ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH

PERCEPTION ABOUT PALLIATIVE CARE AND FACTORS INFLUENCING THE LIKELIHOOD OF SERVICE UTILIZATION AMONG ADULT CANCER PATIENTS IN TIKUR ANBESSA SPECIALIZED HOSPITAL, ETHIOPIA

BY

MIHERET FIKRE TEKLEMARIAM (BSc)

A THESIS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES OF ADDIS ABABA UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF PUBLIC HEALTH IN HEALTH SERVICE MANAGEMENT.

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ACRONYMS AND ABBREVIATIONS

AOR	Adjusted Odds Ratio
CI	Confidence Interval
COR	Crude Odds Ratio
DALY	Disability-Adjusted Life Years
EOL	End of Life
LMICs	Low and Middle-Income Countries
NCDs	Non-Communicable Diseases
PC	Palliative care
QoL	Quality of life
REC	Research and Ethical Committee
SPSS	Statistical Package for Social Sciences
TASH	Tikur Anbessa Specialized Hospital
WHO	World Health Organization
WPCA	Worldwide Palliative Care Alliance

ABSTRACT

Background: There is a significant global disparity on the provision of palliative care services for individuals with life-limiting illnesses and palliative care remains an urgent, neglected need in developing countries. In Ethiopia, there is a paucity of information on the patient's perception about palliative care and the factors influencing the likelihood of service utilization among adult cancer patients.

Objectives: To assess the perception about palliative care and factors influencing the likelihood of service utilization among adult cancer patients in Tikur Anbessa Specialized Hospital, Ethiopia from January 1to March 31, 2019.

Methods: A facility-based cross-sectional study conducted among 304 systematically selectedadult cancer patients in the cancer unit of Tikur Anbessa Specialized Hospital. A pre-tested structured interviewer-administered questionnaire was used for data collection. Multivariable binary logistic regression model was carried out to control for the potential confounders and to identify the independent factors associated with palliative care service utilization. P-value <0.05 was used to declare statistical significance and goodness of fit of the model assessed using Hosmer and Lemeshow goodness of fit test.

Results: A little more than half of the patients had aperception on the availability of palliative care service174(57.2%), adult cancer patients who earn≥ 1,500-birrs monthly income were 2.36 times more likely to utilize palliative care service as compared to their counterparts who earn a monthly income of <1,500 birrs (AOR=2.36, 95% CI 1.37,4.06), after controlling the effect of other covariates. Similarly, having family members of more than two was associated with higher utilization (AOR=2.28, 95% CI 1.02,5.13)

Conclusion and recommendations: Significant number of adult cancer patients were nothaving perception about utilizing palliative care service and higher monthly income and having more than two family memberswere the factors strongly associated with higher likelihood of palliativecare service utilization. Multiple stakeholders should be involved in reducing the financial constraints that hinder patients not to utilize palliative care service and to improve social support for those who have few or no family members.

Keywords: perception; Palliative care; Service utilization; Adult cancer; Tikur Anbessa

1. INTRODUCTION

1.1 Background

Cancer is a collection of more than 150 diseases characterized by the development of abnormal cells that divide uncontrollably and have an ability to infiltrate and destroy normal body tissue(1).Cancer is caused by the interaction of many factors like genetic factors, environmental factors and repetitive exposure of an individual to certain risk factors like tobacco smoking, alcohol, radiation,chronic inflammation and immunosuppression increases the likelihood of cancer development.Treatment options for cancer includes chemotherapy, radiotherapy and surgery(2).

There is significant global disparity on the availability, accessibility of cancer treatment options and patient survival(3), in sub-Saharan Africa the cancer burden is underestimated due to lack of appropriate diagnosis, poor access to care, absence/shortage of well-trained human resource, and infrastructure(4). Cancer is one of the major causes of poverty, this is due to the financial catastrophe (>30% out of pocket health care expenditure) following treatment for cancer, which also affects the quality of life of the patient by increasing psychological distress and economic hardship(5).

According to the World Health Organization (WHO) definition, palliative careis an approach that improves the Quality of Life (QoL) of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems including physical, psychosocial and spiritual problems (6).The main aim of palliative care is to optimize the comfort, function and social support of patients and their families at all stages of disease(7).

Palliative care is a multidisciplinary approach which neither hastens nor postpones death but it can positively influence the course of the illness if it is started early. Early palliative care not only improves the QoL of patients but it also reduces unnecessary hospitalizations and use of health-care services (8,9).Palliative care is required for a wide range of diseases and cancer is the second most common chronic disease among adults in need of palliative care, which accounts for 34% of adults following cardiovascular diseases which accounts for 38.5% (6,8).

Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care, whereby 80 % of cancer patients will experience moderate to severe pain at the end of their lives (10).Palliative care is an essential component of a comprehensive response to Non-Communicable Diseases (NCDs) as outlined in theWHOglobal action plan for the prevention and control of NCDs 2013–2020 (11).

The global need for palliative care among cancer patients is increasing with a rapid pace due to the world's aging population (8), and due to the increasing burden of modifiable risk factors for cancer such as smoking, overweight, physical inactivity and adoption of western lifestyle, globalization, urbanization and economic development (12).However, there remains a huge unmet need for palliative care for those with chronic life-limiting health problems with a significant variation for cancer palliative care in most parts of the world and particularly in sub-Saharan African countries (13)

1.2Statement of the Problem

According to the GLOBOCAN 2018 report, there were 18.1 million new cancer cases, 9.6 million cancer deaths globally(14).It is projected that an estimated over 21 million people will have cancerand 13 million people will die of cancer in the year 2030 (15). There is a significant global disparity on provision of palliative care services for individuals with life-limiting illnesses, each year of the 40 million people globally in need of palliative care and 20 million people at the end of life; just 14% receive it, most of them are adults and children in high-income countries(7).

Developing countries account for 80% of the global cancer burden and more than half of them are living in Africa, that have only 5% of available medical resources used to diagnose, treat and to provide comprehensive palliative care(14).According to the Worldwide Palliative Care Alliance (WPCA) report, there is zero availability of palliative care service in 42% of the world's countries. The critical absence of palliative care services in low-resource settings results in significant costs being absorbed by the individual, family and local community(6).The factors associated with poor palliative care service utilization among cancer patients in developing countries are complex, multi-dimensional, layered, and inadequately understood(16).

In Africa, 346,203 adults (69.3/100,000 populations)needpalliative care service from the major NCDs at the end of life. There is a large gap between the number of people in need of palliative care services and those who are can receive it (6,8). Most patients with cancer in Africa are diagnosed when they are terminally ill, and only 5% can receive any chemotherapy (17). In Ethiopia cancer accounts for about 5.8% of the total national mortality and the annual incidence of cancer is around 60,960 cases and the annual mortality is more than 44,000 (18).

Cancer incidence in Ethiopia at present is estimated to be 150,000 cases per year, of which less than 1% receive specialist treatment.Access to palliative radiotherapy or chemotherapy is a major problem because currently there are only 2 cobalt units (one is not functional) and 4 practicing oncologists to serve such a large population (19). In Ethiopia, there are studies conducted to assess the factors associated with palliative care service utilization from the patient side or caregiver side, the previous studies conducted in Ethiopia were mainly focused among health professionals' attitude and perception of palliative care. The palliative care service and its associated factors are not yet determined in our set up.

1.3Rationale of the study

Palliative care is poorly addressed public health problem with scarce data on the factors associated with service utilization. Palliative care service in Africa and particularly in Ethiopia is in its infancy stage with very few published studies. The previously conducted studies in the African continent and particularly in Ethiopia were mainly focused on knowledge, attitude, and practice of patients and they were not holistic enough to completely understand the more complex factors of palliative care service utilization. There is an information gap on the deeper, more complex factors and their potential solutions among adult cancer patients and this information is critical to ensure optimum delivery of comprehensive palliative care service.

1.4Significance of the study

This study helps patients and their families in accessing timely and patient-centered services by identifying perception and the potential factors associated with palliative care service utilization. This study will also help policymakers and health planners in designing best and culturally appropriate palliative care policies used to improve the quality of palliative care which ultimately improves the socio-economic development community, the region and the nation as a whole.

2. LITERATURE REVIEW

2.1 Overview of palliative care service

Palliative care service provision is a multidisciplinary approach that supports patients and their caregivers(20). Palliative care should be provided by palliative care specialists who work in an integrated approach with a patient's primary care clinicians and other treating specialists, however, in resource-poor settings, it can be delivered by any trained clinician (21). Palliative care service should also assess the caregiver's capacity to provide care, creatingawareness on the patient's diseases condition, prognosis, providing bereavement counseling service with the ultimate goal ofoffering a support system to help patients live as actively as possible until death (21,22).

Palliative care service should be provided through person-centered and integrated health services that pay special attention to the specific needs and preferences of individuals (7).Even though palliative care service is explicitly recognized under the human right to health,there is poor access to this service because of the shortage of trained workforce, training programs(23) and the inadequate attention given for the service in resource-poor settings (24).

Palliative care service utilization has been associated with better outcomes, including enhanced patient care, increased patient satisfaction, improved symptom control, and improved financial performance of institutions.Globally, palliative care service utilization is limited because of a number of factors, in united states palliative care service utilization among adults is more than 90% (25), whereas in Europeit ranges from 50-65% of adult cancer patients received palliative care service by their general practitioners whereas 29-47% patients received specialist palliative care service(26).

In Africa, millions ofcancer patients are experiencing unnecessary suffering and pain without access to oral Morphine (27). Access to culturally appropriate holistic palliative care (including effective pain management) is not available(28). A survey of hospice and palliative care services on the continent found that 45% of African countries had no identified hospice or palliative care activity, and only 9% could be classified as having the necessary services approaching some measure of integration with mainstream health provision, showing that there is significant unmet palliative care need in Africa (29).

A hospital-based cross-sectional study conducted to assess the rehabilitation service utilization and associated factors among 388 adult cancer patients at Black Lion hospital, Ethiopia found that 26% of cancer patients received rehabilitation service at least once. Approximately one-fourth (23.2%, 90/388) were satisfied with the cancer rehabilitation service (30).

2.2 Factorsinfluencing palliative care service utilization

2.2.1 Financial factors

An exploratory qualitative study conducted in Canada found that higher socioeconomic status was associated with a higher likelihood of a palliative care service utilization, this helps the patient to have better health and health care understanding, a higher capacity for advocacy, a more stable home environment, and more caregiver support(31).According to the Texas Cancer Registry Medicare data, the median amount paid for palliative care service over the last six months for adult cancer patients was $38,530 and only 30% ofhospice unenrolled patients received palliative care service at least once (32).

A hospital-based cross-sectional study was conducted to assess the rehabilitation service utilization and associated factors among 388 adult cancer patients at TASH, Ethiopia found that higher cost of palliative care service 28.9% (86/298) and inaccessibility 46.6% (124/298) due to cost of transportation were the factors that affect service utilization (33). Similarly, a mixed case series studyconducted in Addis Ababa and Jimma found that the out-of-pocket costs of medical care (medications, medical treatments, and transportation to receive medical care or purchase medications) over the preceding month was $207. Families are also devastated by the costs of medical care and are forced to sell major assets such as wedding gold, livestock, homes, and land. Opioid analgesics were not prescribed for 24% of patients and 64%of the patients reported having sold their homes and other significant sources of wealth to pay for medical care (34).

2.2.2 Health system factors

According to the African Palliative care Association report (APCA) report and a qualitative study conducted in South Africa (35), palliative care was developed in Africa by motivated 'pioneer' individuals, rather than through mainstream national health systems.Palliative care remains absent from in many of African national health policies or basic care packages, with almost half of African countries identifying no hospice or palliative care activity. In Africa, the main health system-related challenges for providing palliative care service among cancer patients are the absence of government national health policies, essential medicines policy, education policies,logistical challenges, poorpublic awareness and understanding(36).

Similarly, a cross-sectional study conducted in South Africa found, lack of access to appropriate analgesics, adequately trained health professionals, ineffective pain management and palliative care and limited human and physical resources were the major challenges to effective provision of palliative care service (37). In line with above studies a hospital-based cross-sectional quantitative studyconducted to assess the rehabilitation service utilization and associated factors among 388 adult cancer patients at TASH, Ethiopia found that lack of availability of adequate space 60.7% (181/298),lack of health care professionals 50.3% (150/298) with experience in cancer care were the factors associated with palliative care service utilization. After adjusting for all the predictor variables, knowing someone with cancer, lack of support, lack of professionals, lack of awareness, unavailability of the service and lack of knowledge were significantly associated with rehabilitation service utilization(33).

2.2.3 Knowledge factors

A cross-sectional, exploratory qualitative study was conducted in Australia to explore initial perceptions of palliative care among patients with advanced cancer and their families found that palliative care was exclusively end-of-life care and they negatively associated with diminished care, non-medically focused care with particular emphasis on pain relief and comfort. PC is also perceived as a diminished possibility, whereby it is a place to wait for death, an end to perceived hope, a time of dependency and care when there is no any other alternative (38).

A cross-sectional quantitative study was conducted to assess knowledge, attitude, practice and associated factors towards palliative care among 341 randomly selected nurses working in selected hospitals of Addis Ababa found that only 30.5% nurses had good knowledge towards PC. A Significant number of nurses 103 (30.2%) felt uncomfortable talking about death with a dying patient and they usually refused to be assigned to give care for dying people 83 (34.3%). More than three-quarter of nurses (83.6%) were hiding the truth for their patients. It was also found that the majority of nurses (36.4) were providing PC for cancer patients (39).

An institution-based cross-sectional study was conducted to assess the knowledge, accessibility, and utilization of PC services among 384 adult cancer patients receiving palliative care service at Tikur Anbessa specialized hospital (TASH), Ethiopia found that majority of respondents 85 (60.7 %) reported that they had no knowledge of PC services for cancer. It was found that the client's previous knowledge, physical well-being, social well-being, monthly income, and marital status were significantly associated with respondent's utilization of PC services (39).

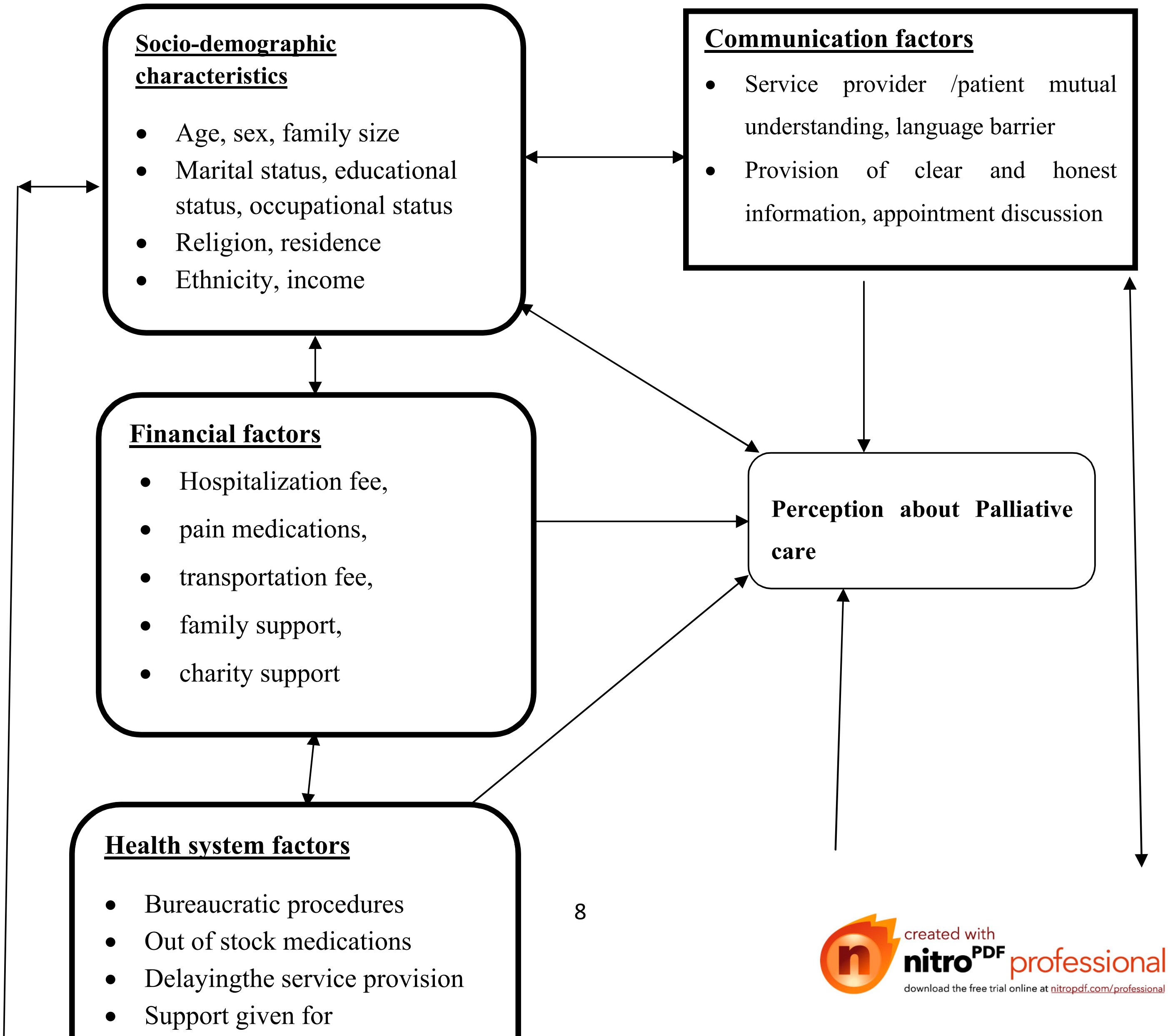
2.2.4 Communication factors

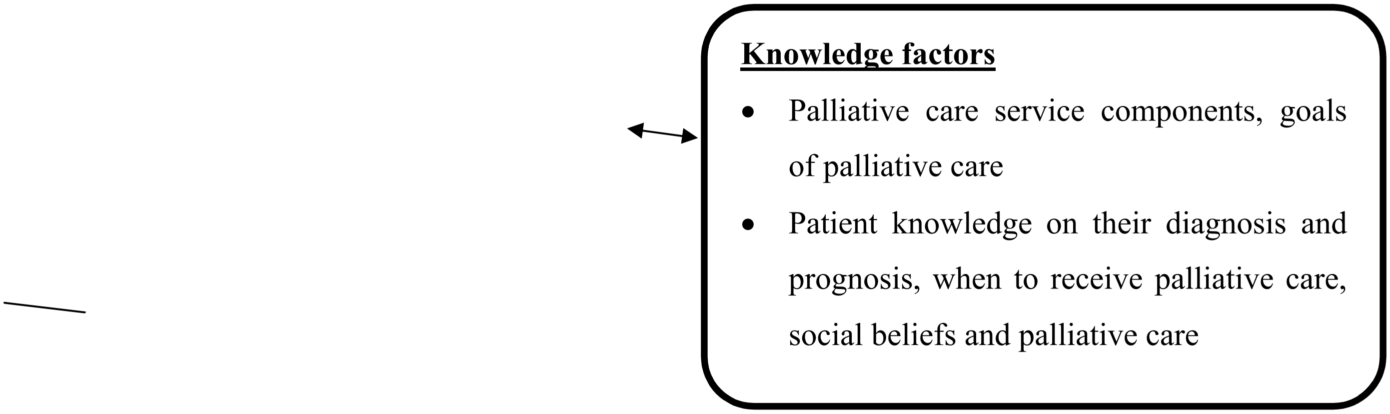
In a study conducted to assess the impact of palliative care consultation on symptom assessment, communication needs, and palliative interventions found that service providers avoid conversations about death and dying in order not to upset young patients and their families and such conversations will disrupt the "culture of hope" (40). Similarly, a prospective cohort study conducted in the United States found that individual physician characteristics are among the strongest predictors of whether a patient receives hospice care (41).

a multi-centered study evaluating a communication skills training model for clinicians showed that 87% of cancer patients wanted all possible information, both good and bad news and 98% (2203) preferred to know whether or not theirillness was cancer. The few 58/440 (13.2%) patients who stated that in general they preferred to leave disclosure ofdetails up to thetreating physician, tended to be older patients more than 70 years of age ($\chi^2 = 26.01$, df = 2,P< 0.0001), majority of patients with cancer want a great deal of specific information concerning their illness andtreatment. Failure to disclose such information because significant numbers of patients prefer not to know is untenable(42).

In Ethiopia palliative care service provision is limited in Tikur Anbessa Hospital (there are progress in decentralizing the service to other public hospitals) because of many uninvestigated factors, some of which are related to the patient with regard to knowledge to palliative care service, financial constraints, factors related to the health system which can affect patient or caregiver and physician communication. There is a need to quantify the factors which are strongly associated with palliative care service utilization,to improve the consequences to the patient, caregiver, family and the nation as a whole.

2.3 Conceptual Framework





Knowledge factors

- Palliative care service components, goals of palliative care
- Patient knowledge on their diagnosis and prognosis, when to receive palliative care, social beliefs and palliative care

Figure 1: Adapted and modified socio-ecological model (43) for describing factorsthat affectpalliative care service utilization among adult cancer patients, 2019.

2.4 Research questions

1. What is the perception about palliative care serviceamong adult cancer patients?
2. What are thefactors associated with palliative care service utilization?

3. OBJECTIVES

3.1 General Objective

To assess the perceptionabout palliative care and factors influencing the likelihood of service utilization among adult cancer patients in Tikur Anbessa specialized hospital, from January 1 to march 31, 2019.

3.2 Specific Objectives

1. To assess the perceptionon the availability of palliative careamong adult cancer patients in Tikur Anbessa Specialized Hospital, Ethiopia from January 1 to March 31, 2019.
2. To identify factors associated with the utilization of palliative care serviceamong adult cancer patients in Tikur Anbessa Specialized Hospital, Ethiopia from January 1 to March 31, 2019.

4 METHODS AND MATERIALS

4.1 Study area and period

The study was conducted at the cancer unit of Tikur Anbessa Specialized Hospital (TASH)located in Addis Ababa, the capital city of Ethiopia. TASH is the only tertiary referral hospital in the country with over 700 beds, whereby palliative care services and treatment virtually exists. The Hospital has 20 beds devoted to cancer care and there are three in-patient and two out-patient rooms in the oncology department and on average ten adult cancer patients receive palliative care service from the cancer unit of TASH daily(44). The cancer unit provides chemotherapy, radiation therapy; complain therapy and other supportive and palliative care services. It is the main center for cancer registry, early detection, prevention, standard treatment and palliative care in Addis Ababa.TASH also acts as a teaching hospital for college of health science, Addis Ababa University for the training of highly skilled undergraduate and postgraduate medical students, dentists, radiologists, and other allied health science professionals(45). The study was conducted from January 1 to March 31, 2019.

4.2 Study design

A facility-based cross-sectional study was conducted

4.3 Populations

4.3.1 Source population

All adult cancer patients (aged ≥ 18 years) diagnosed in the cancer unit of TASH were considered as the source population.

4.3.2 Study Population

Systematically selected adult cancer patients (aged ≥18 years) diagnosed with cancer in the cancer unit of TASH were considered as the study population.

4.4 Eligibility criteria

4.4.1 Inclusion criteria

All adult cancer patientswho had diagnosed with any type of cancer before the data collection period were included in the study.

4.4.2 Exclusion criteria

Those newly diagnosed cancer patients diagnosed during the data collection period, those critically ill patients; those who have knownhearing problem and cognitively impaired to give consent were excluded from the study.

4.5 Sample size determination and sampling technique

4.5.1 Sample size determination

The sample size was determined by applyinga single population proportion formula using Epi Info version 7.2.3.1 software (46), with the assumptions of a 95% level of confidence, 5% margin of error. Accordingly, sample size was determined for each specific objective, the first specific objective provided the largest sample size to detect a statistically significant difference, palliative care utilization among adult cancer patients was 26% (33),with these assumptions the sample size was 296 and after adding 10% non-response rate the final sample size was 329.

4.5.2 Sampling technique

Systematic random sampling technique was used to select the study participants and the registration log book of adult cancer patients was obtained from the cancer unit of TASH and in 2010 E.C there were a total of 28,814adult cancer patients came to receive chemotherapy and radiotherapy services and over the last quarter of the same fiscal year 6,354 adult cancer patients received chemotherapy and radiotherapy services. The sampling interval (K) was obtained by dividing 6,354 to 329 and it was (K= 19.3), so that every 20thadult cancer patient coming to receive the routineservice was recruited to the study.

4.6 Data collection instrument and process

4.6.1 Data collection instrument

A pre-tested structured interviewer-administered questionnaire was used to collect the data. The questionnaire was derived from different works of literature and contains important variables, which were organized according to the objective of the study. The interviewer-administered questionnaire was prepared in English then translated into the local language (Amharic) and re-translated back to English to maintain its consistency. The responses were scored on 5 points Likert scale, that is 1 (Strongly Disagree), 2 (Disagree), 3 (neutral), 4 (Agree) to 5 (Strongly Agree). An equal number of positively and negatively worded questions were formulated, to determine the proportion of adult cancer patients who utilized palliative care service the five Likert scales were adjusted into a 0 to 100 scale by utilizing a Likert transformation formula. The respondents who score above the mean of the adjusted score were considered as those who have good perception about palliative care and more likely to utilize palliative care service and those respondents who scored below the mean of the adjusted score were considered as those who do not have good perception about palliative care and less likely to utilize palliative care service.

4.6.2 Data Collection Process

Data were collected by face-to-face interviews in a quiet and confidential room at the cancer unit of TASH after patients have received their respective service by four degree holder nurses and supervised by one master's degree holder nurse who was not providing palliative care service on the cancer unit of TASH and the data collectors were independent of the usual care and training was given for the data collectors on the contents of the questionnaire and how to approach the respondents for two days prior to the data collection period by the principal investigator.

4.7 Operational definitions

Adult cancer: The diseases of the population aged 18 years and above (6).

Caregiver: An individual is considered as a caregiver if s/he is a spouse, relatives or friends involved in the patients' care (6).

Hospice care: is an end-of-life medical, psychological and spiritual support care provided by health professionals and volunteers (6).

Terminal cancer: refers to an advanced stage when curative treatment is no longer useful, the disease is assessed to be incurable and the patient's condition is progressively deteriorating, has a life expectancy of six months or less (6,47).

Unmet palliative care: needs management of symptoms, financial burden, psychosocial burden born by family caregivers and other marginalized groups (8).

Physical Support: it is support given for the treatment of pain and other symptoms such as maintaining cognition function, safety, mobility, swallowing, excretion and physiologic system of the body (47).

Psychological Support: it is a support given for maintainingpersonality, strengths, behavior, motivation along with prevention and treatment of depression, anxiety emotions (e.g., anger, distress, hopelessness, and loneliness), fears (e.g., abandonment, burden, and death) and control, dignity, independenceConflict, guilt, stress, coping responses, self-image and self-esteem (47).

Palliative care service utilization: The respondents who score above the mean of the adjusted score were considered as those who has good perception and more likely utilized about palliative care serviceand those respondents who scored below the mean of the adjusted score were considered as those who do not have good perception about palliative care and less likely utilized palliative care service.

Social Support: It is support given for maintainingcultural values, beliefs, and practices. It is also maintaining relationships, roles with family, friends, and community along with prevention of sense of isolation and abandonment, which also includes reconciliation safe, comforting environment, privacy, intimacy along with participating in routines, rituals, recreation, vocation financial resources and family caregiver protection guardianship and custody issues (47).

Spiritual Support: it is support given for meaning, value existential, transcendental values, beliefs, practices, affiliations, spiritual advisors, rites, rituals symbols and icons (20).

4.8 Study variables

4.8.1 Dependent variable

Perception about palliative care service

4.8.2 Independent variables

The independent variables are:

1. Socio-demographic characteristics: has 10 items,
2. Knowledgefactors: has 6 items
3. Financial factors: has 5 items,
4. Communication factors: has 4 items and
5. health system factors which have 8 items

4.9 Data Processing and management

The collected data was coded and checked for its consistency and completeness up to the end of each data collection period. Before the analysis, the whole data were cleaned and 20% of the data were double-entered randomly to check for data entry errors and Epi Info version 7.2.3.1 software (46) was used for data entry.

4.10 Data Analysis

The entered data were exported to Statistical Package for the Social Sciences (SPSS) version 25.0 for windows. Descriptive statistics were presented inmedians with interquartile range for numerical variables and categorical variables were presented using frequency and percentages. Chi-square test and logistic regression were computed to assess the statistical association.

The bivariate analysis was done to check the existence of crude association and to select candidate variables, those variables which are clinically important and having ($P < 0.25$) were included into the final model (48). Confounding was checked and percentage change in the regression coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect model was also be checked and partial likelihood ratio test result with p-value > 0.05 and Variance inflation factor less than 10 indicating the non-existence of multicollineality among the independent variables.

The multivariable binary logistic regression model was used to identify the independent factors associated with perception of palliative care service utilization. The summary measures of estimated crude (COR) and adjusted odds ratios (AOR) with 95% confidence interval were presented and P-value less than 0.05 was used to declare statistical significance and goodness of fit of the model was assessed by using Hosmer and Lemeshow goodness of fit test. Finally, the results were presented in statements, tables, and figures.

4.11 Data quality assurance

To assure the quality of the data, properly designed data collection tool was prepared before beginning of the actual data collection process and closed supervision were carried out by the principal investigator during data collection, the collected data were reviewed by the principal investigator, any problems faced in the time of data collection were discussed and corrective measures were made immediately. The pretest was done one week before the actual data collection period among17 (5%) of similar study populations in Saint Paul hospital to ensure clarity, wordings, logical sequence and skip patterns and some or total modification were done on questions that created any ambiguity and that have an effect on the consistency of data. During the pre-test, internal consistency among the questionnaire items was also assessed by Cronbach's alpha (α) and it was greater than 0.7 that suggeststhe items were internally consistent.

4.12 Ethical considerations

Ethical approval was obtained from the research and ethical committee (REC) of the School of Public Health, college of health science, Addis Ababa University. The chief executive director of TASH was informed about the objective of the study and written permission was obtained before starting data collection. All participants were asked to provide written Informed consent if they can write and for those who cannot write they were asked to use inked thumbprint the consent form in the presence of an independent witness.

Each respondent was informed about the objective of the study and assurance of confidentiality, risks, and benefits. The extracted data will not be used for any other purpose and all the collected patient information was stored anonymously. The data were stored on a password-protected computer, and paper data collection forms were stored in a locked cabinet in the principal investigator's office.

4.13 Dissemination of findings

After the completion of the study, the finding report after being defended at the School of Public Health, College of Health Science, Addis Ababa University it will be submitted to School of Graduate Studies of Addis Ababa University, principal and co-advisors of the thesis, TASH medical director office, and concerned others. The result will be disseminated through workshops, seminars and published in an international, professional high impact journal.

5. RESULTS

5.1 Socio-demographic characteristics of patients

There were 304 adult cancer patientswho participated in the study, with a response rate of 92.4%. The median age of the patients was 56 years, with an interquartile range of (44.3 - 62) years. One hundred eighty-one (59.5%) of the patients were females and 173(56.9%) of the patients were rural residents. Concerning the patient's family size 169(55.6%) of them had more than five families as shown below in (Table 1).

Table 1: Socio-demographic characteristics of adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital, Ethiopia, 2019 (n=304).

Patient Profile		**Frequency**	**Percent**
Age (years)	< 35	57	18.8
	≥ 35	247	81.2
Sex	Female	181	59.5
	Male	123	40.5
Religion	Orthodox	192	63.2
	Muslim	80	26.3

	Protestant	31	10.2
	Others	1	0.3
Residence	Rural	173	56.9
	Urban	131	43.1
Educational status	No formal schooling	147	48.4
	Primary completed	39	12.8
	Secondary completed	69	22.7
	College/university	48	15.8
	Postgraduate degree	1	0.3
Ethnicity	Amhara	110	36.2
	Oromo	102	33.6
	Tigre	29	9.5
	Sidama	47	15.5
	Wolayta	14	4.6
	Others	2	0.7
Marital status	Single	58	19.1
	Married	191	62.8
	Divorced	15	4.9
	Widowed	40	13.2
Occupational status	Housewife	86	28.3
	Farmer	69	22.7
	Self-employed / NGO[1]	64	21.1
	Government employee	44	14.5
	Student	28	9.2
	Others	13	4.2
Average family monthly income (in Ethiopian birr)	<500	18	5.9
	500- 1,500	78	25.7
	1,500-2,500	94	30.9

	>2,500	114	37.5

[1]NGO= Non-governmental organization

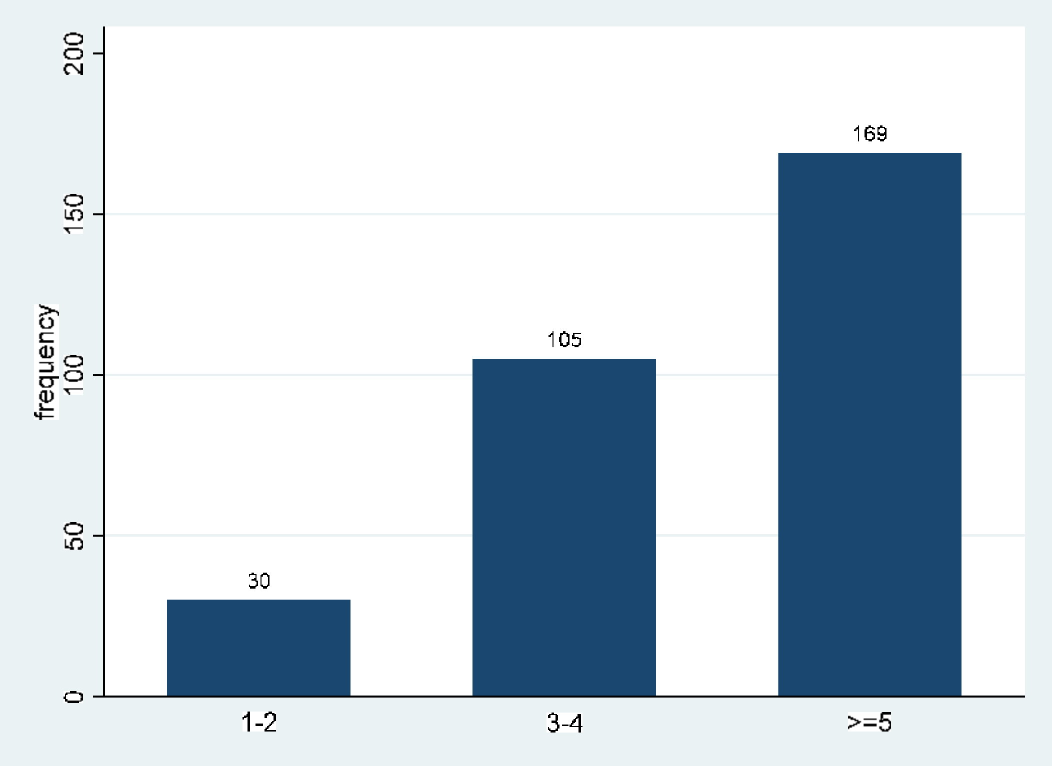


Figure 2: The family size of adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital, Ethiopia, 2019 (n=304).

Concerning the family size of adult cancer patients receiving palliative care service, 169(55.6%) of them had more than five family members, followed by those who had three to fourfamily members, 105(34.54%) as shown above (Figure 2).

5.2 Perception and knowledge of Palliative care service

In the Likert scale data analysis, there were four domains (Financial, Health system,Knowledge and Communication factors) each containing 5, 8, 6 and 4 Likert items respectively with the overall Cronbach's alpha level of 0.75, indicating very good internal consistency of the items. Concerning the financial factors, 235(77.3%) of patients strongly agreed that patients are facing difficulty in obtaining transportation while they travel to the hospital to receive palliative care service. The total mean score of financial barrier items was 22.51, which ranges from 4.2 to 4.8 and a standard deviation of 0.49 to 0.92 as shown below (Table 2).

Table 2: Financial factorsfaced by adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital,Ethiopia, 2019 (n=304).

Items	Strongly disagree Frequency (%)	Disagree Frequency (%)	Neutral Frequency (%)	Agree Frequency (%)	Strongly agree Frequency (%)	Mean /SD
Patients are facing financial shortage for hospitalization fee	2(0.7)	2(0.7)	9(3)	93(30.6)	198(65.1)	4.6(0.65)
Patients are facing financial loss for buying the prescribed medications (opioid analgesic)	1(0.3)	2(0.7)	2(0.7)	79(26)	220(72.4)	4.7(0.55)
While traveling to the hospital patients are having difficulty in obtaining transportation	1(0.3)	1(0.3)		67(22)	235(77.3)	4.8(0.49)
Patients are forced to stop palliative care service due to lack of family support	20(6.6)	16(5.3)	1(0.3)	97(31.9)	170(55.9)	4.3(1.14)
Families are forced to stop palliative care service due to lack of	134(44.1)	132(43.4)	12(3.9)	22(7.2)	4(1.3)	4.2(0.92)

financial support by charities						
Total mean score						**22.51**

Concerning the health system factors, 174(57.2%) of patients strongly agree that there is delay during transfer patient data from the medical record room to the service provider room and 214(70.4%) of patients are forced to buy prescribed medications outside due to stock-outs. A significant number of patients agree that patients should be provided with the recreation facilities within the hospital premises while they are receiving palliative care servicesand the total mean score of health system factors items was 29.16 as shown below (Table 3).

Table 3: Health system factors faced by adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital,Ethiopia, 2019 (n=304)

Items	Strongly disagree Frequency (%)	Disagree Frequency (%)	Neutral Frequency (%)	Agree Frequency (%)	Strongly agree Frequency (%)	Mean /SD
The hospital has bureaucraticprocedures for receiving care	3(1)	28(9.2)	11(3.6)	139(45.7)	123(40.5)	4.15 (0.94)
Patients are forced to buy prescribed medications outside due to stock-outs	6(2)	8(2.6)	4(1.3)	214(70.4)	72(23.7)	4.11 (0.72)
Patients should be provided with the recreation facilities within the hospital premises	3(1)	11(3.6)	46(15.1)	216(71.1)	28(9.2)	3.84 (0.67)
The service providersprovide support for the patients/caregivers duringthe visit	1(0.3)	55(18.1)	51(16.8)	133(43.8)	64(21.1)	3.67 (1.01)
palliative care can be	3(1)	57(18.8)	50(16.4)	124(40.8)	70(23)	3.76

delivered concurrently with curative cancer treatments						(1.06)
Palliative care represents a distinct phase in cancer treatment.	67(22)	94(30.9)	61(20.1)	78(25.7)	4(1.3)	2.53 (1.13)
The service providers give enough time and attention to their patients	22(7.2)	139(45.7)	31(10.2)	82(27)	30(9.9)	2.87 (1.18)
There isdelay during transfer patient data from the medical record room to the service provider room	6(2)	28(9.2)	2(0.7)	94(30.9)	174(57.2)	4.32 (1.01)
Total mean score						**29.16**

Concerning knowledge factors that hinder patients not to utilize palliative care service revealed that 97(31.9%) of patients believe that palliative care should be started when medical and surgical methods of treatment are ineffective. One hundred sixty-six patients (54.6%) of patients were not informed about their diagnosis and prognosis by their respective service provider. The total mean score of the items in the knowledge factors was15.1 as shown below (Table 4).

Table 4: Knowledge factorsfaced by adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital,Ethiopia, 2019 (n=304).

Items	**Strongly disagree Frequency (%)**	**Disagree Frequency (%)**	**Neutral Frequency (%)**	**Agree Frequency (%)**	**Strongly agree Frequency (%)**	**Mean /SD**
Palliative care is essentially the care for terminally ill patients.	61(20.1)	84(27.6)	31(10.2)	126(41.4)	2(0.7)	2.75 (1.2)
Palliative care is all about pain management	43(14.1)	49(16.1)	16(5.3)	184(60.5)	12(3.9)	3.24 (1.2)
Palliative care is a service only for patients with cancer.	59(19.4)	83(27.3)	24(7.9)	130(42.8)	8(2.6)	2.88(1.7)
Palliative care should be started when medical and surgical methods of treatment are ineffective.	63(20.7)	89(29.3)	53(17.4)	97(31.9)	2(0.7)	2.63(1.2)
Physicians routinely inform patients about their diagnosis and prognosis	112(36.8)	166(54.6)	6(2)	11(3.6)	9(3)	1.81(0.9)
Physiciansdiscuss end-of-life issues with their patients	0	11(3.6)	13(4.3)	164(53.9)	116(38.2)	1.73(0.7)
Total mean score						**15.1**

Concerning the communication factors that patients face, while they receive palliative care service were, 142(46.7%) of patients were not provided clear appointments about their next visit. One hundred fifteen (37.8%) patients or their respective caregiver doesn't receive clear and honest information about their condition and prognosis. The total mean score of the items was 2.7 as shown below (Table 5).

Table 5: Communication factors faced by adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital, Ethiopia, 2019 (n=304).

Items	Strongly disagree Frequency (%)	Disagree Frequency (%)	Neutral Frequency (%)	Agree Frequency (%)	Strongly agree Frequency (%)	Mean /SD
The service providers give clear appointments about the next visit	67(22)	142(46.7)	29(9.5)	60(19.7)	6(2)	2.33(1.1)
There are agreements between patients and service providers when discussing their patient needs	3(1)	56(18.4)	40(13.2)	142(46.7)	63(20.7)	2.32(1.1)
Patients/ respective caregiverreceive clear and honest information about their condition and prognosis	53(17.4)	48(15.8)	13(4.3)	115(37.8)	75(24.7)	3.37(1.4)
There are language factors betweenservice providers and patients	45(14.8)	94(30.9)	84(27.6)	75(24.7)	6(2)	2.68(1.1)

/caregivers						
Total mean score						**2.7**

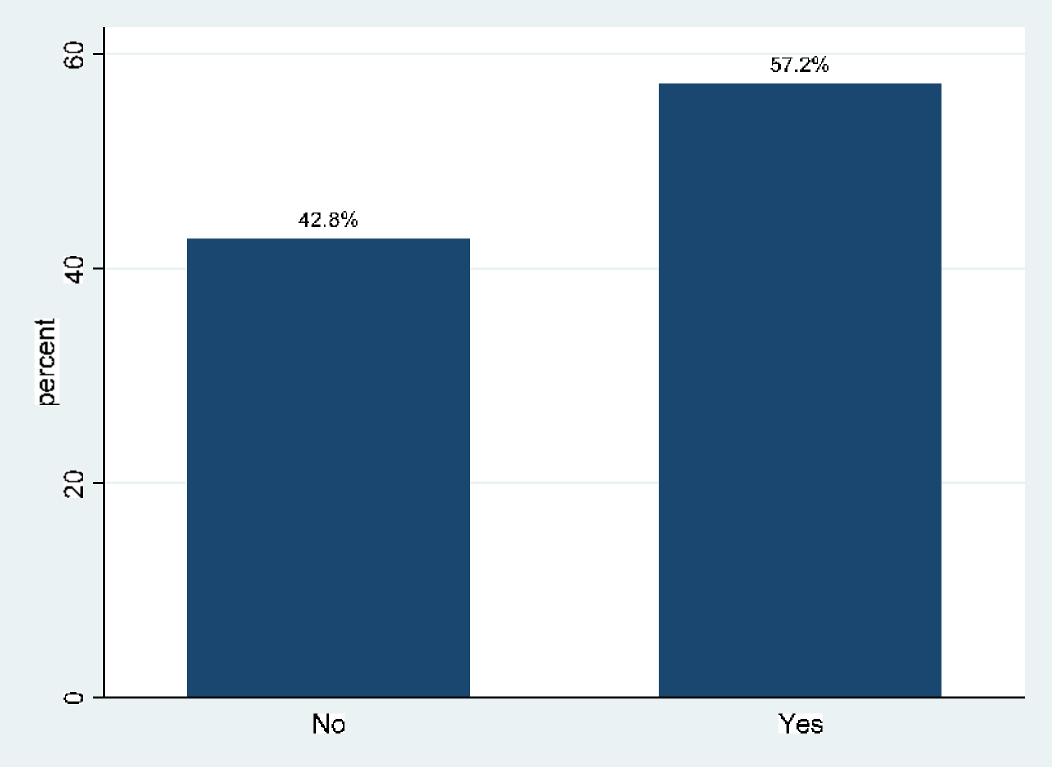


Figure 3: perception aboutPalliative care service utilization among adult cancer patients in Tikur Anbessa Specialized Hospital,Ethiopia, 2019 (n=304).

130(42.8%) of adult cancer patients are not have good perception and less likely to utilized palliative care and 174(57.2%) of patients has good perception about palliative care and more likely to utilized palliative care service as shown above (Figure 3).

5.3 Factors influencing the likelihood of palliative care service utilization

There is a statistically significant association between educational status and palliative care service utilization (χ^2= 6.4, df=1, P-value=0.01).Similarly, there is a statistically significant association between marital status, occupational status, family size, and average family monthly income. There is nostatistically significant association between age of the patient and palliative care service utilization (χ^2= 2.8, df=1, P-value=0.1). Similarly, there is no statistically significant association between the sex of the patient and palliative care service utilization as shown below (Table 6).

Table 6: Chi-square test for determining factors associated with palliative care service utilization among adult cancer patients in Tikur Anbessa Specialized Hospital,Ethiopia, 2019 (n=304).

Characteristics		**Palliative care service utilization**		**χ^2 value (df)**	**P-value (χ^2)**
		Yes	**No**		
Age (years)	<35	30(9.9)	27(8.9)	2.8(1)	0.1
	≥ 35	100(32.9)	147(48.4)		
Sex	Male	52(17.1)	71(23.4)	0.02(1)	0.9
	Female	78(25.7)	103(33.9)		
Residence	Urban	55(18.1)	76(25)	0.06(1)	0.8
	Rural	75(24.7)	98(32.2)		
Educational status	No formal schooling	52(17.1)	95(31.3)	6.4(1)	0.01*
	Formal schooling	78(25.7)	79(26)		
Marital status	Single	34(24.8)	24(33.2)	7.4(1)	0.007*
	Married	96(31.6)	150(49.3)		
Occupational status	Government Employed	26(8.6)	18(5.9)	5.6(1)	0.02*
	Non-government	104(34.2)	156(51.3)		
Family size	≤2	18(5.9)	12(3.9)	4.1(1)	0.04*
	≥3	112(36.8)	162(53.3)		
Monthly income (in ETB)	<1,500	50(16.4)	46(15.1)	4.98(1)	0.03*
	≥1,500	80(26.3)	128(42.1)		

In the final multivariable binary logistic regression model those variables which were clinically important (sex of the patient and place of residence) and variables which had P-value < 0.25 in the bivariate analysis and non-collinear independent variables were the candidate variables included in the final model. The variables selected for the multivariable analysis were the age and sex of the patient, place of residence, educational status, occupational status, marital status, family size and average family monthly as shown below (Table 7).

According to the final multivariable binary logistic regression model, after controlling the effect of confounders patients who earn more than 1,500-birr monthly income been 2.36 times more likely to utilize palliative care service as compared to their counterparts who earn a monthly income of less than 1,500 birrs (AOR=2.36, 95% CI 1.37,4.06).

Similarly, those patients who had more than two family membersbeen2.28 times more likely to utilize palliative care service as compared to their counterparts who had less than or equal to two family members (AOR= 2.28, 95% CI 1.02, 5.13), after controlling the effect of other confounders. After controlling the potential confounders, the odds of utilizing palliative care service among individuals who had formal schooling was 49% less likely than their counterparts who had no formal schooling (AOR=0.51, 95% CI 0.23,0.94).

The chance of utilizing palliative care service among government employers was 58% less likelythan their counterpart non-government employers (AOR= 0.42, 95% CI 0.20, 0.87) after controlling the effect of other confounders as shown below(Table 7).

Table 7: Bivariate and Multivariable binary logistic regression for determining factors influencing the likelihood palliative care service utilization among adult cancer patients in Tikur Anbessa Specialized Hospital,Ethiopia, 2019 (n=304).

Characteristics		**Palliative care service utilization**		**COR**	**P-value**	**AOR (95% CI)**	**P-value**
		Yes	**No**				
Age (years)	<35	30(9.9)	27(8.9)	Ref			
	≥ 35	100(32.9)	147(48.4)	1.63	0.10	0.87(0.37,2.10)	0.76
Sex	Female	78(25.7)	103(33.9)	Ref			
	Male	52(17.1)	71(23.4)	1.03	0.89	1.12(0.67,1.87)	0.67
Residence	Rural	75(24.7)	98(32.2)	Ref			
	Urban	55(18.1)	76(25)	1.10	0.81	1.45(0.82,2.56)	0.21
Educational status	No formal schooling	52(17.1)	95(31.3)	Ref			
	Formal schooling	**78(25.7)**	**79(26)**	**0.55**	**0.01**	**0.51(0.23,0.94)**	**0.03***
Marital status	Single	34(24.8)	24(33.2)	Ref			
	Married	96(31.6)	150(49.3)	2.21	0.01	2.14(0.88,5.23)	0.10
Occupational status	Non-government	26(8.6)	18(5.9)	Ref			
	Government Employed	**104(34.2)**	**156(51.3)**	**0.46**	**0.02**	**0.42(0.20,0.87)**	**0.02***
Family size	≤2	18(5.9)	12(3.9)	Ref			
	≥3	**112(36.8)**	**162(53.3)**	**2.17**	**0.05**	**2.28(1.02,5.13)**	**0.04***
Monthly income (birr)	<1,500	50(16.4)	46(15.1)	Ref			
	≥1,500	**80(26.3)**	**128(42.1)**	**1.74**	**0.03**	**2.36(1.37,4.06)**	**0.002***

* indicates the variables were significant at $P<0.05$, COR= Crude odds ratio, AOR= Adjusted odds ratio, CI= confidence interval, Ref= reference group (those least to utilize palliative care service were considered as a reference group).

6. DISCUSSIONS

Palliative care is poorly addressed public health problem with scarce data on the factors associated with service utilizationand this is the first Ethiopian study which tried to assess palliative care service utilization and associated factors among adult cancer patients receiving palliative care service in Tikur Anbessa Specialized Hospital, found that 57.2% of adult cancer patients utilized palliative care service. Among those who utilized palliative care service the majority of them have more than three family members and earn more than 1,500-birr monthly income. In contrast to this, a study conducted before five years in the same study area found that only 26%(33)of adult cancer patients received the service, this could be due to improvement of palliative care service over time.

Palliative care service utilization in united states is more than 90% (25), whereas in Europe it ranges from 50-65% of adult cancer patients received palliative care service by their general practitioners whereas 29-47% patients received specialist palliative care service (26). This could be due to the differences in the accessibility, affordability and socio-economic status of the countries. A survey of hospice and palliative care services on conducted in Africa found that only 9% (29) of cancer patients were receiving the necessary palliative care service, this shows that there is significant unmet palliative care need.

In our study older cancer patients were13% less likely to utilize palliative care service as compared to younger cancer patients, but this was not statistically significant after controlling the effect of other covariates. Even though male cancer patients are more likely to utilize palliative care serviceas compared to female patients after controlling the effect other confounders, this was not found to be statistically significant difference. In contrast this, a study conducted in Belgium found that female cancer patients were almost three times more likely to utilize palliative care service as compared to male cancer patients (49). This can be explained by differences in socio-economic status of patients and sample size.

In spite of being statistically non-significant, urban residents were 45% more likely to utilize palliative care servicethan their counterpart rural residents after controlling the effect of other covariates. Those adult cancer patients who have formal schooling were 49% less likely to utilize palliative care service as compared to those who have no formal schooling. This might be due to the difference in the proportion of the patients, majority of them had formal schooling.

Those married adult cancer patients were two times more likely to utilize palliative care service as compared to those who are single, even though it was not statistically significant difference. In line with our study, a study conducted in Qatar (50) found that married patients were found to utilize more than single patients after controlling the effect of other covariates. In contrast to these studies, a study conducted in Addis Ababa found that, single patients were more likely to utilize palliative care service (30). This can be explained by single patients want to be relatively healthy for the next marriage and they want to live a quality life as compared to those who are already married.

Adult cancer patients who have more than three family members are almost three times more likely to utilize palliative care serviceas compared to those who have less than three family members, after controlling for the potential confounders. In agreement with our study, a study conducted in Addis Ababa (30) found that Adult cancer patients who have more family members were almost two times more likely to utilize palliative care service as compared to those who don’t have any family support or social services. This could be due to the involvement of the family members in the provision of social, economic and moral support given for their family members.

In contrast to our study, a study conducted in Australia found that those living alone are more likely to receive palliative care service (51).This can be explained by the complete allocation of their income for palliative care service, since they don’t have any extra expense to be used by other family members. Adult cancer patients who earn more than 1,500-birr monthly income were almost three times more likely to utilize palliative care service as compared to their counterparts who earn a monthly income of less than 1,500 birrs, after controlling the effect of other covariates. In line without study, a study conducted in Canada (31), Texas (32) found that higher socioeconomic status was associated with a higher likelihood of a palliative care service utilization, this helps the patient to have better health and health care understanding, a higher capacity for advocacy, a more stable home environment, and more caregiver support.

Similarly a study conducted in Addis Abba found that almost 30% (33)of patients face a higher cost of palliative care service and around half of the patients were not able to access the service. Similarly, a study conducted in Addis Ababa and Jimma found that opioid analgesics were not prescribed for 24% of patients and 64% of the patients reported having sold their homes and other significant sources of wealth to pay for medical care (34).

7. STRENGTH AND LIMITATION OF THE STUDY

7.1 strengths of the study

Thisis the firststudy in Ethiopia that tried to address the financial, health system, knowledge and communication factorswhichare associated with palliative care service utilization from the patient side using standard method of data collection and standard models of identifying factors for palliative care service.

7.2 Limitation of the study

The study is not without limitations, first, the study does not measure actual service utilization and it was measured by considering the perception of the respondents on the factors related to financial, health system, knowledge, communication so that the outcome is simply a proxy indicator for use of palliative care not actual service use. Second it would have been better if it includes supplementary qualitative aspect from the service provider side, so that the factors can be more identified, since the service is mainly confined in Tikur Anbessa, the findings of this study may not be representative of the whole nation.

8. CONCLUSION AND RECOMMENDATIONS

8.1 Conclusions

This study found that significant number of adult cancer patients were not have good perception and more likelihood service utilization. also, around half of the patients had faced financial shortage to receive the service, health system related bureaucracies, knowledge and communication difficulties while they were receiving palliative care service. Higher monthly income and having more than two family members were the factors associated with palliative care service utilization.

8.2 Recommendations

Clinicians: We recommend clinicians to strengthen informing patients about their diagnosis, prognosis and subsequent follow up, so as to ultimately improve the quality of life of the patient until death.

Researchers: We recommend researchers and the scientific community as whole to determine the factors associated with palliative care service utilization by conducting community-based studies using mixed approaches of both qualitative and quantitative methods from different stakeholders involved in palliative care service provision.

Policy makers: We recommend policy makers to design locally appropriate strategies to reduce the health system bureaucracies, financial constraints that hinder patients not to utilize palliative care service and to improve social support for those who have few or no family members.

Non-governmental organizations: We recommend non-governmental organizations to strengthen the financial and social support given for cancer patients while receiving palliative care serviceand to integrate them to the community-based hospice care.

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Annex

AnnexI: English version of the information sheet

PERCEPTION ABOUT PALLIATIVE CARE AND FACTORS INFULEMCING THE LIKELIHOOD OF SERVICE UTILIZATION AMONG ADULT CANCER PATIENTS IN TIKUR ANBESSA SPECIALIZED HOSPITAL

Hello: Good morning /afternoon?

I would like to start by extending a sincere welcome. It is my pleasure to introduce myself, my name is__________________________I am data collector of MihretFikre who is graduating student by Master of Public Health with specialty in Health System Management at the school of Public Health, Addis Ababa University. I am here today to collect data on *'' perception about Palliative care and factor influencing the likelihood of service utilization among adult cancer patients in Tikur Anbessa Specialized Hospital*.

Procedures

Your selection for this particular study is randomly and participation in this study is based on your voluntariness. You have a full right not to participate in this study; however, we encourage you to participate since your responses are very important to look at the potential factors to palliative care service utilization. If you agree to participate, you will be asked some general questions about your background, such as your age, marital status, education level, ethnicity, religion, income, and occupational status. You will also be asked about specific questions on the type of cancer diagnosis made, time since when you accessed palliative care and on your functional status. We want you to reflect your personal experiences or views on the possible factors that patients are facing when they access palliative care service. The interview will last about 20 to 30 minutes.Therefore, your honest and genuine responses are crucial for the success of this study.

Risks and discomforts

In this particular study, there are no procedures and questions that may harm or give you a feeling of discomfort. You can refuse to answer any question or stop the interview at any time. It is also your right not to give a response to some of our questions if you don't want to respond.

Benefits

What we will learn from the research will be used to recommend policymakers and health planners to appropriately design effective and accessible palliative care service. In the course of the interview, you may learn new information about palliative care.

Confidentiality

Your name will not be recorded on the questionnaire either reported in any project document and all your answers will be strictly confidential and will be kept in a locked cabinet. The findings of this study will be presented in different seminars and workshops and your personal information will not be mentioned. If you have any questions, please feel free to ask at any time. Therefore, your honest and genuine responses are crucial for the success of this study. So, we kindly request your participation. Do you have any questions concerning this study? If you want to ask a further clarification on the study you can contact MihretFikre, the principal investigator of this study via her cell phone number 0911-543474 or email address mihretliya@gmail.com at any time that you need clarification.

May I have your permission to go to the consent form?

- **Yes.............. (Continue)**
- **No................... (Stop)**

Annex II : English version of the consent form

According to the above information given to me regarding the objective of the study, procedures, risks, and discomforts, benefits of the study and confidentiality of the responses, I agree to be interviewed for all the questions that the interviewer asks me and I approve with my signature. If the participant is unable to sign please ask her/him to put inked thumbprints on the consent form.

Name and signature of the consenting interviewer______________________, _________
Respondent signature____________________________

May I have your permission to proceed to the interview?

1. **Yes............. (If Yes, start the interview)**
2. **No.................. (Thank you, stop here)**

Result of the interview:

1. **Completed**
2. **Partially completed**

Supervisors name & signature________________________, ____________
The time that the interview has started______________________________
The time that the interview has completed___________________________

Annex III : English version of the questionnaire

Instruction: circle the response from the alternatives

Part one: Socio-demographic characteristics

Patient Profile			
Age (years) ______________________________		**Sex**	1. Male
			2. Female
Religion	1. Orthodox	**Educational status**	1. No formal schooling
	2. Muslim		2. Primary completed
	3. Protestant		3. Secondary completed
	4. Others (specify___)		4. College/university
Ethnicity	1. Oromo		5. Postgraduate degree
	2. Amhara	**Marital status**	1. Single
	3. Tigre		2. Married
	4. Sidama		3. Divorced
	5. Wolayta		4. Widowed
	6. Others (specify)	**Residence**	1. Urban
Family size	1. 1-2		2. Rural
	2. 3-4	**Occupational status**	1. Government employee
	3. ≥5		2. Self-employed / NGO
Average family monthly income (in ETB)	1. <500		3. Farmer
	2. 500- 1,500		4. student
	3. 1,500-2,500		5. Housewife
	4. >2,500		6. Others (specify___)

Part two: Factors to palliative care service utilization

Instruction: ✓ he response from the alternatives

Items	Responses				
	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
A. Financial Factors					
Patients are facing financial shortage for hospitalization fee					
Patients are facing financial loss for buying the prescribed medications (opioid analgesic)					
While traveling to the hospital patients are having difficulty in paying for transportation					
Patients are not forced to stop palliative care service due to lack of family support					
Families are not forced to stop palliative care service due to lack of financial support by charities					
B. Health system factors					
The hospital has no bureaucratic procedures for receiving care					
Patients are forced to buy prescribed medications outside due to stock-outs					
Patients should be provided with the recreation					

facilities within the hospital premises					
The service providers do not provide support for the patients/caregivers during the visit					
palliative care cannot be delivered concurrently with curative cancer treatments					
Palliative care represents a distinct phase in cancer treatment.					
The service providers give enough time and attention to their patients					
There is no delay during transfer patient data from the medical record room to the service provider room					
C. Knowledge and cultural factors					
Palliative care is essentially the care for terminally ill patients.					
Palliative care is all about pain management					
Palliative care is a service only for patients with cancer.					
Palliative care should be started when medical and surgical methods of treatment are ineffective.					
Physicians routinely inform patients about their diagnosis and prognosis					
Physicians don't discuss end-of-life issues with					

their patients					
D. Communication factors					
The service providers give clear appointments about the next visit					
There is a difficulty of mutual agreement between patients and service providers					
There are disagreements between patients and service providers when discussing their patient needs					
Patients/ respective caregiver receives clear and honest information about their condition and prognosis					
There are language factors can between service providers and patients /caregivers					

Annex IV: Amharic version of the information sheet

የማስታገስክብካቤአጠቃቀምናተዛማጅችግሮችበካንሰርህሙማንበጥቁርአንበሳስፔሻላይዝድሆስፒታል፣ኢትዮጵያ

ክፍልአንድ፡- መረጃቅጽ

ሄሎ፡እንደምንአደሩ/ዋሉ?

እንኳንበደህናመጡእያልኩኝየከበረሰላምታዬንበማቅረብራሴንሳስተዋውቅእጅግበጣምደስይለኛል፡፡ስሜ________________ ______ይባላልእኔየምህረትፍቅሬተክለማርያምመረጃሰብሳቢነኝ፤ምህረትፍቅሬተክለማርያምበአዲስኣበባዩኒቨርስቲ፣ጤናሳይንስኮሌጅ፣ሕብረተሰብጤናአጠባበቅትምህርትቤትበ*“Masters of Public Health with specialty in Health Service Management”* ማስተርስበሕብረተሰብጤናአጠባበቅንዑስዘርፍበጤናአገልግሎትአስተዳደርተመራቂተማሪነች፡፡ዛሬእኔእዚህየተገኘሁትየሳቸውንጥናታዊፅሁፍመረጃለመሰብሰብነው፡፡

የጥናታዊፅሁፉኣሰራሮች

እርስዎለዚህጥናታዊፅሁፍያለቅድመሁኔታእንደኣጋጣሚነውየተመረጡትበመሆኑምወደዚህጥናታዊፅሁፍለመሳተፍየእርስዎሙሉፍቃደኝነትንይጠይቃል፡፡ያለመሳተፍሙሉመብትቢኖርዎትምእንዲሳተፉእንጠይቃለንምክንያቱምበሚሰጡንመረጃለኣገልግሎቱበጣምፈታኝየሆኑትችግሮችንለመለየትይጠቅመናል፡፡እርስዎየሚሳተፉከሆነኣንዳንድኣጠቃላይጥያቄዎችንማለትምስለእድሜዎ፣የትዳርሁኔታዎ፣የትምህርትዝግጅትዎ፣ብሄርዎ፣ሃይማኖትዎ፣የገቢመጠንዎእናየስራዓይነትዎንይጠየቃሉ፡፡

በመቀጠልምኣንዳንድጠለቅያሉጥያቄዎችንማለትምምንዓይነትየካንሰርታማሚመሆንዎን፣ኣገልግሎቱንእንዴትእየተጠቀሙእንደሆነናባጠቃላይየህመምዎደረጃእንጠይቅዎታለን፡፡በመጨረሻምየምንጠይቅዎትንጥያቄደግሞየእርስዎልምድወይምግላዊኣስተያየትንየምሰጡበትንጥያቄዎችንማለትምኣገልግሎቱንለማግኘትእንቅፋትየሆኑችግሮችንምንምንእንደሆኑእንዲገልፁልንእንጠይቅዎታለን፡፡ቃለ-መጠየቁከ 20-30 ደቂቃዎችሊወስድይችላል፡፡

የጥናታዊፅሁፉየጎንዮሽጉዳቶች

በዚህጥናታዊፅሁፍምንምዓይነትአሰራርወይምጥያቄበእርስዎመብት፣ጥቅም፣እንዲሁምምቾትዎንየሚያሳጣ፣በህይወትዎላይጉዳትየሚያደርስወይምአደጋላይየሚጥልአሰራርወይምጥያቄበፍፁምአንጠይቅዎትም፡፡እርስዎበፈለጉትግዜጥያቄዎችንበሙሉምሆነበከፊልያለመመለስመብትአልዎት፡፡

የጥናታዊፅሁፉጥቅሞች

በዚህጥናታዊፅሁፍዉጤትመሰረትለሚመለከተውአካልችግሮቹንበሚገባመፍታትእዲችሉአቅጣጫዎችንበማስቀመጥታማሚዎችንበቂናተደራሽየሆነአገልግሎቶችንእንዲያገኙይረዳቸዋል፡፡በመቀጠልምለእርስዎበቃለመጠይቁእግረመንገድአንዳንድጠቃሚየሆኑአዳዲስመረጃዎችለያገኙይችላሉ፡፡

ሚስጥርንስለመጠበቅ

የእርስዎስምበቃለ-መጠይቁቅፅናበሌሎችመርሃግብሮችበፍፁምእንደማይፃፍእየገለፅንልዎየእርስዎመልስበጣምሚስጥራዊበሆነቦታናማንምሊያገኘውበማይችልመልኩበቁልፍብቻየሚከፈትሳጥንበጥንቃቄእናስቀምጠዋለን፡፡የዚህጥናታዊፅሁፍግኝቶችበተለያዩመርሃግብሮችበሚቀርብበትግዜየእርስዎግላዊመረጃዎችንኣይቀርቡም፡፡ጥያቄካለዎትበማንኛውምግዜናቦታመጠየቅይችላሉ፡፡የበለጠመረጃንመጠየቅከፈለጉየጥናታዊፅሁፉንባለቤትናተመራማሪምህረትፍቅሬተክለማርያምንበማንኛውምሰዓትበዚህስልክቁጥር+251 911 34 74 54ወይምበኢ-ሜልኣድራሻmiheretliya@gmail.comማግኘትይችላሉ፡፡

ወደየፍቃደኝነትቅፅእንዲሄድይፈቀድልኛል?

ሀ. አዎ__________________________ (አዎከሆነየቀጥሉ)

ለ. አይሆንም_____________________ (በቃያቁሙ፤እናመሰግናለን)

Annex V: Amharic version of the consent form

ክፍልሁለት፡የአማርኛፍቃደኝነትቅፅ

ከላይበተሰጠኝመረጃማለትምስለጥናታዊፅሁፉዓላማ፤አሰራር፤የጎኑዮሽጉዳቶች፤ጥቅሞችናምስጥርንስለመጠበቅበሚገባስለተገለፅልኝለዚህጥናታዊፅሁፍቃለ-መጠይቅለምጠዩቁኝጥያቄዎችለመመለስየተስማማሁኝመሆኔንበፍርማዬአረጋግጣለሁኝ፡፡

የፍቃደኝነትቅፁንያስሞላቸውመረጃሰብሳቢስምናፊርማ____________________

የተሳታፊው/ዋፊርማ________________________________

- **ወደቀጣዩቃለ-መጠይቅእንዲገባይፈቀድልኛል?**

ሀ. **አዎ_**____________________ (አዎከሆነየቀጥሉ)

ለ. አይሆንም________________ (በቃያቁሙ፤እናመሰግናለን)

የቃለ-መጠይቁዉጤት

ሀ. ሙሉበሙሉምላሽሰጥተዋል

ለ. በከፊልመልሰዋል

የበላይተቆጣጣሪው/ዋስምናፊርማ_____________________________________

ቃለ-መጠይቁየተጀመረበትግዜ____

ቃለ-መጠይቁያበቃበትግዜ____

Annex VI: Amharic version of the Questionnaire

ክፍልሶስት፡የአማርኛቃለ-መጠይቅ

ትዕዛዝ፡ካሉትምርጫዎችየእርስዎምርጫያክብቡ

ክፍልአንድ፡የማህበረሰባዊመግለጫዎች

የታካሚመረጃ			
ዕድሜ(በዓመት)	______________________	**ፆታ**	1. ወንድ
			2. ሴት
ሃይማኖት	1. ኦርቶዶክስ	**የትምህርትደረጃ**	1. በመደበኛያልተማረ
	2. ሙስሊም		2. መደበኛያጠናቀቀ
	3. ፕሮቶስታንት		3. ሁለተኛደረጃያጠናቀ
	4. ሌሎች (ግልፅያርጉት_____)		4. ኮሌጅ /ዩኒቨርስቲ
ብሄር	1. ኦሮሞ		5. የድህረምረቃድግሪያለው/ላት
	2. አማራ	**የትዳርሁኔታ**	1. ያላገባ/ች
	3. ትግሬ		2. ያገባ/ች
	4. ሰዳማ		3. የፈታ/ች
	5. ወላይታ		4.ባልዋ/ሚስቱየሞተባት/የሞተችበት
	6. ሌሎች (ግልፅያርጉት_____)	**መኖርያቦታ**	1. ከተማ
የቤተሰብብዛት	1. 1-2		2. ገጠር
	2. 3-4	**የስራሁኔታ**	1. የመንግስትሰራተኛ
	3. ≥5		2. በግልየሚሰራ/የሚትሰራ
አማካኝወርሃዊየቤተሰብገቢ(በብር)	1. <500		3. ገበሬ
	2. 500- 1,500		4. ተማሪ
	3. 1,500-2,500		5. የቤትእመቤት
	4. >2,500		6. ሌሎች (ግልፅያርጉት_____)

ክፍልሁለት: ማስታገስክብካቤአገልግሎትለማግኘትየሚያጋጥሙተዛማጅችግሮች

ትዕዛዝ:እባክዎየሚፈልጉትንመልስበማድረ ✓ ንየመልሱ

ጥያቄዎች	መልሶች				
	በፍፁምአልስማማም	አልስማማም	ገለልተኛ	እስማማለሁኝ	በጣምእስማማለሁኝ
ሀ. የገንዘብችግሮች					
ታካሚዎችየሆፒታልክፍያንለመክፈልከፍተኛየሆነየገንዘብእጠረትይገጠማቸዋል					
ታካሚዎችየታዘዘላቸውንየህመምማስታገሻመድሃንትለመግዛትከፍተኛየሆነየገንዘብእጠረትይገጠማቸዋል					
ታካሚዎችወደሆስፒታልለመሄድየትራንስፖርትክፍያንለመክፈልከፍተኛየሆነየገንዘብእጠረትይገጠማቸዋል					
ታካሚዎችየቤተሰብእርዳታንበማጣታቸውየተነሳየማስታገስክብካቤአገልግሎትእንዲያቋርጡይገደዳሉ					
የታካሚቤተሰቦችከበጎኣድራጎትድርጅቶችእርዳታንበማጣታቸውየተነሳየማስታገስአገልግሎትንእንዲያቋርጡኣይገደዱም					
ለ. የጤናስርዓትችግሮች					
በሆስፒታሉኣገልግሎትንለማግኘትብዙየመንግስትኣሰራርመከተልኣያስፈልግም					
በሆስፒታሉመድሃኒትባለመኖሩታካሚዎችየታዘዘላቸውንየህመምማስታገሻመድሃንትለመግዛትከግልመድሃንትመደብርይገዛሉ					
ለታካሚዎችየሚሆንመዝናኛበሆስፒታሉግቢውስጥልዘጋጅላቸውይገባል					
የጤናባለሙያዎችለታካሚዎቻቸውወይምቤተሰቦቻቸውበጉብኝትግዜምንምዓይነትእገዛኣያደርጉላቸውም					
የማስታገስክብካቤኣገልግሎትከፈውስህክምናጋርበኣንድነትኣይሰጥም					

የማስታገስክብካቤኣገልግሎትበተለየመልክየሚሰጥየካንሰርህክምናዜዴነው					
የጤናባለሙያዎችለታካሚዎቻቸውበቂየሆነግዜናትኩረትይሰጣሉ					
የታካሚዎችንመረጃወደሚመለከተው·ብቁባለሙያለመድረስምንምዓይነትመዘገየትየለም					
ሐ. የእውቀትችግሮች					
የማስታገስክብካቤኣገልግሎትበምትኣፋፍላይለሚገኙታካሚዎችብቻየሚሰጥኣገልግሎትነው					
የማስታገስክብካቤኣገልግሎትዓላማህመምንማስታገስብቻነው					
የማስታገስክብካቤኣገልግሎትለካንሰርህሙማንብቻየሚሰጥኣገልግሎትነው					
የማስታገስክብካቤኣገልግሎትመጀመርያለበትየውስጥዴዌፈውስውይምየቆዶህክምናመንገዶችሳይሳካስቀርብቻነው					
የጤናባለሙያዎችየታካሚዎቻቸውበሽታምንነትማሳወቅኣይጠበቅባቸውም					
የጤናባለሙያዎችከታካሚዎቻቸውበማስታገስክብካቤጉዳዮችዙርያመወያየትየለባቸውም					
መ. የመግባባትችግሮች					
የጤናባለሙያዎችለታካሚዎቻቸውግልፅየሆነየቀጠሮግዜኣያሳውቅዋቸውም					
የጤናባለሙያዎችየታካሚዎቻቸውፍላጎትከመረዳትኣንፃርመግባባትኣይችሉም					
ጤናባለሙያዎችለታካሚዎቻቸውግልፅናታማኝበሆነመልኩየበሽታቸውማንንትናቀጣይሁኔታኣያሳውቅዋቸውም					
በታካሚዎቸእናጤናባለሙያዎችበቋንቋያለመግባባትሁኔታይታያል					

Curriculum vitae of the principal investigator

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Current position

- Senior professional nurse

Qualification

- BSC in Nursing from Addis Ababa university.

Specialty training and short course

- Research ethics at Armauer Hansen research institute
- Multi drug resistant tuberculosis (MDR TB) training on 2016 by ALERT center
- Online GCP training in 2016
- PICT training in collaboration with alert training center in 2017
- Emergency nursing care at TEBTA training center in 2012
- Customer handling training on 2003 E.C
- Assisting patient with mechanical ventilator in 2002

Professional Experience

ALERT HOSPITAL; From MAY 2015 till now am working in ICU

TEKELE HAYMANOT GENERAL HOSPITAL: From Jan 2012- May 2015 at this period of time, I was worked as ER and ICU nurse

- I was faced many critical patients like medical, surgical, pediatric emergencies, respiratory emergencies poisoning emergencies, cardiac emergencies and other patients and manage accordingly.
- Asses patient condition and identify their emergencies
- Resuscitate and assist for intubation and ventilation during respiratory arrest
- Assist catheter insertion for dialysis when the patient is renal failure and poisoned
- Monitor patient at bed side consciously
- Give an ordered drugs and necessary nursing care accordingly

BETHEL TEACHING GENERAL HOSPITA; from Sep 2009-nov 2011

I was worked in ICU department as an ICU nurse

- Asses patient condition and identify their emergencies
- Resuscitate and assist for intubation and ventilation during respiratory arrest
- Assist catheter insertion for dialysis when the patient is renal failure and poisoned
- Monitor patient at bed side consciously
- Give an ordered drugs and necessary nursing care accordingly

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Extracurricular activities, Professional membership

- Participate in humanitarian activity in Macedonia elderly and mentally ill peoples helping center for the past 4 years
- Member in Ethiopian Nursing association
- Ethiopian public health association
- Ethiopian women's association

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Annex VII: Declaration

Letter of declaration

I, the under signed, MPH student declared that this is my original work in partial fulfillment of the requirements for the degree of master of Public Health in Health Service Management, which has never been presented in this or any other University. All the resources and materials used for the thesis development fully acknowledged as complete references.

Name**:** MiheretFikre Teklemariam (BSc)

Date of submission: November 4,2019 **Signature: ___________________**

Approval of the primary advisor

This thesis work has been submitted for examination with our approval as University primary advisor

Name of primary advisor:Dr. MesfinAddise (MD, MPH)

______________________ **November 4,2019**

Signature **Date**