ADDIS ABABA UNIVERSITY

INSTITUTE OF EDUCATIONAL RESEARCH

THE ROLE OF HEALTH EDUCATION IN AIDS

TREATMENT ADHERENCE

ASSESSMENT OF CHALLENGES IN ADDIS ABABA HEALTH CENTERS

Submitted in Partial Fulfillment of the Requirements for Master of Arts Degree in Educational Research and Development

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

This chapter introduces the theme of the study by providing background information regarding the nature of the problem, its extent and related facts. It also explains the objectives and the basic research questions of the study. In addition, it describes the significance, basic assumptions, limitations and delimitation of the study.

1.2 Background of the Study

With the introduction of the highly active antiretroviral therapy treatment, HlV related mortality and morbidity have dramatically decreased(WHO, 2006).In line with this, progresses were made where the fatal disease was effectively changed into a manageable chronic illness. However, ART is not a cure and it must be taken for life delivered as part of a comprehensive care to prolong and enhance the quality of life of people living with HIV/AIDS (WHO, 2004).

As a chronic disease, HIV requires the use of HAART for an undetermined amount of time. The aim of HAART is to suppress the replication of HIV to the point of reaching undetectable levels, and its successful outcomes depend largely on medication adherence (Schonnesson, Williams, Ross, Diamond, and Keel, 2007). Adherence rates vary as a function

of illness severity and the patient's perception of the effect that their adherence is likely to have (Godwin-Rabkin and Chesney, 1999).

Adherence to HAART often represents a complex and demanding set of challenges. Although newer formulations of HAART often require both fewer pills and fewer dosing times, the behavior can still be a demanding one in light of the other medical, psychological, sociological and economic burdens that people living with HIV face (Halkitis, 2002).

Some of the potential consequences include viral resistance, antiretroviral regimens that are no longer effective, progression of HIV disease and increased morbidity and mortality (UNAIDS, 2009, p.41).That is why helping patients integrate medications into their daily lives is one of the most crucial and challenging tasks for health care providers. They can improve their patients' success with adherence when they approach this issue with the understanding that adherence to HIV/AIDS treatment involves more than simply remembering to take medications. Rather, it is a complex issue involving social, economic, and psychological factors (Chesney, 2006).

In Ethiopia, non-adherence as a problem is yet to attract adequate attention as the focus is now"getting more people on ART as only 34.9% of people living with HIV in need of treatment are actually accessing it" (UNAIDS, 2008, p. 36). Nevertheless, recent reports and studies have pointed out the formidable challenge we are facing as a consequence to lack of adherenceto ART. A study conducted at Yirgalem Hospital in south Ethiopia, for

instance,indicated "the low level of adherence among patients". According to this study there was only 74.2% adherence rate (Markos, Worku& Davey, 2006, p.3).

In another study in five East African countries including Ethiopia, very low adherence level was found in health facilities (Johnson & Witt, 2007). This study also identified the kinds of interventions that have been put in place to address the challenge of non-adherence. These include Patient education/counseling before and after ARVs, providing care and support to patients, Systematic monitoring at the clinic, social support, use of community-based health workers, fast-track services at the health care facility, use of reminder devices, reimbursement of travel expenses and so on (Johnson& Witt et al, 2007).

In much of the literature, it was indicated that a well-designed continuous adherence education is the most feasible, applicable and effective method that can significantly improves clients'behavior for adherence (WHO, 2003). This seems to be an accepted principle in Ethiopia too where health facilities focus on providing ongoing counseling and information for their ART clients (Ministry of Health, 2005, p. 64). In doing so, the Ethiopian Ministry of Health (MOH) have trained and deployed adherence counselors who were supposed to educate and follow up ART clients (MOH, 2005).

So here comes the puzzle. If the education intervention is the primary method for improving adherence, how is it working as a strategy in our health facilities? Has it been effective in bringing the desired result? What is the reason behind the low level of adherence reported

to be then? On the other hand, could there be gaps in the education process that could affect its effectiveness?

The main purpose of this study was to come up with possible answers to these key questions. Consequently, the result of the study is expected to indicate the role of education in tackling the challenge and locate where the problem lies. The study attempted to uncover if there were gaps or challenges in the process of the education intervention and based on the findings tried to forward suggestions for the future.

1.3 Statement of the Problem

As pointed out earlier, inadequate adherence to ART treatment is associated with a host of consequences including detectable viral loads, declining immune system, disease progression, episodes of opportunistic infections and long term resistance of the virus to the treatment. However, lack of optimal adherence level is a huge problem among patients globally (WHO, 2003).

A number of rigorous reviews have found that, in developed countries, adherence among patients suffering chronic diseases averages only 50% even if it varies between 37% and 83% depending on the demographic characteristics of patient populations. This represents a tremendous challenge to population health efforts where success is determined primarily by adherence to long-term therapies. The magnitude and impact of poor adherence in developing countries is assumed to be even higher given the paucity of health resources and inequities in access to health care (WHO, 2003).

This problem is evident in Ethiopia as well. In fact, the level of adherence to ART in the country is one of the lowest. A report by Federal Ministry of Health indicated that the national average adherence rate was around 74% even though there are some variations in the degree of the problem from region to region (MOH, 2005, p.22). This report also indicated that, the level is even considerably lower in the capital Addis Ababa (71.4%) despite the relatively better accessibility to the treatment services compared to rural areas (MOH, 2005).

Why the adherence level is low? A number of factors could be listed out here. Among them lack of adequate information by the client is one. That is why many health institutions focus on educating their clients before, during and after the start of the actual treatment. The same is true in Ethiopia where health providers give regular education and counseling to their patients.

Normally, we assume that if the patients understand the significance of adherence they would have better level of adherence even if it could not avoid the problem altogether. Therefore, if we can improve the effectiveness of the education, we could increase the likelihood that clients would develop desired behaviors and thereby decreasing non adherence rate. That is why this study is curious to understand the process of patient education in selected health facilities. This would enable us to see if there are gaps in it that would be fixed to improve its effectiveness for the future.

The main purpose of this study is to understand the role of health education as an intervention for ART adherence and assess its effectiveness in the health facilities included

here. The aim is to identify major gaps or challenges and forward recommended actions that can be done to minimize them.

1.4 Objective of the Study

1.3.1 General Objective

The overall objective of this study is to assess the role of health education in promoting ART adherence and explore if there were challenges in the process of education of patients which could affect the level of adherence among them.

1.3.2 Specific Objectives

The specific objectives of the study were the following:

A. To identify and understand the role of health education in ART adherence.
B. To assess if there were challenges and identify major gaps in the health education for ART adherence.
C. To suggest possible solutions that could increase the effectiveness of adherence education for the future.

1.5 Basic Research Questions

As indicated earlier, the main objective of this study was to assess the role of health education in promoting adherence to ART and identify challenges that constrain the effectiveness of this education in the selected health centers.

Accordingly, the study attempted to address three basic questions.

A. What is the role of health education in enhancing ART adherence and address the problem of non-adherence?
B. What are the challenges/gaps in the health education for ART adherence in health facilities?
C. What can be suggested to increase the effectiveness of the continuous education?

In providing answers to the above questions, the study aimed to explore existing situations and assess major challenges related to the provision of education through the use of the CIPP model of evaluation (which is described in detail below). The goal of doing all this is to understand the reasons behind the problem and look into possible solutions for the future.

1.5 Significance of the Study

The study is expected to inform concerned bodies about the nature of the problem, its magnitude, existing challenges and actions that needed to be implemented for the future. In general, the results of the study will:

1. At policy level, it will help concerned bodies understand nature and extent of the problem of non-adherence in health centers and prepare appropriate policies for implementation;
2. In theory, the study will enable us identify some of the major challenges and/or existing gaps in the provision of education intended to improve adherence in patients.

3. In practice, the study will help inform health facilities, policy makers, health care providers and others involved where the gaps lie and what can be done to alleviate the problem for the future.

1.6 Basic Assumptions of the study

It is very imperative here to mention and briefly describe the basic assumptions of this study. It basically emanates from the researcher's work experiences in HIV prevention, care and treatment coupled with some readings to the related literature. It would be very helpful to understand how the research questions were formulated and the logic behind the use of the designs and methods used to conduct the study.

The following were the three basic assumptions that lead to the conduct of the study.

A. Providing continuous health education for clients on ART treatment and the importance of their adherence would increase their knowledge, skill and attitude that would significantly improve the patients level of adherence.

B. Effective education as to how ART treatment drugs function and clear understanding by clients would motivate them for higher level of compliance as to the requirements.

C. The presence of gaps in the context, and/or input, and/or process of the health education would affect the knowledge, skills and attitude of clients thereby developing poor adherence behavior that leads to low adherence rate.

1.8 Delimitation of the Study

This study was conducted in ten health centers (Arada, Akaki, Addis Ketema, Bole, Entoto, Gulele, Kazanchis, Kolfe, Nifas Silk 01, Lideta health centers). All of these health centers are located in Addis Ababa city administration. In total, there are 25 ART providing government health centers in this city. The reason behind the health centers over hospitals and private health facilities is simply because they have started the provision of ART relatively recently and the problem seems to be more prevalent on these centers.

1.9 Limitation of the Study

The following could be mentioned as the limitations of the study:

- The reported adherence levels were to a large extent based on self-reported data which could minimize the reliability of the information;
- Adherence behavior is a result of many factors. As such, it is difficult to attribute the results to the health education only and the study has little control over interfering variables.

1.10 Operational Definition of Key Terms and Concepts

Here are some of the key concepts and their operational definition as used in this study.

A. **Adherence** refers to "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" (WHO, 2003: 34)

B. Adherence Education: refers to the process of providing information and skills necessary for clients to adhere to the ARV.

C. **Adherence Behavior** refers to act of the taking of ARV drugs in compliance with the prescription of the health care worker.

D. **Challenge** refers to the presence of situations which hinders the successfulness of a certain activity or initiative.

E. **"Lost to follow up**" is a concept used to describe patients who missed the treatment for at least one month

CHAPTER TWO

REVIEW OF RELATED LITERATURE

2.1 Introduction

In this chapter, the study has presented an overview of what has been studied and the methods used to answer the questions this paper has set out to provide answer to. It has three sub sections. The first was defining the topic with attempts to explain as to the reason behind selecting the theme of the study. Next, previous studies were assessed to indicate what has been known so far in the area and finally to relate these literature into the objectives of the current study.

This review has basically focused on three major themes: defining the concepts ART and adherence, assessing the factors affecting adherence, and analyzing the interventions used to improve adherence among AIDS patients with particular emphasis on the impact of patient education. And eventually attempts were made to relate the existing body of knowledge with the objectives of this study and suggest gaps and areas that require further research.

2.2 Defining ART and Adherence

Before going into the details of the review, it would be very imperative to define the problem and the basic concepts related to it.

2.2.1 Anti-Retroviral Therapy (ART)

Anti-Retroviral Therapy is the administration of different medications known as Anti-Retroviral drugs in order to suppress the replication of the human immunodeficiency

virus (WHO, 2003). Treatment with these combinations of drugs is also known as Highly Active Antiretroviral Therapy (usually referred as ART). ART changes a uniformly fatal disease to a manageable chronic illness. Successful use of ART suppresses viral replication, slowing down disease progression, improving immunity and delaying mortality. But it is not a cure and it must be taken for life(WHO, 2003).

Anti-retroviral therapy has resulted in a significant decrease in the morbidity and mortality rates of HIV/AIDS patients (Jerene, 2006). AIDS is now considered to be a chronic rather than a fatal illness due to this treatment (Chesney, 2006). A study in Zambia monitored the condition and behavior of 27,115 patients who had been taking ART for more than 12 months. It has indicated that a higher median CD4+count were reported in those who were optimally adherent when compared to those patients who were poorly adherent (Chi, Cantrell, &Zulu, 2009). In addition, the extent of death was also higher in those patients who were poorly adherent (Chi, Cantrell, &Zulu, 2009). In another study, Gifford (2000) showed that adherence to ART was significantly associated with the level of viral suppression. Accordingly, in order to obtain the long-term benefits of ART, patients must strictly adhere to the treatment with as near perfect level (Chesney, 2003).

2.2.2 Adherence to ART

Even though, different authors define the term "adherence" in different ways, it generally refers to "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" (WHO, 2003, p. 34). From this definition we can understand that adherence is "not a single event". It is rather a "dynamic process" that needs to be addressed with significant follow-up (Deribe, Amberbir and Beyene, 2008).

Adherence to ART is "a major predictor of the success in HIV/AIDS treatment (WHO, 2003). Hardon (2001) asserts that once initiated, ART is a life-long treatment that consists of multiple medications to be taken two to three times a day. A number of studies have shown that a more than 95% adherence rate is required if a patient is to receive all the benefits of ART and minimize the possibility of treatment failure (Chesney, 2006).

2.2.3 Non-adherence to ART

Previous studies have clearly indicated the far reaching consequences of non-adherence to ART (WHO, 2004). In Senegal, study found out a difference in the viral load among patients. Those who had maintained more than 90% adherence rate in the previous six months showed no detectable viral load while in those who maintained an adherence rate of less than 90% showed a detectable viral load. In a similar study in Malawi study, the adherence rate of patients who self-reported an adherence rate of less than 80% was regarded as the best predictor of detectable viral load during follow-up visits (Ferdinand, Jenin, & Brasher, 2006).

2.3 Factors Affecting Adherence to ART

In his study, Chesney indicated that the factors that affect adherence to ART can be classified into four categories: (1) patient-related factors; (2) treatment-related factors; (3)

factors related to provider-patient relationship; (4) health care system related factors. According to him, adherence to ART must take into consideration a variety of social, cultural, economic and personal factors indicating the complexity of the problem (Chesney, 2006).

Several other studies also showed the social, psychological, clinical and behavioral factors that are associated with non-adherence. In a study that Deribe, Amberbir and Beyene (2008) undertook in Jimma University Specialized Hospital in Southwest Ethiopia, 28% of the total number of patients who commenced ART missed two or more visits to the ART clinic on their appointed dates. The reasons that the participants in this study gave for missing their appointments included "a loss of hope in the efficacy of the medication, a lack of food, the debilitating effects of bouts of mental illness, a belief in the power of holy water to achieve what ART could not, the fact that they did not have the money required for transport, and the effect of various other illnesses that made their attendance impossible" (Deribe Amberbir and Beyene, 2008).

In a similar study by Markos and his colleagues (2008) indicated other reasons for non-adherence including "being too busy to attend or simply forgetting to attend, changes in the daily routines of the participants, their periodic absences from home, the effect of patients who had reported disagreeable side effects in the month prior to the study, the fact that they lived too far from the ART clinic, and the necessity to attend to the needs of their dependents" (Markos, Worku and Davey). Tadious and Davey also stated that factors that are correlated with adherence included "having regular follow-up at the clinic, not being

depressed, having no side effects, a regimen that fitted the daily routine and satisfaction with the relationship with doctors"(Tedious and Davey, 2006).

On the other hand Socio-economic and cultural factors were also among the factors affecting adherence. In this regard, Tadious and Davey demonstrated that social support and access to treatment were critical factors in determining adherence to HAART. Social support was also identified as an independent predictor of adherence (Deribe, Amberbir and Beyene, 2008).

In sub-Saharan African countries, economic obstacles such as a lack of the necessary funds needed to journey to the health care facility in those cases where patients had to travel long distances to get to the clinic, also constituted important reasons for sub-optimal adherence. Chesney concluded that adherence to ART can be improved by addressing whatever social, economic and psychosocial issues there might be before a course of treatment commences. It is obviously pointless to begin a course of ART treatment in those cases where a patient does not have the capacity, motivation or resources to practice optimal adherence(Chesney, 2006).

2.4 Interventions for ART Adherence

Various kinds of behavioral interventions were suggested and implemented by institutions and researchers. In a survey conducted in five East African countries including Ethiopia, for instance, ten major types of interventions were reported to be used to improve adherence. These are "patient counseling before starting ARVs, repeated counseling after ARVs, use of a

support/care person, systematic monitoring at the clinic, social support, use of a technological device, use of community-based health workers, fast-track services at the health care facility, use of reminder devices, and reimbursement of travel expenses" (Johnson, & Witt, 2007, p. 9). Other sources also have listed more or less similar areas of intervention (WHO, 2003).

2.5 The Impact of Patient Education on ART Adherence

A number of studies were reviewed to see the impact of education on medication adherence behavior of HIV/AIDS patients (Mini, Mothi, & Swamy, 2003). Even if there are differences in outcomes, almost all of them suggested the positive impact education has in improving adherence among clients of diverse nature.

Similarly, Halkities compared an experimental group that participated in an educational program and a control group with standard care. It turns out that patients' knowledge and adherence behavior has improved considerably after the educational intervention. In the survey cited earlier conducted by Johnson et al, it was reported that pre and post ARV education and follow up counseling was the most effective intervention used by health providers participated in the study (Halkitis, 2002).

Even though there are a number of studies on the impact of education adherence to ART or any other chronic care treatment, there has been little done on what kind of education (the methods, processes and contents) are supposed to bring positive impact or the other way round. It is very difficult to claim all education interventions are successful. And even if we say so, which kind of approach is more successful is a point that needs further study.

2.6 ART in Ethiopia

In January 2005 with support from the Global Fund and PEPFAR, Ethiopia has launched free ART program "accelerating access to HIV/AIDS Treatment in Ethiopia road map 2004-2006". In June of 2005, the road map targets to treat 100 thousand patients by the end of 2006 and with a goal of universal access by 2008. In 2006 December 96,897 PLWHA had ever been enrolled at 192 ART sites 58,405 had ever started ART and 46,045 were alive and receiving the treatment which constitutes dropout rate of 21.2 %. For patients who had ever started treatment the actual retention rate was 78.8%. By the end of October 2007,113,298 patients had ever started, ART and a quarter reported lost to follow up at the same year. The number of ART sites serving the civilian population of Ethiopia increased from 49 in late 2005 to 101 in December 2006, and by the end of 2007, it was 270 (Akalu, 2009).

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents the methodology used to conduct, analyze and present the study. It explains how the research was designed and what methods were utilized with the justification as to why those methods were selected. It provides information regarding the research design, the study population and the sample size and technique used to select sample out of the entire population. In addition to this, it describes the kinds of instruments used to collect the data required and how it was analyzed to answer the research questions the study has set out to answer.

The purpose of the study was to understand the role of education for adherence to ART and to identify the major challenges that existed that could have hindered its effectiveness in meeting the objectives. Using the CIPP model, the study assessed the education intervention, identified its challenges and/or weaknesses in the process and forwarded some suggestions as possible solutions for the future.

3.2 Research Design

This is basically a descriptive research. The descriptive design was preferred as it fits for purpose. It enabled the study to define and describe the nature of the problem of non-adherence in the selected health facilities and elaborate why the situation was the way it was revealed. In either way, the study intended to assess the role education has in the

clients' adherence behavior and identify and locate if there were gaps in the process of education that hindered this role.

This design was used as it is very relevant and convenient to describe the problem and/or the existing condition. It was an important tool in clarifying the extent of the problem, the factors that facilitates or constrains the situation, and the interventions implemented to bring about the desired behavior.

3.2 Research Methods

The research methods describe the study population, geographic area, participants, the sampling procedure, the methods of data collection and analysis plan.

3.2.1 Study Population

The study population comprises all clients attending ART treatment in the ten health centers selected and covered. In total, 27504 patients attending ART are the population of this study.

3.2.2 Study Area

The geographic area of this study is restricted to the city administration of Addis Ababa. All the health centers selected and included here for this assessment are located within the boundary of the city. As such, the findings of the study are supposed to represent this study area.

3.2.3 Study Participants

Basically, three types of participants were involved in providing information for this study. These were the patients attending ART treatment, the Adherence counselors and the managers of health centers.

A. Patients or Clients

These are HIV Positive Persons who have been attending ART treatment in the selected health facilities and who started the treatment at least six months prior to the commencement of the study. They were the primary sources of information for this study.

B. Adherence Counselors

Obviously, these were supposed to be health workers who were directly involved in the provision of adherence education and follow up of clients under treatment in the selected health facilities. They were selected as they were the ones who actually provided the education and so were identified as key informants. Due to their direct experience on the matter they were considered to know a lot about the issue under study.

C. Health Center Managers

These were basically the managers of respective health centers and/or heads of departments there. They were responsible for running the program and managing the system and have had a significant contribution on how treatments work. They were

interviewed on a wide range of issues which they were supposed to have adequate knowledge about.

3.2.4 Sampling Procedure

The logic of taking samples is clear. It was difficult to participate all patients (to cover the whole population) for many reasons. So the study took some of them who could represent the entire population. In this case, the total population includes 26 ART providing health centers and six hospitals in Addis Ababa and a total of more than seventy thousand persons who were attending the treatment during the period of data collection.

3.2.5 Eligibility Criteria

The study set some criteria for selecting sample participants. These were:

a. Participants should be willing to provide their consent to disclose any information after they were informed about the study.
b. Each participant patient has to attend ART for at least six months prior to the commencement of the study.

3.2.6 Sample Size

Sample size refers to the number of participants needed to participate in the study for it to reach and draw a reasonable and valid conclusion. The widely used formula for estimating the size of the sample forwarded by was utilized here (Castillo& Cleary, 2007). The formula is stated as follows:

$$N = p(1-p) * (z^2)/d^2$$

Where p is the anticipated adherence proportion

d is the precision required for either sample of the proportion (d=0.05)

z is the cut-off value of the normal distribution (z = 1.96)

According to the report by Addis Ababa Health Bureau, there are a total 57455 ART clients in Addis Ababa. Out of these, some 27504 were attending at the health centers where as the rest were at hospitals. The average proportion of adherence is estimated to be 76.4% (AAHB, 2012). So as per the formula p= 0.764

N= 0.764 (0.236) * (3.84)/0.0025
N= 0.180304 * 1536.64
N= 277

But considering the non-respondent rate, 10% was added and 305 persons or an average of about 30 clients were included in the sample from each health center.

3.2.7 Sampling Technique

The sampling technique refers to the procedures used to select persons who participated in providing the required information. In this study, different techniques were employed for this purpose as the participants were of different categories (the patients, the care providers and managers of the centers).

A. Selection of Health Centers

There were 10 sub cities and 25 ART providing health centers in Addis Ababa where some of them have 2 and some 3 centers. Considering the variations in the socioeconomic status of the sub cities, it was believed that a representation of each was critical. As such, it was decided that each sub city would have an assigned quota where at least one health center should be included from each. Consequently, all 25 health centers were listed and using a lottery method one was picked from each. Accordingly the following centers were selected and included for the study.

Table 1: List of Selected Health Centers for the study under each sub city

No	Name of Health Center	Sub city
1	Arada	Arada
2	Addis Ketema	Addis Ketema
3	Bole 17	Bole
4	Kazanchis	Kirkos
5	Entoto	Yeka
6	Gulele	Gulele
7	Kality	AkakiKality
8	Lideta	Lideta
9	Kolfe	KolfeKeranyo
10	Nifas Silk 01	Nifas Silk Lafto

B. Selection of Patients

As per the selection criteria, only patients who have attended ART for six months or more prior to the commencement of the study were included. So those who do not qualify this were excluded from the selection process. Then to select among those who

qualified, a systematic random sampling method was employed. From the list of clients under the ART registration book, one would be picked randomly and then every k^{th}(the ratio of the population to the sample size) client was included based on the determined sample size.

Table 2: Number of Patients included for the sample from each Health Center

No	Name of Health Center	# of Clients	%	# of clients included in study sample
1	Arada	2355	8.56	26
2	Addis Ketema	3145	11.43	35
3	Bole 17	2399	8.72	27
4	Kazanchis	3716	13.51	41
5	Entoto	3226	11.73	36
6	Gulele	1907	6.93	21
7	Kality	3203	11.65	36
8	Lideta	2506	9.11	28
9	Kolfe	2770	10.07	30
10	Nifas Silk 01	2277	8.28	25
	Total	27504	100.00	305

C. Counselors and Managers

All adherence counselors were included without any selection criterion applied as they were very few. Similarly health center managers were included on the assumption that they were key informants who knew the systemic and organizational issues involved in the problem of the study.

3.2.8 Methods of Data Collection

The methods of data collection refer to the ways in which the required information was gathered for the study. As pointed out earlier, the study had employed the CIPP model as it intends to examine the adherence education program and identify gaps that need decisions to be made for improvement. Accordingly, different kinds of instruments were employed for data collection depending on the type of data needed to be generated and the source of the information the data was supposed to be collected from. Basically, four major instruments were used.

A. Structured Questionnaire

A short structured questionnaire was developed and used to gather data that helped to assess a range of issues. The questionnaires used the Likert rating scale method where participants had to express their opinion from strongly agree to strongly disagree for each item presented. Each of them had included items that specifically asked their targeted participants aimed to assess the CIPP of the adherence education from their own perspectives and to relate their responses and eventually locate strengths and weaknesses in each component.

B. Document/Content Analysis

Content analysis is a technique of data collection through scrutinizing the contents of a certain material related to the research topic. In this study, it was used for analyzing two kinds of documents assumed to have the necessary data. The first includes reports of

different organizations on ART in Ethiopia in general and Addis Ababa in particular focusing on the selected health centers. This data enabled to show how the service has been provided and related issues that explain the topic of this study. The second is the adherence manual used to educate clients. It was used to review and/or evaluate the contents of the manual against standard criteria. In both situations it was used to understand and assess context, input, process and/or product of the intervention.

C. In-depth Interview (IDI)

This data collection method was used to examine various issues in depth by interviewing selected key informants supposed to have adequate knowledge and experience on the matter. Through IDI, the investigated and understood the nature of the problem, the factors involved and the reasons behind all these by discussing with officials at federal, regional, woreda and health center level. The managers of respective health facilities were particularly the focus as they were key personnel with the knowledge and experiences to provide their assessment.

The interviewing was intentionally scheduled to be conducted after data from document review and questionnaires were collected and analyzed. This enabled the interviewer to have a grasp of the issues needed to be explored through probing and those which needed clarification as to why they were the way they were. As usual the questions were structured on the bases of the CIPP and each component was addressed adequately.

D. Observation

Another important instrument utilized was non participant observation. With this method, the most important component of the CIPP- implementation process was adequately addressed. The adherence sessions were observed by attending randomly selected 2 sessions in two different centers where both clients and service counselors were willing to provide their full consent. And indeed, some very crucial information was gained through this method.

3.2.9 Procedures and Processes

Some procedures and processes were followed while planning, conducting and reporting the study. The procedures and processes refers to the ways used to conduct the study including how it was planned, executed and monitored to ensure that valid and reliable data was generated and appropriate analysis was made. It shows how the study was approached and conducted with relevant explanation the strengths and limitations involved. It also indicates the processes and steps the study has passed through before, during and after the data gathering process.

Getting ethical clearance, development and piloting of data collection instruments, recruitment and orientation of data collectors, facilitation of the data collection process, and supervision were some of the procedures used to conduct an ethically sound study.

A. Piloting and Administration of Data Collection Instruments

Appropriate data gathering instruments were developed and refined after getting comments from the advisor and colleagues. Then the questionnaire was piloted by administering them to clients who indicated some ambiguity in some of the items. So these issues were addressed before the questionnaire was actually administered to participants.

Various techniques were used to determine the validity and reliability of the data collection instruments. The face validity and content validity of the instrument was assessed by experienced researchers.

B. Getting Ethical Clearance

Since the study was planned to be conducted at health facilities, it required getting ethical clearance from Addis Ababa Health Bureau which was the responsible body supposed to provide an approval for a go ahead. As such the proposal was submitted to the bureau and the ethical committee of the bureau reviewed the technical proposal and approved it to be conducted. The bureau then wrote a letter to all the 10 health centers so that all necessary data could be accessed.

C. Recruitment and Orientation of Data Collectors

This refers to the selection of data collectors who actually gathered the information needed. After criteria were established to select the kind of persons who would fit in to

the job, they were recruited. Then they were trained on how to approach participants, get informed consent and how they should fill out the instruments.

D. Facilitation and Support to Data Collectors

The data collection process was facilitated to see if there were issues to be sorted out and to provide technical support. The data collection schedule was planned in a way that actually enabled the researcher address this support. Accordingly, each center started the data collection in different day from the other so that initial challenges were dealt with in time.

E. Data Cleaning

The data collected have gone through some process of cleaning where data was checked for any possible errors. So it was checked and rechecked for completeness, accuracy and consistency. Items found to be incomplete were discarded.

3.2.10 Type of Data

The data collected encompasses both qualitative and quantitative nature. In this study the qualitative information was used to describe, for instance, the role of health education on adherence, assess and indicate the magnitude of the problem and analyze the content, strategies and ways of communication used to educate clients under treatment and eventually show the strengths and weaknesses of the education process.

Quantitative information is basically numeric in nature which allows the study to examine the statistics like the numbers of patients; those who were adhering and those who were not, the trend so far and so on. It enabled the study to indicate the degree of the problem.

3.2.11 Presentation of Findings and Discussion

Major findings of the study were presented for analysis and discussion in a way that provides answer to the guiding questions effectively. First data was categorized as per the CIPP Model into four parts and raw data was presented. Then appropriate discussion was made by relating the findings with the research questions.

The method used was analyzing data by using tables and graphs and discussing them appropriately. The data from the questionnaires were entered into spreadsheet and appropriate analysis was conducted by using the various methods. Frequencies were particularly utilized to see trends and variations in opinions among participants on a number of points. Descriptive statistics was used largely for analysis and discussion of findings. It was used to summarize and describe the data to assess the level and/or distribution of any particular characteristic. Simple statistics such as mean, standard deviation and percentages were used as to describe the distribution of a variable in the study. Tables and graphs were the most frequently used. It helped to present issues like the demographic characteristics of patients, the existing level of adherence, and the magnitude of the problem and so on.

3.3Conceptual Framework of the study

There are several theories and models developed by different scholars and used to assess how an individual's behavior develops and to evaluate the effectiveness of interventions in producing some desired behaviors for an intended outcome. After examining some of them, the CIPP model of evaluation was chosen to be used for conducting the study. The CIPP (Context, Input, Process, and Product) is a model that "provides a framework for detecting defects and/or strengths in educational programs" (Stufflebeam, 2003a, p. 36).

The reason behind the selection of this model was fitness for the purpose. The application of this model is believed to enable the study analyze all components of the health education intervention program from every angle (i.e. the context, input, process and product). By assessing issues with patients, health care providers, the management, the implementation processes, the curriculum, and the system, it would be possible to identify the bottlenecks of the education. It follows that a comprehensive assessment of the adherence education allows the study to review its impact on clients' behavior and identify if there are gaps in these elements and processes.

3.3.1 Defining CIPP

The CIPP model was devised by Guba, and further developed by Stufflebeam, after the observation that traditional approaches to evaluation designs were found to be limited and often too rigid for evaluating dynamic social contexts (Stella, Nicolette, and David, 2010). The model requires the evaluation of context, input, process and product in judging a program's value. It is a decision-focused approach to evaluation and emphasizes the

systematic provision of information for program management. It aims to provide an analytic and rational basis for program decision-making, based on a cycle of planning, structuring, implementing and reviewing and revising decisions.

Stufflebeam thought that evaluation should be a process of delineating, obtaining and providing useful information to decision-makers, with the overall goal of program improvement. In this case program evaluation is defined as the systematic collection of information about the activities, characteristics, and outcome of programs for use by specific people to reduce uncertainties, improve effectiveness, and make decisions with regard to what those programs are doing and affecting (Patton, 1986). As such, the purpose of evaluation is to establish and provide useful information for judging decision alternatives; assist an audience to judge and improve the worth of an educational program; and help the improvement of policies and programs (Stufflebeam, 2003).

3.3.2 Purpose of CIPP

The CIPP Model emphasizes that evaluation's most important purposeis not to prove, but to improve. Evaluation is thus conceived primarily as a functional activity oriented in the long run to stimulating, aiding, and assisting efforts to strengthen and improve enterprises. Consistent with its improvement focus, the CIPP Model places priority on guiding the planning and implementation of development efforts. The model's intent is thus to supply evaluation users with timely, valid information of use in identifying an appropriate area for development (Patton,1986).

3.3.3 Components of the CIPP Model

There are four concepts in CIPP model: Context, Input, Process, and Product evaluation. Each component asks specific questions pertaining to the current stage of development within the evaluated process. By asking these questions, CIPP can inform a number of decisions such as the goals, plans or strategies to carry out a project, and what activities need priority or further attention (Stella, Nicolette & David, 2010). The following is a summary of the four components of CIPP model as described by Stufflebeam.

A. Context Evaluation

In context evaluation, we assess needs, problems, and opportunities with in a defined environment as they aid to define and assess goals. It includes the assessment of policies, surroundings, needs and so on(Stella, Nicolette & David, 2010).

B. Input Evaluation

This involves an examination of the intended content of an education program. It relates to deciding the resources and strategies used to achieve educational goals and objectives(Stella, Nicolette & David, 2010). The purpose this evaluation would enable to decide on resources needed. Therefore, it assesses programmatic, financial and personnel resources to be used for revising educational plan(Patton, 1986).

C. Process Evaluation

According to Patton, process evaluation is concerned with the implementation of a program. As such it is necessary to describe the needs and goals of the program so that

it will be possible to evaluate based on initial objectives. Its aims are to identify mistakes and to provide information for decisions. Process evaluation can provide regular feedback to leaders of the program (Patton, 1986).

D. Product Evaluation

Obviously this component aims to assess the outcomes of program activities and to find out whether they have actually made the difference. The results could determine whether the content should continue, to be modified, or terminated. Based upon the information related to background, input, and process, it tries to see the difference between outcomes and a predetermined standard and provide a reasonable explanation for decision-making(Stella, Nicolette & David, 2010).

3.3.4 Limitations of CIPP Model

Critics including Patton outlined that even if there are such strengths of the model, it also has some weaknesses. The following are some of them (Patton, 1986).

1. The thoroughness of the model is one of its major limitations. From a theoretical perspective the model is complete, robust and egalitarian, though it is also idealistic and dependent on unique situations.

2. There could be a number of situations exist in practice which prevent evaluations from running smoothly, most notably the politics occurring within and between departments and organizations and therefore often present in the creation (and consequently the evaluation) of a learning space.

3. The equity provided to all stakeholder groups, together with the requirement of input from them, means that the process of evaluation can be slow, costly and complex.

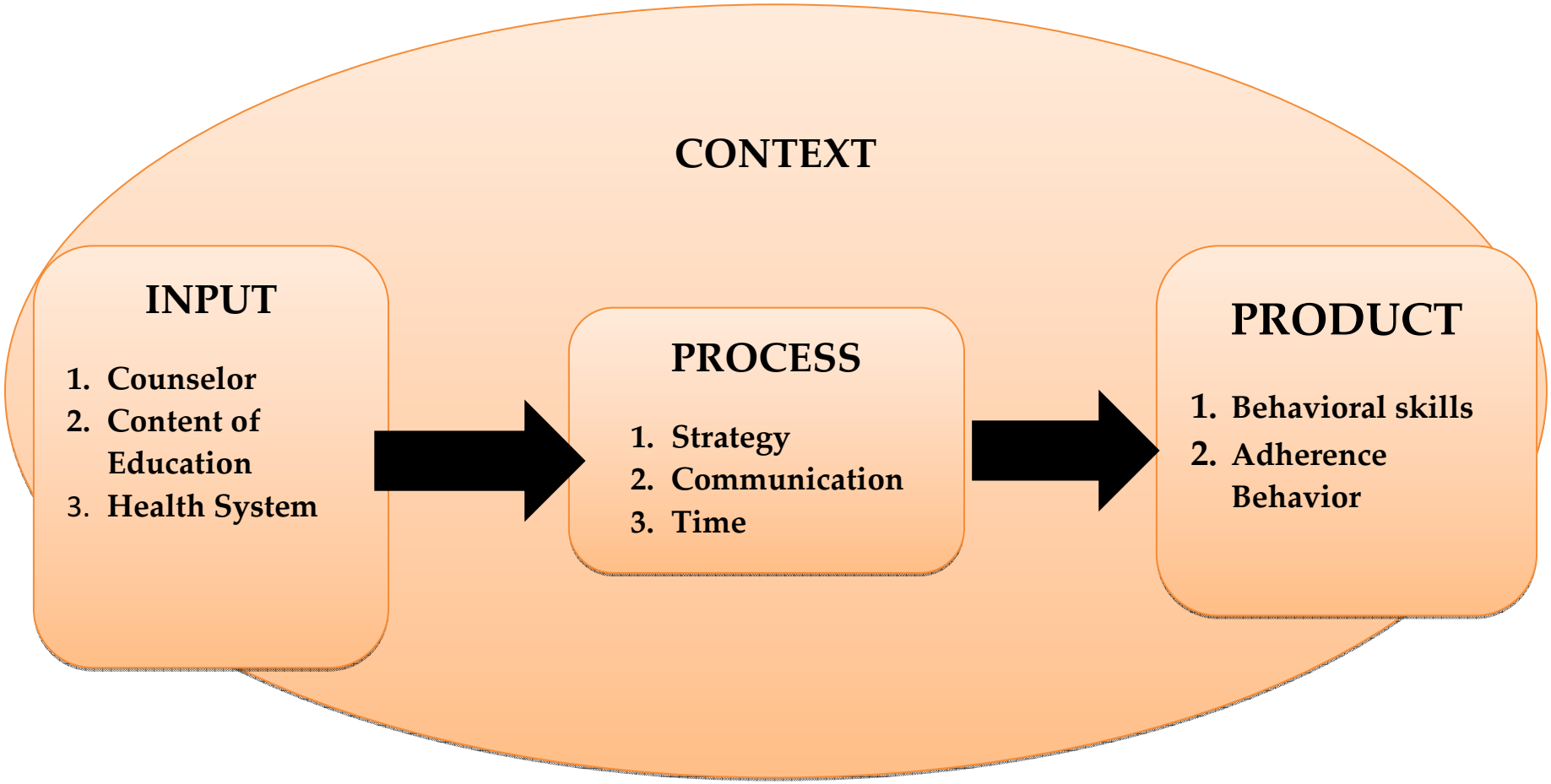
4. Finally, it is in practice still a top-down, managerial model dependent on rational decisions made at management level, although some collaboration is required.

3.4 Ethical Considerations

Ethical issues were taken into account seriously in every step of the study process. All procedures were in place to make sure that the study participants received their deserved human rights. Accordingly, the study was planned and applied the three principles of ethics: beneficence, human dignity, and justice.

As per the principle of beneficence, the study has done everything necessary to avoid any risk of participants that could arise due to their participation. The data was collected at the health center where they get the treatment. They were adequately informed about the purpose of the study and they have the right to participate or not.

FIGURE 1: CIPP MODEL OF EVALUATION ADAPTED FROM STUFFLBEAM,



The study also ensured that all participants are respected and dignified in all the research process. These include a right to self-determination and the right of the participant to full disclosure of the facts. They were informed that they had an absolute right to decide whether they want to participate or not. They were included only when they were willing and prepared to provide their informed written consent in the knowledge that they had the right to withdraw from the study at any time and without the need for any explanation or justification.

In addition, the study procedures were ethically just where the participants were treated fairly and equally. They were assured that the information they impart for the purpose of research will be kept completely private and will not be disclosed without their written consent.

CHAPTER FOUR

MAJOR FINDINGS AND DISCUSSION

4.1Introduction

This section presents the major findings of the study with appropriate analysis and discussion as to the implications of the findings. As planned, the required data was collected by using a questionnaire, in-depth interview, document analysis and observation techniques. Next, the findings were categorized into specific issues as per the basic research questions and according to the CIPP model which the study has chosen to this purpose. Then presentations were made in a logical flow and in a way that is clear and informative.

The main purpose of the study was to understand the role of education for adherence to ART in Addis Ababa and to identify the major challenges that exist in the provision of the education. Using the CIPP model, the study assessed the intervention, identified weaknesses in the process and forward possible solutions.

4.2 Description of Health Centers

Reviewed documents and interviews with health center managers indicated that all of the selected centers were government owned and most of them (80%) were established in the last 20 years. Besides, the majority of them (90%) have started providing ART services in a relatively same time (2007) and only one health center (Addis Ketema) which started one year earlier (2006).

The number of clients attending ART currently in these facilities ranges from 1907 to 3716. Most of the clients on ART are female (64%) compared to males.

Table 3 Number of ART Clients by Health Center

No	Name of Health Center	Number of Patients on ART
1	Arada	2355
2	Addis Ketema	3145
3	Bole 17	2399
4	Kazanchis	3716
5	Entoto	3226
6	Gulele	1907
7	Kality	3203
8	Lideta	2506
9	Kolfe	2770
10	Nifas Silk 01	2277
	Total	27504

4.2.6 Demographic Characteristics of Participants

As discussed in the previous section, there were three types of participants in this study: ART patients, counselors and health center managers. The demographic characteristics of each are presented and analyzed here under.

A. Demographics of Patient Participants

The actual number of patient participants who filled out the questionnaires were 292. Their demographics were analyzed using Microsoft Excel and presented below usingtables and graphs.

Table 4: The Demographics of Patient Participants

DEMOGRAPHIC CHARACTERISTICS							
SEX	**Male**	**Female**	**Total**				
	185	107	292				
AGE	**<21**	**21 - 30**	**31 - 40**	**41 - 50**	**>50**		
	34	79	99	65	15		
MS	**Single**	**Married**	**Divorced**	**Widowed**	**Total**		
	90	139	28	35	292		
Religion	**Orthodox**	**Catholic**	**Protestant**	**Muslim**	**Other**	**Total**	
	114	12	45	85	6	292	
Educational Level	**Illiterate**	**Able to read & write**	**Primary**	**Secondary**	**Vocational**	**Tertiary**	**Total**
	68	48	109	38	20	9	292
Income Level	**<500**	**500 - 1500**	**1501 - 2500**	**2501 - 3500**	**3501 - 4500**	**>4500**	**Total**
	66	92	78	11	23	22	292

B. Demographics of Service Providers

In total, 10 adherence counselors have participated in the study. Their age ranges from 22 to 42 and gender wise the majority of them were females (60%). They were all nonprofessional "community" or "lay" counselors as they were called. Besides, as reported by health managers most of the counselors were HIV positive themselves.

C. Health Center Managers

Among the ten managers interviewed for this study, 6 of them were below 40 years of age. They were dominantly male (9 of them) and married (7 of them). Educationally, most had first degree in public health: health officer (5), nursing (3) or environmental health (2) professions.

4.2 Contextual Evaluation

As indicated in the conceptual framework, context evaluation is concerned with providing information about policies, needs, goals and problems surrounding a certain program. In this case, the data needed helped to describe the state of ART treatment in Ethiopia with particular emphasis on Addis Ababa and the level of ART adherence in general. In other words, conceptual evaluation provides answer to our first research question: what is the level of non-adherence and its magnitude in the selected health centers?

The main source for contextual data was document analysis. Various types of published and unpublished documents including reports and assessments conducted by the Ministry of Health, Addis Ababa Health Bureau, UNAIDS, and WHO were reviewed for this purpose. Attempts were also made to supplement and triangulate this data by interviewing key personnel at the federal, regional and health center levels.

4.2.1 ART in Ethiopia

According to MOH, ART has been started in Ethiopia in 2005 with the support of a host of international aid agencies particularly PEPFAR. Initially, MOH selected only 49 public hospitals to provide the treatment and for an estimated 250, 000 people who were supposed to live with the virus and needed the drugs during that time. Health Care providers and community level workers were trained on how to provide services. By the beginning of 2007, most health centers around the country have begun providing the

service after it was found evident that the demand has increased considerably in many regions.

On the other hand, UNAIDS reported that by the end of 2011 "there were a total of 333,434 individuals on ART in Ethiopia. Out of which 16000 were children (constituting 20% of the eligible clients) and 24, 9174 adults (86%)" (UNAIDS, 2012, p.33). The report also indicated that even if tremendous achievements were made in HIV prevention, care and impact mitigation, a lot remains to be done in increasing the number of ART clients and improve the quality of services (UNAIDS et al, 2012).

In addition, the low level of adherence in almost all health facilities was considered as one of the biggest challenges in treatment interventions in the country. Let alone the low adherence, the number of "clients lost to follow up" (clients dropping) the treatment for days and months was still significant (MOH, 2010, p.16).

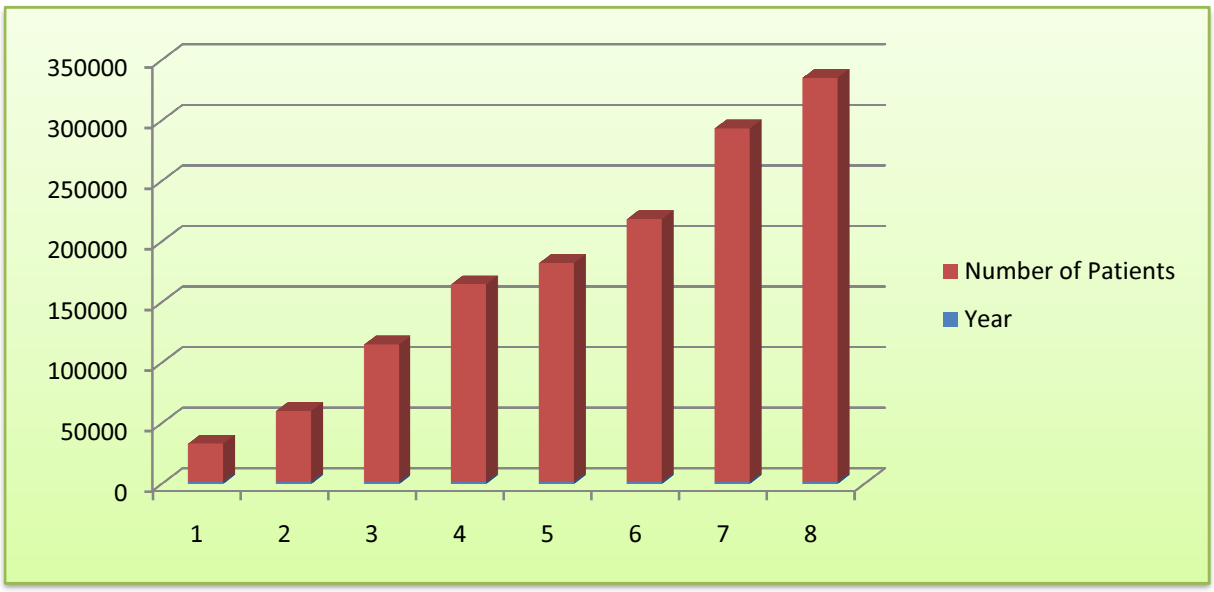
Table 8: Number of Persons Ever Started ART in Ethiopia (MOH & UNAIDS, 2012)

Year	2005	2006	2007	2008	2009	2010	2011	2012
Number of Patients	31406	58405	113298	162877	180447	216724	291622	333434

As indicated in table, the number of persons attending ART services in the country had been increasing considerably over the years. However, it should be noted that the number is still well below the expected number believed to be eligible for the treatment (UNAIDS et al,

2012). Therefore despite the progresses made, there remains a lot to be done in increasing coverage.

Figure 4: Trend of Number of Patients Attending ART in Ethiopia



4.2.2 ART in Addis Ababa

In Addis Ababa, 9 government and public hospitals, 12 private health facilities and 26 government health centers were providing ART to 62390 persons (AAHB, 2011, p. 42). The annual progress report for 2003 EFY by the bureau indicated positive achievements in especially in the last five years where the number of AIDS patients attending ART increased dramatically (AAHB, et al, p. 77).

However, some formidable challenges were mentioned in the report as well. First of all, the coverage was still far from the estimated number of individuals eligible for the treatment.

Second, there was very low adherence rate among patients with nearly 25% of clients were lost to follow up. This was in fact much worse than some regions like Amhara (17%).

Efforts continued towards improving the situation by the bureau as well as facilities. The primary way in this effort was educating clients in various ways even though there is still a long way to go in this regard (AAHB, 2012).

4.2.3 Challenges of ART Treatment in Ethiopia

In the initial stages, the main challenge was the stigma and discrimination attached to the treatment (MOH, 2007, P.35). People were afraid to undertake HIV testing and attend facilities for treatment. They used to stay at home until they become sick and bed bound. So the coverage was very little compared to the estimated number of individuals supposed to be living with the virus. At the same time, there were only a few hospitals providing the treatment over the country which was also a limitation (MOH et al).

In the subsequent years, as people became more aware and the drugs become available in more accessible health facilities, the coverage has increased dramatically especially in the years after 2008 even though the coverage was still not satisfactory. However, over the last few years the low level of adherence among patients was the main problem related to ART in Ethiopia in general and Addis Ababa in particular.

The severity of the problem of non-adherence was described in different reports and studies. In a study that was conducted in 2006 in Amahara region in Baherdar Felege Hiwot Hospital and Gonder Referral Hospital showed that the lost to follow up rate is18% and 19%

respectively and the majority of the patients who were traced retrospectively were found to be dead (Gugsa, 2008).

A number of reasons were found to be behind to this low level of adherence. In a study in three public hospitals in Addis Ababa, Akalu has found the most frequently mentioned reasons for "defaulting". Among these, the three top reasons were 1) Religious beliefs/spirituality or alternative healing 2) Lack of food/shelter/ money 3) Fear of treatment's side effects (Akalu, 2009, p.40).

4.2.4 Policies, Goals and Priorities

Following the introduction of ART, the MOH had issued an implementation guideline. The document deals with issues like eligibility criteria, mode of provision, role of individuals, communities, health care facilities and so on. It also indicated the urgency to reach as many patients as possible (MOH, 2005).

The Strategic Plan Manual (SPM Ⅱ) clearly outlined the goals and priorities of MOH within the five years from 2009 to 2014. The general goal is to intensify responses to HIV and AIDS in the country. Increasing access to ART services was indicated to be one of the three priority intervention areas in this strategic plan. Accordingly the goal is to reach all (100%) of HIV infected patients for ART and to reduce AIDS related mortality by 95% by the end of 2014 (MOH, 2009, p.41). The document also presented the strategies for implementing these goals and priorities.

More specifically, SPM Ⅱ planned that enhancing treatment literacy and adherence counseling would be given more attention "as adherence to treatment is one of the major factors for optimal treatment outcomes". The strategies for increasing adherence were developing and enforcing guidelines for treatment literacy and adherence, strengthening adherence counseling by health workers and expert patients, advocating and disseminating treatment literacy and adherence messages in media, follow up of loss to follow up of patients and strengthening community support mechanisms for adherence on treatment (MOH, 2009, p. 42).

4.3 Input Evaluation

Most of the information presented in this section was generated from the in-depth interview conducted with health facility managers, some care providers and a few clients. It attempted to provide information on a range of issues from baseline assessment and strategy to the capacity of health care providers, to the availability of facilities and supporting materials, and the support of management system that could determine the effectiveness of the adherence education.

4.3.1 Baseline Assessment and Program Strategy

One indicator of input or readiness was conducting assessment that would serve as a baseline or benchmark for health facilities. The assessment could identify needs, gaps and feasibility of program. Based on the assessment, a strategy would be developed as well.

As far as assessments were concerned, the study found out that even if there were attempts to review the existing capacity of health facilities, comprehensive and detailed assessments haven't been conducted that indicated their readiness, needs and gaps in starting the provision of ART initially.

As the initiative came from MOH, the study has tried to get information on this from the ministry. There were no documents found that could explain what was done during that time. An ART expert of the ministry reported that since there was a huge urgency to get started the treatment, the assessment did not get due attention. However, he said that nongovernmental partners have done their own assessments in different regions where they work. In Addis Ababa, for instance, John Hopkins University has made some assessments.

4.3.2 Capacity Adherence Counselors

This was one of the critical indicators of input. An assessment of the number of available service providers and their capacity in terms of their knowledge, attitude and practice indicated their potential strengths and weaknesses or problems.

Regarding their number, each health center has three to five persons who provide the treatment as well as adherence support. This seemed to be incompatible with the number of clients they have (2834 on average). Unsurprisingly, all of the health center managers reported that the number was inadequate compared to the number patients they were supposed to educate and follow up. The average provider-patient ratio was 1 provider to 881 clients. This clearly indicated the presence of a huge gap and the extent of the existing

problem. The participants believed that it obviously compromised the quality of services provided.

On the other hand, the majority of patients evaluated the knowledge and skill of adherence counselors as "good" and "fair" with 36% and 29% respectively. This result was consistent with the assessment of center managers who attributed it to their low level of education, inadequate training and inadequate work experience. As indicated above, all of the adherence counselors were educationally at secondary or high school level. In addition, they were not professional counselors even though they were trained on ART and adherence counseling. The high turn-over also meant that most of them lacked the required related work experience.

4.3.3 Adherence Manual

The adherence manual was another important component of input that was considered to have a detrimental factor in the provision of the education. The relevance and clarity of the contents of the manual to the level of counselors is critical.

Three points were assessed in this regard. The first was the availability of uniform guiding manual. Accordingly, most of the counselors (70%) reported to have a training manual as part of the ART training they were provided. So there was no guiding manual prepared for adherence alone. It was recognized that there were some differences among the manuals as they were adapted by different implementing agencies. As indicated above, MOH has a plan to develop and implement a guideline for adherence as part of its priority for five years.

The second issue was the content of the manual. It was expected to be simple and user friendly. In terms of the language, there was only an English version with lots of technical terms. The counselors indicated that the language was one of the major challenges. They reported it would have been better if there was an Amharic version.

Third, the complexity of the subject matter were said to be beyond the level of the counselors. The content analysis showed that some of the concepts needed some background in health and/or in psychology. It seemed to be very demanding to understand and communicate to clients. The counselors said that even if they have the manual they did not usually refer to it due to this problem. They rather preferred to read leaflets and brochures prepared in local languages.

What is more, the manual needed to be updated as many things have been changed regarding the nature of the drug and the way it should be taken. Most of the counselors were trained two or more years back. Some of them have taken refreshment trainings more frequently than used to be provided.

4.3.4 Rooms and Materials

Even though the capacity of counselors and the manual were important factors, all are irrelevant without the presence of convenient physical environment where the education could be provided. Educational aids were also believed to play a significant role in facilitating the adherence education.

In line with this, almost all participants' have said that the number of rooms were inadequate for providing the service. Most of the centers have one or two rooms for ART services where the nurses and adherence counselors sit together. They thought it could have been better if two or more rooms were allocated for ART so that it would be much comfortable for clients and providers to discuss issues freely. It was also observed that some centers used curtains to make partition for counselors even if that did not seem to be the right answers to the problem. The counselors also reported that there were not enough educational aids (leaflets, posters, etc) made for the purpose.

4.3.5 Support from Management

Support from management refers to communication, relationship, availing materials and facilitation of need based trainings. Most of the counselors reported that they had good communication with the management. They said that they have biweekly meetings with them where they discuss various challenges and issues. Most of the problems were believed to be beyond the health center otherwise they provided with the support needed.

However, some counselors reported not to have a good relationship with their supervisors due to various factors and believed that the support was far from adequate.

4.4 Process Evaluation

Process evaluation relates to the implementation of the adherence education program. At this stage, how the implementation was done and how it has gone against the plan was assessed aiming to provide feedback on efficiency and achievement. Core issues include relationship between the provider and client, effectiveness of communication, and attention of clients and counselors.

Positive relationship between a client and counselor is decisive for the education or counseling to be effective and bring about a good result. In this study both patients and adherence counselors were asked to evaluate the relationship with each other.

The responses showed that most of the patients either disagreed (42%) or strongly disagreed (28%) that they had good relationship with their respective adherence counselor. Contrary to this, the majority of counselors (70%) had reported to have good relation with their clients. From the observation, it was noticed that while a few clients was seen to chat and smile with counselors, many approached the counselors as strangers even if some of these clients have been on treatment for a year or more.

On the other hand, the communication between the patients and counselors was taken to be important tool for implementation. Even though most of the patients had agreed to have good communication with their counselor, they disagreed with the idea that the communication was two way. More than half of the patient participants (53%) have reported that they were not usually encouraged by respective counselor to speak their personal problems during counseling sessions.

The counselors for their part reported that they tried to communicate with their clients as much as possible. But they also said that sometimes it was difficult to ask clients about their problems due to time constraints and fatigue. However, from the session observations it was noticed that the counselors were asking clients about side effects, their adherence or if "there was any problem". The managers have also indicated the presence of good communication in accordance with "the follow up protocol".

One major challenge might be the language where the counselors use many English terms while communicating with clients. There were a lot of technical jargons used as well even though some of these were already familiar to clients. In addition as far as language was concerned, some counselors reported that there were patients with little understanding of Amharic which created a barrier.

Some counselors also reported that clients lacked motivation and attentiveness during sessions which also created challenge in the process. But others attributed this to the distracting environment of the facilities that created this problem.

Finally it was founded that the physical environment was another important factor at this level. Obviously, effective communication requires silence and uninterrupted session where clients and counselors could discuss issues with ease. Only two facilities reported to have separate rooms for adherence counseling sessions. The rest of the health centers cited many challenges related to this. The details are discussed below.

4.5 Product Evaluation

Product evaluation is concerned with the outcome or result the adherence education had brought about. This was done by comparing the achievements of the education with the goals planned by the program. Some predetermined standards could also be used to indicate how the intervention had worked out.

The goal of adherence programs was to increase the adherence level among clients through continuous education. As we pointed out earlier, at least 95% adherence was considered to be the desired or optimal level required for it to be successful.

The study attempted to evaluate the outcome of the intervention by using data from different sources. But this was found to be the most demanding task of all. First the only measurement of adherence of clients was self-report that could not be claimed as adequately valid and reliable. Second, it was very difficult to get a previously established measured level for these health centers. Third and most importantly it was impossible to claim the level of adherence measured to be as a result of only the education as this could also be attained due to other interventions or factors.

Having said this, data from document analysis (reports and records) indicated different results. Some reports by AAHB showed that there were improvements over time with the level of adherence increasing and the number of clients lost to follow up deceasing in the last few years. And the reports said this was a result the increased awareness among clients.

However, these same reports also indicated the adherence level to be still low and it was one of the major challenges for the treatment for the long term.

Client records of each health center could also designate the results of the level of adherence where the number of clients lost to follow up could be used as a reference to show the magnitude of the problem. As put in the table below, the number of clients lost to follow up was between 16% and 27%. These numbers of LTFU rates were significant to show that initial interventions were not as such successful.

Apart from the document analysis, patients were asked to indicate the average number of pills they might miss in a month as part of the questionnaire. This is what is called self-reported measure of adherence. The result indicated that at least 7 pills were missed by patients on average.

Asked their opinion about the role of the education, the majority of the patients either strongly agreed (53%) or agreed (30%) that they have benefited from the education they received in improving their adherence behavior. Besides, about 72% of them agreed or disagreed with the idea that they would have a better adherence behavior if they had received the education properly. On the other hand, they have pointed many problems and challenges in the treatment as well as the education provided and indicated that a lot remains to be done to increase the effectiveness of the education.

Attempts were made to get the assessment of counselors and managers even though they found it very difficult to answer. First most of the counselors believed that the education

had played a significant role in improving the level of adherence. But they also thought I could have been much better with better resources. Similarly, many of the managers believed that the education have made a difference even if there were considerable gaps. Most of the clients have improved their adherence behavior due to the continuous education.

4.6 DISCUSSION ON FINDINGS

4.6.1 The Problem of Non-adherence

The findings of the study clearly indicated that non adherence was really a problem in all the centers covered. Almost all data sources pointed out that non-adherence was the main challenge in ART treatment currently. The only question would be how severe the problem.

It should be said that more intensive study was needed to determine the magnitude of the problem in our health centers. Having said that, different sources including this study has provided some results in this regard.

A. In a study in conducted in 2009, Akalu discovered that the overall rate of lost to follow up was about 24% in five public health institutions in Addis Ababa (Akalu, 2009, p. 8). As such, the adherence level was supposed to be less than this figure as lost to follow up is a much worse indicator of adherence.
B. Other studies conducted in other parts of Ethiopia indicated more or less similar results. For example at Yirgalem Hospital in south Ethiopia the non-adherence rate

was 25.8%. In Baherdar Felege Hiwot and Gondar Referral Hospitals of the Amahara regional state, the rate was about 18% and 19% respectively.

C. The reviewed documents by MOH, AAHB, WHO, and UNAIDS also indicated the presence an overall adherence rate ranging between 65% to about 80%.

D. In this study, from self-reported data of patients indicated that on average 13% non-adherence rate was reported. This means missing about four days of allocated pills. Setting the weakness in accuracy of self-report as a measurement aside, this was an indicative of the level of adherence among sampled patients.

Therefore, available data indicated that there was low level in adherence in Addis Ababa or Ethiopia. And the magnitude was so considerable that appropriate interventions needed to be implemented to mitigate the impact of poor adherence and minimize its consequences.

4.6.2The Role of Health Education in Adherence

Among all the issues in this study, this one seemed to be the easiest to answer from the results. The findings indicated that continuous education was in fact one of the determining factors in facilitating patients level of adherence. In this regard:

A. Patient participants said that their adherence might have been much worse if it was without the continuous education they received. It enabled them understand the benefits of adherence and the consequences that could result due to lack of proper adherence. The education had played a lot in developing the behavior and skills necessary to improve their adherence level.

B. The response from counselors and managers agreed with patients as well. In their set up education was considered to be the primary intervention for enhancing adherence.

C. Previous studies on adherence interventions pointed out that continuous education was one of the effective methods among others used for enhancing adherence behavior. Major organizations like WHO also indicated the importance of education in increasing adherence.

4.6.3 Major Challenges

The presence of positive strides being aside, there were nevertheless many challenges identified by the study at different levels: context, input, process and product levels. Even though the challenges were treated separately for the sake of discussion, it should be known that they are intricately related to one another.

At context level, there were gaps particularly at the initial stage where adequate preparation was not done. There was no a "fully fledged" assessment conducted to show possible challenges and how they would be addressed. As pointed out this was mainly because of the "urgency" during that time.

It was only in 2009 that the SPM II clearly described the policies and goals. In this document the priority given to adherence was indicated unambiguously but then it did not adequately demonstrate how interventions could be introduced and implemented. In addition even

though the documents have indicated the enormous attention required for tackling non-adherence, the guideline for adherence education was not still developed and implemented.

Most importantly, there remains a lack assessment to identify critical needs of health centers and clients. The documents do not adequately indicate the existing gaps other than the need to address the problem. Such major issues as shortages in man power, lack of training, materials and so on should have been addressed fully.

At the input level, the main challenges were related to adherence counselors including the low level of education, lack of adequate training, and lack of experience. Among these, the most critical seemed to be their education. As pointed out earlier, most of the adherence counselors were at the level of secondary education and there were some even below this level. As far as the managers were concerned this was done intentionally to make sure that positive clients have greater involvement in the issue. Moreover, it was assumed that patients would feel easy knowing the counselors are positive themselves.

However, considering the complexity of the subject matter, this was found to be a huge gap in the provision of the education. The issue required some technical background and obviously it was difficult for the counselors to handle everything effectively. This coupled with the lack of training exacerbated the problem. In fact, it was reported that there were counselors who were never been trained on counseling but were supposed to provide the education.

On the other hand, due to the reported high turnover, it was difficult for some health centers to provide training every time they hire a new counselor. Besides, it was revealed

that the training was offered by NGOs who support the centers in strengthening services. As such the centers were forced to wait until the supporting organization provided the training. This had implications on the sustainability of the program as well since the supporting NGOs were reported to provide the support for a definite time period and the government was expected to take over after that. What is more, lack of experience of the matter was indicated by health centers' managers. This was mainly due to the turnover of staff which the centers could not handle. `

Challenges related to clients included their low learning capacity, language barriers, and their beliefs and attitudes. Most of the patients were either at the primary or below level of education which was reported to be a barrier for the effectiveness of the education. It was also considered to be a source of frustration for both patients and providers. It usually took time to get clients understand the basics of the treatment. This added up with the relative novelty and complexity of the content made the process much more perplexing. Besides, some counselors reported that there were some patients who could not even understand Amharic particularly those coming from the surrounding of the Addis Ababa city as they preferred to speake Oromiffa and rarely other local languages. This also created barrier where there was no common language medium between providers and patients.

But as far as the patients are concerned, by far the most considerable challenge mentioned during the data collection was their wrong beliefs and attitudes. Many were believed to possess lots of misconceptions about the disease and the treatment itself. The belief that "AIDS is a result of some curse" was reported to be still there. As a result, patients believed

that the treatment contradicts with their religious background and consider taking the drugs as something against their religious commitment.

Some of the participants pointed out the improvements in this regard in the past few years. The positive stride made in orthodox Christians was a big instance for this after the patriarch declared that "it was possible to take drugs with holy water". However, a lot remains to be done to alleviate the problem posed by this challenge.

The third major challenge relates to the Manual. First the manual is not specific as such and lacks clarity. It is definitely demanding for the capacity of counselors. The language is not local even though there were some attempts to translate to Amharic; it remained to be a challenge.

Other challenges could be categorized to health centers' system and managerial issues. These constraints were relatively easier to deal with than those mentioned above. Nevertheless, it created barrier to the adherence education and counseling process. The following were mentioned:

A. The inadequacy and inconvenience of rooms,
B. Shortage of staff and problems with recruitment,
C. Lack of educational aids and materials
D. Lack of support from the management,
E. High turnover of staff, and
F. Lack of motivational scheme for counselors.

The first two problems were the most critical. The presence of adequate number of staff and rooms could minimize lots of challenges if attended. In almost all health centers, there were one or two rooms allocated for ART and adherence counseling. And two or three service providers sit in the same room. In fact, in four health centers even the data clerks were with nurses and counselors. For adherence counselors, this was considered as unfavorable climate for patients to feel at ease and speak to the counselor.

On the other hand, it was found that there were only some rare learning materials or aids (leaflets, posters etc) which could facilitate the learning process. The participants indicated that there used to be a lot of educational materials available in the past especially while the treatment was introduced. The problem was rather the lack of user friendly nature of the materials. But these days, even those materials were hard to find. They related this to lack of sustainability of such activities as many of these kinds of aids were produced and distributed by NGOs. Currently, these NGOs are not as active as they used to be and that is the source of the gap.

It was also found out that the recruitment of adherence counselors was considered to be a source of challenge for the effectiveness of the adherence education. Many of the participants believed that there were gaps in hiring the right kinds of counselors. First and for most it was mandatory that counselors be HIV positive themselves. This was thought to facilitate disclosure in patients coming for treatment and create a sense of involvement among them. But later it was identified as a constraint. The counselors could be frequently absent due to their illness or they have their own personal stress that affected the process and so on.

Staff turnover was practically everywhere in the health centers. Even though, no formal assessments were made by the centers, the lack of supportive environment and low salary were the reasons frequently mentioned for the turn over. Besides, some of the participants stated that there should have been a motivational scheme for counselors comparable to the task they were supposed to accomplish.

At Process Level**,** There were challenges due to time constraint, communication barriers, lack of attention and lack of privacy. As reported above the time constraint was actually due to the presence of too many patients in a day. It hinders counselors to treat their clients as per the protocol. It was in fact a critical and defining factor in all the whole of the education. Besides this, lack of adequate time to make assessments on the patient's adherence issues before going into the education. Providers needed to adequately assess issues case by case in order to have positive progress forward.

The communication barriers were those which hinder the two way interaction between the counselor and the client which could either be lack of clarity and simplicity of the content of the subject. Since most of the clients were of low level of educational status, client friendly presentation of learning contents would help them grasp important points. However, patients reported that this was not usually the case. This could also be related to the capacity of counselors. The use of technical jargons was indicated as a barrier as well. The fact that some of the patients didn't even communicate Amharic was also mentioned as a problem in three health facilities.

Moreover, the lack of attention during the education either in the provider or the patient was described as a major challenge. This could be related to their psychological state. In fact, some of the adherence counselors claimed that it is difficult to get the attention of some of their clients.

Finally, adherence counselors believed that lack of ensuring privacy and confidentiality to patients was among the main challenges in their centers. They said that this is due to the lack of rooms where other clients attend treatment services in the same room at the same time. This was believed to affect patients to be at ease while receiving the counseling.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In the previous chapter, the findings were presented, analyzed and discussed. Now it is time to make concluding remarks and forward some suggestions as to what should be done to alleviate the challenges discovered.

5.2 Conclusions

No doubt there is a concern as to the low level of adherence and indeed it found to be a formidable challenge. We could see it even when there was no fully fledged study that indicated the complete extent of the problem in Addis Ababa or in Ethiopia as a whole. Even the number of patients quitting the treatment altogether was too many suggesting that it could result in grave consequences.

Even though there were tremendous improvements made in the last few years, those results were so meager compared to what was expected to be achieved. There was a priority to increase the accessibility and coverage as there were many who could not obtain the drugs. The adherence issue had not been provided adequate attention due to this. As a result the problem had increased to the level where it is today.

At a theoretical level, there were challenges due to lack of scientific studies resulting with very little understanding of problem, its nature and extent. It has to be said that there are

very few studies conducted to indicate how the education and health sectors should have to work together for better results. There remains a lot more to be done in the area to really widen our knowledge of the significant role the integration these streams in our country. While there were a number of studies conducted in identifying the factors involved in non-adherence behavior, one can rarely find which of the interventions were successful and why. For example in the case at hand, many writers have pointed out that continuous education and counseling was necessary and could play a significant role, but they have never indicated as to how and what could hinder this role in different situations.

There were problems at policy level as well which were partly due to the lack of research indicated earlier. Policies have to be devised after assessments were conducted which enable contextualize it as per the situations in different places. Besides this, they have to be revised with trends and progresses over time. It has not been the case in the case of this program.

6.3 Recommendations

As we know the CIPP model is an improvement oriented method of evaluation and its goal is to give information for decision makers to resolve issues, challenges and problems. As such, it is imperative to forward some feedback based on the findings to be considered by policy makers, decision makers, managers and implementers at different levels aiming to at least minimize the impact these gaps are posing.

A. For the Research Community in Health Education

Further studies should be conducted intensively to assess and understand the extent of the problem and to identify the factors involved in it. This would enable to effectively lobby for changes in policy and draw more resources to the cause. It would also help us understand the importance of integration of the two fields (education and health) in tackling this kind of problems.

B. For MOH and Health Bureaus

Apparently, MOH and RHBs are the most responsible body in addressing the issues and challenges discussed here. Three suggestions:

i. Continuous assessments should be undertaken to come up with information that enable make appropriate decisions at every step with follow up. We have to reassess and reconsider the policies, goals and priorities in line with the current context.

ii. We have to review once again the progress made and trends established in ART adherence and the role of education in facilitating that. Even though continuous education was put as a strategy to improve adherence, its process has never been evaluated so far. But if we can look deeply into the situation, it is possible to see why things are going the way they are. Why are the facilities failed consistently to address the problem of adherence adequately? The answer to this would mean understanding strengths, identifying weak links and gaps and finding effective solutions.

iii. Clearly, the health education is not as such strong. This is due to the lack of attention to it and the resulting lack of professionals in the area. Therefore, as the

health policy is prevention oriented, we need to train and deploy more health educators.

iv. There is a risk of overdependence on international donor agencies for much of the activities in ART program. Some of the activities are run with a complete support of these organizations. The adherence education program could be an example for the case in point. It was found that the counselors were fully paid by NGOs and supportive educational materials used to be availed by them. Obviously they will not support the program forever. Therefore, there must be a sustainability plan in place before it is too late as some of the NGOs are already phasing out.

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