ADDIS ABABA UNIVERSITY

COLLEGE OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

UTILIZATION OF PALLIATIVE CARE SERVICE AND ITS AFFECTING FACTORS AMONG ADULT CANCER PATIENTS IN JIMMA UNIVERSITY MEDICAL CENTER, JIMMA, SOUTH WEST, ETHIOPIA, DECEMBER 2024.

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A THESIS SUBMITTED TO ADDIS ABEBA UNIVERSITY, SCHOOL OF NURSING AND MIDWIFERY, DEPARTMENT OF NURSING IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCES IN ONCOLOGY NURSING

DECEMBER 2024

ADDIS ABABA, ETHIOPIA

APPROVAL SHEET

ADDIS ABABA UNIVERSITY

COLLEGE HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

I, the undersigned MSc student, declare that I have submitted my original work on a title Utilization of Palliative Care Service and Factors Affecting Among Adult Cancer Patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, December 2024.

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Signature Date_____ _____

DEDICATION

This thesis is dedicated to the memory of [A female cancer patient with 10 years old, I met on my last attachment, saying her father "□□□ □□□ □□□□□□" while she is on chemotherapy], whose courageous journey with cancer profoundly shaped my understanding of palliative care's vital role. It is also dedicated to the countless cancer patients and their families who navigate the complexities of this disease with resilience and grace, reminding us of the urgent need for improved access to and quality of compassionate palliative care.

STATEMENT OF DECLARATION

By my signature below, I declare and affirm that this thesis is my own work. I have followed all ethical principles of scholarship in the preparation, data collection, data analysis and completion of this thesis. All scholarly matter that is included in the thesis has been given recognition through citation. I affirm that I have cited and referenced all sources used in this document. Every effort has been made to avoid plagiarism in the preparation of this thesis.

This thesis is submitted in partial fulfillment of the requirement for a graduate degree from the Addis Ababa University at College of Health Sciences, School of Allied Health Sciences department of Nursing and Midwifery. The thesis is deposited in the Addis Ababa University Digital Library and is made available to local, national and international scientific community. I solemnly declare that this thesis has not been submitted to any other institution anywhere for the award of any academic degree, diploma or certificate.

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ACKNOWLEDGEMENTS

First, I would like to thank first of all to my Almighty God who is always with me and give me pleasure, health, time and capacity to do everything in my life. Secondly, I give thanks to my Advisor **Mr. DEBELA G., BSc, MSc (Assistant Professor)**, in Jimma University, college of health science who give me the brief and helpful guidance to do this proposal draft in order to help me in precedent of my research/thesis development, which also helped us in doing a lot of searching and reading materials. Next, I am grateful to show my appreciation to my co-advisor **Sr. SOSINA Workineh (BScN, MCON)** for her encouragement and kindness.

Last but not least, my appreciation goes to my friends, and health library staffs, who have my side `all way towards the accomplishment of this paper.

ACRONYMS AND ABBREVIATIONS

AOR	Adjusted Odds Ratio
APCA	African Palliative care Association
CI	Confidence Interval
COR	Crude Odds Ratio
DALY	Disability-Adjusted Life Years
EOL	End of Life
GLOBOCAN	Global Cancer Incidence, Mortality and Prevalence
HDI	Human development Index
IRB	Institutional Review Board
JUMC	Jimma University Medical Center
LMICs	Low and Middle-Income Countries
NCDs	Non-Communicable Diseases
NMSC	Non-melanoma skin cancer
PC	Palliative care
QoL	Quality of life
SPSS	Statistical Package for Social Sciences
TASH	Tikur Anbessa Specialized Hospital
WHO	World Health Organization
WPCA	Worldwide Palliative Care Alliance

TABLE OF CONTENT

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Background: Cancer is a collection of more than 150 diseases characterized by abnormal cell growth. Palliative care is required for cancer, and is an approach to improve quality of life for those facing life-threatening illness. Factors affecting the utilization of palliative care service includes sociodemographic characteristic, clinical factors, knowledge factors, financial factors, communication factors, health system factors and perception about palliative care which has four domains.

Objectives: To assess the utilization of palliative care service and factors affecting among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, December 2024.

Methodology: A facility-based cross-sectional study was employed. Systematic random sampling technique was used to select the study participants from the cancer unit of Jimma University Medical Center. A structured interviewer-administered questionnaire was used to collect the data. The entered data is exported to Statistical Package for the Social Sciences (SPSS) version 26.0 for windows. Logistic regression is computed to assess the statistical association. The multivariable logistic regression model is used to identify the independent factors associated with palliative care service utilization.

Result: About 409 participants' responded questionnaire giving a 98.8% response rate. In this study we found that the prevalence of palliative care utilization among adult cancer patients in Jimma University Medical Center was 39.4%. Factors that associated with palliative care utilization were including: male patients (AOR = 2.51, 95% CI: 1.49-4.19), higher educational attainment (diploma and above) (AOR = 2.43, 95% CI: 1.18-5.01), Employed patients (AOR = 2.12, 95% CI: 1.07-4.13), patients possessing good knowledge (AOR = 3.26, 95% CI: 2.08-5.11) and patients with a good perception of palliative care (AOR = 1.78, 95% CI: 1.14-2.81), were found to be statistically significant association with utilization of palliative care.

Conclusion and Recommendations: The utilization of palliative care services was low. And being male, having good educational status, employment and having good perception for palliative care are among factors identified. Additionally, about half of the patients encountered financial difficulties, health system bureaucracies, and challenges in knowledge and communication while receiving palliative care.

Keywords: Palliative care, adult cancer patients, Utilization, Factors affecting.

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 (1).

As per Global Cancer Incidence, Mortality and Prevalence (GLOBOCAN) 2020, the number of new cancer cases diagnosed in 2020 was 19.3 million, and almost 10.0 million died due to cancer. Also, in Sub-Saharan Africa there were 801 392 new cancer cases, 5,20 1,58 cancer deaths (2). Which is underestimated due to lack of appropriate diagnosis, poor access to care, absence/shortage of well-trained human resource, and infrastructure (5). In Africa there were 11,092,09 new cancer cases, 7,114,29 cancer deaths. A total of 77,352 new cancer cases and 51,865 cancer deaths were estimated to have occurred in Ethiopia with number of prevalent cases in 5 years were 1,308,58 in 2020 (2). Treatment options for cancer includes Surgery, chemotherapy, radiotherapy, Immunotherapy, Hormonal therapy, Targeted therapy and Stem Cell transplant (3). However, there is significant global disparity on the availability, accessibility of cancer treatment options and patient survival (4). On top of that cancer impose significant catastrophes such as economic hardship and increased psychological distress which would affect quality of life in return (6).

Palliative care is 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 (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 (9,10).

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 (8). Palliative care is required for a wide range of Chronic 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% (7,9). Palliative care is an essential component of a comprehensive response to Non-Communicable Diseases (NCDs) as outlined in the World health Organization (WHO) global action plan for the prevention and control of NCDs 2013–2020 (12). 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 (11).

The global need for palliative care among cancer patients is increasing with a rapid pace due to the world's aging population (9), 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 (13). 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 (14). Therefore, Palliative care is a crucial aspect of medical care for individuals with serious or terminal illnesses, as it aims to alleviate suffering and improve the quality of life. Despite the potential benefits of palliative care, there is a lack of understanding about the factors that influence the utilization of these services. This research aims to fill this gap by examining the attitudes and beliefs of individuals towards palliative care, as well as the social, cultural, and economic factors that may impact their decision to utilize these services. By gaining a deeper understanding of these factors and identifying the need, this study aims to provide valuable insights that can inform the development of more effective interventions and policies to promote the utilization of palliative care. This research is therefore essential in ensuring that individuals have access to the care they need during their most vulnerable moments.

1.2. Statement of the Problem

It is projected that worldwide, an estimated 28.4 million new cancer cases including (Non melanoma skin cancer (NMSC), except basal cell carcinoma) are projected to occur in 2040, a 47% increase from the corresponding 19.3 million cases in 2020, assuming that national rates estimated in 2020 remain constant. The relative magnitude of increase is most striking in low HDI countries (95%) and in medium Human development index (HDI) countries (64%). In terms of the absolute burden, the high HDI countries are expected to experience the greatest increase in incidence, with 4.1 million new cases more in 2040 compared with 2020. This projection is solely due to the growth and aging of the population and may be further exacerbated by an increasing prevalence of risk factors in many parts of the world (2).

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 (15).

In Africa, 346,203 adults (69.3/100,000 populations) need palliative care service from the major Non-Communicable Diseases (NCDs) at the end of life.

In the Global Atlas of Palliative Care at the End of Life, WHO and the Worldwide Hospice Palliative Care Alliance estimated that in 2011, 20·4 million people who died required palliative care. This number is then doubled based on the assumption that about the same number of people need palliative care for reasons other than pain and for longer periods of time, giving a total of 40 million people in need of palliative care every year (16,17). There is a large gap between the number of people in need of palliative care services and those who can receive it (7,9). Most patients with cancer in Africa are diagnosed when they are terminally ill, and only 5% can receive any chemotherapy (18).

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 (8).

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 (7). The factors associated with poor palliative care service utilization among cancer patients in developing countries are complex, multi-dimensional, layered, and inadequately understood (2). In August 2016, Ministers of Health from more than 26 African countries adopted the Kampala declaration and committed to providing leadership in implementing the 2014 World Health Assembly resolution on palliative care. This resolution supports the integration of palliative care to offer patient- centered services aimed at improving quality of life and ensuring dignified care for those with life-threatening illness such as cancer. Thirteen countries now include palliative care as part of their national cancer control plans and six countries: Malawi, Mozambique, Rwanda, Swaziland, Tanzania and Zimbabwe have standalone palliative care policies (19). 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 (20). 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 (20). 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 utilization of palliative care service and factors affecting are not yet determined in Jimma, Oromia region, Southwest Ethiopia; therefore, the purpose of this study is to determine the utilization of palliative care services and its affecting factors, with the goal of enhancing the quality of life in cancer patients by providing them with timely and patient-centered palliative care.

1.3. Significance 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.

First, understanding the utilization of palliative care among adult cancer patients is important for researchers in order to identify any potential barriers to palliative care utilization and to develop strategies to improve access to and utilization of palliative care services.

For nursing and healthcare workers, understanding the factors that influence the likelihood of palliative care utilization can help inform the provision of palliative care services, as well as assist in the development of strategies to improve access to palliative care for those who may be less likely to utilize these services.

Additionally, understanding the perception of palliative care among adult cancer patients can help healthcare providers tailor their communication and education about palliative care to better meet the needs and preferences of their patients.

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 (21). 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 (8). 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 (22). Palliative care service should also assess the caregiver's capacity to provide care, creating awareness on the patient's diseases condition, prognosis, providing bereavement counseling service with the ultimate goal of offering a support system to help patients live as actively as possible until death (23). 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).

2.2. Utilization of palliative care service

Utilizing palliative care services has been linked to positive results, such as higher quality patient care, improved patient contentment, better symptom management, and increased financial success of organizations (30).

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% (29), 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 (31).

In Africa, millions of cancer patients are experiencing unnecessary suffering and pain without access to oral Morphine (32). Access to culturally appropriate holistic palliative care (including effective pain management) is not available (32).

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 (28).

A hospital-based cross-sectional study conducted to assess the rehabilitation service utilization and associated factors among 388 adult cancer patients at Tikur Anbessa Specialized 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 (38). Additionally, a facility-based cross-sectional study conducted among 304 systematically selected adult cancer patients in the cancer unit of Tikur Anbessa Specialized Hospital, 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 (49).

2.3. Factors influencing palliative care service utilization

2.3.1. Socio-demographic factors

Socio-demographic factors such as age, gender, race, education, and income can influence palliative care perception and service utilization. For example, research has shown that older individuals are more likely to perceive palliative care as being beneficial and to utilize palliative care services (34). Similarly, individuals with lower levels of education may be less likely to understand the benefits of palliative care and may therefore be less likely to utilize palliative care services (34). There is also evidence to suggest that certain racial and ethnic groups may be less likely to receive palliative care services, potentially due to cultural or linguistic barriers (33). Income may also play a role in palliative care utilization, as individuals with lower income may be less likely to have access to or be able to afford palliative care services (34).

Overall, it is important for healthcare providers to be aware of these socio-demographic factors and to take them into consideration when providing palliative care to ensure that all individuals have equal access to and are able to benefit from palliative care services.

2.3.2. Financial factors

An exploratory qualitative study conducted in Canada showed 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 (35).

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% of hospice unenrolled patients received palliative care service at least once (36).

A hospital-based cross-sectional study was conducted to assess the rehabilitation service utilization and associated factors among 388 adult cancer patients at Tikur Anbessa Specialized Hospital (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 (38).

Similarly, a mixed case series study conducted 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 (39).

2.3.3. Health system factors

According to the African Palliative care Association report (APCA) report and a qualitative study conducted in South Africa (40), 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, poor public awareness and understanding (41).

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 (42).

In line with above studies a hospital-based cross-sectional quantitative study conducted 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 (38).

2.3.4. 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. Palliative care (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 (43).

An institution-based cross-sectional study was conducted to assess the knowledge, accessibility and utilization of palliative care services for adult cancer patients by their perspective at Tikur Anbessa Specialized Hospital (TASH), Addis Ababa, Ethiopia; among most of the selected respondents participated in the survey (384 out of 403). The response rate was 95%.

Of total respondents, around 239 (62.2 %) had previous knowledge of cancer PC services. Out of this, 86.6 % (207 out of 239) respondents were ≥35 years of age and knowledgeable of PC services. The rest 145 (37.8 %) respondents reported that they had no knowledge of PC services for cancer. About 113 (47.3 %) respondents had knowledge of PC but they had no any formal education. (44). 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 (44).

2.3.5. 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" (45).

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 (45).

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 their illness was cancer. The few 58/440 (13.2%) patients who stated that in general they preferred to leave disclosure of details up to the treating 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 and treatment.

2.3.6. Perception of palliative care service

The perception of palliative care varies among different groups of people, including healthcare providers, patients, and caregivers. One study found that many healthcare providers view palliative care as a form of end-of-life care that is only appropriate for patients with terminal illnesses (25).

However, palliative care can be provided at any stage of a serious illness and can be beneficial for improving the quality of life for both the patient and the family. For example, a systematic review of randomized controlled trials found that palliative care can improve symptom management, reduce hospitalizations, and increase patient satisfaction (24). Patients and caregivers may also have misconceptions about palliative care. Some may view it as a sign of giving up or abandoning hope for a cure (26). Others may fear that receiving palliative care means that they will receive less aggressive treatment for their illness (26). However, palliative care can be provided alongside curative treatment and can actually improve the effectiveness of treatment by addressing symptoms and improving overall well-being (24). It is important for healthcare providers to educate patients and caregivers about the benefits of palliative care and to address any misconceptions or fears they may have. Open and honest communication about the goals of care and the potential benefits of palliative care can help individuals make informed decisions about their treatment and improve their quality of life.

2.4. Conceptual Framework

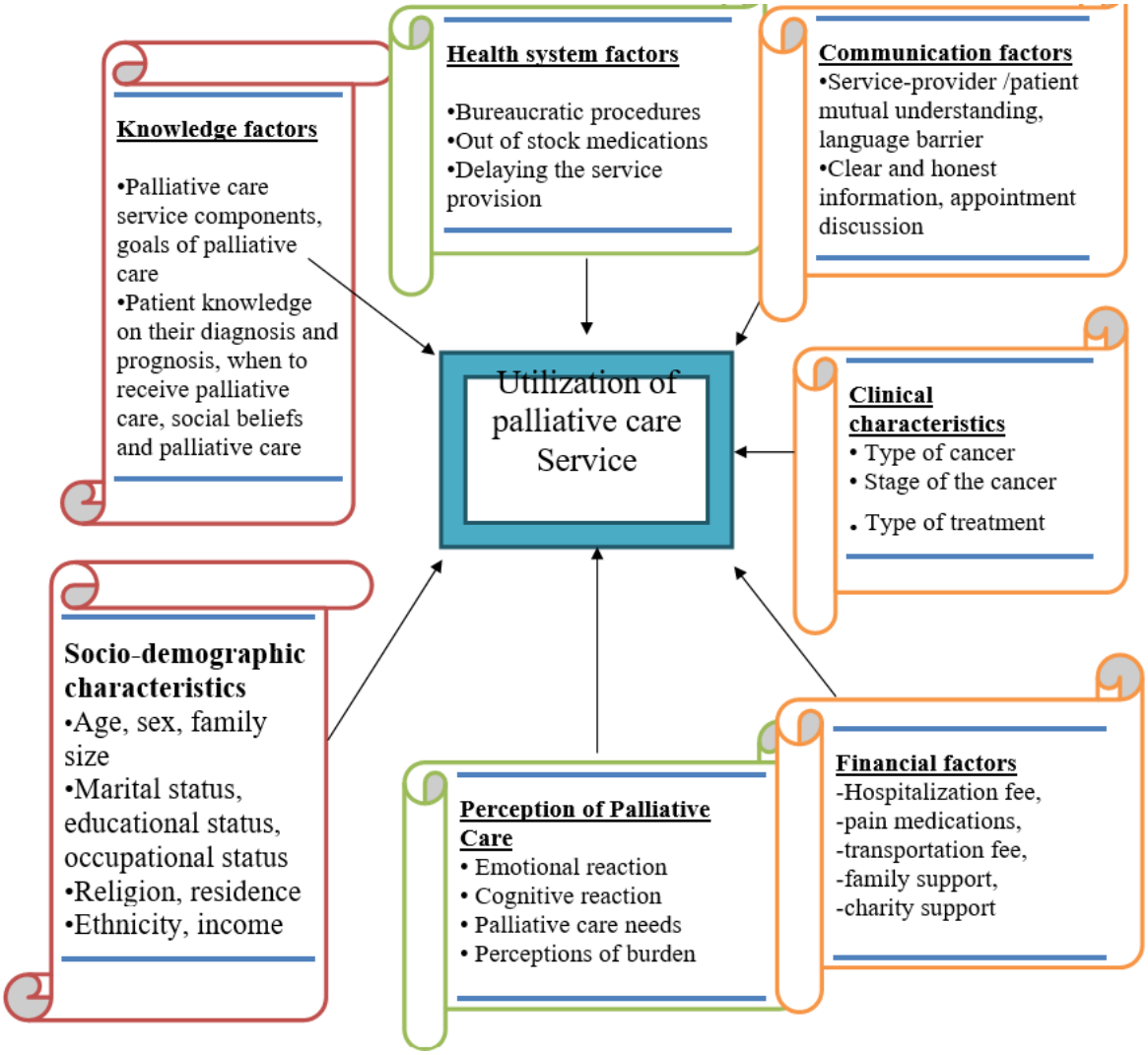

Figure 1: A conceptual framework adapted and modified socio-ecological model for describing factors affecting utilization of palliative care service among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024, December 2024. (46).

3. OBJECTIVES

3.1. General Objective

- To assess the utilization of palliative care service and its affecting factors among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, December 2024.

3.2. Specific Objectives

- To determine the utilization of palliative care service among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, December 2024.
- To identify factors affecting with the utilization of palliative care service among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, December 2024.

4. METHODS AND MATERIALS

4.1. Study area and period

The study was conducted at the cancer unit of Jimma University Medical Center (JUMC) located in Jimma, Oromia region, South West Ethiopia. JUMC is the most popular referral hospital in the country, with over 636 beds, where palliative care services and treatment are virtually available. The hospital has 20 beds devoted to cancer care, with 12 beds for inpatient and 8 beds for outpatient or day care in the oncology department. On average, 8 adult cancer patients receive palliative care services from the cancer unit of JUMC daily. According to the past six months' report, there are an average of 60 new patients and 150 repeat patients were managed every month. The cancer unit provides chemotherapy, radiation therapy, pain management therapy, and other supportive and palliative care services. It is the center for cancer registry, early detection, prevention, standard treatment, and palliative care in South West Ethiopia. JUMC also serves as a teaching hospital for the College of Health Science at Jimma University, where undergraduate and postgraduate medical students, dentists, radiologists, and other allied health science professionals (Nursing, Midwifery, Anesthesia, Medical laboratory and Pharmacy) are trained. The study was conducted from February 20 to December 25, 2024.

4.2. Study design

A facility-based cross-sectional study was employed.

4.3. Source population

All adult cancer patients (aged ≥ 18 years) treated in the cancer unit of JUMC was considered as the source population.

4.4. Study Population

All systematically selected adult cancer patients (aged ≥18 years) treated in the cancer unit of JUMC was considered as the study population.

4.5. Inclusion criteria

All adult cancer patients who had diagnosed with any type of cancer before the data collection period was included in the study.

4.6. Exclusion criteria

Those critically ill patients; those who have known hearing problem and cognitively impaired to give consent were excluded from the study.

4.7. Sample size determination

The sample size for this particular study was calculated using formula for a single population proportion considering the following assumptions:

95% confidence level, margin of error (0.05), the study done in TASH before 4 years shows that the proportion of adult cancer patients has good perception about palliative care and more likely to utilized palliative care service was **57.2%**. (49)

(p= 57.2%) is substituted in the following

single population proportion formula.

$$n = \frac{(Z\alpha/2)2\ p\ (1-p)}{d^2}$$

$$= \frac{(1.96)2\ (0.572)\ (0.428)}{(0.05)2} = 376$$

The total sample size is **414** by adding non-response rate of 10%, this sample size was used for assessing the utilization of palliative care.

Where n= required sample size

Z= critical value for normal distribution at 95% confidence level which equals to

1.96 (z value at α =0.05)

P= (Proportion of good perception about palliative care and more likely to utilized palliative care service 57.2%)

d= 0.05 (5% margin of error).

4.8. 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 Jimma University Medical Center /JUMC/ and in 2014/15 E.C. There are a total of **2445** adult cancer patients were registered and come to receive chemotherapy and radiotherapy services. Over the last quarter of the same fiscal year **539** adult cancer patients received chemotherapy and radiotherapy services. Initially, the oncology follows up regular patients, monthly flow data was obtained from the head of nurse of adult clinical oncology. From the monthly incoming patient flow, daily patient flow was calculated. Then the sample size was divided by those calculated number of patients per day. The gained number was number of data that is going to be gathered each day to get **414** participants in 35 days.

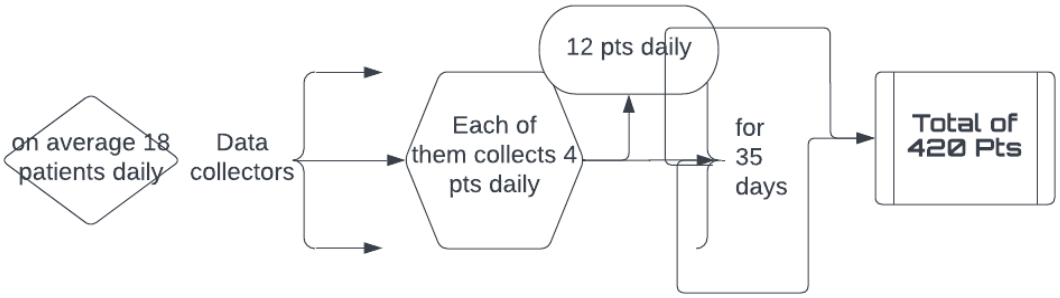

Figure 2: Diagrammatic representation of sampling and data collection procedures to assess utilization of palliative care service and it's affecting factors among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, December 2024.

4.9. Data collection instrument and process

4.9.1. Data collection instrument

A pre-tested structured interviewer-administered questionnaire was used to collect the data. The questionnaire is derived from different works of literature and contains important variables, which were organized according to the objective of the study (48, 49).

Factors affecting service utilization: this tool was designed by the researchers after reviewing a numerous literature and has four parts. Which is standard and the internal consistency (Cronbach's alpha coefficients >0.76) (48).

Part I; will assess Socio-demographic status (age, residence area, occupation, marital status, monthly income, education level, and type of health insurance).

Part II; will assess clinical characteristics (stage of the cancer, type of treatments (type of chemotherapy, radiotherapy and Hormonal Therapy), and type of surgery).

Part III; will assess the patients current status related to palliative care service utilization.

Part IV; The other four factors (Knowledge factors: has 4 items, Financial factors: has 5 items, Communication factors: has 7 items and Health system factors which have 7 items). 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 (49).

Part V; Perception of palliative care instrument /PPCI/: The principal components analysis identified four domains (emotional reactions and cognitive reactions to palliative care, palliative care needs and perceptions of burden) containing eight factors (negative and positive feelings; hopeless, supported, disrupted; emotional and practical needs; and perceptions of burden). Therefore, responses reflected either a positive or negative evaluation of the item topic and in turn helped explain participants' feelings and behaviors towards palliative care. For each section, participants were asked to rate their level of agreement (on that day) with each item on a seven-point Likert type scale (1 = strongly disagree to 7 = strongly agree) [48].

4.9.2. Data Collection Process

Data was collected by face-to-face interviews in a quiet and confidential room at the cancer unit of JUMC after patients have received their respective service by three degree holder nurses and supervised by principal investigator and the data collectors was 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.

4.10. Operational Definitions

Palliative care service utilization: The respondents who says **[Yes]** was considered as who utilized the service and says **[No]** were considered as who don't utilized the service.

Perception about palliative care: Factors was either scored separately on a scale of 1 to 7 with higher scores representing strong levels of agreement (domains 1=Emotional reaction, 2=Cognitive reaction, and 4=perception of burden) or summed and then added to generate a total score for the domain (domain 3 = palliative care need). (48)

- **Good/Positive Perception about palliative care:** Participants who scores above the mean of the adjusted score was considered as having good or positive perception about palliative care. (48)
- **Poor/Negative Perception about palliative care:** Participants who scores below the mean of the adjusted score was considered as having poor or negative perception about palliative care. (48)

Knowledge factors affecting service utilization: who score above the mean of the adjusted score was considered as factors affecting and scored below the mean of the adjusted score were considered as those who do not affect utilization (49).

Health system factors affecting service utilization: who score above the mean of the adjusted score was considered as factors affecting and scored below the mean of the adjusted score were considered as those who do not affect utilization (49).

Financial factors affecting service utilization: who score above the mean of the adjusted score was considered as factors affecting and scored below the mean of the adjusted score were considered as those who do not affect utilization (49).

Communication factors affecting service utilization: who score above the mean of the adjusted score were considered as factors affecting and scored below the mean of the adjusted score was considered as those who do not affect utilization (49).

4.11. Study Variables

4.11.1. Dependent variable

- Utilization of palliative care service

4.11.2. Independent variables

- Socio-demographic characteristics: has 9 items,
- Clinical characteristics
- Knowledge factors: has 4 items
- Financial factors: has 5 items,
- Communication factors: has 7 items and
- Health system factors which have 7 items
- Perception of palliative care (perception of burden: 3 items, palliative care needs: 13 items, emotional reactions: 7 items and cognitive reactions: 13 items).

4.12. Data Analysis

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 was cleaned and 20% of the data was double-entered randomly to check for data entry errors and Epi info version 7.2.5 software (47) was used for data entry.

The entered data is exported to Statistical Package for the Social Sciences (SPSS) version 26.0 for windows. Descriptive statistics is presented in medians with interquartile range for numerical variables and categorical variables were presented using frequency and percentages. Logistic regression is computed to assess the statistical association.

The bivariate analysis was applied 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.

Confounding is checked and percentage change in the regression coefficients (β) less than 20% reveals an absence of confounder. Interaction for the main effect model will 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 multicollinearity among the independent variables. The multivariable logistic regression model is used to identify the independent factors associated with palliative care service utilization. The summary measures of estimated crude (COR) and adjusted odds ratios (AOR) with 95% confidence interval is presented and P-value less than 0.05 is 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.

4.13. Data quality assurance

To assure the quality of the data, properly designed data collection tool is 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 was reviewed by the principal investigator, any problems faced in the time of data collection is discussed and corrective measures are made immediately.

The pretest was done one week before the actual data collection period among 20 (5%) of similar study populations in Tikur Anbessa Specialized hospital to ensure clarity, wordings, logical sequence and skip patterns and some or total modification was 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 assessed by Cronbach's alpha (α) and it was greater than 0.7 that suggests the items were internally consistent.

4.14. Ethical considerations

Ethical approval is obtained from the Institutional Review Board (IRB) of the School of Nursing and Midwifery, college of health science, Addis Ababa University. The chief executive director of JUMC 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 are 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 was stored on a password- protected computer, and paper data collection forms were stored in a locked cabinet in the principal investigator's office.

4.15. Dissemination of findings

After the completion of the study, the finding report after being defended at the School of Nursing and Midwifery, College of Health Science, Addis Ababa University it was 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 was disseminated through workshops, seminars and published in an international, professional high impact journal.

5. RESULTS

5.1 Socio-demographic characteristics

A total of 414 adult cancer patients in Jimma University Medical Center, 409 of them were participated in the study with the response rate of 98.8%. The majority of patients fall within the 18-47 age range (48.7%), with mean age of the study subjects were 47 years and standard deviation of ±13.9. The majority of patients were male (65.3%) and residing in rural areas (65.8%). The predominant religion among the patients is Orthodox Christianity (65.0%). Most patients were married (77.8%) and have varying levels of educational attainment, with 33.0% unable to read and write and 13.4% were attained tertiary education. Occupational status indicates that 51.1% were self-employed. Regarding family size, 69.2% of the patients have families of five or more members. In terms of monthly income, 48.2% earn more than 3000 ETB and 21% earn less than 1500 ETB (Table 1).

Table 1: Socio-demographic characteristics adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024.

Variables	Category	Frequency	Percentage
Age	18-47	199	48.7
	48-63	161	39.4
	64 and above	49	12.0
Sex	Male	267	65.3
	Female	142	34.7
Residence	Urban	140	34.2
	Rural	269	65.8
Religion	Orthodox	266	65.0
	Muslim	109	26.7
	Protestant	34	8.3
Marital status	Single	42	10.3
	Married	318	77.8
	Divorced	22	5.4
	Widowed	27	6.6
Educational status	Unable to read and write	135	33.0
	Primary (1-8)	121	29.6
	Secondary (9-12)	98	24.0

	Tertiary (Diploma and above)	55	13.4
Occupational status	Employed	94	23.0
	Self-employed	209	51.1
	Non-employed	106	25.9
Family size	<5	126	30.8
	>=5	283	69.2
Monthly Income	<1500	86	21.0
	1500-3000	126	30.8
	>3000	197	48.2

5.2: Clinical characteristics of adult cancer patients

The clinical characteristics of adult cancer patients at the Jimma University Medical Center, Jimma, Southwest, Ethiopia. The most common type of cancer among these patients is carcinoma (26.2%), followed by sarcoma (19.6%). The stages of cancer reveal that a significant number of patients are diagnosed at advanced stages, with 42.1% at Stage IV followed by 32.3% at Stage III. Treatment modalities show that radiotherapy is the most frequently used (34.2%), followed by chemotherapy (28.9%) (Table 2).

Table 2: Clinical characteristics of adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024.

Variables	Category	Frequency	Percentage
Type of cancer	Carcinoma	107	26.2
	Sarcoma	80	19.6
	Lymphoma	47	11.5
	Leukemia	18	4.4
Stage of the cancer	Stage I	36	8.8
	Stage II	69	16.9
	Stage III	132	32.3
	Stage IV	172	42.1
Type of treatment	Chemotherapy	118	28.9
	Radiotherapy	140	34.2
	Hormonal Therapy	89	21.8
	Surgery	62	15.2

5.3: Factors to palliative care service utilization

Factors affecting palliative care service utilization, such as financial factors, knowledge factors, communication, and health system factors, were measured using a Likert scale ranging from strongly disagree to strongly agree. Who score above the mean of the adjusted score was considered as factors affecting which recoded as "YES" and scored below the mean of the adjusted score were considered as those who do not affect utilization which recoded as "NO". The data indicate that patients have relatively significant factors across various items. Financial factors to palliative care have an adjusted mean score of 3.01 with SD of 0.296 is 79.95%, Health system factors have adjusted mean score of 2.94 with SD of 0.23 is 83.37%, Knowledge factors have adjusted mean score of 2.72 with SD of 0.32 is 75.06% and Communication factors have a slightly higher adjusted mean score of 3.05 with SD of 0.23 is 85.82%.

Table 3: Factors affecting palliative care service utilization among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024.

Variables	Category	Frequency	Percentage
Financial Factors	**Yes**	327	79.95
	No	82	20.05
Health system factors	**Yes**	341	83.37
	No	68	16.63
Knowledge factors	**Yes**	307	75.06
	No	102	24.94
Communication factors	**Yes**	351	85.82
	No	58	14.18

5.3.1: Perceptions about Palliative Care

Table 7 presents, the mean and standard deviation of perception domains about palliative care among adult cancer patients at the Jimma University Medical Center. The data indicate that patients have relatively high and consistent perceptions across various domains. Emotional reactions to palliative care have a mean score of 5.13 (±0.698), cognitive reactions have a slightly higher mean score of 5.24 (±0.540), and palliative care needs have a mean score of 5.19 (±0.587). Perceptions of burden are the highest among the domains, with a mean score of 5.58 (±1.06). Overall, the general perception of palliative care is positive, with an overall mean score of 5.28 (±0.514).

Table 4: Mean and standard deviation of Perceptions domains about Palliative Care among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024

Domains	Mean±Std.
Emotional reactions to palliative care	5.13±.698
Cognitive reactions to palliative care	5.24±.540
Palliative care needs	5.19±.587
Perceptions of burden	5.58±1.06
Overall perception	5.28 ±.514

5.5: Utilization of palliative care service among adult cancer patients

The prevalence of palliative care utilization among adult cancer patients in Jimma University Medical Center was 39.36% [95% CI: 34.6, 44.3%] (Figure 1). This means that out of the total patients, 39.4% were utilizing palliative care services, while 60.6% were not.

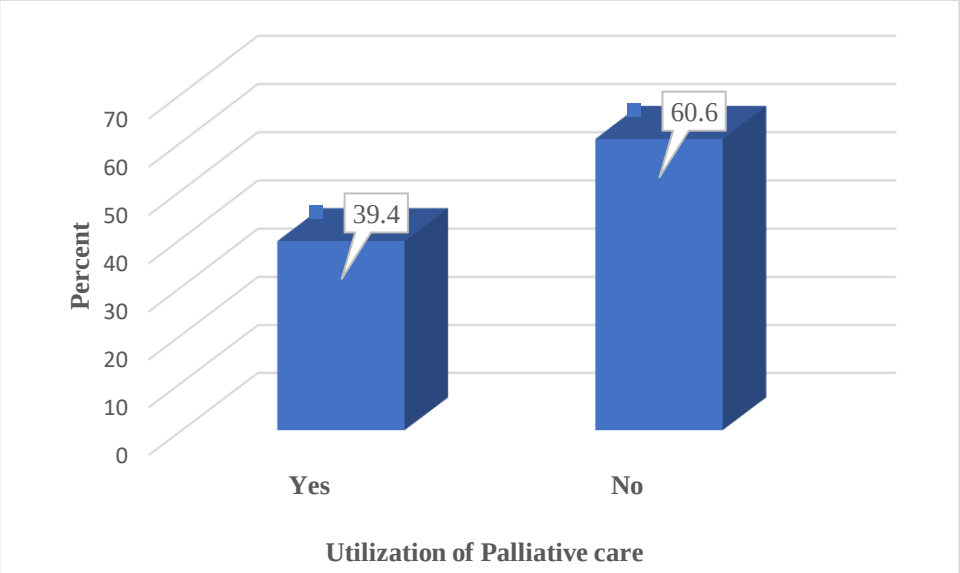

Figure 3: Palliative care service utilization status among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024

5.6: Factors affecting with the utilization of palliative care service

To identify factors affecting with the utilization of palliative care service among adult cancer patients in Jimma University Medical Center, bivariable and multivariable binary logistic regression analyses were used. In the bivariate analysis, factors that had p-value < 0.25 were selected as candidate variables for the multivariable analysis. Age, sex, marital status, educational status, occupational status, stage of the cancer, knowledge about utilization of palliative care service, communication, and perception of palliative care were selected as a candidate variable for multivariable logistic regression model.

Model fitness was checked by Hosmer and Lemeshow test and the p-value was 0.644, shows that the p-value is greater than 0.05, then fails to reject the null hypothesis, and it is stated that the logistic model is good for the data set.

The result of multivariable analysis showed that sex, educational status, occupational status, knowledge about utilization of palliative care service, and perception of palliative were identified as the associated factors associated with the utilization of palliative care service among adult cancer patients in Jimma University Medical Center, Southwest, Ethiopia.

Accordingly, from socio demographic factors the model showed that, male patients were 2.51 times more likely to utilize palliative care services compared to female patients (AOR = 2.51, 95% CI: 1.49-4.19). Additionally, patients with higher educational attainment (diploma and above) were 2.43 times more likely to use palliative care services compared to those unable to read and write (AOR = 2.43, 95% CI: 1.18-5.01). Employed patients show a higher likelihood of utilizing palliative care services, being 2.12 times more likely to do so compared to non-employed patients (AOR = 2.12, 95% CI: 1.07-4.13).

Knowledge about palliative care significantly impacts utilization, with patients possessing good knowledge being 3.26 times more likely to use these services (AOR = 3.26, 95% CI: 2.08-5.11). Moreover, patients with a good perception of palliative care are 1.78 times more likely to utilize the services compared to those with a poor perception (AOR = 1.78, 95% CI: 1.14-2.81) (8).

Table 5: Multivariable analysis of factors affecting with the utilization of palliative care service among adult cancer patients in Jimma University Medical Center, Jimma, Southwest, Ethiopia, 2024

Variables	Category	Utilization of palliative care service		COR (95%CI)	AOR (95%CI)	P-value
		Yes	No			
Age	18-47	132(66.3)	67(33.7)	.449(.238.,84(	.646(.305,1.37)	.254
	48-63	93(57.8)	68(42.2)	.647(.340,1.2	1.01(.483,2.10)	.984
	64 and above	23(46.9)	26(53.1)		1	
Sex	Male	147(55.1)	120(44.9)	2.01(1.30,3.1	2.51(1.49,4.19)	.000*
	Female	101(71.1)	41(28.9)		1	
Marital status	Single	27(64.3)	15(35.7)		1	
	Married	195(61.3)	123(38.7)	1.14(.581,2.22)	.794(.353,1.78)	.577
	Divorced	14(63.6)	8(36.4)	1.03(.351,3.01)	1.53(.426,5.52)	.513
	Widowed	12(44.4)	15(55.6)	2.25(.838,6.04)	1.89(.564,6.32)	.302
Educational status	Unable to read and write	87(64.4)	48(35.6)		1	
	Primary	70(57.9)	51(42.1)	1.32(.797,2.19)	1.26(.718,2.21)	.421
	Secondary	65(66.3)	33(33.7)	.920(.532,1.59)	.933(.502,1.73)	.826
	Diploma and above	26(47.3)	29(52.7)	2.02(1.07,3.82)	2.43(1.18,5.01)	.016*
Occupational status	Employed	48(51.1)	46(48.9)	1.94(1.09,3.45)	2.12(1.07,4.13)	.030*
	Self-employed	129(61.7)	80(38.3)	1.26(.769,2.06)	1.37(.786,2.39)	.266
	Non-employed	71(67.0)	35(33.0)		1	
Stage of the cancer	Stage I	22(61.1)	14(38.9)		1	
	Stage II	45(65.2)	24(34.8)	.838(.364,1.98)	.510(.194,1.34)	.172
	Stage III	70(53.0)	62(47.0)	1.39(.656,2.95)	.981(.418,2.29)	.964
	Stage IV	111(64.5)	61(35.5)	.864(.412,1.81)	.634(.274,1.47)	.288
Knowledge	Poor	161(73.2)	59(26.8)		1	
	Good	87(46.0)	102(54.0)	3.19(2.12,4.84)	3.26(2.08,5.11)	.000*
Communication	No	110(68.3)	51(31.7)		1	
	Yes	138(55.6)	110(44.4)	1.72(1.14,2.61)	1.42(.889,2.27)	.142
Perception of palliative care	Poor	128(65.3)	68(34.7)		1	
	Good	120(56.3)	93(43.7)	1.46(.978,2.18)	1.78(1.14,2.81)	.012*

indicates significance at 5% level, COR: Crude odd ratio, AOR: Adjusted odd ratio, 1: reference categories, CI: Confidence interval

6. DISCUSSIONS

This institutional based cross-sectional study with the objective of assessing the utilization of palliative care service and its affecting factors. The study determined and identified factors affecting the utilization of palliative care service in Jimma University Medical Center, Jimma, Southwest, Ethiopia.

Palliative care is poorly addressed public health problem with scarce data on the factors associated with service utilization and this is the first study in Jimma medical center which tried to assess palliative care service utilization and associated factors among adult cancer patients receiving palliative care service, found that 39.4% of adult cancer patients utilized palliative care service. Palliative care service utilization in United States is more than 90% (29), 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 (31). This could be due to the differences in the accessibility, affordability and socio-economic status of the countries. This study was a little bit more than previous studies conducted in Asia (35.0%) (52) and less than other studies conducted in the United States (41.9%) (51), In Ethiopia, a study conducted before seven years in black lion found that only 26% of adult cancer patients received the service (38), but less than another study done at TASH (57.2%) (49), this could be due to JUMC is being late and new institution to be oncology center to give the service.

The study revealed that male patients were significantly more likely to utilize palliative care services than females, with male patients having 2.51 times higher odds of utilization (AOR = 2.51, 95% CI: 1.49-4.19). 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 (53). This can be explained by differences in socio-economic status of patients and sample size. Globally, similar gender disparities are less pronounced, attributed to more equitable healthcare access in high-income countries. But it aligns with findings from Ethiopian studies, including Tikur Anbessa Specialized Hospital, where male patients exhibited greater healthcare utilization due to fewer caregiving responsibilities (49).

Educational attainment also played a significant role, with patients possessing a diploma or higher education being 2.43 times more likely to utilize palliative care compared to those unable to read and write (AOR = 2.12, 95% CI: 1.07-4.13). Studies in sub-Saharan Africa corroborate this finding, showing that education enhances health-seeking behavior and understanding of palliative care benefits. The study in Ethiopia also shows almost near similar finding patients diagnosed with cancer who have college or university education were 2.3 times more likely to use palliative care services (55).

This may be explained by the fact that people with higher level of education easily understand the written and oral instructions given by health care professionals, following instructions like prescriptions or appointment schedules, and understanding the health care system well enough to obtain needed services. Regarding occupation, employed patients were 2.12 times more likely to utilize palliative care services compared to non-employed patients (AOR = 3.26, 95% CI: 2.08-5.11). This reflects the financial capacity and access benefits associated with employment. Similar results have been reported in African countries like Kenya and Uganda, where employment correlates with healthcare affordability (41). In high-income countries, employment often provides insurance coverage, further facilitating service access.

In terms of clinical characteristics of cancer patients, most patients were diagnosed at advanced stages (42.1% in Stage IV), reflecting late healthcare-seeking behavior and diagnostic delays. This is consistent with findings across sub-Saharan Africa, where late-stage diagnoses are prevalent due to limited screening programs and inadequate healthcare infrastructure (41). Globally, there are key differences in the stage of cancer diagnoses. Studies from high-income countries report earlier-stage diagnoses due to robust screening programs and widespread public awareness (7). This disparity underscores the need for improved cancer prevention and early detection strategies in Ethiopia.

Good knowledge of palliative care significantly increased service utilization, with knowledgeable patients being 3.26 times more likely to utilize services (AOR = 2.43, 95% CI: 1.18-5.01). Global studies echo the importance of awareness campaigns in improving utilization, as observed in countries with comprehensive palliative care education (7). This aligns with findings from Tikur Anbessa, where knowledge gaps were a primary barrier (44).

Positive perception of palliative care was significantly associated with higher utilization. About 56.3% of patients had a good perception, and 1.78 times more likely to utilize the services compared to those with a poor perception (AOR = 1.78, 95% CI: 1.14-2.81), recognizing palliative care's role in enhancing quality of life. These results suggest that while patients acknowledge their emotional and cognitive responses and recognize the necessity of palliative care, they also perceive a significant burden associated with it. These findings are consistent with Ethiopian and African studies (49, 41), which highlight cultural stigmas around palliative care. Globally, efforts to integrate palliative care into standard oncology have improved perceptions and utilization rates (7).

Financial challenges were significant barriers, with 48.2% of patients earning more than 3,000 ETB monthly, yet many facing financial shortages, medication costs, lack of financial support from family and

charities; despite no difficulties in transportation. A study conducted in Canada (34), Texas (35) 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% (38) of patients face a higher cost of palliative care service and around half of the patients were not able to access the service.

Health system factors also influenced utilization, and patients generally feel perceptions of no bureaucratic barriers, buying medications outside due to stock-outs, insufficient recreation facilities, lack of support from providers were among factors affecting; And delay during transfer patient data from the medical record room to the service provider room is not. These findings are consistent with studies conducted in Ethiopia, such as Tikur Anbessa Specialized Hospital, where shortages of medications and inadequate provider support were reported as major barriers (49). Similar challenges are reported across Africa, while high-income countries mitigate these issues through streamlined systems and robust provider-patient communication (41). In sub-Saharan Africa, similar challenges persist due to underfunded health systems, limited infrastructure, and a shortage of trained personnel (56). A study in Uganda also highlighted frequent medication stock-outs and delays in accessing care as significant barriers (28). However, the delay during transfer of patient data from the medical record room to the service provider room was not found to be a significant factor in this study. Globally, high-income countries address these issues through streamlined systems, electronic health records, and robust provider-patient communication, resulting in more efficient service delivery (57).

Effective communication was associated with higher utilization, Majority of the factors scored above mean; physicians: providing diagnosis information, fail to discuss end-of-life issues with their patients, giving clear next-visit appointments, challenge to reach mutual agreement, language barriers and patients/ respective caregiver receives clear and honest information about their condition and prognosis are among factors affecting utilization of palliative care. Whereas, disagreements between providers and patients while discussing patient need is not. These findings align with Ethiopian studies, such as those conducted at Tikur Anbessa. Globally, patient-centered communication models, which prioritize transparency, empathy, and clarity, have been shown to enhance trust and improve healthcare utilization (57). In high-income countries, these models have been effectively integrated into oncology and palliative care frameworks, reducing misconceptions and addressing patient needs more comprehensively (58).

7. STRENGTH AND LIMITATION OF THE STUDY

Strengths of the study

This is the first study in southwest region of Ethiopia that tried to address the financial, health system, knowledge and communication factors, and also by using structured instrument "Perception of palliative care instrument /PPCI/" which are 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.

Additionally; the study measures 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 strong and helpful.

Limitation of the study

The study is not without limitations, some limitations are:

- There were time and resource restrictions, i.e. our study could not cover large areas.
- The study is a cross-sectional study and it may be difficult to identify all the factors affecting utilization of palliative care services
- 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 Jimma university medical center for the southwest region, the findings of this study may not be representative of the whole nation.

8. CONCLUSION AND RECOMMENDATIONS

CONCLUSIONS

This study aimed to determine and identify factors affecting the utilization of palliative care services among adult cancer patients at Jimma University Medical Center. Using a cross-sectional design and multivariable logistic regression analysis, it highlighted critical socio-demographic, clinical, financial, health system, and communication-related factors influencing utilization.

The utilization of palliative care services was low. Major findings include the significant role of male gender, higher education levels, and employment in increasing palliative care utilization. Knowledge and positive perception of palliative care also emerged as key determinants. Barriers such as financial constraints, medication stock-outs, inadequate provider support, and communication challenges, including language barriers, were identified as critical issues. Conversely, delays in data transfer and disagreements between providers and patients were not significant barriers.

Globally, similar factors have been reported, with high-income countries addressing these challenges through streamlined systems, robust communication models, and universal healthcare. In sub-Saharan Africa, including Ethiopia, systemic barriers persist due to limited resources and infrastructure.

Finally, addressing knowledge gaps, improving financial and systemic support, and fostering effective communication are essential to enhance palliative care utilization in Ethiopia. The findings underscore the need for multi-faceted interventions tailored to local contexts, drawing lessons from global best practices to improve access and quality of care for cancer patients.

RECOMMENDATIONS:

These recommendations aim to address the systemic, clinical, and policy-level barriers identified in the study, fostering an improved and equitable palliative care system at institutional, regional and national level:

Organizational Development:

- To establish dedicated palliative care units in the hospitals with trained professionals and resources to provide comprehensive palliative care.
- To implement digital health systems by adopting electronic medical records to streamline patient data transfer and reduce administrative delays.
- To expand training programs by providing continuous training for healthcare providers to improve communication and management of palliative care services.

Clinical Issues:

- To enhance early diagnosis and referrals by strengthening cancer screening programs to ensure timely diagnosis and integration of palliative care early in treatment.
- To improve provider support by increasing the number of trained palliative care providers to address the gaps in provider support reported by patients.
- To address medication stock-outs by developing partnerships with pharmaceutical suppliers to ensure consistent availability of essential medications, including opioids.

Policy Implications:

- To develop national palliative care policies by establishing comprehensive policies integrating palliative care into the national healthcare framework, emphasizing accessibility and affordability.
- To subsidize palliative care costs by introducing government or NGO-supported financial assistance programs to reduce out-of-pocket expenses for patients.
- To mandate provider-patient communication standards by enforcing guidelines requiring physicians to discuss prognosis, end-of-life issues, and treatment options transparently.

Other Relevant Issues:

- To establish public awareness campaigns by conducting nationwide awareness programs to educate the public about palliative care, addressing misconceptions and stigma.
- To sustain research and monitoring by establishing mechanisms to monitor and evaluate palliative care services regularly, ensuring quality improvement and evidence-based practice.

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ANNEX

Annex I: English version of the information sheet

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 **ABDI BIRATU** who is graduating student by Master of Science with specialty in Oncology Nursing at the school of Nursing and Midwifery, Addis Ababa University. I am here today to collect data on.

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 was 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 was 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 was strictly confidential and was kept in a locked cabinet. The findings of this study was 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 **ABDI BIRATU**, the principal investigator of this study via her cell phone number **0913637505**.

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, 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:

- ❑ **Completed**
- ❑ **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			
101. Age (years) _____		**102. Sex**	**1. Male**
			2. Female
103. Religion	**1. Orthodox**	**104. Educational status**	**1. Unable to read and write**
	2. Muslim		**2. Primary (1-8)**
	3. Protestant		**3.Secondary (9-12)**
	4. Others (specify____)		**4.Tertiary (Diploma and abov**
105. Marital status	**1. Single**	**106. Occupational status**	**1. Employed**
	2. Married		**2. Self-employed**
	3. Divorced		**3. Non-employed**
	4. Widowed	**Part two: Clinical characteristics**	
107. Residence	**1. Urban**	**201. Type of cancer**	**Carcinoma**
	2. Rural		**Sarcoma**
			Lymphoma
			Leukemia
			Others
108. Family size in numbers	_____	**202. Stage of t cancer**	**1.Stage I**
			2.Stage II
			3.Stage III
109. Average family monthly income (in ETB)	_____		**4.Stage IV**
		203. Type of treatment	**1.Chemotherapy**
			2.Radiotherapy
			3.Hormonal Therapy
			4.Surgery
			5.Other/combination----------

Part three: Palliative care service utilization

Please answer the following questions by ticking the box next to the answer that is most true for you.

Items	YES	NO
301. Are you currently receiving palliative care?		

Part four

Factors to palliative care service utilization

Instruction: ✓ **T**he response from the alternatives

Items	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Financial Factors					
401. You are facing financial shortage for hospitalization fee					
402. You are facing financial loss for buying the prescribed medications (opioid analgesic)					
403. While traveling to the hospital patients are having difficulty in paying for transportation					
404. You are not forced to stop palliative care servi due to lack of financial support from family					
405. Families are not forced to stop palliative care service due to lack of financial support by charities					
Health system factors					
501. The hospital has no bureaucratic procedures for receiving care					
502. You are forced to buy prescribed medications outside due to stock-outs					
503. You should be provided with the recreation facilities within the hospital premises					
504. The service providers do not provide support for the patients/caregivers during the visit					

505. Palliative care cannot be delivered concurrently with curative cancer treatments					
506. The service providers give enough time and attention to their patients					
507. There is no delay during transfer patient data fror the medical record room to the service provider room					
Knowledge and cultural factors					
601. Palliative care is essentially the care for terminally ill patients.					
602. Palliative care is all about pain management					
603. Palliative care is a service only for patients with cancer.					
604. Palliative care should be started when medical an surgical methods of treatment are ineffective.					
Communication factors					
701. Physicians routinely inform patients about their diagnosis and prognosis					
702. Physicians don't discuss end-of-life issues with their patients					
703. The service providers give clear appointments about the next visit					
704. There is a difficulty of mutual agreement between patients and service providers					
705. There are disagreements between patients and service providers when discussing their patient needs					
706. Patients/ respective caregiver receives clear and honest information about their condition and prognosi					
707. There are language factors can between service providers and patients /caregivers					

Part five

Perceptions about Palliative Care

Instructions: Please circle the number between 1 and 7 that describes the extent to which you agree with each of the following statements.

A. Emotional reactions to palliative care

How strongly do you agree with the following statements today? **When I think about palliative care, I feel:**							
Items	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
801. I feel scared	**1**	**2**	**3**	**4**	**5**	**6**	**7**
802. I feel hopeful	**1**	**2**	**3**	**4**	**5**	**6**	**7**
803. I feel stressed	**1**	**2**	**3**	**4**	**5**	**6**	**7**
804. I feel secure	**1**	**2**	**3**	**4**	**5**	**6**	**7**
805. I feel depressed	**1**	**2**	**3**	**4**	**5**	**6**	**7**
806. I feel anxious	**1**	**2**	**3**	**4**	**5**	**6**	**7**
807. I feel reassured	**1**	**2**	**3**	**4**	**5**	**6**	**7**

B. Cognitive reactions to palliative care

If a palliative care referral was suggested for me today I would:							
Items	Strongly disagree	Disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Agree	Strongly agree
808. Think the more support I get the better I will feel	**1**	**2**	**3**	**4**	**5**	**6**	**7**
809. Think my cancer is out of control	**1**	**2**	**3**	**4**	**5**	**6**	**7**
810. Think my doctor really cared about what is happening to me	**1**	**2**	**3**	**4**	**5**	**6**	**7**
811. Think nothing more can be done	**1**	**2**	**3**	**4**	**5**	**6**	**7**
812. Think I am at the end of the road	**1**	**2**	**3**	**4**	**5**	**6**	**7**
813. Think my doctor has given up on m	**1**	**2**	**3**	**4**	**5**	**6**	**7**
814. Think my illness is terminal	**1**	**2**	**3**	**4**	**5**	**6**	**7**
815. Think I will lose contact with my current doctors and nurses	**1**	**2**	**3**	**4**	**5**	**6**	**7**
816. Think about the future more positively	**1**	**2**	**3**	**4**	**5**	**6**	**7**
817. Feel more in control of my situation	**1**	**2**	**3**	**4**	**5**	**6**	**7**

818. See this as having strangers coming into my home	**1**	**2**	**3**	**4**	**5**	**6**	**7**
819. Be worried that they would disrupt my daily routine	**1**	**2**	**3**	**4**	**5**	**6**	**7**
820. Worry that they would talk to me about dying	**1**	**2**	**3**	**4**	**5**	**6**	**7**

C. Palliative care needs

These are areas of need palliative care services can assist you and your family and friends with. Please rate how they apply to your situation today.							
Items	Strongly disagree	Disagree	Somewhat disagree	Neither agre nor disagree	Somewhat agree	Agree	Strongly agree
822. My family or friends need help with my physical care	**1**	**2**	**3**	**4**	**5**	**6**	**7**
823.I need help to manage physical symptoms such as pain	**1**	**2**	**3**	**4**	**5**	**6**	**7**
824. I need emotional support	**1**	**2**	**3**	**4**	**5**	**6**	**7**
825. I need help to manage my medication	**1**	**2**	**3**	**4**	**5**	**6**	**7**
826. I want to talk with someone about dying	**1**	**2**	**3**	**4**	**5**	**6**	**7**
827. My family or friends need emotional support	**1**	**2**	**3**	**4**	**5**	**6**	**7**
828. I need spiritual support	**1**	**2**	**3**	**4**	**5**	**6**	**7**
829. I want someone to talk to my family or friends about my illness	**1**	**2**	**3**	**4**	**5**	**6**	**7**
830. I want help to find meaning in my cancer experience	**1**	**2**	**3**	**4**	**5**	**6**	**7**
831. I want to prepare now for what might happen in the future	**1**	**2**	**3**	**4**	**5**	**6**	**7**
832. I need help with my daily activities such as showering	**1**	**2**	**3**	**4**	**5**	**6**	**7**
833. I want to talk to someone who understands what I am going through	**1**	**2**	**3**	**4**	**5**	**6**	**7**
834. I want my family and friends to prepare now for what might happen in the future	**1**	**2**	**3**	**4**	**5**	**6**	**7**

D. Perceptions of burden

How strongly do you agree with the following statements today? **When I think about my current health situation:**							
Items	Strongly disagree	Disagree	Somewhat disagree	Neither agre nor disagree	Somewhat agree	Agree	Strongly agree
835. I worry I am a burden to others	**1**	**2**	**3**	**4**	**5**	**6**	**7**
836. I feel I depend too much on others to do things for me	**1**	**2**	**3**	**4**	**5**	**6**	**7**
837. I worry that my family and friends don't have enough time for themselves because of what they do for me	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Annex IV: Amharic version of the information sheet

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[illegible]

[illegible]

[illegible]

[illegible]-[illegible]20-30 [illegible]

[illegible]

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[illegible]?

[illegible]. [illegible] ______________________ ([illegible])

[illegible]. [illegible] __________________ ([illegible])

Annex V: Amharic version of the consent form

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Annex VI: Amharic version of the Questionnaire

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ሀ. የገንዘብችግሮች					
401.የሆፒታልክፍያንለመክፈልከፍተኛየሆነየገንዘብእጠረትች					
402.የታዘዘውንየህመምማስታገሻመድሃንትለመግዛትከፍተኛየሆነየገንዘብእጠረትይገጥሞታል					
403.ወደሆስፒታልለመሄድየትራንስፖርትክፍያንለመክፈልከፍተኛየሆነየገንዘብእጠረትይገጥሞታል					
404.የቤተሰብእርዳታንበማጣታቸውየተነሳየማስታገስክብካቤአገልግሎትእንዲያቋርጡይገደዳሉ					
405.የታካሚቤተሰቦችከበጎኣድራጎትድርጅቶችእርዳታንበማጣታቸውየተነሳየማታገስአገልግሎትንእንዲያቋርጡኣይገደዱም					
ለ. የጤናስርዓትችግሮች					
501.በሆስፒታሉኣገልግሎትንለማግኘትብዙየመንግሰትኣሰራርመከተልኣያስፈልግም					

502.በሆስፒታሉመድሃኒትባለመኖሩየታዘዘላቸውንየህመምማስታገሻመድሃኒት መግዛትከግልመድሃኒትመደብርይገዛሉ					
503.ለታካሚዎችየሚሆንመዝናኛበሆስፒታሉግቢውስጥልዘጋጅላቸውይገባል					
504.የጤናባለሙያዎችለታካሚዎቻቸውወይምቤተሰቦቻቸውበጉብኝትግዜምገ ምዓይነትእገዛላያደርጉላቸውም					
505.የማስታገስክብካቤአገልግሎትከፈውስህክምናጋርበአንድነትአይሰጥም					

506.የጤናባለሙያዎችለታካሚዎቻቸውበቂየሆነግዜናትኩረትይሰጣሉ					
507.የታካሚዎችንመረጃወደሚመለከተውብቁባለሙያለመድረስምንምዓይነትመ ገየትየለም					
ሐ. የእውቀትችግሮች					
601.የማስታገስክብካቤአገልግሎትበምትአፋፍላይለሚገኙታካሚዎችብቻየሚሰጥ ልግሎትነው					
602.የማስታገስክብካቤአገልግሎትዓላማህመምንማስታገስብቻነው					
603.የማስታገስክብካቤአገልግሎትለካንሰርህሙማንብቻየሚሰጥአገልግሎትነው					
604.የማስታገስክብካቤአገልግሎትመጀመርያለበትየውስጥዴዌፈውስውይምየቆዶ ክምናመንገዶችሳይሳካስቀርብቻነው					
መ. የመግባባትችግሮች					
701.የጤናባለሙያዎችየታካሚዎቻቸውበሽታምንነትማሳወቅአይጠበቅባቸውም					
702.የጤናባለሙያዎችከታካሚዎቻቸውበማስታገስክብካቤጉዳዮችዙርያመወያየት ለባቸውም					
703.የጤናባለሙያዎችለታካሚዎቻቸውግልፅየሆነየቀጠሮግዜአያሰውቅዋቸውም					
704. በታካሚዎች እና በአገልግሎት አቅራቢዎች መካከል የጋራ ስምምነት ችግር አ ።					
705.የጤናባለሙያዎችየታካሚዎቻቸውፍላጎትከመረዳትአንፃርመግባባትአይችሉ					

706.ጤናባለሙያዎችለታካሚዎቻቸውግልፅናታማኝበሆነመልኩየበሽታቸውማንነ ናቀጣይሁኔታኣያሳውቅዋቸውም					
707.በታካሚዎቸእናጤናባለሙያዎችበቋንቋያለመግባባትሁኔታይታያል					

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805. □□□□□ □□□□ □□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
806. □□□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
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808. □□□□ □□□ □□□□ □□□ □□□□ □□□ □□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
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810. □□□□ □□□ □□□ □□ □□□□□ □□□ □□□ □□□ □□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
811. □□□ □□□ □□□ □□□□ □□□□□□□ □□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
812. □□□□□ □□□□ □□ □□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
813. □□□□ □□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**

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815. □□□ □□□ □□□□ □□ □□□□ □□ □□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
816. □□□□□□ □□□□ □□□□□□ □□□ □□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
817. □□□□□ □□□□□□ □□□□ □□□ □□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
818. □□ □□ □□□□ □□□□□ □□□□ □□□□□ □□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
819. □□□□ □□□□ □□□□□□□□ □□□□□□□□□ □□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
820. □□ □□ □□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**

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822. □□□□□ □□□ □□□□ □□□□□ □□□□□□ □□□□ □□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
823.□□□ □□□ □□ □□□□ □□□□□□ □□□□□□ □□□□ □□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
824. □□□□ □□□ □□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
825. □□□□□□ □□□□□□ □□□□ □□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
826. □□ □□ □□□□ □□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
827. □□□□□ □□□ □□□□ □□□□ □□□ □□□□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
828. □□□□□ □□□ □□□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**

829. □□ □□□□ □□□□□□ □□□ □□□□□ □□ □□□□□ □□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
830. □□□□□ □□□□□ □□□ □□□□ □□□□□ □□□□ □□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
831. □□□□ □□ □□□□ □□□□□□ □□□ □□□□□ □□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
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833. □□□□□□□ □□□ □□□□ □□ □□ □□□□□ □□□□□□	**1**	**2**	**3**	**4**	**5**	**6**	**7**
834. □□□□□ □□ □□□□ □□□□ □□□□□ □□□ □□□ □□□□□□ □□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**

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	በፍፁምአል ስማማም	ኣልስማማም	በተወሰነ ኣልስማማም	ገለል ተኛ	እስማማ ለሁ	በተወሰነ እስማማለ	በጣምእስማ ማለሁ
835. □□□□ □□□ □□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
836. □□□ □□□ □□□ □□ □□□ □□□□□□□□□□ □□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**
837. □□□□□ □□ □□□□ □□□ □□□□□□□ □□□ □□□□□ □□□□□ □□ □□ □□□□□□□ □□□□□□ □	**1**	**2**	**3**	**4**	**5**	**6**	**7**