A MODEL FOR DELIVERING COST- EFFECTIVE PALLIATIVE CARE IN A RESOURCE SCARCE SETTING IN ETHIOPIA

BY

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A MODEL FOR DELIVERING COST-EFFECTIVE PALLIATIVE CARE IN A RESOURCE SCARCE SETTING: IN ETHIOPIA

I declare that the above dissertation is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declared that I submitted the dissertation to originality checking software and that it falls with the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at UNISA for another qualification or at any other higher education institution.

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Abstract

Palliative care model development greatly varies between countries based on their socioeconomic status, cultures, religious beliefs and presence of sufficient health, infrastructure, in order to meet the unique needs of patients with life-threatening illnesses. Furthermore, a palliative care model that can be established in developed countries may not necessarily work in developing countries.

Therefore, the purpose of this study was to develop a cost-effective palliative care model that is suitable to the Ethiopian setting. The objectives were to explore the nature and extent of existing palliative care services in Ethiopia, determine the factors that impact on effective application of palliative care in Ethiopian setting, as well as explore best-practice palliative care models that are available internationally, with specific emphasis on resource-poor contexts and to develop an appropriate model of palliative care in Ethiopia.

The researcher used a qualitative approach using constructivism paradigm to understand and explore palliative care situation in Ethiopia in order to develop a palliative care model. Purposive sampling technique was employed to select key informants and group discussants at different levels of health system, ranging from national levels to frontline health extension workers so as to get adequate information about palliative care experiences. Specifically, data were collected from different Key informants such as policy makers, programe and hospital managers, non-governmental organizations, religious leaders, health professionals and frontline health workers. Besides, group discussions were also held with nurses. Accordingly, 29 key informants interviews were conducted and five focus group discussions were done with nurses who were working at four chronic illness hospitals of Jimma Zone. Data transcription and translation were done verbatim. Atlas ti 7.1 software assisted data management and analysis. All ethical principles and the trustworthiness of the data were maintained throughout the research process. Moreover, the researcher included analyses of available literature of existing palliative care delivery models in different settings so as to capture global perspectives and factors that would play a role in shaping the delivery of palliative care services and taken into account, in the development of customized palliative care model for Ethiopia context.

Following in-depth understanding of the factors that play a role in shaping the palliative care process, the researcher developed and validated data which were then used to derive a contextually relevant palliative care model, “P-care model” for the Ethiopia context. This model meets the prominent challenges and gaps related to patients, health professionals, health system and challenges non-governmental organizations are facing in implementing palliative care services in Ethiopia.

The researchers ensured the clarity, consistency, relevance, comprehensiveness, adaptability, practicability and usefulness of the model within the Ethiopian context. The model was validated through collecting feedback and input from senior practitioners in the field and key role players such as policy makers, managers, program officers and academic staff and researchers. Finally, based on the feedback and input , the palliative care model was further refined and recommendations were forwarded to policy makers ,clinicians ,academic staff, researchers and non-governmental organizations. Moreover, in order to create awareness for health professionals, training was given on palliative care in Jimma Medical Centre and Shanen Gibe General Hospital.

In conclusion, although there was a significant encouragement for palliative care movement in Ethiopia, from practical application, it had a narrow scope in its coverage and implementation. Therefore, the palliative care model developed from this research may help to deliver cost-effective palliative care for patients with life-threatening illnesses in resource poor settings. This can be achieved through integration of community-based palliative care approach using public health methods to address the above gaps and challenges in resource scarce settings, and it may also be useful in other settings as well.

Key words

Model of palliative care, palliative care, cost effective, resource poor setting, factors affecting delivery of palliative care, enabling factors, Ethiopia

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DEDICATION

This thesis is dedicated to my late mother Alemitu Amente, who lost her life due to a stroke.

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List of Acronyms and Abbreviations

AIDS: Acquired Immunodeficiency Syndrome
ART: Anti-Retroviral Therapy
APCA: African Palliative Care Association
CBO: Community-Based Organization
CDC: Center of Disease Control
CHBC: Community Home Based Care
FGD: Focus Group Discussion
FMOH: Ethiopian Federal Ministry of Health
HAU: Hospice Africa-Uganda
H BC: Home Based Care
HDI: Human Development Index
HEW: Health Extension Workers
HIV: Human Immunodeficiency Virus
HSSP: Health Sector Strategic Plan,
JUMC: Jimma University Medical Center
KII: Key Informant Interviews
LMICs: Low- and Middle-Income Countries
PC: Palliative Care
PFSA: Ethiopian Pharmaceutical Fund and Supply Agency
PHC: Primary Health Care
PHCU: Primary Health Care Unit
PLWHAs: People Living With HIV/AIDS
NCCP National Cancer Control Plan
NCD: Non-communicable Diseases
NGO: Non-governmental Organization
TAPCOO: Tesfa Addis Parents Childhood Cancer Organization
WHO: World Health Organization
WPCA - Worldwide Palliative Care Alliance

CHAPTER ONE

1.1 Background and Context

In this chapter, an overview of the study is provided. This chapter considers the research background, the context of the study and the statement of the research problem. The study seeks to focus on the importance and explore the scope of palliative care services for patients with life threatening conditions from global, national, and regional perspectives. The purpose of the study is, therefore, designed to develop a palliative care model that is cost effective, feasible and culturally acceptable in resource poor countries like Ethiopia. Furthermore, it describes the burden and the magnitude of the problems related to palliative care service delivery and elaborates on the factors that affect the delivery of palliative care.

1.2 Introduction and Background to the Research

Modern palliative care emerged during the 1960s in United Kingdom. This movement began as a response to the unmet needs of terminally ill patients and their families. The concept of palliative care was started by Dr Cicely Saunders ,whose vision for improving the care of the dying at hospice which encompassed the physical,psychologicaland spiritual domains whilst emphasis the importance of rigorous clinical practice, training and research(Clark& Graham 2011:1) However, the hospice movement soon became a global phenomenon which included patients with all life-threatening diseases. Although the development of the hospice movement evolved in different ways around the world, the essence is currently intended to applied holistic priniciples to the care of those early in their disease trajectory and in different settings through multidisciplinary team . This includes disciplines such as religion, social welfare, medicine in all forms, and others.

The important aspects of palliative care should be integrated in all health services, also in resource-poor countries such as Ethiopia where the disease profile reflects a high incidence of terminal illnesses such as HIV/AIDs, different forms of cancer and other emerging high-risk diseases for which no cure exists as is evident with the current COVID-infections.

The World Health Organization (WHO 2002:1) defines palliative care as an approach which improves the quality of life of patients facing life-threatening illness, through the prevention, assessment, and treatment of pain and other physical, psychological, and spiritual needs as well as support for their families. However, in resource poor settings, the need for palliative care was further expanded to include the provision of social and legal support to assist with poverty alleviation, food security and where appropriate, planning for future care of potential orphans.(Gwyther & Krakaue 2013:4)

Palliative care is basic human right (Brennan 2007:494). However, access to pain relief and palliative care is little or non-existant for most of patients in low and middle income countries(Knaul,Farmer,Krakauer,DeLima,Bhadelia,Kwete &Connor 2018:2). Therefore, palliative care should be applicable from the early diagnosis of a life-threatening illness throughout the course of the illness,. It is offered in conjunction with other therapies (Hawley 2017:1). These are intended to prolong life, such as antiretroviral treatment, chemotherapy and radiation therapy (Gwyther & Krakaue 2013:2).

Lucas (2002:3) explains that palliative care is not an alternative to other models of health care. It is also not in competition with treatment approaches which provide antiretroviral and other advanced therapies, nor is it a “poor relative” to be implemented where such therapies are inaccessible. It is an essential part of a comprehensive healthcare system. Studies show that integration of disease oriented care and palliative care is important to provide optimal care for the patients (Gwyther 2008 :517). However, palliative care is lacking in many developing countries or is not integrated into the existing health care system, and low resource countries give more priority to the prevention of infectious diseases rather than palliative care.

Despite the significance of early integration of palliative care with disease management, many people living with a chronic, life-threatening illness either do not receive any palliative care service or receive services only in the last phase of their illness (Hawley 2017:2). Therefore, patients experience a sense of abandonment by their doctors and doctors in turn experience a sense of failure if the disease continues to progress to a stage where it is not curable this can results frustration to the patients (Gwyther 2008 :517).

Palliative care has been placed as a priority on the global health agenda. The World Health Assembly Resolution (WHA 67.19) of 2014 directed member states to integrate evidence-based cost effective and equitable palliative care services in the continuum of care across all levels of care (WHO 2014:2). Access to palliative care is increasingly regarded an fundamental human right (Gwyther,Brennan & Harding 2009:3). Moreover, palliative care is a core component of Sustainable Development Goal 3 to achieve universal health coverage (WHO 2014:8).

A public health strategy for integrated palliative care describes four components or pillars which include policy development, education, drug availability and implementation strategies (Stjernswärd,Foley & Ferris 2007:2). A fifth pillar, namely, research, has since been added (Harding etal 2013:14).These components are always applied with the cultural context, disease demographics, socioeconomic and health care system of the country(Rhee, Garralda, Namisango, Luyirika, Lima, Powell & Centeno 2018:10).

The African Palliative Care Association (APCA) was established to continue advocating for integrated palliative care in Africa and to work with palliative care providers across Africa to upgrade and implement public health strategies and standards. Its ultimate goal remains that all African people with life-limiting illness will have access to the best palliative care service whenever this is required (African Palliative Care Association May 2011).

Globally, as the demand for palliative care has increased, there has been a rapid growth in specialist and generalist palliative care service provision with a range of models of palliative care (Brereton,Clark,Ingleton,Gardiner,Preston,Ryan & Goyder 2017:2). These models depend on and are influenced by socioeconomic conditions, cultural contexts, communication, decision making, private publicly funded health care system and levels of education among health professionals in different settings (Bruera, Lima, Wenk & Farr 2016:1).

The need for context-specific model of palliative care delivery must respond to the differing nature and staging of illness as well as the cultural, social and spiritual beliefs about illness and death within the context of the available range of health and social services (WHO 2016 :13). Despite the recent growth, palliative care in Africa remains accessible to less than an estimated 5% of those in need (Downing, Grant, Leng & Namukwaya 2015:2) with cancer rates expected to rise by 400% by 2050. Moreover, the need for palliative care services on the continent will continue to outgrow capacity (Colebunders,John, Muganzi, Lynen & Kambugu 2005:7).

Furthermore, Sub-Sahara Africa is still the region affected by the highest global incidence of HIV/AIDS, with cancer rates and other chronic conditions also increasing. In addition, at least 2 million patients need end-of-life palliative care at any time; however, less than 15% of all patients who need palliative care in the region currently have access to this critical service (Yennurajalingam, Amos , Weru, Addo Opare-Lokko, Arthur, Nguyen, & Baker 2019:2).

Only 16 African countries had established National Palliative Care Associations (PCAS) as of April 2011, and only a few countries were in the process of including palliative care in their national plans and policies (Grant,Downing,Leng &Namukwaya 2012:19). Palliative care in Ethiopia is in its infancy, with limited access for those in needs, yet due to the tireless efforts of its advocates and supporters, it continues to grow. A limitation in the Ethiopian health system is that palliative care is currently not part of medical training nor is it an option for specialty training (Reid, Gudina, Ayers, Tigineh & Azmera 2018:2).

According to Wube, Home and Stuer (2010:8), home care and community-based care of HIV/AIDS patients were maintained by community support group like traditional burial societies (Iddirs), which help to give continuum of care for patients living with HIV/AIDS in 14 major sub-cities in Addis Ababa. Besides community support groups like Iddir help in establishing palliative care provision in the community through home based care programs (The National palliative care guideline 2016:66). Iddir is a local association in Ethiopia which serves as a sort of insurance program run by a community or a group to meet emergency situations (Aredo 1993:7).

Currently, a study shows that palliative care provision in Ethiopia is made through two non-governmental organizations such as Hospice-Ethiopia and Strong Hearts Ethiopia which are mostly funded by external donors. These organizations are the two small non-profit organizations located in Addis Ababa, the capital of Ethiopia, which are the only licensed palliative care institutions in the country (Reid etal 2018:3). Each provides home-based hospice care to approximately 20-30 patients at any given time. Services include home visits by a nurse, pain and symptom management including provision of oral morphine and psychosocial support. Oral morphine is available at hospital level for the patients in Ethiopia. However, the majority (81%) of the people live in a rural setting (World Fact Book 2014:3) with varied cultures, socioeconomic status and insufficient health care infrastructure.

A study shows that in Ethiopia, palliative care is new and very little is known about the types of palliative care service provision to the patients (Kassa, Murugan, Zewdu, Hailu & Woldeyohannes 2014:1). Moreover, in Ethiopia, the health system in the country have traditionally concentrated on the control of communicable diseases. (The National Cancer Control Plan of Ethiopia, Cancer & Plan 2016-2020:7). There appears to be lack of clarity and understanding about how large the palliative care burden in Ethiopia is due to lack of evidence-based data. There is also little knowledge available about both the model of care being implemented in Addis Ababa as well as the appropriateness of such a model (Ayres 2015:74). This shows that there is a wide gap in the development, comprehensiveness, quality and scope of palliative care services in Ethiopia.

1.3 Statement of the research problem

As the world population ages and prevalence of cancer and other non-communicable diseases including life-threatening diseases continue to rise in low- and middle-income countries, the global, regional, and national needs for palliative care are increasing.

It is estimated that about 40 million people around the world need palliative care services each year. Seventy-eight percent of these people live in low-and middle-income countries with almost half of them living in Africa. Worldwide, only about 14% of people, who need palliative care currently receive it (WHO 2018:1). Moreover, according to WHO estimates, 1% of the total population of Africa will need palliative care and approximately 9.67 million people are in need of palliative care across Africa (Dix 2011:20).

In a 2011 study of 234 countries and territories, it was found that 42% had no palliative care services at all and further 32% had only isolated palliative care services (Lynch, Connor & Clark 2013:45). Moreover, a study done by Seya (2011:18) reported that 83% of the world's population lived in countries with low to non-existent access to opioid pain relief.

Annually, within a global context, 54 million people die (all causes), 30 million people die from progressive organ failure and other degenerative diseases, 8.5 million people die from cancer and 1.5 million people die from HIV/AIDs. With technological advances in public health and care provision, life expectancy is increasing rapidly in many parts of the world and it is estimated that currently, almost 1 in 10 people are 60 years old or above. By 2050, this proportion will have risen to 1 in 5. An aging population brings with it a rise in chronic conditions and multiple co-morbidities which result in the increased need of palliative care (Murtagh, Murtagh, Bausewein, Verne, Groeneveld,Kaloki & Higginson 2014:49-58).

Research shows that many people living with a chronic life threatening illness either do not receive any palliative care service or receive services only in the last phase of their illness (Hawley 2017:1). Furthermore, the millions of individuals who die without receiving palliative care in low in come country, experience pain and suffering at the end of their lives (Anderson & Grant, 2017:1). It was further found that patients with serious illness and their families receive substandard medical care, which includes symptoms not being treated, unmet psychosocial needs, severe caregiver burden and low patient and family satisfaction (Meier 2011).

According to World Health Organization, non-communicable diseases kill 41 million people each year, which is equivalent to 71% of all deaths globally and over 85% of these premature deaths occur in low and middle-income countries (WHO 2018:2). Despite the presence of life-threatening illness,most of these patients either do not receive palliative care services or it is received in the last stages their life (Hawley 2017:1) In 2018, 37.9 million people were living with HIV/AIDS globally.Sub Saharan African countries accounted for 71% of the estimated global cases, which is the highest global burden (Kibret, Ferede, Leshargie, Wagnew, Ketema & Alebe 2019:1).

In Africa, a study shows that there were limited palliative care services at home or hospital, with increased diseases burden, great geographical distances, access health services, late presentation of disease, limited financial resources, lack of trained health care professionals, inadequate access to essential medicines, which limits the access of palliative care provision for life threatening patients l (Emmanuel & Kamonyo 2018:2).

In 2017, the National HIV prevalence rate in Ethiopia was 0.9% and 722,248 newly infected people were recorded during the same period of which 60.5% were female. Annual, AIDS–related deaths during the same period were 15,600 (Kibret et.al 2019:1). The HIV burden was heterogeneous as it showed disparity across geographic areas and population groups. Among regions and city administrations, the burden was highest in Addis Ababa city administration followed by Gambella Regional State and Harari, where the HIV prevalence was 5%, 4.1% and 2.9% respectively. While it was lowest in Southern Nations, Nationalities and people region (SNNPR) and Benishangul Gumuz Regional States with HIV prevalence of 0.54% and 0.6% respectively (the Federal Ministry of Health 2016:16 National comperehensive HIV/AIDS care and tratment:2018:4)

In addition, according to the Global Cancer Observatory of 2018, in Ethiopia, the estimated annual incidence of cancer was around 67,573 cases and the annual mortality was over 47,954 and over 80% of deaths from non-communicable diseases were caused by four main diseases such as cardiovascular, cancer, diabetes mellitus and chronic obstructive pulmonary diseases and one of the planned interventions by the Federal Ministry of Health to reduce the burden of cancer was through provision of palliative care (The National Cancer Control Plan of Ethiopia, Cancer & Plan 2016-2020:7).

Moreover, estimates from the WHO from (2008) indicated a non-communicable disease related annual death rate of 34% in Ethiopia (WHO, 2010). Of this, cardiovascular disease accounted for 15%, cancer for 4% and respiratory disease for 4% of all causes of death. Furthermore, diabetes accounted for 2%, injuries for 9% and other non-communicable diseases for 9% of the causes of deaths in the same years.

The most prevalent cancers in Ethiopia among the adult population were: cancer of breast, cervix and colorectal cancer constituting, 33% of the cancer in the women and colectal and non hodakin lymphoma were the commonest malignancies in man (Memirie, Habtemariam, Asefa, Deressa, Abayneh, Tsegaye, & Verguet 2018:1-2). Furthermore, in Addis Ababa, report of on verbal autopsy of burial surveillance showed that 51% of deaths were attributed to non-communicable diseases followed by 42% died of communicable disease and 6% died due to injuries (Misganaw, Mariam, Araya 2013:1-2).

Despite, the increased prevalence of non-communicable diseases in Ethiopia, the current health care system of the country is traditionally concentrated on control of communicable disease. Moreover, there is only one fully functioning public radiotherapy center and only five oncologists in the country (Haileselassie, Mulugeta, Tigeneh, Kaba & Labisso 2019:2) and the ratio of hospice palliative care services to population was 2:82,825,000 in Ethiopia (Lynch et.al 2013:1103).

This anticipated growth in life threating illness in the country highlights the urgent need to improve access to palliative care, the need for an appropriate and contextualised model of palliative care of Ethiopia, is evident and will be the focus of the study.

1.4 Significance of the study

In a resource-poor setting, the implications of poverty and other socio-economic factors that impact on access to palliative care access are enormous and public health systems are generally weak (Harding 2008:515). Despite a growth in the number of palliative care services in resource-poor countries, the integration of curative and palliative care is poor. In order to effectively advocate to clinicians, policy makers, funders, and educators, there is a need to demonstrate the effectiveness of integrated palliative care and to offer models of care that are locally appropriate and have proven effectiveness in terms of both costs and outcomes (Harding & Higginson 2005:1971). In Africa, understanding model of palliative care delivery is the key to implement palliative care provisions; but, research is very limited on palliative care in the region (Downing,Grant,Leng &Namukwaya 2015:3).Similarly , there was no published research paper related to palliative care model in Ethiopian setting and also that showes the integration of palliative care services in to existing health care system

A model of palliative care delivery to meet the unique needs of people with all life-threatening illness in different cultures and communities in Ethiopia will be valuable to inform policy and promote cost-effective, acceptable and culturally acceptable palliative care. Thus, this research is needed to develop a cost-effective model of palliative care services in resource scarce setting.

1.5 Research questions

1. What is the current nature and extent of palliative care in Ethiopia?
2. What are the unmet needs and priorities in terms of palliative care in Ethiopia?
3. What are the factors that can affect cost-effective palliative care?
4. What is a feasible, cost effective model for palliative care in Ethiopian context?

1.6 Research aim/purpose

The aim of this study is to develop a cost-effective model for palliative care in Ethiopia setting.

1.7 Research objectives

The objectives of this research are to:

1. Explore the nature and extent of existing palliative care services in Ethiopia.
2. Determine the factors that influence the effectiveness of palliative care in Ethiopia.
3. Explore the best-practice palliative care models available internationally, with specific emphasis on resource-poor contexts.
4. Develop an appropriate palliative care model for Ethiopia setting.

1.8 Definition of key concepts

A Model of care

A Model of Care is defined as the way health services are delivered. It outlines best practice care and services for patients as they progress through the stages of a condition, injury or event. It aims to ensure that people get the right care, at the right time, by the right team and in the right place (Agency for Clinical Innovation 2013:4)

Palliative care is an approach that improves the quality of life of patients and the families facing the problems associated with life threatening innless ,through the prevention and relief of suffering by means of early identification and impeccable of pain and other problems physical, psychological and spiritual (WHO 2006:1).

Public health approach: is the science and art of preventing disease, prolonging life and promoting the health of entire populations through the organized efforts of society(Higginson & Koffman 2005:46) .

1.9 Operational definition

Community support: In this study, those who are rendering basic health care services and providing referral linkage to the patients in the community (includes community volunteers and extension health workers, iddiri).

I**ddir**: is defined as an association made up by a group of persons united by ties of families and friendships by living in the same district, jobs or by belonging to the same ethnic group Is a deeply rooted cultural practice throughout Ethiopia with Iddir group in every community. The aims of Iddir groups are closely with the goal of advancing palliative care in communities throughout Ethiopia

Hospice care: in this study, hospice care is defined as specialized palliative care services delivered by Hospice Ethiopia and Strong Hearts Ethiopia, which are located in Addis Ababa.

Palliative care partnership: for this study, local partnerships include NGOs who are directly supporting the palliative care services provision by providing both technical and financial support regarding palliative care services.

Policy makers: for this study, defined as experts of palliative care professionals at National & Regional health offices who are formulating polices, strategy, guidelines, advocacy to support and strengthen initiation and expansion of palliative care services.

1.10 Theoretical grounding of the study

According to constructivism paradigm, truth and meaning do not exist in some external world; but, created by the subject's interactions with the world. Therefore, knowledge is socially constructed and so, subjects construct their own meaning in different ways even with regards to the same phenomenon (David , 2004:7). Moreover, Adil and khalid Care, 2016:21)also state that the central endeavor of interpretive paradigm is understanding the subjective world of human experience. As a result, the paradigm that underpins this study is constructivism in which the researcher developed palliative care mode through elaboration and looking at the deep insight of key informants and discussants with the following conceptual framework components as mentioned below in the diagram as the main objective of the study is to construct palliative care model which best suits to resource scarce setting in Ethiopia

In this study, a conceptual framework that includes the elements and context of palliative care in resource –poor environments are used. A comprehensive approach took into consideration both factors such as palliative care barriers and enabling factors that affect palliative care model development in resource poor settings (Maharaj & Harding 2016:9).

The frameworks follow the one that directly influence care such as policy makers, legal support, social environments, culture and believe of patients, types of service delivery, level of palliative care provision, setting of the services delivery, health systems and disease burden and enabling factors to develop palliative care model was elaborated(Figure 1. 1).

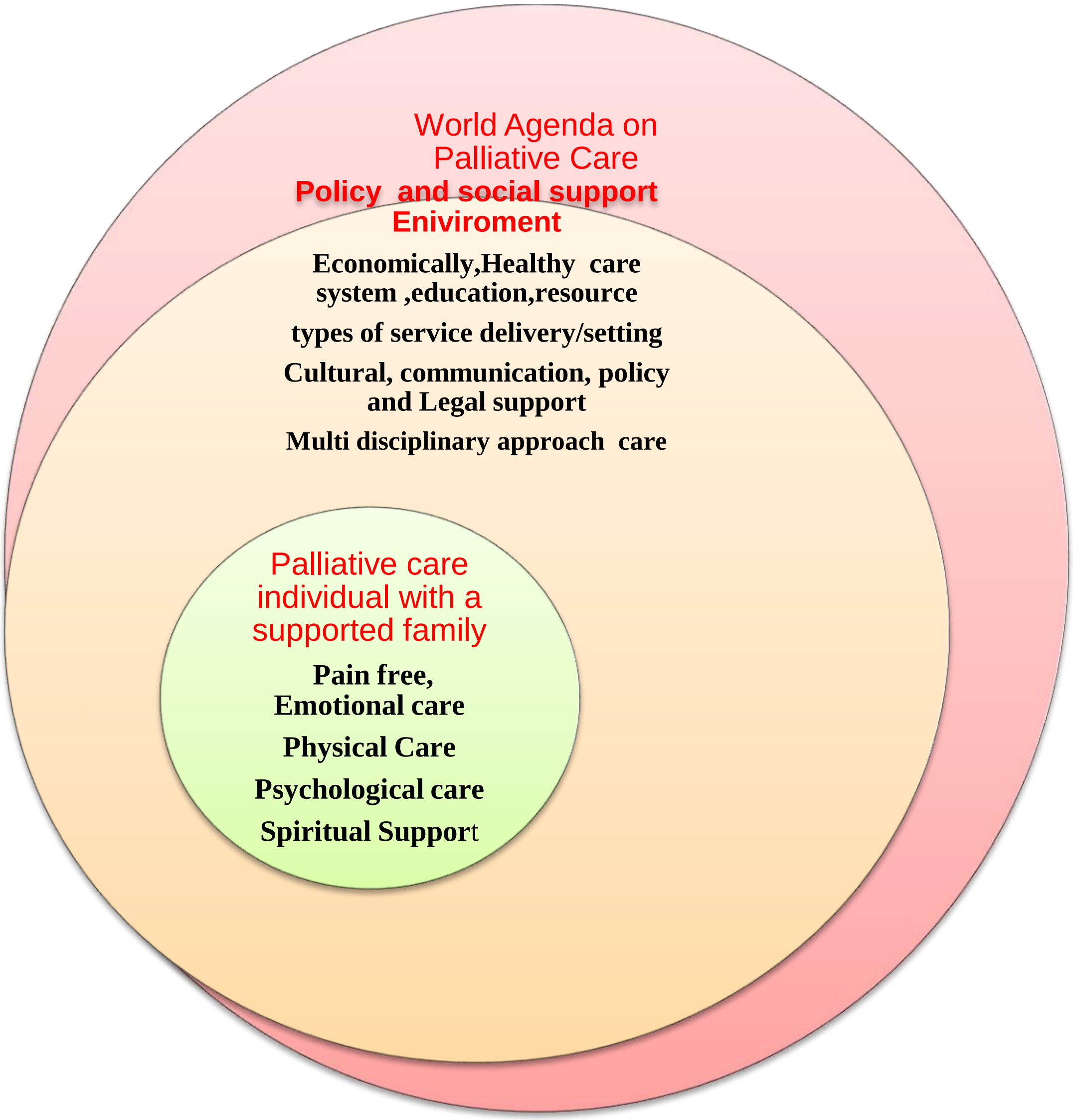

Figure 1:1 Conceptual framework to develop a model of palliative care service(Maharaj & Harding 2016:17)

1.10 Research Design and Methods

A qualitative approach also helps to build a vigorous understanding of a topic ,un packing the meanings people ascribe to activities ,situation and circumstances (Nagy & Leavy 2017:124). Moreover, as it is shown the reviewed literature, qualitative approaches have been applied in researching palliative care issues in Africa (Dowiing 2008:18).

In this study, the researcher used a qualitative approach using constructivism paradigm to understand and explore palliative care situation in Ethiopia inorder to develop a palliative care model qualitative methods to gather and analysis the data. The rationale behind using a qualitative approach was to get an in-depth understanding of the information about palliative care delivery services in Ethiopia from key informants, and focus group discussants. Besides, it helps in elaborating the participants' experiences on the factors that affect palliative care provision. It was also an appropriate way to obtain information about enabling factors that could assist in the development of an acceptable and appropriate palliative care service model in Ethiopia

.1.10.1 Research Setting

The current study was done indifferent parts of Addis Ababa and Jimma zone

Addis Ababa (the capital city of Ethiopia),and Jimma Zone, were selected purposively for this study. The current study was done indifferent parts of Addis Ababa and Jimma zoneAddis Ababa (the capital city of Ethiopia),and Jimma Zone, were selected purposively for this study. Addis Ababa has several palliative care orientated institutions such as services by the Ministry of Health and different NGOs. Policy makers and experts of palliative care are concentrated in Addis Ababa as well as several hospitals, which are rendering palliative care services. It is only in Addis Ababa that a cancer (Oncology) center in Tikur Anbessa Hospital where specialized services such as radiotherapy are available. Hospice Ethiopia and Strong Hearts Ethiopia, the two licensed nonprofit palliative care provision organizations in Ethiopia are also base in Addis Ababa (Reid etal 2018:3).

Jimma is found in oromia region.Four public hospitals in Jimma Zone; namely, Jimma University Medical Centre, Shenen Gibe Hospital, Limu Genet Hospital and Agaro Hospital were selected as the settings for the study. Jimma University Medical Center and Shenen Gibe Hospitals are situated in Jimma town, and Limu Genet and Agaro Hospitals are found in Jimma District. All these hospitals serve patients with varieties of chronic illness, and patients are followed up through services provided in decentralized clinics. Moreover, care-giving organizations and faith-based organizations that are found in Jimma Zone that were supporting patients with life threatening illness were included in the study..

1.10.2 Sampling technique and sampling size

Purposive sampling technique was employed to select key informants and group discussants at different levels of health system, ranging from national levels to frontline health extension workers so as to get adequate information about palliative care experiences. Specifically, data was collected from different Key informants such as policy makers, programme and hospital managers, non-governmental organizations, religious leaders, health professionals and frontline health workers. and group discussions were also held with nurses .By considering inclusion and exclusion criteria's and the participants were initially recruited through institutional and organizational website ,in person interaction and telephone conversations .

Accordingly, 29 key informants interviews were conducted and five group discussions were done with 30 nurses who were working at four chronic illness hospitals of Jimma Zone. This study has three phases.

Phase One: It will include scope of literature review of existing delivery models in different international perspectives. Factors relevant to the delivery of palliative care will be noted and considered in the development of customized palliative care in Ethiopia.

Phase Two: includes population, sampling, data collection and data analysis. During phase ll, in-depth interviews with key informants and focus group discussions with health professionals working in four hospitals in Jimma zone will be involved to explore the current nature and extent of palliative care to obtain, existing and projected needs and gaps in the current palliative care provision in Ethiopia. Key informants will consist of policy makers, supportive stakeholders, managers, program officers, community leaders and health care facility coordinators and for focus group discussion Nurses who are working in the chronic illness of four hospitals in Jimma town will be involved.

Phase Three: includes development and evaluation of the model for delivering cost effective palliative care. During the final phase, following data analysis and considering the conclusive of results, a draft palliative care model for palliative care in Ethiopia will be developed. This model will then be evaluated by different stakeholders by using validation criteria to determine its competitiveness, relevance, practicability, untouched area, acceptability and feasibility within the Ethiopian context. Inputs from key role players namely policy makers, supportive stakeholders, managers, program officers community leaders and health care facility coordinators will again critical looked at by researcher and all comments and suggestions from key informants and discussants will be incorporated in the final palliative care model development and also it will help to develop strategic plan for the implementation of the newly developed palliative care model in Ethiopia.

1.10.3 Data collection methods and procedures

The qualitative data collection methods enabled the researcher to obtain more in-depth information and clarify certain issues that are related to cost- effective palliative care model that can be used for Ethiopian settings since there is limited palliative care research in the country. In this study, in-depth interviews and focus group interviews were employed to obtain data for the development and refinement of palliative care model for Ethiopia

1.10.4 Data analysis and management

The researcher organized all transcriptions and translations documents of 29 Key Informants and 5 Focus group discussants, field notes and audio recorded files in order to give a sense of it to create and develop model of palliative care in Ethiopian settings.

The researcher used the computer software ATLAS-ti 7.0. Firstly, the transcribed document and then, the transcribed word files were converted into text files. After that, they were imported into ATLAS-ti software for coding and other subsequent aspects of the data management to analyze and narrate the findings of research. Data were managed by converting the narrative data into smaller, more manageable segments. Finally, the deductive coding approach was applied and pre-existing coding framework was used. Categories and subcategories were developed into themes for each participant and across different participants, and finally, the meaning of the theme was interpreted. Besides data from Key informant and focuse group discussants were analyses together using ATLAS-ti 7.0 software

1.10.5 Establishing trustworthiness in qualitative analysis

According to Shenton (2004:63), trustworthiness refers to the quality value of the final results and conclusions reached in qualitative research. Trustworthiness ensures the scientific rigor in qualitative studies. Polit and Beck (2010:492) describes the four criteria which used to ensure trustworthiness of a study includes: Credibility, Dependability Conformability, Transferability. Therefore, each criteria was elaborated in the research process of this study were considered and addressed during in the research process .as described and discussed under chapter three

1.10.6 Ethical considerations

.The researcher considered all ethical principles requirements throughout the research process in order to protect the right of the participants and the institutions that were involved in the study. Thus, the following ethical considerations were adhered to protecting the rights of the study participants and those of the institutions involved.

First, the ethical clearance was obtained from the Research and Ethics Committee of the Department of Health Studies of the University of South Africa (Annexure 1). Then, after getting approval from the university, UNISA Addis Ababa Branch was written a support letter to Oromia Health Bureau in order to get an ethical letter to conduct the study (Annexure 2). Ethical approval letter was obtained from Oromia Regional Health Bureau (Annexure 3) to the respected administrative offices and Hospitals before involving them in the study. Moreover, Ethical clearance was obtained from ethical review board of Jimma University, Institutes of Health Sciences. Therefore, official Permission was obtained from the concerned bodies at all levels that are annexed in this study, and the four fundamental ethical principles were maintained through the research and have been applied as follows

1.11 Structure of the Dissertation

This research will be structured and organized in to seven chapters.

Chapter One Orientation of the study

This chapter gives an overview and description of the background and context of the research problem which leads logically to the statement of the problem. The significance, purpose objectives, research questions and theoretical background and approach to the study as well as concept clarification serves to inform and orientate the reader.

Chapter Two Literature review

In chapter two, a comprehensive literature review will serve to provide evidence of the latest trends and development in the field at national, continental and international levels.

Chapter Three Research design and methods

In chapter three the application and operationalization of the research methodology is reported. Account is given about the study population, sampling, quality assurance. Besides, to assure the scientific requires of the study the four criteria of trustworthiness such as credibility, dependability, confirmability and transferability will be considered and addressed during in the research process. In this chapter, all ethical principle requirements throughout the research process will be mentioned and addressed during the study .

Chapter Four: Analysis, presentation and description of the research finding

In this chapter, the process and management of data analysis will be presented. The findings and the interpretation of the findings will be reported.

Chapter Five Discussion and application of the findings

In this chapter, the findings of the study will be discussed, compared and argued. Literature will be integrated and the meaning of similarities and differences will be explored and utilized as pointers towards the development of a palliative care model.

Chapter Six Development of the palliative care model

In chapter six, the development of a draft palliative care model for palliative care in Ethiopia will be discussed. The process of validating and refining of this model will also be described.

Chapter Seven Conclusion and recommendations

In the last chapter, the study report will conclude the summative findings of the study in terms of the study objectives will be justified and recommendations for implementation of the model as well as recommendations for further research will be made.

1.12 Conclusion

In chapter 1, an overview of the study was provided to orientate the reader to the context, nature of and approach to the research problem. It was concluded that Ethiopia is in dire need for an appropriate and cost-effective palliative care model, taking into consideration the lack of resources in spite of the increasing need.

CHAPTER TWO

Literature Review

2.1 Introduction

Ramdhani and Amin (2014:49) define literature as the body of knowledge within a specific topic of interest. Literature is reviewed for different reasons, including identifying and refining a research problem, refining research questions, and orientating the researcher to what is known and not known about an area of interest (Polit & Beck 2010:88). The review of literature aids the researcher to determine gaps and inconsistencies in the body of research on a specific topic. Studying recently published literature also sensitizes the researcher to the latest trends and developments in the field.

The primary objective of literature review for this study is to review existing models of palliative care internationally and nationally, which will assist the researcher to develop a best practice model of palliative care that is effective and applicable for cost-effective management of patients with chronic illness within an Ethiopian context. Moreover, through the literature review, the researcher intends to identify specific elements and priorities of palliative care in resource scarce settings.

Literature has been accessed from World Health Organization's publications, books, journals, international and national reports, policy documents, palliative care guidelines, reports of the African Palliative Care Association, health facility reports, non-governmental organizational reports, hospices reports, and dictionaries. Internet searches using search engines such as such as Google scholar, CINAHL, MedLine, Science direct and Pub Med have been used to access data bases and websites. Ary, Jacobs, Irvine and Walker (2018:63) identified steps that can be utilized in the process of reviewing literature, which are formulating the research question, objective, searching the extent literatures, summary of sources, synthesis of sources, analysis of data and authorization of the text. All these avenues have been pursued by the researcher.

This chapter presents a critical review of literature around the research topic and is further divided into different parts. Part one describes the levels of palliative care and cost related to palliative care provisions, the context of palliative care service delivery in Africa and Ethiopia are explored. This is followed by critical reviews of articles on international and national palliative care models, advantages and disadvantages of each model, and its implications and relevance to the study setting. Then elaborating elements of cost effective palliative care practices in order to develop best palliative care practices for resource scare settings . In part two, the theoretical framework used for this study and its application to the study are discussed and accounted for. In part three, barriers and enabling factors that affect palliative care model development are elaborated and discussed.

Table 2.1 The summary of searching strategies for Literature Review

Searching yea**rs**	2005 to 2020	
Key words	Palliative care, model of palliative care, factors affecting palliative care, enabling factors, cost effective palliative care, hospice care ,levels of palliative care provisions	
Searching engine used	PubMed CINAHL MedLine Science Direct WHO document International and national palliative care reports African Palliative Care Association reports, Policy documents Health facility reports	

2.2 Levels of palliative care provisions

According to Nabudere,Obuku and Lamorde (2014:8) the level of palliative care provision can be categorized into three levels, which are primary level (basic), secondary (Intermediate) and tertiary (specialist) levels. However, another study classifies the care given as usual care (levels 1 and 2) and specialist palliative care services, which is only given by specialist palliative care team (Gomes,Calanzani, Curiale, Mccrone & Higginson 2013:5).

A study shows that all the three levels of palliative care should be provided throughout the health care system from home or community to health facilities which require palliative clinical skills to address patient needs and to provide clear referral pathways within the health system (Nabudere, Obuku & Lamorde 2014:8). Therefore, patients should get access of palliative care when he/she has a journey from community to health facilities or from health facilities to community.

The aim of the palliative care model to make patients with a life –threatening illness in order to easily access to the levels of palliative care provision based on his/her needs regardless of care setting or diagnosis to bring a quality of life (Ryan, Creedon & Myers 2019:37)**.**

Meta-analysis of reviewed literature in Australia revealed that models of palliative care should integrate specialist expertise with primary and community care services and transitions across setting and there should be clinical networks of health professionals and organizations from primary, secondary and tertiary care working in coordinated manners (Luckett et.al 2014:1). Besides, patients and families themselves often play an active role in determining which services they want to receive and it increases their capacity to respond rapidly to individual patient needs and their preferences (Luckett et al 2014:15).

African Palliative Care Association developed standards for each levels of palliative care provisions and elaborates the qualification requirements or criteria for each level of palliative care service delivery in order to ensure the quality of palliative care for patients with life-threatening illness (African Palliative Care Association 2010:19). Moreover, research findings indicate that failure to distinguish between these three levels may lead to confusion (Quilt & Abernety 2013:2).Therefore, this study elaborates the three levels of palliative care provisions in different models of palliative care as follows:

Study done in seven palliative care programs in Malawi and Kenya found out that no two palliative care programs are identical. However, there were significant similarity that allows the construction of typology of palliative care models and the services were constructed differently with in the different levels of care (at primary, secondary and tertiary) and model of palliative care delivery should reflect multidirectional and cyclic in order to provide multiple palliative care delivery packages to respond for the patients and their families palliative care needs. Moreover, the patients may enter the system at different points in their illness and may come in and out of the system as per their needs.

Level 1: Primary Level- This level represents what are essential or minimum packages of palliative care (African Palliative Care Association, 2010:19). This care is provided by trained nurses in basic palliative care who train and supervise community volunteers and family care caregivers, and are supervised at the district level by health professionals (WHO 2016:14).

At primary level, all health professionals should have the basic palliative care training, this primary palliative care can be given at the community level or at a facility based palliative care model. It also allows the majority of patients to access palliative care services by addressing basic care package (Bruera & Sweeney 2002:8).

It provides basic clinical and supportive care services using a holistic approach to manage basic clinical and non-clinical problems such as treating opportunistic infections and managing mild pain by using the WHO analgesic ladder. These were referred for moderate and severe pain and also work on adherence and referral of patients and their families to secondary or tertiary levels for more advanced and specialist care (African Palliative Care Association, 2010:19.).

Furthermore, a study done in Malawi and Kenya revealed that the community palliative care model is nurse-lead and more patient centered; but is less qualified and less trained than specialist level of model of palliative care service (Downing, Grant, Leng & Namukwaya 2015:16).

Level 2: Secondary level- This is general palliative care, at intermediate level, in which patients and families will benefit from the expertise health care professionals, They have had some additional training and experience in palliative care perhaps to diploma level, such intermediate level expertise may be available in hospitals or community settings (African Palliative Care Association, 2010:19). On the other hand, generalist palliative care provider is used to refer to those health and social care professionals practicing at level one or two (Ryan, Creedon & Myers 2019:37).

Level 3: **Tertiary level**- Specialist palliative care services are those services whose core activity is limited to the provision of palliative care. These services are involved in case of patients with more complex and demanding care needs and consequently, require a greater degree of training, staff and other resources. (African Palliative Care Association, 2010:19).

In specialist palliative care services because of the nature of the needs, it is analogous to secondary or tertiary health care services. When referring to both services, providing a palliative care approach as part of usual care provision (level 1 and 2) and specialist palliative care is used when referring to specialist palliative care only. They have skills to manage more complex and difficult cases (Ryan, Creedon & Myers 2019:37).

The specialist palliative care team consists of physicians, nurses, social workers and pharmacists. They all have advanced palliative care training and provide education and training in palliative care. (Braga Da Cruz & Nunes 2016:4).

Similarly, the research study done by Quill and Abernethy (2013:1174) described that the activities that can be done by specialist palliative care level, which include: management of refractory pain or other symptoms, management of more complex depression, anxiety, grief and existential distress, assistance with conflict resolution regarding goals or methods of treatment within families, among treatment teams, assistance in addressing cases of near futility, also providing palliative care educations and training for health professionals.

Another study showed that at specialist level of palliative care model, the service tended to be led by doctors. It is more medical and more specialist and more multidisciplinary in nature than the community model. There was a clear shift from more patient centered services in the community to professional centered in specialist palliative care. (Downing et.al 2015:7).

This study also further explained that specialist care was more trained and had clear role than community based model, therefore, the specialist palliative care gives consultation services to in patients admitted through other primary care teams, there were referrals to the services and also refer out to other palliative care providers thus creating a circle of referral, but at district hospital level ,the model of palliative care to be led by nurse and there was referral in and refer out of patients to get palliative care services ,which was up ward to tertiary care, specialist clinic, across to other hospitals and downward to health centers and downward to local community organizations (Downing et.al 2015:7).

Similarly, organizations rendering palliative care play a great role in maintaining appropriate referral pathways and thus, palliative care should be incorporated into existing health care system at all levels of care such as community, primary care and tertiary care levels (Ryan,Ireland, National, Palliative care programe 2019:82).

Moreover, the national palliative care guidelines of Ethiopia (2016:66) described that maintaining continuum of care is the critical point to address palliative care needs of patients as they pass through the referral pathways between community and facility based palliative care services.

In conclusion, palliative care can be given at primary, secondary and tertiary levels in the health care system. It also should be integrated into the existing health care system. Therefore, patients who need palliative care should get an easy access of the services on their journeys to the health facilities or to the community. Besides, palliative care services should be a continuum to address the need of patients with life-threating illnesses. Thus, having the concept of levels of palliative care provision and referral system and integration of these levels in the healthcare system plays a pivotal role in developing palliative care model.

2.2.1 Cost related to palliative care service provision

A study done by Anderson and Grant (2017:1-3), revealed that, financial estimates are necessary to promote the expansion and longevity of palliative care services. According to this study, cost of illness include direct costs that measure the resources used to treat illness, which includes staff time, radiotherapy ,chemotherapy and advanced imaging. While the indirect costs include costs that usually measure lost productivity (the patient or family member taking time off work or school).

The finding of the study indicates that in high income settings, practicing provision of palliative care for incurable diseases has been proven to be cost effective. However, in low income settings, it showed that the absence of this service, the presence of fragile health system and the lack of integration palliative care services can lead to significant economic loss to the individuals, families, and communities that can even pass to the future generations with less economic growth in the settings.

This finding argued that palliative care is the strategy to reduce the direct, indirect and social costs that incurable diseases can cause, such as fragile health care system, lack of the safety nets of insurance schemes and social support programs, which are the major challenges.

Studies done in Canada, Italy, Norway, Sweden, UK, and USA on cost effectiveness of home based care services show that there are significant benefits of home palliative care services, as compared to usual care. The results show that, home palliative care increases the chance of dying at home and reduces the symptom burden for patients with malignancy with odds ratio of 2.21 and P-value of 0.003. Furthermore, the research recommended that further study should be conducted on cost effectiveness, especially for patients with non-malignant tumours, to enable a comparison of different models of palliative care (Gomes et.al 2013:8).

A study in USA to establish the association of cost saving with hospital palliative care consultation programs, revealed that hospital palliative care teams are associated with significant hospital cost saving. Palliative care patients who were discharged alive had an adjusted net savings of $ 1696 costs per admission (P=.004) and $279 indirect cost per day (P<.001), with significant reductions in laboratory and intensive care unit. (Morrison,Penrod,Cassel,Caust-Ellenbogen,Litke,Spragens & Meier 2008:1783). The authors argued that there were significant association between hospital palliative care consultation team and hospital cost saving.

Similarly, a cost analysis of hospital based palliative care outreach program in South Africa showed that hospital outreach services have the potential to avert hospital admission and the cost per hospital outreach visit was US$ 71 and US$ 80 respectively. The cost per outreach visit was 50% less than the average cost of in-patients at a hospital. This improves the quality of life of patients in their home environment and reduces over crowed services in lower resource poor setting (Bajwah, Oluyase, Gao, Evans,Grande & Higginson 2020:8).

Studies conducted in Malawi, Kenya, Rwanda, Uganda and Zambia found that families prioritized the immediate need to seek for cures for their ill family member over saving funds for future household costs. Due to the reluctance of the clinical staff to address the bad news, the progression of the incurable diseases lead the families to be more vulnerable to both direct and indirect costs . Families considered the diseases as cured and continuous for prioritizing for cure which further leads to direct and indirect costs (Anderson & Grant 2017:1). Furthermore, fragile health care system, lack of the safety nets of insurance schemes and social support programmes are the major challenges identified in the study findings

Similarly, in Ethiopia, in a cohort of patients with cancer, we found that reported medical costs, including medications, treatments and travel to health facilities, necessitated the sale of livestock, homes, and wedding gold, as well as pulling children from school as the fees became unaffordable (Anderson & Grant 2017:1). Besides, the recent study done in three outpatient clinics and Hospice patient home reveals that ,there is a statistical relationships between pain and cost, in which, majority of oncology patients wished to die at home and the patients reported pain control as the top reason they preferred a hospital death (Anderson et.al 2018:1).

Similarly, a study done by Kassa et.al (2014:3) indicates that, there is limited health infrastructure and funding for patient with advance cancer and in need of palliative care A study by Ayers (2015:34), revealed that in Ethiopia, the main care providers for patients with palliative care needs are the family at great financial and emotional cost. Palliative care does not only support the patient, but, the family helps reduce the financial costs by planning appropriate individualized care at home.

Furthermore, about 80% of reported cases of cancer are diagnosed at advanced stages; this is largely due to inadequate screening and early detection and treatment services, inadequate diagnostic facilities and poorly structured referral. In addition, the country has very few cancer specialists (only 4 qualified oncologists for the entire population). This makes it difficult for a great majority of the population to access cancer treatment services, which results in long waiting times and cause many potentially curable tumors to progress to incurable stages (Haileselassie, Mulugeta, Tigeneh, Kaba, & Labisso 2019:33)

To overcome the above cost related problems, research findings showed that integration of palliative care with curative services is the most cost-effective pathway to high quality healthcare provision into existing health care system (Currow, Editor & Clark 2018:276). Moreover, models of palliative care should be integrated with all healthcare systems in providing primary, secondary and tertiary palliative care to reduce both direct and indirect cost to bring quality of life for patients with life-threating illnesses. Therefore, palliative care is more cost-effective for patients with life-threating illnesses especially during end-of-life care.

The reviewed literature highlighted that palliative care reduces both direct and indirect costs and also it is cost effective when it is given in conjunction with curative services. Moreover, the literature showed that the model of palliative care should be applied to all diagnosis and also should be cost effective. It is therefore very crucial to look at elements of cost effective palliative care in order to develop a palliative care model for the Ethiopian context.

A study done by The World Health Organization on implementing and planning of palliative care revealed that, integrated community based home care in South Africa is cost effective and can be applied to all diagnosis because of various reasons including it being patient centered, it involves the patients families and the care is given by trained and community volunteers who are supported and supervised by trained health professionals.

The model has a link with different partners and there is referral system to and from other facilities such as primary health care clinics and hospitals and the quality of care is assessed by audit on the bases of patient reported outcome.

Integration of palliative care into existing health care system by public health principle is the most suitable approach to develop palliative care in developing countries (Ddungu, 2011:729). Integration of palliative care to existing health care system is cost effective , as a result, The World Health Organization encourages the governments to integrate palliative care into existing health care system in order to give palliative care provision for life threating patients and their families.

2.3 Disease burden and need of palliative care

2.3.1 Disease burden and need of palliative care in Africa

The need for context-specific model of palliative care delivery must respond to the differing nature and staging of the illness as well as the cultural, social, and spiritual practices about illness and death within the context of the available range of health and social services (WHO 2016 :13).

Africa is mainly affected by HIV/AIDS, cancer and emerging chronic illness, this is compounded by the existence of poor resources. A study revealed that low resource countries shared two –thirds of the global burden of disease (Grant, Downing, Luyirika, Murphy, Namukwaya, Kiyange, Atieno, Sali, et al 2017:1) with experiences of unnecessary suffering and pain due to lack of access to morphine (Christian et.al 2014:3).

Despite increased prevalence and growth of non-communicable diseases, there is a greater gap between palliative care needs and service provision. Palliative care and pain management are challenges that are faced in resource limited setting like Africa (Lentsoane,Meyer, Schellack & Cameron 2017:2).

In Africa, there was a paucity of information on history of hospice development and palliative care provision with weak evidence of policy and practical development (Clark, Wright, Hunt & Lynch 2007:698).

A recent study also revealed that in Africa, only five percent (5%) of people who need palliative care received it, although, there is progress in the development of palliative care provision in the continent (Downing, Hons, Grant, Leng & Namukwaya 2015:1).Another study showed that Uganda, South Africa, Rwanda and Kenya had the highest number of hospice and palliative care services in Africa. However,19% (9/48) of the countries in Africa had no hospice and palliative care services (Rhee et.al 2017:9).

Therefore, palliative care remains under developed in some of African countries, although there has been growth on the continent. A study done by ynch et.al (2013:1099) showed the mapping level of different countries based on their current status and progress of palliative and hospice establishment. In Africa, 28 of the countries had no palliative care services with most palliative care services concentrated in Kenya, South Africa, Uganda with 14% of the countries showing an increase in palliative care services provision (Downing, Hons, etal 2017:1). This study showed that though there has been growth in the development of palliative care in Africa, there is still a gap in its provision. Therefore, based on the above study, the mapping level categorized African countries into different levels as shown in Table 2.2.

Table 1.2 African countries on their palliative care integration and development

Group	Level of categories	Country
Group 1	No known activity	Benin, Burkina-faso, Burundi, Centeral Chad, Comoros, Djibouti, Equatorial Guinea, Eritrea, Gabon, Libya, Niger Somalia
Group 2	Capacity building	Algeria, Republic of Congo

Group 3a	Isolated provision	Angola, Ethiopia, Ghana, Gambia, Nigeria
Group 3b	Generalized provision	Cote divoire
Group 4a	Preliminary integration	Kenya, Zambia, Zimbabwe, Tanzania
Group 4b	Advance integration	Uganda

In summary, palliative care development and its progress in Africa varies between countries, They are categorized in different groups based on their palliative care services provisions. Palliative care has grown in Africa, in which 14 countries moved to the higher class as shown above. However, despite the burden of non-communicable diseases in Africa, only 5% of patients who needs palliative care can access the services, and 19% of the countries had no hospice and palliative care services. Ethiopia was categorized under group 3 in which there was isolated palliative care provision.

2.3.2 Disease burden and the need for palliative care in Ethiopia

This section is divided into three parts. It begins with a brief description of diseases burden and needs of palliative care in Ethiopia. Then, it is followed by structure of health care delivery in Ethiopia. The third part describes the palliative care development in Ethiopia.

The need for palliative care in developing countries is significant and increasing due to the high disease burden, however, palliative care is rarely accessible in low and middle income countries, often with less health social conditions, less access to prevention, diagnosis and treatment of health problems (WHO 2018:3).

When setting up a model of care, the predominant illnesses that require palliative care may affect palliative care delivery (Ayres 2015:58). Therefore, it is very important to describe the burden of the diseases in Ethiopia setting in order to show the palliative burden and needs for patients with life-threating illnesses.

2.3.2.1 Overview of Ethiopia

Ethiopia is located in the North Eastern part of Africa, also known as horn of Africa. It is a land locked country boardering Djibouti, Eritrea, Kenya, Somalia, Sudan and South

Sudan and has been using Djibouti's main port for the last two decades.With the recent peace talks with Eritrea, Ethiopia is set to resume accessing the Eritrean ports for its international trade (WHO 2020:1).

Ethiopia is the second most populous country in Africa and expected to become the ninth most populous country in the world by 2050. With an average life expectancy of 56.2 years and of the total population (Central statistics authority of Ethiopia 2016:10), 80% live in rural area and occupies a total area of 1,100,000 square kilometers (420,000 sq. mi) (CSA 2016:10). Per capita income is $850 and the country aims to reach lower- middle income status by 2025 (World Bank 2020:1).

According to the Ethiopian Health Sector Strategic Plan (HSDP- III) 2005/06-2009/10, in Ethiopia, the ratios of physician and nurses per 10,000 populations was 0.3% and 2% respectively. The country was ranked in the lowest quintile among African nations in terms of density of health care personnel. Furthermore, there was also a problem of uneven distribution of the limited health workforce among and within districts and an inappropriate use of available skills (Abebe 2015:7).

2.3.2.2 Disease burden in Ethiopia

A study shows, non-communicable diseases have been a neglected area in many low and middle-income countries, due to the heavy burden of communicable diseases (Abebe et .al 2015:34-8).

Based on the 2013 data from the Addis Ababa Cancer Registry, breast cancer accounted for 31.4%, cervical cancer for 14.3% and ovarian cancer for 6.3% of all cancer cases. Despite the high death rate due to chronic disease in Ethiopia, the health system is not yet well equipped to address the challenges of chronic diseases until Health Sector Development Program–IV (EPHA 2012:36-54).

This indicates that, while the benefit of curative treatments for people living with serious illness is often limited, our health care delivery system remains almost exclusively focused on the treatment of acute and reversible illness, rather than on supporting quality of life and life-long illness in Ethiopia. This has led to a gap between what people need and palliative care services in the setting.

2.3.2.3 Health care system of Ethiopia

Organizational structure influences palliative care development (Dahlin 2015:2) and delivery of palliative care can change dramatically according to decision making and private versus publicly funded health care systems, in different settings (Eduardo & Catherine 2002:1). Furthermore, Brereton et al (2017:2) states that a key influence on palliative care provision in each country is the way that palliative care and health care are funded in different systems. Also, WHO (2016:17) indicates that palliative care delivery services should consider the country social needs and the health care system context Health Systems consist of all organizations, product, people and actions whose primary intent is to promote, restore or maintain health (Federal Ministry of Health, Ethiopia, HSTP 2015-2020:18).

This section describes the health care system of Ethiopia followed by the need for palliative care policy and its implementation in Ethiopia. This may help in integrating and establishing palliative care models in resource scare settings.Ethiopia’s health system is structured into three – tiers system as primary ,secondary, and tertiary levels of health care (Figure 2.1). The primary level health care includes primary hospitals, health center and health post which are rendering health service coverage for the following populations: primary hospitals (60,000 – 100,000), health center (15,000 – 25,000) and health posts (3,000 – 5,000) with decreasing scope for clinical coverage. Furthermore, the primary health coverage unit comprises five satellite health posts (WHO 2014:4).While, the secondary level health care delivery system includes general hospital which serves about 1-1.5 million people and tertiary level health care delivery system includes tertiary hospital which serves 3.5 to 5 million people (WHO 2014:4).

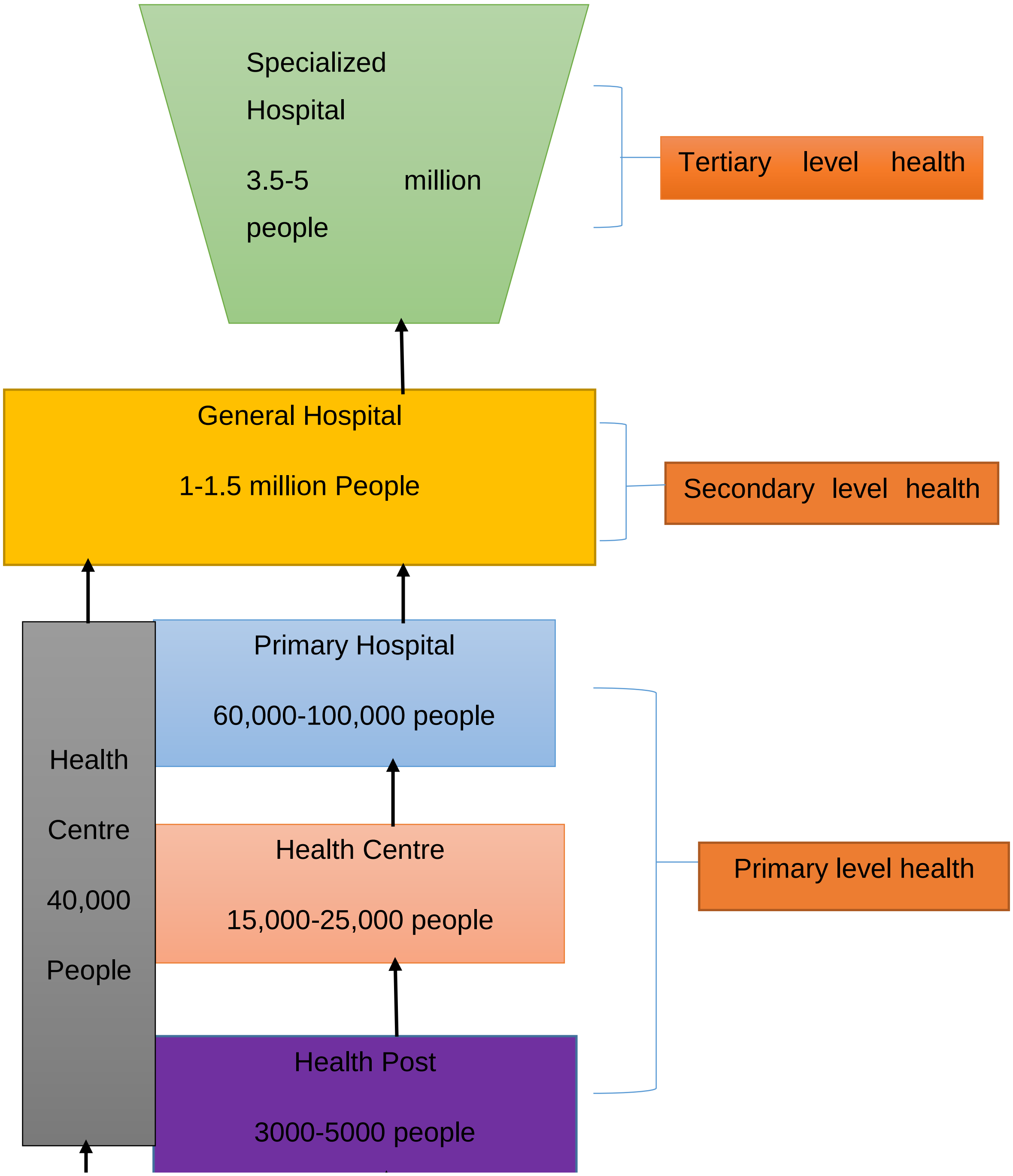

Figure 2 .1 Shows Ethiopian Health Tier System and its scope of coverage

Ethiopia health care systems traditionally concentrated on the control of communicable diseases and the national health coverage is still poor: 75% of urban and 42% of rural dwellers live within walking distance to a health facility; most of the rural population has no access to modern medical care (Anderson & Grant, 2017:1-9) .

Briefly, understanding a country's healthcare system is very important in developing a palliative care model. This is because WHO encourages countries to integrate palliative care into their existing health care systems. Therefore, Ethiopia's healthcare system shows decentralization of the services from central to peripheral areas. Additionally, it focuses on primary healthcare principle. As a result, it is crucial for establishing palliative care model and integrating palliative care services into health system.

2.3.2.4 The need for palliative care in Ethiopia

According to WHO Global Atlas of palliative care (2014), there is insufficient access to palliative care services worldwide, with the majority of unmet needs being in low- and middle-income countries. However, palliative care is an important part of the world health agenda. On 22, May, 2014 the World Health Assembly passed resolution EB 134 R7, which requires that Member States should address palliative care within a continuum of care. The regulation states unequivocally that relief from pain, whether, physical, psychological or spiritual is the ethical responsibility of health care providers and government institutions that support health care provision (WHO 2014:12). Therefore, governments are required to include palliative care in the planning and implementation of health care services. This includes having appropriate palliative care policies at local and national levels, providing budgetary support, ensuring appropriate access to need medications and supporting training and ongoing education on palliative care (WHO 2014:6).

The need for a palliative care service in Ethiopia is paramount due to the lack of curative services. Palliative care is relatively a new concept in Ethiopia and is developed from the palliative care needs arising from the HIV/AIDS epidemic. The, now rising number of cancer cases and people suffering from non-communicable conditions has increased the need for this specialized care even further (The Ethiopia National

Palliative Care Guideline 2016:81**).** There is lack of curative services in Ethiopia, therefore, need of palliative care services is very vital**.**

Recent research conducted in Ethiopia reveals that in oncology, 95.5% of the population endorsed moderate or severe pain, while 24% were not prescribed analgesia. Importantly, 80% of the non-communicable disease population reported moderate or severe pain. In addition, there are extensive unmet palliative care needs in Ethiopia. Untreated pain and high costs of illness are the major contributors to psychosocial distress and financial crisis in this Ethiopian population (Reid et.al 2018:1). Similarly, a study done by Meier (2011:343-80) shows that people with serious illness and their families, receive substandard medical care, including untreated symptoms, unmet psychosocial needs, severe caregiver burden and low patient and family satisfaction. This implies that patients in Ethiopia who need palliative care do not access such services.

2.3.2.5 Policy and Implementation of Palliative care in Ethiopia

Palliative care in Ethiopia is in its early stage, yet due to the tireless efforts of its advocates and supporters, it continues to grow. Nevertheless, Ethiopians living with life-threatening conditions have limited access to palliative care (The Ethiopia National Palliative Care Guideline 2016:1).

“Hospice Ethiopia” and “Strong Hearts” are two small non-profit organizations located in Addis Ababa, which are the only licensed palliative care institutions in the country. (Reid,et.al 2018:3). Hospice Ethiopia, a local non-governmental organization, was established in 2003 by Sister Tsigereda Yisafowessen in the country and is trying to address this problem through care for patients with chronic illnesses, HIV and cancer. Both these two small non-profit organizations rely on fundraising and donors for finance.

In Ethiopia, the Federal Ministry of Health (FMOH) recognizes the importance of palliative care as part of the country’s health strategy and developed national palliative care guidelines. These guidelines are integrated in the training of health professionals. on 2016 (National palliative care guideline 2016:1). The Federal Ministry of Health is also involved in an important project known as ‘Pain Free Hospital Initiative’ (PFHI) that aims to provide teaching on pain assessment and control to doctors, nurses and pharmacists in hospitals in Addis Ababa along with the provision of oral morphine solution **(**FMOH 2016).

In order for palliative care to be developed and integrated into national health systems, it must first be included in all relevant national health plans, policies, strategies, and guidelines and most importantly, implemented. Therefore, the following are policy initiatives and commitments on plans, strategies and guidelines that are included in national health system:

1. National Palliative Care Guidelines, June, 2016
2. National Pain Management Guidelines were completed in 2014
3. National Cancer control plan 2016-2020
4. National Strategy for the Prevention and Control of Non-communicable Diseases 2015-2020.
5. Comprehensive National HIV/AIDS Training Guideline 2005 and up dated up to 2018
6. Non-communicable Diseases Training Manual.
7. Establishment of Technical working group of palliative care at Federal Ministry of Health level.

2.4 Conceptual analyses of models of care

Development of a palliative care model is complex and is developed in various ways internationally and its development varies from country to country due to different factors such as socioeconomic factors, cultural variation, health infrastructures and burden of the disease (Edurdo & Catherine 2001:1). Moreover, local needs and resource availability determine significantly when and how a palliative care model is developed (Bond, Lavy & Wolldridge 2008:16).

According to World Health Organization, palliative care service delivery can be established and expanded in various ways, which could be started at community, then extend to facilities or started at facilities levels and then, extend to community,or they can also be started at the same time in both facilities and community based on countries existing resources and context (WHO 2016:17). It is better for the researcher to look at the perspectives of different scholars on the descriptions of models of care. This helps to develop a cost effective palliative care model and contextualize it to the Ethiopian setting.

Findings from a systematic review by Brereton et.al (2017:2) describe a model of care as any structured care model involving multiple components that include, who delivers the palliative care, the intervention, settings in which palliative care is given, to whom it is given and how it is given, when it is given and for what purposes.

Moreover, in a report of the Department of Health, Western Australia (2008:7) the aim of a model of care is described as the provision of best practice care and services within a health care system for a person or population group as they progress through the stages of a condition, injury or event and ensuring people get the right care, at the right time, by the right team and in the right place.

2.4.1 Evolution and development of palliative care models

According to the Oxford text book of Palliative Medicine(1998:3-8), the traditional idea of palliative care has been based on the hospice model of care developed in the United Kingdom in the 1960s from which modern palliative care emerged. This modern model of palliative care was founded in the UK by British Doctor, Dame Cicely Saunders. She built a life affirming philosophy around the belief that dying is a natural as being born and death should be free from suffering and determined to understand the best way of controlling pain (African Palliative Care Association 2010:4). Saunders evolved the concept of total pain, which includes not just the physical but also social, emotional and spiritual aspects of suffering (Milićević 2002:6).

In 1967, Saunders opened St. Christopher’s Hospice at Sydenham in South East London and then, evolved as a home-based service(African Palliative Care Association 2010:4). St Christopher’s Hospice quickly became an inspiring model for others, differing significantly from earlier homes for people nearing death by taking a threepronged approach, namely combining excellent clinical care, education and research. This movement brought change in the life of the patients and caretakers and now makes palliative care accepted as integral part of health care policies globally. This initial British movement soon became global and developed in different ways around the world to accommodate various contexts. There is currently worldwide recognition for the need to extend the philosophy, knowledge and skills developed from a traditional hospice model that traditionally focused on people terminally ill with cancer, to provide access to care for all people with a life treating illness and their families (Eduardo & Catherine 2002:2).

In summary, palliative development was started in the United Kingdom by providing hospice care for terminally ill patients; then, expanded to different countries with broader concepts. Globally, the need for palliative care grew due to increase in life- threating illnesses such as HIV/AIDS, cancer and other non-communicable diseases. Therefore, WHO recommended that palliative care should be given for all life-threatening illnesses from diagnosis up to bereavement. Furthermore, the World Health Organization encourages the integration of palliative care into mainstream health systems and development of evidence–based palliative care practices. In a study done by Harding and Higginson (2014:6), it was found that the field of palliative care as an integral part of global health is gaining greater attention, aiming to establish appropriate, locally relevant, feasible and effective palliative care for all irrespective of diagnosis, place of care or geographical region.

2.4.2 Palliative care models in different international and national perspectives

A study conducted by Harding and Higginson (2014:6) indicated that palliative care is an integral part of global health which is gaining greater attention.It aims to establish appropriate, locally relevant, feasible and effective palliative care for all irrespective of diagnosis, place of care or geographic region. Another study conducted by Eduardo and Catherine (2002:1), described that the delivery of palliative care varies greatly between developed and developing countries.

The challenge for palliative care workers in the developing world is to develop a culturally and socioeconomically appropriate and acceptable system for long-term care (LTC) and palliative care that is accessible to most of those who need it (Kumar 2007:624).

2.4.2.1 Descriptions of the Community-Based Palliative Care Model

A Regional Community-Based Palliative Care Model (Kerala, India**)**

Description of the model

Kerala’s community-based palliative care model has been recognized in global palliative care and public health discourse as a viable model because it incorporates palliative care in the primary healthcare system. Moreover, it involves community members (*Global Atlas of Palliative Care at the End of Life* 2014:58) with extending low-cost, and resource effective care (Rajith , Pallavi , Sunitha and, Chitra 2019:271). The model was initiated by a civil society organization in Calicut in the early 1990s.

Neighborhood Network in Palliative Care was established by a small group of lay people meeting to discuss what could be done for patients with Chronic diseases in their neighborhood (Bond,Lavy & Wooldridge 2008:16). They were joined by some doctors and social workers who were interested in palliative care (Kumar 2013:216-222). This has grown into a large network of trained volunteers as Neighborhood Network in Palliative Care.

The Neighborhood Network in Palliative Care (NNPC) is a community-based project, aimed at empowering local communities to look after their own chronically ill and dying patients. In the program, community volunteers play an active role in planning, evaluating, monitoring, and modifying the program (Centeno & Rhee 2018:28). Moreover, Neighborhood Network in Palliative Care is an attempt to develop a sustainable community-owned service capable of offering comprehensive long term care and palliative care to most of patients who are in need of palliative care (Kumar, 2007:222).

In Neighborhood Network in Palliative Care program, volunteers from the local community were trained to identify problems of the chronically ill patients in their area and to intervene effectively. There was active support from a network of trained professionals to community volunteer. Following that, the volunteers were encouraged to form groups of 10 to 15 community volunteers to identify the problems of the chronically ill people in their area after training and organizing appropriate interventions.

These groups are supported by trained doctors and nurses to work closely with the existing Palliative care facilities in their area and act as the link between the patient in the community and the health care providers in the institution.

A study done by Centeno and Rhee (2018:28). shows that more than 90% of the resources for the Neighborhood Network in Palliative Care projects are being raised locally through small donations of less than 15 cents for expansion into nontraditional areas in palliative care. Moreover, it works collaboratively with local government, receiving value and support.

Roles of volunteers in the network

The volunteers perform regular home visit to follow up on the patient seen by the palliative care team, identify and address a variety of non-medical issues, including financial problems, recognizing patients in need of care, organizing programs to create awareness in the community and raising funds for PC activities. Community volunteers act as the link between the patient in the community and the health care providers in the institution (Kumar 2007:623-627).

The Neighborhood Network in Palliative Care does not aim to replace health care professionals with volunteers. Instead, what is being attempted is to supplement the efforts of trained doctors and nurses in psychosocial and spiritual support by trained volunteers in the community. Groups of trained volunteers are teamed with palliative care professionals and health care facilities in their communities (Kumar 2007:623-627)

Furthermore, the unit has an outpatient clinic and home care services. It is inspired by the concept of primary health care., The network has replaced the earlier hierarchical doctor-led structure in Palliative care in Northern Kerala with a network of community, volunteer-led, autonomous initiatives (Suresh 2007:623-627). Kumar (2013:216-222) describes the main components of Kerala’s program as: (1) Community mobilization and ownership by the local community (2) Involvement of the local self-government institutions (3) Incorporation of palliative care in the primary healthcare system .

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Most of the patients choosing to stay in the program, agree that home-based care is valued, but clinical and psychological support skills are required to assist the families and their caregivers when caring for patients.

The aforementioned studies, described that the involvement of community participation in palliative care development enhances the sustainability of the program It also encourages the community to solve their own problems, and has a broad coverage to address the palliative care needs in resource poor settings.

Advantages of Community-Based Palliative Care Model

The above model has large coverage of palliative care services in a resource poor settings and relies on locally generated community funds, which has the great advantage on the sustainability of this model in the community.

A study by Content and Rhee (2018:28) reported that the development of palliative care in Asia has been more difficult in rural areas. Programs, such as The Neighborhood Network in Palliative Care, provide information on innovative models that can be utilized in settings with constrained resources (financial and human resources), to assist professionals in delivering high quality palliative care to patients.

Furthermore, according to Global Atlas of palliative care (WHO 2014:48), Kerala model is a highly sustainable model due to direct ownership by the community. In addition, the local and state governments, which value NNPC’s services to the communities, provided $3.6 million as parallel support. In the model, services are given by a team such as trained community volunteers, trained doctors and nurses. Besides, this model model addresses the palliative care domains such as physical, emotional, social and spiritual care for the patients and also responds to the primary or basic palliative care in the community.

A study that has done by Kumar (2013:216) showed that Kerala model has achieved remarkable success. Approximately, 90% of all palliative care services in India are now reportedly provided in Kerala, although this region represents just 3% of the country’s population.

Furthermore, the Kerala model has a link with other facilities such as outpatient and inpatient departments (Kumar 2013:216). Moreover, it works with local government and engages the local government to identify and prioritize the local health needs; it was inspired by the concept of primary health care.

A study shows that palliative care provided in community settings (as compared to in-patient settings) results in significant clinical benefits such as improved symptom management, increased survival and better caregivers outcomes (Bainbridge, Seow & Sussman 2016:8) .

According to Liz ,Julia and Mhoira (2012:19) , the Community-based models strengthen the evidence that holistic care can be delivered outside a clinic and create new pathways from the community into formal health services. They make use of a range of community resources to do this (Liz ,Julia & Mhoira 2012:19).

Disadvantages of Community-based models

With its scope of coverage, the model is not popular in other parts of the country. It serves only for 3% of the total populations of India. The community -based model reviewed in this study has few disadvantages about which the literature is unclear about the frequency of health professionals visits to the community.

Implications of this model

From the above literature review, we can easily understand that the community-based model was started by few committed community members to support patients and families of lifetime illness in their surrounding after discussing how to give care and help in their neighborhoods. They were also trained and interested professionals who helped the community and volunteers; then, grown to a large network who identify and care for patients in the community. Thus, this model implies how palliative care services start depending on local needs and resources. They empower the community to deliver palliative care services. Consequently the service was part of community health care, which applies the principles of primary health care approach which is supported by WHO palliative care integration (Kumar 2013:216).

Relevance of community-based palliative care model for Ethiopian setting

A study done by Wube,Home and Stuer (2010:1) in Addis Ababa, shows that home and community - based care integrate palliative care through a continuum of care in 14 major cities with links to local health facilities, community support systems through traditional burial societies (Idirs), which makes it possible for the program to provide holistic care to people living with HIV/PLWHIV) and their family members.

Furthermore, a study done by Ayers (2015:55) describes that in Ethiopia, some local stakeholders involved in planning palliative care have already visited Kerala to look at the work being carried out and they felt that a community-led initiative model might be potentially suitable way forward for Ethiopia. Therefore, this model might be appropriate in Ethiopian setting because the majority of the Ethiopian population lives in rural areas and there are also geographical variations.

Over and above this, the ratio of physicians to population is 0.02/1000 (Rhee et al 2017:30)**.** In order to function well in Ethiopian setting, this model should have appropriate referral systems linkage to supporting organizations, it should have well-trained professional teams as well as dedicated community volunteers, who regularly visit the community to address the palliative care needs of the patients and their families. Currently the country is implementing a primary health approach policy, Ethiopia has opened a Family medicine program, so that the graduates have a community visiting program especially in Addis and Hospice Ethiopia. In addition, there are health extension workers who are trained and provide services in the community. This has brought a significant reduction in maternal and infant mortality in Ethiopia. Such experiences could help to develop community based palliative care. However, the workload of the health extension workers should be taken into consideration, when the government engages them. Informal local groups such as Iddir, Ekub, Mahiber, are formed by neighbors, religious groups, working organization and gender based units. They help each other during different events like weddings, funerals, bereavements, holidays etc. The main role of these informal groups is to pool financial resources through member contributions for use during different occasions. These informal groups might help the development of community-based palliative care.

2.4.2.2 Integrated community-based home care in South Africa

This model was initially started by South Coast Hospice in response to the AIDS epidemic and funded by national department of health. Currently, the model has rolled out to seven hospices and is mentored by the South Africa Hospice Palliative Care Association to achieve the standards. This model provides palliative care in patients' homes through the use of trained community care workers, supervised by a professional nurse, backed by strong network of community organizations including the local clinic and district hospital. Thus, patients and family are at the center of the model and care providers focus on the patients' identified needs (WHO 2016:17).

The following palliative care activities have been given by this model: empowering family members and neighbors to cope in caring for patients at home, identifying and training community caregivers and linking them with primary health clinics and hospitals promoting referral through reducing burden of care from heath system.

According WHO's (2016:17) report, integrated community-based home care is applicable to all diagnosis and is cost effective for the following reason: care is provided in patients' home and supported by families and neighbors.

It also involves primary care providers who are trained by palliative care and non-professional community caregivers. There are also professional nurses who are trained as primary care givers. They support, supervise and visit patients' home and give care.

Furthermore, palliative care that is given to a patient is assessed by audit on the basis of patient – reported outcome with good referral system to and from health and welfare services, referral to palliative care interdisciplinary team or inpatient hospice facilities.

This report argued that the model has two important strengths, namely:

1. Trained community members who give home care and are supervised by the hospice

2. Ability to reach more people and encourage collaboration between primary care providers, hospitals, clinic and hospices.

a) The following can be considered as elements of a cost effective palliative care modelCare given at patients' home and the care given is patient and family centered.
b) There are trained primary care givers from the community and support from health professionals for giving quality of care, which was assessed by audit and good referral systems.

2.4.2.3 Hospital based palliative care teams

Hospital-based palliative care teams*:* In this example of a hospital-based palliative care model generalist, intermediate or specialist levels of care are delivered. This may include both inpatient and outpatient services and expanding the hospital models to be those at the district and specialist levels and within the community model (Julia, Liz, Mhoira & Elizabeth 2015:364). This indicates that the palliative care started in the hospital set up and then, its services were expanded to the local Nairobi community but, the above community based models were started in the community by community volunteers.

According to a study conducted by Elizabeth (2011:31), hospital palliative care in Africa is relatively a new and developing area of palliative care that addresses the needs of hospital-based patients and bridges the gap in service provision for patients who get palliative care in the community but are unable to access it when in hospital. Many patients with life-limiting illnesses are seen in hospital for significant periods of time before they are referred on to community-based services. Therefore, Hospitals provide a unique opportunity for the introduction of palliative care early in the disease trajectory. Hospital palliative care services also ensure continuity of care by referring patients to palliative care services in the community upon discharge.

Description of the model

Hospital based palliative care team

The palliative care unit at Kenyatta National hospital is funded and supported by the Kenyan government. It offers specialist palliative care, delivered by one part-time doctor and three nursing staff and it has approximately 20 cases per month.

The Palliative Care Unit is based within the Kenyatta National Hospital, Kenya's national tertiary referral hospital in Nairobi, and receives patients from across Kenya. The hospital also gives services to the local Nairobi community (Grant, Downing, Leng & Namukwaya 2012:5:9). The hospital-based palliative care in Kenya illustrates the value of specialist services within the hospital context. This is a model of palliative care delivery that is growing in the region and it provides palliative care services for all patients with-in the hospital. Services provided by this palliative care unit include: counseling and support, adherence support, pain relief and symptom control. It does not provide wound management and bereavement support is limited. The unit is not a stand-alone unit with all the infrastructure of an independent unit, such as beds and other equipment, rather patients are integrated in other units/wards where they receive specialized palliative care (Grant, Downing, Leng & Namukwaya 2012:5:19). This hospital-based model of palliative care further incorporates principles such as shared responsibility, provision of expert advice, structured referral processes, training and capacity building. On the other hand, policies and cultures in the hospital were the model is based, does not allow some flexibility in terms of integration of palliative care in all hospital wards where the services are required, the palliative care model does not function effectively (Grant, Downing, Leng & Namukwaya 2012:5:19).

Advantages of this model

The main advantages are the provision of palliative care services for all patients within the hospital and refers to Nairobi Hospice and offers specialty palliative care model services including counseling, support, adherence support, pain relief and symptom controland wound management. It is a doctor lead palliative care program.

A study conducted in the Portuguese health system describes advantages of hospital based palliative care model (Braga Da Cruz & Nunes 2016:74). It takes care of the patient and family simultaneously, encompassing a physical, emotional and spiritual approach and there is also availability of equipment and specialized medical teams, offering 24 hours of professional assistance and it promotes greater safety to the patient and family.

Disadvantage of this model

Bereavement support is limited. The unit has no beds; therefore, its patients are attended to in other wards. Furthermore, different studies highlight the disadvantages of hospital based palliative care as follows:If it stands alone, without the other palliative care services, It is unable to provide complete care for the dying person the families unless a home based services is offered (Qasem 2010:121). A similar study done in the Portuguese health system revealed that there is less privacy for patients and their families. The family does not actively participate in the support, as much as they would like and access to the patient by the family may be difficult (Braga Da Cruz & Nunes 2016:74).

Implication of Hospital based palliative care model

The implication of this model is that, it gives specialist palliative care services to all patients and has link to the community. Further, Hospital -based palliative care model helps to manage symptoms and pain and also patients have a chance to be seen by palliative care specialist, however, hospital-based palliative care should have a set up alongside of existing medical services: which allows patients to be transferred easily as their condition deteriorates.

Relevance of hospital based palliative care model in Ethiopia setting

Even though the hospital model is very important, in the Ethiopian setting, there are few hospitals and very limited palliative care specialists, most of whom are living in the capital city of Ethiopia, while most of the patients are from rural areas. Consequently, in order to be effective, this model should be used in conjunction with community-based palliative care model.

2.4.2.4 Description of Home-based models of palliative care

Gomes, Calanzani, Curiale, Mccrone and Higginson (2013:2) define home-based palliative care as models of palliative care delivered within the patiens or their carer’s own home. This type of care is growing nowadays but, it requires more intensive development. Therefore, it needs more focus on coordination from service agencies and clinical care providers (Dahlin 2015:3).

Description of the model

The College of Medicine, Home -Based Care Project operates in the Bangwe and Limbe regions of Blantyre, Malawi, both areas with a high HIV/AIDS prevalence. Many patients have AIDS-related symptoms, cancer, or severe pain due to cryptococcal meningitis and neuropathies. The programme was established as a stand-alone service in response to need in the community and now, works out of two government health centres (Grant ,Downing, Leng & Namukwaya 2012:5:14).

The services include voluntary counseling and testing, anti-retroviral therapy (ART) adherence support, free basic medications, catheter and wound care. The programme also assists with nutritional and income generation support through links with other local organizations. Patients are seen in their own homes. Pain relief and symptom control, counselling and support are also provided (Grant, Downing, Leng & Namukwaya 2012:5:14).

Patients are seen at home or in a weekly palliative care clinic. Services include counseling and support for patients and their families, pain relief and symptom control, nutritional and bereavement support as well asherbal remedies. In Africa, home-based care is a well-established model of care provision within the context of HIV/AIDS (Grant ,Downing ,Leng & Namukwaya 2012:5:6).

Home-based care (HBC) has been the most common service model in Africa, because it is cheap and, most of the time, acceptable to the patient and family, since it respects cultural practices (Jagwe & Barnard 2002; Merriman.A 2002). With this goal in mind, patients should be provided the opportunity to die in their homes if that is their wish. The palliative care team should provide the best care in the home for as long as possible. Most patients with incurable advanced illnesses do not have the choice of receiving Palliative Home Care Services and therefore die in institutions.

A home-based model further reduces the direct and indirect costs of visits and admissions to hospitals for patients, quite substantially. In a study done by Harding and Higginson (2005:1971), it is shown that in an African setting where resources are limited, home and community based palliative cares are largely successfully with respect to community capacity, resources involvement and clinical supervision.

Furthermore, a study done in a rural setting in Uganda shows that home-based treatment and care for multi-drug resistance tuberculosis was acceptable to patients, families, communities and health care workers and was seen as preferable to hospital-based care by most respondents. Home-based care was perceived as safe, conducive to recovery, facilitating psychosocial support and allows more free time and earning potential for patients and caretakers (Horter et al 2014:1).

Being at home during the terminal phases of a disease provides the benefits to the patients of autonomy, privacy, freedom and a feeling of being safe within a caring circle of family and friends. Because the family can potentially anticipate the loss, they have better chance for successful bereavement.

A study by Harding and Higginson 2004 revealed that, home-based care is by far the most common model, which is flexible and offers cultural appropriate palliative care provision in sub-Saharan Africa countries, with limited resources. While this is the most common model of care in Africa, families and volunteers need to be trained on basic symptom control and health workers in place to provide necessary care (Harding & Higginson, 2004).

The home based model of care, which was started during the era of HIV/AIDS epidemic is relevant to the Ethiopia context. At that time, home based care was given for patients with HIV/AIDS by trained volunteers from community. Most of the home-based care was funded by non-governmental and faith-based organizations. Currently, this approach has not been well practiced because availability of ART drugs changes the quality of HIV/AIDS patients.

Advantages of home-based care model

According to Braga and Nunes (2016:74), the effectiveness and cost effectiveness of home-based palliative care is that chronic diseases produced many symptoms that cause significant distress for patients and this is particularly evident in diseases where treatment is not possible and the main focus is on the control of symptoms. The symptoms experienced by these patients are not presented in isolation, rather , in cluster and may encompasses, fatigue, muscle and joint pain, chest pain, difficulty sleeping, sexual dysfunction, irritability, anxiety, difficulty concentrating, decreased appetite, nausea, vomiting, constipation and are highly correlated with depression and may compromise therapy. Therefore, the study highlighted that these symptoms have expressively and statistically significant decreases when patients receive palliative care at home instead of at the hospital.

A study done in the Portuguese health system describes advantages of home based palliative care model (Braga da Cruz & Nunes 2016:74) as patients feel more comfortable, safe and loved. It is easier for the family to spend time with the patient allowing the family to be more involved in the process of patient care. Additionally, the home based model of care has great flexibility in the daily 24 hour routine.

Disadvantage of home-based care model

In some cases, home palliative care may result in increased anxiety and the possibility of a family crisis. Although, by staying at home, the patient may partially return the equilibrium to the family, this equilibrium may be disturbed by the disease progression and by the changes in the patient's mood and behavior. The family members, who witness the patient's progressive deterioration, suffer and may experience various emotions (fear, frustration, guilt, anger) which can cause mental health disorders.

In addition, the disease may have a negative impact on the family's economic and financial condition due to expenses associated with the medical treatment, the fees for the healthcare personnel and the reduced income associated with work absenteeism.

A study done in the Portuguese health system describes disadvantages of home-based palliative care model as (Braga da Cruz & Nunes 2016:74), care may be inadequate or insufficient, especially in emergency situations. The family may feel uncomfortable to have a person dying at home and it also requires a permanent care giver for 24 hours daily.

On the other hand, another study indicates that care at home is difficult or impossible if patient does not wish so, lives alone or far away, cannot afford the care expenses, needs higher skilled care and if the family is physically or emotionally tired and cannot deal with uncontrolled symptoms or if the home does not meet the minimal comfort needs (Cantwell , Turco , Brenneis et. al).

Implication of home-based care model

As mentioned in the reviews, chronic diseases have many symptoms that cause significant distress for the patients and their families. These symptoms have very expressively and statistically significant decreases when patients receive palliative care at home. However, in order to establish home based model of palliative care, there must be availability of a multi-disciplinary team, institutional support, availability of resources, time to provide care and adequacy of staff training. The use of community volunteers, empowering families and careers, which determine the effectiveness of home based model of care is also required.

In addition to the above description, the presence of home-based care model alone does not give guaranty to manage complex symptoms. Therefore, home based model of care should have structural referral process, the home based palliative care team should be able to assess the patient's condition and in cases were patients have complex problems, they should be able to access facilitates or referrals to other models of palliative care delivery such as the hospital based model.

From the reviewed literature, the implications of home-based model palliative care has provided at grass root level and involves both patients and the families but needs mult-disciplinary coordination, regular support and monitoring.

Implications of the home-based model for Ethiopian setting

Home based model care was started during the era of HIV/AIDS epidemic relevant to Ethiopia context. At that time, home-based care was given for patients with HIV/AIDS by trained volunteers from community. Most of the home-based care was funded by Non-Governmental and faith-based organizations. Currently, this approach is not well practiced since the availability of ARV drugs changes the quality of lifeof HIV/AIDS patients. Most family structures are extended families (grandparents, children, grandchildren, uncles and aunts) who tend to live together or nearby and the burden of care is the responsibility of the entire family and strong community structures like idir. Furthermore, it encourages the community to find solutions together when providing palliative care (Thayyil & Cherumanalil 2012:213-218).

2.4.2.5 Hospice Africa Uganda palliative care delivery model

Description of the Model

Hospice Africa Uganda (HAU) was started in 1993 and has become an internationally renowed model for palliative care provision in Africa, which is rendering palliative care services mainly for patients with cancer, HIV/AIDS and their families. Hospice Africa Uganda is funded by a non-governmental organization mostly through grants and donations, (Hospice Africa Uganda 2016a).

Hospice Africa Uganda (HAU) has been giving the services through home-based care within defined operational area even though, it does not have in-patient facilities. It was established to provide appropriate palliative care services to patients with cancer and/or HIV/AIDS and their families (Too 2011:20-21). HAU has three branches, Makindye, Little Hoima Hospice and Mobile Hospice Mbarara to deliver palliative care services. The core of its work is its outpatient services and home visits. In addition, it provides outreach to communities, provides consultations at Mulago National Hospital and conducts monthly visits to partner hospitals. It also provides innovative models such as mobile clinics (Centeno & Rhee 2018:22).

Too (2011:20-21), further describes the palliative care delivery at Hospice Africa Uganda as out-patients service and clinics based at health facilities like hospitals, home visits to follow up of patients who are unable to access palliative care services due to their deteriorating condition. Outreach is achieved using mobile units, day care services and community volunteer workers (partnerships with volunteers).

The team is made up of a core team of nurses overseen by a Nurse Supervisor and a Clinical Director, who is a doctor. The team also consists of social workers and lay counselors. They also have a team of Community Health Volunteers, who identify and provide linkage to care to eligible patients for community outreaches.

Advantages of Hospice Africa Uganda palliative care delivery model

From the above literatures reviewed, the following are some of advantages of Hospice Africa Uganda: It provides different services such as out-patients service, home visits service to follow up of patients, outreach service using mobile units, day care services and community volunteer workers. Also, there is team work which includes nurses, clinical directors, social workers and community volunteers.

It has played a key role in advocating for a national palliative care policy as well as for nurses to be able to prescribe basic medications for palliative care in Uganda. It provides education to healthcare providers across Africa through its Institute of Hospice and Palliative care and also offers short courses, diplomas, and a Bachelor’s degree in palliative medicine, and it is planning to start offering a Masters level qualification.

Disadvantage of Hospice Africa Uganda palliative care delivery model

In the above review of Hospice Africa Uganda palliative care delivery model, the disadvantage of the model was not-well articulated.

Implication of Hospice Africa Uganda palliative care delivery model

In Hospice Africa Ugandan palliative care delivery model, there is a team work of different professionals and has also aligned its service delivery to hospital and home-based care. It gives training for health professionals, community volunteers and families Furthermore; it offers palliative care training for other African countries.

Implications of Hospice Africa Uganda palliative care delivery model for Ethiopia setting

Hospice Ethiopia was established following some training by Hopsice Africa Uganda. Ethiopia has a population of about 100 million, yet there is only one hospice in the country, which is based in the capital, Addis Ababa. It gives care to people with serious illness and their families, and also trains healthcare workers in palliative care. The pioneers of Hospice Ethiopia were trained in palliative care in Hospice Africa Uganda palliative center.

2.4.2.5 Primary health care focused palliative care model

In a public health approach, a population-based perspective responding equitably to the need for palliative care rather than according to diagnostic findings is used. Implementing the palliative approach can be done in all settings by promoting integrated systems of care and combining this general approach with referral to specialized palliative care services to manage the complex cases. This approach will promote and achieve coverage for all types of patients and their families in all settings of care, meeting all dimensions of need with principles of universal access, equity, quality, and efficiency (Gómez-Batiste,Murray,Thomas, Blay, Boyd, Moine, & Engels:123).

Advocacy, summary on models of developing palliative care in sub-Saharan Africa reports indicate that palliative care in Africa is being developed as a public health oriented, primary health care focused model. This model has been established to work with communities and utilizes community capital through well-trained and incentivized volunteers and by empowering families to care for sick relatives.(Grant, Downing, Leng & Namukwaya 2012:1). Community palliative care models where palliative care is integrated into a home-based care program demonstrate how, through a holistic patient and family centered approach, medical problems and related social issues are identified and addressed (Grant, Downing , Leng & Namukwaya 2012:1-2).

Research finding indicates that palliative care is relatively a new discipline in the African continent and its development is hampered by the fact that it is not integrated into health systems (Mwangi-Powell & Dix 2011:19).

2.5 Barriers to palliative care delivery in resource scare settings

Palliative care provision is the most important challenge faced in resource limited Africa (Lentsoane, Meyer, Schellack & Cameron 2014:420). Besides, this study shows challenges are a multiple in nature and interrelated each other .

WHO advocates public health strategies to integrate palliative care into existing health care system. This can be done through implementation of the major pillars, which are governmental commitment, palliative care education and training, availability of resources and essential drugs and conducting research related to palliative care. (Stjernsward, Foley & Ferris 2007: 514)

Therefore, most of the factors that affect palliative care service delivery should be assessed in terms of WHO recommendations in order to provide palliative care for people who are in need of it. These factors would influence the palliative care service provision at different settings which include governmental and policy related factors, availability of resources and essential drugs, palliative care education and training and availability of palliative care funds.

2.5.1 Government and policy related factors

As with any health initiative, the most important factor is government commitment. This includes commitment to palliative care in general, drug availability and education. Specific support for palliative care should ideally be in the context of general commitment to improving general health-care structures and access to health care for the country’s population (Webster etal 2007:32). Therefore, governmental commitment is the corner stone for palliative care service implementation and model development. Moreover, good policies lay the groundwork for an effective health care system and society. They facilitate the implementation of palliative care programs aimed at providing care for all people in need of these services and they ensure equitable access to affordable medications and therapies. The lack of good policies can lead to unnecessary suffering and costs for patients, families and society (Stjernsward, Foley & Ferris 2007: 514).

Worldwide palliative care alliances also recommend that all governments should integrate palliative care into their country's health system alongside curative care (Gunyther & Krakauer 2013:4). Besides, the WHA resolution 67/19, adopted in May 2014, called for member states to develop appropriate policy that strengthens and supports the comprehensive strengthening of the health system (Kamonyo 2018:3).

A study shows that government commitment and policies are the key for palliative care integration and provision in all levels of health care systems. Without supporting polices, it is difficult for any palliative care development to occur, but in some countries there is no governmental support and existing appropriate policies that support the provision of palliative care (*Global Atlas of Palliative Care at the End of Life* 2014:27). Currently, only 20 out of 234 countries globally have achieved high-level integration of palliative care into mainstream health service provision and only one of these countries is low middle income countries (Breffni 2015:2).

A qualitative study done in Iran shows a lack of existence of palliative care guidelines and protocols in the primary care and education, which are an important part of policy for palliative care implementation (Khoshnazar et al 2016:3). In Africa, palliative care policy development is a great challenge to integrate palliative care service delivery and most of countries have not yet included it in their national polices or regulations (Ddungu 2011:731). Only two out of 53 countries in Africa have standalone national policies, strategies and implementation plans, while four countries have integrated palliative care in to public health services (Ntizimira et al 2014:2).

There is lack of governmental policies that recognize palliative care as an essential health component (Ddungu 2011:728), this hinders palliative care investment and limits access resulting in the absence of critical mass for palliative care at policy level (Luyirika, Namisango, Garanganga, Monjane & Ginindza 2016:4). Most African governments have no awareness on the importance and integration of palliative care to health care systems and give the priority to curative services. There is also lack of palliative care decentralization from the central hospitals to the community or patients homes with the key services being given at hospital level (Ntizimira et al 2018:1).

Similarly, a study done in Nigeria revealed that there are challenges on governmental policies implementation and in the integration of palliative care with in health care systems (Galvan et al 2016:1). A study done by Murray (2007:4) described different factors that affect palliative care delivery that related to the policies of the health care system and how they integrated palliative care into the continuum of primary health and long-term care commitments hinders the integration and delivery of palliative care provisions.

In Ethiopia, palliative care is part of the specialty team under the clinical services directorate at Federal Ministry of Health and national palliative care guidelines were completed and printed in June 2016. However, there is no national palliative care association but there is a periodic national palliative care conference for palliative care in Ethiopia.

It is argued that most of middle- and low-income country do not integrate palliative care into the existing health care system, as a result palliative care was not existent in most countries or there is very little coverage due to government's failure to give priority to the need of palliative care. Therefore, governments have been encouraged to include palliative care in to the national health plan and policies in order to integrate palliative care in to the health care system at all levels, which is the key to understand how palliative care works in the health system. The World Health Organization, Chronic Care Framework (WHO 2002:5) explains that positive policy environments and links between the community and health care organizations are critical factors to support chronic care delivery models.

2.5.2 Funding related Barriers

The WHA resolution 67/19, which was adopted in May 2014, called for member states to allocate appropriate and ensure adequate domestic funding and allocation of human resources for palliative care improvement initiatives.

One of the factors that affect palliative care model delivery is lack of adequate financial support. Most palliative care is provided by non-governmental, faith, or community-based organizations with no inbuilt sustainability (Faith & Olivia 2011:19), and still remains too heavily dependent on external funding rather than integrated health sector expenditure (Anderson & Grant 2017:3).

The majority of hospice services are not an extension of existing medical services, since they were started through NGOs and charities that predominantly started a home care service or set up an in-patient hospice facility (Wright et.al 2006:8). In Uganda, most palliative care centers rely on external donors for funding and this makes palliative care planning difficult (Nabudere et.al 2014:6). Similarly, in Ethiopia, Hospice Ethiopia has been relying on external donors for funding and there was lack of governmental finance available for palliative care (Ayers 2015:58).

Studies show that in Ethiopia, funding levels are far from compatible to cater for the needs and support of people living with HIV/AIDs and orphaned and vulnerable children (Woldie, Sudhakar & Feyissa 2015:1). Besides, study done by Li , Davis and Gamier (2011:294) showed that Palliative care is not yet supported by a national policy or governmental funding , which account for more the world's population.

2.5.3 Drugs related barriers

For effective implementation of palliative care and bringing quality of life for patients with life threatening illnesses, essential drugs especially opioids like morphine are very important.

Globally, more than 7.6 million people die from cancer annually and most people with advanced cancer suffer from severe and totally disabling pain. In many countries, people in severe pain have little or no access to opioid medications. This is because many countries have no predictable access to opioid medications and many more countries have restrictions that render the use of opioids for chronic and worsening cancer pain almost impossible to access (Kamonyo 2018:3).

The WHO further emphasizes the importance of pain relief in its palliative care strategy and identifies the availability of opioids as one of the 'pillars' to support the planning of care (Stjernswa et.al 2007:4). However, in most African health systems there is a misunderstanding on the use of opioids, such as fear of addiction, opiophobia or a fear of opioids that results in unnecessary pain at the end of life (Ntizimira etal 2014:2).

The African Palliative Care Association also reported the following barriers related to pain medication specially opioids: unavailability of medications, restriction on legislation on prescribing of opioids to doctors, low doctors –patient ratio. (African Palliative Care Association 2011:6.) Morphine was prescribed by nurses only in eight African countries, in line with this report, in Ethiopia, even trained nurses cannot prescribe morphine and it can only prescribed by a nonspecialized physician. The conception of morphine per capital (mg/capite/year) was 0.03 in 2008,which was much lower than global morphine conception (Rhee et.al 2917:44). This could create a huge burden of suffering with limited access to pain medication and other palliative care intervention in Ethiopia. (kassa etal 2014:1). Similarly, study done in Botswana shows that there is shortage of morphine, which is only physicians prescribe it.(Lavigne et al., 2019:6)

Moreover, 91% of the study participants from five hospices in South Africa reported that there was problem in accessing pain medication and availability. Only one of the five hospices kept pain medication in stock and had no policy for administering pain medication.

Research finding revealed that most of children in sub-Saharan Africa are dying from unnecessary pain and agony because of challenges related to opioids, which includes lack of access to medication such as oral morphine, restrictive laws, lack of trained health professions, opiodsphobia and lack of funds to purchase opioids (Downing, Boucher, Daniels & Nkosi 2018:1).

A study done by Emmanuel and Kamonyo (2018:57) shows that 50% of those who died from HIV and 80% of those who died from cancer experienced moderate or severe pain. About 92,000 of those deaths required treatment with opioid analgesics, in accordance to WHO pain treatment guidelines.

In Ethiopia, a study done by Kassa et.al (2014:9) revealed that nearly 60.7% of the respondent nurses treated patients with chronic pain by using paracetamol or ibuprofen and this might be related to unavailability of opioids or lack of awareness on managing chronic pain.

2.5.4 Education related barriers

Well trained and competent health professionals are very essential to the implemention and development of the palliative care model in order to give quality of services for patients with life threatening illness (Downing, Hons, et.al 2015:369). Therefore, both in-service and pre-service palliative care training should be given to health professionals in primary, secondary and tertiary levels for the effectiveness palliative care service provision.

The WHO (2016:53) indicates that most of health professionals receive limited or no training in palliative care in their pre-service studies. The WHO advises that palliative care be integrated into the curriculum of both under and post graduate studies, however, a study shows that most of African countries do not include palliative care content in their curricula. There is lack of both in-service and pre-service palliative care training which obscures the quality of palliative care service provision.

Research conducted by Nabudere et.al (2014:8) reveals that many health professionals considered palliative care as end stage support for dying which diverts precious time and resources away from curable conditions in most of developing countries. According to a study done in Portugal, educational institutions gave more attention for curative treatment and lacked in the training of health professionals in palliative care treatment resulting in difficulties in implementing palliative care (Braga Da Cruz & Nunes 2016:74).

A study revealed that in Ethiopia, there was limited knowledge and understanding of the Ethiopian government in the involvement of palliative care education needs for health professionals, traditional healers and the public (Ayers 2015:75). Both medical schools and nursing schools in the country did not include palliative care education as optional or mandatory courses in their respective curriculums (Rhee et al.2017:44.), There was also no certification in palliative care for physicians.

2.5.5 Research related Barriers

The WHO considered palliative care research as one pillar for the development of palliative care and advises governments to assign funds to conduct palliative care research and also encourage the staff to carry out palliative care research.

The African Palliative Care Association also reported that there is lack of formal evidence from resources research and also for monitoring and evaluation of palliative care (African Palliative Care Association 20110:3). Moreover, a study done by Gysels, Pell Straus and Pool (2011:8) shows that there is minimal research in Africa on palliative care model development and this insufficient local research hinders the health decision makers from understanding the complex burden of palliative care and suitable models of palliative care for best delivery.

Studies show that challenges that affect the development of palliative research in Africa include lack of critical palliative care research among healthcare professionals, absence of dedicated financial support and absence of strategic plans.

Furthermore, in Africa, there is also lack of methodologically robust evidence- based information on the effectiveness of palliative care and access to culturally appropriate, holistic palliative care is best limited and at worst non-existent (Dix 2011:17). According to (Grant,et al. 2015:2), in Africa, understanding palliative care model delivery is curial but research related to palliative care is minimal.

Funding for palliative care research should be protected by ring fencing resources (Nabudere,Obuku, & Lamorde 2015:27). Similarly, a study done by Ayers (2015:75) revealed that there was lack of clarity and understanding about how large palliative care burden is in Ethiopia due to lack of general research. There was also little knowledge on how models of care were implemented in Addis Ababa.

The above reviewed literature showed that barriers which affect palliative care provision include, a lack of policies and legislations, disease burden, unavailability of essential palliative care medication, inadequate palliative care funds, lack of integration of palliative care into the curriculum, a lack of empowerment of health professionals through in-service and pre-service palliative care and engaging palliative care research.

2.5.6 Diseases burden, inadequate facilities and referral process related factors

According to The World Health Organization (2006:6), disease burden combined with shortage of health professional per population are the key barriers to the delivery of palliative care in sub-Saharan Africa, which further affects the integration of palliative care in the region,. A study done in Uganda showed that long distances to health facilities with unavailability of drugs were a bottleneck to health care access in Uganda.

2.6 Enabling factors for the development of palliative care model

Existing enabling factors should be assessed and used correctly in order to develop palliative care models in resource scarce setting. A study by (Reference) indicated that in low resource settings, integration of palliative care in to existing local health care system is one of enabling factors and is advisable in such settings. Besides, when palliative care services are incorporated into existing health care system, it can be delivered with minimal financial cost while resulting in enormous physical, social and emotional benefit for patients. Therefore, coordinators and funders should focus on the work of palliative care integration into existing health care system.

Furthermore, cross-country comparisons studies done to assess barriers and facilitators to care for the terminally ill in Canada, England and United States of America showed that dedicated and stable funding and having standards of practice and guidelines were identified as enabling factors for provision of palliative care.

A systemic review on end of life care in sub-Saharan Africa indicated that providing training for health professionals at district may increase access of palliative care and patients can prefer the site of palliative care provision. The findings of the study showed that lack of support from professionals and extended families caused the patients to prefer institutional care rather than home based care. Similarly, another study showed that home based care programs were an excellent way of delivering holistic care if families, volunteers are taught how to give basic care and get support from health professionals.

2.7 Best practice of palliative care Model

The above reviewed of literature, highlighted that there were different models of palliative care delivery system such as community-based palliative care, hospital based palliative care model, home based palliative care model, hospice based palliative care model and public health integrated palliative care model. These models were critically reviewed starting from their descriptions, the way each model was developed, the palliative care teams and their roles in the provision of the palliative care delivery were elaborated.

Furthermore, each model was examined and the advantages and disadvantages were discussed and their implications to the Ethiopian context were deliberated. Each model was then critically assessed and compared with the others in order to develop and understand a cost-effective palliative care model that is adapted to the local culture and circumstances feasible in Ethiopia. Reviewed literature showed that even though different palliative care settings exist, patients should get palliative care services at each levels such as primary, secondary and tertiary levels with a network of palliative care champions and good referral system to provide holistic care.

Furthermore, the development of palliative care model can be started in the community and then extend to hospital level or they can be started in the hospital then the services extended to community level. When looking at the model of palliative care development we should consider patient’s needs, cultures and the existing local resources.. The reviewed literature indicated the public health approach urgently needs to integrate the palliative care in to the existing health care systems. , They argued from the literature reviewed that there is no solo model of palliative care that addresses the multiple needs of patients with life-threating illness (Abel, Kellehear & Karapliagou 2018:3). A public health approach that has close partnerships between clinical services and communities/civic institutions is the optimal practical model. Moreover, integrated community-based home care is applicable to all diagnoses and is cost effective one (WHO 2016:17).

Hence, palliative care can be delivered in many different ways but the primary thing to be done is to integrate the model to existing public health care systems in to all services and settings and with coordination of care using primary health care approach in order to be accessible by any one in need of the services. Moreover, this study indicates, in the Indian state of Kerala, the community-based model has become a model for the integration of palliative care into the public system of healthcare. This approach is consistent with the 2014 resolution of the World Health Assembly that palliative care be included in all national health policies and budgets and integrated across all health care levels, including in community- and home-based care settings (De Lima & Radbruch 2014:384).

This study also highlighted that a hospital based palliative care model can provide pain and severe symptoms management and also helps to introduce palliative care early and refers patient to palliative care services in the community up on discharge from hospital.

Another study revealed that the main focus of palliative care provision in Africa is through home based and community-based models. The authors argued that the model should encompass both community and hospital based care,.The growing development of palliative care in sub-Saharan Africa is designed and structured in different ways but all can be tied by a public health approach and had similar practices (Downing, Hons, et.al 2015:363).

The African Palliative Care Association standards also advocate that patients should get access to palliative care at primary level, intermediate level and tertiary level with appropriate health professionals. Furthermore, the researcher also observed that, there was no perfect palliative care model that can stand alone.

2.8 Characteristics of a cost-effective palliative care model

The reviewed literature highlighted that palliative care reduces both direct and indirect costs and also it is cost effective when it is given in conjunction with curative services. Moreover, the literature showed that the model of palliative care should be applied to all diagnosis and also should be cost effective. It is therefore very crucial to look at elements of cost effective palliative care in order to develop a palliative care model for the Ethiopian context.

A study done by The World Health Organization on implementing and planning of palliative care revealed that, integrated community based home care in South Africa is cost effective and can be applied to all diagnosis because of various reasons including it being patient centered, it involves the patients families and the care is given by trained and community volunteers who are supported and supervised by trained health professionals.

The model has a link with different partners and there is referral system to and from other facilities such as primary health care clinics and hospitals and the quality of care is assessed by audit on the bases of patient reported outcome.

Integration of palliative care into existing health care system by public health principle is the most suitable approach to develop palliative care in developing countries (Ddungu, 2011:729). Integration of palliative care to existing health care system is cost effective , as a result, The World Health Organization encourages the governments to integrate palliative care into existing health care system in order to give palliative care provision for life threating patients and their families.

Therefore, inclusion of palliative care within universal health coverage is the most important pillar in the development and integration of palliative care in poor resource settings.

A study showed that hospital outreach services have the potential to avert hospital admissions in general overcrowded services in low-resource settings and may improve the quality of life of patients in their home environment. Furthermore, integration of expertise in different health care facilities at primary, secondary and tertiary levels are the key elements for a cost-effective palliative care model.

The Ethiopian palliative care guidelines also reported that the critical point in palliative care services is to ensure the continuum of care and address patient needs as they passed through the referral pathways between community and facility based palliative care services. Moreover, another author argued that good referral and networking in palliative care service delivery, patient centered care and staff training and education are elements that revolve around the model development.

2.9 Conclusion

The literature review was done through reviewing prior research conducted in different parts of the world on palliative care model settings. It was focused on the international and national perspectives best practice models of palliative care and their relevance to Ethiopia to develop a model of palliative care. The implication of the models to the current study setting were elaborated. Finally, barriers and enabling factors to develop palliative care were thoroughly discussed in order to develop cost effective palliative care model in Ethiopia.

CHAPTER THREE

Research Design and Methods

3.1 Introduction

In this chapter, the application of the research design and method is discussed. The chapter includes study design, study population, sampling, sampling designs, data collection and process. The trustworthiness of the qualitative data and issues related to ethical principles throughout the study are explained in this chapter.

3.2 Research design

Research methodology is a scientific approach that shows how the research is systematically conducted in order to solve a research problem thoroughly (Bhushan& Alok 2011:1). It identifies research problems within a standardized set of procedures, techniques and methods relevant to the research problems and meeting the purpose of the research in the most valid and rigorous way (Creswell 2013: 12).

According to Pandey and Mishra (2015:18), research design is a framework or plan of a study that is used as a guide in collecting and analyzing the data in a manner that aims to generalize the findings of the sample to the population. It is similar to a blueprint which we need to plan the methods to be adopted for collecting the relevant data and techniques to be used in preparation of the research project (Pandey & Mishra 2015:18). Thus, a researcher should use an appropriate research design that is scientifically sound to address his/her research questions and objectives.

Research methods include all the techniques and methods, which are employed when conducting the research. These include research setting and duration, the population, sample size, sampling technique, method of data collection and method of data analysis (Gray,Grove & Sutherland 2016:106).

Therefore, the selection of a research design depends on factors such as the nature of the research problem, objective and research questions that will be addressed, researcher experiences on the topic, the target population for the study and the available resource to conduct the study.

In this study, a qualitative study design was employed using indepth interviews and focus group discussions as data collection methods to develop cost-effective palliative care model in Ethiopia. According to Spruyt (2016:367) the primary concerns of a qualitative research are exploring the way in which people view their world and identifying the way in which people interact with each other to construct their social worlds rather than manipulating or modifying those worlds. It also seeks to answer questions that explore processes or the meanings of events or other elements of the social world. Spruyt argues that qualitative research is eminently suited for palliative care medicine.

A qualitative approach also helps to build a vigorous understanding of a topic, unpacking the meanings people ascribe to activities, situation and circumstances (Nagy & Leavy 2017:124). Moreover, as it is shown in the reviewed literature, qualitative approaches have been applied in researching palliative care issues in Africa (Dowiing 2008:18).

In this study, the researcher used qualitative methods to gather and analyse the data. The rationale behind using a qualitative approach was to get an in-depth understanding of the information about palliative care delivery services in Ethiopia from key informants, stakeholders and focus group discussants. Additionally, it helps in elaborating the participants' experiences on the factors that affect palliative care provision. It was also an appropriate way to obtain information about enabling factors that could assist in the development of an acceptable and appropriate palliative care service model in Ethiopia.

The qualitative phase was therefore applied as the second phase of the research and used in-depth interviews with policymakers, programme managers, health workers, community representatives and organizations delivering any form of palliative care in Ethiopia. Focus group discussions with nurses who work in the chronic illness sections of four hospitals in Jimma zone were also conducted .The study is divided into three phases to enhance its rigor.

The first phase: This phase included scope reviewing of literature of existing palliative care delivery models from different international perspectives. This process allows the analysis of the context and understanding of palliative care dimensions and delivery models and the factors that influence these. Therefore, this phase guided the development of best practice and cost-effective palliative care model in resource scarce settings.

The second phase: This phase included study populations ,sampling techniques ,data collection, data analysis. In-depth interviews were conducted with key informants and focus group discussions with nurses working in chronic illness clinics to explore the palliative care dimensions and to obtain detailed and contextualized information about the current and projected challenges as well as the needs and gaps in the current palliative care provision in Ethiopia. Inputs were explored from policy makers, supportive stakeholders, managers, program officers, community leaders and healthcare facility coordinators. Additionally, all of the respondents were actively involved in palliative care in development through direct operation or through strategic/management capacity in Ethiopia.

The third phase: In the final phase, after analysis of data and based on the finding of the study and reviewed literature, a draft of palliative care model was developed. After which the final draft of the model was given to different key informants for review and comment.

The researcher incorporated all the comments and suggestions given from the stakeholders and re-sent the draft to the experts with validation scores that included the following evaluation criteria: clarity and consistence, relevance, practicability and usefulness, importance for research practice, comprehensiveness and adaptability in untouched areas in Ethiopia. Finally, the validation scores were analysed. Moreover, input from key role players of the Hospital such as Chief Academic Director of the

Hospital, Clinical Director, Hospice Ethiopia, Jimma University academic staffs, Local NGOs, Nursing Director, Community leaders, and healthcare facility coordinators were, further explored and their comments and suggestions were included in the final model of palliative care. Finally, the researcher presented the final p-care model for stakeholders who were from Jimma University Medical Center.

3.3 Research Strategy

Ethiopia is situated in the Horn of Africa and is surrounded by Eritrea, Kenya, Djibouti, Somalia, Sudan and South Sudan. It is the second largest African country following Nigeria (World Bank 2020:1). Based on 2020 Worldo Meter projection, Ethiopia has a total population of 114,963,588 living in an area of 1,000,000 square kilometers. Ethiopia is one of the fastest-growing economies in the world and is the second most populous country in Africa, with in a density of 115 per km^2 (Worldo Meter in 2020).

Ethiopia ranks 12th regarding countries (dependency) by population. Its economy is mainly based on farming which accounts for 46.3% of the gross domestic product (GDP); 78.7% of the population lives in rural settings (Worldo Meter 2020). In terms of the human development index, Ethiopia is listed as number 174 (out of 195 countries) and the health expenditure per capital is 72.96 USD. The physician ratio per 1000 people is 0.02 (Rhee et.al 2017:30).

Ethiopia is a multi-lingual and multi-ethnic country. It embraces a complex variety of nationalities and people from different linguistic groups, diverse customs and cultures (Ethiopia, Ministry of Foreign Affairs 2014:9-10).

Ethiopia has a federal government system, which comprises of nine regional statesnamely, Afar, Amhara, Benishangul-Gumuz, Gambela, Harar, Oromia, Somali, Southern Nations Nationalities and people (SNNP) and Tigray. There are two administrative hubs; namely, Addis Ababa and Dire Dawa Administration Councils. The regional states and city administrations are divided into 847 administrative woredas (districts). A woreda/district is the basic decentralized administrative unit under the authority of an administrative council (Ethiopia, Ministry of Foreign Affairs 2014:10).

Addis Ababa (the capital city of Ethiopia), the Oromia region and specifically the Jimma Zone, were selected purposefully for this study. Addis Ababa has several palliative care orientated institutions such as services by the Ministry of Health and different NGOs. Policy makers and experts of palliative care are concentrated in Addis Ababa as well as in several hospitals, which render palliative care services. It is only in Addis Ababa that a cancer (Oncology) center at Tikur Anbessa Hospital offers specialized services such as radiotherapy. Hospice Ethiopia and Strong Hearts Ethiopia, the two licensed non-profit palliative care provision organizations in Ethiopia are also based in Addis Ababa (Reid etal 2018:3).

Oromia is geographically very large in comparison with other regions and nearly one third of the Ethiopian population resides in this region. Four public hospitals in Jimma Zone; namely, Jimma University Medical Centre, Shenen Gibe Hospital, Limu Genet Hospital and Agaro Hospital were selected as the settings for the study. Jimma University Medical Center and Shenen Gibe Hospitals are situated in Jimma town and Limu Genet and Agaro Hospitals are found in Jimma District. All these hospitals serve patients with a variety of chronic illness and patients are followed up through services provided in decentralized clinics. Care-giving organizations and faith-based organizations that are located in Jimma Zone that support patients with life threatening illness, were also included in the study.

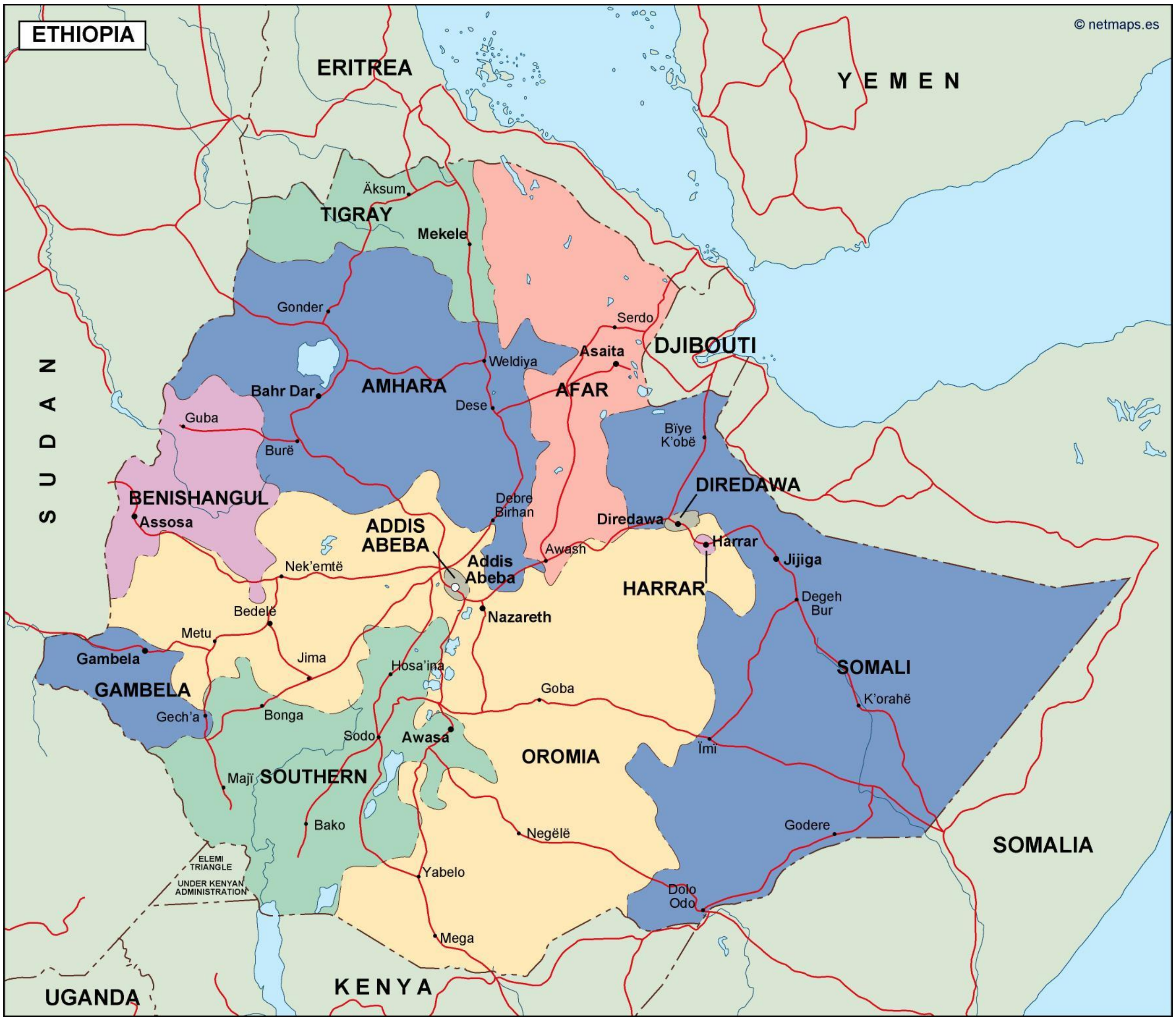

Figure 3.1 Map of Ethiopia that shows the study areas such Addis Ababa, Oromia region and Jimma zone(source :Ethiopia mapping agency)

3.3 Populations

A study population can be described as a group of people or objects with common defining characteristics in which a researcher is interested and on which the results of the study will be applied (Polit & Beck 2010:306). Moreover, Pandey and Mishra (2015:18) suggest that the researcher must decide the way of selecting a sample for his/her study prior to any type of data collection to obtain a sample from a given populations by considering inclusion and exclusion criteria.

The study populations for each phase vary and are described below:

First phase: The purpose of the first phase was to conduct an extensive literature review that explores best practices in palliative care and understands the factors that affect palliative care service provisions in Ethiopia. It also focused on elaborating enabling factors that helps to develop palliative care service in resource scarce settings. Therefore, the literature covered local, regional and global perspectives.

Peer reviewed literature that was published in the period ranging from 2005 to 2020 was analyzed taking into account models of palliative care and factors affecting palliative care provision.

Inclusion criteria:

The study population in the first phase included existing documents and literature that was written in English and peer reviewed. Since there was limited palliative care research in Africa and Ethiopia, papers published in the last 15 years were included in the searching criteria, it covered the period from 2005 to 2020..

Therefore, the following key words and phrases were used in the searching pertinent literature. Model of palliative care, palliative care, level of palliative care provision, cost-effective palliative care, resource scarce setting, factors affecting palliative care provision and developing countries.

The following search strategies/engines were used to explore the international and national models of palliative care, which are used for resource scarce settings such as PubMed, CINAHL, MidLine, Science Direct, WHO publications, international and national palliative care reports, African Palliative Care Association reports, policy documents and health facility reports.One hundred and nine (109) articles were analyzed. Literature specific to the African context accounted for forty-six (46) journal articles, of which only eighteen (18) specifically referred to sub-Saharan Africa. Three

(3) published articles mentioned the presence of two licensed NGOs in Addis Ababa that provide palliative care services. However, there was no published research paper related to palliative care model in Ethiopian setting and none that showed the integration of palliative care provisions. The implementation and outcome of phase one is mainly discussed in chapter 2.

Phase two: The purpose of this phase was to explore the current nature and extent of palliative care in Ethiopia as well as to obtain existing and projected needs and gaps in the current palliative care provision through in-depth interviewes and with key informant and focus group discussions.

The study participants included policy makers, supportive stakeholders, managers, program officers, community leaders, healthcare facility coordinators and health professionals with the view to exploring the current and projected needs and gaps in the current palliative care provision in Ethiopia. The study participants were selected from the Federal Ministry of Health, non-governmental organizations, faith-based organizations, hospitals, zonal health departments, and health extension workers as shown in Figure 3:2.

They were also requested to provide input in refining the best palliative care model after the draft model was refined. For the focus group discussions, the following study populations were included, all nurses who work in chronic illness clinics and render services for patients with life-threatening illness in their respective hospitals.

In this study, the following inclusion and exclusion criteria were used to select the study participants that were involved in in-depth interview and focus group discussion.

Inclusion criteria for in-depth interview

The study populations purposively included stakeholders and health professionals who fulfilled the following inclusion criteria:

Stakeholders who were currently involved in palliative care provision/support to patients with chronic illness, running their activities in most or all part of the country and those who were older than 2 years. Besides, health professionals who had at least six months experience on rendering palliative care services to their patients in chronic clinic.

Inclusion criteria for focus group discussion

The focus group discussions included male and female nurses who were currently working in chronic illness clinics in four of the public hospitals in the Jimma zone.

Phase three: Phase three consisted of the integration of data collected during phase 2 as well as the integration of literature review during phase 1 to develop a draft model for palliative care in Ethiopia. The developed model was reviewed by stakeholders such as policy makers, Hospice Ethiopia, Jimma University academic staffs, Jimma University Medical Center staff and non-governmental organizations. Then, the researcher included all comments and suggestions given by the key informants and the stakeholders and refined it. Finally, all stakeholders evaluated the P-care model using validation criteria scores (Annexure 7) The outcome of phase 2 and 3 is described chapter five and chapter six.

3.4 Sample size and sampling techniques

According to Pandey and Mishra (2015:18) sampling is the means of selecting a given number of subjects from a defined population as representative of that population. Sampling in qualitative research is a process of selecting participants or site. Researchers are purposeful in selecting participants and settings because they are believed to be sufficient to provide maximum in and understanding of what they are studying (Ary, Jacobs, Irvine & Walker 2018:428).

Purposive sampling is done based on inclusion and exclusion criteria decided upon prior to the selection process (Polit & Beck 2010:294). Moreover, in qualitative research, there is no general rule about the number of participants included in the study. However, the primary criteria of sample size is redundancy of information and sampling should be terminated when no information is forthcoming from new units (Ary, Jacobs, Irvine & Walker 2018:429).

The purpose and objectives of the study and the characteristics of the study population (such as size and diversity) determine which and how many people to select (Hancock 2006:22). In this study, the researcher applied purposive sampling to achieve the objectives of the study. Key informants and focus group discussants were purposively selected because the in-depth information they have about palliative care service delivery in Ethiopia. Based on this, the following study participants were selected as outlined in Figure 3.2.

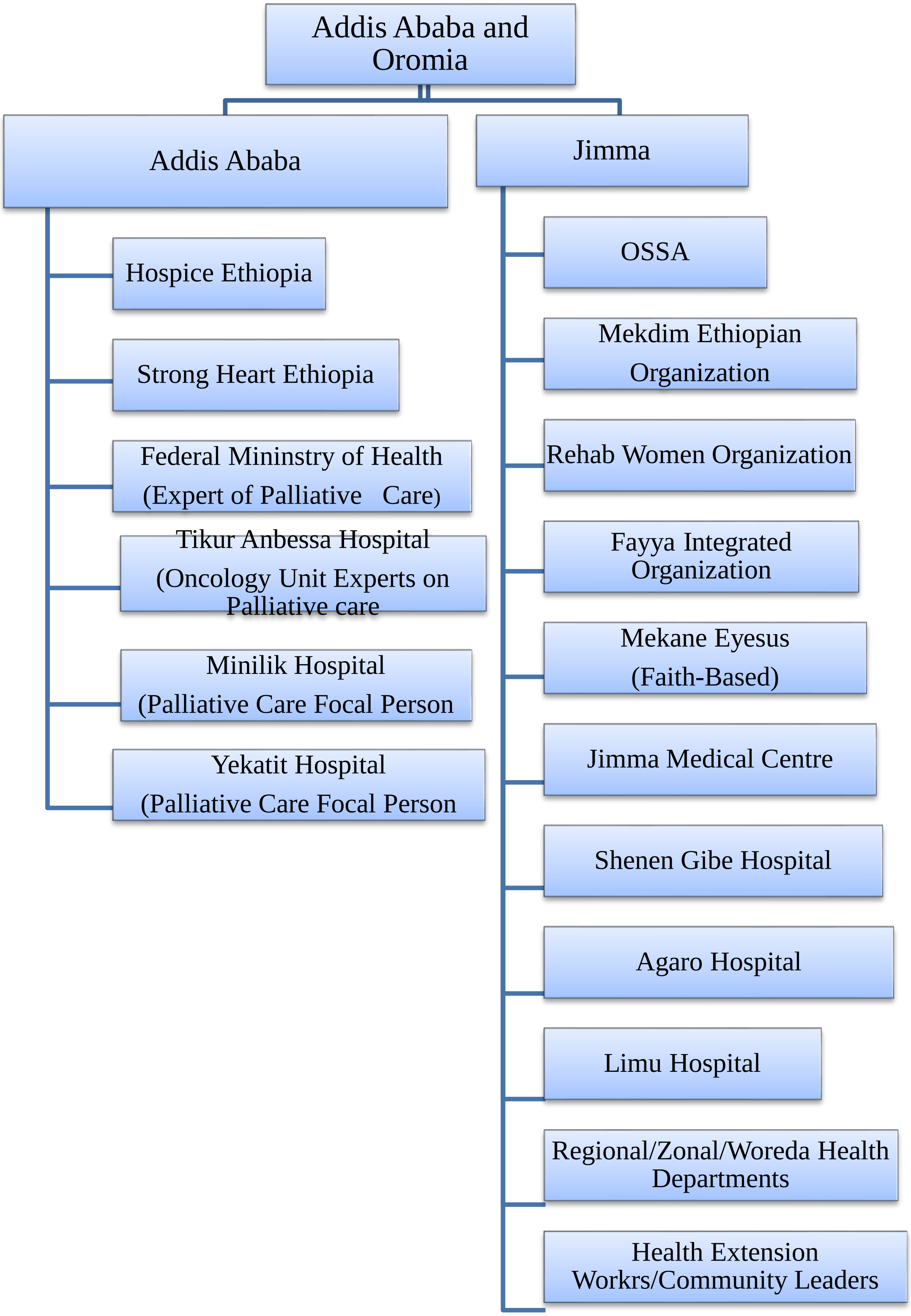

Figure 3.2 Study design for in-depth interview

3.4.1 Sample size for in-depth interviews

A total of 29 in-depth interviews were conducted on participants (key informants) that included participants starting from Addis Ababa to Jimma Zone. The participants of this study were selected purposively because they had rich knowledge and in-depth information about palliative care in Ethiopia. Accordingly, respondents at all levels, such as policy makers, hospices, managers and program coordinators ranging from the federal level to the districts were involved in an in-depth interview. At district level, extension health workers and community leaders or representatives who were supporting palliative care were included.

Furthermore, faith-based organizations were also included in the interviews because they had rich knowledge and in-depth information about palliative care in Ethiopia. Currently, there are five non-governmental organizations and four faith-based organizations supporting palliative care in Jimma Zone. The heads or representatives of these organizations were interviewed. Interviews were conducted until saturation of data. The sampling scheme for key informant interviews is summarized in Table 3.1.

Table 2.1 The sampling scheme for key informant interviews

The sampling scheme for key informant interviews

Target Institutions/Levels	Number of study participants
Community leaders	2
Health extension workers	4
Hospitals at Tertiary and zonal levels	6
Expert on palliative care at policy makers (National level)	3
Hospices coordinators (Hospice Ethiopia and strong	2

Ethiopia)	
Regional level (Program Managers of Oromia Health Bureau)	1
Zonal level (Program Managers of Jimma Zone Health Bureau)	1
District level (Program Managers of Jimma town Health Bureau)	1
Program Coordinators of Chronic Illness follow-up Clinics (Cancer, HIV/AIDS, Stroke units, Oncology units, Cardiac, Diabetes)	5
Faith-based Organizations	2
Non-governmental organizations	4
Total	29

3.4.2 Sample size for Focus Group Discussions (FGD)

A focus group discussion is a qualitative data collection method in which one or two researchers and several study participants meet as a group to discuss a given research topic. The focus group strategy is designed to obtain the perspective of the normative group and not an individual perspective (Gray, Grove, & Sutherland 2017:413). Therefore, the researcher used focus groups discussion to obtain their perceptions and interactions on issues of palliative care services given at their respective hospitals.

A total of 30 nurses, who were working in chronic illness of four hospitals in Jimma zone, participated in the focus group discussion by using purposive sampling techniques based on their experience and knowledge of giving palliative care for patients with life-threatening illnesses. A total of five focus group discussions were conducted at four selected hospitals. Each group consisted ofsix nurses. Of the five FGDs, two were conducted at the Chronic Illness Clinic and Pediatric Cancer Unit of Jimma University Medical Center. The study participants were homogenous in professions with males and female participants.

The focus groups corresponded with the health facilities illustrated in Figure 3.3:

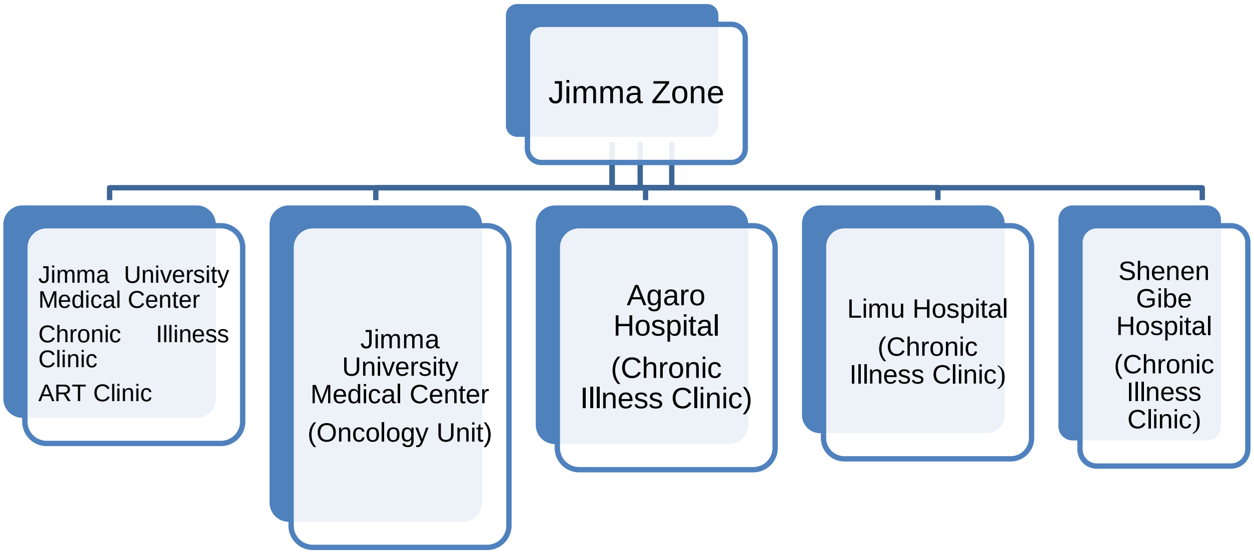

Figure 3.3 Study design for focus group discussion

In this study, a total of five focus group discussions that included thirty health professionals from four hospitals in the Jimma zone, who fulfilled the inclusion criteria, were held.

Health professionals currently working and rendering palliative care services for patients with life threatening illness at chronic illness follow-up clinics of the four selected hospitals were involved in focused group discussions at their respective hospitals as shown in Table 3.2.

Table 3.2 The sampling scheme for FGDs

Focus groups	Number of professionals	Participants profile
Focused group 1 Jimma University Medical Center	6	Nurse
Focused group 2 Shenen Gibe hospital	6	Nurse
Focused group 3 Agaro hospital	6	Nurse
Focused group 4 Limmu hospital	6	Nurse
Focused group 5 Jimma University Oncology Center	6	Nurse
Total	30	Nurse

3.5 Data collection methods and procedures

In qualitative research, the most common type of data collection methods are observation, interviewing and document analysis (Ary, Jacobs, Soronsen and Razaviour 2018:431). The qualitative data collection methods enabled the researcher to obtain more in-depth information and clarify certain issues that are related to cost- effective and culturally acceptable palliative care models that can be used for Ethiopian settings since there is limited palliative care research in the country. In this study, in-depth interviews and focus group interviews were employed to obtain data for the development and refinement of palliative care model for Ethiopia.

3.5.1 In-depth interview

The researcher developed in-depth interview guidelines based on themes derived from literature. This interview guide was prepared in English and also translated into the local language (Amharic language) with guiding and probing questions. Further, the interviews were conducted with the aid of an interview guide that used open-ended questions with probes that gave the participants the opportunity to respond in their own words and to speak freely and easily during the interview. Furthermore, the draft of the in-depth interviews was critically evaluated by supervisors, policy makers and academic staffs of Jimma University, who had experiences in qualitative research.

The researcher conducted the first in-depth interviews to pre-test the interview guide with its probing. The pretest was done in Jimma University Medical Center with two of the managers, who were the Surgical and Medical Department heads, in order to check any vagueness of the interview guides and its probing potential. Minor corrections were done on probing words and the interview guide. The researcher checked and corrected the understandability and applicability of the interview guides and probing questions and made the necessary adjustments. This also helped him to determine the appropriate time frame for the interviews. Resultantly, the interview took 35 to 60 minutes, and the discussions took 1 hour and 40 minutes to 2 hours. The two participants were excluded from the main study.

The researcher used interview guide to begin the interview and the probing questions assisted in exploring the current needs, gaps and challenges related to palliative care provision in Ethiopian settings. Interviews were conducted by the primary researcher and two assistant researchers, who had experience in qualitative data collection. The assistant data collectors, who assisted the researcher, were given an orientation on how to assist the researcher in arranging the room, installing voice recorders and monitoring the recorders. They were also given a brief on the purpose of the study, how to obtain consent and ensure confidentiality and privacy of the participants before actual data collection. Data collectors were advised to keep the interviews as natural as possible by using open-ended questions according to the interview guide and to allow the participants to share their ideas freely. They also took note of and interpreted the nonverbal communication and expressions relevant to the study.

Before the interview, the researcher went to each interviewee’s office with the consent form, shown in Annexures 1 and 2, to obtain their consent, arrange the venue and make appointments for all in-depth interviews. The participants were requested for permission to use voice recording during the interview. The researcher introduced himself and explained the purpose of the study to all key informants. After obtaining consent, he ensured that the privacy of the respondents and confidentiality of the information they provided was maintained (Annexures 1 and 2).

The principal investigator moderated, guided and controlled the discussions and interviews until saturation of data was reached. (Annexure 4). Further, the researcher endeavoured to keep the interviews as natural as possible by using open-ended questions to allow the participants to tell their ideas freely. He also took notes and interpreted the non-verbal interaction and expressions relevant to the study.

The researcher asked the interviewees whether there was anything else he/she would have liked to share with the researcher. Finally, the interview ended with a summary of the discussion of the main points and the researcher asked whether the participants had any questions or not.

3.5.2 Focus group interviews

A focus group is a qualitative data collection method in which a researcher and several participants meet as a group to discuss a given research topic. This is effective for accessing a broad range of views on a specific topic as opposed to achieving group consensus (Hancock 2006:22). In other instances, the gap between what staff or individuals say and what happens in reality can be better understood because there are multiple understandings and meanings that are revealed by participants in focus group discussions. In addition, focus group discussion can be a powerful research tool which can deliver valuable spontaneous information in a short time and at a relative low cost (Hancock 2006:22-23).

This is because participants have the opportunity to build on each other's comments as it stimulates thinking. Focus group discussions can produce high quality and rich data because respondents have the opportunity to clarify and respond to questions (Polit & Beck 2010:322). Before the actual data collection, the researcher went to each hospital with ethical letter from the University of South Africa and Oromia Health Bureau

(Annexes I and II) in order to get permission to conduct the study and also to get the appropriate participants as well as to arrange the time and venues for discussions.

The researcher then went to each study site to prepare for the sessions by informing health professionals, who were working in the chronic illness clinic of four hospitals and explaining the purpose of the study. Following warm greetings, the participants were given the opportunity to ask questions and get clarification. The researcher invited them to the study and expressed his interest in having their views and opinions on palliative care service delivery and the factors affecting the provision of palliative care for chronic illness patients at their organizations. After the first meeting, the researcher arranged for convenient times and location for focus group discussions for six health professionals per hospital who accepted to participate in the study.

On the day of the actual data collection, the researcher and the two assistants prepared the discussion room and arranged the seating. The researcher then welcomed the discussants and explained the objective of the study to each of them. Next, the ground rules for the FGDs were set. This included giving codes 1 to6 for each of the participants and advising them to use their codes when they want to speak or give responses. The participants were also informed to respect one another.

In the process of conducting focus discussions, the researcher maintained reflective thinking and critically evaluated his role and impact on the whole process. He also ensured that he remained as objective as possible. The researcher made sure that all the participants read the information sheet and understood it before signing to participate in the study. The researcher highlighted the need to explain procedures to participants before discussions and moderated the discussion using guides with probing questions and asking each participant turn by turn. Each participants had the chance to reflect his/her views after calling out the code given to him/her.

The researcher moderated the focus discussions throughout. The researcher probed for more detailed responses or for better understanding The facilitator also ensured that the discussion did not deviate too much from the topic under discussion. He also attempted to allow everybody to participate and observed that the discussion was not dominated by one or two participants.

The researcher spent his initial time in helping the participants to relax and build rapport and trust. Then, it was followed by a session explaining the purpose of the study and why the researcher involved them as participants. The starting time and anticipated time of the discussions were set such that the discussions did not last longer than 2 hours. Finally, all of the discussions were recorded on a digital voice recorder. Notes were taken by the researcher and research assistants to complement the transcription of the discussion with the participants.

3.6 Data analysis and management

Data analysis in qualitative research is a time consuming and difficult process because, typically, the researcher faces massive amount of field notes, interview transcripts, audio recording, photos, reflections or information from documents all of which must be examined and interpreted (Ary,Jacobs,Sorensen & Razavieh 2018:481).The researcher organized all transcriptions and translations documents of 29 Key informants and 5 Focus group discussants, field notes and audio recorded files in order to give a sense of it to create and develop model of palliative care in Ethiopian settings.

Transcripts and notes provide large amounts of textual data; but, the researcher has to make sense of the data by transforming the data, sorting and interpreting them in order to formulate explanations of experience (Ary,Jacobs,Sorensen & Razavieh 2018:481). In this study, the researcher used the common local Amharic language during the interview and focus group discussion. He listened to the voice recorder repeatedly and then, immediately transcribed and translated the notes from Amharic into English. Further, the two research assistants and the researcher used notes recorded during the in-depth interview and focus group discussion to cross-check the broad meaning of the transcript and to check for accuracy, inconsistencies or missing points. These experts had experience in translation and transcription of qualitative research. In addition, the staff who conducted the transcription had a MA degree in Teaching English as a Foreign Language (TEFL). The other staff member had a MSc degree in Health

Education and Behavioral Science. Both were PhD candidates. They are duly acknowledged in this thesis. In addition, the two staff members had experience in qualitative research data analysis and management, they also looked at the translations dates and data analysis to ensure the validity of the data. The researcher sent all transcribed, translated and audiotape recorded documents on flash disc to his supervisor. All criteria pertaining to credibility of qualitative research were maintained throughout data analysis and management as shown under trustworthiness.

Data was analyzed using a thematic analysis approach in which the main themes and categories were identified and the qualitative data were analyzed by using verbatim translation and transcription of the recorded interviews by the researcher. The transcript was read and re-read by the primary researcher and then, codes were assigned and a coding structure was created. Data meaning units were then aligned under their respective codes. This was followed by axial and selective coding to develop higher codes (categories and sub-themes).

The researcher used the ATLAS-ti 7.0 computer software. Firstly, the transcribed document and then the transcribed word files were converted into text files. Thereafter, they were imported into ATLAS-ti software for coding and other subsequent aspects of the data management in order to analyze and narrate the findings of the research. Data was managed by converting the narrative data into smaller, more manageable segments. Finally, the deductive coding approach was applied and pre-existing coding framework was used. Categories and subcategories were developed into themes for each participant and across different participants, and finally, the meaning of the theme was interpreted.

3.7 Establishing trustworthiness in qualitative analysis

According to Shenton (2004:63), trustworthiness refers to the quality value of the final results and conclusions reached in qualitative research. Trustworthiness ensures scientific rigor in qualitative studies. Shenton (2004:64) describes the four criteria which were used to ensure trustworthiness of a study including: Credibility (in preference to internal validity), Dependability (in preference to reliability) Conformability (in preference to objectivity) Transferability (in preference to external validity, generalizability).Therefore, each criteria was elaborated in the research process of this study as follows:

3.7.1 Credibility

One of the key criteria addressed by positivist researchers is that of internal validity in which they seek to ensure that their study measures or tests what it is actually intended to measure. According to Ary, Jacobs,Soronsen and Razaviour (2018:498), credibility in qualitative research concerns the truthfulness of the findings of the inquiry. It involves how well the researcher has established confidence in the findings based on the research design, participants and context.

In this study, the following criteria is used by researcher such as prolonged engagement, triangulation, peer assessment and member checks to maintain credibility of the qualitative data collection process. The details of each component of credibility was describes as follows:

Prolonged engagement

According to Jensen (2008:139) prolonged engagement includes establishing enough contact with the participants and the context in order to get the information the researcher needs.

The researcher ensures prolonged engagement by spending 1 to 2 hours during data collection through visit during key informant interviews and focus group discussion to establish rapport with the KII and group discussants. The participants were allowed to express their opinions freely, without interruption, in a conducive environment The interview was conducted until data saturation was reached. Moreover, the researcher also had ample time in data collection and data analysis activities to have an in-depth understanding of participants' views and opinions on palliative care provision.

Peer assessment

Leech and Onwuegbuzie (2008:200) state that during the process of peer debriefing, the researcher discusses the findings of study with trusted and knowledgeable colleagues in the study areas to share experiences and get deep understanding of his research study. Peer debriefing enables the researcher to prevent bias on the research findings and encourages the researcher to get more knowledge of data capture, in order to understand the participants' perspectives and resolve methodological issues. In this study, the researcher had time to discuss with experts of palliative care at ministry level, during palliative care training and also with university staff members who have ample experience with qualitative research to avoid bias and misrepresentation of the data. In addition, the researcher had telephone conversations with palliative care researchers and volunteers who had worked at ministry level in order to get more insight on palliative care provision in the Ethiopian setting.

Member checking

Member checks is a participant's feedback technique, in which, the study participants agree with what the researcher has said about them. The researcher's sharing his/her interpretation of the data with the participants in order to clear up miscommunication, identify inaccuracy and obtain additional data (Ary, Jacobs,Soronsen & Razaviour (2018:500). Even though member checking or respondent validations were tiresome and time consuming, the researcher explained the importance on this process and participants. In this study member checks were done at the end of data collection in which the researcher shared the transcribed documents to some of the study participants such as key informants from Jimma University Medical center and Hospice Ethiopia in order to check the accuracy and interpretations of the finding of study. Moreover, the researcher incorporated all comments and suggestions given during the process of member checking. The researcher also had frequent contact and phone calls with some of the participants who work at the Federal Ministry of Health (FMOH) and Hospice Ethiopia to clarify some information that was gathered during data collection.

Triangulation

According to Polit and Beck (2010:497), triangulation refers to the use of multiple references to draw conclusions about what constitutes truth. There are four types of triangulation (data, investigator, method and theory) identified to ensure the credibility of a study (Polit & Beck 2010:497). In the current study, the researcher used data, method and theory triangulation methods. Data triangulation involves the use of multiple data sources (Polit & Beck 2010:497). In this study, the researcher collected data from different sources using in-depth interviews starting from FMOH to community level workers (i.e. health extension workers) and focus group discussion with health professionals from different hospitals in Jimma Zone in order to get detailed information. Furthermore, the researcher used the data of both in-depth interview and focus group discussion and triangulated them in order to give a concise and integrated results to ensure its credibility, which were elaborated and discussed under chapter four of the studies

3.7.2 Dependability

Dependability is described as a criterion used to judge the accuracy, completeness and accessibility of the research process (Sandelowski 2000:300). Dependability puts emphasis on the need for the researcher to account for the process in which research takes place. Thus, in the current study, dependability of the trustworthiness of the study was maintained through the integrity of the study in which the researcher had developed the data collection instrument based on the objective of the study, research questions, reviewed literature and the conceptual framework of the study. Moreover, prior to the actual data collection, the data collection tools were reviewed and appraised by the research supervisor and experts such as academic staff of Jimma University that had extensive experience in qualitative research. The researcher maintained and integrated the logical flow of the contents starting from introduction part of the study up to the conclusion.

The researcher gave emphasis to research data and the circumstances of their production and provided a detailed report on data processing, data analysis and data interpretation. The results were then compared, and any variation in the themes, categories and subcategories were noted. Furthermore, this information was provided so that those who may have interest to repeat the study may be aware of how unique the situation was as suggested by Kitto,Choster and Grbich (2008:244). Besides, the research findings should clearly show how the research design has been implemented. The researcher process was carefully and accurately documented and shared with the experts on the areas of palliative care. The researcher also kept thorough notes and records of activities and he data well-organized in a retrievable form.

3.7.3 Transferability

Transferability is described as the extent to which other people can see the similarities in the finding of a study (Kitto,Choster & Grbich 2008:244). Furthermore, transferability is the extent to which the findings of a particular inquiry have applicability in other contexts or with other participants. The transferability of the findings in this study was maintained by a description of the research process, findings and sharing pertinent gaps in palliative care research in Ethiopia. The final palliative care model and strategic plan were developed and sent to key participants for evaluation and validation using validation score that included clarity and consistence, relevance, practiceability and usefulness, importance , comprehensiveness and adaptability that was described under Chapter 6. All key informants filled the validation score and returned it to the researcher and also agreed on the importance of the p-care model. Therefore, this paves the way for other researchers to use the finding of this study as a baseline data. Furthermore, the information from this study can asisst policy makers in developing a pilot model. Such a study can be carried out in similar settings.

3.7.4 Conformabilit*y*

Another method of checking trustworthiness of the current study was done by applying conformability. Conformabilit*y* is ensured through an auditing process.

In this study, the researcher established conformability through an audit trail by which all the transcribed documents were audio recorded, and some of the pictures taken during data collection periods, were sent to the research supervisor with the permission of the participants. The final draft of the model was given to some of the key informants such as manager of Hospice Ethiopia, Policy makers at FMHO and Clinical director of Jimma University, Head of the Department of Nursing and Midwifery Hospice ,Internist ,Pediatric oncologist, Managers of NGOS, Psychiatrists, the Nursing Director in order to get their comments and suggestions. These informants were also involved in the validation process of the model which is found in chapter six of this study.

Finally, the researcher will keep field notes and the audio-tape records in locked file cabinet in a safe place after the completion of the study and publication of the research.

3.8 Ethical considerations

Qualitative research, according to Mahlungulu and Uys (2004:19), like all forms of research, is subject to a code of ethics for the protection of the research participants to ensure the scientific integrity of this study. The researcher considered all ethical principles requirements throughout the research process in order to protect the rights of the participants and the institutions that were involved in the study. Thus, the following ethical considerations were adhered to protecting the rights of the study participants and those of the institutions involved.

3.8.1 Permission to conduct the study

First, the ethical clearance was obtained from the Research and Ethics Committee of the Department of Health Studies of the University of South Africa (Annexure 1). Then, after getting approval from the university, UNISA Addis Ababa Branch wrote a support letter to Oromia Health Bureau in order to get an ethical letter to conduct the study (Annexure 2). Additionally, an ethical approval letter was obtained from Oromia Regional Health Bureau (Annexure 3) and shared with the respective administrative offices and Hospitals before involving them in the study. Additional ethical clearance were obtained from ethical review board of Jimma University, Institutes of Health

Sciences. Therefore, official permission was obtained from the concerned bodies at all levels that are annexed in this study.

The four fundamental ethical principles were maintained through the research and have been applied as follows.

3.8.2 Voluntary participation

Ethics is defined as a system of moral values concerned with the degree to which research procedures follow professional, legal and social obligations concerning the participants (Polit & Beck 2010:717). In this study, research participants were not coerced into participating in the study and they participated on a voluntary basis having met the incursion criteria. The rights of the study participants were protected during the research process by, obtaining informed consent at each levels of the study and explaining to each respondent and discussant on the purpose and benefits of the study.

3.8.3 Informed consent

Informed consent means that the participants know the purpose, implications, conditions, rights and responsibilities of the research (Polit & Beck 2010:342) .

A consent form and information leaflets were provided to ensure informed consent (Annexures). All participants expressed fully informed consent, individually at the time of recruitment and were informed about the aim and objectives of the study as well as the other ethical principles involved.

In this study, for those who agreed to participate, an information letter was shared, and informed consent was obtained (Annexes 4). Informed consent was obtained for using voice recorder anonymously during both in-depth interview and focused group discussions. Participants were given full information about the study as to what its requirements, purpose and benefits. Moreover, the researcher explained to the study participants that they have the right not to answer any question if they do not want to and the right to quit participation at any point without any penalty.

3.8.4 Privacy and confidentiality

Confidentiality is concerned with the respect for people's privacy, and this involves not revealing the participants identity to anyone other than the researchers and, all who were involved in the study (Polit & Beck 2010:342).

In this study, all the information acquired through the research process was kept confidential and access to the data was restricted only to the research teams. To attain confidentiality, the researcher informed and reassured all the participants that their opinions in the in-depth interviews and focus group discussions would not be shared to any third parties. Codes were given to participants in the focused group discussion instead of naming the participants. This prevented identification and the possibility of victimization. All the questions were coded and all data sources were kept protected in private place. Moreover, the researcher gave pseudonyms for audio-recorded files and for the name of experts who were involved in the validation report of the P- model. All the questions were coded and kept by their dates and file names. All data files were kept protected in a private place. All information from in-depth interview and focus group discussion was used for research only, only the researcher had access to research data. No one was able to see the data except the researcher and his team and the data was used only for the research purpose.

Privacy: According to Burns and Grove (2016:282) privacy refers to an individual's right to determine the time, extent and general circumstances under which information will be shared with or withheld from others. In this study, before the actual data collection period, the researcher and the two assistants visited each study area and chose an appropriate place for the participants based on their willingness in order to make the environment conducive. A "keep silent'' notice was posted on the doors in order to ward of any disturbances.

Anonymity: Respect for person's autonomy requires ensuring that the research participants participate in the research voluntarily and are fully informed about the research (Bordens & Abbott 2013:200). In this study, the researcher assigned codes for all KII and FGDs participants, Therefore, their names were not mentioned in the questionnaires, in translations and transcriptions files. All audio tape, photos and transcribed data were kept in the locked file cabinet in safe place

Their identity was not linked to their contributions during the interviews. In addition to this, the audio-tapes, transcripts and demographic data were stored in a safe place, and analysis was done on data without revealing the identity of the individual. Names of the participants were not included on report or presentation.

3.8.5 Protection from harm

During this study the researcher used the following ethical principles that protects the study participants from any risk of physical or psychological harm

Beneficence: shows the importance of reducing harm and maximizing benefits for participants or the society as a whole (Polit & Beck 2010:90). This study, there was no intervention and thus human subjects were not involved in any interventionNo Harm or discomfort was anticipated during the course of this reasearch. Palliative care training was given to 58 health professionals, who came from two of the study sites.

Non-maleficence: In any study, the researcher should ensure that participants are protected from harm (Polit & Beck 2010:90). In this study, there was no physical, psychological, financial or social risk to the study participants.

Justice: The participants should share the benefit and burden fairly and the inclusion and exclusion criteria should be fair for the participants (National Ethics Advisory Committee 2012:8-9) therefore, the study population should be treated equally. In this study, the researcher ensured the right of the participants to be treated fairly/equally throughout the processes of data collection.

3.9 Conclusions

This chapter has provided a detailed overview of the sequential multi-stage methodology that was applied to the study. The research process was described in detail in terms of the study population, sampling, data collection processes, data management and maintaining ethical principles and scientific rigor throughout the study.

The data analysis process and interpretation of data will be discussed in the next chapter.

CHAPTER FOUR

Analysis, interpretation and presentation of findings of research

4.1 Introduction

This chapter deals with the process of data analysis and the interpretation of the research findings that will be used to develop the model for palliative care.. The discussion of the results is complemented with tables and figures. An evidence trial is provided on topics of the status of palliative care provision, domains of holistic care provision, palliative care delivery approach in the settings, the challenges related to palliative care services delivery and enabling factors that help in developing palliative care services delivery in Ethiopia.

- The thematic analysis of the data resulted in themes that were carefully considered and interpreted within the parameters of the theoretical framework and the research questions, namely:
- What is the current nature and extent of palliative care in Ethiopia?
- What are the unmet needs and priorities in terms of palliative care in Ethiopia?
- What are the challenges of effective palliative care in Ethiopia?
- What are the current best practices of palliative care models nationally and internationally?
- What is a feasible and effective model for palliative care in an Ethiopian context?

4.2 Data management and analysis

According to Burns and Groves (2017:68), the intent of qualitative data analysis is to organize the data into a meaningful, individualized interpretation, framework, or theory that describes the phenomenon under study. In addition, the analysis and interpretations of qualitative data can be influenced by the researcher’s perception and belief. Therefore, the qualitative findings are unique to that particular study.

The researcher began the data analysis process on the first day of data collection. Doing so helped him to correct any unclear issues and refine the tools for the subsequent interviews and focus group discussion sessions. Therefore, data were generated and analyzed from data sets of audio-recorded file, field notes and transcribed documents of 29 KIIs and 5 FGDs. Thus, transcriptions and translations were done verbatim, and each document of the interview and FGD was transcribed to get immersed into the data and the context of the study.

The researcher transcribed verbatim of the audio-recorded file of the in-depth interviews and FGDs through the repeated listing of the recorded audio file. In the analysis, the Amharic transcripts were translated into English. The researcher had support from his colleagues, who are fluent in both English and Amharic languages and have experience in checking the details, grammar, contents and consistency between the Amharic and its English equivalent. Moreover, before the actual data analysis, the transcripts were read independently by the research team and coded separately in order to enhance intercoder reliability and to establish verified code structures.

Therefore, the engagement of the researcher in the transcriptions and translation of the interviews and FGDS familiarized him with the context of the data management process. Moreover, it helped the researcher to get an in-depth insight and understanding of the palliative care research data. The data management and analysis followed detailed analysis of participants' information such as their thoughts, ideas and knowledge of palliative care.

The researcher used ATLAS/ti 7, which is a qualitative data analysis software programme for data management and analysis. Therefore, all transcribed documents of the interviews and FGDs were changed into enrich text, then transported to ATLAS/ ti software to create the primary documents in software window. Following this, initial codes were identified and created by reading and re-reading the transcribed documents line –by- line using the software.

The codes were compared across the primary documents, and similar codes were grouped to form code, families/categories so that the concepts and linkage among the categories were explored and constructed to develop the main themes. Filed notes and memos were used to elaborate themes. As such the analysis followed a thematic analysis approach in which main themes and categories were identified and analyzed to describe palliative care service delivery in Ethiopia.

In this way, 1072 primary codes were extracted from the analysis of five FGDs and 29 in-depth interviews. The researcher categorized it into 185 code families and then, networks were created and associations and links explored to build a conceptual model for palliative care in Ethiopian context. Throughout the analysis process, memos were written to show reflectivity of the participants.

The network view of the Atlas ti software showed the relationships between the families. It also indicated how thematic areas related to each other. This study described and presented the main themes and sub-themes that were extracted from the families/categories. The findings of the analysis were presented by narratives and elaborated by their direct quotes.

4.3 Demographic characteristics of the study participants

The study participants had different knowledge and experiences in palliative care provision in Ethiopian setting. Therefore, the researcher described the sociodemographic characteristics of both key informants and FGDs discussants as shown in the Table 4.1.

Table 4.1 The socio-demographic characteristics of key informants

Characteristics		**Number of participants** **N= 29**
Sex	Male	16
	Female	13
Age in years	20-24	3
	25-29	7
	30-34	9
	35-39	6

	40-44	3
	45-50	1
Professions	Nurse	7
	Physicians	10
	Health officers	2
	Managers	5
	Social worker	1
	Extension health workers	4
Institutions	Federal Ministry of Health	3
	Hospitals	7
	Non-governmental organizations	4
	Hospice Ethiopia	1
	Faith based organizations	2
	Managers	5
	Strong Heart Ethiopia	1
Position	Hospital managers	4
	Palliative care focal persons	4
	Palliative care clinical advisory at Ministry of Health	3
	Manager of Hospice Ethiopia	1
	Managers of non-governmental organization	4
	Managers of faith-based organization	2
	Community leaders	3
	Service providers	4

Educational status	PhD	1
	Medical doctors	6
	MSc degree	10
	BSc degree	9
	Diploma	3
Total		29

Thirty health care professionals working in chronic clinics of four different hospitals in Jimma Zone were involved in five focus group discussions. Two of FGDs were conducted in Oncology and Chronic illness of Jimma University Medical Center. A summary of their socio-demographic characteristics is presented in Table 4.2.

Table 4.2 Socio-demographic characteristics of FGDs participants

Characteristics		**Number of participants N= 30**
Sex	Male	13
	Female	17
Age in years	20- 24	9
	25-30	14
	31-34	6
	35 to 40	1
Professions	Nurses	28
	Health officer	2
Educational status	BSc degree	27
	MSc. Degree	3

Institutions	Jimma Medical Center	6
	Shenen Gibe Hospital	6
	Limu Genet Hospital	6
	Agaro Hospital	6
	Jimma Medical Center ,Oncology Unit	6

4.4 Analysis of data

To come up with the final codes and categories, the researcher performed the following steps: all the transcribed documents from key informants and discussants were converted into enriched text and used Atlas ti software to create primary documents for the key informants and focus group discussion documents separately. Following this, the researcher used the software to create the code line by line. Then, the analysis showed that 1,072 primary codes emerged from the analysis of 5 focus group discussions and 29 Key informants. By examining the codes and identifying similarities and relevance of the codes and by reduction, a total of 32 categories and 7 main themes were developed (Table 2).

The codes derived from the definition of palliative care include concepts such as chronic illness, holistic care, comprehensive care, supportive care and end of life care. Examples of the categories created include, palliative care integration, advocacy, challenges, education and training and level of palliative care. Super codes emerged, followed by study themes which were created. The networks were created to see the relationships between the categories. Finally, the following themes were created: scope of palliative care provision practice in Ethiopia, palliative care delivery approach, domains of holistic palliative care delivering, knowledge and practice of palliative care provision among service providers, barriers to deliver palliative care service, actions that can support the strengthening of palliative care model development and ways forward (Table 4.3).

Table 4.3 Main themes and categories emerged after data analysis.

Ser. no	Major themes	Categories
1	Scope of palliative care in Ethiopia	Current status of palliative care practice
		Existing policies and strategies to deliver palliative care
		Level of palliative care integration in Ethiopia
		Existing training and education in palliative care in Ethiopia
2	Current Palliative care service delivery approach in Ethiopia	Levels of palliative care provision
		Hub and spoke approach
		Hospice palliative care approach
		Out patient hospital based palliative care
		Hub and spoke approach
3	Domain of holistic palliative care delivery	Physical care
		Pain free initiative
		Psychological care
		Spiritual care
		Social care
		Bereavement care
4	Knowledge and practice of palliative care provision among service providers	Understanding the concept of palliative care
		Multidisciplinary team approach
		Education and training on palliative care
		Level of palliative care practice/provision
5	Barriers to delivering palliative care service delivery	Patients related factors
		Providers related factors
		Health care system related factors
		Research related factors
		Partnerships related factors
6	Action that enhances palliative care development in Ethiopia	Presence of community engagement

		Integrating into hospital transformation guideline
		Presence of extension health workers, HDAs
7	Recommendations for improved palliative care in Ethiopia	Ways forward to stakeholders

4.5. Theme 1 Scope of palliative care service delivery in Ethiopian setting

The analysis in this study showed that most of the key informants from Addis Ababa were aware of the status of palliative care services in Ethiopia. However, those participants in Jimma, had limited awareness of the functions and scope of palliative care. Based on this, rich information was obtained from key informants from Addis Ababa as described below. The above theme described the current scope of palliative care service delivery in Ethiopia. This further included four emergent categories such as current status of palliative care provision, existing policy that delivery palliative care service provision, level of integration and advocacy into the health-care system and education and training. Each category is described as follows:

4.5.1 Category 1 Status of palliative care service provision in Ethiopia

According to most of the participants in the study, palliative care is not well developed, limited in scope, rudimentary and at its early stage in Ethiopia. One of the study participants, (KI1) explained the status of palliative care in Ethiopia as follows:

"… I have been working for the Ministry for three years. Three years ago, we set up a national palliative care plan. So, I have been involved in making that plan in a team and then, working out to carry out the plan. Therefore, the Federal Ministry of Health recognized the importance of palliative care as part of the country's health strategies and has done the following activities, such as engaged palliative care in health strategic transformation plan and also assigned palliative care advisor and officers at level of clinical advisor directorate at FMOH professionals and we developed national palliative care guidelines and gave palliative care training for health professionals coming from Addis Ababa and different regions of the country "[KII:1. 52 Years old FMOH].

One of the study participants explained that the status of palliative care in Ethiopia and mentioned its recent inclusion in the Ethiopian hospital transformation guideline as mentioned below:

"In Ethiopia, palliative care is not as such developed. It has been three years since it was started. But, now, the Federal Ministry of Health has developed a National palliative care guideline and included as one chapter in the Ethiopian Hospital transformation guideline; so, the job is started. Since it is considered as one standard, all hospitals have to implement it. Thus, the Ministry of Health has designed it as one standard and it is going to be implemented in all hospitals" [KII:4, 30 Years old at tertiary hospital in Addis Ababa].

In the same talk, one of the study participants described the activities done on palliative care at national level as follows:

"…I have served at this position for two years. I am working on the launching of national palliative care clinic and strengthening it. To do this, the training of professionals like in-service training is done. The other is pre-service training, which aims at teaching Physicians and Nursing students about palliative care at college before graduation. So, we are working on making palliative care part of the curriculum. Now, palliative care and pain training are incorporated into the curriculum of four Nursing specialties; we have developed palliative care pre services training for Medicine and in the future, it will be extended to other professionals". [KII:2, 36 Years old at FMOH]

Additionally, one of the study participants explained the status of palliative care service in their hospital and they had developed palliative care strategic plan for implementation as stated below:

"The Ethiopian Ministry of Health has started the implementation of Ethiopia Hospital Transformation Guideline since July, 2015. One of the four transformation agenda of this EHSTP is the quality and equity of health care. Improving quality of health services in a timely agenda is the only means to achieve a better health outcome for our clients and to improve their overall experiences in every hospital visit.

Our hospital established a palliative care unit and offers basic palliative care services for patients who have been visiting the hospital since 2016 in a collaboration with FMOH and Hospice Ethiopia. We also have developed a palliative care unit strategic plan for 2017 -2020 and our palliative care office is located on the ground floor of new building and around human resource office. When any patient needs palliative care team, he/she could visit our office or contact us. Even for terminally ill patients who need home based palliative care, they refer to us on time for palliative care service delivery. *". [KII: 5, 32 Years old at a tertiary hospital]*

With regards to the current status of palliative care in Ethiopia, one study participant stated that there was a movement for the development of palliative care: as follows:

"There is a commitment on the part of the government; but, I do not know whether it is enough or not. The Ministry of Health has organized the Palliative Care Department and it is rendering the service. Under the department, "pain free hospital", service is being given. So, this is what was started 9 years ago". [KII: 9,41 years old, Oncologist working in a tertiary hospital*]*

Furthermore, another study participant stated that the establishment of palliative care provision in the hospital where he works was very recent and described as follows:
"We started palliative care recently; not more than three months; so, it is new. In a week, we have one clinic; it is Thursday in the afternoon. It is not well organized. We are also taking the training at staff level now. However, now, we are working with Hospice-Ethiopia; we visit the patients and help them at the clinic". [KII:8,29 years old nurse]

In contrast to the above key informant, one study participant described the status of palliative care provisions at their hospital as follows:

"One oncologist and I have taken basic palliative care training at Alert Hospital for 3 days, and then at the end of the training we developed an action plan to establish palliative care at our hospital. We did not open the palliative care unit and I am not

confident to say we are giving palliative service to the patient" [KII:24, 34 years old Nurse]

As shown in the accounts above , more information on the status of palliative care development in Ethiopia was obtained from study participants of Addis Ababa than those from Jimma Zone. It shows that the Federal Ministry of health values the palliative care initiatives.

In an Ethiopian setting, the following activities have been done:
The palliative care advisor and team was assigned at Ministry level, pain and palliative care guidelines were developed and palliative care was integrated into hospital transformation guideline to be implemented in public hospitals in Ethiopia. However, palliative care development is at an early stage and its practical implementation at hospital levels was inconsistent and showed the recent development at which few hospitals established the palliative care set up, and others have not yet establish the unit, after they had received palliative care training by FMOH.

4.5.2 Category 2: Existing policies and strategies to deliver palliative care

The intitial strategies on palliative care development is the presence of governmental policy to integrate palliative care provision into the existing health care system, working on advocacy, integration of palliative care education into the different curriculum of health professionals, providing training for health professionals to build their capacity as well as allocation of the appropriate palliative funds. In this regard, one of the participants at the FMOH mentioned that the current policies and strategies on palliative care are as follows:

"Little is done on the level of policy, even though, palliative care advisors and officers are assigned at the level of clinical divisor directorate at FMOH, and also palliative care is included in the Ethiopia hospital transformation guidelines, there is no as such palliative care policy in the FMOH level and strategic plan for palliative care is in the process of drafting and not yet completed in Ethiopia". [KII:4, 28 Years old FMOH]

Another study participant described the advocacy of palliative care at the ministry level as follows:

"…Palliative care advocacy is not extensively done in our country ,there is a wide gap in palliative care awareness in the community, health workers and patients and his/her families. To overcome such burden, advocacy is very important ,as I said at the Ministry level ,we used air time to advocate palliative care through Ethiopia local TV channels called Walta and EBS for two times to create awareness of palliative care for the community but such awareness creation trend should not be done for only two times ,it should continue and be sustainable".[36 years old KI:2 at FMOH]

As indicated in the above category, even though there was palliative care advisory team at the Ministry level and also palliative care is integrated as a chapter in hospital transformation guidelines, palliative care policy was not yet strongly developed and a draft palliative care strategy document was in the process of being finalized by FMOH. Furthermore, palliative care advocacy was also not done well as a respondent said that it is only on air two times on local television. Therefore, much work is expected from the stakeholders to develop palliative care policies and strategies at national and local levels that will enhance the implantation of palliative care provisions in the health care system of Ethiopia. Attention and wide coverage for palliative care advocacy are very important in order to create awareness for the community, patients, families and health professionals.

4.5.3 Category 3 Level of palliative care integration in Ethiopia

Regarding palliative care integration in Ethiopia, one of the Key informant said that building isolated palliative care units was very difficult in the Ethiopian setting but we have to integrate the palliative care service provision into the existing health system as noted below:

"……..we rarely have one hospice here in Ethiopia. And to have lots of buildings for palliative care is not realistic with the population that we have. So, we have to use a system that is already existing. The government does not afford to build specific,

standalone unit for palliative care because the number of patients that we have is not realistic to use another approach. We have to use the system already set by the government. That is the main reason for working with the Ministry of Health to get good coverage; it has to be aided by Ministry of Health". [KII:1, 52 years old at FMOH]

Palliative care was not well integrated into a national health care system and also into a social system in Ethiopia .One study participant reported that, "…Although palliative care is integrated in to Ethiopia hospital transformation guideline as one chapter (in chapter 12) to be implemented by all public hospitals in Ethiopia, hospitals were almost not well performing on issue of palliative care during our monitoring and evaluation, they were performing activities that they were evaluated like communicable diseases, infection preventions and oxygen therapy.

So, as I mentioned above hospitals are busy on the services evaluate their status nationally. Therefore, the evaluation services at the national level strategic plan should include palliative care activities in hospital key performance evaluation list". [28 years old KII:3 at FMOH]

Another study participant reported that, "One of the components of palliative care is a pain. Pain score and treatment is integrated as 5th of the vital signs and also included in the vital sign charts in public hospitals. Therefore, hospitals should implement pain assessment and treatment as national pain guideline protocol" [36 years old KII:2 at FHOH]

Similarly, study participant reported that, currently, "there was no strong integration of palliative care service and support from existing social or any charity organizations at ministry level, but FHOH and the hospice Ethiopia are working in some level, not strong and national level". [28 years old KII:3 at FMOH]

As shown in this category, integration of palliative care into existing healthcare system is crucial. Pain assessment and scores are included in vital signs charts of the patients as 5th. However, the palliative care integration level was not strong enough. Palliative care should be integrated in all healthcare system starting from tertiary hospital to health post, with good communication and referral system. Patients will get palliative care when passing through healthcare system, rather than developing a separate building and a system for palliative care activities in Ethiopian setting.

4.5.4 Category 4 Existing training and education in palliative care in Ethiopia

In order to develop a palliative care model, awareness of health professionals, community and family is very important. The respondents described the level of training and palliative care course integration in the curricula of different disciplines' as follows: In order to develop a palliative care model, the awareness of health professionals is very important. There were variabilities among study respondents in the availability of trained human resource in palliative care in Ethiopia.

The respondents described the level of training and palliative care course integration in the curricula of different disciplines' as follows:

"We train Nurses, Doctors, Social Workers and Pharmacists. In addition, we train them for one week. Training has been given for 12 hospitals, which are found in Addis Ababa. Even for Paul and it was also given last year, we share them full experiences about palliative care and we encourage them to arrange palliative room in their hospital". [KII:1, 52 Years old FMOH]

"The Federal Ministry of Health in collaboration of various international organizations (eg : UK based palliative care charity,)gave basic palliative care training and training of trainers on palliative care for three days and five days respectively, the training were given by Physicians, Nurses and Social workers come from UK. (eg: UK based palliative care charity). In addition to that training, they also help us financially even if it is small, Besides, we are working with The American Cancer Society on "pain free initiative" and "Palliative Care training"; we work with them sharing resources. However, we have to do more because palliative care is not only required for Addis Ababa but also for regions. So, last year, we gave training to regions. We need financial support,

organizations that support and we also need to organize resources". [KII:2 36 Years old FMOH]. *.*

Another KII informant described the importance of including palliative care courses to the curricula of health professionals and the level of its integration.

"Now, activities are underway to include in a medical curriculum; it has been included in curricula's for nursing specialties. The problem that we had that first-degree graduates do not have the concept of palliative care. So, after they graduate, they face challenges with regard to palliative care and pain management. Now, in the curriculum of Family Medicine, palliative care is included". [KII:12, 32 years old, a *physician* working in a tertiary hospital*]*

In contrast to the above report, most of the study participants in the zonal levels reported that there was a lack of palliative care training in their health facilities.

"I have serviced in this hospital for 8 years and I have taken a lot of trainings on both communicable and no communicable diseases ,but not on palliative care ,I remember , I have taken comprehensive HIV/AIDS training ,where the issue of palliative care was barely integrated into the manual which was almost half page in its content. Most of the trainers discussed it scarcely ". [FGD 3, 29 years nurse working in ART clinic*]*

Furthermore, the discussants in FGD3 said that, we did not have any palliative training so far and there was no palliative care guideline in our hospital to use it as references

As this category shows, basic palliative care trainer of trainers and pain assessment and treatment were given for health professionals for 3 and 5 days, respectively. This training was given by FMOH in collaboration with The American Cancer Society as pain free initiative project and a UK based charity. Palliative care is integrated in nursing specialties. However, the researcher observed that almost all study participants in Jimma zone did not have any palliative care training, with only a few from Jimma University Medical Center reporting that they had certificate training on pain assessment and treatment which was given by the Federal Ministry of Health and American Cancer

Society, Pain Free Initiative Project but no palliative care training. The palliative care guideline was not available in all study areas of Jimma zone, however , the researcher had a chance to look at the hard copy of palliative care guideline at Ministry level during KII interview. Training of health professionals and integration of palliative care in the curricula of nursing specialties were encouraging activities done by the FMOH. However, these palliative care activities and integration should be tailored to the regional and zone levels and the integration of palliative care courses should also include other medical health curricula so that graduates will have the concept of palliative care. The researcher identified that there was a gap in palliative care awareness among health professionals during focus group discussions.

4.6. Theme 2 Current palliative care services delivery approach in Ethiopia

Palliative care service provision is at an early stage of development in Ethiopia. In most of the study areas, palliative care was not yet implemented during the time that this study was carried out. However, few such services are available.

The study participants reported that ,there are different palliative care service delivery approach in Ethiopian setting. According to this, the following palliative care services were delivered using the following palliative care approaches such as, Hub and Spoke approach, Hospice Ethiopia, Strong Heart Ethiopia have been practiced in the Addis Ababa setting and Outreach approach was practiced in one of zonal hospitals

4.6.1 Category 1 Hub and Spokes approach

Quite a few of the study participants from Addis Ababa had information and were involved in the set-up of the Hub and Spokes palliative care approach in their facilities. This was not the case with participants from Jimma Zone. One of the study participants from the Ministry of Health explained the presence of a palliative care approach as follows:

"We have been using Hub and Spoke approach as a setup. So, we have a bicycle wheel and the center of the wheel is the hub and then, the upside is the spoke of the hub. Therefore, in the hub, because of the hospital and because of the morphine, it

must be a hospital setup. Therefore, like we have the hub, in this hub, we train nurses, Doctors, Social Workers and Pharmacists. Moreover, we train them for one week. We give them full experience about palliative care and they will then form this Hub; we ask them to arrange the room in the hospital and they will see patients in the OPD department. Then, they will see patients by doing rounds. As a result, they do not take over the care from another department. But, they work with the departments. We also link that to health centers. **.** *Therefore, we had trained staffs working 8 health centers in Addis for the first hubs. Next year, we will be training for health professionals of many health centers. Then, form a hub in the hospital, the health centers and then, health centers because of the morphine for patients with severe pain. They need to send them to the hospital and get the morphine and then, treated at the health center. In addition, for health extension workers, actually, we give training for them. And then, we link them with other community services like here in Addis, we have hospice Ethiopia. So, we will link them out to NGOs or Macedonia or other community like Sisters of Mercy that we can use". [KII:1, 52 Years old FMOH]*

Then she has drew a picture of Hub and Spoke approach on plain paper to make it clearer to me, as shown in the Figure 4.1 below

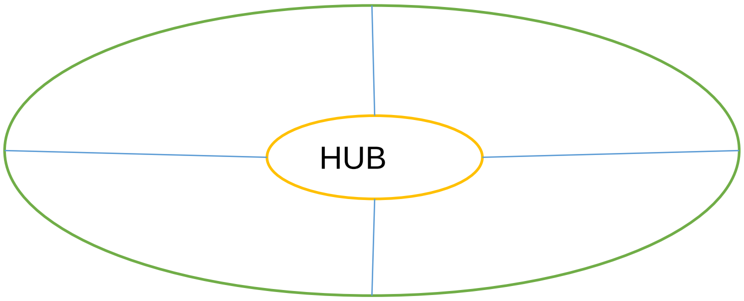

Figure 4.1 Hub and Spokes approach

A 32 years old physician at a tertiary Hospital in Addis Ababa KII:5 described the hub and spoke approach of palliative care and the activities done in the hospital as follows:

“We established hub and spoke approach palliative care in our hospital and this unit is giving in-patient and out-patient palliative care services and has a focal person, who is working 6 days per a week. Each department has a focal person working on palliative care in the hospital and we have referral linkage with Hospice Ethiopia. Furthermore, the unit gives awareness to the staff and training on palliative care for medical college staff”.

On the same topic, another study participant described the type of palliative care approach they were practicing in their facility as stated below:

“The palliative care approach that we are using is a kind of bicycle wheel approach I. There is a central hub; this means for example, if you take yours,’ there can be one hub centrally in Jimma University Hospital. The central hub can give services to different departments. But, the center should have Physicians and, other staff members who permanently help, the patients’, beds for patients who have chronic illness. After the job is done in the central hub, it has to be discharged to the nearest health center. For example, a palliative care patient may be admitted for two or three months. We do not admit them for the whole two months; we have to strengthen the surrounding health centers. After giving training on pain management and palliative care, we can refer them to health posts and we can give them help on how they follow”. [KII: 4, 34 years Old, *physician* working in tertiary hospital*]*

However, contrary to the views of the above participants, one study participant in Addis Ababa expresses the existence of palliative care services in Ethiopia as follows:

“There is no independent palliative care model here. I know that in developed nations like England, there is a model by which they work in hospice including spiritual component. However, regarding our country, there is nothing that I tell you. A month and a half ago, there was a start. I know that we were requested to refer to palliative care from Oncology Department. But, how effective it is will be known in the future. What I want to say is that there is a start and if there is a start, there will be a time by

which it reaches a good stage". *[KII:9 ,*41 years Old, Oncologist working in a tertiary hospital*]*

Similarly, another respondent described the palliative care service provision at Black Lion Hospital as follows:

"What makes palliative care unique here is that it is only given in an Oncology Unit in this hospital. In a week, it is given for two days: Tuesday and Thursday. It is usually given for those who are very weak and highly ill". *[KII:7,*25 years old, oncologist nurse working in tertiary Hospital*]*

The participants were requested to describe other palliative care models, which could fit into an Ethiopian setting. Then, one of the study participants explained the importance of community-based palliative care model in the Ethiopian context as stated below:

"Ya…. You can have like the community-based model. When we look at the population of Ethiopia, 100 million, it is ultimately like to be in the community. The reason why we are doing like this is because of the morphine. When we go to patients with severe pain; they need to have morphine. And morphine is only available at the hospitals. So, we are using this model at this time. But, ultimately, it needs to be community-based and especially, when going to the regions. So, community-based is the one to be used by health centers. Then, you can have clinics. That is another model. You can use hospice, which is another model. Nevertheless, we only have one hospice here in Ethiopia. And to have lots of buildings for palliative care is not realistic with the population that we have. So, we have to use a system that is already available. That is why we are using the Hub and spokes approach because the government cannot afford to build specific, standalone unit for palliative care and that is because the volume of patients that we have is not realistic to use another model". *[KII:1,52 Years old, FMOH]*

The Hub and Spoke approach is hospital-based palliative care service delivery approach that has been started by Ministry of Health recently, but in most of the hospitals, this approach is not practically implemented yet. However, in Yekatit 12 and

Minilik II hospitals, the palliative care units have been established as a room at the ground floor and one physician is working as palliative care focal person. Moreover, he showed the researcher some of the palliative care documents such as the palliative strategic plan of the hospital, and palliative care leaflets during the interview. This approach is currently focused on hospitals, but the approach has the following challenges: the services were not extended to the regions and to the community where the majority of patients live; palliative care funds were not assigned to run these activities; morphine is only prescribed by physicians and available at hospital level. Key informants and FGDs discussants in Jimma zone did not have experience of Hub and Spoke approach.

Therefore, this approach should be integrated and decentralized to the district hospital, health center, health post and community levels. As the ratio of physician to patients is very low in Ethiopia, morphine could be given by trained nurses and also made available in health centers and district hospitals.

4.6.3 Category 2 Hospice palliative care approach

Participants commented on hospice care in Ethiopia and stated that there is only one hospice in Ethiopia. It is located in the capital, Addis Ababa, and was founded in 2003 by Sister Tsigreda Yisfawessen, a medical nurse and palliative care professional who received training in Hospice Africa Uganda. She started by giving home-based care at her residence. Then, it was extended and transferred to a hospice.

Figure 4.2 shows partial view of Hospice Ethiopia, Addis Ababa,kotebe kara yeka

The study participants mentioned the palliative care service delivery at Hospice Ethiopia in an in-depth interview; one participant mentioned the following in regard to the historical development and services given by hospice Ethiopia:

‘‘Hospice Ethiopia is the only full-service palliative and hospice care organization in the country trying to address the huge need with limited staff and budget. Hospice Ethiopia is non- governmental, non -political, non- religious and non -profit organization which is funded by donors. It has been about fifteen years since it was founded by the Ex-

Manager, Sr. Tsigereda Yisfawosson, a medical nurse and palliative care professional; she is an Ethiopian and so after getting some training in Uganda, she came to Ethiopia and identified the gaps in palliative care service. At that time, she started to help patients at her home; and then, she changed it into an organization in 2003 and it was registered under proclamation number 621/2009. Therefore, It gives a service for 270 patients annually and has the following programs: home based care, out-patient care, day care program, and bereavement support.

Furthermore, it gives training together with the Federal ministry of health. The challenges related with Hospice Ethiopia is lack of its premises, lack of adequate and sustainable funds and expansion services to support the FMOH plan. The existing staff members' of Hospice Ethiopia are as follows: one executive director, one volunteer doctor, one health officer, two nurses, one social worker, one administrative and finance, one cashier, one cleaner, one guard and one driver". [KII:17,34 Years old].

Only one of the study participants explained that they had referral linkage with Hospice Ethiopia, as mentioned below:

"Each department has a focal person working on palliative care in the hospital and we have also referral linkage with Hospice Ethiopia". *[KII:11, 23 years old clinical nurse]*.

"We are working with Hospice Ethiopia. They have signed to work with the Ministry of Health to give trainings with them. We have only one Hospice and hospitals are working with hospice and refer patients to Hospice even though there is only one Hospice in Ethiopia" [KII:2 ,29 years old physician].

"The palliative care program has started by the Ministry of Health. We greatly appreciate the start. We are giving the training in cooperation with Hospice-Ethiopia" [KII:17,34 Years old].

On the other side, one study participant described that the level of partnership between Federal Ministry of Health and Hospice Ethiopia was not strong.

"... But, FMoH and the Hospice - Ethiopia are working in some level. But, not strong enough at national level" [KII:3, 28 Years old FMOH].

Table 4.4 Summary of Programs and service provisions in Hospice Ethiopia

Ser. no	**Programs**	**Service provisions**
1	Home- based care	Comprehensive palliative/hospice care services are delivered to bedridden patients in their home including physical, psychological, spiritual and bereavement support.
2	Outpatient care	Comprehensive palliative/hospice care services are delivered for those patients. Who are able to come to the center and bereavement support at home.
	Day care program	This is a weekly program conducted at the hospice center to provide psychosocial and spiritual support in a group setting, sharing experience among patients with entertainment and accommodation, at the same time if they have pain relief as well. Additionally, they are engaged in appropriate hand crafts production to help themselves.
	Bereavement support	Hospice Ethiopia provides culturally appropriate bereavement support for families those who lost their beloved ones due to life threating illness.
	Training	Hospice Ethiopia builds the capacity of health professionals through short- and long-term training to make them able to provide palliative /hospice care services for their patients.

Hospice-Ethiopia gives the following palliative care services: outpatient care, home-based care, day care and bereavement care services for patients with life-threatening illnesses such as Cancer, HIV/Aids, hypertension and diabetes. It provides such services to approximately 270 patients annually. The patients are referred from Zewuditu Memorial, Yekatit 12 and Black Lion hospitals and sometimes patients come to the organization themselves in order to access the services. Some of the challenges related to palliative service delivery in hospice Ethiopia includes, lack of funds in that, it relies on external donors and inadequate supply of palliative care medications like morphine. There were inconsistencies in the referral system and appropriate attention was not given from the above hospitals. Therefore, this has contributed to the development of the palliative care model for Ethiopia setting, but needs further work to create good communications and referral system between Hospice-Ethiopia and hospitals. The Federal Ministry of Health should give emphasise and support the services provided by Hospice Ethiopia to bring quality of life for patients with life-threatening illnesses.

4.6.3 Category 3 Outpatient, hospital based palliative care approach

One study participant working in a tertiary hospital described that they were giving palliative care services to cancer patients who are very weak and ill, on Tuesdays and Thursdays at an outpatient clinic.

‘‘What makes palliative care unique here is that it is only given in the Oncology Unit in this hospital. In a week, it is given for two days: Tuesday and Thursday. It is usually given for those who are very weak and highly ill’’. [KII:19,31 years old oncologist nurse]

Furthermore, one of the respondents at zonal hospital described the experiences in which the hospital used to give outreach services for chronic illness patients in their catchment area

‘‘Previously we were giving chronic care for patients with diabetes, hypertension and epilepsy patients at their living eight woredas to get easy access of care and drugs and also advise from the expert . Every month, one medical internist and nurses were

visiting some of health centers in Jimma zone such as Agaro, Serbo, Seka ,Yebu,Dedo, Asendabo, Omonada and Shebe health centers. The following activities were done by the project such as treating patients, giving advice, nursing care, donating B/p apparatus and giving training for nurses two times in years

These projects were funded by Tropical Health and Education Trust (THET) organization of the UK Government, but currently, the fund has discontinued .as the result the work is not strongly done as it used to be. But, such experience should be extended and hand over by government, in which hospitals are working with health centers with champions of professional expertise". [FGD2 38 years nurses working Chronic Clinic at Jimma zone*]*

The researcher developed an understanding on how the hospital is working with the surrounding health centers. This outreach activity may be cost-effective since the services can be given near to patients' residence. This type of chronic care service delivery is very important to develop a current model of palliative care, in which health center, health post, district hospital and tertiary hospitals are working together to give palliative care services for patients.

For the best functioning of the service adequate palliative care training for all health professionals should be given at all levels of the above health institutions. Good communication and referral system should exist between these health care systems.

4.6.4 Category 4 Strong Heart Ethiopia

Strong Heart Ethiopia is another non-governmental organization found in Kore, Lafto sub city , Addis Ababa. It gives the following services: home based care, pain relief, nutrition support , medical fees and provides toiletries and products, used to keep their personal hygiene for patients with life threating illness. A care provider described the service rendered by Strong Heart Ethiopia as follows:

“We give home-based care, treat the physical symptoms, give health education to the patients, provide support on drugs and nutrition and cover medical fees.” (KII 13 28 years nurse)

Another study participant described that they are working with Strong Heart Ethiopia as stated below:

“Strong Heart Ethiopia is another NGO working on palliative care. They can see patients here”. (KII:6, 36 years old, participant.)

On conclusion,Strong Heart is also another non-governmental organization giving palliative care services in Addis Ababa. It gives home-based care, physical treatment and provides health education and support for drug. It also covers medical fees. Therefore, such an organization is very important to develop a model of palliative care in Ethiopia.

Table 4.5 Summary of palliative care provisions in Ethiopia

Se no	**Approach**	**Scope/range of services**	**Illustrative quotes**	**Respondents id**
1	**Hub and Spoke approach**	Established at Black Lion Hospital, Yekatit 12 Hospital, Aleret Hospital, Minilik Hospital and St Paoul Hospital	a kind of bicycle wheel model. There is a central hub	*KII:3,KII:5 KII:6, KII:12 , KII:28*
2	Hospice Ethiopia	It also gives full service of palliative care and hospice care organization in the country. It provides home- based care, out-patient care,	The only hospice found in Ethiopia governmental, funded by donors. We refer the patient	*KII:17 , KII:2 ,* KII:6, KII:17

		inpatient care, day care program, and bereavement support. Furthermore, it gives training.	to Hospice Ethiopia	
3	Strong Heart Ethiopia	The NGO working on palliative care gives home-based care, pain relief,supporting nutrition, drugs and providing materials used to keep their personal hygiene for patients with life threating illness.		*KII:6,* (KII 13)
4	Outreach services	Phased out		*FGDs 2*

4.6.5 Category 5 Levels of palliative care provisions and referral system in Ethiopia

The levels of palliative care provisions in Ethiopia are scarce, except for a few tertiary hospitals, a few oncologist and nurses give PC for patients with cancer. One of the key respondents at tertiary level said that*“ PC care initiative in Ethiopia is at an early stage and should include the primary ,secondary and tertiary levels . In our set up patients are referred from the all parts of Ethiopia in order to get radio therapy and chemotherapy, therefore, these patients get at least primary PC at district hospital and health center ,when they return to their homes” [KII: 9, 41* years Old, Oncologist working in tertiary hospital*]*

A key informant from Hospice Ethiopia said that patients are referred from different tertiary hospitals of Ethiopia such as Yekatit 12 Hospital, Zewditu Memorial Hospital and Saint Paul Hospital, sometimes, the patients came without referral to get the services.

These patients would get the service through home visits and day care by the Hospice staff. Basic palliative care such as pain management and treating major symptoms were also given. In relation to this, there are some challenges including, inconstency of referral system and challenge relating to funding ,which is dependant on external donors as well as inadequacy of oral morphine supply''. [KII:17, 34 Years old].

The above category shows the levels of palliative care provision, in which Hospice Ethiopia provides basic palliative care such as home-based care, psychological care, bereavement care and day care. However, there were no organized levels of palliative care provision are observed. There are inconsistencies of referral systems for palliative care provision in Ethiopia. Primary, secondary and tertiary levels of palliative care provisions are very important and should be available in all healthcare systems to develop palliative care model in Ethiopia setting.

4.7 Theme 3 Domains of palliative care delivery

The analysis revealed that most health professionals who had participated in the focus group discussions mentioned that they were focusing more on disease treatment approach rather than holistic care and patient and family centered care. One of the study participants elaborated the scope of palliative care delivery as:

''Many times, we will focus on treating the main diseases; but, it is not known that it has spiritual component, social component or psychosocial component; and in general, it is not concerned with these components. Our main concern is curing the diseases. It is about curing the disease. For example, if it is hypertension, it is treating the disease. Beyond this, it is not our concern. Moreover, even physical component also is not complete; it is disease focused treatment in the country and our hospital is also the same''. [FGD 3, 23 years old nurse from Oncology Clinic*]*

Similarly, another study participant explained the domains of palliative care provision as follows:

‘‘In our country, we were more focusing on treating the disease and we miss the other components of the palliative care such as the psychological, social and spiritual issues”. [FGD 4, 28 years old nurse from Oncology Clinic*]*

Another study participant described the area of focus at Ministry of Health’s level as follows:

‘‘As I have told you, the Ministry of Health is giving more attention to communicable disease than non-communicable diseases”. [KII:14,29 Years old FMOH]

Furthermore, the study participants elaborated the importance of holistic care approach and this approach was not fully practiced in their practical set-up as described below:

‘‘Even though palliative care is comprehensive, in our setup, we implement only partially. It is not holistic approach. Even the training in palliative care is only half day training. But, if we work well in palliative care, it will have better outcome than medical treatment’’. [FGD1,25 years old nurse from ART Clinic]

Another study participant described that they were focusing more on disease treatment because of high patient flow, and thus, due to work overload, there is limited accomplishment of all other components of palliative care. He further argued as follows:

*‘‘Even though we are working on palliative care, I am not confident that it is being fully implemented. That means, in line with the number of Oncologists we have, one Oncologist may see up to forty patients and in order to consult, the Physician may need from forty minutes up to an hour.’’ For example, if I have 40 to 50 patients, what I do is I allocate my time as much as possible and I will try to treat them; but, there is no enough time to do all activities. I believe all the activities will be fully practical if awareness is created, the number of professionals increased and the number of patients allocated to Doctors is limited”. [KII:9,*41 years old, oncologist working in tertiary hospital*].*

The domain of palliative care includes holistic care that includes physical care, psychological care, spiritual care, social care and bereavement care. Therefore, this study assesses which components of palliative care are delivered to patients with life-threating illnesses within the health institutions as shown below:

4.7.1 Category 1 Physical care components

Taking a holistic approach, palliative care includes physical care, psychological care, social care, spiritual care, end of life care and bereavement care. Thus, this study assessed which components of palliative care dimensions were being givento the life threating illness patients.

Concerning the physical components of palliative care a 27 years old health professional, with six years of work experience shared his idea as follows.

“We give them physical care; we prescribe those appropriate medications and also treating the pain and major symptoms of the patients. Watching *people in pain is something that I do not like to work with; so, I have to asses and provide anti pain” [FGDs 2 ,27 years old health care provider]*

Moreover, a 29 years old physician noted,

“Now, we are working on pain management: physical pain management and breaking bad news. We are not as such working on spiritual and social care components.”

Similarly, one of the study participants in focus group discussion explained that the physical care provisions as:

“Palliative care is being implemented selectively because all the components of palliative care cannot being implemented. When the patient comes, what we do is we give immediate treatment. Much is not done beyond that. Most of the time, we think that palliative care is given after all the treatments are done. But, what has to be done is from the beginning up to the end”. [FGDs 2 ,36 years old health care provider]

A 28 years old female nurse in focus group discussion opined that

“… Palliative care is all about pain management; so, currently, morphine is preferable drug for severe pain management; but we do not have morphine in our hospital. In instead, we give tramadol or diclofenac injections for pediatrics, even morphine suspension form is not currently available in our hospital”. [FGDs 4, 28 years old health care provider]

As the above category shows, most of the respondents treated and focused on the disease part. From the components of palliative care, they were mostly addressing the physical care component mainly in pain assessment and management. However, they managed patient pain with anti-pain, but they had a challenge in using the appropriate drug to manage the pain because of lack of drugs like morphine in their health institutions.

4.7.2 Category 2 Spiritual care component

Further, this study assessed whether the spiritual component of the palliative care was given to the patients. One participant described the dimension of spiritual care as follows:

"We give medical aspects of palliative care as a component of medical treatment and it is not that much good enough. Sometimes, we also give psychological therapy especially for children who have HIV. Physiotherapy and psychomotor stimulation are also found in our ward. But, we are not using spiritual care because the setting here is not comfortable because there are different religious views. Also, there is confusion among health care providers concerning this component and due to these reasons, we are not using spiritual care here. In case of social care, it's not that much strong but sometimes, we use this for refugees from South Sudan and orphans; we give social support for them". [FGD3 participant from ART Clinic].

"On HIV and Cancer, there are patients who go to get spiritual care privately. We advise them to go there and similarly not to interrupt their medications. Otherwise, there is no such support at health institution level. In my previous working place, I remember that there was a priest from an Orthodox church, who was serving there. But now, I haven't seen him. So, if it is implemented, it has to be in all directions". [31 years health care provider]

"We take information from the patient on how they want to get spiritual care, but we could not link to religious Leaders as Patient need. Until now, we didn't invite religious leaders, rather our social workers support them by enhancing/encouraging them to do by them or nurses informally can pray to them based on their spiritual experiences.

Otherwise, there exists no formal spiritual care and support for patients in chronic clinic, including cancer which is very crucial”. [FGD2 health professional from Chronic Clinic*]*

“We give ART drugs, Prevention and treatment of opportunistic infections, pain and symptom management even though there is lack of opioids in ART clinic, again no formal spiritual care”. FGD 3 health professional from ART Clinic*]*

*“Spiritually, we didn’t do anything here but to avoid problems related to holy water, we do with adherence issue well”. [*FGDs 3 health professional from ART Clinic*]*

On the other hand, the following study participant explained how the spiritual care component was given for the patients in their facilities as described below:

“We have a chart to investigate the spiritual aspects. Our staff members are also trained on palliative care. So, we try to assess those who have spiritual problems. For example, there are issues which are raised believing that this disease is a curse; it is God who brought it to me; when I die, God will not receive me and those who are cancer patients are those whom God doesn’t like and the likes. For all these issues, there are activities that we do as professionals. We advise and sometimes, pray for them according to their religions. According to their interest, when they request for religious leaders, we facilitate for them so that their religious fathers will come and pray for them”. [**34** years old Manager at Hospice Ethiopia*]*

Similarly, an FGD participant emphasized that patients shared their experiences and also prayed together during coffee ceremony at the pediatric oncology unit.

*“Currently, we have coffee ceremony here in our cancer unit and also we encourage them to pray or make “Dua” “ዱአ“ as many of them are Islam religion followers. The coffee ceremony is served every Friday; they discuss and chat with each other. Finally, sharing their life experiences, but this experience was only for child with cancer not done for other chronic illness in our hospital and again no spiritual connection for spiritual councilors”. [*FGDs 1 health professional from oncology unit*]*

There was no formal spiritual care in the health institutions as the religious leaders were not consulted to give the spiritual care, but informally the health professionals advise the patients to have spiritual care according to their religions. In Jimma University Medical Centers Pediatric Cancer Unit, parents came together and had a coffee ceremony and prayed and chatted together. This interesting experience should be strengthened and expanded to other institutions and applied to other chronic illness too. Furthermore, spiritual religious leaders should be considered as members of the palliative care multidisciplinary team. Thus, we have to incorporate them in the development of palliative care model in the Ethiopian setting.

4.7.3. Category 3 Social care component

The study participants were asked whether they were addressing the social components of palliative care or not to their patients. Accordingly, one of study participants explained how they were addressing the social care as follow:

"In general, we do not have social support for all patients in our hospital. However, what we do here is attaching patients to missionaries and these missionaries support medical care but, in case of social support, it is not that much good. We have one social worker in our hospital and what he does is facilitating the medical care by finding financial support". [KII 12 ,37 years hospital manager Jimma zone]

Regarding the linkage, a physician working in Jimma zone also described as follows

*"There is informal care link with SOS children village and with missionaries of charity, where they give some social support by their own initiatives. However, there is no formal link between our hospitals these institutions". [*KII 17, 32 years old Physician in Jimma zone*]*

One of the components of palliative care is social care. As such, there was not social care for patients with life-threatening illness, but some of the study participants said that through their social care provider they linked poor patients to Macedonia, Missionary charity and local nongovernmental NGOs in order to get social support. Therefore, such social care should be considered as part of palliative care model development.

4.7.4. Category 4 Bereavement care component

With regards to care given after end of life, only one study participant from Hospice Ethiopia mentioned that care was given after death as follows:

A 34 year old study participant reported: "We give culturally appropriate bereavement support for families those who lost their beloved ones due to life threatening illness in Hospice Ethiopia". [KII:17, 34 years old].

On the other hand, most study participants did not mention the bereavement care in their interview. Even through bereavement care is one of the components of holistic palliative care that is given to families who lost their beloved ones, such care was only provided by Hospice Ethiopia. Other study participants did not mention this and had no experience on giving bereavement care. WHO encourages countries to include such care while giving palliative care for patients with life-threating illnesses.

4.8 Theme-4 Knowledge and practice of palliative care delivery

This study further looked into the knowledge and practice of providers on palliative care service delivery to life threating illness. To this end, the theme has categories such as practice on multidisciplinary team approach, and knowledge of palliative care such as duration of care and definition of palliative care.

4.8.1 Category.1 presence and practice of multi-disciplinary

The presence and support of multi-disciplinary team approach at health facilities is an integral element in giving holistic care for life-threating illness but defient in most of study settings .

"…. That has to be given is palliative care service, but what palliative care embraces is not only this. Psychologists and Sociologists are also needed to contribute their parts. For example, I gave treatment for a patient who cannot eat and speak. So, in such a case, if there are many professionals, they will contribute their parts. With absence of

these professions, it is difficult to say that there is palliative care. A palliative care should include psychologists, sociologists, psychiatrists and the likes. Then, Oncologists, Pathologists, Radiation Professionals, and Speech Professionals all would be involved". [41 years old, oncologist working in tertiary hospital*]*

"Palliative care can be given by health care professionals for example, by physicians, and nurses. If the patient needs physical therapy, physiotherapists must be involved; psychologists also must be involved because psychological support must be given. Also, clinical pharmacists must be involved in pain management. Families and community must be involved because this palliative care is given usually for chronic diseases at home. Any trained individual also can be part of this palliative care services. However, now, the burden is on physicians since other health care providers are not involved. So, we are working to participate with other healthcare providers. The team is not full. Other health care providers are not involved in round. We have to work in collaboration with nurses, pharmacies and social workers. Personally, I encourage this collaboration because our patients came terminally; we have to give palliative care to increase their quality of life." [KII. 27,38 year's old physician working on pediatric oncology unit]

Providing palliative care for patients with chronic illnesses needs multidisciplinary teams. However, most of the health professionals reported that there was no such team work practiced in their institutions. Each health professional carries out their duty individually rather than contributing to the team. The team approach is crucial to give palliative care, since most of patients with chronic illnesses visithealth institutions at the last stage of their illnesses. This multidisciplinary team includes a physician, nurse and a social worker. Counselors, religious leaders, psychiatrists, speech professionals, families and patients are also part of the team.

4.8.2. Category 2 Understanding concept of palliative care

Most of the participants defined palliative care as chronic care, holistic care and continuum of care, support care and end of life care as follows:

"Palliative care is holistic care; it includes care, medication, symptom management, psychological support and the likes given for any chronic disease and the services continue until post death". [26 years, FGDs 4 at chronic illness*]*

Again, one participant noted the importance of palliative care in ART Clinic.

"HIV shifted from a fatal disease to manageable chronic illness. Therefore, palliative care is important to bring quality of life; HAART is not a cure and has many side effects. We give ART drugs, Prevention and treatment of opportunistic infections, pain and symptom management even though there are lack of opioids in ART clinic. Again, no formal spiritual care". [34 years FGDs 1 health professional from ART Clinic*]*.

"Patients think that cancer/Chronic illness is incurable; so, they do not follow the care properly. They have pain and stress. So, it is good if we connect them with care givers. Palliative care mostly understood as the management of chronic care does not only require medication; it also involves as psychosocial care. Some of them considered it as punishment from God; it is devil's work. So, it needs strong counseling and reassurance. As to my knowledge, palliative care is mostly provided for HIV/AIDs patients not for other disease in our set up". FGDs 2 at oncology illness*]*

A study participant from Jimma Zone said that perception and awareness towards palliative care was very limited. He explained the situation as follows:

"The level of palliative care in our country is very poor and even though, palliative care is a human right that every individual should get this but, the perception of clients, care givers and professionals' on palliative care is very low in our country and thus, the service of giving this care is very low". [KII: 11,36 years old Internist in one of Jimma zone hospital]

This study also tried to find out what the appropriate time to start palliative care for the patients was and also when to stop providing the service. Most of the KIIs respondents considered that palliative care should be given at the end of life when medical treatment fails.

*“Mostly, palliative care is highly related with end of life when curative rate is low. It must be started at any time during the time of treatment. In other ways, I don’t believe that when there is definitive treatment, we don’t give palliative care. So, we give both treatments parallel. But, most professionals believe that palliative care is given when there is no definitive treatment”. [*KII:9, *23 years old oncologist nurse]*

Additionally, one study participant described the time to start palliative care as stated below:

“If there is a client, it must be started at any time during treatment especially today, and it is an evolving discipline. Previously, palliative care was considered for terminal patients, but, now, it must be started at any time as the patient starts to get medical care”. [37 years old physician from Jimma zone]

There was a diverse understanding of the concept of palliative care among the health professionals. Some of them explained it as chronic care, holistic care, end-of-life care and supportive care. However, some of them considered it as the care given to the patients when the medical treatment fails. In reality, palliative care should be provided together with medical treatment.

4.9. Theme 5 Barriers to delivering palliative care

This study also identified various challenges to delivering palliative care services. The study participants explained the barriers that hinder the delivery of palliative care in their facilities. Based on this finding, the major ones include: patient related factors, provider related factors,,resaech related factors, health system related factors and partnerships related factors. Therefore, this theme dealt with major barriers to delivering palliative care services in their facilities. It consist of five categories, and each category will be discussed in detail below:

4.9.1 Category 1 patients related factors

The study participants explained that patient related challenges were frequently cited as a barrier to accessing palliative care services provision which included late presentation to health institutions, lack of awareness about disease conditions, poverty and discontinuing their treatment, lost from there clinical follow up by considered cancer diagnosis as death /end of life and loss of hope were barriers related to patients.

FGD participants described that most of the patients came to the health facilities so late after the disease was advanced and after they had visited private health institutions and traditional healers.

"Many times, our community didn't have good awareness on the importance of follow up to the care for life long illness. So, patients come late after the problem is complicated. Example, cancer after late stage. This is because of lack of community awareness and sometimes, they go to traditional healers. And visiting different types of health institutions and treated for other opportunistic diseases". [FGD2, 26 years clinical nurse]

Another KII participant elaborated that patients came to health facilities late after the disease had advanced.

"Most of the time, they come late. If you take cancer patients, they come to here after the disease is in advanced stage because when the disease starts, it has nonspecific manifestation and individuals take analgesics and stay in their home but, when the diseases is advanced, they come here with referral or without referral paper". [40 years internist from hospital]

A 28 years clinical Nurse who participated on FGD1, described that lack of patients' awareness and consideration of cancer disease as deadly, loss of hope were some of challenges.

"Patients are lacking quality of life because of different factors such as they considered cancer disease as death, loss of hope and interest to stay at hospital and even wish to die at home; even psychosocial distress and financial crisis are the major problems in most of our patients". [28 years FGDs 1]

Similarly, the above participants clarified that patients did not want to stay at hospital and rather they want to die at their home as stated below:

*"…. loss of hope and interest to stay at hospital and even wish to die at home. Even psychosocial distress and financial crisis are the major problems in most of our patients". [*A 28 years clinical participated on FGD1*]*

Other respondents also emphasized the reason why patients stop their medication and lose out on follow up visits is that they were using holy water, prayers and DuA.

"… Sometimes, they left medications after starting the medication; they (patients) say "HOLY WATER ", "PRAY", "DUA" will heal us and stop their medication and lost, but we teach them not to stop taking the medication and to use both together" [a 24 years Health officer on FGD4]

"… sometimes, a patient changes his/her permanent address, cannot be located; that was challenging", [FGD4 32 years old nurse]

Similarly, A 26 year old study participant in a focus group discussion described how patients lost medical follow ups due to their religious practices as,

"… Many patients lost their medical management follow up; as they go for religious practices. They said we are healed and lost from the care to include spiritual care in medical management; we must work with clergy". [FGD2 26 years old nurse*]*

Further, the finding of this study showed that some patients considered chronic disease as punishment from GOD and also considered them as a curse. The following study participants described as follows:

"Patient consider the disease as curse as from evil in case of epilepsy and this should be corrected through palliative care, education of patients' families and community". [FGD4 26 years old nurse*]*

"Patients think that cancer/Chronic illness is incurable; so, they do not follow the care properly. They have pain and stress; so, it is good if we connect them with care givers. Some of them considered it as punishment from God; it is devil's work. So, it needs strong counseling and reassurance. As to my knowledge, palliative care is mostly provided for HIV/AIDs patients not for other disease in our setup. For families, we tell everything about their child condition, like their probability of dying, recovering. We tell them healing and dying is God's work and tell them to pray". *[FGD4 34* years old nurse*]*

"… because of other factors, most patients are lack quality of life such as socioeconomic factors and considered cancer disease as death, loss of hope and interest to stay at hospital and even wish to die at home. Even psychosocial distress and financial crisis are the major problems in most of our patients ". [FGD4 22 years old nurse*]*

Some respondents gave the following possible solutions for the above challenges related to the patients and said that,

"The patients believe that it is curse; but, when they come here, they will learn and also they will see the change. Since it is chronic disease, they become angry. Many patients want to follow traditional management but as their awareness increases, they tag to medical management & supporting management". [FGD4 25 years old nurse*]*

*"… Additionally, we give them our phone number to contact us if there is a need at any time. So, in challenges, they communicate with us". [*FGD 4, 38 years old at Chronic Illness Clinic*]*

As the above category shows, there are patient related barriers, which include late presentation to health institutions to receive palliative care services after using different things such as herbal remedies, spiritual rituals and some time lost from their follow up. Additionally, lack of awareness about the disease condition, poverty and discontinuing their treatment were also found to be other patient related barriers. Study participants used different tracing mechanisms such as calling patients on their phones and solving their problems. This tracing mechanism is very important in the provision of palliative care.

4.9.2 Category 2 Providers related factors

Providers play a key roles ,In providing palliative care for patients with life threatening illness , therefore ,this research assessed any factors related to providers that can hinder the delivery of palliative care in the study settings and the findings of these study showed that there are lack of awareness on the palliative care , lack of in-service and pre-service training on palliative care, lack of palliative care in the curricula of different disciples of health professionals and very limited palliative care research are conducted

"The main thing that is taken as obstacle is the knowhow of professionals are very low. If health care professional's knowledge and attitude is good, it's possible for the health care managers to create the system. So, to increase the awareness of management personnel and health care providers, training should be given. After that, it's possible to give this palliative care appropriately". [KII:9 41 years old, oncologist working in tertiary hospital*]*

"We have to hear to treat the patient but, our time is lost by dealing with hospital administrators. The problem of awareness is not only that of health care providers but it is also with hospital administrators. There is a problem of owning this unit as ours. We didn't get medications when we want; so, we have to work on the awareness because the gap is related with this awareness". [KII:27 38 year's old oncologist at Jimma zone]

"I believe that majority of our staffs are not trained and have no enough knowledge on this; so, the main thing is that this is not included in pre-service training and there is no enough in-service trainings. Generally, the knowledge, attitude and practice of palliative care are low". [KII:9 40 years hospital manager]

"The cost and the willingness of the professionals to give these analgesics is also another problem. When we take pethidine, most of the professionals are not willing to give because the patients may develop addiction. They believe that they don't deserve these analgesics". [KII:9 40 years hospital manager]

"Health professionals give more focus on prescribing medication alone, even palliative care is not only for patient, but also for families or care givers though we focus more on medications and even if given palliative care, more focus is for patients. As to me, I have not seen palliative care guideline here in our facility, did not have palliative care standards, but I have pain management guideline in soft copy". [FGD1 27 years old]

"We have analysis to treat the pain of cancer patients including morphine, but sometimes, there is shortage in morphine and I also fear the side effects of these drugs.

Even, it causes addiction and respiratory distress". [FGD 2 24 years nurses*]*

We did not learn palliative care on pre-services and also we didn't have guideline and protocol for palliative care. Lack of training makes it difficult to provide the service. *[* FGD 2 24 years nurses*]*

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"To tell you the truth, every professional doesn't have enough knowledge on this palliative care because it is neglected area in under and post graduate fields. There is no adequate formal learning and training for professionals in this area". [KII:26, 32 years old physician]

According to the study participants, lack of palliative care training is the major challenge. One of the participants explained her practice of palliative care training as follows:

"Up to now, no. What I remember is when Ethio-morpheme started here, I took one day training. There was no training on palliative care. Since palliative care includes many things, it is better to incorporate all the services. If that is so, there will be patient satisfaction and the activities will be done in a better way. So, it is better, especially for cancer patients if the service is inclusive ". [KII:23 30 clinical nurse]

"As I mentioned before, the training is at low level. Palliative care should be included in pre-service training; but, in our country context, it is not found, and as I know, there is no training given for physicians before they graduate even one lecture and I believe the majority of our staff members are not trained and have no enough knowledge on this. So, the main thing is that this is not included in pre-service training and there is no enough in service trainings". [KII:19 physician at Jimma zone]

Palliative care is not included in the curriculum, but I believe it should be included. Related to training especially on HIV, there are in service trainings but, there is no pre service training. Most health care professionals do not care about palliative care; they focus on treating the disease. There is an awareness gap; most professionals believe that palliative care is only administering analgesics. They do not believe it includes spiritual, social, and psychological aspects of palliative care and this is a problem. The other problems are there is no palliative care unit here. There is no multidisciplinary *approach, and no experience sharing and high staff turnover are some of the problems in applying palliative care. [KII:9 40 years hospital manager]*

"I didn't take pre-services, training, but I take in services training in compressive ART training only two pages, but, sometimes, trainer jump the palliative care portion and it was attached at last pages of the training manual". [FGD1 27 Years nurses]

"I have taken pain management training for three days and palliative care in ART training should be given for all health professions". [FGD1 23 Years nurses]

Another respondent described the importance of giving the training service as stated below:

"Chronic diseases are not healing, so we have to give service for those not healing patients. This is done through training. So, before providing the service , training of palliative care is mandatory to give holistic care. I have learnt on job; it is through experience". [FGD3, 35 Years nurses]

''We train Nurses, Doctors, Social Workers and Pharmacists. And we train them for one week. We give them full experience about palliative care and they will then, form this hub; we ask them to assign room in the hospital; training has been given for 12 hospitals which are found in Addis Ababa. Even for Paul and it was also given last year''. [KII:3, 36 Years old FMOH]

''Training is also being given. Physicians, Nurses and Social workers come from UK to give training to help us. They give us training and they also help us financially even if it is smallB. esides, we are working with The American Cancer Society on "pain free initiative" and "Palliative Care training"; we work with them sharing resources. However, we have to do more because palliative care is not only required for Addis Ababa. but also for regions. So, last year, we gave training for regions. We need financial support, organizations that support and we also need to organize resources''. [KII:14, 29 Years old FMOH].

Another KII informant described the importance of palliative care courses to be included in the curricula of health professionals and level of its integration.

‘‘Now, activities are being on the way to include in a medical curriculum; it has been included in curricula’s for Nursing specialties. The problem that we had was that first degree graduates do not have the concept of palliative care. So, after they graduate, they face challenges with regard to palliative care and pain management. Now, in the curriculum of Family Medicine, palliative care is included’’. [KII:12, 29 years old, *physician* working in tertiary hospital*]*

4.9.3 Category 3 Research related factors

Participants reported that very limited research is done in Ethiopia because thematic research area focused on communicable diseases.

“I In our country, researches done on palliative care are very limited; we can count them saying one, two. For example, there is one research done by one doctor, Dr. Nicolas; there was one research conducted in 2012 at AAU and published. It is about the dosage of morphin and how it can be started for Ethiopians. Apart from these, I think there are, only very limited researches conducted so far. So, if Universities conduct research on such topics, and trains professionals on palliative care, it will help our country “[.KII:11 36 years old Internist in one of Jimma Zone Hospital]

“I don’t remember any research conducted on this issue when I was conducting my research. When I say policy in addition to training, it must be one thematic area for researchers. But, it is not thematic area; even where it is thematic area, most researchers are not interested in conducting in this area. They do their research in disease related areas like hypertension, DM and others but in this area, it is low. “[KII:11 36 years old Internist in one of Jimma Zone Hospital]

By the same token, the above study participant explained that there was limited knowledge and a negative attitude among the professionals towards palliative care research.

“Yes, more concern is given for the disease related conditions not to palliative care. This may come from little knowledge and attitude. There is a bad attitude in our country from professionals that if a patient comes and cures from his disease, it is enough. Are patients getting competent treatment and whether they are happy, it isn’t a matter of professionals? In addition, with the level of policy, it is related with CRC. And the level of attainment of this CRC is also low; that’s why the level of palliative care is low“[KII:11 36 years old Internist in one of Jimma Zone Hospital]

4.9.4 Category 4 Health care system related factors

This study further assessed health care system related challenges to provision of palliative care which included shortage of resource, drugs, reagents, chemotherapy, radiotherapy and weak facility community linkage.

*“There are two physicians and some nurses who have been taking the training, but II said previously, there is high staff turnover and the trained nurses are not here. We have shortage of professionals, but there are unemployed health professionals. If the government employ them and send them to the community, they play vital role to address those patients who do not visit the hospital. So, awareness creation and strength of the health extension services are needed as they services are only effective on town. [*FGD3 *35 years nurses]*

The other is there is some problem in supply especially drugs like morphine. Even when there is availability, it is intermittent. The cost and the willingness of the professionals to give these analgesics is also another problem.

“Moreover, there is financial issue while providing the service; the drugs are expensive. Some patients are unable to pay for; so, they must pass through process which helps them to take the treatment until that patients are suffering due to pain”. [FGD3, 30 years old nurses from chronic Clinic*]*

“We have analysis to treat the pain of cancer patients including morphine, but sometimes, there is shortage in morphine [FGD2, 28 years old nurses from ART Clinic*]*

*We give ART drugs, Prevention and treatment of opportunistic infections, pain and symptom management even though there are lack of opioids in ART clinic; again, no formal spiritual care". [*FGDs 2, 25 years old nurses*]*

"The major problem is interruption of supply of chemotherapy drugs and opioids especially morphine. Previously, oral morphine was available but now, there is shortage .Further, and the traditional way of supply chain management is the major problem of our supply chain system. There is also a gap in the PFSA because there was a time when the chemotherapy drugs are available at central PFSA but, were not available in our setting.

"Moreover, there is financial issue while providing the service; the drugs are expensive. Some patients are unable to pay for so, they must pass through process which helps them to take the treatment, until then, patients are suffering due to pain". KII:19 physician at Oncology Unit]

4.9.5 Category 5 Partnerships related factors

One of the key informants at Ministry level explained that there was no non-governmental organization working on palliative care and very few on non-communicable diseases. More attention is given for communicable diseases especially on treatment and preventions.

"In our country, organizations that work on non-communicable diseases are few. On the other hand, they work on communicable diseases. Even, it became difficult for us to discuss with CDC because they talk about prevention and communicable diseases. So, there is no one who works with Ministry of Health". [KII:2, 36 years old, FMOH]

This study also showed that ,there is weak facility-community interface

We did not give end-of-life care because there are challenges, for example, it is difficult to give in the society; we only give the service here and we are not in the level of outreach services. FGDs 5, 32 years old nurse from chronic clinic.

This study assessed different local non-governmental organizations and Faith-based organization at Jimma Zone to look at the degree at which they were rendering palliative care provisions. Based on this, the following local non-governmental organizations in Jimma zone were interviewed: Mekdem Ethiopia, Organization for Social Service Health and Development, Feya Integrated Development Organization, and Ethiopian Evangelical Church Mekan Eeyesus Social Service/Jimma Branch (FOBs).

Results showed that the majority of the organizations interviewed worked in the area of HIV/AIDS, providing palliative care. Most of the managers of local NGOs and FBOS highlighted, in the in-depth interviews, that the financial donors supporting patients were much lower than the previous donations. Also, there was incompatibility between need and supply. The number of patients who need support is very high.

All of the study participants reported that funding for their projects was largely dependent on external sources,they relied exclusively on donations to function. This constraint limits operation and hinders care capacity. All partners reported that there was a big challenge to deliver the care and support to patients.

Table 4.6 summery existing local NGOs and FBOs working on HIV/AIDS in Jimma town and scope services delivery

Ser. no	Name of Organization	Location	Services delivered to patients	Challenges
	Organization for Social Service Health and Development	Jimma town	Care and support for HIV AIDS patients Work on adherence, positive livening and prevention, training of peer educators, establishing anti AIDs club Support on education, medical aspects and in economy HIV/AIDS education and awareness. Help in income generation	The budget is from USAID Our agreement is also for five years. However, they terminated it in three years.
	Mekdem Ethiopia	Jimma town	Counseling and follow-up program and adherence support prevention of HIV from child-to mother	Mismatch between budget demand and supply Selecting 12 persons per quarter from 615 to support their food requirements no system and

				budget to communicate with faith based organizations and social care support there is no commitment on the part of government. Repetition of data of clients from different NGOs . Almost everything they do is similar.
			Provide home-based care. trained volunteers Food and health facility support (for 12 persons per quarter), helps them income generating activities training on income generating activities	

	Feya Integrated Development organization	Jimma town	Giving care and treatment services for HIV patients among the community. Follow the patients for adherence, drug side effects. Training on saving and forming community –care coalition by integrating with community	there is no challenge; but, we do not have many machines for viral load and CD4 counts
	Ethiopian Evangelical Church Mekane Eyesus Social Service Development Commission	Jimma town	Care and support of HIV/AIDS, Work on adherence Providing psychological care, Training on saving money, Educational support for orphans , tracing lost patient, hygiene and sanitation	Lack of adequate funding delay of budget. Mismatch between the clients' demand and our service. Most of the time, HIV patients are mobile Fear of stigma and discrimination

This category has shown that most of the aforementioned local NGOs have been giving service for patients with HIV/AIDS, but not for other chronic illnesses that need palliative care .Besides, there is also inadequate fund across all the local NGOs; the funds are from external donors. Both international and local partnerships are very important in provision of palliative care and in developing palliative care model in Ethiopia.

4.10 Theme 6 Actions that support palliative care model development

The above theme described the actions that support the strengthening of palliative care model development in Ethiopia setting. This further included four emergent categories such as presence of strong community structures, integration of palliative care in to existing health system and presence of family medicine program in Ethiopia, extension health workers and health development army in the community, training of health professionals on palliative care. Each category was described as follows:

4.10.1 Category 1 Presence of strong community structures

Quite a few of the respondents argued that since Ethiopia has a population of more than 100 million and most of them live in the rural area, community based model of palliative care could fit to the setting because there are presence of strong community structures and such social networks surround ill patients and their families, which enhances the development of palliative care model in Ethiopia setting.

One of the study participants (KII1) explained as follows:

''… Ya, you can have like the community-based model; when we look at population of Ethiopia 100 million, it ultimately likes to be in the community. So, it needs to be community-based model and specially. It goes to the regions. So, community-based is the one to be used by health centers. Then, you can have clinics. But, when we go to patients with severe pain, they need to have morphine. But, morphine is only available at the hospitals. So, we are using this hub and spoke approach at this time''. [KII:3, 36 Years old FMOH]

The same respondent described that the existence of very strong social network in Ethiopia setting could make it easy to deliver palliative care to people as stated below:

‘‘I think for palliative care in Ethiopia, there are very positive things. One is the social network that supports surrounding people. You know, in my county, one of the biggest issues is to find careers and to find people that would visit. Palliative care is easy to set up here because we have an amazing social system. We have religious leaders; we have neighbors; we have the “idir”; we have the “ekub” and we have the “Mehabers”. We have all these massive groups’’. *[KII:1, 52 Years old FMOH]*

‘‘Ya . So, one of the things we are trying to do is working with the “idirs”, hospice Ethiopia; we are just trying to apply for a proposal to get money. So, we can train some things like that. It is also one thing that we have on a national policy as well to work with the “Idirs” because these were used very well in HIV/AIDS pandemic; so, they can be used for palliative care. That is a very important thing to mobilize’’. *[*KII: 1 *52 Years old FMOH]*

4.10.2 Category 2 Integration of palliative care in to existing health system

One of the KI said that building isolated palliative care unit was very difficult for the Ethiopian setting, however, integrated palliative care service provision into the existing health system would work better, as noted below:

“ … we rarely have one hospice here in Ethiopia. And to have lots of buildings for palliative care is not realistic with the population that we have. So, we have to use the system that is already available. That is why we are using the hub and spoke approach because the government does not afford to build specific, standalone unit for palliative care because the volume of patients that we cannot enable us to use another model. *We have to use the system already set by the government. That is the main reason for working with the Ministry of Health to get good coverage; it has to be aided by Ministry of Health. [KII:1,52 Years old FMOH].*

Similarly, one KII informant explained that the importance of palliative care service integration and its referral systems at health care facilities after each hospital developed Hub and spoke approach.

"… we are training staffs from hospitals so that they will open a hub. Then, the hub will be at the center so that they will assess those who are there. Following that, we will link them with health organizations. After we train those who are in organizations, we will link those who are in hospitals with those who are in health centers. After those who are on health centers are trained, we will make them train those who are on health posts. They have what we call family health by which they work within the community. The family health includes many disciplines. Just like that, they have to work on palliative care in the community by discussing with those who are poor and those who are suffering from diseases so that they will go to health posts and get treatment and if morpheme is required, they will be referred to hospitals". [KII:14 29 Years old FMOH].

4.10.3 Category 3 Presences of extension health workers and others

KII said that presence of these health professionals in Ethiopian health care system could enhance the development of community-based palliative care model at grass root levels.

"… Now, the number of Family Medicine graduates is increasing. So, they have their own independent department at Black Lion Hospital. There is a department called Family Medicine. Last time, we had a workshop and their explanation about their job description was very interesting and their position is here on primary hospital. So, the number of patients who come to tertiary hospitals may decrease and what they do is very interesting; they will also visit patients at home-based level. They have what we call family health by which they work within the community. The family health includes many disciplines. Just like that, they have to work on palliative care in the community by discussing with those who are poor and those who are suffering from diseases so that they will go to health posts and get treatment and if morphine is required, they will be referred to hospitals. So, we are intending that the referral system from the community

up to the hospital has to be done like this. So, we will advertise it in the future and to do that, it needs to work on many things''. *[KII:14, 29 Years old FMOH].*

Furthermore, one respondent described the importance of health extension program and health development army program to provide palliative care to family at house hold level.

''I am working on 16 health packages which include hygiene and environmental sanitation, family health, health education and prevention in the community and addressing universal health access. Currently, our new modules address non communicable diseases and a bit cancer and palliative care; so, we are screening for chronic diseases in the family and we advise them to have health seeking behaviors''. *[27 years old health extension worker in Jimma town].*

''Again, health development army is another option to address this issues because there is social networking one - in five group with women in centered working in maternal services; so, better to use them as scale up of palliative care provision in the community'' [25 years Health Extension worker in Jimma town].

4:11 Theme 7 Recommendations for improved palliative care in Ethiopia

This consists of one category including the participants suggestions and ways forwarded to establish palliative care development in an Ethiopian setting.,Since non communicable diseases such as diabetes, hypertension, cancer, cardiac diseases and early stage of organ failure are prevalent, most participants were supportive of the need for more pallicative care services in Ethiopia.

Most of the study participants agreed that the establishment of palliative care does not required huge buildings,rather it is possible to integrate the palliative care services into the existing health care systems of Ethiopia with good referral and partnerships to support this.

Therefore, the Federal Ministry of Health and other stakeholders should facilitate the integration of palliative care into existing health care systems in the community. This will enhance the accessibility and affordability of palliative care to those people in need of this service. Furthermore, the study participants recommended the development of important palliative care policies, strategies and standards for the delivery of palliative care in the health care system.

In order to fulfill this, education of health professionals in palliative care is critical. Therefore, extensive pre service and in service palliative care training should be mandatory. Support should be rendered to these health professionals so that they transfer the learned skills into their work settings and they should be encouraged to appoint palliative care champions. Appropriate budgets should be allocated to ensure availability of palliative care medications and other important resources. Working with the NGO sector in delivery of palliative care is also key.

4:12 Conclusion

This chapter described and presented the findings of the study, which included the themes that emerged from the data analysis encompassing the scope of palliative care delivery service, domains of palliative care provision, knowledge and practice of health professionals on palliative care service delivery, challenges of palliative care delivery, strengthening and enabling factors to develop palliative care model and suggestions that were forwarded to improve the palliative care provision in the Ethiopian set up.

The next chapter will present the discussion and development of best practice palliative care model in resource scare setting to improve palliative care provision for patients with life-threating illnesses.

CHAPTER FIVE

Discussion and Application of the Findings

5 Introduction

The previous chapter outlined the data analysis and research findings. This chapter encompasses the major findings of the study which will be discussed and interpreted in light of research evidence from previous studies. Therefore, in this discussion section, I will briefly highlight the themes described in the chapter four. In chapter 6, Palliative care model will be developed for Ethiopia setting based on the findings of this study. This model will then be presented to key stakeholders to give their inputs to verify, adapt and refine.

To my knowledge, the present study is the first of its kind in the Ethiopia and it is an untouched area. Therefore, this work is ground breaking in the Ethiopia context.

5.1 Overview of the research discussion

In this study, seven themes were extracted from the in-depth interviews and focus group discussion analyses in order to explore and develop cost effective palliative care model in resource scarce setting. The themes that emerged from the study were interpreted and discussed using literature sources and in line with theoretical framework that includes the elements and context of palliative care in resource - poor environments and objectives of the study. This study assessed the existing provision of palliative care in Ethiopia, starting from Federal Ministry of Health to community levels in order to stablish the extent of palliative care provisions and the palliative care model practiced in the setting. It examined the existing challenges and opportunities in the current palliative care service provision in order to develop palliative care model that is appropriate in resource scarce setting.

Seven themes were extracted from the in-depth interviews and focus group discussion analysis to explore and develop cost effective palliative care model in resource scarce setting. The emergent themes have been interpreted and discussed employing literature sources and consistent with the theoretical framework which comprises the elements and context of palliative care in resource-poor environments as well as the objectives of the study. The seven themes emerging from the study are listed below:

- **THEME 1**: Scope of palliative care in Ethiopia
- **THEME 2**: Current Palliative care service delivery approaches
- **THEME 3**: Domain of Holistic palliative care delivery
- **THEME 4**: Knowledge and practice of palliative care provision among service providers.
- **THEME 5**: Barriers to palliative care service delivery
- **THEME 6**: Actions that can support the strengthening of palliative care model development
- **THEME 7**: Recommendations for improved palliative care in Ethiopia

5.2 Scope of palliative care provision in Ethiopia

This study found that despite an increasing burden of chronic diseases and palliative care need in Ethiopia, there was a significant encouragement for the palliative care movement in the country. The Federal Ministry of Health recognizes and supports palliative care measures aimed at improving quality of life of people with life-limiting illnesses. It however falls short in actual practice in terms of coverage and implementation of the services. Palliative care is still not available to many patients in the region. These findings are supported by a recent study done in Ethiopia that showed there is an extensive unmet need for palliative care while the burden of non-communicable diseases and cancer is increasing (kaba et. al. 2021:1). Despite the fact that the provision of palliative care is vital in improving patients' quality of life and ensuring responsive health system in the country, palliative care is still not available to many patients in the regions of Ethiopia.

The WHO's recommendation for the integration of palliative care into the existing health care system (Grant et.al 2017:1) calls for supportive governmental policies, strategies, guidelines, education and training. However, limited initiatives were undertaken by the Ministry of Health in achieving this purpose.

5.2.1 Palliative care policies, strategies and guidelines

The current study revealed that Federal Ministry of Health values palliative care as an important discipline. Consequently, it is included as a chapter in the Hospital Transformation Guideline in order to be implemented in all public hospitals. It also endorsed a pain score policy where the pain score was considered as the 5th vital sign to be managed and practiced within the existing health care system. Moreover, the Hub and Spokes approach of palliative care model was highlighted in the previously set policy for delivering palliative care services in hospital settings. There was a palliative care clinical advisor and clinical officer team at the level Ministry of Health which lead and coordinated palliative care services in the country. The national palliative care guidelines and pain management guidelines have been developed and printed out. These findings were supported by other studies which indicate that palliative care was included in the training for physicians in a basic ARV program (Onyeka,Velijanashvili, Abdissa,Manase & Kordzaia 2013:601) and National Palliative care guidelines published in June 2016 and are currently being printed.

However, the palliative care strategic plan was not yet complete and the draft version was in the process of being formated. Although Ethiopia is not a member of any formal palliative care associations, national palliative care day has been celebrated since 2019.

5.2.2 Education and palliative care training

Trained and competent health professionals are essential for palliative care services' provision. Education and training are important pillars of the World Health Organization's public health model for palliative care service delivery (Stjernswa, Edin, Foley & Ferris 2007:490).

The tireless contributions of Dr. Nicola Ayers towards capacity building and establishment of palliative care over the past four years in Ethiopia in collaboration with UK-based charitable organization is worth mentioning. Health professionals such as doctors, nurses, pharmacists and social workers received two days training on Basic palliative care and three days' for training of trainers (TOT) Palliative care training (in three rounds) in order to develop Hub and Spokes model of palliative care in their respective hospitals. Palliative care has also been integrated into Nursing specialties curricula such as, Oncology Nursing, Medical Nursing and Surgical Nursing. Furthermore, Family Medicine graduates have been taking palliative care courses and have a practical attachment at Hospice Ethiopia. In line with these findings, the reviewed literature showed that the key to delivery of palliative care is the training of healthcare workers in the principles and practice of palliative care (Gwyther& Krakauer 2013:6).

However, the current study revealed that the integration of palliative care into the curricula did not include other programs such as all undergraduate and post graduate Medical and Nursing curricula; consequently, many graduate doctors and nurses lacked training in provision of basic palliative care. As part of the year's a long pain free hospital initiatives project, the Ministry of Health professionals for pain assessment and management including provision of oral morphine as well as integration of pain management and practice with existing health care system.

Despite capacity building on palliative care, this study indicated that most of the participants in the regional state did not have any palliative care training in pre-service and in-services training and there was high turnover of trained staffs. Similarly, the study done by (Rhee et.al 2017:86) reported that both medical and nursing schools in the country did not include palliative care education as optional or mandatory requirements. However, the current study revealed that Ministry of Health has plans to include pre-service palliative care trainings in both medical and nursing programs.

Furthermore, there had been collaboration between the Ministry of Health and American Cancer Society in the Pain Free Hospital initiatives project for one year. During this period, health professionals were trained in assessment and management of pain and the provision of oral morphine. Pain management has since been meshed with the existing health care systems. Independent hospital initiatives have also given training to health professionals on pain management and treatment as well as awareness on pain relief.

According to Lynch, Connor and Clark (2013:1099) in their global mapping of palliative care development, Ethiopia has moved from category 2 countries in which there were only capacity building activities without service establishment, to category 3a countries in which there were isolated palliative care provision characterized by the development of palliative care activism that was patchy in scope and not well-supported.

Although Ethiopia moved from category 2 to category 3, findings of a recent study showed that Palliative care in Ethiopia is in its early stage since patients living with life-threatening conditions have limited access to palliative care. A limitation in the Ethiopian health system is that palliative care is currently not part of medical training nor is it an option for specialty training (Anderson et.al 2018:3).

5.3 Current Palliative care service delivery approaches in Ethiopia

A model of care is described as an overarching design for the provision of a particular type of health care service (Davidson et.al 2006:3). In this study, the model of care includes the setting that provides palliative care for the life threatening illness, its levels of palliative care provisions and the team involved in the provisions of palliative care.

Palliative care can be delivered in different settings based on existing resource and local needs. Currently, there are palliative care delivery approaches practiced in Ethiopia such as Hub and Spokes approach, Hospice Approach, Outpatient hospital based approach and outreach hospital based chronic care approach.

5.3.1 Hub and spokes palliative care approach

The finding of this study showed that the Federal Ministry of Health does not have an official palliative care policy although there was pain score policy. Ethiopia has implemented palliative care service delivery using Hub and Spoke approach after building staff capacity through palliative care training.

The Hub and spokes model is like a bicycle wheel in which the center of the wheel is the hub and the upside of the hub is the spoke. So, the hospital is the equivalent of the hub since drugs like morphine are available exclusively at hospital level in Ethiopia set up.

Although this model is at the inception stage, twelve hospitals in Addis Ababa and two more in the regions were proactive in functioning as palliative care hubs. However, while some hospitals have developed fully functional hubs, others were in the process of developing them, but the majority had made no effort at all.

Although palliative care strategy is under finalization at the level of Federal Ministry of Health, there is no palliative care policy across the health care system. Though palliative care has been included in the hospital transformation guideline, currently, hospitals are not evaluated for palliative care services provision. Instead, the evaluation focuses on pain management and pain score rather than palliative care service provision. This finding is also consistent with a study done by Rhee (2017:44) which confirms that PC is presently limited to Addis Ababa. Another finding from this study revealed that establishing a national policy, offers the best way to ensure adequate palliative care for the greatest number of patients and families in a cost-effective manner (Clark, Wright, Hunt & Lynch 2007:708).

The result of the current study showed the challenges related to the Hub and Spoke approach. Since Ethiopia has more than 100 million people, a community based palliative care approach would be more suitable even though Hub and Spokes approach would be helpful and seems to be working in Ethiopia. Furthermore, a community-based approach would require a center or ‘hub’ such as a local hospital to support the provision of morphine and provide specialized services and training.

Harding and Higginson (2003:1971) drew attention to the success of home and community-based palliative care in African setting via community capacity and resources involvement and clinical supervision. In line with these findings, the study

indicated that most of the Ethiopian population lives in rural areas with geographical variations (World fact book 2014:3). Morphine is also only prescribed by physicians.
Another study highlighted that for a country where half of the population lives in remote areas (18 inhabitants/km^2), there is need to set up a home care programme that can ensure services are available even in very remote areas (Devi, Tang & Corbex 2010:31).

Further, even though hub and spokes approach of palliative care mode is currently applied in major urban settings such as Addis Ababa, it is unclear whether the model is practicable in the regions given that Ethiopia's geography and the fact the majority of people live in the rural area. Therefore, there is paucity of evidence for policy makers since they do not have enough evidence to determine which model or combination of models would be best suited to the Ethiopia setting or preferred by Ethiopian patients and families.

The WHO recommended that for resource constrained country, where the number of people needing care is high and the number of nurses and doctors to provide that care is low, a successful approach is the provision of care through trained community care givers or volunteers who are supervised by health care professionals (WHO 2013:5).

Similarly**,** WHO 2009:3 recommended a community-based palliative care model for Ethiopia due its large population and geography and the fact that the majority of people live in a rural setting. Moreover, the study showed that Ethiopia has limited palliative care provision and there was little known about how palliative care is accessed and cultural context on what palliative care looks like with regards to the giving and receiving of care (Ayers 2015:47).

A recent study showed that although the focus of palliative care provision within Sub-Saharan Africa has often been at the community/home-based level, it is important that services encompass both the community and the hospital setting by focusing on a public health model approach that integrates care into national health systems to increase accessibility (Downing, Hons, Grant, Leng & Namukwaya 2015:364).

Therefore, the standalone hub and spoke approach is unable to provide complete palliative care services for patients with life threatening illnesses and their families in Ethiopia's setting, unless, integrated community and home-based services are considered to render palliative care services in the rural setting of the country.

5.3.2 Hospice palliative care approach

The finding of this study showed that Hospice Ethiopia was another model for palliative care services provision. It is a non- governmental, non -political, non- religious and non-profit organization which is supported mainly by external donors. It is the only hospice in Ethiopia, located in the capital, Addis Ababa. Hospice Ethiopia was founded in 2003 by Sister Tsigeda Yisfawosson, a medical Nurse and palliative care professional, following training by Hospice Africa, Uganda. She started by giving home-based care at her residence. Then, she upgraded the service to a hospice. Similarly, in most Africa countries, hospice and palliative care development were in response to the needs of people with cancer or HIV (Lucas 2000:3). They were also developed by motivated pioneering individuals rather than through main stream organizations (Lynch et al., 2013). A study conducted in 2015, showed that this model was developed within the Ethiopian cultural context which involves care delivery by local for locals(Ayers 2015:256).

The current study also showed that Hospice Ethiopia delivered the following programs: home based care, out-patient care, day care and bereavement support. The study done by Ayres indicated that the hospice had a memorandum of understanding with two governmental hospitals in the capital and a local clinic with limited resources (Ayers 2015:265).

Similarly, a study conducted by Anderson et.al (2018:3) showed that Hospice Ethiopia and Strong Hearts are two small non-profit organizations located in Addis Ababa, are the only licensed palliative care institutions in the country. They try to address problems related to care for patients with chronic illnesses, like HIV and cancer patients. Both organizations rely on fundraising and donors for finance.

5.3.3 Strong heart Ethiopia palliative care approach

Strong Heart Ethiopia is another non-governmental organization found in Kore, Lafto sub city, Addis Ababa and it provides the following services: home-based care, pain relief, supporting nutrition, covering medical fees and providing materials used to maintain personal hygiene for patients with life threating illness.

The majority of hospice services are not an extension of existing medical services, as they were established through NGOs and charities that predominantly started as home care services or were set up as in-patient hospice facilities, as is the case with Ethiopia (Wright *et al.* 2006:8). Another study shows that Palliative care is not yet supported by a national policy or governmental funding in China or India which together account for one third of the world’s population (Li , Davis & Gamier 2011:294).

5.3.4 Outreach programme approach

This investigation found that the outreach programme was given near the patients’ residence by Jimma University Medical Center in collaboration with Tropical Health and Education Trust (THET) organization of the UK Government. With the help of the outreach programme, professional teams went to health centers at Woreda level to provide chronic care for patients with diabetes, hypertension, epilepsy and cardiac disease. This program empowered nurses who were providing similar service at respective health centers by training them once a year. This was the scope for the development of palliative care model in Ethiopia in which the tertiary hospitals work with health centers and health posts.

This finding is supported by meta-analysis of reviewed literature in Australia which revealed that models of palliative care should integrate specialist expertise with primary and community care services and transitions across settings. Additionally, according to the meta-analysis, there should be clinical networks of health professionals and organizations from primary, secondary and tertiary care working in a coordinated manner (Luckett et al. 2014:1). Furthermore, patients and families often play an active role in determining which services they want to receive and it increases their capacity to respond rapidly to individual patient needs and their preferences (Lucket et al 2014:15)

5.3.4 Outpatient hospital based palliative care approach

This study indicates that out patient, hospital-based care was given by one of the tertiary hospitals in which the patients were appointed in the clinic to get palliative care for two days per week. The services given are mainly pain assessment and management, while palliative care is beyond that in which other components of palliative care such as psychological, social and spiritual care are included. Similarly Study showed early integration of outpatient care benefits with advance cancer and also the health care system, the development of robust and capable outpatient clinic is necessary to meet the growing demand for these services a among patients with advance cancer . (Esme et al 2021:187)

5.4 Domain of Holistic palliative care delivery

The study showed that there were deficiencies in the provision of palliative care packages to the patients in most of the study settings. The focus of care was on the treatment of diseases while excluding other equally important components of comprehensive palliative care such as psychological, social, and spiritual and bereavement care. The findings were supported by a recent study done in Ethiopia in which the existing programe is more focus on treatment of symptoms with limited psychosocial, emotional, spiritual and economic support (Mirgissa et.al 2021:1) .This indicates that despite increased needs of palliative care services in resource-poor countries, there is no evidence to support calls for integration of curative and palliative care. Moreover, study done in Portugal, educational institutions gave more attention for curative treatment and lacked in the training of health professionals in palliative care treatment resulting in difficulties in implementing palliative care (Braga Da Cruz & Nunes 2016:74). However ,study done by Liz,Julla and Mhoira (2012:4) indicated the provision of holistic approach which centred on both patients and their families to avoid the silo approach to disease treatment addresses and captures both patient and family needs.

5:5 Knowledge and practice of palliative care provision among service providers

Providing palliative care is pivotal for patients with life threating illnesses. In order to perform this, health professionals should have knowledge and understanding of palliative care given for the patients and their families. This study revealed that most of the participants from Jimma zone had inadequate knowledge about palliative care due to the following possible reasons: they have not been trained and palliative care was not included in the curricula of both under and post graduate study of nursing and medical schools in Ethiopia. However, most of the study participants defined palliative as comprehensive, chronic and supportive care. Furthermore, they agreed that palliative care is being given at the end of life and when patient's conditions are deteriorating. Similarly study done by Trevor, Deepa and Joseph (2019:1) showed that there were insufficient knowledge and low level of awareness a among of patients, families, the public and health care professionals about palliative care services and their benefits. Therefore ,palliative care education necessary and should be the first step to improve awareness and knowledge of health professionals to delivery effective palliative care provision

5.6 Challenges and gaps in palliative care provision in Ethiopia

Despite the palliative care development initiatives and health professional training in Ethiopia, this study revealed that like any other area of health, especially in less resourced countries, there were major challenges related to the establishment and provision of palliative care services. These challenges can be patient-related, provider related, health system related or drugs and research related. These factors all influence the instituting of a model for provision of palliative care in Ethiopia.

This observation is supported by qualitative findings from perceptions of seven African countries such Cote-dvaire, Ghana, Kenya, Mozambique, Nambia, South Africa and Sudan. Here, palliative care development is likely to be compromised due to challenges such as lack of palliative care education, lack of standards, limited availability and accessibility to morphine, poverty, disease burden and lack of funds for palliative care (Rhee et.al 2018:13). The aforementioned challenges were also compounded by poor health, social infrastructure and limited health financing in most of African countries (Kassa, Murugan, Zewdu, Hailu, & Woldeyohannes 2014:2).

5.5.1 Policy related factors

The major challenges for health professionals were identified as lack of clear cut policy together with the absence of appropriate strategic implementation plans, which are practically relevant to various levels of health care. Moreover, health policies of the government emphasized on communicable diseases rather than non-communicable. As a result, dearth of funds was always a stumbling block for effective and efficient palliative care.

The current finding is also consistent with a study that describes the palliative care journey in Kenya and Uganda. The limitations in policy and regulatory failure to integrate palliative care in public and private health care systems, lack of funds and trained professionals, lack of funds and t were the main gaps and challenges related to palliative care provisions (Kamonyo 2018:52). The study also revealed that most African countries do not have appropriate polices to integrate palliative care into their national health care system (Ddungu 2011:733).

There was scant research publication on palliative care in Ethiopia which is in line with the findings by (Rhee et.al 2017:28-29). The Ministry of Health has been endowed with an advisory on palliative care, however, absence of membership to the Africa Palliative Care Association or any palliative care association, scant research publication on palliative care, were some of the lacunae in the country. Similar observations were reported by (Rhee et.al 2017:28-29).

One of the factors that affect palliative care model delivery is lack of adequate financial support. Most palliative care services are provided by non-governmental, faith, or community-based organizations with no in-built sustainability (Faith & Olivia 2011:19).
A study showed that there were no funds assigned for palliative care from Ministry of Health and this affects the delivery of palliative care provision and establishment of palliative care model. Participants reported that the Ministry gives more focus for

communicable diseases than non-communicable diseases. Furthermore, there is no strong and organized support for palliative care activities through international non-governmental organizations or foreign governments, who are capable of funding palliative care provision in Ethiopia. This observation was supported by Lucas (2018:1317). He states that palliative care funding is one of major challenges in which palliative care provision in Africa and it is still largely dependent on external donors.

5.5.2 Patients related factors

The study by Ababa,(2014) found delayed presentation by patients to health facilities often after unsuccessful treatment from private clinics, traditional healers and religious institutions. By this time the diseases would have advanced and become untreatable. Therefore, late presentation to health facilities and myths and misconceptions about the disease as a curse and considered as end of their life were the biggest challenges related to cancer patients. Further, this study showed that lack of awareness about disease conditions, poverty and loss from follow up and loss of hope were challenges linked to patients. The findings were also supported by Kassa (2014:2) who noted that patients with cancer and other chronic illness came to health institutions presenting late stages of the diseases (Haileselassie et.al 2019:1). This might be due to lack of patient awareness to disease condition and lack of diagnostic facilities in Ethiopia.

5.5.3 Providers related factors

Health professionals have an important role in improving palliative care service for patients with life threatening illness. The current study identified provider related factors that impeded the proper delivery of palliative care for patients with life threatening illnesses. This includes lack of knowledge and practice of palliative care especially at regional and zonal levels, lack of multi-disciplinary team approach, more emphasis on disease treatment with medications alone and high turnover of trained health professionals.

Despite the palliative care and pain management training at Federal and University hospitals level, the researcher found that most participants from Jimma Zone hospitals lacked knowledge and practice of palliative care which affected the provision of quality of palliative care to patients with life threatening illness. Furthermore, lack of multidisciplinary palliative care teams was amongst the factor that hinders delivery of all packages of palliative care. This affects the provision of palliative care and the way patients were cared for.(Ddungu 2011:733) indicates all countries should implement comprehensive palliative care through a multi-sectorial approach. Therefore, multidisciplinary teams are found to be more effective than unilateral disciplinary teams.

Improving palliation, patient education and patient empowerment are vital with respect to cancer care in the country. The current study revealed that in many study settings, patients and their families were receiving inadequate information about their diagnosis and prognosis. Patient visits were only meant for collecting their monthly medication. A study done by (Ddungu 2011:733) showed that government needs to ensure holistic care based on patients' need and promote awareness of patients and their families.

The researchers' findings reveal that some of the physicians reported that even though they had training on palliative care, the shortage of Oncologists, patient over-load and lack of multidisciplinary team were some of the factors that affect the provision of palliative care. According to Eleanor,Esayas, Nicola,Wondimagegnu and Yoseph (2018:7), most patients were not appropriately counseled on the prognosis and were still in search for a cure, often at high cost. The ratio of physicians to population is 1/48,000 (Anderson, Kebede, Ayers , Tigineh, & Mamo 2018:3). Similarly, another study showed that ratio of physician in Ethiopia were 0.02 per 1000 in 2010 and there was only one hospice for the entire population in the country (Rhee et.al 2017:44).
Study participants noted that there were inadequate health professionals especially in relation to number of physicians per number of patients who need palliative care. The researchers' findings reveal that some of the physicians reported that even though they had training on palliative care, lack of an adequate number of Oncologists, patient over load negatively affected the provision of palliative care. Also, there were no trained palliative care professionals at most of the study settings.

The current study also revealed that there were challenges related to the availability of essential medication, its supply and cost. With regards to medication, the major problem is the interruption of supply of chemotherapy drugs and opioids especially morphine. Previously, oral morphine was available however, at the time this study was being conducted; there was an acute shortage of the drug. Furthermore, the traditional way of supply-chain management was noted as a major problem in the drug supply chain system during this study. This finding is supported by study done by Salahadin and Ethan (2020:1) in which opiates are essentially unavailable in Ethiopia except in a few urban hospitals that leaves those in chronic pain to suffer without relief . Besides, this study revealed that like other African countries, in Ethiopia, Physicians were the only professionals authorized to prescribe morphine which is available exclusively in hospitals. Many of them are however reluctant or afraid to prescribe it.(Lavigne et al.2018:453)

WHO emphasizes the importance of pain relief in its palliative care strategy and identifies the availability of opioids as one of the ‘pillars’ to support the planning of care (WHO 1990:8) .Furthermore ,study done by Ayers (2015:62)showed that availability of opioids has an impact when setting up a model of care, this is because health professionals are unable to provide adequate pain and symptom control

Human Rights Watch (2011:7) also identifies poorly functioning medical supply systems, unnecessary restrictive legislation and fear among health workers as barriers that affect palliative care and pain management.

5.5.5 Health system related factors

Health care system related barriers are other factors that affect the implementation of effective palliative care service provision in Ethiopia.

This study further revealed that there are health care system related challenges to provide palliative care in the study area. Inadequate man power, there is lack of assigned funds for palliative care provision, Palliative care is not included in the hospital strategic plan ,there is .limited cancer center with few radiotherapy center, Besides there to adequacy of drugs, reagents, chemotherapy and radiotherapy and weak facility community linkage. As these findings indicate, there are few cancer treatment centers in Ethiopia and most of them located in large cities with no or few radiotherapy centers, thus patients in the rural area cannot access it due to the distance barriers and poverty. The finding is supported by study done in Africa countries in which palliative care service delivery at hospital or home challenged with increased disease burden, great geographical distances, limited access to health services, late presentation of patients , limited financial resources, lack of trained health care professionals, and inadequate access to essential medicines, which limits the access of palliative care provision for life threatening patients (Emmanuel & Kamonyo 2018:2). Besides, systematic reviews by Hammoda, Alex and Justina (2020:1) showed that knowledge deficits of health care providers about palliative care, inadequate number of trained work force, limited physical infrastructure and insufficient drugs for symptoms relief were challenges seen in provision of palliative care for patients with cancer in low and middle-income countries.

Therefore, providing adequate training for health care providers, assigning trained work force and making drugs available for symptoms control can improve the palliative care provision in developing country like Ethiopia. Besides, Stjernsward etal (2007:4) explained that there must be palliative care fund and service delivery model in a place that provide the financial and man power resources and service structure that support the delivery of effective palliative care.

5.5.6 Research related factors

The findings of this study showed that palliative care is not part of the national research thematic area and there is dearth of published palliative care research in Ethiopia. One study participants expressed, *“Policy gives more attention to research thematic area on communicable diseases and preventions but not much on palliative care*”. This finding is supported by, a study done by Ayers (2015:75) which revealed that there was lack of clarity and understanding about how large palliative care burden in Ethiopia. This is due to lack of general research, also, evidence from the report from Atlas Africa Palliative Care Association shows that there were three palliative care research projects conducted done Ethiopia (Rhee et.al 2017:44).

According to Grant et al. (2015:2), in Africa, understanding palliative care model delivery is curial but research related to palliative care is minimal and funding for palliative care research protected by ring fencing resource (Nabudere,Obuku, & Lamorde 2015:27).however , WHO considered palliative care research as one pillar for the development of palliative care and advises governments to assign adequate funds to conduct palliative care research. They also encourage staff from different institutions to carry out research on palliative care. Therefore, developing, implementing and monitoring of palliative care research might help in delivering palliative care in way that are feasible and acceptable in resource poor country and also provide answer relevant to the local context

5.5.7 Partnerships related factors

Coordinated and partnerships of key stakeholders are playing a great role in providing palliative care to meet the current needs of patients with life threating illness.

A study revealed that most of the existing local, non-governmental health organizations that exist in Jimma zone mainly depend on external donors, with deficiency of funds to run their activities. Besides, most of them render services only for HIV/AIDS patients' One of the factors that affect palliative care model delivery is lack of adequate financial support. Most palliative care is provided by non-governmental, faith, or community-based organizations with no inbuilt sustainability (Faith & Olivia 2011:19), and still remains too heavily dependent on external funding rather than integrated health sector expenditure (Anderson & Grant 2017:3). Besides, most of them render services only for HIV/AIDS patients' .This finding is supported by a study done by (Charlence and Martyn 2019:1) described that most of the local Non-governmental organizations depend on external donors. And the following barriers were hindering palliative care: financial matter, perception issue, logistical concerns and governmental polices. Similarly Studies show that in Ethiopia, funding levels are far from compatible to cater for the needs and support of people living with HIV/AIDs and orphaned and vulnerable children (Woldie, Sudhakar & Feyissa 2015:1) In contrast, A study that has done by Kumar (2013:216) showed that Kerala model has achieved remarkable success.

Approximately, 90% of all palliative care services in India are now reportedly provided in Kerala, it works with local government and engages the local government to identify and prioritize the local health needs; it was inspired by the concept of primary health care. Therefore, such experience should be tailored to the other sites for the sustainability of palliative care services since funding is the most constraint factor to deliver palliative care in sub-Saharan Africa. Moreover, palliative care should be integrated into the national health care system of the country to alleviate fund related challenges to palliative care services provision.

5.6 Actions that can support palliative care model development

The present study identified that there are opportunities for fortifying and enhancing the palliative care development in Ethiopia. The study participants described a number of factors which play a great role in establishing palliative care model in Ethiopia. These include the presence of strong community structures, integration of palliative care into the hospital transformation guideline, presence of palliative guideline, presence of family medicine program, presence of extension health workers and health development army in the community.

5.7 Conclusion

This chapter presented and discussed the current provisions of palliative care in Ethiopia, domain of palliative care provision and palliative care models practiced in the country. This section also elaborated and discussed the existing challenges and opportunities in the current palliative care services provision in order to develop palliative care model that is appropriate in resource scarce setting. It also indicates the opportunities that strengthen and enhance the palliative care development in Ethiopia. The next chapter will present the procedures of developing a model of palliative care for Ethiopia setting.

CHAPTER SIX

Palliative care model development for Ethiopian setting

6.1 Introduction

This chapter describes the development of palliative care model for an Ethiopian setting. The proposed palliative care model was developed through intensive literature review and findings from experts and other segment of the study groups. This chapter describes the rationale and objective of developing the palliative care model, components and pathways in the model, the targets audience and the human resource requirements to implement palliative care according to the proposed model. Finally, this chapter presents strategies that are important in the implementation of the P-Care model in the different levels of the healthcare system. The validation process of the model, the exit strategy and the dissemination plan were also presented.

Findings from a systematic review describe that models are often classified with reference to the setting in which they are delivered (Brereton et.al 2017: 2). In this study, the model of care includes the setting in which the palliative care is provided, the level of care as well as the different palliative care champions participating in the provisions of the care in the Ethiopian context.

A model of palliative care delivery must be developed and adapted to meet the unique needs of people with all life-threatening illness in different cultures, communities and countries (Grant & Downing 2011:18-22). There is a need to integrate palliative care into the existing health care system of the country to deliver contextually relevant and effective palliative care in resource scarce settings

6.2 Justification for P-Care model of palliative care development

Despite an increased burden of chronic diseases and palliative care needs in Ethiopia, studies carried out on palliative care are extremely limited. As a result, data on cost effectiveness of palliative care model is non-existent. Moreover, studies conducted in different cultural context and socioeconomic settings may not be applicable to Ethiopian situation. Palliative care development should consider the existing resources in the country and it should also be integrated into the existing healthcare system. Therefore, in an effort to deliver most effective and efficient palliative care services, a contextually relevant conceptual model is necessary.

To this effect, in this study, P-Care model is developed and adapted to address the unique needs of people with all life-threatening illnesses in different cultures and communities in Ethiopia. The P-Care model is developed based of the findings of the current study and reviewed literature to address the challenges and gaps in the provision of palliative care services in resource scarce settings like Ethiopia.

The researcher had deep insight from reviewed literature regarding how different models of palliative care work within different health systems, particularly, in resource scarce settings. This analysis of models provided the basis to develop P-Care model which is important for future planning for palliative care service provision in Ethiopia.

The main goal of this model development is to offer cost-effective palliative care provision in resource scarce setting using both community and facility approach. This will in turn help decision makers to evaluate the current palliative care service delivery in Ethiopia. Furthermore, it helps the decision makers to develop palliative care policies, strategies and future steps for better palliative care service provision in the country. It will also provide baseline data about the development of cost-effective palliative care model in the resource limited settings for other researcher. Hence, the experience gained may be replicated in other low income settings.

6.3 Process of model development

The reviewed literature showed that even though there were different palliative care models/setting, patients should get palliative care services at each level such as primary, secondary and tertiary with a network of palliative care champions and good referral system to provide holistic care.

Research findings showed that currently, palliative care delivery approach through Hub and Spoke approach, Hospice Ethiopia, strong heart Ethiopia and outreach activities was done for chronic illness patients by Jimma University (evidenced by key respondents (1, 2,4,7,13,17,19.).and discussant's (FGD2) However, this hospital-based (hub and spoke approach) palliative care and Hospice Ethiopia and Strong Heart Ethiopia are currently found in Addis Ababa; yet, the majority of patients come from the rural part of Ethiopia. *" PC care initiative in Ethiopia is at an early stage and should include the primary ,secondary and tertiary levels . In our set up patients are referred from the all parts of Ethiopia in order to get radio therapy and chemotherapy, therefore, these patients get at least primary PC at district hospital and health center ,when they return to their homes" [KII: 9, 41* years Old, Oncologist working in tertiary hospital*]*

The key participants reported that the current palliative care service delivery should be extended to /district /home-based care by using frontline health workers and trained community volunteers in rural and urban parts of the country.

Involving and utilizing volunteers' in health care setting of low and middle income countries are effective ways for lowering costs and economic burden of delivering palliative care provision in the model. However, appropriate training should be given to enhance their performance and quality of care provisions to the patients.

In Ethiopia in addition to health extension workers and community volunteers, there are informal groups like "iddir" and "Ekubi" in the community through which people are helping each other during illness and grieving. Besides, the presence of such informal groups and health extension works were recommended by some of the study participants in order to extend palliative care at community level in the presence of health extension workers (KII 1,2,17).

Additionally, the reviewed literature revealed that an integrated community based palliative care model using a public health care approach to deliver palliative care service is recommended for low income countries, WHO 2016:17-25(WHO has taken as an example(kerala ,palliative care model in India , integrated community based home care, in South Africa),

Palliative care should be addressed at primary health care, district and tertiary levels in order to ensure the holistic care for patients with lifetime illness and presence of good referral systems among primary health care, district hospital, tertiary hospitals and hospice care for well-functioning of palliative care service delivery model in Ethiopia setting. Therefore, P indicates that the path ways and communication between the levels, while patients are in need of palliative care services in different settings in the model. In conclusion, the literature reviewed and results of the study showed that an integrated palliative care model which involves a hospital based model (Hub and spoke approach), a hospice palliative care model and which also extends to community and home based palliative care works best.

This palliative care delivery approach and the pathway or referral system is presented by the P care model. This can be done through training of health workers and volunteers. Moreover, there should be palliative care provision with effective referral system and feedback between the community/home based services, Hospice Ethiopia and in all levels of the heath facilities in order to meet the needs of patients with life threating illness.

Moreover, the reviewed literature highlighted that palliative care reduces both direct and indirect costs and also it is cost effective when it is given in conjunction with curative services. Moreover, the literature showed that the model of palliative care should be applied to all diagnosis and also should be cost effective. It is therefore very crucial to look at elements of cost effective palliative care in order to develop a palliative care model for the Ethiopian context.

6.4 The development of P-Care model of palliative care for Ethiopia

The development of the P-care model of palliative care followed logically from the following sources:

- ✓ Evidence from literature (review of relevant literature at international and national levels)
- ✓ Research findings from key informants
- ✓ The draft model was validated by presenting the model to relevant stakeholders in Ethiopia, refining the model and then, validating the model
- ✓ Expert feedback on validation report of the draft of P-care model of palliative care.

6.5 Scope of the P-Care model of palliative care

The palliative care clinical skills required should be determined by patient needs and provided through different referral pathways within the healthcare system from home or community-based care through health facilities within the context of primary, secondary and tertiary palliative care service provisions as indicated in Figure 6.1. Components of the P-Care model include both home/community, hospice and facility based palliative care services provision.

6.6 Description of P-Care palliative care model

In the model, **P** stands for palliative care. The aim of this model is to provide services for patients with life-threatening illness regardless of diagnosis by addressing the palliative care needs of patients and their families during their illness trajectory in different palliative care delivery settings. Furthermore, the P model encompasses the palliative care services given in facility and community/home settings depending on the local needs and available local resources. Therefore, the patient should be able to get palliative care services in any setting.

The P-Care palliative care model is a cyclical and multidirectional journey as opposed to a unilateral directional journey and patients may join the system at different points in their illnesses. They may come in and out of the system as necessary. Thus, palliative care should not be considered as only given in the facilities. It can be also given in the community even in patients' home with limited resources.

The double arrow in the P model shows patients' referral pathway to palliative care services in order to get holistic care, which includes physical care, psychological care, social care and spiritual care based on patients' needs, which can be non-complex needs. They can be addressed by primary care providers or complex needs, which require palliative care specialists or experts. In addition, it shows the relationships between the tertiary hospitals; primary hospital, Hospice Ethiopia and community/home based palliative care services delivery and the responsibility of all health professionals, community members, patients and families to provide holistic care in Ethiopian setting.

Each of the settings indicate patient referral pathway within the health sectors. Ethiopia's health system comprises of hospitals, health centers, health stations and health posts, in decreasing order of clinical capabilities. The health service system is federally decentralized into these areas.

The critical point in palliative care services is to ensure the continuum of care and address patients' needs as they pass through the referral pathways between community and facility based palliative care services. Thus, this P care model encompasses various models of care being used for palliative care implementation in Ethiopian settings. Each setting has its role and responsibility to deliver palliative care services and there should be coordination and integration of palliative care services across all settings with other medical, health or community care providers.

Palliative care should reach all patients in need of it. To achieve these services in Ethiopian context, stakeholders have to strengthen services that can be done at community level and at primary healthcare levels that include health posts, health centers and primary hospitals. This can also be achieved by involving community participation through iddir, families, care givers, patient themselves, religious and community leaders. This continuum of care prevents repeated hospitalization of the patients. Therefore, the P-care model of palliative care serves to provide guidance and framework to strengthen and implement the palliative care services in Ethiopia.

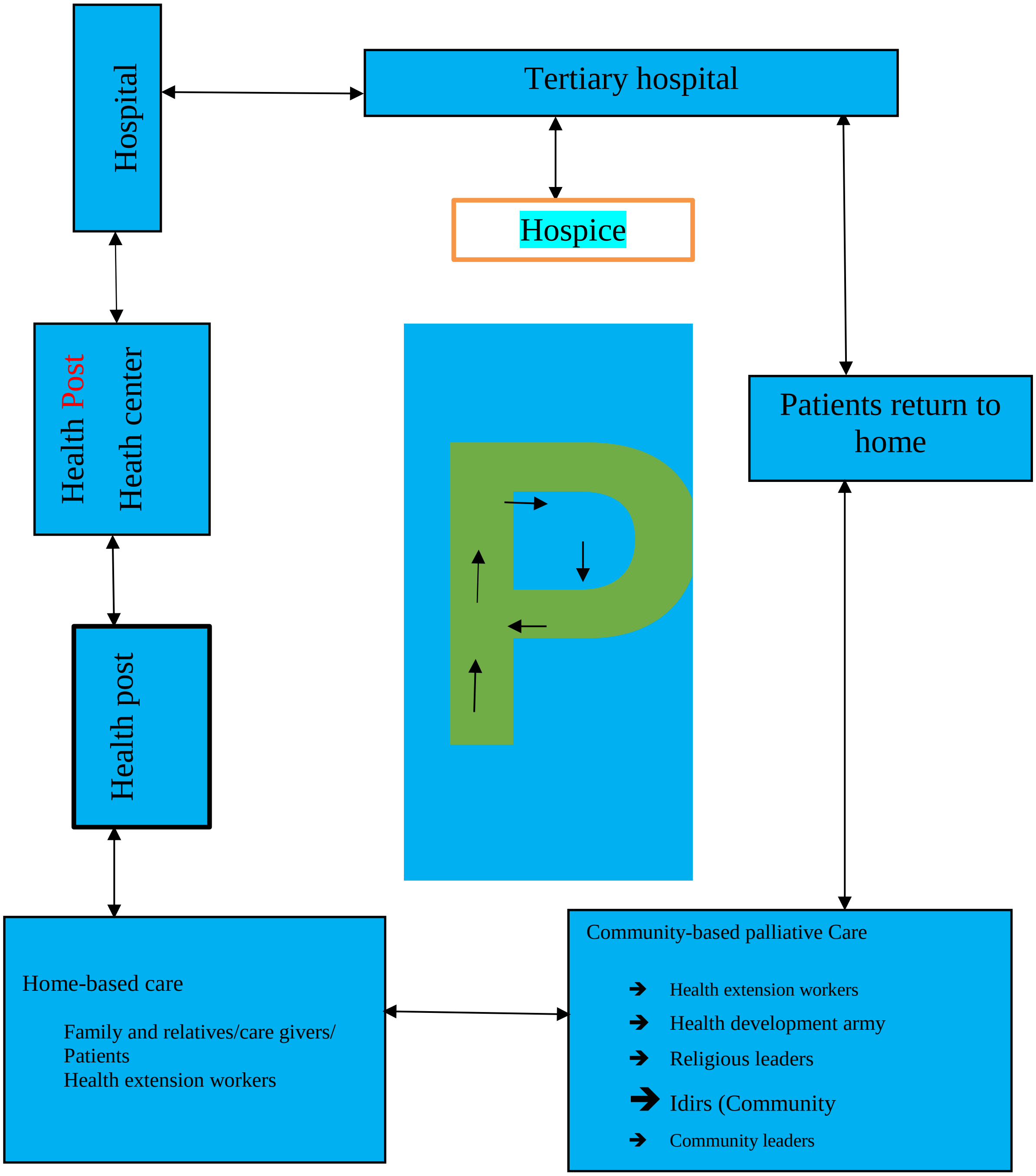

Figure 6.1 Palliative Care model for Ethiopian setting

6.7 General objective of P-Care palliative care development

The general objective of developing P-Care is to develop a palliative care model that is best practiced in the resource limited settings to cater for the palliative care needs of patients and their families during their illness trajectory in different palliative care delivery settings.

Specific objectives of P-Care Palliative care development

The specific objectives include:

1. to improve access for palliative care at all tiers of the health care system
2. to create the awareness of the palliative care model to communities and stakeholders
3. to increase community awareness and access to palliative care
4. to improve health professionals' knowledge and practice of palliative care
5. to create community engagement/participation
6. to establish palliative care as part of the continuum of care

6.8 Components of p-care palliative model

Description of home-based care palliative care model

1. Home-based care model

One of the components of p-care model is home based care approach which is given at patients' living environment. This care can be given by families neighbors, community volunteers and colleagues. This care is to be supported by trained nurses and other frontline health workers. Literature showed that home-based palliative care is by far the most common approach to provide palliative care in in sub-Saharan African countries. Moreover, the family members are integrated into the process because the person's illness affects not only the patient, but also his/her family as a whole and - any difficulties experienced by the family would have an impact on the patient, too.

Home-based care in Ethiopia context

In Ethiopia, Hospice Ethiopia gives home based care for patients mainly for cancer and HIV/Aids patients for 270-300 patients in Addis Ababa. It also has referral systems from different public hospitals in order to give home based care. Therefore,it is recommended that this is trialed in other regions.

Furthermore, home-based care is a well-established model of care provision within the context of HIV/AIDS. Literature shows that home- and community-based care implement palliative care through the continuum of care linked to local health facilities. Community support through traditional burial societies (idirs) makes it possible for the program to provide holistic care for people living with HIV (PLHIV) and their family members.

Mainly the family, close friends and relatives provide care at home. The patient is in the familiar environment, a place with memories, love and happiness. Ethiopia has a strong community infrastructure with FBO and community support groups such as ‘iddir’, which can be involved in establishing palliative care services and health extension workers play an important role in the provision of day-to-day home-based care such as giving advice, support, education to patients, families and communities and linking the patients with the next level, if need arises. Even though this model is appropriate to the Ethiopian setting, hospital based palliative care at district and tertiary levels must be available in order to refer the patients with major symptoms, so that they receive chemotherapy, radiotherapy, medication and specialist palliative consultations.

A multidisciplinary team needed in this model

Home-based care should involve the following palliative care champions in an Ethiopian setting: community volunteers, families, health developmental army, health extension workers, community based organizations, faith-based organizations and health professionals such as nurses, family physicians who are taught how to provide basic symptom control and health workers who provide the necessary drugs and backup support.

Capacity building for home-based care champions

According to the WHO (2016:14), there is an essential package of home-based care which includes treating and managing mild symptoms, counseling, support for adherence, access to essential medication support, psychological care, spiritual care and social care and giving culturally amenable care. Furthermore, the WHO advises that the home environment should be a safe and accessible place for medication and equipment storage. It is important that the home is accessible via different modes of transport and also has mobile phone signal for communication. Further, it is suggested that all palliative care champions undergo basic training. Therefore, training is an essential component of the P-Care model. In order for the champions to do all the above activities capacity building is mandatory the home-based care champions, should have knowledge and skills to provide primary palliative care services. Such training should include both theoretical and practical components. It should also be offered to family, caregivers with simple printed guidelines on caring for the patient at home. Furthermore, to increase community awareness of palliative care, local resources and support networks can be mobilized and community health workers can provide training to the locals.

Referral system for home-based model

The presence of a home-based care model alone cannot guarantee the management of complex symptoms. Therefore, the home-based model of care should have the structural referral process. The home-based palliative care team should be able to assess the patient, and in the event that they have complex problems, facilitate the patient's referral to other models of palliative care delivery such as the hospital-based model shown in the P-Care model figure.

Patients that are cared for at home should be supported from different levels of palliative care services during the course of illness. Therefore, it is important that there are referral pathways and these can be facility-based palliative care or hospice.

On the other hand, the referral process can be from facility-based palliative care to home-based care or community-based care to ensure patient continues to improve. Thus, in a well-functioning health care system, there is integration and interaction between models of palliative care. It is important to maintain referral pathway as the home-based care team is able to facilitate referral to other palliative care service providers , in case it is needed.

2. Community-based palliative model

Description ofcommunity-based palliative care

Community-based palliative care services are those offered at a community health center or that run through community participation. Community participation is the involvement of people in a community to solve their own problems. This includes community involvement in the needs assessment, planning, implementation, resource mobilization, day-to-day management and evaluation of the program. Community-based palliative care model provide palliative care in a person’s home with trained community care workers supervised by a professional nurse, backed by a strong network of community organizations including health post, health center, or district hospital. In addition, this P-care model will empower the community and local stakeholders through palliative care training so that they will be able to give primary palliative care to the patient in need of it. Doing so will lessen the burden of care for the health care system.

The community-based approach can be initiated in collaboration with the local health authorities and should follow the planning processes used in the health system. In addition, it can be used by community organizations that wish to establish a palliative care service for their community. This can later be integrated into the health system. Care is most commonly provided in the community and homes although some run small clinics at local health centers.

Community-based palliative care model In Ethiopian context

In Ethiopia, Community home based care was well practiced during the era of the HIV/AIDS epidemic, and it was a powerful mechanism for mobilizing attention and compelling response to the issue of HIV/AIDS crisis that causes increasing bed occupancy with terminally ill patients. In order to cope with this crisis, many community organizations in Ethiopia introduced community “home-based care" (CHBC) schemes for persons with HIV or AIDS diagnosis. However, currently, most of these organizations were phased out because of the availability of ART services. Therefore, such experiences should be trialed in palliative services for chronic illness in Ethiopia settings.

Moreover, the Ethiopian National Palliative care guideline was developed in order to address the needs of population requiring palliative care so as to ensure its availability and accessibility. A public health care approach is vital with the principles of task shifting, decentralization of service, standardization and simplification. Furthermore, most reviewed literature indicated that community-based model was the most feasible method in African context. In Ethiopia, a study done by Ayres (2014:55) suggested that community-led initiative model might be potentially suitable for our country. Moreover, the findings from this research showed that some of the key informants believed that integrated community based palliative care approach best fits the Ethiopia setting.

This model might be appropriate in an Ethiopian setting because most Ethiopian populations live in rural areas (81 %) (World Fact Book 2014:3). Also, there is geographical variation. Besides, the ratio of physician-to-population is 1/48,000 (Anderson, Kebede, Ayers , Tigineh & Mamo 2018:3). Therefore, to establish community-based model in Ethiopian setting, the following things should be considered:

The model should have appropriate referral systems. Linkage to supporting organizations should have well-trained professional teams and dedicated community volunteers who visit the community to address the palliative care needs of the patients and the families. Involvement of community leaders, patients and families in the model approach is also vital. Furthermore, this model should be integrated into existing health care systems in Ethiopia.

Referral system is another core component of community based palliative care approach.

Most of the time, the community-based model of palliative care was led by the nurse, with referrals being received from local health facilities including the district hospitals and also from specialist services across the country. Referral to and from health facilities and welfare services is central to ensuring that care matches patient needs, including referral to a palliative care interdisciplinary team or inpatient hospice facility. In cases where patients are referred for specialist intervention, this will be addressed by primary or tertiary hospital.

3. Hospice Ethiopia

Another component of the P-Care model is creating partnerships with local and international NGO's and charity-based and faith-based organizations that enhance the quality of palliative care in Ethiopia. Palliative care is not only performed in health care system and also not only supported by the government. Therefore, there should be good partnerships between the government and stakeholders to support palliative care in the settings as the gaps highlighted in the findings of this study imply.

Hospice Ethiopia and Strong Heart Ethiopia are the two NGOs rendering palliative care services for patients with life–threatening illnesses. As indicated in the P-Care model, patients can be referred to Hospice Ethiopia from different hospitals to get the services. In addition, self-referred patients can visit this organization to get the services. As the reviewed literature indicates, patients can get the following services: home-based care, day care and outpatient care. Therefore, there should be strong communication with the referral system to the health facilities and non-governmental organizations. Moreover, such important palliative care services provision should be tailored to other bodies in the country in order to give holistic care to patients.

4. Facility based palliative care approach

The P-Care model also shows the patients' journey in the health-care system of Ethiopia. As the reviewed literature shows, the health-care system in Ethiopia is decentralized from central to peripheral and it has three tries tiers that include tertiary level, district level and primary health-care units and follows the principle of primary health care. Therefore, the P-care mode is a hybrid, which contains facilities and home /community-based care and encourages the integration of palliative care into existing health facilities.

As indicated in the P-Care model, health facilities such as health post, health center, district hospital and tertiary hospital should give at least primary palliative care service for patients with life-threatening illnesses when they have visited the healthcare system. Health professionals at all facility levels should get basic palliative care training. There should also be a good referral system between all facilities in order to give palliative care services in Ethiopia. Furthermore, all necessary resources should be available which include: essential palliative care medicine, palliative care polices, guidelines, strategies and funds in order to give holistic palliative care services.

Process of the development of strategies

Scope of the proposed strategies of the P-Care model

The scope of the proposed strategies of the P-Care model was applied from the policy makers to the community levels by involving the Ministry of Health, public health hospitals, health centers, health posts, patients' homes and the community. The target groups for P-Care model strategies were policy makers, health professionals, managers, community leaders, community volunteers and patients along with their families.

6.9 Purpose of P-Care model of palliative care strategies

The purpose of P-Care model strategies is to ensure effective provision of palliative care services through integrated community palliative care model using public health approach.

6.10 Objectives of P-Care model strategies

The objectives are:

1. to describe the strategies that could help the health care system to implement p-care model;
2. to overcome the palliative care challenges that were found in the current research findings using P-Care model of palliative care provision in resource poor settings.

3. to ensure effective provision of a better palliative care service integration.

6.11 Evaluation of the model

After completing the draft document, the researcher selected experienced health professionals who had ample experiences and knowledgeable in the area of palliative care and related fields. To this point, the following bodies filled validation criteria: policy makers from the Ministry of Health, Jimma University academic staff members, Jimma University Medical Centre, Shenen Gibe General Hospital, Hospice Ethiopia and NGOs. The documents were then sent to them via e-mail in order for them to give their critique and suggestions. Next, all the feedback provided was incorporated by the researcher and re-sent to all experts with validation criteria in order for them to evaluate the documents. The researcher prepared the validation criteria based on the literature review (David 2005:24) The following P-Care model validation criteria were used to evaluate the documents: clarity and consistency, relevance, comprehensiveness and adaptability, importance for research practice and evaluation, untouched area in Ethiopian setting.(Annexure 7).

These experts were requested to evaluate the P-Care model document and to rate it according to the criteria provided, which includes ‘not acceptable’, ‘needs major revision’ and ‘acceptable as described’. All the experts provided their feedback and gave the scores under ‘acceptable as’ described in the Table 6:1. None of the experts gave the score under ‘not acceptable’ or ‘needs major revision’. Finally, the validation results were calculated and analyzed. More than 95% of the respondents considered the P-Care model as ‘acceptable’. 5% of the experts gave their minor comments under the validation criteria of comprehensiveness and adaptability. The researcher therefore incorporated all the comments and suggestions given in the final P-Care model document. On the issue of adaptability and comprehensiveness, the researcher recommends that policy makers carry out a pilot study for the implementation of the P-Care model.

Table 6.1 List of experts who participated in validation report

Pseudo name	Qualification	Area of Expertise	Years of Services
Naso	Pediatric Hematologist and Oncologist	Pediatric Oncology Pain Management	Two years as oncologist; six years as pediatrician
Qali	BSc, MPH, Nurse Professional, Stroke Nurse Leader	Critical Care , ICU,NICU, Stroke Unit Team Leader Nursing and Midwifery Director	Two years in ICU; one year in NICU; 4 years in stroke unit; one year as nursing director
Beko	MSc (N), M.Phil, Pg Diploma (Preventive and Promotive Health Care), PhD, Professor	Psychiatry Nursing	35 years
Sadu	RN, MSc, Assistant Professor, School Head	Maternity Nursing	6 years
Mark	MA, Development Studies	NGO, Health Service Management (Manager) Licensed Management Consultant Public Police Making, R & D	19 years
Sun	MPH ,Public Health Professional	Medical Service System Strength at Federal Ministry of Health, palliative Care and Pain Management	10 years

Tufa	MD, Clinical Director	Chief Clinical Director, Health planning	6 years
Funi	Hospice Manager, MPH, Public Health Professional, Diploma in Advanced Palliative Care	Director of Hospice Ethiopia	13 years
Banti	Consultant, Professor of Internal Medicine	Internal Medicine	13 years

The researcher collected the validation report from each of the experts. After which, he summarized the average score of each expert's feedback. As a final point, he calculated the results and analyzed as shown in Table 6.2.

Table 6.2 Experts rating of the proposed P-Care model of palliative care

Se no	criteria	Not acceptable or needs major revision	Acceptable with recommended changes	Acceptable as described
1	Clarity and consistency	0%(n=0)	0%(n=0)	100%
2	Relevance	0%(n=0)	0%(n=0)	100%
3	Practicability and usefulness	0%(n=0)	0%(n=0)	100%
4	Importance for research practice and evaluation	0%(n=0)	3%	97%
5	Comprehensiveness and adaptability	0%(n=0)	4%	97%
6	Untouched area in Ethiopian setting	0%(n=0)	0%(n=0)	100%

In conclusion, most of the experts gave their feedback, accepting the model as is. The percentage they gave was 95%. Moreover, the remaining 5% rated it as acceptable with modification especially on comprehensiveness and adaptability, practicability and usefulness of the model. Based on their evaluation, this model is very important in narrowing the gap and addressing the challenges relating to palliative care provision in Ethiopian setting with the aim of providing a better quality of life for patients with life-threatening illnesses.

6.12 Implementation done by the researcher

As a researcher, after I had attended training on basic and TOT on palliative care by the Ministry of Health and palliative experts from UK for 3 and 5 days respectively, I returned to Jimma and prepared an action plan, training schedule and the required budget to carry out the training. The palliative care and pain management training was given to 26 health professionals and 33 health professionals who came from Jimma University Medical Center and Shenen Gibe General Hospital respectively for five days(Annexure 8).

After the training, I assigned palliative care Focal persons for each hospital. Apart from this, I established multidisciplinary palliative care teams for each of the above hospitals. I developed a palliative care strategic plan for Jimma University Medical Centre. I also developed terms of reference on palliative care for Jimma University Medical Centre and pain and palliative care desktop references for health professionals in order to refer palliative care and pain related issues. I conducted a palliative care meeting with hospital stakeholders in which the Clinical Director of the Hospital was a chairperson. The researcher was both Secretary and palliative care focal person for Jimma University Medical Centre. After the discussions, the hospital managers promised to open palliative care units at their institutions.

6.13 Proposed strategies

Strategy 1: Basic palliative care training for all health professionals

To implement this model, there must be basic palliative care training for all health professionals (from all multidisciplinary team) such as doctors, nurses, pharmacists, social workers, psychologists, religious leaders, community leaders and community members including patients and their families.

In addition, this training should involve health workers and all stakeholders at tertiary, district and community levels. Moreover, after giving basic palliative care training, the researcher set up palliative care committees with palliative care focal persons in order to run palliative care issues in these facilities.

Strategy 2: Establishing multidisciplinary palliative team in the hospital

This multidisciplinary team includes doctors, nurses, pharmacists, social workers, psychologists and religious leaders to give holistic care after they are given basic palliative care training.

Strategy 3: Establishing palliative care unit in the hospital

This P-Care palliative care model is a hybrid model, which includes facility-based and community-based (home-based model). Thus, the establishment of palliative care does not need sophisticated building. We can give palliative care by integrating it into the existing health care system.

Strategy 4: Establishing good palliative care referral system

Building palliative care is about making good relationships; there must be palliative care referral system at each level of the healthcare system delivery starting from tertiary hospital to the community level.

As a result, preparing palliative care formats such as format for psychological assessment, social needs assessment, pain assessment, physical care assessment, bereavement assessment and end-of-life care assessment is crucial. Furthermore, training on how to use these formats should be given.

Strategy 5: Monitoring and evaluation

Each hospital should have a process and tools for monitoring and evaluating the success of palliative care provision. Monitoring the palliative care activities given to patients and reporting to the concerned bodies is vital.

Strategy 6: Increasing the awareness of the community to participate on palliative care issues

The community volunteers will be involved in the palliative care provision of patients with chronic illness.

Strategy 7: Involvement of non-governmental and faith-based organizations

Since most of the palliative care and hospices in Africa are supported by non-governmental organizations and stakeholders, the government should involve international and local non-governmental organizations to support palliative care provision in Ethiopia.

Strategy 8: Improving supply of and access for palliative care medications

Supply of palliative care medications such as opioids and morphine should be available in all healthcare systems with good regulatory policies in Ethiopia. Furthermore, trained nurses should be able to prescribe morpheme to patients.

Strategy 9: **Integrating palliative care trainings into both undergraduate and postgraduate health science studies**

Strategy 10: Establishing palliative care association at national level

Ethiopia should establish a national palliative care association. Ethiopia’s Ministry of health should facilitate palliative care membership with organisations such as the National Palliative Care Association and also The African Palliative Care Association.

Strategy 11: **Capacity building**

Formal training of palliative care specialties should be given at university level by integrating the palliative care into the curriculum, which will be for undergraduate or postgraduate program. Basic palliative care training should be given for health professionals at each healthcare system to increase their knowledge and the skills in order to bring quality of life for patients with life-threatening illnesses.

In order to allow the implementation of p care model, training should be given to health professionals at different health care system. The training will also be provided to community agents that can help to increase community awareness about palliative care. Therefore, basic palliative care training and advanced palliative care training should be delivered to all the stakeholders as per the WHO guideline which includes the credit hours and curriculum for palliative care training (WHO 2016 :85-86).

Training was given for the implementation of this model to nurses, clinical pharmacist, doctors and social workers as well as psychologists from Jimma University and Shene Gibe hospitals. The training provided a comprehensive overview of palliative care practice. An orientation to palliative care and pain was given for head nurses in Jimma University Medical Centre as a means to monitor and evaluate the palliative care activities done in the hospital. Furthermore, it allowed the professionals to assess and treat pain, according to the WHO guidelines and to provide holistic palliative care. The training was provided by the researcher and Oncologist from Jimma University Medical Centre. The training should have also involved healthcare professionals working in the community as well as health extension workers and community volunteers in order to deliver integrated community based palliative care in the community and at patients homes.

Available resources

Human resources:

1. Mr Endalew Hailu: RN, MSc, PhD Fellow in Nursing Philosophy, Palliative Care Researcher, Jimma University, Has Basic and TOT Certificates in Palliative Care
2. Dr Diriba Fufa: MD, Pediatrician, Pediatric Oncologist, Expert in Palliative Care,Has TOT Certificate in Palliative Care
3. Mr Ermias Mulat (MPH, Palliative Care Advisor at Federal Ministry of Health, Has Basic and TOT Certificates in Palliative Care)
4. Dr Nicola Ayers (PhD), Palliative Care Advisor, Clinical Services Directorate, Federal Ministry of Health, Addis Ababa
5. Dr. David N Korones , M.D Department of pediatrics, Hematology and Oncology in USA
6. Dr Esayas Kebede Gudina (MD, DTMH, PhD), Consultant physician and Professor of internal medicine, palliative care researcher
7. Mr Ephirem Abatihun, Health Officer, MPH, Manager of Hospice Ethiopia, Certified in Advanced Palliative Care Diploma , Certified in Palliative Care Training from Uganda

6.13.1 Stakeholders involved on implementation of P-Care model

For the implementation of this model, stakeholders starting from the Ministry of Health to the community level should be involved and carry out their activities at each level.

6:13.2 Activities to be done at Ministry of Health level

1. At the Ministry of Health level they should integrate this model into the national healthcare system in order to implement it at each level of healthcare with a public health approach model. This will enhance the accessibility and affordability of palliative care to people in need of the service.
2. Developing palliative care strategies, policies and standards which will be implemented at each level of the healthcare system;
3. Integrating palliative care into the curricula of health professionals especially for medical students and nursing students;

4. Assuring the availability of palliative care essential medicines at all levels of health care system such as availability of morpheme;
5. Modifying the policy related with morphine prescription in which the trained nurses can prescribe morphine for patients in need of it;
6. Enhancing the establishment of palliative care champions at all health care systems;
7. Working in collaboration with NGOs in delivering palliative care services;
8. Monitoring and evaluating palliative care activities in all health care systems;
9. Facilitating both in-service and pre-service training for health professionals;
10. Allocating palliative care fund in all health care systems;
11. Integrating palliative care research in thematic research areas of the Ministry of Health;
12. Enhancing good referral system of palliative care at all health care systems;
13. Working on advocacies to enhance the awareness of the public/community about palliative care issues using different media such as TV and radio;
14. Establishment of national palliative care association in Ethiopia which will facilitate registration to become ; facilitating to be membership a member of the African Palliative Care Association.

6.13.3 Activities to be done by public hospitals

1. Establishing palliative care units;
2. Assigning a palliative care focal person;
3. Establishing multidisciplinary palliative care teams;
4. Providing holistic palliative care;
5. Availing essential palliative care medicines;
6. Monitoring and evaluation of palliative care activities in the hospital;
7. Creating awareness on palliative care among health professionals;
8. Establishing a good referral system.

6.14. Activities to be done by researchers

1. Since the palliative care program is a new approach and untouched area in the Ethiopian setting, researchers should be interested in working on this area to narrow the existing gaps and challenges.
2. Validating the model and piloting it in similar setting using quantitative study approach is vital. In the current study, the researcher did not look at the view of patients/families towards palliative care provision. Hence, other researchers should include these dimensions.

6.15 Beneficiaries from P-Care model of palliative care

- All patients with life-threatening illnesses;
- Families/care givers/guardians;
- All Health professionals.

Indicators will be:

Increased number of patients and family members seen at out-patient clinics.
Increased number of patients seen as an in-patients.
Increased number of patients seen at Hospice Ethiopia.
Increased number of patients seen at Strong Heart Ethiopia.
Increased number of patients seen in community clinics
Increased number of patients received palliative care in the community.
Increased number of patients receiving palliative care at home.
Increased number of patients to whom morphine is prescribed.
Increased number of trained communities volunteers in palliative care.
Increased number of trained health professionals on palliative care

6.16 Conclusions

The P-Care model was developed following a review of pertinent literature and local data from the Federal Ministry of Health, healthcare facilities and care providers. It provides important lessons for healthcare systems not only for the extension of palliative care but even more significantly, for palliative care service provision with goal of improving quality of life for patients with life-threatening illnesses. The P-Care model allows the exploration of the interaction between service pathways, service reach, service settings and important pre-service and in-service trainings.

Strategic interventions are needed at the levels of policy, clinical care and the community to promote P- care model of palliative care provision. There is no one model of palliative care service provision that is appropriate for each setting. Palliative care research is currently the most neglected domain and efforts are needed to ensure that it is implemented in clinical palliative care services. Furthermore, the findings of this research may provide insights and would help other researchers to test and validate this P-Care model. It also lays a foundation for future planning for palliative care in Ethiopia.

CHAPTER SEVEN

Conclusions and recommendations

7.1 Introduction

The aim of this study was to develop a cost-effective palliative care model in resource scare settings in order to improve palliative care provision for patients with life-threating illnesses. Prior to developing a model of palliative care, the researcher first assessed the current status of palliative care provision in Ethiopia. Then, the gaps and the challenges related to palliative care implementation were elaborated. These were categorized as patient related challenges, policy related, provider related challenges, health system related challenges and drug related challenge and non-governmental organizations related challenges. Furthermore, the current study showed the existing opportunities for the establishment of palliative care model in an Ethiopian setting using in-depth interviews and focus group discussions with stakeholders. Finally, the findings of the study were presented and discussed in chapter four and chapter five, respectively.

In chapter six, based on the findings of the study and the reviewed literature, a model of palliative care for Ethiopia setting was developed and proposed. This chapter describes the conclusion of the current study, the contribution of the study and the limitation of the study. Finally, it puts foward recommendations.

7.2 Conclusions

The current study indicated that palliative care development in Ethiopia showed a slow progress as its establishment was in early stage. However, the Federal Ministry of Health was involved in the following activities related to palliative care: assigning a palliative care advisory at ministry level, developing palliative care guidelines, giving training for health professionals on palliative care and pain management. Additionally, they facilitated the practicing Hub and Spokes approach to palliative care in some of the tertiary public hospitals with the existence of small non-governmental organization such as Hospice Ethiopia and Strong Hearts Ethiopia which are mainly dependent on external fund donations.

The study assessed the current provision of palliative care in Ethiopia. The domains of palliative care provision gaps and the challenges that impaired its provision were also assessed. The following challenges were captured through in-depth interviews and focus group discussions.

Finally, the model of palliative care was developed from the derived primary data and reviewed literature. The findings of the study were then discussed along with experiences of other similar countries in sub-Saharan Africa and beyond with possible justification. Following these findings, the P-care model of palliative care, which mostly focused on integrated community palliative care mode with involvement of primary healthcare approach, was developed.

7.3 Recommendations

Based on the findings of the study, the following recommendations are forwarded:

7.3.1 For Federal Ministry of Health and policy makers

It is necessary to:

1. Provide palliative care training for health professionals at all levels of the health care system

2. Develop educational programs which integrate palliative care into both undergraduate and postgraduate programmes curricula;

3. Facilitate the establishment of palliative models in hospitals and extend these palliative care services to home and community levels;

4. Continuously evaluate and monitor the delivery of palliative services;

4. Develop a complete national strategic palliative care plan, palliative care guidelines, policies and allocation of a sustainable palliative care budget at each level;

5. Encourage both local and non-governmental organizations to be involved in palliative care provision;

6. Increase community awareness through advocacy and using mass media;

7. Implement an integrated community based palliative care with primary public health palliative care approach;

8. Develop a national palliative care association and make Ethiopia a member of the African Palliative Association;

9. Strengthen the involvement of religious leaders, social support groups and civil organizations.

10. Establish Information Communication Technology platforms such as Short Message Service (SMS) delivery to easily send information to patients. Increase the utilization of mobile phone technology to aid communication and to pass important massage to increase the awareness of the community.

11. Consider volunteers to give palliative care services at home and community levels. Incentives and motivation strategies should be maintained for the sustainability of the home-based or community-based palliative care services.

7.3.2 For public hospitals

It is advisable to:

1. Implement P-care model according to hospital transformation guideline;

2. Be involved in the provision of palliative care that includes physical, psychological, social and spiritual care;

3. Establish a multidisciplinary palliative care team that includes doctors, nurses, pharmacist, social workers, psychologists and clinical directors from the hospitals;

4. Avail palliative care essential medicine in hospitals and work on sustainable supply of medication such as opioids in order to treat adequately patients pain and symptoms;

5. Evaluate and monitor palliative care provision in hospitals;

6. Strengthen good palliative care system with other health facilities and non-governmental organizations;

7. Provide patient and family centered care;

8. Preparing palliative care terms of reference and standard operational guidelines for the implementation of palliative care services;

9. Assign a palliative care budget to deliver palliative care activities in the hospital;

10. Provide palliative care training for health professionals and also assign the necessary resources;

12. Work on community awareness to minimize stigma and discrimination of patients with chronic illnesses.

7.3.3 For non-governmental organizations

It is essential to consider both local and international stakeholders to be involved in the establishment of palliative care services and support the existing palliative care service model. The following is recommended:

1. Creating a network with of local and international stakeholders in order give holistic care that includes physical, psychological, social and spiritual care;

2.Assign necessary resources to maintain the sustainability of palliative care services delivery and also budget for stakeholders’ palliative care;

3. Assist with the provision of social support and items like food, clothes, educational material, covering finances for medical bills, education and transportation for those who less advantaged;

4. Encourage the stakeholders to engage in community-based palliative care.

7.3.4 For patients

1. It is recommended that patients should have be aware of their conditions awareness and visit health institutions early;

2. If the illness is terminal, patients should enroll themselves on palliative care programs given at the health institutions;

3 Avoiding stigma and discrimination through patient empowerment and education;

4 Assist patients to use mobile phones for calling or sending short messages to communicate with health professionals or their colleagues;

5. The patient and their family should participate in patient centered care.

7.3.5 For researchers

1. Since there is limited palliative care research across the country, it is encouraged that researchers to be involved in palliative care research activities as suggested;

2. Validate P-care model using a quantitative study design can be the focus of future research;

3.Explore the cost effectiveness of different palliative care models and work on research themes focused on palliative care models.

7.4 Contribution of the study

To the researcher's knowledge, this study is the first of its kind in Ethiopia, which involved different bodies, the Federal Ministry of Health, the community, non-governmental organizations and faith-based organizations, to assess the current situation of palliative care in Ethiopia in order to develop a model of palliative care for the Ethiopian setting. The lessons learned will also help policy makers, NGO's, faith-based organisations, hospital administrations and community leaders in providing quality palliative care for patients with life-threatening illness. The study also helped the current researcher to develop a model of palliative care that can be used in an Ethiopia setting. It may therefore serve as a baseline for future research projects and assessments.

This study also elaborates and gives insight on challenges related to palliative care delivery in Ethiopia. This provides fertile ground to improve the palliative care provision and helps policy makers and healthcare planners to expand their understanding of current practice of palliative care model practice in Ethiopia. P-care model was developed based on pertinent reviewed literatures and local data, which will help in provision of palliative care by enhancing integrated community-based model of palliative care by considering public health approach.

Strategic interventions are needed at the levels of policy, clinical care and the community to promote P-care model of palliative care provision. Since palliative care research is currently a mostly neglected domain, efforts are needed to ensure its implementation in clinical palliative care services. Further, the findings of this research may provide insights and pointers to researchers to test and validate this P-care model and provide direction for future planning of palliative care in Ethiopia.

Finally, there is no one model of palliative care service provision that is appropriate for each setting. Therefore, it may serve as a baseline for future research project and assessment.

7.5 Limitation of the study

Both the interviews and focus group discussions were conducted to the level of saturation since the data collection involved all stakeholders. The limitation of the study was that due to limited resources, it did not involve views of patients with life-threatening illness to assess the gaps in palliative care provisions. It would be useful if such study included patients’ view’s on palliative care. The findings of the study results are not specific, but can be transferable to other similar settings.

7.6. Conclusion

This chapter described the conclusions, recommendations, contributions and limitations of the study on the P–care model of palliative for Ethiopia setting. However, there will be an assessment for the responsible stakeholders to carry out the implementation of this model in order to provide palliative care for patients with life threatening illness and their families. This also brings a better quality of life. Interested researchers can conduct a pilot study using this model in selected study areas

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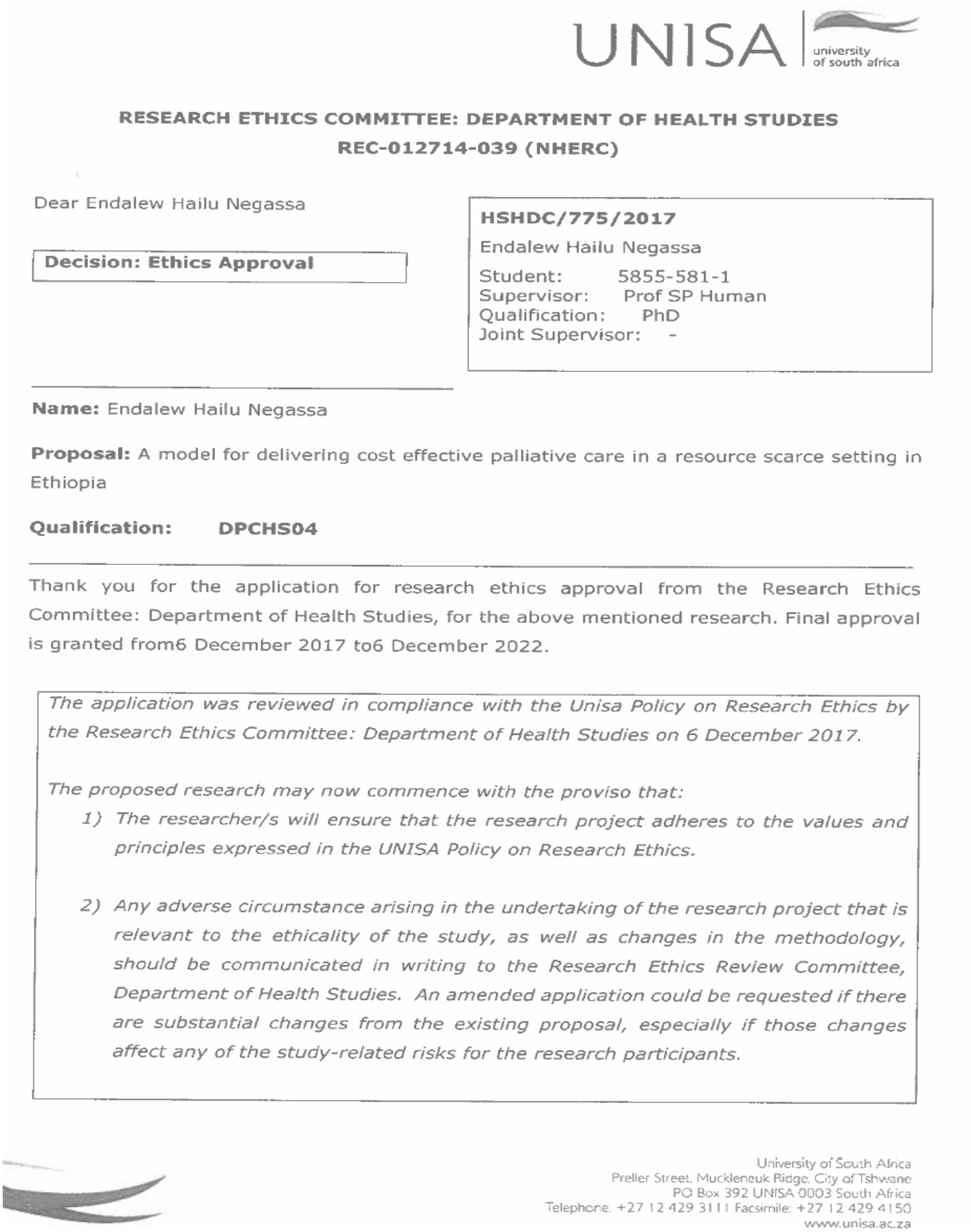
Annexure One Ethical Clearance letter from UNISA



UNISA
university
of south africa

RESEARCH ETHICS COMMITTEE: DEPARTMENT OF HEALTH STUDIES
REC-012714-039 (NHERC)

Dear Endalew Hailu Negassa

Decision: Ethics Approval

HSHDC/775/2017
Endalew Hailu Negassa
Student: 5855-581-1
Supervisor: Prof SP Human
Qualification: PhD
Joint Supervisor: -

Name: Endalew Hailu Negassa

Proposal: A model for delivering cost effective palliative care in a resource scarce setting in Ethiopia

Qualification: **DPCHS04**

Thank you for the application for research ethics approval from the Research Ethics Committee: Department of Health Studies, for the above mentioned research. Final approval is granted from6 December 2017 to6 December 2022.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Research Ethics Committee: Department of Health Studies on 6 December 2017.

The proposed research may now commence with the proviso that:

1) *The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.*

2) *Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Research Ethics Review Committee, Department of Health Studies. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.*

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

3) *The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.*

4) *[Stipulate any reporting requirements if applicable].*

Note:

The reference numbers [top middle and right corner of this communiqué] should be clearly indicated on all forms of communication [e.g. Webmail, E-mail messages, letters] with the intended research participants, as well as with the Research Ethics Committee: Department of Health Studies.

Kind regards,

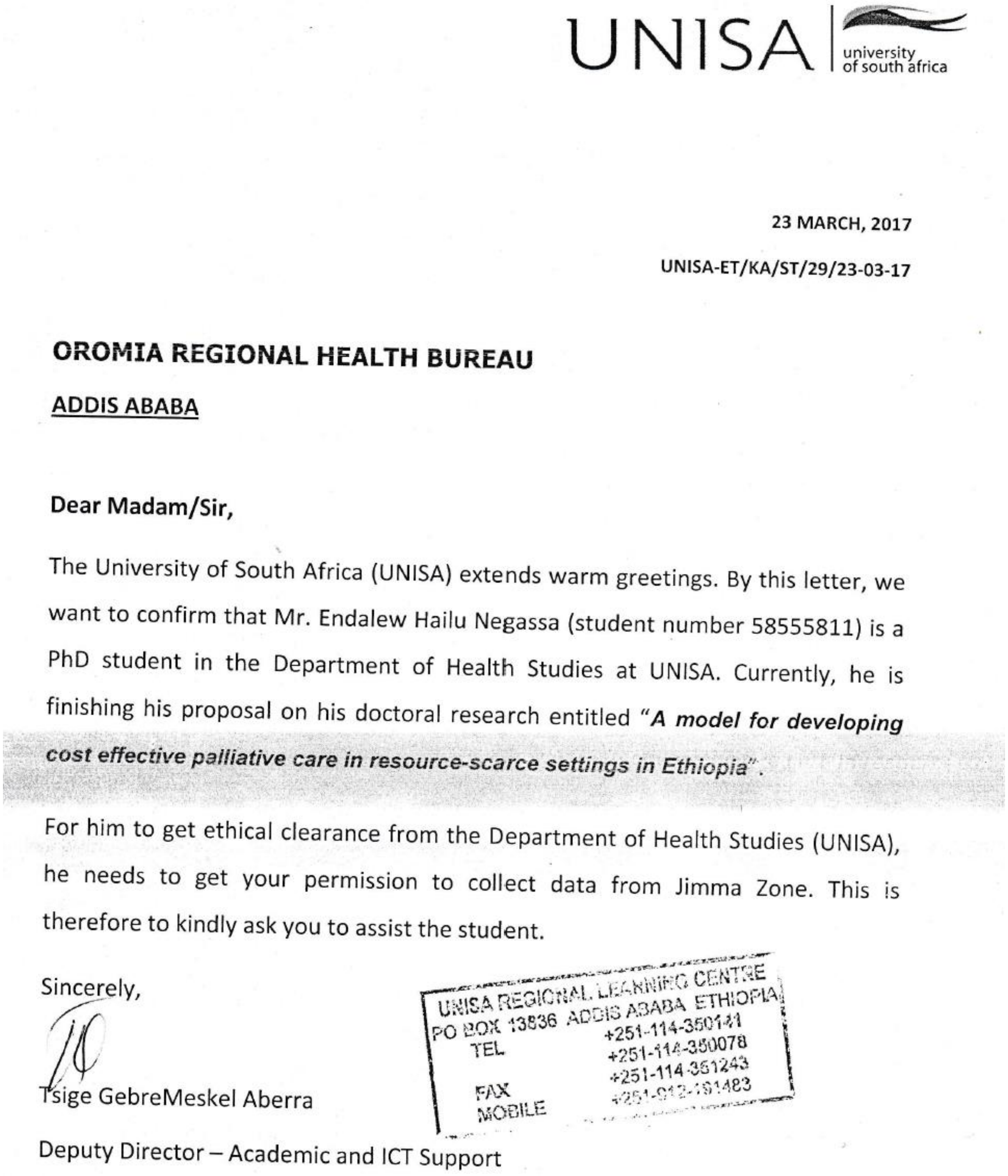
Prof

Prof JE Maritz
CHAIRPERSON
maritje@unisa.ac.za

Prof MM Moleki
ACADEMIC CHAIRPERSON
molekmm@unisa.ac.za

Prof A Phillips
DEAN COLLEGE OF HUMAN SCIENCES

Annexure Two Supporting letter from UNISA Addis Ababa branch



UNISA university of south africa

23 MARCH, 2017

UNISA-ET/KA/ST/29/23-03-17

OROMIA REGIONAL HEALTH BUREAU

ADDIS ABABA

Dear Madam/Sir,

The University of South Africa (UNISA) extends warm greetings. By this letter, we want to confirm that Mr. Endalew Hailu Negassa (student number 58555811) is a PhD student in the Department of Health Studies at UNISA. Currently, he is finishing his proposal on his doctoral research entitled ***"A model for developing cost effective palliative care in resource-scarce settings in Ethiopia"***.

For him to get ethical clearance from the Department of Health Studies (UNISA), he needs to get your permission to collect data from Jimma Zone. This is therefore to kindly ask you to assist the student.

Sincerely,

Tsige GebreMeskel Aberra

Deputy Director – Academic and ICT Support

UNISA REGIONAL LEARNING CENTRE
PO BOX 13836 ADDIS ABABA ETHIOPIA
TEL +251-114-350141
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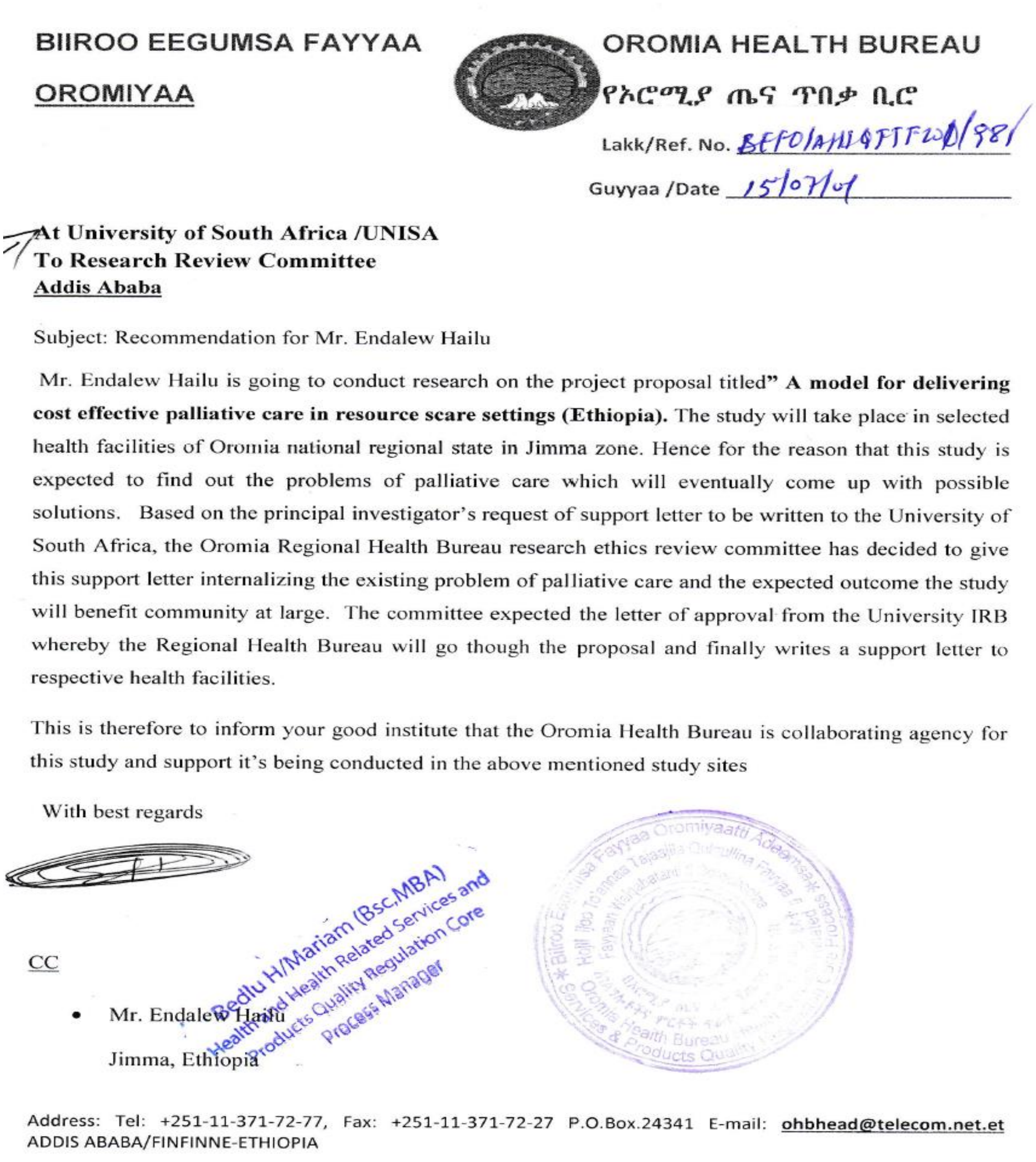
Annexure Three support letter from Oromia Health Bureau to conduct the study



BIIROO EEGUMSA FAYYAA
OROMIYAA

OROMIA HEALTH BUREAU
የኦሮሚያ ጤና ጥበቃ ቢሮ

Lakk/Ref. No. BEFO/AHI9FTF20D/981/

Guyyaa /Date 15/07/01

At University of South Africa /UNISA
To Research Review Committee
Addis Ababa

Subject: Recommendation for Mr. Endalew Hailu

Mr. Endalew Hailu is going to conduct research on the project proposal titled" **A model for delivering cost effective palliative care in resource scare settings (Ethiopia).** The study will take place in selected health facilities of Oromia national regional state in Jimma zone. Hence for the reason that this study is expected to find out the problems of palliative care which will eventually come up with possible solutions. Based on the principal investigator's request of support letter to be written to the University of South Africa, the Oromia Regional Health Bureau research ethics review committee has decided to give this support letter internalizing the existing problem of palliative care and the expected outcome the study will benefit community at large. The committee expected the letter of approval from the University IRB whereby the Regional Health Bureau will go though the proposal and finally writes a support letter to respective health facilities.

This is therefore to inform your good institute that the Oromia Health Bureau is collaborating agency for this study and support it's being conducted in the above mentioned study sites

With best regards

Bedlu H/Mariam (Bsc,MBA)
Health and Health Related Services and
Products Quality Regulation Core
Process Manager

CC

- Mr. Endalew Hailu
  Jimma, Ethiopia

Address: Tel: +251-11-371-72-77, Fax: +251-11-371-72-27 P.O.Box.24341 E-mail: ohbhead@telecom.net.et
ADDIS ABABA/FINFINNE-ETHIOPIA

Annexure Four Informed consent samples for Key informants and FGDs

Informed Consent for Key informants

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

Research Title: A model for delivering cost effective palliative care in resource scarce settings,in Ethiopia

Institution: University of South African (UNISA)

Department of Health Studies

Researcher: Mr. Endalew Hailu Negassa

Supervisor: Professor Sarie Human

Dear Respondent,

The purpose of this study is to develop cost effective palliative care model in resource scarce setting, Ethiopia.

You are being requested for an information about palliative care services provision in Ethiopia and you are selected as one of our study participants and thus, we kindly request you to participate in the study. If you are willing to participate in the study, we will have an interview with you. This will take approximately 50-90minutes to complete. In the interview, this research primarily focuses on the nature and extent of palliative care, its challenge, the needs and priorities of palliative care provision in Ethiopia. During interview, no one else except the researcher and research assistant, who observe and record the main points of the interview, will be present. With your permission. We would also like to record the interview so that we do not miss anything you say. It is on voluntary basis and you are not coerced to do so. You will be free to withdraw from the study at any time and you will not be victimized.

You are assured that any information you share will remain strictly confidential and the contents will only be discussed between the researcher and assistant researcher and will be kept in a secured place.

There will be no monetary compensation for your participation in the study but long term benefits are for improvement of Palliative care services provision and to develop a cost effective model for palliative care that is applicable and acceptable in resource scarce setting.

I ………………………………………………….. understood that I am being asked to participate in the above mentioned study. I realize that I cannot participate in this study if I am younger than 18years.

I realize that my participation in this study is entirely voluntary and I may withdraw from this study at any time I wish without penalty and that minimum risk is expected from my participation in this study.

The study has been explained to me. I have read and understood this consent form; all of my questions have been answered and I agree to participate in the above mentioned study.

Signature of the Respondent ………………………………. Date……………………
Signature of the Witness …………………………….... Date……………………

Signature of the Researcher ……………………………… Date……………………

Contact details of the researcher: Endalew Hailu (Tel: +251-911048847

E-mail:endale.10@gmail.com

Contact details of the Chairperson of the Research and Ethics committee

Professor JE Maritz: E-mail:maritje@unisa.ac.za

Thank you very much!

Informed Consent for Focused group discussion

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in West Ethiopia

Interview guide for Focused group discussion with Health professionals

Research Title: A model for delivering cost effective palliative care in resource scarce settings,in Ethiopia

Institution: University of South African (UNISA)

Department of Health Studies

Researcher: Mr. Endalew Hailu Negassa

Supervisor: Professor Sarie Human

Dear Respondent,

The purpose of this study is to develop cost effective palliative care model in resource scarce setting, Ethiopia.

You are being requested for information about palliative care services provision in Ethiopia and you are selected as one of our study participants and thus, we kindly request you to participate in the study. If you are willing to participate in the study, we will have focused group discussion with you. This will take approximately 50-90minutes to complete. In the discussion, this research primarily focuses on nature and extent of palliative care, its challenge, the needs and priorities of palliative care provision in Ethiopia. During interview, no one else except the researcher and research assistant, who observe and record the main points of the interview, will be present. With your permission, we would also like to record the interview so that we do not miss anything you say. It is on voluntary basis and you are

Annexure Five English Version for qualitative data collection tools

Qualitative toos l used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia.

General Information

Position (responsibility) ____________

Work experience in the area__________

Educational status _________

Sex __________

Age___________

I: Interview guide for key stakeholders (Policy makers, Regional Health Bureaus, Zonal/Woreda Health Departments)

Can you tell me about yourself? Probe: your experience on palliative care, education, responsibility

What do you mean by palliative care: probe do you heard /know about palliative care? probe, please tell me more ?

What are the nature and extent of palliative care in Ethiopia?

Probe: Describe the current situation, its scope? Would you say more or elaborate? Is there any palliative care association in Ethiopia?

How about palliative care policies, strategies and advocacies? Probe: Past, Present, Future. Please tell me more

What types of models of palliative care exist in Ethiopian health care system?

Probe: mention them, how these models relate (fit) with/ to local health care system

How do the national level (MOH) Department works together? What is the job (responsibility) of ,What does each level do to ensure that the palliative care services they are supposed to ?

National level department

The next level (provincial)

The next level local (district)

Probe: How is it integrated with chronic life treating diseases?

What are the gaps in the current palliative care provision in Ethiopia/to the local area?

What are the Challenges, Obstacles of delivering palliative care services to Local and National level? Probe more on practice: palliative care implementation (Training, support, polices, advocacies, Education) implementation of palliative care services

Probe: tell me more, service linked challenges, provider linked challenges

Probe: How do you manage the challenge or Obstacles? Please tell me more

9. What things need to be included in the palliative care services in the future?

QUALITATIVE DATA COLLECTION TOOL (In-depth Interview)

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia.

General Information

Position (responsibility) ____________

Work experience in the area__________

Educational status _________

Sex __________

Age___________

I Interview guide for Health Professionals (Chief and academic Director, Dean of Medical Faculty , Department Heads, Nursing director, Oncology unit :Doctors Pharmacy, Nurses,)

1 .Can you tell me about yourself? Probe: your experience on palliative care, education, responsibility

What do you mean by palliative care: probe do you heard it /know about palliative care? Probe, please tell me more?

Probe: How do understand palliative care

Probe: when you provide it,

Probe: For whom do you give palliative care?

Probe, whose responsibility is providing palliative care?

Probe: what really it look like, can you tell me your experience

What types of support /palliative care are rendering your giving in the Hospital /organization rendering to patients? Probe :Tell me more, what else

Probe: physical care/support, psychosocial care, social care, spiritual care

Probe: what else, can you describe any activities that you are not providing due to different reason?

Probe: availability of drugs, training, lack of multi-disciplinary approach, funds/donors related issue, Reason?, Do you tried to avoid such barriers & how? , Which barrier do you think needs urgent solution? Why ?

4. What are the nature and extent of palliative care in your hospital?

Probe: Describe the current situation, its scope? Would you say more or elaborate?

Probe : what else , can you describe any activities that you are not providing due to different reason?

5. What are the gaps in the current palliative care provision in your hospital /to the local area?

6. What are the Challenges, Obstacles of delivering palliative care services to your Hospital/Department? Probe: more on practice: palliative care implementation (Training, support, polices, advocacies, Education) implementation of palliative care services

Probe: tell me more, service linked challenges, provider linked challenges

Probe: How do you manage the challenge or Obstacles? Please tell me more

7. What things need to be included in the palliative care services in the future?

ANNEX III: Interview guide for stakeholders (NGOs)

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia.

General Information

Position (responsibility) ____________

Work experience in the area__________

Educational status ________

Sex _________

Age__________

Guiding Questions

Can you tell me more about yourself? probe : position in the organization, your experience of offering Palliative care services to chronic life threatening patients

What do you mean by palliative care: probe do you heard /know about palliative care? probe, please tell me more ?

What is the role of your organization in delivery of palliative care services to patients? Probe:please tell me more. probe: physical care ,psychological care social care, spiritual care

What type of support is your organization rendering to patients? Probe :Tell me more, what else

What are the main obstacles/challenges of palliative care service delivered to patients? probe : please tell me more."

What things need to be included in the palliative care services in the futures? Probe :please tell me more

Interview guide-Program Coordinators of chronic illness follow -up clinics

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia.

. General Information

Position (responsibility) ____________

Work experience in the area__________

Educational status ________

Sex _________

Age__________

Can you tell me more about yourself? And your experience of offering Palliative care services to chronic life threatening diseases

Can you describe the scope of palliative care, you are providing for the patients with chronic life threatening diseases? probe: what else, can you describe more

What types of supports are your facility rendering to chronic life threatening diseases ? probe: what else, what are factors that have impact to give effective palliative care

How do you address patients and family, caregivers' needs in the context of a resource-poor setting?

What are the needs and priorities of palliative care in your facility? probe: what else

What are the challenges you have to carry out palliative care services? Probe: please tell me more, elaborate, can you describe any activities that you are not providing due to different reason?

What things need to be included in the palliative care services in the future?

Interview guide- Faith based Organizations

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia

General Information

Position (responsibility) ____________

Work experience in the area__________

Educational status _________

Sex __________

Age___________

Can you tell me more about yourself? And your experience of offering. Palliative care services to patients

What is the role of your organization in addressing palliative care services for chronic life threatening diseases? Probe: mention them, please tell me more?

Which components of palliative care services, are you giving for chronic life threatening diseases in your health facility? Probe: mention them, please tell me more?

What are the main obstacles/challenges of palliative care service delivered to patients? probe : please tell me more."

Interview guide-Hospices (Hospice Ethiopia and Strong Hearts Ethiopia),

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia

General Information

. Position (responsibility) ____________

Work experience in the area__________

Educational status ________

Sex _________

Age__________

1. Can you tell me more about yourself? And your experience of offering Palliative care services to patients?

Probe: How many staffs do you have?

2. What is the role of your organization in addressing palliative care services for chronic life threatening diseases? Probe: mention them, please tell me more? scope of delivery (Urban vs Rural, Geographical coverage)

Probe: Source of funds / resource, network/partnerships.

3. Which components of palliative care services, are you giving for chronic life threatening diseases in your health facility?

Probe: mention them, please tell me more? In-patient facilities, home based care, out patients department

Probe: types of patients and diseases condition

4. How do you address patients and family, caregivers' needs in the context of a resource-poor setting?

5. What are the main obstacles/challenges of palliative care service delivered to patients? Probe: please, tell me more.

6. How do you mitigate the challenge/ obstacles that you faced?

Interview guide - Community support groups (Extension health workers and volunteers' workers)

Qualitative tool used to develop cost effective palliative care model in resource scarce setting in Ethiopia.

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia

General Information

. Position (responsibility) ____________

Work experience in the area__________

Educational status _________

Sex __________

Age___________

Can you tell me more about yourself? And your experience of offering. Palliative care services to patients

What is the role of extension health workers in addressing palliative care services for chronic life threatening diseases? Probe: mention them, please tell me more?

Which components of palliative care services are you giving for chronic life threatening diseases in your health facility? Probe: mention them, please tell me more?

How do you address patients and family, caregivers' needs in the context of a resource-poor setting?

What are the main obstacles/challenges of palliative care service delivered to patients? probe : please, tell me more

Qualitative Data Collection Tool (Focused group discussion)

Qualitative tool used to assess palliative care services in Ethiopia to develop cost effective palliative care model in resource scarce setting.

Research Title: A model for delivering cost effective palliative care in resource scarce settings,in Ethiopia

A Guide for developing cost effective palliative care model in resource scarce settings in Ethiopia.

ANNEX I: Interview guide for Focused group discussion with Health professionals

Guiding Questions

What do you mean by palliative care ? probe :your experience on palliative care, education, responsibility

Which components of palliative care are given for patients with chronic life threatening diseases in your health facility?

Probe: can you describe them? Which components are not given by your health facilities? Probe: why?

Is there any palliative guide line ,protocols and reporting format in your clinic

How do you address patients’ and family, caregivers' needs in the context of a resource-poor setting?

What are the enabling factors for the provision of palliative care in your facility

Probe: availability of drugs, education, training, lack of multi-disciplinary approach, funds/donors related issue, others (specify it).

What have been the main challenges that you faced so far? Please, tell more.

What types of models of palliative care exist in Ethiopian health care system?

Probe: Mention them, how these models relate (fit) with to local health care system

Annexure Six Sample for Amharic version data Collection Tools

Amharic version of the tool

ሁለተናዊ የጤና እንክብካቤ እና የማስታገስ አገልግሎት የትግበራ ሁኔታን በተመለከተ የተዘጋጀ የጥናት መጠይቅ፡፡

የጥልቅ መጠይቅ መመሪያ እና የስምምነት ውል

የጥናቱ ርዕስ ሁለተናዊ የጤና እንክብካቤ እና የማስታገስ አገልግሎት ሞዴልን በኢትዮጲያ ለማዘጋጀት የቀረበ ሲሆን በቅድሚያ ጊዜዎትን መሰዋት አድርገው በጥናቱ ላይ ለመሳተፍ ፍቃደኛ ስለሆኑ አመሰግናለው፡

- ጤና ይስጥልን ስሜ እንዳለው ሀይሉ ሲሆን በአሁኑ ጊዜ ሦስተኛ ድግሪዬን **(PhD)** በደቡብ አፍሪካ ዩኒቨርሲቲ በመከታተል ላይ የምገኝ ስሆን የጥናቴ ምርዕስ ሁለተናዊ የጤና እንክብካቤ እና የማስታገስ አገልግሎት ሞዴልን በኢትዮጲያ ለማዘጋጀት የቀረበ ነው፡፡ በመሆኑም እርሶ ብለት የስራ ልምድ እና የትምህርት ዝግጅት በዚህ ጥናት ላይ እንዲሳተፉ እና የጥልቅ ቃለ መጠይቅ እንዲያደርጉ እርሶ ተመርጠዋል፡፡ ቃለ መጠይቁም 30 ደቂቃ ይፈጃል የሚሰጡትን ምላሽ ድምፅ ሰለሚቀዳ እና አንዳንድ ማስታወሻ እወስዳለው የሚሰጡት ምላሽ ሚስጥራዊነቱ የተጠበቀ እና መረጃው ከተመራማሪው ውጭ እንደ ማይወጣ እና እርሶም በቃለ መጠይቁ ለመሳተፍ የማይፈልጉ ከሆነ በመሀከል ማቋረጥ ይችላሉ፡፡

  በጥናቱ ላይ መሳተፍ ይፈልጋሉ

  ☐ አዎ

  ☐ አልፈልግም

1. የጥልቅ ቃለ መጠይቅ ጥያቄዎች (ለሀገር አቀፍ፡ ለክልል፡ ለዞን እና ለወረዳ ሀላፊዎች)

   አጠቃላይ መረጃ

   1. የስራ ድርሻ/ሀላፊነት---
   2. የስራ ልምድ--
   3. የትምህርት ደረጃ---
   4. ፆታ--
   5. ዕድሜ---

ክፍል አንድ

1. ስለ ራስዎት ሊገልፁልኝ ይችላሉ?

   ማቅርከር(Probe)፡ - በሁለተንዊ የጤና እንክብከቤ እና ማስታገስ ላይ ያሉት የስራ ልምድ እና ሀላፊነት እና የትምህርት ደረጃ ቢያካፍሉን ?

2. ስለ ሁለንተናዊ የጤና እንክብከቤ እና የማስታገስ ስራ ሰምተው ያውቃሉ?(about palliative care)
3. በአሁኑ ጊዜ ሁለንተናዊ የጤና እንክብከቤ እና ማስታገስ በተመለከተ በሀገር አቀፍ ደረጃ ያሉት ፖሊሲዎች፤ ሂደቶች እና ተግባራቶች ምን ይመስላሉ?

   ማቅረከር ፡ -ይህን ሁኔታ ካለፈው ልምድ አካያ ምን ይመስላለል?

   ማቅረከር ፡ - አሁን ያለበት ነባራዊ ሁኔታስ ምን ይመስላል?

   ማቅረከር፡ - ካለው ነባራዊ ሁኔታ በመነሳት በቀጣይ ምን መሆን ወይም መሠራት እንደሚፈልጉ ቢገልፁልን?

4. በሀገር አቀፍ ደረጃ በአሁን ጊዜ ሁለንተናዊ የጤና እንክብከቤ እና ማስታገስ አገልግሎት ተግባር ለሚፈጸምዋ ምትጠቀሙበት ሞዴል (የአገልግሎት ሰጭ አይነቶች) ወይም ፍሬምወርክ ምን ይመስላል?

   ማቅረከር ፡ - ይህን ጉዳይ በጥልቀት ቢያብራሩልን?

5. በሀገር አቀፍ ደረጃ ያለው ሁለንተናዊ የጤና እንክብከቤ እና የማስታገስ አገልግሎት ከክልሎች እና በተዋረድ ካሉ የዞን እና የወረዳ የጤና ፅ/ቤቶች ጋር ያለው የሥራ ግንኙነት እና ድርሻ ምን ይመስላል?

ማቅርከር ፡ - የሪፈራል ሥርዓቱ የተቀናጀ ነው?

ማቅርከር ፡ - በዚህ ዘርፍ የስልጠና እና ያቅም ግንባታ ስራዎች ምን ይመስላሉ?

6. በአሁኑ ጊዜ በኢትዮጲያ ሁለንተናዊ የጤና እንክብከቤ እና የማስታገስ ሥራ ምን ይመስላል ? ምን ደረጃ ላይ ይሆን ቢብራሩልን ፡ ፡

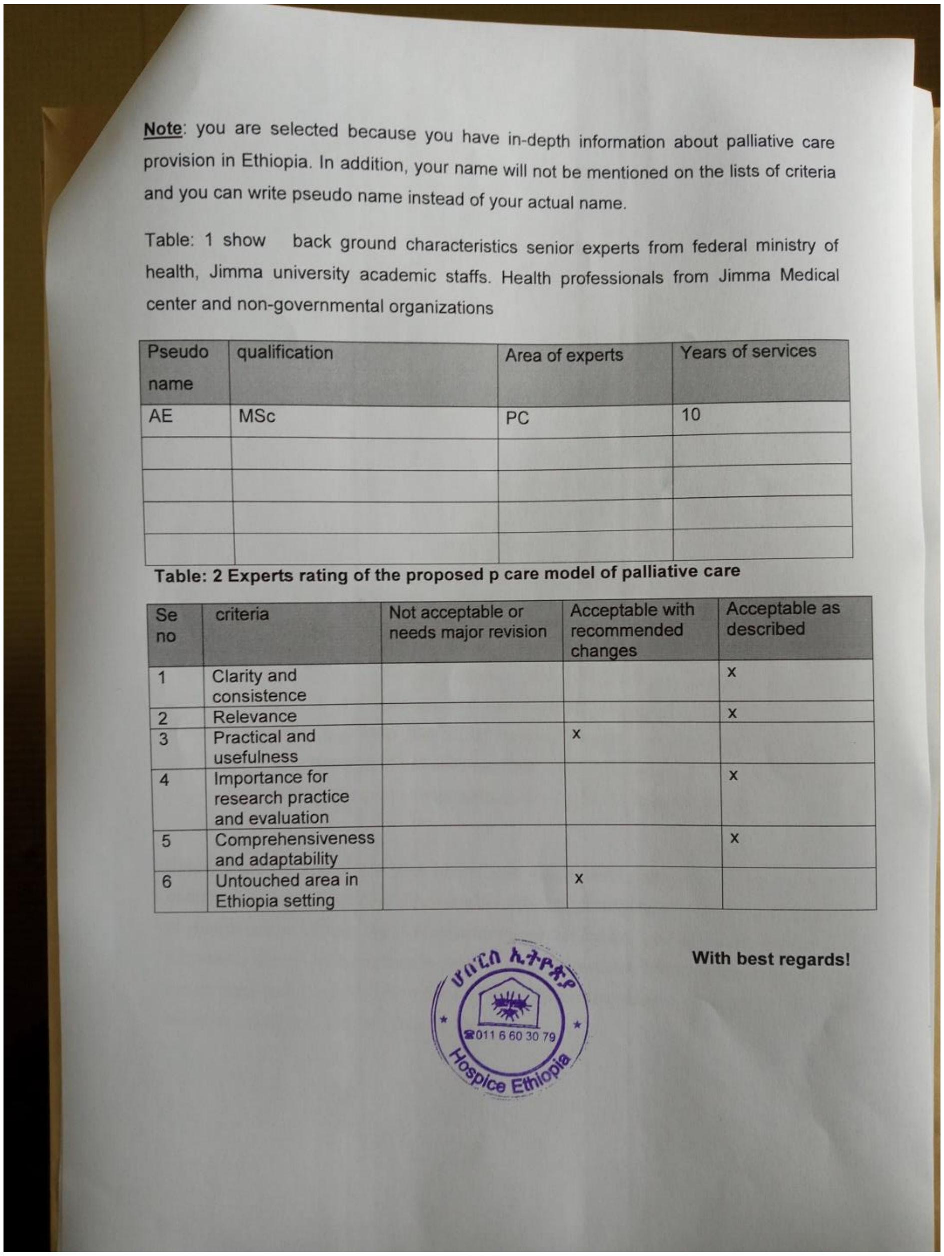
ማቅርከር ፡ - በአሁን ጊዜ ያለው ነባራዊ ሁኔታ ምን ይመስላል ? ይህን ቢብራሩልን

7. በሁለንተናዊ የጤና እንክብከቤና ማስታገስ ለማቀባበር ያሉት ተግዳሮቶች፤ እንቅፋቶች እና ማሰናክሎች በሀገር አቀፍ ደረጃ እና በአከባቢያ(Local) ደረጃ ምን ይመስላል ፡ ፡

   ማቅረከረ ፡ - ስልጠና በተመለከተ፤ ፖሊሲን በተመለከተ፤ ግብአትን በተመለከተ፤ ከችግሩ ጋር በተያያዘ የትምህርት አሰጣጥን በተመለከተ፤ ወይም ስርዓት ትምህርትን በተመለከተ በዚ ዘርፍ የተደረጉ ጥናት እና ምርምሮች ካሉ ቢያብራሩልን?

መከራከር፡ - እላይ የተዘረዘሩት ተግዳሮቶች እና ማሰናክሎች ለመፍታት(ለማለፍ) ያደረጉት ጥረት ካለ ቢያብራሩልን?

Annexure Seven Sample for Validation Results



Note: you are selected because you have in-depth information about palliative care provision in Ethiopia. In addition, your name will not be mentioned on the lists of criteria and you can write pseudo name instead of your actual name.

Table: 1 show back ground characteristics senior experts from federal ministry of health, Jimma university academic staffs. Health professionals from Jimma Medical center and non-governmental organizations

Pseudo name	qualification	Area of experts	Years of services
AE	MSc	PC	10

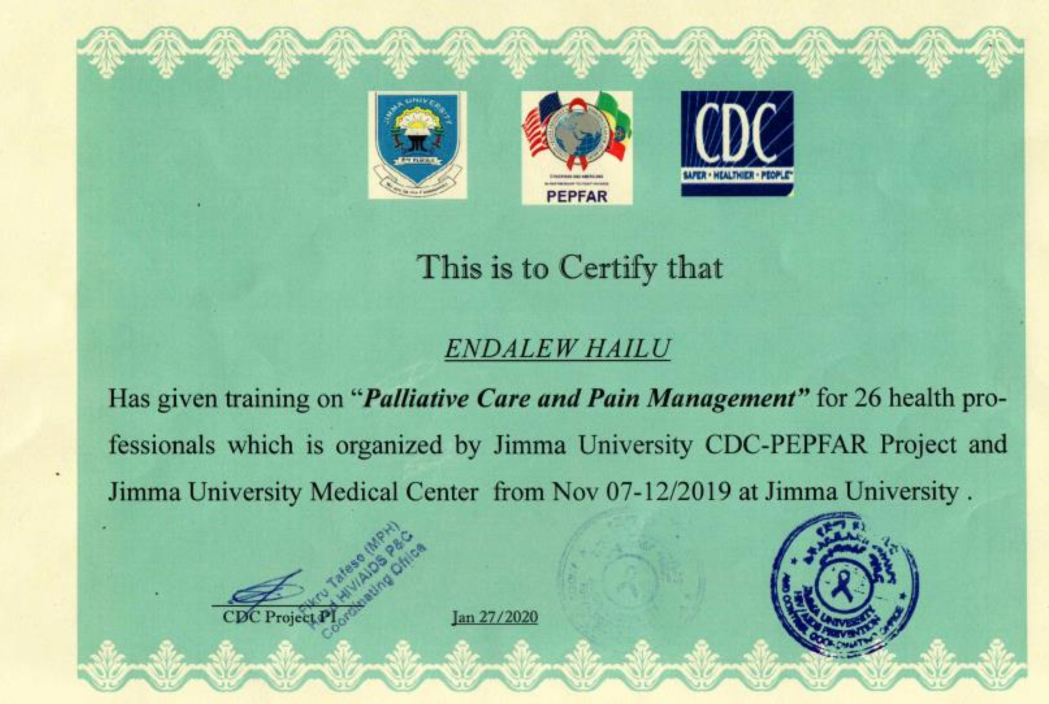
Table: 2 Experts rating of the proposed p care model of palliative care

Se no	criteria	Not acceptable or needs major revision	Acceptable with recommended changes	Acceptable as described
1	Clarity and consistence			x
2	Relevance			x
3	Practical and usefulness		x	
4	Importance for research practice and evaluation			x
5	Comprehensiveness and adaptability			x
6	Untouched area in Ethiopia setting		x	

ሆስፒስ ኢትዮጵያ
☎011 6 60 30 79
Hospice Ethiopia

With best regards!

Annexure Eight Certificates awarded for training implementation



PEPFAR

CDC

SAFER • HEALTHIER • PEOPLE™

This is to Certify that

ENDALEW HAILU

Has given training on "***Palliative Care and Pain Management***" for 26 health professionals which is organized by Jimma University CDC-PEPFAR Project and Jimma University Medical Center from Nov 07-12/2019 at Jimma University .

ikru Tafese (MPH)
[illegible] HIV/AIDS P&C
Coordinating Office

CDC Project PI

Jan 27/2020

This is to certify that

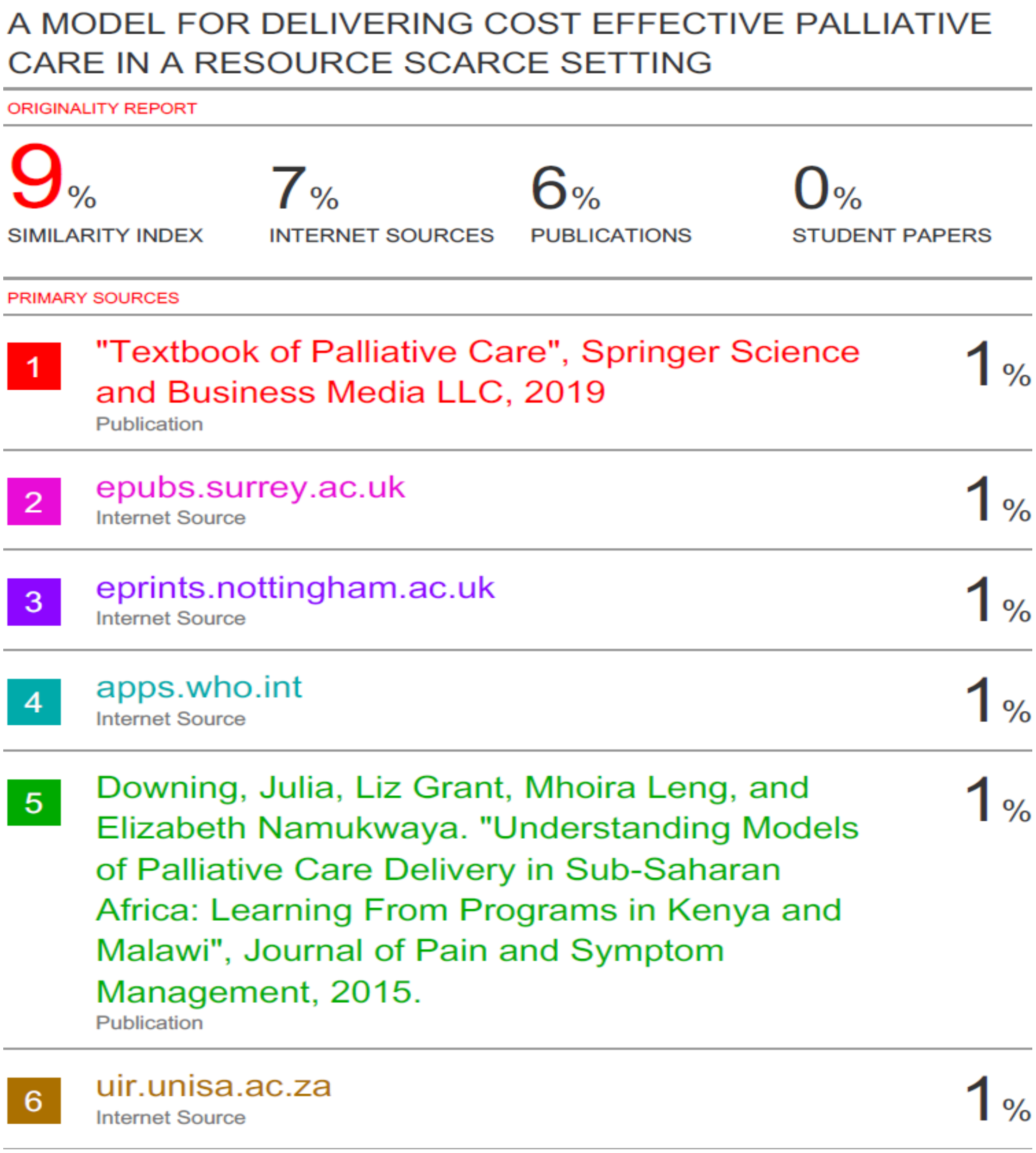
Mr ENDALEW HAILU

Has given training on "***Palliative Care and Pain Management***" for 33 health professionals as part of his PhD implementation phase which is organized by Shenen Gibe Hospital from March 07-12/2019 at Jimma town, Ethiopia.

With best regards

Dr. Geleta Abebe
Medical Director

Annexure Nine Certificate of Turutine



A MODEL FOR DELIVERING COST EFFECTIVE PALLIATIVE CARE IN A RESOURCE SCARCE SETTING

ORIGINALITY REPORT

9%	7%	6%	0%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

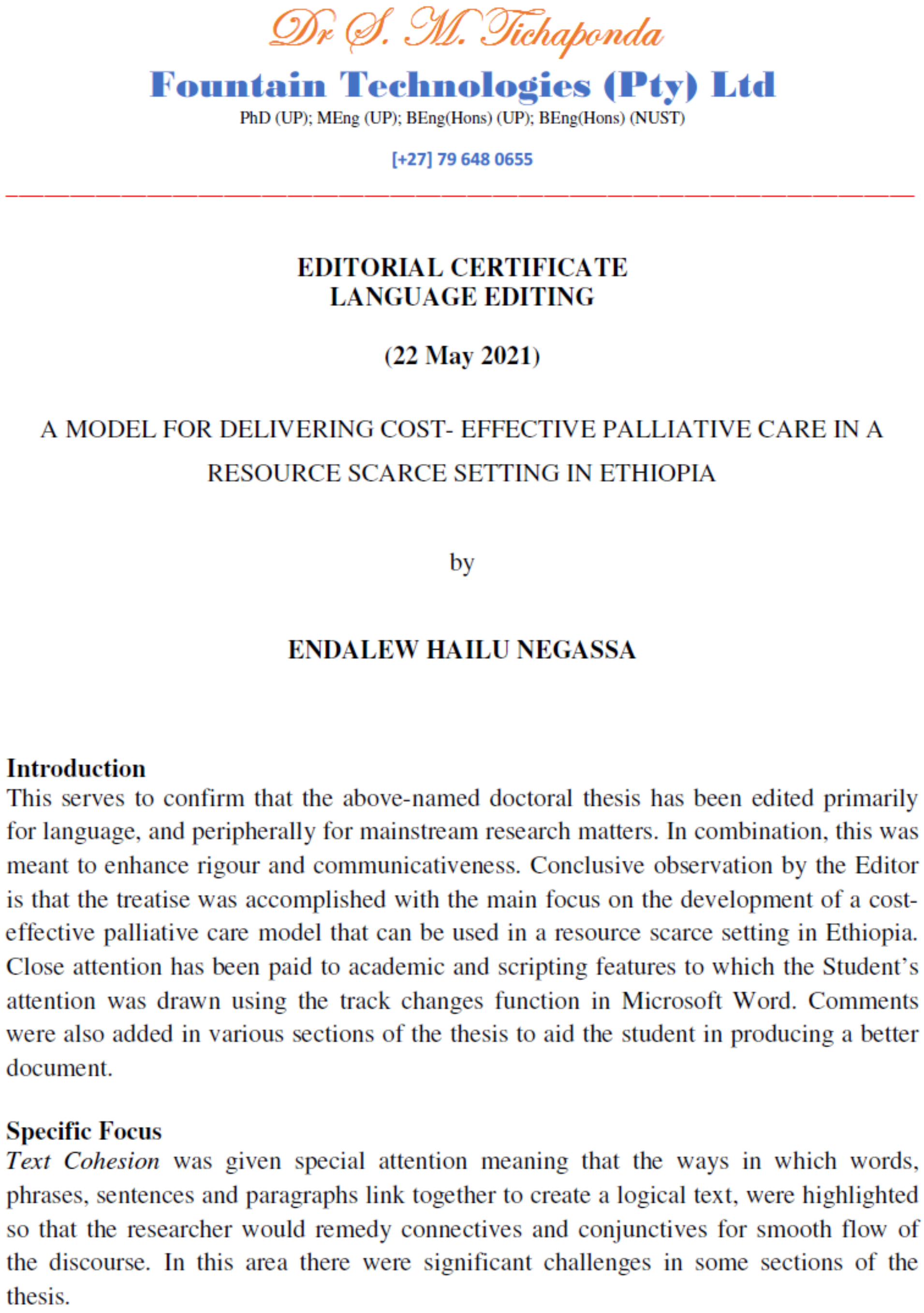
PRIMARY SOURCES

1	"Textbook of Palliative Care", Springer Science and Business Media LLC, 2019 Publication	1%
2	epubs.surrey.ac.uk Internet Source	1%
3	eprints.nottingham.ac.uk Internet Source	1%
4	apps.who.int Internet Source	1%
5	Downing, Julia, Liz Grant, Mhoira Leng, and Elizabeth Namukwaya. "Understanding Models of Palliative Care Delivery in Sub-Saharan Africa: Learning From Programs in Kenya and Malawi", Journal of Pain and Symptom Management, 2015. Publication	1%
6	uir.unisa.ac.za Internet Source	1%

7	www.dianaprincessofwalesmemorialfund.org Internet Source	1 %
8	Suresh K. Kumar. "Kerala, India: A Regional Community-Based Palliative Care Model", Journal of Pain and Symptom Management, 2007 Publication	1 %
9	link.springer.com Internet Source	1 %
10	www.science.gov Internet Source	1 %

Exclude quotes	On	Exclude matches	< 1%
Exclude bibliography	On		

Annexure Ten certificate of language editing and proofreading



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EDITORIAL CERTIFICATE
LANGUAGE EDITING

(22 May 2021)

A MODEL FOR DELIVERING COST- EFFECTIVE PALLIATIVE CARE IN A RESOURCE SCARCE SETTING IN ETHIOPIA

by

ENDALEW HAILU NEGASSA

Introduction

This serves to confirm that the above-named doctoral thesis has been edited primarily for language, and peripherally for mainstream research matters. In combination, this was meant to enhance rigour and communicativeness. Conclusive observation by the Editor is that the treatise was accomplished with the main focus on the development of a cost-effective palliative care model that can be used in a resource scarce setting in Ethiopia. Close attention has been paid to academic and scripting features to which the Student's attention was drawn using the track changes function in Microsoft Word. Comments were also added in various sections of the thesis to aid the student in producing a better document.

Specific Focus

Text Cohesion was given special attention meaning that the ways in which words, phrases, sentences and paragraphs link together to create a logical text, were highlighted so that the researcher would remedy connectives and conjunctives for smooth flow of the discourse. In this area there were significant challenges in some sections of the thesis.

Referencing: The researcher is advised to go correct the in-text referencing for the Harvard referencing style, which he is using. This will aid in improving the flow of the sentences in the thesis.

Tense: Normally, when writing the proposal, common practice is to use the auxiliary verb, 'will'. Typically, the final report, such as this one, should be in the past tense, alternating with the simple present. The researcher is advised to go through the entire document and attend to tense as appropriate.

Repetitiveness: As a stylistic feature it destroys the tempo of communication. There was a significant amount of repetition in several chapters. It is the Editor's advice that the researcher reads the chapters very closely, and prune cases of repetition. The Editor also highlighted areas where repetition was identified, so that the thesis reads more smoothly.

Ambiguities: Where ambiguities have been noted, the researcher's attention has been drawn to them, so that he could revisit and correct accordingly. Several cases arose, where The Editor was not sure of what the researcher wanted to communicate, these have been highlighted and the researcher was advised revise and correct accordingly.

Lexical items: At general level*,* the researcher's command of language is adequate. Notwithstanding, his/her attention was drawn to instances where more appropriate lexical items than those used, were recommended for amendment. There is need for meticulous revision and attention to spelling. There has been highlights within the text.

Punctuation: Judicious use of punctuation marks: full stop, comma, semi-colon, colon, etc. is a critical requirement for a communicative text, and accounts for cohesion. The researcher made adequate use of these, although cases arose were there is need for revision. For example, the author frequently made use of the comma at incorrect places in the senetences. He also often forgot to put fullstops at the end of full sentences. Notwithstanding, the Editor closely read the document, and drew attention to some of the instances that eluded the researcher.

Language additions: There were instances when the Editor added words or phrases to promote increased communicativeness. The researcher is expected to look at the suggestions, and determine what to accept and what not to accept.

Copy and Paste: The researcher must be commended for producing an original document with virtually no plagiarism detected as evidenced by the low Turnitin score retained for the document.

Document Coherence was given special editorial attention to ensure the quality of forming a unified whole. The researcher's attention was drawn to issues of cross-referencing (both retrospective and prospective), and interrelatedness of paragraphs and chapters so that they do not stand as discreet units. This is often achieved by occasionally stating research questions/objectives of the study/research problem occasionally in the write-up.

Paragraphing: The paragraphing is perfect, but one notices that there are examples of lack of logic, where ideas are thrown in without linking with previous ones. In some instances, the researcher makes use of one sentence paragraphs. These have, been highlighted in the Editor's report, please, look very closely at this and formart accordingly.

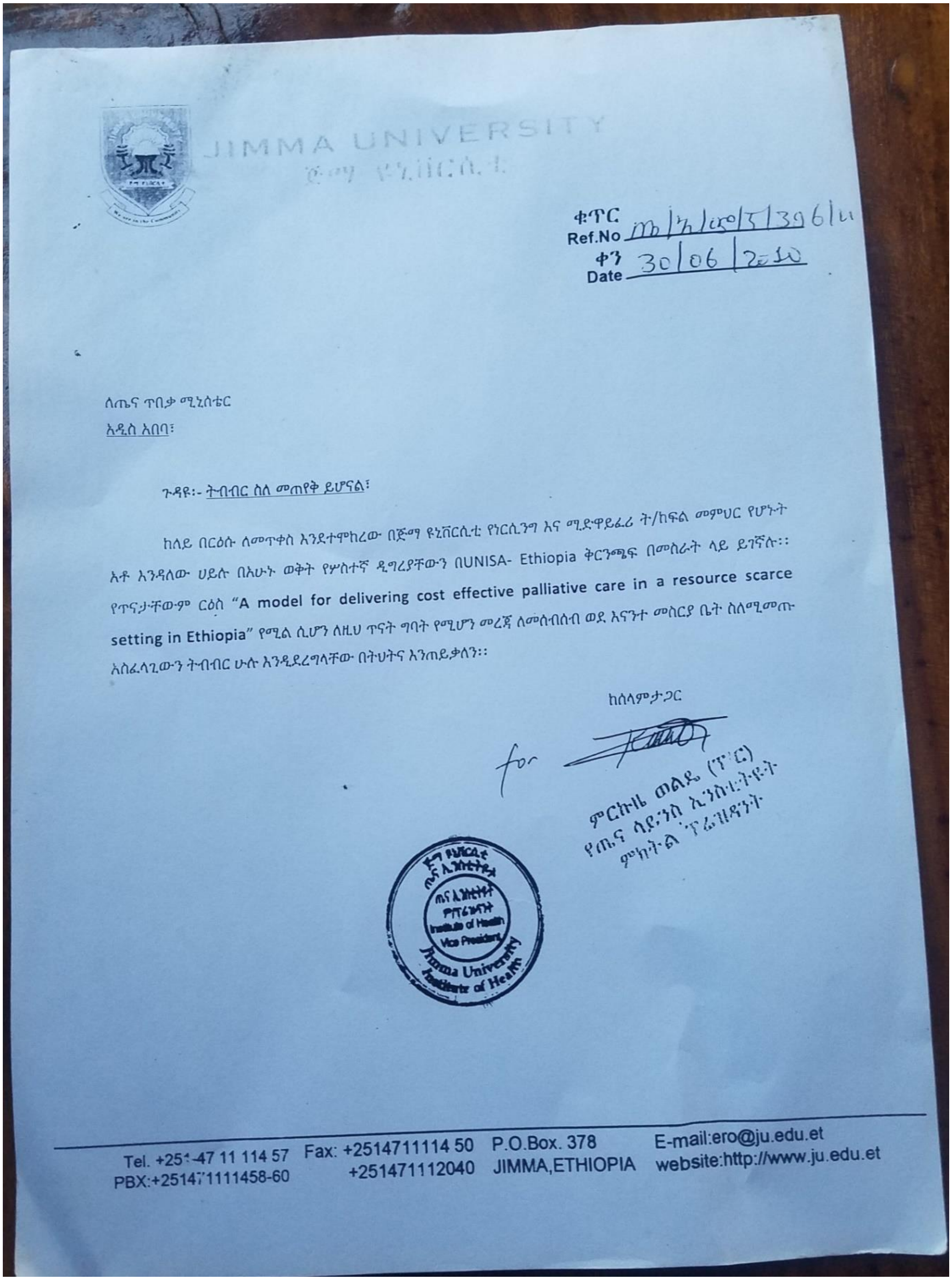
General advice: In view of the observations made above, the researcher is advised to take time and make meticulous revision of the entire document, and accommodate where necessary. Given, the researchers general command of English, I am confident that the candidate will be able to accommodate the changes suggested with limited need for a second round of language editing. I remain available to assist should you find it necessary to contact me.

Conclusion

To the best of my capacity, I have given the write-up undivided attention, supported with thorough scrutiny of matters linguistic. It remains for the researcher to consider suggestions, and accommodate what they consider helpful, while rejecting suggestions that do not enhance the quality of the Thesis. It is my conviction that accommodation of the suggestions will make the study more effective. Moreover, the study has great relevance to the provision of palliative care in Ethiopia in a resource scare setting.

Dr. S.M. Tichapondwa (PhD)

Annexure Eleven Ethical letter to Federal Ministry of Health



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ቁጥር Ref.No ጤ/ኢ/ሥ0/5/396/ሀ
ቀን Date 30/06/2010

ለጤና ጥበቃ ሚኒስቴር
<u>አዲስ አበባ፣</u>

ጉዳዩ፡- <u>ትብብር ስለ መጠየቅ ይሆናል፣</u>

ከላይ በርዕሱ ለመጥቀስ እንደተሞከረው በጅማ ዩኒቨርሲቲ የነርሲንግ እና ሚድዋይፈሪ ት/ክፍል መምህር የሆኑት አቶ እንዳለው ሀይሉ በአሁኑ ወቅት የሦስተኛ ዲግሪያቸውን በUNISA- Ethiopia ቅርንጫፍ በመስራት ላይ ይገኛሉ:: የጥናታቸውም ርዕስ "A model for delivering cost effective palliative care in a resource scarce setting in Ethiopia" የሚል ሲሆን ለዚህ ጥናት ግባት የሚሆን መረጃ ለመሰብሰብ ወደ እናንተ መስርያ ቤት ስለሚመጡ አስፈላጊውን ትብብር ሁሉ እንዲደረግላቸው በትህትና እንጠይቃለን::

ከሰላምታ ጋር

for

ምርኩዜ ወልዴ (ፕ/ር)
የጤና ሳይንስ ኢንስቲትዩት
ምክትል ፕሬዝዳንት

Institute of Health Vice President

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