

**ADDIS ABABA UNIVERSITY  
COLLEGE OF HEALTH SCIENCE  
SCHOOL OF PUBLIC HEALTH**

**UNMET PALLIATIVE CARE NEEDS OF PEOPLE  
LIVING WITH HIV AND AIDS IN HAWASSA,  
ETHIOPIA**

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A Thesis submitted to the School of Graduate Studies of Addis Ababa University as partial fulfillment of the requirements for the degree of Master of Public Health.

May, 2012 Addis Ababa, Ethiopia

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**Approve by the examining board**

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## **Acknowledgement**

I would like to express my sincere thanks to my advisor Dr Getnet Mitike for his guidance, advice, assistance and unreserved help throughout the whole work of this thesis.

I would like to acknowledge persons in Hawassa referral hospital, Adare hospital and Bushullo health center including all study participants for their overall assistance and cooperation during data collection that I undertook.

I also thank Addis Ababa University for financing this thesis work and my husband for covering my living expenses throughout the study period. I am also thankful to all my colleagues for their advice and support.

Finally, I would like to thank my husband and my parents for their continuous support and encouragement.

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## **Acronyms**

AIDS	Acquired Immunodeficiency Syndrome
ART ID No.	ART Identification Number
ART	Antiretroviral Therapy
EDHS	Ethiopian Demography and Health Survey
FGD	Focus Group Discussion
HAART	Highly Active Antiretroviral Therapy
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
Qol	Quality of life
PLHIV	People living with HIV
SPSS	Statistical Package for Social Science
USA	United States of America
WHO	World Health Organization

## Abstract

**Background:** The World Health Organization defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with threatening illnesses. Assessing the palliative care needs of people living with HIV and AIDS (PLHIV) and providing them with adequate care and support has a special significance in combating the AIDS epidemic.

**Objective:** The main objective of this study is to assess unmet palliative care needs of people living with HIV and AIDS in Hawassa town.

**Methods:** A descriptive cross-sectional study design was conducted to assess palliative care needs of PLHIV and qualitative method was applied to triangulate the findings. Adult PLHIV on ART for at least 6 months were randomly selected for quantitative data. The reason for this is that, palliative care team visit and gives support for PLHIV every 3 months. So PLHIV who have been on ART at least for 6 months have more knowledge about palliative care and have a chance to be visited by palliative care team. For qualitative data health care providers and the PLHIV were purposely selected and a total of 6 in-depth individual interviews and four focus group discussions were conducted. Quantitative data was entered in to SPSS for analysis and qualitative data is analyzed using thematic analysis. Findings of the quantitative data supplemented with qualitative results using the process of triangulation.

**Result:** A total of 390 (121 males and 269 females) PLHIV and 17 (7 males and 10 females) health workers included in this study. The mean age of study participants was  $32.9 \pm 9.6$  years. As the result of this study the most common unmet palliative care needs are financial assistance (59%), pain relief (48.7%), free treatment for OI (47.9%), nutritional support (38.7%), shelter (28.7%) and home based care (21.3%). Multiple regression analysis showed that all the identified unmet needs for palliative care were more among unemployed PLHIV than employed ( $p < 0.05$ ). The health care providers indicated that shortage of staff, lack of funding, lack of equipment and lack of strong policy on palliative care program were the main barrier to meet the need of palliative care among PLHIV.

**Conclusion and recommendation:** In conclusion the identified palliative needs in this study include financial assistance, nutritional support, treatment for opportunistic infections, shelter. Home based care and pain relief. These findings could be used as base for the development of a

comprehensive palliative care policy and programmes for PLHIV in Hawassa. So the government and other donor agencies should give emphasis to access and availability of palliative care services.

*Key words: Palliative care need, PLHIV*

# **1. Introduction**

## **1.1 Back ground of the study**

HIV/AIDS is still a threatening pandemic that has eroded many lives and affected the growth and development of many countries, especially in sub-Saharan Africa where the pandemic is increasing and the quality of life (QoL) of people living with HIV and AIDS (PLHIV) has been undermined. More than 90 % of the estimated 42 million people living with the human immunodeficiency virus and acquired immunodeficiency syndrome (HIV and AIDS) around the globe are found in the resource limited countries of Africa, Asia, Caribbean and Latin America (1). In sub-Saharan Africa HIV and AIDS is the most pressing concern with 22.5 million infected people in 2009, which is two thirds (68%) of the global population living with HIV and AIDS (2).

With an estimated 1.1 million people living with HIV, Ethiopia has one of the largest populations of HIV infected people in the world. However, HIV prevalence among the adult population is lower than many sub-Saharan African countries (3). According to the 2007 Single Point Estimate, there were an estimated 1,116,216 people living with HIV in 2009, of which 336,160 were eligible for ART. There were an estimated 131,145 new HIV infection (57% Female) and 44,751 AIDS-related deaths (57% Female) (4). The HIV prevalence among adults in Ethiopian Demographic and health survey (EDHS) 2011 is 1.5% and the prevalence of HIV and AIDS in urban areas is 4.2% (5). Hawassa town is not different from other urban areas of the country.

The World Health Organization (WHO) defines palliative care as an approach that improves the QoL of patients and their families facing the problems associated with threatening illnesses such as cancer and HIV and AIDS; through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychological, and spiritual (6). In order to improve patient's situation, an approach that is receiving considerable attention worldwide, especially in sub-Saharan Africa, is palliative care. However, most of the countries in sub-Saharan Africa have not yet incorporated palliative care in their agenda (7).

## **1.2. Statement of the problem**

HIV and AIDS remain as a major public health problem in our country. Like any other country in Sub-Saharan Africa, the Ethiopian government has made various attempts to combat this problem by enhance the treatment and care of PLHIVs.

The Government of Ethiopia put in place a national HIV and AIDS policy in 1998 to create an enabling environment to fight the pandemic. Since then Ethiopia has made notable achievements in the response against HIV and AIDS. A number of other supporting policies, strategies and guidelines were also developed, distributed and utilized to guide comprehensive HIV prevention, treatment, care and support services at affordable cost for all needy individual and family. In order to ensure that quality HIV and AIDS services are delivered at the community level, various guidelines and standards were developed, distributed and being implemented in 2008 and 2009 (8).

There were an estimated 1,116,216 people living with HIV in 2009, of which 336,160 were eligible for ART. Even if there is free access for ART, only 53% PLHIVs were on ART and there were an estimated 44,751 AIDS-related deaths (5). This suggests that there are still many PLHIV who are not included in the care and treatment. This is linked to the limited resources available in the country to address the needs of PLHIVs. An approach that receiving considerable attention worldwide to those chronically sick people is palliative cares (7). Therefore, in order to make an effective planning and to provide quality care, assessing both met and unmet palliative care needs is crucial.

## **2. Rationale of the study**

Evaluating the palliative care needs of PLHIV and providing them with adequate care and support has a special significance in combating the AIDS epidemic. There is shortage of data on the palliative care needs of PLHIV in Ethiopia as well in Hawassa where this study is conducted. This situation hampers the efforts to formulate informed policies and programmes that will develop and encourage the use of palliative care to meet the needs of PLHIVs. To meet this gap, this study focused on the identification of met and unmet palliative care needs of adults living with HIV and AIDS in Hawassa town.

Thus, it is expected that the present study is primarily contribute to the growing body of knowledge about palliative care in Ethiopia, and particularly in Hawassa. Furthermore this study will serve as a base line for the development of a comprehensive palliative care policy and programmes for PLHIV in Hawassa.

### **3. Literature review**

#### **3.1. Definition of palliative care**

The WHO definition of palliative care previously stressed its relevance to patients not responsive to curative therapy. The present definition extended to comprehensive care, tailored to meet the needs of people experiencing life-threatening illnesses, as well as their families, by improving their quality of life (QoL) (5). According to WHO Palliative care is globally recognized as a legitimate component of health care and evidence shows that palliative care is effective in improving the QoL by meeting the needs of people with threatening illness and their families. In addition, the WHO recommended that palliative care should be provided to all patients with life threatening illness such as cancer and HIV and AIDS (5).

Study conducted in the USA on palliative care for patients with AIDS at a large urban teaching hospital indicate that pain, psychosocial issues, depression, anxiety, nausea/ vomiting, insomnia and family conflicts were problems experienced by PLHIVs. However, after the palliative care intervention and follow up, the most successful resolution of problems was seen for psychosocial issues (91%), pain (90%), and nausea/ vomiting (90%). Less successful resolution was seen for memory problems (26%), fatigue/ weakness (66%), and depression (68%) (9).

#### **3.2 Palliative care program/services**

Although the definition of palliative care is globally relevant, whatever constitutes palliative care needs and services in sub-Saharan Africa is continent-specific, particularly in the light of the extent of poverty and HIV disease (10). Necessary components include practical care, pain and symptoms control, counseling/emotional/psychological support, income generation, financial support for food, shelter, funeral costs, school fees, spiritual support and orphan care (11). This suggests that palliative care in sub-Saharan Africa should incorporate the above-mentioned services for the programme to be effective and meet the needs of PLHIVs.

The main places for palliative care for PLHIV include hospitals, hospices and homes. Palliative care for PLHIV in tertiary hospitals focuses mainly on pain and symptom management, although they admit that the need to address social, emotional, psychological and spiritual care is urgent.

### **3.3 Palliative care needs of people living with HIV and AIDS**

Palliative care needs for PLHIV are multifaceted, depending on many factors such as the stage of the disease, the health infrastructure or system of each country and the socio-economic status of PLHIV. However, studies shows that pain relief and symptom management, psychological support, spiritual support, food and financial support are the most predominant palliative care needs for PLHIV in many countries across the globe (6, 7 and 10).

#### **3.3.1. Medical care access**

In Ethiopia, according to the 2007 Single Point Estimate, there were an estimated 1,116,216 people living with HIV in 2009, of which 336,160 were eligible for ART. As of end of 2009 there were a total of 176,644 PLHIV were on ART and the remaining 47% PLHIV could not access health care service (5). This suggests that access to medical care in Ethiopia is limited. The main factor causing the limitation of access to medical care is poverty (7).

#### **3.3.2. Psychological support**

According to Harding and Higginson's report on palliative care in sub-Saharan Africa PLHIV and their families need emotional and psychological support (10). A study on palliative care needs of PLHIV in Rwanda revealed that 11% of PLHIV with psychological conditions who received psychological support improved significantly in psychological functions (12).

#### **3.3.3. Nutritional support**

Nutritional support in HIV patients is also one of the needs that need to be addressed. HIV compromises the immune system of infected persons, increasing their susceptibility to other infections, which can negatively affect nutritional status. Conversely, malnutrition increases the severity of the HIV disease by further weakening the immune system, which decreases the body's ability to fight HIV and other infections(13).

A study carried out in British Columbia, Canada, on food insecurity and hunger prevalence among PLHIV showed that the occurrence of food insecurity or lack of food was nearly five times higher than in the general Canadian population (14).

Thesis finding on impact of food and nutrition security on adherence to Anti-Retroviral Therapy (ART) in Dire Dawa Provisional Administration, Ethiopia indicates that 15.8% of PLHIV on ART had mild malnutrition and 14.3% of had moderate to severe malnutrition (15). This shows that nutritional support to PLHIV on ART should not be undermined.

#### **3.3.4. Financial support**

It is well known that poverty affects sub-Saharan African countries and that the effect of poverty leads to poor health infrastructure and ill health, especially in PLHIV. HIV and AIDS will result in a loss of income for PLHIV and a switch of household expenditures to health care costs, as well as funeral and mourning costs (16). Hence financial support is required in order to enable PLHIV to meet their needs like medical care access, food and others.

Study conducted in Rwanda indicates 77.2% of PLHIV were in need of financial assistance (12).

#### **3.3.5. Home-based care**

Home Based Care is one of the most effective methods of providing palliative care to those who are chronically or terminally ill in the home setting. It is an ideal model for the holistic approach to care. This care was provided for PLHIV who were bedridden because of AIDS and for HIV infected children. Trained home care agents, including individuals with and without the virus, provided this care (17).

Study conducted in Rwanda shows majority (62%) of PLHIV perceived HBC care as a palliative care need (12).

Another study conducted in Zimbabwe indicates 33% of HIV and AIDS patients in Zimbabwe needed HBC (18).

HBC offers flexibility and an increased potential for culturally appropriate care, but is limited by the suitability and availability of a home and family care network, and by the geographic area that can be feasibly covered by palliative care providers (10).

#### **4. Research question**

The study will try to answer the following questions

- 1- What are the most common palliative care needs among people living with HIV and AIDS in Hawassa town?
- 2- Are there factors that hamper palliative care service in Hawassa town?

## 5. Objectives

**General objective:** To assess palliative care needs of people living with HIV and AIDS in Hawassa town.

**Specific objectives:**

1. To identify met and unmet palliative care needs of PLHIV.
2. To determine the extent to which palliative care needs are met.
3. To identify factors that affect palliative care need of PLHIV in Hawassa town.

## **6. Materials and Methods**

### **6.1. Study Areas and study period**

The present study was conducted at Hawassa town. Hawassa town is located 270 km south of Addis Ababa with a total area of 157.21 square kilometers. According to the projections made based on the 2007 Census the total population of Hawassa town is 258,808. In Hawassa town there were 3 hospitals (2 governmental and 1 private hospital) and 1 nongovernmental health center. The 2 governmental Hospitals and 1 nongovernmental health center had ART unit. Hawassa referral Hospital Established in 2005 and ART unit started in 2006. Adare Hospital previously known as Awassa Health Center and it upgraded to a hospital in 2011. The study was conducted from August, 2011 to May, 2012.

### **6.2. Study population**

The study population of this research was adults from the age of 18 years and above who were diagnosed as HIV positive and on ART in Hawassa referral, Adare hospital and Bushullo health center.

#### **Inclusion criteria**

PLHIV fulfilling the following criteria were enrolled in this study

- Age  $\geq$ 18 years with the cognitive ability to comprehend and communicate
- PLHIV who have been treated with ART for at least 6 months

#### **Exclusion criteria**

- Individuals < 18 years of age, those with severe cognitive problems and those with disabilities such as blindness or deafness were excluded. - -
- PLHIV who have been treated with ART for less than 6 months

### **6.3. Source population**

Source population of the present study was all adult people living with HIV and AIDS in Hawassa town.

### **6.4. Study unit**

Palliative care team visit and gives support for PLHIV every 3 months. So PLHIV who have

been on ART at least for 6 months have more knowledge about palliative care and have a chance to be visited by palliative care team. Considering this the study unit of this project was randomly selected PLHIV  $\geq 18$  years of age and who have been on ART for at least 6 months in Hawassa Referral Hospital, Adare Hospital and Bushulo Health Center ART units.

### 6.5. Study Design

Institution based descriptive cross-sectional study design supplemented with qualitative study.

### 6.6. Sample Size

To determine the sample size for the quantitative data, the following assumptions were taken into account. Proportion of met and unmet palliative care need in the area is not known. So 47% prevalence of unmet home based care need was taken from a study in Rwanda (12) to calculate the size of the study population.

Using single proportion formula

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

Where n= Sample size of PLHIV

P= The prevalence of unmet home based care need from a study in Rwanda which is= 0.47

d= Degree of precision=0.05

$$n = 1.96^2 \frac{0.47(0.53)}{(0.05)^2}$$

-

$$= 383$$

Considering 10% non-response rate: n= 38+ 383= **421**.

Based on the staff number of ART unit in Hawassa Referral Hospital, Adare Hospital and Bushullo Health Center, the existing **17** health workers were included in this study.

### 6.7. Sampling method

**Quantitative:** The existing two government hospitals and one health center that provide ART service in Hawassa town was taken. A unique ART ID number is used as a sampling frame and then systematic random sampling method was used to select PLHIVs on ART who are eligible to participate in this study. Health workers involved in HIV and AIDS care were purposively selected.

**Qualitative:** A purposive sampling method is used in order to gather in-depth information from the key informants who had an overview on palliative care of PLHIVs and to obtain an understanding of feelings and perceptions from PLHIVs (beneficiaries) and health providers (coordinators).

## **6.8. Data collection**

This study had utilized two methods of data collection, namely quantitative and qualitative.

### **6.8.1 Quantitative method**

The quantitative parts of the research contain a questionnaire for PLHIV and it includes socio demographic status, HIV-related question and care and support questions. The questionnaire for health workers and PLHIV adapted from a literature done by Steward and his colleagues (19). Questions included in the questionnaire of health workers are information related to HIV and AIDS and palliative care needs, information on facilities or service provided and personal information. Prior to data collection both questionnaires for PLHIV and health workers were translated from English to Amharic.

### **6.8.2 Qualitative method**

For the qualitative component of the study, a total of 6 in-depth, individual interviews were carried out with coordinators of HIV and AIDS care unit, including palliative care and PLHIVs. Four focus group discussions, two for each sex group were conducted. Six to eight participants were included in each FGD. Semi structured guide were prepared to probe discussions as well as interviews.

## **6.9. Data quality assurance**

To ensure data quality a pre-tested standard questionnaire was used. Training for the data collectors was given before data collection. Supervision and on spot checking of the data collection procedure was made. Every day, at the end of the data collection discussion was made with the data collectors and problems encountered were discussed and timely solutions were given. The completeness of the questionnaire was checked before data entry.

## **6.10. Data collection procedures**

The procedure of data collection started with the distribution of the request letters to the authorities of both hospitals and bushulo health center for their approval of the study and permission to conduct the study.

Six nurse data collectors and 1 health officer supervisor were trained for two consecutive days with the objective of standardizing the data collection instrument among the data collectors and providing them with basic skills of communicating with the study participants. Before the actual data collection pursued a pre-test of the instrument and the procedure was conducted and corrective measures are taken. The selection of PLHIVs was based on the inclusion criteria with the help of the head of HIV and AIDS care unit. In addition, patients' medical file was used to get the HIV status profile and the medication that the patient was on.

With regard to qualitative research, six individual in-depth interviews and four FGD was conducted. Each group for FGD consisted six to eight PLHIVs who were selected and agreed to participate in the study by giving consent. Open ended focus group discussion guide and in-depth interview guide was prepared, which are adopted from standardized interview guide questions. These questions are slightly modified so as to relevant for the study objectives and according to the local context. The main focus of the discussion include their perceived palliative care needs, their views and feelings about the palliative care and services provided to them with regard to their illnesses.

## **6.11. Variables**

**6.11.1. Dependant variables:** are Perceived palliative care needs (both met and unmet) of PLHIV. These are nutritional needs, financial need, medical care needs, pain relief, shelter and HBC.

**6.11.2. Independent variables:** are Socio demographic characteristics (Age, sex, marital status, level of education and occupation), Current health status and visiting history by palliative care team.

## **6.12. Data Analysis procedures**

### **6.12.1. Quantitative analysis**

Data collected through a structured interview questionnaire for people living with HIV and AIDS and self-administered questionnaire for health workers was entered and analyzed by SPSS version 20. After any detection of errors an immediate correction was made. Analysis of

variables was made using frequency distribution, mean, cross-tabulation, Chi-squared test, bivariate and multivariate logistic regression. Odds Ratios (OR) is used to look into the association between the dependent and independent variables. P-value <0.05 at 95% CI is used to define statistical associations between variables.

#### **6.12.2. Qualitative analysis**

Analysis of the qualitative data begins with the transcription and translation of interviews into English. All notes and audio tape recordings of the interviews were fully transcribed, then analyzed by coding and identifying themes. In order to gain a deeper understanding of the general results, quantitative data were compared and supplemented with qualitative findings and vice versa using the process of triangulation methods.

#### **6.13. Ethical Consideration**

The ethical clearance for the study was obtained from the Research and Ethics Committee of AAU-School of Public Health. Then prior permission from Hawassa Referral Hospital Adare Hospital and Bushulo Health Center authorities were taken to interview both health workers and PLHIV. Informed written consent was obtained from the study participants. The aims and importance of the study was explained to the respondents and their consent was sought prior to data collection. Issues of respect, confidentiality (for e.g. using code number instead of participant's name) and anonymity were maintained and this was explained to participants. The right to withdraw at any time was guaranteed to every participant.

#### **6.14. Dissemination and Utilization of Results**

The result of the study is submitted to Addis Ababa University, School of Public Health and to other places where the results would be of contribution.

#### **6.15. Operational definitions**

##### **1. Palliative care**

The WHO defines palliative care as an approach that improves the QoL of patients and their families facing the problems associated with life threatening illnesses such as cancer, HIV and AIDS; through the prevention and relief of suffering by means of early

identification and careful assessment and treatment of pain and other problems, physical, psychological, and spiritual (6).

## **2. Home-based care**

The WHO defines HBC as the provision of health services by formal and informal care givers in the home in order to promote, restore, and maintain a person's maximal level of comfort, function and health, including care towards a dignified death (6). In resource limited countries like Ethiopia community home based care is defined as any form of care given to ill people in their homes. Such care includes physical, psychosocial and spiritual activities.

## **3. Needs**

In this study needs reflect the disease status of the patients and the areas where assistance could improve the patients' situation or decrease the demand for health care.

## **4. Palliative care needs**

Palliative care need is not only based on the epidemiological profile of PLHIV and the type of group that require palliative care. It also includes the accessibility and availability of health care services, the amount of care already received, and the ability of the patient or other resources to pay for the services (21). In this study unmet need of palliative care is the number or percent of PLHIV who require palliative care but who are not currently taking the care.

## **5. Quality of life (QoL)**

The definitions and descriptions of QoL include both objective and subjective indicators of physical and psychological phenomena (22). Objective indicators include income, living situations and physical functioning. On the other hand, subjective evaluations of QoL represent the individual's perception of important life domains and satisfaction with those domains. QoL reflects an individual's sense of well-being and satisfaction with life (9). In this study, the focus is based on the health related quality of life.

## **7. Results**

This section briefly describes both quantitative and qualitative results from PLHIVs and Health care providers. In both case, quantitative results described accordingly and qualitative results described by the phrases told by the study subjects. In order to keep the confidentiality of the study subjects the transcribed data are quoted in the form of PLHIVs and health care provider.

### **1. Quantitative result**

#### **1.1. Socio-demographic characteristics of study participants (PLHIV)**

ART registration book was used from three study site to identify 421 PLHIV, who have been registered for at least six months prior to the survey. Of the total 421 eligible subjects 390 PLHIV (121 males and 269 females) consented to participate in this study giving a response rate of 93%. The mean age of study participants was  $32.9 \pm 9.6$  years. Among the 390 study participants interviewed 54.6% were married while 14.4% were never married. Assessment of educational status of the study participants showed that 77.4% of them attended elementary school or higher education. Majority of the study participants were unemployed (71.5%). Socio demographic characteristics of the study participants were presented in table1 below.

**Table-1. Socio-demographic characteristics of the study participants Hawassa, Ethiopia, May 2012**

Variables	Sex	
	Male n= 121	Female n=269
<b>Age in group</b>		
18-24 yrs	9(7.4%)	51(19%)
25-34yrs	45(37.2%)	138(51.3%)
35-44yrs	43(35.5%)	51(19%)
≥ 45	24(19.8%)	29(10.8%)
<b>Marital status</b>		
Never married	26(21.5%)	30(11.2%)
Married	72(59.5%)	142(52.8%)
Widowed	8(6.6%)	61(22.7%)
Divorced	15(12.4%)	36(13.4%)
<b>Education</b>		
No school attended	11(9.1%)	77(28.6%)
Primary	34(28.1%)	80(29.7%)
Secondary	59(48.8%)	87(32.3%)
Tertiary	17(14%)	25(9.3%)
<b>Occupation</b>		
Employed	56(46.3%)	55(20.4%)
Unemployed	65(53.7%)	214(79.6%)

## **1. 2. Health information related to HIV and AIDS**

### **i) The duration of knowledge of HIV status**

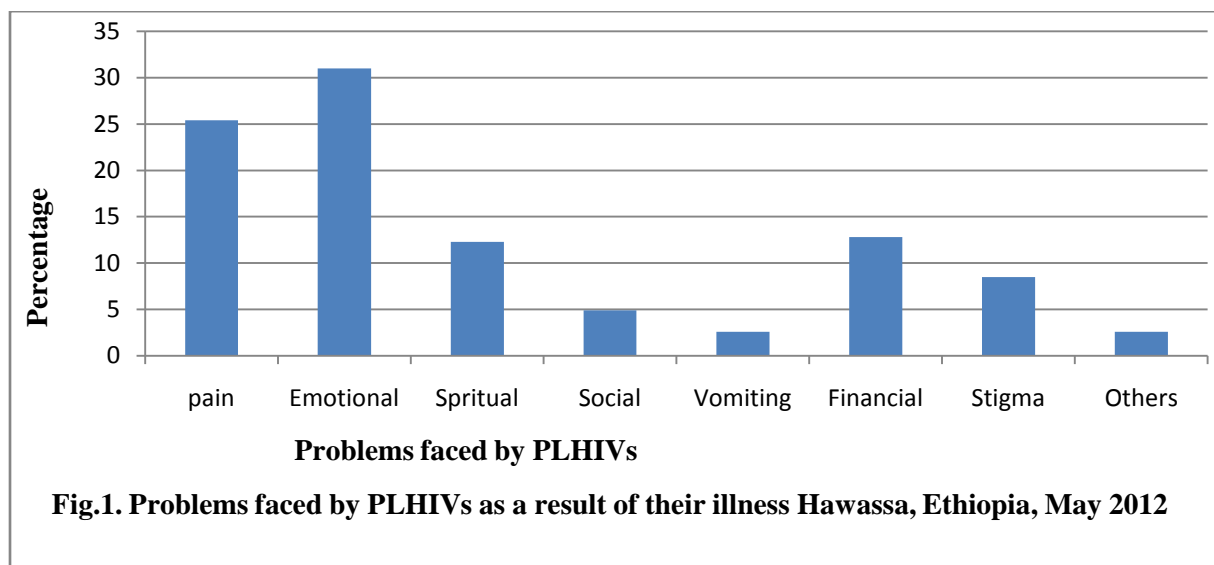
Close to 124 (32%) of study participants had known their HIV status for 3-4 years before the survey and only 3% had known their HIV status for greater than 9 years. 114 (29.2%), 99 (25.4%), and 41 (10.5%) PLHIV had known their HIV status for 1-2yrs, 5-8yrs and <1yr, respectively.

## ii) The present health status of study participants

The presence or absence of sign and symptoms related to HIV and AIDS was reported by the study participants. Based on this report, majority of the study participants 53.1% (n=207) had sign and symptoms and 46.9% (n=183) study participants had no sign and symptoms related to HIV and AIDS. Among participants with sign and symptoms, 47.4% (185) reported that the presence of sign and symptoms limits their activity of daily life. The association between the present health status of PLHIV and limitation in activity of daily life (ADL) is tested by Chi-squared test and thus shows statistically significant association ( $p < 0.000$ ).

## iii) Problems faced by PLHIVs due to HIV and AIDS

The study also identifies the problems faced by PLHIVs as a result of their illness. Emotional (31%), pain (25.4%) and financial (12.8%) problems were the leading problems that PLHIVs experienced due to HIV and AIDS. The detailed information presented in Figure 1.



\*Others include loss of job, lack of food and divorce.

## iv) Medications

The result showed that all study participants were not using herbal medicine. Majority (58.2%) study participants reported use of ARV and 41.8% used both ARV and prophylactic antibiotics. All of them can access ART service without any problem.

## v) Visits from palliative care team

Majority of study participants 312 (79.7%) were not visited by palliative care team. Seventy eight (20%) PLHIV visited by people came from different organizations at home and hospital while they were admitted. Among those visited participants 58 PLHIV were visited by those HBC givers that came from local NGO and 20 PLHIV were visited by hospital palliative care team. As participants mentioned that the team helped them by providing drugs for opportunistic infection (n=14), counseling (n=21), food (n=42), anti pain (22) and financial support (n=1).

#### **Vi) Perceived palliative care needs by PLHIV**

The study participants recognize their own palliative care needs. Each participant identifies one or more than one palliative care needs. There were 6 perceived palliative care needs identified by most PLHIVs. These are financial assistance, pain relief, treatment for OI, nutritional support, shelter and home based care. Majority of the study participants (n= 230) identified the need for financial support is unmet and only 1 PLHIV reported financial support from NGO. The second unmet palliative care need is pain relief (n=190). The detailed information is presented in table 2.

**Table-2. Current users and unmet needs for palliative care among PLHIV in Hawassa, Ethiopia, May 2012**

<b>Palliative care needs*</b>	<b>Current users</b>	<b>Unmet need for palliative care</b>
Financial assistance	1(0.3%)	230 (59%)
Pain relief	22 (5.6%)	190 (48.7%)
Treatment for OI	14 (3.6%)	187 (47.9%)
Nutritional support	42 (10.8%)	151 (38.7%)
Shelter	0 (0%)	112 (28.7%)
Home based care	58 (14.9%)	83 (21.3%)

\*There are multiple responses for the question

Bivariate and multivariate regression analyses were done to look for variables contributing for all palliative care needs identified by the PLHIV. The analysis for each identified needs described as follows.

### **Nutritional support**

The result showed that sex, level of education, occupation and visiting history of the PLHIV were significantly associated with the need for nutritional support. PLHIV with level of education of primary and no school attended were need more nutritional support than secondary and tertiary level (COR 2.94, 95%CI 1.22-7.09). But this association is not statistically significant when adjusted for other independent variables. Regarding to sex, female PLHIV need two times more nutritional support than males (AOR 2.41, 95%CI 1.25-4.65).

Comparing employed PLHIV with unemployed, the unemployed PLHIV had more need for nutritional support (AOR 11.20, 95%CI 5.96-27.28).

PLHIV who were no visiting history had three times more nutritional support than those with visiting history (AOR 3.44, 95%CI 1.67-7.05). The detailed presented in table 4.

**Table-3. Perceived need for nutritional support against socio demographic variables of the study participants, Hawassa, Ethiopia, May2012**

Variables	Need for nutritional support		Crude OR (95%CI)	Adjusted OR (95%CI)
	Yes (n=151)	No (n=209)		
<b>Age in group</b>				
≥ 45	20 (13.2%)	28 (13.4%)	1.00	1.00
18-24	16 (10.5%)	43 (20.6%)	1.92(0.85,4.32)	2.12(0.73,6.18)
25-34	81 (53.3%)	90 (43%)	0.79(0.42, 1.52)	0.73(0.31,1.76)
35-44	35 (23%)	48 (23%)	1.01(0.49, 2.07)	0.81(0.32,2.06)
<b>Sex of participants</b>				
Male	49(32.2%)	64(30.6%)	1.00	1.00
Female	103(67.8%)	145(69.4%)	0.92(0.59,1.44)	<b>2.41(1.25,4.65)*</b>
<b>Marital status</b>				
Never married	21(13.8%)	35(16.7%)	1.00	1.00
Married	78(51.3%)	120(57.4%)	1.05(0.57, 1.92)	1.46(0.66, 3.22)
Widowed	29(19.1%)	34(16.3%)	0.83(0.41, 1.71)	1.21(0.44, 3.34)
Divorced	24(15.8%)	20(9.6%)	0.86(0.31, 1.46)	0.43(0.14, 1.17)
<b>Level of education</b>				
Tertiary	8(5.3%)	34(16.3%)	1.00	1.00
No school attended	36(23.7%)	45(21.5%)	<b>2.94(1.22, 7.09)*</b>	1.69(0.53, 5.39)
Primary	52(34.2%)	51(24.4%)	<b>2.83(1.25, 5.91)*</b>	1.29(0.42, 3.95)
Secondary	56(36.8%)	79(37.8%)	1.11(0.65, 1.91)	1.23(0.42, 3.63)
<b>Occupation</b>				
Employed	8(5.3%)	95(45.5%)	1.00	1.00
Unemployed	144(94.7%)	114 (54.5%)	<b>13.73(6.44,29.31)*</b>	<b>11.20(5.96,27.28)*</b>
<b>Current health status</b>				
With no symptoms	68(44.7%)	103(49.3%)	1.00	1.00
With symptoms	84(55.3%)	106(50.7%)	0.84(0.55, 1.3)	1.44(0.85, 2.45)
<b>Visiting history</b>				
Yes	42(27.6%)	20(9.6%)	1.00	1.00
No	109(71.7%)	189(90.4%)	<b>3.52(1.92, 6.32)*</b>	<b>3.44(1.67,7.05)*</b>

### **The need for shelter**

The need for shelter was analyzed against the independent variables including sex, occupation and visiting history of PLHIV and was found significantly associated. As it showed, males had two times more need for shelter than females in only (AOR 2.19, 95%CI 1.14-4.21). Analysis also showed that unemployed PLHIV had more need for shelter than employed (AOR 18.25,

95%CI 9.62-28.96). Regarding to visiting history, those PLHIV who were not visited had two times more need for shelter than the visited PLHIV (AOR 2.06, 95%CI 1.05-4.05) . The detailed presented in table 4.

**Table-4. Perceived need for shelter against socio demographic variables of the study participants, Hawassa, Ethiopia, May2012**

Variables	Perceived need for shelter		Crude OR (95%CI)	Adjusted OR (95%CI)
	Yes (n=115)	No(n=246)		
<b>Age in group</b>				
≥ 45	12(10.4%)	47(19.1%)	1.00	1.00
18-24	57(49.6%)	114(46.3%)	2.35(0.99, 5.56)	2.99(0.99, 9.02)
25-34	28(24.3%)	55(22.4%)	1.20(0.62, 2.33)	1.26(0.53, 3.04)
35-44	18(15.7%)	30(12.2%)	1.22(0.58, 2.57)	1.15(0.45, 2.92)
<b>Sex of participants</b>				
Female	77(67%)	171(69.5%)	1.00	1.00
Male	38(33%)	75(30.5%)	1.14(0.71, 1.83)	<b>2.19(1.14, 4.21)*</b>
<b>Marital status</b>				
Never married	17(14.8%)	39(15.9%)	1.00	1.00
Married	59(51.3%)	139(56.5%)	1.01(0.57, 1.99)	1.57(0.69, 3.55)
Widowed	25(21.7%)	38(15.4%)	0.66(0.31, 1.12)	1.13(0.41, 3.14)
Divorced	14(12.2%)	30(12.2%)	0.93(0.49, 2.66)	1.00(0.35,2.92)
<b>Level of education</b>				
Tertiary	28(24.3%)	53(21.5%)	1.00	1.00
No school attended	39(33.9%)	64(26%)	0.46(0.21, 1.31)	1.79(0.47,6.80)
Primary	43(37.4%)	92(37.4%)	0.54(0.15,1.98)	1.49(0.40,5.47)
Secondary	5(4.3%)	37(15%)	0.63(0.18, 2.28)	1.25(0.34, 4.53)
<b>Occupation</b>				
Employed	113(98.3%)	145(58.9%)	1.00	1.00
Unemployed	2(1.7%)	101(39.6%)	<b>19.01(9.42,31.23)*</b>	<b>18.25(9.62,28.96)*</b>
<b>Current health status</b>				
With no symptoms	51(44.3%)	120(48.8%)	1.00	1.00
With symptoms	64(55.7%)	126(51.2%)	0.85(0.54, 1.33)	1.31(0.76, 2.27)
<b>Visiting history</b>				
Yes	84(73%)	215(87.4%)	1.00	1.00
No	31(27%)	31(12.6%)	<b>2.47(1.41,4.34)*</b>	<b>2.06(1.05, 4.05)*</b>

## The need for HBC

Concerning the need for HBC, the regression analysis shows sex, occupation and visiting history of PLHIV were significantly associated with the need for HBC. Those female PLHIV had two times more need for HBC than males (AOR 2.17, 95%CI 1.12-4.21). PLHIV who were unemployed had more need for HBC than unemployed. This association is significant in both

bivariate analysis (COR 15.62, 95%CI 4.81-50.73) and multivariate analysis (AOR 20.01, 95%CI 8.23-52.68). Regarding to visiting history, those PLHIV with no visiting history had two times more need than the visited PLHIV (AOR 2.29, 95%CI 1.16-4.53). The details are presented in table 5.

**Table-5. Perceived need for free home based care against socio demographic variables of the study participants, Hawassa, Ethiopia, May2012**

Variables	Perceived need for HBC		Crude OR (95%CI)	Adjusted OR (95%CI)
	Yes (n=81)	No (n=279)		
<b>Age in group</b>				
18-24	9(11.1%)	50(17.9%)	1.00	1.00
25-34	38(46.9%)	133(47.7%)	0.63(0.28, 1.39)	0.59(0.26, 1.37)
35-44	23(28.4%)	59(21.1%)	0.46(0.19, 1.08)	0.43(0.16, 1.15)
≥ 45	11(13.6%)	37(13.3%)	0.61(0.23,1.61)	1.73(0.23, 2.35)
<b>Sex of participants</b>				
Male	30(37%)	83(29.4%)	1.00	1.00
Female	51(63%)	196(70.3%)	1.39(0.83, 2.33)	<b>2.17(1.12,4.21)*</b>
<b>Marital status</b>				
Never married	11(13.6%)	45(16.1%)	1.00	1.00
Married	43(53.1%)	154(55.2%)	0.87(0.42, 1.84)	1.23(0.55, 3.00)
Widowed	19(23.5%)	44(15.8%)	0.55(0.24, 1.33)	0.93(0.32, 2.71)
Divorced	8(9.9%)	36(12.9%)	1.11(0.40, 3.02)	1.39(0.44, 4.37)
<b>Level of education</b>				
Tertiary	4(4.9%)	38(13.6%)	1.00	1.00
No school attended	19(23.5%)	62(22.2%)	0.34(0.11, 1.09)	3.09(0.86, 11.14)
Primary	28(34.6%)	74(26.5%)	0.28(0.09, 0.85)	2.49(0.72, 8.61)
Secondary	30(37%)	105(37.6%)	0.37(0.12, 1.15)	2.28(0.67, 7.72)
<b>Working situation</b>				
Employed	6(7.4%)	103(36.9%)	1.00	1.00
Unemployed	75(92.59%)	176(63.1%)	<b>15.62(4.81,50.73)*</b>	<b>20.01(8.23,52.68)*</b>
<b>Current health status</b>				
With no symptoms	34(42%)	137(49.1%)	1.00	1.00
With symptoms	47(58%)	142(50.9%)	0.86(0.53, 1.41)	1.23(0.69, 2.17)
<b>Visiting history</b>				
Yes	24(29.6%)	67(13.3%)	1.00	1.00
No	57(70.4%)	242(86.7%)	<b>2.53(1.41, 4.55)*</b>	<b>2.29(1.16,4.53)*</b>

### The need for financial assistance

Factors found to be associated with the need for financial assistance were sex, occupation and visiting history. The need for financial assistance is twice more in female than male (AOR 2.56, 95%CI 1.39-4.75). The analysis also shows unemployed PLHIV had more need for financial support than the employed. This association is significant in both bivariate (COR 3.66, 95%CI 2.27-5.89) and multivariate analysis (AOR 5.58, 95%CI 2.97-10.47). PLHIV with no visiting history had more need for financial assistance than the visited PLHIV in both bivariate (COR 4.63, 95% CI 2.13-10.08) and multivariate (AOR 3.76, 95%CI 1.64-8.67) analysis. The details are presented in table6.

**Table-6. Perceived need for financial assistance against socio demographic variables of the study participants, Hawassa, Ethiopia, May, 2012**

Variables	The need for financial assistance		Crude OR (95%CI)	Adjusted OR (95%CI)
	Yes (n=230)	No (n=130)		
<b>Age in group</b>				
18-24	31(13.5%)	28(21.4%)	1.00	1.00
25-34	118(51.3%)	53(40.5%)	0.59(0.33, 1.06)	0.93 (0.34, 2.26)
35-44	49(21.3%)	33(26%)	0.78(0.91, 1.54)	0.89(0.39, 1.97)
≥ 45	32(13.9%)	16(12.2%)	0.55(0.25, 1.22)	0.86(0.33, 2.23)
<b>Sex of participants</b>				
Male	77(33.5%)	36(27.5%)	1.00	1.00
Female	153(66.5%)	95(72.5%)	1.34(0.83, 2.06)	<b>2.56(1.39, 4.75)*</b>
<b>Marital status</b>				
Never married	32(13.9%)	24(18.3%)	1.00	1.00
Married	129(56.1%)	69(52.7%)	0.72(0.39, 1.32)	0.81(0.40, 1.63)
Widowed	45(19.6%)	18(13.7%)	0.53(0.25, 1.14)	0.54(0.21, 1.38)
Divorced	24(10.4%)	20(15.3%)	1.11(0.50, 2.46)	1.18(0.47, 2.97)
<b>Level of education</b>				
Tertiary	25(10.9%)	17(13%)	1.00	1.00
No school attended	52(22.6%)	29(22.1%)	0.81(0.46, 1.44)	2.43(0.94, 6.30)
Primary	73(31.7%)	30(22.9%)	1.19(0.69, 2.04)	1.80(0.72, 4.49)
Secondary	80(34.8%)	55(42%)	0.98(0.47, 2.08)	2.22(0.96,5.3)
<b>Occupation</b>				
Unemployed	43(18.7%)	70(54.2%)	1.00	1.00
Employed	187(81.3%)	600(45.8%)	<b>3.66(2.27,5.89)*</b>	<b>5.58(2.97,10.47)*</b>
<b>Current health status</b>				
With no symptom	104(45.2%)	67(51.1%)	1.00	1.00
With symptom	126(54.8%)	63(48.9%)	0.79(0.52, 1.22)	0.96(0.56, 1.58)
<b>Visiting history</b>				
Yes	154(23.5%)	8(6.1%)	1.00	1.00
No	76(76.5%)	123(93.9%)	<b>4.63(2.13, 10.08)*</b>	<b>3.76(1.64, 8.67)*</b>

## The need for free treatment of OI

Regarding to the need for free treatment of OI the analysis shows occupation and visiting history of PLHIV associated with it. It is found that those PLHIV who were unemployed had more need for free treatment of OI than employed (AOR 1.89, 95%CI 1.21-2.89). PLHIV who were not visited by palliative care team had more need for free treatment of OI (AOR 5.17, 95%CI 2.44-10.93). The detailed presented in table 7.

**Table-7. Perceived need for free treatment of opportunistic infection against socio-demographic variables of the study participants, Hawassa, Ethiopia, May2012**

Variables	The need for free treatment of OI		Crude OR (95%CI)	Adjusted OR (95%CI)
	Yes (n=187)	No (n=173)		
<b>Age in group</b>				
≥ 45	28(15%)	20(11.5%)	1.00	1.00
18-24	18(9.6%)	41(23.6%)	3.19(1.44,7.08)	2.56(0.99,6.62)
25-34	95(50.8%)	76(43.7%)	1.12(0.59, 2.14)	0.96(0.45, 2.21)
35-44	46(24.6%)	37(21.3%)	1.15(0.56, 2.37)	1.01(0.45, 2.21)
<b>Sex of participants</b>				
Male	122(65.2%)	147(72.4%)	1.00	1.00
Female	65(34.8%)	56(27.6%)	1.41(0.90, 2.21)	1.52(0.88, 2.63)
<b>Marital status</b>				
Never married	30(16%)	26(12.8%)	1.00	1.00
Married	95(50.8%)	119(58.6%)	1.26(0.69, 2.29)	1.73(0.74, 4.02)
Widowed	39(20.9%)	30(14.8%)	0.71(0.34, 1.17)	0.98(0.51, 2.47)
Divorced	23(12.3%)	28(13.8%)	1.05(0.45, 2.32)	1.73(0.79, 3.80)
<b>Level of education</b>				
Tertiary	40(21.4%)	48(23.6%)	1.00	1.00
No school attended	52(27.8%)	62(30.5%)	0.98(0.57, 1.74)	0.52(0.22, 1.23)
Primary	75(40.1%)	71(35%)	0.79(0.46, 1.34)	0.52(0.23, 1.19)
Secondary	20(10.7%)	22(10.8%)	0.92(0.44, 1.92)	0.79(0.37, 1.71)
<b>Occupation</b>				
Employed	143(76.5%)	136(67%)	1.00	1.00
Unemployed	44(23.5%)	67(33%)	<b>1.68(1.06, 2.67)*</b>	<b>1.89(1.21,2.89)*</b>
<b>Current health status</b>				
With no symptom	79(42.2%)	104(51.2%)	1.00	1.00
With symptom	108(57.8%)	99(48.8%)	0.69(0.47, 1.04)	0.78(0.50, 1.21)
<b>Visiting history</b>				
Yes	52(57.8%)	39(19.2%)	1.00	1.00
No	135(72.2)	164(80.8%)	<b>6.19(3.03,12.67)*</b>	<b>5.17(2.44, 10.93)*</b>

## The need for pain relief

The analysis shows the need for pain relief is more in females than males. This association was significant in both bivariate analysis (COR 1.72, 95%CI 1.09-2.71) and multivariate analysis (AOR 1.80, 95%CI 1.05-3.13). With regard to occupation, those unemployed PLHIV had more need for pain relief than employed PLHIV (AOR 1.83, 95%CI 1.03-3.24).The details are presented in table8.

**Table-8. Perceived need for pain relief against socio demographic variables of the study participants, Hawassa, Ethiopia, May2012**

Variables	The need for pain relief		Crude OR (95%CI)	Adjusted OR (95%CI)
	Yes (n=190)	No (n=170)		
<b>Age in group</b>				
18-24	22(11.6%)	37(21.8%)	1.00	1.00
25-34	94(49.5%)	77(45.3%)	2.27(1.07, 4.82)	0.54(0.23, 1.29)
35-44	45(23.7%)	38(22.4%)	1.17(0.63, 2.17)	1.04(0.52, 2.08)
≥ 45	29(15.3%)	18(10.6%)	1.35(0.68, 2.67)	0.81(0.39, 1.65)
<b>Sex of participants</b>				
Male	70(36.8%)	43(25.3%)	1.00	1.00
Female	120(63.2%)	127(74.7%)	<b>1.72(1.09, 2.71)*</b>	<b>1.80(1.05, 3.13)*</b>
<b>Marital status</b>				
Never married	28(14.7%)	27(14.4%)	1.00	1.00
Married	103(54.2%)	94(55.3%)	1.04(0.57, 1.86)	1.25(0.55, 2.84)
Widowed	35(18.4%)	28(16.5%)	0.78(0.38, 1.58)	1.11(0.59, 2.09)
Divorced	24(12.6%)	20(11.8%)	1.21(0.57, 2.58)	1.66(0.76, 3.61)
<b>Level of education</b>				
Tertiary	23(12.1%)	19(11.2%)	1.00	1.00
No school attended	37(19.5%)	43(25.3%)	0.85(0.49, 1.49)	0.54(0.23, 1.25)
Primary	55(28.9%)	47(27.6%)	0.79(0.47, 1.35)	0.61(0.27, 1.36)
Secondary	75(39.5%)	61(35.9%)	0.75(0.36, 1.58)	0.75(0.35,1.59)
<b>Occupation</b>				
Employed	49(25.8)	54(31.0%)	1.00	1.00
Unemployed	141(74.2%)	116(68.2%)	0.72(0.46, 1.18)	<b>1.83(1.03, 3.24)*</b>
<b>Current health status</b>				
With no symptom	84(44.2%)	87(51.2%)	1.00	1.00
With symptom	106(55.8%)	83(48.8%)	0.89(0.59, 1.33)	0.93(0.60,1.43)
<b>Visiting history</b>				
Yes	49(25.8%)	12(7.1%)	1.00	1.00
No	141(74.2%)	158(92.9%)	<b>4.57(2.34, 8.95)*</b>	<b>3.95(1.96, 7.98)*</b>

## **Vii) Preferred place for care in phase of terminal illness**

Majority (86.2%) of study participants preferred care in hospital during phase of terminal illness while 10.7% and 3.7% would prefer care at home and any place, respectively. Reasons to select care in hospital were better treatment in hospital, need for various investigation, to avoid stigma and discrimination and unwillingness to disclose themselves to family and neighbors. Those study participants that preferred care at home reasoned that care at home is cheaper than hospital care.

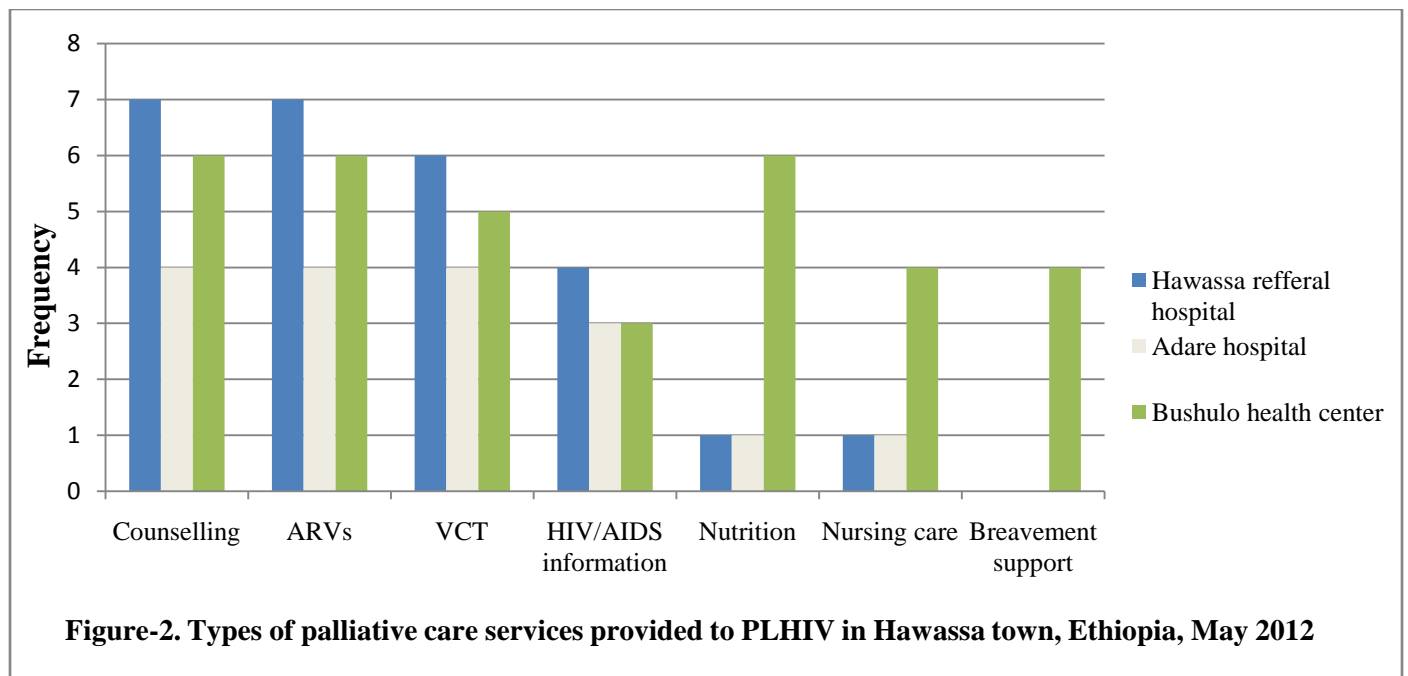
### **1.2.1. Socio demographic characteristics of health workers involved in the study.**

A total of seventeen health workers (7 from Hawassa referral hospital, 6 from Bushulo health center and 4 from Adare hospital) involved in this study. All of them were responsible health workers in HIV and AIDS care unit. The mean age of participants was 32yrs with the minimum age of 23yrs and maximum age of 42yrs. Majority (10) were females and 7 were males. Regarding to the qualification of the health care providers, seven were nurses, 1 was medical doctor, 8 were health officers and 1 was a social worker. A total of 11 health care providers involved in this study were working at outpatient department, 4 were working at counseling unit and 2 were at inpatient unit.

### **1.2.2. Type of health care services provided to PLHIVs**

All health care providers involved in this study said that ARVs and counseling services for PLHIVs avail in their health facility. The detailed information presented in figure 4.

On top of these services, for family of PLHIVs their facilities provide counseling service (n=16), Nutrition support (n=5), HIV/AIDS information (n=17) and bereavement support (n=4)



### 1.2.3. Palliative care team

The study showed that palliative care team is present in three study sites. Twelve (70.6%) study participants rate the service of their team as totally inadequate and 29.4% (5) rate it as inadequate.

### 1.2.4. Obstacles to meet palliative care needs of PLHIVs

The study participants reported that barriers to meet palliative care needs of PLHIVs include Shortage of staff, lack of funding, lack of equipment, lack of strong policy on palliative care program. The detailed information is presented in table 9.

**Table-9. Obstacles to meet palliative care needs of PLHIV in Hawassa town, Ethiopia, May 2012.**

<b>Variables</b>	<b>Frequency</b>
<b>Obstacles to meet palliative Care needs of PLHIV*</b>	
Shortage of staff	15
Lack of funding	17
Lack of equipment	16
Lack of strong policy	14

\*There are multiple response for the question

### **1.2.5. Training on HIV/AIDS related issues and palliative care**

Majority of study participants (13) had received training on HIV and AIDS related issues but only 4 health care providers had received training on palliative care.

## **2. Qualitative result**

Qualitative data were collected to triangulate the research results of the quantitative data. Focus Group Discussion among PLHIVs and in-depth interviews with key informants including PLHIV and coordinators of palliative care units were conducted. Participants were enrolled in four FGDs by their sex categories and two FGD for each sex were conducted. The following two common themes emerged from discussions. These are problems faced by PLHIVs and the need for palliative care.

### **2.1 Problems faced by PLHIV**

According to the qualitative result there are also problems faced by PLHIVs which is in line with the quantitative findings. At the beginning of the discussion most of the participants were cool while they became emotional at the middle when they talk about their problems.

Participants explained why PLHIVs had financial problem. One of the female FGD participant said that *“My husband died 3 years back and I have 4 kids. Last week one of my children was seriously sick but I don’t have money to take him to hospital (PLHIV). Another participant also said that “Opportunistic infections repeatedly present among PLHIV. Drugs for the treatment of OI are expensive and the patients cannot afford. On the other hand frequent occurrence of this infection affects financial capacity of the family of PLHIV. Previously hospitals provide drugs free of charge to treat opportunistic infections for PLHIV. But currently hospitals do not provide any drug other than ARV and cotrimoxazole. We need free of charge drugs to treat OIs so that patients access drugs (Health care provider).*

The participants also mentioned the presence of stigma which leads to rejection. According to the participants report, most PLHIVs were stigmatized by their community member which is another problem that worsens life for PLHIVs.

One of the participants quoted saying *“I live in private house and because of my disease status within the last 5 months I change 3 private houses. In this week I have diarrhea and I use toilet room frequently. The owner of our house locks the toilet room yesterday. When I ask her, the answer was you can leave. Now I don’t know where I am going” (PLHIV).*

Additionally participants also mentioned that the community still has a negative attitude towards HIV. One female participant explains that *“For 5 years I did not disclose my status to my sister while she was living with me. Two month’s back I told her my status and she saw me as HIV itself. Finally she decided to leave me. At that time I was so sad, disturbed...” (PLHIV)*

The other issue participants reported that most of the patients are complaining of paresthesia and numbness of feet’s and hands. Health care providers further explained this *“Peripheral neuropathy is the main cause of pain. This pain is frequently observed in patients, who had taken D<sub>4</sub>T. In our hospital we don’t have strong enough analgesia. For that we counsel patients before starting the ARV but most of the time patients continually complain about painful feet”.*

## **2.2 The need for palliative care**

All participants discussed that holistic palliative care for HIV patients is unquestionable. In the interviews and discussions many palliative care needs were described but the need for treatment

for OIs, financial assistance, food, shelter, Home based care and pain relief were better emphasized.

### **Treatment for opportunistic infections**

The majority of participants explained that the prior need that requires emergency support is providing free drugs to treat OIs. Most of the patients (PLHIV) are people living in poor condition. Because of this PLHIVs are frequently affected by opportunistic infections. One of the participants further explained that *“We are very satisfied on accessing ARV drugs freely but taking ART only cannot protect us from different infections. As you see this scaly lesion in my face, hands and back appears 2 weeks back. When I report to the physician working in this unit, he gave me a prescription to buy the drug from hospital pharmacy. There was only 5 birr in my pocket. I can’t afford I can’t...” (PLHIV).*

*The root cause to stop such support to PLHIV is the current economic crisis throughout the country. Previously (1 year back) there was free drug in the stock to treat OIs at OPD level and admission until they are discharged. But now we can’t help those PLHIVs who have no money.”(Health care provider)*

### **Financial assistance**

There is a profound need for financial assistance by the participants. Majority of the participants were young and needs financial assistance to start a small scale business. Others need continual financial support because they have no skill to run business. As one participant noted that *“It is difficult to send children to school without exercise book, cloth, pens and pencil. I need financial support so that my children will continue to go to school”.* (PLHIV)

Another participant explained *“I need financial assistance to begin small business. So I will lead independent life”.* (PLHIV)

*“I need financial support to start vocational trainings that help me to develop skill in my interest like hair styling. So I can work and be self sufficient.”(PLHIV)*

### **Food**

In general, most of the participants reported that ART helps a lot but it requires more frequent food. Now a day some of our friends who start ART did not have a good adherence because of lack of food. In order to solve this problem PLHIVs reduce the food they take, taking portion or skipping meals. And some of them are forced to do unnecessary things. As one participant mentioned *“when I fail to find any food to eat, I am forced to work as commercial sex worker. For better money sometimes I did sexual intercourse without condom”*. (PLHIV)

The other participant also further explained *“Today the unit nurse told me my weight reduced by 5Kg from the last month and CD4 count is also decreased. Most of the time there is no food... then I took the drug without food. I know the reason for reduction of both weight and CD4 is lack of food but help...”*. (PLHIV)

### **Shelter**

Concerning shelter they reported that, house rent was better in the past than these days. As one of the participants mentioned; *“The rising price of house rent in this town is another major problem. There are people who owned a number of private houses but are currently living in relatively cheap kebele /government/ houses, while we are paying whatever we have for private house owners, which we could have spent on food. And the administration is doing nothing to alleviate this problem. The problem of shelter in Hwassa is not associated only with its expensiveness but also with stigma.”* (PLHIV)

### **Home based care**

HBC is one of the most important tools to support those chronically ill patients. All the FGD participants agreed on the need for HBC. One of them mentioned *“Couple of years ago I was lonely very sick and on the verge of death no one was there to help me when a local NGO workers found me. They provided me with food medication and a passionate care. With this I recovered very soon. But, now a day there is no such support from NGOs, government or anyone else in Hwassa. Few weeks ago a neighbor of mine, who was on ART, died from HIV and AIDS. She was lonely with no one there to care for her.”* (PLHIV)

The other participant also further explained *“Palliative care team provides very poor service to PLHIV in our hospital. We mainly focus on ARV services while we should include other services*

*like HBC and other support required by the patients. Some of palliative care team members get training about palliative care but the unit is not well equipped to provide such services.” (Health care provider)*

### **Pain Relief**

Majority of the participants complain about the side effects of the ARV and the pain caused by OI. One participant noted that *“The usual drug that is prescribed to us to relive pain is paracetmol and ibuprofen which is not strong. So we need strong anti pain drug, we are suffering from lack of it.” (PLHIV)*

## 8. Discussion

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illnesses like HIV and AIDS (6). It is therefore important to investigate palliative care needs of PLHIV to develop comprehensive palliative care programs. This study has provided problems experienced by PLHIV as a result of the illness and their perceived palliative care needs. According to this study the most frequent problems experienced by PLHIV include financial problem, emotional problem, pain and stigma. Regarding to perceived palliative care needs, financial assistance, nutritional support, Home based care, shelter, free treatment for OI and pain relief were identified.

The findings related to demographic factors in this study suggest that the mean age of PLHIV is relatively low ( $32.9 \pm 9.6$  years). It indicates that HIV and AIDS is more common among young adults from the age group of 15-49 years. The explanation for this is that, at this age group individuals become more sexually active which in turn exposes them to be at high risk of HIV infection. Regarding to sex 68.9% of the study participants were females. This finding is also consistent with UNAIDS report (21). The reasons may be young women are particularly vulnerable to HIV infection than young men due to biological vulnerability, early marriage and economic disempowerment. Majority of the study participants included with in age group 18-34yrs. This indicates that there is new HIV infection among the young population.

The health status of PLHIV affects their activity of daily life (ADL) and this relationship is statistically significant ( $p < 0.000$ ). This indicates that those PLHIV with frequent sign and symptom of the disease were not self sufficient. So they need holistic support.

In order to ensure quality HIV and AIDS services are delivered to PLHIV, the government of Ethiopia developed multisect-oral strategic plan.(8) Despite this effort, PLHIV still facing different problems. This study found that financial and Emotional problems are the leading problems that PLHIVs experienced due to their illness. This is similar to that reported in other study (9). Probably, increase in price of food, increase in price of house rent, increase in price of health care which is beyond the paying capacity of PLHIV contributes to this problem. In addition, frequent occurrence of opportunistic infections forces the patients to spend their money on health care.

Pain is found to be another problem that is faced by PLHIV. In most cases pain is caused by the side effects of ARV drugs and opportunistic infections. The international narcotics board recommends opioids to control severe pain (27) but lack of such opioids to treat severe pain in Ethiopia may be the reason for this problem.

On top of the above stigma is still a problem that PLHIV faced by their family and community members. Majority of participants live in private houses. Because of stigma they are forced to change houses frequently as well as live alone away from their family. The reason may be limited knowledge about HIV and AIDS and limited psychosocial support to the family members of PLHIV.

In this study 58.2% of study participants used ART and 41.8% used both ART and prophylactic antibiotics. All of them had got ART service without any problem. PLHIV express their felling by stating *we are very satisfied on accessing ART drugs freely*. This indicates that the health care facilities provide well organized and sustainable ART service to PLHIV.

In this study, palliative care needs are identified by PLHIV and the health workers also had similar perception of palliative care needs for PLHIV. There are many needs mentioned but the major identified palliative care needs are financial assistance, treatment for opportunistic infection, nutrition (food) support, shelter, home based care and pain relief.

### **Financial assistance**

Financial assistance is one of the identified palliative care need by PLHIV. In this study 59% of PLHIV were in need of financial assistance and only one participant had got financial support by one local NGO. This finding is also consistent with the previous studies (12, 23). The reason could be the nature of disease (HIV and AIDS) which will result in disruption of work and income of PLHIV. In addition to this HIV and AIDS will also causes loss of income for PLHIV, and a switch of household expenditures to health care costs (16). Therefore the need of financial assistance to begin small scale business and vocational training were suggested by PLHIV as the means to be self sufficient.

Multivariate analysis showed that female PLHIV need more financial assistance than male PLHIV. The reason may be economically females are disempowered. So they need more money

to manage their household cost. Unemployment appears to have a significant bearing on need of financial assistance because the need for financial assistance among unemployed PLHIV was found to be more than employed.

### **Home based care**

HBC has to be viewed as one component in continuum of care and services necessary for optimal health care service delivery to individual with HIV and AIDS. In this study 21.3% of PLHIV are in need of HBC service whereas 14.9% of PLHIV were visited by HBC team. The need for HBC in this study is less than similar studies conducted in Rwanda and Zimbabwe (12, 18). The reason for this is that, studies done in Rwanda and Zimbabwe were conducted at national level but this study conducted in only Hawassa town. PLHIV also mentioned that, currently HBC service is discontinued for majority of PLHIV in Hawassa and create a great challenge especially for those who cannot reach to health care facility. Because of this, patients die alone without any care giver. The reason may be in most of African countries including Ethiopia HBC service is initiated and supported by international donor agencies (23). Because of world economic crisis withdrawal of support by these donor agencies put the service under question. Health care providers also mentioned that the government health care facilities are not equipped to provide such services, hence HBC for PLHIV remain insufficient. Multivariate analysis showed that PLHIV who were unemployed had more need for HBC than employed. The reason could be that employment empowers the patients economically so they can access care by other means. The analysis also shows female PLHIV had less need for HBC than male PLHIV. The reason might be in most cases females are not economically powerful so they cannot be self sufficient. PLHIV with no visiting history had more need for home based care than PLHIV with visiting history. The reason might be the need for HBC of those visited PLHIV is met

### **Treatment for opportunistic infection**

In this study 47.9% of participants currently in need of free treatment for opportunistic infections and only 3.6% PLHIV had get access for free OI treatment. Previous study is also in agreement with this finding (12). Both PLHIV and health care providers mentioned that free treatment for opportunistic infections is an emergency palliative care need. PLHIVs could have access to ART and cotrimoxazole free of charge. However, support for free treatment of opportunistic infections is discontinued despite frequent occurrence of OI. Thus access for treatment of opportunistic

infections and other related health care depends on the ability of PLHIV to pay for health care. The reason may be the current world economic crises that affect the supporting donor agencies. Bivariate and multivariate analysis showed that PLHIV who were unemployed had more need for free treatment of OI than employed. This could partially be explained by their inability to pay for treatment of OI. The other reason might be those employed PLHIV had better access to get food than the unemployed one which in turn decreases some preventable OIs.

### **Nutrition (Food)**

To achieve the full benefit of ART, maintenance of adequate food consumption, nutrient intake levels and meeting special nutritional needs are critical (24). However in this study nearly 39% of participants identify nutritional support as palliative care need and 10.8% of participants had their need met with food assistance. Study conducted in Ethiopia also showed that nutrition insecurities were serious problem of PLHIV on ART (15). This indicates that how the problem is serious among PLHIV. It is not stopped by getting food but it creates favorable condition for transmission of the disease HIV and AIDS. In both bivariate and multivariate analysis, unemployed PLHIV had more need for nutritional support than employed. The reason is obvious in that employment secure income of PLHIV, so it reduces most problems of patients associated with their illness including need for nutritional support. The analysis also showed that female PLHIV had more need for nutritional support than male PLHIV. This might be due to females are economically dependent so they need support. Probably, pregnancy and child care make females more vulnerable to nutritional deficiency

### **Shelter**

Palliative-care service in African countries include home based care, pain and symptom control, financial, emotional and spiritual support, and also food, shelter, legal help, and school fees. (26) However participants reported that there is no support regarding shelter. Twenty eight percent of participants mentioned shelter as one of their palliative care need. PLHIV also confirms the need for shelter by stating '*The rising price of house rent in this town and associated stigma is serious problem that we face and we pay for house at the expense of food.* From this point of view we can say that providing only ART in poor community who suffer from lack of their basic needs cannot make the patients fully beneficent from ART. Because of their purchasing capacity they are forced to choose one from equally important basic needs. Which in turn affect the adherence of ART (15). Multivariate analysis shows female PLHIV had more need for shelter than males.

Culturally males are the one that lead their family and females are dependent on males. In Ethiopia most of family is headed by males (4). This may contribute to the difference. Analysis also showed that unemployed PLHIV had more need for shelter than employed. The reason could be the unemployed PLHIV had less capacity to buy or to pay for it.

### **Pain relief**

In this study majority of participants (48.7%) identify pain relief as palliative care need. They also mentioned that side effect of the drug and OI are the root cause for pain. On the other hand health care providers confirms the patients idea by stating *there is no other anti pain than paracetamol and ibuprofen in their facility*. WHO also give emphasis on controlling severe pain by opioids like morphine (25). From this point of view we can say that, Pain relief and symptom management appear to be ineffective.

Regarding to preference of site for care during phase of terminal illness majority preferred care in hospital rather than at home. This finding was also consistent with the previous study done in Africa (24). The reason may be fear of stigma at home and thinking of better treatment in hospital.

The finding of this study indicates that medical care mainly ART, HIV and AIDS information and counseling services are available to PLHIV in health care facilities. This finding is also comparable to Ethiopian progress report on HIV and AIDS, 2010 (5). On top of this, nutritional support, nursing care and bereavement support is given to PLHIV but these services are provided by Bushulo Health Center. The reason may be that Bushulo Health Center is supported by nongovernmental organizations.

Regarding to training related to palliative care and HIV and AIDS 70.6% (12) study participants rate the service of their team as totally inadequate and 29.4% (5) rate as inadequate. This indicates that, there is no organizational effort to coordinate palliative care services.

Health care providers also identify obstacles to meet palliative care needs of PLHIV. These are shortage of staff, lack of funding, lack of equipment, lack of strong policy on palliative care program. Similar problems are also identified in other studies done Africa (11, 12).

## **9. Limitation and strength of the study**

### **Strength**

In this study both quantitative and qualitative methods are used. Therefore those issues that needed more explanation were explored in a better way. The sample size of this study was fair enough to generalize the findings to the target population.

### **Limitation**

Although this study made an effort to assess perspective of health care providers, views from stakeholders like NGOs, community leaders and other political leaders were not mentioned. There was no any medical investigation or assessment tools used to identify sign and symptoms and the reported symptoms are based on the participant's response.

## **10. Conclusion**

The result of this study provides palliative care needs of PLHIV, problems faced by PLHIV and factors that hinder provision of palliative care services in Hawassa, Ethiopia. The identified needs in this study could be used as a base line for the development of a comprehensive palliative care policy and programmes for PLHIV in Hawassa.

HIV and AIDS remains a disease with several economical and social consequences. It primarily affects those who are socially disadvantaged groups and the poor people. Because of this the identified palliative care needs are rooted in poverty and they are unmet. These needs are financial assistance, free treatment for opportunistic infections, nutritional support, shelter, home based care and pain relief. This study also shows working condition has significant association with all identified palliative care needs.

PLHIV live in Hawassa town face many problems as a result of their illness. This study found that financial, emotional, stigma and pain are the leading problems.

The available health care services for PLHIV in health care facilities are provision of ARVs, HIV and AIDS information and counseling. All PLHIV mentioned as they are taking ART without any problem. So provision of ARVs is the met need.

## **11. Recommendation**

On the basis of the results, the following recommendations were made to improve the existing care and support services for PLHIV.

1. The health policy should give emphasis to access and availability of free drugs for treatment of opportunistic infections. Because this is the urgent need of PLHIV.
2. It is important to establish sustainable income generating schemes. Through this activity most needs of PLHIV will be addressed.
3. It is essential to expand health care services at hospital level by incorporating most palliative care services. So patients can access easily
4. It is important to train all health care providers of palliative care team on palliative care and HIV and AIDS.
5. There is a need of continuous community awareness raising program through education about the transmission and prevention of HIV and AIDS and importance of palliative care to reduce stigma.
6. Ongoing research activities on met and unmet palliative care needs are recommended as part of quality assurance

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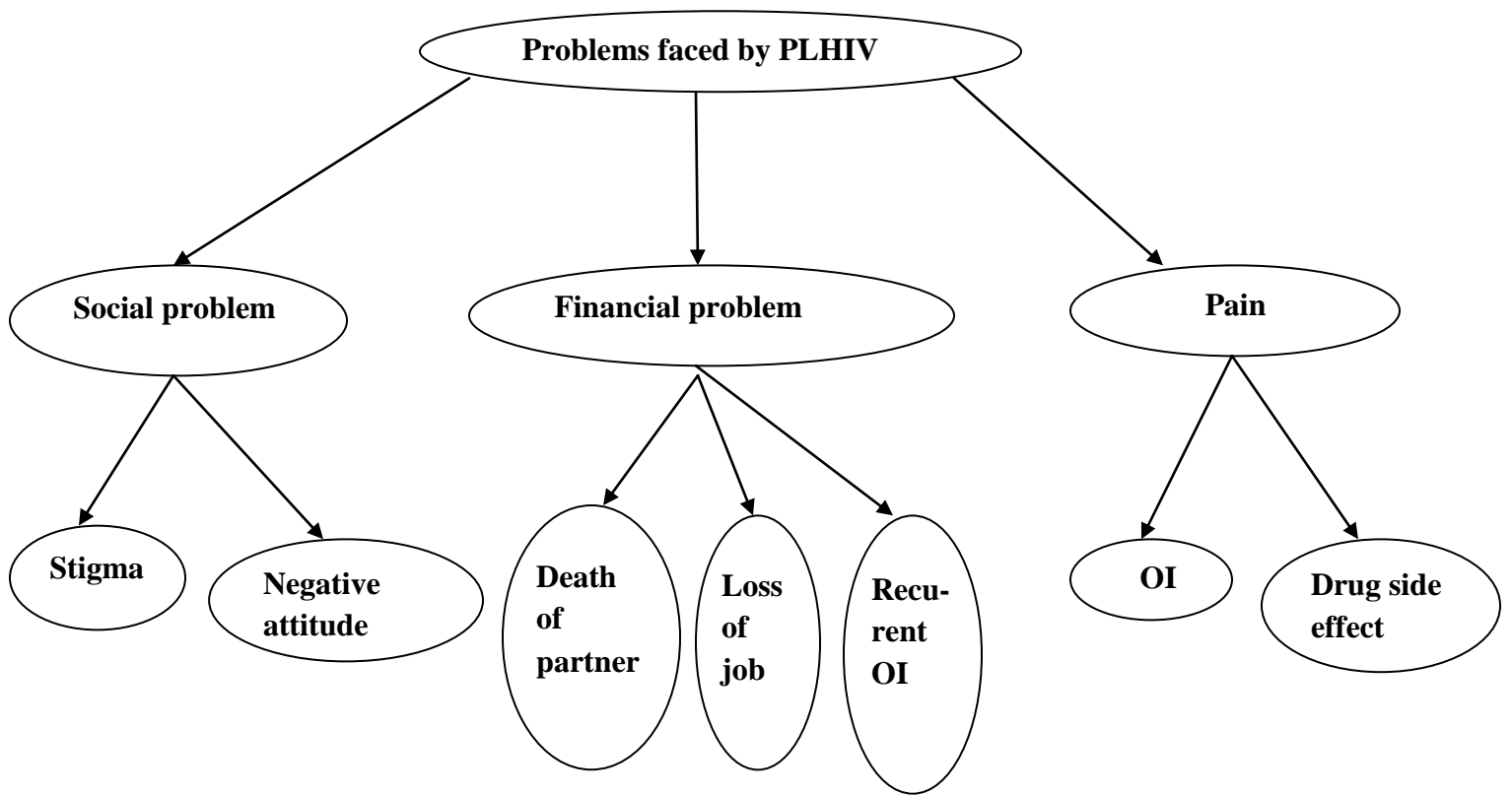
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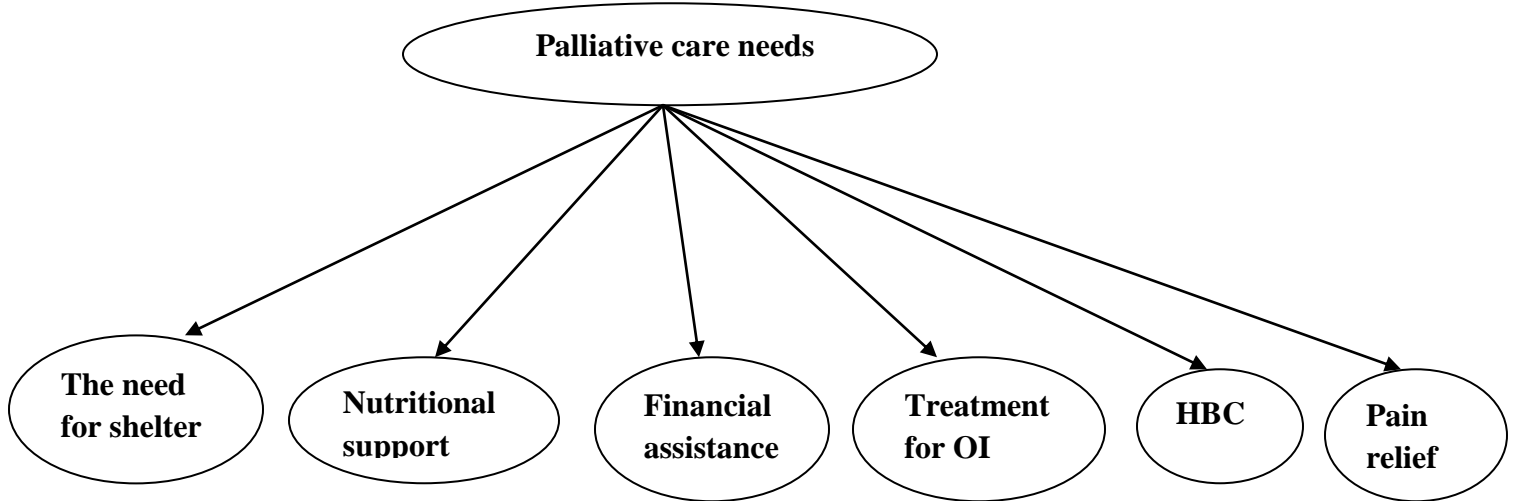
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## **Annex I. Final map for qualitative analysis**

### **Theme 1**



**Theme 2**



**Annex II. Informed Consent Form (English version)**

**A. STUDY INFORMATION SHEET**

Good morning/afternoon, my name is Selamawit Nane and I am one of the data collectors for the study being conducted by Addis Ababa University College of Health Sciences School of Public health. You are selected scientifically to be participant of this study if you give me consent after you have understood the following information.

**Aim of the study:**

The present study will primarily aim to investigate palliative care needs of PLWHA in Hawassa town and will therefore serve as a basis for the development of a comprehensive palliative care policy and program for PLWAHs.

**Harm of the study:**

The study has no harm except that participants will spend up to 15 minutes in the interview.

**Confidentiality:**

The information contained within the questionnaire and any recorded document will be kept confidential and any of your information you provide will be used only by the research team and will, by no means, be revealed to a third party. Code number will be used instead of your name and the investigator will have access the code sample only for all the information.

**Right to not participate or withdraw from the study:**

Your participation is on your willingness. You have full right to refuse, withdraw or completely reject or all of your participation in the study. But we encourage your full participation as the answers you give on this form.

If you have any problem my contact address is

Mobile phone \_\_\_\_0911167851

Email address ---- selam\_nane@yahoo.com

**B. Consent form for the study subject**

For participation as a volunteer in the research undertaking

Code number\_\_\_\_\_

Hello, how are you? My name is \_\_\_\_\_. I came from Addis Ababa University School of public health. I am conducting a study to investigate palliative care needs of PLWHAs in your hospital. You have been chosen scientifically to be part of the study and your contribution in filling this questionnaire will be very important in order to improve the quality of care delivery and quality of life of people living with HIV/AIDS.

We will ask you questions in a place where other people or conditions couldn't interfere. We would like to assure you that your participation on this research will not affect any of your treatment and other benefit that you get from any organization.

We would be thankful if you spend some time (15min.) with us answering questions related to the issues described above.

May I get your permission to participate in this study?

If yes, sign below and continue to next page for the interview

Signature of the interviewee\_\_\_\_\_ Date\_\_\_\_\_

If no, continue to next patient

Interviewer's Name \_\_\_\_\_ Signature\_\_\_\_\_

Date of interview \_\_\_\_\_ Time started\_\_\_\_\_ time finished\_\_\_\_\_

Supervisor's Name \_\_\_\_\_ Signature\_\_\_\_\_

I thank you for your cooperation

### **Annex III. Questionnaire**

#### **1. Questionnaire for people living with HIV/AIDS**

A) Socio demographic characteristics

1. Age\_\_\_\_\_

2. Sex Female  Male

3. Marital Status

- Single never married  Widowed  Separated  
 Married  Divorced

4. What is your highest level of Education?

- No school attended  Secondary  
 Primary  Tertiary

5. What is your occupation?

- Student  Businessman  Unemployed  
 Housewife  Civil servant  Others\_\_\_\_\_

B) HIV-RELATED HEALTH INFORMATION

6. For how long have you know you are HIV positive?

- Less than 1 yr  3-4 yrs  Over 9 yrs  
 1-2 yrs  5-8 yrs  I really cannot remember

7. Please indicate your current health status:

- No symptoms  Symptoms regularly  Do not know  
 Symptoms most of the time  Advance stage of HIV

8. To what extent does your current health status limit your ability to take part in everyday activities?

- Not at all  A moderate amount  A lot  
 A little  Quite a bit

9. Which of the following problems are you facing mainly as a result of your illness? (**Tick all that apply**)

- Pain  Emotional  Vomiting  Stigmatization  
 Spiritual  Social  Financial  Other (specify) -----

C. INFORMATION AND SUPPORT SERVICES

10. What type of medication are you currently using? (**Tick all that apply**)

- Anti-Retroviral drugs
- ARVs and prophylactic antibiotic

11. Do you have people who visit you regularly being at home or admitted?

- Yes                       No

12. If yes, who are they? (Tick all that apply?)

- Medical Doctor                                       Social worker
- Friends from neighborhood                       Counselor
- Relatives     Religious leaders
- Nurse     Physiotherapist
- Other (Specify) -----

13. Where do they come from? (Tick all that apply?)

- Home based care team                                       Church
- Hospital –based Palliative care team                       Other (Specify) -----

**If a Home care team has visited you, please proceed to questions 14. If a Hospital-based Palliative has visited you care team, please proceed to question 15. Tick all that apply**

14. How has the home-based care team helped you?

- providing drugs                                       Providing food
- Counseling     Financially
- Providing Massage                                       Preparing my will
- Others (specify)

15. How has the hospital based palliative care team helped you?

- Providing drugs                                       Providing food
- Counseling     Financially
- Providing Massage                                       Preparing my will
- Others (specify)

**If a Home based care team or a Hospital-based Palliative has not yet visited you, please proceed to questions 16. Tick all that apply**

16. How would you like to be helped by a home care team/ hospital-based palliative care team in order to meet your needs?

-----  
-----

18. Where do you prefer to be looked after in terminally ill phase?

- Home
- Hospital
- Home based care centre
- I really do not mind where
- Other (specify)

19. Give reasons for your answer

-----  
-----  
-----

***THANK YOU FOR YOUR PARTICIPTION***



8. Please indicate services provided by your palliative care programs

- Palliative care education
- Bereavement support
- Inpatient-hospital (No specific Unit)
- In-Hospital (Palliative care unit)
- Financial support
- Legal support
- Home - based care

9. What care/service do you provide for PLHIV in your facility? **(Tick all that apply)**

- Counseling
- Bereavement support
- Financial
- HIV and AIDS information
- Nutrition
- Nursing care
- Tri-therapy/ARVs
- Home based care
- VCT
- Other (specify)-----

10. What care/service do you provide for the family of PLHIV in your facility? **(Tick all that apply)**

- Counseling
- HIV and AIDS information
- Nutrition
- Financial support.
- VCT
- Others \_\_\_\_\_

11. What care/service do you provide for the family of PLHIV in your facility? **(Tick all that apply)**

- Counseling
- HIV and AIDS information
- Nutrition
- Financial support
- VCT
- Other (specify) -----

12. At your department/facility do you have enough assets/equipment to meet the demands of PLHIV?

- Yes
- No

**C. INFORMATION RELATED TO HIV and AIDS AND PALLIATIVE CARE NEEDS**

13. Did you receive any training related to HIV and AIDS?

- Yes
- No

If Yes, where and what type of training? \_\_\_\_\_

14. Did you receive formal palliative care training?

- Yes
- No

15. Rating of HIV and AIDS training

- Totally inadequate
- Generally Adequate
- Generally Inadequate
- Totally adequate

16. Rating of palliative care training

- Totally inadequate
- Generally adequate
- Generally inadequate
- Totally adequate

17. What is your opinion on the needs and obstacles that your department has to optimal palliative care in looking after HIV and AIDS adult patients and their families? (**Tick all that apply**)

- Lack of skills
  - Lack funding
  - Lack of space for counseling
  - Lack of policy
  - Stigmatization
  - Culture issues
  - Other (please indicate)-----
- 

**THANKS FOR YOUR PARTICIPATION!**

### **3 - In-depth interview questions for both coordinators and PLHIV: Semi-structured interview guide.**

- 1- Would you describe frequently presented symptoms in PLHIV and why?
- 2- Describe problems experienced by PLHIVs?
- 3- How do you describe different medications and medical care used by PLHIV?
- 4- Would you explain palliative care services provided to PLHIV in your facility and the extent to which AIDS patient needs are met? (for coordinators)
- 5- How do you explain supports provided to PLHIV by hospital based palliative care and home based care team?
- 6- What are the services provided to families of PLHIV by your hospital?
- 7- How do you describe palliative care team in your hospital? (for coordinators)
- 8- Explain obstacles in meeting palliative care needs for PLHIV? (for coordinators)

**THANKS FOR YOUR PARTICIPATION!**

#### **4. Open-ended interview guide questions for FGDs**

1- Would you describe the extent of palliative care activities that performed by health care providers for PLHIV in your community?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

2- Who are providing palliative care for PLHIV in your community?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

3- How do you describe palliative care activities for PLHIV in your community?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

4- What constraints do palliative care providers encounter as they provide care for PLHIV?

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

5- Do you think palliative care givers need more information about how to care for PLHIV?

If yes, what kinds of information? What is the most urgent need?)

Probe:-

Would you explain further?

Would you give us an example?

Is there anything else?

6- Do you have any suggestions on how the work of palliative care teams can be improved?

**THANKS FOR YOUR PARTICIPATION!**

# Annex I. Informed Consent Form (Amharic version)

## ሀ. የተሳታፊዎች መረጃ ቅጽ

### 1. የጥናቱ አላማ

በአለማችን ኤች. አይ. ቪ. ኤዲስ በሽታ ያመጣው ጫና ከፊተኛ መሆኑ የሚታወቅ ሲሆን በተለይም በአፍሪካ ከሰሀራ በታች ባሉት አገራት የ ኤች. አይ. ቪ. ኤዲስ ሥርጭትና በኤች. አይ. ቪ ኤዲስ ምክንያት የሚሞቱ ሰዎች በርካታ ናቸው። የዚህ ጥናት ዋና ትኩረት ከ ኤች. አይ. ቪ ኤዲስ ጋር አብረው የሚኖሩ ሰዎች ስለ መድሃናዊ ጤና ክብካቤ ያላቸውን ፍላጎቶች በሐዋሳ ከተማ ማጥናት ነው። በዚህም ለቀጣይ በሁሉን አቀፍ መድሃናዊ የጤና ክብካቤ ዙሪያ ለሚዘጋጁ ፖሊሲ እንደ መነሻ የገለግላል።

### 2. ምስጢራዊነት

በዚህ መጠይቅ የሚሰበሰብ ማናቸውም መረጃ በሚሰጥር የሚያዝ ነው። በዚህ መጠይቅ የሚሰጡት መረጃ ጥቅም ላይ የሚውለው በአጥኚ ቡድኑ ብቻ ሲሆን መረጃው ለሌላ ማናቸውም ሦስተኛ ወገን በምንም አይነት ተላልፎ አይሰጥም። የርሶን ማንነት በ ሚያመለክት ስም ፋንታ የሚሰጡት መረጃ የሚመዘገበው የሚሰጥር ቁጥር ስለሚሆን ጥናት አድራጊዎች የሚያዩት ቁጥሩን ብቻ ነው።

### 3. በጥናቱ ላለመሳተፍ ወይም በማናቸውም ጊዜ ለማቋረጥ ስላለ መብት

በዚህ ጥናት የሚሳተፉት ሙሉ ፈቃደኛ ሲሆኑ ብቻ ነው። መረጃ ላለመስጠት ላለመተባበርም ሆነ ከጥናቱ ተሳታፊነት ለመገለል ሙሉ መብት አለዎት። ነገርግን የጥናቱ ውጤት ለወደፊት የመፍትሔ አቅጣጫ ሊያሳይ ስለሚችል መረጃ በመስጠት እንዲሳተፉ ይበረታታሉ።

### 4. የጥናት ተሳታፊዎች ከጉዳት ስለመጠበቅ

የጥናቱ ተሳታፊዎች በመድሃናዊ ጤና ክብካቤ ዙሪያ የተለያዩ ጥያቄዎችን ለ 15 ደቂቃ ይጠየቃሉ። በዚህ ወቅት ተሳታፊዎቻችን እንዳይረበሹ በፀጥታ ቦታ ቃለመጠይቅ በማድረግ ምንም አይነት ጉዳት እንዳይደርስባቸውም ጥንቃቄ ይደረጋል። በተጨማሪ በጥናቱ ምክንያት ተሳታፊዎችን ምንም አይነት ጉዳት እንደማይደርስባቸው የጥናቱ ቡድን ያረጋግጣል።

ለ. የስምምነት መግለጫ

ተራ ቁጥር \_\_\_\_\_ 55

እንደምን አለህ? ስሜ \_\_\_\_\_ ይባላል። እኔ የመጣሁት ከ አ/አ/ዩ/ከኅ/ብ/ሰ/ብ ጤና ሳይንስ ትም/ት ክፍል በሚያካሂደው ጥናት ውስጥ በጊዜያዊ መረጃ ሰብሳቢነት በመስራት ላይ እገኛለሁ። የጥናቱ አላማ ከ ኤች. አይ. ቪ ኤድስ ጋር አብረው የሚኖሩ ሰዎች ስለ መድሃናዊ ጤና ክብካቤ ያላቸውን ፍላጎቶች በሐዋሳ ከተማ ማወቅ ነው። ስለሆነም እርስዎ በዚህ ጥናት እንዲሳተፉ በእጣ ተመርጠዋል። የእርስዎ በዚህ ጥናት መሳተፍ ለ መድሃናዊ ጤና ክብካቤ አገልግሎት መሻሻል ከፍተኛ አስተዋጽኦ አለው።

ይህ ቃለ መጠይቅ በሚደረግበት ወቅት ጣልቃ የሚገባ ማንም አይኖርም። በተጨማሪም በዚህ ጥናት በመሳተፍዎ ምክንያት የሚያገኙት ህክምና ወይም ሌሎች ጥቅማ ጥቅሞች እንደማይቀሩ እናረጋግጣለን።

ከላይ በገለጽነው መረጃ መሰረት ከኛ ጋር ለ 15 ደቂቃ በትእግስትና በጥምና አዳምጠው ቃለ መጠይቁን ለመመለስ የሚያደርጉትን ጥረት እያደነቅን በቅድሚያ ከልብ እናመሰግናለን።

በጥናቱ ለመሳተፍ ፈቃደኛ ነዎት? ፈቃደኛ ከሆኑ ከታች ባለው ቦታ ያስፈርሙና ወደ ሚቀጥለው ገጽ ይሸጋገሩ

የተሳታፊው ፊርማ \_\_\_\_\_ ቀን \_\_\_\_\_

ፈቃደኛ ካልሆኑ አመስግነው ያሰናብቱ

ያረጋገጠው/ችው ጠያቂ ስም \_\_\_\_\_ ፊርማ \_\_\_\_\_

ቀን \_\_\_\_\_ መጠይቁ የተጀመረበት ሰአት \_\_\_\_\_ መጠይቁ ያለቀበት ሰአት \_\_\_\_\_

የተቆጣጣሪ ስም \_\_\_\_\_ ፊርማ \_\_\_\_\_

ስለ ትብብርዎ እናመሰግናለን

## Annex II. Questionnaire

1. ከ ኤች.አይ.ቪ ዲስ ቫይረስ ጋር ለሚኖሩ ተሳታፊዎች የተዘጋጀ ቃለ መጠይቅ

ሀ) የግል ሁኔታ /መረጃ/

1. እድሜ \_\_\_\_\_

2. የታ ሴት  ወንድ  ሴት

3. የጋብቻ ሁኔታ

ያላገባ  ያገባ  የትዳር አጋር በሞት የተለየ

ፈት  በተለያዩ ምክኒያት ለየብቻ የሚኖሩ

4. የትምህርት ደረጃ  መደበኛ ትምህርት ያልተማረ  አንደኛ ደረጃ  
  ሁለተኛ  ስኞት

ኮሌጅና ከዛ በላይ

5. የሥራ ሁኔታ  ተማሪ  የቤት እመቤት   
 ነጋዴ  የመንግሥት  ሥራተኛ  ስራ አ  ሌላ

ለ) ከ ኤች. አይ. ቪ --- ጋር የተያያዘ የጤና መረጃ

6. የ ኤች. አይ. ቪ ቫይረስ በደምዎ መኖሩን ካወቁ ምን ያህል ጊዜ ይሆናል?

ከ 1 ዓመት ያነሰ  ከ 1 - 2 ዓመት  ከ 3 - 4 ዓመት  ከ 5 - 8 አመት

ከ 9 አመት በላይ  አላውቀውም

7. በአሁን ሰዓት ያሉበት የጤና ሁኔታ ምን ይመስላል?

የበሽታ ምልክት አይታይብኝም  አልፎ አልፎ ምልክቶች ይታያሉ  ምልክቶች ሁልጊዜ እየታዩብኝ ነው

ከፍተኛ የ ኤች. አይ. ቪ ደረጃ ላይ እገኛለሁ  አላውቅም

8. አሁን ያሉበት የጤና ሁኔታ የእለት ተእለት እንቅስቃሴ/እንደ መልበስ፣ መመገብና፣ መታጠብ

የመሳሰሉትን/ እንዳያደርጉ ምን ያህል ያግድዎታል?

ምንም አልቸገርም  እቸገራለሁ

9. ከህመምዎ የተነሳ የሚይዝዎ ችግር ላይ ምልክት ያድርጉ

አካላዊ ህመም  የስሜት ጉዳት  ትውከት

ማህበራዊ ችግሮች  መገለል  የመንፈስ ችግር

የገንዘብ ችግር  ሌላ ካለ ይጥቀሱ

ሐ) ስለ ሚሰጥ የድጋፍ አገልግሎት መረጃ

10. አሁን ምን አይነት መድሀኒት እየወሰዱ ይገኛሉ?

- ፀረ ኤች. አይ. ቪ መድኃኒት
- ፀረ ተዋህሲያንና ፀረ ኤች. አይ. ቪ

11. በቤት ወይም ሆስፒታል ተኝተው ሳሉ በየጊዜው የሚጎበኝዎት ሰዎች አሉ?

- አዎ
- የሉ

12. መልስዎ አዎ ከሆነ ጎብኚዎችዎ እነማን ናቸው? ምልክት ያድርጉ

- ሐኪሞች
- ወዳጆችና ጎረቤቶች
- የስጋ ዘመዶች
- ነርሶች
- ማህበራዊ ሰራተኞች
- የምክር አገልግሎት ሰጪ
- የሀይማኖት መሪዎች
- ወገኛ
- ሌላ ካለ ይግለፁ\_\_\_\_\_

13. ጎብኚዎቻችሁ የሚመጡት ከየት ነው?

- ከቤት ለቤት ጤና እንክብካቤ ሰጪ ቡድን
- ከሆስፒታል መድሐናዊ ጤና ክብካቤ ሰጪ ቡድን
- ከ ቤተክርስቲያን
- ከሌላ ቦታ ከሆነ ይግለፁ\_\_\_\_\_

ቤት ለቤት ጤና ክብካቤ ቡድን ጎብኝቶቻችሁ ከሆነ ወደ ጥያቄ 14 ይሂዱ። የሆስፒታል መድሀናዊ ጤና ክብካቤ ቡድን ከጎበኝዎት ወደ ጥያቄ 15 ሂደው የሚመለከተው ላይ ምልክት ያድርጉ

14. የቤት ለቤት ጤና እንክብካቤ ሰጪ ቡድን በምን መንገድ ረዳዎት?

- መድሀኒት በመስጠት
- በምክር አገልግሎት
- ማሳጅ አገልግሎት
- ምግብ በመስጠት
- በገንዘብ በመደገፍ
- ኑዛዜ በማዘጋጀት
- ሌላ ካለ ይግለፁ

15. የሆስፒታል መድሐናዊ ጤና ክብካቤ ሰጪ ቡድን በምን መንገድ ረዳዎት?

- መድሀኒት በመስጠት
- በምክር አገልግሎት
- ማሳጅ አገልግሎት
- ምግብ በመስጠት
- በገንዘብ በመደገፍ
- ኑዛዜ በማዘጋጀት
- ሌላ ካለ ይግለፁ

የ ሆስፒታልም ሆነ የቤት ለቤት ጤና ክብካቤ ቡድን እስከ አሁን ጎብኝቶቻችሁ የማያውቅ ከሆነ እባክዎ ጥያቄ 16ን ይመልሱ

16. የ ሆስፒታል ወይም የቤት ለቤት ጤና ክብካቤ ቡድን ፍላጎትዎን ለሚሟላት በምን እንሲረዳዎት ይፈልጋሉ?

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17. በጠና በታመሙበት ጊዜ የት ክትትል ቢደረግልዎት ይመርጣሉ?

- በቤት       በሆስፒታል       በቤት ለቤት ክትትል ማዕከል       የትም ቢሆን ግድየለኝም
- ሌላ ቦታ ካለ ይግለጹ

18. ከላይ ለሰጡት ምላሽ ምክኒያትዎን ይግለጹ \_\_\_\_\_

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ስለተሳትፎዎ አመሰግናለሁ

**3. የግል ቃለ መጠይቅ መመሪያ**

1. ከኤች አይ ቪ ኤድስ ጋር ባሉ ሰዎች በተደጋጋሚ የሚታዩ ምልክቶች የትኞቹ ናቸው ለምን?
2. ከኤች አይ ቪ ኤድስ ጋር ያሉ ሰዎችን የሚያጋጥሟቸውን ችግሮች ይግለጹ?
3. ከኤች አይ ቪ ኤድስ ጋር ላሉ ሰዎች የሚሰጠውን የመድሃኒት አቅርቦትና የ ህክምና አገልግሎት እንዴት ይገልጹታል?
4. በዚህ የህክምና ማእከል የሚሰጠውን መድሃናዊ የጤና ክብካቤ አገልግሎት ዝርዝርና የትኛው የኤች አይ ቪ ኤድስ በሽተኞች ፍላጎት እንደተሟላ ቢገልጹልን?
5. በሆስፒታል በሚሰጥ መድሃናዊ እንክብካቤና በቤት ለቤት እንክብካቤ ሰጪ ቡድን ለኤች አይ ቪ ኤድስ ህሙማን የሚደረግ ድጋፍ እንዴት ነው የሚገልጹት?
6. በዚህ ሆስፒታል ለኤች አይ ቪ ኤድስ ህሙማን ቤተሰብ ምን ዓይነት አገልግሎት ነው የሚሰጠው?
7. በዚህ ሆስፒታል ያለውን የመድሃናዊ ጤና ክብካቤ ሰጪ ቡድን እንዴት ያዩታል?
8. መድሃናዊ የጤና እንክብካቤ አገልግሎት ከኤች አይ ቪ ኤድስ ጋር ላሉ ሰዎች እንዳይሰጥ ያጋጠሙ ችግሮችን ይግለጹ?

**4. የቡድን ወይይት መመሪያ**

1. በዚህ ከተማ ከ ኤች አይ ቪ ኤድስ ጋር ላሉ ሰዎች ምን ያህል መድሃናዊ የጤና ክብካቤ አገልግሎቶች እንዳሉ ቢገልጹ?
2. በዚህ ከተማ ከ ኤች አይ ቪ ኤድስ ጋር ላሉ ሰዎች መድሃናዊ የጤና ክብካቤ አገልግሎት የሚሰጥ ማነዉ?
3. በናንተ አከባቢ የሚሰጠዉን መድሃናዊ የጤና ክብካቤ አገልግሎት እንዴት ነዉ የምትገልጹት?
4. መድሃናዊ የጤና ክብካቤ አገልግሎትሰጪዎች አገልግሎቱን ሲሰጡ ምን እጥረት አጋጥሟቸዉ ያዉቃል?
5. በናንተ በኩል ለመድሃናዊ የጤና ክብካቤ አገልግሎትሰጪዎች አገልግሎቱን የሚያጠናክር ተጨማሪ መረጃ ካለ ይጠቁሙ; የትኛዉ ፍላጎት ነዉ በቅድሚያ መሟላት ያለበት?
6. መድሃናዊ የጤና ክብካቤ አገልግሎት እንዴት መሻሻል እንዳለበት ተጨማሪ ሀሳብ ካለ ይግለጹ?

**ASSURANCE OF PRINCIPAL INVESTIGATOR**

The undersigned agrees to accept responsibility for the scientific ethical and technical  
Conduct of the research project and for provision of required progress reports as  
Per terms and conditions of the Research Publications Office in effect at the time of  
Grant is forwarded as the result of this application.

Name of the student: Selamawit Nane (BSc)

Date. \_\_\_\_\_ Signature \_\_\_\_\_

**Approval of the primary Advisor**

Name of the primary advisor: Dr. Getnet Mitike (MD, MPH, PhD)

Date. \_\_\_\_\_ Signature \_\_\_\_\_