ADDIS ABABA UNIVERSITY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH

HEALTH FACILITY-HOUSEHOLD NEXUS FOR PALLIATIVE CARE AMONG ADULT CANCER PATIENTS IN ADDIS ABABA, ETHIOPIA

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ABBREVIATIONS AND ACRONYMS

CSOs– Civil Society Organization

ED– Emergency Department

FBOs –Faith-Based Organizations

FGD –Focus Group Discussion

GPC – General Palliative Care

HBC – Home-Based Care

HCBC – Home and Community-Based Care

IDI- In-Depth Interview

KII – Key Informant Interview

NCD – Non-Communicable Disease

NGOs – Nongovernmental organizations

PC – Palliative Care

PPOC – Preferred Place of Care

PPOD – Preferred Place of Death

SPC – Specialty Palliative Care

WHO – World Health Organization

Abstract

Background: Based on a world health organization report in 2020, over 56 million people are estimated requiring palliative care every year and of which 76% are from Low and Middle-income countries; where a majority of 67.1% are adults; of those, 69% of palliative care need is associated with non-communicable diseases, and only 14% of people who needs palliative care are currently receive it; mainly cancer accounts for 34% out of the non-communicable diseases in need of palliative care. The critical point in palliative care services is to ensure the continuum of care and address patient needs as they pass through the referral pathways between the community and facility-based palliative care services.

Objective: To explore the nexus of health facility and household palliative care for adult cancer patients in Addis Ababa Ethiopia.

Method: Qualitative study was conducted in Addis Ababa from August 01- September 30, 2020. The investigator conducted an in-depth and key informant interviews through an open ended interview guide. Data were audio-recorded, transcribed verbatim, and finally imported to Open code version 4.02 software for coding and analyzing. Tanahashi framework was adopted to classify and organize data according to the key themes, concepts, and emerging categories.

Results: Twenty-five respondents participated in this study. The continuum of palliative care was described as the relation between hospitals and home-based palliative care whereas non-governmental support the community and health facilities by hosting training; volunteers contributes a lot to the continuum of palliative care starts at household level respondents stated that volunteers, family members, hospital care providers, and neighbors are used as a connective plug for the continuum of palliative care.

Conclusion: The continuum of palliative care mainly depends on volunteers, non-governmental organizations based in Addis Ababa which includes hospitals in the loop of continuity. However, volunteers link cancer patients from the community to home-based palliative care. Mainly shortage of pain relief medications, turnover of staff, shortage of educated personnel, was mentioned as a barrier to the continuum of palliative care whereas availability of national palliative care policy, working palliative team/group, and commitment were facilitators.

Keywords: **N**exus, Continuity**, C**ontinuum of care, palliative care, cancer, Addis Ababa

1. Introduction

1.1. Background

Cancer is an important public health problem and it is an important cause of morbidity and mortality in every world region; it is estimated worldwide that 18.1 million new cancer cases and 9.6 million cancer deaths were reported in 2018 by the Global Organization Board Of Cancer Association Network (GLOBOCAN) (1). Approximately 70% of deaths from cancer occur in low and middle-income countries(2).

In the continent of Africa, cancer is also an increasingly significant public health problem, the current share of cancer deaths and the incidence is 7.3% and 5.8% respectively(1), the World Health Organization(WHO) projection suggests that cancer incidence and mortality will double to 1.8 million new cases and 970,000 deaths per year by 2030(3). In Ethiopia, cancer accounts for 5.8% of total national mortality, and the annual incidence will be estimated to around 60,960 cases and the annual mortality will be over 44,000(4).

Palliative care (PC) is an approach that improves the quality of life of patients and their families facing the problem associated with a life-threatening illness, through the prevention and relief of suffering by early identification and impeccable assessment (5)(6)(7).

Palliative care services use a team approach to address the needs of patients and their families, including bereavement counseling(5–8).

In general, Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy by integrating relief from pain, psychosocial and spiritual aspects of patient care and it intends neither to hasten nor postpone death and offers which affirms life and regards dying as a normal process; and offers a support system to help patients live as actively as possible until death, to help the family cope during the patients' illness and in their bereavement; to enhance the quality of life (5)(6).

Patients who receive PC experience improved quality of life, fewer depressive symptoms decreased emergency room visits, hospital admissions, and lower healthcare expenditures, achieved with modest program costs. as well as higher levels of satisfaction with care. PC should be provided in the context of the continuum of care and not only at the end of life(9).

In 2014 the World Health Assembly (WHA) passed resolution WHA.19 “Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course”; to strengthen and integrate palliative care throughout their health care systems following the WHO public health model, which includes ensuring that policies are in place, comprehensive education on palliative care is available, essential palliative care medicines are available and affordable, and that programs are funded and implemented (10).

Palliative care is not limited to any one care setting. Palliative care is provided wherever a person’s care takes place, whether this is the patient’s own home, a care facility, hospice inpatient unit, hospital, or outpatient or daycare service. However, Home-Based Palliative Care (HBPC) is one of the primary models of care that is helping to increase its accessibility and ensure the sustainability of palliative care(11).

Hospice care is end-of-life care provided by health professionals and volunteers. They give medical, psychological, and spiritual support. The goal of the care is to help people who are dying have peace, comfort, and dignity. The caregivers try to control pain and other symptoms so a person can remain as alert and comfortable as possible. Hospice programs also provide services to support a patient’s family(5)(12).

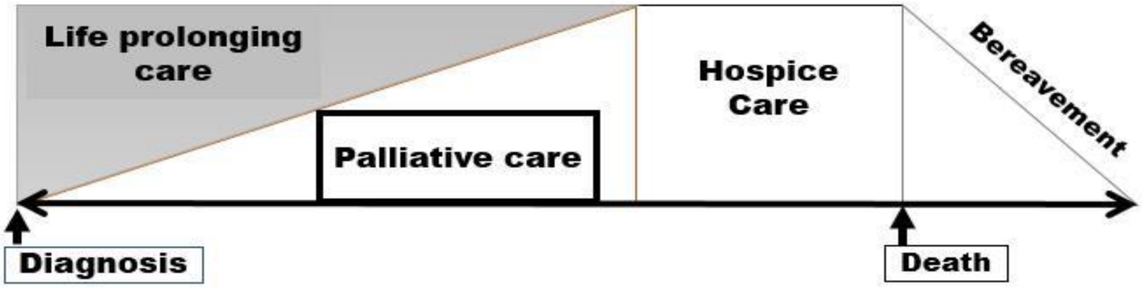

Figure 1:Palliative care engrossment for cancer patients from diagnosis up to bereavement (5)(13).

There are different models of care being used for palliative care implementation. These include home-based, facility-based, and hospice-based care. These models should be coordinated for the successful implementation of the PC program(4)(12).

WHO defines home care as the delivery of health services by formal and informal caregivers at home to promote, restore, and maintain a person’s maximum level of comfort, function, and health including care for a benevolent death(5,6). It avoids unnecessary curative treatments and optimizes the use of Specialist Palliative Care (SPC) expertise; This home-based provision relies on the strength of family support and the enthusiasm of the volunteers(14).

The strength of HBPC models of palliative care is the dignity and privacy it gives to the patient and their families to be cared for in the comfort of the patient’s home, giving psychological, social, as well as spiritual support (15) and HBPC, educates and empowers the community and it reduces the isolation and stigma which often comes with an incurable illness(4)(12).

Most families prefer to care for the ill throughout their illness, home-based care services ensure continuity of care for patients and empower the caregiver in the family by teaching them simple and cost-effective methods of caring for the patients therefore this is important in resource-poor settings where access to institutional care is difficult(16)(17).

Ethiopia has a strong community infrastructure with Faith-Based organizations (FBOs), Civil Society Organization (CSOs), and community support groups such as “iddirs” which could involve in palliative care services (4)(12).

1.2. Statement of the problem

The global need for palliative care will continue to grow as a result of the rising burden of non-communicable disease, it is expected that as people's lifestyles change, along with their nutritional preferences and work patterns, and aging populations there may be an increase in the incidence of chronic, life-limiting diseases(7).

Based on a WHO report in 2020, over 56.8 million people require palliative care every year Worldwide including 31.1 million before and 25.7 million close to the end of life; the majority 67.1% in need of PC are adults; among adults, 36.5 million people of palliative care need is associated with NCDs, such as cancer, HIV/AIDS, and cerebrovascular diseases(CVDs); mainly cancer accounts for 34% in need of palliative care out of the NCDs second to CVDs and from all palliative care need 76% are from low-income countries(5)(6).

In 2004, WHO advocated PC as being a public health issue and access to such care is recognized by United Nations Conventions as a human right yet there are significant disparities in the provision of PC services for individuals with a life-limiting illness; of the 56.8 million people globally in need of palliative care, only 14% receive it, mostly in high-income countries(18).

In Africa, an estimated 80% of cancer patients are diagnosed with late-stage disease where access to curative treatment such as chemotherapy or radiotherapy is limited which makes the need for palliative care high (19). Besides, compared to high-income countries, the availability of treatment services is less than 30% in low-income countries(20).

The critical point in palliative care services is to ensure the continuum of care and address patient needs as they pass through the referral pathways between community and facility-based palliative care services(12)(21).

Some of the mentioned barriers for adequate provision of palliative and continuum of care is lack of training and awareness of palliative care among health professionals, and limited access to essential analgesics because of legal and regulatory restrictions i.e. the use of strong opioids, such as oral morphine, lack of recognition of the importance of palliative care from universities, Non-Governmental Organizations (NGOs)(22)(23). Consequently, resources are distributed elsewhere, and not toward PC provision which is a major barrier to improving access to PC(24)(1).

In 2018 Ethiopian NCDs patients accounted for 39% from that 7% accounts for cancer; by 2030, 4% of the Ethiopian population will be aged sixty-five years or over given that the prevalence of chronic conditions increases with age, the demand for palliative and end of life care is likely to increase(15)(1).

Currently in Ethiopia, the health care system acknowledges the importance of palliative care so, the concept is included in both the national cancer control and national palliative care guideline of the FMOH; which focuses on ensuring availability and accessibility of palliative care and states as one of the objectives specified to assure palliative care access to the wider population is by integrating PC services into Primary Health Care (PHC) and through leveraging the already existing community/home-based care delivery system is a basic step (25). It is planned to strengthen home-based palliative care and volunteerism through community volunteers and health extension workers(4).

Studies have shown that Home-Based palliative care is a preferred model by patients and family caregivers which requires to smoothen the continuum of palliative care from facility level through the integration of the service to the current chain of health delivery system, but no published studies were found with a focus on the continuum of palliative care for adult cancer patients in Ethiopia which might create information gap eventually, this study aims to explore health facility to household nexus for palliative care provision.

1.3. Significance of the study

Findings from this study would provide detailed information about the existing continuum of care and barriers to and facilitators for palliative care service and help policymakers, NGOs working on cancer to make their insight wide on the evidence-based intervention of continuum of palliative care since the nexus have significant importance on the way to improve the quality of life of cancer patients and facilitate peaceful death. The findings of the current study are expected to add knowledge to palliative care and it reflects where to focus furthermore regarding the continuum of care, the study highlighted the continuum of care & how it should be supported by rigorous and locally relevant research indicating appropriate, feasible and effective care.

The study might also provide baseline information for stakeholders by basing it on the values and goals of people dealing with cancer. Also, it would help as reference material for other researchers and students interested in further studies on this issue.

2. Literature Review

2.1. Burden of cancer

Cancer is becoming more prevalent worldwide and remains one of the leading causes of death in developing countries; According to the WHO (2018), the prevalence of cancer has reached 18.1 million in the world, and Recently, the cancer-related death rate has been reported to about 9.6 million, which makes cancer the second leading cause of death worldwide(26)(27).

Globally, cancer is one of the predominant conditions for which palliative care is offered(5). Cancer incidence in Ethiopia at present is estimated to be 125,000 to 150,000 per year(28). Throughout the world, many patients present to their healthcare system late, when their disease is advanced especially, individual's with cancer are more apt to present when their disease is far advanced and incurable, so, therapies to control it are frequently ineffective and palliative care is very significant for those patients(29).

Its greatest impact is evident in countries with limited cancer prevention, screening, and treatment services such as countries with lower income and destitute populations have high exposure to carcinogens, unhealthy lifestyle and occupational factors, and not as much health education is provided to counter these risks or advocate for health care change (27).

In 2018 Ethiopian NCDs patients accounted for 39% of that 7% accounts for cancer; by 2030, the prevalence of chronic conditions increases with age, the demand for palliative and end of life care is likely to increase(15)(1).

2.2. Palliative care

Chronic NCDs are the main cause of death in the world and the number of people affected by NCDs is increasing and Low- and medium-income countries (LMICs) are facing a significant increase in the incidence of NCD such as cancer, in reality, almost 50% of the world's countries have no access to palliative care5 while 76% of the global palliative care need comes from LMIC (5)(7)(6)(30).

From a human rights perspective, all individuals are entitled to dignity, respect, and fair treatment across the life course, palliative care has been asserted to be a human right. Human and civil rights advocacy groups also suggest that the lack of palliative care treatment for the sick and dying is a type of torture, suffering, and cruel and punishment (7)(30).

PC can be delivered in at least two levels: general palliative care and specialist palliative care; The general palliative care approach would be used in settings and services only occasionally treating PC patients. In contrast, specialist palliative care applies to a team of appropriately trained physicians, nurses, social workers, chaplains, and others whose expertise is required to optimize the quality of life for those with a life-threatening or debilitating chronic illness (5).

A major advance in the development of PC in sub-Saharan Africa came with the "Cape Town Declaration" in November 2002 it stated that palliative is the right of every adult and child with a life-limiting illness, and stressing that palliative care should be integrated into existing healthcare systems within the continuum of care oriented upon policies, drug availability, education of health professionals, and implementation of palliative care at all levels (31)(10)(32).

A study was done in the USA and in the Indian state of Kerala in palliative care program, describes Primary diagnosis at enrollment to the home connection (home-based palliative care) was the most common neoplasm 51% and 61% respectively (14) (33).

Globally, NCDs cause 70% of all deaths and generates 93% of adult palliative care needs with an estimated 37.4% of all deaths need palliative care; annually over 56.8 million people need palliative care services the majority of these people 67% are adults, with 34% of them being patients diagnosed with cancer(5)(34). These conditions require progressive and continuous care, with timely access to PC(5)

2.4. Models of palliative care

There are different types of models for the implementation of palliative care such as home-based, facility-based, and hospice-based care.

2.4.1. Home-based palliative care

Home-based palliative care services help reduce the symptom burden people may experience as a result of advanced illness, without increasing grief for family caregivers after the patient dies; a 'good death' in a developing country occurs when the dying person is being cared for at home, is free from pain or other distressing symptoms, feels no stigma, is at peace, and has their basic needs met without feeling dependent on others; thus, patients who wish to die at home should have affordable home palliative care with bereavement support(35)(36)(37).

Studies showed a significant reduction of symptom burden, increased patient satisfaction, reduced ED visits, inpatient admissions, and costs besides, Caregivers in the home-based care group reported less pain and less depression and anxiety (13)(38)(39)

The home-based care services ensure continuity of care for patients and empower the caregiver in the family by teaching them simple and cost-effective methods of caring for the patients. This is important in resource-poor settings where access to institutional care is difficult (40).

In a study done in Northern America, California the net reduction in costs per participant, reduction in hospital usage, and its costs determined the overall cost reduction in home-based primary care studies (41).In West Africa, Nigeria, Families were appreciative of the subsidized home-based palliative care services provided; this reduced the burden of taking patients to and fro from the hospital and the purchase of oral morphine (11).

In Ethiopian, a study done on the costs of medical care revealed cost of medications, and transportation to receive medical care were highest in the oncology group at the meantime families were overwhelmed by the costs of medical care 64% and 68% of patients reported that they were obligated to sell substantial sources of wealth and a family member had taken leave to care for them, resulting in indirect lost respectively(42).

According to the systematic review done on cost-effectiveness commissioning of end of life; costs of care from every model of care perspective are higher costs of care at the hospital, medium costs in nursing care and hospice care; and lower costs for home care (43).

Studies in Taiwan and Japan concluded that the home is the best place to care for the terminally ill, the majority of patients who stated preferred place of cared 84% and 58% of respondents preferred home as the place for end-of-life cancer care (43)(44).

A population-based study from Spain found that the frequency of deaths in the hospital lower among patients in the geographic area with palliative home care compared to the area without palliative care(45).

A recent meta-analysis found that receiving home palliative care doubles the odds of dying at home and reduce symptom burden, especially for patients with cancer (38).

In Ethiopia, Family Health International, in collaboration with government, local NGOs, and community organizations, jointly implements home and community-based care (HCBC) within the continuum of care to address the needs of poor, chronically ill, and bedridden and the home-based care have a substantial role in improving the quality of life of patients and families (11).

2.4.2. Facility-based palliative care

It is well established that there is a mismatch between the location in which care takes place at the end of life and the individual's preferred place of care whereas many people at their end of life would prefer to be cared for at home, around 90% of people spend time in hospital in their final year of life. It also reports that there is still an excessive number of hospital admissions that could be avoided if patients were offered high-quality community support (46).

Most patients with terminal illnesses cannot afford expensive hospital care and are discharged home as a result, many terminally ill patients have often neglected without formal services a studies of home-based cancer patients, revealed 71% complained of ineffective pain control and 74% of family caregivers wanted to receive assistance with symptom control at home (47)

2.5. Integration and continuum care

2.5.1. Continuum of Care

Continuity of care: the extent to which a series of health care services is experienced as connected, coherent, and is consistent with a patient's health needs and personal conditions. Three interrelated dimensions of continuity of care have been stated: (i.) Relational continuity refers to having ongoing therapeutic relationships with one or more providers, (ii.) Informational continuity denotes the use of information about past events and personal circumstances to make current care appropriate for each individual and (iii.) Management continuity referring to a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs. As patients and family caregivers can have an important role in securing continuity (21)(48). Palliative care should be provided through an integrated, collaborative, community resource-linked continuum of care that focuses on home-based care (12).

Continuity of care is associated with lower rates of emergency department visits, decreased hospital deaths, supportive needs improved patient satisfaction, better utilization of services, and significant cost savings with palliative care being met. However, continuity of care is often overlooked in care provision for patients with advanced diseases who usually receive care from multiple health care professionals (21)(49). Though, the focus of care from the hospital to the home and community can be achieved with integrated care(13).

Lack of continuity of care can cause undesired experiences with palliative care provision, for example, feeling unsafe during illness transitions, patients being transferred between multidisciplinary teams, and suboptimal support for problems and needs (50).

2.5.2. Integration of palliative care provision

Integrated palliative care focuses on coordinating different care services centered on the need of each patient with advanced illnesses and their family to ensure continuity of care (24).

Integrated palliative care has been increasingly proposed since it has the potential to improve continuity of care experiences and also concerning the quality of life, survival rates, and cost-effectiveness of palliative care for patients with advanced diseases so integration into existing health structures is key to PC provision, along with a well-defined patient referral system, to ensure that care is provided sustainably, appropriately and to majorly advance in increasing its accessibility (50).

Briefly, the higher the level of integration of the service, the greater the capacity to offer palliative care/ its accessibility. However, challenges exist to the provision of palliative services through HBC, these challenges are the limited visit from professional attached to the HBC (i.e. distance covered by a single care provider, had limited access to a vehicle, with the high disease burden across the region, the demand for palliative care service surpasses supply and significant shortage in skilled palliative care professionals (19)(51).

Developing services that are sustainable within the context of a high burden of disease is crucial, but limited resources are a persistent challenge and one that is faced by clinicians in the HBC setting regularly. Therefore, the care must be linked closely within the community and integrated into existing healthcare structures.

2.5.3. Conceptual framework

To ensure the continuum of palliative care from facility to household, an adequate palliative care delivery, composed of the four components is required. These four gears are Policy, Education, Service provision, and Medications which are mainly involved with policy & decision-makers. For the effective connection of PC care provision to a household, the linkage should be maintained via the integration to the health system.

Indeed, its use could facilitate the engagement of the patient, their family members/caregiver, and care providers with the healthcare system for sustainability and accessibility of the service based on this conceptual framework all these parties have a key role in the continuum of care in this study (Figure 2).

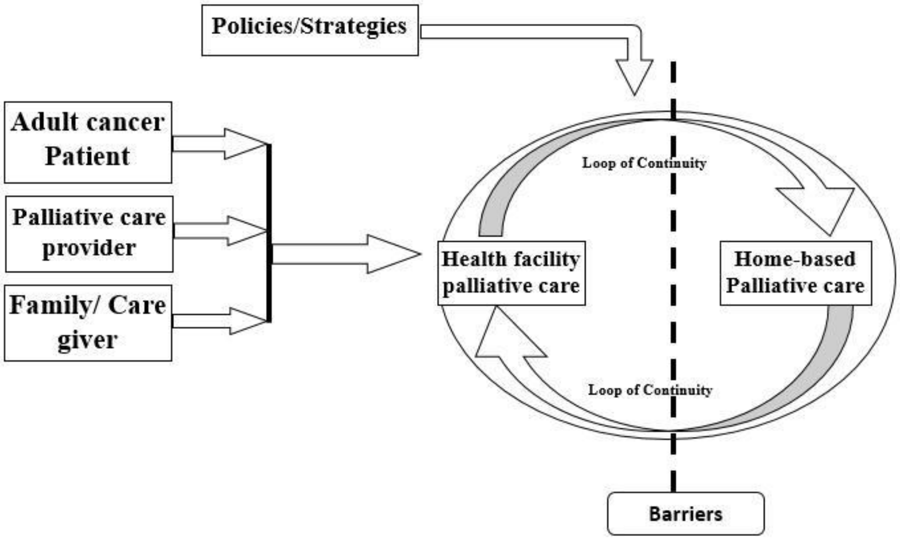

Figure 2:Conceptual framework to explore the nexus of clinical to household palliative care for adult cancer patients based in the palliative care centers in Addis Ababa Ethiopia.

3. Objective

3.1. General objective

To explore the nexus of clinical to household palliative care for adult cancer patients based in the palliative care centers in Addis Ababa, Ethiopia 2019/20.

3.2. Specific objectives

1. To investigate the nexus of palliative care provision at a health facility and household levels
2. To explore patients, caregiver, provider, and policy level barriers for and facilitators to palliative care service provision.
3. To explore patients, caregiver, provider and policy level barriers and facilitators of health facility and household nexus for palliative care provision

4. Method

4.1. Study area and period

The study was conducted from August 01, 2020 - September 30, 2020, in Addis Ababa which is the capital city of Ethiopia; one of the fastest-growing cities on the continent. Rendering to the 2007 census projection for 2020, the total number of populations of the city is 4.8 million. The main languages spoken in the city is Amharic (52).

With the epidemiological shift of the burden of disease from communicable to NCDs, the long waiting time of cancer patients for curative treatment, limited treatment availability, and priority is given to younger patients leads to a potential need for palliative care service. Since Addis Ababa is the only city where palliative care service is provided the selected study areas were in two government hospitals, hospice Ethiopia and the ministry of health

4.1.1. Tikur Anbessa Specialized Hospital

Tikur Anbessa Hospital is located in Addis Ababa, Ethiopia. It is the only tertiary referral hospital in Ethiopia, and, where cancer treatment and PC services practically exist. This hospital has 5 beds devoted to palliative care and administered by Addis Ababa University.

4.1.4. Yekatit 12 memorial hospital medical college

Yekatit 12 memorial hospital medical college is Found in front of Sidest kilo square in Addis Ababa Ethiopia. It is one of the largest specialized hospitals in the city government of Addis Ababa and also provides palliative care for seriously ill patients for the past consecutive 3 years period for cancer patients.

4.1.5. Hospice Ethiopia

Hospice Ethiopia care is a non-governmental organization founded in 2003 and based in the capital, Addis Ababa. Hospice Ethiopia provides care to people with serious illness and their families, trains healthcare workers in palliative care, and conducts advocacy to raise awareness of palliative care and to create an enabling environment for providing palliative care in Ethiopia.

4.1.6. Ministry of health

The Ministry of Health (MoH) is a government ministry of Ethiopia, responsible for public health concerns. Its head office is on Sudan Street in Addis Ababa.

4.2. Study Approach

A qualitative study was conducted in two governmental hospitals, one hospice center, and MOH. Qualitative study is a useful method since it helps to focus on the events of patients, relatives, and professionals and their views on the patient-professional interaction and the organization of the health care system; it also enables a rich, straight description of an event in the analytical process and presentation of data particularly it is relevant to gain obtain firsthand knowledge of patients', relatives' or professionals' events with a particular topic and answers to questions of special relevance to policymakers. An additional advantage of this method is that it is suitable if time or resources are limited (53)(54).

4.3. Eligibility criteria

4.3.1. Inclusion criteria

For recruiting patients, the study participants fulfilled the following criteria

- 18 years old and above,
- Patients diagnosed with cancer and who are informed about their illness.
- Those who can give consent,
- Patients receiving palliative care service.

For recruiting health care providers, the study participants fulfilled the following criteria

- Physician, oncologists, nurses providing palliative care service

For recruiting policymakers, the study participants fulfilled the following criteria

- Past and Currently involved in health policy decision

4.3.2. Exclusion criteria

- Cancer patients who can’t/unable to communicate didn’t take part in this study.

4.4. Study participant’s recruitment

4.4.1. Study Participants

Study participants were palliative care providers such as nurses, physicians, and specialists, in the respective health facilities, policymakers from FMOH who were experienced in their area of expertise for these specific participants key informant interview were conducted after explaining the objective and the process of the study.

The other participants recruited were cancer patients in the selected palliative care providing facilities, family caregivers, and Volunteers for those participants in-depth interview was conducted after explaining the process of the study and reaching consensus.

4.4.2. Selection of study participants

To select participants for this study, we used purposeful sampling so that we can make sure the exact participants who fit into this study were chosen. Purposeful sampling is a technique that involves identifying and selecting individuals or groups of individuals that are experienced or knowledgeable about a phenomenon of interest or information-rich cases (55). Besides, willingness to take part in the study, and the ability to communicate experiences and opinions in a coherent, easy-to-understand, and insightful manner.

To recruit study participants, the Maximum variation technique was used since Maximum variation sampling aims at capturing and describing the central themes or principal outcomes that cut across plenty of participants or program variation and patterns that emerge from a great variety of particular interest and value in capturing the core experiences and central, shared aspects or impacts of a program some in rural areas, and some in urban areas the investigator includes both rural and urban dwellers to be sure that the geographical variation among participants was represented in the study and by identifying diverse characteristics like setting such as government hospitals and NGOs working on palliative care service, health care provides who have had quite different experiences, to understand variations (53). This can often help the researcher to identify common themes that are evident across the sample to ensure that the sample reflects a diverse group in terms of skill level, professional experience, and policy implementation(56).

First, the principal investigator (PI) Identify a location where the PI personally select participants then contacted the selected hospital medical directors or department head then discussed briefly the objective and process of the study; then Make a list of and Identifying the characteristics of Participants who meets the criteria of the study.

By Contacting health care providers who can suggest participants(patients) who fit in this study, for instance, asking physicians or nurses to nominate patients who match the criteria.

4.5. Data collection procedures

We targeted potential individuals from five groups, namely: Patients, Caregivers, Health care providers, volunteers, and policymakers. The investigators identified local site coordinators who arranged the recruitment in each of the participating two hospitals and one NGO and facilitated on-site access to the research team. These coordinators provided a list of potential participants for each group. By using this list, participants within each group were selected through the purposive sampling technique.

We chose to conduct in-depth interviews with cancer patients, caregivers and volunteers by going to their home to gain deep insight into their perspective of the nexus of PC, barriers to, and facilitators for PC and the principal investigator also resolve some ambiguities in the first interview with a repeated visit until clarity is reached.

The investigator conducted a key informant interview for health care providers in different settings like government hospitals and NGOs and policymakers at the ministry to illustrate the continuum of care.

Questions such as socio-demographic characteristics, cancer diagnosis, stage of cancer, treatment, understanding of palliative care, barriers to and facilitators for the palliative care and continuum of care, areas of improvement were asked for patients and.

The investigator also explored health care providers, policymakers with a question such as socio-demographic status, their understanding of PC, current practice, how palliative care is appropriate for people with progressive illness, availability of medication in the public health sector, barriers to and facilitators for the palliative care and continuum of care, on how the continuum of palliative care is active on the current health system, and challenges and areas of improvement.

Data collection continued until data saturation i.e. no new data obtained from the interviews. The researcher directed the interviews to achieve the objectives of the study through probing questions. Saturation is commonly used as the criterion to determine when sampling should cease in the qualitative study; that is when additional interviews do not result in new concepts or the point in data collection and analysis when new information produces little or no change to the codebook.

To determine when data saturation occurs, analysis ideally occurs concurrently with data collection in an iterative cycle i.e., the decision was smoothed through constant comparison of data; this was done during and after data collection. The investigator moves back and forth between the data and emerging thematic identification and interpretation to observe reoccurring patterns and themes in the data.

During the interview, memos and scribbles were specifically and independently noted; the interview guide was continuously modified throughout the data collection to include newly occurred issues and to improve the clarity of the interview questions. The investigator has conducted all the interviews following the interview guide. All data were collected by the principal investigator and facilitated by the health care provider working in the selected hospital and organization. The interview was conducted in patients’ homes and private rooms in the hospitals where participants’ privacy was kept All interviews were conducted in the participants’ Amharic and audios were recorded by using tape-recorder. The duration of each interview was ranged from 30 to 50 min.

Since qualitative research involves the “researcher as the instrument”, the researcher's use of self is a primary tool for data collection(57). The researcher includes relevant information about the participants, in the form of background demographic data. The unique characteristics of key informants were explained why they were selected.

4.6. Trustworthiness

The four basic criteria to maintain the rigor of qualitative study were upheld, findings focusing on the credibility, dependability, transferability, and conformability of the study.

Credibility: Before starting the actual data collection, the investigators first get familiarized with the study setting, to access trustworthiness and real information, the investigator established a close and friendly relationship and start the conversation by introducing each other, and participants were encouraged to feel free and talk openly and good interview technique which helps to build rapport. Feedback and guidance from qualitative experts (advisors) were used in managing the data, Peer debriefing was also done during data analysis to confirm findings by other peers by presenting the study findings to them and receive their comments to improve quality. Prolonged engagement in the field or research site and taking adequate time with study participants were maintained,

Dependability: in the process of safeguarding dependability the investigator confirmed the content of the transcripts by reviewing the audio records of the interview. Notes taken during the interview and transcription verbatim were saved for verifying the process and to endure consistency of the interpretations.

The investigator checks for the similarity of the codes by code-recode strategy, peer-reviewing (experts in the field of qualitative research/advisors) until a consensus was reached on the selected categorizations and codes, peer examination at which another researcher also coded some of the translated data and a difference in the coding with the investigator was revised and discussed to clarify the research findings and safeguarding informants' identity was also preserved.

Transferability: to warrant transferability findings were smoothed by providing sufficient information about the research context, methodology and the study participants were selected purposively who fulfill the inclusion criteria, the result addressed by providing a thick description of time, place, context and, the analysis was described in detail so that reader can use and replicate the study.

Conformability: The investigator reflected on and considered prior personal expectations and experiences to reduce bias during data collection, coding, and analysis. the researcher guaranteed confirmability through, words of study participants, through audit trial, and triangulation by data source since it is collected from different sources, e.g., different people, by methods since different data collection strategies were used such as individual interviews, key informant interview.

4.7. Data Analysis procedures

Immediately after finishing each interview session, information stored on an audio recorder listened to the words of participants, and their description of issues was internalized and transcribed verbatim by the interviewer. Subsequently, a preliminary analysis was done to see for saturation of the information and emerging themes.

The audio-recorded interviews were transcribed in Amharic, translated into English, and aligned with the field notes of the interviewer. Thematic analysis was applied to the transcribed interviews.

A codebook was developed after interviewing a few study participants to guide the researcher coding consistency throughout the data analysis process. Emerging ideas during the interview were added to the codebook and similar ideas were combined with earlier codes.

Data were coded by the researcher and in case of discrepancies between the two the advisors were involved to verify and reach a decision. Data analysis was facilitated by Open-code version 4.02., besides, another peer researcher also coded some of the translated data, and inconsistency of coding with the investigator was revised and discussed to clarify the research findings. Before the analysis, a consensus was reached among the team on the coded themes and subthemes.

We adopted the Tanahashi framework approach to analysis to classify and organize data according to the key themes, concepts, and emerging categories.

Tanahashi's effective coverage stages have five important stages that sequentially lead to the desired health outcome, this five-stage are availability, accessibility, affordability, contact, and effectiveness where availability shows what resources are available in what amount for delivering a PC service that includes number of health facilities providing PC, trained health care professional, availability drugs, equipment which is necessary for the provision of the service the second stage is accessibility refers to available resources but inconveniently located, therefore hindering physical access like distance from a health care provider, distance and transportation in time.

Table 1:List of themes, categories, and codes

Themes	**Categories/codes**
Availability	• Resource ○ Number of health facilities, ○ Trained personnel, ○ Work overload ○ Drugs(pain relief) ○ Equipment
Accessibility	• Physical access ○ Distance from an HCP, ○ Distance and transportation is time. ○ Cost of service
Acceptability	• Affordability, ○ Transportation Cost ○ Conventional medicine ○ BUY-in from Hospitals, ○ Waiting time
Contact	• Continuity of care ○ Neighbors ○ Volunteers ○ Professionals ○ Iddirs ○ Professionals
Effectiveness	• Quality and effectiveness of service ○ Physical ○ Focusing on tratment ○ Phycological ○ Social ○ Spiritual

The third stage acceptability, after the service is accessible, it still needs to be acceptable by population service factors such as cultural acceptability, religion, type of facility, the capacity of facilities, and people who are willing to use the service, can be defined as acceptability. Continuity of care provided by the institutions and professionals expressed as contact between the palliative care service provider and the user/patients; in the process of service, provision continuity does not always assure a fruitful intervention where the quality of service answers whether all the services of the palliative care program accessible and provided at the correct intervals (58).

4.8. Ethical Considerations

Ethical approval for the study was obtained from the Research Ethics Committee (REC) of the School of Public Health, College of Health Sciences of Addis Ababa University with approval number 64/2020, and a letter of support was written to selected hospitals and organizations from Addis Ababa University School of public health to inform them about the study.

The investigator explained the objective of the study and all the necessary information to the study participants; the participants were informed that the information obtained from them was only accessed by the principal investigator and written informed consent was obtained from the study participants. Data was kept confidential and it was used only for this research purpose.

The study participants were informed that they were no any direct incentives but given to participants and they were expected to allot 30 - 50 minutes of their time for the in-depth interview and they were also be informed about relatively minor risk i.e. some discomfort and anxiety in discussing issues related to their illness because some questions seemed to be sensitive and personal but the investigator covered each question smoothly and gave enough time to relax and answer each question properly. Concerning respecting their right they were entitled to ask any questions and were not forced to participate and could withdraw at any time while the interview was conducted.

Due to the current COVID-19 pandemic, appropriate precautions were taken while conducting face-to-face interviews such as hand washing/sanitization, keeping the appropriate distance, and wearing a mask in every interview.

4.9. Dissemination plan

The final result was submitted to Addis Ababa University College of Health Sciences, School of Public Health, and after approval, in the defense, the findings of this study will be communicated through presentation and discussion, on seminars and workshops. The key findings and recommendations will be reported to responsible bodies; the publication of the findings of the research will be made in a national or international peer-reviewed journal.

5. Findings

The findings of this study are concise based on five thematic areas as it was guided by the framework the first theme that emerged to understand and articulate those themes, we first investigate the continuum of palliative care within this theme there are categories of availability and accessibility of continuum of care and how it operates are included.

Themes such as availability, accessibility, acceptability, contact, and effectiveness were used to articulate barriers to and facilitators for palliative care and continuum of care. Findings of the study are described using categories with continuous text and established by the themes.

In writing the findings, the following terms are used “most/major for more than 12 respondent’s response, some: -for responses of 5-9 participants, and few for responses of 3-4 participants[1].

5.2. Participant’s socio-demographic characteristics

A total of 24 study participants of both sexes has participated in key informants and in-depth interviews. Their age was ranging from 22 to 59 years. Out of the total study participants, six were palliative care service providers, nine of them were patients, seven of them were caregivers, two of them were volunteers. Among the participants, twelve of them were males, two with no formal education, two with primary, five completed secondary education, and fourteen are diploma or above holders. Sixteen respondents were Married, Eight of them were single. Four patients participants were unemployed and six care providers were government employees the remaining were private employees.

Table 2:Socio-demographic status of respondents

		Provider	Caregiver	Patient	Policymaker
Age	20-39	6	6	2	-
	40-59	0	1	7	2
Sex	Male	2	3	3	1
	Female	4	4	6	1

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[1] In writing the findings, the following terms are used “most/major for more than 12 respondent’s response, some: -for responses of 5-9 participants, and few for responses of 3-4 participants.

Marital status	Never Married	3	4	1	-
	Married	3	3	6	2
	Divorced	-	-	-	-
	Widow	-	-	2	-
Education	No formal Education	-	-	2	-
	Read and Write	-	-	1	-
	Primary	-	-	2	-
	Secondary	-	3	2	-
	Diploma and Above	6	4	2	2
Employment	Housewife	-	-	-	-
	Government employee	3	4	-	-
	Private	3	3	-	-
	Volunteers	-	-	-	2

5.3. Nexus of Palliative care

Most of the participants admitted the obtainability of the nexus of palliative care service from household to facility level in a very extremely limited fashion in Addis Ababa and care providers are also on duty for maintaining the linkage of the patient from hospitals to Hospice Ethiopia and from the community to hospice Ethiopia.

> “It is available in Addis Ababa working at the community level and there are some health centers already doing home visits but not in an official capacity that needs to develop; even though the service has developed in the last five years there is still an awful lot of work such as writing a home care guideline to help people at the community level.” (52 years old female Advocator/consultant)

A practical situation but informal linkage where patients can access a continuum of palliative care from Hospital to a community level was described below as

> “She was a nurse from Yekatit hospital when I went there for my pain due to blood clot and stated about all my problems, she took me to an office and advised me to talk to the NGO working in this area then she contacted them form me called and give them my contacts and they directly came to my home for a visit.”

Nevertheless, one of the participants articulated the availability and the accessibility of palliative care as it was active a while ago but currently, the service is getting compressed to Addis Ababa though, MOH is working to extend the program.

> “In HIV care it is more or less integrated with the training of health providers taking care of such patients initially but later enthusiasm for PC waned and disappeared. MOH is

> beginning to establish hubs in some hospitals in Addis Ababa and regional capitals but not yet at the health center and home-based care levels” (Male 55 years old, Advocator/consultant)

On the other hand, some of the Rural dweller participants mentioned that the absence of the Tuesday and Thursday Service (palliative care) and the continuum of the service at all levels in their village.

> “…let alone giving us the service at home it was enough if we get the Tuesday and Thursday service at the zonal hospital; we are dying waiting for our appointment there was no one responsible for this connection...” (Male 45 years old, Throat cancer patient)

One respondent stated continuum of palliative care is not doctors or nurses only; its everybodys working together the family member, the community leaders, the “idder” and everybody to support the patients and the family.

> “*50 ሎሚ ለ አንድም ሰው ሸክሙ ነው ለ 50 ሰው ውበት ነው (50 lemon is a burden for 1 man but for 50 people it is a beauty)* the more we share the burden the more we have the continuity and it needs to be shared with the patients, family, community, hospital staffs, the religious staffs, the social worker staffs”

5.3.1. How the Nexus operates

According to the findings of this study, most respondents stated that volunteers, Family members, hospital care providers, and neighbors are used as a connective plug for the continuum of palliative care. Here a 25 years old female Volunteer explained how she linked Patients for palliative care

> “I usually get patient by searching or by chance asking my neighbors if someone is suffering from cancer, HIV, Diabetes, and hypertension to promote the service hospice Ethiopia; I usually talk to patients where ever and whenever I get the chance with the intention to communicate them about the service. Until now, I have link five patients for Hospice Ethiopia from Tikur Anbessa and my village”

A 30 years old health care provider also elaborate on this idea on how the nexus of palliative care operates from the facility level to a household setting

> “We link Patients only from Addis Ababa since hospice Ethiopias service is limited due to available resources and human power. Either we contact using a referral form describing

> name, phone number and conditions of the patient or using a phone call describing the patient identity and their condition" (30 years old female care provide)

Furthermore, some participants also mentioned family members, neighbors were also involved to maintain and endure the linkage of patients from home and facility level. Neighbors who were the victim of terminal illness and benefited from palliative care plays an informal but important role in helping other victims of the illness in the loop of continuity. A 38 years old male cancer patient stated as

> "…there was one health professional in the neighborhood and I heard that she was the one who told them about me. After she saw me suffering, she told me there is a working group in this area, I didn't have any information about the service, almost I had given up on the medicine and the health care system, even withdrawing myself from any treatment I was talking..."

Besides, other respondents also stated their initiation of the continuum of palliative care from household to facility-level was effective after somebody from the family who had the information about the care was involved and boost the patient's motivation to start using the service. A 45-years old caregiver/Family stated:

> "…the patient's sister was the one who informed hospice Ethiopia as she heard there is a charity organization that helps cancer patients' home to home then they visited her at home and starts receiving the service…"

The continuum of palliative care was described by most respondents as the relationship between government health facilities and NGO exchanging in-need cancer patients and the fact that the NGO support the community(volunteers, neighbors, the family of the patient) and health facilities by advocating for PC and hosting training to enhance knowledge in the process; volunteers contribute a lot for the continuum of palliative care to help start at household level by surveilling cancer patients from the community; despite the above, a missing link appear between the community and health facility. A Family Medicine specialist from the hospital stated that

> "We have a memorandum of understanding with the NGO to work in collaboration with each other on palliative care to strengthen palliative care and the continuity mainly we contact the NGO either by a Phone call or a written patient history document"

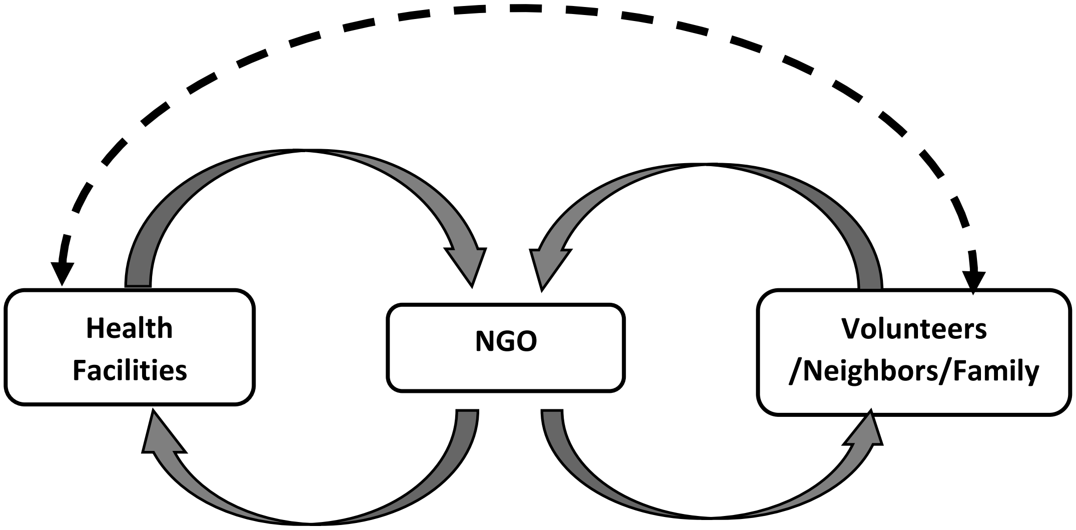

Figure 2: Continuum of palliative care amongst health facility, NGO, and community

5.4. Barriers and Facilitator's

5.4.1. Availability

Barriers

The majority of the barriers that participants mentioned affect patients such as Turnover of staff, turnover CEO, and lack of attention from higher officials as a main barrier to the nexus despite the fact trained care providers are anticipated to contribute a lot in this deserted area nonetheless it worsens the current situation in abolishing what has been built since.

> "… as a trainer and a teacher Continuity is always very difficult when working with government hospitals, the turnover of staffs is thought-provoking; we train and build a strong palliative care team and then two years later its different staffs and different CEO however as more people are trained the more continuity comes." (52 years old female policymaker."

Most of the study participants mentioned a lack of Morphine as the major reason since morphine is the drug of choice for pain relief for cancer patients; it gets out of stock immediately even though the professional wanted to give it and the patient needs the medication.

> "The shortages appeared as supply dwindled again because of lack of ownership and donor-driven nature of the initiative. Immediately PFSA began to import from Switzerland to supply those Hospitals above demanding for it" (52 years old female Advocator/consultant)

Most key informant responds Shortage of educated personnel and trained staffs as a barrier to the nexus even though education is one of the building blocks of palliative care and a crucial point in the continuum of palliative care.

> “Capacity building, train PC to doctors and nurses in the undergraduate and postgraduate program so that PC is not only actively advocated by these professionals but also integrated into their routine practice and service of the community”

The other problems upraised were related to barriers related to turnover and shortage of trained staff/care provider.

> “…as a consultation base we provide palliative care this doesn’t mean that we provide all those in need because of the shortage of trained health professionals (doctors, nurses, and social workers). that is because of lack of a designation unless trained staffs stay at their positions and serve, we couldn’t provide the service appropriately” (30-year-old female health care provider).

Facilitators

Most of the participants revealed that the availability of NGOs, administrators support, policy and guideline development in the area of palliative care, the palliative care service is available at the hospital, and Buy-in from hospital management are worthy facilitators for the palliative care service use by the patients.

> “… NGOs that support us from abroad, that is a good deal for us, and our administrators are very eager to find different funds and support and are working towards influencing policymakers on this issue” (25 years old female health care provider)

Respondents mentioned the availability of policy and guideline development in the area of palliative care. The availability of guidelines is a potential facilitator for palliative care.

> “…so, we have the Ethiopian national palliative care guideline. Even though Palliative care is the same chapter as rehabilitation in the Ethiopian hospital transformation guideline it is also now in the primary health care guideline which is going to be developed and in the five-year strategic plan for palliative care which will then be verified next month by the management team at the ministry of health.” (52 years old female Advocator/consultant)

Some of the respondents were thankful that the service by it-self being available is a good reason for them to use it.

> “…I am very happy that I can get the Tuesday and Thursday service here at TASH and to get an anti-pain or sort of thing when I am in pain, it is very good for me and I am happy that at least the service is there. (42 years old female cancer patient)

A policymaker discussed the importance of palliative care getting due attention by hospital managers, which is very crucial for the service.

> "… One of the big things is about getting the buy-in from hospital management to see this is an important thing at black lion the officials understand the importance of palliative care which is fantastic to get the hospital Management Buy-in" (52 years old female Advocator/consultant)

5.4.2. Accessibility

Barriers

Palliative care service is a relatively new concept in our country. Even if hospitals and care providers want to do many activities concerning this area, they are in much need of support from the government and stakeholders for acknowledgment.

> "…unless policymakers and higher officials have a good approach to this, they will not let you work on anything, they will halt you, so palliative care have not gained enough attention from the government, that is a big obstacle" (33 years old male health care provider)

On the other hand, some Rural dweller participants mentioned that the absence of the Tuesday and Thursday Service (palliative care) provided at Tikur Anbessa and also the connection of the service at all levels in their village.

> "…let alone giving us the service at home it was enough if we get the Tuesday and Thursday service at the zonal hospital; we are dying waiting for our appointment there was no one responsible for this connection..." (Male 45 years old, Throat cancer patient)

Most study participants agreed that late diagnosis and absence of diagnosing instruments were major challenges for them. As patients were not diagnosed earlier, they won't get palliative care service as soon as they deserve it.

> "She went first to a health center and other clinics but her illness was not diagnosed earlier the tumor stayed and reached an advanced stage. Therefore, the medical instrument which is crucial for the diagnosis of cancer should be available; they were giving her simple medication saying that it is just her menstrual cycle for a long time." (45 years old female caregiver)

Lack of awareness among health care providers, and them only focusing on treating or prescribing drugs and considering palliative care as luxury were major concerns raised from the side of health care providers as being a barrier to palliative care. One health care provider said;

> “Primary barriers is a big knowledge gap in health care providers. Even At the institution's level, they only focus on the disease, not on the status of the patient's pain and suffering. In general palliative care in a country level is not much-practiced too much work is needed for the health workers.” (28 years old female health care provider)

Furthermore, some participants mentioned the importance of including Family member during the discussion in palliative care visits as it is a critical pinpoint which shouldn’t be missed

> “…. the problem I usually faced was my family was not able to attend palliative care service during follow up, so especially things related to sexual intercourse, I would have preferred if my husband attend the session as the discussion can help him to be aware and understand my situation but he had no awareness only focuses on his feelings so the service should be provided together with family. Unless the advice for me alone is non-sense and meaningless…” (42 years old female cervical cancer patient)

Facilitators

Most of the participants admitted the obtainability of the nexus of palliative care service from household to facility level in a very extremely limited fashion in Addis Ababa and care providers are also on duty for maintaining the linkage of the patient from hospitals to Hospice Ethiopia and from the community to hospice Ethiopia.

> “It is available in Addis Ababa working at the community level and there are some health centers already doing home visits but not in an official capacity that needs to develop. Although the service has developed in the last five years there is still an awful lot of work such as writing a home care guideline to help people at the community level.” (52 years old female Advocator/consultant)

Nevertheless, one of the participants articulated the accessibility of palliative care as it was active a while ago but currently, the service is getting compressed to Addis Ababa but currently, MOH is working to extend the program.

> “In HIV care it is more or less integrated with the training of health providers taking care of such patients initially but later enthusiasm for PC waned and disappeared. MOH is beginning to establish hubs in some hospitals in Addis Ababa and regional capitals but not

> yet at the health center and home-based care levels" (Male 55 years old, Advocators/consultant)

5.4.3. Acceptability

Barriers

Some of the respondents raised infrastructure such as the capacity of NGO is limited to enroll all patients for the service to be provided that limits and delays the continuum of care.

> "Our organization may not have the capacity to admit all linked patients from hospitals due to human resource and financial strength so in this situation we might not support all in need patients at the household level and outpatient level." (28 years old female health care provider)

One of the issues mentioned by most of the patients as a barrier to palliative care was transportation. A cancer patient described as the following;

> "...last week I came on Tuesday at TASH and they told me to come back on Thursday, as the doctor was already gone, I came from a Hossana the transportation made me late so I waited till Thursday" (30 years old, male cancer patient)

Some of the study participants mentioned that it is difficult for them to afford the medication ordered by the doctors beyond that availability of prescribed drugs is also under question. Here below a cancer patient described as following

> "…even if my family are sending me money, I was not able to afford to buy medications since the drugs are too much expensive." (30 years old, male cancer patient)

Some participants mentioned that Ethiopian culture can also be a barrier to palliative care. Participants described providing palliative care as feeling anxious as to deal with a dying cancer patient. This service is provided from diagnosis until bereavement.

> "…It is very anxious, always dealing with a dying patient is hard for us culturally to cope with such fact so defiantly this is a barrier" (30 years old female care provider)

Some participants also mentioned the preference of conventional medicine by patients as a barrier to palliative care service even though it is not wrong to it has its effect on the late diagnosis of cancer and delayed start-up of palliative care.

> "Because one of the issues with cancer patients is that people when they find a lump or something the first thing they do is go to a traditional healer or they go to a priest or they

> go to *Tsebe*l (holy water) or they go whatever and then what happens is it will take them longer to go health center for them to get to an oncologist in time.” (52 years old female Advocator/consultant)

Facilitators

In Ethiopian culture, people will sit and drink coffee talk to each other, and share their burden was considered Ethiopian culture is considered a facilitator and plays a major role in palliative care.

> “… the Ethiopian culture is an amazing culture for palliative care because there is a caring support the way people live, the way that people are living together, the way that people help their family these all is an amazing facilitator for palliative care....” (52-year-old Advocator/consultant)

The strong spiritual attachment and involvement amongst the community also play a vital role in palliative care.

> “There is a spiritual component here in Ethiopia; the spiritual component is very strong here unlike developed countries here everybody is still well connected.” (52-year-old Advocator/consultant)

5.4.4. Contact

Barriers

Most participants were reporting on the absence of time for discussion with their care providers. If proper time and space for discussion are not provided for patients and family caregivers, this could be a major reason for the barrier of palliative care.

> “yes, there is no enough time, they just call you by name, you get in, they will write you medication and ask some few questions and next person will be called, that is it. There is no discussion” (30 years old male cancer patient)

Additionally, limiting the palliative care service to specific days was a barrier to palliative care and even patients miss interpret the concept of the service with the name of specific days as a result most patients know palliative care as the “Tuesday and Thursday service”. A cervical cancer patient stated her feelings as follows;

> “I only find the doctor who aided me last time on Tuesday but If I came other than these days, I might not get this service; for instance, if I come tomorrow, I am sure they will tell me to go back” (42-year-old female cervical cancer patient)

Moreover, some participants reported expanding the service to fulfill the need of the population at a large but the shortage of connector, overwhelmed health extension worker with lots of activities becoming ineffective, Volunteerism is not a culture, lack of Government and public commitment needs to improve.

> "…human resource is mandatory to facilitate the link a volunteer living in Yeka sub-city isn't supposed to work in Bole so, another person for Bole and the same with other areas therefore to improve the linkage we need to recruit and train different volunteers from different Sub-city." (A 32 years old female health care provider)

Facilitators

One respondent stated culture as a facilitator for the nexus of palliative care in a way that how the society interacts in a different circumstance, live together, share burdens, ideas, the community bonding, spiritual alertness, which makes it easier for the nexus and palliative care in curtailing the burden for a palliative care provider in the social and spiritual component.

> "One of the facilitators for the nexus of palliative is Ethiopian culture which is an amazing spice for palliative care because there is a caring support, the way that people are living together, the way that people help their family and the fact people will sit and drink coffee talk to people and share their burden is astonishing"

Iddirs (self-help community burial organizations) are potential sources of volunteers and forum for mobilizing the community to support home-based palliative care services.

5.4.5. Effectiveness

Barriers

Most health care provider was raising the issue of work overload which leads to only treating the physical symptoms of patients by ignoring the other components of palliative care.

> "…to tell you the truth we are focusing on managing physical symptoms but spending time to heal the psychosocial, spiritual problems concerning the number of the patients and the burden of the work it is difficult for us to manage" (30 years old health care provider)

Furthermore, some participants mentioned the importance of including Family member during the discussion in palliative care visits as it is a critical pinpoint which shouldn't be missed

> "…. the problem I usually faced was my family was not able to attend palliative care service during follow up, so especially things related to sexual intercourse, I would have preferred if my husband attend the session as the discussion can help him to be aware and understand my situation but he had no awareness only focuses on his feelings so the service

> should be provided together with family. Unless the advice for me alone is non-sense and meaningless…" (42 years old female cervical cancer patient)

Most health care providers explained that palliative care service at the moment is provided in a general form which one provider support patients physical, psychological, social, and spiritual need all together that leads to the ineffective way of providing the service and pushes health care providers only to focus on the physical component. A 29 years old health care provider stated

> "Currently we are supporting patients physical need only due to different reasons such as human resource, drug availability, and financial constraint but it would have been better if the full component of palliative care service was provided"

Facilitators

Health care providers explained that patients, their pain, and suffering, and their need for the service is what is keeping the providers to go ahead.

> "The primary facilitators are our patients, who were in pain at the time of enrollment after getting our services some get relieved from their pain and suffering, some start the job they quit which answers their financial problems in general patient's improvement shows us how palliative care is essential for them…" (28 years old, health care provider)

6. Discussion

This study tried to explore the health facility-household nexus for palliative care among adult cancer patients in Addis Ababa. Respondents narrated their views on the continuum of palliative care, barriers to and facilitators for palliative care service provision and nexus of palliative care respectively and participants also revealed an area of improvement for formal delivery of palliative care and better utilization of the service.

In this study, we found that mainly the shortage of pain relief medications (opioid) was mentioned as a barrier to the availability of palliative care and continuum of care. This finding is consistent with other studies in Africa which reported a lack of access to pain medications and other essential medicines (20)(22)(59,60)(61). A meta-analysis of 122 studies addressing cancer patient's difficulty in getting access to their prescribed opioid medications(62). Opioids are the main treatment of cancer-related pain, and one of the components of palliative care is relieving cancer patients from pain, and lack of access to this medication is mentioned as the main barrier to the PC service. This is due to developed countries such as the United States, Canada, European nations accounted for more than 90% of the global consumption of opioid despite the fact LMICs consumed only 10% of global opioids(63).

In this study the turnover of staff, lack of basic training for staffs, shortage of educated health professional in palliative care (i.e., training in PC at the undergraduate level), lack of attention from higher officials, has been identified as a core barrier and our study is supported by a study done in Tikur Anbessa specialized hospital, Ethiopia nurses have poor knowledge and practice towards palliative care and the authors concluded that lack of training and formal education (64). In another study, done in Uganda health professionals from different African regions were enrolled and attends courses that range from short to diploma level courses (65). This implies education is a basic tool to combat such barriers in sustained fashion but it is still largely omitted from university curricula.

Participants mentioned the presence of NGOs and GOs working in this area, administrators support from hospitals, development of palliative care policy and guideline, and staff's commitment to work in the position were facilitators of the availability of palliative care this finding in line with previous studies done in Europe and Africa stated facilitator to the progress of palliative care as the existence of national palliative care working group, the existence of PC teams and commitment to the initiative in diverse areas. the availability of the health care provider, venerable provider to the patient relationship, and experience (49) (66).

Lack of access to palliative care is a major problem worldwide in this study absence of palliative care service providing facilities in rural inhabitants, even though the service is available for urban dwellers inconveniently location of service providers which hinders the physical accessibility of palliative care, and majorly transportation was mentioned as the main barrier for accessibility of palliative care provision Palliative-care coverage is particularly limited for patients in inaccessible geographical areas,51and providers note that patients in rural areas are seen less often by nursing and clinical staff, necessitating more quality assistance and supervision this concept is parallel with studies done in Canada reported distance and location in part determine the utilization of services and influence health outcomes so, (67)(68). This implies PC is affected by geography location and wait time thus, people who were located closer to sites of care delivery are more likely to utilize the services because of reduced mobility and obtain better health outcomes

Even though distance, wait time and transportations were detailed as a barrier the study also found that the existence of NGO working on a home-based model of palliative care and presence of volunteers were mentioned as a facilitator this finding is consistent with a study done in Nigeria, which families were appreciative of the HBPC services which reduced the burden of taking patients to and fro from the hospital (11) and in Uganda PC services largely rely on community volunteers where volunteers increased new referrals by more than double and families to identify those who need palliative care (65)(69). This implies that the home-based palliative care model is the best approach to expand palliative care service in the continuum of care.

Besides, providers considering PC as luxury care, this finding of this study contradicts with a study done in Germany which in 2009 palliative care education was integrated into the undergraduate curriculum as part of mandatory training and to get the license to practice medicine by legislation (70). This indicates health care providers no longer consider PC as luxury care if palliative care was combined in the curricula of the current medical education system.

In our study lack of consistent communication of care providers with patients, lack of discussion time with patients, and not involving family member during discussion time Similar to other findings that reported barriers related to PC of providers, providers not talking about patients' problems, needs, and preferences as the disease progresses, difficulties of patients in dealing with the diagnosis denial or hesitant attitude towards the prognosis (66). This might be due to structure lack availability of appropriate space, work overload, and knowledge gap.

In our finding conventional medicine/traditional healers are often the first place mentioned for seeking curative service for their illness resulting in late diagnosis, late recruitment to palliative care service, and withdrawal from PC programs. This finding is supported by the study done in Africa for seeking curative service for cancer from traditional healers, herbalists are common (69). This might be due to Ethiopians have exhaustive relation to their religious and cultural healers and were an expression of pain is associated with weakness and higher waiting time for radiotherapy and chemotherapy may also lead them to this decision.

In our study lack of access to pain medications and other essential medicines due to legal and regulatory limitations, was repeatedly raised as a barrier for the continuum of PC. This finding is consistent with studies done in Ethiopia and many Africa which reported access to opioids is inadequate because of several factors such as legal and regulatory restrictions, cultural misperceptions about pain, inadequate training of healthcare providers, procurement challenges, weak health systems, and concerns about diversion, addiction, and misuse(22)(66)(69)(65).

On the other hand, to guarantee greater community coverage of palliative care, Uganda has pioneered the prescription of morphine by nurses(65). This implies that concerns related to medication accessibility in the primary health care units can be halted through offering training for nurses on how and to whom to prescribe opioid analgesics and improving the legal and regulatory policy restriction in opioids.

In this study, Iddirs (self-help community burial organizations) are potential sources of volunteers and forum for mobilizing the community to support home-based palliative care services, Health care providers working to liaise patients with NGO and assessing patients with morning ward rounds, Volunteers, neighbors, and community structure were referred as facilitators of the continuum of care. This finding supported by studies that the inclusion of community structures, such as churches (71)(72), or health workers that are often seen as ‘external’ to the health system (i.e. CHWs, caregivers, and volunteers) facilitated the integration of PC principles due to their close links with the community(69)(73) also, combined ward rounds and assessment between PC team members and other staff, locating a PC team close towards in which they frequently work, creating multidisciplinary teams and clinics or the use of a PC coordinator to liaise with other staff (74).

Patients and families will care most about the quality of the palliative care they receive. They will be hoping for a consistent approach to their care that includes a thorough assessment, provides them with the information to make their own decisions, and involves them in care planning and delivery (75). the critical moment for emphasizing quality for PC team should place a primary emphasis on providing cancer patients with the psychosocial, spiritual support for end-of-life care Nevertheless, we observe in our analysis that only the physical component is provided and lack of communication is a major problem stated by most respondents.

Even though some respondents explained there is much work planned to extend palliative care coverage they mentioned a lot has to be done on the quality, accessibility, and scope of PC; this finding is consistent with the study done in sub-Saharan Africa revealing ensuring quality is important to make palliative care accessible for those who need it through HBC models of service, it is also important not to reduce the quality of care being provided (19).

In our study effectiveness of the service was explored but all the four component of the PC is not practiced, rather only the physical component and provided Quality can be assessed through continuous quality improvement framework, explored through all the services of the palliative care program accessible, and continuity in palliative care among different levels of caregivers and institutions (76)

In this study some of the participants mentioned with primary care are the key interface for palliative care eventually that is where people come first as a country there are many things already positive in PC; the social, psychological, and spiritual support is part of Ethiopian culture, it needs organizing to give patients quality of life. This finding contradicts with the WHO effectiveness program that indicates PC should be accessible to the majority of the target population and should be carried equitably across all levels of care, in public or private; over 80% of advanced cancer patients will benefit from relatively simple and low-cost interventions that can be integrated into primary health-care and home care services(76).

7. Strength and limitation

To the best of our knowledge, this is the first study on the continuum of palliative care in Ethiopia. The approach we used also helped us to explore the unnavigated or overlooked area; employing maximum variation as a technique assisted us to look at different perspectives from diverse participants and gradual selection of study aided the study to incorporate information-rich participants.

Because of the current situation of COVID we were not able to do focus group discussions, as a result, we might have missed group dynamic idea about the continuum of PC and was not able to fully explore different professional alliance and discrepancy on barriers to and facilitators for palliative care and nexus of the service.

Data of the findings were generated from only home-based palliative care and out-patients palliative care users therefore we were limited to explore the perspective of in-patients since patients might contradict the standard curative and rehabilitative treatment with palliative care service.

8. Conclusion and Recommendations

Conclusion

Based on our findings we conclude that the continuum of palliative care mainly depends on volunteers, NGO based in Addis Ababa which includes hospitals in the loop of continuity however, volunteers had no chance to reach the hospitals in feeding cancer patients for palliative care besides primary health care units such as health centers, primary hospitals were missed in the process since palliative care provision is only provided in few specialized hospitals in Addis Ababa.

Our study also addressed the lack of access to basic and specialized palliative care training and educations, availability of medications, cost, turn over of trained staff was a hindering factor for the continuum of palliative care service. We identified also there is no responsible structure for the implementation of palliative care, policy directions and guidance are missing as such in other departments like maternal and child health.

However, facilitator to the progress of palliative care and the continuity where the availability of policy, national palliative care working group, volunteers, neighbors, family members, NGO, health care providers commitment,

Considering the lack of palliative care options in Ethiopia and the challenges patients and caregivers in programs are facing, a clear organizational structure including ongoing training and supervision of care providers is essential. The preference for home-based care calls for the active involvement of community-based networks and structures.

Continuum of the service provider can be developed through achieving integration of palliative care into the existing health care, including research as a fifth pillar on palliative care intervention to succeed in this country because context on culture, medicine and available needs to be researched to get best practice and support the system in education-related issues peal recurrent barriers.

Recommendations

Based on the findings, to ensure the continuum of PC service in a sustained long-term way the need to provide multiple interventions at the individual, and organizational levels are suggested to responsible bodies to tackle barriers in the area.

FMOH

- In collaboration with other sectors like Medias, it is better to develop appropriate community based massive awareness-raising programs on palliative care service provision.
- It is better if the government works to increase the availability and accessibility of opioid analgesics.
- Since there are shortages in skilled palliative care professionals within the study area it is recommended if palliative care providers
- It is recommended that if integrating PC into primary care for better access for the sustainability of services and the continuum of care of all level
- It is good if additional palliative care hubs are availed so that the patients could get an accessible continuum of care.
- Translating the concept of Palliative Care and core terminologies into working (official) language to help community ownership.
- Conducting researches and motivating researchers to gain a comprehensive understanding of culturally appropriate palliative care approaches; and
- Most importantly active engagement by all stakeholders.

NGOs

- Creating awareness of PC among policymakers, healthcare providers
- It is better if work in collaboration with different hospitals on consistent and sustainable referral linkages

Hospitals

- It is better to incorporate Palliative care into their system
- It is recommended if PC is provided daily

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Annexes

Annex 1:Information sheet for patients and family members

Greetings! My name is Yonas Abate student of public health at Addis Ababa University. I am researching to explore the nexus of a facility to household palliative care for adult cancer patients in Addis Ababa, Ethiopia for the partial fulfillment of a second degree; you are chosen to participate in this study. The choice is made purposively. Before you decide whether to participate or not in this study, I would like to explain to you the objective of the study, any risks, benefits, procedures, and what is expected from you.

The objective of the study: the study will explore the nexus of clinical to household palliative care for adult cancer patients based in Addis Ababa, Ethiopia

Procedure: If you join this study, we will ask you to take part in IDI which will take about 25 to 60 minutes. The discussion and the interview will be in the Amharic language. With your permission, the discussion and interview will be tape-recorded. Participants will be selected in a purposive manner based on the inclusion criteria using a recruitment script. Open-ended questions will be used to guide the interview. Discussions will be audio recorded and later transcribed and translated to English by the researcher. I will re-visit you based on your willingness for missed or untouched issues if any.

The benefit of the study: There are no implicit direct benefits for the study participants. If you don't have enough information you will be provided with information about home-based palliative care at the end of your participation. Also, if there is any information gap about palliative care that will be discussed. Additionally, the study will help to explore the continuity of care and see the barriers to effective implementation of continuity of palliative care in Addis Ababa, Ethiopia.

Risks/discomforts: We believe the risks of this study are relatively minor and likely to be rare. There could be some discomfort and anxiety in discussing issues related to your illness/ family member illness, but I will go through each question smoothly and I will give you enough time to relax and answer each question. You are expected to allot 25-60 minutes of their time for the IDIs.

Rights of participants: You are completely free to take part or not in this study. If you decide that you do not want to be part of the study, this will not be held against you and you will not be disadvantaged in any way. You are also free to withdraw from the study at any time if you feel that you cannot proceed. You can ask any question which is not clear to you.

Data Sharing: During the study, only the study PIs will have access to the study data including consent documents. Research Ethics Board could have access to data if needed as part of human safety protection requirements.

Data Confidentiality: Necessary measures such as De-identification of data and Safety storage of data will be taken to ensure data confidentiality. All study team members will be informed regarding the need to keep all information from participants confidential, as well as what needs to happen should any breach of confidentiality occur. During report sharing and communication of results, no personal individual identifiers like name or physical address will be used.

Protecting your privacy during data collection: Any data with personal information will be handled with confidentiality, and the privacy of subjects respected at all stages of the research. Respondents' privacy will be respected through the informed consent process and the procedures during the data collection. Personal identifiers (including name) will not be recorded. Primary data will be handled only by the researchers, and the data will be password protected. During data analysis, again data will be stored through a password-protected system, and data is analyzed using codes, without personal identifiers.

Would you want to take part in the study?

1- No (thank you)

2- Yes (take informed consent)

Annex 2:Informed consent for patients and family members

The objective, benefits, harms, procedures, and confidentially of the study have been read and explained to me in the language I comprehend. I further understand that, taking part in this study and withdraw from participating at any time without having a reason is purely voluntary. I am also told that I may be revisited and I agree to participate in this study.

Participant:

Sign (signature or thumbprint) .... Date ....

Annex 3:Interview guide adult cancer Patients

1. Introduce yourself to me? Probe: sex, marital status, education, employment, and religion?
2. Can you tell me about your diagnosis? PROB: When did the problems start? What happened next? Did you seek any advice? From whom?
3. Have you ever heard about palliative care? PROB: the term by itself, palliative care provision components, possible places of care?
4. Have you ever received home-based palliative care for yourself? PROB: if yes, what services did you receive, who provided you the service, when did you start taking the service? If no, will you accept the service if you are provided with it?
5. What were the facilitators for you to get palliative care service? Probe: from health facilities; from health care providers; from your perspective
6. What were the barriers for you to get palliative care service? Probe: from health facilities; from health care providers; from your perspective
7. What were the facilitators for you to get a home-based palliative care service? Probe: from health facilities; from health care providers; from your perspective; who facilitated for you to get this service; how is your relationship with the health care providers? How close are you?
8. What were the barriers for you to get home-based palliative care service? Probe: from health facilities; from health care providers; from your perspective; who facilitated for you to get this service;
9. Are you involved in decisions and planning process? PROB: Are you Informed and involved in care and treatment decisions? Is there an appropriate space, accommodation, and time for interaction with the health care provider? How? What do you think might have caused this?
10. Has your problem got worse/better after you started palliative care? How has this affected your day to day life? **PROB**: daily living (work; in the house; social activities) what do you like about palliative care service? Why?
11. Where do you prefer to be in the time of care and death? Did you plan to discuss with the health care provider and family? **PROB:** what measures taken to fulfill these preferences?
12. Can you suggest to me how palliative care nexus from facility to household and from household to facility be insured?
13. Any other concerns you want to share with me or if there is anything you want to add?

Annex 4:Interview guide for Families/Primary caregiver

1. Can you introduce yourself to me? Probe: sex, marital status, education, employment, religion, relationship with the patient
2. What do you think of when you hear the word PC?
3. Can you tell me how palliative care is appropriate for cancer patients? Prob: when do you consider the service should be provided? When did you decide to bring the patient to the hospital?
4. Are you able to respond to the patient's palliative care needs? Prob What, if any, challenges do you meet when taking care of patients with cancer? Social, psychological, spiritual, and physical
5. Do you involve in decisions and planning? Prob: Are you Informed and involved in care and treatment decisions by the health care providers? Is there an appropriate space, accommodation, and time for interaction with health care providers? What do you think might have caused this?
6. Do you talk with patients about their spiritual or adequately attempt to assess patients' access to spiritual and religious needs? Prob: how and when? What, if any, challenges do you meet?
7. What do you need to be able to increase your knowledge of PC? How do you ensure proper support during the end-of-life experience? What, if any, challenges do you meet?
8. Do you have a specific time or day to give this palliative care service?
9. What were the facilitators for your ill family member to get palliative care service? Probe: from health facilities; from health care providers; from your perspective
10. What were the barriers for your ill family member to get palliative care service? Probe: from health facilities; from health care providers; from your perspective
11. What were the facilitators for your ill family member to get home-based palliative care service? Probe: from health facilities; from health care providers; from your perspective; who facilitated for you to get this service; how is your relationship with the health care providers? How close are you?

12. What were the barriers for your ill family member to get home-based palliative care service? Probe: from health facilities; from health care providers; from your perspective; who facilitated for you to get this service;
13. Do you discuss with the patient and health care provider on preferred place of care and death? Probing: what measures taken to comply with these preferences? Are you involved in the decision-making process? How? When? What, if any, challenges do you meet? How do you go about the next step? Do you initiate a discussion about the future? Have you ever shared a personal address with providers?
14. Can you give me any suggestion on how we can ensure the continuity of palliative care from the facility to household and vise versa?
15. Any other concerns you want to share with me or if there is anything you want to add?

Thank you for your kind cooperation, I will re-visit you based on your willingness for missed or untouched issues if any.

Annex 5:Information sheet for health care providers and policymakers

Greetings! My name is Yonas Abate student of public health at Addis Ababa University. I am researching to explore the nexus of clinical to household palliative care for adult cancer patients based in Addis Ababa, Ethiopia for the partial fulfillment of a second degree; you are chosen to participate in this study. The choice is made purposively. Before you decide whether to participate or not in this study, I would like to explain to you the objective of the study, any risks, benefits, procedures, and what is expected from you.

The objective of the study: the study will explore the nexus of clinical to household palliative care for adult cancer patients based in Addis Ababa, Ethiopia

Procedure: If you join this study, we will ask you to take part in KII which will take about 25 to 60 minutes. The discussion and the interview will be in the Amharic language. With your permission, the discussion and interview will be tape-recorded. Participants will be selected in a purposive manner based on the inclusion criteria using a recruitment script. openended questions will be used to guide the interview. Discussions will be audio recorded and later transcribed and translated to English by the researcher. I will re-visit you based on your willingness for missed or untouched issues if any.

The benefit of the study: There are no implicit direct benefits for the study participants but after finishing the study, the information gathered might benefit those patients require palliative care and will come up with a a recommendation for continuity of care and the discussion will help in identifying the barriers for effective implementation of continuity of palliative care.

Risks/discomforts: We believe the risks of this study are relatively minor and likely to be rare. You are expected to allot 25-60 minutes of your time for the KIIs.

Rights of participants: You are completely free to take part or not in this study. If you decide that you do not want to be part of the study, this will not be held against you and you will not be disadvantaged in any way. You are also free to withdraw from the study at any time if you feel that you cannot proceed. You can ask any question which is not clear to you.

Data Sharing: During the study, only the study PIs will have access to the study data including consent documents. Research Ethics Board could have access to data if needed as part of human safety protection requirements.

Data Confidentiality: Necessary measures such as de-identification of data and Safety storage of data will be taken to ensure data confidentiality. All study team members will be informed regarding the need to keep all information from participants confidential, as well as what needs to happen should any breach of confidentiality occur. During report sharing and communication of results, no personal individual identifiers like name or physical address will be used.

Protecting your privacy during data collection: Any data with personal information will be handled with confidentiality, and the privacy of subjects respected at all stages of the research. Respondents' privacy will be respected through the informed consent process and the procedures during the data collection. Personal identifiers (including name) will not be recorded. Primary data will be handled only by the researchers, and the data will be password protected. During data analysis, again data will be stored through a password-protected system,, and data is analyzed using codes, without personal identifiers.

Would you want to take part in the study?

1- No (say thank you)

2- Yes (take informed consent)

Annex 6:Informed consent for health care providers and policymakers

The objective, benefits, harms, procedures,, and confidentially of the study have been read and explained to me in the language I comprehend. I further understand that, taking part in this study and withdraw from participating at any time without having a reason is purely voluntary. I am also told that I may be revisited and I agree to participate in this study.

Participant:

Sign (signature or thumbprint) .... Date ....

Annex 7:Interview guide for health care providers

1. Can you introduce yourself to me? Probe: sex, marital status, educational status, employment, your work experience? Related to palliative care?
2. What do you think of when you hear the word PC?
3. Tell me how palliative care is appropriate for people with advanced, progressive conditions? Prob: when do you consider the service should be provided? Who should provide it? Can you tell me the least criteria for the composure of the support team?
4. How about home-based palliative care? Tell me how palliative care is appropriate for people with cancer? Probe: if you provide home-based palliative care how do you enroll patients in the program?
5. Are you able to respond to the the patient’s palliative care? Prob What, if any, challenges do you meet when taking care of patients with adult cancer?
6. What were the facilitators for patients to get palliative care service? Probe: from health facilities; from health care providers; from your perspective; policy;
7. What were the barriers for patients to get palliative care service? Probe: from health facilities; from health care providers; from your perspective
8. What were the facilitators for patients to get home-based palliative care service? Probe: from health facilities; from health care providers; from your perspective; who facilitated for you to get this service; how is your relationship with the health care providers? How close are you?
9. What were the barriers for patients to get home-based palliative care service? Probe: from health facilities; from health care providers; from your perspective; how is your relationship with the patients? How close are you?
10. Is there a link from a health facility to home-based care service for these patients? Probe: where is the link should be, do you think there is a gap there? Who should work on linking patients in this bridge?
11. Do you discuss with the patient and family, on the the preferred place of death and care? Probing: what measures taken to comply with these preferences? What influences the place of care preference of patients? Are you involved in the the decision making process? How? When? What, if any, challenges do you meet?

12. Do you prepare patients and family members/ caregivers for possible changes in health status? Prob: About medication side effects, who to call when patients become ill? What, if any, challenges do you meet?
13. Do you involve family members/caregivers in decisions and planning? Prob: Are they Informed and involved in care and treatment decisions? Is there appropriate space, accommodation, and time for interaction with patients and their families and for exchange with the team? How? What do you think might have caused this?
14. Do you talk with patients about their spiritual or adequately attempt to assess patients' access to spiritual and religious needs? Prob: how and when do you provide emotional support? What, if any, challenges do you meet?
15. What do you need to be able to increase your competencies in PC for patients with cancer? Prob: what adequate prerequisites do you have for effective communication (i.e. training and education, as well as access to updated information and technology?) What, if any, challenges do you meet?
16. How do you ensure the continuity of palliative care nexus from facility to household and from household to facility be insured after informing prognosis of the disease? Prob: How do you go about the next step? Do you initiate a discussion about the future?
17. How do you ensure proper support during the end-of-life experience? Do you discuss the need for the the availability of bereavement counseling for patients and families? What, if any, challenges do you meet?
18. Anything we didn't mention but missing and want to discuss takes the time?

Thank you for your kind cooperation, I will re-visit you based on your willingness for missed or untouched issues if any.

Annex 8:Interview guide for Pallaitive care Advocators/Higher official consultants

1. Can you please introduce yourself? Probe; Age, Educational, Marital status, Employment status, Experience in the area?
2. What is your contribution/involvement in palliative care? probe for cancer patients, hospice, policy development?
3. Is there a national/Region specific strategy for the implementation of palliative care provision? PROB: Is the policy operational, underdevelopment, or not in effect? What is planned?
4. Is palliative care service provision for patients with cancer in the public health available? Prob: in the primary health care, community or home-based care or if any?
5. Can you explain how the continuum of palliative care is active in the current health system? Who are involved and at what stage? What has been done so far?
6. Can you tell me Drug availability [Is medication (oral morphine) available in primary health care facilities of the public health sector? PROB: Why? Are they available year long? What about Morphine production and transaction in our country?
7. How do you ensure the continuity of palliative care from health facility to household? PROB: Infrastructure for providing home-based palliative care services in the community? Palliative care education? Implementation? What are the challenges and the solution?
8. What are the faced barriers for the nexus of palliative care from health facility to household level? PROB: what barriers have you ever faced before what solution did you offer; and was the solution effective?
9. What are the facilitators for the nexus of health facility to household palliative care provision? PROB: what the possible facilitators; and what is planned concerning the policy, implementation?
10. Do you have continuous monitoring and evaluation? Who are to be monitored and evaluated? Based on what? Do you initiate a discussion about the future? Does the legislation have a regular review to improve access to palliative care?
11. So finally what should be done/Areas of improvement to improve palliative care and the nexus?
12. Anything we didn’t mention but missing and want to discuss takes the time?

Thank you for your kind cooperation, I will re-visit you based on your willingness for missed or untouched issues if any.

Annex 9:Amharic version of interview guide

አባሪ 9-ለታካሚዎች እና ለቤተሰብ አባላት የመረጃ ወረቀት

ሰላምታ! ስሜ ዮናስ አባተ በአዲስ አበባ ዩኒቨርሲቲ የህዝብ ጤና ተማሪ ነኝ፡፡ ለሁለተኛ ዲግሪ ማጠናቀቂያ ላይ የተመሠረተውን አዲስ አበባን መሠረት ያደረገ የአዋቂ ካንሰር ህመምተኞችን ከቤታቸው ወደ ጤና ተቋም እንዲሁም ከ ጤና ተቋም ወደ ቤታቸው ያለውን ግንኙነት መስተጋብር ጥናታዊ ምርምር አደርጋለሁ፡፡ በዚህ ጥናት ውስጥ እንዲሳተፉ ተመርጠዋል :: ምርጫው ሆን ተብሎ የተደረገ ነው :: በዚህ ጥናት ውስጥ ለመሳተፍ ወይም ላለመሳተፍ ከመወሰንዎ በፊት የጥናቱን ዓላማ ፣ ማንኛውንም አደጋዎች ፣ ጥቅሞች ፣ አሰራሮች እና ከእርስዎ ምን እንደሚጠበቅ ላብራራላችሁ እፈልጋለሁ ::

የጥናቱ ዓላማ- ጥናቱ በአዲስ አበባ ፣ የአዋቂ ካንሰር ህመምተኞችን ከቤታቸው ወደ ጤና ተቋም እንዲሁም ከ ጤና ተቋም ወደ ቤታቸው ያለውን ግንኙነት መስተጋብር በእንክብካቤ እና ድጋፍ መስጠትን ይዳስሳል ::

አሰራር- ይህንን ጥናት ከተቀላቀሉ ከ 25 እስከ 60 ደቂቃ ያህል የሚወስድ በግል (በተናጠል) በሚደረግ ቃለመጠይቅ

ውስጥ እንዲሳተፉ እንጠይቅዎታለን :: ውይይቱ እና ቃለመጠይቁ በአማርኛ ቋንቋ ይሆናል :: በእርስዎ ፈቃድ ውይይቱ እና ቃለመጠይቁ በቴፕ ይቀመጣሉ :: የምልመላ ስክሪፕትን በመጠቀም ላይ በመመርኮዝ ተሳታፊዎች ይመረጣሉ :: ቃለ-ምልልሱን ለመምራት ከፊል የተዋቀሩ የመመሪያ ጥያቄዎች ጥቅም ላይ ይውላሉ :: ውይይቶች በድምጽ የተቀረጹ በኋላ በተመራማሪው ወደ እንግሊዝኛ ይተረጎማሉ :: ያልተነኩ ጉዳዮች ካሉ በፈቃደኝነት ላይ በመመርኮዝ እንደገና እጎበኛችኋለሁ ::

የጥናቱ ጥቅም- ለጥናቱ ተሳታፊዎች ቀጥተኛ ጥቅሞች የሉም :: በቂ መረጃ ከሌለዎት በተሳትፎዎ መጨረሻ ላይ በቤት ለቤት ስላለው ህክምና መረጃ ይሰጥዎታል። በተጨማሪም ፣ ስለ ህክምና የመረጃ ክፍተት ካለ ውይይት የሚደረግበት ይሆናል :: በተጨማሪም ጥናቱ የእንክብካቤ ቀጣይነትን ለመመርመር እና ሕክምናን በአዲስ አበባ ፣ ኢትዮጵያ ውጤታማ በሆነ መንገድ ለመተግበር እንቅፋቶችን ለማየት ይረዳል ::

አደጋዎች / አለመመችዎች- የዚህ ጥናት አደጋ በአንፃራዊ ሁኔታ ቀላል እና እምብዛም የማይሆን ሊሆን ይችላል ብለን እናምናለን :: ከህመምዎ / ከቤተሰብዎ አባል ህመም ጋር በተያያዙ ጉዳዮች ላይ ስንወያይ አንዳንድ ያለመመቸት እና ጭንቀት ሊኖር ይችላል ፣ ነገር ግን እያንዳንዱን ጥያቄ በቀስታ እጠይቀዎታለሁ፤፤ እና ለእያንዳንዱ ጥያቄ መልስ ለመስጠት በቂ ጊዜ እሰጠዎታለሁ :: ለ በግል (በተናጠል) በሚደረግ ቃለመጠይቅ ጊዜያቸውን ከ25-60 ደቂቃዎች እንዲመድቡ ይጠበቅብዎታል ::

የተሳታፊዎች መብቶች- በዚህ ጥናት ውስጥ ለመሳተፍ ወይም ላለመሳተፍ ሙሉ በሙሉ ነፃ ነዎት :: የጥናቱ አካል መሆን እንደማይፈልጉ ከወሰኑ ይህ በእርስዎ በምንም መንገድ ችግር አይፈጥርም :: መቀጠል እንደማይችሉ ከተሰማዎት በማንኛውም ጊዜ ከጥናቱ ለማቆረጥ ነፃ ነዎት :: ለእርስዎ ግልጽ ያልሆነ ማንኛውንም ጥያቄ መጠየቅ ይችላሉ ::

የመረጃ ማጋራት- በጥናቱ ወቅት የጥናት ተመራማሪዎች (PIs) ጋር ብቻ የፈቃድ ሰነዶችን ጨምሮ ማግኘት ይችላል :: የምርምር ሥነምግባር ቦርድ እንደ ሰብአዊ ደህንነት ጥበቃ መስፈርቶች አካል ሆኖ አስፈላጊ ከሆነ መረጃ ማግኘት ይችላል ::

የመረጃ ምስጢራዊነት- ሁሉንም የጥናት ቡድን አባላት ከተሳታፊዎች ሁሉንም መረጃዎች በሚስጥር መያዝ አስፈላጊ ስለመሆኑ እንዲሁም ማንኛውም ሚስጥራዊነት መጣስ ቢከሰት ምን መደረግ እንዳለበት ይነገራቸዋል ፡፡ በሪፖርት መጋራት እና በውጤቶች መግባባት ወቅት እንደ ስም ወይም አካላዊ አድራሻ ያሉ የግል መለያዎች ጥቅም ላይ አይውሉም ፡፡

በመረጃ አሰባሰብ ወቅት ግላዊነትዎን መጠበቅ- ማንኛውም የግል መረጃ ያለው መረጃ በሚስጥራዊነት እና በሁሉም የምርምር ደረጃዎች የተከበሩ የርዕሰ ጉዳዮች ግላዊነት ይደረጋል ፡፡ በተጠያቂው የስምምነት ሂደት እና በመረጃ አሰባሰቡ ወቅት የተሳታፊዎች ግላዊነት ይከበራል። የግል መለያዎች (ስምንም ጨምሮ) አይመዘገቡም ፡፡ የመጀመሪያ ደረጃ መረጃዎች የሚከናወኑት በተመራማሪዎቹ ብቻ ሲሆን መረጃው በይለፍ ቃል የተጠበቀ ይሆናል ፡፡ በመረጃ ትንተና ወቅት እንደገና መረጃ በይለፍ ቃል በተጠበቀ ስርዓት በኩል ይቀመጣል እና መረጃዎችን ያለ የግል መለያዎች ይተነትናል ፡፡

በጥናቱ ውስጥ መሳተፍ ይፈልጋሉ?

1- አይ (አመሰግናለሁ)

2- አዎ (በመረጃ ላይ የተመሠረተ ስምምነት ይውሰዱ)

አባሪ 10-ለታካሚዎች እና ለቤተሰብ አባላት በመረጃ የተደገፈ ስምምነት

የጥናቱ ዓላማ ፣ ጥቅሞች ፣ ጉዳቶች ፣ አሰራሮች እና በምስጢር አጠባበቅ በሚገባኝ ቋንቋ ተነቦልኛል ተብራርቶልኛል ፡፡ በተጨማሪ በዚህ ጥናት ውስጥ መሳተፌ እና ያለ ምክንያት በማንኛውም ጊዜ ከመሳተፍ ራስን ማግለል እንደሚቻል ተረድቻለሁ ፡፡ እንደገና ልጠየቅ እንደምችል ተነግሮኝ ፡፡ በዚህ ጥናት ውስጥ ለመሳተፍ እስማማለሁ ፡፡

ተሳታፊ

ይፈርሙ (ፊርማ ወይም አውራ ጣት) .... ቀን ....

አባሪ 11-የቃለ መጠይቅ መመሪያ ለአዋቂ ካንሰር ህመምተኞች

1. ራስዎን ለእኔ ማስተዋወቅ ይችላሉ? ምርመራ-ፆታ፣ የጋብቻ ሁኔታ ፣ ትምህርት ፣ ሥራ ፣ሃይማኖት፣ የካንሰር ሁኔታ እና ባህሪ ምርመራ፣ደረጃ፣ሕክምና?
2. .ስለ ካንሰር ምርመራዎ ሊነግሩኝ ይችላሉ? ምርመራ: - ችግሮቹ መቼ ጀመሩ? ከዚያ በኋላ ምን ሆነ? ምን ምክር ፈልገዋል? ከማን?
3. የህመም ስቃይ እፎይታ እንክብካበቤ ሲባል ሰምተው ያውቃለሉ? ምርመራ: ቃሉ በራሱ ፣ የህመም ስቃይ እፎይታ እንክብካበቤ የሚሰጡ አካላት ፣ ሊኖሩ የሚችሉ እንክብካቤ ቦታዎች?
4. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ ለራስዎ ተቀብለው ያውቃሉ? ምርመራ: አዎ ከሆነ ምን አገልግሎት አግኝተዋል ፣ አገልግሎቱን የሰጠዎት ማን ነው ፣ መቼ አገልግሎቱን መውሰድ ጀመሩ? የለም ከሆነ አገልግሎቱን ካገኙ ይቀበላሉ?
5. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት እንዲያገኙ ለእርስዎ አመቻቾች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ
6. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለማግኘት እንቅፋቶች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ
7. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት እንዲያገኙ ለእርስዎ አመቻቾች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ; ይህንን አገልግሎት እንዲያገኙ ያመቻችልዎት ማን ነው; ከጤና እንክብካቤ አቅራቢዎች ጋር ያለዎት ግንኙነት እንዴት ነው? ምን ያህል ይቀራረባሉ?
8. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለማግኘት እንቅፋቶች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ; ይህንን አገልግሎት እንዲያገኙ ያመቻችልዎት ማን ነው
9. በውሳኔዎች እና በእቅድ ሂደት ውስጥ ተሳታፊ ነዎት? ምርመራ-እርስዎ በእንክብካቤ እና ህክምና ውሳኔዎች ውስጥ ተሳታፊ ነዎት? ከጤና ባለሞያ ጋር ለመግባባት ተስማሚ ቦታ ፣ ማረፊያ እና ጊዜ አለ? እንዴት? ይህ ምን ሊሆን ይችላል ብለው ያስባሉ?
10. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ማግኘት ከጀመሩ በኋላ ችግርዎ ተባብሷል/ተሻሽሏል? ይህ በዕለት ተዕለት ሕይወትዎ ላይ ምን ተጽዕኖ አሳድሯል? ምርመራ- ዕለታዊ ኑሮ እንቅስቃሴዎች (ሥራ ፣ በቤት ውስጥ ፣ ማህበራዊ እንቅስቃሴዎች) ስለ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ምን ይወዳሉ? እንዴት?
11. በእንክብካቤ እና በሞት ጊዜ የት መሆንን ይመርጣሉ? እርስዎ / ከጤና ባለሞያው እና ከቤተሰብ ጋር ለመወያየት አቅደዋል? ምርመራ: እነዚህን ምርጫዎች ለማሟላት ምን እርምጃዎች ተወስደዋል?
12. ይህ የህመም ስቃይ እፎይታ እንክብካበቤ እንዴት ከህክምና ተቋም ወደቤት እንዲሁም ከቤት ወደ ህክምና ተቋም እንዴት ሊቀጥል ይችላል?
13. ከእኔ ጋር ሊያጋሯቸው የሚፈልጓቸው ሌሎች ማናቸውም ጉዳዮች ወይም ማከል የሚፈልጉት ነገር ካለ?

አባሪ 12-የቃለ መጠይቅ መመሪያ ለቤተሰብ/ዋና አስታማሚ

1. ራስዎን ለእኔ ማስተዋወቅ ይችላሉ? ምርመራ-ፆታ፣ የጋብቻ ሁኔታ ፣ ትምህርት ፣ ሥራ ፣ሃይማኖት፣ የካንሰር ሁኔታ እና ባህሪ ምርመራ፣ደረጃ፣ሕክምና? ከታካሚው ጋር ያለዎት ግንኙነት
2. የህመም ስቃይ እፎይታ እንክብካበቤ ሲባል ሰምተው ያውቃለሉ? ምርመራ: ቃሉ በራሱ ፣ የህመም ስቃይ እፎይታ እንክብካበቤ የሚሰጡ አካላት ፣ ሊኖሩ የሚችሉ እንክብካቤ ቦታዎች?
3. ለካንሰር ህመምተኞች የህመም ስቃይ እፎይታ እንክብካበቤ ምን ያህል ተገቢ እንደሆነ ሊነግሩኝ ይችላሉ? ምርመራ-አገልግሎቱ መቼ መሰጠት እንዳለበት ያሰቡት መቼ ነው? ታካሚውን ወደ ሆስፒታል ለማምጣት መቼ ወሰኑ?
4. የህመም ስቃይ እፎይታ እንክብካበቤ ፍላጎት ምላሽ መስጠት ይችላሉ? ምርመራ፡ ካንሰር ያለባቸውን ህመምተኞች በሚንከባከቡበት ጊዜ ምን ዓይነት ችግሮች ያጋጥሙዎታል? ማህበራዊ ፣ ስነልቦናዊ ፣ መንፈሳዊ እና አካላዊ
5. በውሳኔዎች እና በእቅድ ሂደት ውስጥ ተሳታፊ ነዎት? ምርመራ-እርስዎ በእንክብካቤ እና ህክምና ውሳኔዎች ውስጥ ተሳታፊ ነዎት? ከጤና ባለሞያ ጋር ለመግባባት ተስማሚ ቦታ ፣ ማረፊያ እና ጊዜ አለ? እንዴት? ይህ ምን ሊሆን ይችላል ብለው ያስባሉ?
6. ከሕመምተኞች ጋር ስለ መንፈሳዊ ወይም ሃይማኖታዊ ፍላጎቶች ይወያያሉ ወርም ሕመምተኞች በበቂ ሁኔታ እነዚህን ፍላጎቶች ለሞሞላት ምን ያደርጋሉ? ምርመራ: እንዴት እና መቼ? ምን ችግሮች ያጋጥሙዎታል?
7. የህመም ስቃይ እፎይታ እንክብካበቤ ውስጥ እውቀትዎን ለማሳደግ ምን ያስፈልግዎታል? በህይወት-መጨረሻ ተሞክሮ ወቅት ተቢውን ድጋፍ እንዴት ያረጋግጣሉ? ምን ችግሮች ያጋጥሙዎታል?
8. ይህንን የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለመስጠት የተወሰነ ጊዜ ወይም ቀን አለዎት?
9. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት የታመመው የቤተሰብ አባልዎት እንዲያገኙ አመቻቾች ምን ነበሩ? ምርመራከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ
10. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለማግኘት እንቅፋቶች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ
11. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት የታመመው የቤተሰብ አባልዎት እንዲያገኙ አመቻቾች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ; ይህንን አገልግሎት ታማሚው እንዲያገኙ ያመቻችልዎት ማን ነው; ከጤና እንክብካቤ አቅራቢዎች ጋር ያለዎት ግንኙነት እንዴት ነው? ምን ያህል ይቀራረባሉ?
12. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለማግኘት እንቅፋቶች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ;
13. በእንክብካቤ እና በሞት ጊዜ የት መሆንን ይመርጣሉ? እርስዎ / ከጤና ባለሞያው እና ከቤተሰብ ጋር ለመወያየት አቅደዋል? ምርመራ: እነዚህን ምርጫዎች ለማሟላት ምን እርምጃዎች ተወስደዋል? በውሳኔ አሰጣጥ ሂደት ውስጥ

ተሳትፈዋል? እንዴት? መቼ? ችግሮች ካሉ ምን አጋጠመውት? ወደ ቀጣዩ ደረጃ እንዴት ይሄዳሉ? ስለወደፊቱ ውይይት ጀምረዋል? የግል አድራሻን ለጤና ባለሞያዎች አጋርተው ያውቃሉ?

14. ይህ የህመም ስቃይ እፎይታ እንክብካበቤ እንዴት ከህክምና ተቆም ወደ ቤት እንዲሁም ከቤት ወደ ህክምና ተቆም እንዴት ሊቀጥል ይችላል?
15. ከእኔ ጋር ሊያጋሯቸው የሚፈልጓቸው ሌሎች ማናቸውም ጉዳዮች ወይም ማከል የሚፈልጉት ነገር ካለ?

ስለ ትብብርዎ አመሰግናለሁ ፣ ያልተነኩ ጉዳዮች ካሉ በፈቃደኝነትዎ ላይ ተመስርቼ እንደገና እጎበኛለሁ ፡፡

አባሪ 13- ለጤና እንክብካቤ አቅራቢዎች እና ፖሊሲ አውጪዎች የመረጃ ወረቀት

ሰላምታ! ስሜ ዮናስ አባተ በአዲስ አበባ ዩኒቨርሲቲ የህ/ብ ጤና ተማሪ ነኝ፡፡ ለሁለተኛ ዲግሪ ማጠናቀቂያ ላይ የተመሠረተውን አዲስ አበባን መሠረት ያደረገ የአዋቂ ካንሰር ህመምተኞችን ከቤታቸው ወደ ጤና ተቋም እንዲሁም ከ ጤና ተቋም ወደ ቤታቸው ያለውን ግንኙነት መስተጋብር ጥናታዊ ምርምር አደርጋለሁ፡፡ በዚህ ጥናት ውስጥ እንዲሳተፉ ተመርጠዋል ፡፡ ምርጫው ሆን ተብሎ የተደረገ ነው ፡፡ በዚህ ጥናት ውስጥ ለመሳተፍ ወይም ላለመሳተፍ ከመወሰንዎ በፊት የጥናቱን ዓላማ ፣ ማንኛውንም አደጋዎች ፣ ጥቅሞች ፣ አሰራሮች እና ከእርስዎ ምን እንደሚጠበቅ ላብራራላችሁ እፈልጋለሁ ፡፡

የጥናቱ ዓላማ- ጥናቱ በአዲስ አበባ ፣ የአዋቂ ካንሰር ህመምተኞችን ከቤታቸው ወደ ጤና ተቋም እንዲሁም ከ ጤና ተቋም ወደ ቤታቸው ያለውን ግንኙነት መስተጋብር በእንክብካቤ እና ድጋፍ መስጠትን ይዳስሳል ፡፡

አሰራር- ይህንን ጥናት ከተቀላቀሉ ከ 25 እስከ 60 ደቂቃ ያህል የሚወስድ በግል (በተናጠል) በሚደረግ ቃለመጠይቅ ውስጥ እንዲሳተፉ እንጠይቅዎታለን ፡፡ ውይይቱ እና ቃለመጠይቁ በአማርኛ ቋንቋ ይሆናል ፡፡ በእርስዎ ፈቃድ ውይይቱ እና ቃለመጠይቁ በቴፕ ይቀመጣሉ ፡፡ የምልመላ ስክሪፐትን በመጠቀም ላይ በመመርኮዝ ተሳታፊዎች ይመረጣሉ ፡፡ ቃለ-ምልልሱን ለመምራት ከፊል የተዋቀሩ የመመሪያ ጥያቄዎች ጥቅም ላይ ይውላሉ ፡፡ ውይይቶች በድምጽ የተቀረጹ በኋላ በተመራማሪው ወደ እንግሊዝኛ ይተረጎማሉ ፡፡ ያልተነኩ ጉዳዮች ካሉ በፈቃደኝነት ላይ በመመርኮዝ እንደገና እጎበኛችኋለሁ ፡፡

የጥናቱ ጥቅም- ለጥናቱ ተሳታፊዎች ቀጥተኛ ጥቅሞች የሉም ፡፡ በተጨማሪም ጥናቱ የእንክብካቤ ቀጣይነትን ለመመርመር እና ሕክምናን በአዲስ አበባ ፣ ኢትዮጵያ ውጤታማ በሆነ መንገድ ለመተግበር እንቅፋቶችን ለማየት ይረዳል ፡፡

አደጋዎች / አለመመችዎች- የዚህ ጥናት አደጋ በአንፃራዊ ሁኔታ ቀላል እና እምብዛም የማይሆን ሊሆን ይችላል ብለን እናምናለን ለ በግል (በተናጠል) በሚደረግ ቃለመጠይቅ ጊዜዎትን ከ25-60 ደቂቃዎች እንዲመድቡ ይጠበቅብዎታል ፡፡

የተሳታፊዎች መብቶች- በዚህ ጥናት ውስጥ ለመሳተፍ ወይም ላለመሳተፍ ሙሉ በሙሉ ነፃ ነዎት ፡፡ የጥናቱ አካል መሆን እንደማይፈልጉ ከወሰኑ ይህ በእርስዎ በምንም መንገድ ችግር አይፈጥርም ፡፡ መቀጠል እንደማይችሉ ከተሰማዎት በማንኛውም ጊዜ ከጥናቱ ለማቆረጥ ነፃ ነዎት ፡፡ ለእርስዎ ግልጽ ያልሆነ ማንኛውንም ጥያቄ መጠየቅ ይችላሉ ፡፡

የመረጃ ማጋራት- በጥናቱ ወቅት የጥናት ተመራማሪዎች (PIs) ጋር ብቻ የፈቃድ ሰነዶችን ጨምሮ ማግኘት ይችላል ፡፡ የምርምር ሥነምግባር ቦርድ እንደ ሰብአዊ ደህንነት ጥበቃ መስፈርቶች አካል ሆኖ አስፈላጊ ከሆነ መረጃ ማግኘት ይችላል ፡፡

የመረጃ ምስጢራዊነት- ሁሉንም የጥናት ቡድን አባላት ከተሳታፊዎች ሁሉንም መረጃዎች በሚስጥር መያዝ አስፈላጊ ስለመሆኑ እንዲሁም ማንኛውም ሚስጥራዊነት መጣስ ቢከሰት ምን መደረግ እንዳለበት ይነገራቸዋል ፡፡ በሪፖርት መጋራት እና በውጤቶች መግባባት ወቅት እንደ ስም ወይም አካላዊ አድራሻ ያሉ የግል መለያዎች ጥቅም ላይ አይውሉም ፡፡

በመረጃ አሰባሰብ ወቅት ግላዊነትዎን መጠበቅ- ማንኛውም የግል መረጃ ያለው መረጃ በሚስጥራዊነት እና በሁሉም የምርምር ደረጃዎች የተከበሩ የርዕሰ ጉዳዮች ግላዊነት ይደረጋል ፡፡ በተጠያቂው የስምምነት ሂደት እና በመረጃ አሰባሰቡ ወቅት የተሳታፊዎች ግላዊነት ይከበራል። የግል መለያዎች (ስምንም ጨምሮ) አይመዘገቡም ፡፡ የመጀመሪያ ደረጃ መረጃዎች የሚከናወኑት በተመራማሪዎቹ ብቻ ሲሆን መረጃው በይለፍ ቃል የተጠበቀ ይሆናል ፡፡ በመረጃ ትንተና ወቅት እንደገና መረጃ በይለፍ ቃል በተጠበቀ ስርዓት በኩል ይቀመጣል እና መረጃዎችን ያለ የግል መለያዎች ይተነትናል ፡፡

በጥናቱ ውስጥ መሳተፍ ይፈልጋሉ?

1- አይ (አመሰግናለሁ)

2- አዎ (በመረጃ ላይ የተመሠረተ ስምምነት ይውሰዱ)

አባሪ 14- ለጤና እንክብካቤ አቅራቢዎች እና ፖሊሲ አውጪዎች በመረጃ የተደገፈ ስምምነት

የጥናቱ ዓላማ ፣ ጥቅሞች ፣ ጉዳቶች ፣ አሰራሮች እና በምስጢር አጠባበቅ በሚገባኝ ቋንቋ ተነቦልኛል ተብራርቶልኛል ፡፡ በተጨማሪ በዚህ ጥናት ውስጥ መሳተፌ እና ያለ ምክንያት በማንኛውም ጊዜ ከመሳተፍ ራስን ማግለል እንደሚቻል ተረድቻለሁ ፡፡ እንደገና ልጠየቅ እንደምችል ተነግሮኝ ፡፡ በዚህ ጥናት ውስጥ ለመሳተፍ እስማማለሁ ፡፡

ተሳታፊ

ይፈርሙ (ፊርማ ወይም አውራ ጣት) .... ቀን ....

አባሪ 15-የቃለ መጠይቅ መመሪያ ለጤና ባለሞያ

1. ራስዎን ለእኔ ማስተዋወቅ ይችላሉ? ምርመራ-ፆታ፣ የጋብቻ ሁኔታ ፣ ትምህርት ፣ ሥራ ፣ሃይማኖት፣ የስራ ልምድ፤
2. የህመም ስቃይ እፎይታ እንክብካበቤ ሲባል ሰምተው ያውቃለሉ? ምርመራ: ቃሉ በራሱ ፣ የህመም ስቃይ እፎይታ እንክብካበቤ የሚሰጡ አካላት ፣ ሊኖሩ የሚችሉ እንክብካቤ ቦታዎች?
3. ለካንሰር ህመምተኞች የህመም ስቃይ እፎይታ እንክብካበቤ ምን ያህል ተገቢ እንደሆነ ሊነግሩኝ ይችላሉ? ምርመራ-አገልግሎቱ መቼ መሰጠት እንዳለበት ያሰቡት መቼ ነው? ለድጋፍ ቡድኑ ውህደት አነስተኛውን መስፈርት ሊነግሩኝ ይችላሉ?
4. በቤት ላይ የተመሠረተ የህመም ስቃይ እፎይታ እንክብካበቤ እንዴት ነው? የካንሰር ህመም ላለባቸው ሰዎች የህመም ስቃይ እፎይታ እንክብካበቤ ምን ያህል ተገቢ እንደሆነ ይንገሩኝ? ምርመራ-ቤትን መሠረት ያደረገ የህመም ማስታገሻ አገልግሎት የሚሰጡ ከሆነ በሽተኞችን ወደ ፕሮግራሙ እንዴት ያስገባሉ?
5. የህመም ስቃይ እፎይታ እንክብካበቤ ፍላጎት ምላሽ መስጠት ይችላሉ? ምርመራ፡ ካንሰር ያለባቸውን ህመምተኞች በሚንከባከቡበት ጊዜ ምን ዓይነት ችግሮች ያጋጥሙዎታል? ማህበራዊ ፣ ስነልቦናዊ ፣ መንፈሳዊ እና አካላዊ
6. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ታማሚ እንዲያገኝ አመቻቾች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ፤ ከ ፖሊሲ
7. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለማግኘት እንቅፋቶች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ
8. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ታማሚዎች እንዲያገኙ አመቻቾች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ; ይህንን አገልግሎት ታማሚዎች እንዲያገኙ ያመቻቹልዎት ማን ነው; ከታካሚች ጋር ያለዎት ግንኙነት እንዴት ነው? ምን ያህል ይቀራረባሉ?
9. ቤት ለቤት የሚሰጥ የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለማግኘት እንቅፋቶች ምን ነበሩ? ምርመራ-ከጤና ተቋማት; ከጤና እንክብካቤ አቅራቢዎች; ከእርስዎ እይታ;
10. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ከጤና ተቋም እስከ ቤት እንዲሁም ከቤት እስከ ጤና ተቋም እንክብካቤ አገልግሎት የሚያገናኝ አለ? ምርመራ: - አገናኙ የት መሆን አለበት ፣ እዚያ ላይ ክፍተት አለ ብለው ያስባሉ? በዚህ ድልድይ ውስጥ ታካሚዎችን በማገናኘት ላይ ማን መሥራት አለበት?
11. ተመራጭ በሆነ የሞት እና እንክብካቤ ቦታ ላይ ከሕመምተኛው እና ከቤተሰቡ ጋር እውቅና ሰጥተው ተወያይተዋል? እነዚህን ምርጫዎች ለማክበር ምን እርምጃዎች ተወስደዋል? የታካሚዎች እንክብካቤ ምርጫ ቦታ ላይ ምን ተጽዕኖ ያሳድራል? በውሳኔ አሰጣጥ ሂደት ውስጥ ተሳትፈዋል? እንዴት? መቼ? ካለ ፣ ምን ችግሮች ያጋጥሙዎታል?
12. በጤና ሁኔታ ላይ ለሚከሰቱ ለውጦች ህመምተኞችን እና የቤተሰብ አባላትን / ተንከባካቢዎችን ያዘጋጃሉ? ምርመራ: ስለ መድሃኒት የጎንዮሽ ጉዳቶች ፣ ህመምተኞች ሲታመሙ ማን ይደውላል? ፣ ምን ችግሮች ያጋጥሙዎታል?

13. የቤተሰብ አባላትን / ተንከባካቢዎችን በውሳኔዎች እና በእቅድ ውስጥ ያሳትፋሉ? ምርመራ- እነሱ በመረጃ እና በእንክብካቤ እና በሕክምና ውሳኔዎች ውስጥ ተሳትፈዋል? ከሕመምተኞች እና ከቤተሰቦቻቸው ጋር ለመግባባት ተስማሚ ቦታ ፣ ማረፊያ እና ጊዜ አለ? እንዴት? ይህ ምን ሊሆን ይችላል ብለው ያስባሉ?
14. ከሕመምተኞች ጋር ስለ መንፈሳዊ ወይም ሃይማኖታዊ ፍላጎቶች የሕመምተኞችን ፍላጎቶች ለመገምገም በበቂ ሁኔታ ስለማድረግ ይነጋገራሉ? ምርመራ- እንዴት እና መቼ ስነ ልቦናዊ ድጋፍ ይሰጣሉ? ፣ ምን ችግሮች አጋጥሙዎታል?
15. በህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ውስጥ ችሎታዎን ለማሳደግ ምን ያስፈልግዎታል? ምርመራ: - ውጤታማ ግንኙነትን (ማለትም ስልጠና እና ትምህርት እንዲሁም የዘመኑ መረጃዎችን እና ቴክኖሎጂን የማግኘት ምን ምን በቂ ቅድመ ሁኔታዎች አሉዎት?) ምን ችግሮች አሉ?
16. የበሽታውን ቅድመ-ትንበያ ካሳወቁ በኋላ የህመም ስቃይ እፎይታ እንክብካበቤ ቀጣይነት እንዴት ያረጋግጣል? ምርመራ- ወደ ቀጣዩ ደረጃ እንዴት ይሄዳሉ? ስለወደፊቱ ውይይት ያደርጋሉ?
17. በህይወት መጨረሻ ላይ ተገቢውን ድጋፍ እንዴት ያረጋግጣሉ? ለታካሚዎች እና ለቤተሰቦች የሀዘንተኛ የምክር አገልግሎት ስለመኖሩ ይወያያሉ? ፣ ምን ችግሮች አጋጥሙዎታል
18. ከእኔ ጋር ሊያጋሯቸው የሚፈልጓቸው ሌሎች ማናቸውም ጉዳዮች ወይም ማከል የሚፈልጉት ነገር ካለ?

ስለ ትብብርዎ አመሰግናለሁ ፣ ያልተነኩ ጉዳዮች ካሉ በፈቃደኝነትዎ ላይ ተመስርቼ እንደገና እጎበኛለሁ ፡፡

አባሪ 16 ለፖሊሲ አውጭዎች የቃለ መጠይቅ መመሪያ

1. እባክዎን እራስዎን ያስተዋውቁ? ምርመራ; ዕድሜ ፣ የትምህርት ፣ የጋብቻ ሁኔታ ፣ የቅጥር ሁኔታ ፣ የህመም ስቃይ እፎይታ እንክብካበቤ ያለዎት ልምድ?
2. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ውስጥ የእርስዎ አስተዋጽኦ/ ተሳትፎ ምንድነው? ምርመራ- ሆስፒስ ፣ ፖሊሲ ማውጣት?
3. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ተግባራዊ ለማድረግ ብሄራዊ/ ክልል ልዩ ስትራቴጂ አለ? ምርመራ: - ፖሊሲው እየሠራ ነው ፣ ፖሊሲውአይሠራም ወይም አገልግሎት ላይ አይደለም? የታቀደው ምንድን ነው?
4. የካንሰር ህመምተኞች የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለሕዝብ ይሰጣል? ምርመራ: የመጀመሪያ ደረጃ የጤና እንክብካቤ ተቆም ፣በማህበረሰብ ወይም በቤት-ተኮር እንክብካቤ ካለ?
5. የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ቀጣይነት ባለው ወቅታዊ የጤና ስርዓት ላይ እንዴት እንደሚሰራ ማብራራት ይችላሉ? እነማን ይሳተፋሉ፤ እና በምን ደረጃ ላይ ይገኛሉ? እስካሁን ምን ተደርጓል?
6. በሕዝብ ጤና ዘርፍ የመጀመሪያ ደረጃ የጤና እንክብካቤ ተቋማት ውስጥ የመድኃኒት አቅርቦት [መድኃኒት (የአፍ ሞርፊን) ይገኛል? ምርመራ-ለምን? እነሱ ዓመቱን በሙሉ ይገኛሉ? በአገራችን ስላለው ሞርፊን ምርት እና ግብይትስ?
7. ከጤና ተቋም እስከ ቤት ድረስ እንዲሁም ከቤት እስከ ጤና ተቋም የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ቀጣይነት እንዴት ያረጋግጣል? ምርመራ- በማህበረሰቡ ውስጥ ቤት-ተኮር የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ለመስጠት መሰረተ ልማት? የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ትምህርት? ትግበራ? ተግዳሮቶቹ እና መፍትሄው ምንድናቸው?
8. ከጤና ተቋም እስከ ቤት እንዲሁም ከቤት ከጤና ተቋም የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ትስስር ምን ያጋጠማቸው ችግሮች አሉ? ምርመራ- ከመፍትሔው በፊት ምን ዓይነት መሰናክሎችን አጋጥመው ያውቃሉ; እና መፍትሄው ውጤታማ ነበር?
9. ከጤና ተቋማት ወደ ቤት ለቤት እንዲሁም ከቤት እስከ ጤና ተቋም የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት አቅርቦት ጋር ተያያዥነት ያላቸው አመቻቾች ምንድናቸው? ምርመራ: ምን ሊሆኑ የሚችሉ አስተባባሪዎች; ፖሊሲውን ፣ አተገባበሩን በተመለከተ ምን እየታቀደ ነው?
10. ቀጣይነት ያለው ክትትል እና ግምገማ አለዎት? ክትትል የሚደረግባቸው ማን ነው? በምን ላይ የተመሠረተ? የህግ አውጭው የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት ተደራሽነትን ለማሻሻል መደበኛ ግምገማ አለው?
11. ስለዚህ በመጨረሻ ምን መደረግ አለበት / የህመም ስቃይ እፎይታ እንክብካበቤ አገልግሎት እና ከጤና ተቋማት ወደ ቤት ለቤት እንዲሁም ከቤት ለቤት ወደ ከጤና ተቋማት ትስስርን ለማሻሻል የመሻሻል ምን የደረግ?
12. ያልጠቀስነው ነገር ለመወያየት የሚፈልጉት ነገር ካለ?

ስለ ትብብርዎ አመሰግናለሁ ፣ ያልተነኩ ጉዳዮች ካሉ በፈቃደኝነትዎ ላይ ተመስርቼ እንደገና እጎበኛለሁ ፡፡

Annex 10:Code book

Codes	**Code description**
Drugs	Medications used for cancer patients on PC i.e. opioids
Lack of equipment	Cancer patients not able to find medical equipment's like a colostomy bag
Distance from an HCP	The patient's distance from the facility that PC service is being provided
Transportation in time	The distance from patient home to the facility and duration of time it takes during the use of transportation
Cultural acceptability	The cultural acceptability of the PC service
Community Volunteer	Community volunteers accepting the PC and being a bridge to bring patients to the facility that provide PC
Institutions	An institution that provides palliative care have a link and referral system between them The linkage of patients between facility to home and from home to facility
Professionals	Patients able to find the same health professional whenever they have a visit to the health facility
Physical	Provision of relief from pain and other distressing symptoms
Psychological	Support for cancer patients for any psychological symptoms i.e depression, anxiety
Social	social care, including help with things like washing, dressing, or eating
Spiritual	spirituality can be largely faith-based , by which patients based on their preference and religion get support from religious leaders
Availability of policy	The policy that supports and promotes PC in the county is available
Palliative care	An approach that improves the quality of lives of patients and their families who face up with the problems accompanied by life-threatening conditions i.e.cancer
Improved Quality Of Life	Patients being comfortable and receiving good care as a result of access to PC service
A holistic approach of PC	a comprehensive approach to cancer treatment that addresses physical, emotional, logistical, and spiritual issues for patients and their family members

Tuesday and Thursday	Cancer patients identifying the PC service on the days it is provided
During diagnosis	Time of initiation of PC service during first cancer diagnosis
At any stage	Time of initiation of PC service at any cancer stage
Administrators dedication	Administrators being motivated to look for fund and NGO support for continuing providing PC
Buy- in from hospital management	PC service being accepted by higher bodies
Turnover of staff	An HCP who is trained for PC leaves the health facility
Home	Preference of patients to receive PC service at home
NGO's support	Different NGO support is available to support the provision of PC service
Lack of Awareness	Respondents have inadequate knowledge about PC service
Focusing on only treating/only perception	HCP providers only focus on treating cancer and push aside the palliative care needs of the patient
Not acknowledged by the government	The government not giving due attention to PC
Considered as luxury	PC is considered as a luxury service rather than as a basic need for cancer patients
Lack of awareness about home care	HCP have a lack of awareness about facilities that provide home care
Not diagnosed earlier	Patients not being diagnosed earlier for cancer
Absence of designated people	no assigned individuals responsible for PC service was a barrier for the service
Iddirs, spiritual, Social bond	Social activities in Ethiopia such as Iddir are good social supports for cancer patients
Being outside of Addis	Patients that were outside of Addis had less access to home-based palliative care
Promotions	Home-based PC service had fewer media promotions
CEO turnover	High turnover of CEO affected nexus of PC service.
Absence of time	Cancer patients not finding enough time to discuss their illness and other PC needs with the HCP

Work overload	HCP overwhelmed with many duties are overloaded and don’t give attention to PC
Conventional medicine	traditional medication,holy water
Shortage of staff/Care provider	Shortage of health care provider who works on PC
Neighbors, family members, HCPs	Sources of information about home-based PC for patients
Absence of diagnosing instrument	Diagnostics for cancer not being available which in turn cause late diagnosis

Annex 11: Assurance of principal investigator

ASSURANCE OF PRINCIPAL INVESTIGATOR

I, the undersigned MPH student declare that this thesis is my original work in fulfillment of the requirement for the master of public health in health education and promotion.

Name of the student: Yonas Abate

Date.___________________

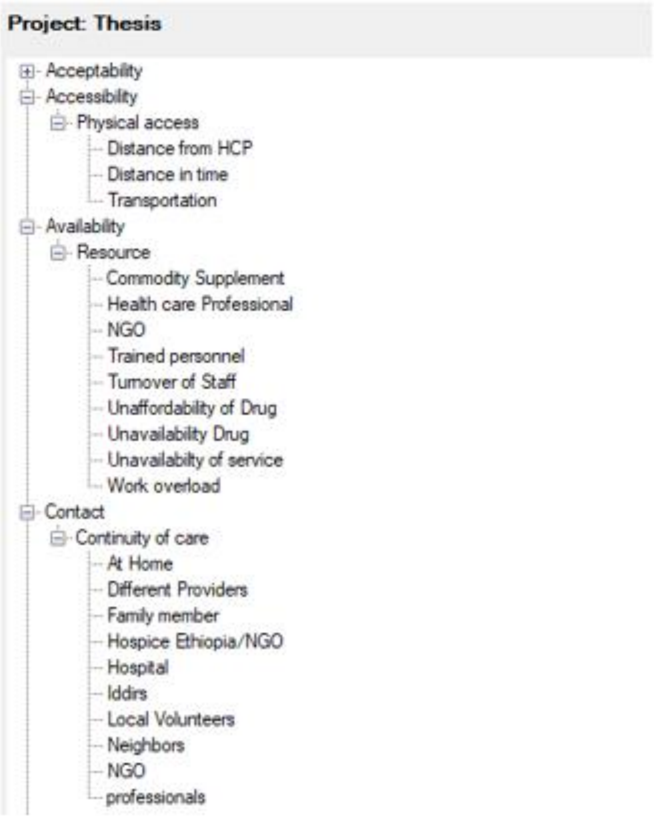
Signature _________________

Approval of the primary Advisor

This thesis work has been submitted with our approval as the university advisor.

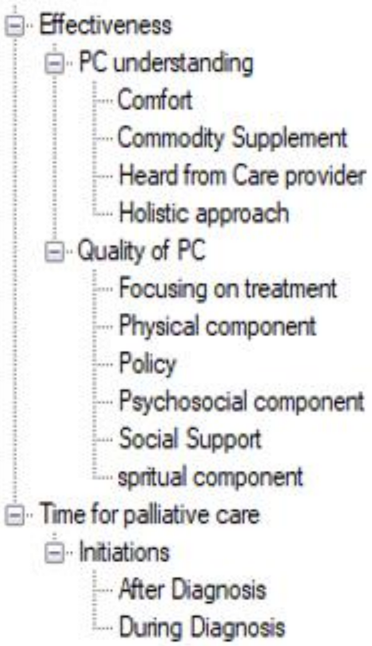
Name of the advisor: Ms. Kalkidan Solomon

Date. _____________________ Signature __________________



Project: Thesis

- Acceptability
- Accessibility
  - Physical access
    - Distance from HCP
    - Distance in time
    - Transportation
- Availability
  - Resource
    - Commodity Supplement
    - Health care Professional
    - NGO
    - Trained personnel
    - Turnover of Staff
    - Unaffordability of Drug
    - Unavailability Drug
    - Unavailabilty of service
    - Work overload
- Contact
  - Continuity of care
    - At Home
    - Different Providers
    - Family member
    - Hospice Ethiopia/NGO
    - Hospital
    - Iddirs
    - Local Volunteers
    - Neighbors
    - NGO
    - professionals



- Effectiveness
  - PC understanding
    - Comfort
    - Commodity Supplement
    - Heard from Care provider
    - Holistic approach
  - Quality of PC
    - Focusing on treatment
    - Physical component
    - Policy
    - Psychosocial component
    - Social Support
    - spritual component
- Time for palliative care
  - Initiations
    - After Diagnosis
    - During Diagnosis