



Barriers and facilitators to Antiretroviral therapy adherence  
among clients with HIV in Hawassa, Southern Ethiopia: a  
qualitative grounded theory study

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**Jimma, Ethiopia**

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## **Abstracts**

**Background:** Antiretroviral therapy adherence is widely recognized as a critical health promotion strategy for HIV positive individuals on therapy and it is the 'Achilles heel' of successful outcome. A better understanding of factors that influence clients' adherence to ART can improve to develop culturally appropriate and effective interventions which are in turn more likely to lead to successful and sustainable programs for clients with HIV/AIDS.

**Objectives:** This study aims to explore clients' and health care professionals' views about factors that facilitate and constrain optimal adherence to ART among HIV Clients.

**Methods:** In this qualitative study, grounded theory study design was used. The study was conducted in Hawassa town, Southern Ethiopia. A theoretical sampling method was employed, and the data were collected using non-participant observation and semi structured in-depth interviews by the principal investigator from February to April 2014 GC.

**Analysis:** Simultaneous data collection and analysis was used and taped data and note were transcribed into Amharic then translated into English by the PI. The grounded theory approach was used for analyzing the data as a whole. The analysis began by using the constant comparison approach. The coding process was preceded by open coding, axial and selective coding. All of the codes used were inductive. To manage the overall coding process, Atlas.ti software was used. To assure the quality of the research findings the researcher was consider the different set of criteria to focusing on the credibility, dependability, transferability and Confirmability of the study.

**Result:** Economic constraints, substance misuse, simply forgetting and being busy, fear of stigma and discrimination, pill burden and medication side effects were major reason for client being non-adherent. Disclosure of HIV status, using an adherence aid, prospects of living longer, social support, experiencing better health and trusting health workers emerged as facilitators of adherent to ART.

**Conclusion:** Understanding barriers and facilitators to ART adherence can help in the design of an appropriate and targeted intervention. Policy-makers should develop appropriate social policy to promote adherence among ART-prescribed clients whilst Healthcare providers should address some of the practical and cultural issues around ART.

**Keywords:** Grounded theory, ART, HIV/AIDS, qualitative research

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## **Acronyms and abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARVs	Antiretrovirals
DHS	Demographic and Health Survey
HCPs	Health care providers
HIV	Human Immune Deficiency Virus
MOH	Ministry of Health
PLWHIV	People living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
UNAIDS	United Nations Joint Programme on AIDS
UNICEF	United Nations Children’s Emergency Fund
WHO	World Health Organization

# CHAPTER I: INTRODUCTION

## 1.1 Background

The emergence of the human immunodeficiency virus (HIV) epidemic is one of the biggest public health challenges the world has ever seen in recent history(1-2). Globally, an estimated 35.3 (32.2–38.8) million people were living with HIV in 2012, an increase from previous years as more people are receiving the life-saving antiretroviral therapy. There were 2.3 (1.9–2.7) million new HIV infections globally, showing a 33% decline in the number of new infections from 3.4 (3.1–3.7) million in 2001. An estimated 0.8% of adults aged 15-49 years worldwide are living with HIV, although the burden of the epidemic continues to vary considerably between countries and regions. The epidemic continues to disproportionately affect sub-Saharan Africa, home to 70% of all new HIV infections in 2012(3).

The number of people dying from AIDS-related causes began to decline in the mid-2000s because of scaled-up antiretroviral therapy and the steady decline in HIV incidence since the peak in 1997(3-4). In 2012, this decline continued, with evidence that the drop in the number of people dying from AIDS-related causes is accelerating in several countries. Antiretroviral therapy not only prevents AIDS-related illness and death: it also has the potential to significantly reduce the risk of HIV transmission and the spread of tuberculosis. As of December 2012, an estimated 9.7 million people in low- and middle-income countries were receiving antiretroviral therapy, an increase of 1.6 million over 2011(5). Declines in the annual number of AIDS-related deaths illustrate the powerful health benefits of scaled-up antiretroviral treatment. From a high of 2.3 (2.1–2.6) million in 2005, the annual number of AIDS-related deaths fell to 1.6 (1.4–1.9) million in 2012. The number of people dying from AIDS-related causes in sub-Saharan Africa also declined from 2005 to 2011, although the region still accounted for the highest percent of all the people dying from AIDS in 2012(3, 5).

Ethiopia, officially known as the Federal Democratic Republic of Ethiopia, is located in East Africa commonly recognized as The Horn of Africa. It is the tenth largest country in Africa. The population of Ethiopia in 2007 was estimated at 74 million. Currently, based on projections from the national census of 2007, it is estimated at 83 million, making the nation the second most

populous country in Africa and one of the seriously HIV affected countries in sub-Saharan Africa(1, 4).

According to the UNAIDS report, estimated HIV prevalence in adult ages between 15-49 is 1.3% (1.2%- 1.5%) in 2012. Evidence shows that recent infection has decreased in the country and prevalence among young people has shown a remarkable decline over the last six years. Currently, an estimated number of 760,000 people live with HIV and the estimated number of people needing Anti-Retroviral Treatment (ART) stands at 400,000 for adults(3, 6).

Adherence is defined by WHO as “the extent to which a person’s behavior- taking medication, following a diet, and or executing lifestyle changes, corresponds with agreed recommendations from a health care provider(7). Studies have indicated that at least 95% adherence to ART drug regimen is optimal. Adherence to treatment differs from compliance which only refers to a client’s behavior that conforms to medical orders(8-9).

Non-adherence to ART refers to not taking the medication correctly, taking it inconsistently or in missing doses which is another factor that leads to increases in the frequency of opportunistic infections, faster progression of the disease and a substantial decline in health for the PLWHIV(10). The lowered amount of chemicals in the body also reduces suppression and thus the viral load rebounds, causing an increase in the risk of the viral strain quickly becoming drug resistant. Studies have found a strong statistical relationship between the failure to obtain scheduled pharmacy refills and a more rapid progression to AIDS(11-12). Treatment options in this case become fewer as resistance to one drug will sometimes lead to resistance to other similar drugs in the same group leading to cross-resistance(10).

As ART is scaled up in Ethiopia, there is a need for community mobilization and empowerment in order to address factors that constrain adherence to ART. An understanding of these factors is crucial in order to plan for the scaling up of access to ART.

## **1.2 Statement of the problem**

The introduction of ART has offered hope to people living with HIV (PLHIV) and has been credited with improving the quality of life significantly and reducing mortality. Scaled-up antiretroviral therapy also helps reduce the number of new HIV infections by reducing the virus circulating within a setting or population. Antiretroviral therapy averted 6.6 million AIDS-

related deaths worldwide, including 5.5 million deaths in low- and middle-income countries from 1995 to 2012(3). Even if, ART is the single most dramatic development yet in the treatment of HIV(13), many have been described as being inconsistent with their treatment regimens, either not taking prescribed medication, taking medications only when they felt up to it, or needing breaks(14). Currently, ART adherence is widely recognized as a critical health promotion strategies for HIV positive individuals on therapy(13), given that medication-taking behavior can enormously affect an individual's response; it is the 'Achilles heel' of successful outcome(15).

Non-adherence is a major barrier to using antiretroviral therapy (ART) in Africa(16). A recent study on adherence to HIV treatment in Africa have shown promising results with adequate adherence rates estimated at 77% among adults in sub-Saharan Africa compared to 55% in North America but rates vary significantly by setting(17-18). However, sub-optimal levels of adherence in Africa have also been reported (19-20). Several studies have shown that adherence rates decrease significantly over time(21-22).

Since 2003, the Government of Ethiopia has been introduced and offered ART program through the health sector with the goal to prolong the lives, to restore the mental and physical functions and to improve the quality of life of PLWHIV(2). But there is continuing concern at the level of adherence. A recent studies conducted in Ethiopia have reported adherence rate of 88.1%(23), which is below the near perfect optimal adherence (=95%) required for treatment success and to help delay the emergence of drug-resistant strains of HIV(24).

To date, numerous studies in Ethiopia, investigating and describing adherence rates. However, qualitative studies are also needed in order to identify barriers and Facilitators to adherence. Qualitative research generates information from the respondent's perspective in order to develop culturally appropriate and effective interventions which are in turn more likely to lead to successful and sustainable programs(25). To the best of our knowledge, no reports of previous qualitative adult ART adherence studies have been published in the study center Hawassa. The scope of this study is to examine and conceptualize barriers and facilitators to adherence among people undergoing ART in Hawassa, Ethiopia. In view of the fact that, a better understanding of factors that influence clients' adherence to ART can improve treatment programs of clients with HIV/AIDS.

## **SIGNIFICANCE OF THE STUDY**

The Government of Ethiopia launched its fee-based ART initiative in 2003 and free ART initiative in 2005(2). However, up to now, Achievement of optimal medication adherence(26-27) are becoming the greatest challenges in the management of HIV/AIDS in Ethiopia.

Although Ethiopia is described in most reports as a success story to emulate in sub-Saharan Africa(3, 5), there is a need to assess the quality of care and adherence among people receiving these life-extending medicines. So far, very little is known about factors influencing optimal ART adherence among people living with HIV in Ethiopia and specifically in Hawassa, and how it could be improved. Since the service was recently introduced, it is vital that qualitative studies are needed in order to identify barriers and facilitators to optimal adherence among people on ART and the health facilities providing ART service.

This study will help to contribute a major step forward for the international literature and Ethiopian research into HIV/AIDS and adherence to ART, and serve as an impetus for further studies in this area. In addition, since the study will provides new evidence on the different factors to which the problems of ART non-adherence exist among PLWHIV in the context of Ethiopian culture. It will also inform the MOH and other policy-makers in Ethiopia on ways of improving or maintaining adherence to ART as access to ARV medicines is scaled up nationwide.

## CHAPTER II: RESEARCH QUESTION AND OBJECTIVES

### 2.1. Research Question

The research question focus on the area of exploring clients' and health care professionals' views about factors that facilitate and constrain optimal adherence to ART among HIV Clients in Hawassa, Southern Ethiopia, and suggests possible ways to improve optimal adherence in the future.

- *What are clients' and health care professionals' views regarding the factors that facilitate and constrain for optimal adherence to ART among HIV Clients in Hawassa, Southern Ethiopia?*

### 2.2. Objective

#### **General objective:**

- To explore clients' and health care professionals' views about factors that facilitate and constrain optimal adherence to ART among HIV Clients in Hawassa, Southern Ethiopia.

#### **Specific objective:**

- To explore factors that motivates and sustain optimal ART adherence.
- To explore barriers to optimal ART adherence.

## **CHAPTER III: METHODS AND MATERIALS**

### **3.1 Study area and period**

The study was conducted in Hawassa town, the capital of the Southern Nations Nationalities and People's Region, which is located about 275 kilometers south of the nation's capital Addis Ababa and lies on the main road joining Ethiopia to Kenya. It bounded by Lake Hawassa in the west, Hawassa Zuria woreda in the south, Wondo-Genet Woreda in the east part and Oromiya region in the North. Geographically, it lies between 07<sup>0</sup> 05' latitude North and 38<sup>0</sup> 29' longitude East. According to the 2007 census result Hawassa city has a population of 259,803 and of this 133,637 were males and 126,166 were females.

The city has two governmental and three private hospital, 5 health center, 15 health posts, 47 private clinics and drug store, and 12 diagnostic laboratories and pharmacies. Among the health facilities providing ART in the town, the study investigates factors that facilitate or constrain adherence to ART for people on treatment at the two selected health care facilities, one public hospital(Adare Hospital) and one public Health centers( Hawassa Millennium Health center). These two facilities were chosen because they had already been providing ARVs for at least one year time and had increased number of ARVs user relatively from other health facilities. The hospitals are located within center of Hawassa City and launched its ART programme in 2006, while the Millennium Health center programme started in early 2012. At the time of the study, Adare Hospital had a total of 982 registered ARV users and in Hawassa Millennium Health center there were 91 ARV users. The study was carried out from February to April 2014 GC.

### **3.2 Study Design**

Qualitative research aimed to help understand social phenomena in a natural rather than an experimental setting while emphasizing the experiences, attitudes, and views of the participants rather than providing quantified answers to a question. Qualitative research focuses on obtaining deep and meaningful information from small groups which fulfill certain criteria set out by the researcher and has the ability to assist with guiding future health practice. Quantitative research is unable to consider the individuality of human experience and for this reason the researcher believes a qualitative approach is more suited to the proposed study.

There are different research designs within qualitative research which include phenomenology, grounded theory, exploratory, and descriptive. In this study, *a grounded theory study design* was used to explore the research question as this is well suited to the study of human experiences and aimed by considering cultural diversity of the participant under study to generate concepts, a model or a substantive theory which is complete, coherent and sheds light on the area under study rather than testing hypotheses based on existing theory. Despite the fact that events are processed and interpreted through the eyes of both participant, researcher and also since it , thus a construction, the grounding of theory in data tends to make it more reflective of practical situations than speculatively derived theory(28).Grounded theory encompasses a specific methodology on how to get from systematic data collection to producing a multivariate conceptual theory and provides a series of systematic, exact methods that start with collecting data and guides the researcher through the analytical process.

### **3.3 Study Participants**

All clients who were receiving ARV treatment at the study sites fulfilling inclusion criteria and Health care workers at the selected health care facilities who were involved in counseling and providing ARV medicines (e.g. nurses, doctors and counselor).

### **3.4 Inclusion and Exclusion Criteria for interviewees**

#### **Inclusion Criteria:**

##### *Clients*

- Age 18 years or over and willing to participate in the study.
- On ART for one month.

##### *Health care workers*

- Worked at the ART clinic for greater than one month and willing to participate in the study.

#### **Exclusion Criteria:**

##### *Clients*

- Clients who were severely ill and unable to respond to the interviews.
- Those who had just been referred or transferred from another site to the study site.
- Not identified by the assistance of adherence counselors.

##### *Health care workers*

- Staff worked at the ART clinic and not selected by health facilities manager or senior health worker at the clinic.



### **3.5 Sample Size Determination and Sampling Technique**

#### **3.5.1 Sample Size Determination**

Qualitative research focuses on the quality of information obtained rather than the quantity and size of the sample(29). There is little guidance regarding exact sample sizes for qualitative research in the literature, as sample size is influenced by the available resources and the feasibility of acquiring the sample(30). For this study theoretical sampling methods was employed on the data collection and analyses process. This type of sampling used as a process for determining the sample size where data are analyzed as they are collected and the researcher decides what data to collect next, based on the analysis. Sampling were completed when theoretical saturation reached: “theoretical saturation is the point in category development at which no new properties, dimensions, or relationships emerge during analysis”(31). For this study a total of 28 participants (23 from ARV users and 5 health care providers) were participated.

#### **3.5.2 Sampling Technique**

In keeping with qualitative principles, the intention of this study has not to yield generalizable data(32) but rather to gain an in-depth understanding of the participants’ perspectives. A non-probability purposive sampling and theoretical sampling strategies was used. Purposive sampling was made to seek participants with a variety of ages, gender, duration of ART use and educational status as the study progressed in an attempt to obtain diverse perspectives. Intensity and criterion based purposive Sampling was used to identify common themes that transcend a focused sample. Theoretical sampling was also used to provide further insights on the evolving understanding obtained during data analysis. Due to the nature of non-probability sampling, the criteria for sampling was based on the availability and willingness of people to participate in the study, and participation was completely voluntary(33).

The intensity purposive sample includes those individuals who were able to provide services relevant to the research problem. The use of intensity purposive sampling does not allow for random sampling, therefore all persons in a given category were not given an equal chance of being sampled. This sample includes Health care workers fulfilling the inclusion criteria. The intensity purposive sample (doctor, nurses, and counselors) was identified with the assistance of

the health facilities manager or senior health worker at the clinic. Interviews were set up with these participants by the health facilities manager or senior health worker.

The sample group also includes individuals on ARV treatment. This sample group was reflective of criterion purposive sampling. The sample thus was chosen to reflect those who were the most likely to provide the most meaningful information in relation to the aims and objectives specific to this research based on theoretical sampling strategies and the judgment of the researcher (33). The participants on treatment were identified with the assistance of one of the adherence counselors to identify and recruit relevant adherent and non-adherent men and women, participants who fulfil the inclusion criteria's, as there was already an established relationship of trust with the clients who have been receiving their treatment at the health facilities. All the participants were informed verbally about the study by the counselor on the day they attend the clinic and a choice was given to the participants to meet with the researcher. The researcher then arrange for a convenient time to meet with the participants whilst they wait for their treatment. As this sample was drawn from health facilities in a specific area, it envisages that there were some common characteristics in terms of ethnic and socio-economic background. It was hoped that this may have assist in the facilitation of the sharing of common experiences. By including this range of participants it was hoped that a more holistic and in-depth understanding of the research aims and objectives were achieved.

### **3.6 Data collection**

Observations and in-depth interviews qualitative data collection methods were used. Semi-structured interviews were conducted with ARV users, health care providers and site managers from both facilities which were conducted in both facilities with notes compiled on themes related to adherence.

#### ***In-depth interviews***

Semi-structured, open-ended interview guides with flexible probing, ideal for investigating personal and professional experiences of ART adherence from the subjective perspective of each respondent and also for obtaining information from site managers to ascertain to what extent adherence to ART medication considered important prior to program commencement were utilized. A comfortable, private room, free from interruptions was used for the duration of the

interviews. Each session was last between 45 and 90 minutes for the in-depth interviews. Only one session were conducted per day. There was a room for modification in the field for the duration of interviews and the session.

### ***Observation (consultation)***

Observational notes were taken and later used in data analysis. The notes were used to help fill in any gaps in the data obtained during in-depth interviews. Observations, at each facility, were conducted on:

- **Health facilities**

These was observed with a focus on issues such as structural outlay, privacy, conducive environment (structure, cleanliness, and workers' attitudes and availability of Standard Treatment Guidelines); availability of medicines, adherence reminders, and availability of adherence support strategies.

- **Health care workers**

Health care workers observation was conducted with the aim is to explore aspects such as interactions between clients and service providers in the health facilities.

### **3.7 Data Collection Instruments**

An open, semi-structured Amharic version interview guide which was first drafted in English and then translated to Amharic and back translated to English by another person was used to collect data. The questions was open-ended, however, for ARV user an interview guide was used to cover fixed themes such as: client's perception and knowledge of HIV/AIDS; information received about ART; perceived barriers and facilitators to ART; and experiences before and after starting ART. In addition, notes and memos were written after each interview and observation. Often, by using digital audio recorder the client's own words was also used to confirm that the indentified words or phrases are really grounded in the data, rather than being generated from an implicit hypothesis or from the researcher's preconceptions.

### **3.8 Definition of Terms**

- **Adherence:** Is the extent to which a person's behavior- taking medication, following a diet, and or executing lifestyle changes, corresponds with agreed recommendations from a health care provider. Poor adherence rates (less than 95% adherence) can lead

to treatment failure and to the emergence of drug-resistant strains of HIV.

- **Antiretrovirals (ARVs):** Medicines designed to suppress the replication of HIV and prevent the progression of AIDS.
- **Antiretroviral Therapy (ART):** HIV treatment involving the use of a triple combination of ARVs.
- **Clients:** People who use the ART treatment services available at the health facilities.

### **3.9 Data Processing and Analysis Procedures**

Data collection and data analysis occur simultaneously in qualitative research, as the emerging results may require further data collection. The investigators were concurrently gathering, managing and interpreting data. Accurate transcribing of audio taped interviews as soon as possible after the interview was done before data analysis occurs. Digital audio recordings of the interviews were transcribed verbatim in English by interpreter on each interview. The data was entered into the **ATLAS.ti7** software which helps to structure and manage the data.

The data analyses process were occurred in three stages: open/ initial, selective, and theoretical coding. In the open/ initial coding process, the transcripts were inductively analyzed line by line, and several codes were developed to assess the data. Subsequently, the open codes were clustered into categories.

Analysis was done on each interview, until the core category emerged as a main concern. Once the core category generate, the sampling became selective in line with this category. Sub-categories and their properties were developed using further data collection and a constant comparison of the data as a whole. In the theoretical phase of the analysis, the relationships between the core category and its sub-categories were determined and described. The process was continued until no new properties emerge and theoretical saturation reached. In accordance with the grounded theory method, memos were written during the entire analytical process to record ideas about emerging categories and assumptions about their relationships(28).

### **3.10 Rigour and Trustworthiness of study**

Rigour relates to establishing the trustworthiness of the data and study. To assure the quality of the research findings the researcher was consider the different set of criteria to focusing on the credibility, dependability, transferability and Confirmability of the study(34).

#### **Credibility**

Credibility focuses on the truth and value relating to the findings of the study and the representation of these(35). The investigator was increase the credibility of the findings through triangulation of study subjects and triangulation of qualitative data collection methods, especially non participant observation and semi-structured interviewing techniques, tape recordings of the interviews, transcriptions of these verbatim this were increase the accuracy of the descriptions of participants' experiences and delaying of the literature review to increase the credibility of the findings(36).

And also to gain rich picture of the adherence factor the investigator was triangulate the data sources from both users of ART service and the health care workers who deliver it which was increase the credibility of the findings. In addition the investigator was also developing an early familiarity with the culture of the selected health facilities in order to gain an adequate understanding of the organization and to establish a relationship of trust.

#### **Dependability**

Dependability relates to the reliability of data over time and different conditions and refers to the detail and information provided by the study to allow others to replicate the methods of the researcher and reach the same conclusions(36). One of the ways in which the investigator was shown to be dependable were to involve the participants once the data as analyzed the interpretations and findings of the study was be returned to at least three of the participants especially for the health workers to determine if the investigator had presented a true picture from their perspective. In addition, by keeping the data available for describing the operational detail about the research design and data gathering, so that the findings, discussions, conclusions and recommendations was traced for verification and ensure comparability.

## **Transferability**

Transferability or fittingness of a study is the extent to which the findings of a qualitative study can be of use to other populations or settings similar to those in the study(37). By indicating the readers of the research report to make their own judgments about the relevance of the findings to their situation and comments provided by an independent group of experts or lecturers from Jimma University to ensure conceptual clarity of data was ensured for transferability. These independent experts were asked to comment on the both the credibility and transferability of the findings. This was done by establishing the degree of similarity in the respondent's views with other research material on the same subject matter. Additionally, differences were explored and alternative explanations were also been sought.

## **Confirmability**

Confirmability of a study establishes that “data, findings and interpretation are clearly linked” and the participants along with other research professionals support and agree with the researcher's interpretation of the findings(35). By describing the procedures and decisions that were made to trace the course of the research step-by-step using the “audit trail” the researcher showed the achievement of Confirmability in addition to all of the above criteria for keeping trustworthiness of the study.

The investigator was using these criteria as a guide to ensure trustworthiness and robustness of the study. In addition to this, in order to ensure the study were conducted in a rigorous manner, the researcher aimed to avoid using bias throughout the process, aimed to reduce any sources of error which may present and the research was carried out in a systematic way relating to design, data collection, analysis and interpretation. The researcher used constant comparative analysis methods to modify and check correctness and consistency of the data collection tools and research instruments throughout the data collection period.

Accurate records were kept of all interviews and interactions with participants, as the careful recording of data is crucial to the study. The storage of data was done in an organized, secure manner and was disposed of confidentially and appropriately when necessary. Hand written information was typed into a word document for electronic secure storage with correct dates, locations and identities in the form of pseudonyms. Rigour is attained through strict attention to

detail, adhering to procedures and through consistency and accuracy throughout the research process(38), each of which the investigator was consider at all times.

### **3.11 Role of the Researcher**

The role of researcher in the study includes preparing the proposal to conduct the research, act as the primary data collector, the centre of the interpretation and analytic process of the data and presenter of the finding of the result. Therefore in order to enhance credibility researchers should make explicit what they bring in terms of qualifications, experience and perspective(39). My world view tends to be a holistic perspective, seeing humans as beings with biological, psychological, emotional, and spiritual dimensions. The interplay of the human system with the natural systems of the world, along with the man-made systems of society and cultures, is the interaction, which presents problems to be solved.

My educational background and work experience provide me a unique lens through which to conduct this study. I received a Bsc degree in Nursing in July 2007 GC and taught cognitive and creative development through nursing for five years. Before I joined Arba Minch College of Health Science working as instructor for health science students, I have been a focal person and clinician on HIV care and ART center in Chuko Health center which is found in Southern Nation Nationalities and People's Regional state, Sidama zone, Chuko woreda, for one years and two month. Working within focal person and clinician over this time has meant that I have in my role as counselor and provider of ART for PLWHIV, had experience of several ARV users who have faced the problem of poor adherence, an experience that I have never forgotten.

The significance of exploring this area came to my mind when I read research findings which suggested that studies conducted in Ethiopia have reported ART adherence rate of 88.1%(23), which is below the near perfect optimal adherence (=95%) required for treatment success and to help delay the emergence of drug-resistant strains of HIV(24). So my perspective on commencing the study will to try and find out the issues that facilitate and constrain optimal adherence to ART among HIV Clients as it was something that had held my interest for a long time. Researcher should be honest about their theoretical perspective from the outset, this it is hoped, is evident in the reading of this study(40).

### **3.12 Ethical Considerations**

To conduct the study in an appropriate manner the following measures were taken:

**Informed Consent:** During data collection, the respondents were informed about the full nature and purpose of the study to get their verbal consent as well as to maximize the response level. The respondents were ensured that all information taken will be kept confidential by using codes to identify participants instead of names, medical record numbers, or any other personal identifiers. They were also clearly informed about their right to refuse to be involved in the study or withdraw at any time during the interview session. Consent forms requesting permission to conduct the interviews as well as permission to audiotape the interviews were handed out at the same time. Once the letter of consent returned, appropriate arrangements were made for the interviews to be conducted.

**Privacy and Confidentiality:** The informed consent and interview procedures were conducted completely in a private setting or room. Confidentiality was guaranteed by not writing and recording names on the study tools. Completed written and recorded information were kept in a secured place. Generally, every effort was made to follow all WHO ethical and safety recommendations for research.

**Ethical Approval:** The following procedures would be followed to ensure ethical practices. Ethical approval for the study was obtained from Ethical Review Committee of the College of Public Health and Medical Sciences, Jimma University. Permission was obtained from the facilities ART centers. Verbal consent was obtained from each clients being treated by ART before each interview. The interviewer wouldn't make pressure of any kind on the study participants to participate in the study. The interviewers were informed about the place of the interview, which was selected to ensure confidentiality and comfort, and was offered other optional places to avoid any inconvenience.

### **3.14 Dissemination Plan**

After the result was interpreted the report will be prepared by the principal investigator. Two types of reports will be prepared. The first thesis will be submitted to Health Education and Behavioral science department, Faculty of Public Health and Medical Science, Jimma University. The other will be distributed to the institutions from which data were collected and for stakeholders. The findings will be disseminated through workshop that will be organized by the evaluator in collaboration with the stakeholders. Presentation and publication to scientific forum and journals will also be considered.



## CHAPTER IV: RESULT

A total of 28 in-depth interviews with twenty-three clients, 2 Health officers, 1 clinical nurse, 1 case manager and 1 adherence supporter with an average of 8 pages transcription for the interview were taken during the data collection periods. The characteristics of the interviewed clients and healthcare providers (all are female) are presented in Table 1 and Table 2 respectively.

**Table 1** Characteristics of clients involved in in-depth interview from health setup in Hawassa, February - April 2014 (N=23)

Characteristics of participants		Frequency
<b>Gender</b>	Male	<b>10</b>
	Female	<b>13</b>
<b>Age in years</b>	35 years and below	<b>15</b>
	Above 35 years old	<b>8</b>
<b>Educational level</b>	Illiterate	<b>3</b>
	Primary education (1-8 grade)	<b>13</b>
	Secondary education (9-12)	<b>6</b>
	Tertiary and above (college and above)	<b>1</b>
<b>Duration since knowing HIV test result</b>	Less than 3 years	<b>14</b>
	Above 3 years	<b>9</b>
<b>Length of time on ART treatment</b>	Taking ART <12 months	<b>12</b>
	Taking ART > 12 months	<b>11</b>

**Table 2.** Characteristics of healthcare providers involved in in-depth interview from health setup in Hawassa, February - April 2014 GC (N=5)

Profession	Age in years	Level of education	Position	Experience with ART (year)
Health officer	38	Bsc	ART clinic focal person	3
Health officer	46	Bsc	ART clinic focal person	4
Clinical nurse	25	Diploma	ART nurse	3
Laboratory technician	29	Diploma	Adherence supporter	3
Case manager	33	Certificates	Case manager	6

The study tries to identify several perceived barriers and facilitators to client adherence to ART. The central themes were Barriers and Facilitators of ART adherence and alongside this main theme, four additional emerged themes were classified as: (I) individual clients' beliefs and behaviors related; (II) socioeconomic and cultural related; (III) Healthcare provision and system related; (IV) drug related themes on barriers and facilitators of ART adherence. Each theme was classified into categories as presented below and shown in figure 1. Each category with listed codes under the categories which is reported from clients and/or health care providers is presented in detail with descriptions and quotes cited in the text to support the categories.

#### **4.1 Individual clients' beliefs and behaviors related barriers and facilitators theme**

In-depth interview with all the participants recognized the following individual client's beliefs and behaviors related barriers and facilitators to ART adherence.

##### **4.1.1 Barriers**

Feeling better (drug holiday), substance-misuse (Alcohol use), perception about ART, simply forgetting and being busy and having responsibilities of family work were reported as barriers to adherence.

###### ***4.1.1.1 Feeling better (drug holiday)***

It was mentioned by both interviewed clients and health care workers that some clients would skip their dose when they were feeling better or their CD4 test result improved.

For example, a 34 year- old female ARV user told a story about her neighborhood friend client said:

*“There is this client in my neighborhood. She has stopped taking her medication after becoming well. She says that the drugs are too many to be taken every day in the morning and evening as if it is a prayer.”*

A 25 year-old female clinical nurse also agreed that lack of self motivation to take the drug due to feeling better continuously results in low adherence. She said:

*“..... Some clients, after taking the ART drug for 6 to 12 months, their CD4 count increased and health status is better and have no symptoms, they (ARV users) assumed as they have cured and then they stop using it (ARVs) ...”.*

#### **4.1.1.2 Substance-misuse (Alcohol use)**

Misuse of substance was mentioned by both health care providers and clients, as one of the reason why some clients were not adhering to their ARV medications.

A 35 years old married male ARV user who was a former alcohol drinker reported how alcohol affects his time for taking the ARV drug said:

*“I used to drink alcohol until 9 to 10PM night, this condition seriously affected the schedule of my pills; hence forth, I was taking the pills irregularly. Take however currently I stopped taking alcohol and become very strict in taking my pills on time every day.”*

#### **4.1.1.3 Simply forgetting and being busy**

Both clients and health care professionals reported that most clients forgot their medication due to daily routine activities, busy and away from home, having responsibilities of family work and social events like wedding and moun.

A 38 years old male client disclosed:

*“yes I missed some doses (ARVs) because I simply forgot”.*

And also a 30 years old male ARV user told story how he forgot the drugs due to wedding:

*“Unless I forgot my medication at home due to certain occasions, there is nothing that can prevent me from taking my medication at any way. Yes, let me tell you what I faced once. I remembered, there was my friend’s wedding and I was with my friends, that day I forget taking my medication with me and that was the only moment I had never take medication in my life”.*

#### **4.1.1.4 Having responsibilities of family work**

A 30 years old female ARV user also disclosed of simply forgetting due to having responsibilities of family work.

*“.....I remember I stop took my pills for 3 days, it is because of my daughter have developed severe pain so at that time I should do everything to save my daughter life even that day I don’t worry about my life but I think and worry for my daughter life and that is the only reason.....”.*

#### **4.1.2 Facilitators**

Adherence aids, responsibilities for family especially for children, experiencing better health, and prospects of living longer, daily schedules and Disclosure of HIV status were perceived as facilitators to ART adherence.

##### ***4.1.2.1 Adherence aids***

Setting alarms on watches and mobile phones were most frequently mentioned by both clients and health care professionals as a ways to cope with their medication in different situations. In addition, ART clients also used TV or radio programs to remind them to take their pills.

A mobile phone alarm is the most common adherence aid that many ARV users often use to take their medications.

For example a 29 years old male ARV user said:

*“Always I set a reminder alarm on my mobile phone to take my pills on time and it helps me to remind of the time of my medication even when I was busy ....”*

##### ***4.1.2.2 Responsibilities for family and children***

It was mentioned by both Health care workers and several ARV users that caring for family and especially having responsibility for looking after children to raise and educate was one of the most frequently- mentioned facilitators of adherence. Clients who were worried about the future of their children showed a relatively good adherence.

A 29 years old client said:

*“I have the responsibilities to care for my daughters until she get married, she is 14 years old now”*.

A 57 years old married men describes his feeling and why he took ARV drug:

*“..... for example, when I see my daughter I weep internally all the time because I always dream the best future life for he and I have also responsible for her too. By taking my drugs regularly and on time I don’t hesitate looking her until my death.....”*

#### **4.1.2.3 Prospects of living longer**

“Prospects of living longer” was related to the fact that some of the participants were severely ill when they were diagnosed and started on medications. Some clients had to start medications immediately after being diagnosed and they agreed to do so because they did not have any other life-saving option.

A 38 years old female client also describe as:

*“Still today I didn’t forget to take my pills on time because the pills gave me the opportunity to live again and for me it is also the main reason of staying alive still. So, simply if didn’t do it, I wouldn’t have any other choice to live.”*

A 35 year male client also described his motivation for taking medications as,

*“..... the first reason which facilitate me to take the drug regularly is to live longer and Secondly; I guess we don’t know what will happen in the near future may be everything become changed and we will become completely cured from this disease because everyone in this world wish to live longer no one said I want to die and also we don’t know when we die even we see and hear that most of the people die with any other causes like car accident & with many others conditions as we stay longer until now. So it is my obligation to take the drug by giving strict attention it & more over to live .....”*

#### **4.1.2.4 Daily schedules**

Adjusting an appropriate time for taking ARVs was described by ARV users as another way of helping them to adapt to their ARV regimens.

A 35 years male ARV user’s said:

*“As I told you before I took my pills always night at 9:00 pm, and I have save my brain alarm, when it’s time to take my pills it starts to ring... it’s nine...time to take your pill.”*

## **4.2 Socio-economic and cultural related theme**

HIV is still a sensitive social, economical and cultural issue in Ethiopia, and the findings of this study also supported this by identifying the barriers and facilitators below.

### **4.2.1 Barriers**

Economic constraints, stigma and discrimination, barriers relating to religion and rituals, lack of emotional/psychological support and social events were reported as barriers to adherence.

#### ***4.2.1.1 Economic constraints***

Participants in this study reported that economic worries related to unemployment, food insecurity, charges for diagnosis and treatment and cost of transport problems were some of the economic-related difficulties they have experienced in trying to adhere to the treatment regimen. Individuals who were unemployed had difficulties in meeting their food needs and in facing challenges of getting to and from health care facilities which are often not in the immediate vicinity. The following quotes from ARV users highlight the challenges faced by people living with HIV/AIDS around unemployment and not having money.

A 68 years old unemployed male client said the challenge he faced due to economic constraints:

*“.....because I am in a serious economic problem and nobody supports me, I am not getting my daily breakfast, lunch and dinner properly. If I had money I would buy vegetables, fruits any other important food item which increases my immunity against the disease and my body weight too. So being under poor economic condition is my major problem.....”*

A 36 years old ART clinic focal person also added consequence of money and adherence:

*“..... sometimes they do (not) have food at all at home, so they will not be taking their drugs (ARVs) because they will be hungry”*

#### ***4.2.1.2 Stigma and discrimination***

Despite the positive benefits of ART, throughout the interviews, both ARV user and health care professionals mentioned that most ARV user were more likely to tell their HIV status to people they live with, and were less likely to tell others, even their very close relatives such as parents, brothers, and sisters. Many of them reported stigma and discrimination related to being HIV positive were still present in their communities and have a strong influence on how clients

adhere to their medications and this leads ARV users to hide pills, occasional skipping of medications and failing to keep clinic appointments for drug refills or examinations. Fear of being discriminated against them and their family by other members of the community, stigma and job loss or abandonment were the most frequently mentioned.

A 35 years old female describes about her fear of being discriminated against them and their family by other members of the community as:

*“Other than my children, no one knows whether I took this medication or not and also I don’t want others to know. I would like to go out confidential; without anyone staring and talking at me and my children’s because our place is a talkative place which prevents our free movement in and out from home.....”*

One of the adherence supporters worker in the hospital also expressed that:

*“Many clients still hide their ARV treatment from their relatives, staffs even from their family because they are afraid that they will lose their social activities and respect if their community and family know their status.....”*

#### **4.2.1.3 Barriers relating to religion and rituals**

People live in a community and need to abide by their local and traditional religious and cultural rituals, which can influence adherence to ART. Religious rituals like fasting and holy water were found to influence medication taking.

A 29 years old male reported:

*“I didn’t take my drugs when I visit church for Holly water and the like because I do not want to be seen by anyone because it is not allowed not only to take drug but also to drink water in the church and by the way due to a condition like this sometimes I postponed the time of taking my pills”*.

#### **4.2.2 Facilitators**

Disclosure of HIV status and social support, support program for income generating activities and looking someone improved with ART were reported as facilitators of adherence.

##### **4.2.2.1 Disclosure of HIV status and social support**

Despite being regarded by many as an important barrier to adherence, it was mentioned by some clients and health care professionals that self-disclosure of HIV status as a critical facilitator of ART adherence, usually linked to the support the ARV users received from partners, children,

parents, peers, and self-help groups. Most of the ARV users who have a child reported that especially children play an active role in reminding and encouraging clients to take their pills, even they are also becoming the main reason for living for many ARV users.

As a 28 years old female client reported about her child role in reminding and encouraging support due to self disclosure of HIV status to her family that:

*“The drug schedule does not take my time because I take during the night time. I take the drug exactly at 9 pm. If I forget to take the drug at 9 pm, my children remind me the time. I take bacterium tablets after lunch at 2pm. At all times my children help me through remembering the time to take the drug. They woke me up from sleep or in a presence of a guest so that I should not miss the right time. Hence, I am taking the drug seriously as it is for my survival and also so that my children don’t miss a parent since their father has died.”*

A 68 years old male client also reports the support he received from his former employer after disclosing his HIV result:

*“.... yes at that time when I was diagnosed and know my HIV status they (his employer) were also there even they heard I had TB and they also giving me advise to take my pills on time regularly and also sometimes they support me by giving foods.....”.*

### **4.3 Healthcare provision and system related themes**

The impact that the healthcare provision and system related condition should not be underestimated. The barriers and facilitators conditions that have an impact on adherence in this study described below.

#### **4.3.1 Barriers**

Poor clinic infrastructure and perceive stigma, Fatigue of healthcare providers, Long waiting time at facility (card room) and charges for diagnosis(except CD4 & CBC) were reported as barriers to adherence.

##### **4.3.1.1 Poor clinic infrastructure and perceive stigma**

From the observational finding and the interview made with clients and health care workers the poor hospital ART clinic location and setup which is found in front of the hospitals cafeteria and the unsatisfactory conditions of the ART room for counseling and keeping client confidentiality



during clinical visits were perceived as a major barrier to adherence. This is because examining clients; data clerk activity, counseling and consultations often took place in the same and open rooms in the presence of other frustrated clients and different health professionals. Many therefore found it difficult to speak openly, as they were worried that peers would judge or expose their current condition.

#### ***4.3.1.2 Long waiting time at facility (card room)***

The time that the clients spends at the health care facility especially around the hospitals card room often leads to frustration and places an additional burden on those who have not disclosed their status to others and on those who may not have adequate support from those around them, which can impact negatively on adherence levels as been reported by the clients in this study.

#### ***4.3.1.3 Charges for diagnosis***

All clients and health care provider involved in this study reported that all of the clients enrolled in the ART clinic receive their ARVs and some of the laboratory diagnosis checkup like CD4 & CBC free of charge was considered as facilitators of ART adherence. However, the additional ART related cost that a client had to pay was described as a constraint to adherence and a major reason why some individuals do not come to the health facilities to fill their prescription, even when the treatment itself is free of charges, especially for many ARV users who were poor, and did not have a job.

A 46 years old female ART clinic focal person noted:

*“..... the other problem occur at this area is that clients needed to bear the treatment for most of OI’s treatments and diagnostic (laboratory) costs except for CBC and CD4 even if most of the client have the problem of money .....”.*

#### **4.3.2 Facilitators**

Nutritional support from both health care providers and clients; Counseling and education, trusting health workers and government policy of free ART treatment from clients were mentioned as important for improving adherence.

##### ***4.3.2.1 Nutritional support***

The Food by Prescription (FBP) nutritional support was mentioned by both clients and health care professionals as important for improving adherence.

#### **4.3.2.2 Counseling and education**

Most Clients said the education and counseling they received about ART in the ART clinics, majorly from Adherent supporter and case managers which they shared their lived previous experience motivated them to take the medication. From the observational finding and interview of clients reports suggest that adherence supporter, case managers and health care professional provided education, which focused on the importance of perfect adherence, strategies to improve adherence, consequences of non-adherence, possible side effects of the medications, and the duration of treatment required in a comfortable manner for a clients and this have a positive influence on adherence.

All of the clients reported having optimal interaction and felt very well supported by all their healthcare providers, the government policy of free ART treatment and the strategies of giving cards to receive their drug in any health facilities during unconditional movement were also another facilitator for them to continue taking ART.

A 35 years old male client describes his motivation on government policy of free ART treatment as a facilitator by saying:

*“.....On my part I don’t have any inconvenience which could force me to miss the date and time to take the drug. This could only happen through my negligence. Sometimes I may pass the right time for some ten minutes. Since our government provides us the drug free, we have no more cost other than some transport cost. This encourages us to take the drug consistently. We should not need to have an appointment or some other advice to take the drugs.”*

#### **4.4 Drug related theme**

Pill burden and side effects of the drug were the major reason for clients to be non-adherent; while the consistent and contrasting themes experiencing self-improvement of health were the main reason for facilitating adherence in this study.

##### **4.4.1 Barriers**

Pill burden (duration of the treatment, frequency of dosing,), size of the drugs and side effects of the drugs were reported as barriers to adherence.

Most ARVs users mentioned pill burden as being one of the major challenges of adhering treatment and in addition to ARV drugs, some clients were also taking anti-TB drugs and co-trimoxazole for PCP prophylaxis; and some in addition had to take drugs for other illnesses. Side

effects were experienced by almost all of the participants, mainly at the beginning of ARVs treatment or upon initiation of concomitant treatment. Among side effects clients mentioned were blurred vision, itching of the skin, generalized body weakness, body shape disturbance, poor appetite, nausea, burning of the stomach, headache, bad dreams, rash and vomiting.

The following response from a 57 years-old married men indicates the overall difficulties that ARV users faced related to pill burden, side effects of the drugs, the size of the drugs and its inappropriateness of the drug for handling and moving and his general ARV drug related hopes and how this may serve as a barrier to complete adherence to the treatment:

Report related to the side effects of the drug:

*“Generally, the majority of users have a fear for the side effects of the drugs. Hence, we recommend for the replacement of such drugs through studies and giving due emphasis for this issue. There are rumors in the community in relation to the side effects like for example for some individual “the drug result in growth of hump over the shoulders of the users like that of an ox”, for me as you see “it creates depressions over the face”, for others too “it changes the shape of the users that is fat body above and thin body below the loin forming two different shapes within an individual..” ..... “Some drugs have harmful effects and I (we) wish this drugs need to be replaced by another safe drugs.”*

Report related to the size of the drug:

*“Moreover, related to the size of the drug, you see this drug which I took it now is too large which fills mouth & even difficult to pass through esophagus unless you take it with adequate water. This one is also one of the reasons why we can’t able to go anywhere by having it much drug at a time. Hence, we suggest the drug size to decrease.”*

Report related to the formulation of the drug:

*“Further facilitating access of drugs in injection form is the idea of all & I hope I am waiting it once up on a time. For example if taken once acting for long duration as vaccination did ,we are very happy & everybody wishing & waiting it “as farmers waiting rain for cultivation” , especially all ART users including me hopefully waiting injection preparation acting for long duration.”*

#### 4.4.2 Facilitators

Experience of directly observing improved health among other ART user, experiencing self-improvement of health on ART and having a simple regimen were frequently reported as important for improving adherence.

Most ARV users were very optimistic about ART efficacy, fear of doing worse without adhering to ART, experiencing improved health on using ART and the experience of directly observing improved health among other ART clients within one's social network were a prime motivator for adherence. Both clients and health care provider were reported ART had increased their body-weight and appetite, reduced opportunistic infections, and improved their quality of life of clients using it.

A 35 years old Male client expressing his experiencing of self- improvement of health on ART that:

*“..... taking the antiretrovirals have helped us a lot even it increase our CD4, for example I can see for myself: when I started the treatment my CD4 was 246 but after I took the treatment for 3 month my CD4 increased around 400 and not only that but also I didn't expose for any disease still now, so this one is also best evidence about the effectiveness of the drugs. I believe that the treatment helps because in some way I am seeing the results.”*

A 25 years old female clinical nurse also added:

*“..... yes for example most of our client were coming after they develop OI because most of the client check their HIV status after they observe and develop some sign and symptoms of the disease there is only some clients who is coming to check there results voluterly so after they took the drug they see improvement of health after treatment of OIs and progressive increments of CD4 counts were makes them to develop trust on the drugs and adhere well”.*

Furthermore, both clients and healthcare workers explained that the fear of returning to a poor physical state or, even worse, death, strongly motivated them to adhere.

## **Observation of health facilities**

The information below was derived mainly from structured observations of the health facilities, non-participant observation of client and health care provider interaction and from notes taken by the researchers and from interview with site managers at Adare hospital and Millennium Health center health care facilities.

Concerning to structural issues of the two health facilities, both health care providers and ARV users highlighted a number of structural problems in the health facilities which had a potential impact on adherence to ART. At both of the health facilities, for example, there was no separate room for consultation and thus no possibility of confidentiality for clients. At the time of this data collection period in Adare hospital, for example, all of the ART clinic health workers were sharing a single room and consulting with four different ARV users at the same time. However, clients frequently mentioned that they were accorded respect. Elsewhere, at Millennium Health center, the waiting area was limited and confidentiality was compromised by lack of space and the number of consultation rooms that were shared. Although the quality of the infrastructure varied between the two facilities, particularly in Adare Hospital, even if there is a good hope of building under construction at the time of the data collection, the poor hospital ART clinic location and setup which is found in front of the hospitals cafeteria and the unsatisfactory conditions of the ART room for counseling and keeping client confidentiality during clinical visits were perceived as a major barrier to adherence.

There were reports of wide variations in the length of time ARV users had to wait at the clinics. According to ARV users report and observational findings, waiting times varied from less than 10 minutes to 30 minutes depending on the work load of the staff and client flow.

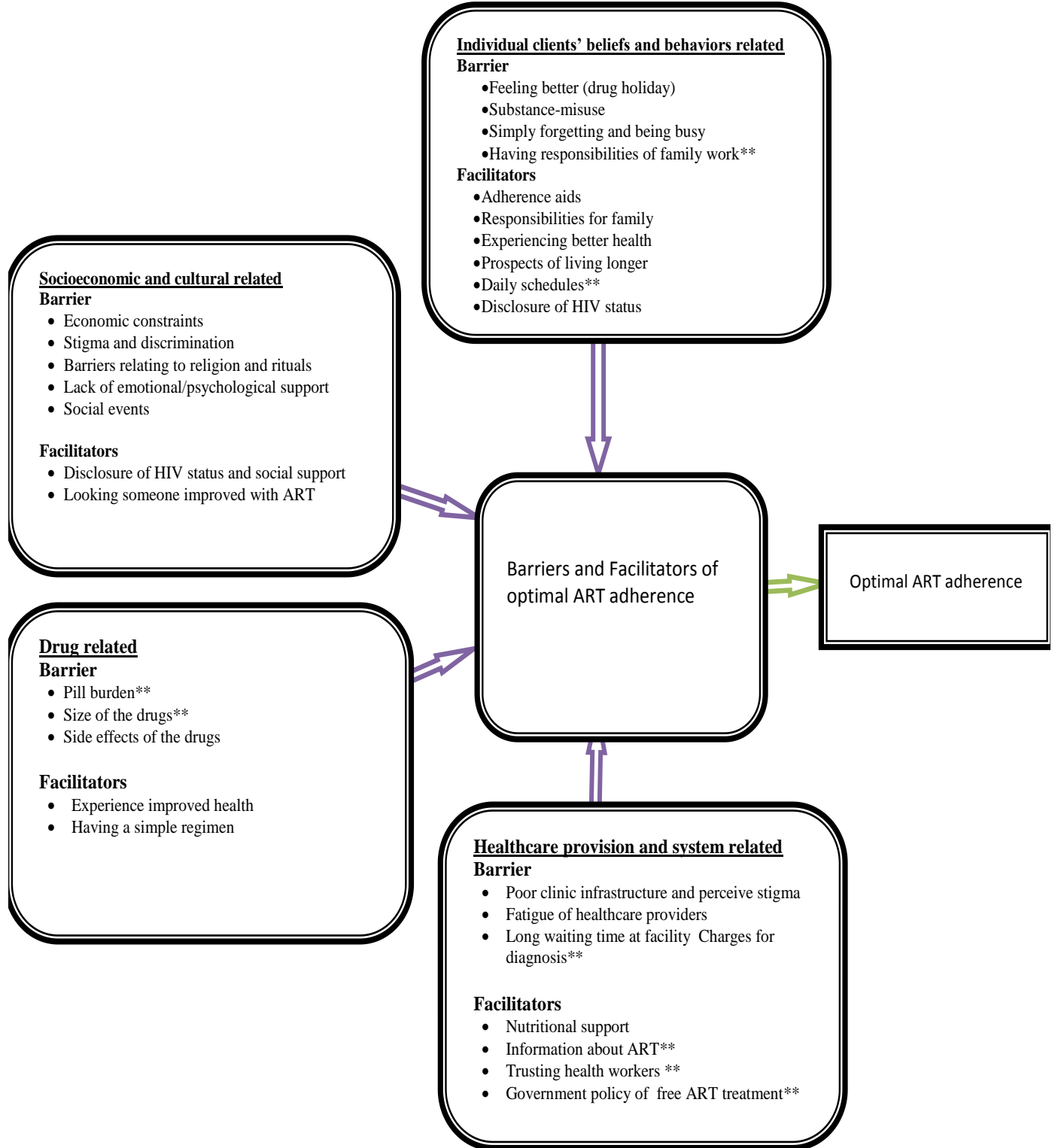
Concerning the availability of medicines, the prescribed ARV drugs were usually available in the two facilities. Although medicines for opportunistic infections were reported to be available at both of the facilities, these were not provided free of charge with the exception of anti-tuberculosis medicines and cotrimoxazol .

Both of the facilities operated the service from Monday to Friday. The eligibility criteria were the same in both of facilities since they followed the national national guidelines for commencement of therapy. The clients were encouraged to

come with adherence support partners but the lack of a partner did not disqualify anyone from being put on ART and pre-treatment adherence counseling was done on a one-to-one basis. At the time of the study, equipment for measuring CD4 counts and viral load was not available at Millennium Health center and at Adare hospital it is available.

Staff in the two facilities had a range of different opinions on employment-related issues, such as staffing and conditions of service, education and training, working conditions. For example the most common request in Millennium Health center was that more staff should be employed in order to cope with the increasing number of ARV users, especially there is no adherence supporter to perform counseling, the researcher is also observing through the data collection period there is only one health officer working in the ART clinic which have a positive impacts on adherence. In contrast, clients largely expressed appreciation for the quality for the quality of care provided, despite complaint about long waiting times. During non-participant observation of consultations, three new ARV users who came to start treatment all of them were told about the possible side-effects, the importance of continuing with the treatment, how to use ARVs, what to do if they forget to take a dose. However, there was no discussion about other reproductive health needs, such as contraception and safer sex, in any of the observed consultation.

**Figure 1. Theoretical frame work of Barriers and Facilitators to ART adherence brought up the study June 2014**



N.B. Those asterisk (\*) under the barrier and facilitators categories indicates the categories are only mentioned by clients and the rest all indicates the report of both clients and health care provider.

## **CHAPTER V: DISCUSSION**

To the researchers knowledge this is the first in-depth qualitative study on facilitators and barriers of ART medication adherence among people living with HIV in Hawassa, Southern Ethiopia.

The study identified barriers and facilitators which were diverse in nature, with a wide spectrum of factors related to individual clients' beliefs and behaviors, to socioeconomic and cultural, to the health services and treatment related issues.

The study identified that using an adherence aid, prospects of living longer, disclosure of HIV status, social support, experiencing better health and trusting health workers were the most frequently cited facilitators. In addition, economic constraints, substance misuse, simply forgetting and being busy, fear of stigma and discrimination, pill burden and medication side effects were the most frequent cited barriers. Most of the results of this study are similar to those of other qualitative studies in developing countries(41) and findings reported in other regions of Ethiopia(42-44) and elsewhere in resource-limited settings(45-47). The major findings that had significant impact on constraining and facilitating adherence from this research finding highlighted above are discussed below.

### **Barrier**

The major findings that had significant impact on constraining adherence including substance misuse, economic constraints, stigma and discrimination, pill burden and medication side effects and the new or the rarely reported findings highlighted above are discussed below.

The major individual clients' beliefs and behaviors constraints that negatively affected adherence in this study was Substance misuse especially alcohol use. Both clients and health care workers were mentioned a direct link between alcohol abuse and non-adherence because alcohol drinkers often "ignore" or "forget" their medications. Some clients also believed that drinking alcohol and taking ARVs together was harmful, and decided to "skip the pills".



The study revealed that substance misuse especially alcohol use increased non-adherence, and similar findings have been Reported elsewhere(46, 48-49).In addition, other study also showed that not using substances increased adherence(50).

Socio-economic constraints, such as unemployment and food insecurity had major constraints that negatively affected undesirable effects on medication adherence and remaining in care in this sample. Antiretrovirals are free of charge in many places in Africa, including Ethiopia, but treatment-related expenses still hinder clients' access to treatment(51-52). The findings of this study are in concordance with those from other studies which have found that lack of food due to poverty is a common obstacle to clients taking their treatment(53-55). Lack of food was mentioned by both clients and health care professionals as a cause of non-adherence, and it has been identified before in some studies as a factor responsible for clients defaulting from their treatments(56-57).

Socio-cultural factors, such as stigma and discrimination and religious rituals, also had undesirable effects on medication adherence and remaining in care in this sample. Interviewees from some clients and health care professionals experienced that stigma and discrimination was still widespread from both their own family and their local community.

Some participants did not take medicine in front of people they knew due to fear of being identified as HIV-positive(58). Elsewhere, seeking treatment at health facilities far away from home to hide their HIV status from family and colleagues is consistent with findings of other qualitative studies(59). In addition, the threat of social stigma may prevent clients from informing their status to others.

Interventions targeting communities to improve social awareness in the general public including information provision, skill building, counseling and facilitating interaction between people with HIV/AIDS and the community, has the potential to reduce stigma and improve ART adherence(60-61).

Other barriers to adherence rose during the interviews included local cultural factors, especially religious activities; Clients miss or delay medications to fulfill the religious obligations. Religious and social discouragers may be underexplored causes of non-adherence which must be investigated and addressed when commencing ART in countries such as Ethiopia. One study

done in Ethiopia has also found seeking traditional treatment and/or holy water treatment to be the most important reason for clients being lost to follow-up care(62).

The possible intervention could come from the concerned governmental and nongovernmental and religious leaders who could stress the importance of continuing to take medicine during religious festivals. The study findings reinforce the importance of considering the religious and spiritual beliefs of PLWH as part of medical care. It is believed that most religions found in Ethiopia, give freedom to eat on fasting days, especially for the sick, children, and older people. Hence, this message needs to be reinforced during counseling.

The observational finding of the study and the interview made with clients and health care workers described poor clinical infrastructure, with insufficient facilities for conducting confidential consultations, prevented clients from communicating openly with HCPs. Insufficient counseling could facilitate misunderstandings about taking ART, leading to lower adherence. Confidentiality at treatment centers, especially at card rooms, was another issue that emerged from the study. Studies from Botswana and Senegal have suggested that HIV clients tended to reduce clinical visits because of the risk of being seen by others and potentially having their HIV status exposed(17, 63). This illustrates the importance of taking confidentiality and stigma issues and creating infrastructure that is more agreeable to client confidentiality is an imperative consideration when the provision of ART is being scaled up.

Medication side effect symptoms are frequent in people treated with ARV and are one of the most important biological elements associated with non-adherence(64-65). Almost all the respondents reported that side effects contributed in a significant way to how they managed their regimen. All ARV medication is associated with adverse side effects ranging from mild to severe, and it is crucial for medical practitioners to manage these symptoms(65-66). However, as has been seen in the discussion on the complexity of treatment, taking extra medication to counter the side effects may add to the pill burden for the PLWHA, placing the PLWHA under further pressure. This is supported by research where it was found that those who were put on mono-therapy instead of dual or triple therapy showed better adherence outcomes(66).

## **Facilitators**

In Hawassa, HIV positive individuals may be in particular need of ART adherence interventions that address strategies to improve adherence through the client-provider relationship and improve strategies to incorporate ART pill taking regimens into a busy urban lifestyle where individuals may feel stigmatized by their HIV positive status. One effective strategy that may address these factors in an environment such as Hawassa, Ethiopia may involve the use of electronic devices, like mobile phones and alarms. Mobile phones have been successfully used to support client medication adherence in developed countries(67) and in resource-constrained settings such as Uganda(68), Kenya(69-70) and South Africa(71). Mobile phones might be an ideal tool to improve ART adherences for HIV clients in Hawassa because they can be private, interactive, efficient, affordable, convenient, and useful as a reminder tool.

A remarkable finding in this study was that clients' feeling of improved health and Disclosure of HIV status could be a barrier as well as a facilitator to adherence. Clients and health care professionals mentioned that clients were motivated to continue taking their medications when they began to feel better after being started on ART. On the other hand, some clients were not to continue taking their medication when they felt better. Improvement of subjective health has to be understood in the context of clients' beliefs about the treatment and how well informed they were. Some clients believed they were healed and therefore did not understand why they should continue taking their medication. Earlier studies also reported that feeling better could act as a barrier or as a facilitator to adherence(72). Adherence counseling is commonly offered to clients at the start of ART. However, these findings indicate that the stage of treatment when clients are starting to feel better could be a critical turning point with regards to adherence. Thus, counseling activities that specifically target clients during this treatment phase may be worth considering.

### **Strength and Limitations**

The finding of this study is based on interviews with a total of 23 patients and five health professionals, and is limited to one geographical area. But the findings offer an understanding of the complexity and dynamics of the different factors that may influence patients' adherence to ART. The results of this study reflect diversity in views and experiences; the researcher also triangulated data sources and subject in order to strengthen the validity of the results, although it cannot determine to what extent different factors are important barriers or facilitators in other contexts. The other limitation of this study is that the researcher was not able to interview people who did not seek help at a clinic.

## **CHAPTER VI: CONCLUSION AND RECOMMENDATION**

Overall, most of the findings of this study were similar to the facilitators and challenges experienced by clients on ART in other resource constrained settings. The study revealed a range of barriers to adherence: economic constraints, substance misuse, simply forgetting and being busy, fear of stigma and discrimination, pill burden and medication side effects. Experiencing better health, adherence aid, prospects of living longer, disclosure of HIV status, social support, and trusting health workers were the most-frequently reported facilitators. It is necessary to recognize and overcome the key barriers and promote measures to facilitate adherence. Priority should be given to improving adherence by providing (i) financial incentives, (ii) better access to treatment services, (iii) education and counseling to deal with religious and ritual obstacles, social stigma, and discrimination. All these are expected to be useful in overcoming the barriers to ART adherence. In addition, healthcare providers should explain the side effects and how to handle these. It is crucial to prioritize adherence because of its impact on treatment efficacy and ultimately on clients' quality of life and life-expectancy. Policy-makers should be aware of these key barriers and consider social policy which encourages clients to achieve optimal adherence.

### **RECOMMENDATIONS**

Recommendations for government, policy makers and concerned NGO's regarding adherence to ART treatment

- Behavioral change interventions designed to modify the individual client, work and home-related barriers to adherence should be developed and evaluated.
- Sustained community mobilization, education and counseling to deal with religious and ritual obstacles, aimed at mitigating stigma and discrimination in an effort to create an environment in which people can disclose and take their ARVs without fear of discovery.
- Make greater efforts to procure newer drugs that will decrease the complexity as well as the many side effects currently experienced by ARV drug users who are taking the current drug regimens.
- Loans and food support. Due to the prevailing poverty in the country, loans and food support to ARV users should be considered by the Government and NGOs.

Recommendations for the concerned health facilities and government regarding adherence to ART treatment

- Improving health facility infrastructures and services. This can be used to facilitate the work activity of health care provider and to manage the constraints of confidentiality and stigma issues for ARV users.
- Employ adequate numbers of staff. More trained staff is needed to cope with increasing workloads and fatigue in ART clinic. This will also help clients by reducing waiting times in ART clinics.

Recommendation for future research

- Self disclosure and drug side effects were found to be the main emerging constraints in this study. Further studies are needed to explore these variables in greater depth.
- Conduct interventional studies. Interventional studies are recommended in order to sustain and promote adherence to ARVs. It is also the wish of the investigators to continue with interventional studies if funds are made available.

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# Appendices

## Appendix A: Oral consent form for in-depth interview

### Research Study: Barriers and facilitators to Antiretroviral therapy adherence among clients with HIV in Hawassa.

Hello. My name is **Habtamu Wondiye**, I am a master of public health student at Jimma University and I am working to explore the barriers and facilitators to Antiretroviral therapy adherence among clients with HIV in this ART clinic of the facilities. We are talking to people whom we believe have knowledge about the issue under study. The findings will inform policy- and decision-makers and consequently help the laws, policies and programs to be based on the reality on the ground, and hence, your involvement is highly appreciated.

The study has received ethical approval from the Ethical Review Committee of the College of Public Health and Medical Sciences, Jimma University and permission also obtained from the facilities ART centers. Participation involves completing an interview which will take approximately between 45 and 90 minutes. It can be scheduled at a time and place of your choosing. The interview will be recorded, but any information (such as your name and job position) will not be attached to the recording. I will do my best to keep your information safe by securing the digital recording and transcript in a password-protected computer, and by keeping any written notes from your interview in a box that will be accessible only to study personnel. There is no direct benefit to you for participating in this study. However, the hope is that by exploring the factors of client's experiences of ART adherence, this will lead to improving the quality of client care and create the opportunity for positive changes within adherence practice.

Participants have the right to withdraw from the study at any time throughout the process, without penalty. If you require any additional information or have any further questions relating to the study please contact me at 0921452844 or email me at [wondiye.habtamu@yahoo.com](mailto:wondiye.habtamu@yahoo.com).

#### Are you willing to be part of the study?

Every aspect of the research outlined above has been fully explained to the volunteer in Amharic. I further agree to keep confidential everything said by the interviewee.

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(Name and Signature of person obtaining consent)

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(Date)

## **Appendix B: List of Guidelines**

**GUIDELINES for EXPLORATORY QUALITATIVE RESEARCH Study on  
“Barriers and facilitators to antiretroviral therapy adherence among clients  
with HIV in Hawassa, Southern Ethiopia: a qualitative grounded theory  
study”**

### **List of Guidelines**

- 1. Guidelines 1: Semi-structured interview with health care workers**
- 2. Guidelines 2: Semi-structured interview with ARV users**
- 3. Guidelines 3: Semi-structured interview with site manager**
- 4. Guidelines 4: Observation of consultation with health workers**
- 5. Guidelines 5: Guide for observation of health facility**

## Guidelines 1: Semi-structured interview with health care workers

Guidelines for semi-structured interviews with health workers (to be adapted for use with different type of health workers – medical doctors, nurses, counselors, pharmacists)

Name of facility: \_\_\_\_\_

Name of interviewer: \_\_\_\_\_

Interview number: \_\_\_\_\_

Date: \_\_\_\_\_

**Objective:** To explore health providers' point of view on:

- ✓ Quality of health care provided and the current ART service operations
- ✓ ART adherence among their clients, reasons for clients' non-adherence, solutions for ART adherence improvement
- ✓ Challenges of their works and suggestions for ART adherence service improvement.

### Note:

At the beginning: greeting (to create rapport), introduce to the study, statement of confidentiality, get consent form.

### Contents

#### 1. Background information on informant (health worker)

a) Sex	M / F
b) Age	_____ years
c) Profession	
e) Role in ARV programme	
f) Involved in programme since ....	

## **2. Tasks and training**

- a) What is your job in this clinic? (tasks and responsibilities focus on the ART work)
- b) How long have you been doing this job?
- c) What specific training have you received for this job in relation to ART? Tell me about the training (topics, time, locations, organizers, etc.)
- d) Do you think this training has been sufficient? (Knowledge and skills gained, apply them in your work, etc.). What ART topics that you want to learn more?

## **3. Drugs, treatment and procedures**

- a) Which treatment guidelines for HIV/AIDS management do you use at this facility? (Give details if necessary, e.g. national guidelines, donor organization, etc)
- b) Are the drugs in the guidelines you use to dispense always available? (Give details – how often, reason, what do you do about it)
- c) Are the drugs you prescribe always available? (If not, give details – how often, reason, what do you do about it)
- d) Have you had periods where your clients have not been able to get their medications because they were not available in stock?
- e) How reliable are your lab and diagnostic support services? Do results come in on time? (Probe for more details).
- f) What is your procedure when a client is put on ARV drugs for the first time? (New client enrolment: What are the criteria for selecting ART clients? How is this selection process? How long does it take? What clients do, how they do it, where, when? What and how information are they given (adverse side effects, diet, timing of dose, obtaining refills, interactions with other drugs, prevention)).
- g) What is your procedure when a client switches regimens?
- h) In what ways are ARV-users informed about and prepared for ARV treatment?



i) What kind of information do they receive? Please describe it to us:

- ✓ The disease process (i.e. HIV and AIDS)
- ✓ How the disease affects the body
- ✓ How ARVs work
- ✓ How to use them
- ✓ The need to continue treatment
- ✓ What to do if a pill is forgotten
- ✓ Possible interactions with other drugs  
(including traditional medicines)
- ✓ Which side effects can occur & what to do if they occur
- ✓ (Breast) feeding requirements
- ✓ When and where to get re-supply

Who is giving this information?

#### 4. Adherence issues

- a) How do you think your clients do, generally speaking, in terms of adherence to ART?
- b) Generally speaking, do your clients keep their appointments? How do you measure ART adherence level among your clients? Give your definition of “optimal adherence”
- c) Could you estimate the percentage of your clients who you think are “sufficiently adherent” to ART? (Respondent gives their definition of ‘sufficiently adherent’ what level is that?) \*\*
- d) What do you use to determine adherence (probe: appointments, refills?)
- e) We would like to get your views on the following that may influence their adherence (probe): From your experience
  - How would you compare adherence between women and men?
  - How would you compare adherence between older clients and younger clients
  - How does a client’s educational level/ employment/marital status affect adherence?
  - How do you think that cost time conflict to clients’ influences adherence?
  - How do you think that time conflict to clients’ influences adherence?
  - How do you think the distance to the health facility affects adherence?

- From your experience how do you think the following affect adherence?
  - ✗ Having or not having a treatment-support partner? (Family and social supports, use adherence aids)
  - ✗ Duration of treatment?
  - ✗ Side effects?
  - ✗ Lack of food?
  - ✗ Clients' knowledge and believe about HIV/AIDS and ART?
  - ✗ Their risk behaviors (using alcohol, drug, smoking, etc.)?
  - ✗ Their physical, mental and health states (functional status, depress, health state at initiation of therapy, seriousness of disease over time, etc.?)
- f) Do you have a standard practice at this facility to support your clients to adhere their treatment? If yes, is it documented? Can we see it?
- g) How can therapeutic effectiveness, adverse side effects, and the emergence of drug resistance be monitored?
- h) What are the main challenges you face in supporting your clients to adhere to ART (especially for longer term users)?
- i) What do you think could be done to improve the ART adherence among your clients?

## 5. Challenges and staff support

- a) What are the main challenges you and your colleagues face more generally in your work? (If necessary, prompt workload, stress, burnout)
- b) Have you ever been afraid of being infected with HIV through your work? What were you specifically afraid about? How do you feel now about the HIV-infection risks? Do you take any extra precautions when working with them?
- c) Have these challenges changed in any way since you started working at the ARV clinic?
- d) Is any special support made available for staff engaged in management of HIV/AIDS at this facility? If no, do you think there is a need to have such support?
- e) Is there anything you would like to see done differently in this facility? If yes, what?

Is there anything else you would like to tell us or ask us?

**Thank you for your time and co-operation!**

## Guidelines 2: Semi-structured interview with ARV users

Name of health facility where client contacted: \_\_\_\_\_

Name of interviewer: \_\_\_\_\_

Interview number: \_\_\_\_\_

Date: \_\_\_\_\_

### Objective:

1. Discover client's perceptions, beliefs, attitudes and behaviors related to HIV/AIDS and ART.
2. Explore adherence problems and client's views and experiences of ART ( including reasons why they follow or do not follow ART regimens, related factors such as quality of care in the current treatment clinic; cost consideration, family/social network support; history of HIV diagnosis and treatment).
3. Propose possible solution improving ART adherence from ARV users' point of view.

### Note:

- ART clients will be contacted initially by a physician at the health clinic, but the interview can be conducted at another time and place that are convenient for the clients.
- At the beginning: greeting(to create rapport), briefly introduce to the purposes of the study, emphasize the confidentiality in their consent form, which was obtained by his/her physician.

### Content

#### 1. personal information

a) Sex	M / F
b) Age	_____ Years
c) Educational level	
d) Who do you live with? (Husband, children, mother etc.)	
e) Employment: current and before having HIV positive	
f) Distance from facility (in time or distance)	

## **2. Medical history of client**

- a) When and where you were first diagnosed with HIV?
- b) What made you decide to go for testing?
- c) When did you start treatment for HIV (ARVs)?
- d) How do you feel about your health since you started treatment?
- e) How would you describe your health since you started treatment?(Better, Same, Worse)

## **3. Client knowledge about HIV/AIDS**

We would like to understand what people actually know about the illness that they have. Can you tell me what you know about HIV/AIDS? (Allow client to say what they want, then probe on the following: cause of HIV infection, transition to AIDS, prevention for themselves and others, etc.)

Apart from this, is there anything else you may have heard from your community that explains AIDS in a different way?

## **4. Knowledge about ARVs**

We would like to understand what people know about HIV/AIDS medicines. Could you help us with this by telling me what you know about ARVs? (Allow client to say what they want, then probe on the following: benefits, improves quality of life, lifelong treatment, knowledge about side effects).

## **5. Assessment of adherence and non-adherence**

We are trying to find out how clients manage to take their medicines – for some people it's not a problem, but we also know that others don't always find it easy. Please feel free to be open about the problems you face with this. Everything you say here will remain confidential, and will not be shared with anyone at the clinic.

- a) Do you have your medicines with you? May I see them? Please can you tell me when you take each of the medicines?
- b) Are there any other medications you are taking (e.g. traditional medicines, herbs, medicines from other hospitals, clinics, shops/chemist, etc.)
- c) Over the last two days, when did you take your pills? (Not including today – starting from last night and back.) (Complete 'sun-and-moon chart', or other checklist)
- d) Did you perhaps miss any? (Confirming (c), sympathetic manner. Details if yes.)
- e) This is a very important question. We appreciate how difficult it can be to take pills on a daily basis. If you sometimes miss a dose, please can you tell me what causes this to happen? Can you give an example or two? (Include even if 'simply forgot').
- f) On the other hand, what is it that *helps* you to take your pills regularly and on time? (e.g. friend, family, cell-phone, clock etc.)
- g) Have you disclosed your status to any one? If so, who? Do they help you to take your pills? **[If not covered in (f)]**
- h) Have you had your treatment changed at any moment since you were started on ARVs? If yes, why? (e.g. treatment failure, side-effects, drug not available).
- i) Have you ever missed an appointment at your ART center? (Reasons, and details on type of consultation: review/refill, counselling etc.)
- j) What do you think happens in your body if you skip your ARV medicines?
- k) Have you ever thought about stopping HIV/AIDS medicines (ARVs)? If yes, details.

## 6. Perception about HIV/AIDS, ARVs and stigma

Have you ever had any experience of being treated differently because of your HIV status?  
(In your family, at work, at the church etc)

## 7. Cost considerations

- a) How much do you have to pay to cover your travel expenses when you visit the clinic?
- b) What is the cost of registering at the clinic (if any)?
- c) What is the cost of the ARV medicines that you take (if any)?
- d) Do you lose any income as a result of your coming to the clinic?

- e) Do you incur any other costs as a result of your taking ARVs?
- f) What have you and/or your family had to give up in order to be able to take your medicines regularly?

**8. Quality of care**

- a) What do you think of the service you receive at this clinic? (General, open-ended, and then prompt, as below: ask for details as necessary)
  - Do you feel listened to?    **Yes** \_\_\_\_\_ **No** \_\_\_\_\_
  - Are you given the chance to state your problems and ask questions?  
      **Yes** \_\_\_\_\_    **No** \_\_\_\_\_
  - Are you treated with respect?    **Yes** \_\_\_\_\_ **No** \_\_\_\_\_
  - Do you feel you can trust the health workers?    **Yes** \_\_\_\_\_ **No** \_\_\_\_\_
  - Do you have privacy during consultation and counseling?    **Yes** \_\_\_ **No** \_\_\_
  - How do you find the environment of the clinic? \_\_\_\_\_
- b) How long did you spend altogether at the clinic when you last went for review?
- c) How long did you have to wait before being attended to?
- d) What do health staffs do to support and follow-up with your treatment?  
\_\_\_\_\_

**9. Social and family support:**

- a) How do you get help from your family (financial and emotional support? From whom?)
- b) How about from others (friend, partner, social group, project/program, NGOs etc?)
- c) Are you happy with their supports? How do you expect to get more support from your family and others?
- d) Have you participated in any social groups and/or community-based program? (clubs, peer education, home based-care support). If yes, how do you like it?
- e) Have you ever had any experience of being treated differently because of your HIV status?

## **10. High-risk behaviors**

- a) Drink containing alcohol (wine, beer): how often? How much? Get drunk?
- b) Smoking: how often? How much?
- c) Substance abuse: how often? How much?

## **11. Perceived problems and possible solutions**

- a) What do you perceive as the biggest problem regarding taking ARV treatment?
- b) What do you think could be done to improve this?

**Do you have any questions for me?**

**Thank you for your time and co-operation!**



### **Guidelines 3: Semi-structured interview with site manager**

Name of health facility: \_\_\_\_\_

Name of interviewer: \_\_\_\_\_

Officer interviewed: \_\_\_\_\_

Date of interviewed: \_\_\_\_\_

#### **Note**

Interviewer appropriately greets person to be interviewed, explains purpose of the interview. The main purpose of these interviews shall be to ascertain to what extent adherence to medication was considered important prior to programme commencement.

- What strategies were put in place to encourage good adherence.
- What strategies were put in place to monitor adherence.
- What strategies are being put in place to improve adherence.

The interviewer shall probe where relevant - the questions below are merely a guide.

***But we shall start with these questions.***

1. When did the facility start providing ART?
2. Number of workers & type of staff involved in ART?
3. Number of staff trained & type of training?
4. Total number of clients on treatment at the facility?
5. Total number of clients seen per day?
6. Availability of reference materials, formularies etc.?
7. Criteria for eligibility to ART (documentary/verbal)?
8. We would like to know about the national roll out of ARVs, when and how did it all happen?
9. How was your office involved in it?
  
10. What in your opinion do you reckon to have been the greatest challenge you faced

with the rollout?

11. How did you overcome the challenge?
12. What number of clients would you be looking at in the next one year by your projections?
13. Do you always receive your order as at and when due?
14. There had been times in the past when your clients had their ARV supply rationed because of inadequate stock, what do you know about this?
15. What mechanisms do you have to ensure availability and sustenance of ARV supply?
16. What do think the adherence levels of your clients' in terms of taking ARVs is?
17. What strategies have you in place to ensure clients receiving ARVs adhere well enough to their treatment?
18. Do you have any reporting and monitoring system for this?
19. Given your experience with your ARV programme is there any thing you would like to see done differently?
20. Do you think there are opportunities for improvement in your programme, if yes probe?

## Guidelines 4: Observation of consultation with health workers

(Medical doctor, Nurse, Pharmacist, Counselor, Receptionist, laboratory personnel).

Guide has to be adapted, taking into account the type of consultation to be observed

(Don't forget informal, unstructured observations!!!)

Name of health facility: \_\_\_\_\_

Name of interviewer: \_\_\_\_\_

Date: \_\_\_\_\_

Consultation: Start time: ----- End time: -----

Observation of consultation with: \_\_\_\_\_

(Medical doctor, Nurse, Counselor, Pharmaceutical staff, other: \_\_\_\_\_)

### 1. Background information on informant

a) Sex	M/F
b) Age	..... Years (ask or estimate)

### 2. Reason / Aim of the consultation:

- Counseling
- Initiation of active ARV treatment
- Routine follow-up
- Other reason: .....

### 3. Is client well received?

(If not, describe) Yes \_\_\_\_\_ No \_\_\_\_\_

4. Was the client greeted in a friendly manner? Yes \_\_\_\_\_ No \_\_\_\_\_

5. Does the consultation take place in privacy? Yes \_\_\_\_\_ No \_\_\_\_\_

6. Does the health worker ask about any symptoms? Yes \_\_\_\_\_ No \_\_\_\_\_

7. Is the client invited to ask questions? Yes \_\_\_\_\_ No \_\_\_\_\_

(If yes, what do they ask? Was the question addressed?)

Details:

\_\_\_\_\_

8. Is the client told what to do next  
(Within the health facility)? Yes \_\_\_\_\_ No \_\_\_\_\_

Is the client told where to go for that? Yes \_\_\_\_\_ No \_\_\_\_\_

9. Is the sequence of events in relation to treatment protocols explained  
to *new* clients? (Requires training for observer) Yes \_\_\_\_\_ No \_\_\_\_\_

10. (a) **If new clients, do** they receive comprehensive general information about ARVs?

*(Tick if covered, X if not covered):*

- How ARVs work
- How to use them
- The need to continue treatment
- What to do if a pill is forgotten/missed
- Possible interactions with other drugs, including traditional medicines
- Which side effects (for the different drugs) may occur
- What to do if they occur
- (Breast) feeding requirements
- When and where to get re-supply
- Requirement to bring unused medicines

(b) Are clients (especially new and those switching regimens) given the following  
information about ARVs: *(Tick if covered, X if not covered):*

- Dosage (number of tablets to take and how often)
- Times of when to take the medicines
- How to take them in relation to meals (where necessary)
- What to do if vomit the pill
- What to do if forgets to take medicine on time
- What to do if dose is missed
- What to do if travelling?

**(c) For follow-up users only:**

Does the health worker ask if the client missed a dose? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, does the health worker explain the effects of missing dose? Yes \_\_\_\_\_ No \_\_\_\_\_

Does the health worker offer support to not miss the doses? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, describe

---

11. Did the provider listen carefully to the client? Yes \_\_\_\_\_ No \_\_\_\_\_

12. Was any written information given? (**new clients**) Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, bring a copy of it if possible.

**13. For follow up clients only:**

Does the health worker count the client's pills before giving  
him/ her a new supply? Yes \_\_\_\_\_ No \_\_\_\_\_

14. Does the health worker ask the client if they are taking  
any other medicines Yes \_\_\_\_\_ No \_\_\_\_\_

15. Does the client receive specific tools to remind them  
to take their medicines? Yes \_\_\_\_\_ No \_\_\_\_\_

## **Guidelines 5: Guide for observation of health facility**

Name of observer: \_\_\_\_\_

Name of health facility: \_\_\_\_\_

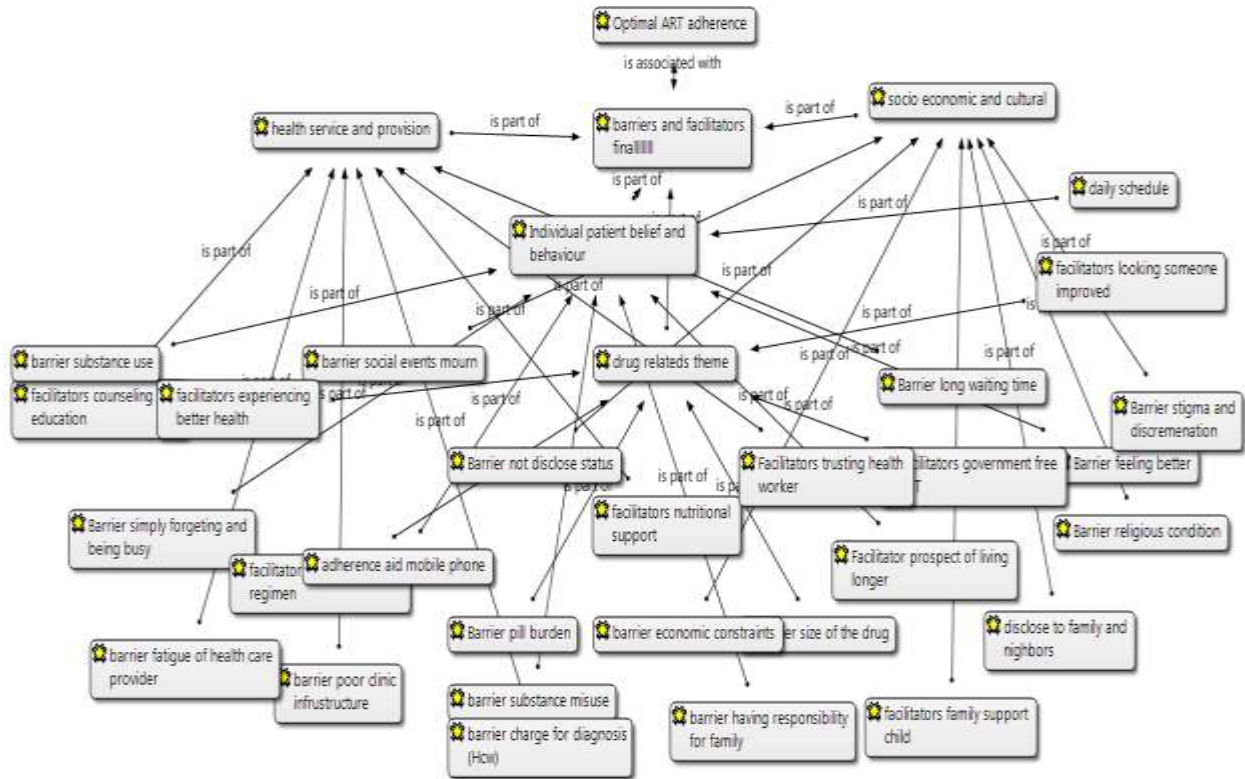
Date/time observation took place: \_\_\_\_\_

This observation shall be conducted by the researchers.

The purpose is to give a descriptive of the setting under which care takes place.

1. Describe the health facility setting in general.
2. Describe the location and setting of the ARV clinic and support services (pharmacy, laboratory, social welfare/counseling).
3. Describe the sanitary condition of the environment, how clean or dirty is it, check out the toilets. Describe
4. Where are clients received? Is there privacy? Describe what you see
5. What is the general attitude of health workers, are they receptive and willing to assist clients or are they impatient? Describe what you see what notices or information are displayed for clients to read, describe
6. Specifically look through where clients get ARVs to see if there is any piece of information emphasizing the need for good adherence or telling people how to improve adherence.

ATLAS .ti output for network of categories and themes



**ASSURANCE OF PRINCIPAL INVESTIGATOR**

I, the undersigned agree 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 college Public Health and Medical sciences in effect at the time of grant is forwarded as the result of this application.

Name of the student: \_\_\_\_\_

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

**APPROVAL OF ADVISORS AND DEPARTMENT HEAD**

Name of the first advisor: \_\_\_\_\_

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

Name of the second advisor: \_\_\_\_\_

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