

“How could I take my pills when I can’t even afford food?”

Barriers to adherence to antiretroviral treatment for HIV  
infected adults in Ethiopia

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Centre for International Health  
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This thesis is submitted in partial fulfilment of the requirements for the degree of Master of  
Philosophy in International Health at the University of Bergen.

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## Abstract

**Problem statement:** The regime of antiretroviral therapy (ART) which transforms HIV/AIDS from a deadly disease into a possible chronic condition has become increasingly available for a growing number of patients in sub-Saharan Africa. As the regime requires a strong level of adherence, there is a rising anxiety due to recent research which shows that a big proportion of patients who started on ART, are no longer in the program after two years. These findings underline the need to understand what kinds of challenges are faced by these patients related to the specific context in where they are situated. This study aims to look into the Ethiopian context where ART has been provided free of charge since 2005. Even though Ethiopia shares many characteristics related to adherence found in other sub-Saharan countries, the healing method by holy water in the Orthodox Church in relationship to ART is particular and is an issue for debate.

**Objectives:** To identify major determinants associated with adherence of antiretroviral treatment among HIV infected adults in Ethiopia

**Methods:** Most of the data collection was done in Dilla town in south Ethiopia. It was obtained during fieldwork which lasted from the 10th of June to the 20th of August 2007. Experiences were recorded from patients and health providers in both governmental and non-governmental organisations associated with the ART program in Dilla as well as from Orthodox priests were collected. Interviews were conducted among 19 patients, 10 health providers and 7 Orthodox priests. Documentary review, participant observation as well as one focus group discussion was also done. The data was analyzed using elements from The Framework Analysis.

**Results:** Self-reported adherence is very high among the HIV patients interviewed. Poverty associated factors related to basic needs for food, shelter and employment turned out to be the major barriers to adherence. Though hampered by stigma and discrimination, access to ART and “wrap around” services facilitates disclosure of HIV status. Holy water is widely used by HIV patients and may both compete with and complement adherence to ART. Investment by international donors in training and technical support in HIV care is crucial for the ART programs and strengthens the health system in general

**Conclusions/Recommendations:** HIV/AIDS care is strongly associated with poverty. HIV/AIDS must be treated in the context of economic development, access and right to treatment and strengthening of the general health system.

## Table of contents

Abstract.....	iii
Table of contents .....	iv
Acronyms and Abbreviations .....	vi
Acknowledgement .....	vii
<b>CHAPTER 1- BACKGROUND.....</b>	<b>1</b>
<b>Introduction.....</b>	<b>1</b>
<b>ART and adherence .....</b>	<b>2</b>
The age of ART .....	2
The ART regime .....	2
The problem of adherence .....	3
Adherence in relationship to possession cults and religious healing .....	6
Promoting adherence in low-income countries .....	7
<b>The Ethiopian context.....</b>	<b>8</b>
<b>A history of poverty and repression.....</b>	<b>8</b>
The Abyssinian kingdom and Haile Selasse .....	8
The Derg regime .....	9
Ethiopia after the Derg regime.....	10
<b>The Ethiopian Orthodox Church.....</b>	<b>11</b>
The expansion of the church in the Abyssinian Kingdom .....	11
A church of diversity .....	12
Religious healing .....	13
<b>The health sector.....</b>	<b>15</b>
HIV/AIDS in Ethiopia .....	16
<b>CHAPTER 2- METHODOLOGY AND ANALYTICAL APPROACHES.....</b>	<b>18</b>
<b>Study objectives.....</b>	<b>18</b>
Main objective.....	18
Study objectives .....	18
<b>Methods.....</b>	<b>18</b>
<b>Study setting.....</b>	<b>18</b>
Health Care and major actors associated with the ART program in Dilla .....	20
<b>Study design .....</b>	<b>22</b>
<b>Study population and characteristics.....</b>	<b>23</b>
<b>Sampling method and recruitment of study participants .....</b>	<b>23</b>
Patients.....	24
Health providers.....	24
Priests.....	25
<b>Data collection methods .....</b>	<b>25</b>
Semi- structured in –dept interviews .....	26
Focus group discussion.....	26
Participant observation / Field notes.....	27
Documentary review.....	27
<b>Ethical issues and informed consent .....</b>	<b>27</b>
<b>Research assistance and translation.....</b>	<b>28</b>
<b>Reflections on my position in the study .....</b>	<b>29</b>
<b>Data analysis .....</b>	<b>30</b>
<b>Conceptual framework .....</b>	<b>32</b>
Structural violence.....	33
The health care system with the three sectors of care .....	33

<b>CHAPTER 3- FINDINGS .....</b>	<b>35</b>
<b>The ART program in Dilla .....</b>	<b>35</b>
<b>The organisation of the services .....</b>	<b>35</b>
Confidentiality issues.....	36
<b>The adherence regime and counselling.....</b>	<b>36</b>
<b>Patients’ evaluation of their own adherence .....</b>	<b>37</b>
<b>Patients’ evaluation of the services at the ART unit.....</b>	<b>39</b>
<b>Health systems challenges and the problem of adherence .....</b>	<b>41</b>
<b>Religious healing .....</b>	<b>43</b>
<b>“A day of Healing”: The practice of holy water witnessed from the outside .....</b>	<b>43</b>
<b>Explaining HIV/AIDS as possession by evil spirits and moral uncleanness.....</b>	<b>46</b>
<b>The regime of the holy water .....</b>	<b>48</b>
<b>The aim of the regime.....</b>	<b>50</b>
<b>The organisation of the holy water regime.....</b>	<b>51</b>
The actors involved.....	51
The rituals performed .....	51
<b>Use of holy water among the patients .....</b>	<b>52</b>
<b>Holy water and adherence to ART.....</b>	<b>54</b>
The dilemma of the priests.....	54
<b>Health workers’ experiences with holy water and ART .....</b>	<b>55</b>
<b>Social and economic issues influencing adherence.....</b>	<b>57</b>
<b>Poverty and basic needs .....</b>	<b>57</b>
Shelter and food.....	57
Lack of employment.....	60
<b>Disclosure and the risk of losing shelter and livelihood .....</b>	<b>61</b>
<b>The coffee ceremony .....</b>	<b>63</b>
<b>Disclosure in relationship to ART and “wrap-around services” .....</b>	<b>64</b>
<b>CHAPTER 4- DISCUSSION.....</b>	<b>68</b>
<b>Discussion of methods and approaches.....</b>	<b>68</b>
<b>Discussion of the findings .....</b>	<b>70</b>
The significance of ARV treatment and “wrap around services” on disclosure.....	70
Holy water: A barrier or complement to ART treatment.....	72
Strength of an ART program - strength of the Health System.....	75
Facing structural violence: Facing structural approaches.....	77
<b>CHAPTER 5- CONCLUDING REMARKS.....</b>	<b>81</b>
<b>References.....</b>	<b>82</b>
<b>Annex .....</b>	<b>87</b>
<b>Annex 1- Interview guide for patients .....</b>	<b>87</b>
<b>Annex 2 - Introduction letter with informed consent .....</b>	<b>92</b>
<b>Annex 3- Ethical clearance .....</b>	<b>93</b>
<b>Annex 4- Ethical clearance .....</b>	<b>94</b>

## Acronyms and Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
FHI	Family Health International
HAART	Highly Active Antiretroviral Therapy
HAPCO	HIV/AIDS Prevention and Control Office
HIV	Human Immunodeficiency Virus
IRIS	Immune Reconstitution Inflammatory Syndrome
NGO	Non-governmental organisation
PEPFAR	The United States President's Emergency Plan for AIDS Relief
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother to child transmission
SNNPR	The South Nations Nationalities and People's Region
STIs	Sexual transmitted infections
Tsehai	Technical Support for the Ethiopian HIV/AIDS ART initiative
TB	Tuberculosis
UNAIDS	The Joint United Nations Program on HIV/AIDS
VCT	Voluntary counselling and testing
WFP	The World Food Program
WHO	World Health Organisation

## Acknowledgement

I am greatly indebted to a vast number of people who have devoted their time in assisting me these two years. As issues related both to the health system and healing by holy water might be sensitive, I have decided to not mention any names neither in this part, nor in the thesis itself. However, I wish to express my appreciation to all of you I met during my fieldwork in Ethiopia. Special thanks go to the medical staff at Dilla Hospital who willingly gave their time and attention for my questions. I really appreciated the time spent with you and I hope some of you are still serving the HIV patients at the hospital. My gratefulness goes also to all the governmental and non-governmental institutions I visited. Your way of facilitating my stay and my work in Ethiopia was extraordinary. I am so very much thankful to my research assistant as well as my friends at the University of Dilla and my host family. Your generosity is so much of an example to me.

I want especially to thank the patients who accepted to talk to me. I will never forget your courage. My gratefulness goes also to the Orthodox priests who openly revealed some of the mysteries related to holy water.

I want to thank for the scholarship I received from The Nordic Africa Institute in Sweden and especially for introducing me to an Ethiopian historian who gave me valuable insight into the holy water issue. I am most grateful.

I feel free to mention two persons who have been crucial in this process. Karen Marie Moland has been my supervisor and given valuable support and advice through the process. Philip Halliday was willing to correct my English performance in the thesis on a very short notice. However, he is not responsible for the grammatical mistakes I still may have overlooked. I am very much grateful to both of you.

## CHAPTER 1- BACKGROUND

### Introduction

The latest reports from the World Health Organisation (WHO) and the United Nations (UN) show that even if AIDS is the leading cause of death in sub-Saharan Africa, there are signs that the annual number of new cases is declining on the continent hardest hit by the HIV epidemic. At the moment it is estimated that 22.5 million people live with the virus which is 68% of the total number of HIV infected individuals in the world. 61% of these are women (UNAIDS and WHO, 2007).

As the debate regarding antiretroviral treatment (ART) is repeatedly on the medical agenda, the focus is slightly shifting from the discussion of whether it is cost –effective to provide this treatment to poverty affected societies, to a deep concern about accessibility and adherence of those affected. Several studies show that the same level of adherence and sometimes even better than in western countries may be obtained in ART programs in low-income countries. However, there is a growing concern related to these issues (Wakabi, 2008) and a call for more investigation to detect what kind of local determinants may hamper the adherence in the different contexts (Mills et al., 2006).

Some societies possess specific features or healing traditions that may interfere with ART like healing by holy water in Ethiopia. Prior to the study, one of my assumptions was that this may be one of the issues that affects the treatment outcome negatively and contributes to treatment failure. Furthermore, my previous experience as a nurse working in low income countries, had made me believe that factors related to the professional health sector and the individual health provider, play a significant role in determining patients' adherence. These issues were the points of departure for the study of determinants for adherence to ART in Ethiopia.



## **ART and adherence**

### **The age of ART**

The area of HIV/AIDS is characterized by rapid changes and ambitious goals. In 2003 the World Health Organisation (WHO) launched the 3 by 5 initiative which set the goal to treat three million people living with HIV/AIDS in developing countries by 2005. This initiative was followed up in 2005 by the goal of providing universal access for those in need by 2010. A newly realised report from WHO shows that 3 million HIV patients in the world are now on ARV treatment. It means that 31% of those in need of treatment are receiving it. Grants from donors like the Global Fund to Fight AIDS, Tuberculosis and Malaria, the World Bank and the United States President's Emergency Plan for AIDS Relief (PEPFAR), together with a significant decrease in prices, have made antiretroviral drugs (ARV) accessible and in some countries free of charge for an increasing number of people (WHO et al., 2008)

The financial issues concerning funding of ARV drugs in low-income countries are still of great concern, and it is still not clear who will continue to provide grants to sustain the current programmes and second line drugs (WorldBank, 2006). However, at the moment it seems like the focus has shifted away from access to drugs to a deep concern for the shortage of health professionals at all levels in many countries (Kober, 2004). The brain drainage, both external to western countries but also internal to the private sector and non-governmental organisations (NGO's), limits the expansion of ARV programmes. According to figures from The Joint United Nations Program on HIV/AIDS (UNAIDS), two-thirds of people living with the virus are found in sub-Saharan Africa while only 3% of the health workers in the world are located there (UNAIDS, 2007). High staff turnover, concentration of professionals in urban areas, difficult working conditions, low salary, inadequate commitment and motivation are keywords in the debate.

### **The ART regime**

1996 marks the year for the break through of Highly Active Antiretroviral Therapy (HAART) which to a great extent has transformed HIV/AIDS from a lethal condition with a natural course of 11 years into a chronic disease (UNAIDS and WHO, 2007). The initiation of a

multiple-drug regime denoted antiretroviral therapy (ART), is supposed to be introduced when the patient's immune system has declined severely, measured in CD4 cells. The viral load and the patient's clinical appearance are also major guidelines, but the viral load can seldom be measured in developing countries. CD4 cells count can be offered in an increasing number of hospitals. A patient should start treatment before he drops below a CD4 count of 200 cells/micro l and some indicate an even higher cut off point. Several sites which provide ART rely only on clinical signs which are classified in a staging system (A,B,C) developed by WHO. Opportunistic infections indicating severe immunodeficiency, that means patients in stage C (AIDS) but also often in stage B, should start treatment. The guidelines require frequent updating and changing. Once a patient has started on ART, a lifelong treatment has begun.

Among 5-10% of patients who for a long period of time have suffered from severe immunodeficiency (a CD 4 count less than 200 cells/micro l) develop Immune Reconstitution Inflammatory Syndrome (IRIS) during the first week after starting treatment with ART. It does not mean that ART has failed, but the patient has to be monitored very closely as the condition may be lethal (Hoffman et al., 2007).

### **The problem of adherence**

In a report from 2003 WHO (WHO, 2003) defined adherence as:

*“The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.”*

The concept of adherence, which emphasizes an agreement between provider and patient, replaces the word *compliance* which has traditionally focused on the patient's obligation to comply with the doctor's instructions. The definition of adherence does not only include patients who have started on treatment, but takes additionally into account the fact that some might refuse to start on the treatment proposed. Several studies have shown that in order to maintain a suppressed viral load, an adherence of >95% is required. The consequences of low adherence are individual treatment failure and contribution to resistant strains in the society. In order to group factors that can predict adherence WHO has come up with four:

1) Characteristics of the regime. 2) Features of the individual patient. 3) The patient-provider relationship. 4) The health system (WHO, 2003).

Before proceeding further to the reasons for poor adherence, it is necessary to get an estimate of the magnitude of the problem as well as refer to some of the discussions related to the level of adherence obtained in different contexts. According to the report from WHO, approximately one-third of the patients on HAART take their medication as prescribed by the doctor. Quiet recently, a study investigating long term adherence of ART received much attention. The study aimed to investigate 32 scientific reports between the years 2000-2007. The overall conclusion was that only between 46%-85% of patients who started on ART treatment in sub-Saharan Africa, are still in the program after two years. Loss to follow up followed by death was the major reasons for attrition. The author focuses on better tracing mechanism as well as initiation of ART on an earlier stage. Programs which have shown a good level of adherence should serve as models for other initiatives (Rosen et al., 2007).

It has been a rather heated debate among researchers when it comes to the question if adherence to ART in developing countries is poorer than in high-income countries with good infrastructure. The impact of socio-economic factors and the level of education have also been discussed. Stevens et al.(2004) suggests that one has to be vigilant scaling up ART programs without the presence of a stable setting. He also claims that adherence in Africa is lower than in industrialized countries, and the risk of resistance should take precedence over accessibility.

Several researchers reacted negatively to these statements referring to other studies conducted for example in Senegal and Botswana which show an adherence rate better than obtained in Europe. Orrell C and her colleagues gave the following response to the article *“Poor adherence to medical therapy is not restricted to the poor or to Africa. Adherence to medical therapy appears to be related to the quality of health care programmes rather than a socio-economic, educational or intrinsic racial attribute”*(Stevens et al., 2004).

What kind of reasons do patients give for not adhering to the treatment prescribed?

The study from Senegal (Lanièce et al., 2003) demonstrated that financial issues like transportation costs and types of drug combinations were important factors. A study from Uganda identified the relationship between marital status and adherence and the level of

monthly income, (Byakika-Tusiime et al., 2005), while research from South Africa described difficulties with the administration of the drugs (being away from home, running out of pills, problems with the dosing schedule) and the fear of stigmatization from one's partner (Nachega et al., 2004). Findings from Rwanda revealed that the majority of patients interviewed feared the effect of increased appetite due to ART resulting in not having enough food to eat (Au et al., 2006).

A qualitative study from Botswana, Uganda and Tanzania showed that transportation cost, hunger and waiting time were major barriers to good adherence as well as stigma related issues and side-effects of treatment (Hardon et al., 2007).

A study conducted in Malawi in 2003, showed that only 13.6% of patients with tuberculosis who were eligible for and offered ART free of charge, started treatment in the following months. A mapping of the patients geographically, showed a significant association between the cost of transport and ARV acceptance. Higher cost decreased the likelihood of acceptance to start treatment (Zachariah et al., 2005). A qualitative study from Tanzania published in 2006, revealed that stigma in the society, supplementary food cost and previous negative experiences with the health system seemed to be the major reasons of reluctance. Low cost interventions changed the attitude both towards treatment and disclosure for some of them (Mshana et al., 2006).

Quite recently, an analysis of qualitative and quantitative studies from both developing and developed countries was published aiming to examine patient-reported barriers and facilitators to HAART. Financial constraints and access in general to medical treatment were the two major findings from developing settings (Mills et al., 2006).

Studies from Ethiopia investigating determinants for adherence of ART are not numerous. Healing by holy water, lack of access to public transport and fear of disclosure have been reported (Jerene et al., 2006). Lessons drawn from a tuberculosis program in the South Nations Nationalities and People's Region (SNNPR) show a high level of treatment interruption and defaults, mostly due to factors associated with difficult physical access (Shargie and Lindtjorn, 2007).

A study from 2005, (Pound et al., 2005) made a synthesis of 42 qualitative studies of medicine taking. Even though the sample does not hold any studies from sub-Saharan Africa, some of the elements are valuable to highlight. In the case of HIV infected patients, undesirable effects of the ART treatment were considered so bad that the question of whether it was worth continuing was raised. The same weighing up was also done when it came to fear of disclosure as some patients would not start ARV treatment or postpone or forget to take their dose as long as they were not alone. Patients on long-term treatment were often likely to stop treatment to see if it made any difference in their well-being.

The arrival of antiretroviral treatment has changed HIV/AIDS from a deadly disease into a chronic condition (Van Damme et al., 2006). However, in some contexts, the treatment does not create the expected interest. A recent study where 197 individuals were interviewed, concludes that there is a lack of enthusiasm towards ART partly because it cannot provide cure. The reluctance is present even among health workers who in some cases advise the clients to seek traditional healers instead of ARV (Chopra et al., 2006). Nevertheless, experiences from South - Africa must be interpreted with caution because of the authorities' particular interpretations of the HIV infection and ARV treatment. Lack of enthusiasm towards modern treatment is also mirrored in religious healing frequently used.

### **Adherence in relationship to possession cults and religious healing**

Dilger (2007) discusses in his article the role of a Pentecostal church in Tanzania where biomedical interpretations of disease are mixed with a conviction that HIV is caused by evil spirits. Through exorcism of the spirit, the patient may be considered cured from HIV. He additionally declares that modernity and modern therapy like ART, only partly succeed in satisfying people's need, which results in them searching for alternative treatment options.

Possession by evil spirits has traditionally provided an explanatory framework for physical and psychological afflictions in Ethiopia (Hamer and Hamer, 1966). Vecchiato (1993) shows that phenomena that exists in traditional possession cults in the country, continue in new healing forms in Protestant, Orthodox and independent Islamic religious movements. As for the Pentecostal movement, alternative explanations for suffering and the prospective of getting cured, attract many to seek religious healing in addition to, or as an alternative to modern medicine

## **Promoting adherence in low-income countries**

What kinds of interventions have been introduced to ensure good adherence in resource-poor settings? Some studies have been conducted and a common feature of them is the presence of a well functioning community – based program. In Haiti, investment in public health facilities has permitted the ART program to be integrated among other activities like reproductive health, treatment of tuberculosis and STDs. Taking the economical constrains of the patients into consideration, medical investigations as well as treatment have been provided free of charge. In addition to this, food-support and expenses related to transportation have been covered for those in need. A very important feature, partly described as the backbone in the program, is the presence of community health workers who in some settings have visited the patients daily to give emotional support as well as make sure that the prescribed dose has been taken. The level of adherence and minimal treatment failure have proven to be better than that which might be found in more affluent contexts (Koenig et al., 2004, Farmer, 2005).

On the African continent, Paul Weidle and his team incorporated some of the same elements in their home-based community program in Uganda, but addressed the challenges related to transportation cost by providing weekly home-delivery of drugs. The level of adherence was measured by examining viral load and CD4 count and the results were excellent (Weidle et al., 2006).

In order to improve ARV treatment outcome taking into account economic deprivation and food shortage, several donors like the Bill and Melinda Gates Foundation, PEPFAR and the World Food Program (WFP) have started during the last two years to fund programs which aim to increase food production in Africa as well as include food support as a part of the ART program. (MedicalNewsToday, 2007)

As the background section illustrates, the problem of adherence in low- income countries involves many additional aspects which both the definition of adherence and the factors predicting adherence as mentioned by WHO only partly cover. Hence, in the following chapter I will give a historical introduction to the Ethiopian context which emphasis structural issues that have an impact on individual adherence and health care in general and on HIV/AIDS and adherence to the ART regime in particular.

## **The Ethiopian context**

The concept of *structural violence* which is part of the conceptual framework in the thesis will be presented in next chapter. However, the main focus of this section is to understand the history behind the structural and economic realities the population face today. This section will therefore start with a presentation of the historical context focusing on the south of the country particularly in the Gedeo Zone. It is followed by an introduction to the Orthodox Church and healing by holy water, and ends with a presentation of the Ethiopian health system and the arrival of HIV/AIDS.

### **A history of poverty and repression**

#### The Abyssenian kingdom and Haile Selasse

Ethiopia with its geographical boundaries as we know the country today, is not more than hundred years old with the last area, Ogaden, situated on the border to Somalia, incorporated in 1948 by the last emperor, Haile Sellassie (Mammo, 1999). Except for five years of occupation by the Italiens (1936-1941), Ethiopia was never colonized. However, the Abyssenian kingdom of Tigrean and Amharic rulers in the northern part of the country conquered the southern tribes and established a land tenure system. Several scholars have therefore compared the marches to the South both to colonisation and feudalism in the Medieval Europe, while others draw the attention towards more traditional African kingdoms (Donham and James, 1986).

The land in the South was often considered unsettled and given as a reward to soldiers and nobilities instead of salaries. The traditional landowner became a *gebbar* entitled to pay tax to the new soldier settlers or landlords. In addition to taxes, the *gebbar* was obliged to perform several duties accordingly to what one might be tempted to describe as slave contracts. Forced labour, the exploitation of both human and ecological resources was a measure for the settler soldiers to get as much benefit as possible during the period they were employed by the government (Mammo, 1999).



The Gedeo Zone is traditionally known for coffee and *enset* which is the false banana plant only cultivated in Southern Ethiopia. It has been given the name: “The three of hunger” for its significance in times of hunger and deprivation (Tadesse, 2002). The *gebbar* had the possibility to pay their tax in commodities and *enset* was the main one until 1920 when it was replaced by coffee. The heavy reliability on one crop, contributes significantly to the vulnerability of the economy and food security in the area today.

When Haile Seillasse was enthroned in 1930, he started a modernization process in the country where schools and hospitals were constructed and students sent to western countries for higher education. He also introduced a new administrative reform in 1941 where better off *gebbars* who previously had been landowners, were given back their plots, enabling them to start paying tax to the crown instead of to the settlers. Land was also given to noblemen, military officials and supporters of the emperor, while the peasants were given the unpleasant job of supporting the luxuriant lifestyle of the privileged class. Through this policy, land was increasingly transferred into the hands of a small privileged class as well as of the crown and the church. In 1960 this resulted in social unrest and peasant revolt which prepared the ground for the revolution in 1979 (Mammo, 1999).

### The Derg regime

After years of unrest, economic deprivation, unemployment and growing dissatisfaction with the regime of Haile Seilasse, 1974 became the year when students, civil servants, trade unions, lower clergy, taxi-drivers, factory-workers and, in the end, the armed forces joined hands and started the revolution which became the end of the old empire.

The Ethiopian Student Movement which had been established in 1960 after a peasant revolt, had been radicalized and even more determined to bring about the end of the regime and change the situation for the poor. Even though, from the very beginning, they strongly agitated for a civil government, they took active part in the implementation of the new legislation and land distribution put in place by the new Marxist regime, the Derg. Private ownership became illegal as land was turned into the property of the masses. Peasants were told to become members of Peasant Association, in charge of distributing the land among themselves. Modernized farms were turned into co-operatives and state farms benefited from agricultural developments like fertilizers, improved seeds and credits. Almost four million people were forced to move from drought affected areas into assumingly less densely



populated areas as in the south. Opposition to rules and regulations was punished by imprisonment or execution (Mammo, 1999).

### Ethiopia after the Derg regime

Centralization of power and decision-making have characterized the different regimes in Ethiopia. The government replacing the Derg in 1991, tried to build the structure of a decentralized system often called ethnic federalism, based on ethnicity and language. The sub-units are devised into nine regions and two administrative areas, followed by the *Zone*, *Worodas* and *Kebele* as the smallest administrative unit (Ayenew, 2002).

In 2005, violence followed the election of a new government. Several people were killed and others arrested as a result of opposing the results. The prime minister succeeded in remaining in office, but the event resulted in several donors, among them the World Bank, stopping funding the federal government and transferring resources directly to the *Worodas* (Unit, 2007).

Ethiopia has gained a reputation as a country characterized by recurrent episodes of drought and famine where millions have been in risk of dying from hunger and starvation. In addition to that, the war with the neighbouring country, Eritrea, has been extremely costly both in terms of human life and resources allocated for that purpose. The country ranks as number 169 on the Human Development Index (UN, 2007/2008).

The food security in Ethiopia is therefore a major concern as the country is exposed to environmental changes which strongly affect an already vulnerable region. High population growth resulting in pressure and degradation of cultivated land are severe treats to survival (HAPCO, 2007). The government estimates that 52% of the population is food-insecure. (Brigsten et al., 2005) . Figures from WHO show that 50, 7 % of children less than five years old are stunted, while 34, 7 % are underweight. Life expectance at birth is 50 years for men and 53 years for women. Under -5 mortality rate is estimated to 164 per 1000 (WHO, 2007).

The figures from IMF for 2006/7 show a growth in real GDP in 9.4%. At the same time, a matter of great concern is the heavy inflation estimated at 14% as an annual average with food prices driving the percentage up. Ethiopia as well as other low-income countries faces the harsh conditions of increased food prices which account for about 50% of the consumers'

price index. The main source of income for the country is agricultural products where coffee accounts for most of the export products followed by oilseeds and *khat* (narcotic drug) (Unit, 2007). It is estimated that 85% of the population is employed in the agricultural sector (HAPCO, 2007). Ethiopia is the largest producer and exporter of coffee in Africa, well-known for its high quality. It is also the backbone of the economy in the country as it contributed up to 41% of foreign exchange earnings in 2005. Changes in the international market and price collapses such as in 2002 have affected the national economy enormously, not to mention the individual coffee farmer as well as traders and exporters (Petit, 2007).

Arriving in the capital and continuing by road to the main cities a visitor is quickly struck by the construction of new buildings and roads. New shopping centres with imported goods are popping up and the number of new cars with domestic owners is increasing rapidly. Even though the figures show economic growth, the increased inequalities have according to some scholars contributed negatively to reduction of poverty in the country (Brigsten et al., 2005). As such a great majority of the population is constantly living under conditions which hardly let them survive, additional “shocks” like the death or serious illness of the breadwinner, failed harvest or sudden unemployment, might be the final obstacle to survival (Oxfam, 2001).

The illiteracy rate in Ethiopia is 58% for men and 55% for women and very high compared to other countries in the region (WHO, 2007). Even though enrolment of students both in primary and higher education has been considerable, especially in urban contexts, the quality of education in all the levels is a major concern. The combination of many students, few teachers and overloaded classrooms is part of a big problem. It is estimated that only 30% of children from rural areas complete six years of education. (Negash, 2006)

## **The Ethiopian Orthodox Church**

### The expansion of the church in the Abyssinian Kingdom

Tracing its origin back to the arrival of Frumentius, a Syrian Christian in the fourth century and the conversion of King Ezana of Axum, some years later, the Judaistic influence of the country had already begun, according to the Orthodox Church, with the encounter between King Solomon and the Queen of Sheba. Though perceived as a legend by scholars, the son

conceived from this relationship, Menelik, brought the Arc of Covenant to Ethiopia where it still resides according to the Church. The close connection with the mother church in Egypt and the neighbouring countries was interrupted when the oppressing movement of Islam started in the seventh century and isolated the country from the rest of the Christian world. Centuries of isolation both in terms of cultural and religious influence, has resulted in the development of a very particular branch of the Christian body. Today the Ethiopian Orthodox Church is a part of what is called the Oriental Orthodox Churches which include the orthodox churches in Syria, Eritrea, Armenia, Egypt and India (Chaillot, 2002).

While treating subjects related to the Orthodox Church in Ethiopia, it is very important to see how it is historically embedded with the state. As Mammo (1999) points out, parallels to mediaeval Europe can be drawn where the church and the state had mutual interests in supporting each other. The hierarchy with the king situated on the top followed by the clergy who transformed the kings laws into spiritual commandments, was an efficient way of governing the peasants. As a reward for the service, considerable land was given to the church to whom the peasants were obliged to pay tax.

As pointed out earlier; the arrival of the settlers from north, rooted in the Orthodox tradition also brought the church to the south of the country. Even though sporadic attempts to Christianise the southern areas were made from the 15th century (Tolo, 1998), the expansion of the church has to be seen in relationship to the imperial building of the Abyssinia kingdom. According to some scholars, the multiple concentrations of churches in the Gedeo Zone was at that time, not a result of proselyte activism, but a need for the landlords to settle closer to their valuable coffee estates which expanded rapidly in the 1920s. The Orthodox Church was therefore closely associated to the power and the landholders, and did not find great support in the Gedeo population (Donham and James, 1986, Tolo, 1998).

### A church of diversity

The church hierarchy consists of the patriarch, bishops, priests and deacons. The education of priests may differ a lot both in length and content. Some have been enrolled in governmental schools and also attended secular education, while others have only received religious teaching given in the courtyard of the church or a monastery. During the last sixty years, six Clergy Training Centres have been established in different parts of the country in order to

upgrade the traditional teaching. At the Theological College of the Holy Trinity in Addis Abeba it is possible to obtain both a diploma (three years) and a degree (five years) which contain both theological and general subjects. The Patriarch is the head of the church and was until 1959 from Egypt, assigned by the Coptic Church. The Patriarch since 1992 is Abuna Paulos, an Ethiopian monk with a doctoral degree from the Princeton Theological Seminary in the United States (Chaillot, 2002).

A very important part of church life and history in Ethiopia is the monastic life where both monks and nuns may be linked up to a community. There are about 800 monasteries in the country. The monasteries have the reputation of traditionally being the principal teaching centres and theological disputes have mostly been carried out by monks, not priests (Bakke, 1986). In addition to that, some of the monks chose to become eremites and live in very remote areas where they reside in great simplicity in a cave, hut or a hollowed tree. At some special occasions they enter public places to preach and sometimes criticize aggressively both ordinary and important personalities, proclaiming that the Holy Spirit or a saint has revealed a message to them in a dream (Chaillot, 2002).

Even though the church is rooted in the Judaistic-Christian tradition several scholars emphasise the integration of elements from traditional Amharic religion. Both systems uses evil spirits as models of explanations for disease and healers often have a kind of referral systems between themselves independent of religious faith. Magical formulas and amulets are prescribed as treatment for ailments in addition to holy water and pilgrimages. The practitioners are often the Debetras, who are non-ordained clergymen in charge of the church music, but additionally may be denoted as magicians, both loved and feared for the supernatural power they possess. Both holy Christian sites and healers are visited by patients from other religious backgrounds (Messing, 1968, Slikkerveer, 1990, Bakke, 1986).

### Religious healing

It is not possible to give an introduction of the Orthodox Church in Ethiopia without mentioning food restrictions and fasting. During fasting, the Christians are expected to refrain from meat and animal products like milk, butter and egg. There are 250 fasting days in the year but believers more than 7 years old are expected to fast about 180 days. Fasting days means that neither food nor liquids should be taken before noon at the earliest. Pregnant women, travellers and serious sick patients do not have the obligation to fast (Church, 1970).

Fasting is a precondition before utilisation of holy water.

Searching databases using “holy water” and “Ethiopian Orthodox Church as keywords”, did not yield many results. A recent article in the area of mental health disorder mentions the phenomena, categorized as “traditional treatment.” (Jacobsson, 2002). In his book on medical pluralism in Ethiopia, Teshome (2006) describes the procedure of exorcism: Prayer, holy water and identification of the evil spirit are the major features in the ceremony. Vecchiato (1993) describes a visit to the holy water site in Wallame, four kilometres from Dilla town where he met the same healer as I interviewed during my fieldwork. Belief in God and the power in the holy water, *tebel*, heals suffering caused by evil spirits.

What is the official view of the Orthodox Church regarding this subject? Very few books published by the Church itself are translated into English. The only book found which treats the subject is no longer for sale, but contains the following passage:

*”Holy water is blessed by the priest for the purpose of seeking from God a blessing on those who use it and protection from the power of darkness. It is a symbol of interior cleaning, interior purification. Holy water is used in the blessing of everything which the church wishes to sanctify. Besides the use of baptismal water, the sprinkling with holy water is part of many sermonise. After the birth of a child the confessor priest asperses the house and all within with holy water, cords for the neck (mateb) are blessed and demons are exorcised with holy water. If a man is sick, sometimes holy water is supplied for drinking pouring over his hands and sprinkling his face and body. Holy water sanctifies whoever is touched by it, frees him from uncleanness and attacks of the power of darkness, and secures that wherever it is sprinkled there is freedom from pestilence and snares*

*(EthiopianOrthodoxChurch, 1970)*

As we may see from the quotation; holy water is not only used for curing diseases but also as a blessing and protection against evil forces and for exorcism.

It is estimated that 85% of Ethiopians seek medical help from other sources than modern medicine (Teshome, 2006). Since the introduction of ART to Ethiopia, the question whether you may combine it with holy water has been a matter of concern both among the laity and

the clergy in the Orthodox Church. The criticism of the Church from the medical community, activists and donors, led in May 2007 to a declaration by His Holiness Abune Paulos, Patriarch of the Ethiopian Orthodox in which he stated that it is possible to use ART treatment at the same time using holy water. As my interviews will show later on; it is necessary to quote his announcement: *"Both are gifts of God, they neither contradict nor resist each other," "You can swallow your drugs with the holy water"* (Plusnews, 2007).

In September 2007, several international news agencies, among them Skynews, made a number of reports from St Mary on Mount Entoto outside Addis Ababa. The head priest, Father Geberemedhen, states clearly that patients are not allowed to take their ARV drugs as long as they are using holy water (SkyNews, 2007a, SkyNews, 2007b).

### **The health sector**

The Health Sector Development Program (HSDP) which was drafted in 1993/94 and given a timeframe of 20 years, is closely linked up to the Ethiopian Governmental-led Sustainable Development and Poverty Reduction Program (SDPRP) which in 2006/7 was replaced by the Plan for Accelerated and Sustained Development to end Poverty (PASDEP) (Unit, 2007). The main objective is to reduce poverty through economic growth and used as a roadmap to reach the Millennium Goals. The HSDP focuses on deliveries of preventive and curative health, based on a community - health delivering system where the four sectors; public, private, NGOs and traditional healers are included. The private sector started to operate in a legal framework in 1995 and is highly represented in, for example, hospitals, clinics and pharmacies (Worldbank et al., 2005).

A qualitative study conducted by the World Bank in 2005 to assess the performance of health workers in the country, mirrored a depressive situation where concentration of professionals in urban settings and lack of accountability leads to a situation where health workers devote their time to private clinics though employed by the government. Poor patients have access only to low quality health services in facilities run by the government which lack even the most basic equipments and drugs (Lindelov and Serneels, 2006).

The public health sector is organized in 5 levels where the Health Posts are the smallest unit followed by Primary Health Care Unites (PHCU) often called Health Centres (HC), District Hospitals, Zonal Hospitals and Specialized Hospitals. The Ethiopian government has a plan

of assigning two health extension workers to each Health Post, and it is still widely debated as to what extent they should provide curative care in addition to preventive activities.

As for the governmental structures as a whole, the health sector has also gone through a process of massive decentralization where budget allocations are delivered as block grants directly to the Worodas. They are in charge of setting the priorities and delivering services like construction of Health Centres (HS) and Health Posts (HP) (Worldbank et al., 2005). Total governmental expenditure on health out of GNP is estimated to 5,3%, while 35,2% of total expenditure on health comes from external sources (WHO, 2007).

Narrowing the focus down to the AIDS /HIV infection, prise en charge and management issues have been subject to several changes throughout the years, but since 2002 the HIV/AIDS Prevention and Control Office (HAPCO) has been the main body in the development and implementation of strategic plans in the areas of prevention, care, treatment and support. According to the Strategic Plan for Intensifying Multi sectoral HIV/AIDS Response (SPM 2004-2008), HAPCO is accountable to the Ministry of Health and the Regional Health Bureaus and is in charge of coordination, resource mobilisation, multi sectoral monitoring and evaluation at national and regional level. Decentralization and community-mobilisation come back as keywords. The report is build on the principals of the “Three Ones” (One agreed HIV/AIDS Action framework for coordination among partners, One National AIDS Coordination Authority with extended mandate, One agreed Monitoring and Evaluation System on Country level.) (MOH, 2006). In 2007, HAPCO delivered The Multisectoral Plan of Action for Universal Access which is an integrated component of PASDEP, summarizing the effort of the last years as well as focusing on the challenges and objectivities for the period of 2007 to 2010 (HAPCO, 2007).

### **HIV/AIDS in Ethiopia**

The first cases of AIDS in Ethiopia were detected in 1986. It has been a challenge to obtain good estimates of prevalence but the latest figures for 2007 show a total prevalence in the country of 2, 1% where 0, 9% of cases are found in rural areas and 7, 7% in urban. When it comes to SNNPR the prevalence is 0.7% in rural areas and 7.4% in urban which mean a slight decrease in the cities in the region and a stable situation in the countryside. Women are more affected than men (1, 7% against 2, 6%) Almost a million people are estimated to live with



HIV/AIDS in the country. 132,410 of those are found in SNNPR (MOH, 2007). It is estimated that approximately 50% of hospital beds are occupied by HIV infected patients which heavily affects the already overburdened health sector (HAPCO, 2007).

Management and prise en charge of a lethal infectious disease might be a complicated task even in a high income country. In a context where about 83% of the total population lives in rural areas where health care and infrastructure is very limited and 50% of the total number of HIV infected individuals reside in these areas, the task is immense. 75% of urban households and about 42% of rural households live within proximity of 10 kilometres to the nearest health facilities. Ethiopia has the lowest physician-per-1000-persons ration in the world which is 0.04 compared to the average in Sub Saharan Africa which is 0.1 per 1000 people. The ratio of nurses is 1: 4 882 with some of them only having one year of training (Worldbank et al., 2005). It is very important to be aware that most of the health professionals are found in urban areas, and curative assistance in a rural health facility might be severely limited both in terms of personnel and drugs.

In the beginning of 2005, antiretroviral treatment became free of charge. At that time, the estimate of the number of patients in need of ART was 277 800 while only 13% of them were currently on treatment. In 2007, 32 % of those in need received treatment in 272 health facilities. Several partners, mainly the World Bank, The Global Fund and PEPFAR have contributed significantly to financing the activities. According to the latest estimates from HAPCO, the period 2006 to 2012 will require an input of 34, 2 billion Ethiopian birr (US\$ 3, 9 billion) where 42% is allocated for care and support and 25% for treatment. For the year 2007/2008, 41% is covered by the different partners, but these funds will decrease considerably (HAPCO, 2007).



## **CHAPTER 2- METHODOLOGY AND ANALYTICAL APPROACHES**

### **Study objectives**

#### **Main objective**

To identify major determinants associated with adherence to antiretroviral treatment among HIV infected adults in South - Ethiopia

#### **Study objectives**

- To explore barriers to and facilitators of ART adherence at the family and community level in Dilla
- To investigate factors within the health delivery system that may strengthen or weaken ART adherence
- To describe the holy water healing regime of the Christian Orthodox Church in Ethiopia
- To explore the use of holy water among HIV positive individuals and ART users in Dilla

### **Methods**

In the following chapter, I will present the study setting and my methods. Aspects related to the way the data has been analysed will be treated here, while discussions related to the methodology chosen, the findings in the study and their validity will be addressed in chapter four.

#### **Study setting**

The study took place in one of the most populated regions in Ethiopia, The Southern Nations Nationalities and People's Region (SNNPR) which is the home of approximately 15 million of the 80 million people living in Ethiopia. Awassa is the centre of SNNPR which is one of the regions with the highest number of HIV infected individuals in the country.

The region is divided into zones. Gedeo Zone which is famous for the Yirgacheffe and the Sidama type of coffee is one of the most populated areas in the country, resulting in small plots for the individual landowner. The Zone is also known for the cultivation of *enset*, (the false banana plant) as well as fruit and *khat*. Most of the data-collection was carried out in Dilla town, the commercial centre for coffee production and distribution, located on the main road leading to Kenya. Dilla is also a university town characterized as semi-urban with a young population and is the home of 64 000 inhabitants. As the majority of the economic activities are related to the coffee harvest, the town is characterized by seasonal employment in all sectors. It leads to a big influx and mobility of people resulting in prostitution and high prevalence of HIV.

Even though the Gedeo people make up the majority in the Zone with 81% of the total population, Dilla represents a much greater diversity of ethnic groups due to the influence of governmental workers employed in the sectors of health and education as well as the coffee production and distribution. The same features are reflected in religious composition where only 22% of the population in the Zone are Orthodox Christians while the proportion in Dilla town is much higher. There are four Orthodox Churches in town and historically it has had much influence as already described. The rest of the population belongs to Protestantism and Islam but as both ethnic and religious statistics are sensitive issues in this context, reliable figures have been impossible to obtain (CentralStatisticAuthority, 1996).

The study was initially planned to only include participants in Dilla town. However, fear of stigma and disclosure had made some HIV patients attend ART programs in other locations like Awassa, Yirgalem and Yirgacheffe. Yirgacheffe is situated 45 kilometres further south of Dilla and the location for the only health centre in the catchments area of the hospital providing ART. As I was interested in the experiences and opinions among health providers, I decided to extend the area geographically also because the head offices of NGOs and governmental organisations were located in Awassa. Extending the study setting geographically resulted also in the possibility to include priests in Yirgacheffe and Awassa.

### Health Care and major actors associated with the ART program in Dilla

When it comes to health services, six private clinics may be found in town. Dilla district hospital was founded by a faith based organisation called “Sudan Interior Mission”, but for several decades has belonged to the government. According to the Medical Director, the nearest established hospital south of Dilla is 4000 km. away. Even though the catchments area is supposed to cover 800 000 patients, the hospital is in reality estimated to serve between 1.5 to 2 million people. The hospital compound is situated on a slope, south of the town. The units are located in separate buildings and joint together by cemented pavements. The ART unit is an integrated part of the hospital and can not be identified as different from the other services. Patients coming for consultations do not have to sit in the waiting area at the entrance of the hospital, but go directly to the ART unit. Even though the Regional hospital in Awassa is officially the referral hospital, most of the medical evacuations are directed towards the hospital in Yirgalem situated on the road to Awassa. Yirgalem is a small town but the hospital is well known in the region for its reputation of good quality of care.

International NGOs are not very visible in Dilla, but financial support from international donors is channelled through local NGOs and churches. In the field of HIV/AIDS, Samaritan Plus, a faith based USAID supported organisation has engaged in preventive activities. The national HIV/AIDS Prevention and Control Office (HAPCO) is represented by two offices, one for the Zona and one for the Woroda (Dilla town).

The ARV treatment in Dilla was initiated in collaboration between the hospitals, NGOs and the John Hopkins University in the autumn of 2005. The Regional HAPCO is in charge of the implementation of the program, while the role of the NGOs is to assist, mentor and fill the gaps of need according to HAPCO’s Regional Head of Care and Support. The Zonal and Woroda HAPCO is in charge of the coordination of activities between the different actors as well as the implementation of the program locally.

One of the major collaborators in the ART program is The John Hopkins University in Baltimore. Through their program called: Technical Support for the Ethiopian HIV/AIDS ART initiative (Tsehai) which is operating in four regions in Ethiopia, one among several tasks is to provide technical support to the hospitals in SNNPR. They have been in charge of training personnel and supports all TB/HIV related activities as well as monthly follow up

where physicians, nurses, pharmacists and clerks are monitored. They do also conduct training sections for physicians who are working or are supposed to work in ART programs.

When it comes to individual care and support,” wrap-around services,” I was told at the hospital that three national NGOs/faith based organisations were engaged. One of them was the Ethiopian Orthodox Church which previously had an office in town organizing the support. When I arrived it was closed down and moved to Awassa. The Orthodox Church relies on temporary funding. This means that they are not in a possession to make sustainable plans for a prolonged period of time. Tesfa goh is an organisation based in several towns where seropositive patients who have disclosed, actively take part in official meetings by presenting their stories as well as being involved in income generating projects. The manager of the organisation had just left and his successor not yet found resulting in a limited access to information for my part. According to my informant at the Zona HAPCO, the organisation is strong when it comes to mobilization and campaigns. They are funded by HAPCO but has limitations when it comes to management of activities

Medan Acts is the biggest and the most influential actor in HIV care in Dilla and was frequently mentioned in my conversations both with patients and health workers. A broader presentation is therefore needed as I will return back to them several times. Medan Acts is a nationwide Christian organisation linked to the Kale Heywet Church and operates in three towns in SNNPR. During an organisational capacity assessment they were chosen as partners by the Family Health International (FHI) who for the time being is their major donor. Operational in Dilla from 2001, they started visiting homes where bedridden patients lived. Some of the patients got assistance to travel to the hospital in Yirgalem where ARV treatment was available before the program started in Dilla. Today the organisation is involved in preventive activities, like family planning and assistance to orphans and vulnerable children, as well as the community-based home care program where 60 caregivers from the community and 5 nurses are involved. They operate as a link between the patient and the hospital as the caregiver in some cases visits the patient up till three times a week. The nurses are in charge of the follow- up of patients and caregivers as well as conducting training sessions for them. They also provide basic medical care and adherence counselling. The organisation works in close collaboration with the idirs which are in charge of assigning caregivers.

The World Food Program gives food assistance for the most vulnerable patients through the NGOs, mainly Medan Acts after a clinical assessment by the physician at the ART unit.

In addition to channel support through Medan Acts, Family Health International, (FHI) is providing technical support and follows up Health Centres in the region which have started ART programs or is in the process of starting. According to the regional manager, FHI has a team of three medical doctors who visit the centres twice a month and give clinical mentorship. This initiative started in October 2006.

The Iddirs may be described as independent community associations found both in rural and urban areas. Their main objective is to assist the members of the association during bereavement both with financial and practical help. Most of the people are members of one or several iddirs which have become a social structure in the civil society and are often approached by both governmental and nongovernmental organisations vis-à-vis development issues (Pankhurst and Mariam, 2000). The iddirs have the responsibility to recruit caregivers working for Medan Acts and they also participate in coordination meetings with the *woroda* HAPCO, the hospital and the NGOs.

### **Study design**

The study has a qualitative design which and focuses on the “*way people in particular settings come to understand, account for, take actions and otherwise manage their day – to-day situation.*” (p.7) (Miles and Huberman, 1994). Qualitative research aims to understand the meanings that individual or societies relate to specific events or phenomena, and is a good tool when it comes to investigating areas which have not been well studied (Malterud, 2006) like for the case of ART in relationship to healing by holy water in the Ethiopian Orthodox Church. There are several approaches within the methodology itself. When there is a need to investigate the quality and impact of a specific on-going program in a context, The Framework Analysis which often is used in applied policy research became the tool in this study. It is a deductive method which uses results from previous research to structure the work from the onset, like in the interview guides (Ritchie and Spencer, 1994).

### **Study population and characteristics**

The study population consisted of three groups: patients on ART, health providers and local Orthodox priests. Nineteen (19) patients, seven (7) priests, four (3) nurses, seven (7) medical doctors and administrators participated in the study. Among the patients, ten (10) were male and nine (9) female. Among the health providers, only two were women. Priests in the Orthodox Church in Ethiopia are all male.

Regarding the education level, a majority of the patients had completed fourth grade while three of them had never attended school. None of them exceeded eleventh grade. Eight of the patients answered no to my questions on occupation, while the rest had sporadic jobs or were selling things in the local market. Three of the patients lived outside Dilla. Two of them were in merchandise and one of them appeared to be better off than the big majority. All except one of the patients spoke Amharic. Duration of ARV treatment had varied from one month to two years at the time of the interviews.

All the health providers interviewed were associated with ART programs as either nurses or physicians in clinical practice or as administrators of programs in the governmental sector as well as NGOs. The physicians at the hospital in Dilla were new graduates from the medical faculty and had stayed for maximum eight months at the hospital. They were assigned for six months each to the ART unit. The nurse who coordinated the program as well as my informants in Awassa and Yirgachefe had been at their posts from the beginning, while the physician in Yirgalem had one and a half year of experience at the ART unit.

The Orthodox priests represented a great variety of age and level of education. All of them had received several years of informal religious teaching which two of them as adults tried to complement by attending classes on primary level in governmental schools. One of them, the healer in Wallame was not ordained but has in this study been classified as priest. Two priests had attended higher theological education.

### **Sampling method and recruitment of study participants**

Selection of participants in qualitative research is often called *purposeful sampling*.

Individuals are selected because they possess certain features which may be the focus for investigation. They may be denoted as “information-rich cases” which may provide in-depth

knowledge about the specific research area. There exist several methods but this study has partly used *typical case sampling* and *convenient sampling* for selection of patient informants with the assistance of the nurse in charge of coordination of the ART program in Dilla. The selection of Orthodox priests and health providers was done through *snowball and chain sampling* (Patton, 1990).

### Patients

The criteria for selection of patient participants became a compromise between the study objectives and what it was possible to obtain in the hospital context. They consisted of three elements: 1) Adults currently on ART treatment. 2) Residences from both Dilla town and surrounding villages. 3) Gender balance. 16 of the patients were interviewed in the hospital. The initial plan was to go through the files of patients with an appointment for the next day and select participants, trying to focus on those who from the record seemed to have problems with adherence. Due to financial reasons as well as the time aspect, it turned out that the nurse asked those who were present to participate, explaining the content of the letter of informed consent. Before asking the patients to participate, she gave me a short description of the person to ensure that he/she fitted well with my criteria. Everyone, except for one patient who did not have time, volunteered to participate. Three individual patient interviews took place in the courtyard of Tesfa goh. All of them were working as caregivers for the organisation and were used to expressing themselves and speaking in public about their situation. It resulted in longer and sometimes more fruitful interviews as they had stayed longer on treatment which enabled them to describe changes over time in their own life and the mentality in the society towards HIV patients and ARV treatment.

### Health providers

The selection of health providers was based on the result of the mapping of actors related to the ART program. Health providers in charge of the ART programs in Dilla, Awassa, Yirgalem and Yirgache were visited. I also visited the Woroda HAPCO as well as The Zonal HAPCO in Dilla. During my first days at the hospital I was informed about the collaboration with the two NGOs in town, Tesfa goh and Medan Acts. As most of the assistance was provided by Medan Acts and information from them was easily accessible, I visited them three times and Tesfa goh one time. In Awassa, I interviewed the Manager as well as the

Head of Care and Support in the region of Family Health International (FHI) and the Regional Leader of the John Hopkins Initiative (Tsehai). I additionally had an interview with the HAPCO Regional Head of Care and Support.

### Priests

Regarding the selection of participants among the priest, I was fortunate to utilize the contacts of my research assistant who himself was an Orthodox Christian. The first interview was with one of his students in primary school in Yirgachèfè, a priest in his thirties. Through that gateway we were able to access two other priests in Dilla as well as the healer in Wallame and a visiting priest from Awassa who had a reputation for having extraordinary gifts of healing. Arriving at Awassa, I got in contact with another research assistant who also was an Orthodox Christian and due to his contacts in the church I got the chance to interview two priests in the St. Gabriel Church which is the principal church in Awassa. I was not given permission to interview the priest in charge of the holy water site as two other priests with higher education and possessions were assigned as spokesmen and were available for interviews. Both of them were taking part in the theological education of priests and one of them had previously been the leader of the church.

### **Data collection methods**

The collection of data was done during fieldwork which lasted from the 10th of June to the 20th of August 2007. Two months were spent in Dilla where most of the data was collected. The last month was spent in Awassa. The study uses triangulation which means that several methods for data collection were utilized as well as three different interest groups interviewed.

After the field study in Ethiopia, one month was spent in Uppsala in Sweden where I had been granted a scholarship at the Nordiska Afrikainstitutet. Through the research director of the centre, I was able to make an interview with an Ethiopian scholar, a historian who provided interesting insights into the area



### Semi- structured in –dept interviews

Peoples' experiences, opinions and perspective are of major interest in qualitative research and may emerge through interviews. In order to be sure that the topic of interest is well covered as well as structuring the time available during the interview, an interview guide is prepared in advance (Patton, 1990). As the study included three different groups, an interview guide was prepared for each of them. All patients except for one who was very concerned vis-à-vis disclosure, accepted that the interviews be recorded. The interviews lasted about 45 minutes. The openness and willingness to share experiences which was the focus for the interview, was significant.

The focus for the interviews with health providers was also related to their experiences with the programs. During the interviews with health workers, I had to divert from the interview guide and only select themes as it had to be adapted both to those working in clinical settings as well as administrators of programs. Seven interviews were recorded and transcribed.

The interviews with the Orthodox priests differed a lot in quality and content. The interview with a priest from Awassa who carried out healing sessions in Dilla and the priest of the St. Gabriel church in Dilla lasted a maximum of 15 minutes each due to their limited time schedule. However, they gave valuable answers to the questions which were treated. The rest of the interviews approached one hour. Five of them were recorded. The priests were also surprisingly open and gave valuable answers related to the focus of the interview: the regime and practise of holy water.

### Focus group discussion

Focus group discussions are a cost- effective way to gather lots of information in a short period of time as the group often consists of 6-10 informants. It should be well planned, focused on the topic with a topic guide and include an assistant to take notes and be in charge of the tape recorder (Patton, 1990). The only focus group discussion I conducted was not at all planned as I had imagined stigma and fear of disclosure would make it impossible. However, as I had made an agreement with the manager of Medan Acts to interview some of their beneficiaries, it turned out that he had collected a group of five at the time of my appointment. When I asked them whether they would feel comfortable to talk to me as a group, they all

responded positively. The group consisted of three women and two men who had been on ART for a period of two months to two years. As I was not prepared for this, I decided to use questions from my interview guide in the discussion which was recorded. It turned out very well as people expressed themselves freely, provided me with new elements and confirmed lessons drawn from the individual interviews especially related to reduction of stigma and the effect of the coffee ceremony.

### Participant observation / Field notes

Participant observation is the main method used in ethnographic studies as it is a way to enter into the daily activities and routines in a given context. It provides a good opportunity to conduct informal interviews which often take the form of a normal conversation (Parahoo, 1997).

Two weeks were spent at the unit before the first patient interview was conducted. During that time I was getting an overview of the unit and the routines as well as observing the patient consultations and listening to the experiences of those working there. When I did not have interviews, I continued to spend time in the unit as well as sometimes following the physicians on their daily round at the medical ward. The primary objective was to be familiarised with the setting as well as the routines and the structure of the program. During the whole time of data collection, I made extensive field notes which according to Malterud is the foundation for analysis of participatory observations (Malterud, 2006)

### Documentary review

I went through research articles from different countries and contexts to see what kind of barriers to ART treatment had already been identified. Using Paul Farmer's framework of *structural violence* created the need to understand more of the historical context of Ethiopia as well as the contemporary situation. Research articles in the field of ART treatment in Ethiopia are not many but provided some insight. Veccaci's article from the healing centre in Wallame outside Dilla gave me the idea to visit the place as well as shedding some light on the connection between spirit possession and sickness.

### **Ethical issues and informed consent**

Before coming to Ethiopia, ethical clearance to conduct the study was obtained from the Regional committee for medical research in West- Norway, REK-Vest. Arriving in Ethiopia,

the same permission was granted from the South Nations Nationalities and People's Regional State Health Bureau which also later on gave me the permission to interview health workers in the hospitals in Awassa and Yirgalem. On my visits to the Health Centre in Yirgachefe and the NGOs in Dilla, the manager of the hospital provided me with a letter of recommendation.

The major challenge during the field study was to find a good translator who at the same time also could assist me as a research assistant. Even though most of the interviewees have the Gedeo language as their first language, everyone except for one patient spoke Amharic which was used during the interviews. The medical doctors at the hospital were very concerned to avoid having patients exposed to someone well known in Dilla town. Both requirements were met through using a teacher situated in Yirgachefe who volunteered to work with me for three weeks and was considered trustworthy by both health workers and patients.

Before starting the interviews, the research assistant explained the content of the letter of informed consent. Looking back, I can readily see that the letter should have been translated into Amharic. I also asked for permission to use the tape recorder, clarifying that the material would not be used for any other purposes than my research. Except for one man, they all agreed to let me use it.

My major distress was related to the feelings of exploiting patients' emotions on very difficult subjects like discrimination in the society and lack of social support. "*Interviews are interventions. They affect people*" (p. 405) (Patton, 1990). Some of them started crying as they talked about these issues, and I am not sure that they appreciated having those burdens and feelings brought to the surface. No follow up was scheduled afterwards. Money cannot of course not compensate for this, but as economic deprivation plays a major role in the life of people in such a setting, it would in my view, have been appropriate to make some kind of contribution.

### **Research assistance and translation**

As I do not speak Amharic and the knowledge of the language is indispensable for doing research in Ethiopia, I was fortunate to get assistance from a teacher who in addition to his job was undertaking a Bachelor degree in English at the University in Dilla. He was available for the three weeks we were interviewing patients, health workers and priests in Dilla and

Yirgachefe. In order to conduct two interviews with priests in Awassa, I was assisted by another research assistant, also with a Bachelor degree.

The combination of limited budget, confidentiality issues and difficulties in finding people with a good level of English, made it necessary to do make compromises transcribing the interviews. We usually conducted two patient interviews in the morning and used the afternoons to translate and write them down. My research assistant listened to the recorder and translated while I was typing the text on the computer. I instructed him to make the translation as close as possible to the origin. Even though it did not become a word by word translation, I was satisfied with the result as I knew it had been done as accurately as possible.

All the interviews with the priests were conducted with the assistance of research assistant, while most of the interviews with the health workers were done alone as we were able to communicate in English. The data obtained from health workers is partly results of informal conversations and recorded interviews which I transcribed myself.

### **Reflections on my position in the study**

Entering as a foreigner into such established contexts as the medical and religious settings may be described as, it is not evident that access to information will be easy. However, the friendly openness and willingness to assist from health workers in both governmental and NGO institutions was remarkable. Language problems were the only factor limiting my work as I do not speak Amharic and the level of English was good only among those with higher education. Challenges relating to the health system were discussed and I was often surprised by the openness to share thoughts and experiences. The fact that I was a nurse seemed to facilitate the conversations and was apparently not a threat to their position. On the other hand, as I was closely associated with the health system both as a nurse but also by the fact that language barriers limited informal communication to health professionals, this may have restricted patients I interviewed at the hospital from revealing their real opinion regarding the health system. The question to what extent that may have distorted my findings will be further treated in chapter four.

As my research assistants both in Dilla and Awassa were Orthodox Christians and had a personal relationship with some of the priests, we easily got the permission to do interviews. I was told that I would not have been given the same access if I had arrived with a research

assistant who was Protestant as they would not have trusted the interpretation. The fact that I was a woman and connected to the professional sector did not seem to create barriers.

During my stay in Dilla, I spent the morning at the hospital. If I did not have interviews to transcribe in the afternoon, I used to go to the university where I had been granted the permission to use the library and internet access. Informal conversations with people I met there gave me valuable insights into the contemporary situation in the region and the country as a whole.

### **Data analysis**

Both before and after the field study, the principal source of methodology has been found in Jane Ritchie's and Liz Spencer's work on Analytical Framework (Ritchie and Spencer, 1994). As my study to a certain degree may come under the label of applied policy research, this framework has proven to be useful. Contrary to the Grounded Theory where coding of the data emerges from the material itself, the Framework Analysis which has been used in this study, has utilized a more deductive approach. As Miles & Huberman (1994) advocate, when the researcher has knowledge both from theories and previous research, he/she should in this case use it to structure the work from the onset. Even though little research has been conducted in the area of adherence in Ethiopia, results from studies published from other settings were set as themes in the three interview guides. This did not imply that the guides were followed step by step, but it assured that problem areas known from other contexts were investigated, assessed and more easily classified.

To a certain extent, the analysis started during data collection as subjects which emerged from the first interviews, were further investigated in the interviews to follow.

It is important to mention that the Framework Analysis was only utilized in patient interviews. The interviews with the priests and especially health workers were analyzed more superficially. In the interviews with the priests, subjects related to specific points of interest were selected and collected in themes like the explanations of the meaning of holy water. As the presentation of the results will show, opinions from health workers are referred to more than properly analyzed when it comes to specific areas which are already highlighted by the patients.

The first step in the Framework Analysis which often is used in policy and health research is familiarisation of the data. As my data consisted of interviews with 19 patients, 11 health workers, 7 priests and one focus group interview as well as extended personal field notes and documents from the NGOs which volunteered to deliver their reports, it provided a good outline for the next step to be taken. That involved identification of a thematic framework (similar to coding) where themes developed from the onset in the interview guide together with new issues emerging from the data obtained, were grouped into themes and concepts. The framework was then applied to the interviews which in the litterateur are called indexing and charting. It means that the different elements and subject in the interview is grouped together related to the code/index developed for each subject. While charting mainly is a question of synthesising the text, the responses in my interview were already very concentrated and focused on the questions given which made it possible to quote the whole passage.

Inspired by Swallow (2003) who shows how to organize interviews in an Excel chart, the indexes/codes were put on the horizontal axis and responses from each participant with their social-democratic features on the vertical axis. In the next phase I pulled together the different indexes/codes which were associated and related to each other like poverty related issues, stigma and disclosure, the health system and holy water. In the framework analysis, the next steps involves mapping and ranging the nature of phenomena as well as finding association and create typologies Even though the literature encourages it, I tried to be very careful to relate characteristics to specific individuals and groups and create associations. The sample-size and the sampling procedure demand caution in my view creating associations between for example social-demographic conditions and utilisation of holy water.

According to Ritchie and Lewis (2003), analyzing data from a field study should be performed in hierarchical steps where data which are coded and grouped in themes should be described and finally interpreted in order to find meaning or explanations for a phenomena. Scholars do not agree whether it is possible to talk about causal explanations within qualitative research, but the nature of the methodology is concerned about "*the way in which people understand and give meaning to their social world.*" (p.215) (Ritchie and Lewis, 2003)

In my work and presentation of data, I am not sure to what extent I have been able to climb to the top of the ladder described. There are several reasons but the main one is related to the methodology I was using during my field study. As previously described, use of a translator during interviews and not having the text transcribed word by word, creates a situation where in my opinion one has to be very cautious not to over interpret the text. Secondly; it appeared early during data collection that the three interview guides I had developed beforehand, were too detailed and ambitious given the time available. When it came to the patient interviews, I was warned by the health professionals that patients might feel that one hour of interview would be too long, due to the fact they did not want to spend a long time at the unit. Even though they were given the estimated timeframe, it turned out that way. As my research assistant had to translate the responses for me, these required time as well. I tried my best to keep it as short as possible and the average time became about 45 minutes. This left me with the choice whether to limit myself to specific areas like consequences of disclosure, or stick to the overall objective of the study. I preferred the last option which resulted in less probing of each question. However, even though it was a vast area to cover, the answers are very concrete and comprehensible and the interviews characterized by openness and willingness to share experiences and thoughts.

My fear is not of incorrect, poor translation or distorted result because of that. The responses given during interviews are direct answers to my questions. My concern is more about not having been able to discover more underlying and hidden aspects that may not have been vocalized. Because of the fact that I did not speak the language and did not know the local cultural features, I sometimes had the feeling that I only found answers to what I was looking for or, more precisely, was actually asking about about. Patients, Orthodox priests as well as governmental officials and NGO employers, revealed themselves and their opinions surprisingly openly and free.

## Conceptual framework

Adherence to ART treatment has to be studied both in relationship to individual behaviour and economic and structural realities in the local and global context. In order to create a balance between these spheres, two theoretical frameworks will be presented underlining the different aspects.



## **Structural violence**

In his writing, Paul Farmer frequently turns around the concept of *structural violence*. The expression dates back to Johan Galtung and scholars from the tradition of liberation theology. He does not provide an exact definition or a theory but uses case-studies which he emphasises have to be “*historically deep and geographically wide*” enough to be used as examples of ways in which political, economic, religious and cultural structures in a given society create pathologies of powers which keep humans in the grip of poverty for generations. Every country has its own history and power structures in which some of the major questions concern who controls the land and the system of production as well as the distribution to the population.

Paul Farmer points to the fact that disease and suffering is not equally distributed as it is the most marginalized, unprivileged groups and individuals who carry the heaviest burden of our most serious infectious diseases like AIDS, Tuberculosis and Malaria. They are at the same time part of the groups who have limited access to health care.

Paul Farmer argues strongly to include social and economic rights in the traditional civil rights. He holds that violation of human rights is not only linked to torture, rape and killing but also to social inequalities and poverty (Farmer, 2005, Farmer et al., 2006).

The concept of *structural violence* has also been applied to explain forces behind stigma and discrimination of e.g HIV infected patients (Castro and Farmer, 2005). The authors claim that stigma and discrimination are a part of a belief system related to disease which often is based on social inequalities. The social forces on which a society is constructed, influence who is to blame, whether those forces might are related to gender, racism or poverty. As previously described, social inequalities are deeply rooted in historical and economic events and structures in a given society. When a disease like HIV/AIDS is associated with groups which are already marginalized, such as homosexuals, intravenous drug users, black or poor, the association between disease and those affected creates stigma and discrimination.

## **The health care system with the three sectors of care**

Following *structural violence* as a framework, the presentation of the historical and economic context in which the patient is found becomes essential but not sufficient to understand adherence at the individual level. In addition to focus on structural factors on a macro level it



is additionally important to understand individual choices and health seeking behaviour in particular. Kleinman's model which will be used as the analytical tool in the thesis, divides health services into three sectors of care: 1) The Popular sector is the domain of lay, non-professional actors often family members, friends and neighbours. Self-medication belongs also to this sphere. 2) The Folk sector consists of sacred or secular healers linked up to the religious practise in a given area. 3) The Professional sector is related to modern, western medicine and in the domain of HIV/AIDS represented by the ARV treatment. Each of the sectors holds separate explanations for disease, and offers separate treatment options and drugs. According to Kleinman it is important to consider these sectors as systems originated from a given social and cultural context with their own significance, function and structure. It is for the patient to choose and evaluate the effect of the treatment provided by the different sectors. Often, especially when we talk of a life-threatening disease, people will seek help from all the different actors regardless of religious and socioeconomic status. They will pay visits to the different sectors as well as adhere or not to recommendations given depending on the level of satisfaction with the effect and quality of care. Problems might arise if one of the sectors excludes the use of the other. In this case it is also important to bear in mind that decisions and acceptability to treatment is not always based on individual preferences, but closely linked to belief systems in family and society as a whole (Helman, 2000, Kleinman, 1981).

Even though both the folk sector and the popular sector in Dilla is vast and contains a multitude of different treatment options related to Islam, Christianity or traditional religion, this study will include only the official healing regime of the Orthodox Church as an alternative to modern medicine.

## **CHAPTER 3- FINDINGS**

### **The ART program in Dilla**

The ART program had been running for almost two years at the time of the field study. In my interview with the Medical Director, he gives me the latest statistics which show that patients the number of patients registered as ever having started on ART at Dilla hospital is 406. Out of those; 31 have died, 51 have dropped out from the program, (they have not appeared for the last three consultations), 22 were transferred out; (they have decided to follow treatment at another location), 25 are registered as lost; (they have not appeared for the last two consultations), 2 have stopped treatment, 8 have restarted treatment. 46 were transferred in (coming from another location where they started treatment, most probably at Yirgalem hospital)

### **The organisation of the services**

The ART unit provides voluntary counselling and testing (VCT), and treatment for Tuberculosis as well as ARV treatment. When the patient comes to the unit, the first stop is the clerk's office where he is registered. The clerk is additionally in charge of presenting the statistics and monthly reports to the Ministry of Health as well as to the John Hopkins initiative. One nurse and one physician are directly involved in patient consultation. The nurse is coordinating the activities. After registration, the patient will be seen by the nurse who screens for medical dysfunctions using standardized questions. When a new patient is registered, his whole medical and social history is recorded as well. If the medical assessment by the nurse reveals complications, she directs the patient on to the physician. The physician will determine if there is a need for more medical examinations like X -ray or change of treatment regime. If the CD4 count is less than 350 cells/micro l, the patient should start on Bactrim prophylaxis as well. Opportunistic infections are supposed to be treated before ART is initiated. The final stop is with the pharmacist who gives the necessary provision of drugs. A CD4 count is performed every sixth month for patients on ARV treatment, and every three month for those who have not yet started.

### Confidentiality issues

The number of patients scheduled for each day varies from two to thirty. Some come without appointments. As most of them come in the morning, the corridor outside the offices becomes the waiting area and is very crowded during that time of the day. Most of the afternoons are quiet with only a few individuals arriving. There is only one bench to sit at. Tuberculosis patients who come for testing and procurement of drugs, are waiting further down in the corridor. The doors into the offices for the nurse and the physician are closed while they have patients, but the consultations are characterized by many interruptions from fellow colleagues and other patients. Journals and other confidential materials are lying on the desk in the room and not always covered. However, nobody seems to take any notice of it.

### **The adherence regime and counselling**

New patient very seldom start directly on treatment even though they might be eligible to. The program has a very strong focus on adherence counselling which should be given on two separate occasions. The nurse, the physician as well as the pharmacist are involved and the patient is supposed to repeat information given by the last care provider visited. Ideally, time from determination of eligibility to the start on ART, should be two weeks

The patients are told to select a specific time in the morning and evening which suits them best and to buy a watch which allows them to take the pills at the exact time chosen. The nurse is very concerned about the time aspect and stresses them the importance of keeping strictly to the schedule of twelve hours between each dose. For her it is a question of minutes which later on is reflected in the patient interviews where some of them say that they had forgotten a dose for 15 minutes.

Quite some time is devoted to explaining what kind of side-effects might appear like severe itching and gastric acid. The patients are urged to contact the hospital without interrupting the treatment if problems occur. The nurse says she has even given her mobile number to some patients who started on treatment. The first appointment scheduled after starting ART is after two weeks as side-effects are likely to happen during that time. The patient might also develop the Immune reconstitution inflammatory syndrome (IRIS) which in some cases is life threatening. As soon as the patient is in a stable medical condition and considered adherent, new appointments are given with an interval of one to two months (some cases three)

depending on travel distant, clinical condition and level of adherence. Drugs for two additional days after the scheduled appointment are given in case of any inconveniences appearing.

During the consultation with the nurse, subjects like nutrition, family planning and condom promotion are also discussed. Women who are sexual active, are advised to take an injection of contraceptive in addition to using a condom. In order to have a balanced diet, patients are advised not to sell all their vegetables, eggs and fruits on the market, but use them in their diet. Some of the patients also make the nurse aware of their social and economical worries as she, in some cases is the only one who know their status. Time devoted to each patient depends on the number of patients waiting outside.

The patients are advised to disclose their HIV status to a friend or a relative and leave a telephone number in their file in case they do not show up for appointments. That is not a requirement for accessing ARV treatment. According to the clerk, the hospital makes a telephone call without saying who they are, asking for the patient if he or she fails to come. No other tracing mechanism exists.

### **Patients' evaluation of their own adherence**

*Until God himself calls me (die) I will never stop taking the pills.*

(Woman 43, 15 months on ART)

Phrasing the questions like: How is it to take pills every day? Do you sometimes forget to take your pills? And: Have you forgotten any doses last month? I was often astonished by the similarity of the answers I got and the devotion to follow treatment exactly as prescribed. As already mentioned, the nurse at the unit strongly advises each patient to choose the best time for him/her, to take the dose and to stick faithfully to it. Of course it is impossible to know whether a person is telling the truth, but several of the answers were phrased like the following ones:

*"It is very easy for me. I have yet not forgotten. I only forgot to take the pills for one day. I was busy and I forgot for 20 minutes."* (Male 26, on ART for eight months)

*“Nobody helps me to remember taking pills on time. I usually bring pills to my working place and take them there. I sometimes forget and take them 15-20 min after.”*

(Female 35, on ART for one month)

Many patients said they had forgotten to take their pills but added that it was a question of minutes not a missed dose. A few had disclosed their status to their children or only told them that they were in need of regular medical treatment. Those children were of great help when it came to following the time schedule but most of the patients had to rely only on their own memory. Several mentioned that they had bought watches. A break of daily routine like travelling or long working hours could sometimes disturb the schedule.

When I continued to ask if they had missed any doses last month, everybody answered negatively.

*“It is a question of life. How could I forget? Could you forget your lunch or dinner? It is just like that.”*

(Male 40, on ART for 14 months)

*“It is very easy. (To take pills every day) I have not forgotten taking pills, even not this month. The reason is that I know the value of ART. I know how I was before starting ART.”*

(Male 30, on ART for 19 months)

During the group discussion at Medan Acts, several of the participants referred to the time they started taking drugs. At that time they sometimes missed doses but after a while it was established as a habit like the need for food. Some compared following the treatment as a kind of addiction.

In the first interviews I asked the question whether they ever had been thinking of stopping taking ART. A few referred back to the first weeks of treatment where the side-effects were severe. Itching and gastric acid happened frequently. Some had a history of irregularity in following the schedule, which resulted in a deterioration of the condition. Once recovering, the motivation to adhere was very high. Anyhow, I became very cautious asking this question because the reactions were strong sometimes as if I had assumed that the person had a complete lack of understanding and commitment.

*“Never, how could you ever ask me a question like this. (If he had ever thought about stopping treatment) I will never stop ART.”* (Male 32, on ART for 20 months)

*“I have already experienced what happened when I took the drugs irregularly so I know what will happen if I stop taking them at all.”*  
(Female 28, on ART for 12 months)

*“(Surprised by the question) I want to be alive. Why should I stoop? That’s why I kept the appointment and came today.”* (Female 35, on ART for 1 month)

The awareness of the consequences of stopping treatment was high among all of them except for one patient who said he took the drugs regularly but according to him the doctor had not told him what would happen if he stopped. For the rest of the patients, their own experiences became valuable when in came to adhere to the treatment. It was for many related to the misery they lived in before they started on ART but also to the time they had to face the consequences of not taking the treatment regularly. Some referred also to other patients’ lack of adherence and what it had taught them. On many occasions they referred back to advice and warnings given by the health workers.

A few of the patients referred to “drug holidays” which describes a situation where some patients would not take drugs on special church events. One of the patients related this mainly to those who were abusing alcohol and *khat* while others had not even heard the expression. It is impossible to estimate the impact of this but none of my informants seemed to belong to this group.

### **Patients’ evaluation of the services at the ART unit**

During the patient interviews, one of the questions was related to their opinions on the reception they got at the ART unit. With a very few exceptions, the responses were very positive

*“I lack words to express the treatment they give us. If it was not for them (the health workers) I could not survive. Sometimes they give us money and prepare food for us and we consider them as our family. I appreciate them for all the treatment they give us.”* (Male 35, first patient in ART program in Dilla)

My research assistant as well as some of the patients, expressed surprise at the way they were received by the health workers at the unit compared to previous experiences with the health sector and the reputation the profession has. Some remarked also that HIV patients were given more positive attention compared to those who were HIV negative. The nurse who coordinated the activities was frequently mentioned by the patients but also by her fellow colleagues for her feeling of responsibility for the individual patient and the services at the unit.

*“I got very nice treatment from them (health workers). They treat me well. When we are tested for other diseases we are given priority related to other patients. So all treatment we get here is nice.”* (Female 24, on ART for 10 months)

*“Other patients face lots of difficulties coming to the hospital. But for the ones who are HIV infected things are smoother. The health workers are active, treat us good and give us priority. We get what we need in time.”* (Male 42, on ART for 7 months)

A few complained that the health personnel had more time before for discussion and one who had been on treatment for a longer period, felt that time spent at the unit was too long and that people did not respond well to his complaints.

*“About health workers, some of them treat us well, but others don’t even care about us. We go there. We stay for a long time to get ART. We wait for a long time. Even sometime they insult us when we ask them. But sometime since I am a patient I may insult them. So since they are educated, they have to calm down. So I can say that: some health workers treat us well, some do not so it is different from person to person.”* (Male 30, on ART for 19 months)

A major concern for the patients during the time of fieldwork, was the of question of whether or not additional treatment, such as inpatient care, as well as drugs for opportunistic infections

were free off charge. The Regional Health Bureau (apparently under pressure from the donors) had told the hospital to ensure that HIV infected patients did not pay for these services. According to the medical director, the hospital had followed the instructions for a month, but the promised reimbursement was not forthcoming and patients were informed that only the ART drugs would be free. New meetings followed resulting in all treatment being given for free. The Medical Director expressed doubts to the sustainability of this practice fearing that it would not last for a long time. The discussion troubled the patients a lot and among some of them there was a fear that this would also include the ART drugs.

*“At the beginning when we started ART they assured the drug would be free of charge the whole life. But ones upon a time in a meeting, another man said it will be a time in the future when patient will have to pay for the drugs. That is what I am worried about”*

(Male 30, on ART for 19 months)

*“My fear is that if I stoop and the fact that the drugs are expensive I fear I will die. We don't have any income.... If these medicines stop I fear all of us will die in one day. And the people are aware of the consequences if the drugs stop. People will die”*

(Male 35, first patient in ART program in Dilla)

The fear expressed by these patients is genuine and well-founded as their existence in many ways depends on a well functioning health system and international donations. As patients they are the first to be made aware of the weaknesses within the health delivery services.

### **Health systems challenges and the problem of adherence**

The health system in the region is as for rest of the country, facing enormous challenges when it comes to infrastructure, funding and manpower. The catchments area of Dilla hospital is as already mentioned, very big which makes the services inaccessible for a big part of the population. It is impossible to look at these questions in depth but I will concentrate on some aspects related to manpower as well as coordination and supervision of the ART activities.

One of the emerging subjects for discussion which was raised after only a few days was the level of salaries for governmental workers. Employees, both in the sector of health and education complained that their salaries were not sufficient to cover even basic needs, at least



not accommodation. All the medical doctors in the hospital had a part-time commitment in a private clinic. The salary of the medical director was in fact lower than my hostess who had seven years of school and worked half-days at the Ethiopian Telecommunication. The level of frustration about these issues was very high, with some of them counting the months left to fulfil their obligations to the government before being free to leave for better options.

*“I can for sure say that none of the physicians are interested to sit for years waiting for their government salaries. They can not even make their ends meet. That’s why most of them are leaving the countries..... Here there is also another influx. They influx to the private clinics. I hope that will be my fate too. After 6 months I am planning to leave. Because, if I have substituted somebody else. I have carried out my government responsibilities. I have to go for my own responsibilities. My government may not meet that. I see that.”*

(Physician in Dilla)

It is unnecessary to say that the numerous NGOs and private clinics could make their choices among the very best qualified professionals. The sustainability of the medical staff at the hospital was therefore one of the major concerns.

In the interview with the Head of the Regional Program of The John Hopkins Initiative, he confirmed that human resources are one the main problems in the region and the major obstacle to scaling up the ART program. Training and technical assistance is provided to numerous health workers who stay in the facilities for a few months or leave straight after training. He also addressed the problem of the low compensation provided by the government compared to the private sector.

As previously mentioned, I had the opportunity to visit the health centre in Yirgachefe which provides ART and is in the catchments area of the hospital, situated 45 minutes from Dilla. Health centres are supposed to be supervised by the referring hospital, but lack of personnel had made this impossible. Family Health International (FHI) is the implementing partner in charge of training and supervision of centres which provide ART or are in the process of being given accreditation. Every second week, a medical doctor from FHI comes from Awassa town which lies 3-4 hours further north, bypassing Dilla hospital on the way. The nurse in charge of the patients on ART in Yirgachefe, said she was not even aware of who

was working in the same program in Dilla. Even though the price of the bus ticket to Dilla was only 6 birr, patients used to start ARV treatment only on clinical indications.

In my interview both with the leaders of FHI and The Jon Hopkins initiative, they admitted that in spite of good personal relationship between the two program directors and Regional HAPCO, there was a lack of coordination between the activities in the health centres and the hospital when it came to training and supervision of health workers as well as patient related assistance. This led to missed opportunities relating to tracing defaulters and the possibility of starting ARV treatment on a CD4 result rather because of clinical indications.

## **Religious healing**

Even though the professional sector of care and the ART program seemed to enjoy a high level of trust and the self-reported adherence level was good, people do also resort to religious healing. The following case demonstrates how healing by holy water is a question of emotions, authority, rituals and symbols. It is impossible to analyse all the elements the case reveals, but some will be extracted, explained and commented on the section which follows.

### **“A day of Healing”: The practice of holy water witnessed from the outside**

Vecchiato (1993) who previously has been referred to in the thesis, describes a visit to the holy water site in Wallame which is located three kilometres outside Dilla town. Together with my research assistant and a deacon, we arrive at the site seven o'clock in the morning.

The site is located at the bottom of a slope close to the river. The area is surrounded by small huts and houses where patients and their families live during the stay. People arrive while the healer is giving his sermon, some to acquire holy water to bring home, some to sit in the pool inside the healing centre and be sprinkled afterwards (baptized). Before entering the pool, men and women head for the same location in the river where they wash themselves, women only wearing their underpants.

Once the sermon has finished, the healer comes out telling me to come and witness the healing session going on inside. I am given a short sight into the pool where the men are sited before I enter the location for the women.

A wall partly separates the two pools. They are covered by icons of saints and Virgin Mary. Entering the pool for women, of whom there may be 25, the healer starts throwing water violating on each of them (sprinkling). All age groups are represented, even a baby. People appear calm, even those who are thought to be possessed. There are no signs of unconsciousness or strange behaviour except for one girl who has to be held when the priest sprinkles her. While the healer sprinkles the patients, the following questions are directed to the spirit thought to be in the person: *What kind of evil spirit are you? Where did you catch her/him? How many are you? For how many years have you been with her /him? Would you like to leave the person or stay?* The priest continues: *Promise me not to catch her again, in the name of God.* He ends the session by ordering the patient to scream 7 times in order for the spirit to leave. The cross is sometimes put on the patient's head and sometimes used to touch the sick part of the body.

After the session is over, the healer invites us into a house nearby where he gives the interview. He explains the symbolism of the cross used during the healing session: *“Jesus himself was on the cross. The power of God is there. If they are possessed, they start crying if they are touch by the cross. If the cross is put on the sick part of the body, the patient is healed. God is secretly in the cross.”* The quotes which will follow later related to the holy water, show that the same characteristics are associated with that issue.

It is already midday when we arrive in town and enter the biggest church called Abu'e which has been the scene of spectacular healing sessions for the last two weeks. Both the hospital staff and patients have spoken about a priest coming from Awassa with special gifts of healing. During the last days, the ART unit has been very quiet partly because patients have postponed their appointments, wanting to see the priest. According to the nurse, none of the patients have stopped the ARV treatment. Rumours say that some people, among them HIV patients have been sitting in the church for days, praying and fasting in order to get cured. The whole town is marked by the event and as we enter the church compound, several hundred are gathered.

The priest is standing outside the entrance of the church with a crowd of people around him, women at one side, men on the other. A man on the stage is filming

everything. A woman testifies how she was captured by spirits for several years but now has been delivered. Those who know they have evil spirits approach the priest. He asks the same questions that were used in Wallama while he beats them with a rope and touch them with his cross.

My research assistant explains that the patient is told to scream seven times which is the sign of the spirit's willingness to leave the person. He adds that the holy water works better if you are undressed.

After an hour, the congregation is told to move to the back of the church. People who want to become Orthodox Christians are told to gather together with those who were found to be possessed. Most of them, both women and men take off their clothes and are left only with underpants and skirts. The priest and his friends go up onto the top of a lorry which has been brought into the middle of the crowd. The cameraman is with them. The priest changes his clergy dress for a waterproof jacket before he starts to sprinkle, using a garden house-pipe. He starts with the group who want to convert or getting rid of their evil spirit before he directs the water towards the spectators. When a person gives a specific reaction like screaming, he is brought forward and given an extra amount of water. After a while the priest takes a break and starts filming the crowd with the video camera while he encourages them to sing and clap.

According to my research assistant, the sprinkling of the spectators may have two functions: The first one is related to a way of diagnosing evil spirits in a person who will automatically start to scream if that is the case. The second function has more the character of blessing the individual.

After an hour we are given permission to interview the priest. He explains that during these seven days, many have come to seek help, among them HIV infected people who have been healed. If patients pray, fast and use holy water it is sure that they will be healed. If this is not happening it might be due to a lack of strong faith. He continues by saying that those who possess a strong faith are advised to stop taking the ART drugs, start fasting and use holy water. If the faith is weak, it is better to continue with the drugs. According to the priest, four patients on ART treatment have approached him; two have stopped their ARV treatment.

A few days before I leave Dilla, I am able to interview the priest in charge of the Abu'e church. He confirms that four patients have stopped the ARV treatment. Visiting the Medan Acts, the manager confirms that among the four who stopped treatment as a result of the activities of the priest, one was admitted to the hospital. Thanks to the caregivers and the nurses of Medan Acts, all of them were identified and have resumed ART treatment.

### **Explaining HIV/AIDS as possession by evil spirits and moral uncleanness**

The case presented illustrates how HIV/AIDS is understood and dealt with by some in a framework of possession by evil spirits. As the church is divided on these issues also, the answers differ considerably. Even though the sample consists of only six priests and one healer, the interviews are characterized by big variations. In response to my question about whether HIV was due to possession by evil spirits, the healer in Wallame gave the following answer:

*“The word HIV is given by human being. The virus itself is the evil spirit. When patients are sprinkled the spirits shout: People gave us the name HIV but we are spirits. When patients enter the water and is sprinkled, the spirit says: I am the virus! I am the cancer.....”*

This corresponded also with the view of the visiting priest from Awassa and the priest in charge of the Abu'n church in Dilla. The priest in Yirgacheffe responded in a less categorical manner and underlined what had already been said regarding the significance of the scream during exorcism:

*“Every physical condition may in fact be related to evil spirits but some are more likely to be caused by spirits. Some (patients) with HIV have evil spirits while some have not. It is difficult to categorize. Most of the time the patients who are possessed will scream and shout during the ceremony of holy water but some spirits are quiet. If he is not shouting, it is likely not to be an evil spirit but you can not be sure.”*

The two priests interviewed in Awassa were older and had higher theological education. They were specially assigned to do interviews with me as I was not given permission to talk to the person in charge of the holy water in that church. One of them gave the following quote:

*“It is not a question of evil spirits according to the church. The church accepts the international definition of HIV. It is based on that one when we teach people to protect themselves against multiple sex partners and also to use condoms and that HIV is a sexual transmitting disease.”*

The three extracts of the interviews show the great variation within the church regarding the relationship between possession and HIV ending with a political correct understanding of the condition.

During the exorcism we witnessed in Dilla, the healer and the priest addressed their questions to the evil spirit in the patient. One of the questions was related to where the spirit caught the patient which may refer to the conviction that evil spirits reside in geographical locations like rivers, forests and whirlwinds (Vecchiato, 1993). According to my research assistant, there is no shame associated to being possessed by an evil spirit as it may attack people who happen to be at the wrong place at the wrong time.

At the same time, it seems like the Church makes a connection between HIV/AIDS and moral uncleanness. One of the priests made the association between HIV/AIDS and evil spirits in the sense that some HIV infected people are known to have a promiscuous lifestyle, wanting to transmit the virus to other people. According to him this is proof that the virus is an evil spirit.

The Ethiopian scholar claimed that the whole issue of HIV/AIDS is very challenging for the church as it is often caused by a practice that goes against the church. It can be that HIV/AIDS is a result of extramarital sex which is a practise the church condemns. The moral uncleanness of the disease makes the person unworthy to get in contact with the holy item. According to him, the fact that modern treatment and holy water should not be combined is new.

Morality according to these priests was expressed through the way women were dressed, which had made them put some restrictions in place for those who wanted to visit a holy site. One of the priests expressed it like this:

*“Women should not wear jeans, miniskirt or cosmetics. This are respected places. God is in those places. HIV infected women are associated with this features.”*

However, as the diversity is big within the church and the priests' opinion is partly related to their educational background, it is important not to make any final conclusions about the position of the church.

### **The regime of the holy water**

Asking the question: What is holy water to the priests, I was given the same answer from all of them: *“The power of God is in the water.”* They continued by expressing in different manners that it is ordinary water which has been blessed by prayers and therefore has been transformed into water which has the ability to cure. According to one of the priests, the name holy water in *Gez* is *tebel*; meaning soil, which implies it originates from the soil. One of the priests in charge of the theological education of priests in Awassa, extended the meaning to also include the soil at the holy water site which some people use to paint their faces with in order to get cured. An Ethiopian scholar emphasized the same feature in my interview with him in Sweden. Holy water or *tebel* does not only mean pure water or soil but could also be a combination of both products. People may travel long distances to acquire *tebel* from a specific site.

When I asked the priests of the biblical background of the holy water issue, they linked it up to events both from the old and new testaments like Naaman being cured from his leprosy by taking seven baths in the River of Jordan on the prophet Elisa's instructions (Book of Kings Ch. 5). Miracles of Jesus as well as his baptism were also frequently referred to:

*“Holy water is not only the practice of the church but also found in the bible. The gospel of John Ch. 9.1-7 describes the situation when a blind man is healed by Jesus who puts a dough of saliva and sands on the eyes and tells him to go and wash himself in the river of Siloa.”* (Priest in the St. Michael Church in Dilla)

In what way does ordinary water turn into holy water? According to the priests, there are two ways by which this is possible: By a religious act or by being found in a special geographical location. In the first case; any water fenced from any source can be blessed and prayed over by a priest articulating: *“God is almighty! God is eternal! God is powerful!”* “After a few minutes of praying, the water has turned into a sacred item. The specific locations are often situated near rivers or in church compounds. The history behind a holy water source is often

linked to a revelation given by a Saint in a dream of a highly religious person. The Saint may tell the believer to dig in a specific place where the water emerges. Sometimes a church is built on that site, but the water may also emerge in the compound during the construction of a church.

Using the holy water only as a sacred item is not enough to be cured as all the priests mentioned faith as a crucial factor in order to be cured. Confession of sins, not being in conflict with other people, prayers and fasting were listed as preconditions for a good result. Most of them explained that some people did not get cured because they lacked faith in God and the healing power of the water. If they fulfilled these criteria, they would be healed. The priest in Yirgachefe summarized it like this:

*“Before receiving holy water, a patient is expected to confess his sins to a priest. He will be told to pray and fast depending of the degree of the problem. If a patient is not cured, it is due to the fact that he has not confessed and hides secrets. He is just taking holy water without confessing sins, praying and fasting. He doesn’t believe in holy water.”*

The holy water phenomenon is therefore not only a question of a holy item, but rituals and obligations to be fulfilled as precondition for cure.

Fasting is one of the main preconditions to getting healed by holy water.

The Ethiopian scholar explained it like this: *“Fasting is and was the symbol of adherence to the Ethiopian Orthodox Church”*. He describes the significance as: *“Fasting is how you show your inner self to God. Fasting purifies. ... Fasting is not only a demonstration that you are a Christian; it is also a condition for you to be saved. Fasting is the instrument you use to come closer to God.”* He continues by explaining how Ethiopian Christianity is expressed in terms of fasting. *“If you want to find out whether this person is a serious Christian or not, the first question you ask: does he fast? If the answer is yes, you could rely on that.”* The implication of this becomes very clear when we come to the use of holy water with ART.



### **The aim of the regime**

Even though the focus for this study has been holy water in relationship to HIV/AIDS and ART, it is important to be aware that from the Church's point of view, holy water has a wide range of functions. According to the reference cited in the first chapter expressed by the church itself, holy water is a symbol of interior cleaning. It is used during baptism, blessings of churches and people's homes as well as a protection against demons and in exorcism. It has a very close connection to uncleanness, attacks from evil powers and diseases. Contrary to the treatment of ART, holy water is supposed to cure HIV/AIDS. This view seems to be the most prevalent among the priests even though some would express themselves carefully.

On the question as to whether holy water may cure diseases, one of the priests in St. Gabriel Church in Awassa gave the following answer:

*"Yes they (patients seeking holy water) always get cured. If they did not get cured, they would not waste their time there. Many are coming to stay there, not only from the Orthodox Church but also Muslims and Protestants."*

Some of them priests added that if a patient was not cured at the site they were in charge of, they referred them to other locations in the country. The water in these places could correspond better to their disease as was expressed by the priest in the Abu'n Church:

*"Everyone who uses holy water may not be cured but it has its own reason. Everyone might not be cured at the same holy water site. Some get cured by St. Gabriel's water, some by St. Georges, some by St. Kedane Merat, some by St. Johannes."*

Only one of the informants, an elderly blind priest in Awassa mentioned that not everyone would be cured without putting the blame on the patient's lack of ability to follow the obligations. He referred instead to the apostle Paul who according to him was cured in the soul but not in the flesh.

My research assistant in Dilla stated what seemed to be the perception among lay people regarding holy water:

*"If you have 100% faith, you might get cured, but most people do not possess that so sometimes you can only hope/expect an improvement of the situation"*

## **The organisation of the holy water regime**

### The actors involved

Most of the time, holy water sites are connected to a church. According to my research assistant, the church assigns a priest or a debtera to the site who is known to possess special gifts of healing. The healing centre in Wallame was previously independent with a history of lay men serving there. It is now connected to the St. Micheal church in Dilla.

### The rituals performed

During my interviews with the priests, I got familiar with three ways of using holy water; sprinkling, drinking and bathing. Sprinkling seemed to be used more as a blessing but also as a way to diagnose evil spirits in a person as the spirit inside him would react with a scream once touched by the holy item. During exorcism, sprinkling would turn into more violent throwing of an abundance of water into the patient's face.

If the patient has what a priest called: internal disease which seemingly is associated with possession by evil spirits, he should drink the water. Both patients and priests said that drinking holy water used to be followed by vomiting. When the holy water comes in contact with the internal sick part, being an evil spirit or something else, it will automatically cause vomiting according to the priest in the Abu'n Church in Dilla:

*“Patients drink holy water not to vomit. The purpose is not vomiting. But when they drink, the holy water itself makes them vomit. Because the power of God is inside the holy water and it works as a drug, sometimes people vomit. So when the holy water enters inside, the dirty things and other things want to leave the place. “*

I was given several answers when it came to the required quantity of water. Some said one to two litres, some said as much as possible even up to six litres. One of the priests related the amount to the quantity and kind of “dirt” which is inside the patient. Through vomiting and diarrhoea caused by the blessed water, the “dirt” will slowly be removed and the patient healed.

Patients who are possessed by evil spirits are also invited to take a bath for 30- 60 minutes in holy water, being a river or a pool from a natural spring. Before entering the pool, they have to undress and wash themselves in ordinary water. Hot springs which are often used may be defined either as holy water sites, or as secular places for relaxation and physical well-being run by secular institutions.

### **Use of holy water among the patients**

After my first days at the hospital I had to ask myself the following question: Is the focus on holy water only another example of an outsider's need to find an exotic explanatory framework for a situation as devastating as extreme poverty? As I later will describe; the reality of poverty and stigma seemed to overshadow whatever else could be described as barriers to treatment and adherence.

However, when I started to interview the patients on the issue of holy water, I soon recognized that almost all of them had a history of previous or current contact with the healing method. Although, only 11 of them declared themselves to be Orthodox Christians, at least half of the rest mentioned a previous history of usage.

Many testified that they had used holy water before but stopped when they started on ART. As to my question about why they interrupted treatment, some related it to lack of time and resources. The site at Wallame which is most frequented, lies about 4 kilometres outside town. Depending on their economic capacity, users may take a taxi or walk to reach the session which starts at 6 a.m. As the ceremony might take two hours and include fasting and an abundance of water followed by vomiting and diarrhoea, it is exhausting and might be difficult to combine with regular work. However, some of the women devoted the early morning hours to it, resting for an hour and taking the ART pills afterward.

*“I use holy water in the morning from 8-9 and I rest from 9-10 and I take the pills at 10. Holy water is good for me and if someone believes in the holy water and uses it, it is obvious that one will be helped. And therefore I use holy water since it helps me to feel healthy in my kidney. I had pain in my kidney. I haven't faced any difficulties using both together. Because I use holy water one hour before I take the pills and when I take holy water I usually vomit after.”* (Female 25, on ART for 1 year)

This woman added another issue associated with the practice of holy water among HIV patients. The reason for using holy water may not only be limited to seeking a cure for the HIV virus or the evil spirit, but also to getting relief from other misery. The same issue was also mentioned by another woman who invested a lot to get to the holy water at Wallame.

*“I use holy water in the early morning and then I come back to sleep up to 8 when I wake up to take ART. Even sometimes I go to the holy water site to stay there for 7 days. To do that I sold the wheat I got at Medan Acts and paid for bed and food. But now since I have no money I can not go there. But using the holy water helped me a lot. Last time I had some wounds on my body. After taking holy water I got cured from that. Yes it is possible to combine holy water and ART. I use it in the early morning. I come back and take the pills after sleeping.”*

(Female 19, on ART for 9 months)

A couple of the patients had stopped because the doctor had advised them not to use it, while two of them referred to friends who advised them not to combine ART and holy water. When I asked what kind of advice the priests gave regarding the combination of treatments, the answers differed a lot, mirroring the variety of responses I was given later on from the priests on the same question. Some had been given the advice not to combine, while others had not been given restrictions. As a result of this, some had stopped using holy water all together, while e.g. one of them still used to wash herself with it but not drink it.

Even though there was an overwhelmingly positive attitude towards holy water among my informants, I would like to extract two of the interviews which diverted from the majority. One of them, the only Muslim participant, answered positively to my question about whether he used holy water. He added that he did not use it in order to get healed, but for enjoyment as the hot spring was comfortable to sit in. Another patient who originated from a different city, declared that in spite of being an Orthodox Christian, he did not believe in the healing power of the holy water. He referred to several cases where people had stopped their ARV treatment and died as a result of it. Like the Muslim participant he had benefited from the hot springs, not because they were sacred, but due to the fact that the hot water itself gave relief.

## **Holy water and adherence to ART**

### The dilemma of the priests

When I asked the priests whether the ART drugs could be combined with holy water the answers followed the same pattern as for the question related to evil spirits and HIV/AIDS. Those who believed HIV/AIDS was a result of possession by evil spirits, advised patients not to combine the two treatment options. In answer to my question about whether it is possible to take ART and holy water at the same time, the healer in Wallame gave the following answer:

*“Only God gives life.*

*One can use ART to live long*

*If they want to live they should stop ART and only use holy water. It is impossible to use both at same time”*

The two priests in Awassa referred to the proclamation by the Patriarch where he gives the permission to use both. As they viewed HIV/AIDS as a chronic disease, they told patients to continue their ARV treatment. When I reminded the priest in the Abu'n church in Dilla about the same message delivered by the Patriarch, I was given a very interesting answer. He confirmed that he and his colleagues had discussed the statement and arrived at the conclusion that the Patriarch had used the word “use” which he said gave patients permission to be sprinkled or to take a bath in holy water. It was not a permission to drink. As the following quote shows, it is clear that the whole issue was a difficult dilemma for him:

*“We don't advice people who come to stop or use ART. For patients on ART we advice them not to drink holy water because if they get cured, we will not know if that was because of holy water or ART. We tell them only to wash themselves in it. After staying for a week seeing changes only after washing, they themselves stop ART and start drinking. But we don't advice them. But logically it is believed that a person should not use two things at the same time. But since people are worried about the disease, we don't advice them, we don't say anything; use both or one. The Book itself (the bible) doesn't allow patients to use two things at the same time. They themselves come, they wash themselves for one or two weeks, after seeing good improvement,*

*they themselves stop (the ART). We don't ask: Why do you start or why do you stop? We don't say like that."*

In his duty as a priest to relieve suffering, it seems like he found himself caught up between what he understood as biblical teaching and the reality he met faced with peoples' misery. This underlines what the Ethiopian scholar suggested: it is preferable both for the patient and the priest that the aetiology of the disease is not known to him. The medical diagnose is not of interest as the patient is treated as a sick person at the holy water site, not as an HIV patient. This may also be part of the explanation as to why they are visited frequently. As the HIV status is not known, the risk of stigmatisation is much lower.

The visiting priest from Awassa encouraged patients with a strong faith in God to stop ART. However, it was interesting to notice that the patients I interviewed who had been in contact with him, said they had been told not to stop ART. According to one of the female participants, he had said she should have delayed starting on ART and tried only holy water first but encouraged her strongly at the same time to take her ARV drugs regularly.

### **Health workers' experiences with holy water and ART**

What were the experiences of the health professionals on issues related to adherence to ART and holy water?

Except for financial factors, the main obstacle to adherence according to the medical doctor in the ART program in Yirgalem hospital was the impact of factors related to the Orthodox faith. However, an Orthodox Christian himself, he made a link between repeatedly fasting in the morning as well as before using holy water and the difficulty in following the scheduled time for the morning doses of ART.

*"There are lots of patients who have discontinued medication for one, two, three months while they are attending the holy water..... as a physician I have seen a lot of patients who have discontinued the medication because of holy water."*

According to the nurse in charge of the ART program in Awassa, patients with a limited educational background would often stop the ART treatment when they went to the holy

water site. In his opinion, well educated patients would more often combine the two treatment options.

Linking the impact of holy water to poor adherence is very difficult. The patients in my interviews seemed to have found their way and those who wanted to combine the two treatment options, were limited by economic constrains, not theological. They had adjusted to the recommendations of both regimes by fasting before holy water early in the morning, and eating and taking the ART drugs afterwards. However, as the case at the beginning of the chapter shows, the population and the patients are easily fascinated by and attracted to someone proclaiming healing. As a matter of fact, four patients seemed to have stopped their medication after the encounter with the priest from Awassa, signalling the gravity of the problem.

The dilemma of not having enough food to feed himself and his family and the prospect of getting healed by holy water, became very visible in one of the male patients who had started to lose weight.

As a father of four children, he had been on ART for 14 months. The food ration from Medan Acts did not cover the needs of the family and for the moment he tried to collect money to go to the holy water site in Wallame to stay for two weeks. In answer to my question about whether he would stop taking the ART drugs, he repeated several times that he would continue at the same time using holy water. He gave the impression of being distressed and the question is to what extend he will be able to stick to his decision once he hear the opinion of the healer in Wallame on this issue.

This case does not only illustrate the holy water practise among patients but demonstrates in a very clear manner the link between religious healing and economic deprivation which is the subject for next section.

## **Social and economic issues influencing adherence**

The assumptions regarding determinants to ART treatment were from the point of departure related to factors in the professional health sector as well as healing by holy water. However, it seems like poverty-related issues turns out to be what one may characterize as the main barrier to treatment. Even though poverty is mainly related to questions of basic need for food and shelter, social issues such as stigma and discrimination also played a major role.

Entering the waiting area in the hospital, it is not difficult to understand why the Medical Director describes his institution as a hospital for the poor. Patients who can afford it, prefer to go to one of the 6 private clinics in town. They have a reputation for better service as well as for being cleaner and for having health professionals present most of the time. Even though these clinics provide neither VCT nor ARV treatment, the patients in the unit of the hospital where these services are offered have the same appearance of poverty. In my frequent conversations with the nurse who coordinates the program, she regular comes back to the deprivation her patients are living under: *“The level of adherence is good. Food is the problem.”*

### **Poverty and basic needs**

#### Shelter and food

When the program started in Dilla, the socio –economic context was taken into consideration resulting in the collaboration with NGOs and later on the World Food Program (WFP). The medical doctor assigned to the ART unit, is in charge of assessing the patients’ clinical status and body mass index to determine if they are eligible for food assistance. According to the Medical Director, most of the patients from Dilla receive food assistance. Disclosure is not a requirement to be registered as a beneficiary.

The Manager of Medan Acts explained that when the collaboration with WFP started, each of the NGOs was given a defined number of patients to support. Medan Acts had been given assistance for 220 beneficiaries, but had included 300 by the end of July. He linked this to the fact that the reduction of stigma had created a higher flow of patients than previously expected. For the time being they were under strong pressure from the WFP to discharge



patients who had received assistance for more than six months and were ambulatory. The criteria demanded that only patients on ART should receive food support but some others had apparently also been included. The physician at the ART clinic presumed that some of the patients appeared to simulate symptoms, asking for ART in order to be included as beneficiaries.

The agreement dictated that only patients from Dilla town may benefit from the support from Medan Acts. One of the health professionals at the hospital said that it happened that they wrote on the patient's card that he originated from Dilla in order to get assistance even though that was not the reality. The nurse in the health centre in Yirgachefe added that she sometimes had to strongly advise her patients not to move to Dilla to be incorporated as beneficiaries.

The treats of losing food assistance were maybe the major worry mentioned by my informants. Many of them used to sell some of the food on the market in order to pay house rent. The ration supported several family members at the same time. Eleven of those who were asked whether they had enough food to eat, answered that it was insufficient. Five were not asked the question. Without being able to bring better estimates, there could be signs that family heads suffered the most because of having many children to share the ration with. Some of the informants mentioned without being asked that they doubted they had a balanced diet. Asking the nurse for clarification, she explained that patients were told to use whatever they had at home, but many of them sold their eggs and fruit in order to get some cash.

The recent threat of losing the food assistance also became an issue during the focus group interview. The motivation to follow treatment was closely associated with accessibility to food and other support.

*If we were not given support but only ART free of charge, it would have been meaningless just taking the drugs.* (Man 24, on ART for 2 years)

Facing budget shortages, as was the case for Medan Acts combined with a demand for a renewed strategy from donors, had forced the leaders of the organisation to propose changes. In my interviews with the Medan Acts, Tesfagoh, Family Health International (FHI) and

HAPCO, the representatives came back regularly to initiatives related to income generating activities.

FHI through Medan Acts as the implementing agency in the home- based care program, had started to canalize the assistance more into income generating activities. Medan Acts had recently organized meetings with their beneficiaries in order to make them reflect on what kind of activities could be suitable and told them to form community self-help groups where patients who were discharged from food assistance would participate.

The new move produced fear among the patients:

*I manage 6 members in my family and am really worried because of this. So if they discharge us from this help, I expect that we will be taken back to where we were before.* (Male, 30 on ART for 19 months)

Food assistance was also associated with many other issues, which the following quote will show:

*E.g. last time they informed us (coordinator/manager of Medan Acts) that they are planning to stop providing help for the patients. They told us to start making our own money. So if that happens I expect the virus to expand because we are getting help from the government and we are teaching the public. While we are teaching we tell the community that even we are infected by the virus, we are getting help from the government. ....So if the community hears this, and believe those who are infected will not get help from the organisation, it will be very bad because those who have their own money will be able to hide themselves. If those who are poor are not helped, I believe the disease will expand more and more. So if this help did not exist, we would already been dead. So the existence of organisations like this is very important for patients as well as for other members of the community. Only taking pills by itself is meaningless for us.* (Man 37, ART 2 years)

This quote reveals several interesting issues. The big resistance to “make their own money” may be used as an argument for donor-dependency as it leaves an impression that the government should give HIV patient a contribution because they serve the society in HIV prevention activities.

Secondly, the possibility of acquiring food assistance even though that could mean disclosure seemed to have created a situation where those who were poor became open about their status, while those who could feed themselves and maybe be treated at another location, were still hiding. However, the message is clear: ARV treatment in itself is not enough for someone who is not able to satisfy his basic needs for food and shelter.

In addition to food, the need for shelter was among the biggest concerns for my informants. None of the patients coming from Dilla town owned their own houses and the monthly rent was a constant subject of anxiety. As previously mentioned, some patients sold part of their food ration from WFP in order to cover the expenses. Most of the patients shared rooms with close family members. As I will come back to later, stigma and discrimination had forced some of them to change location. According to the Regional Head of Care and Support for FHI, housing is now the main current focus for the moment after WFP started food assistance.

#### Lack of employment

Most of the patients said they did not have regular employment. Unemployment was frequently mentioned as a stress factor especially among the male patients. Some of them expressed feelings of shame at having to rely on NGOs and other family members. Some women were able to get involved in small income generating activities like baking injera and handcraft as well as buying and selling small assets at the market. As explained in next chapter, stigma had caused some of the women to lose their income as they were not wanted as housemaids anymore after disclosure.

On my way to the hospital in the mornings, I had to cross the centre of town. Every day, a group of 50-60 men used to be lined up on the main street with their axes and spades waiting for someone to hire them for the day. Several among them would be waiting in vain as those who looked strong were given priority. Male heads of families who had to share the food ration with the rest of the family, faced problems regaining the strength a physically demanding job requires. Lack of education limited them to manual work.

One of the patients who had not been able to regain his previous physical strength expressed his life in these terms:

*“I face a lot of problem because I am the head of the family and I got these children when I was healthy and now I am responsible to feed the whole family including myself. So I have very serious financial problems at the moment. I can not get enough food for breakfast, lunch and dinner. This is because I can not work as much as healthy people and as I did before.”*

(Male 40, on ART for 14 months)

Job opportunities in Dilla are limited especially for those who lack higher education and do not possess the means to start small enterprises such as merchandise or handcraft. As the town is the centre for coffee production and distribution, the main activities are based on seasonal employment. When the coffee harvest starts at the end of September, job opportunities increase considerably in the fields as well as in the hotels, shops and in other sectors like transportation and construction.

In my interviews with the nurses and physicians in charge of the ART programs in Dilla, Yirgachefe, Awassa and Yirgalem, all of them suggested that economic constrains was the main barrier to adherence for their patients. They often related missed appointments and interrupted treatment to travel expenses while the nurse in the program in Dilla focused on the food shortage that many of her patients complained of.

### **Disclosure and the risk of losing shelter and livelihood**

In addition to worries associated with economic constrains, fear of disclosure and expected negative reactions from the society are still of a great concern. Six patients had chosen to disclose their status to the whole community. For the rest, a majority had only told the family and a few neighbours.

Only one of my informants among the patients did not want me to record the interview. He is a Muslim trade, 42 years old and comes from a village outside Dilla. Both he and his wife have been on ARV treatment for seven months and use to come for procurement of drugs every second month. In answer to my question as to why they have chosen not to disclose, he answers that he personally would have preferred to do so but they have no choice if they want to protect the children and their feelings. Knowing the status of the parents, the children would have been ignored by neighbours and in a position were they would not have been able

to take part in normal activities in the village. He also imagines that the children themselves would have been ashamed of their parents.

According to the patients and some of the health professionals, the stigma in the villages is higher compared to in the towns where people have been more exposed both to information but also to the effects of the ARV treatment. However, the nurse in Yirgachèfè explains that while HIV patients from the surrounding villages would ask for her in the ART unit if she were not there, people from town would just leave. Her explanation is related to the fact that the town is small and those working in the unit are well known among the population, which leads to a much higher risk of unwanted disclosure.

A woman in her late twenties is sitting in front of me. One year ago, she arrives to the hospital from the village to deliver her firstborn. A caesarean needs to be undertaken and during the procedure she is found to be HIV positive. Her parents-in-law are informed. They force her husband to divorce her and decide to keep her newborn baby with them while she is forced to leave the village. She ends up in Dilla where she rents a room with a family. Her CD4 count is low at that time and the doctor advises her to start on ART. She fears the pills without knowing why but decides to follow the advice as she has seen other patients with the same disease improve from the treatment. In addition to the support from Medan Acts, she tries to sell assets at the local market. Because she does not take pills at work, the daily schedule is irregular in the beginning and she ends up developing tuberculosis. The combination of treatments gives serious psychological side-effects but she adds that this episode has taught her to follow strictly the pill schedule and made her fully aware of what will happen if she completely stops treatment. In the morning she takes holy water from eight to nine o'clock. She rests from nine to ten when she takes her ART drugs. In addition to the family, the neighbours are aware of her status. In the beginning they ignore her completely. She invites them for a coffee ceremony, and now they visit each other and eat together

## **The coffee ceremony**

In her article about the coffee ceremony in Ethiopia, Rita Pankhurst (1997) gives an extended historical background for what we may witness visiting a fashionable restaurant in Addis Ababa or a rural village in the countryside. In spite of what one would imagine, Pankhurst says the present form is a relatively new institution though increasingly popular.

The coffee ceremony may be performed at any time of the day but often after church in the morning or dinner in the evening. It is a social gathering often enjoyed by women and a moment for relaxation, friendly conversation and gossip. The main ingredients are the coffee beans which are roasted on a thin frying pan over a low stove filled with charcoal and incense. Once finished they are pounded and put into the *jäbäna*, the black clay pot with hot water where the coffee is left to settle. The small Chinese looking cups are taken out from the small table and put upon the tray. The coffee is served in three rounds adding more water when the pot is empty. The most honoured guest or important family member is always served first followed by the others in the ranking system.

The participants during the group discussion at Medan Acts explained to me that those who want, invites the nurse from Medan Acts and their personal caregiver to have a coffee ceremony in their home. The patient invites all his neighbours and introduces himself to the community as HIV positive. The nurse explains how HIV is transmitted but emphasizes also that normal interpersonal contact like shaking hands, eating and drinking together do not pose any danger.

In the interview with the Leader for Care and Support of Family Health International in Awassa, she describes how the organisation is using this tradition as one of their major tool in the effort to strengthen adherence to ART as well as an instrument in HIV prevention and the reduction of stigma and discrimination in the society. The patient himself participates actively in the ceremony advocating ART and PMTCT programs as well as condom promotion. The coffee ceremony is therefore not only for the individual patient, but for the community as a whole. The following two cases reflect the significance of the ceremony

A member of the focus group rented a room with a family. When they got to know he was infected, they tried by all means to make him leave, even bringing him to the

police station. To avoid the same thing happening when he moved to a new location, he arranged a coffee ceremony for his new neighbours.

On of the other participants in the group, a mother of seven children, adds to his story by telling us how she came to the point in life when she went to the Manager of Medan Acts, begging him to take care of her children and she leave the area. This happened after being denied shelter several times because of her HIV status. The Manager of Medan Acts went to the leaders of the Kebale to ask for their assistance. The family was given a house but the neighbours wanted them to leave, denying her children entry to their homes. After the coffee ceremony the whole situation changed. For the time being the same neighbours come to her house to fetch water. They eat together and her children visit their homes.

These cases are good examples on how HIV prevention and care has been integrated in a local tradition which is acceptable in the population and has demonstrated efficiency in passing on a sensible message as well as strengthening adherence. The Manager of Medan Acts, the Regional Manager as well as the Head of Care and Support in FHI emphasized that the level of adherence of patients in the home-based care program was very good. They related this to the repeated counselling by health personnel at the hospital, the caregivers, the nurses in the programs and the coffee ceremonies. As their beneficiaries only come from the towns, they were able to have a close follow up

### **Disclosure in relationship to ART and “wrap-around services”**

One of my questions focused on the time when the patient was advised by the physician to start ART. As most of them present themselves in an advanced stage, the time between diagnosis and start of treatment is often short. Less than half of my informants had heard about ART before starting on treatment. In the beginning there were lots of presumptions about ART. The drugs had a reputation for killing people. The Medical Director also adds that most of the patients actually died in the beginning as a result of starting treatment in an advanced stage and not surviving the immune reconstitution inflammatory syndrome (IRIS). One patient mentioned that the drugs previously were viewed by some in the society as a method introduced by the government to kill HIV patients in order to protect the rest of the society. It took weeks and months before some were convinced by the health personnel to

begin, starting treatment more as a result of fatalism than hope of improvement. One woman told me she said goodbye to her children before she took her first dose, convinced that it would kill her.

As time has gone by and both the community and patients have seen that those they thought would die quickly have, in fact, come back to life, the attitude towards treatment has changed. There is hope of a new life even to the extent that it is worth revealing oneself to the community.

*“Before testing, seeing my physical appearance, many people suspected I had this disease and for that reason did not treat me well. But now since I have disclosed, all the members of the community including the church respects and treats me well like any other member of the community.”* (Male 30, one ART for 19 months)

Only one of my informants tells me that he regrets having been open about his status. This has cost him a job in the military and he feels that people disapprove him receiving assistance from Medan Acts. If he had kept quiet he would have been given treatment for free from the military. However, the experiences were different as some informants expressed the fact that disclosure had helped them both financially and emotionally as people anyhow had understood the seriousness of their disease and had imagined that they had HIV.

*If I hide myself I am the one who are disadvantages. But if I disclose myself to you, it will be easier because you will help me financially and emotionally. That's why we chose to disclose. To reduce stigma ...For the patients it is positive to disclose as well as for the community* (Man 24, ART 2 years)

One of the other patients mentions also that the community sometimes valued that people were open about their status:

*“At the beginning people were not treating me well. Later on, after disclosing and teaching in the public, the community has changed their attitude towards me. So people will develop a negative attitude towards you if you hide yourself. But if you disclose they accept and treat you well. At this time I can say that they treat me well and I have a good relation with all the members of the community”*



(Female 28, on ART for 1 Year)

However, several stories also showed that the reduction of stigma often reaches its limit when it comes to questions of employment. Even though people for example were willing to greet and share a meal with an HIV infected woman, employing her as their housemaid would not happen. One of my informants told me that a nurse she knew wanted to find a housemaid. After the patient proposed herself, the nurse refused saying she could transmit the disease to her:

*Yes people make differences between HIV patients and others when they want to employ someone. The lady you interview before was working in someone's house as a baker. Once upon the time there was a big meeting in the hall in town. She disclosed her status to the people. When she came back to home, the family that had employed her said that: "if we had known you were infected, we would not have employed you. So from today you have to stop working."* (Male 30, on ART for 19 months)

Among the health workers at the hospital in Dilla the opinions regarding reduction of stigma varied. Most of them claimed the change was considerable and that the issue of poverty was more of a problem. Patients who previously had gone to Yirgalem for treatment, had decided to continue in Dilla. Of course it is impossible to say whether this was a result of a lack of finances for transportation, or of an increased acceptance in the society. The Medical Director emphasized the fact that most of the patients are enrolled in one of the NGOs, linked to assistance from the WPF and known in town as being seropositive. Some have married each other, living an ordinary life and not afraid of revealing themselves. In the discussion with health providers, we often came back to the issue that disclosure seemed to be more common among the poor who had the opportunity to get assistance from the NGOs. Living in a state of extreme poverty often means that there is nothing more to lose. The number of choices becomes limited and the whole issue is reduced to a question of survival or not.

As previously mentioned, patients who have the means choose often to go to Yirgalem, Awassa or Addis Ababa to get tested and follow treatment of ART. The ART program had been running for one year when I interviewed the nurse who has been coordinating the activities the whole time. According to him, he could not see that the introduction of ART had had any impact on the level of stigma for the time being. He did not have the actual number of patients from Dilla, but estimated roughly a figure of 20.

The situation at Yirgalem hospital is quite different. The hospital has a very good reputation and several patients prefer to go there because of the quality of care received. The ART program started in 2002. The drugs were not free of charge at that time, so only a limited number of people could afford to start. The physician in charge of the unit estimated that approximately 50 patients come from Dilla, mostly from what he described as middle class. When I asked to what extent the introduction of ART has changed anything relating to stigma and discrimination, he said it has been reduced but patients who are able to, would still prefer to access treatment from a different site than their nearby facility. According to him, the community looks upon the ART as miraculous drugs and it has changed its attitude to some extent as it has witnessed their effect.

According to the Head of the Regional HABCO, no assessments have been conducted to answer the correlation between availability of ART and reduced stigma, but his observation would be that the effectiveness of treatment encourages patients to come forward.

## CHAPTER 4- DISCUSSION

In the interviews with patients on ART; the major obstacle to start but also to continue treatment, turned out to be poverty. Stigma and discrimination were still, though maybe less so in Dilla town, hampering people from seeking treatment. Once a person had started, emerging side-effects made some of them, in spite of good adherence counselling, stop treatment or take the medication irregularly. After recovering, the devotion to treatment was very strong and the fear of not getting the ART drugs free of charge anymore a constant worry. Changes in daily routines, such as being away from home, made some of them forget to take the pills at the appropriate time, but not to miss a dose. Practical arrangements, such as involving the children in the pill schedule as well as possessing a watch, boosted good adherence. Healing through holy water was widely practiced and did in some cases affect the ARV treatment.

The following section starts with a discussion of methodology. It is followed by a discussion of the major findings where the first part treats the significance of the "wrap-around services" and ART on disclosure. Healing through holy water and the implications for ARV treatment is treated in the second part. Moving gradually from a micro level where local determinants are more present, the third part deals with challenges related to the health system. Finally; taking into account the fact that a local ART program is not isolated from either historical, economic or political structures, the need to create viable responses to *structural violence*, is discussed at the end of the thesis.

### **Discussion of methods and approaches**

Tracing defaulters and questioning them about why they were not in the ART program anymore would of course have been the best method to explore determinants to non-adherence. That was unfortunately not possible. I acted on the assumption that patients in the program could provide me with relevant answers as they may face similar challenges as those who did not start on treatment or defaulted from the program. Anyhow, in spite of the limitations of this methodology, it was the only way to obtain information.

To compensate for these limitations, I tried to approach as many sources of information as I possibly could have access to. Validation was ensured through triangulation where different data collection methods were used. They include interviews, focus group discussion, participatory observations and literature studies but also selection of different target groups like patients, health providers and religious leaders. Voices have been given both to health workers in NGOs and governmental institutions. Statements from the different groups have not contradicted but underlined each other. I have not made any causation as the method it self does not permit it. The presentation of how data was obtained and the way it was analysed has been as transparent as possible.

The overall objective has been to identify determinants to adherence to ARV treatment. Hence, to what extent do the results provide valid answers to the objectives? First of all it is important to clarify what my study has tried to answer as the picture may appear confusing to some extent: At the one hand, the statistics and information from health providers communicate the existence of an adherence problem. On the other hand; the patients I interviewed claimed they had a good level of adherence and from the way they expressed themselves, I do strongly believe that they gave an accurate picture of their own drug use. As I did not interview those who defaulted from the program, I can only claim that my results provide the answers of what threatens the adherence of the patients in my study. Never less, it corresponds well with studies already published from similar contexts and is an answer to the call for more studies of local determinants to ART adherence (Mays and Pope, 2000).

What could have received a stronger focus, is a deeper analysis of the factors which make individuals take their final decision as many of these questions are not only linked to well defined determinants but more diffuse and hidden questions related to confidence in and the authority of individuals in the different health sectors of care. That would have demanded more time, probing and a stronger focus on this particular aspect to the expense of a broader perspective.

The last area I want to draw attention to is the overall positive attitude among patients towards the health professionals at the ART unit. To what extent does the satisfaction with the services relate to the fact that the interviews were conducted in the hospital area and treatment and access to food assistance in the hands of the health providers? Additionally; what are the risks associated with using the nurse who coordinates the ART program in the selection of

participants? The answers to both of these questions are crucial when it comes to the reliability of results especially related to the professional sector. What I personally observed was that it was those patients who arrived first at the unit who were asked to participate. There are no guaranties that manipulation in the selection of participants did not happen, but I find it hard to believe.

The framework of *structural violence* only partially explains questions relating to adherence as the patients I interviewed adhered well to treatment. However, in my opinion, the framework is perfectly appropriate to the context in Dilla where such a big proportion of the population depends heavily on an international commodity like coffee. Prices on the international market, affect the producer directly, as well as the network around. The extreme rise in food-prices the last year, shows even more clearly to what an extent every corner of the world is bound together in the global trade. The combination of the framework of *structural violence* and Kleinman's model of the health care system, succeed in showing adherence to be both a political and economic challenge on a macro level and mirror some of the local components which determine individual health seeking behaviour.

## **Discussion of the findings**

### **The significance of ARV treatment and “wrap around services” on disclosure**

Only a few years back, the mainstream among scholars in the field and overseas policy makers, pointed out that only prevention, not treatment of HIV should be made accessible to low-income countries. Prevention in terms of behaviour change was the principal objective. Arguments based on cost – effectiveness, lack of infrastructure and weak health systems were used as reasons not to increase access to ARV treatment for patients in sub-Saharan Africa. A few voices were raised against this, among them Arthur Kleinman who pointed out that it was a moral imperative to secure treatment also for HIV patients in low-income countries (Kleinman, 2006)

The debate is partly still going on and some are still not convinced that the positive impact of HAART programs overshadows the negative consequences as the accessibility of ART easily attracts attention at the expense of traditional preventive activities (Marseille et al., 2002).

However, experiences, not least in South Africa has shown that it is very difficult to succeed in the field of prevention if there is no treatment available (Levy et al., 2005). It should not be difficult to envisage the lack of motivation to expose oneself to the risk of total rejection from family and community without even having access to a lifesaving treatment.

Dark forces in society like stigma and discrimination make it very difficult to adhere to treatment as fear of disclosure causes some to start treatment far from their home location. Frequently, this is a treatment that, for economic reason, they are not able to continue. Those I interviewed who had travelled to Dilla to start treatment to avoid disclosure, were men. It is very hard to imagine that women would have been able to do the same. Studies have shown that disclosure increases the likelihood of good adherence (Ramadhani et al., 2007) and has resulted in an effort to make patients reveal their status to at least one person in their nearby surrounding. Some of the patients in Dilla had disclosed to either partner or children who reminded them to take pills at the scheduled time. Fear of taking pills at the workplace and in the presence of other people, made some delay the dose. This has also been seen in other studies (Mills et al., 2006).

In my discussions with health professionals at Dilla Hospital and the manager of Medan Acts, it seemed like poor patients approved as beneficiaries of an NGO, were overrepresented among those who had disclosed their status. The reality of living in extreme poverty put an individual in a situation where there is nothing more to lose. The better-off will not risk their reputation and may therefore choose not to disclose. To a certain extent it may result in HIV/AIDS being even more associated with the poor and poverty as patients who have disclosed and promote testing and treatment publicly, are among those who receive support from the NGOs as for the case in Dilla. However, the “wrap around” services together with the visible effect of ART treatment may have contributed to a change in attitude in Dilla. The coffee ceremony as an integrated part of the activities had proven to be a very essential tool both when it came to prevention of new infections, decreased barriers towards HIV infected patients and adherence to ARV treatment.

On the web page of Family Health International, it is possible to read how Medan Acts together with 25 finalists from a group of 517, was nominated in 2006 to the Red Ribbon Award at the International Aids Conference in Toronto. The price is in recognition of *outstanding community leadership in the fight against AIDS* and refers directly to the use of

the coffee ceremony in dealing with the community (FamilyHealthInternational, 2006). In recent years, non-governmental organisations have started to use the ceremony in community mobilization programs. Pankhurst refers in her article to Save the Children Norway – Ethiopia who wanted to establish foster homes for children in Ethiopia (Pankhurst, 1997). The relaxed atmosphere proved to be a perfect moment to discuss specific topics. Zenebe (2006) witnessed how women seemed to feel very comfortable treating sensitive issues related to sexuality and HIV/AIDS during their coffee ceremony conducted by an NGO. The women expressed the feeling of not attending an education program which made them participate actively.

Lessons drawn from these experiences underline the need to find the entry points for discussion which may be different in each culture. Just as changes in the resistance pattern of medical drugs occur frequently and need close surveillance, so attitudes and perceptions (stigma) in a society are not static but rather may change rapidly depending on whether or not there is intervention. There is no reason to believe that culture is static and issues related to stigma and discrimination not objects of rapid changes. This issue is also highlighted by Castro and Farmer (2005) who argue that an effective ART program which gives access to treatment to everyone leads to a rapid decrease in the level of stigma. They argue that the superficial understanding of stigma as a barrier to testing and treatment, lacks credibility as long as such a program is non-existing.

Decentralization of ART programs to health centres to improve access for people in remote areas is essential (HAPCO, 2007). However, if the “wrap around services” provided by the WFP and the NGOs which might have reduced stigma in Dilla are not implemented, the high level of stigma in a society where everyone knows each other, may reduce willingness to undergo treatment. In Yirgachefe, the ART unite had been operating for 16 months but the nurse showed her protocol where only 34 patients were enrolled in the program. According to her, lack of awareness but also stigma may be the reason behind these figures.

### **Holy water: A barrier or complement to ART treatment**

In spite of several attempts to find the reason why ART and holy water should not be combined, I have to admit that the principal cause is still not clear to me. Some of the priests and patients related it to practical issues as use of holy water requires fasting which

contradicts the advice given for ARV treatment. Using holy water is also very time-consuming as well as demanding as it is followed by vomiting. As faith in God and the holy water was underlined as a precondition to get cured by most of the priests, using ART would be a sign of distrust. The patient would be putting his confidence in two different healing methods and not in God alone. According to the priest in the Abu'n church in Dilla, the bible forbids that.

As I elaborated in the previous chapter, the spiritual leaders in the church have very different theoretical background and practice ranging from university degrees to no secular training at all. That may be one of the reasons why the answers on these issues differed a lot. According to the Ethiopian Scholar, the church is very decentralized and only united on very few central issues of dogmas like the nature of Christ. It does not have a common policy and speaks with different voices depending on who the questions are addressed to. The diversity is demonstrated between monasteries and churches as well as between priests partly depending on level of their education. One of the priests from Awassa who had been teaching for 37 years, explained that monks and hermits used to come to the churches trying to attract the population by declaring a message from God or the Virgin Mary which sometimes could be in opposition to proclamations from the Patriarch. They used to get strong support from ordinary people and even the priest was forced to agree with their message in order not to get into difficulties himself, such as being beaten. I was also told by a close family member of the leader of the priests in Dilla that the arrival of the priest from Awassa was not welcomed by him and some of his colleagues. However, the opinion of the population in town was strongly in favour of the visiting priest, and it seemed like those opposing him preferred to keep quiet waiting for the phenomenon to evaporate.

What does this information have to do with adherence? In my view it is crucial for activists or health workers who want to approach the Orthodox Church on questions related to the combination of ART and holy water, to be aware of the diversities in the church itself. This diversity becomes even clearer in the different opinions regarding the Patriarch. During informal conversations with people I got to know that the current patriarch comes from the same ethnic group as the ruling government and that his credibility is not universally recognised since he is seen more of a political leader among some. His proclamation related to ART drugs and holy water will therefore not be given authority among some believers. One of my informants also stated that the Patriarch did not even have any choice about whether to



give his proclamation since the pressure from donors vocalized by the American ambassador was immense. As I am not able to document these assumptions, they may only be denoted as anecdotal though very interesting

According to Kleinman it is essential to study health care as cultural systems and see how the different actors within the system interact with each other as well as understand the belief about the origin of disease. As the Orthodox Church is embedded both with the state and rooted in traditional belief systems, it has a tremendous influence in the life of the followers. From early childhood, the believers have been offered their own individual spiritual father (priest) who they are accountable to and take advices from. Patients who have never been exposed to other systems like the modern medical sector, might find themselves on a crossroads between two authorities who in some cases even compete against each other. The question on who to trust and rely on becomes very important if the practice of one excludes the use of the other like sometimes happens with the combination holy water and ART.

Patients who have benefited from education may be in a better position to make their own choice because they have been given means to consider the different options. However, observations during the consultation and interviews with the patients revealed that the issue seemed to be related just as much to their confidence in the health provider as to their formal education. On the other hand, external factors relating to economic power may hamper the efforts to follow personal preferences and convictions. The interviews on Sky News show that poor patients may not possess the means to consider HIV as a chronic disease even though the drugs are free of charge. Additional costs like transport fees and lack of employment, as a result of stigma and discrimination, force some of them to stop the ARV treatment not because of a lack of confidence in the efficacy but because of the lack of economic ability to bear the consequences of a chronic disease. In other words: It is not always a matter of trust or distrust in relation to modern medicine, but a result of lack of accessibility to the services. Curing propaganda by the church, becomes the only option for some as it represents a hope for a life without HIV on earth and salvation after death.

It is very tempting to conclude that healing through holy water is just another example of how power structures, in this context related to religion, increase suffering among those who are already extremely vulnerable. Patients who have benefited from an education and can bear the economic consequences of the disease, are more aware of the different opinions in the church

or have a spiritual father who is willing to integrate the different healing methods so are less susceptible. To a certain extent, there are reasons to claim that holy water in some cases may be a barrier to ARV treatment and that those who are already the most vulnerable, are also those who suffer most from this barrier. On the other hand, the hope born out from the possibility of being cured from HIV, seemed to strengthen the patients. Faith in the power of God and support from fellow believers, were mentioned by both Protestant and Orthodox Christians as a very important encouragement in life. For that reason, it is difficult to completely condemn the practice and it may be better instead to investigate possibilities for integrating this worldview with modern treatment.

Advices from the health workers in my study differed as some patients had been told to stop taking holy water while others were told it was okay to combine. To a certain extent, that seemed to correspond with the denomination of the health workers, whether they belonged to the Orthodox or the Protestant church. Even though the health professionals at the different sites recognized the challenges related to this issue, there seemed to be a lack of willingness to engage in a conversation with the different actors in the church. At the same time, as the church itself is divided on this issue, the approach would maybe more efficient if it were directed towards the individual patient and priest. The conclusion from the interviews with the patients in the program showed that those who wanted to use the healing method had adopted the recommendations of both of the sectors.

### **Strength of an ART program - strength of the Health System**

Some of the discussions related to investment in access to treatment of HIV/AIDS, have expressed concern about the extent that the focus on HIV/AIDS and ART has been at the expense of other emerging medical areas in low-income countries. I addressed this question with the medical doctors at Dilla hospital as well as with the NGOs and found that they had a common understanding of the issue. Investment both in training of personnel and in material had benefited the whole hospital in terms of laboratory equipments and patient care in general. The staff did not get paid any more to work in the ART unit and the medical doctors serve there for six months before being transferred to another. The investment in training and supervision may therefore give “a spill over” to other areas of the hospital as one of the physician said. Studies have also showed that HIV prevention and care, may strengthen the existing health care system (Walton et al., 2004).

As the ART program is an integrated part of the hospital, both the weaknesses and strengths of the institution and the sector as a whole will affect the quality of care provided. As mentioned earlier, both patients and my research assistant expressed surprise when it came to the way they were received by health workers compared to previous experiences with the sector.

During my stay at the hospital in Dilla, I witnessed several consultations both with the physician and the nurse. The nurse was seeing all the patients and only referring new patients and those with specific medical needs to the doctor. Even though the language barrier blocked much of the information, I could clearly feel the atmosphere of confidence and respect. Everyone seemed to be treated equally and it seemed that there was a deep feeling of confidence especially between the nurse and her patients. Going back to factors that are likely to influence adherence; characteristics of the regime, features of the individual patient, the patient-provider relationship and the health system are regarded as the most important ones, according to WHO (2003). During the time of data collection, determinants related to the hospital care for HIV patients were surprisingly well maintained, given the conditions in the sector as a whole. Even though the figures show a situation where many patients drop out from the program, the patients interviewed expressed their appreciation of the care they received at the unit, as they referred back often to the information given by the doctors and the nurse. The quote by Paul Farmer underlines the same fact: " *Outcomes are related to the quality of the program rather than quality of the patients ideas' about the disease.*" (Farmer, 2005)

However, as the ART program is heavily donor based both in terms of technical and human support, there is a big question mark as to whether training and supervision which is the duty of Regional HAPCO, would have existed without the implementing agencies. According to Ethiopian medical doctors working for these agencies, it would have been non-existent because of the lack of capacity in the sector. As mentioned earlier, the discrepancy between calculated needs for the years to come and available funding is increasing as external donor support decrease according to the last estimates from HAPCO. Some of them like PEPFAR make a commitment on an annual basis creating lots of insecurities about whether necessary funds will be available or not. It is also important to be aware of the fact that even though the input of overseas supplies might sounds huge, some agencies like PEPFAR estimates that

about 45% of their donation will cover supervision visits from international experts. (HAPCO, 2007)

The severe lack of trained professionals and the escape to better paid options on the national and international scene, devastate both the ART programs and other activities. Even though both physicians and nurses may be motivated to work for the poor as employment in a government hospital implies, they often find themselves trapped in a system where they are neither accountable to nor rewarded by the employer. As a result of that, the interest for many will not be in the governmental institution where they are employed, but in the private clinic from which their income comes. Even though donors continue to support both care and “wrap-around” services, it is difficult to see how the sector will be able to keep their professionals as long as these issues are not dealt with. On the other hand, if donors to ARV programs are serious about the right to treatment, how is it then possible that the same nations that support these programs are also the first to recruit health professionals from the very country in which the programs are in operation (Koenig et al., 2004)?

The visit to the health centre in Yirgachefe revealed another major weakness in the system related to the lack of coordination and collaboration between the different actors. Due to lack of capacity within the sector, two different NGOs had been given the role of training and supervising personnel and activities at the facilities, The John Hopkins University in the hospitals and Family Health International at the health centre level. The potential for a referral system of patients, tracking defaulters, utilization of the CD4 counter at the hospital in Dilla as well as professional coaching for the benefit of users, was not at all exploited. As the quality of an ART program is very significant for patient adherence, there is absolutely room for improvements which does not have to be expensive.

### **Facing structural violence: Facing structural approaches**

One of the keywords emerging from the data is the word motivation to start and follow ART treatment. It is impossible for a Westerner with only a theoretical knowledge of poverty to understand what it really means not to be able to meet basic needs such as food and shelter. As the title implies: What need is there of a lifesaving treatment offered free of charge when there is no place to sleep and no food to eat? If we add that the same person suffers from

considerable physical and psychological distress with little confidence in the treatment offered, it is by no means sure that he will follow the recommendations given by health workers as the definition of adherence implies. In many cases, a patient is further obliged to weigh up the risk of having his status known by the community as against the benefits he might gain from the treatment offered.

Dealing with poverty as a determinant to adherence to ART is challenging due to the multitude of issues associated with it. It is totally out of the scope of this study to do more than scratch the surface of the subject but it is related to a strong conviction that HIV/AIDS and adherence to ART treatment has to be dealt with within a framework of social justice and not only as a subject primarily connected to gender, culture and behaviour.

Taking the sector of agriculture as an example, drought and climate change have often been referred to as causes of hunger. However, some scholars suggest that political and structural factors have added considerably to incomplete food production. In a very interesting article, Dessalegn Rahmato refers to the crisis in 1994 and 1999 and says that: "*Death and starvation have structural causes and is not a product of temporary social or environmental shocks.*" (p.2). He continues by expressing his view that the historical background of the land tenure system, growing land fragmentation as a result of population growth, environmental degradation and lack of implementation of new technology are some of the factors that move farmers from a state of poverty into a downward slide into destitution (Rahmato, 2003). Poor infrastructure and roads have resulted in a lack of access to markets where farmers can get good prices for their products and therefore seen as major obstacles in trade and in reduction of poverty (Brigsten et al., 2005). When we know that 85% of the population is employed in the sector of agriculture, everything affecting this sector has an impact on the great majority of the inhabitants of the country.

Touching the field of education, the illiteracy level, as mentioned earlier, is very high in the country. Studies have made a connection between the level of education and adherence to ART predicting that low education may lead to lower level of adherence (Golin et al., 2002). Even though some of the health providers mentioned that lack of education created low awareness and adherence, it seemed to me that good counselling and confidence in the health worker compensated for some of that.

So, what do the focus on land issues, agriculture, market, infrastructure, education and other political issues have to do with HIV/AIDS and ART? In his work, Paul Farmer devotes lots of attention to the social, historical structural, religious and cultural structures of a country before he continues with the medical and anthropological issues which are his disciplines. He refers to epidemiology which shows that the poor are sicker than the non-poor as their suffering is often a combination of increased exposure to pathogens and poor access to health services. He often uses tuberculosis as an illustration as it is both a disease which is closely associated with poor living conditions and poor nutrition as well as with poor access to efficient treatment. On the question of the resurgence of tuberculosis which is also closely associated with HIV, providers of medical treatment have a tendency to blame poor adherence on either biological factors or cultural barriers. In his work in Haiti, he refers to a heated discussion in his team where physicians and nurses blamed poor adherence among their clients on patients' lack of understanding of prolonged treatment and cultural beliefs on sorcery. When they carried out research on these issues, it was found as most of the community workers had already emphasized, that most of the factors associated with poor adherence were related to economic factors. (Farmer, 2005)

In a country like Ethiopia where such a great percentage are living in great poverty, the injustice caused both by external but not least internal factors has to be understood and dealt with, even in the field of medicine. Providing ART treatment to patients living in a society characterized by poverty and a high level of stigma towards HIV/AIDS, demands more than drugs free of charge even though that is a major step forward. As already discussed; the question of adherence must be addressed with multiple approaches, described as “wrap-around services where the reality of where people live is faced up to..

When the program in Dilla started, many of those factors were taken into consideration through collaboration between the professional health sector, national and international NGOs and the World Food Program. Poor families and individuals who would not have been able to survive purely on drugs free of charge, were traced, taken to the hospitals and given food assistance as well as continuous home visits. However, it is difficult to imagine how this assistance could possibly be provided, even in the short-term, given the increased patient load and the rapid changes in donor strategies. The shift towards a focus on income generating activities seemed vital, provided that the needs of poor, bedridden patients are met. Also, if physical access to ART treatment is supposed to be an option for those living in at distance

from an ART unit, the issue of transportation costs as well as decentralized facilities must be addressed.

Even though this kind of assistance is crucial and is an essential part of an ART program in low-income settings, it must never overshadow the need to face and change the structures in the society which continue to keep people in deep poverty. It is therefore interesting to witness that the development plan for the health sector (HSDP) is as already mentioned, closely linked up to plans for eradication of poverty (PASDEP). Only time will tell whether policy makers both international and national as well as independent donors, are committed to taking the steps needed.

## CHAPTER 5- CONCLUDING REMARKS

Figures related to the HIV/AIDS epidemic show that women in Ethiopia are more affected than men. However, when we see the lack of investment and commitment in the area of safe motherhood in low income countries, we should be very careful not to link HIV/AIDS too much with gender and cultural issues. We risk losing strong and important actors on the way. HIV/AIDS is strongly connected to poverty, both for men and women and not at least for children. HIV/AIDS must be treated in the context of economic development, access and right to treatment and strengthening of the general health system.

One of the main duties for individuals and groups working in the area of HIV/AIDS in the future, is to constantly address Paul Farmer's question to policymakers and power institutions: How is it possible that "*the most basic right-the right to survive is trampled in an age of great affluence*" (p.6) (Farmer, 2005).



## References

- AU, J. T. J. T., KAYITENKORE, K. K., SHUTES, E. E., KARITA, E. E., PETERS, P. J. P. J., TICHACEK, A. A. & ALLEN, S. A. S. A. (2006) Access to adequate nutrition is a major potential obstacle to antiretroviral adherence among HIV-infected individuals in Rwanda. *AIDS*, 20, 2116-8.
- AYENEW, M. (2002) Decentralization in Ethiopia. IN ZEWEDE, B. & PAUSEWANG, S. (Eds.) *Ethiopia. The Challenge of Democracy from Below*. Stockholm, Nordiska Afrikainstitutet Forum for Social Studies.
- BAKKE, J. (1986) *Cristian Ministry: Patterns and Functions within the Ethihopian Evangelical Church Mekane Yesus*, Oslo, Solum Forlag A.S/Humanities press:New Jersey.
- BRIGSTEN, A., SHIMELES, A. & KEBEDE, B. (2005) *Poverty Income Distribution and Labour Markets in Ethiopia*, Uppsala, Almqvist & Wiksell Trycker AB.
- BYAKIKA-TUSIIME, J. J., OYUGI, J. J. H., TUMWIKIRIZE, W. W. A., KATABIRA, E. E. T., MUGYENYI, P. P. N. & BANGSBERG, D. D. R. (2005) Adherence to HIV antiretroviral therapy in HIV+ Ugandan patients purchasing therapy. *International journal of STD & AIDS*, 16, 38-41.
- CASTRO, A. & FARMER, P. (2005) Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *Am J Public Health*, 95, 53-9.
- CENTRALSTATISTICAUTHORITY (1996) The 1994 Population and Housing Census of Ethiopia Results for Southern Nations, Nationalities and Peoples' Region. Addis Ababa.
- CHAILLOT, C. (2002) *The Ethiopian Orthodox Tewahedo Church Tradition*, Paris, Intra-Orthodox Church Dialogue.
- CHOPRA, M. M., KENDALL, C. C., HILL, Z. Z., SCHAAAY, N. N., NKONKI, L. L. L. L. & DOHERTY, T. M. T. M. (2006) "Nothing new": responses to the introduction of antiretroviral drugs in South Africa. *AIDS*, 20, 1975-7.
- CHURCH, T. E. O. (1970) *The Church of Ethiopia: A panorama of history and spiritual life*, Addis Ababa, The Ethiopian Orthodox Church.
- DILGER, H. (2007) Healing the Wounds of Modernity: Salvation, Community and Care in a Neo-Pentecostal Church in Dar Es Salaam, Tanzania. *Journal of Religion in Africa*, 37, 59-83.
- DONHAM, D. & JAMES, W. (1986) *The Southern Marches of Imperial Ethiopia*. ETHIOPIANORTHODOXCHURCH (1970) "*The Ethiopian Orthodox Church*" Addis Ababa, The Ethiopian Orthodox Church Mission
- FAMILYHEALTHINTERNATIONAL (2006) FHI/Ethiopia Activites Recognized at Interantional AIDS Conference.
- FARMER, P. (2005) *Pathologies of Power health, human rights and the new war on the poor*, Berkeley and Los Angeles Press, University of Calefornia Press.
- FARMER, P. E., NIZEYE, B., STULAC, S. & KESHAVJEE, S. (2006) Structural violence and clinical medicine. *PLoS Med*, 3, e449.
- GOLIN, C. E., LIU, H., HAYS, R. D., MILLER, L. G., BECK, C. K., ICKOVICS, J., KAPLAN, A. H. & WENGER, N. S. (2002) A prospective study of predictors of adherence to combination antiretroviral medication. *J Gen Intern Med*, 17, 756-65.

- HAMER, J. & HAMER, I. (1966) Spirit Possession and Its Socio-Psychological Implications among the Sidamo on Southwest Ethiopia  
*Ethnology*, 5.
- HAPCO (2007) Multisectoral plan of action for universal access to HIV prevention, treatment, care and support in Ethiopia 2007-2010. Addis Ababa.
- HARDON, A. P., AKURUT, D., COMORO, C., EKEZIE, C., IRUNDE, H. F., GERRITS, T., KGLATWANE, J., KINSMAN, J., KWASA, R., MARIDADI, J., MOROKA, T. M., MOYO, S., NAKIYEMBA, A., NSIMBA, S., OGENYI, R., OYABBA, T., TEMU, F. & LAING, R. (2007) Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa. *AIDS Care*, 19, 658-65.
- HELMAN, C. (2000) *Culture, health and illness*, Oxford university press.
- HOFFMAN, C., ROCKSTROH, J. K. & KAMPS, B. S. (2007) HIV medicine 2007. Flying Publisher.
- JACOBSSON, L. (2002) Traditional treatment of mental and psychosomatic disorders in Ethiopia. *International Congress Series*, 1241, 265-269.
- JERENE, D. D., NAESS, A. A. & LINDTJØRN, B. B. (2006) Antiretroviral therapy at a district hospital in Ethiopia prevents death and tuberculosis in a cohort of HIV patients. *AIDS research & therapy*, 3, 10.
- KLEINMAN, A. (1981) *Patients and Healers in the Context of Culture: An Exploration of the borderland between Anthropology, Medicine and Psychiatry*, Los Angeles London.
- KLEINMAN, A. (2006) *What Really Matters. Living a Moral Life Amidst Uncertainty and Danger*, Oxford New York, Oxford University Press.
- KOBER, K. D., WV (2004) Scaling up access to antiretroviral treatment in southern Africa: Who will do the job? *Lancet*, 364, 103-105.
- KOENIG, S. P., LEANDRE, F. & FARMER, P. E. (2004) Scaling-up HIV treatment programmes in resource-limited settings: the rural Haiti experience. *Aids*, 18 Suppl 3, S21-5.
- LANIÈCE, I. I., CISS, M. M., DESCLAUX, A. A., DIOP, K. K., MBODJ, F. F., NDIAYE, B. B., SYLLA, O. O., DELAPORTE, E. E. & NDOYE, I. I. (2003) Adherence to HAART and its principal determinants in a cohort of Senegalese adults. *AIDS*, 17 Suppl 3, 8.
- LEVY, N. C., MIKSAD, R. A. & FEIN, O. T. (2005) From treatment to prevention: the interplay between HIV/AIDS treatment availability and HIV/AIDS prevention programming in Khayelitsha, South Africa. *J Urban Health*, 82, 498-509.
- LINDELOW, M. & SERNEELS, P. (2006) The performance of health workers in Ethiopia: results from qualitative research. *Soc Sci Med*, 62, 2225-35.
- MALTERUD, K. (2006) *Kvalitative metoder i medisinsk forskning*, Oslo, Universitetsforlaget.
- MAMMO, T. (1999) *The Paradox of Africa's Poverty: The role of indigenous knowledge, traditional practices and local institutions - the case of Ethiopia*, Asmara, The Red Sea Press.
- MARSEILLE, E., HOFMANN, P. B. & KAHN, J. G. (2002) HIV prevention before HAART in sub-Saharan Africa. *Lancet*, 359, 1851-6.
- MAYS, N. & POPE, C. (2000) Qualitative research in health care. Assessing quality in qualitative research. *Bmj*, 320, 50-2.
- MEDICALNEWSTODAY (2007) With Malnutrition in Africa Decreasing effectiveness of Antiretrovirals, Program Provides Food Access to HIV positive People.
- MESSING, S. D. (1968) Interdigitation of Mystical and Physical Healing in Ethiopia.

- MILES, M. B. & HUBERMAN, A. M. (1994) *Qualitative Data Analysis: an expanded sourcebook*, London, SAGE Publications.
- MILLS, E. J., NACHEGA, J. B., BUCHAN, I., ORBINSKI, J., ATTARAN, A., SINGH, S., RACHLIS, B., WU, P., COOPER, C., THABANE, L., WILSON, K., GUYATT, G. H. & BANGSBERG, D. R. (2006) Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. *Jama*, 296, 679-90.
- MOH (2006) AIDS in Ethiopia. IN REPORT, S. (Ed.), Federal Ministry of Health/National HIV/AIDS prevention and control office
- MOH (2007) Single point HIV estimate prevalence.
- MSHANA, G. H. G. H., WAMOYI, J. J., BUSZA, J. J., ZABA, B. B., CHANGALUCHA, J. J., KALUVYA, S. S. & URASSA, M. M. (2006) Barriers to accessing antiretroviral therapy in Kisesa, Tanzania: a qualitative study of early rural referrals to the national program. *AIDS patient care and STDs*, 20, 649-57.
- NACHEGA, J. J. B., STEIN, D. D. M., LEHMAN, D. D. A., HLATSHWAYO, D. D., MOTHOPENG, R. R., CHAISSON, R. R. E. & KARSTAEDT, A. A. S. (2004) Adherence to antiretroviral therapy in HIV-infected adults in Soweto, South Africa. *AIDS research and human retroviruses*, 20, 1053-6.
- NEGASH, T. (2006) Education in Ethiopia: From crisis to the brink of collapse. *Nordiska Africa Institutet*, Discussion Paper 33.
- OXFAM (2001) Access to Health and Education Services in Ethiopia: Supply, Demand and Governmental Policy. London, Oxfam Print Unit.
- PANKHURST, A. & MARIAM, D. H. (2000) The Iddir in Ethiopia: Historical Development, Social Function, and Potential Role in HIV/AIDS Prevention and Control. *Northeast African Studies*, 7, 35-58.
- PANKHURST, R. (1997) The coffee ceremony and the history of coffee consumption in Ethiopia. *Papers of the XIIIth international conference of Ethiopian studies*. Shokado Book Sellers
- PARAHOO, K. (1997) *Nursing Research: Principles, Process and Issues*, New York, Palgrave Macmillan.
- PATTON, M. Q. (1990) *Qualitative Research & Evaluation Methods*, Thousand Oaks, Sage Publications.
- PETIT, N. (2007) Ethiopia's Coffee Sector: A Bitter or Better Future? *Journal of Agrarian Change*, 7, 225-263.
- PLUSNEWS, I. (2007) ETHIOPIA: Church endorses 'holy water' and ARVs as people flock to miracle mountain.
- POUND, P., BRITTEN, N., MORGAN, M., YARDLEY, L., POPE, C., DAKER-WHITE, G. & CAMPBELL, R. (2005) Resisting medicines: a synthesis of qualitative studies of medicine taking. *Soc Sci Med*, 61, 133-55.
- RAHMATO, D. (2003) Poverty and Agricultural Involution. IN RAHMATO, D. (Ed.) *Some Aspects of Poverty in Ethiopia: Three Selected Papers*. Addis Ababa, Forum for Social Studies.
- RAMADHANI, H. O., THIELMAN, N. M., LANDMAN, K. Z., NDOZI, E. M., GAO, F., KIRCHHERR, J. L., SHAH, R., SHAO, H. J., MORPETH, S. C., MCNEILL, J. D., SHAO, J. F., BARTLETT, J. A. & CRUMP, J. A. (2007) Predictors of incomplete adherence, virologic failure, and antiviral drug resistance among HIV-infected adults receiving antiretroviral therapy in Tanzania. *Clin Infect Dis*, 45, 1492-8.
- RITCHIE, J. & LEWIS, J. (2003) *Qualitative Research Practice*, London, SAGE Publications Ltd.

- RITCHIE, J. & SPENCER, L. (1994) *Qualitative data analysis for applied policy research*, London  
New York, Routledge.
- ROSEN, S., FOX, M. P. & GILL, C. J. (2007) Patient retention in antiretroviral therapy programs in sub-Saharan Africa: a systematic review. *PLoS Med*, 4, e298.
- SHARGIE, E. B. & LINDTJORN, B. (2007) Determinants of treatment adherence among smear-positive pulmonary tuberculosis patients in Southern Ethiopia. *PLoS Med*, 4, e37.
- SKYNEWS (2007a) Aids Victims Risk Lives.
- SKYNEWS (2007b) "It was like a holocaust".
- SLIKKERVEER, L. J. (1990) *Plural Medical Systems in the Horn of Africa: The Legacy of "Sheikh" Hippocrates*, London, Kegan Paul International Limited.
- STEVENS, W. W., KAYE, S. S. & CORRAH, T. T. (2004) Antiretroviral therapy in Africa. *BMJ*, 328, 280-2.
- SWALLOW, V., NEWTON, J. & VAN LOTTUM, C. (2003) How to manage and display qualitative data using "Framework" and Microsoft Excel. *J Clin Nurs*, 12, 610-2.
- TADESSE, K. K. (2002) *Five Thousand Years of Sustainability? A case study of Gedeo land use (Southern Ethiopia)*, Heelsum, Treemail Publishers
- TESHOME, W. (2006) *Medical Pluralism in Ethiopia*, Aachen, Shaker Verlag GmbH.
- TOLO, A. (1998) *Sidama and Ethiopian. The Emergence of The Mekane Yesus Church in Sidama*, Uppsala, Studia Missionalia Upsaliensia.
- UN (2007/2008) Human Development Report.
- UNAIDS (2007) Financial Resources Required to Achieve Universal Access to HIV Prevention, Treatment, Care and Support.
- UNAIDS & WHO (2007) AIDS epidemic update.
- UNIT, T. E. I. (2007) Ethiopia, Country Report.
- VAN DAMME, W., KOBER, K. & LAGA, M. (2006) The real challenges for scaling up ART in sub-Saharan Africa. *Aids*, 20, 653-6.
- VECCHIATO, N. L. (1993) Illness, Therapy and Change in Ethiopian Possession Cults. *Africa: Journal of the International African Institute*, 63, 176-196.
- WAKABI, W. (2008) Low ART adherence in Africa. *Lancet Infect Dis*, 8, 94.
- WALTON, D. A., FARMER, P. E., LAMBERT, W., LEANDRE, F., KOENIG, S. P. & MUKHERJEE, J. S. (2004) Integrated HIV prevention and care strengthens primary health care: lessons from rural Haiti. *J Public Health Policy*, 25, 137-58.
- WEIDLE, P. J. P. J., WAMAI, N. N., SOLBERG, P. P., LIECHTY, C. C., SENDAGALA, S. S., WERE, W. W., MERMIN, J. J., BUCHACZ, K. K., BEHUMBIIZE, P. P., RANSOM, R. L. R. L. & BUNNELL, R. R. (2006) Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *The lancet*, 368, 1587-94.
- WHO (2003) Adherence for long-term therapies-evidence for action. Geneva.
- WHO (2007) World Health Statistics. France.
- WHO, UNAIDS & UNICEF (2008) Towards universal access, scaling up priority HIV/AIDS interventions in the health sector. Progress report 2008.
- WORLDBANK (2006) AIDS treatment is a lifetime commitment-But who will pay? Asks the World Bank. *Medical News Today*.
- WORLDBANK, DEVELOPEMENT, A. R. H. & MINISTRY OF HEALTH, E. (2005) Ethiopia, a Country Status Report on Health and Poverty.
- ZACHARIAH, R. R., TECK, R. R., ASCURRA, O. O., GOMANI, P. P., MANZI, M. M., HUMBLET, P. P., NUNN, P. P., SALANIPONI, F. F. M. L. & HARRIES, A. A. D. (2005) Can we get more HIV-positive tuberculosis patients on antiretroviral treatment

in a rural district of Malawi? *The international journal of tuberculosis and lung disease*, 9, 238-47.

ZENEBE, M. (2006) Negotiating Gender and Sexuality in th HIV/AIDS Discourse in Addis Ababa, Ethiopia: Contradictions and Paradoxes. *Sociology*. Tromsø, Universtiy of Tromsø.

## Annex

### Annex 1- Interview guide for patients

Research questions	Categories	Interview questions
Opening questions		<ul style="list-style-type: none"> <li>• Can you tell me about the day you got the message that you were HIV positive?</li> <li>• Can you tell me about the day the doctor first spoke to you about the ART?               <ul style="list-style-type: none"> <li>- What did he/she say?</li> <li>- How did you react when he said you should start on ARV treatment?</li> <li>- What had you heard about ARV before? What do people say about ARV? (probe: positive-negative)</li> <li>- Did you seek advice from anyone outside the hospital? Who?</li> <li>- What made you choose to start?</li> <li>- Was it anything particular which made the decision difficult? Why?</li> </ul> </li> </ul>
Individual/family level	<p><b>1.1</b> Attitude/Stigma</p> <p><b>1.2</b> Adm. of pills</p> <p><b>1.3</b> Meaning</p> <p><b>1.4</b> Side-effects</p> <p><b>1.5</b> Travel distant</p>	<p><b>1.1</b> Who is aware of your disease? If no one: Why have you not said anything? What would happen? How were they informed? How did they react when they were informed? What did you feel in this process? Now? How does it affect you that you have/have not disclosed to someone? In which way?</p> <p><b>1.2</b> How is it to take medication every day? Do you find it difficult to remember/ stick to the time schedule? Do you forget sometimes to take the pills? What are you doing to avoid forgetting? Are there situations where you find it particular difficult to take the pills? What do you do then? Do you remember if you forgot to take one dose during the last month? Does it happen that people on ARV treatment share drugs with other people? Has that occurred to you?</p> <p><b>1.3</b> How do you think the pills work? What do you think would happen if you stop taking them? ( for a few days, for good?)</p> <p><b>1.4</b> Did you recognise any differences after you started to take the pills? Better – Worse? Have you ever been thinking of stopping the treatment because of side-effects or other reasons?</p> <p><b>1.5</b> How often are you going to the hospital to get</p>



	<p><b>1.6 Financial</b></p> <p><b>1.7 Nutrition</b></p> <p><b>1.8 Support</b></p>	<p>drugs? How do you get there? (means of transport) How much do you have to pay in order to get there? How much time do you have to spend on the road? How is it to get permission from your employer?</p> <p><b>1.6</b> In which way are you and your family affected financially by your disease? Probe: school fees, food, work. Costs related directly to treatment (transport, expenses at the health facilities). Have you ever thought that you had to stop the ART for financial reasons?</p> <p><b>1.7</b> How is your appetite after you started treatment? Are you able to eat as much as you want? (enough food)</p> <p><b>1.8</b> Where do you get the strength to continue the treatment? What motivates you? Do you have anyone to talk to about your condition? Is there anyone who helps reminding you taking the pills?</p>
Society/Religion	<p><b>2.1 Attitude/Stigma</b></p> <p><b>2.2 Holy Water</b></p> <p><b>2.3 Support</b></p>	<p><b>2.1</b> Is anyone outside your family aware of your status? Who? If not: how do you explain the regular visits to the hospital? Why can you not tell? What would happen? If yes: how did they react when they got the information? Do they treat you differently compared to before? Did you notice any change in their attitude after you started on ART (weight gain) How do you feel about it?</p> <p><b>2.2</b> What kind of healing practices exist outside the hospital? Do think it works? In which way? Do you take holy water? What does holy water mean to you? (Probe: meaning, healing, supplement) Is it possible to take both ARV and holy water? What do the priests say? What are people doing?</p> <p><b>2.3</b> Who supports you? What kind of support? (emotional, food, financial, idir, labour assistance)</p>
Health System	<p><b>3.1 Financial</b></p> <p><b>3.2 Attitude/Stigma</b></p> <p><b>3.3 Waiting time</b></p> <p><b>3.4 Support/Information</b></p>	<p><b>3.1</b> The ARV drugs are free, but do you have additional costs when you are at the hospital?</p> <p><b>3.2</b> How are the health personnel receiving you at the clinic/hospital? Do you think they treat you differently compared to patients who are not infected? If yes: Why? In which way? How does that affect you?</p> <p><b>3.3</b> How long time do you have to wait in the hospital compound before the consultation?</p> <p><b>3.4</b> Do you feel confident enough to raise all the concerns you have? Do you feel they take time to listen to you, inform and support you? Are you given drugs for an extended period in case you are not able to arrive at the time of appointment? (flexibility) What happens if you are not able to go to the hospital for drug supplies? Is there any</p>

		health-worker locally who assists you in this process? Could something else have been done to make things easier for you?
Ranking		<ul style="list-style-type: none"> <li>• We have been discussing several aspects concerning the ART, would you like to add something we have not mentioned? (List factors mentioned.)</li> <li>• Is it possible for you to rank which of the factors that contributes most to the difficulties you face following the treatment?</li> <li>• If you considered stopping ART: What would have been the main reason? What do you think would have happened to you then?</li> </ul>



## Interview guide for religious leaders

Awareness	<b>1.1</b>	<b>1.1</b> How do people in the society talk about HIV infected people? Do you know if any of your church members are HIV positive? How were you informed? (Person itself, neighbours, family members) How did you react?
Perception	<b>2.1</b> General	<b>2.1</b> What is the opinion of the official church (protestant, orthodox) on the problem of HIV/AIDS? Probe: reasons behind (spiritual meaning, possession) How do you think your church members view it?
	<b>2.2</b> Personal	<b>2.2</b> What is your personal view? Do you feel that you approach an HIV infected person differently than someone who is not infected? If yes: Why? In which way?
Action	<b>3.1</b>	<b>3.1</b> Do you sometimes address the problem of HIV/AIDS in your sermons? What do you say? Do people approach you to talk about their problems related to the disease? What kind of advice/support do you give them? Do you think they follow your advice?
	<b>3.2</b> Healing practices	<b>3.2</b> What can the church do for people who have been infected with HIV? What kind of healing practises are offered?
	<b>3.3</b> Holy water	<b>3.3</b> Holy water: What is it? In which way does it work? Does it always work? What could be the reason if it does not work? What can people do if it does not work? What kind of people ask for holy water? Education level? Religion? According to the church practice: is it possible to combine it with ART? In which way? What would happen if a patient combined the two? What are you told from your superiors when it comes to ART in relation to holy water? What do you tell people? Do you have the impression that they follow your advice?
	<b>3.4</b> Support	<b>3.4</b> Is it possible to talk openly about the disease in the church? What kind of support does the church give to the patients and their families? (emotional, practical, financially) Are your church members eager to support people with HIV? Do you self find it important to support them? In which way? Are there anything you feel could have been done better by you personal or by the church? Is there anything you would like to add to what we already have been talking about?

### Interview guide for health workers

Personal experience	<p><b>1.1</b> Personal background</p> <p><b>1.2</b> Perception</p>	<p><b>1.1</b> For how long time have you been working with PLWHA? How do you find it? Do you feel that you have been given enough training in order to carry out your job? What is your motivation to care for HIV patients? (meaning) Are you satisfied by your own performance?</p> <p><b>1.2</b> According to your personal view: Do you feel that HIV patients are treated differently in the hospital compared to other patients? If yes: in which way, why? Do you feel that you are behaving differently compared to other patients? If yes: in which way, why? Are you afraid of getting infected? If yes: How does this fear affect your behaviour?</p>
Supposed barriers for patients on ARV	<p><b>2.1</b> Individual</p> <p><b>2.2</b> Society</p> <p><b>2.3</b> Health system</p> <p><b>2.4</b> Ranking</p>	<p><b>2.1</b> From your experience: How do the patients react when you advice them to start on ART? What do they give for reasons? Does it often happen that patients do not show up for appointments/drug procurement? What happens then? What is the role of the extended health worker in this? Do patients often complain about side-effects? Do they sometimes want to stop treatment because of that? Do you often have to change to second-line drugs because of side-effects? What kind of patient categories is vulnerable to low adherence? (education level, distance from hospital, sex, financial situation, other)How much do you think travel distance and additional costs contribute to uptake and adherence?</p> <p><b>2.2</b> Do you get the impression that patients fear being recognized as HIV positive? (High degree of stigma) How much do you focus on disclosure? Have many of your patients disclosed? How does stigma affect the willingness to start treatment and adherence?</p> <p><b>2.3</b> According to your personal view, do you think there might be obstacles in the health system it self which make it difficult for patients to start and adhere to treatment? Which? Why? How flexible are the guidelines and the interpretation of them in finding practical solutions for the patients' drug procurement? What kind of information do you give? In which way have the investments done related to ARV treatment and care affected other activities? Do you feel it has strengthened or weakened the health system? In which way?</p> <p><b>2.4</b> From your experience: are there any aspects in this are we have not been mentioning yet? Could you please rank the different barriers for your patients accepting to start on ART?</p>
Suggestions for improvement	<p><b>3.1</b> Within the health system</p> <p><b>3.2</b> Personal</p>	<p><b>3.1</b> What could be done within the health system to improve the situation for HIV patients? (logistic, finances, attitude, flexibility)</p> <p><b>3.2</b> Could you think about anything with your own behaviour which could either encourage or discourage patients to seek help?</p>

**Annex 2 - Introduction letter with informed consent**

My name is Margrethe Mork. I am a nurse coming from Norway. As a part of further studies I have been given the permission to conduct a study aiming to investigate the conditions for patients with HIV in need of ARV treatment.

I would like to ask if you would be willing to share your own experience with me. If you permit it I will record the interview which might take approximate one hour. The tape will be destroyed as soon as I have written my thesis. The responses will be made anonymously which means that no one will be able to trace what your have been saying.

This is a voluntary session which has no relation to the activities in the clinic or affects your treatment. Please feel free to withdraw without any explanation if you want to during the interview.

.....

Name

.....

Date

**Annex 3- Ethical clearance**

UNIVERSITETET I BERGEN  
Regional komité for medisinsk forskningsetikk, Vest-Norge (REK Vest)

To whom it may concern

Deres ref	Var ref	Dato
	2007/6160-086.07/ars	04.05.07

**Confirmation**

We hereby confirm that the research protocol, *Uptake and adherence to antiretroviral treatment among HIV positive adults in Ethiopia: provider and user perspective*, by *Margrethe Mork*, has been evaluated by The Regional Committee for Medical Research Ethics in Western Norway (REK Vest).

The protocol is approved.

Sincerely,

Arne Salbu  
Secretary

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Annex 4- Ethical clearance



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South Nations Nationalities and People's Regional State Health Bureau



ቁጥር: የግ 0037-126/3406  
Ref. No  
ቀን: 4/10/99  
Date

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ጉዳይ ፣ ትብብር ስለመጠየቅ ፣

በኖርዌይ ሀገር ባርኔን ዩኒቨርሲቲ የማስተርስ ዲግሪ ተማሪ የሆኑት Margrethe Mork በክልላችን ከሚገኙ በተመረጡ የጤና ድርጅቶች Uptake and adherence to antiretroviral treatment among Hiv positive adults in Ethiopia provider and users perspectives በሚል ርዕስ ለሚሠሩት ጥናት አስፈላጊውን የሥራ ትብብር በናንተ በኩል እንዲደረግላቸው እናስታውቃለን።

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- ለ Margrethe Mork አዋሳ



ኤች አይ ቪ ኤድስን በጋራ እንከላክል!!

*Kare*  
ታሪ ጫዊኛ ደበዛ  
Kare Chawicha Debessa  
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