INDICATIONS AND QUALITY OF LIFE IN TRACHEOSTOMIZED PATIENTS AT MUHIMBILI NATIONAL HOSPITAL

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Indications and Quality Of Life in Tracheostomized Patients at Muhimbili National Hospital

By

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A dissertation submitted in partial fulfillment for the
Degree of Masters of Medicine in Otorhinolaryngology of the
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CERTIFICATION

The undersigned certify that they have read and hereby recommended for acceptance by Muhimbili University of health and allied sciences a dissertation entitled “Indications and quality of life in tracheostomized patients at muhimbili national hospital” in partial fulfillment for the Degree of Masters of Medicine in Otorhinolaryngology of the Muhimbili University of Health and Allied Sciences.

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DECLARATION AND COPTRIGHT

I, Rashid Mwemgamba Ally, declare that this **dissertation** is my own work and that it has not been presented to any other University or Institution for a similar or any other degree award

Signature: _____ Date:_____

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Last but not the least, I wish to extend my genuine recognition to all the patients who despite their condition took their time to be interviewed during the study as they were the most crucial element for the development of this report.

DEDICATION

I would like to dedicate this work to my father Ally Mwemgamba and my mother Mary Sulley for their endless support and encouragement.

AND

To my children, brothers and sisters.

ABSTRACT

Background: Tracheostomy is a surgical procedure in which an incision is made on the anterior aspect of the neck allowing a direct airway through an incision into the trachea. It is a common intervention in alleviating conditions involving airway pathologies. Like many other surgical intervention, tracheostomy can also lead to undesirable complications leading to negative impact on quality of life of patients. Furthermore, tracheostomized patients tend to have primary disease which may also have the influence on Quality of life. Hence Indications and QOL assessment has become paramount importance to analyze significance improvement in treatment in tracheostomies such that more focus can be made on affected aspects so that to improve support measures among tracheostomies for an overall better outcome of these patients.

Objective: To determine the Indications and quality of life in tracheostomized patients at Muhimbili National Hospital.

Materials and Methods: This was a hospital-based analytical cross-sectional study conducted at Muhimbili National Hospital in Dar es salaam, Tanzania for 6 months from November 2020 to May 2021 which included consented Tracheostomized patients who had tracheostomy for at least 1 week. Data was collected in form of an interview using a well-structured Questionnaire which included the modified version of TQOL instrument developed by the University of Washington to evaluate TQOL based on 12 items. Data regarding indications and primary diagnosis was extracted from patient's records, hence termed as predictive factors. The TQOL instrument's scoring manual was applied to obtain an average score of QOL before and after tracheostomy, where by the higher the average scores the better the QOL. Analysis of variance (ANOVA) and sample paired t test were used in analysis and statistical significant was determined for the predictive factors before and after tracheostomy.

Results: A total of 73 patients with tracheostomy were assessed in this study of whom 49(67.1%) were Males and 24(32.9%) were Females with age ranging from 18 to 87 years and mean age of all participants was 49.1 ± 18.2. UAO with Laryngeal carcinoma was the leading Indication and primary diagnosis (26%) for tracheostomy. The mean scores for QOL before and after tracheostomy were (49.6) ± 12.38 and (62.4) ± 14.78 respectively with the mean scores difference of 12.8. Young Patients with age < 48years were found to have high mean scores of QOL before and after tracheostomy with mean scores of 56.5 and 74.3 respectively compared to Elderly patients >63 years who had significant low mean scores of QOL before and after tracheostomy 39.2 and 48.2 respectively. Females had higher score for QOL than Males both before and after Tracheostomy. There was a statistically significant association between Indications with Primary diagnosis and the mean score of QOL before tracheostomy and after tracheostomy. Oropharyngeal carcinoma had low mean scores before and after tracheostomy with mean scores of 38.1 and 45.9 respectively. The highest mean score was observed after tracheostomy with highest score in patients with laryngeal Trauma 85.1.

Conclusion: Upper airway obstruction secondary to head and neck malignancy remains the commonest indication for tracheostomy in our center. Tracheostomy had shown impact in improving QOL. The age of the patient and primary disease are the significant predictors of QOL among patients with tracheostomy.

Recommendations: Healthcare professionals should be aware of different domains that affect QOL so that they can use a multidisciplinary strategy to optimize their clinical management in Tanzania.

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LIST OF ABREVIATIONS

ANOVA	Analysis of Variance
ATS	Access to surgery
BC	Before Christ
CI	confidence intervals
DPGS	Director of Postgraduate Studies
ENT/ORL	Ear, Nose & Throat / Otorhinolaryngology
EMD	Emergency Medicine Department
FI	Failure of Intubation
HMS	Hospital management system
ICU	Intensive Care Unit
MHNS	Major Head and neck surgery
MMED	Masters of Medicine
MNH	Muhimbili National Hospital
MUHAS	Muhimbili University of Health and Allied Sciences
ORL	Otorhinolaryngology
PI	Prolonged Intubation
P-value	Probability value
QOL	Quality of Life
SD	standard deviation
SPSS	Statistical Package for the Social Sciences
TQOL	Tracheostomies Quality of Life
MoHCDEC	Ministry of Health, Community Development, Gender, Elderly and Children
MSQOL	Mean score Quality of life
UAO	Upper airway obstruction
VCP	Vocal cord paralysis

DEFINITION OF TERMS

- **Tracheostomy** is an opening in the anterior wall of trachea and converted into a stoma on the skin surface.
- **Tracheostomized** patient is an Individual who underwent tracheostomy and has tracheostomy tube in situ.
- **Tracheostomy** is the surgical formation of temporary or permanent opening into the trachea following tracheostomy.
- **Quality of life** is individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.
- **Mechanical ventilation** is the technique through which gas is moved toward and from the lung through an external device connected directly to the patient.
- **Upper airway obstruction** is defined as blockage of any portion of the airway above the thoracic inlet.
- **Pulmonary toilet** is the cleaning of secretions from the airway of a person.
- **Tumor** is an abnormal mass of tissue which results when cells divide and/or do not die more than normal. It is commonly equated to neoplasm. A tumor or neoplasm may be benign (not cancer) or malignant (cancer).

CHAPTER ONE

1.0 INTRODUCTION

1.1 BACKGROUND

Tracheostomy is the creation of an opening in the anterior tracheal wall. It is a surgical procedure in which an incision is made on the anterior aspect of the neck allowing a direct airway through an incision into the trachea hence a person can breathe without the use of the nose or mouth in cases of airway obstruction. The operative techniques of tracheostomy can be open tracheostomy or percutaneous tracheostomy (1).

The first known depiction of tracheostomy is from 3600 BC, on Egyptian tablets whereby the sword was used to open the airway of a soldier choking from a bone lodged in his throat (2). Up-to-date tracheostomy has remained to be common in alleviating conditions involving airway pathologies. Depending on the condition of the patient in which tracheostomy is performed; it can be lifesaving in critical illnesses for management of acute airway obstruction or for long term access to airway and breathing (1,2) Tracheostomy is indicated in airway obstruction conditions such as epiglottitis, tumor, angioedema, foreign body, and blunt or penetrating neck trauma. It can also be performed in patients in cases of prolonged mechanical ventilation, pulmonary toilet and surgical access during head and neck cancer reconstruction and extensive maxillofacial fractures (1).

A number of literatures have shown several indications of tracheostomy in different settings, however one of the most common indication stated by different authors is the airway obstruction due to trauma (1–4) while other research findings have reported of tumors to be the other common indications of tracheostomy (5–7).

Like many other surgical intervention, tracheostomy can also lead to undesirable complications leading to negative impact on quality of life of patients, which is the ability of the patients to fulfill basic life demands, to be able to do the simplest tasks on their own. This also includes the way disease hinders the patient not only physically but also socially and economically (8). Studies have also revealed that some tracheostomized patients may experience reduced self-esteem (9). Tracheostomized patients tend to have primary disease which may also have the influence on Quality of life.

1.2 PROBLEM STATEMENT

Tracheostomy has remained to be the common surgical intervention in alleviating conditions involving airway pathologies both in emergency for saving the lives of critically ill patients and long term access to airway and breathing.

Although tracheostomy is effective in easing patients' illnesses relating to airway and breathing it can also lead to undesirable effects which can interfere with patients' quality of life.

Muhimbili National Hospital is the largest national referral hospital in Tanzania has been performing the procedure to save the lives of many. Despite the popularity of tracheostomy still there are no sufficient information published on the indications and quality of life in tracheostomized patients. Hence it of paramount important to assess indications and their quality of life in order to better understands the impact of tracheostomy in their daily routine and tries to focus on aspects that can improve the support measures.

Therefore this study aimed to determine indications and QOL in tracheostomized patients and also to uncover predictive factors that significantly influence QOL in these patients.

1.3 CONCEPTUAL FRAMEWORK

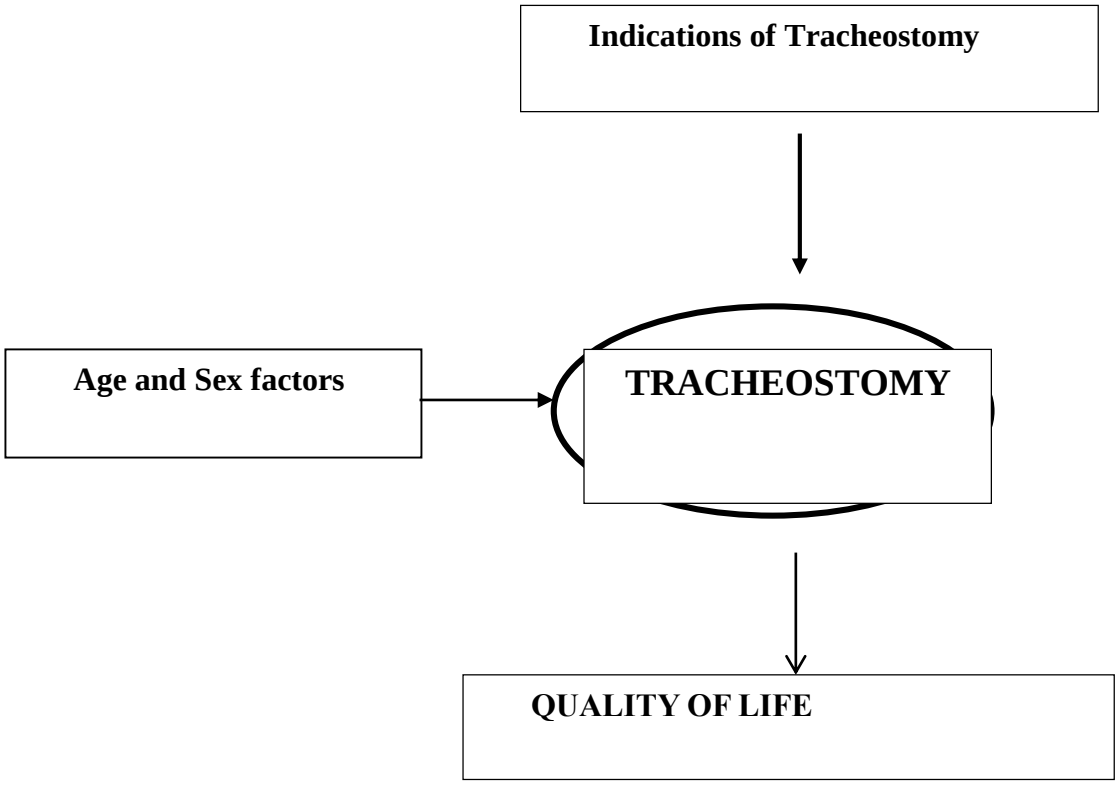


Figure 1: Indicating Conceptual framework

1.4 RATIONALE OF THE STUDY

This study aimed in getting better understanding and insight of the impact of tracheostomy among tracheostomies in Tanzania. The information obtained from this study will illuminate the problem and the issues relating to the indications and quality of life of tracheostomized patients. The findings will provide an opportunity for healthcare providers and the health authorities including the hospital management and Ministry of Health to come up with customized protocols and guidelines for care and management of these patients which can be locally applicable not only at the facility but also country wise to ensure quality healthcare service is maximized.

This study was also a partial fulfillment of the requiment for the award of a Masters in Medicine degree in otorhinolaryngology at MUHAS.

1.5 RESEARCH QUESTIONS

1. What are the Age and sex characteristics of tracheostomized patients?
2. What are the indications of tracheostomy?
3. What is the quality of life of tracheostomized patients?

1.6 OBJECTIVES

1.6.1 BROAD OBJECTIVES

To determine the indications and quality of life of tracheostomized patients at Muhimbili National Hospital.

1.6.2 SPECIFIC OBJECTIVES

1. To assess age and sex characteristics of tracheostomized patients at MNH.
2. To determine the indications of tracheostomy at MNH.
3. To determine the quality of life of tracheostomized patients at MNH.

1.7 LITERATURE REVIEW

Tracheostomy is one of the very important lifesaving surgical procedures which have proven to be effective in easing conditions involving airway and breathing. The most common indications for tracheostomy includes acute respiratory failure and need for prolonged mechanical ventilation (representing two thirds of all cases) and traumatic or catastrophic neurologic insult requiring airway, or mechanical ventilation or both (2). Although it helps in avoiding the hindrance of the upper airway to allow ventilation process to continue taking place tracheotomy is not without risk. Depending on different factors, complications vary. Literature have shown different complications which can occur early or late. Some of the complications mentioned in different studies include; hemorrhage, structure damage, failure of procedure, pneumothorax, aspiration event, air embolism, loss of airway and death (2,10) .

1.7.1 INDICATIONS OF TRACHEOSTOMY

Several research findings have revealed a number of indications in different settings. A study conducted at a university teaching hospital in northwestern of Tanzania on A retrospective review of 214 cases reported the most common indication for tracheostomy to be the upper airway obstruction secondary to traumatic causes in 55.1% of patients, followed by upper airway obstruction due to neoplastic causes in 39.3% of cases (4). However many literatures have shown that the most common indication of tracheostomy to be upper airway obstruction secondary to tumors. For example, a study conducted in north Nigeria on indication and outcome of tracheostomy, a ten years review revealed 60.5% of patients underwent tracheostomy were due to upper airway obstruction caused by tumors while trauma accounted for 26.3% only (11). Other research findings from Nigeria include a multicenter review on tracheostomy in northern Nigeria and a ten years' experience on tracheostomy in Sokoto, northwestern Nigeria which reported the commonest indication of tracheostomy to be airway obstruction due to head and neck tumors accounting for 37.8% and 67.6% respectively (5,6). A different study done in Iraq on tracheostomy: cross-sectional study of indications in relation to age group in al-yarmouk teaching hospital reported similar findings (7).

1.7.2 QUALITY OF LIFE OF TRACHEOSTOMIZED PATIENTS

Tracheostomy is done for the purpose of improving the health of those acute critically ill patients as well as those requiring prolonged mechanical ventilation. However studies are showing that tracheostomy itself can also impact the quality of life of patients (12). An evaluation of the quality of life in patients with tracheostomy conducted by Gul N. and Karadag A. shows QOL scores of patients, whose life span with tracheostomy is three months to one year, who have received chemotherapy or radiotherapy, have difficulties in breathing and eating are lower in the various sub-dimensions of the QOL scale hence concluding that tracheostomy has a profoundly negative impact on quality of life (13).

A research on long term tracheostomy ventilation in neuromuscular diseases by Narayanaswami R., et al, study participants reported of restricted of activities such as bathing and travelling(14). Since tracheostomy can have an impact both physically and psychosocially, an observation was made by researchers and they found that quality of life seems to depend on self-esteem whereby improved self-esteem may also improve quality of life (15). Gilony D. on the study of the effects of tracheostomy on well-being and body-image perception concluded that reduced scores after tracheostomy indicate an overall diminished quality of life(16).

Psychosocial is one of the challenges in some patients following tracheostomy. The research on life after tracheostomy the experiences of adults in the Kumasi Metropolis, Ghana revealed that the use of tracheostomy tube affects physical and psychosocial life resulting in reduced quality of life. Participants complained of a change in appearance and body image, reduced self-esteem and altered sexuality. Due to this new look, participants socially isolated themselves from most social activities or had to put up a camouflage behavior (cover the tube with extra clothing) to be a part of these social events. (17). Hashmi NK. et al in his study on quality of life and self-image in patients undergoing tracheostomy concluded that there is a decline in mental health postoperatively, which we attribute to worsening self-esteem (9).

A study entitled quality of life improves with return of voice in tracheostomy patients in intensive care: An observational study the authors' findings led to the conclusion that improved self-esteem may also improve quality of care (15). Gilony D. et al, on his study on effects of

tracheostomy on well-being and body-image perception found reduced scores after tracheostomy indicating an overall diminished quality of life. These changes correlate with personality traits. Decannulated patients exhibited only slight improvement indicating an incomplete psychosocial recovery (16)

CHAPTER TWO

2.0 MATERIALS AND METHODOLOGY

2.1 STUDY DESIGN

This was analytical cross-sectional hospital based study.

2.2 STUDY DURATION

This study was conducted for the period of 6 months, from November 2020 to May2021

2.3 STUDY SETTING

This study was conducted at Muhimbili National Hospital (MNH) in Dar es salaam, Tanzania. MNH is a national referral hospital, research center and a teaching hospital for Muhimbili University of Health and Allied Sciences. It has 1,500 bed capacity and attending 2,000 outpatients per day. MNH operates at an open door policy where all ORL patients who come for treatment are attended.

The hospital has several departments including ORL which is one of the specialized departments within MNH and it provides services to outpatients and inpatients. The facility has ICU rooms, emergency department, inpatients and outpatients services etc.

An average of 15 tracheostomies is performed every month at MNH according to HMS registry of January 2020 to June 2020. Patients are admitted either from EMD, ORL clinic and other department after ENT review and thorough investigations in the ward. For patients requiring tracheostomy, the procedure is performed in the main theater and patients stay in the ward for an average of 7 days. After discharge, patients are scheduled for follow up clinic after 14 days.

2.4 STUDY POPULATION

This study included all tracheostomized patients attended at MNH during the period of the study.

2.5 SAMPLE SIZE ESTIMATIONS

The sample size was calculated using Finite population correction factor formula.

Sample size calculation

$$n = \frac{n_0 N}{n_0 + (N-1)}$$

Where;-

n= estimated sample size

n_0= sample size without considering the finite population correction factor.

N=Population size

$$n = \frac{152 * 75 =}{152 + (75-1)}$$

$$n = \frac{50}{}$$

Adding 10% of non-responders n=55

Hence a minimum sample size adjusted for response was 55 which were considered as the sampling frame.

2.6 SAMPLE SELECTION

Convenience sampling was used to include samples in this study to establish the sample population by considering the following criteria.

Inclusion criteria:

- Tracheostomized patients attending MNH where by each patient
    - Had tracheostomy at least for 7 days
    - Was aged 18 years and above
    - Consented to participate in the study

Exclusion criteria:

- Tracheostomized patients who could not comprehend during the interview session

2.7 VARIABLES

The modified version of TQOL instrument validated from the University of Washington was used to evaluate patient's QOL, dependent variable. The instrument assesses QOL based on 12 items.

The independent variables that were assessed in this study, termed as predictive factors that influence QOL in tracheostomized patient were:

- Age and sex factors
- Indications of tracheostomy
- Primary diagnosis of the patients

Age was recorded in years (continuous variables) and Sex was considered either male or female.

The Indications of tracheostomy were prolonged mechanical ventilation, pulmonary toilet, surgical access, airway obstruction, failed intubation, Tracheolaryngeal trauma and others.

The Primary diagnosis were those underlying disease that necessitate need of Intubation or Indication of tracheostomy like Tumors of the upper aero-digestive tract like Oropharynx, Larynx, Hypopharynx and other diseases like Respiratory papillomatosis, Pneumonia , Cardiovascular accident etc.

2.8 DATA COLLECTIONS

Informed consent was obtained from sample population who willingly volunteered to participate in this study.

Collection of data was done through interview carried out in Swahili language by Principle investigator and a research assistant. The research assistant was trained on how to fill the questionnaire prior to data collection commence for accuracy data insurance.

The pretested well-structured questionnaire administered verbally was used to collect data from the study participants and filled by principal investigator and trained research assistant. For the participants at the clinic data were collected at the time of clinic visit whereby for the patient in the wards and ICU data were collected in their respective wards. The participants who were involved into the study were those who were at least with the minimum period of 7 days post tracheostomy, such that the effects of tracheostomy in the QOL are taken into account at that particular point in time of study because of the time constrains, low budget and dynamicity of QOL.

After completion, the questionnaire was subjected to the TQOL instrument's scoring manual to score each item of QOL in it.

2.9 DATA COLLECTION TOOL

The questionnaire included the validated TQOL instrument as well additional items that had been developed by the principal investigator after extensive literature review.

The TQOL instrument consists of total 12 items which was overall comfort, airway pain, comfort of breathing, appearance, activity, neck movement, secretions clearing, swallowing, speech, mood, anxiety, and sleep. The scores for each item range from 0 to 100, with a composite score of 0-1200. Low scores indicate poor QOL, and high scores indicate better QOL. These questions were directly asked to the participants and interviewer directly filled the response into the questionnaire.

The additional items addressed in this study assist to determine predictive factors that influence QOL in Tracheostomized patients. These factors which had been categorized into socio-demographic factors, Indications and primary disease for Tracheostomy were well outlined in the questionnaire and its information was obtained from the patient's health record at MNH except for the socio-demographic section.

2.10 SCORING TOOL

The TQOL instrument's scoring manual provided by University of Washington was used to obtain scores for each item of QOL. This contributed a meaningful standardization to ensure reliability in assessment of QOL in tracheostomized patients whereby the higher the score the better QOL and vice versa.

The scores were transformed and computed to obtain average score of QOL using pre-determined formula, which later on was used to obtain mean scores of QOL.

2.11 DATA ANALYSIS

Data collected were entered into SPSS software package version 24 provided by IBM. After successful data entry, data were thoroughly cleaned for accuracy, completeness and internal consistency and then analysis was carried out.

The results are presented in frequency distribution tables and Bar graphs while mean and standard deviation were obtained.

Paired sample T test was used to determine mean scores difference of QOL before and after tracheostomy and Analysis of variance (ANOVA) test was used to statistically compare the mean scores of QOL according to predictive factors to determine the significant of predictive factors to QOL in tracheostomized patient.

Level of significance that used was 0.05 for a 95% confidence, hence a p-value of less than or equal to 0.05 was considered of statistical significance**.**

2.12 ETHICAL ISSUES

This study obtained ethical clearance and review from Directorate of Research and publication committee of MUHAS.

Approval to conduct study was obtained from Executive director of MNH.

Permission was granted by University of Washington for the use of TQOL instrument and its scoring manual.

Written informed consent translated in Kiswahili was obtained from every participant who willingly volunteered to participate in the study after being informed about the aim of the study, importance of the findings and utility of its knowledge.

The participants' information was kept with utmost confidentiality to ensure professional ethical standard and participants' identities were kept anonymous.

2.13 STUDY LIMITATIONS.

QOL is a subjective topic and it involves variables that may confound its assessment however the most common of them were acknowledged and included in this study by the principal investigator.

The qualitative aspect of QOL per se was not assessed in this study due its longevity and complexity in data collection and interpretation which was beyond the principal investigator's knowledge and experience in the field of study.

The dynamicity of QOL among Tracheostomized patients over the course of tracheostomy was considered in this study due to time and financial constraints required for their follow-up hence focus was on those with the period of at least 7 days post tracheostomy, such that the effects of it was taken into account at that particular point in time of study.

CHAPTER THREE

3.0 RESULTS

3.1 Age and Sex characteristics of study participants.

A total of 73 patients with tracheostomy were assessed in this study with age ranging from 18 to 87 years and mean age of all participants was 49.1 with a standard deviation of 18.2. The most prevalent (39.7%) age group was 18 to 47 years.

There were 49 Males and 24 Females with approximately Male to Female ratio of 2:1 (Table 1).

Table 1: Age and Sex characteristics

A: Age group	**Frequency(N)**	**Percentage (%)**
18-47	29	39.7
48-63	26	35.6
>63	18	24.7
B: Sex		
Male	49	67.1
Female	24	32.9

3.2 Distribution of Indications and primary diagnosis

UAO with Laryngeal carcinoma was the leading Indication and primary diagnosis (26%),followed by UAO with hypopharyngeal carcinoma (19.2%) , UAO with respiratory papillomatosis (13.7%), Prolonged intubation in Cerebrovascular accident(9.6%) and the least was access to surgery in Ameloblastoma (2.7) (Table 2)

Table 2: Distribution of Indications and primary diagnosis

Indications	Primary diagnosis	N (%)
Upper airway obstruction		
	Laryngeal Carcinoma	19(26)
	Hypopharyngeal carcinoma	14(19.2)
	Oropharyngeal carcinoma	4(5.5)
	Ludwig's angina	3(4.1)
	Respiratory papillomatosis	10(13.7)
	Vocal cord paralysis	3(4.1)
Prolonged Intubation		
	Cerebrovascular accident	7(9.6)
	Severe Pneumonia	4(5.5)
	Severe Malaria	4(5.5)
Laryngeal trauma		
	Cut throat	3(4.1)
Access to surgery		
	Ameloblastoma	2(2.7)

3.3 Mean scores of QOL before and after Tracheostomy.

The mean score for QOL before tracheostomy was lower (49.6) ± 12.38 compared to after tracheostomy (62.4) ± 14.78 (Table 3).

Table 3: Mean score for QOL Before and after tracheostomy

Mean score of QOL	Mean(SD)
Before Tracheostomy	49.6(12.38)
After Tracheostomy	62.4(14.78)

3.4 Comparison of mean score of QOL before and after tracheostomy

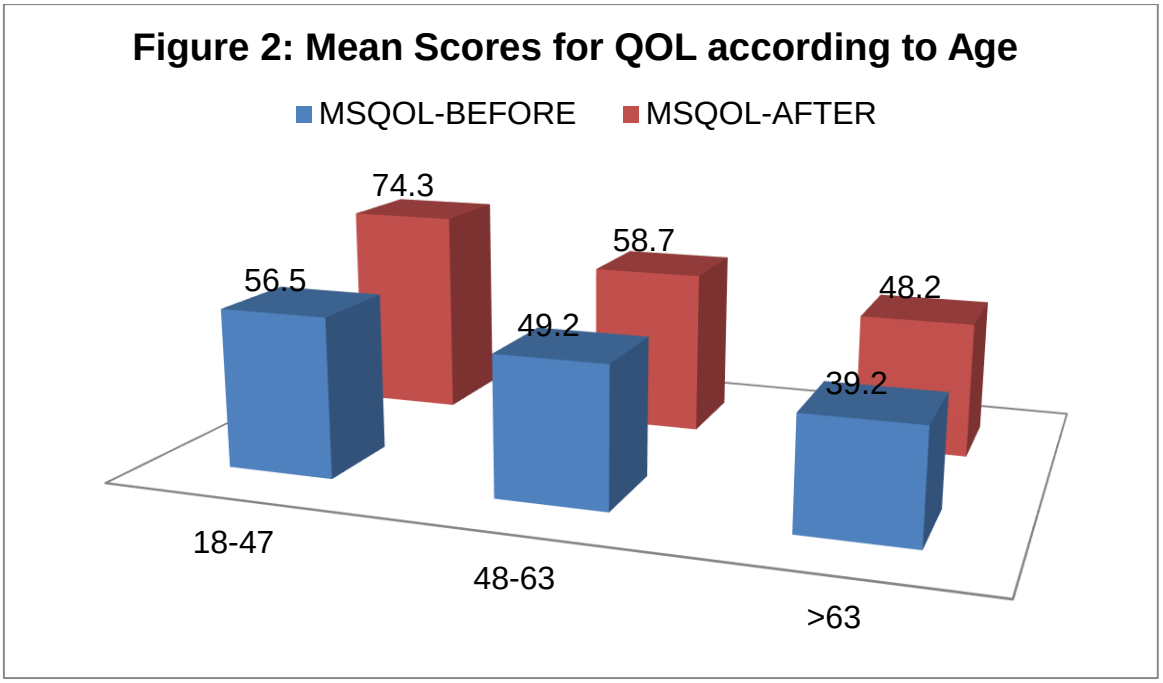
The mean scores difference of the QOL and their difference in mean scores with 95% confidence intervals (CI) before and after tracheostomy is shown in Table 4. There was a statistically significant increase of QOL after tracheostomy. On average the mean scores of QOL after tracheostomy were 12.8 higher than the average mean score of QOL before tracheostomy.

: **Table 4: Comparison of mean score of QOL before and after tracheostomy**

	Paired Differences							
				95% CI of the Difference				
	Mean	**Std. Deviation**	**Std. error mean**	**lower**	**upper**	**T**	**df**	**sig**
MSQOL Before – MSQOL after Tracheostomy	**12.79566**	12.15862	1.42306	-15.63248	-9.95885	-8.992	72	**.000**

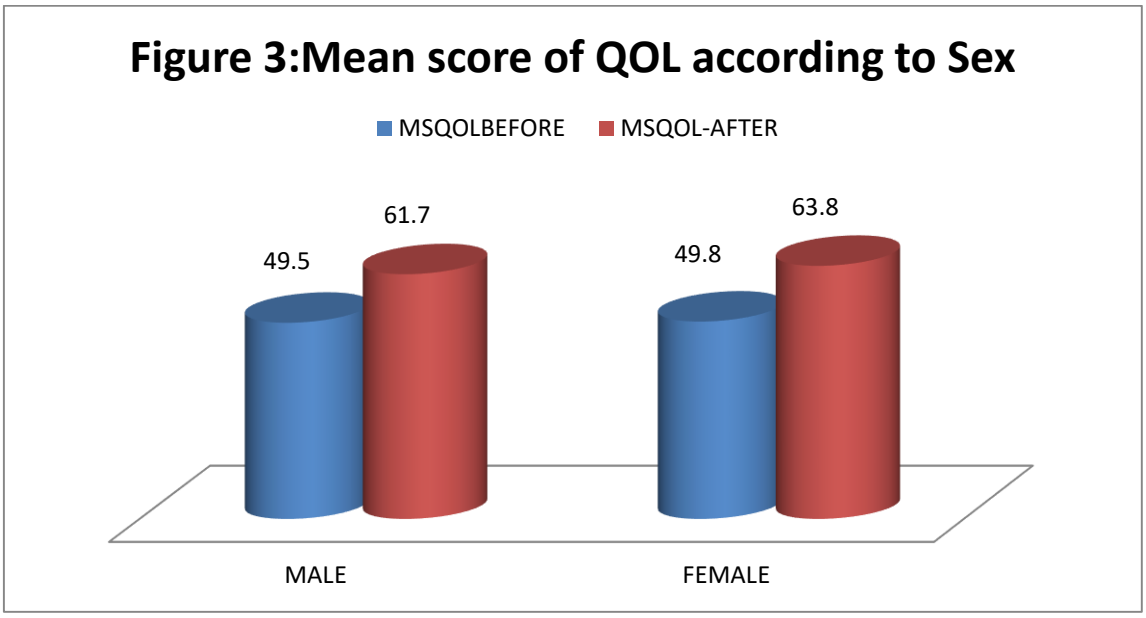
3.5 Mean score for QOL according to Age

Patients with age < 48years had higher mean score of QOL before and after tracheostomy with mean scores of 56.5 and 74.3 respectively. The lowest mean score of QOL before and after tracheostomy was at age >63 years with mean scores of 39.2 and 48.2 respectively. These differences were found to be statistically significant both before and after tracheostomy (Figure 2). (P=.000)



3.6 Mean score for QOL according to Sex

Females had higher score for QOL than Males both before and after Tracheostomy (Figure 3). However statistically there was no significant difference between Males and Females in mean score of QOL before and after tracheostomy.



3.7 Mean score for QOL according to Indication and Primary disease

There was a statistically significant association between Indication with Primary diagnosis and the mean score of QOL before tracheostomy (P=.000) where by Patients with UAO with Oropharyngeal carcinoma (38.1) hypopharyngeal (39.5) and laryngeal carcinoma (42.2) had least mean score of QOL , with the highest mean score was observed in access to surgery in Ameloblastoma (68.1) (Table 5).

The highest mean score was observed after tracheostomy with highest score in patients laryngeal Trauma (85.1) followed by UAO in Respiratory papillomatosis (78.7), Severe malaria (74.1) and lowest mean score being on the patients with UAO with Oropharyngeal carcinoma (45.9). This observation was statistically significant. (P=.000) (Table 5)

Table 5: Mean score for QOL according to Indications and primary disease

Indications	Primary diagnosis	MSQOL-Before	MSQOL-After
Upper airway obstruction			
	Laryngeal Carcinoma	42.2	55.7
	Hypopharyngeal carcinoma	39.5	48
	Oropharyngeal carcinoma	38.1	45.9
	Ludwig's angina	46.2	74.1
	Respiratory papillomatosis	66	78.7
	Vocal cord paralysis	54.4	67.6
Prolonged Intubation			
	Caerebrovascular accident	45	65.3
	Severe Pneumonia	49.4	69.7
	Severe Malaria	51	75
Laryngeal trauma			
	Cut throat	52	85.1
Access to surgery			
	Ameloblastoma	68.1	73.7

CHAPTER FOUR

4.0 DISCUSSION

Tracheostomy is the important old lifesaving surgical procedure particularly in our environment where patient present in advanced stages in upper airway obstruction (2, 10, 24). Tracheostomy has a profound impact in patient's daily life. Although it helps in avoiding the hindrance of the upper airway to allow ventilation process to continue taking place tracheotomy can also lead to undesirable negative impact on quality of life of patients including reduced self-esteem (9). As such it is important to assess the QOL among patients with tracheostomy.

Tracheostomy was observed in this study to be most common among age group 18-47 years with mean age of 49.1 years. This is in keeping with findings from studies done by J. Gilyoma et al in Tanzania (4), B. S. Alabi et al in Nigeria (10), Mita Mariam Sabu et al in India (28) and Muir et al in France (24) in which they all found mean age for tracheostomy to be around 3rd decade.

The Male preponderance (Male to Female ration of 2:1) of tracheostomy encountered in this study is in agreement with several works in Tanzania (4), Kenya (27), Nigeria (5, 6, 10) and also in other countries like France (24), New Zealand (16) and India (28, 32). This can be due to increase susceptibility of habits, activities and behavior which necessitated the risk for tracheostomy in some of the Male. Also the facts that Head and Neck Neoplasm like Laryngeal carcinoma are more common in men have added to the higher proportion of Males.

It was found that in this study that UAO secondary to Laryngeal carcinoma was the commonest indication for tracheostomy. It was followed by other diagnoses leading to UAO such as Hypopharyngeal carcinoma, Oropharyngeal carcinoma, Respiratory papillomatosis and Ludwig's angina. These findings were in congruence with a study done by Gilyoma et al in Tanzania (4) which shows the commonest indication for tracheostomy was UAO due to trauma followed by UAO due to neoplastic causes where Laryngeal carcinoma was the most indication of UAO among neoplasm. Other studies in Africa had similar findings to our study in which UAO secondary to Laryngeal carcinoma and other neck and head malignancies were the main indications for tracheostomy (10, 20, 30). Also Ammar et al in Basrah Iraq (7) established UAO

secondary to tumors was the commonest indication for tracheostomy and a review by Fernandez-Bussy who established UAO due to variable causes was primary indication for tracheostomy (26). Prolonged intubation was the other Indication for tracheostomy found in this study. The major indication for prolonged intubation requiring ICU care and tracheostomy was found to be cerebrovascular accident. Unlike other studies which shows the major indication for prolonged requiring ICU care and tracheostomy to be Road traffic trauma followed by Polytrauma (4, 28). This difference was attributed to the type of hospital, admission policies and difference in methodology of the study, whereby our study was done at the hospital which is not the primary hospital care for the traumatic patients. Severe Pneumonia and severe malaria were other indications that necessitated prolonged intubation and tracheostomy in ICU. Other indications of tracheostomy were found to be Laryngotracheal injury and access to head and neck surgery.

Mean score for QOL before and after tracheostomy was shown to improve in this study from 49.1 to 62 respectively. This pattern was similar to study by Pandian who demonstrated an improved score for tracheostomized patients in pain and speech domains after 5 days post tracheostomy (11). Also study done by Hashmi et al showed an improvement in physical composite score of QOL before and after tracheostomy (9) and study done by Gul et al (12) found that the QOL improved with increased period of living with tracheostomy. The reason for this improvement is explained by increased overall comfort, breathing and patient adaptation to tracheostomy with time.

In this study it was found that MSQOL was higher in the age group of less than 48 years, reflecting good quality in that young age. This pattern was similar to a study in Padova Italy(33) which showed better mood score in tracheostomized patients as compared to controls with mean ages of 61.8 and 62.6 years respectively. This is maybe attributed to the fact that at younger ages physiologic functions like speech, swallowing are relatively better compared to older counterparts.

This study showed that female patients had better scores than their counterparts although it was not statistically significant. This finding has inconsistent comparison from other studies with some showing better score in women (34, 35), some worse score (40) and other showing no

difference between genders (39). However these studies were done to assess QOL among patients with head and neck cancers.

Another important result obtained from this study is that Primary disease had impact in mean score of QOL where by patients with Head and Neck Neoplasm had low mean score of QOL. These findings were consistent with studies that assessed QOL of patients with Head and Neck cancers (34-37). This is so because of impairment in physiological functions like Speech, moisturizing, lubrication, chewing and swallowing in patients with Head and neck neoplasm that had contributed to low mean score of QOL compared to Non Neoplastic patients.

CHAPTER FIVE

5.1 CONCLUSION

Tracheostomy was found to be done more frequently in males than females.

Upper airway obstruction secondary to head and neck malignancy remains the commonest indication for tracheostomy in our center.

Tracheostomy had shown great impact in improving QOL.

The age of the patient and primary disease are the significant predictors of QOL among patients with tracheostomy.

5.2 RECOMMENDATION

A proper assessment of healthcare quality of life may be helpful to better understand the needs of tracheostomized patients and improve their different aspects of QOL. Healthcare professionals should be aware of different domains that affect QOL so that they can use a multidisciplinary strategy to optimize their clinical management.

Specialized counseling and tracheostomy care education to both patients and relatives are of paramount importance in preparing them psychologically during the course of the treatment and may improve QOL significantly.

This study has opened a window for further studies to assess the long-term QOL in patient with permanent tracheostomy.

5.3 DISSEMINATION PLAN

This Dissertation report is the complied findings of this study which was presented to the Department of Otorhinolaryngology at MUHAS and shall be submitted to Director of Postgraduate Studies (DPGS) of MUHAS as a partial fulfillment of the requirements for the award of the Masters of Medicine in Otorhinolaryngology.

Copy of this study shall also be submitted to the Executive director of MNH through directorate of clinical services for the aim of utilizing knowledge obtained from this study for provision of better health services. The manuscript of the study will be prepared for publication and presentation in scientific journals.

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APPENDICES

Appendix i: CONSENT FORM (English Version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES (MUHAS)

SCHOOL OF MEDICINE

DEPARTMENT OF OTORHINOLARYNGOLOGY

INFORMED CONSENT FORM

Identification No.: _____

Introduction:

Hello my name is Dr. Rashid M Ally from the Muhimbili University of Health and Allied Sciences carrying out a research on indications and quality of life in patients Tracheostomied patients at Muhimbili National Hospital. The aim of the study is to determine the indications and quality of life for tracheostomized patients in MNH

Methodology of this study:

This study mainly involves responding to a questionnaire consisting of standardized questions from the Tracheostomized patient quality of life instrument as well as other sections with questions related to your socio-demographic characteristics and reason for tracheostomy.

If you agree to join the study, your medical information will be used for research purpose. Participation in this study will be completely voluntary. Information obtained from you will be

kept confidential. Only identification number will be written on screening form and all information collected will be entered into computers.

We do not expect any harm will happen to you because of joining in this study. You may refuse to participate or withdraw from the study at any time. Refusal to participate or withdrawal from the study will not involve penalty or loss of any benefit. You will be treated and followed up as per the usual treatment protocol; the results of the study will contribute to the present knowledge about Quality of life for tracheostomized patients and improve health care for tracheostomized patients.

If you ever have questions about this study, you should contact the principal investigator Dr. Rashid Mwemgamba Ally cell phone number 0769533887/0782557464 or you may contact Dr Bruno Sunguya, Chairperson of the Research and Publication Committee at Muhimbili University of Health and Allied Sciences. Telephone Number: 2150302 – 6. Box 65001, Dar es Salaam

I ……..have read the contents in this form and am well clear to me. My questions have been answered and I agree to be enrolled into the study and I'm signing here while in a well sound mind without any undue influence from the researcher.

Signature of participant…….

Signature of principal researcher…….

Appendix ii: CONSENT FORM (Swahili Version)

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI (MUHAS)

SHULE YA UDAKTARI

IDARA YA PUA, SIKIO NA KOO

FOMU YA RIDHAA

Namba ya utambulisho: _____

Utangulizi:

Habari, naitwa Dr. Rashid Mwemgamba kutoka Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili nafanya Utafiti kuangalia sababu na ubora wa maisha kwa wagonjwa waliofanyiwa tracheostomi katika hospitali ya Muhimbili idara ya pua koo na masikio.

Utendaji wa utafiti huu:

Utafiti huu sana sana unahusu kujibu dodoso inayojumuisha maswali yenye viwango kutoka chombo cha ubora wa maisha ya wagonjwa waliofanyiwa tracheostomi pamoja na vifungu vingine vya maswali yanayohusu taarifa zako za kijamii na kidemografia kama mgonjwa kwa ujumla na pia sababu yaw ewe kufanyiwa tracheostomi.

Kama utakubali kushiriki huu Utafiti, taarifa zako za kitabibu zitatumika kwa lengo la utafiti.. Ushiriki wa Utafiti huu ni wa hiyari na taarifa zitakazopatikana zitahifadhiwa kwa usiri

mkubwa.Namba ya utambulisho ndio itatumika kwa utambulisho na taarifa zote zitakazopatikana zitahifadhiwa kaitka computer yenye namba siri ili sizidukuliwe.
Hakuna madhara yeyote yatakayokupata kwasababu ya kushiriki kwenye huu utafiti. Unaruhusiwa kutokushiriki au kujitoa kushiriki katika huu utafiti muda wowote.Kutokushiriki kwako au kujitoa hakutaathiri tiba yako.Utatibiwa nakufuatiliwa kama matibabu yako yanavyohitaji na kustahili upate.Matokeo ya utafiti huu utatupa mwangaza na ufahamu wa ubora wa maisha wa wagonjwa wanaofanyiwa huu upasuaji na matokeo yake na kuboresha zaidi ubora wa maisha yao.

Kama utakuwa na swali lolote kuhusu huu utafiti unaweza kuwasiliana na mtafiti mkuu Dr Rashid Mwemgamba Ally kwa namba ya simu 0769533887/0782557464 au unaweza wasiliana na Dr Bruno Sunguya, Mwenyekiti wa Kamati ya Utafiti na Uchapishaji, Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili. Telephone Number: 2150302 – 6. Box65001, Dar es Salaam

Mimi ……..nimesoma na kuelewa kilichoandikwa kwenye hii fomu.Maswali yangu yamejibiwa na nimeafiki kushiriki na nasaini hapa nikiwa nimeelewa na bila kushurutishwa na mtafiti..

Saini ya mshiriki……..

Saini ya mtafiti/msaidizi…….

Appendix iii: QUESTIONNAIRE AND EXTRACTION FORM

Questionnaire and Extraction form (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES (MUHAS)

SCHOOL OF MEDICINE

DEPARTMENT OF OTORHINOLARYNGOLOGY

QUESTIONNAIRE AND EXTRACTION FORM

Identification No.: _____

Title of the study:

"Indications and quality of life in tracheostomized patients at Muhimbili national hospital"

Instructions to interviewer:

- Interviewers include principal investigator and selected postgraduate students
- This questionnaire is to be filled by the interviewer only and it should not be left to the study participant under any circumstances
- There are 4 sections, I-IV and all questions in each section should be filled in its entirety
- Response to questions of sections I, III and IV are to be obtained from the patient
- Response for section II and are to be extracted from patient's health record at MNH.
- Please fill in the blanks and insert √ in the boxes where appropriate

Section I: Socio-demographic factors (2 questions)?

1. Age:_____ years

2. Sex: a) Male□ b) Female□

Section II: REASON FOR TRACHEOSTOMY

1. What is the reason for the tracheostomy insertion?
    - Prolonged mechanical ventilation
    - Failure intubation
    - Pulmonary toilet
    - Surgical access
    - Airway protection
    - Airway obstruction
    - Others specify……

2. What is the Primary Diagnosis?

   Mention …….....

Section III: TRACHEOSTOMY QOL instrument- Before tracheostomy

1. Overall Comfort
    - I had severe discomfort at rest
    - I had moderate discomfort at rest
    - I had mild discomfort at rest
    - I had no discomfort at rest

2. Airway Pain
    - I had severe pain, not controlled by narcotics
    - I had severe pain but controlled by narcotics
    - I had moderate pain which required regular medications (non-narcotic)
    - I had mild pain not needed medication
    - I had no pain even without medication

3. Comfort of Breathing
    - I had severe difficulty with breathing
    - I had moderate difficulty with breathing
    - I had mild difficulty with breathing
    - I had no difficulty with breathing

4. Activity
    - I was usually in bed or in a chair and house-bound
    - I did not have the energy to do my daily activities
    - My exercise tolerance had decreased, but I was still able to do my daily activities
    - I was able to do the same amount of exercise, but I was more tired
5. Limitations to moving neck –implications in daily life
    - I had limits of my neck movement, and it prevented me from doing some of my daily activities
    - I had limits of my neck movement, but I was still able to do my daily activities without difficulty
    - I had limits of my neck movement to a minor degree
    - I had no limit of my neck movement

6. Swallowing I cannot swallow at all
    - I could not swallow at all
    - I could not swallow
    - I could swallow only certain consistencies food and liquid (e.g. pureed, thickened liquids)
    - I could swallow all foods and liquids

7. Speech
    - I could not speak at all
    - I could speak occasionally
    - I could speak most of the times but not always
    - I was able to speak whenever I wanted

8. How easy is it to clear/cough up secretions
    - I was not able to clear secretions completely
    - I was occasionally unable to clear secretions
    - I was often unable to clear secretions
    - I was always able to clear secretions

9. Mood
    - I was extremely depressed about my condition
    - I was somewhat depressed about my condition
    - I was generally in a good mood
    - I was always in a good mood

10. Anxiety
    - I was very anxious about my condition
    - I was moderately anxious about my condition
    - I was a little anxious about my condition
    - I was not anxious about my condition

11. Sleep
    - I could not sleep at all
    - My sleep was poor
    - My sleep was moderate
    - My sleep was excellent

12. Appearance
    - I felt significantly disfigured and could not be with people because of my appearance
    - The change in my appearance bothered me, but I had not changed my daily activities because of my appearance
    - I felt significantly disfigured and limited my activities because of my appearance
    - The change in my appearance was minor

Section IV: TRACHEOSTOMY QOL instrument- After tracheostomy

13. Overall Comfort
    - I have severe discomfort at rest
    - I have moderate discomfort at rest
    - I have mild discomfort at rest
    - I have no discomfort at rest

14. Airway Pain
    - I have severe pain, not controlled by narcotics
    - I have severe pain but controlled by narcotics
    - I have moderate pain which requires regular medications (non-narcotic)
    - I have mild pain not needing medication
    - I have no pain even without medication

15. Comfort of Breathing
    - I have severe difficulty with breathing
    - I have moderate difficulty with breathing
    - I have mild difficulty with breathing
    - I have no difficulty with breathing

16. Activity
    - I am usually in bed or in a chair and house-bound
    - I do not have the energy to do my daily activities
    - My exercise tolerance has decreased, but I am still able to do my daily activities
    - I am able to do the same amount of exercise, but am more tired

17. Limitations to moving neck –implications in daily life
    - I have limits of my neck movement, and it prevents me from doing some my daily activities
    - I have limits of my neck movement, but I am still able to do my daily activities without difficulty
    - I have limits of my neck movement to a minor degree
    - I have no limit of my neck movement

18. Swallowing I cannot swallow at all
    - I cannot swallow
    - I can swallow only certain consistencies food and liquid (e.g. pureed, thickened liquids)
    - I can swallow all foods and liquids

19. Speech
    - I cannot speak at all
    - I can speak occasionally
    - I can speak most of the times but not always
    - I am able to speak whenever I want

20. How easy is it to clear/cough up secretions
    - Never able to clear secretions completely
    - Occasionally unable to clear secretions
    - Often unable to clear secretions
    - Always able to clear secretions

21. Mood
    - I am extremely depressed about my condition
    - I am somewhat depressed about my condition
    - I am generally in a good mood
    - I am always in a good mood

22. Anxiety
    - I am very anxious about my condition
    - I am moderately anxious about my condition
    - I am a little anxious about my condition
    - I am not anxious about my condition

23. Sleep
    - I cannot sleep at all
    - My sleep is poor
    - My sleep is moderate
    - My sleep is excellent

24. Appearance
    - I feel significantly disfigured and cannot be with people because of my appearance
    - I feel significantly disfigured and limited my activities because of my appearance
    - The change in my appearance bothers me, but I have not changed my daily activities because of my appearance
    - The change in my appearance is minor

Appendix iv: Questionnaire Swahili version)

CHUO KIKUU CHA SAYANSI NA AFYA SHIRIKISHI MUHIMBILI (MUHAS)

SHULE YA UDAKTARI

IDARA YA PUA, SIKIO NA KOO

DODOSO NA FOMU YA UKUSANYAJI

Namba ya utambulisho: _____

Mada ya utafiti:

“Sababu na bora wa maisha kwa wagonjwa waliofanyiwa tracheostomi katika hospitali ya Taifa Muhimbili”

“**Maelekezo kwa mhojaji:**

• Mahoiiano inatakiwa kufanyiwa na mtafiti mkuu na mtafiti msaidizi

• Dodoso hii inapaswa kujazwa na mhojaji pekee na sio kuachwa kwa mshiriki wa utafiti chini ya mazingira yoyote

• Kuna vipengele 4, I-IV na maswali yote katika kila kipengele lazima ijazwe kwa ukamilifu

• Majibu ya maswali ya vipengele I, III na IV vinahitaji kupatikana kwa mgonjwa

• Majibu ya vipengele II vinahitaji kukusanywa kutoka kwenye rekodi za mgonjwa katika hospitali ya Taifa Muhimbili

• Tafadhali jaza nafasi zilizo wazi na weka alama √ katika sanduku inapofaa

Kipengele cha I: Maswala ya kijamii na kidemographia (Maswali 2)

1. Umri: Miaka _____

2. Jinsia: a) Kiume□ b) Kike□

Kipengele cha II: sababu ya kuwekewa tracheostomi/trakiostomi

1. Ni sababu ipi ilikupelekea kuwekewa trakiostomi/tracheostomi?
   - Kukaa kwenye mashine ya kupumulia kwa muda mrefu
   - Kushindwa kwa intubesheni
   - Kutolewa makohozi mengi kwenye njia ya kupumulia
   - Kwa ajili ya kulinda njia ya hewa
   - Kuwezesha upasuaji uweze kufanyika
   - Kuziba kwa njia ya hewa
   - Nyinginezo, (tafadhali fafanua) ……..

2. Ni upi ulikuwa ugonjwa wa msingi?

   Taja …….....

Kipengele III: zana ya kupimia kiwango cha ubora wa maisha kwa wagonjwa wenye tracheostomi/trakeostomi kabla ya trakeostomi

1. Ahueni/Unafuu wa jumla

- Nilijiskia vibaya kupita kiasi nilipopumzika
- Nilijiskia vibaya kwa wastani nilipopumzika
- Nilijiskia vibaya kwa mbali nilipopumzika
- Sikujiskiii vibaya kabisa nilipopumzia

3. Maumivu katika njia ya hewa
    - Nilipata maumivu makali yasiyopoozwa na dawa za kutuliza maumivu/mihadarati
    - Nilipata maumivu makali lakini yaliweza kupoozwa na dawa za kutuliza maumivu/mihadarati
    - Nilipata maumivu ya wastani yaliyoweza kupoozwa kwa dawa za kawaida (siyo mihadarati)
    - Nilipata maumivu kwa mbali yasiyohitaji dawa za kuyatuliza
    - Sikuhisi maumivu yoyote hata bila dawa za kutuliza maumivu
4. Unafuu/ahueni ya upumuaji
    - Nilipumua kwa tabu kupita kiasi
    - Nilipumua kwa tabu kiasi cha wastani
    - Nilipumua kwa tabu kiasi
    - Nilipumua bila tatizo/tabu kabisa
5. Uwezo wa kufanya shughuli
    - Nilikuwa kitandani au kwenye kiti wakati wote au sikuweza kabisa kutoka nje ya nyumba
    - Sikuwa na nguvu ya kufanya shughuli zangu za kila siku
    - uvumilivu wangu katika mazoezi ulipungua lakini bado niliweza kufanya shughuli zangu za kila siku
    - Niliweza kufanya kiwango kile kile cha mazoezi lakini nilichoka sana
6. Ugumu wa kuzungusha shingo –athari zake kwenye maisha ya kila siku
    - Nilipata ugumu wa kuzungusha/kutembeza shingo na hii ilinizuia kufanya baadhi ya shughuli zangu za kila siku
    - Nilipata ugumu wa kuzungusha/kutembeza shingo lakini bado niliweza kufanya shughuli zangu za kila siku bila shida
    - Nilipata ugumu wa kuzungusha shingo yangu kwa kiasi kidogo sana
    - Sikupata ugumu wowote katika kuzungusha shingo yangu
7. Kumeza
    - Sikuweza kabisa kumeza kitu chochote
    - Sikuwe kumeza kutokana na mpira
    - Niliweza kumeza vyakula teketeke na vimiminika (mfano, vimiminika na vimiminika vizito)
    - Niliweza kumeza vyakula na vinywaji vyote

8. Kuzungumza
    - Sikuweza kuongea kabisa
    - Niliweza kuongea kwa nadra
    - Niliweza kuongea sana lakini sio wakati wote
    - Niliweza kuongea kila ninapohitaji
9. Ulipata urahisi kiasi gani katika kuondoa au kusafisha uchafu kama makohozi kooni?
    - Sikuweza kabisa kuondoa uchafu
    - Mara nyingi nilishindwa kuondoa uchafu kooni
    - Mara chache nilishindwa kuondoa uchafu
    - niliweza kuondoa uchafu kooni wakati wote
10. Hisia
    - Nilisononeka kupita kiasi kutokana na hali yangu
    - Nilisononeka kwa kiasi fulani kutokana na hali yangu
    - Kwa ujumla nilijiskia vizuri
    - Nilijisikia vizuri wakati wote
11. Wasiwasi
    - Nilikuwa na wasiwasi/mashaka sana kuhusu hali yangu
    - Nilikuwa na wasiwasi/mashaka kiasi cha wastani kuhusu hali yangu
    - Nilikuwa na wasiwasi/mashaka kiasi kuhusu hali yangu
    - Sikuwa na wasiwasi/mashaka kuhusu hali yangu
12. Usingizi
    - Sikupata usingizi kabisa
    - Nilipata usingizi kwa mashaka
    - Nilipata usingizi kwa wastani
    - Ninapata usingizi mnono kabisa
13. Muonekano
    - Nilijihisi kwamba muonekano wangu umeharibika sana na sikuweza kujumuika na watu wengine kwa sbabu ya muonekano huu
    - Nilijihisi kwamba muonekano wangu umeharibika na shughuli zangu ziliathirika kutokana na muonekano huu
    - Mabadiliko katika muonekano wangu yalinihangaisha lakini sikubadili wala kuathiri shughuli zangu kutokana na muonekano wangu
    - Mabadiliko kwenye muonekano wangu ilikuwa ni jambo dogo sana kwangu

Kipengele IV: zana ya kupimia kiwango cha ubora wa maisha kwa wagonjwa wenye tracheostomi/trakeostomi baada ya trakeostomi

1. Ahueni/Unafuu wa jumla

- Najiskia vibaya kupita kiasi ninapopumzika
- Ninajiskia vibaya kwa wastani ninapopumzika
- Ninajiskia vibaya kwa mbali ninapopumzika
- Sijiskiii vibaya kabisa ninapopumzika

2. Maumivu katika njia ya hewa

- Ninapata maumivu makali yasiyopoozwa na dawa za kutuliza maumivu/mihadarati
- Ninapata maumivu makali lakini yanaweza kupoozwa na dawa za kutuliza maumivu/mihadarati
- Ninapata maumivu ya wastani yanayoweza kupoozwa kwa dawa za kawaida (siyo mihadarati)
- Nina maumivu kwa mbali yasiyohitaji dawa za kuyatuliza
- Sihisi maumivu yoyote hata bila dawa za kutuliza maumivu

3. Unafuu/ahueni ya upumuaji

- Ninapumua kwa tabu kupita kiasi
- Ninapumua kwa tabu kiasi cha wastani
- Ninapumua kwa tabu kiasi
- Ninapumua bila tatizo/tabu kabisa

4. Uwezo wa kufanya shughuli

- Nipo kitandani au kwenye kiti wakati wote au siwezi kabisa kutoka nje ya nyumba
- Sina nguvu ya kufanya shughuli zangu za kila siku
- uvumilivu wangu katika mazoezi umepungua lakini bado ninaweza kufanya shughuli zangu za kila siku
- Ninaweza kufanya kiwango kile kile cha mazoezi lakini nimechoka sana
-

5. Ugumu wa kuzungusha shingo –athari zake kwenye maisha ya kila siku
    - Ninapata ugumu wa kuzungusha/kutembeza shingo na hii inanizuia kufanya baadhi ya shughuli zangu za kila siku
    - Ninapata ugumu wa kuzungusha/kutembeza shingo lakini bado nianweza kufanya shughuli zangu za kila siku bila shida
    - Ninapata ugumu wa kuzungusha shingo yangu kwa kiasi kidogo sana
    - Sipati ugumu wowote katika kuzungusha shingo yangu

6. Kumeza
    - Siwezi kabisa kumeza kitu chochote
    - Siwezi kumeza kutokana na mpira wa kupumulia
    - Naweza kumeza vyakula teketeke na vimiminika (mfano, vimiminika na vimiminika vizito)
    - Naweza kumeza vyakula na vinywaji vyote
7. Kuzungumza
    - Siwezi kuongea kabisa
    - Naweza kuongea kwa nadra
    - Naweza kuongea sana lakini sio wakati wote
    - Naweza kuongea kila ninapohitaji
8. Unapata urahisi kiasi gani katika kuondoa au kusafisha uchafu kama makohozi kooni?
    - Siwezi kabisa kuondoa uchafu
    - Mara nyingi nashindwa kuondoa uchafu kooni
    - Mara chache nashindwa kuondoa uchafu
    - naweza kuondoa uchafu kooni wakati wote
9. Hisia
    - Ninasononeka kupita kiasi kutokana na hali yangu
    - Ninasononeka kwa kiasi fulani kutokana na hali yangu
    - Kwa ujumla ninajiskia vizuri
    - Ninajiskia vizuri wakati wote
    -
10. Wasiwasi
    - Nina wasiwasi/mashaka sana kuhusu hali yangu
    - Nina wasiwasi/mashaka kiasi cha wastani kuhusu hali yangu
    - Nina wasiwasi/mashaka kiasi kuhusu hali yangu
    - Sina wasiwasi/mashaka kuhusu hali yangu

11. Usingizi
    - Sipati usingizi kabisa
    - Ninapata usingizi kwa mashaka
    - Ninapata usingizi kwa wastani
    - Ninapata usingizi mnono kabisa
12. Muonekano
    - Najihisi kwamba muonekano wangu umeharibika sana na siwezi kujumuika na watu wengine kwa sbabu ya mwonekano huu
    - Najihisi kwamba muonekano wangu umeharibika na shughuli zangu zimeathirika kutokana na mwonekano huu
    - Mabadiliko katika muonekano wangu yananihangaisha lakini sijabadili wala kuathiri shughuli zangu kutokana na mwonekano wangu
    - Mabadiliko kwenye muonekano wangu ni jambo dogo sana kwangu

Appendix v: TQOL Scoring Tool

Overall Comfort	100	I have no discomfort at rest
	67	There is mild discomfort at rest
	33	I have moderate discomfort at rest
	0	I have severe discomfort at rest
Airway Pain	100	I have no pain even without medication
	75	There is mild pain not needing medication
	50	I have moderate pain which requires regular medication (non-
	25	I have severe pain but controlled by narcotics
	0	I have severe pain, not controlled by narcotics
Comfort of Breathing	100	I have no difficulty with breathing
	67	There is mild difficulty with breathing
	33	I have moderate difficulty with breathing
	0	I have severe difficulty with breathing
Activity	100	I am able to do the same amount of exercise, but am more tired
	67	My exercise tolerance has decreased, but I am still able to do my
	33	I do not have the energy to do my daily activities
	0	I am usually in bed or in a chair and house-bound
Limitations to moving neck –implications in daily life	100	I had no limit of my neck movement
	67	I had limits of my neck movement to a minor degree
	33	I had limits of my neck movement, but I was still able to do my
	0	I had limits of my neck movement, and it prevented me from
Swallowing	100	I can swallow all foods and liquids
	67	I can swallow only certain consistencies food and liquid (e.g.
	33	I cannot swallow because of the breathing tube
	0	I cannot swallow at all

Speech	100	I am able to speak whenever I want
	67	I can speak most of the time but not always
	33	I can speak occasionally
	0	I cannot speak at all
How easy is it to clear/cough up secretions	100	I was always able to clear secretions
	67	I was often unable to clear secretions
	33	I was occasionally unable to clear secretions
	0	I was never able to clear secretions completely
Mood	100	I am always in a good mood
	67	I am generally in a good mood
	33	I am somewhat depressed about my condition
	0	I am extremely depressed about my condition
Anxiety	100	I am not anxious about my condition
	67	I am a little anxious about my condition
	33	I am moderately anxious about my condition
	0	I am very anxious about my condition
Sleep	100	My sleep is excellent
	67	My sleep is moderate
	33	My sleep is poor
	0	I cannot sleep at all
12. Appearance	100	The change in my appearance is minor
	67	I feel significantly disfigured and limited my activities because of
	33	The change in my appearance bothers me, but I haven't changed
	0	I feel significantly disfigured and cannot be with people because
QOL-MV Average		Sum of scores / 12