiating verbal communication; 73.33% of them said that the voice disorder affected the patients' eye contact with family members during verbal communication episodes.

**Table 4. 2: Social Impact of Voice Disorders on Patients**

| Variable | Obs | Mean | Std. Dev. | Min | Max |
|---|---|---|---|---|---|
| **Fumbles** | 15 | 0.8 | 0.414039 | 0 | 1 |
| **eye contact** | 15 | 0.7333 | 0.457738 | 0 | 1 |
| **struggles to talk** | 15 | 0.5333 | 0.516398 | 0 | 1 |
| **freely talks** | 15 | 0.4 | 0.507093 | 0 | 1 |
| **avoid eye contact** | 15 | 0.2667 | 0.457738 | 0 | 1 |
| **clearly convey the message** | 15 | 0.1333 | 0.351866 | 0 | 1 |

The researcher observed that some patients freely interacted with family members; however, it was also noted that at times, some family members were more focused on their phones than the patient leading to minimal verbal communication at crucial times when the patient needed attention. The interview schedule revealed that patients had limited social interactions due to the voice condition. They confessed having lost most friends as a result of the voice disorder. Some of the patients also said that their families had generally become quieter from their spouses to the children as reported below.

> [1]"*My wife keeps quiet a lot. She moves very close to me when she wants to talk yet I can hear quite well."*
>
> *"Our meal times are very quiet unlike long time ago when I would use it to initiate family discussions. The children are quieter around me than before."*

In addition, it was noted that the patients depend on family members for assistance in verbal communication; their goals in life changed and standard of life lowered; the

family expectations also dropped in some cases. From the FGDs, family members admitted reduced levels of daily social interactions as the patient is limited in verbal communication. The above patients had not gone through any voice rehabilitation hence had difficulty in communication. These findings are in line with those of Tuomi, Johansson, Andréll, and Finizia (2015) that previously demonstrated that voice rehabilitation after laryngeal cancer treatment greatly improved communication, boosted social function, social contact and general quality of life of patients and vice versa. In this case, we find low social interaction more so at family level due to interference with verbal communication.

The above findings further confirm that patients with voice disorders face myriad challenges stemming from restricted participation and limitation in voice activities. These patients therefore risk malfunctioning hence further risk psychological and physical complications due to inability to exercise, enjoy a family outing or participate in social activities freely (Ma & Yiu, 2001).

Relating the above findings to psychological impact theory and social impacts (Finsterbusch, 1984), negative social impact as seen in this case of limited family interaction due to voice disorder has significant negative psychological impact as seen in strain and frustrations that arise as a result. This qualifies Stow and Dodd's (2003) findings that such patients may become depressed, anxious and develop low- self-esteem. This may lead to poor self-perception and consequent development of maladjusted behavior. This normally comes as a result of increased difficulty in communicating with others.

### 4.5 Psychological impact of the voice disorders on the laryngeal cancer patients and families

In an attempt to establish the psychological effect of the voice disorders, table 4.3 isolates the researchers' findings from observation on the psychological effect of voice disorders on the patients and their families. The table shows that 80% (mean of 0.8) of the patients and families experienced sadness, concurring with findings by Zerbeto and Chun (2012) in Brazil that showed that a patient requiring special care such as those with voice disorders have a higher probability of influencing the environmental and emotional aspects of others in the family. It was further noted from the FGD that family members were not happy with the patients' voice condition and wished it was reversible or would get better with time. In addition, 60% of the patients were tense as a result of the voice disorder especially at initiating verbal communication.

**Table 4. 3: Psychological Effect of Voice Disorders on Patients**

| Variable | Obs | Mean | Std. Dev. | Min | Max |
|---|---|---|---|---|---|
| **sad** | 15 | 0.8 | 0.414039 | 0 | 1 |
| **Calm** | 15 | 0.6667 | 0.48795 | 0 | 1 |
| **Tense** | 15 | 0.6 | 0.507093 | 0 | 1 |
| **Restless** | 15 | 0.3333 | 0.48795 | 0 | 1 |
| **Relaxed** | 15 | 0.2 | 0.414039 | 0 | 1 |
| **Happy** | 15 | 0.1333 | 0.351866 | 0 | 1 |

The researcher observed that most of the patients when faced with the challenge of initiating verbal communication fidgeted on chair, had a tense facial expression, avoided eye contact, over-manipulated the lips, had dilation of pupils, frowned and kept rubbing hands together. These are key indicators of the patient struggling to communicate verbally hence a source of stress.

Deary et al (2003) reported earlier that presence of voice disorders such as severe dysphonic voices increased the patients' inability to express themselves. This leads to considerable functional restrictions triggering stress to the patient (Aronson &Bless, 2009). The above restrictions can therefore be linked to psychological distress. From the FGD, it was revealed that the family members get stressed too in the case of misunderstanding the patient's attempts at verbal communication. A caregiver confessed that:

> [2]*"Stress levels have increased especially when one fails to understand the patient in the process of verbal communication".*

The findings conform to those in a study done in Sweden by Bergstrom, Ward and Finizia (2016) which confirmed prevalence of distress after laryngeal cancer treatment specifically regarding voice rehabilitation after laryngeal cancer. In addition, from the Focus Group Discussions, it was clear that worry and fear affected the family members more when the patient was out unaccompanied. The family members got worried of the patient's safety whereas the patients in most cases relied on caregiver for safety. Worry and fear are strong indicators of anxiety hence justifying the fact that anxiety levels went up when the patients were out unaccompanied.

Anxiety was also noted among some patients based on how people reacted when they spoke. This seemed to hinder their confidence in participating in many outdoor activities as stated by one of the patients:

> [3] *"My condition has interfered with my participation in church activities since many people frown at the quality of my voice causing me a lot of anxiety."*

One respondent, a matatu driver admitted his limitations at work due to the voice condition. He admitted that he could not shout nor engage with colleagues well in a noisy environments hence feeling like quitting the job. He further says that sometimes he feels others want to exploit him due to his voice condition. It is therefore clear that the direct effect of the voice disorder on speech puts the patients at risk of being ignored, laughed at or exploited at place of work. Consequently, such a patient may become depressed, anxious and develop low- self-esteem. Roy and Bless (2000) also agree that such patients are usually self-restrained and anxious in everyday lifestyle.

The interviews revealed that some cultural perspectives considered patients with voice disorders as cursed, which supports the findings by Mwihaki (2003) who established that most families consider communication disorders a curse hence unbearable reflection on them. Similar perspectives included patients or their families believing that they are paying for a wrong thing they had done or viewing the condition as a punishment from God. Such beliefs affect not only the patient but the family as well exposing them to distress and negative psychological effects.

### 4.6 Coping behavior developed by the laryngeal cancer patients and their families in verbal communication

The interview schedule revealed that some of the patients cope by avoiding situations or places where their voice disorder would become evident, staying indoors or taking it out on others emotionally. For instance, one patient confessed to have ignored attempts at communicating verbally with any of the family members after an instance of failed verbal communication with one member. This usually affected how they related afterwards. In addition, this frustration made such patients project their negative emotions towards innocent family members, children included. This is a confession from one of the patients;

> [4]"*Sometimes when my situation gets really bad, I find myself taking it out on others around me."*

Some patients confessed that they were coping with their condition by avoiding social gatherings, avoiding going to new places where people do not know them and also staying indoors among others. These mechanisms though seem to work for the patients; they are self-isolating strategies that in the long run may lead to withdrawal hence negative psychological effect. Consequently, if rehabilitation is not done in good time, there is likelihood of deteriorated family relationships with special reference to communication, which may lead to permanent negative effect on the social life of partners as demonstrated by attendance to fewer social occasions and lack of enjoyment of leisure as before.

The researcher also observed that the patients' efforts in initiating verbal communication were accompanied by tense facial expression, over-manipulation of lips, and dilation of pupils, rapid blinking of eyes, and rubbing of hands. These are

negative coping strategies adopted by the patients in adjusting to their condition in verbal communication. The family members/ caregivers were responsive often by nodding their heads too much hence confusing the patient or moving too close to the patient denying them their personal space. In some instances, the caregivers/family members responded rather too loudly while talking to the patients hence drawing unnecessary attention from the social setting yet the patients have no problem with hearing. These are negative coping strategies

Data from Focus Group Discussions revealed that family members/caregivers accommodated the patients by creating a conducive environment which is quiet for the patient, avoiding too much verbal engagement in new environments or noisy environments and developing good lip-reading skills. These are good strategies but in real sense, the patients feel left out in terms of verbal communication. When the environment is too quiet, the patient may tend to focus more on their condition leading to stress and negative psychological symptoms. In avoiding verbal engagement with the patient in social settings, the patient generally may feel neglected leading to withdrawal behavior. Such patients may feel irritated by the neglect they face in social settings.

Relating the above findings to psychological impact theory and social impacts by Finsterbusch (1984), voice disorders after laryngeal cancer treatment present a force that threatens the individual well-being. The stressor which is the voice disorder elicits negative coping behavior from the patients and family members leading to strain both physically and psychologically.

Furthermore, the strain the patients have in verbal communication and the general frustrations they encounter in their daily lives as they interact with their family

members and others lead to an excess of negative against positive effects. This, in relation to the life satisfaction theory negates happiness hence leading to negative psychological impact as seen in rise in anxiety levels, low levels of interaction and lack of confidence which is a pointer to low self –esteem.

# CHAPTER FIVE

# SUMMARY, CONCLUSION AND RECOMMENDATIONS

## 5.1 Introduction

This chapter presents the summary, conclusion and recommendations from the findings of the study. It also presents suggestions for further research. The study investigated voice disorders and their psychosocial impact on laryngeal cancer patients and their families at Kenyatta National Hospital, Nairobi City County-Kenya. The study was guided by three objectives being: To determine the social impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic); To establish the psychological impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic) and to find out coping behavior developed by the laryngeal cancer patients and their families in verbal communication at Kenyatta National Hospital (ENT).

By focusing on voice disorders and their psychosocial impact on laryngeal cancer patients and their families, this study assumed that the presence of voice disorders after laryngeal cancer treatment affect patients and their families socially and psychologically. In this respect, the recommendations are made on what stakeholders can include in the intervention programs for efficient and effective rehabilitation of patients with voice disorders.

## 5.2 Summary of Research Findings

The purpose of this study was to establish the social and psychological impact of voice disorders on laryngeal cancer patients and their families. The focus group

discussions, interview and observation schedules duly filled provided sufficient data for viable analysis.

The first objective was to determine the social impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic). The findings revealed that patients had limited social interactions due to the voice condition. They confessed having lost most friends as a result of the voice disorder. The patients also reported that their families had generally become quieter from their spouses to the children.

In addition, it was noted that the patients depended on family members for assistance in verbal communication; their goals in life changed and standard of life lowered; the family expectations also dropped in some cases. The family members also admitted reduced levels of daily social interactions as the patient is limited in verbal communication.

The second objective was to establish the psychological impact of the voice disorders on the laryngeal cancer patients and families at Kenyatta National Hospital (ENT clinic). The study found that the patients and their families experienced sadness hence a higher probability of the patient influencing the environmental and emotional aspects of others in the family. The family members were not happy with the patients' voice condition and wished it was reversible or would get better with time. In addition, most of the patients experienced tension as a result of the voice disorder especially at the initiation of verbal communication.

Moreover, the patients struggled with verbal communication triggering stress and psychological factors due to functional restrictions. It was also noted that anxiety levels shot up especially when the patient goes out unaccompanied both from the

patient as well as family members regarding safety. Anxiety was also noted among some patients based on how people react when they speak. This seemed to hinder their confidence in participating in many activities exposing the patients to depression due low self-esteem.

The third objective was to find out coping behaviors developed by the laryngeal cancer patients and their families in verbal communication at Kenyatta National Hospital (ENT). As discussed above, it came out as a great concern that most of the patients and caregivers/family members adopted negative coping strategies during verbal communication. Some of these strategies included avoiding social gatherings, staying indoors, avoiding going to new places or meeting new people among the patients. The family members on the other hand nodded too much as the patients tried to engage in verbal communication hence confusing the patients, shouted back in response yet the patients did not have hearing problems and avoided engaging the patients in verbal communication in social gatherings among others.

The strategies adopted by caregivers/family members either confused the patients or denied them their personal space. On the other hand, those strategies adopted by patients either strained them physically or psychologically. A major concern also arose where some of these strategies were seen to cause a rift among family members where the patient vented his/her emotions on whoever was around. Some coping strategies such as not engaging the patient in verbal communication in social settings were seen to cause withdrawal and stress to the patient.

## 5.3 Conclusions

The study resulted in the following three major conclusions:

Firstly, presence of voice disorders made the patients have limited verbal interactions, lose many friends and the families became unusually quiet in the effort to provide a conducive atmosphere for them. It was also concluded that there was an over-reliance of the patient on family member/caregiver. In addition, it was noted that the patients depended on family members for assistance in verbal communication; their goals in life changed and standard of life lowered; the family expectations also dropped in some cases. The family members also admitted reduced levels of daily social interactions as the patient is limited in verbal communication. This brings to light the fact that severity in voice disorders as seen in laryngeal cancer patients makes them candidates of psychological distress (Deary et al, 2003).

Furthermore, the patients were generally sad as well as family members confessing being unhappy about the patients' conditions. Moreover, the patients' struggle at initiating verbal communicational led to functional restrictions triggering psychological distress.

Looking at Ma and Yiu's (2003) analysis of the effect of voice disorders on everyday activities, they concluded that such patients risk social malfunctioning just as seen in heightened anxiety levels due to people's reactions to the patients' voice in this study. This leads to lack of confidence among the patients and family members in engaging in verbal communication in social settings. In addition, this led to lower self-esteem among the patients. Avoidance of such engagements by family members led to withdrawal of the patients and stress.

Thirdly, it came out clearly that both family members and the patients had many aspects of negative coping strategies. For instance, failure to engage the patients in verbal communication in social settings caused the patients to withdraw brewing stress. This finding provides a link to Jochmann and Ossietzky (2005) finding that in East Africa, some patients with communication disorders are even hidden because neighbors will not tolerate them. Mwihaki (2003) also recorded the high levels of stigma that is linked to disability in the same region. Some of the patients totally avoided social settings and meeting new people among other negative coping strategies. Tension exhibited by most patients at initiating verbal communication caused them both physical and psychological strain. In addition, venting of anger on family members when the patient is frustrated caused a rift in the family affecting relationships.

### 5.4 Recommendations

Investigating voice disorders and their psychosocial impact on laryngeal cancer patients and their families at Kenyatta National Hospital is an embrace of best practice in inclusion of speech therapy in the multi-disciplinary care for enhanced rehabilitation of laryngeal cancer patients. Determining the social impact of the voice disorders on the laryngeal cancer patients and families highlights the major influence that it has on daily interactions of patients with their families hence the need for effective early intervention focusing on both patient and family/caregiver for effective rehabilitation.

By investigating the psychological effect of the voice disorders on the laryngeal cancer patients and families the study seeks to enlighten the clinicians of the myriad sources of patient challenges hence the need for a multidisciplinary approach in

treatment and rehabilitation plan for these patients. Moreover, finding out the coping behavior developed by the laryngeal cancer patient and family in verbal communication provides an important platform upon which speech therapists can focus as they draft their various intervention plans.

The following recommendations are based on the findings of the study.

i. Need for increased public awareness on voice disorders after laryngeal cancer treatment, functional limitations and the social impact it has on the patient and family.

ii. Inclusion of stakeholders in recommending, financing and following up on multi-disciplinary approach in the support and intervention needs of laryngeal cancer patients and families.

iii. Need for the Ministry of Health to engage more speech therapists in hospitals to facilitate effective early intervention for laryngeal cancer patients and families in regard to communication and elimination of negative coping strategies for both patient and family members.

**5. 5 Suggestions for Further Research**

Further research should be done focusing on willingness of family members to be involved in the intervention plan for rehabilitation of laryngeal cancer patients with voice disorders. The speech therapists may be willing to work with the family members/caregivers but they may not be consistent, serious and willing to engage in the rehabilitation process. Further research should also be done using other designs other than a case study design.

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## APPENDICES

### Appendix I: Consent Form

### CONSENT FORM

KENYATTA UNIVERSITY

SCHOOL OF EDUCATION (SPECIAL NEEDS DEPARTMENT)

MASTER OF EDUCATION (SPEECH AND LANGUAGE PATHOLOGY)

RESEARCH TITLE: "***Voice disorders and their psychosocial impact on laryngeal cancer patients and their families".***

***(Please read this consent form carefully before you decide to participate in this study.)***

**Purpose of the research study:**

The purpose of this study is to establish the psychological and social impact of voice disorders on laryngeal cancer patients and their families.

Following a prior appointment with the researcher you will be visited at the ENT clinic at Kenyatta National Hospital. You will be requested to respond to a fifteen to twenty minute interview. A family member/caregiver will be requested on a specific day to attend a Focus Group Discussion for thirty to forty minutes.

**Time required:**

Fifteen to twenty minute session. The researcher will request to have at least two sessions with the patient at different times. The first session will be for preparation and signing of consent while the second session will be for the interview.

**Benefits of the study:**

The findings of this study will be shared with policy makers with a view to influence better therapy services for laryngeal cancer patients with voice disorders and their families.

**Confidentiality:**

Your identity will be kept confidential as dictated by law. The information you provide will be assigned a code number. Any list attaching your true identity to this file will be kept under lock in the supervisor's office. Upon completion of this study

and analysis of data collected, the list will be destroyed and your name not used in any publication.

**Voluntary participation:**

Participation in this study is completely voluntary. If by any chance you choose to withdraw from the study before completion, any earlier collected data will be discarded. No penalty whatsoever is put on anyone who chooses to withdraw.

Kindly sign in the space provided indicating willingness to participate.

Patient's Name _____

Signature _____ (Date) _____

Witness (family member) _____

Signature _____ (Date) _____

## Appendix II: Interview Schedule

### INTERVIEW SCHEDULE

**(To be administered to the patients only)**

**SECTION A**

Time of Interview: _____ Date:_____

Place: _____

Interviewee (Initials): _____

Age: _____

Sex: _____

Marital Status: _____

Occupation: _____

**SECTION B**

1. What brings you to the clinic today?

   _____

   _____

2. Who usually brings you to the clinic?

   _____

   _____

**SECTION C**

3. Share with me your experiences with verbal communication as a result of the voice condition.

   _____

   _____

   _____

   _____

4. What is your immediate reaction in a situation where a family member fails to understand your effort in communicating?

_____

_____

_____

_____

_____

5. Briefly describe how you feel after such an experience.

_____

_____

_____

_____

6. How do these experiences influence your interaction with other family members?

_____

_____

_____

_____

7. In your opinion, how has this voice condition (disorder) affected your life style?

_____

_____

_____

_____

8. Briefly describe other challenges that you have experienced in communication due to the voice disorder.

_____

_____

_____

_____

9. Looking at your overall life, describe your satisfaction in the following areas in light of the changes in your voice?

   Social interactions

   _____

   _____

   Social relations

   _____

   _____

   Independence in communication

   _____

   _____

   Comfort in different environmental features while communicating

   _____

   _____

   Cultural perspectives

   _____

   _____

   Your goals in life

_____

_____

Your standard of life

_____

_____

Family expectations

_____

_____

10. Describe some coping mechanisms you have adopted to help you with the voice disorder?

_____

_____

_____

_____

_____

_____

_____

_____

_____

11. Briefly describe changes you may have noticed in specific family members in trying to adjust to your voice condition.

_____

_____

_____

_____

_____

_____

12. How do you feel about the changes that the above mentioned family members have made in communicating with you?

_____

_____

_____

_____

13. What would you wish that other family members may do to make you more comfortable in the process of speaking?

_____

_____

_____

_____

**Thank you for your co-operation**

## Appendix III: Observation Schedule

### OBSERVATION SCHEDULE

**SECTION A**

Time of observation: _____ Date:_____

Site: _____

Person being observed (Initials) _____

Age: _____

Sex: _____

Marital Status: _____

Occupation: _____

(***Instructions to observer: Record actions/reactions you see and any comments you hear under the following headings***)

1. Patient's general confidence and vibrancy indicators.
   - Calm Restless
   - Eye contact Avoids eye contact
   - Relaxed Tense
   - Happy Sad
   - Freely talks Struggles to talk
   - Clearly conveys the message Fumbles

2. General interaction (withdrawn or freely interacts with family member/caregiver).

   _____

   _____

   _____

   _____

3. Verbal/non-verbal reactions of patient and family member/caregiver in a verbal communication episode.
    a. Patient

    b. Family member/caregiver

    c. Style of interaction after this episode.

4. Patient's verbal and non-verbal efforts in initiating communication.

5. Verbal/non-verbal cues demonstrated by the family member/ caregiver in response to the patient's communication.

6. Any other relevant observation.

**END**

## Appendix IV: Focus Group Discussions

### FOCUS GROUP DISCUSSION QUESTIONS

**Date: _____** **Time: _____**

**Discussion Site: _____**

**Number of Participants**: _____

1. Mention the various modes of communication that we use in our homes.

   _____

   _____

2. Which mode is the most common?

   _____

   _____

3. Share your experiences in verbal communication with the patients since the commencement of the voice disorder.

   a) How would you describe your confidence in verbal communication with the patient in a social set-up based on these experiences?

      _____

      _____

   b) How has this affected your social interactions in the family?

      _____

      _____

4. How do you feel about the patient's condition in relation to verbal communication?

   _____

   _____

5. How has the voice condition affected your life-style as a family?

   _____

   _____

6. Share some coping strategies that you have adopted to accommodate the patient's voice condition.

   a) Could others share more coping strategies that they have adopted?

      _____

      _____

7. What adjustments have you made as a family member/caregiver to accommodate the patient's voice condition?

   a) Have you experienced any challenge due to these adjustments? Please explain.

      _____

      _____

   b) How have these challenges affected your daily operations at home?

      _____

      _____

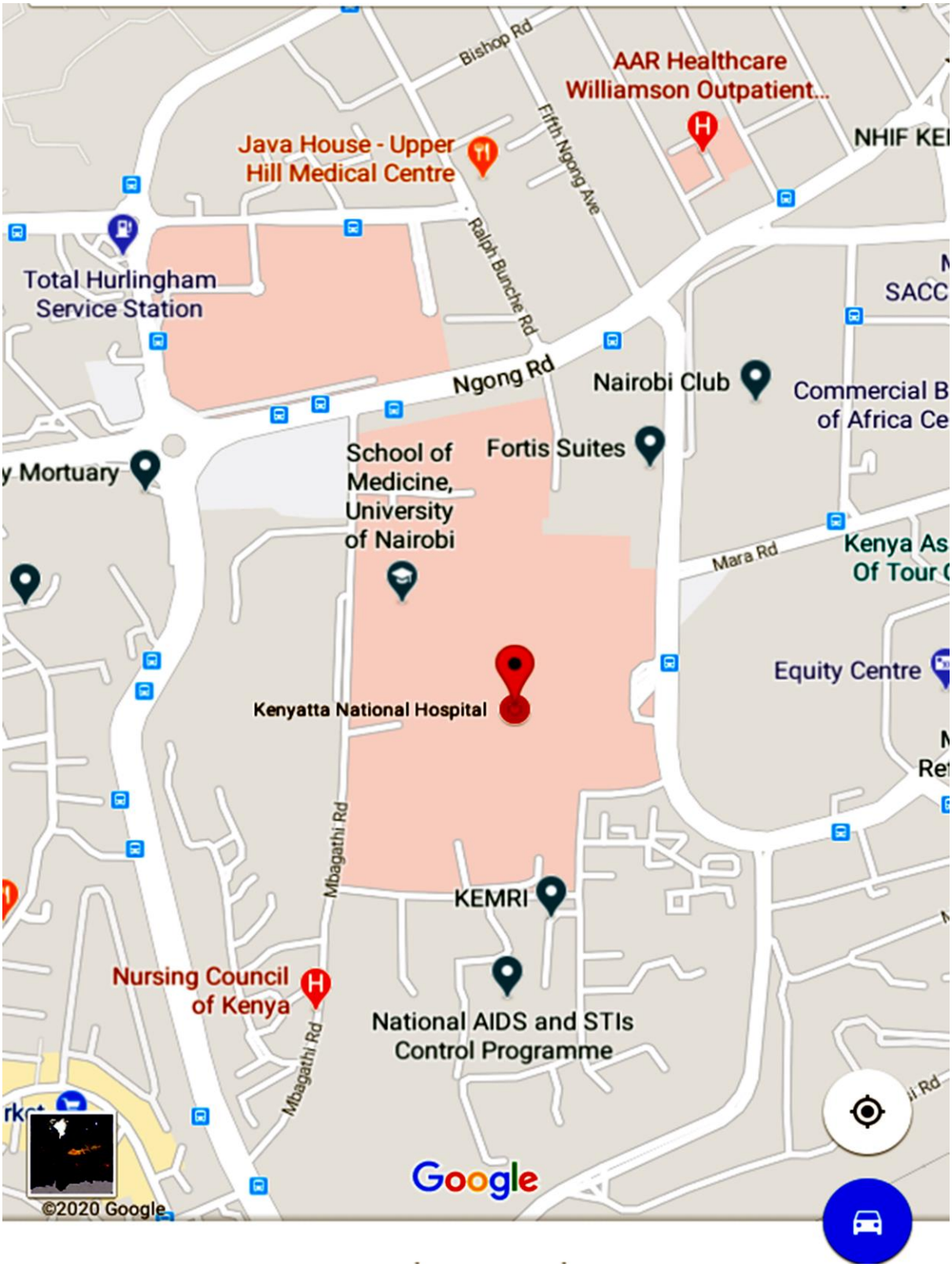
8. Share your ideas on how we can improve verbal communication in the family in the presence of a voice disorder.

   _____

   _____

**END**

## Appendix V: Map

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## Appendix VI: Approval of Research Proposal from Graduate School

KENYATTA UNIVERSITY
GRADUATE SCHOOL

E-mail: dean-graduate@ku.ac.ke
Website: www.ku.ac.ke
P.O. Box 43844, 00100
NAIROBI, KENYA
Tel. 020-8704150

Internal Memo

**FROM:** Dean, Graduate School **DATE:** 8th August, 2018

**TO:** **Ms. Abong'o Anyango Pheny**
**C/o Department of Special Needs Education**

**REF:** E55/CE/26221/14

**SUBJECT:** APPROVAL OF RESEARCH PROPOSAL

We acknowledge receipt of your Research Proposal after fulfilling recommendations raised by the Graduate School Board of 4th July, 2018.

You may now proceed with your Data collection, subject to clearance with the Director General, National Commission for Science, Technology & Innovation.

As you embark on your data collection, please note that you will be required to submit to Graduate School completed Supervision Tracking Forms per semester. The form has been developed to replace the Progress Report Forms. The Supervision Tracking Forms are available at the University's Website under Graduate School webpage downloads.

Thank you.

HARRIET ISABOKE
FOR: DEAN, GRADUATE SCHOOL

CC. Chairman, Department of Special Needs Education

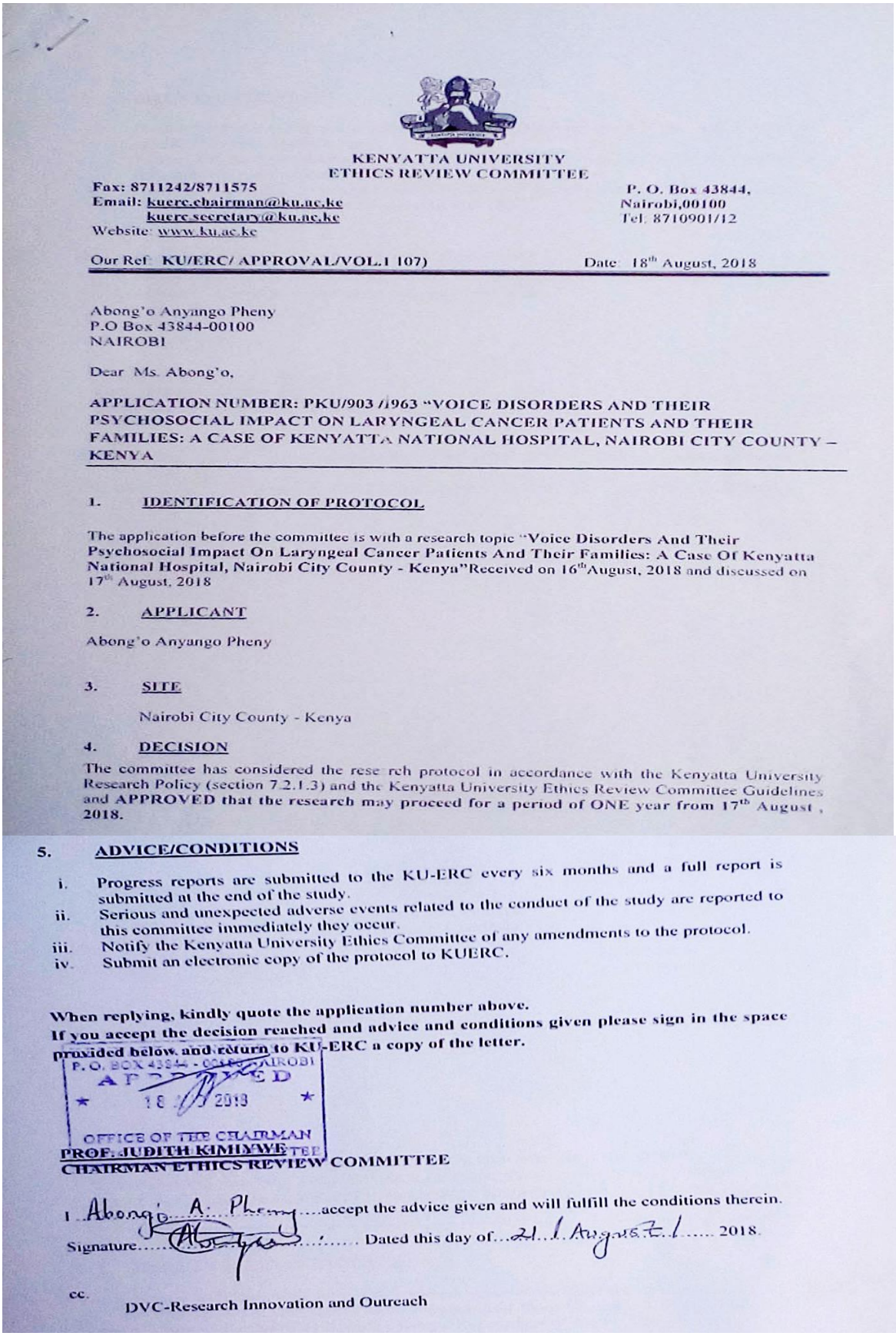
Supervisors:

1. Dr. Abuom Tom
   C/o Department of Special Needs Education
   Kenyatta University

2. Dr. Jessina Muthee
   C/o Department of Special Needs Education
   Kenyatta University

HI/cww

## Appendix VII: Research Approval from Ethics Review Committee Kenyatta University



KENYATTA UNIVERSITY
ETHICS REVIEW COMMITTEE

Fax: 8711242/8711575
Email: kuerc.chairman@ku.ac.ke
kuerc.secretary@ku.ac.ke
Website: www.ku.ac.ke

P. O. Box 43844,
Nairobi,00100
Tel: 8710901/12

Our Ref: KU/ERC/ APPROVAL/VOL.1 107) Date: 18th August, 2018

Abong'o Anyango Pheny
P.O Box 43844-00100
NAIROBI

Dear Ms. Abong'o,

**APPLICATION NUMBER: PKU/903 /1963 "VOICE DISORDERS AND THEIR PSYCHOSOCIAL IMPACT ON LARYNGEAL CANCER PATIENTS AND THEIR FAMILIES: A CASE OF KENYATTA NATIONAL HOSPITAL, NAIROBI CITY COUNTY – KENYA**

**1. IDENTIFICATION OF PROTOCOL**

The application before the committee is with a research topic "**Voice Disorders And Their Psychosocial Impact On Laryngeal Cancer Patients And Their Families: A Case Of Kenyatta National Hospital, Nairobi City County - Kenya**"Received on 16th August, 2018 and discussed on 17th August, 2018

**2. APPLICANT**

Abong'o Anyango Pheny

**3. SITE**

Nairobi City County - Kenya

**4. DECISION**

The committee has considered the research protocol in accordance with the Kenyatta University Research Policy (section 7.2.1.3) and the Kenyatta University Ethics Review Committee Guidelines and **APPROVED that the research may proceed for a period of ONE year from 17th August , 2018.**

**5. ADVICE/CONDITIONS**

i. Progress reports are submitted to the KU-ERC every six months and a full report is submitted at the end of the study.
ii. Serious and unexpected adverse events related to the conduct of the study are reported to this committee immediately they occur.
iii. Notify the Kenyatta University Ethics Committee of any amendments to the protocol.
iv. Submit an electronic copy of the protocol to KUERC.

**When replying, kindly quote the application number above.**
**If you accept the decision reached and advice and conditions given please sign in the space provided below and return to KU-ERC a copy of the letter.**

P.O. BOX 43844 - 00100 NAIROBI
APPROVED
18 / 8 / 2018
OFFICE OF THE CHAIRMAN

**PROF. JUDITH KIMIYWE**
**CHAIRMAN ETHICS REVIEW COMMITTEE**

I Abong'o A. Pheny ....accept the advice given and will fulfill the conditions therein.

Signature..... Dated this day of...21st August..... 2018.

cc.
DVC-Research Innovation and Outreach

## Appendix VII: Research Authorization from Ministry of Education

Republic of Kenya
MINISTRY OF EDUCATION
STATE DEPARTMENT OF EARLY LEARNING & BASIC EDUCATION

Telegrams: "SCHOOLING", Nairobi
Telephone: Nairobi 020 2453699
Email: rcenairobi@gmail.com
cdenairobi@gmail.com

When replying please quote

REGIONAL COORDINATOR OF EDUCATION
NAIROBI REGION
NYAYO HOUSE
P.O. Box 74629 – 00200
NAIROBI

Ref: RCE/NRB/RESEARCH/1 VOL. I

DATE: 18th February, 2019

Pheny Anyango Abongo
Kenyatta University
P O Box 43844 - 00100
**NAIROBI**

**RE: RESEARCH AUTHORIZATION**

We are in receipt of a letter from the National Commission for Science, Technology and Innovation regarding research authorization in Nairobi County on "***Voice disorders and their psychosocial impact on laryngeal cancer patients and their families: A case of Kenyatta National Hospital, Nairobi City County-Kenya***".

This office has no objection and authority is hereby granted for a period ending **17th January, 2020** as indicated in the request letter.

Kindly inform the Sub County Director of Education of the Sub County you intend to visit.

**KINOTI KIOGORA**
**FOR: REGIONAL COORDINATOR OF EDUCATION**
**NAIROBI**

C.C

Director General/CEO
National Commission for Science, Technology and Innovation
**NAIROBI**

## Appendix IX: Research Authorization from Ministry of Education State Department for Early Learning & Basic Education

REPUBLIC OF KENYA

**MINISTRY OF EDUCATION**

**State Department for Early Learning & Basic Education**

Telegrams: "EDUCATION", Eldoret
Telephone: 053-2063342 or 2031421/2
Mobile : 0719 12 72 12/0732 260 280
Email: cdeuasingishucounty@yahoo.com
: cdeuasingishucounty@gmail.com
When replying please quote:

Office of The County Director of Education,
Uasin Gishu County,
P.O. Box 9843-30100,
ELDORET.

Ref: No. MOEST/UGC/TRN/9/VOL. IV/27

20TH FEBRUARY, 2019

Pheny Anyango Abongo
Kenyatta University
P.O Box 43844 -00100
**NAIROBI**

**RE: RESEARCH AUTHORIZATION**

This office has received a request authorizing you to carry out research on *"Voice disorders and their psychosocial impact on laryngeal cancer patients and their families" in* Uasin Gishu County.

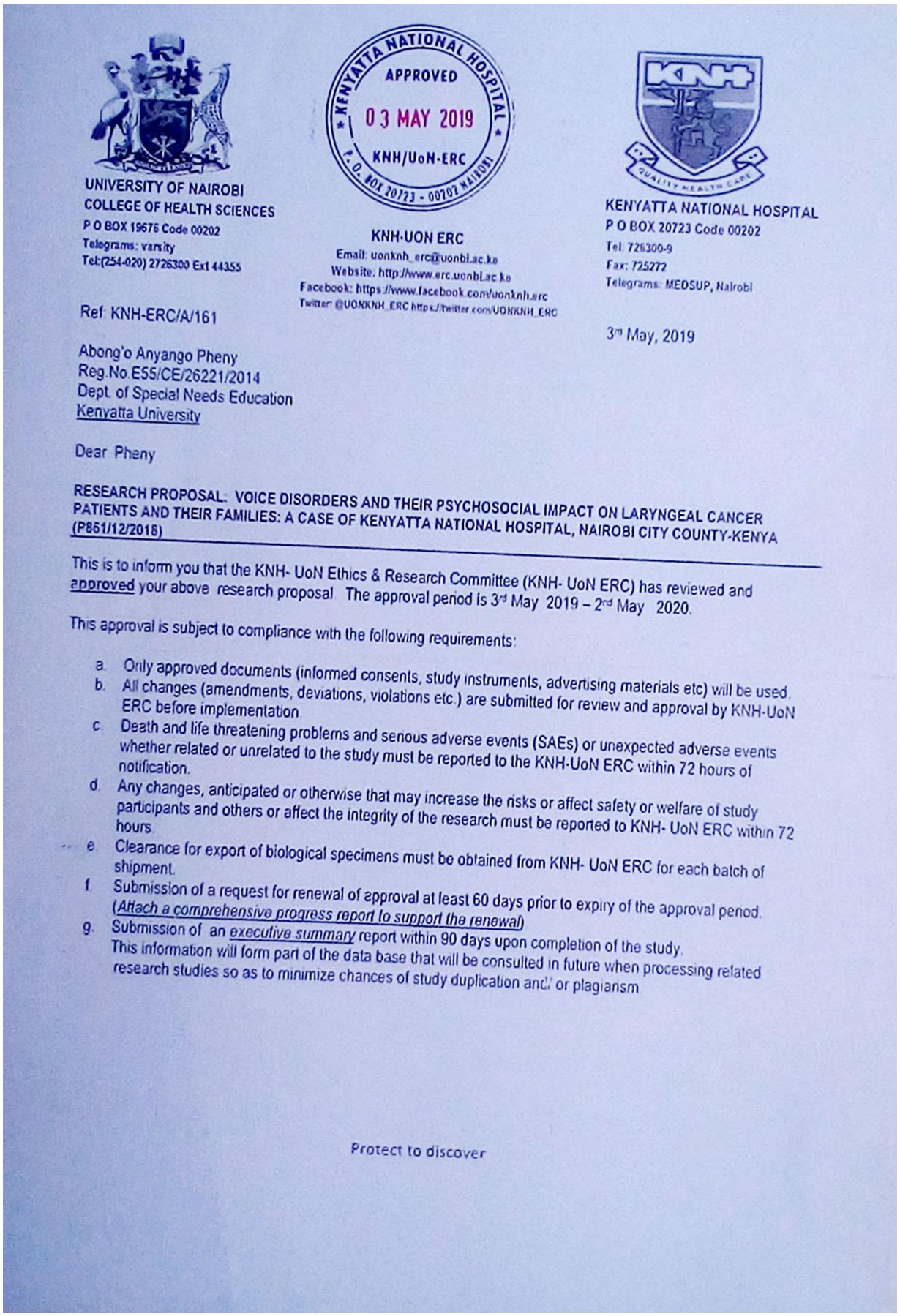
We wish to inform you that the request has been granted until 17th January, 2020. The authorities concerned are therefore requested to give you maximum support.

We take this opportunity to wish you well during this data collection.

FOR COUNTY DIRECTOR OF EDUCATION
UASIN GISHU COUNTY
P.O. Box 9843-30100 ELDORET
Tel. 0719-127 212/ 053-2063342

**Julius Yano**
***For:* COUNTY DIRECTOR OF EDUCATION**
**UASIN GISHU.**

## Appendix X: Research Approval from Kenyatta National Hospital



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KENYATTA NATIONAL HOSPITAL
APPROVED
03 MAY 2019
KNH/UoN-ERC
P. O. BOX 20723 - 00202 NAIROBI

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/161

3rd May, 2019

Abong'o Anyango Pheny
Reg.No.E55/CE/26221/2014
Dept. of Special Needs Education
Kenyatta University

Dear Pheny

**RESEARCH PROPOSAL: VOICE DISORDERS AND THEIR PSYCHOSOCIAL IMPACT ON LARYNGEAL CANCER PATIENTS AND THEIR FAMILIES: A CASE OF KENYATTA NATIONAL HOSPITAL, NAIROBI CITY COUNTY-KENYA (P851/12/2018)**

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and approved your above research proposal. The approval period is 3rd May 2019 – 2nd May 2020.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*)
g. Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover

## Appendix XI: Research Approval from Institutional Research and Ethics Committee (IREC) Moi University

**INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)**

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
COLLEGE OF HEALTH SCIENCES
P.O. BOX 4606
ELDORET
Tel: 33471/2/3

11th July, 2019

Reference: IREC/2019/183

Pheny Anyango Abongo,
Kenyatta University,
P.O. Box 43844-00100,,
**NAIROBI- KENYA.**

INSTITUTIONAL RESEARCH & ETHICS COMMITTEE
11 JUL 2019
APPROVED
P. O. Box 4606 - 30100 ELDORET

Dear Ms. Abongo,

**RE: EXEMPT APPROVAL**

The Institutional Research and Ethics Committee has reviewed your proposal titled:

***"Voice Disorders and their Psychosocial Impact on Laryngeal Cancer Patients and their Families: A Case of Kenyatta National Hospital, Nairobi City County -Kenya".***

The study has been given Exempt Approval as per our SOP's. You are therefore permitted to commence your investigations.

Note that this approval is for 1 year; it will thus expire on 10th July, 2020. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Sincerely,

**PROF. E. WERE**
**CHAIRMAN**
**INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE**

cc:

| | | |
|---|---|---|
| CEO | - | MTRH |
| Principal | - | CHS |
| Dean | - | SOM |
| Dean | - | SPH |
| Dean | - | SOD |
| Dean | - | SON |

**Appendix XII: Research Approval from Moi Teaching and Referral Hospital**

An ISO 9001:2015 Certified Hospital

# MOI TEACHING AND REFERRAL HOSPITAL

Telephone :( +254)053-2033471/2/3/4
Mobile: 722-201277/0722-209795/0734-600461/0734-683361
Fax: 053-2061749
Email: ceo@mtrh.go.ke/directorsofficemtrh@gmail.com

Nandi Road
P.O. Box 3 – 30100
**ELDORET,** KENYA

**Ref:** ELD/MTRH/R&P/10/2/V.2/2010

17th July, 2019

Pheny Anyango Abongo,
Kenyatta University,
P.O. Box 43844-00100,
**NAIROBI-KENYA.**

## APPROVAL TO CONDUCT RESEARCH AT MTRH

Upon obtaining approval from the Institutional Research and Ethics Committee (IREC) to conduct your research proposal titled:-

***"Voice Disorders and their Psychosocial Impact on Laryngeal Cancer Patients and their Families: A Case of Kenyatta National Hospital, Nairobi County - Kenya".***

You are hereby permitted to commence your investigation at Moi Teaching and Referral Hospital.

MOI TEACHING AND REFERRAL HOSPITAL
CEO
APPROVED
18 JUL 2019
P. O. Box [illegible]-30100, ELDORET

18/07/2019

**DR. WILSON K. ARUASA, *MBS***
**CHIEF EXECUTIVE OFFICER**
**MOI TEACHING AND REFERRAL HOSPITAL**

cc - Senior Director, (CS)
- Director of Nursing Services (DNS)
- HOD, HRISM

## Appendix XIII: Research Approval from National Commission for Science, Technology and Innovation (NACOSTI)

**NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY AND INNOVATION**

Telephone:+254-20-2213471, 2241349,3310571,2219420
Fax:+254-20-318245,318249
Email: dg@nacosti.go.ke
Website : www.nacosti.go.ke
When replying please quote

NACOSTI, Upper Kabete
Off Waiyaki Way
P.O. Box 30623-00100
NAIROBI-KENYA

Ref: No. **NACOSTI/P/19/15193/27074**

Date: **17th January, 2019**

Pheny Anyango Abongo
Kenyatta University
P.O. Box 43844-00100
**NAIROBI.**

**RE: RESEARCH AUTHORIZATION**

Following your application for authority to carry out research on ***"Voice disorders and their psychosocial impact on laryngeal cancer patients and their families: A case of Kenyatta National Hospital, Nairobi City County-Kenya"*** I am pleased to inform you that you have been authorized to undertake research in **Nairobi and Uasin Gishu Counties** for the period ending **17th January, 2020.**

You are advised to report to **the County Commissioners, the County Directors of Education and the County Directors of Health Services, Nairobi and Uasin Gishu Counties** before embarking on the research project.

Kindly note that, as an applicant who has been licensed under the Science, Technology and Innovation Act, 2013 to conduct research in Kenya, you shall deposit **a copy** of the final research report to the Commission within **one year** of completion. The soft copy of the same should be submitted through the Online Research Information System.

COUNTY COMMISSIONER UASIN GISHU COUNTY 20/2/19.

**GODFREY P. KALERWA MSc., MBA, MKIM**
**FOR: DIRECTOR-GENERAL/CEO**

Copy to:

The County Commissioner
Nairobi County.

18/02/2019 COUNTY COMMISSIONER NAIROBI COUNTY P.O. Box 30124-00100, NBI TEL: 341366

The County Director of Education
Nairobi County.

The County Directors of Health Services
Nairobi County.

The County Commissioner
Uasin Gishu County.

The County Director of Education
Uasin Gishu County.

The County Directors of Health Services
Uasin Gishu County.

COUNTY DIRECTOR-CLINICAL SERVICES
20 FEB 2019
UASIN GISHU COUNTY
P. O. Box 5665-30100, ELDORET

## Appendix XIII: Research Permit from NACOSTI

THIS IS TO CERTIFY THAT:
*MS. PHENY ANYANGO ABONGO*
of KENYATTA UNIVERSITY, 28113-100
NAIROBI,has been permitted to conduct
research in *Nairobi, Uasin-Gishu Counties*

on the topic: *VOICE DISORDERS AND THEIR PSYCHOSOCIAL IMPACT ON LARYNGEAL CANCER PATIENTS AND THEIR FAMILIES: A CASE OF KENYATTA NATIONAL HOSPITAL, NAIROBI CITY COUNTY-KENYA*

for the period ending:
*17th January,2020*

Permit No : NACOSTI/P/19/15193/27074
Date Of Issue : 17th January,2019
Fee Recieved :Ksh 1000

.....
*Applicant's Signature*

.....
*Director General*
*National Commission for Science, Technology & Innovation*

**THE SCIENCE, TECHNOLOGY AND INNOVATION ACT, 2013**

The Grant of Research Licenses is guided by the Science, Technology and Innovation (Research Licensing) Regulations, 2014.

**CONDITIONS**

1. The License is valid for the proposed research, location and specified period.
2. The License and any rights thereunder are non-transferable.
3. The Licensee shall inform the County Governor before commencement of the research.
4. Excavation, filming and collection of specimens are subject to further necessary clearance from relevant Government Agencies.
5. The License does not give authority to transfer research materials.
6. NACOSTI may monitor and evaluate the licensed research project.
7. The Licensee shall submit one hard copy and upload a soft copy of their final report within one year of completion of the research.
8. NACOSTI reserves the right to modify the conditions of the License including cancellation without prior notice.

National Commission for Science, Technology and innovation
P.O. Box 30623 - 00100, Nairobi, Kenya
TEL: 020 400 7000, 0713 788787, 0735 404245
Email: dg@nacosti.go.ke, registry@nacosti.go.ke
Website: www.nacosti.go.ke

REPUBLIC OF KENYA

NACOSTI

**National Commission for Science, Technology and Innovation**

**RESEARCH LICENSE**

**Serial No.A 22757**

**CONDITIONS: see back page**