

**THE HALLMARKS OF SUCCESSFUL ALARYNGEAL VOICE REHABILITATION  
FOLLOWING A TOTAL LARYNGECTOMY USING TRACHEO-ESOPHAGEAL  
PUNCTURE WITH VOICE PROSTHESIS: PERSPECTIVES OF KEY ROLE  
PLAYERS**

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DEGREE MASTER OF COMMUNICATION PATHOLOGY  
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BY  
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## DECLARATION

### **The Hallmarks of Successful Alaryngeal Voice Rehabilitation following a Total Laryngectomy using Tracheo-Esophageal Puncture with Voice Prosthesis: Perspectives of Key Role Players**

I, Suvanya Naidu, declare that:

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Signed: \_\_\_\_\_

Date: 18/03/2013

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## ABSTRACT

A total laryngectomy (TL) affects the quality of life (QoL) of individuals who have undergone this surgical procedure, as changes are seen in respiration, swallowing and communication. The aim of this study was to gather perspectives of the hallmarks of successful alaryngeal voice rehabilitation by tracheo-esophageal puncture (TEP) with voice prosthesis of laryngectomy patients from key role players based at a public hospital in Gauteng Province, South Africa. A qualitative method of inquiry was used, namely a single-program, collective case study. A focus group, comprising of four individuals who had undergone a total laryngectomy, was held to identify the participants' views about successful voice rehabilitation. From this focus group, one successful communicator was identified to be interviewed individually. Five semi-structured, face-to-face individual interviews using open-ended questions were conducted with five key role players in alaryngeal voice rehabilitation. The interviewees comprised of the successfully rehabilitated person with total laryngectomy (PWTL), his caregiver, an ear, nose and throat surgeon, speech-language pathologist and specialist nurse, to gather their perspectives on the factors that contributed to successful alaryngeal voice rehabilitation using TES. The Thematic Framework Approach was used to qualitatively analyze the data. Factors identified as contributing to success included patient selection for tracheo-esophageal puncture, information provision, support in the form of support groups, spiritual as well as family support, stomal care, the skill of the team and key management issues. Issues related to finance adversely affect the provision of voice prostheses and/or the provision of correctly sized prostheses and accessories. Systems have been implemented at the hospital to provide the option of TEP with voice prosthesis without much consideration to the other two alaryngeal options; namely esophageal speech and electrolarynx speech. Implications for clinical practice have been identified especially the need to provide more social support services to persons with TL.

## LIST OF ABBREVIATIONS

CG	:	Caregiver
DOH	:	Department of Health
ENT	:	Ear, nose and throat specialist or otolaryngologist
FG	:	Focus Group
HME	:	Heat and Moisture Exchanger
PE	:	Pharyngeo-esophageal
PES	:	Pharyngo-esophageal segment
PWTL	:	Person with total laryngectomy
PsWTL	:	Persons with total laryngectomy
QoL	:	Quality of life
SES	:	Socio-economic status
SLP	:	Speech-Language Pathologist
SN	:	Specialist Nurse
TE	:	Tracheo-esophageal
TEP	:	Tracheo-esophageal Puncture
TES	:	Tracheo-esophageal Speech
TL	:	Total Laryngectomy
VP	:	Velo-pharyngeal

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## **CHAPTER ONE: ORIENTATION**

### **1.1. Introduction**

The purpose of this research was to gather multiple perspectives of successful alaryngeal voice rehabilitation via tracheo- esophageal puncture with voice prosthesis from key-role players based at a public hospital in South Africa. The information gathered from this study aims to improve service delivery by informing clinical practice, and prompting further research in the field of Speech-Language Pathology in South Africa. Communication and swallowing both fall within the scope of practice of speech-language pathologists (SLPs) working within the field of laryngectomy management. In this study however, the researcher has chosen to focus only on communication, more specifically voice rehabilitation, as TEP with voice prosthesis continues to challenge clinicians worldwide. Furthermore, TEP was conceptualized to improve communication by means of surgical voice restoration. The use of TEP does have anatomical and clinical implications for swallowing which is an important field in itself; however these will not be discussed as communication in the form of voice rehabilitation is the main focus of this study.

An orientation to the present research study is provided in this chapter. It comprises of a background to the research, the problem statement, with a discussion on the focus of this study, the definitions of terms used in this study, and an outline of each of the following chapters.

### **1.2. Background**

The following case study has been provided to illustrate the context and background of this research:

**Mr John<sup>1</sup> recently underwent a total laryngectomy at a tertiary hospital in Johannesburg. He was told that the operation was needed to save his life and that it may affect his eating and definitely his ability to voice. He envisaged a lonely and dull future but agreed to the operation. A few weeks later with the expertise and skill of a dedicated rehabilitation team, he was discharged from the hospital and was almost immediately able to communicate functionally with a tiny device placed in his neck. He learned how to care for the device and was told to come back when it gave problems.**

A laryngectomy is indicated during a late-stage cancer, commonly of squamous cell origin in the mucous membrane of the upper aero-digestive tract which may include the cavities and surrounding organs of the mouth, nose and throat, salivary glands as well as the larynx (Hilgers, 2004; Mohebbati & Shah, 2010). Malignant tumours found in this region are commonly referred to as cancers of the head and neck (Hilgers, 2004).

“A total laryngectomy includes the complete removal of the larynx as well as the thyroid and cricoid cartilages, the hyoid bone, two tracheal rings, and the extrinsic strap muscles” (Hopkins, Gross, Knutson, & Candia, 2005, p. 10).

In recent years, concurrent use of organ sparing techniques such as radiotherapy and chemotherapy have been used more often to treat the cancer, resulting in fewer total laryngectomies being performed (Kazi, n.d.; Mohebbati & Shah, 2010). However, many doctors have no choice but to perform a laryngectomy to save the life of a patient after numerous failed attempts to rid the patient of cancer using the organ sparing techniques. Therefore, total laryngectomy (TL) is used as a salvage procedure (Kazi, Pawar, Sayed & Dwivedi, 2010; Mohebbati & Shah, 2010).

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<sup>1</sup> Not his real name

Total laryngectomy remains a valuable treatment alternative for advanced laryngeal cancer (Genden, Ferlito, Rinaldo, Silver, Fagen, Sua' rez, Langendijk, Lefebvre, Bradley, Leemans, Chen, Jose, Wolf, 2008). The advanced laryngeal cancer may be primary in some individuals, or secondary to other cancers that have spread to the larynx. Ignorance and a lack of public awareness of the signs and symptoms of laryngeal cancer and resultant late presentation of the patient with symptoms commonly seen in Sub-Saharan Africa contribute to the typical treatment option being TL (Iseh, 2011). Furthermore, the cost of performing a TL has been found to be significantly less than that of organ preserving methods of cancer treatment (Genden et al., 2008), prompting hospitals with budgetary constraints to consider the more cost-effective TL. A TL affects more than one life function necessary to ensure an improved quality of life (QoL) (Eadie & Doyle, 2005).

### **1.3. Quality of Life after a Total Laryngectomy**

Quality of life is commonly used as a measurement of successful treatment for various diseases (Palmer & Graham, 2004). Historically, positive QoL in laryngeal cancer was viewed merely as the successful treatment of the cancer with little or no regard for post-treatment well-being (Palmer & Graham, 2004). One such example of treatment is a TL. However, the QoL in individuals undergoing a TL has improved considerably over the past 30 years with the technological advances seen in voice and speech rehabilitation (Kazi et al., 2010; Kapila, Deore, Palav, Kazi, Shah & Jagade, 2011). Some of the facets that have contributed to the upliftment in the perceived QoL of these individuals included improvements with respiration, swallowing and voice. The focus of this study as mentioned above is voice rehabilitation.

After a TL, the individual will experience changes in olfaction, respiration, swallowing, and communication brought about by a surgically altered anatomy that may influence his/her QoL. Factors affecting QoL may include though are not limited to physical, emotional, functional domains as well as concerns related to the recurrence of the cancer (Palmer & Graham, 2004). A survey conducted by Palmer and Graham (2004), revealed that those who were capable of breathing with no assistance, ate with minimal difficulty, and communicated functionally, enjoyed higher levels of QoL (Palmer & Graham, 2004; Eadie & Doyle, 2005). Communication especially had positive correlations with improved QoL, as it enables social interaction and also increases one's chances of finding employment thereby maintaining independence and dignity (Palmer & Graham, 2004).

#### **1.4. Vital Life Functions affected by Total Laryngectomy**

Vital life functions significantly affected post-laryngectomy include breathing, eating, olfaction, and communication.

##### *1.4.1. Effect on breathing*

Individuals who have undergone a laryngectomy will no longer be able to breathe through their nasal cavities as the new site for breathing is the neck via a permanent stoma (Hilgers, 2004). The stoma does not provide the natural humidification, filtration and cleansing features as the nasal cavity (Ackerstaff, Hilgers, Aaronson & Balm, 1994). Air is inhaled and exhaled through a stoma in the neck, with an ideal diameter of approximately 15mm (Paleri, Wight, Owen, Hurren & Stafford, 2006), large enough for foreign particles, flying insects, rain water, exposure to fumes, among others, to enter the lungs. Special precautions would have to be implemented to protect the stoma. Changes to one's lifestyle may be made with regard to washing and swimming with modifications that are available to improve safety.

Further effects on breathing may be directly influenced by the size of the stoma, which is known to decrease in diameter for some individuals over time (Calder, MacAndie & MacGregor, 2006), thereby restricting airflow. The stoma is also a common site of infection and granulation formation as this opening was surgically created (Albirmawy, Elsheikh, Saafan & Elsheikh, 2006; Calder et al., 2006).

#### *1.4.2. Effect on eating*

Changes in eating may result as swallowing and the loss of taste occur post-laryngectomy, which may affect one's enjoyment of food leading to changes in nutritional habits that may lead to compromised nutrition and a reduced QoL (Lennie, Christman & Jadack, 2001). The effects of radiation therapy may lead to xerostomia, i.e. a dry mouth, which would affect the mastication process at the oral preparatory phase of swallowing (Genden et al., 2008). Remedies for this may include taking sips of water after each mouthful of food to ease the mastication process to form a cohesive bolus to swallow, or by including liquid-based dishes such as soups as part of meals (Casper & Colton, 1998). Another issue is as a result of the surgical procedure required for tracheo-esophageal voicing which results in the creation of a fistula between the back of the trachea to the esophagus for the placement of a voice prosthesis. In the case of an inadequately placed prosthesis, aspiration of liquids or food may occur (Casper & Colton, 1998).

#### *1.4.3. Effect on olfaction*

The individual who has not had a laryngectomy is able to smell via olfactory receptors in the nasal cavity (Heald & Schiffman, 1997). However since the airway of an individual who has undergone a laryngectomy is no longer through the nasal cavity the sense of smell is almost completely lost (Hilgers, 2004). Mechanisms to improve the sense of smell have been



developed and do form part of rehabilitation programmes used today (Risberg-Berlin, Ryden, Moller & Finizia, 2009).

#### *1.4.4. Effect on communication*

The effect of a laryngectomy on communication compromises the verbal communication due to a loss of the source of sound, the larynx. Each individual has his/her own unique voice quality; however with a total laryngectomy which is literally defined as the removal of the larynx (Hopkins et al., 2005) the individual no longer has the voice he or she was born with. Palmer & Graham (2004) conducted a survey with 170 laryngectomees to identify the factors that improved QoL in an individual, and found that communication fared highly with increased QoL in persons with total laryngectomy (PWTL). The drastic change from being able to voice, to voiceless may have negative implications for social participation, being able to work, and having a sense of 'belonging' in one's community.

### **1.5. Alaryngeal Communication Options**

Individuals who have undergone a laryngectomy may communicate by means of one or more of the three alaryngeal voicing methods which include esophageal speech, electrolarynx speech and tracheo-esophageal speech as discussed below.

#### *1.5.1. Esophageal speech (ES)*

Esophageal speech refers to a process whereby air is forced into the esophagus, trapped in the pharyngo-esophageal segment and expelled via the oral cavity thereby creating a new source of sound that can be shaped into speech by means of the articulators (Hopkins et al., 2005).

If mastered, esophageal speech is probably the best method to use as it requires no further surgery, no costly device, and is hands free (Kazi et al., 2010). The challenges with esophageal speech are that it is a lengthy and difficult process to master with varying rates of success seen globally (Hilgers, 2004). Also, the voice quality is unnatural, and the length of utterance is dependent on the amount of air trapped in the esophagus, which is limited. The number of people who master esophageal speech to become clear and articulate speakers is few (Hilgers, 2004).

### *1.5.2. Electrolarynx speech*

An electrolarynx is a hand-held electrical device that is held against the base of the chin or cheek which sends sound vibrations through the mucosa of the skin that are then shaped into speech by the articulators (Hopkins et al., 2005; Xi, 2010). The sound produced is robotic and monotonous. The cost of an electrolarynx is high, and requires frequent battery replacements. Furthermore, the individual would always need to make use of one hand to use the device (Kazi, n.d).

### *1.5.3. Tracheo-esophageal speech*

Tracheo-esophageal speech is the resultant form of communication from tracheo-esophageal puncture with voice prosthesis, a surgical voice restoration method whereby a fistula is surgically created between the trachea and esophagus to allow air to be directed into the esophagus via a one-directional voice prosthesis to enable voice production (Kazi, 2007). Thereafter, the voice produced is shaped by the oral articulators to produce speech. Tracheo-esophageal speech is the preferred alaryngeal method available and the voice rehabilitation method of choice following a total laryngectomy (Kazi et al., 2010). However there is no

evidence that any single method is the best for each and every patient (Frowen & Perry, 2001; Kazi 2007).

### **1.6. Problem Statement**

Voice and speech rehabilitation following a laryngectomy includes the use of one or a combination of the three alaryngeal methods discussed above: namely esophageal speech (ES), electrolarynx speech, and tracheo-esophageal speech (TES) (Xi 2010). Of the three alaryngeal voice methods available, TES boasts the highest success rates (Pawar et al., 2008; Kazi, Nutting, Rhys-Evans & Harrington, 2009; Elmiyeh, Dwivedi, Jallali, Chisholm, Kazi, Clarke & Rhys-Evans, 2010; Kapila et al., 2011). Tracheo-esophageal speech within the South African context is therefore the focus of this study.

Evidence suggests that TES provides the best sounding voice in terms of naturalness, volume, and speech intelligibility, and can be hands-free (Op De Coul, Ackerstaff, Van As-Brooks, Van Den Hoogen, Meeuwis, Manni & Hilgers, 2005; Kazi et al., 2009; Kapila et al., 2011) and is the quickest of all the alaryngeal methods to master, thus making it the “gold-standard” in alaryngeal voice rehabilitation (Hilgers, 2004). However, TES is expensive. There is a high cost involved with the use of this device, including regular check-ups for re-sizing and valve replacement (Staffieri, Mostafea, Varghese, Kitcher, Jalisi, Fagan, Staffieri & Marioni, 2006; Pawar et al., 2008). The high cost incurred may pose financial constraints on a hospital in a developing country, where the incidence of laryngeal cancer is said to be great (Staffieri et al., 2006; Kazi, 2007).

The management of persons with total laryngectomy via TES is multidisciplinary in nature (Frowen & Perry, 2001; Ryan, Yong, Pracy & Simo, 2004; Collins, Flynn, Melville,

Richardson & Eastwood, 2005), requiring the involvement of highly skilled medical personnel including but not limited to an ear, nose and throat (ENT) surgeon, specialist nurse (SN), a speech-language pathologist (SLP), and in some cases a psychologist. A developing country like South Africa would find it challenging to sustain a system of providing TEP with voice prosthesis (VP) given the high cost involved in the maintenance of the device, close monitoring and the regular follow-up procedures it requires. South Africa's health budget is strained to meet the population's needs. HIV/AIDS and Tuberculosis are top priority diseases that account for a large percentage of the health budget. Furthermore, our public health sector is facing a shortage of skilled healthcare professionals (Human Rights Commission, 2009). Despite these challenges, successful cases of TES with voice prostheses have been reported in South African public hospitals (Fagan, Lentin, Oyarzabal, Isaacs & Sellars, 2002; Cornu, Vlantis, Elliot & Gregor, 2003).

Regardless of the high global success rates of TES (Hilgers, 2004; Kazi et al., 2010), a small percentage of people are still not able to develop TES despite being suitable candidates for the procedure (Frowen & Perry, 2001). Among the studies done on TES there is a strong focus from a singular perspective, i.e. either the patient's perspective (Noonan & Hegarty, 2010), or the ENT surgeon's (Kazi et al., 2010) or the SLT's (Culton & Gerwin, 1998). This tendency is further emphasised by a dearth of studies that pay attention to the caregiver's perspective. In this study, the term CG refers generally to a person who provides care and support to the PWTL. The CG would know the PWTL from a personal perspective. The CG may be a family member, friend, paid carer. He/she may provide care in the form of assistance with activities of daily living, chores, moral support, family support, be a companion to the PWTL, accompany him/her to health check-ups, among others. Few

studies, however, have identified the various factors that promote successful use of TES from the perspectives of multiple role players.

It is in this light that this study has been done. This study aims to fill a gap in the literature by gaining the perspectives of multiple role players on successful TES use; namely the patient, his/her caregiver, the ENT surgeon, SLP and SN, with specific focus on a public sector hospital in South Africa. Gathering of multiple perspectives provides a holistic account of the voice rehabilitative process from beginning to end. Multiple perspectives allow the reader to gauge whether there is consistency in goals and to identify the gaps or shortcomings within the voice rehabilitation process.

### **1.7. Research Question**

What are the hallmarks of successful voice rehabilitation by tracheo-esophageal speech at a public hospital in South Africa?

### **1.8. Definition of Terms**

The following terms that have been frequently used in the study are defined as follows within the context of this study:

#### **Laryngectomy**

A laryngectomy refers to the surgical procedure where part of, or the entire larynx otherwise known as the voice box, is removed due to a very advanced stage of cancer.

#### **Total laryngectomy (TL)**

“A total laryngectomy includes the complete removal of the larynx as well as the thyroid and cricoid cartilages, the hyoid bone, two tracheal rings, and the extrinsic strap muscles” (Hopkins, Gross, Knutson & Candia, 2005, p. 10).

## **Laryngectomy**

This term refers to a person who has undergone a TL. However, in this study “person with total laryngectomy” (PWTL) will be used to refer to such a person.

## **Tracheo-esophageal puncture (TEP)**

A tracheo-esophageal puncture “is a procedure whereby a puncture is created between the posterior wall of the tracheostome and the upper esophagus into which a one-way silicone valve is inserted” (Kazi, 2007, p. 188).

## **Tracheo-esophageal speech (TES)**

“Tracheo-esophageal speech is based on the premise that exhaled tracheal air is shunted into the pharynx through a small, silicone valved prosthesis into a fistulous tract to produce a sound that can be used for speech” (Kazi, 2007, p. 188). The airway is closed off as exhaled air is redirected to the oral cavity whereby the sound is made intelligible by the articulators for speech.

## **Quality of Life**

Quality of life refers to the overall wellbeing of the individual (Palmer & Graham, 2004). It may increase or decrease with a change in medical condition or a life situation (Kazi, 2007).

## **1.9. Outline of Chapters**

Chapter 1 provides an orientation to the study and describes the research problem and a motivation for the current study. A glossary with definitions of terms used in the study is also included in this chapter.

Chapter 2 provides a review of the literature pertaining to the effects of a total laryngectomy on the QoL of the individual. The chapter also discusses the successes, challenges and complications associated with TEP with voice prosthesis. The voice rehabilitation team

members are identified and factors that contribute to the successful rehabilitation of the PWTL are highlighted.

Chapter 3 presents the aims and objectives of the study and describes the methodology used to achieve these. A qualitative method of inquiry was used. Data was collected using a focus group and semi-structured face-to-face interviews of all key role players.

Chapter 4 presents an interpretation of the findings based on the objectives outlined for analysis.

Chapter 5 presents the conclusions derived from the present study and provides recommendations for future research and clinical practice.

### **1.10. Summary of Chapter**

This chapter provided a background to the study, the problem statement, a background to the laryngectomy procedure and the effects it has on the life of the individual, particularly its impact on communication. The three alaryngeal voicing options post-laryngectomy have been introduced and the rationale for why TEP has been the focus of this study has been provided. The next chapter provides a review of the literature.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1. Introduction**

This study aimed to look at the hallmarks of successful alaryngeal voice rehabilitation using TES from the perspectives of key role players involved in the management of PsWTL in a large South African public hospital. This chapter provides a review of the literature which assists in delineating the problem statement of the present study. Information about the South African healthcare system is presented in order to gain more clarity about the context in which the present study was conducted. The effects on the quality of life of individuals who have undergone a TL, as well as a discussion on why TES came to become the “gold standard” in alaryngeal voice rehabilitation around the world including South Africa, are discussed. The complications associated with TES as well as the hallmarks of success in TES according to the literature are discussed. The voice rehabilitation team members are identified and factors that contribute to the successful rehabilitation of the PWTL, as defined by the current literature in the field are highlighted.

### **2.2. Review of the State of Healthcare in South Africa**

South Africa’s first free and fair democratic elections held in 1994 heralded a transformation to redress the inequalities of the apartheid regime. The nature of this divisive system purposefully ensured that racial groups were treated differently, and that only a few would benefit from the best infrastructure. Section 27 in the Bill of Rights as set out in Chapter 2 of the Constitution of the Republic South Africa, (Act 108 of 1996) clearly outlines that “everyone has the right to access health care”. In this regard, South African national government departments place great emphasis on policy formulation to tackle the problems of the past such as poverty, unemployment, poor housing and infrastructure, and access to healthcare.



The Department of Health (DOH) is a national government department that aims to meet the healthcare needs of South Africa through its nine provincial departments. The mission of the DOH is “a long and healthy life for all South Africans” (Department of Health homepage). The DOH aims to reach its goals via legislative frameworks and policy objectives implemented to tackle healthcare challenges of South African citizens. Despite the efforts made by the South African government, the public sector is finding it increasingly difficult to meet the needs of the population as it currently provides healthcare to approximately 80% of South Africans (National Treasury, 2012). Other challenges include staff shortages, stressful working conditions, and limited access to healthcare for health screenings and follow-up (Human Rights Commission, 2009). Furthermore, a large percentage of South Africans reside in rural areas where access to hospitals is limited (Department of Health, 2000). Health professionals mostly choose to work in urban areas, therefore the challenge lies in retaining professionals in rural areas. Another significant challenge is the burden of managing diseases such as HIV/AIDS and Tuberculosis which are prioritized by the government as South Africa’s statistics of these diseases are some of the highest in the world (Human Rights Commission, 2009).

The focus of the present study is on voice rehabilitation of laryngectomy patients in South Africa. Laryngectomy management would form part of cancer care as the primary diagnosis leading to a laryngectomy, is cancer. Tracheo-esophageal speech as a method of communication following a laryngectomy is dependent on the provision of the voice prosthesis by the healthcare provider. A voice prosthesis would be considered to be an assistive device. A National Rehabilitation Policy (Department of Health, 2000) is in place that documents the guiding principles behind services rendered as part of rehabilitation, in

particular the provision of assistive devices such as the prostheses used to establish TES. This National Rehabilitation Policy (NRP) is discussed below in section 2.3.

### **2.3. The National Rehabilitation Policy**

The NRP is a policy guideline that provides information on how rehabilitation programmes should function in South Africa (Department of Health, 2000). The goal of the NRP is to improve access to rehabilitation services in keeping with the values enshrined in the Constitution. This policy enables key stakeholders within the public domain to ensure that equal opportunities are afforded to individuals with disabilities regardless of one's financial or geographical situation, thus providing some support to people who find themselves in harsh economic circumstances. This policy is of relevance to individuals who have undergone a laryngectomy with surgical voice restoration and who are no longer able to use their natural voice as it discusses in detail the provision of assistive devices. The policy outlines that assistive devices should be made available to patients and that a dedicated budget should be used to allow for the provision of these devices. Furthermore, the policy emphasises the underlying principles of rehabilitation; i.e. the patient should be involved in decision making; that information provision should be individualized and provided in a manner whereby the patient understands what is being conveyed (Department of Health, 2000).

### **2.4. Laryngeal Cancer and Laryngectomy Incidence in South Africa**

Staffieri et al. (2006) suggest that the incidence of cancer in developing countries is high, and that laryngectomies continue to be the main form of laryngeal cancer treatment in developing countries due to limited oncological resources (Staffieri et al., 2006). Whether this applies to South Africa or not is not yet known.

The most recent South African statistics on laryngeal cancer were published in 2004 by the National Cancer Registry, nearly a decade ago (National Cancer Registry, 2004). The results revealed that in males, the lifetime risk of developing cancer of the larynx was expressed as 2.19 in 100 000 cases. In females, the lifetime risk was 0.29 in 100 000 cases (National Cancer Registry, 2004). The results indicate that males are more likely to be diagnosed with cancer of the larynx than females. A series of personal communications looking specifically at laryngeal cancer statistics and ascertaining whether the number of laryngectomies was increasing or decreasing in South Africa revealed that no databases followed the trends of these diseases<sup>2</sup> or the incidence of laryngectomy operations in South Africa<sup>3</sup>, and that it was difficult to predict whether they were increasing or decreasing.<sup>4</sup> Therefore, given these testimonies by key head and neck surgeons in South Africa, it is disappointing that current statistical data on laryngeal cancer and laryngectomy procedures are not being captured on a national scale. Health statistics provide valuable information to assess and ultimately meet the needs of a population (CANSA, n.d.).

## **2.5. Tracheo-Esophageal Puncture with Voice Prosthesis**

“A tracheo-esophageal puncture is created between the posterior wall of the tracheostome and the upper esophagus into which a one-way silicone valve is inserted. Tracheo-esophageal speech is based on the premise that exhaled tracheal air is shunted into the pharynx through a small, silicone valved prosthesis into a fistulous tract. The voice prosthesis serves as a mono-directional valve to protect the airway from salivary soiling, and opens to direct air within the [pharyngo-esophageal] segment” (Kazi, 2007, p. 188).

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<sup>2</sup> Head of ENT Department, University of Cape Town - 30/01/2012

<sup>3</sup> Spokesperson of the South African Head and Neck Oncology Society – 06/11/2012

<sup>4</sup> Private sector ENT surgeon who performs laryngectomies – 06/11/2012

Thereafter, the voice produced is shaped by the oral articulators to produce speech. Tracheo-esophageal speech is the most favored alaryngeal voice rehabilitation method available and the preferred speech rehabilitation method following a TL. However no alaryngeal communication method alone is the best for each and every patient (Kazi, 2007). Despite improvements made in the design of the prostheses, TES is not successful on all patients who are suitable candidates (Perry, 1997; Kapila et al., 2011). There are a number of pre-requisites and rigorous patient selection criteria that are considered when selecting an individual for TEP. These are explained in section 2.5.3 below.

Studies suggest that tracheo-esophageal speech (TES) is more natural sounding than esophageal speech and electrolarynx speech because pulmonary air is used for voicing (Kazi, 2007). Prior to the great deal of attention paid to TES by researchers and clinicians alike, esophageal speech (ES) was considered the ‘gold standard’ in alaryngeal voicing. Numerous studies have compared the voice quality of TES and ES to see which means of alaryngeal communication was better. Studies using objective measures (Debruyne, Delaere, Wouters & Uwents, 1994; Max, Steurs & De Bruyn, 1996) and subjective measures (Nieboer, De Graaf & Schutte, 1988; Pindzola & Cain, 1988) to assess voice quality between esophageal speakers and tracheo-esophageal speakers, have found TES to be more like natural speech. Objective measures include acoustic analyses, videofluoroscopy, and digital high speed imaging (Jongmans, 2008). Subjective measures include perceptual analyses. Perceptual analyses may be conducted by trained, untrained or naive listeners (Jongmans, 2008). The measure is subjective but more realistic in the sense that human beings are judging the voice quality of the TE speaker by observing factors such as pitch, loudness, intelligibility, rate of speech, visual presentation, extraneous speaking noise and overall communicative effectiveness among other aspects (Van As, 2001). Successful TES would have to pass either

objective or subjective analyses or a combination of both. Cornu, et al., (2003) analysed their patients' speech via objective and subjective measures. Due to the state of public healthcare in South Africa (Human Rights Commission, 2009), whereby funds are not freely available, not all speech therapy and ENT departments in the public sector may be equipped with highly specialised equipment to objectively assess voice quality and therefore may have to rely on subjective measures.

The TEP procedure can be performed as a primary procedure at the time of laryngectomy or as a secondary procedure, i.e. a performed a few weeks after the laryngectomy (Hopkins, et al., 2005). Researchers have shed light on the benefits of voice restoration as a primary procedure (Frowen & Perry, 2001; Golhar, 2010; Kapila et al., 2011). Recently, primary procedure is found to be more common. However a secondary procedure is indicated in patients undergoing radiotherapy who have a high risk of developing a fistula (Kapila et al., 2011). Regardless of whether TEP procedure occurs at the time of the laryngectomy or shortly after, Brown, Hilgers, Irish and Balm's (2003) study demonstrated that patients' own perceptions of voice quality showed little difference when comparing voice quality of the primary and secondary TEP procedures.

#### *2.5.1. Historical review behind surgical voice restoration via TEP following a laryngectomy*

A historical review of TEP has been provided to shed some light on the major advances that have taken place over the years in the field of alaryngeal voice rehabilitation. The first total laryngectomy was performed by Theodore Billroth in 1873 (Hopkins et al., 2005). At nearly the same time, Billroth's assistant Gussenbauer created a reed valve that was placed in the patient's pharyngostome that enabled exhaled air to create vibrations to be sent into the pharynx and oral cavity to be shaped by the articulators for speech (Kazi, n.d). Voice

restoration had thus begun around the same time that the first laryngectomy took place in 1873.

Over the course of the century, voice restoration continued to challenge surgeons. Various surgical techniques were created, example the Amatsu method and a technique by Staffieri in the late 1970s (Kazi, n.d). Both the Amatsu and Staffieri methods employed a similar concept, i.e. a connection was created between the esophagus and trachea which enabled pulmonary air to come into the throat in a manner that resulted in speech (Hilgers, 2004). Both these techniques were discontinued as they either resulted in aspiration or leakage around the fistula (Pawar et al., 2008). In 1980, a surgical technique was developed by Mark Singer and Eric Blom whereby a prosthesis made from silicon rubber was inserted into a fistula between the trachea and esophagus, which enabled the production of voice while protecting the airway from aspiration of saliva, fluids or food (Pawar et al., 2008). This technique introduced by Singer and Blom, known as tracheo-esophageal puncture with voice prosthesis, came to revolutionize prosthetic voice rehabilitation following a laryngectomy.

Since the development of TEP with voice prosthesis over 30 years ago, various advances and modifications have been made to the initial design (Deshpande, 2010). Some valves are indwelling while others are ex-dwelling (Hopkins et al., 2005). Ex-dwelling valves can be removed for cleaning while indwelling valves require cleaning in-situ (Kazi, 2007). A heat and moisture exchange (HME) function is available in some valves. This innovative mechanism retains the heat and moisture from exhaled air to heat and moisten inhaled air, homogenous to the natural filtration and cleansing system of the human nose (Pawar et al., 2008).

Modifications have been made to the original design to increase the lifespan of the device, as needed in cases where microbial colonization and biofilm formation (Wild, Mehta, & Conboy, 2004) render the device inactive. Such modifications include a change in the raw material that makes up the device; or by adding biosurfactants to the device to improve the device's resistance to microbial infection (Genden et al., 2008). Some valves enable hands-free speech while others require digital occlusion (Op de Coul et al., 2005). A fixation difficulty however exists with automatic speaking valves (ASV) that enable hands-free speech (Op de Coul et al., 2005). There are ranges of valves available to suit different individuals. The major types mentioned in the literature include the Provox range of speech valves designed by the Netherlands Cancer Institute, and the Blom-Singer range developed by In-health Technologies Ltd (Kapila et al., 2011). The type of valve chosen is dependent on the budget of a hospital (Fagan et al., 2002) and the skill and preference of the surgeon.

In a developing country like South Africa, consideration of the cost of the device will have to be made. Studies have shown high success rates from TES in South Africa (Fagan et al., 2002; Cornu et al., 2003). The high success rate in one hospital at least has been attributed to management by “an ongoing, dedicated, experienced ENT/SLP team, good education from day 1, and an open door policy once a week where patients can come in and be seen by the team” (R. Lentin, personal communication, November 06, 2012<sup>5</sup>). However despite the advances made with this alaryngeal method, there are still a number of complications with the device (Malik, Bruce, & Cherry, 2007) as discussed in the section that follows.

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<sup>5</sup> Roslyn Lentin, SLP at Groote Schuur Hospital and co-author of Fagan, et al., (2002)

### *2.5.2. Complications associated with TES*

Even though TES offers the patient an improved voice restoration procedure, it is fraught with a range of complications. Table 2.1 (page 28) provides a summary of studies about complications associated with TES use. Perspectives from SLPs, some having had experience working with TES from as early as the 1980s, were gathered in a survey conducted in the USA (Culton & Gerwin, 1998) where the complications experienced at that time, continue to challenge ENT surgeons and SLPs today. Such challenges may be divided into device related complications, the body's response to the device, and other issues related to patient selection.

The main device related complications documented included obstruction and leakage through and around the prosthesis, insertion and fitting problems, sizing the prosthesis, inadequate cleaning, air seal and leakage around housing, prosthesis failure and short lifespan, biofilm formation, reduced fixation, disconnection of valve (Culton & Gerwin, 1998; Makitie, Niemensivu, Juvas, Aaltonen, Back & Lehtonen, 2003; Ten Hallers, Marres, Rakhorst, Hagen, Staffieri, Van De Laan, Van Der Houwen & Verkerke, 2005; Calder et al., 2006; Albirmawy et al., 2006; Pawar et al., 2008; Deshpande, 2010; Golhar, 2010). Bodily complications included excessive mucous production, granulation formation, fungal infection, infection, large stoma, small stoma, stomal stenosis, migration of fistula, closure of fistula, second fistula, dysphagia, stomach gas, hypersensitive gag, hypersensitive cough, tracheo-bronchial inflammation, peristomal cellulitis, aspiration, hypertonic voice, wet voice, aphonia, dysphonia, nosocomial infections (Culton & Gerwin, 1998; Makitie et al., 2003; Wild et al., 2004; Ten Hallers et al., 2005; Calder et al., 2006; Albirmawy et al., 2006; Deshpande, 2010; Golhar, 2010).



Complications relating to poor patient selection include difficulties with digital occlusion related to poor manual dexterity and non-specified physical limitations (Culton & Gerwin, 1998). However, none of the patient selection difficulties were found in the later studies which imply that improved awareness of patient selection may have been adopted to avoid such complications.

**Table 2.1.: Summary of Studies on the Complications associated with Tracheo-Esophageal Speech**

	<b>Researcher/s (Country)</b>	<b>Year</b>	<b>Title</b>	<b>Main Aims</b>	<b>Research Design</b>	<b>Subjects</b>	<b>Bodily Complications</b>	<b>Device Complications</b>
1	Culton & Gerwin (USA)  <i>Communicative Disorders</i>	1998	Current trends in laryngectomy rehabilitation: a survey of speech-language pathologists	To determine the perceptions of experienced SLPs regarding current practices in the speech rehabilitation of laryngectomy patients since the introduction of the TEP – voice prosthesis technique in 1980.	Descriptive survey	151 Speech language pathologists involved in laryngectomy management	Secretions Inability to speak Psychological problems, fear Candida Granuloma Esophageal stenosis Dysphagia Hypertonic, cricopharyngeal spasm Dislodgement of prosthesis Poor voice Problems with digital stoma valving Physical limitations Puncture/ fistula migration Small stoma	Leakage around/ through prosthesis Insertion/ fitting problems Sizing the prosthesis Inadequate cleaning Air seal/ leakage around housing Prosthesis failure/ short lifespan
2	Makitie, Niemensivu, Juvas, Aaltonen, Back & Lehtonen (Finland)  <i>ENT – Head and neck surgery</i>	2003	Post-laryngectomy voice restoration using a voice prosthesis: a single institution’s ten-year experience	To describe the speech rehabilitation outcomes of patients treated with total laryngectomy or total laryngo-pharyngectomy & insertion of Provox voice prostheses.	Retrospective Chart Review	95 patients post-laryngectomy who underwent insertion of a voice prosthesis	Granulation formation Leakage around fistula	Obstruction Leakage Inadequate prosthesis size
3	Ten Hallers, Marres, Rakhorst, Hagen, Staffieri, Van Der Laan, Van Der Houwen & Verkerke (The Netherlands) <i>BioMedical Engineering/ ENT surgery</i>	2005	Difficulties in the fixation of prostheses for voice rehabilitation after laryngectomy	To provide a review of the literature on fixation problems with shunt valves, tracheostoma valves, and heat & moisture exchange filters	Retrospective Review of literature	Literature review of 71 studies	Fistula enlargement Infection Mucous leakage	Biofilm formation Leakage through valve Reduced fixation Disconnection of the valve

	<b>Researcher/s (Country)</b>	<b>Year</b>	<b>Title</b>	<b>Main Aims</b>	<b>Research Design</b>	<b>Subjects</b>	<b>Bodily Complications</b>	<b>Device Complications</b>
4	Calder, Mac Andie & MacGregor (Scotland)  <i>ENT Surgery</i>	2006	Tracheo-esophageal voice prostheses complications in north Glasgow	To determine: 1) the rates of complications, admissions to hospitals and requirements for further surgery in patients fitted with tracheoesophageal fistula speech valves 2) whether any factors were predictive of complications	Retrospective case note review	99 patients post-laryngectomy	Granulations Large fistula Loss of valve Loss of voice Closure of fistula Dysphagia Infection Second Fistula	Leakage
5	Albirmawy, Elsheikh, Saafan & Elsheikh (Egypt)  <i>ENT Surgery/ Surgical Oncology</i>	2006	Managing problems with trachea-esophageal puncture for alaryngeal voice rehabilitation	Researchers present their experiences with the TEP technique , paying special attention to the incidence & management of these adverse events	Retrospective clinical analysis	75 laryngectomized patients who underwent TEP for voice restoration	Large Tracheostoma Small Tracheostoma Aphonia/ dysohonia Stomach gas Hypotonic voice Wet voice Hypersensitive gag Hypersensitive cough Tracheobronchial inflammation Peristomal cellulitis Narrowing stoma Granuloma Excessive phlegm production Aspiration	Leakage in and around prosthesis Failure of elective closure Microbial Colonization of valve
6	Pawar, Sayed, Kazi & Jagade (India)  <i>ENT – Head and neck surgery</i>	2008	Current status & future prospects in prosthetic voice rehabilitation following laryngectomy	The article attempts to sum up the historical background and current state of surgical voice rehabilitation following TL	Retrospective journal review of PubMed & MEDLINE databases	20 published articles were found to be of relevance to the study.		Leakage through & around voice prosthesis Biofilm formation Obstruction of prosthesis

	<b>Researcher/s (Country)</b>	<b>Year</b>	<b>Title</b>	<b>Main Aims</b>	<b>Research Design</b>	<b>Subjects</b>	<b>Bodily Complications</b>	<b>Device Complications</b>
7	Deshpande (India)  <i>Surgical Oncology</i>	2010	Prosthetic voice rehabilitation after total laryngectomy	To provide an overview of prosthetic voice rehabilitation after total laryngectomy	Retrospective journal review	21 published articles	Failure to phonate Granulation	Leakage Displacement of prosthesis
8	Golhar (India)  <i>ENT Surgery</i>	2010	Tracheo oesophageal puncture voice: an Indian perspective	Author provides own experiences using TEP in Indian perspective during 15 years	Retrospective study	160 patients who underwent TEP for voice rehabilitation after laryngectomy	Granulations around TEP Migration of fistula Excessive mucous production Difficulty reinserting prosthesis Spontaneous expulsion of prosthesis	Leakage around prosthesis

*\*Professional background of researchers have been provided in italics*

### 2.5.3. *Factors that contribute to successful use of TES*

There are a number of factors that contribute to the successful TES with voice prosthesis. Factors such as patient's candidacy (Perry, 1997), a multi-disciplinary team approach (Frowen & Perry, 2001), the provision of information (Newell, Ziegler, Stafford & Lewin, 2004), support by means of support groups (Golhar, 2010), spiritual (Puchalski, 2012) and family support (Relic, Mazemda, Arens, Koller & Glanz, 2001), therapy and compliance (Jongmans, 2008), socio-economic status (Palmer & Graham, 2004) and stoma care (Schiech, 2007). Each of these factors is discussed below in more detail.

- Selection of individuals for TEP

Individuals considered for TEP must first meet the necessary criteria for TES as outlined by Andrews (1987 in Kazi, n.d).

- Self motivation and mental stability;
- knowledge of one's anatomy and the functioning of the voice prosthesis;
- adequate dexterity of the fingers and hands for stoma occlusion;
- adequate vision to easily locate the stoma for occlusion and cleaning;
- considerable narrowing of the hypopharynx should be ruled out;
- insufflations of the esophagus by means of a catheter should result in speech production;
- the individual should have an unrestricted airflow and adequate breath control for speech;
- a stoma with an ideal diameter to house a prosthesis whilst maintaining airflow.

Furthermore, adequate PE segment tonicity is required for successful tracheo-esophageal voicing (Perry, 1997). In such cases where a patient who underwent a laryngectomy is found

to have limited PE segment tonicity, an inferior constrictor myotomy and secondary TEP is suggested (Perry, 1997). Other factors ensuring the success of TES would include an adequate cognitive ability to carry out stoma care (Kazi, 2007) as well as care of the voice prosthesis, the overall health condition of the patient, and age of the patient (Hopkins et al., 2005). A patient with memory difficulties may forget to clean the stoma, therefore adequate cognitive functioning is vital. Persons with total laryngectomy have to meet the above criteria that may best ensure successful TES.

- Team approach

Various studies advocate the use of a multi-disciplinary team for successful laryngectomy management to assist with the many aspects affected post-laryngectomy (Frowen & Perry, 2001; Ryan et al., 2004; Collins et al., 2005). The main team members involved in laryngectomy rehabilitation with a particular emphasis on voice restoration would include the ear, nose and throat (ENT) surgeon, specialist nurse, speech-language pathologist (SLP) and in some cases, the psychologist (Frowen & Perry, 2001; Ryan et al., 2004; Collins et al., 2005, Culton & Gerwin, 1998; Hopkins et al., 2005; Sharma, Nagarkar, Jindal, Kaur & Gupta, 2008). The caregiver is also considered a vital team member of the voice rehabilitation team, however there is a dearth of information in the literature pertaining to the role of the CG.

- ENT Surgeon

The ENT surgeon works closely with the SLP pre-operatively discussing surgical strategies for voice restoration prior to performing the surgical removal of the larynx, and any other surgical procedures that would improve alaryngeal voice restoration (Kazi, 2007; Mohebbati & Shah, 2010). Procedures such as a pharyngeal constrictor myotomy, together with the

secondary tracheo-esophageal puncture may be discussed (Perry, 1997). The ENT surgeon would also address post-operative complications such as tracheostomal problems and nosocomial infections (Wild, Mehta & Conboy, 2004). Furthermore, the ENT surgeon works together with the specialist nurse, who is involved in preparation of the surgery and in-hospital care especially wound care (Frowen & Perry, 2001; Mohebaty & Shah, 2010).

- Specialist Nurse

The ENT nurse, also known as the specialist nurse (SN), is aptly skilled to deal with the person with total laryngectomy (PWTL) at all stages of intervention (Noonan & Hegarty, 2010). Much of nursing involvement takes place at the bedside of the patient during and directly after the surgical procedure until discharge. Nurses work in collaboration with the ENT surgeon and SLP in the administration of enteral feeds and medication. The nurse is trained in the education and practice of stoma and tracheostomy care, to monitor the site of surgery, to assist the PWTL in communicating their needs within the ward (Schiech, 2007). The clinical input of nurses specialising in cancer has been seen as highly valuable (Thorne, Bultz & Baile, 2005), therefore the nurse is a vital member of the rehabilitation team.

- The Speech-Language Pathologist

The speech-language pathologist (SLP) is one of the key voice rehabilitation team members (Casper & Colton, 1998). The SLP works closely with the PWTL from the pre-operative stage, as it is the role of the SLP to provide pre-operative counselling that would entail a detailed explanation of the surgery and consequences. Post-surgery, the SLP is actively involved in evaluating communication and swallowing. The SLP may also review plans for rehabilitation with the PWTL, the specifics of which will be determined by the

type of treatment the individual receives and the choices that have been made regarding communication options (Casper & Colton, 1998). According to Culton & Gerwin, (1998) the SLP plays a major role in choosing an appropriate alaryngeal treatment option best suited for each individual. However, more recent research that takes into account the individual needs of patients (Lennie et al., 2001) highlight that patients should be involved in decision making. Therefore, the role of the SLP is to provide the necessary information that would enable the PWTL to make an informed decision about which alaryngeal voicing option to choose (Kazi et al., 2010).

- The Psychologist

The psychologist may also be a member of the rehabilitation team as psychological intervention begins in the pre-operative stage, with counselling the patient and family about a cancer diagnosis and identification of psychological stressors that may impede the rehabilitation process (Sharma et al., 2008). Psycho-social well-being is a determinant for improved quality of life and also has implications for voice rehabilitation (Palmer & Graham, 2004). The PWTL would require certain intrinsic coping strategies to deal with the enormity of challenges that may ensue (Sharma et al., 2008). Thus, the psychologist plays a vital role in supporting the patient and promoting psycho-social well-being throughout the rehabilitation process.

- The Caregiver

The caregiver (CG) is considered to be a vital member of the team in terms of providing emotional and moral support, and/or care with activities of daily living if necessary.



The successful restoration of voice by TEP depends on the adequate knowledge base, clinical training, and the accumulated clinical expertise of each member of the voice rehabilitation team (Frowen & Perry, 2001; Kazi, 2007).

- Educational information

The PWTL receives ongoing information before, during and after the laryngectomy. This information aims to help prepare the PWTL and his/her caregiver for the journey ahead (Lennie et al., 2001; Cady, 2002). Therefore, it is vital that correct and valuable information is conveyed by members of the voice rehabilitation team, who have been trained to work with individuals who have had laryngectomies (Kazi, 2007). Individualized information should be provided to patients as opposed to general information packs designed solely for laryngectomy surgery. Every experience is different and specific aspects affecting an individual should thus be integrated into the general information pack or counselling session (Newell et al., 2004). Some of the information shared and demonstrated may include cleaning of the stoma and device, and steaming procedures, issues related to psychological, social, marital concerns and diet (Palmer & Graham, 2004).

In the South African context, where any of the eleven official languages and numerous unofficial languages may be spoken and/or understood by patients, it would improve the patient's understanding if information provision could occur in the first language of the patient and caregiver. However, this is only likely in the case where interpreters proficient in multiple languages are employed for this purpose. Pictures as well as demonstrations may assist in teaching pertinent issues (Newell et al., 2004) such as stoma care, especially in cases where the patients are illiterate, a common occurrence in South Africa (Human Rights Commission, 2009). The National Rehabilitation Policy (Department of Health, 2000) also

highlights the need for improved efforts to be made by health care professionals to ensure that information is provided at a level where patients understand what is being conveyed, with minimal use of medical jargon. The purpose of information sharing is to ensure that the patient is empowered to make an informed decision.

- Autonomy

The choice of the most suitable alaryngeal method to adopt must be decided upon by the PWTL himself (Kazi et al., 2010). Once information has been conveyed, the PWTL needs to be made aware of the fact that the decision on a suitable alaryngeal method is his to make. Perry (1997) advocates that although the decision is the patient's to make, the SLP should guide his/her decision. The principles of the National Rehabilitation Policy (Department of Health, 2000) emphasise that patients themselves should participate in making informed decisions about their health. Health professionals need to provide patients with all the necessary information that would enable them to make an informed decision.

- Support

- *Support Groups*

The aim of support groups is to provide education and support for PWTL. These groups are usually attended by PsWTL at all stages of rehabilitation. Individuals who have yet to undergo a TL should be encouraged to regularly attend these groups to best prepare themselves for the future, thereby ensuring social integration of some kind which promotes QoL (Golhar, 2010). With the technological advancements in our digital age, social media has proven to be another health support mechanism (Chou, Hunt, Beckjord, Moser & Hesse, 2009). For example, the advent of laryngectomy support groups as seen on social

networking sites such as Twitter and Facebook has resulted in PsWTL obtaining alternative support in unconventional fora<sup>6</sup>. However, given that less than 40% of South African households have access to the internet (Census, 2012) a large proportion of the population may not have access to such “virtual” social support mechanisms.

– *Patient visitor*

Goktas, Fleiner, Paschen, Lammert & Schrom (2008) discussed the benefits of having contact with rehabilitated individuals who themselves have undergone a similar procedure and who can share their experiences and knowledge with individuals about to undergo the procedure. A patient visitor therefore is someone who has already had a laryngectomy and who is going through, or has been through the rehabilitation process. The patient visitor may help the person about to undergo a TL set realistic goals for him/herself and provide some insight about what to expect after the operation. Hilgers (2004) discussed a patient visitor at his hospital who spoke such good esophageal speech that many of his patients who had listened to him, had to have some of their expectations toned down. Therefore, multiple patient visitors with a range of communication patterns should be used as examples for patients to realise that the results of a laryngectomy are never the same for any two people. Having a patient visitor also provides an opportunity for the person about to undergo a laryngectomy to ask any pertinent questions that may be worrying him/her.

– *Spiritual support*

An Internet based laryngectomy support group was found on Facebook, a well-known social networking site where members included PsWTL, family members, SLPs and other interested individuals who participate in the group either by initiating a topic for discussion

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<sup>6</sup> Group: Laryngectomy Support: <http://www.facebook.com/#!/groups/laryngectomy/>

or by contributing to an existing discussion. An interesting observation was the number of posts where members of the group either requested that positive thoughts and prayers be sent to a particular individual about to undergo a test or surgical procedure, or posts where members thanked others for their prayers.

Research suggests that there are positive correlations between spirituality and well-being (Visser, Garssen & Vingerhoets, 2010). Spirituality helps individuals find meaning within their lives during moments of extreme stress, chronic illness and the possibility of death (Puchalski, 2012). Likewise, in the afore-mentioned Facebook group, it appears that some cancer patients seek solace in spirituality to help them ease the burden of their disease, and that prayer and spirituality creates hope.

– *Family support.*

A prospective cross-sectional study conducted by Relic et al. (2001), that looked at quality of life and coping in 29 PsWTL who belonged to a support group, found that the support of family was valued most above all else when overcoming disease related problems and the consequences of treatment. Supportive family members may be considered as caregivers. Family members thus need to be involved in decision making (Relic et al., 2001) and ideally should be present when the diagnosis of cancer is made, to provide emotional support for the patient, so that they are not alone during this traumatic event. The above findings were confirmed by an Icelandic study that looked at coping strategies, and more specifically on how cancer patients perceived care. It was found that family involvement was viewed as support and a rich source of providing hope (Hjorleifsdottir, Hallberg, Gunnarsdottir & Bolmsjo, 2008).

- Socio-economic status (SES)

Socio-economic status has an impact on the success of TE voice acquisition in individuals (Palmer & Graham, 2004). Access to healthcare, information, transport and basic needs such as having access to clean running water are vital to individuals who may be considered for TEP, or who currently use TES as their main form of alaryngeal communication. A voice prosthesis requires regular cleaning, steaming and maintenance, and is thus highly dependent on one's socio-economic status in order to achieve success (Kazi et al., 2010). Employment and income yielded positive correlations with QoL in Palmer & Graham's (2004) study. Fagan et al., (2002) found no correlation between speech, employment and access to healthcare. They did however find that speech is affected by the quality of housing and literacy in a South African based study that utilised retrospective analysis. However that study was conducted at a single hospital and therefore cannot be generalised to describe all Third World communities.

- Therapy/ Compliance

Speech-Language pathology intervention is the most intense aspect of rehabilitation for a PWTL (Schiech, 2007). A survey questionnaire study that looked at SLPs views on QoL and rehabilitation found that all SLPs who participated in that study required six speech therapy sessions or less to see positive results, with 20% of SLPs requiring ten or more sessions (Culton & Gerwin, 1998). A Dutch based speech therapy rehabilitation programme advocates a minimum of 15 speech therapy lessons for the PWTL and highlighted the intensive and dedicated approach required for success (Jongmans, 2008). Therefore, the varied therapy durations as described in the literature are aligned with the varied results seen in individuals after a laryngectomy. Rightfully so, there is no "one size fits all" approach to management

because every individual is different. Therefore efforts to individualize therapy based on the unique needs of each individual should exist.

- Stoma care

Stoma care has been highlighted in the literature (Hilgers, Ackerstaff, Van As, Balm, Van Den Brekel & Tan, 2003; Kazi, 2007; Schiech, 2007; Mohebati & Shah, 2010). Stoma care may be administered initially by a specialist nurse and SLP, and thereafter practiced by the PWTL him/herself. Stoma care is vital for various reasons, mainly to facilitate breathing, and to aid in tracheo-esophageal voicing (Hilgers et al., 2003). Stoma care consists of cleaning the stoma by removing any secretions, treating fungal infections or foreign particles and steaming the tracheal area to soften thickened secretions and to provide humidity which cleanses inhaled air. The development of the heat and moisture exchange (HME) function for voice prostheses assists with improved breathing and voicing (Hilgers et al., 2003). However, due to the financial challenges faced by the public sector in South Africa, the provision of HMEs may be limited and consideration would have to be made to educating PsWTL about more cost-effective humidification practices. Furthermore, cleaning improves the lifespan of the voice prosthesis.

## **2.6. Summary of Chapter**

This chapter provided a review of the literature pertaining to the problem statement within the context of this study, i.e. the South African public healthcare system. Tracheo-esophageal puncture with voice prosthesis is discussed in detail in terms of how it achieved its “gold standard” status amongst the rest of the alaryngeal methods, the complications associated with the TEP procedure as well as the hallmarks of successful TES as found in the literature. The next chapter discusses the methods employed to carry out the current study.

## **CHAPTER THREE: METHODOLOGY**

### **3.1. Introduction**

This chapter describes and provides a rationale for the methods used in this study. The research design, participant selection criteria, data collection and data analysis methods are detailed below. Ethical considerations have also been outlined in this chapter.

### **3.2. Aim**

To gather insights of the hallmarks of successful alaryngeal voice rehabilitation using TES with voice prosthesis following a total laryngectomy as a result of cancer of the larynx, from key role players: a) the person with a total laryngectomy (PWTL) b) the PWTL's caregiver, and c) the voice rehabilitation team.

### **3.3. Objectives**

In the interests of achieving the above-mentioned aim, the following objectives were identified:

- 1) To explore the process of alaryngeal voice rehabilitation by TES with voice prosthesis.
- 2) To establish how the PWTL, CG and the voice rehabilitation team (ENT surgeon, nurse, SLP) consider successful voice rehabilitation when using TES.
- 3) To highlight the factors promoting successful voice rehabilitation post-TL with TES.
- 4) To highlight the factors impeding successful voice rehabilitation post-TL with TES.

### **3.4. Research Design**

A qualitative method of inquiry was chosen, namely a single-program, collective case study (Yin, 1994; Stake, 1995) as it allowed for multiple perspectives to be gained within a single site.

*“Case study research is a qualitative approach in which the investigator explores a bounded system i.e. the case, through detailed in-depth data collection involving multiple sources of information (e.g. observations, interviews, audiovisual material, and documents). These detailed data collection procedures allow for the reporting of case descriptions and emerging case-based themes” (Creswell, 2007, p.73).*

The single program or case selected for the present study was a large government hospital. The hospital was the “bounded system” (Creswell, 2007, p. 73) where management of the patients with laryngectomies occurred. The case study allowed for access to the in-depth perspectives of key role players involved in the voice rehabilitation process. Purposeful sampling methods were used. The aims of the research were carried out by means of a focus group and semi-structured interviews using open-ended questions.

### **3.5. Participants**

Participants were recruited from the single case study site. This study aimed to explore the hallmarks of successful voice rehabilitation following total laryngectomy. Participants included in the investigation were persons with total laryngectomy for the focus group, and a single individual PWTL for the in-depth interview, a caregiver and the main professionals included in a voice rehabilitation team. The case study and each of these participants are described further below.

#### *3.5.1. The case*

Hospital X was selected as the single case for investigation because it is one of the largest public hospitals in South Africa which provides free and subsidized health-care to a vast number of South African citizens residing in both urban and rural areas of Gauteng province



(The University of the Witwatersrand, n.d.). Additionally Hospital X was selected because it provides medical, surgical and rehabilitative services to patients with head and neck cancers including cancer of the larynx, who have undergone total laryngectomies. Hospital X was also chosen because of its geographical location which was easily accessible to the researcher.

### *3.5.2. Persons with total laryngectomy*

Participants, who were persons with total laryngectomy (PsWTL), were included in two phases of the study, i.e. a focus group comprising of the four PsWTL, and a single participant in an individual in-depth interview. All the participants had been diagnosed with advanced stage of cancer of the larynx that could not be treated with chemotherapy or radiotherapy alone or concurrently, and thus required a salvage procedure which in each case was, a TL with TEP.

The focus group (FG) included four PsWTL. These participants were recruited by one of the resident SLPs based at Hospital X. Few PsWTL who receive therapy at the hospital fitted the participant selection criteria, therefore a minimum number of four participants for the FG was considered appropriate as smaller numbers are easier to manage (Greenbaum, 1997; McLafferty, 2004). The SLP at Hospital X was thought to be the most appropriate individual to select the participants for the focus group as she had been trained in the field of communication pathology, and of more relevance, she holds monthly laryngectomy support groups which include patients that have undergone total laryngectomies. Section 3.5.4.2 provides details on the criteria used to select the participants included in the focus group.

A single PWTL was then selected from the focus group participants for further in-depth interviews. Section 3.5.4.3 details the selection criteria used to select this PWTL from the focus group members for the individual interview.

### *3.5.3. The rehabilitation team*

The key role players involved in voice rehabilitation post-laryngectomy at this hospital were also each interviewed individually. This included the PWTL's caregiver, the ear nose and throat (ENT) surgeon, the speech-language pathologist (SLP) and the specialist nurse (SN). No psychologist formed part of the voice rehabilitation team at the hospital because it was reported that the PsWTL at the hospital did not feel that they required psychological intervention. A rationale for the inclusion of the above-mentioned rehabilitation team members is detailed in the literature review. Section 3.5.4.4 details the selection criteria used to select the PWTL's caregiver, and section 3.5.4.5 details the selection criteria for the voice rehabilitation team.

### *3.5.4. Participant selection criteria*

#### *3.5.4.1. The case study.*

Hospital X was chosen as it provides rehabilitation to PsWTL. Hospital X's geographic location was also accessible to the researcher.

#### *3.5.4.2. PsWTL for the focus group (FG).*

A focus group consisting of four PsWTLs was conducted.

*“The benefits of FG research include gaining insights into people's shared understandings of everyday life and the ways in which individuals are influenced by others in a group situation” (Gibbs, 1997).*

Focus groups are known to vary in size and generally no ideal number of participants is necessary to deem a FG as legitimate (Morgan, 1996). According to Greenbaum, (1997) a FG can consist of 4-6 participants. This size group is easier to manage and is deemed a mini-group which allows each participant more time to respond to questions (Greenbaum, 1997; McLafferty, 2004).

Table 3.1. describes the participant selection criteria used in the study to select participants for the focus group and presents motivations for why each of the criteria were important.

**Table 3.1.: Participant Selection Criteria for the Focus Group**

Criteria	Motivation
The participant must have undergone a total laryngectomy (TL) with TEP at least 3 months prior to the data collection phase and not more than 36 months prior to the data collection phase.	The acquisition of voice is quick with the majority of cases seeing a development of voice in less than two weeks (Hilgers, 2004). Furthermore, the time frame of 3 to 36 months post laryngectomy would allow for the participants to recall the details of their clinical experiences.
The participant must have achieved functional communication skills i.e. a high speech intelligibility, and must be deemed a successful communicator using TES by the SLP at Hospital X.	Successful communicators using TES have been selected because their views on success are of considerable interest in this study. Their insights about success and how they managed to achieve success using TES is beneficial to clinicians and others' trying to learn how to communicate using TES.
The participant must have adequate hearing confirmed by the resident SLP.	The persons with total laryngectomy should be able to easily hear the questions posed to them. Patients with hearing loss will be excluded as they may mishear information and provide incorrect responses. Furthermore, the presence of hearing loss may adversely affect the development of intelligible TES (Cantu, Ryan, Tansey & Johnson, 1998). Ideally, there should be no concerns regarding the PWT's hearing status.

Criteria	Motivation
The participant must have receptive (listening) and expressive (spoken) language competence in one of the following: English or Zulu.	These languages were chosen as they are the major languages spoken in Gauteng (Census, 2012) and have been catered for in this study in terms of translation of informed consent letters and question interpretation. Receptive competence is necessary to comprehend the questions and expressive spoken language competence is necessary to describe one's thoughts and views as needed in this study. A bi-lingual interpreter who is fluent in both the languages was on call to interpret the questions for the focus group participants. However all participants had functional competence in English, therefore the interpreter was not needed.

#### 3.5.4.3. PWTL for the individual interview

From the focus group, one PWTL was chosen for the in-depth individual interview. Table 3.2 describes the participant selection criteria for the selection of the PWTL for the individual interview.

**Table 3.2.: Participant selection criteria for the PWTL for the individual interview**

Criteria	Motivation
The PWTL who has the highest level of intelligibility from all the focus group participants at conversation level as determined by subjective analysis of trained listeners.	An audio recording of the focus group session was played to 3 members of staff at the SLP department at Hospital X to subjectively analyze the speech intelligibility of the focus group participants at conversation level. They were required listen to the recordings and measure the intelligibility of the participants using an informal intelligibility scale (Refer to Appendix H) and report on whom they felt communicated most successfully. Based on the feedback, the investigator then chose the participant with the highest intelligibility, volume, rate, breath control, and naturalness of speech for the individual interview.

Criteria	Motivation
The PWTL must have a caregiver who has knowledge of his clinical history since diagnosis.	The PWTL must have a caregiver present who the investigator could interview to gather his/her perspective of successful communication using TES.

#### 3.5.4.4. Caregiver of PWTL.

The caregiver of the PWTL was then interviewed. Table 3.3. outlines the participant selection criteria for the caregiver of the PWTL.

**Table 3.3.: Participant selection criteria for the caregiver of the PWTL**

Criteria	Motivation
The participant must have been the main caregiver of the PWTL from time of diagnosis to present.	The information provided by the caregiver would be the most insightful as he/she would be quite familiar with the PWTL at a social level. Ideally, the caregiver should be a spouse of the PWTL. However, the caregiver may also be a relative, friend or paid caregiver.
The participant must have functional receptive (understanding) and expressive (spoken) language competence of at least one of the following two languages: English and Zulu	As previously stated for the PWTL, these languages were chosen as they are the major languages of Gauteng (Census, 2012) and have been catered for in this study in terms of translation of informed consent letters and question interpretation. A bi-lingual interpreter fluent in both the languages was on call to interpret the questions for the interviews, but was not needed as the caregiver was fluent in English, the language spoken and understood by the investigator.
The participant must have adequate hearing	There should be no concerns regarding the caregiver's hearing status to ensure that all interview questions are heard correctly.

#### 3.5.4.5. *The rehabilitation team*

The members of the voice rehabilitation team were chosen specifically based on their professions which have been indicated by the literature as being key professions in laryngectomy management, namely ENT surgery, ENT nursing, and speech-language pathology. A psychologist does not form part of the laryngectomy management team at this hospital. Professionals who represent each of these professions who work with PsWTL were each invited to participate in the study. Table 3.4. below, outlines the participant selection criteria for the members of the rehabilitation team.

**Table 3.4.: Participant selection criteria for members of the rehabilitation team**

Criteria	Motivation
The participant must be employed at Hospital X as a healthcare professional in his/her respective discipline	Hospital X was chosen because it provides rehabilitation to PsWTL, therefore the rehabilitation team would have to be employed at this hospital.
The participant must be actively involved in voice rehabilitation in laryngectomy management	He/she would have knowledge about the common outcomes of surgery, complications, and mental and physical state from a rehabilitation and medical standpoint, and more specifically voice rehabilitation. This would provide valuable information in that the rehab team member can draw information from other clinical cases to highlight how this particular case has been successful.

#### 3.5.5. *Ethics*

Full Ethical Approval (Please refer to Appendix A) was granted by the Biomedical Research Ethics Committee (BREC) of the University of KwaZulu Natal (UKZN) as well as permission to conduct the study from the Chief Executive Officer (CEO) (Please refer to Appendix B) at Hospital X. Participants were provided with information detailing the aims and objectives of the study via written letters in the two major languages of Gauteng, namely

English and Zulu, with a verbal description where necessary. Each participant who consented to being a part of the study was assured of anonymity and confidentiality and the freedom to withdraw from this study at any stage.

*3.5.6. Description of the participants*

The focus group consisted of four PsWTL as described below. The FG was held at hospital X. Each of the FG participants met the criteria required for the PWTL as discussed in section 3.5.4.2 of this chapter. One of these FG participants was subsequently chosen to be interviewed separately.

In Tables 3.5 to 3.8. details of each of the participants is included. Table 3.5. presents descriptive information about the participants included in the FG. Table 3.6. presents descriptive information about the PWTL for the individual interview. Table 3.7. presents descriptive information about the caregiver of the PWTL. Table 3.8. presents descriptive information about the voice rehabilitation team members.

**Table 3.5.: Descriptive information about the participants included in the FG**

PsWTL	Type of Surgery	Gender	Primary or Secondary Cancer	Date of surgery	Age	Receptive & Expressive Competence in English or Zulu	Highest Educational Level	Employment Status
1	TL	Male	Secondary	07/ 2011	66	✓ BOTH	GRADE 8	Unemployed
2	TL	Male	Secondary	09/ 2011	50	✓ ENGLISH	NO FORMAL SCHOOLING	Unemployed
3	TL	Male	Secondary	11/2011	42	✓ BOTH	GRADE 10	Unemployed
4	TL	Male	Secondary	05/ 2010	35	✓ BOTH	MATRIC	Unemployed

**Table 3.6.: Descriptive information about the PWTL participant for the individual interview**

PWTL	Type of Surgery	Gender	Primary or Secondary Cancer	Date of surgery	Age	Receptive & Expressive Competence in English or Zulu	Highest Educational Level	Employment Status
1	TL	Male	Secondary	07/ 2011	66	✓ BOTH	GRADE 8	Unemployed

**Table 3.7.: Descriptive Information about the CG of the PWTL**

CG	Relationship to PWTL	Gender	Receptive & Expressive Competence in English or Zulu
1	Younger sister	Female	✓ BOTH

**Table 3.8.: Descriptive Information about Voice Rehabilitation Team Members**

Voice Rehab Team Member	Profession	Years of Practice in laryngectomy management
1	ENT Surgeon	5 years
2	Specialist Nurse	+/-20 years
3	Speech-Language Pathologist	+/- 5 years

### **3.6. Data Collection**

#### *3.6.1. Equipment and material for data collection*

Semi-structured interview questions guided the focus group (FG) meeting and the individual interviews as found in Appendix D. For the individual interviews that took place after the FG after all the key role players had been identified, emphasis was placed on the authenticity of the multitude of perspectives (Creswell, 2007), participants were each interviewed separately and encouraged to elaborate on their responses with open ended questions. The researcher followed the lead of the participants and probed further with questions where necessary for



both the focus group and individual interviews. The FG questions were more general, whereas the questions for the individual interview went into more depth about TES. All interviews were audio recorded and video recorded except for three, which were not video recorded as per the request of those three participants. A Samsung (65X Intelli-Zoom) video camera was used for the video recording, and an Olympus VN-711 PC Digital Voice Recorder was used for the audio recording of the interviews.

The main focus of each interview was to gain insight into the participant's perspective of what successful voice rehabilitation meant to him/her. Therefore, the following leading questions were posed to achieve the aim of the study. These questions were chosen to gather specific details about different aspects that contribute to successful voice rehabilitation from all key role players and based on the literature. There was no specific time limit for each interview. The average length of the interviews was approximately sixty minutes due to the room availability at the hospital. Ninety minutes has been recommended as the ideal duration of an interview (Seidman, 1998). However, sixty minutes was found to be a suitable duration as no part of the interview was rushed due to the time constraints.

An informal intelligibility rating scale (Refer to Appendix H) derived from literature pertaining to perceptual analysis of voice (Jongmans, 2008) was used to rate the intelligibility of the tracheo-esophageal speech of the focus group participants. This scale was used by 3 members of staff at the SLP department to identify the PWTL with the highest speech intelligibility.

Table 3.9. details the questions posed at the focus group with motivations.

**Table. 3.9.: Focus Group Questions and Motivations**

No.	Focus Group Questions	Motivation
1	Is TES an easy method to master? Why	Evidence suggests that of the 3 alaryngeal communication methods, TES is the quickest to master (Hilgers, 2004)
2	What are some of the problems that you have experienced with TEP?	TEP is fraught with a range of complications ranging from device related problems to the body's reactions to the surgery and the device as well as difficulties related to poor patient selection (Culton & Gerwin, 1998)
3	How are you dealing with these problems and have you overcome these problems?	The SLP and ENT are trained to deal with trouble shooting problems. Furthermore, the PWTL himself needs to be equipped with adequate knowledge to deal with common complaints, such as obstruction and blockage all related to cleaning and stomal care. Stoma care is vital for various reasons, mainly to facilitate breathing, and to aid in tracheo-esophageal voicing (Hilgers et al., 2003).
4	Are you happy with the way you currently communicate?	Research suggests that communication is linked to higher levels of quality of life post-laryngectomy (Palmer & Graham, 2004)
5	Can you speak confidently in all situations? If not, in which situations do find it difficult to communicate? (on the telephone/ noisy environments)	Research suggests that alaryngeal voice quality is sometimes strained in certain speaking situations such as speaking on the telephone, or in background noise (De Maddalena, 2002)

No.	Focus Group Questions	Motivation
6	Do you feel that people understand you when you speak to them?	Understanding the spoken message is a sign of successful communication and more superior than intelligibility alone (Jongmans, 2008).
7	Do you find it easy to interact with people? Do you go up to strangers and speak to them? How do they react?	A successful communicator would be easily understood by familiar and non-familiar communication partners.  Tracheo-esophageal speech may lead to feelings of self-consciousness as the new voice may attract negative attention (De Maddalena, 2002).
8	Do you enjoy communicating with TEP? Why?	Positive feelings related to the new voice are associated with higher levels of QoL (Palmer & Graham, 2004).
9	Were you seen by a team of professionals? (if yes, did you meet often with your team, how often, was it beneficial)  Do you feel that a team approach to laryngectomy management is good? Why?	A multi-disciplinary team approach to management of PsWTL has been advocated for in the literature (Frowen & Perry, 2001).
10	What is successful rehabilitation in laryngectomy management?  Do you feel that you have been successfully rehabilitated?	Research suggests that speech intelligibility and functional communication are predictors of successful communication (Logemann, 1997).  A successful communicator should not doubt this.
11	If you could provide any advice or suggestions as to how services to laryngectomees can improve, then what would you suggest?	Advice by PsWTL is vital to alert researchers and clinicians' attention to what can be done to improve services delivered to this population.

Table 3.10. displays the questions posed in the individual interviews to the PWTL, his CG, the ENT surgeon, SLP, SN.

**Table 3.10.: Questions to be used in main study**

Objective	Questions to PWTL	Questions to CG	Questions to Voice Rehab Team	Motivation
<p>1) To identify the process of alaryngeal voice rehabilitation by TEP with voice prosthesis.</p>	<ol style="list-style-type: none"> <li>1. Were you fitted with the speech valve at the time of the laryngectomy, or later on?</li> <li>2. How often did you go for speech therapy? (weekly, fortnightly, monthly)</li> <li>3. What was the duration of each speech therapy session? (30, 45, 60 mins)</li> <li>4. How often do you need to visit the hospital for replacement of the speech valve?</li> <li>5. Which professional fits and replaces the speech valve for you? (i.e. ENT, Speech Therapist)</li> <li>6. Do you know how to clean the valve yourself?</li> <li>7. Do you feel that you were properly trained to care for your stoma and valve? (If yes, what aspects helped the most/ if no, then what areas do you feel could have been improved?)</li> <li>8. Which professionals did you visit</li> </ol>	<ol style="list-style-type: none"> <li>1. What is the nature of your relation with (PWTL name)?</li> <li>2. Do you feel that he was properly trained to care for his/her stoma and valve? (If yes, what aspects helped the most/ if no, then what areas do you feel could have been improved?)</li> </ol>	<ol style="list-style-type: none"> <li>1. Please describe your professional role from (start to finish) in a laryngectomy patient's journey.</li> <li>2. How often would you work with these patients?</li> </ol>	<p>Pawar, Sayed, Kazi, Jagade, (2008) have revealed that primary TEP yields better functional outcomes than secondary TEP.</p> <p>The lifespan of each prosthesis varies (Cornu, et al, 2003) depending on the level of care and quality of the device. This information would reveal the level of care taken to clean the device as well as the complexities associated with the fitting and resizing.</p> <p>Early speech rehabilitation is associated with better communicative outcomes (de Maddalena, 2002).</p>

Objective	Questions to PWTL	Questions to CG	Questions to Voice Rehab Team	Motivation
	<p>throughout your journey?</p> <p>9. Does a team approach to management work better?</p>			<p>Adequate stomal care is necessary for respiration and communication (Hilgers, 2004; Mohebati &amp; Shah, 2010)</p> <p>Adequate information provision is vital (Lennie, et al., 2001).</p> <p>Team approach to laryngectomy management is advocated in the literature (Frowen &amp; Perry, 2001).</p>
<p>2) To identify how the PWTL, CG and the voice rehabilitation team perceive successful voice rehabilitation</p>	<p>10. You are currently communicating by TES and speech valve. Was it an easy process learning how to master communication by way of TES? How so?</p> <p>11. What complications did you experience using TES? (excessive secretions, infection, wounds, pain?) How have you managed to deal with these complications?</p>	<p>3.He is currently communicating by TES and speech valve. Was it an easy process for him to learn how to master communication by way of TES? How so?</p> <p>4. What does successful voice rehabilitation mean</p>	<p>3.Do you feel that Mr T., has been successfully rehabilitated? Please elaborate.</p> <p>4. Mr T is communicating functionally using TES. It has been hailed as the 'gold standard' in alaryngeal voice restoration by many. What are your views on</p>	<p>This information will shed light on whether the PWTL feels that he is communicating successfully using TES and to describe what success means to him. The answers will vary amongst the participants.</p> <p>TES despite being the “gold standard” in alaryngeal communication is fraught with challenges (Kazi, 2011)</p>

Objective	Questions to PWTL	Questions to CG	Questions to Voice Rehab Team	Motivation
	<p>12. Has the size of your stoma changed since the laryngectomy? How so?</p> <p>13. What does successful voice rehabilitation mean to you?</p> <p>14. Do you feel that you have been successfully rehabilitated? Please elaborate.</p>	<p>to you?</p> <p>5. Do you feel that he/she been successfully rehabilitated? Please elaborate.</p>	<p>TES.</p> <p>5. What are some of the pros and cons of TES? (in terms of cost, ease of use, maintenance, infection control)</p> <p>6. How important is communication to an individual? Please elaborate.</p>	<p>This question would provide information about what the PWTL's personal views about the pros and cons of the device. These may be similar to those documented in the literature.</p> <p>This would provide information about what the PWTL and other participants felt, were the elements or main factors that underlie successful communication.</p>
<p>3) To identify the factors promoting successful voice rehabilitation post-TL</p>	<p>15. Which factors helped you to speak with TES?</p> <p>16. Did you work before the laryngectomy? (Do you work now?)</p> <p>17. Do you attend regular support group meetings? If yes, then have you found the support groups beneficial in any way? How have they been beneficial?</p>	<p>6. Which factors helped him/her to speak with TEP?</p> <p>7. Did you work before his/her laryngectomy? (Do you work now?)</p> <p>8. Do you attend regular support group meetings? If yes, then have you found the support groups beneficial in any way? How have they been</p>	<p>7. What are some of the intrinsic factors that contribute to a patient's success? (e.g. spiritual, strong-willed, dedicated)</p> <p>8. What are some of the extrinsic factors that contribute to a patient's success? (e.g. Supportive caregiver, role-models, support groups, speech</p>	<p>This would provide invaluable information about what aspect of rehabilitation was perceived as being most beneficial.</p> <p>Attending regular support groups has shown to contribute positively to PWTL (Golhar, 2010).</p>

Objective	Questions to PWTL	Questions to CG	Questions to Voice Rehab Team	Motivation
	<p>18. Apart from the medical care that helped you through your journey, what other factors helped you to communicate effectively? (e.g. Positive attitude, spirituality, caring &amp; supportive family &amp; friends, support groups, speaking to experienced laryngectomees)</p> <p>19. If you could provide any advice or suggestions as to how services to laryngectomees can improve, then what would you suggest?</p> <p>20. What advice would you provide new laryngectomees or people who are about to undergo a laryngectomy?</p>	<p>beneficial?</p> <p>9. Does a team approach to management work better?</p> <p>10. Which part of the medical care that he/she received throughout his/her journey do you feel has benefitted him/her the most?</p> <p>11. Apart from the medical care that helped him/her through his/her journey, what other factors helped him/her to communicate effectively? (e.g. Positive attitude, spirituality, caring &amp; supportive family &amp; friends, support groups, speaking to experienced laryngectomees)</p> <p>12. If you could provide any advice or suggestions as to how services to laryngectomees could</p>	<p>therapist, psychologist)</p>	<p>Employment and income yielded positive correlations with QoL (Palmer &amp; Graham, 2004).</p> <p>Various studies advocate the use of a multi-disciplinary team for successful laryngectomy management to assist with the many aspects affected post-laryngectomy. (Frowen &amp; Perry, 2001; Ryan, Yong, Pracy, &amp; Simo, 2004; Collins, Flynn, Melville, Richardson, &amp; Eastwood, 2005).</p> <p>This information may be beneficial to individuals about to undergo a TL operation.</p> <p>This information may be beneficial to new PWTL.</p>

Objective	Questions to PWTL	Questions to CG	Questions to Voice Rehab Team	Motivation
		<p>improve, then what would you suggest?</p> <p>13. What advice would you provide caregivers of laryngectomees?</p>		<p>This information would be beneficial to professionals and PWTL and contribute to future research in the area.</p>
<p>4) To identify the factors impeding successful voice rehabilitation post-TL.</p>	<p>21. Do you feel that your quality of your life has decreased in some way after the laryngectomy?</p> <p>22. Which aspects have been affected the most? Breathing, communicating, eating?</p> <p>23. What were some of the major challenges that you experienced along your journey?</p> <p>24. There are many laryngectomees who find it difficult to communicate using TEP. Why do you think many people find this procedure difficult?</p>	<p>14. How different are your lives now compared to before the laryngectomy? (were there things that you and Mr. T enjoyed doing that you no longer do/ in what way have your lives been affected?)</p> <p>15. Do you feel that his quality of your life has decreased in some way after the laryngectomy? How so?</p> <p>16. Which aspects have been affected the most? Breathing, communicating, eating?</p> <p>17. Did you work before</p>	<p>9. Please describe some of the major challenges that you faced as a professional treating laryngectomees (e.g. Surgical complications, medical complications, hospital budgetary constraints, Hospital strikes, etc)</p> <p>10. What are some of the challenges that laryngectomy patients face?</p> <p>11. How are these challenges usually overcome?</p>	<p>This would reveal whether the PWTL was content about his/her QOL or not and detail what had changed.</p> <p>Speaking, eating and breathing are known to be significantly affected post-laryngectomy (Palmer &amp; Graham, 2004).</p> <p>This would provide information about the challenges faced, how they were overcome which may be beneficial for new PWTL and professionals.</p>



Objective	Questions to PWTL	Questions to CG	Questions to Voice Rehab Team	Motivation
		<p>his laryngectomy? (Do you work now?)</p> <p>18. What were some of the major challenges that he experienced along his journey?</p> <p>19. There are many laryngectomees who find it difficult to communicate with TES. Why do you think many people find this procedure difficult?</p> <p>20. What complications did he experience using TES? (excessive secretions, infection, wounds, pain?) How has he managed to deal with these complications?</p>	<p>12. Do you feel that South African hospitals are equipped to deal with the demand for TES? (Please elaborate)</p> <p>13. How does a laryngectomy patient's psychological state (mood, motivation, drive) change since the laryngectomy?</p>	<p>This information would be invaluable in describing what could go wrong while using TEP and what the common complexities and challenges that exist.</p> <p>Psycho-social well-being is a determinant for improved QOL and also has implications for voice rehabilitation (Palmer &amp; Graham, 2004).</p>

### 3.6.2. Pilot study

#### 3.6.2.1 Aim.

A pilot study is usually conducted in research as a pre-emptive measure to test the adequacy of a study or certain parts of a study, which may allow the researcher to develop elements of the research better (Woken, n.d). The purpose of using a pilot study in this research was to validate the content of the interview schedule and guide the researcher to ask pertinent questions during the individual interviews that were in keeping with the objectives of the study.

#### 3.6.2.2. Participants for pilot study.

Healthcare professionals representing disciplines commonly found in a laryngectomy voice rehabilitation team were randomly chosen from the MedPages electronic data base within the Gauteng area. They were contacted telephonically to enquire whether they worked with PsWTL and whether they would be interested to be part of the pilot study. As part of the pilot study they were each expected to validate the content of the questions posed to the main participants.

#### 3.6.2.3. Description of pilot study participants.

Table 3.11. provides descriptive information about the pilot study participants who validated the questions that were posed in the study.

**Table 3.11.: Descriptive information about pilot study participants**

Participant	Profession	No. Of years working with PWTL	Work setting
1	SLP	5	Hospital
2	ENT surgeon	10	Private Practice/ Hospital
3	ENT Nurse	16	Hospital

Letters of invitation were sent out to professionals working in laryngectomy management to request their participation in the pilot study (Please refer to Appendix C) together with the semi-structured interview questions (Please refer to Appendix D). The letters of invitation and the questions were emailed to professionals working with PWTLs and their thoughts and suggestions regarding the validity of the proposed questions informed the development of more focused questions.

#### *3.6.2.4. Results of pilot study.*

Constructive feedback was received from the pilot study participants and where necessary, changes were made to questions. The professionals felt that the questions were all relevant, however it was suggested that the terminology used should be more basic. Therefore, changes were made to simplify the terminology used in the questions. All participants of the pilot study felt that a study of this nature is necessary to improve service delivery to individuals who have undergone a TL.

#### *3.6.3. Data collection phases*

The data collection process comprised of the following three phases.

##### *3.6.3.1. Phase one: The focus group.*

Letters of invitation detailing the aim of the study and informed consent were sent to the four persons with TL identified by the SLP at Hospital X (Please refer to Appendices E1 & E2). The focus group (FG) consisted of four participants. Due to the complexities associated with tracheo-esophageal speech, this number was considered to be appropriate to provide each FG participant with an equal voice (Barbour, 2007). During the FG, open ended questions were posed to the PWTL to stimulate a discussion, and to identify their views of successful

rehabilitation. The FG was also used as a platform to identify a PWTL who the investigator felt had achieved success in communication. The FG was conducted in English. A bilingual interpreter proficient in English and Zulu was on call for translation of questions but was not needed as all participants had no difficulties with the level of English used in the FG.

### *3.6.3.2. Phase two: The individual interview with the PWTL.*

An informal intelligibility rating scale (Refer to Appendix H) was used to subjectively analyse the speech intelligibility of the focus group participants. This scale was used by 3 staff members at the SLP department at Hospital X to identify the PWTL who had the highest speech intelligibility. Once a PWTL had been identified for having achieved the highest success in terms of speech intelligibility in communication based on the results of the informal intelligibility scale, then a follow-up, individual interview took place with the selected PWTL. The interview was semi-structured and made use of open ended questions to gain a clear perspective of successful voice rehabilitation following the total laryngectomy. Where necessary, the PWTL was probed further to add more depth and to clarify points which arose. The interview was conducted in English as the PWTL understood and spoke in English. The interview was audio and visually recorded for ease of transcription. The length of the interview was approximately sixty minutes in duration as the room allocated by the SLP administrator was available for sixty minutes. The interview was not rushed and the researcher was able to gather the necessary data in sixty minutes. The individual semi-structured interviews made use of open ended questions to gain perspectives in the respondent's own words. Some responses required prompting such as, "please could you explain further" as the respondent responded in one or two word utterances without much elaboration.

#### *3.6.3.3. Phase three (Part 1): The interview with the caregiver.*

A letter of invitation and informed consent was sent out to the caregiver of the PWTL to participate in the study (Please refer to Appendices F1 & F2). The caregiver of the PWTL was then interviewed by means of a semi-structured interview using open ended questions. The interview was conducted in English as the caregiver spoke fluently in English. The caregiver was probed where necessary to elaborate on responses and provide clarity on points raised.

#### *Part 2): The interviews with the rehabilitation team.*

Letters of invitation were then sent to the ENT, SLP and nursing departments at Hospital X. A representative with laryngectomy management experience from each profession was then allocated by their departmental heads to be interviewed. The ENT surgeon, SLP, and nurse involved in laryngectomy management were each invited to participate in the study (Refer to Appendix G for the rehabilitation team member's letter of invitation and informed consent letter). Each was individually interviewed at Hospital X. The ENT surgeon, SLP, and specialist nurse chose to be audio-recorded only. Data gathered from the interviews was then analysed.

### **3.7. Data Analysis**

Data collection and analysis took place concurrently (Baxter & Jack, 2008). The Thematic Framework Approach was used to qualitatively analyze the data (Pope, Ziebland & Mays, 2000). A thematic analysis of the data allowed for each theme raised by all participants to be discussed separately and compared and contrasted.

The following five stages of qualitative data analysis outlined by Ritchie & Spencer (1994) occurred in this study:

Stage 1: Familiarization: Video and audio recordings of the raw data gathered from the focus group and individual interview discussions were viewed and listened to. The researcher then identified and listed the themes as they emerged.

Stage 2: Identifying a thematic framework: After listing the themes, the researcher identified recurring themes and then assigned codes to each theme.

Stage 3: Indexing: During this stage, responses were listed and themes categorized based on the frequency of their occurrence. This stage also entailed labelling of the data into brief summaries thereby easing the process of retrieval and further investigation (Pope et al., 2000).

Stage 4: Charting: This stage entailed the use of visual descriptions by means of charts and flow diagrams to easily identify the most frequently occurring themes.

Stage 5: Mapping and interpretation: Data was then interpreted and discussed.

Data was classified, i.e. analyzed, compared and presented according to perspectives of the laryngectomee, perspectives of the caregiver, and perspectives of the rehabilitation team.

### **3.8. Trustworthiness**

To ensure trustworthiness, the following steps discussed by Shenton, (2004) were taken into consideration in the implementation of this study:

- **Credibility** refers to whether the research findings are based on truth and factual information (Shenton, 2004). Credibility was assured using the following applications: triangulation and member checking. Triangulation may be achieved by incorporating more than one method to clarify or affirm the results found in the study (Olsen, 2004). Member checking was also incorporated in the study in the following

way: during the interviews where points were unclear, clarity was gained by the investigator by describing what was interpreted by the responses and then confirmed by the participants.

- **Transferability** – To assess whether the findings may be applied in different contexts (Shenton, 2004). Transferability was achieved by providing a detailed description of the case study
  
- **Dependability** – To assess whether the findings of the study are consistent with similar research in the field (Shenton, 2004). An extensive literature review was conducted which confirmed consistency of this research with literature in the field.
  
- **Confirmability** – To assess whether the findings of the study represented the participant's own original views free from researcher's views (Shenton, 2004). To ensure confirmability, a pilot study was conducted, where the semi-structured interview questions were sent out to one professional working with PsWTL from each of the following disciplines: ENT surgery, speech language pathology, and nursing, who pre-validated the content of the questions posed to the main participants. Constructive feedback was received from the pilot study participants and where necessary, changes were made to questions. The aim of the pilot study was to validate the content of the interview schedule; guide the researcher to ask pertinent questions that were in-keeping with the objectives of the study.

Triangulation between responses and with the literature confirmed the trustworthiness of the findings.

### **3.9. Summary of Chapter**

This chapter presented the methodology that was followed in this study. A collective case study design was used to gather multiple perspectives from a single site. Data was gathered by means of a FG and semi structured interviews. Data gathered was analyzed thematically. The findings are presented in the following chapter.



## **CHAPTER FOUR: FINDINGS AND DISCUSSION**

### **4.1. Introduction**

This chapter presents the findings of the data collected as well as a discussion of these findings. The main aim of the research was to identify the hallmarks of successful voice rehabilitation by TES from the perspectives of key role players; namely the PWTL who has been referred to as Mr. T in this chapter, his CG, and the voice rehabilitation team based at a public hospital in South Africa. Thematic analysis revealed five significant themes which will be discussed in this chapter. These themes are management, views on success, factors contributing to success, factors impeding success, and ethics have been organised below to reflect the perspectives of each of the key role players respectively. Verbatim quotes necessary to support the discussion are provided below in italicised font. The researcher was responsible for all this data gathering, analysis and interpretation. The overall findings are then summarised in the concluding paragraph.

### **4.2. Results of the Focus Group**

The FG was conducted with four PsWTL. The purpose of the FG was to identify a PWTL who presented with the most intelligible speech, and who appeared to have achieved success in alaryngeal voice rehabilitation. A participant was chosen, and interviewed individually thereafter. The participant was chosen based on his speech intelligibility which was analysed perceptually by three staff members at Hospital X based on an informal intelligibility rating scale derived from literature on perceptual analysis of TES (Jongmans, 2008). Mr. T who was the participant chosen for the individual interview, communicated intelligibly using TES. He reported having less complications than the other FG participants. His ability to communicate functionally using TES was relatively easy. Results from the individual interviews follow.

### 4.3. Themes

#### 4.3.1. Theme 1: Management

The management of a PWTL includes involvement by a multidisciplinary team of individuals who have designated roles to play; all of which are aimed at improving the medical condition and the communication skills of the PWTL and thereby his QoL (Kazi et al., 2010). The data collected in this study highlighted the individual roles played by each of these key role players as described below.

- ENT surgeon's role in laryngectomy management

The ENT surgeon sums up mainly what the literature states is the role of the ENT surgeon, in terms of identifying the problem and initiating a treatment regimen to eliminate the cancer, determining whether further oncological intervention is needed, and managing the patient further from a medical perspective (Frowen & Perry, 2001; Wild et al., 2004).

*ENT Surgeon: "Our first aim is to quantify the tumour, assess patient eligibility for surgery, and to also determine the outcome post surgery, post tumour resection; what is his further follow-up?; does he need radiotherapy? Is dual modality pigment indicated, can we just follow this man up as normal? That is from the tumour perspective. From a voice perspective, our aim is then to insert a speaking valve and then to formally rehabilitate this patient with regard to form some form of communication."*

The data revealed that the ENT surgeon also addressed post-operative complications such as tracheostomal problems and nosocomial infections (Wild et al., 2004). According to Frowen & Perry (2001), the ENT surgeon works closely with the SLP pre-operatively discussing

strategies for voice restoration. The dominant trends seen in major studies and the National Rehabilitation Policy (Department of Health, 2000) advocate that an informed decision be made by patients together with the rehabilitation team about the most suitable alaryngeal communication option to use (Perry, 1997; Kazi et al., 2010). However, only one option is provided at this hospital.

ENT Surgeon: *“We don’t explain all. We explain the better outcome. Hardly talk about electrolarynx due to cost, and with esophageal speech we don’t mention it because we can’t provide it in this set-up because the speech therapists are not trained to teach it”*

The ENT surgeon raises valid points as to why only one option is provided at this hospital. An electrolarynx is an expensive device and it is unlikely to be provided by the public sector due to its cost.

- Speech-Language Pathologist’s role in laryngectomy management

The SLP is one of the main members involved in the rehabilitation of voice and speech post laryngectomy (Casper & Colton, 1998). In the hospital presented in this report as the case, the SLP provides (*“counselling for the laryngectomy surgery”*). The SLP works closely with the PWTL from the pre-operative stage, as it is the role of the SLP to provide pre-operative counselling that would entail a detailed explanation of the surgery and consequences associated with the type of surgery. Post-surgery, the SLP is actively involved in evaluating communication and swallowing by (*“monitoring, checking that the Foley’s catheter is in place, checking that they’re developing okay in terms of recovery, we check for dysphagia with a quick screening of swallowing to see if there is a leak through the prosthesis itself and then we do a quick trial of voicing post insertion”*). The SLP may also review plans for

rehabilitation with the PWTL, the specifics of which will be determined by the type of treatment the individual receives and the choices that have been made regarding communication options (Casper & Colton, 1998). The role of the SLP is to provide adequate information that would enable the PWTL to make an informed decision about which alaryngeal voicing option to choose (Perry, 1997). Given that TEP with voice prosthesis is the method offered at this hospital for reasons discussed in the section on the ENT surgeon's role, the SLP would thus provide counselling on what to expect with this method only. Therefore, sizing and fitting of the voice prosthesis would then occur with the (*“speech therapist fitting the voice prosthesis in conjunction with the ENTs”*).

The SLP works in collaboration with the ENT surgeon postoperatively as well. Upon discharge, therapy sessions are then scheduled. At this hospital (*“usually one individual voice therapy session is provided”*) where the SLP provides in-depth counselling by going through (*“steaming ideas, stomal hygiene, voicing, just general care of the stoma, brushing the prosthesis, all of those aspects of post laryngectomy care”*). The importance and relevance of stomal hygiene and care cannot be overemphasised due to the vital role and direct effect it has on respiration and voicing. Thus the SLP may provide information together with demonstrations to facilitate an adequate understanding of post-laryngectomy care (Lennie et al., 2001). According to the participating SLP, patients are taught steaming by way of (*“steaming with a bucket [of hot water] and a towel over [one's neck]”*). Given that many of the people who utilise public health in South Africa come from lower socio-economic groups, this method of steaming with the bucket may be a more applicable option for individuals who cannot afford humidifiers or heat and moisture exchangers (HMEs).

The SLP at this hospital thus plays a valuable role in introducing the most cost-effective treatment measures to PsWTL that may be applicable in the South African context. At this hospital, the SLP also runs a monthly (“*SLP/ENT support group*”) with an emphasis on (“*resource development by the patients themselves,*”) which indicates that if empowered, PsWTL could play a valuable role in providing counselling and information provision, thereby easing the workloads of the SLPs which in the public sector are known to be high. However the role of the SLP at this hospital post-discharge differs significantly from what the literature describes as recommended practice in terms of follow-up therapy, duration of intervention afforded to PsWTL (Culton & Gerwin, 1998; Jongmans, 2008).

*Duration of intervention.*

SLP: “*they get just one individual out-patient session and thereafter they have the option to attend our monthly support group once every month*”

The procedure at this hospital is that the PsWTL are afforded only one follow-up out-patient session and thereafter have the option of attending the monthly support group where they will also be examined. The most highly intensive aspect of voice rehabilitation is speech therapy (Schiech, 2007). Some patients like Mr T who are fortunate enough to begin voicing as soon as the voice prosthesis has been inserted may benefit from such a therapy structure that only affords the patient a single speech therapy session. However, the reality is that a large percentage of TE speakers require weeks or months of training to facilitate speaking if the patients develop functional speech at all (Kazi, et al., 2010). The role of the SLP at this hospital is therefore not geared toward the intensive practice of tracheo-esophageal speech, but much rather focused on trouble-shooting and maintenance of the device. This may be attributed to the poor working conditions that public healthcare

professionals face such as a high workload and a shortage of skilled professionals (Human Rights Commission, 2009). The field of laryngectomy management is considered a specialist field (American Speech-Language-Hearing Association, 2004), therefore there may be fewer SLPs trained to work with this population.

The issue of ethics arises here. Why fit a patient with a voice prosthesis without investing the time and dedication needed to hone and master skills required for tracheo-esophageal speech? High workloads and a shortage of SLPs skilled in laryngectomy management, do not seem like valid reasons for providing one out-patient therapy session for persons with total laryngectomy because it denies some individuals who need more therapy to master this technique, thus causing harm to individuals which may impact negatively on their quality of life.

There is a dearth of information providing specific guidelines related to the duration of therapy for PsWTL and how speech therapy should be provided. Only one study was found, by Jongmans (2008) who endeavoured to design a TES rehabilitation programme specifically for speech-language pathologists working with Dutch PsWTL, where techniques used were evidence-based as described in the literature. The speech therapy programme aimed at achieving speech intelligibility in 2 phases: Phase 1 focused on articulation training and comprised of six lessons, with a single lesson being covered per speech therapy session. Phase 2 focused on teaching clear speech and optimal prosody, and comprised of nine lessons. The rehabilitation programme was tested on a group of PsWTL and the findings of her study revealed that only after nine lessons or five weeks i.e. two sessions per week of speech training and diligent homework follow-up by the PWTL, was a significant improvement seen by SLPs (Jongmans, 2008). Studies on TES management

exist which stipulate the number of sessions that have benefitted the patients in those studies to master TES (Culton & Gerwin, 1998; Jongmans, 2008). No consensus has been reached as to exactly how many sessions are needed to master TES, and given the varied surgical, psychological and, social facets seen in PsWTL, no consensus will be reached because ‘no individual is the same.’ Researchers call for ‘individualized’ treatment of the PWTL (Lennie et al., 2001; Kazi et al., 2010). Therefore, it would seem that the recommended practice should be significantly more than a single out-patient session in order to achieve a satisfactory outcome.

- Nurse’s role in laryngectomy management

*Nurse: “Before the operation, the procedure is explained [by the nurse], so they can be able to co-operate. Then, to explain the plan of treatment. I’m there to find out if he’s well informed, to find out what support systems do they have, what information do they have. The support systems need to be aware. I have to ensure that the patient has been seen by the speech therapist before theatre, and before ICU. They will have a NG (nasogastric) tube for the next two weeks. I need to make them aware that they may not be swallowing.”*

The ENT nurse, also known as the specialist nurse, is aptly skilled to deal with PWTL at all stages of intervention (Noonan & Hegarty, 2010). In addition to ensuring that support structures have been put in place, the nurse plays a role in managing the patient within the ward by means of administering enteral feeds, wound care, cleaning the patient, administering medication, talking to family members and monitoring the patient for the entire time that the PWTL is in her care. The nurse is trained in the education and practice of stoma and tracheostomy care, to monitor the site of surgery, to assist the PWTL in communicating

their needs within the ward (Schiech, 2007). Patients with total laryngectomy (PWTL) may find the role of the nurse as very comforting and re-assuring as the nurse is present in the ward before, during and after the surgery.

The management of the PsWTL at this hospital is multidisciplinary. Each of the three key role players has an important part to play in ensuring that the PWTL is adequately cared for and equipped with the necessary knowledge and skills to continue living the highest quality of life achievable for that individual. The caregiver is also considered a vital member of the team who provides moral support and care on a daily basis. The South African public healthcare context is plagued with challenges that may impact on service delivery as described above (Human Rights Commission, 2009).

#### *4.3.2. Second Theme: Views on Success*

In this particular study, all participants including Mr. T, agree that he is communicating successfully. The factors that have been identified as measures of success include **intelligible speech**, and **functional communication**. Mr. T said that he is (*“speaking properly, so that is successful”*). His CG feels that (*“if he wasn’t [successfully rehabilitated], then he wouldn’t be communicating”*). The CG goes on further to describe successful voice rehabilitation: (*“It means you can now communicate. You’ve got something that helps in communication”*). The nurse’s views are very similar to Mr. T’s because she feels that he is successful because, (*“he is talking well”*). The ENT goes into more depth by mentioning speech intelligibility. (*“...if they are able to complete simple sentences with intelligible speech then that’s successful”*). The SLP went further to say, (*“you want your main aim to be functional communication...I was definitely able to understand the conversation ... I would say that rehabilitation from a voice perspective, it definitely sounds like he has been successfully rehabilitated”*).



As seen from the responses, people use different parameters to measure success. In this study, the two that have been highlighted are intelligibility and functional speech. Speech intelligibility refers to how understandable a spoken message is (Logemann, 1997). A sentence can have a good speech intelligibility rate if all the words uttered are clearly produced. Good speech intelligibility is necessary for others to correctly understand what is being said (Jongmans, 2008). Understanding the meaning conveyed in a message is superior to understanding only the clarity of each individual word that was produced (Jongmans, 2008), e.g. thoughts, feelings and needs are made known.

Functional communication refers to the ability to use a particular method of communication, such as spoken language, when required e.g. making one's needs and wants known verbally in that the message is easily understood by both familiar and unfamiliar listeners, for social interaction and work purposes (ASHA, 2003).

A functional communication measure was developed by the American Speech and Hearing Association (ASHA, 2003) to rate a patient's communication and swallow skills during SLP intervention. A rating scale that ranges from Level 1 – little or no functional communication to Level 7 – highest functional level reached is used to measure various disorders commonly treated by SLPs, including alaryngeal communication. Level 7, the highest functional level on the scale for alaryngeal communication reads as follows:

*“The individual's ability to successfully and independently participate in vocational, avocational and social activities is not limited by alaryngeal communication. The individual independently self-monitors communication effectiveness and uses compensatory strategies when encountering difficulty”* (ASHA, 2003, p. 5).

The goal of an alaryngeal voice rehabilitation programme should be to fulfil the above description. Given the close correlation between communication effectiveness and QoL (Palmer & Graham, 2004), the goal of a voice rehabilitation programme should thus be to improve QoL.

#### *4.3.3. Third Theme: Factors contributing to successful voice restoration*

The factors that contribute to success are presented into two of the following categories, i.e. extrinsic and intrinsic factors. Within the category of extrinsic factors, the following sub-themes emerged as significant, i.e. support, in terms of support groups, spiritual support and family support; and education. The intrinsic factor that resonated amongst participants was the strong will to live. Each of these sub-themes will be discussed below under their respective sub-heading.

##### *4.3.3.1. Extrinsic factors.*

- Support Groups

According to Goktas et al. (2008), individuals who attend support groups learn about new and exciting trends in laryngectomy management, and tend to express more satisfaction with life. Mr. T derives much satisfaction from his support group as he attributed much of his progress to, (*“the people of the support group”*). He went on further to explain that he used to experience a great deal of (*“anger”*) and alludes to the support group as being a source of comfort that provided him with coping strategies to deal with his anger as he concludes with: (*“but since I joined them I find I’m happy”*).

Mr. T attributes much of his progress and feeling of wellbeing to the support group that he attends. The SLP also believes that support groups contribute to success:

SLP: *“What we do find is a good service here is the SLT- ENT support group, so after the counselling and care we have a support group each month, with a different topic. Within that session we check each patient’s voice prosthesis and voicing”*

A study conducted by Vakharia, Jaffer Ali & Wang (2007) that compared the quality of life of members of a medical centre who attended a support group and those who did not, found that those who attended the head and neck cancer support group presented with greater satisfaction in the areas of eating habits, emotional well-being and pain management.

Support groups are unique and differ from traditional treatments in the sense that the participants are encouraged to share their problems with the group, and to receive advice from multiple sources including members who may have experienced similar challenges. Since priorities of members of the voice rehabilitation team may differ from the PWT and his family, topics that are not related to communication and swallowing may also be targeted, such as financial worries, coping, difficulties reintegrating into society and marital problems (Cady, 2002). Therefore, facilitators of such support groups ideally identify factors that affect overall well-being, and target these in the support groups.

- Family Support

Mr T’s CG highlighted that (*“family support is there”*). The ENT surgeon observed that, (*“If they have good family support then I notice that speech is better. Without it, they still manage to survive somehow. With that family support they can interact well with people around them”*). Mr T has family support which was also observed by the specialist nurse, (*“His family members also came to see him”*).

Mr. T's CG is his sister and she attends his hospital visits with him and they both live in the same house. Studies (Birkhaug, Aarstad, Aarstad & Olofsson, 2002; Cady, 2002) that looked at family support focused more on marital relationships and the involvement of a spouse. There is a gap in the literature as no studies made mention of sibling relationships. Relic et al. (2001) looked at quality of life and coping in twenty-nine PsWTL who belonged to a support group, and found that the support of family was valued most above all else when overcoming disease related problems and the consequences of treatment. Hjorleifsdottir et al. (2008) also found family support was highly valued by cancer patients and was seen as a rich source of providing hope.

- Spiritual Support

Spiritual support has been viewed positively in the literature on coping strategies adopted by cancer patients (Visser et al., 2010; Puchalski, 2012). In this study, it was found that Mr. T is spiritual and places a great deal of trust and faith in his beliefs. (*"I told myself if God can help me, I can be a success. I was going to be brave. God must give me the strength."*) Spirituality helps individuals find perspective during moments of illness (Puchalski, 2012). Instead of focusing on negativity and the possibility of death, Mr. T chose to strengthen his spiritual beliefs and place his trust in God, a coping strategy that has held him in good stead given the successful outcome of his voice rehabilitation and overall QoL.

The SLP also noticed that spirituality plays a positive role in the PsWTL that she has worked with.

SLP: *"A lot of patients believe that prayer and spirituality like going to church and those sorts of things, assists them a lot in terms of their emotional well-being and we encourage it in our groups as well."*

The SLP mentioned that prayer and spirituality were encouraged in the groups held at the hospital.

- Educational information

Education occurs in the pre-operative stage and informs the patient about why the surgery is necessary and what needs to be done to manage as best as possible after the surgery (Lennie et al., 2001). The SLP highlights the importance of the initial education provided:

*SLP: “The initial education also counts a lot. Often if people have gotten proper counselling and gone through the correct channels of communication and internally if they fully understand what the surgery is about somehow and if they are more positive about it often their experience becomes a better experience and the outcomes are successful.”*

The educational information provided aims to prepare the PWTL and his caregiver for the journey ahead. Therefore, it is vital that correct and valuable information be conveyed by members of the voice rehabilitation team, who have been trained to work with individuals who have had laryngectomies (Kazi, 2007; Kazi et al., 2010). Consideration must be made to the first language of a patient and also to illiterate patients. Individualized information should be provided to patients as opposed to general information packs designed solely for laryngectomy surgery (Newell et al., 2004). Some of the information shared and demonstrated may include cleaning and steaming procedures, issues related to psychological, social, marital concerns as well as diet (Palmer & Graham, 2004). The adequate provision of information promotes autonomy, a key ethical principle that must be exercised and

encouraged in alaryngeal voice rehabilitation due to the complexity of the surgery and when choosing an alaryngeal option to use.

The ENT surgeon agrees that (“*one needs to be educated about rehab.*”) Education for rehabilitation is necessary to firstly choose an alaryngeal option, secondly to understand the requirements of the alaryngeal option chosen for success in communication, and thirdly to understand how to manage common complications related to the device and finally where to seek help and what to do in cases of an emergency. Once a PWTL has been fully informed about the various alaryngeal communication options, the choice of an alaryngeal option should be made by the PWTL him/herself (Kazi et al., 2010).

#### 4.3.3.2. *Intrinsic Factor.*

- Strong will to live

Intrinsic factors that correlated with improved success rates were raised by two participants. The ENT surgeon believes that, (“*being very strong-willed*”) is a factor that contributes to success. The nurse noticed these qualities in Mr. T: (“*He’s a very dedicated person and has a strong will to live. Whenever there was a problem he would ask, “Sister, do I need this?” He is always concerned and does what needs to be done*”). The Icelandic study (Hjorleifsdottir et al., 2007) mentioned previously in this chapter, found that a “strong will” to manage the condition, and being determined to retain normalcy, was evident in those participants who displayed good coping strategies. However, the same study suggested that good coping strategies are largely dependent on factors such as family support, the relationship between healthcare professionals and the patient, belief in the aims of treatment, daily encounters, and faith (Hjorleifsdottir et al., 2008). Therefore, intrinsic qualities that aid coping manifest when social support is available. These findings are supported by Zucca, Boyes, Lecathelinais &

Girgis (2010) who found that reduced support systems were predictors of maladaptive coping strategies in long-term cancer patients, thereby suggesting that good support systems were predictors of adequate coping strategies. Mr. T has family support, spiritual support, access to a support group and is monitored by a medical team on a regular basis. Therefore these factors all contribute to his strong will to live.

#### *4.3.4. Fourth Theme: Factors impeding success*

The main issue that will be discussed is the issue of budget. All rehabilitation team members mentioned that one of the greatest challenges impeding service delivery to persons with total laryngectomy, is budget.

*ENT: "The factor that precludes treatment is that our hospital hasn't been able to pay its suppliers. So, we put in a fistula at the time of the operation. The valves are not readily available, so the valves are not fitted at the time of the operation. If there is no appropriate size valve available, then we have to choose the next best size because of lack of availability of appropriately sized valves. It can be a disaster because it gets coughed out because it is not a strong fit, and voicing is not great. The hospital has not paid its bills so we can't get it. All in all, we insert the valves after 10 days. To give you an example, we currently only have size 10 valves available. Yet the average size valve for patients is 6 or 8. It's an ongoing problem and still happens"*

South African public hospitals are plagued with budgetary constraints (Human Rights Commission, 2009). There is a high cost involved with the use of this device, including regular check-ups for re-sizing and valve replacement which would place a burden on a cash-strapped hospital (Staffieri et al., 2006; Pawar et al., 2008) The high cost incurred may pose

financial constraints on a hospital in a developing country, where the incidence of laryngeal cancer is great (Staffieri et al., 2006; Kazi, 2007). Therefore, consideration should be made to procuring more cost-effective devices.

In a public hospital where consideration has to be made of the use of more cost-effective treatments, the procurement of more reasonably priced voice prostheses is an area that should be explored further, with more proactive collaboration between the Professional Board of Speech, Language and Hearing Professions with advocates in the Department of Health and companies that manufacture voice prostheses for PsWTL.

The two studies that were found which related to the use of voice prostheses in South African public hospital departments (Fagan et al., 2002; Cornu et al., 2003) revealed that Provox and Blom-Singer voice prostheses were each used at two hospitals in SA. The hospital used in this study uses Provox-2 voice prostheses. Provox and Blom-Singer voice prostheses are manufactured in their countries of origin i.e. Sweden and the USA respectively; and are distributed within SA by international or local companies. The cost of airfreight, shipping and taxes all contribute to the high cost of the device, which is borne by the South African Department of Health.

The volatile economic climate forces government departments to consider reducing costs in every avenue, as seen with the roll-out of cheaper generic medication for HIV/AIDS (Human Rights Commission, 2009) that is being supplied by developing countries who procured a tender with the DOH. Why then, is this same rule not applicable for voice prostheses for laryngectomy patients? The quality of the Provox-2 and Blom-Singer voice prostheses have been researched extensively and their merits are impressive. The potential conflict with



providing 'gold standard' treatment and cost-effective services is that the quality of the device may be compromised. However, given the high device complication rate and questionable life span of each and every device, it is worthwhile to investigate whether local or international companies can be used to manufacture voice prostheses at a significantly lower cost. This would decrease the financial burden on hospital departments and allow the voice rehabilitation team to focus on meeting the needs of the people, thereby improving service delivery. This would certainly be beneficial to the provision of health services in South Africa and with a long term view in mind, if such production were subsidised by government, it could be provided at affordable rates.

The SLP confirmed what the ENT had said about the budgetary constraints impacting the availability of voice prostheses for surgery, and went on further to discuss how the accompanying accessories to aid in stoma care are also not freely available if at all.

*SLP: "I think further in detail if we look at budgetary constraints, voice prosthesis is just one aspect of voice rehabilitation, there are a whole lot of assistive devices that must go along with it so something as simple as your cloth protector we usually don't have enough stock of it... one of the biggest challenges is something called stomal stenosis and we have at least 3 patients within our group that have stomal stenosis and these would be very good candidates for lary buttons or lary tubes to keep the stoma more patented from stenosing, but we don't have any budget for that... So even something like the heat moisture exchangers, we aren't allowed to give it to any of our patients we don't have the budget to be able to sustain those because it needs to be replaced daily and our patients aren't able to afford it so we can't really give them that option"*

The ENT nurse has also had to deal with the consequences of budgetary constraints in her clinical practice. (*“The problem is to order the bibs. Sometimes it takes 6 to 8 months to get an order and then we are already out of stock. It is not a shelf item so it very hard.”*)

Thus, strategies aimed at providing post-laryngectomy management in a more cost-effective manner needs urgent review.

#### *4.3.5. Fifth Theme: Ethics*

Healthcare professionals in South Africa are guided by a code of ethics set out by the Health Professions Council of South Africa (HPCSA) to ensure that the services they offer are of the highest standards both professionally and ethically. However, given the challenges described above by the voice rehabilitation team members at the public hospital, the reality is that a chance of success in alaryngeal voicing via TEP with VP will not be achieved by every patient requiring it. This is due to the reality that the policies that guide service delivery cannot be implemented without a steady flow of funds.

Despite the well intentioned policies that aim to provide South African PsWTL with the ‘gold standard’ in alaryngeal voicing, a policy that cannot be followed through or implemented begs the question of whether it is ethical or not.

Similarly, with regard to time spent with each patient, the SLP stated that every laryngectomy patient is given one therapy session post-laryngectomy and thereafter has the option of attending the monthly support group. Studies show that TES is not an easy process for every patient; some may require multiple sessions to practice the technique. It seems that the stance taken by this hospital to provide only TES as an alaryngeal option and that it cannot be fully

sustained with the added financial burden and the inadequate time allocated to mastering the technique, further raises the question of ethics.

Sustainable patient care should be the focus of this highly specialised field of therapy. Instead of modelling international trends that cannot be maintained, focus should be on providing a sustainable, affordable and practical treatment. The National Rehabilitation Policy (Department of Health, 2000) calls for rehabilitation to be more patient centred where the patient is involved in decision making. However, it is difficult for these values to manifest in a system where the needs of patients who require specialised assistive devices are neglected due to a lack of funds because the device is manufactured solely for profit.

When asked whether all 3 alaryngeal voicing options were provided to patients, the ENT responded as follows:

*ENT: "We don't explain all 3. We explain the better outcome. Hardly talk about electrolarynx due to cost, and with ES we don't mention it because we can't provide it in this set-up"*

The SLP backs the claim that only one option is provided

*SLP: "I think the second one [challenge] is that you've put in or implemented a measure where you haven't gone the esophageal voicing route or you haven't gone the electrolarynx route, you've gone the tracheo-esophageal voicing route"*

An autonomous decision therefore cannot be made by a PWTL at this hospital given the fact that only TES is provided. What then would be provided to the PWTL who isn't a candidate for TES? What services will he receive to improve his voicing and communication?

An urgent solution is needed to respond to the challenges faced by healthcare professionals at this hospital and more importantly for the patients they serve.

#### **4.4. Summary of Chapter**

The dominant themes that arose from the findings of the study have been discussed in this chapter. The first dominant theme that was discussed was *management*. The discussion on management relates directly to the first objective; i.e. to identify the process of alaryngeal voice rehabilitation by TEP with voice prosthesis. Management of a PWTL is multidisciplinary in nature, comprising of ENT, SLP and nursing involvement. Management focuses on treating the cancer, the quality of life issues namely breathing, eating and speech. Alaryngeal communication by TEP with voice prosthesis is the main voicing option offered at this hospital.

The second dominant theme that was discussed was **views on success**. Participants' views were discussed. The main factors that arose were *speech intelligibility* and *functional communication* as predictive measures of success, which directly relates to the second objective, i.e. to identify how the PWTL, CG and the voice rehabilitation team perceive success in voice rehabilitation. All participants' unanimously agree that Mr. T has been successfully rehabilitated as his speech intelligibility is high, and he communicates functionally using TES.

The third dominant theme that was discussed was *factors that promote success in voice rehabilitation*. The major factors that promoted success which echoed in the findings, were *support*, in terms of attending a *support group*, *spiritual support* and *family support* and

*educational information*, and the intrinsic factor that emerged was, *a strong will to live*. All these factors were found to have a significant correlation with improved QoL and relate to the third objective, i.e. to identify the factors promoting successful voice rehabilitation post-TL. The fourth theme that was discussed was *factors impeding success*. This study found that the main factor impeding success was the issue of *budget*. The use of TEP with voice prosthesis is a costly practice requiring ample funds for the different resources needed to facilitate improved communication and stomal care.

The fifth dominant theme was *ethics*. The service provided to PsWTL at the hospital raises many ethical issues in the sense that the programme does not appear to be sustainable; furthermore, autonomy is not exercised as PsWTL are only afforded one option of alaryngeal communication, which itself cannot be sustained by the hospital and one may question whether beneficence is maintained. Themes four and five relate to the fourth objective in the study, i.e. to identify the factors impeding successful voice rehabilitation post-TL.

## **CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS**

### **5.1. Introduction**

The previous chapter provided the findings of the study with the ensuing discussion. This chapter provides a brief summary of the key findings, the limitations of the study, and the recommendations in terms of implications for future research and clinical practice.

### **5.2. Conclusion**

In this study the person with total laryngectomy (PWTL) using TES, his caregiver (CG), and the voice rehabilitation team comprising of an ear, nose & throat (ENT) surgeon, a speech-language pathologist (SLP), and a specialist nurse (SN) were interviewed to establish their respective perspectives on the factors that promote and impede the successful acquisition of TES.

One of the main factors that contributed to success in this case, was that the PWTL was part of a support group for head and neck cancer patients, which seemed to contribute to his quality of life (QoL). Being registered with a support group has shown to be beneficial for laryngectomy patients (Golhar, 2010). The PWTL has a very supportive caregiver and has a strong belief in God. He was seen by multiple professionals at the hospital. A multi-disciplinary team approach is necessary to deal with the variety of complexities seen after a laryngectomy (Frowen & Perry, 2001; Ryan et al., 2004; Collins et al., 2005). The PWTL has been successfully rehabilitated which has been confirmed by his CG, the ENT surgeon, the SLP and the SN.

This hospital faces challenges related to cost and DoH policies and guidelines; which may threaten the provision of services to laryngectomy patients in terms of duration of therapy,

the choice of devices, provision of accessories to name a few. The cost incurred with using voice prostheses is e high given that it is an ongoing form of treatment that requires regular replacement and maintenance (Staffieri et al., 2006; Kazi, 2007), a significant challenge for a health system with limited resources.

### **5.3. Limitations**

- Only one hospital was used in the study, therefore it provides no true representation of South African public hospitals as a whole. The hospital was chosen as it was accessible to the researcher.
- Only English and Zulu speakers were catered for in this study, which may have limited the number of potential participants who successfully communicate with TES in languages other than English and Zulu.
- Only persons with TL who had undergone surgery not less than three months before data collection and not more than thirty six months before data collection were chosen to participate in the study, thereby limiting the number of potential candidates who communicate successfully with TES.

### **5.4. Recommendations**

#### *5.4.1. Implications for future research*

- A study of this kind should be done on a national scale to ascertain whether the majority of tertiary healthcare facilities are keeping up to date with current and dominant trends in alaryngeal voice rehabilitation.
- Head and neck cancer statistics in South Africa should be ascertained and their implications for clinical practice highlighted.

- More studies should be conducted in developing countries to determine whether the standard of service delivery is in line with current and dominant trends in alaryngeal voice rehabilitation.
- More research is needed to develop protocols that are consistent.
- The supportive role of the caregiver is often not mentioned in the literature. More studies should be conducted to highlight the supportive role of the caregiver.
- Unemployment is a circumstance many PsWTL find themselves in. More research should be directed at the types of employment that would suit a PWTL.
- More research is needed to develop standardised training material for SLPs in laryngectomy management in South Africa in keeping with international standards.

#### *5.4.2. Implications for clinical practice*

- Efforts should be made to manufacture and produce more cost-effective voice prostheses for developing countries.
- Efforts should be made toward the provision of cost effective accessories that accompany the voice prosthesis and/or education should be provided to the patient and family on how to make accessories such as bibs, etc.
- More therapy time should be afforded to patients to practice TES.
- More support services should be provided to PWTL.

### **5.5. Summary of Chapter**

This chapter provided the key findings of the study, namely, the factors that promote and impede successful TES. This chapter also provided the limitations, and recommendations for future research and clinical practice.



## REFERENCES

- Ackerstaff, A.H., Hilgers, F.J.M., Aaronson, N.K., & Balm, A.J.M. (1994). [Communication, functional disorders and lifestyle changes after total laryngectomy.](#) *Clinical Otolaryngology and Allied Sciences*, 19(4), 295-300.
- Albirmawy, O.A., Elsheikh M.N., Saafan, M.E., & Elsheikh, E. (2006). Managing problems with tracheoesophageal puncture for alaryngeal voice rehabilitation. *The Journal of Laryngology & Otology*, 120, 470-477.
- American Speech-Language-Hearing Association. (2004). Knowledge and skills for speech-language pathologists with respect to evaluation and treatment for tracheoesophageal puncture and prosthesis. doi: 10.1044/policy.KS2004-00070
- Andrews, J.C., Mickel, R.A., Monahan, G.P., Hanson, D.G., & Ward, P.H., (1987). Major complications following tracheo-esophageal puncture for voice rehabilitation. *Laryngoscope*, 97, 562-567. In: Kazi, R.A. (nd). An overview of vocal rehabilitation after laryngectomy. Retrieved on 02/07/2011 from: <http://www.otohns.net/default.asp?id=15001>
- ASHA. (2003) National Outcomes Measurement System (NOMS): Adult Speech-Language Pathology User's Guide. Retrieved on 02/07/2011 from: <http://www.asha.org/members/research/noms>
- Barbour, R. (2007). *Doing focus groups*. London: Sage.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 13, 544-559.
- Birkhaug, E.J., Aarstad, H.J., Aarstad, A.K.H., & Olofsson, J. (2002). Relation between mood, social support and the quality of life in patients with laryngectomies. *European Archives of Otorhinolaryngology*, 259: 197-204. doi: 10.1007/s00404-001-0444-8
- Brown, D.H., Hilgers, F.J., Irish, J.C., & Balm, A.J. (2003). Postlaryngectomy voice rehabilitation: state of the art at the millennium. *World Journal of Surgery*, 27,824-31.
- Cady, J. (2002). Laryngectomy: beyond loss of voice – caring for the patient as a whole. *Clinical Journal of Oncology Nursing*, 6 (6) 1-5. doi:10.1188/02.CJON.xxx-xxx
- Calder, N., MacAndie, A., & MacGregor, F. (2006). Tracheoesophageal voice prostheses complications in north Glasgow. *The Journal of Laryngology & Otology*, 120, 487-491.
- CANSA (n.d). Statistics. Retrieved on 07/11/2012 from: <http://www.cansa.org.za/statistics/>
- Cantu, E., Ryan, W.J., Tansey, S., & Johnson, C.S. (1998). Tracheoesophageal speech predictors of success and social validity ratings. *American Journal of Otolaryngology*, 19 (1), 12-17.

- Casper, J.K., & Colton, R.H. (1998). *Clinical manual for laryngectomy and head/neck cancer rehabilitation*. San Diego, CA: Singular Publishing Group Inc.
- Census, (2012). Census 2011 Key Results. Retrieved on 12/11/2012 from: <http://www.statssa.gov.za/census2011/default.asp>
- Chou, W.S., Hunt, Y.M., Beckjord, E.B., Moser, R.P., & Hesse, B.W. (2009). Social media use in the United States: implications for health communication. *Journal of Medical Internet Research*. doi:10.2196/jmir.1249
- Collins, R., Flynn, A., Melville, A., Richardson, R., & Eastwood, A. (2005). Effective health care: management of head and neck cancers. *Quality and Safety in Health Care*, 14,144-148.
- Cornu, A.S., Vlantis, A.C., Elliot, H., & Gregor, R.T. (2003). Voice rehabilitation after laryngectomy with the ProvoxR voice prosthesis in South Africa. *Journal of Laryngology and Otology*, 117(1), 56-59.
- Creswell, J.W. (2007). *Qualitative inquiry and research design: choosing among five approaches (2<sup>nd</sup> Ed)*. Sage Publications.
- Culton, G. L., & J. M. Gerwin. (1998). Current trends in laryngectomy rehabilitation: a survey of speech-language pathologists. *Otolaryngology Head Neck Surgery*, 118(4), 458-463.
- Debruyne, F., Delaere, P., Wouters, J., & Uwents, P. (1994). Acoustic analysis of tracheoesophageal versus esophageal speech. *Journal of Laryngology and Otology*, 108, 325-328.
- De Maddalena, H. (2002). The influence of early speech rehabilitation with voice prostheses on the psychological state of laryngectomized patients. *European Archives of Oto-rhino Laryngology*, 259, 48-52.
- Department of Health (homepage): Retrieved on 02/11/2012 from: <http://www.doh.gov.za/index.php>
- Department of Health. (2000). *National rehabilitation policy*. Retrieved on 03/11/2012 from: <http://www.doh.gov.za/docs/policy/2000/rehabpolicy.pdf>
- Deshpande, M.S. (2010). Prosthetic voice rehabilitation after total laryngectomy. *Indian Journal of Surgical Oncology*, 1(2), 146-150. doi:10.1007/s13193-010-0028-4
- Eadie, T.L., & Doyle, P.C. (2005). Quality of life in male tracheoesophageal (TE) speakers. *Journal of Rehabilitation Research & Development*, 42, 115-124.
- Elmiyeh, B., Dwivedi, R.C., Jallali, N., Chisholm, E.J., Kazi, R., Clarke, P.M, & Rhys-Evans, P.H. (2010). Surgical voice restoration after total laryngectomy: an overview. *Indian Journal of Cancer*, 47(3), 239-247.

- Fagan, J.J., Lentin, R., Oyarzabal, M.F., Isaacs, S., & Sellars, S.L. (2002). Tracheoesophageal speech in a developing world community. *Archives of Otolaryngology Head Neck Surgery*, 128, 50-53.
- Frowen, J., & Perry, A. (2001). Reasons for success or failure in surgical voice restoration after total laryngectomy: an Australian study. *Journal of Laryngology Otolaryngology*, 115(5), 393-399.
- Genden, E.M., Ferlito, A., Rinaldo, A., Silver, C.E., Fagan, J.J., Sua´rez, C..., Wolf, G.T. (2008). Recent changes in the treatment of patients with advanced laryngeal cancer. *Head and Neck*, 30, 103–110. doi:10.1002/hed.20715
- Gibbs, A. (1997). Focus groups. *Social Research update: University of Surrey*, 19. Retrieved on 11/11/2012 from: <http://sru.soc.surrey.ac.uk/SRU19.html>
- Goktas, O., Fleiner, F., Paschen, C., Lammert, I., & Schrom, T. (2008). Rehabilitation of the olfactory sense after laryngectomy: long-term use of the larynx bypass. *ENT-Ear, Nose & Throat Journal*, 87 (9), 528-536.
- Golhar, S. (2010). Tracheo oesophageal puncture voice: an Indian perspective. *Indian Journal of Otolaryngology Head Neck Surgery*, 62(4), 408–414. doi:10.1007/s12070-010-0108-3
- Greenbaum, T.L. (1997). *The handbook on focus group research*. Sage Publications.
- Heald, A.E., & Schiffman, S.S. (1997). Taste and smell: Neglected senses that contribute to the malnutrition of AIDS. *North Carolina Medical Journal*, 58, 100–104.
- Hilgers, F.J.M., Ackerstaff, A.H., As, C.J.van., Balm, A.J.M., Brekel, M.W.M. van den, Tan, I.B. (2003). Development and clinical assessment of a heat and moisture exchanger with a multi-magnet automatic tracheostoma valve (Provox FreeHands HME) for vocal and pulmonary rehabilitation after total laryngectomy. *Acta Otolaryngologica (Stockholm)*, 123, 91-99.
- Hilgers, F.J.M (2004). *Van verbazing naar vanzelfsprekendheid (From astonishing to predictable speech)*. Faculteit der Gessteswetenschappen. Vossiuspers UvA, Amsterdam.
- Hjorleifsdottir, E., Hallberg, I.R., Gunnarsdottir, E.D., & Bolmsjo, I.A. (2008). Living with cancer and perception of care: Icelandic oncology outpatients, a qualitative study. *Support Care Cancer*, 16, 515-524. doi: 10.1007/s00520-007-0333-9
- Hopkins, L.E., Gross, A.L., Knutson, N.M., & Candia, C.L. (2005). Laryngectomy: An Introductory Overview. *Florida Journal of Communication Disorders*, 22, 7-18.
- Human Rights Commission. (2009). Public Inquiry: Access to public services. Retrieved on 01/07/2012 from: <http://www.info.gov.za/view/DownloadFileAction?id=99769>
- Iseh, K. (2011). Total laryngectomy for laryngeal cancer in a Nigerian tertiary health centre: prognosis and outcome. *Journal of Surgical Technique and Case Report*, 3 (1), 23-30.

- Jongmans, P. (2008). *The intelligibility of tracheoesophageal speech: an analytic and rehabilitation study*. Published PhD Thesis, University of Amsterdam.
- Kapila, M., Deore, N., Palav, R.S., Kazi, R.A., Shah, R.P., & Jagade, M.V. (2011). A brief review of voice restoration following total laryngectomy. *Indian Journal of Cancer*, 48(1), 99-104. doi: 104103/0019-509X.75841
- Kazi, R.A. (n.d.). An overview of vocal rehabilitation after laryngectomy. Retrieved on 02/07/2011 from: <http://www.otohns.net/default.asp?id=15001>
- Kazi, R. (2007). Surgical voice restoration following total laryngectomy. *Journal of Cancer Research and Therapeutics*, 3(4), 188-189.
- Kazi, R., Nutting, C.M., Rhys-Evans, P., & Harrington, K.J. (2009). A short perspective on the surgical restoration of alaryngeal speech. *South Medical Journal*, 102(8), 838-840.
- Kazi R., Pawar P., Sayed S.I., & Dwivedi R.C. (2010). Perspectives on voice rehabilitation following total laryngectomy. *European Journal of Cancer Care*, 19, 703–705.
- Lennie, T.A., Christman, S.K., & Jadack, R.A. (2001). Educational needs and altered eating habits following a total laryngectomy. *Oncology Nursing Forum*, 28(4), 667-674.
- Logemann, A.J. (1997). Speech and swallowing rehabilitation for head and neck cancer patients. *Oncology*, 11(5). Retrieved on 12/11/2012 from: <http://www.psychiatrictimes.com/display/article/10165/97918>
- Makitie, A.A., Niemensivu, R., Juvas, A., Aaltonen, L., Back, L., & Lehtonen, H. (2003). Postlaryngectomy voice restoration using a voice prosthesis: a single institution's ten-year experience. *Annals of Otology, Rhinology, & Laryngology*, 112, 1007-1010.
- Malik, T., Bruce, I., & Cherry, J. (2007). Surgical complications of tracheo-oesophageal puncture and speech valves. *Current Opinions in Otolaryngology and Head Neck Surgery*, 15(2), 117-122.
- Max, L., Steurs, W., & De Bruyn, W. (1996). Vocal capacities in esophageal and tracheoesophageal speakers. *Laryngoscope*, 106, 93-96.
- McLafferty, I. (2004). Focus group interviews as a data collecting strategy. *Journal of Advanced Nursing*, 48, 187–194. doi:10.1111/j.1365-2648.2004.03186
- Mohebati, A., & Shah, J.P. (2010). Total Laryngectomy. *Otorhinolaryngology Clinics: An International Journal*, 2(3), 207-214.
- Morgan, D.L. (1996). Focus Groups. *Annual Review of Sociology*. 22, 129-152. Retrieved on 12/11/2012 from: <http://www.jstor.org/stable/2083427>
- National Cancer Registry, (2004). The 2004 NCR Report. Retrieved on 17/11/2012 from: [http://www.cansa.org.za/files/2012/05/Cancer\\_Registry\\_2004.pdf](http://www.cansa.org.za/files/2012/05/Cancer_Registry_2004.pdf)

- National Treasury (2012). Chapter 6: Social security and the national health insurance. 2012 Budget Review. Retrieved on 02/11/2012 from:  
<http://www.treasury.gov.za/documents/national%20budget/2012/review/default.aspx>
- Newell, R., Ziegler, L., Stafford, N., & Lewin, R.J. (2004). The information needs of head and neck cancer patients prior to surgery. *Annals of The Royal College of Surgeons of England*, 86, 407-410. doi: 10.1308/147870804722
- Nieboer, G.L.J., De Graaf, Tj., & Schutte, H.K. (1988). Esophageal voice quality judgements by means of the semantic differential. *Journal of Phonetics*, 16, 417-436.
- Noonan, B.J., & Hegarty, J. (2010). The impact of total laryngectomy: the patient's perspective. *Oncology Nursing Forum*, 37(3), 293-301.
- Olsen, W. K. (2004). Triangulation in social research: qualitative and quantitative methods can really be mixed. In Holborn, M. (ed.), *Developments in Sociology: An Annual Review*, Ormskirk, Lancs, UK, Causeway Press. Retrieved on 15/03/2013 from:  
<http://ccsr.ac.uk/staff/Triangulation.pdf>
- Op de Coul, B.M.R., Ackerstaff, A.H., Van As-Brooks, C.J., Van Den Hoogen, F.J.A., Meeuwis, C.A., Manni, J.J., & Hilgers, F.J.M. (2005). Compliance, quality of life and quantitative voice quality aspects of hands-free speech. *Acta Oto-Laryngologica*, 125, 629-637.
- Paleri, V., Wight, R.G., Owen, S., Hurren, A., & Stafford, F.W. (2006). Defining the stenotic post-laryngectomy tracheostoma and its impact on the quality of life in laryngectomees: development and validation of a stoma function questionnaire. *Clinical Otolaryngology*, 31, 418-424.
- Palmer, A.D., & Graham, M.S. (2004). The relationship between communication and quality of life in alaryngeal speakers. *Journal of Speech-Language Pathology and Audiology*, 28, 6- 24.
- Pawar, P. V., Sayed, S.I., Kazi, R., & Jagade, M.V. (2008). Current status and future prospects in prosthetic voice rehabilitation following laryngectomy. *Journal of Cancer Research and Therapeutics*, 4(4), 186-191.
- Perry, A. (1997). The role of the speech and language therapist in voice restoration after laryngectomy. *Journal of Laryngology and Otology*, 111(1), 4-7.
- Pindzola, R.H., & Cain, B.H. (1988). Acceptability ratings of tracheoesophageal speech. *Laryngoscope*, 98, 394-397.
- Pope, C., Ziebland, S., & Mays, N. (2000). Qualitative research in health care: analysing qualitative data. *British Medical Journal*, 320(7227):114-6. doi: 10.1136/bmj.320.7227.114
- Puchalski, C.M. (2012). Spirituality in the cancer trajectory. *Annals of Oncology*, 23(3).

- Relic, A., Mazemda, P., Arens, C., Koller, M., & Glanz, H. (2001). Investigating quality of life and coping resources after laryngectomy. *European Archives of Otorhinolaryngology*, 258, 514-517.
- Risberg-Berlin, B., Ryden, A., Moller, R.Y., & Finizia, C. (2009). Effects of total laryngectomy on olfactory function, health-related quality of life, and communication: a 3-year follow-up study. *BioMedical Central Ear, Nose and Throat Disorders* 2009, 9(8). doi: 10.1186/1472-6815-9-8
- Ritchie, J., & Spencer, L. (1994). *Qualitative data analysis for applied policy research*. In: Bryman, A., & Burgess, R.G. (Eds.) (1994). *Analyzing qualitative data*. London: Routledge, p. 94-107.
- Ryan, C., Yong, L., Pracy, P., & Simo, R. (2004). Current trends in voice rehabilitation following laryngectomy in Britain. *Australian Journal of Otolaryngology*, 7, 26-29.
- Schiech, L. (2007). Looking at laryngeal cancer: learn how to support your patient through the physical and emotional challenges of diagnosis, treatment and rehabilitation. *Nursing2007*, 37(5). Retrieved on 05/10/2012 from: [www.nursing2007.com](http://www.nursing2007.com)
- Seidman, I. (1998). *Interviewing as qualitative research*. New York: Teacher's College Press.
- Sharma, D., Nagarkar, A.N., Jindal, P., Kaur, R., & Gupta, A.K. (2008). Personality changes and the role of counseling in the rehabilitation of patients with laryngeal cancer. *Ear, Nose & Throat Journal*, 87(8), E5.
- Shenton, A.K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, IOS Press, 22:63-75. Retrieved on 17/03/2013 from: [http://www.angelfire.com/theforce/shu\\_cohort\\_viii/images/Trustworthypaper.pdf](http://www.angelfire.com/theforce/shu_cohort_viii/images/Trustworthypaper.pdf)
- Staffieri, A., Mostafea, BE., Varghese, BT., Kitcher, E. D. , Jalisi, M. , Fagan, J. J. , Staffieri, C., & Marioni, G. (2006). Cost of tracheo-esophageal prostheses in developing countries. Facing the problem from an internal perspective. *Acta Otolaryngol*, 126, 4-9
- Stake, R.E.(1995). *The art of case study research*. Thousand Oaks, CA: Sage Publications.
- Ten Hallers, E.J.O., Marres, H.A.M., Rakhorst, G., Hagen, R., Staffieri, A., Van De Laan, B.F.A.M., Van Der Houwen, E.B., & Verkerke, G.J. (2005). Difficulties in the fixation of prostheses for voice rehabilitation after laryngectomy. *Acta Oto-Laryngologica*, 125, 804-813.
- The Constitution of the Republic of South Africa, Bill of Rights. (Act 102 of 1996).
- The University of the Witwatersrand. (n.d.). Academic hospitals in Gauteng. Retrieved on 21/08/2010 from: <http://web.wits.ac.za/Academic/Health/ClinicalMed/InternalMedicine/Hospitals/>

- Thorne, S.E., Bultz, B.D., & Baile, W.F. (2005). Is there a cost to poor communication in cancer care? A critical review of the literature. *Psycho-Oncology*, *14*, 875–884. doi: 10.1002/pon.947
- Vakharia, K.T., Jafer Ali, M., & Wang, S.J. (2007). Quality-of-life impact of participation in a head and neck cancer support group. *Otolaryngology Head & Neck Surgery*, *136*(3), 405-410.
- Van As, C.J. (2001). *Tracheoesophageal speech: A multidimensional assessment of voice quality*. Published PhD Thesis, University of Amsterdam.
- Visser, A., Garssen, B., & Vingerhoets, A. (2010). Spirituality and well-being in cancer patients: a review. *Psycho-Oncology*, *19*, 565-572. doi:10.1002/pon.1626
- Wild, D.C., Mehta, D., & Conboy, P.J. (2004). Bacterial colonization of laryngectomy stomas. *The Journal of Laryngology & Otology*, *118*, 710-712.
- Woken, M.D. (n.d). Advantages of a pilot study. Center for Teaching and Learning: University of Illinois, Springfield. Retrieved on 15/03/2013 from: <http://www.uis.edu/ctl/writing/documents/ctlths7.pdf>
- Xi, S. (2010). Effectiveness of voice rehabilitation on vocalisation in postlaryngectomy patients: a systematic review. *International Journal of Evidence Based Healthcare*, *8*(4), 256-258.
- Yin, R.K. (1994). *Case study research: Design and methods* (2<sup>nd</sup> Ed). Thousand Oaks, CA: Sage Publications.
- Zucca, A.C., Boyes, A.W., Lecathelinais, C., & Girgis, A. (2010). Life is precious and I'm making the best of it: coping strategies of long-term cancer survivors. *Psycho-Oncology*, *19*, 1268-1276. doi: 10.1002/pon.1686

## **APPENDICES**

### **Appendix A:**

Letter of approval from the University of KwaZulu Natal Biomedical Research  
Ethics Committee

### **Appendix B:**

Letter of approval from the public health hospital

### **Appendix C:**

Pilot study letter of invitation

### **Appendix D:**

Proposed questions

### **Appendix E1:**

Letter of invitation and informed consent to PWTL (English)

### **Appendix E2:**

Letter of invitation and informed consent to PWTL (Zulu)

### **Appendix F1:**

Letter of invitation and informed consent to CG (English)

### **Appendix F2:**

Letter of invitation and informed consent to CG (Zulu)

### **Appendix G:**

Letter of invitation & informed consent to voice rehab team members

### **Appendix H:**

Intelligibility Scale



**Appendix A:** Letter of approval from the University of KwaZulu Natal Biomedical Research Ethics Committee



**UNIVERSITY OF  
KWAZULU-NATAL**  
**INYUVESI  
YAKWAZULU-NATALI**

**RESEARCH OFFICE**  
Biomedical Research Ethics Administration  
Westville Campus, Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000  
KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604769 - Fax: 27 31 2604609  
Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)  
Website: <http://research.ukzn.ac.za/ResearchEthics/BiomedicalResearchEthics.aspx>

**31 August 2011**

Ms. S Naidu  
PO Box 12294  
Hatfield  
Pretoria  
0028

Dear Ms Naidu

**PROTOCOL: The Hallmarks of successful Alaryngeal Communication by Tracheo-esophageal Puncture (TEP) :A case study of a successfully rehabilitated laryngectomee. REF:BE050/11**

**EXPEDITED APPLICATION**

A sub-committee of the Biomedical Research Ethics Committee has considered and noted your application received on 14 March 2011.

The study was provisionally approved pending appropriate responses to queries raised. Your responses dated 05 July 2011 to queries raised on 07 June 2011 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from 31 August 2011.

This approval is valid for one year from **31 August 2011**. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

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

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/ResearchEthics11415.aspx>.

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

The sub-committee's decision will be **RATIFIED** by a full Committee at its next meeting taking place on **11 October 2011**.

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

Yours sincerely

A handwritten signature in black ink, appearing to read 'D. Wassenaar', written in a cursive style.

Professor D.R Wassenaar  
Chair: Biomedical Research Ethics Committee

**Appendix B: Letter of approval from the public health hospital**

**Appendix B: Letter of approval from the public health hospital**

07-AUG-2011 21:03 To: P.2/2

**MEDICAL ADVISORY COMMITTEE**

**PERMISSION TO CONDUCT RESEARCH**

Date: 03 August 2011

**TITLE OF PROJECT:** The hallmark of successful alaryngeal communication by trachea-esophageal puncture (TEP): perspectives of key role players

**UNIVERSITY:** University of KwaZulu-Natal

**Principal Investigator** Ms S Naidu

**Department:** Speech-language Pathology

**Supervisor (if relevant):** Dr P Rajaram and Dr P Flack

**Permission Head Department (where research conducted)** Yes

**Date of start of proposed study:** August 2011


**Date of completion of data collection:** September 2011

The Medical Advisory Committee recommends that the said research be conducted at \_\_\_\_\_ Hospital. The CEO /management of \_\_\_\_\_ Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the KwaZulu-Natal.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....  
Recommended  
(On behalf of the MAC)  
Date: 03 August 2011

.....  
~~Approved/Not Approved~~  
Hospital Management  
Date: 05/08/2011



Appendix C: Pilot study letter of invitation

DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY, OCCUPATIONAL THERAPY  
& SPEECH-LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES  
Tel: 031 260 7438  
Fax: 031 260 7622  
E-mail: [naidoor1@ukzn.ac.za](mailto:naidoor1@ukzn.ac.za)

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Dear Sir/Madam,

**INVITATION TO PARTICIPATE IN POSTGRADUATE RESEARCH PILOT STUDY**

**Title: The Hallmarks of Successful Alaryngeal Communication by Tracheo-Esophageal Puncture (TEP): Perspectives of Key Role Players**

Thank you for reading this letter. I am a postgraduate student from the University of KwaZulu Natal Speech-Language Pathology Department. I would like to invite you as a healthcare professional who works with laryngectomees to participate in a postgraduate research pilot study.

I am conducting a research study in the field of speech-language pathology, which aims to identify the hallmarks of success from the perspectives of a successfully rehabilitated laryngectomee, his/her caregiver and members of his/her voice rehabilitation team.

The pilot study is being conducted to increase the validity of the questions that will be posed to the voice rehabilitation team participants, namely the ENT surgeon, speech-language therapist, nurse, and psychologist.

Enclosed, please find the proposed questions as well as a comment sheet. Kindly complete the questions as though you were one of the main participants. You will be required to answer the questions and provide feedback and suggestions that will improve the quality and focus of the questions. Feedback and suggestions can be provided on the attached comment sheet. Comments about the questions will be required in the following areas:

- Relevance
- Clarity
- Structure
- Grammar & Style
- Redundancy
- Propriety

Data collection will commence on (date). Kindly complete the questions and comment sheet no later than (time and date), and return to [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com).

Thank you for your interest in this study. Your input is most valuable and much appreciated. Kindly contact me or my research supervisors should you have any queries regarding the study.

Yours faithfully,

---

Ms. Suvanya Naidu  
B. Communication Pathology (Speech-Language Pathology) (UKZN)  
Tel: 083 793 8814  
Email: [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com)

---

Dr. Priya Rajaram  
Research Supervisor  
B.Sp &Hearing (UDW) M.ECI (UP) PhD (UP)  
Email: [Rajaramp@ukzn.ac.za](mailto:Rajaramp@ukzn.ac.za)

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Dr. Penelope Susan Flack  
Research Supervisor  
D. Ed (Educational Studies) (UKZN)  
Email: [Flackp@ukzn.ac.za](mailto:Flackp@ukzn.ac.za)

**COMMENT SHEET FOR PILOT STUDY**

**Please fill in your comments regarding the proposed questions below:**

*How relevant were the questions overall?*

---

---

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**2. Clarity**

*How clear were the questions? Were they easily understood?*

---

---

---

**3. Structure**

*Were the questions structured appropriately in terms of which areas should be probed first, second, and so on?*

---

---

---

**4. Grammar & Style of Questions**

*Did the grammatical structure seem appropriate or somewhat colloquial? Remember, the participants will be interviewed.*

---

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**5. Redundancy**

*Were any questions somewhat repetitive or redundant?*

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---

---

**6. Propriety**

*Were the questions appropriate, respectable, polite?*

---

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**7. Other**

*Please provide any additional comments*

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## **Appendix D: Proposed questions for Focus Group and Individual Studies**

### **Questions to be posed to Laryngectomee Focus Group**

Good Day and welcome to this focus group. I am a postgraduate student from UKZN, and am currently doing research in the area of laryngectomy management. I have a few questions that I would like to ask you. Please feel free to participate in the discussion as much as you can.

Firstly, please can each of you introduce yourself and give us a little introduction about yourself.

All of you have had a tracheo-esophageal puncture (TEP) and are using speech valves to communicate. Many of you are at different stages in mastering the use of TEP.

1. Is TEP an easy method to master? Why
2. What are some of the problems that you have experienced using TEP?
3. How are you dealing with these problems and have you overcome these problems?
4. Are you happy with the way you currently communicate?
5. Can you speak confidently in all situations? If not, in which situations do find it difficult to communicate? (on the telephone/ noisy environments)
6. Do you feel that people understand you when you speak to them?
7. Do you find it easy to interact with people? Do you go up to strangers and speak to them? How do they react?
8. Do you enjoy communicating with TEP? Why
9. Were you seen by a team of professionals? (if yes, did you meet often with your team, how often, was it beneficial)
10. Do you feel that a team approach to laryngectomee management is good? Why?
11. What is successful laryngectomee rehabilitation?
12. Do you feel that you have been successfully rehabilitated?
13. If you could provide any advice or suggestions as to how services to laryngectomees can improve, then what would you suggest?

*Thank you for your time.*



## Questions to be posed to “Successfully Rehabilitated” Laryngectomees

Good Day Mr/Mrs \_\_\_\_\_. Thank you for participating in my study.

I am interested to learn more about your laryngectomy journey, and will be posing many questions to you. Please try to provide as much information as you can.

1. What was your initial reaction when you found out that you were to undergo a laryngectomy?
2. What did you fear the most when you first found out about the laryngectomy? (e.g. Not being able to communicate/breathe/ have swallowing difficulties)
3. How long ago was the operation?
4. Looking back, do you feel that you were mentally prepared for the outcome?
5. What should every person know before they are about to undergo a laryngectomy?
6. How different is your life now compared to before the laryngectomy? (were there things that you enjoyed doing that you no longer do/ in what way has your life been affected)
7. Do you feel that your quality of your life has decreased in some way after the laryngectomy?
8. Which aspects have been affected the most? Breathing, communicating, eating?
9. Did you work before the laryngectomy? (Do you work now?)
10. What were some of the major challenges that you experienced along your journey?
11. You are currently communicating by tracheo-esophageal puncture (TEP) and speech valve. Was it an easy process learning how to master communication by way of TEP? How so?
12. Were you fitted with the speech valve at the time of the laryngectomy, or later on?
13. Which factors helped you to speak with TEP?
14. How long did you need to attend speech therapy? (few months/years)
15. How often did you go for speech therapy? (weekly, fortnightly, monthly)
16. What was the duration of each speech therapy session? (30, 45, 60 mins)
17. Do you attend regular support group meetings? If yes, then have you found the support groups beneficial in any way? How have they been beneficial?
18. How often do you need to visit the hospital for replacement of the speech valve?
19. Which professional fits and replaces the speech valve for you? (i.e. ENT, Speech Therapist)
20. Do you know how to clean the valve yourself?
21. Do you feel that you were properly trained to care for your stoma and valve? (If yes, what aspects helped the most/ if no, then what areas do you feel could have been improved?)
22. There are many laryngectomees who find it difficult to communicate using TEP. Why do you think many people find this procedure difficult?
23. Which professionals did you visit throughout your journey?
24. Does a team approach to management work better?

25. What complications did you experience using TEP? (excessive secretions, infection, wounds, pain?) How have you managed to deal with these complications?
26. Has the size of your stoma changed since the laryngectomy? How so?
27. Which part of the medical care that you received throughout your journey do you feel has benefitted you the most?
28. Apart from the medical care that helped you through your journey, what other factors helped you to communicate effectively? (e.g. Positive attitude, spirituality, caring & supportive family & friends, support groups, speaking to experienced laryngectomees)
29. What does successful voice rehabilitation mean to you?
30. Do you feel that you have been successfully rehabilitated? Please elaborate.
31. If you could provide any advice or suggestions as to how services to laryngectomees can improve, then what would you suggest?
32. What advice would you provide new laryngectomees or people who are about to undergo a laryngectomy?

**Thank you for your time.**

**Questions posed to caregiver of successfully rehabilitated laryngectomee**

Good Day Mr/Mrs \_\_\_\_\_ . Thank you for participating in my study.

I am interested to learn more about your journey as a caregiver of a laryngectomee, and will be posing many questions to you. Please try to provide as much information as you can.

1. What is the nature of your relation with \_\_\_\_\_ and please describe some of the duties that you perform as a caregiver?
2. What was your initial reaction when you found out that \_\_\_\_\_ was to undergo a laryngectomy?
3. What did you fear the most when you first found out about his/her laryngectomy? (e.g. That he would not be able to communicate/breathe/ have swallowing difficulties)
4. Looking back, do you feel that he/she mentally prepared for the outcome?
5. What should every person know before they are about to undergo a laryngectomy?
6. How different are your lives now compared to before the laryngectomy? (were there things that you and \_\_\_\_\_ enjoyed doing that you no longer do/ in what way have your lives been affected?)
7. Do you feel that his/her quality of your life has decreased in some way after the laryngectomy? How so?
8. Which aspects have been affected the most? Breathing, communicating, eating?
9. Did you work before his/her laryngectomy? (Do you work now?)

10. What were some of the major challenges that he/she experienced along his/her journey?
11. He/she is currently communicating by tracheo-esophageal puncture (TEP) and speech valve. Was it an easy process for him/her to learn how to master communication by way of TEP? Elaborate?
12. Which factors helped him/her to speak with TEP?
13. Do you attend regular support group meetings? If yes, then have you found the support groups beneficial in any way? How have they been beneficial?
14. Do you feel that you/he/she was/were properly trained to care for his/her stoma and valve? (If yes, what aspects helped the most/ if no, then what areas do you feel could have been improved?)
15. There are many laryngectomees who find it difficult to communicate using TEP. Why do you think many people find this procedure difficult?
16. Does a team approach to management work better?
17. What complications did he/she experience using TEP? (excessive secretions, infection, wounds, pain?) How has he/she managed to deal with these complications?
18. Which part of the medical care that he/she received throughout his/her journey do you feel has benefitted him/her the most?
19. Apart from the medical care that helped him/her through his/her journey, what other factors helped him/her to communicate effectively? (e.g. Positive attitude, spirituality, caring & supportive family & friends, support groups, speaking to experienced laryngectomees)
20. What does successful voice rehabilitation mean to you?
21. Do you feel that he/she been successfully rehabilitated? Please elaborate.
22. If you could provide any advice or suggestions as to how services to laryngectomees can improve, then what would you suggest?
23. What advice would you provide caregivers of laryngectomees?

**Thank you for your time.**

**Questions to be posed to Voice Rehabilitation Team members (To be pre-validated during Pilot Study)**

Good Day and welcome to this interview. You have been selected to participate in this interview discussion because you have been directly involved in the management of (laryngectomee's name), who considers him/herself to be a successful communicator using tracheo-esophageal puncture (TEP).

1. Please describe your involvement in (laryngectomee's name) journey (i.e. Your professional role).
2. Do you feel that (laryngectomee's name), has been successfully rehabilitated? Please elaborate.

3. What were some of the intrinsic factors that contributed to his/her success? (e.g. spiritual, strong-willed, dedicated)
4. What were some of the extrinsic factors that contributed to his/her success? (e.g. Supportive caregiver, role-models, support groups, speech therapist, psychologist)
5. Please describe some of the major challenges that you faced as a professional treating him/her (e.g. Surgical complications, medical complications, hospital budgetary constraints, Hospital strikes, etc)
6. How often have you seen this patient?
7. How has his/her quality of life changed since the laryngectomy?
8. How has his/her psychological state (mood, motivation, drive) changed since the laryngectomy?
9. How have these challenges been overcome?
10. What were some of the challenges that he/she faced?
11. (Laryngectomee's name) is communicating functionally using TEP. It has been hailed as the 'gold standard' in alaryngeal voice restoration by many. What are your views on TEP.
12. What are some of the pros and cons of TEP? (in terms of cost, ease of use, maintenance, infection control)
13. Do you feel that South African hospitals are equipped to deal with the demand for TEP
14. How important is communication to an individual? Please elaborate.

*Thank you for your time.*

**Appendix E1:** Letter of invitation & informed consent to PWTL (English)

**DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY, OCCUPATIONAL THERAPY  
& SPEECH-LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES  
Tel: 031 260 7438  
Fax: 031 260 7622  
E-mail: naidoor1@ukzn.ac.za**

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Dear Sir/Madam,

**INVITATION TO PARTICIPATE IN POSTGRADUATE RESEARCH STUDY**

Thank you for reading this letter. I am a postgraduate student from the University of KwaZulu Natal Speech-Language Pathology Department. I would like to invite you as a laryngectomee, to participate in a postgraduate research study.

I am doing a study in the area of voice rehabilitation which aims to understand what successful voice rehabilitation is from laryngectomees, caregivers, the speech-language therapist, ENT surgeon, nurse and psychologist (where necessary).

The study aims to explore the level of voice rehabilitation services to laryngectomees. Due to the major life changes associated with a total laryngectomy, it is important that the laryngectomy rehabilitation team members are aware of the challenges and life changing issues associated with a laryngectomy, as well as the important decisions and actions made to overcome these challenges.

You would represent laryngectomees who are currently/have received voice rehabilitation from an ENT specialist or speech-language therapist at the hospital. Please note that you were chosen to participate in this study because you attend the monthly laryngectomy support group at the hospital, and are currently communicating or training to communicate using tracheo-esophageal puncture (TEP).

You would be required to attend a meeting with other laryngectomees/caregivers at the hospital. Questions will be posed to the group to gain a better understanding of how successful communication is viewed. The focus group meeting will be tape recorded. You may also be required to participate in a follow-up individual interview which will be tape and video-recorded.

Ethical guidelines will be strictly followed. Your participation in the study is voluntary and you are free to leave the study at any stage without providing a reason. Your privacy is

guaranteed, as all information will be kept confidential. No harm will be brought to you, your voice rehabilitation team, or the hospital.

Please note that permission to carry out this study at your hospital has been granted by the hospital manager (letter enclosed). Kindly complete the attached informed consent form and return to your speech therapist as soon as possible. Or, you may complete the form electronically and return it to me at [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com).

Thank you for your interest in this study. Kindly contact me or my research supervisors should you have any questions regarding the study. Alternately, you may contact the following department to understand your rights as a participant in this study:

### **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Yours faithfully,

---

Ms. Suvanya Naidu

B. Communication Pathology (Speech-Language Pathology) (UKZN)

Tel: 083 793 8814

Email: [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com)

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Dr. Priya Rajaram

Research Supervisor

B.Sp &Hearing (UDW) M.ECI (UP) PhD (UP)

Email: [Rajaramp@ukzn.ac.za](mailto:Rajaramp@ukzn.ac.za)

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Dr. Penelope Susan Flack

Research Supervisor

D. Ed (Educational Studies) (UKZN)

Email: [Flackp@ukzn.ac.za](mailto:Flackp@ukzn.ac.za)

## **INFORMED CONSENT**

### ***The Hallmarks of Successful Alaryngeal Communication by Tracheo-Esophageal Puncture: Perspectives of Key Role Players***

You have been invited to participate in the above-mentioned study.

#### **Aim of the Study**

The aim of the study is to identify what success is in laryngectomy management from the perspectives of key-role players, namely the members of the laryngectomy team, the laryngectomee and his/her caregiver.

#### **Participant Selection Criteria**

You have been chosen to participate in this study because you have undergone a laryngectomy and have been seen by members of the laryngectomy team based at the hospital. Furthermore, you have undergone a tracheo-esophageal puncture (TEP) according to the speech-language therapist at the hospital. In addition, you have adequate hearing status.

#### **Procedures to be followed**

You will be interviewed by the researcher for approximately 60 minutes together with other laryngectomees/caregivers. The nature of the interview will be on successful communication using TEP, particularly on how you view successful communication using TEP, and whether you feel that you are communicating successfully. Questions will mainly be open-ended as the researcher aims to understand your views on the topic. This will be tape recorded. Please note that you may also be required to participate in an additional interview with the researcher after the focus group meeting, which will be video-recorded.

#### **Benefits of the Study**

Professionals working with laryngectomees would benefit by gaining a better understanding of the challenges faced by laryngectomees, which would hopefully improve the services provided to laryngectomees. New laryngectomees may find this information useful and begin their journeys with a positive outlook.

#### **Ethical Considerations**

- Right to privacy will be maintained throughout the study. Your name, and the name of your hospital will not be used in any part of the study. A false name may be provided to you during the interviews.

- Data gathered will be kept in locked-storage for a minimum period of 5 years and will be disposed thereafter. The results of the study will in no way reflect upon you, your professional team, or the hospital.

- Please note that your participation in this study is voluntary, and that you may choose to withdraw at any time without providing a reason.

**Incentives**

There are no out of pocket expenses that should be incurred by you with regard to this study. All transport costs will be covered.

Kindly contact me on 083 793 8814 should you have any further queries regarding your participation in the study. Alternately, you may contact the following department:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building  
Private Bag X 54001  
Durban  
4000  
KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2604769 - Fax: 27 31 2604609

\*\*\*\*\*

**DECLARATION OF INFORMED CONSENT**

I confirm that I understand the contents of this document, and the nature of the research study. Furthermore, I understand that I can withdraw from the study at any stage.

Please mark appropriately:

- I hereby consent to participating in this study
- I hereby consent to being tape recorded
- I hereby consent to being video recorded
- I do not consent to participating in this study

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



**Appendix E2: Letter of invitation & informed consent to PWTl (Zulu)**

**DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY, OCCUPATIONAL THERAPY  
& SPEECH-LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES  
Tel: 031 260 7438  
Fax: 031 260 7622  
E-mail: naidoor1@ukzn.ac.za**

---



Sawubona

**ISIMEMO SOKUZIBANDAKANYA KUCWANINGO KWEZEMFUNDO EPHAKEME**

Ngiyabonga ngokuthi uthathe ithuba ufunde lencwadi. Ngiwumfundi esikhungweni semfundo ephakeme iNyuvesi yaKwaZulu Natal ngaphansi kophiko locwaningo ngolimi nendlela yokukhuluma phecelezi Speech-Language Pathology Department. Ngifisa ukukumema njengomuntu onakekela abahlinziwe emphinjeni abakhuluma ngesitho sokukhuluma esifakelwe ukuba ube ingxenye yocwaningo.

Ngenza ucwaningo ukuzama ukuthola ukuthi baphumelela kanjani abasisa abafakelwe sitho sokukhuluma emphinjeni, abasiza ukulapha abanekinga yokukhuluma, odokotela bamadlebe, amakhala nomphimbo kanye nabasisa abahlukumezeke emoyeni ngezindlela ezihlukene (uma kunesidingo)

Lolucwaningo luhlose ukunikeza izincomo sokunyusa izinga lokunika usiko kwabaphila nalesisimo sokukhuluma ngesitho sokufakelwa emphinjeni. Impilo yomuntu ohlinziwe wakhishwa igxenye yoqhoqho iyashintsha ngalesosizathu kubalulekile ukuthi abamsizayo ukuthi akwazi ukuphila kangcono nalesosimo aseyiso bafundiswe ngezingqinamba nemiphumela yalokhukuhlinzwa. Kumele futhi bazi ngezinqumo nokwenziwayo ukubhekana nalezo zingqinamba.

Uzomela abafakelwe isitho emphinjeni noma abanakekela abaphila nalesisimo abalashwe noma abalashwa iphimbo udokotela womphimbo, amakhala nezindlebe noma udokotela olapha abanekinga yokukhuluma esibhedlela. Ngithanda wazi ukuthi igama lakho silikhethe ohlwini lwabantu abafakelwe isitho sokukhuluma emphinjeni nasohlwini lwabanakekela abaphila nalesisimo esiluthole esibhedlela kudokotela osiza abanekinga yokukhuluma.

Ukuzibandakanya kwakho kulolucwaningo kuzokwenza uhambe imihlangano neqembu labakhuluma ngesitho sokufakelwa emphinjeni kanye nabanakekeli babo esibhedlela. Imihlangano yenu izoqoshwa ekhasethini kanye nakwivideo. Kungenzeka ucelwe ukubuzwa imibuzo uwedwa ungahlangene nabanye.

Konke okuzokwenziwa kuzokwenziwa ngendlela ehloniphekile. Uvumelekile noma inini ukuyeka ukuba ingxenye yocwaningo uma ungasathandi awudingi nokubeka isizathu sokufisa ukuyeka. Konke ozosazisa kona kuzohlala kuyimfihlo engeke idalulwe. Abukho ubungozi obuzokwenzeka kuwena noma esibhedlela.

Sicela ugcwalise ifomu elinemibuzo uma usuqedile ulishiye nodokotela osiza abanenkinga yokukhuluma esibhedlela. Ungakwazi ukuligcwalisa kwicomputer ifomu mese uyalithumela kulelikheli [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com).

Ngicela wazi ukuthi imvume yokwenza lolucwaningo nginayo ngiyithole kumphathi wesibhedlela ikhona nencwani engiyifakile ukuqinisekisa lokho. Ngicela ugcwalise ifomu yokuvuma ukuba ingxenye yalolucwaningo mese uyinika udokotela wabanenkinga yokukhuluma.

Ngiyabonga isifiso sakho sokuba ingxenye yalolucwaningo. Uma unemibuzo ngalolucwaningo ngicela ungithinte noma uthinte ongiphethe ekwenzeni ucwaningo kuleminingwane engezansi no:

## **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Yimina ozithobayo,

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Ms. Suvanya Naidu

B. Communication Pathology (Speech-Language Pathology) (UKZN)

Tel: 083 793 8814

Email: [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com)

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Dr. Priya Rajaram

Research Supervisor

B.Sp &Hearing (UDW) M.ECI (UP) PhD (UP)

Tel: 031 260 8771

Email: [Rajaramp@ukzn.ac.za](mailto:Rajaramp@ukzn.ac.za)

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Dr. Penelope Susan Flack

Research Supervisor

D. Ed (Educational Studies) (UKZN)

Tel: 031 260 7207

Email: [Flackp@ukzn.ac.za](mailto:Flackp@ukzn.ac.za)

## **IMVUME NGOLWAZI OLUBHALIWE**

### ***Imiphumela emihle yabahlinzwe emphinjeni bafakelwa isitho esisha sokubasiza ukuthi bakhulume: Ukubaluleka kwe mibono ya bantu***

Umenyiwe ukuthi uthathe iqhaza odabeni lwalesihloko esingenhla.

#### **Inhloso yalolucwaningo**

Inhloso yocwaningo ukucobelela ulwazi ngemiphumela emihle yokuphatha ukuhlinza imiphimbo, abahlinzayo, abahlinziwe bafakwa okuzobasiza bakwazi ukukhuluma kanye nababanakekelayo

#### **Bakhethwa kanjani abazothatha iqhaza kulolucwaningoParticipant**

Ukhethiwe ngoba uthola usizo kulesibhedlela oluqhamuka eqenjini lwabalapha asebahlinzwa umphimbo bafakelwa isitho esibasiza ukukhipha iphimbo. You have been chosen to participate in this study because you are a laryngectomee who has been seen by members of the laryngectomy team based at the hospital. Kanti futhi sitholile ngosiza abanenkinga yokukhuluma lana esbhedlela ukuthi uyingxenywe yabalashelwa ukubanenkinga yephimbo asebeke bahlinzwa emphinjeni ukuzama ukubasiza.

#### **Imigomo ekumele ilandelwe**

Uzobuzwa imibuzo umcwaningi ehambisana nabagula ngomphimbo kanye nababanakekelayo isikhathi esilinganiselwa emizuzwini angamashumi ayisthupha. Imibuzo izobe imayelana nemiphumela emihle oyibonayo ngokukhuluma ngesitho esifakelwe sokukhipha iphimbo. Imibuzo izobe ivulelekile ukuthi unabe ngempendulo yakho ukuze umcwaningi aluthole kahle uvo lwakho ngalesihloko. Isimpendulo zizoqoshwa kwivideo nakwicassete. Ngicela wazi ukuthi kungenzeka ucelwe ukuba ingxenywe yokubuzwa kweminye imibuzo okungenzeka iqhamuke emvakokuhlangana kwakho neqembu elithintekayo kulesihloko.

#### **Izinzuzo ngalolucwaningo Benefits of the Study**

Abaqeqeshelwe ukusebenza nabahlinzwa emphinjeni bazosikala kakhulu ngalolucwaningo. Ucwano ngalolucwaningo luzobavezela izingqinamba zabaphila nalesisimo bese luveza izindlela ezingcono zokubasiza. Abasanda kuhlinzwa bafakelwa isitho esisha sokukhuluma bazosikala nabo bakwazi ukwamukela isimo abakuso baphile kahle.

#### **Ethical Considerations**

- Ilungelo lakho lemfiho alizukuhlukunyezwa nanini kulolucwaningo. Igama lakho negama lesibhedlela ngeke lidalulwe kulolucwaningo.

-Ulwazi oluqoqiwe kulolucwaningo luzokhiyelwa lugcinwe iminyaka emihlanu ngemuva kwalokho luzolahlwa. Imiphumela yocwaningo ngeke ize ikhulume ngawe, ithimba labaqeqeshiwe osebenzisana nabo noma isibhedlela

- Uvumelekile noma inini ukuyeka ukuba ingxenywe yocwaningo uma ungasathandi awudingi nokubeka isizathu sokufisa ukuyeka.

**Kukhokhwa Kanjani**

Akukho mali ezokhokhwa umuntu obamba iqhaza kulolucwaningo.

Ngicela ungithinte kulombholo uma unemibuzo ngokuba ingxenye yalolucwaningo 083 793 8814/ no:

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Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

\*\*\*\*\*

**UKUVUMA UKUTHI NGIYAKUQONDA KONKE OKUQUKETHWE ILOMBHALO**

Ngicela ufake uphawu kulokhu okungezansi:

Ngiyavuma ukuba ingxenye yalolucwaningo. Ngiyakuqonda konke okuqukethwe ilombhalo kanye nohlobo lwalolucwaningo. Ngiyazi ukuthi ngingayeka noma inini uma ngizwa ukuthi angisathandi ukuba ingxenye yalolucwaningo.

Ngiyalinikeza igunya lokuqoshwa kwami emsakazwemi

Ngiyalinikeza igunya lokuqoshwa kwami kumabonakude

Angivumi ukuba ingxenye yalolucwaningo

\_\_\_\_\_

Signature Usuku

**Appendix F1: Letter of invitation & informed consent to CG (English)**

**DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY, OCCUPATIONAL THERAPY  
& SPEECH-LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES  
Tel: 031 260 7438  
Fax: 031 260 7622  
E-mail: naidoor1@ukzn.ac.za**

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Dear Sir/Madam,

**INVITATION TO PARTICIPATE IN POSTGRADUATE RESEARCH STUDY**

Thank you for reading this letter. I am a postgraduate student from the University of KwaZulu Natal Speech-Language Pathology Department. I would like to invite you as a caregiver of a laryngectomee to participate in a postgraduate research study.

I am conducting a research study in the field of voice rehabilitation which aims to identify the hallmarks of success from the perspectives of laryngectomees, caregivers, the speech-language therapist, ENT surgeon, nurse and psychologist (where necessary).

The study hopes to provide recommendations to improve the level of voice rehabilitation services to laryngectomees. Due to the major life changes associated with a total laryngectomy, it is important that the laryngectomy rehabilitation team members are aware of the challenges and quality of life issues associated with a laryngectomy, as well as the decisions and actions made to overcome these challenges.

You would represent caregivers of laryngectomees who are currently/have received voice rehabilitation from an ENT specialist or speech-language therapist at the hospital. Please note that you were chosen to participate in this study because you attend the monthly laryngectomy support group at the hospital, and are currently a caregiver of a laryngectomee communicating or training to communicate using tracheo-esophageal puncture.

Your participation would involve a focus group meeting with other laryngectomees/caregivers at the hospital. Questions will be posed to the group to gain a better understanding of how successful communication is viewed. The focus group meeting will be tape recorded. You may also be required to participate in a follow-up individual interview which will be tape and video-recorded.

Ethical guidelines will be strictly followed. Your participation in the study is voluntary and you are free to withdraw from the study at any stage without providing a reason. Your privacy is guaranteed, as all information will be kept confidential. No harm will be brought to you, your voice rehabilitation team, or the hospital.

Please note that permission to carry out this study at your hospital has been granted by the hospital manager (letter enclosed). Kindly complete the attached informed consent form and return to your speech therapist at your earliest convenience. Alternately, you may complete the form in electronic format and return it directly to me at [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com).

Thank you for your interest in this study. Kindly contact my me or my research supervisors should you have any questions regarding the study.

Yours faithfully,

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Ms. Suvanya Naidu  
B. Communication Pathology (Speech-Language Pathology) (UKZN)  
Tel: 083 793 8814  
Email: [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com)

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Dr. Priya Rajaram  
Research Supervisor  
B.Sp &Hearing (UDW) M.ECI (UP) PhD (UP)  
Tel: 031 260 8771  
Email: [Rajaramp@ukzn.ac.za](mailto:Rajaramp@ukzn.ac.za)

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Dr. Penelope Susan Flack  
Research Supervisor  
D. Ed (Educational Studies) (UKZN)  
Tel: 031 260 7207  
Email: [Flackp@ukzn.ac.za](mailto:Flackp@ukzn.ac.za)

## **INFORMED CONSENT**

### ***The Hallmarks of Successful Alaryngeal Communication by Tracheo-Esophageal Puncture: Perspectives of Key Role Players***

You have been invited to participate in the above-mentioned study.

#### **Aim of the Study**

The aim of the study is to identify the hallmarks of success in laryngectomy management from the perspectives of key-role players, namely the members of the laryngectomy team, the laryngectomee and his/her caregiver.

#### **Participant Selection Criteria**

You have been chosen to participate in this study because you are a caregiver of a laryngectomee communicating or training to communicate using tracheo-esophageal puncture (TEP), who has been seen by members of the laryngectomy team based at the hospital.

#### **Procedures to be followed**

You will be interviewed by the researcher for approximately 60 minutes together with other laryngectomees/caregivers. The nature of the interview will be on successful communication using TEP, particularly on how you view successful communication using TEP, and whether you feel that the laryngectomee you care for, is communicating successfully. Questions will mainly be open-ended as the researcher aims to understand your views on the topic. Responses will be tape recorded. Please note that you may also be required to participate in an additional interview with the researcher after the focus group meeting, which will be video-recorded.

#### **Benefits of the Study**

Professionals working with laryngectomees would benefit by gaining a better understanding of the challenges faced by laryngectomees, which would hopefully improve the services provided to laryngectomees. New laryngectomees and caregivers may find this information useful and begin their journeys with a positive outlook.

#### **Ethical Considerations**

- Right to privacy will be maintained throughout the study. Your name, and the name of your hospital will not be used in any part of the study.
- Data gathered will be kept in locked-storage for a minimum period of 5 years and will be disposed thereafter. The results of the study will in no way reflect upon you, your professional team, or the hospital.

- Please note that your participation in this study is voluntary, and that you may choose to withdraw at any time without providing a reason.

**Financial Obligations**

There are no financial obligations that should be incurred by you with regard to this study.

Kindly contact me on 083 793 8814 should you have any further queries regarding your participation in the study.

\*\*\*\*\*

**DECLARATION OF INFORMED CONSENT**

Please mark appropriately:

I hereby consent to participating in this study. I confirm that I understand the contents of this document, and the nature of the research study. Furthermore, I understand that I can withdraw from the study at any stage.

I hereby consent to being tape recorded

I hereby consent to being video recorded

I do not consent to participating in this study

\_\_\_\_\_

Signature

\_\_\_\_\_

Date



**Appendix F2: Letter of invitation & informed consent to CG (Zulu)**

**DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY, OCCUPATIONAL THERAPY  
& SPEECH-LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES  
Tel: 031 260 7438  
Fax: 031 260 7622  
E-mail: naidoor1@ukzn.ac.za**

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Sawubona,

**ISIMEMO SOKUZIBANDAKANYA KUCWANINGO KWEZEMFUNDO  
EPHAKEME**

Nginyabonga ngokuthi uthathe ithuba ufunde lencwadi. Ngiwumfundi esikhungweni semfundo ephakeme iNyuvesi yaKwaZulu Natal ngaphansi kophiko locwaningo ngolimi nendlela yokukhuluma phecelezi Speech-Language Pathology Department. Ngifisa ukukumema njengomuntu onakekela abahlinziwe emphinjeni abakhuluma ngesitho sokukhuluma esifakelwe ukuba ube ingxenye yocwaningo.

Ngenza ucwaningo ukuzama ukuthola ukuthi baphumelela kanjani abasisa abafakelwe sitho sokukhuluma emphinjeni, abasiza ukulapha abanekinga yokukhuluma, odokotela bamadlebe, amakhala nomphimbo kanye nabasisa abahlukumezeke emoyeni ngezindlela ezihlukene (uma kunesidingo)

Lolucwaningo luhlose ukunikeza izincomo sokunyusa izinga lokunika usiko kwabaphila nalesisimo sokukhuluma ngesitho sokufakelwa emphinjeni. Impilo yomuntu ohlinziwe wakhishwa igxenye yoqhoqho iyashintsha ngalesosizathu kubalulekile ukuthi abamsizayo ukuthi akwazi ukuphila kangcono nalesosimo aseyo bafundiswe ngezingqinamba nemiphumela yalokhukuhlinzwa. Kumele futhi bazi ngezinqumo nokwenziwayo ukubhekana nalezo zingqinamba.

Uzomela abafakelwe isitho emphinjeni noma abanakekela abaphila nalesisimo abalashwe noma abalashwa iphimbo udokotela womphimbo, amakhala nezindlebe noma udokotela olapha abanekinga yokukhuluma esibhedlela. Ngithanda wazi ukuthi igama lakho silikhethe ohlwini lwabantu abafakelwe isitho sokukhuluma emphinjeni nasohlwini lwabanakekela abaphila nalesisimo esiluthole esibhedlela kudokotela osiza abanekinga yokukhuluma.

Ukuzibandakanya kwakho kulolucwaningo kuzokwenza uhambe imihlangano neqembu labakhuluma ngesitho sokufakelwa emphinjeni kanye nabanakekeli babo esibhedlela. Imihlangano yenu izoqoshwa ekhasethini kanye nakwivideo. Kungenzeka ucelwe ukubuzwa imibuzo uwedwa unganglangene nabanye.

Konke okuzokwenziwa kuzokwenziwa ngendlela ehloniphekile. Uvumelekile noma inini ukuyeka ukuba ingxenye yocwaningo uma ungasathandi awudingi nokubeka isizathu sokufisa ukuyeka. Konke ozosazisa kona kuzohlala kuyimfihlo engeke idalulwe. Abukho ubungozi obuzokwenzeka kuwena noma isibhedlela.

Sicela ugcalise ifomu elinemibuzo uma usuqedile ulishiye nodokotela osiza abanenkinga yokukhuluma esbhedlela. Ungakwazi ukuligcalisa kwicomputer ifomu mese uyalithumela kulelikheli [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com).

Ngicela wazi ukuthi imvume yokwenza lolucwaningo nginayo ngiyithole kumphathi wesibhedlela ikhona nencwani engiyifakile ukuqinisekisa lokho. Ngicela ugcalise ifomu yokuvuma ukuba ingxenye yalolucwaningo mese uyinika udokotela wabanenkinga yokukhuluma.

Ngiyabonga isifiso sakho sokuba ingxenye yalolucwaningo. Uma unemibuzo ngalolucwaningo ngicela ungithinte noma uthinte ongiphethe ekwenzeni ucwaningo kuleminingwane engezansi.

Yimina ozithobayo,

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Ms. Suvanya Naidu  
B. Communication Pathology (Speech-Language Pathology) (UKZN)  
Tel: 083 793 8814  
Email: [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com)

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Research Supervisor  
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Tel: 031 260 7207  
Email: [Flackp@ukzn.ac.za](mailto:Flackp@ukzn.ac.za)

## **IMVUME NGOLWAZI OLUBHALIWE**

*Imiphumela emihle yabahlinzwe emphinjeni bafakelwa isitho esisha sokubasiza ukuthi bakhulume: Ukubaluleka kwe mibono ya bantu*

Umenyiwe ukuthi uthathe iqhaza odabeni lwalesihloko esingenhla.

### **Inhloso yalolucwaningo**

Inhloso yocwaningo ukucobelela ulwazi ngemiphumela emihle yokuphatha ukuhlinza imiphimbo, abahlinzayo, abanhliziwe bafakwa okuzobasiza bakwazi ukukhuluma kanye nababanekekelayo

### **Bakhethwa kanjani abazothatha iqhaza kulolucwaningoParticipant**

Ukhethiwe ngoba uthola usizo kulesibhedlela oluqhamuka eqenjini lwabalapha asebahlinzwa umphimbo bafakelwa isitho esibasiza ukukhipha iphimbo. You have been chosen to participate in this study because you are a laryngectomee who has been seen by members of the laryngectomy team based at the hospital. Kanti futhi sitholile ngosiza abanenkinga yokukhuluma lana esbhedlela ukuthi uyingxenywe yabalashelwa ukubanenkinga yephimbo asebeke bahlinzwa emphinjeni ukuzama ukubasiza.

### **Imigomo ekumele ilandelwe**

Uzobuzwa imibuzo umcwaningi ehambisana nabagula ngomphimbo kanye nababanekekelayo isikhathi esilinganiselwa emizuzwini angamashumi ayisthupha. Imibuzo izobe imayelana nemiphumela emihle oyibonayo ngokukhuluma ngesitho esifakelwe sokukhipha iphimbo. Imibuzo izobe ivulelekile ukuthi unabe ngempendulo yakho ukuze umcwaningi aluthole kahle uvo lwakho ngalesihloko. Isimpendulo zizoqoshwa kwivideo nakwicassete. Ngicela wazi ukuthi kungenzeka ucelwe ukuba ingxenywe yokubuzwa kweminye imibuzo okungenzeka iqhamuke emvakokuhlangana kwakho neqembu elithintekayo kulesihloko.

### **Izinzuzo ngalolucwaningo Benefits of the Study**

Abaqeqeshelwe ukusebenza nabahlinzwa emphinjeni bazosikala kakhulu ngalolucwaningo. Ucwaningo luzobavezela izingqinamba zabaphila nalesisimo bese luveza izindlela ezingcono zokubasiza. Abasanda kuhlinzwa bafakelwa isitho esisha sokukhuluma bazosikala nabo bakwazi ukwamukela isimo abakuso baphile kahle.

## **Ethical Considerations**

- Ilungelo lakho lemfihlo alizukhlukeyezwa nanini kulolucwaningo. Igama lakho negama lesibhedlela ngeke lidalulwe kulolucwaningo.

-Ulwazi oluqoqiwe kulolucwaningo luzokhiyelwa lugcinwe iminyaka emihlanu ngemuva kwalokho luzolahlwa. Imiphumela yocwaningo ngeke ize ikhulume ngawe, ithimba labaqeqeshiwe osebenzisana nabo noma isibhedlela

- Uvumelekile noma inini ukuyeka ukuba ingxenye yocwaningo uma ungasathandi awudingi nokubeka isizathu sokufisa ukuyeka.

## **Kukhokhwa Kanjani**

Akukho mali ezokhokhwa umuntu obamba iqhaza kulolucwaningo.

Ngicela ungithinte kulombholo uma unemibuzo ngokuba ingxenye yalolucwaningo 083 793 8814

\*\*\*\*\*

## **UKUVUMA UKUTHI NGIYAKUQONDA KONKE OKUQUKETHWE ILOMBHALO**

Ngicela ufake uphawu kulokhu okungezansi:

[ ] Ngiyavuma ukuba ingxenye yalolucwaningo. Ngiyakuqonda konke okuqukethwe ilombhalo kanye nohlobo lwalolucwaningo. Ngiyazi ukuthi ngingayeka noma inini uma ngizwa ukuthi angisathandi ukuba ingxenye yalolucwaningo.

[ ] Ngiyalinikeza igunya lokuqoshwa kwami emsakazwemi

[ ] Ngiyalinikeza igunya lokuqoshwa kwami kumabonakude

[ ] Angivumi ukuba ingxenye yalolucwaningo

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Usuku

**DISCIPLINE OF SPEECH-LANGUAGE PATHOLOGY  
SCHOOL OF AUDIOLOGY, OCCUPATIONAL THERAPY  
& SPEECH-LANGUAGE PATHOLOGY  
FACULTY OF HEALTH SCIENCES  
Tel: 031 260 7438  
Fax: 031 260 7622  
E-mail: naidoor1@ukzn.ac.za**

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Dear Sir/Madam,

**INVITATION TO PARTICIPATE IN POSTGRADUATE RESEARCH STUDY**

Thank you for reading this letter. I am a postgraduate student from the University of KwaZulu Natal Speech-Language Pathology Department. I would like to invite you as a healthcare professional who works with laryngectomees to participate in a postgraduate research study.

I am conducting a research study in the field of speech-language pathology, which aims to identify the hallmarks of success from the perspectives of a successfully rehabilitated laryngectomee, his/her caregiver and members of his/her voice rehabilitation team.

The study may provide valuable information regarding laryngectomee management, and may have implications for improved service delivery with regard to overall laryngectomy management including a particular emphasis on alaryngeal voice restoration. Due to the life altering changes associated with a total laryngectomy, it is imperative that the laryngectomy rehabilitation team members are aware about the roles and views held by laryngectomees, caregivers.

You would represent a profession that makes up the voice rehabilitation team that generally comprises of the ENT surgeon, speech therapist, nurse, and psychologist. You will be required to be qualified in your respective profession, and be registered with the Health Professions Council of South Africa (HPCSA). Furthermore, you will be currently involved in laryngectomy management.

The implementation of the study would entail an individual interview with you and each of the voice rehabilitation team members in their respective disciplines, who have been directly involved in the management of a laryngectomee at the hospital, who considers him/herself to be communicating successfully by tracheo-esophageal puncture. Digital video and audio recordings of the interview would be made.

Ethical guidelines will be strictly adhered to. Participation is completely voluntary and you are free to withdraw from the study at any stage without reason. Privacy will be maintained, as all information will be kept confidential. No harm will be brought to you, or the hospital.

Kindly complete the attached questionnaire and leave it with the speech-language therapist based at your hospital. Alternately, you may complete the form in electronic format and return it directly to me at [suvanya.naidu@gmail.com](mailto:suvanya.naidu@gmail.com).

Please note that permission to conduct this study at your hospital has been granted by the hospital manager (letter enclosed). Kindly complete the attached informed consent form and return to me at your earliest convenience.

Thank you for your interest in this study. Kindly contact me or my research supervisors should you have any queries regarding the study. Alternately, you may contact the Biomedical Research Department:

## **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

Yours faithfully,

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Ms. Suvanya Naidu

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## **INFORMED CONSENT**

### The Hallmarks of Successful Alaryngeal Communication by Tracheo-Esophageal Puncture (TEP): Perspectives of Key Role Players

You have been invited to participate in the above-mentioned study.

#### **Aim of the Study**

The aim of the study is to identify the hallmarks of success in laryngectomy management from the perspectives of key-role players, namely the laryngectomee, his/her caregiver, and his/her voice rehabilitation team.

#### **Participant Selection Criteria**

You have been chosen to participate in this study because you have been directly involved in the management of a successfully rehabilitated laryngectomee communicating via TEP. You are a medical professional currently involved in laryngectomy management based at a hospital, i.e. belonging to one of the following disciplines: ENT surgery, speech-language pathology, nursing, or psychology. Furthermore, your participation is dependent on your active registration with the Health Professions Council of South Africa (HPCSA) in your respective discipline.

#### **Procedures to be followed**

You will be required to participate in an individual interview session with the researcher. The nature of the interview will be on the topic of laryngectomy management with a particular emphasis on how you view successful alaryngeal communication. Questions will mainly be open-ended as the researcher aims to understand your views and perspectives on the topic. Responses will be tape and video recorded.

#### **Benefits of the Study**

Professionals working with laryngectomees would benefit by gaining a better understanding of the challenges faced by the different team members involved in laryngectomy management. The information gained from this study may have implications for improved service delivery to laryngectomees.

#### **Ethical Considerations**

- Right to privacy will be maintained throughout the study. Your name, and the name of your hospital will not be used in the results of this study.
- Data gathered will be kept in storage for a minimum period of 5 years and later disposed. The results of the study will in no way reflect upon you, your profession, or the hospital.

- Please note that your participation in this study is voluntary, and that you may choose to withdraw at any time without reason.

### **Financial Obligations**

There are no financial obligations that should be incurred by the participants of this study.

Kindly contact me on **083 793 8814** should you have any further queries regarding your participation in the study. Alternately you may contact the Biomedical Research Ethics Department:

### **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2604769 - Fax: 27 31 2604609

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### **DECLARATION OF INFORMED CONSENT**

Please mark appropriately:

I hereby consent to participating in this study. I confirm that I understand the contents of this document, and the nature of the research study. Furthermore, I understand that I can withdraw from the study at any stage.

I do not consent to participating in this study

I hereby consent to being audio recorded.

I hereby consent to being video recorded.

\_\_\_\_\_

Signature

\_\_\_\_\_

Date



## Appendix H: Intelligibility Scale

### Intelligibility rating scale to rate the overall speech skills of Focus Group participants

Please rate the focus group participants on a scale of 1 to 5 with 1 being poor and 5 being excellent with regard to

	PWTL 1	PWTL2	PWTL 3	PWTL 4
Speech Intelligibility	_____	_____	_____	_____
Naturalness	_____	_____	_____	_____
Volume	_____	_____	_____	_____
Rate of speech	_____	_____	_____	_____
Voice Quality	_____	_____	_____	_____
Breath control	_____	_____	_____	_____

Participant with the clearest speech: \_\_\_\_\_