ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

ONCOLOGY NURSING PROGRAM

THE IMPACT OF IMPAIRED SWALLOWING RELATED QUALITY OF LIFE OF HEAD AND NECK CANCER SURVIVORS AT TIKUR ANBESSA SPECIALIZED REFERRAL HOSPITAL, ADDIS ABABA, ETHIOPIA, 2019 G.C.

(MIXED METHOD STUDY)

BY: TSEGANESH ASEFA YIFRU (BSc)

A RESEARCH THESIS SUBMITTED TO THE SCHOOL OF NURSING AND MIDWIFERY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS OF MASTERS OF SCIENCE DEGREE IN CLINICAL ONCOLOGY NURSING.

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MASTER OF SCIENCE RESEARCH PROJECT SUBMISSION FORM

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Full title of the research project	The Impact of Impaired Swallowing Related Quality of Life of Head and Neck Cancer Survivors at Tikur Anbessa Specialized Referral Hospital, Addis Ababa, Ethiopia: 2019 G.C (Mixed Method Study)
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APPROVAL BY THE BOARD OF EXAMINATION

This thesis by Tseganesh Asefa is accepted in its present form by the board of examiners as satisfying thesis requirement for the degree of masters in clinical oncology nursing.

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DEDICATION

This research thesis is dedicated to Head and Neck Cancer survivors, who loss/ suffers their life’s without obtaining treatment.

STATEMENT OF DECLARATION

By my signature below, I honestly declared that this research thesis on IMPAIRED SWALLOWING RELATED QUALITY OF LIFE OF HEAD AND NECK CANCER SURVIVOURS AT TIKURE ANBESSA SPECIALIZED REFFERAL HOSPITAL, ADDIS ABABA, ETHIOPIA. Is my own work and all the sources that I have used indicated and acknowledged by means of complete references and this work has not been submitted before for any other degree in any other institutions.

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ACRONYMS/ABBREVIATIONS

ANOVA: ANalysis Of VAriance

DC: Data Collector

ETB: Ethiopian Birr

HAN: Head and Neck

HANC: Head and Neck Cancer

IDI: In Depth Interview

MDADI: MD Anderson Dysphagia Inventory

PI: Principal Investigator

QOL: Quality of Life

SPSS: Statistical Package for the Social Sciences

TASRH: Tikur Anbessa Specialized Referral Hospital

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ABSTRACT

Introduction: Different research and international clinical guidelines deals about the importance of addressing and supporting the Quality of Life needs of individuals with impaired swallowing. However, data support that the presence of swallowing impairment related Quality of Life has not directly addressed in the reviewed studies in Ethiopia.

Objective: This study was conducted to assess factors that affect swallowing related quality of life and it is impacts in head and neck cancer survivors.

Methods: To achieve the objective of this study 102 patients were enrolled in cross sectional study, of whom 7 were purposively selected for in depth interviews of qualitative study. The study was conducted from March to April 2019 G.C at the oncology center of Tikur Anbessa Specialized Referral Hospital, Addis Ababa, Ethiopia. The pre coded data was entered in to EpiData version 4.4.3.1 then exported to Statistical Package for the Social Sciences version 24 for further cleaning, and analysis. The mean comparison analysis and multiple linear regression were calculated. $P \leq 0.05$ took as cut of value to be significant and 95% level of confidence was constructed. For qualitative study purposive sampling technique was used. The data collection process facilitated by using semi structured Amharic interview guide, SONY tape record and filed note. After transcription and translation, data was analyzed manually using Colaizzi's 6 steps of phenomenological analysis. The trustworthiness of a qualitative study ensured by Transferability, credibility, confirmability, and dependability

Result: In mean comparisons analysis, factors which showed a mean significant difference in a MDADI subscale were sex, marital status, working condition, medical expenses, tumor site, tumor T stage, and treatment modality. Furthermore, in multiple linear regression analysis tumor site which was oral cavity/ oropharyngeal carcinoma and medical expenses were a predictor of impaired swallowing related quality of life. Moreover, in qualitative study four themes were identified such as Daily activity, Emotional, Functional, and physical impairments.

Conclusion and recommendation: In this study finding, swallowing related quality of life in head and neck cancer patients was strictly affected by different factors and it had an impact in their life, so measurement should be taken to improve it.

Keys words include: Quality of Life, Head and Neck Cancer, dysphagia, swallowing quality of life.

1. INTRODUCTION

1.1. Background of the Study

The term “Head and neck cancer” do not refer to a single entity, rather to a diverse spectrum of malignancies that arises from the epithelial lining of upper aero digestive tract (1). Histologically, more than 90% of head and neck cancers are squamous cell carcinomas (2). The most common etiologist are lifetime exposure to tobacco, alcohol consumption and oral infection with HPV (3). Men are affected about twice as often as women with head and neck cancer (4).

One of the determinant for the prognosis of this disease is the stage, 66% of the time, head and neck cancers will be found at late stage three and four (5). Once cancer in the lymph nodes, it is more likely to spread throughout the body (6). The treatment modality options depends on anatomical location, stage of tumor, the patient health status and preference such as surgery, radiotherapy, chemotherapy, or some combination (7, 8). Nearly 75 % of patients with head and neck cancer treated with curative or palliative intent by radiotherapy (7). Over half of the patients were managed with radiation therapy combined with chemotherapy (9).

Head and neck cancer arises in anatomically and functionally complex areas, treatment and disease can cause the damage of essential organs, which serves for handing out of food. Dysphagia and xerostomia are the interrelated two common early side effects of HANC treatments (10).

Impaired swallowing in head and neck cancer population has a profound impact on person’s social, and physical well-being (11, 12) such as difficulty to eating solid foods, choking**,** cough up after swallow, strangling to swallow, taking extra time to swallow, altered social interactions, weight loss (13-15) and emotional consequences such as loss of enjoyment with eating , embarrassment, and dissatisfaction (9, 16-18).

Different research continues to suggest the significant impact of living with impaired swallowing on QOL (19). In addition, various international clinical guideline documents deals about the importance of addressing and supporting the QOL needs of individuals (20). In present there are also a number of clinical assessment tools to quantifying the impact of

impaired swallowing on QOL. The MD Anderson Dysphagia Inventory is a valid and reliable tool, which is commonly used in both research and clinical practice to assess patients perception towards the impaired swallowing ability (21).

Because the study on quality of life provide clue about disease in patient's perspective, this is important to change professional assumed care deliver services and health care related decision making in several levels.

However, no data present in Ethiopia regarding this issues as a result recommended assessment and management approaches on impaired swallowing related QOL remain scarce. Studies conducted on swallowing related quality of life of head and neck cancer patients made a huge contribution to improving head and neck cancer care. Therefore, this research endeavors to bring insight on swallowing related quality of life of head and neck cancer patients at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

1.2. Statement of the Problem

Head and neck cancer is a major global health issue with half million new cases diagnosed per year, it is the nine most common malignancy in the world (22) and also accompanying with a high morbidity rate, since it interferes with vital functions of life like eating, drinking, breathing, speech, hearing, and vision (23). Cancer of the lip and oral cavity is the twelfth most common cause of cancer mortality among males and sixteenth among females (6).

The two thirds of the global burden of head and neck cancer cases occur in developing countries. According to Ethiopian hospital registry of cancer pattern in TASH, from six common malignancy cancers, head and neck cancer placed at the first rank in male, and third in female next to gynecological and breast. In addition to this, the study in University of Gondar Hospital reported that HANC is one of the five commonest cancers in the male (24, 25).

More than 50% of individuals diagnosed with cancer of the head and neck experience difficulty swallowing before undergoing treatment, particularly those with advanced stage disease (26). The treatments for head and neck cancer has improved tumor response rate, and survival status (27). However, treatment intensification exacerbate swallowing difficulties (14). The resulting impaired swallowing affects the patient's quality of life multidimensional throughout the course of a treatment and even after a completion of a therapy (28, 29).

Impaired swallowing is a major medical concern in head and neck cancer patient. Potential predictive factors are the (site and stage) of tumor, treatment modalities (extent of surgery, use of adjuvant chemotherapy, radiation therapy or neck dissection) combined with some personal characteristics (30).

Recently the pathophysiological process of swallowing is describing by using instrumental assessments such as video fluoroscopy. It shows swallowing disorder but it may not have a strong relationship with how patients perceive their swallowing problems (31, 32).

In addition, due to a limited numbers of mixed method research conducted to date, data support that the presence of swallowing impairment related quality of life and further investigation into the impact of living with impaired swallowing has not directly addressed in

the reviewed studies in Ethiopia. As a result, this study aiming to assess factors associated with impaired swallowing related quality of life in head and neck cancer survivors and furthermore, explore impacts of impaired swallowing on the everyday lives of people with HNC.

1.3. Significance of the Study

Head and neck cancer is the first top leading malignancy in male, and third in female at study area. Different studies proposed that the importance of addressing swallowing related quality of life in head and neck cancer patients. However, studies suggest this issue has not directly addressed in the reviewed studies in Ethiopia. Hence, the finding of this study may provide evidence-based information for health care practitioner and survivors to understand the significant impact of impaired swallowing related quality of life in head and neck cancer patients.

The result of this study may initiate planner's/ policy maker to open a support groups or programs specifically to patients with swallowing difficulties for head and neck cancer survivors to meet their unique needs of patient. Moreover, the outcome of this study important by providing a base line information about factors of swallowing related quality of life and it is burdens in global, physical, emotional, and functional aspects of life in head and neck cancer survivors for future researchers interested on this topic.

2. LITERATURE REVIEW

2.1. Burden of Impaired Swallowing Related Quality of Life in Head and Neck Cancer Survivors

The study in Spain showed that QOL is impaired because of swallowing problem in 51.7% of patient. Nearly 62% of patients avoided eating with other persons and approximately 37% of patients felt embarrassed at mealtime (26).

The study in England stated that swallowing became very painful like ‘excruciating ‘and ‘pure hell’. If food is attempted to swallow, it may have stuck in the throat, on that condition hard to shift or needed to be spat out that leads an embarrassment, avoided family mealtime, weeding celebration, dinner invitations and ate alone due to a fear of choking in social meal time which increase social isolation (13).

The study in Turkish stated that patients whose food intake were less than 50 % of the meals had worse global health status scores, this results a poor physical and societal role functioning (33). In the same way, the study in Australia showed that severity and duration of the side effects of treatment on eating and swallowing results a feelings of doubt as to whether their life, and ability to eat, would ever return to normal (12). In addition, study in Brisbane, Australia reflected that the physical changes in swallowing also impacted on participants ’ self-image, and no longer eating due to changing eating habits (34).

Furthermore, study in Sweden stated that type food choices & texture is more difficult to eat outside the family, in addition coughing, unclean mouth after the meal, take a long time to eat and eating in socially unaccepted way results feeling left out or shame in respondents (14).

The study in Sweden stated that meal is viewed as a source of stimulation and security. Not being able to eat and join meals means a loss of togetherness and resulted in feelings of social isolation. Informants felt embarrassed about their changed appearance and ways of eating (35). Similarly, another study showed that loss of variety in food selection , coughing, inability to eat in a socially accepted way were the basis for feeling shame and insecure are a negative impact in QoL (36).

The study in Italy indicated that patients with dysphagia undergone reduce of food intake, extended mealtime, and restriction in intake of favorite food or drinks. This indirectly forces them to alter their perceptions towards food and change in appreciation of food, which in turn affecting their social functioning with undergoing emotional changes (37). Disruption of eating is a physical challenges of chewing and swallowing, which is one of the factors affecting weight loss, desire and enjoyment of food over course of treatment all which cause significant impacts on day to day living and quality of life (38).

2.2. Factors Associated with Swallowing Related Quality of Life in Head and Neck Cancer Survivors

The study in brazil, on association between trismus and dysphagia related QoL in survivors of HANC, showed that the worst score of MDADI domain in physical (60.28± 19.00), global (66.63 ±27.01), functional (71.16±17.30), and emotional (73.23 ±17.90) scales (39).

The study in USA, on swallowing related QoL after HANC treatment showed that the mean score of all subject were 67 (±29) for global, 70 (±18) for emotional, 74 (±20) for functional, and 60 (±17) in the physical scale (40). The study in Taiwan the mean global, emotional, functional, and physical dysphagia-related QOL scores were 3.25 (SD = 1.10), 16.89 (SD = 2.63, 17.42 (SD = 3.03), and 16.01 (SD = 3.65), respectively and 7.3% of patients were classified as having impaired swallowing related QoL (41).

2.2.1. Patient Related Factors

The study in Malaysia showed that significant gender differences on women were more emotionally distressed compared to men. The common characteristics are frustration, embarrassment, depression, and contentment due to the inability to enjoy mealtime (42). Similarly, one study identify a positive association between benefit finding and being married/ cohabitating or living alone (43). In contrast, another stated that being female and living with others are statically significant factor for social well-being (44). The study in oral cancer patients showed that higher level of dysphagia associated with surgery and micro vascular reconstruction, older age, male sex, and postoperative radiotherapy (45).

A mixed-methods study on eating experience in long-term survivors of head and neck cancer the positive ratings of QOL and current health status may have been influenced by the support from spouses as 70 % of study participants were married (11).

The study on Employment & return to work following chemo radiation showed that 17% of participants were not satisfied with their current ability to work, which was associated with poorer health-related quality of life & persistent treatment toxicities (46). Similarly The study in brazil, showed that combined treatment was associated with worse QOL scores than single-modality treatment in both the oral cavity/oropharynx and larynx/hypo pharynx groups (47)

2.2.2. Tumor and Treatment Related Factors

Studies in USA, showed that cancer site, & chemotherapy were predictors of decreased QoL. Patients with oropharynx or hypo pharynx and oral cavity or other cancers had worse scores on the health related QOL eating scale compared with patients with cancers of the larynx (30).

A study indicated that the size of initial primary HAN tumor was significantly associated with global assessment of swallowing related QoL & with remaining for all subscales. Patients with primary tumor of the oral cavity and oropharynx had significantly greater swallowing disability that caused an adverse impact on their QoL (21). Conversely, Analysis by tumor size revealed that oropharyngeal cancer patients demonstrated significantly worse functional oral intake compared to laryngeal patients across all time points (48).

Nutrition impact symptoms and associated outcome in post chemotherapy HANC survivors showed that factors highly associated with deteriorated swallowing function after chemotherapy included tumor size, less problem in larynx/ hypo pharynx compared to oral/ oropharynx on the total swallowing related QoL (49).

Oral cavity cancer is one of the most common types of cancer, oral cavity cancer combined with lip, naso pharynx, and pharynx involvement is the 7th most common cancer in the world (50). Similarly, another study stated that oropharynx is the most commonly affected site (70.0%), followed by the larynx (16.7%) (51).

The study on advanced oropharyngeal carcinoma treated with surgery and radiotherapy oncology outcome and functional assessment showed that the lack of association between

tumor T stage T1 & T2 vs T3 &T4 and dysphagia (52). In contrast, the study on dysphagia in HANC patients revealed that independent factor for sever acute dysphagia were T3 & T4 (53).

The study on oral cavity cancer showed that functional and physical dysphagia QOL are greatest at T0, decreased from T1 to T2, and slightly decreased at T3 and T4 (54). Similarly the study on pretreatment swallowing function in patients with head and neck cancer showed that swallow function worsened significantly with increased tumor stage, and patients with oral or pharyngeal lesions had worse swallow function than patients with laryngeal lesions (55). Advanced tumor stage had poorer global domain ($p=0.019$), physical ($p=0.018$), total MDADI ($p=0.006$) (39).

The finding of this study concluded that concurrent chemo radiotherapy the treatment choose for stage 3&4 oropharyngeal carcinoma (40). The study on swallowing-related QoL showed that patients who received chemo radiation for oropharyngeal primaries have significantly better scores on the emotional ($P < .03$) and functional ($P < .02$) subscales than patients underwent surgery followed by radiation. (56). Another study show that Radiotherapy has a negative effects on global (64.21) and physical (61.53) domains MDADI of QOL by lower swallowing functionality (57). The study in Italy on companied modality treatments significantly increase late toxicity, dysphagia (58)

2.3. Conceptual Framework

The conceptual frame work hypothesized that the presence of some personal variables, tumor in head and neck region and it is treatments are directly related with outcome variable, which is swallowing related quality of life.

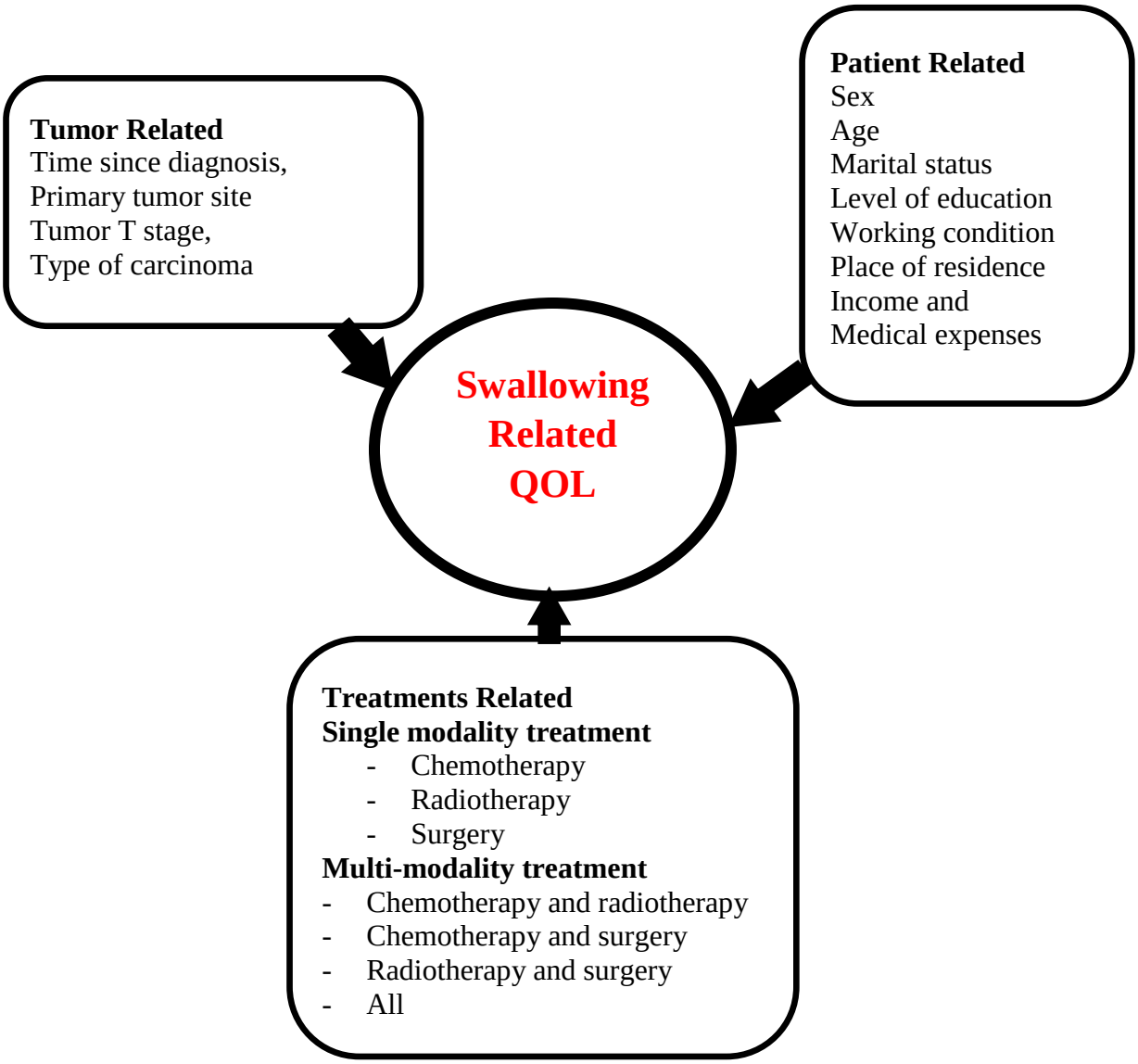

Figure 1: Conceptual frame work of factors that affect swallowing related quality of life, at Tikur Anbessa Specialized Hospital, Addis Ababa, 2019 G.C.

(*source: conceptual frame work partially adopted from revee,2016*) (44).

3. OBJECTIVE

3.1. General Objectives

To assess factors affecting impaired swallowing related quality of life and its impacts in head and neck cancer survivors at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia: 2019 G.C.

3.2. Specific Objectives

To determine swallowing related quality of life in head and neck cancer survivor at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia: 2019 G.C.

To identify associated factors to swallowing related quality of life in head and neck cancer survivor at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia: 2019 G.C.

To describe the impact of swallowing related quality of life in head and neck cancer survivors at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia: 2019 G.C.

4. METHODS

4.1. Study Area and Period

The study was conducted from March to April 2019 G.C at the oncology center, Tikur Anbessa Specialized Referral Hospital, Addis Ababa, Ethiopia. Addis Ababa is the capital city of Ethiopia with a population of 3,475,952 according to the 2007 population census with annual growth rate of 2.7%. Addis Ababa has 13 public, 28 NGO/ private hospitals, 29 health centers, 122 health stations, 37 health posts and 382 modern private clinics (59).

Tikur Anbessa Specialized Referral Hospital is a governmental teaching hospital, located at Kirkos sub-city under the administration of Addis Ababa University, College of Health sciences. The hospital has been inaugurated by the title “Prince Mokonnen the Duke of Harar” Memorial Hospital on 3/11/1973 and combined with the “Princess Tesha” memorial Hospital on 24/5/1975 by the name of Tikur Anbessa Hospital.

The oncology center at the hospital is the only referral center from all corners of the country especially for cancer patients. The hospital has 600 beds of which 18 are allocated to cancer treatment. Of the 201 physicians at the hospital, only two are hematologists, four are medical oncologists, four are radiotherapists, two are surgical oncologists, and one is a pediatric oncologist. Three palliative pain specialists moreover work on the hospital. Only 26 of the Tikur Anbessa 627 nurses are dedicated oncology nurses.

In 2010, more than 260 000 patients were treated at Tikur Anbessa Specialized Referral Hospital, including more than 2000 adults and more than 200 children with cancer. Treatments offered at cancer center of this Hospital is anticancer drugs, surgery, and radiotherapy. The hospital is the only oncology center in the nation providing radiation therapy during the study period (60).

4.2. Study Design

A mixed method approach was carried out, which was simultaneous triangulation, both qualitative and quantitative study design. For quantitative, an institutional based cross sectional study design was used to assess the factors that affects impaired swallowing on quality of life of head and neck cancer survivors. For qualitative, phenomenological study design was used to explore the experiences of impaired swallowing and it is consequences in their life in head and neck cancer survivors.

4.3. Population of Study

4.3.1. Source Population

All adult head and neck cancer patients under treatment at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

4.3.2. Study Population

All adult head and neck cancer patients under treatment presented during study period.

4.3.3. Study Subject

All adult head and neck cancer patients presented during study period, who fulfil the eligibility criteria.

4.4. Eligibility Criteria

4.4.1. Inclusion Criteria

Pathologically proven head and neck cancer

Patients under treatment

4.4.2. Exclusion Criteria

Patients with gross psychopathology and critically ill during data collection time.

Patient with dysphagia other than head and neck cancer.

4.5. Sample Size Determination and Sampling Technique

4.5.1. For quantitative

The study was used a single population proportion formula to calculate sample size n = $\frac{(Z\,\alpha/2)2\ P\ (1-P)}{d2}$, since research has not been in our country, P = estimated proportion of head and neck survivors (50%), the margin of sampling error tolerated (5%) and Z α/2 = the standard normal variable at (1−α) confidence level (5%=1.96). n= $\frac{(1.96)2\ 0.5(1-0.5)}{(0.05)2}$=384. But, the total population (N) was less than 10,000. A correction formula was used to calculate the final sample size (N_F). Thus, $\mathbf{N_F = \frac{n}{1+\frac{n}{N}}}$ = 99 participant. By adding 10% contingency, the total sample size was 109. However, the estimated number of head and neck cancer patients for months from hospital appointment registry book was 105. So no need of applying any type of sampling technique here because the calculated sampling size and estimated were almost the same, as a result this study was use all population who fulfil eligibility criteria.

Census based cross sectional study was used to address all study population presented at study period and time for quantitative study.

4.5.2. For qualitative

Non-probability purposive sampling technique was used to select the study participants to obtain adequate information.

4.6. Study Variables

4.6.1. Dependent Variables

Swallowing related quality of life.

4.6.2. Independent Variables

Demographic variables: - Sex, age, marital status, level of education, working condition, place of resident, income, and medical expenses.

Cancer related variable: -Time since diagnosis, primary tumor site, tumor T stage, and type of carcinoma.

HANC treatments modality: -

- ✓ Single: - Surgery, radiation, and chemotherapy
- ✓ Combined: -
  - Chemotherapy and radiotherapy
  - Chemotherapy and surgery
  - Radiotherapy and surgery
  - All

4.7. Operational definition

The mean score for total MDADI and it is subscale was calculated. In then, the mean score multiplied by 20 to obtain a score with a range of 20 (Extremely low functioning/ impaired swallowing related QoL) to 100 (High functioning/ unimpaired swallowing related QoL). Thus, a higher score represents better swallowing related QoL (21).

4.8. Data Collection Tool and Technique

4.8.1. For Quantitative

The quantitative data was collected through an interview and chart review techniques by using structured Amharic questioner, which was primarily prepared in English then translated in to Amharic by fluent speaker of both languages.

The data collection process was facilitated by BSc nurses, who work at oncology unit at Tikur Anbessa Specialized Referral Hospital. Patients who fulfilled the criteria were interviewed individually in a private meeting room, after explaining the purpose of the study and obtaining an informed consent. The MDADI took less than 10 minutes to complete. Supervisors, who had a MSc in oncology, cross checked the way of data collection, and completeness of the questionnaire.

The MDADI was the first validated and reliable, a 20-item questionnaire specifically for head and neck cancer patients (21). It encompasses four QOL domains: global, emotional, functional, and physical. The global subscale consists of a single question to evaluate how the individuals swallowing impairment affects overall daily routines.

The emotional subscale consists of six questions that assess the degree to which the individual affective responses to the swallowing impairments. The functional subscale includes five questions designed to measure the individual swallowing impairments on daily activities. The eight questions of the physical subscale represent self-perception of swallowing impairments. Each item is scored on a 5 point Likert scale (strongly agree (1), agree (2), no opinion (3), disagree (4), and strongly disagree (5)). Except one item on the emotional subscale (I do not feel self-conscious when I eat) and another on functional subscale (I feel free to go out to eat with my friends, neighbors, and relatives) were scored as 5 points for strongly agree and 1 point for strongly disagree. The first question (global subscale) was scored individually. All other questions regarding each aspect (emotional, functional, physical) of swallowing related QoL were summed.

4.8.2. For Qualitative

The qualitative data collection was done by using a semi structured Amharic interview guide question, which was primarily prepared in English by principal investigator based on previous studies in then translated in to Amharic by fluent speaker of both languages. The participants were purposively selected to share their experience and thoughts related to the phenomena. The interview took place in quite private office in the cancer center at Tikur Anbessa specialized referral hospital. The interview was facilitated by principal investigator, and the mean average time took for interview was 34 minutes. The interviewer took a SONY tape record and field note. All documents were kept properly, and the computer version of the data was also protected by password, which was accessed only by researcher.

4.9. Data Processing and Analysis

4.9.1. For Quantitative

The pre coded data was entered in to EpiData version 4.4.3.1 then exported to SPSS version 24 for further cleaning, and analysis. For statistical purposes, age was dichotomized by mean; marital status, working condition, type of a treatment was dichotomized based on previous studies; tumor stage was dichotomized initial (T1 & T2) and advanced (T3 & T4) using the AJCC staging system 7th edition (61); primary tumor site was grouped in to three based on literatures. Normality testing was carried out for the dependent continuous variables.

Descriptive statistics (frequency distribution, percentage, means, and standard deviations) were used to analyze demographic, and clinical characteristics of participants. The MD Anderson Dysphagia Inventory each item score was transformed in then the total and subscale scores were calculated. Mean comparison analysis, Between-group differences for binary variables were compared using the independent t-test. Between group differences more than two levels variables were evaluated using one-way ANOVA and Post Hoc multiple comparisons. Multiple linear regressions were used to identify factors associated with impaired swallowing related quality of life (total MDADI was a dependent variable). Statistical significance was considered p less than 0.05.

4.9.2. For Qualitative

Prior to analysis, the audio-tapes recordings and field notes of individual interviews were transcribed by the interviewer to obtain the hole senses. In then translated from Amharic to English verbatim by fluent speaker of both languages. It was entered into, and saved as Microsoft Word files by the researcher. Then, analysis was conducted using thematic content analysis techniques. The qualitative data was analyzed manually using codes. The codes were merged into categories and the themes were determined based on grouping of similar categories by using Colaizzi's method six steps of phenomenological analysis. (62).

1. Each informant’s verbatim transcript read to acquire a sense of the whole.
2. Significant statements pertinent to the experiences of the phenomenon studied was extracted from each interview.
3. Meanings was formulated from the significant statements.
4. The formulated meanings were organized into subthemes, themes and then into main themes, when appropriate.
5. A comparison was made between transcripts, subthemes, themes and main themes in order to validate the findings.
6. Description of subthemes, themes and main themes was supported by quotations to further validate the findings.

The analysis was a process by moving back and forth between the parts and the whole of the interviews and between significant statements, subthemes, themes and main using thematic analysis surface.

4.10. Data Quality Assurance

4.10.1. For Quantitative

To ensure the quality of data several approaches were employed such as both qualitative and quantitative approach, which were cross sectional and in depth interview to address the objective of the study and to draw the optimum findings.

The data collection tools were translated in to local languages for better understandings of concepts. In addition, the training was provided for data collectors and supervisors on the purpose of study and procedures of data collection.

After completing the training, the pretest was conducted in 10 head and neck cancer patients who were eligible at the same study area, TASH, before one week of actual data collection time to assess the clarity and applicability of the tools concerning appropriateness or formats of wording questions and a time taken for interview. The data collection process was strictly supervised for it is completeness accuracy, consistency of data and the data were screened for missing values.

To verify the reliability of the questionnaires Cronbach's alpha (α) was calculated based on the recommendation of $\alpha > 0.70$. The overall MDADI questionnaire Cronbach α coefficient was 0.924, which was exceeds the minimum acceptable value and suggests that each item of the MDADI addresses the same concept. The subscale also had reliable (emotional,0.79; functional,0.71; physical,0.89)

4.10.2. For Qualitative

The trustworthiness of a qualitative study is determined by the extent to which it is transferable, confirmable, credible and dependable (63). The researcher was adhering to this principle for the purpose of the study, as stated beneath.

Transferability refers to "the extent to which the findings can be transferred to other settings or groups" (64). In qualitative study the intention is not generalized the findings (65). This study was used the qualitative data for to triangulate or validate results from quantitative study.

Credibility refers to the extent to which data analysis are believable, trustworthy or authentic (65). According to Yilmaz (2013), credibility means that the study participants find the results of the study true or credible (66). To ensure the Credibility of the study the interviewer was openly communicate with participants to tell a true or credible information about their experience.

Confirmability refers to the research findings could be confirmed or correlated by other researchers in the field (65). To ensure confirmability of the study description was supported by quotations.

Dependability refers to a criterion for evaluating integrity in qualitative studies namely the stability of data over time and over conditions; analogous to reliability in quantitative research (67). To ensure dependability of the study information about data collection, time, place, and analysis was provided.

4.11. Ethical Consideration

Ethical clearance was obtained from Institutional Review Board (IRB) of Addis Ababa University, college of health sciences school of Nursing and Midwifery. Institutional Review Board (IRB) approval period from Feb. 20, to July 6, 2019 on protocol number: 011/19/SNM. A supportive letter was obtained from cancer center of Tikur Anbessa Specialized Referral Hospital to conduct data collection. Additionally, an informed consent was obtained from each participant after providing sufficient information. Necessary information was given about the right to refuse participation or to jump some questions unwilling to answer. To ensure the confidentiality of respondents their names was not written on the questionnaire.

4.12. Dissemination of Results

The result of this study will be disseminated or communicated to Addis Ababa University, College of Health Science, School of Nursing and Midwifery, cancer centers of TASH, and other concerned bodies through reports and publication on peer reviewed journal.

5. RESULT

The results of this research for cross sectional study was based on 102 participants who successfully completed the interview and 7 survivors were individually interviewed for qualitative phenomenological study.

5.1. Quantitative Study Result

5.1.1. Socio Demographic Characteristics of Participants in Quantitative Study

A total of 102 participants were surveyed, of whom 55 (53.90%) were male. The mean age of respondents was 42.58 ± 14.08 years (Mean ± SD), with a range from 18 to 76 years. More than half 59 (57.80 %) of the respondents were currently not married or live alone. In regards to participant's education, 34 (33.30%) of the respondents didn't attended formal education while the rest 68 (66.60 %) had completed some level of formal education. Only 26 (25.50%) of population attended higher education.

By occupation, thirty (29.40%) of respondents were unemployed like house wife or student. Most of the participants were, from rural area, and only 26 (25.50%) were from the capital city, Addis Ababa. An average monthly income for 61(59.80%) of the participants were more than 500 ETB (Ethiopian Birr). Seventy-one (69.60%) of respondent had free from medical expenses. (Table. 2)

Table 1 Socio Demographic Characteristics of Participants in Quantitative Study at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

Variable		Frequency	Percent%
Sex	Male	55	53.90
	Female	47	46.10
Age	18 to 43 years	56	54.90
	Above 43 years	46	45.10
	Mean ± SD => 42.58±14.075		
Marital Status	Living alone	59	57.80
	Living with partner	43	42.20
Level of Education	No formal education	34	33.30
	Primary school	24	23.50
	Secondary school	18	17.60
	Above secondary	26	25.50
Working Condition	Employed	72	70.60
	Unemployed	30	29.40
Place of Resident	Addis Ababa	26	25.50
	Regional/Rural	76	74.50
Income	≤500 ETB/month	41	40.20
	500-10000ETB/month	15	14.70
	1100-2000ETB/month	18	17.60
	≥2000ETB/month	28	27.50
Medical Expenses	Fee Paying	31	30.40
	Free	71	69.60

5.1.2. Clinical Characteristics of Participants in Quantitative Study

The most prevalent primary tumor site was nasal cavity/ nasopharyngeal carcinoma 41(40.20%). Majority 61(59.80%) of subjects had advanced stage T3 &T4. (Figure 2).

The most common types of carcinoma were squamous cell carcinoma 64(62.70%). Fifty-seven 55.90% of participants received multi-modality treatment, the remaining 43 (44.10%) took single modality treatment, which was chemotherapy, radiotherapy, or surgery alone at a mean time of data collection. (Figure 3).

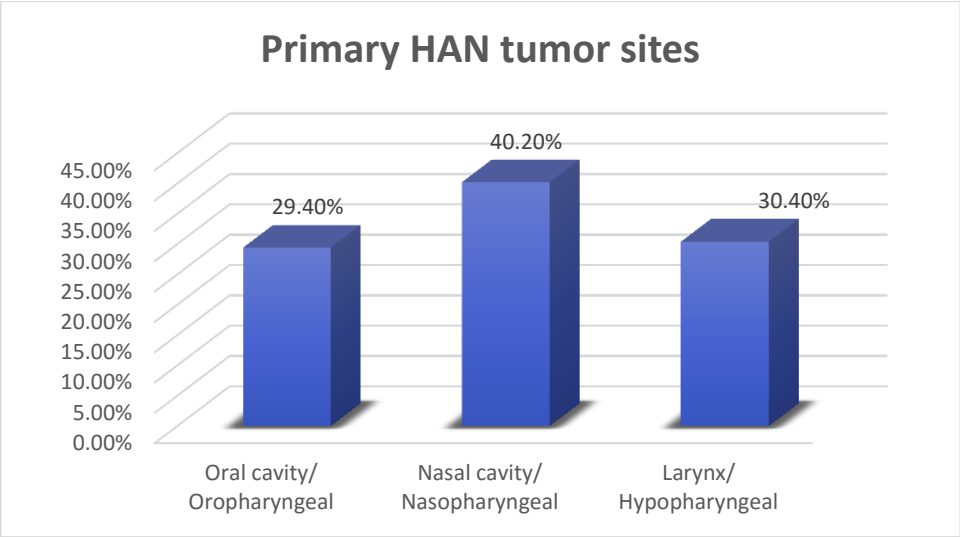

Figure 2 Primary Tumor Sites of Head and Neck Cancer Survivors at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

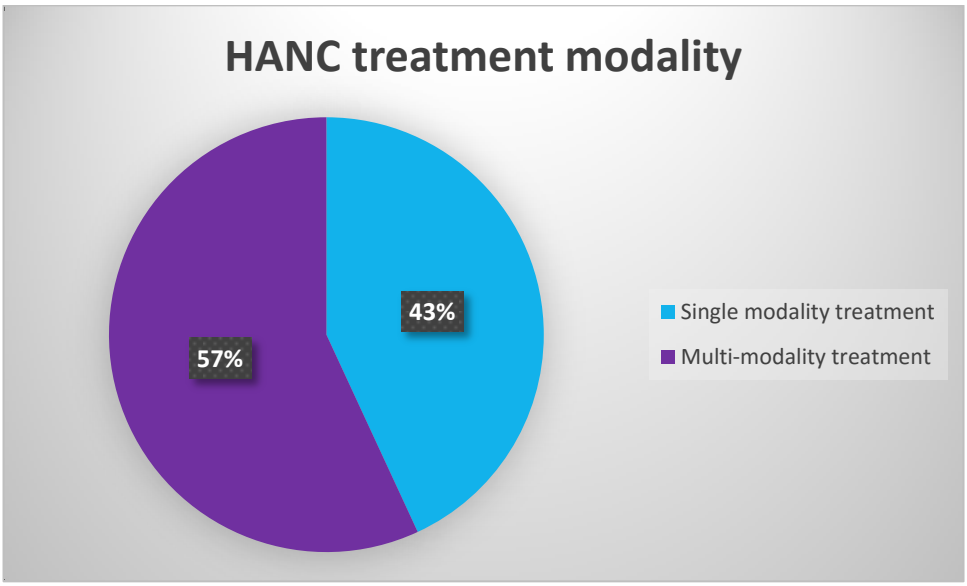

Figure 3 Treatment Modality of Head and Neck Cancer Survivors at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

5.1.3. Swallowing Related Quality of Life of Participants

The mean of MDADI score was (53.34 ± 16.96), the mean of MDADI domain in global score was (44.51± 23.0), physical score was (49.44 ± 19.26), emotional scale was (56.63± 17.44) and functional scale was 57.69 (SD=17.53). (Table 3).

Table 2 Mean and Standard Deviation of MD Andersen Dysphagia Inventory for Head and Neck Cancer Patients at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

	Items no. analyzed together	Mean	Std. Deviation
MDADI total score	1-20	53.34	16.96
Global subscale	1	44.51	23.0
Emotional subscale	E2, E3, E4, E5, E6,E7	56.63	17.44
Functional subscale	F1,F2,F3,F4,F5	57.69	17.53
Physical subscale	P1,P2,P3,P4,P5,P6,P7,P8	49.44	19.26

5.1.4. Mean Differences Between Socio Demographic and Clinical Variable with MDADI subscale

Female head and neck cancer survivors had significantly lower score compared to those who were male in total MDADI (p=0.020), global (p=0.005) and physical (p=0.004) scales.

Marital status, which was living alone were higher mean score value compared with living with spouse or partner at global scale (p=0.003). Unemployed participants had significantly lower score compared to those employed in global (p=0.003) and physical (p=0.039). Except emotional and functional scale, paying their medical expenses or charges were significantly higher mean value than patients who were free of charges in MDADI (p= 0.006), global (p= 0.011), and physical (p=0.000). (Table 4).

Participants with oral cavity/ oropharyngeal primary tumor were a significant mean difference with larynx/ hypo pharyngeal primary, in post hoc tests analysis at MDADI (p=0.048) and physical (p=0.042). Initial tumor T stage were significantly higher mean score than advanced T stage in global scale (p=0.011). Except in emotional and functional scale patients took multi-modality treatment a significant mean difference over single modality treatment in MDADI (0.009), global (p=0.033), and physical (p=0.009). (Table 5).

Table 3 The Mean Differences of MDADI Subscales according to Socio Demographic Characteristics of Participants at TASH, Addis Ababa, Ethiopia, 2019 G.C.

Variable	MDADI (Mean±SD)				
	Total	Global	Emotional	Functional	Physical
Sex					
Male	56.3±18.5	47.6±25.1	58.7±18.9	61.2±17.6	52.6±21.3
Female	49.8±14.4	40.8±19.9	54.3±15.3	53.6±16.8	45.7±15.9
P	0.020*	0.005*	0.135	0.705	0.004*
Age					
18 to 43 years	50.7±16.0	41.8±22.6	53.7±17.1	55.3±17.7	47.1±17.8
Above 43 years	56.5±17.7	47.8±23.3	60.2±17.3	60.5±17.0	52.3±20.7
P	0.315	0.311	0.927	0.721	0.177
Marital status					
Living alone	55.4±16.8	47.8±24.4	58.9±17.3	59.3±16.8	51.5±19.1
Living with partner	50.4±16.9	40.0±20.5	53.6±17.4	55.5±18.5	46.6±19.4
P	0.776	0.003*	0.549	0.439	0.816
Level of education					
No formal Education	52.7±14.7	44.7±20.3	55.2±15.6	56.0±15.0	49.8±16.8
Primary	50.6±14.8	39.2±20.8	53.9±15.8	53.2±17.0	48.0±16.5
Secondary	54.1±22.5	50.0±28.5	57.2±21.5	60.7±20.1	48.1±25.7
Above secondary	56.2±17.8	45.4±24.4	60.6±18.3	62.0±18.8	51.3±20.5
P	0.705	0.508	0.534	0.263	0.929
Working condition					
Employed	54.8±17.6	46.9±24.5	58.0±17.9	59.3±17.6	50.8±20.4
Unemployed	49.9±14.9	38.7±18.1	53.3±15.9	53.9±17.1	46.3±16.1
P	0.117	0.003*	0.192	0.643	0.039*
Place of resident					
Addis Ababa	48.8±17.1	39.2±22.9	52.9±17.5	55.1±19.1	43.8±20.3
Regional /rural	54.9±16.7	46.3±22.9	57.9±17.4	58.6±17.0	51.4±18.6
P	0.551	0.341	0.748	0.759	0.928
Income in ETB/ month					
≤500 ETB/month	51.9±15.9	43.9±21.5	55.0±17.2	54.9±16.5	48.7±17.8
500-1000 ETB/month	53.7±14.9	45.3±23.3	55.3±15.2	57.1±16.1	51.3±16.1
1000-2000 ETB/month	48.8±16.5	38.9±21.1	53.1±16.4	56.2±15.9	42.2±19.8
≥2000ETB/month	58.2±19.3	48.6±26.3	61.9±19.1	63.0±20.2	54.2±21.9
P	0.281	0.580	0.298	0.295	0.218
Medical expenses					
Fee paying	60.7 ±19.7	50.9±25.7	64.3±17.9	65.7±19.3	56.8±24.2
Free	50.1±14.6	41.7±21.3	53.3±16.2	54.2±15.6	46.2±15.8
P	0.006*	0.011*	0.450	0.080	0.000**

t test (for two groups comparison) and one-way ANOVA (for three and above group comparison) were employed, * significant at *p*- value less than 0.05.

Table 4 The Mean Differences of MDADI Subscales according to Clinical and Treatment Variables of Participants at TASH, Addis Ababa, Ethiopia, 2019 G.C.

Variable	MDADI (Mean±SD)				
	Total	Global	Emotional	Functional	Physical
Time since diagnosis					
≤ 6 month	52.1±17.1	44.6±24.3	55.9±16.9	56.5±17.9	47.4±19.0
6 to 12 months	52.9±17.4	46.7±24.4	54.4±18.9	55.8±17.2	50.7±18.9
More than year ago	55.3±16.6	41.9±20.2	60.1±16.2	61.3±17.4	50.2±20.3
P	0.729	0.707	0.389	0.389	0.749
Primary tumor site					
Oral cavity/ Oropharyngeal	57.4±20.8	52.0±28.1	59.3±20.9	60.7±20.5	54.5±22.8
Nasal cavity/ Nasopharyngeal	55.0±16.4	43.9±21.1	59.0±16.4	59.9±16.9	50.8±19.8
Larynx/ Hypopharyngeal	47.2±11.5	38.1±18.2	50.9±13.8	51.9±14.1	42.7±12.2
P	0.044*	0.058	0.086	0.084	0.045*
Tumor T stage					
Initial (Tx/T1 & T2)	57.5±18.2	50.7±24.9	60.5±18.4	61.8±16.8	53.4±20.8
Advanced (T3 & T4)	50.6±15.6	40.3±20.8	54.0±16.4	54.9±17.6	46.8±17.9
P	0.140	0.011*	0.258	0.765	0.068
Type of carcinoma					
Squamous cell	53.0±16.6	44.4±22.1	56.0±17.8	57.2±17.2	49.5±18.8
Adenocarcinoma	55.6±19.5	48.7±25.5	58.3±18.9	60.2±20.2	51.5±22.0
Other	51.3±15.1	38.7±23.3	56.7±13.9	56.0±15.0	45.8±17.2
P	0.730	0.425	0.874	0.725	0.676
Treatment modality					
Single modality Treatment	50.5±14.7	40.9±20.7	55.4±15.9	55.7±16.9	45.2±16.7
Multi-modality treatment	55.5±18.3	47.2±24.5	57.5±18.6	59.2±17.9	52.6±20.6
P	0.009*	0.033*	0.140	0.339	0.009*

t test (for two groups comparison) and one-way ANOVA (for three and above group comparison) were employed, * significant at *p*- value less than 0.05.

5.1.5. Association of Variables and Swallowing Related Quality of Life of Participants

In addition, the multiple regressions were used to assess the effect of a number of factors to predict a swallowing related quality of life. R square value indicated that 13.4% of the variance in the dependent variable is explained by the model. After the variance explained by all other variables in the model were controlled, the respondents, those paying their medical expenses made the strongest unique contribution to explain the swallowing related quality of life score recording a standardized beta value of 0.294. as shown in the table 5; The patient with oral cavity/ oropharyngeal cancer and paying medical expenses were making a significant unique contribution to the prediction of the swallowing related quality of life.

Table 5 The Factors Influencing Swallowing Related Quality of Life of Head and Neck Cancer at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

Variable	Beta squared	P value	95% CI		Collinearity statistics	
			Lower	Upper	Tolerance	VIF
Sex	0.160	0.093	-0.922	11.73	0.969	1.032
Medical expenses	0.294	0.002	3.939	17.64	0.970	1.031
Oral cavity/ oropharyngeal	0.268	0.021	1.536	18.30	0.660	1.516
Nasal cavity/ nasopharyngeal	0.207	0.064	-0.422	14.65	0.705	1.418
Treatment modality	-0.020	0.840	-7.348	5.989	0.882	1.133

CI-Confidence Interval, VIF Variance Inflation Factor

5.2. Qualitative Study Result

5.2.1. Sociodemographic and Clinical Characteristics of Participants in Qualitative Study

Seven participants were individually interviewed, of whom 5 (71.4%) were male. The mean age of respondents was 41.14 ± 10.46 years. More than half 4 (57.1 %) of the respondents were currently married or live with partner, free from medical expenses, nasopharyngeal carcinoma, and an advanced T stage. In regards to participant's education, 2 (28.6%) of the respondents didn't attended formal education. By occupation, 3 (42.9%) of respondents were unemployed like house wife or student. Five (71.4 %) of respondent had. (Table. 6)

Table 6 Socio Demographic Characteristics of Participants in Qualitative Study at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

Variable		Frequency	Percentage %
Sex	Male	5	71.4
	Female	2	28.6
Age	Mean ± SD => 41.14 ± 10.46		
Marital status	Living alone	3	42.9
	Living with partner	4	57.1
Level of education	No formal education	2	28.6
	Secondary education	2	28.6
	Above secondary education	3	42.9
Working condition	Employed	4	57.1
	Unemployed	3	42.9
Place of resident	Addis Ababa	3	42.9
	Regional/ Rural	4	57.1
Income	≤ 500 ETB/ month	2	28.6
	500-1000 ETB/month	1	14.3
	1000-2000 ETB/month	1	14.3
	≥ 2000 ETB/ month	3	42.9
Medical Expenses	Fee paying	2	28.6
	Fee	5	71.4
Time since diagnosis	Less than 6 months	1	14.3
	6-12 months	2	28.6
	More than a year ago	4	57.1
Primary tumor site	Nasopharyngeal	4	57.1
	Oral cavity	3	42.9
Tumor T stage	T1 and T2	3	42.9
	T3 and T4	4	57.1
Treatment modality	Chemotherapy	1	14.3
	Chemotherapy and Radiotherapy	3	42.9
	Radiation and Surgery	1	14.3
	All	2	28.6

5.2.2. The Impact of Impaired Swallowing Related Quality of Life of Participants

Four themes were identified from participants in depth interview. Theme I dales about Daily activity impairment, which were subcategorized in to self-imposed isolation, hopelessness, and dependency. Theme II reviews about Emotional impairment, which was categorized in to distress by present or future conditions and felt embarrassed at a meal time. Theme III discussed about Functional impairment, which were categorized into social handicapped, difficulty to cook meal and financial impact. Theme IV focuses about physical impairments, which were categorized in to food stuck in throat, limit food intake, longer time and trouble to maintain a weight.

Table 7. The Impact of Impaired Swallowing Related Quality of Life among Head and Neck Cancer Patients by Theme, Sub Themes, and Codes, at TASRH, Addis Ababa, Ethiopia, 2019 G.C.

Theme	Sub Themes	Code	IDI no. , page No.
Theme I: Daily activity impairment	Self-imposed isolation	Not attended at work, Absences from education	IDI3, P8; IDI5, P14;
	Hopelessness	lose interests, feel downhearted	IDI6, P18; IDI4,P11;IDI2,P5
	Dependency	life is dependent	IDI7,P20
Theme II: Emotional impairment	Distressed by present or future conditions	Upset, worried, uncertainty	IDI1, P2; IDI5, P1; IDI6, P17;IDI7, P21
	Felt embarrassed at a meal time	Self-conscious, dissatisfaction	IDI2,P5;IDI 4, P 12; IDI6, P17;IDI7,P21
Theme III: Functional impairment	Social handicapped	No longer ate males together, avoid invitation, incapable to present in social occasions	IDI2, P6; IDI3, P9; IDI4, P12;IDI5, P15;IDI6, P18;
	Financial impact	No money, loss money	IDI1,P1,P3;IDI2,P5;IDI4,P14
Theme IV: Physical impairment	Food stuck in throat	struggle/ efforts to swallow,	IDI1, P2; IDI2, P5; IDI3, P8; IDI5, P14; IDI16,P16
	Limit food intake	In amount, Avoid some foods	IDI2,P6; IDI 4,P 10; IDI5, P14;
	Diet modification	Change texture, consistency, difficult to prepare, order	IDI2,P6; DI3,P9; IDI4,P12; IDI 5,P13;IDI6,P18;IDI7,P20
	Longer time	Slow manner eating, tried to chew	IDI 4, P12;IDI6,P16
	Trouble to maintain a weight	Weight loss, little food	IDI2,P6;IDI3,P9; IDI5, P15

5.2.2.1. Theme I: Daily Activity Impairment

Patients with a head and neck cancer faces a swallowing related daily challenge that can impair their quality of life. Swallowing related daily impairments were categorized into: Self-imposed isolation, hopelessness, and dependency.

Self-imposed isolation: - Participants reported that illness disrupt the day to day life in different way, male participants who was employed earlier feel afraid and irritated to stay at home due to illness, and a lack of contact with their companion, male participant 3 and 5 described that they withdraw from work and continuing education respectively.

> "I was a government worker but I could not attend the Ministry of Agriculture right now. When I think this, I feel stressed." Participant 3.
>
> "My illness marked imposition in my life not to continue my education. So I remained at home. My parents tried willingly to treat me but I was very ill and unable to minimized their burden." Participant 5.

Hopelessness: - Most survivors thought that, they worried and fear about what will happen in their life. That cause to lose interests in life, feel downhearted, beside this issue survivor lose hope or plan to do something as expressed by participants:

> "I planned a lot of things to achieve and even I hope to function. Something good. However, I could not do anything in case of my illness" Participant 6.
>
> "I almost pray to god why I became such creature at such level of my life. Even I tried to neglect God as He had no equal power to treat his people." Participant 4.
>
> "I was once a free man but now I feel a lot" Participant 2.

Dependency: - Participants reported that, life is dependent on water. Nevertheless, some institutions prohibited or restricted some items including all bottled drinks. On that situation the patients troubled to getting public services as like as other people. Participant 7 who took a multi-modality treatment for oral cavity cancer expressed that:

> "In my case, I really encountered a serious happening in my mouth as I could not talk and swallow anything to some extent without water. However, it was not permitted to have a bottle of water at hand in bank, in police, and in train station. Even I tried to convince them, somehow people could not understand, Water was part of my soul which elongated my life, that why my daily life dependent on water" Participant. 7

5.2.2.2. Theme II: Physical Impairment

Patients with head and neck cancer had their own perception of swallowing impairments that affects QoL. Swallowing related physical impairments were categorized into: food stuck in throat, limit the food intake, diet modification, longer time to eat, and trouble to maintain a weight.

Food stuck in throat: - Participants expressed that sensation of food trapped or pain when foods pass through throats. They struggle to slip foods down. They could not eat as normal as they eat before illness. Survivors described:

> "I cannot eat just as well as I can eat, and just like any other person. If I do, food will not get down from my throat." Participant 1.
>
> "I make a lot of effort to slip foods over my throat" Participant 2.
>
> "I cannot swallow anything even my saliva" Participant 3.
>
> "When I tried to swallow food my throat was not normal to allow it inside. In the mean time I encountered vomiting. So I simply ate to keep myself alive." participant. 5
>
> "I struggled a lot to swallow the food due to my illness." Participant 6.

Limit the food intake: -Most survivors spoke to overcome swallowing difficulties; they took a mechanism of limiting or avoiding some foods that might aggravate the illness or favorite foods.

> "I loved pepper, but now, I haven't eaten a pepper, it was very aggressive for my illness… I ate very small soft foods just like a baby boy, that's why I'm losing my energy." Participant 2.
>
> Before I prefer to eat dry things like that of kollo/ kitta and sometimes cookies, but after a while I stopped and isolated myself from eating what I wanted." Participant 4.
>
> "My uncle was a butcher; I sometimes ate raw meat weekly as I liked it very much. But now a day I was in trouble to chew and swallow the prepared meat…. When I ate peppers wot it strikes my sore throat and created illness." Participant 5.

Diet modification: - Changing the texture and consistency of food was the common practice to improve their swallowing ability and to minimize difficulties of swallowing. The condition coercion to eat less variety food, that cause less interests to eat:

"After three months my nose was affected I was unable to open my mouth in order to feed myself. I tried a bit injera to eat it by making soft with the help of wot without pepper and some fluid which carried food substances." Participant 5.

"As I felt, I needed variety of food to eat. I understood that such interest was fulfilled if somebody was in a healthy condition." Participant 6.

Preparing a modified suitable food is not easy it requires intentional focuses because cooking a meal more time consuming, participants who were married reported that wife plays a crucial important role in food preparation:

"My wife was stressed to prepare meals for me because she knows my problem." Participant 3.

"My wife guided me how to feed myself." Participant 7.

Ordering people to prepare meals or finding the kind of food as they want somewhat very difficult. As explained by survivors:

"I want to eat a porridge, because it is easy for me but ordering it to prepare was difficult." Participant 2.

"Some of my neighbors could collect some homemade foods in order to feed me. But I could not eat." Participant 4.

"Those people who were around worried about me and tried to prepare suitable food. Yet, their wornness created disturbance in my mind." Participant 6.

Longer time to eat: -The other strong issue conveyed by patients were taking a long time to finish a food while the meal was a very small. To eat small food, they took a long time unlike other person that condition creates to dislike eating together:

"I took long hours to eat some favorable foods and got me tried to chew and swallow as the illness of my throat become harsh." Participant 4.

"Though I had such trouble, I tried to eat a bit in slow manner." Participant 6.

Trouble to maintain a weight: - Unexplained weight loss very common in cancer patients due to different reason. Conversely, in head and neck cancer patient's food stuck in throat, limit the food intake, diet modification, longer time to eat, and other emotional/ functional problem were a reason to unable to keep the body weight, that causes to shame when being with other:

> "I was 67 kilos but now I'm 59k.g" Participant 2.
>
> "I am eating too much little food, that why am 50 K. g." Participant 3.
>
> "My body weight was decreased up to 43 k.g. I compared myself with my colleagues and considered my existing condition as it was worse." Participant 5.

5.2.2.3. Theme III: Emotional Impairment

Participants affective response towards their swallowing difficulty have an emotional impact in quality of life. No association was found between sociodemographic and clinical variables with emotional scale. (Table 3 & 4). However, swallowing related emotional impairments were categorized into: distressed by present or future conditions and embarrassment at meal time.

Distressed by present or future conditions: - Most survivors could speak they upset by being in this condition, and what will happen in the future due to swallowing problem.

> "when I think such trouble in my life while I indulge in different condition, I relay upset myself" Participant 1.
>
> "When I began to swallow the food, I worried a lot and this made me upset and forced me to lose." Participant 5.
>
> "When some people worried about my condition I upset myself and thus terrified me thoroughly." Participant 6.
>
> "What worried me was that how could I enrolled my life when I become aged or tired." Participant 7.

As described above being in this condition due to illness and eating/ swallowing foods, troubled them to dissatisfied while the eat to stay in life.

> "I am not happy when I think about what I eat." Participant 1.
>
> "I always eat the same food without my will, only to cope my illness" participant 2.

Embarrassment at meal time: - In addition, Survivors stated, feel embarrassed or self-conscious because they bothered themselves on their ways of eating/ swallowing to eat in front of other. Loneliness an option especially during meal time.

> "In the past, I had eaten a meal with my friends, but not now, because they are ridiculing me that you are eating like that, I'm embarrassed" Participant 2.
>
> "When I feed myself I did not wanted to see anyone around me because of chocking and unfair feeding of myself." Participant 4.
>
> "I preferred to eat alone instead of disturbing others due to vomiting." Participant 5.
>
> "I could not eat anything somewhere outside my home." Participant 6.
>
> I stopped eating outside my home even if I was eager to taste something. Participant 7.

5.2.2.4. Theme IV: Functional Impairment

Patients with HANC have a functional challenge or limitation to perform a concrete activity that can impair their quality of life. Functional swallowing related quality of life was categorized; socially handicapped, and financial impact.

Socially handicapped: -Participants were self-conscious about eating in front of others, due coughing and spitting out food. The type of food was also a source of shame. participant's loss childhood friend's get-togethers, holiday, weeding and birthday ceremonies because of the bad experience in different occasions meal time.

> "Holyday was happily spending time with my family. We eat foods together, but now I'm worried about how could I swallow it, so I'm sitting in the room to share their happiness." Participant 2.
>
> "People honored me in wedding, but I prefer to be at home because foods prepared at wedding literal a meat, I cannot chew and swallow it at any form, everyone will eat and drink and be happy and enjoy themselves but not me." Participant 3.
>
> "Once I got to my sister baby birthday and started to eat something. in the meantime, the food created illness and I hardly survived after a short breathing interruption. Thus, I allowed myself to be reserved from such kinds of occasion." Participant 6.
>
> "Before my illness my social participation was high, but now I almost hid myself from social activity." Participant 4.

> "I was alone without getting my childhood friends. My lovely friend asked me to participate his wedding ceremony but I was unable to join his weeding due to my illness." Participant 5.

Financial impact*:* - Survivors talked about conditions expose them to outlay money in finding/ choosing appropriate meal, treatments those payed medical expense, transportation and other. Participants also mention the strong issue during illness they did not able to work so they hadn't money, so financially dependent on other was common. Survivors reported:

> "Now am in residency site, with my teenage daughter, she hasn't money, no one will send me any money" Participant 1.
>
> "My medical debit was covered by my sister, I could not able to paid it by myself." Participant 2.

In addition, participants incur unable to pay the medical expenses, that causes sentiment of shamed on debit, one patient express his financially problem have to death:

> "I was so distressed when I thought about this, I was not able to buy medicine, so I was going to lose myself. You see the scar on my neck, this was a result of susidal attempt" Participant 4.

6. DISCUSSION

This study attempted to measure the impact of impaired swallowing related quality of life among adult head and neck cancer patients at TASRH, Addis Ababa, Ethiopia. The mean score for swallowing related QoL was worst in global 44.51 (SD=23.0) with CI [39.9, 49.2], followed by physical 49.44 (SD=19.26) with CI [45.9, 52.5], emotional 56.63 (SD= 17.44) with CI [52.9, 59.7], and functional 57.69 (SD=17.53) with CI [54.4, 60.7]. Which was lower than studies in USA (40), in brazil (39) and in Taiwan (41) ; all this revealed that poorer swallowing related quality of life among Ethiopian HANC patients than elsewhere. The difference might be related to study site, time, and study subject differences.

In this study, female head and neck cancer survivors had significantly lower mean score compared to those who were male in MDADI (p=0.020), global (p=0.005) and physical (p=0.004) scales. Alternatively, the data suggested that emotional subscale score remain equal in both groups. In contrast, the other study supposed that women having significantly higher value on emotional domain compared to the men (42). Probably, men were more opened to their physical and the detrimental changes than emotional, this was similar with finding in Malaysia (42)

This study also showed statically significant association between marital status and global scale. At most survivors living alone were higher mean score value compared with living with spouse or partner at global scale (p=0.003). Conversely, the study in USA 70% of positive rating of QoL have been influenced by spouse (11). This is consistent with findings by Llewelyn et al (43).

In present study, patients expressed several difficulties due to impaired swallowing, which was consistent with study in USA (12). To cope from this challenge, they took a diet modification, finding /cooking a right meal was no longer easy especially for those male and live alone, it required conscious and intentional thought and planning. Correspondingly, the study in New York (68), Asking others to prepare a suitable meal also somewhat difficult and also eating outside home were challenging, most of patients reported a self-consciousness similarly study in Australia and Sweden respectively (14, 34).

All these things impaired swallowing and finding/cooking a right meal was a routine activity that affects everyday life of a patient, male those married might get supports from partner/ spouse as expressed in depth interview. Above all result indicated that being female and live with spouse/ partner were protective effects over swallowing related QoL to had a better social and functional well-being. This was also in line with the study by Reeve et al (44).

The analysis by working condition detected that employed patients demonstrated significant worsen global (p=0.003) and physical (p=0.039) scale compared with unemployed, the participants ability to do a task under question , and conveyed that self-imposition from work, that had an impacts in their QoL especially for those formerly employed males, Just as previously expressed by Semple C.J et al (28, 46).

Patients who had a multi-modality treatment were a higher mean score at MDADI (p=0.009), global (p=0.033) and physical (0.009) scales. The findings agreed with the study in Spain, Brazil, Chicago, and by Lahtinen et al (26, 47, 55, 56).

Furthermore, patients from IDI also express concomitant therapy exacerbate swallowing difficulties, and it had an impacts on quality of life. A long term physical damages of a treatment affecting their feelings whether swallowing ability returns to normal or not. Similarly, the study done by Maurer J. et al. (69), by Nund et al.(68), and in Italy (58). In contrast the study in USA conclude that combined treatment modality, the therapy choose for advanced stage oropharyngeal carcinoma (40).

In the present study, patients who had a primary tumor located at the oral cavity/ oropharyngeal had showed a significant mean difference at MDADI total (p= 0.044), and physical (p=0.045) scales. In contrast, studies in Australia and Chen et al. 2018, were identifies worse functional oral intake in oropharyngeal patients respectively (48, 54).

Furthermore, oral cavity/ oropharyngeal carcinoma was a significant predictor of impaired swallowing related quality of life in multiple linear regression analysis. Means patients with primary tumor of the oral cavity and oropharynx had significantly greater swallowing disability that caused an adverse impact on their QoL. Similarly study by Chen et al. 2001, (21).

This corporate with previous study by Crowder s. et al., kirsh et al and Murphy et al. (49, 51, 53). Above all this study revealed that patients those who had oral cavity/ oropharyngeal cancer and took a multimodality treatment reported the worst swallowing related QoL score (70-73).

This study showed that respondents who were paying their medical expenses significantly higher mean value than patients who were free of charges in MDADI (p= 0.006), global (p= 0.011), and physical (p=0.000) scale. Means lack of insurances associated with poorer swallowing related quality of life. Paying medical expenses was a significant predictor of impaired swallowing related quality of life in multiple linear regression analysis. The finding was similar with other study findings by Reeve et al. and in Norway (44, 74). Financial burden related to medical debit, and it is impact in quality of life also reported in patients in IDI.

However, in this study the initial tumor T stage was significantly higher mean score over advanced T stage in global domain of MDADI (p=0.011). The literature offers conflicting information in this regard, more than 50% of individual's experience difficulty swallowing in advanced stage (26) (54). The possible reason, swallowing impairment was independent of the T stage, suggesting this is a direct consequences of other factor rather than destructive effect of tumor on normal tissue.

In this study participants reported a lot of problems associated with swallowing related quality of life that was not clearly showed in quantitative study. Participant took an effort to swallow foods due to food stuck in the throat, to overcome this condition they limit food intake in amount, modify the diet texture and consistency, eat in slow manner. All these things cause self-consciousness, embarrassment and restriction in social life. Conversely the study in Sweden (14, 38).

7. STRENGTH AND LIMITATION OF STUDY

7.1. Strength of the Study

- The study used both approaches, which were qualitative and quantitative to obtain an optimal findings and provide an explanation in different perspective, so it is more comprehensive than particular study.
- The study is considered as a primary study in assessing swallowing related quality of life in head and neck cancer patients in our country.
- The study used structured and specific questionnaire to head and neck cancer patients in quantitative study and also it used an open ended questions for qualitative study which allows in exploring new ideas.

7.2. Limitation of the Study

- One of the potential limitation of this study was the used non probability purposive sampling technique, in qualitative parts of the study, it might be introduced bias and bound generalizability of the findings.
- The used cross sectional study design in quantitative study part, it also obstructs cause and effects relationships between variables.
- Moreover, the study might introduce social desirability bias because the study outcome based on self-reports.

8. CONCLUSION AND RECOMMENDATIONS

8.1. Conclusion

This study identifies a factors which showed a mean significant difference in a MDADI subscale were sex, marital status, working condition, medical expenses, tumor site, tumor T stage, and treatment modality. And also detect tumor site which was oral cavity/ oropharyngeal carcinoma and medical expenses a predictor of impaired swallowing related quality of life by multiple linear regression analysis.

Moreover, the study explores the impact of impaired swallowing in day to day, emotional, functional, and physical aspects of life of head and neck cancer patients at Tikur Anbessa Specialized Referral Hospital.

8.2. Recommendations

Based on the findings of the study the following recommendations are forwarded to concerned bodies: -

To health care providers

- Especially those who work at oncology department must address the consequence of being head and neck cancer patients, and it is treatment side effect to improve the swallowing related quality of life.
- Needs to focus in addressing issues in emotional, functional and physical aspects of life.

To planners'/ policy maker

- To create an awareness in the society to meet social needs of survivor's.
- To contemplate about the prohibitions all bottled drinks including waters in some institutions while the patients in serious illness.

To future researchers

- To adds some instrumental assessment study like video fluoroscopy
- To include a control group study participant to explore the effect of being head and neck cancer patients
- To use Focused Group Discussion (FGD) that allows participants to share their experiences freely.

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10. APPENDIX

APPENDIX A - Research Participant Information Sheet

Introduction

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to listen the following information carefully. Ask me anything that is unclear or if you would like more information.

Purpose of the study

To assess the impact of impaired swallowing on quality of life of head and neck cancer survivors.

Why have I chosen you?

You have been chosen to take part in this study because you are pathologically proven head and neck cancer patient and under a treatment. The Principal has agreed to this research being carried out. Ethics Approval Panel has reviewed and granted ethics clearance for this project.

Do I have to take part?

Your participation in this survey study is completely VOLUNTARY and you have the right to refuse to be in the study. If you refuse or agree to participate in the study, there will be no implications for you as an individual. It has no personal benefit and foreseeable risk or discomforts associated with this study.

What do I have to do?

To take part in this research you are being asked to complete the interview provided.

What will happen to the results of the research study?

The results of the research study will be submitted in my dissertation. In addition, the research will be published in academic journals. Summary of the research findings will be made available to the cancer centers of TASH, Minster of Health Office, and school of nursing and midwifery department.

Confidentiality:

All information is recorded anonymously and stored on the computer at home, secured by a password. Therefore, your treatment and health status will not be affected. The data will be accessed by supervisors and me.

If you want to participate in the study either sign the attached informed consent or you tell your willingness to participate (oral consent) for data collector.

Contact Person

If you want to know more information and any question, you can contact with the following address: Principal Investigator: - Tseganesh Asefa, Tell No- 0922736330, Email- tseganesh16@gmail.com

APPENDIX B- Research Participant Consent Form

I am willing to participate in this study" the impact of impaired swallowing on quality of life of head and neck cancer survivors at Tikur Anbessa specialized hospital, Addis Ababa, Ethiopia" (circle either yes or no) or give oral consent

Yes

No

Tikur Anbessa specialized hospital oncology unit, Addis Ababa, Ethiopia.

Date ----------

Signature----------

APPENDIX C- Structured English Version Questionnaire for Quantitative Study

The objective of this study to assess the impact of impaired swallowing on quality of life of head and neck cancer survivors at Tikur Anbessa Specialized Hospital, Addis Ababa, Ethiopia.

Introduction: - Dear clients,

First I would like to thank you for your voluntary participation in this study. I politely requested that you respond to the interview accurately and I assure you that your response and identifying data will be kept confidential. The result of this survey will be useful for future planning of health service for quality of life of head and neck cancer patients. Therefore; you are politely requested to give accurate information.

Part one - Structured English Version Questioner about Socio-Demographic Characteristics

1	**Sex**	**1. Male**	**2. Female**
2	Age	---------- (Year)	
3	Marital Status	1. Single 2. Married	3. Divorced 4. Windowed
4	Level of Education	1. Illiterate 2. Primary education	3. Secondary 4. Above secondary
5	Working Condition	1. Civil servant 2. Private Servant 3. House Wife	4. Student 5. Pension 6. Other _____
6	Place of Resident	1. Addis Ababa	2. Regional/ Rural
7	Income	1. ≤500 ETB / in month 2. 500-1,000 ETB / in month	3. 1,1,000-2,000 ETB / in month 4. > 2,000 ETB / in month
8	Medical Expense	1. Fee Paying	2. Free
Part 2: Medical Questions (Data from patient Chart/ History Book)			
9	Time Since Diagnosis	----------(In month)	
10	Primary Cancer Diagnosis	----------	
11	Primary Tumor Site	1. Oropharynx 2. Nasopharynx 3. Larynx 4.	3. Hypopharynxes 5. CUP
12	Tumor T Stage	1. Tx/ T1 2. T2	3. T3 4. T4
13	Type of Carcinoma	1. Squamous cell 2. Adenocarcinoma	3. Other
14	Treatment Modality	1. Chemotherapy 2. Radiation 3. Surgery	4. Chemotherapy and radiation 5. Chemotherapy and surgery 6. Radiation and surgery 7. all

The M.D. Anderson Dysphagia Inventory

This questionnaire asked to views about swallowing ability. This information will help us understand how patients feel about swallowing

The following statements have been made by people who have problems with their swallowing. Some of the statements may apply to you.

Please read each statement and circle the response which best reflects your experience in the past week.

Part Two- Structured English Version Questioner about Swallowing Ability

No	Code		Strongly Agree (1)	Agree (2)	No Opinion (3)	Disagree (4)	Strongly Disagree (5)
1		My swallowing ability limits my day-to-day activities.					
2	E2	I am embarrassed by my eating habits.					
3	F1	People have difficulty cooking for me.					
4	P2	Swallowing is more difficult at the end of the day.					
5	*E7	I do not feel self-conscious when I eat.					
6	E4	I am upset by my swallowing problem.					
7	P6	Swallowing takes great effort.					
8	E5	I do not go out because of my swallowing problem.					
9	F5	My swallowing difficulty has caused me to lose income.					
10	P7	It takes me longer to eat because of my swallowing problem.					
11	P3	People ask me, “Why can’t you eat that?”					
12	E3	Other people are irritated by my eating problem.					
13	P8	I cough when I try to drink liquids.					
14	F3	My swallowing problems limit my social and personal life.					
15	*F2	I feel free to go out to eat with my friends, neighbors, and relatives.					
16	P5	I limit my food intake because of my swallowing difficulty.					
17	P1	I cannot maintain my weight because of my swallowing problem.					
18	E6	I have low self-esteem because of my swallowing problem.					
19	P4	I feel that I am swallowing a huge amount of food.					
20	F4	I feel excluded because of my eating habits.					

APPENDIX D – Semi Structured English Version Questioner for Qualitative Study

General Introduction for the facilitator

Hi, how are you? Are you comfortable for discussion?

I am ……. (Full name of the facilitator) and I am going to facilitate our discussion on your personal views and experiences regarding your swallowing impairment and it is impacts on your life. Before we go further, let us introduce ourselves.

1. Could you describe your experience related to impaired swallowing or dysphagia?

   Probing questions:

   - ✓ What is your felling in your unusual ways of eating?
   - ✓ How it affects your daily activity?
   - ✓ How strong those feelings?

2. What are the physiological effects of impaired swallowing on your life?

   Probing questions:

   - ✓ What do you do when the food stuck in your throat?
   - ✓ What do you do during chocking, coughing up when swallow?
   - ✓ Do you need more time to swallow food?
   - ✓ How much time take to swallow food?
   - ✓ What is your feeling related to weight loss

3. What are the functional impacts of impaired swallowing in your life?

   Probing questions:

   - ✓ What is your feelings when you miss your favorite food types?
   - ✓ Are you comfortable with foods prepared by other persons?
   - ✓ Was there some other or your partners isolate you by your ways of eating?
   - ✓ Do you share a table or eat together with your family?

4. What is your emotional responses regarding swallowing impairment?

   Probing questions:

   - ✓ How do you eat foods outside the family?
   - ✓ Are you dissatisfied in you ways of eating? In what way?
   - ✓ Do you feel embracement, nervous being with impairment?
   - ✓ Do you feel sense of isolation from social eating?
   - ✓ Is you accept invitation for dinner, wedding ceremony

APPENDIX E - Research Participant Information Sheet in Amharic Version

መግብያ

በጥናት ውስጥ እንዲሳተፉ ተጋብዘዋል። እርስዎም በጥናት ውስጥ ለመሳተፍ ከመወሰንዎ በፊት የምርምር ውጤቱ ለምን እንደሚከናወን ፤ለምን እንደሚጠቅም ለመገንዘብ የሚከተሉትን መረጃዎች በጥንቃቄ ያዳምጡ። ግልፅ ያልሆነልዎት ነገር ካለ ወይም ተጨማሪ መረጃ ከፈለጉ መጠየቅ ይችላሉ።

የጥናቱ ዓላማ

የጭንቅላት እና የአንገት ካንሰር በሽታ ምልክቶች በአመጋገብ ላይ እና በአኗኗር ላይ የሚያሳድረው ተፅእኖ ለመመርመር የሚደረግ ጥናት ነው።

ለምንድን ነው የተመረጡት?

በዚህ ጥናት ውስጥ ለመሳተፍ ተመርጠዋል ምክንያቱም እርስዎ የጭንቅላት እና የአንገት ካንሰር ህመም ታመው ህክምና እየወሰዱ በመሆንዎ እና ለመረጃ ቅርብ እንዲሁም የጉዳዩ በለቤት በመሆንዎ ነው። የሆስፒታሉ ርእሰ መስተዳድር እንዲሁም የሥነ ምግባር ኮሚቴ ፕሮጀክቱ እንዲካሔድ ፈቃዳቸውን ሰጥተዋል።

መሳተፍ አለብኝን ?

በዚህ የዳሰሳ ጥናት ውስጥ ያለዎት ተሳትፎ ሙሉ በሙሉ በጎፈቃደኝነትዎ ላይ የተመሰረተ ነው። በጥናቱ ላይ መሳተፍም ሆነ ያለመሳተፍ መብትዎ የተጠበቀ ሲሆን። በመሳተፍዎ ወይንም ባለመሳተፍዎ በግለሰብ ደረጃ ከጥናቱ ጋር የተያያዘ ምንም አይነት የግል ጥቅም ሆነ ጉዳት ሊደረስብዎ አይችልም።

ምን ማድረግ አለብኝ ?

በዚህ ጥናት ውስጥ ለመሳተፍ የተጠየቁትን ቃለ መጠይቅ እንዲያጠናቅቁ በትህትና እጠይቃለሁ።

የምርምር ጥናቱ ውጤት ምን ይሆናል ?

የምርምር ጥናቱ ውጤት ለሁለተኛ ዲግሪ የሚዘጋጅ ጽሁፍ ላይ የሚቀርብ ሲሆን፤ በተጨማሪም ጥናቱ በአካዳሚክ መጽሔቶች ላይ ይታተማል። የምርምር ውጤቱ ማጠቃለያ በጥቁር አንበሳ ካንሰር ህክምና ማዕከል፤ በጤና ሚንስትር ጽፈት ቤት እና የነርስ እና አዋላጅ ትምህርት ቤቶች መምርያ ያገኙታል።

ሚስጥራዊነቱ

ሁሉም መረጃ በኮምፒውተር ውስጥ በይለፍ ቃል የሚጠበቅ ሲሆን የእርስዎን ህክምና ሁኔታም ሆነ የጤናዎ ሁኔታ በምንም ሁኔታ የሚጎዳ አይሆንም።

ይህን መረጃ የሚሰጡት ያለ ምንም ግዴታ በሙሉ ፈቃደኝነትዎ ነዉ። በጥናቱ ላይ ለመሳተፍ የሚፈልጉ ከሆነ ከታች የተያያዘውን መረጃ ስምምነት መፈረም ወይም ደግሞ መስማማትዎን ጥናቱን ለሚሰበስበዉ ሠዉ ይንገሩ።

ለተጨማሪ መረጃ

ተጨማሪ መረጃ ከፈለጉ ወይንም ጥያቄ ከአለዎት ከጥናቱ ባለቤት ጋር ከታች በተጠቀሰው አድራሻ በኩል ማግኘት ይችላሉ። ጸጋነሽ አሰፋ፣ ስልክ- 0922736330፣ ኢሜል-tseganesh16@gmail.com

APPENDIX F- Research Participant consent Form (Amharic Version)

ፈቃደኝነትን የሚያረጋግጥ ቅጽ

እኔ በጥቁር አንበሳ ሆስፒታል የሚታከሙ የጭንቅላት እና የአንገት ካንሰር ያለባቸው ህመምተኞች የምግብ መዋጥ ችሎታዬ ጋር ተያይዞ የሚመጣ የኑሮ ሁኔታ ጥራት ጥናት ላይ ለመሳተፍ ፍቃደኛ ነኝ (አዎ ወይም የለም የሚለዉን ያክብቡ)

1. አዎ

2. የለም

በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል ካንሰር ዩኒት, አዲስ አበባ, ኢትዮድያ

ቀን .....

ፊርማ .....

የምላሽ ሰጪ ፊርማ .....

የጠያቂዉ ሰው ፊርማ …….

APPENDIX G - Structured Amharic Version Questionnaire for Quantitative Study

መመሪያ፣

የዚህ ጥናት ዓላማ በጥቁር አንበሳ ስፔሻላይዝድ ሆስፒታል የጭንቅላት እና የአንገት ካንሰር ላለባቸው ህመምተኞች ሲሆን፣ ይህም ጥናት የሚያተኩረው የጭንቅላት እና የአንገት ካንሰር በሽታ ምልክቶች በአመጋገብ ላይ እና በአኗኗር ላይ የሚያሳድረው ተፅእኖ ለመመርመር የሚደረግ ጥናት ነው።

የተከበራችሁ የጭንቅላት እና የአንገት ካንሰር ያለባችሁ ህመምተኞች ለቃለ መጠይቁ ፈቃደኛ በመሆናችሁ በቅድሚያ አመሰግናለሁ። በመቀጠል ይህንን ቃለ መጠይቅ በትክክል እንድትመልሱልኝ ስጠይቅ የምትመልሱት መልስም ሆነ የእናንተ ማንነት በምንም ዓይነት ሁኔታ ለየትኛውም ወገን እንደማይገለጽ ቃል እገባላችኋለሁ። የዚህ ቃለ መጠይቅ ውጤት ለወደፊ የጭንቅላት እና የአንገት ካንሰር ላለባቸው ህመምተኞች ጠቃሚ ነው። ስለሆነም ትክክለኛውን መልስ በመስጠት እንድትተባበሩን በትህትና እጠይቃለሁ።

ክፍል አንድ- ለጭንቅላት እና አንገት ካንሰር ጥናቶች የተዋቀረ መጠይቅ

ኮድ---------- **ቀን**---------- **ሰዓት**----------

ክፍል 1፣ማህበራዊ እና ስነ-ሕዝብ ተዛማጅ ጥያቄዎች			
1	ፆታ	1. ወንድ 2. ሴት	
2	እድሜ	---------- (በዓመት)	
3	የጋብቻ ሁኔታ	3. ያላገባ 4. ያገባ	3. የተፋታ 4. ባል/ሚስት የሞተባት/በት
4	የትምህርት ደረጃ	5. ያልተማረ/ች 6. የመጀመሪያ ደረጃ	7. ሁለተኛ ደረጃ 8. ከሁለተኛ ደረጃ በላይ
5	የሥራ ሁኔታ	7. የመንግስት ሰራተኛ 8. የግል ሰራተኛ 9. የቤት እመቤት	10. ተማሪ 11. ጡረታ የወጣ/ች 12. ሌላ, እባክዎን _____ ይግለጹ
6	የመኖሪያ አድራሻ	1.ከተማ	2. ክልል/ ገጠር
7	የቤተሰብ ገቢ መጠን	5. ≤500 ብር / በወር 6. ከ 500-1,000 ብር / በወር	7. ከ1,1,000-2,000 ብር / በወር 8. > 2,000 ብር / በወር
8	የህክምና ክፍያ	3. ከፍሎ የሚታከም	4. የነፃ ታካሚ
9	ህመሙ ከተገኘ ምን ያክል ግዜ ሆነው	----------(በወር)	
ክፍል 2: የህክምና ባህሪያት (በመረጃ ሰጪዎች በቻርት ግምገማ አማካይነት መሙላት)			
10	የመጀመሪያ የካንሰር ምርመራ ውጤት	----------	
11	እጢው ቀድሞ የተገኘው የት አከባቢ ነው	5. በአፍዎ ውስጥ 6. በአፍና በጉሮሮ አካባቢ 7. በአፍንጫ እና በጉሮሮ አካባቢ	3.ማንቁርት አካባቢ 4.ከጉሮሮ ዝቅ ብሎ ባለ አካባቢ 5. መነሻው አይታወቅም
12	የእጢው ደረጃ	1. ደረጃ I 2. ደረጃ II	3. ደረጃ III 4. ደረጃ IV
13	የህብረ ህዋስ አይነት	4. እስከመስ 5. አዲኖ ካርሺኖማ	6. ሌላ አይነት
14	አሁን በመዉሰድ ላይ ያሉት የካንሰር ህክምና አይነት	8. ኬሞቴራፒ 9. ጨረር ህክምና 10. ቀዶ ጥገና ሕክም	1. ኬሞቴራፒ እና ጨረር ህክምና 2. ኬሞቴራፒ እና ቀዶ ጥገና 3. ሁሉም

ክፍል ሶስት- የዶክተር አንደርሰን የመዋጥ ችግር መጠይቆች

ይህ መጠይቅ የመዋጥ ችግርን በተመለከተ አስተያየትዎን ይጠይቃል: የሚከተሉት ዓረፍተ ነገሮች ያንብቡና ባለፈው ሳምንት ውስጥ የእርስዎን ተሞክሮ በተሻለ ሁኔታ የሚያንጸባርቀውን ምላሽ ይስጡ።

ቁጥር	ኮድ		በእጅጉ እስማማለሁ (1)	እስማማለሁ (2)	ምንም አተያየት የለኝም(3)	አልስማማም(4)	በእጅጉ አልስማማም(5)
1		የመዋጥ ችሎታዬ የዕለት ተዕለት እንቅስቃሴዬን ይገድባል					
2	ስ2	በአመጋገብ ልማዴ አፍራለሁ					
3	ተ1	ሰዎች ለእኔ ምግብ ለማብሰል ይቸገራሉ					
4	ፊ2	በስተመጨረሻ ምግብ የመዋጥ ችሎታዬ በጣም አስቸጋሪ ሆኖብኛል					
5	*ስ 7	ምግብ በምበላበት ጊዜ በራስ የመተማመን ስሜት አይሰማኝም					
6	ስ4	ምግብ የመዋጥ ችግር በመኖሩ እበሳጫለሁ					
7	ተ6	ምግብ ለመዋጥ ከፍተኛ ጥረት አደርጋለሁ					
8	ስ5	በመዋጥ ችግር ምክንያት ከቤት ውጭ ለመመገብ እቸገራለሁ					
9	ተ5	የምግብ መዋጥ ችግር መኖሩ ለከፍተኛ ወጪ ዳርጎኛል					
10	ፊ7	ከመዋጥ ችግር የተነሳ ለመብላት ረዘም ያለ ጊዜ ይወስድብኛል					
11	ፊ3	ሰዎች “ለምን ይሄን አትበላም?” ብለው ይጠይቁኛል					
12	ስ3	ሌሎች ሰዎች በእኔ አመጋገብ ችግር ምክንያት ይበሳጫሉ					
13	ፊ8	ፈሳሽ ነገር ለመጠጣት ስሞክር ሳል ያስለኛል					
14	ተ3	በምግብ መዋጥ ችግር ምክንያት ማህበራዊና የግል ህይወቴ ተገድቦአል					
15	*ተ 2	ከጓደኞቼ፤ ከጎረቤቶቼ እና ከዘመዶቼ ጋር ምግብ ለመብላት ነጻ የሆነ በራስ የመተማመን ስሜት ይሰማኛል					
16	ፊ5	በመዋጥ ችግር የተነሳ የምግብ መጠን ቀንሻለሁ					
17	ፊ1	በመዋጥ ችግር የተነሳ ክብደቴን መጠበቅ አልቻልኩም					
18	ስ6	በመዋጥ ችግር የተነሳ ለራሴ ዝቅተኛ ስሜት/ ክብር ይሰማኛል					
19	ተ4	ምንም እንኳን ትንሽ ምግብ ቢሆን ትልቅ አድርጌ የዋጥኩ ያክል ይሰማኛል					
20	ተ4	በአመጋገብ ችግር ምክንያት ከአኗኗሬ የተገለልኩ ይመስለኛል					

ስ- ስሜት ፊ- ፊዚዋሎጂ ተ- ተግባር

APPENDIX H - Semi Structured Amharic Version Questioner for Qualitative Study

ትውውቅ

ስላም እንዴት ነህ/ ሽ ለውይይት ዝግጁ ነህ/ሽ

እኔ..... እባላለሁ ። ከእርሶ ጋር ስለ ምግብ መዋጥ ችግር፤ ችግሩ ባጋጠምዎት ሰአት ጀምሮ ያሳለፉትን የህይወት ልምድ፤ ያሳደረብዎትን ተጽእኖ እንወያያለን። ወደ ውይይቱ ከመሄዳችን በፊት እራስዎትን ያስተዋውቁ።

ለጭንቅላት እና ለአንገት ካንሰር ታካሚዎችን የህይወት ልምድን ለመዳሰስ የተዘጋጀ መጠይቅ

1. ከምግብ መዋጥ ችግር ጋር ተያይዞ ያጋጠመዎትን የህይወት ልምድ መግለጽ ይችላሉን?
    - ✓ ያልተለመደ/ አዲስ የአመጋገብ ስርአት መከተልዎ የፈጠረብዎት ስሜት ምንድን ነው?
    - ✓ ምግብ የመዋጥ ችግር በእለት ተእለት እንቅስቃሴዎ ላይ የፈጠረብዎ ተጽእኖ ምንድን ነው?
    - ✓ እነዚህ ስሜቶች ምን ያህል ጠንካራ ናቸው?
2. የምግብ መዋጥ ችግር ምግብ በመዋጥ ትግበራ ላይ ያለው ተጽእኖ?
    - ✓ ምግብ በጉሮሮዎ ውስጥ ተሰንቅሮ አልዋጥ ሲልዎ ምን ያደርጋሉ?
    - ✓ ምግብ ለመዋጥ ሲታገሉ ወይንም አስሎት ምግቡ ሲወጣብዎ ምን ያደርጋሉ?
    - ✓ ምግብ ለመዋጥ ምን ያህል ጊዜ ይወስዳል?
    - ✓ ለመዋጥ ተጨማሪ ጊዜ ያስፈልግዎታል ወይ?
    - ✓ ክብደትዎን በተመለከተ ምን ይላሉ?
3. የምግብ መዋጥ ችግር ማህበራዊ ህይወትዋን ወይንም ከቤት ውጪ የመመገብ ልምድዎን በምን አይነት ሁኔታ ተጽዕኖ አሳድሮቦታል?
    - ✓ የሚወዱትን የምግብ አይነቶችን መመገብ አለመቻልዎ ምን ስሜት ያድርብዎታል?
    - ✓ ሰዎች ያዘጋጅዋቸው ምግቦች ተመችቶት ይበላሉ?
    - ✓ ጓድኞችዎ/ ቤተሰብዎ ያገለሉዋት ይመስልዎታል?
    - ✓ ከቤተሰብዎ ጋር አብረው ይመገባሉ?
4. ስለ ምግብ መዋጥ ችግር ሲያስቡ ምን አይነት ስሜት ይሰማዎታል?
    - ✓ ከቤትዎ ውጪ ማለትም በምግብ ቤት እንዴት ምግብ ይመገባሉ?
    - ✓ በአሁን ሰአት ባለው የአመጋገብ ችግር ይበሳጫሉ?
    - ✓ ሀፍረት ይሰማወታል?
    - ✓ የመገለል/ከሰዎች ጋር ያለመሆን አይነት ስሜት ይሰማዎታል?
    - ✓ ለእራት, ለሠርግ ለመሳሰሉት ማህበራዊ ህይወት ላይ ይሳተፋሉ ?
5. የዕለት ተዕለት እንቅስቃሴዎን በምን አይነት ሁኔታ አስተጓጉሎቦታል?