

ADDIS ABABA UNIVERSITY
SCHOOL OF GRADUATE STUDIES

Coping with the Challenges of AIDS:

The Experience of Persons with HIV/AIDS
in Addis Ababa and their Relations with
Institutions Rendering Health and
Counseling Services

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Counseling Services

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Services

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AAHB	Addis Ababa Health Bureau
ACP	AIDS Control Program
ANC	Ante-Natal Clinic
AHRI	Armauer Hansen Research Institute
CSA	Central Statistical Authority
CHAD-ET	Children Aid – Ethiopia
CRDA	Christian Relief and Development Association
DAC	Department of AIDS Control
ECA	Economic Commission for Africa
ELISA	Enzyme Linked Immunosorbent Assay
ENARP	Ethiopia Netherlands AIDS Research Project
E.C	Ethiopian Calendar
EHNRI	Ethiopian Health and Nutrition Research Institute
GPA	Global Program on AIDS
HIV	Human Immunodeficiency Virus
HIV+	A person whose blood test has HIV
HIV-	A person whose blood test is free from HIV
IEC	Information, Education and communication
IV	Intravenous
HSDP	Health Sector Development Program of Addis Ababa
IDU	Injecting Drug Users
MMM	Medical Missionaries of Mary
MoH	Ministry of Health
NRIH	National Research Institute of Health
NGO	Non Governmental Organisations
OSSA	Organisation for Social Services for AIDS
OPD	Out Patient Department
PWA's	Persons Living with HIV/AIDS
STDs	Sexually Transmitted Diseases
TASO	The AIDS Support Organization
UNAIDS	Joint United Nations Program on HIV/AIDS
WHO	World Health Organisation

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ABSTRACT

This research has focused on investigating a range of issues related to the challenges being faced by Persons With HIV/AIDS (PWAs). Through establishing trust among selected PWAs, particular emphasis was put on examining the nature of the problems they are faced with in their day-to-day lives in the process of interaction with spouses, families, friends and institutions that are rendering services for persons with HIV.

The study has confirmed that the stigma attached to HIV/AIDS is one of the most crucial factors that affect the readiness of PWAs to disclose or not to disclose their sero status to their partners. It is difficult for them to change their sexual behavior even if this involves a potential danger of infecting the other partner.

It has been revealed in this study that there are differential responses by spouses and caregivers to PWAs. Some families and partners have managed to accept the situation in which a member of their family and/or spouse is found and try to offer their support to let him/her live positively with AIDS. On the other hand, there have been instances where the revelation of one's sero status causes instability and separation of partners. The stigma towards PWAs and lack of sufficient knowledge on the part of caregivers has many PWA from getting the necessary care and die with dignity.

In examining the gender perspective of AIDS, major factors which make women more vulnerable to HIV infections were discussed. The low socio-economic status of women does not allow them to have decision making power over sexual relations. Other factors which put women at risk of acquiring HIV include

physiological vulnerability, norms concerning sexuality, violence against women and lack of knowledge about HIV/AIDS.

Counseling has been observed to be a good means of giving psycho-social support for PWAs. Hence, it has helped some PWA's to go public and to come together to form their own network for both handling their personal problems and support each other at times of crises.

The assessment that was carried out among health personnel and counselors to examine the level of attitude, worries and comfort in treating and caring for PWAs showed that, there is often fear among health personnel in giving services to PWAs. On the other hand PWAs have expressed their view that they are not getting proper and adequate services for the health institutions.

- Efforts made by PWAs to establish network among themselves have proved to be a good means to reduce stress and share feelings and experiences among PWAs and serve as a forum to go public.

Efforts to prevent the spread of AIDS and the provision of care and support should be directed to reduce the libeling of PWAs as people different from others and to create a more sympathetic view towards PWAs.

Chapter One

Introduction

1.1 - Statement of the Problem

Infection with the Human Immune Deficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) has become a serious health problem in many countries around the world with social, cultural, economic, demographic, political and legal implications for society. The extent of the epidemic, the age groups it primarily affects and its consequences on families and communities mean that the epidemic has the potential to impact on all aspects of peoples lives. The economic consequences could be observed in both rural and urban settings through a fall in both agricultural and industrial production, to the extent that it could affect national economies.

As AIDS is essentially a sexually transmitted disease, a positive diagnosis may lead to questions about the circumstances in which infection occurred, the sexual life of a person that might have been kept secret, perhaps involving prostitutes or extramarital relations may be revealed. The person may be labeled as immoral. In some circumstances, family, friends and the community may disown Persons with HIV/AIDS (PWAs). Therefore, in the face of these misconceptions and prejudices, how are people trying to live positively with AIDS? What type of relationships do they have with family members, friends and neighbors? What helps some categories of PWAs and families to cope better than others? Are there cultural and social connotations that may influence and/or related to the nature and type of support that is rendered to PWAs? How are surviving family members and spouses coping after the death of the head of the family?

Besides the support expected to be rendered by the family, at times when they are sick, PWAs need medical support from health institutions. However, infectious disease like AIDS could cause fear and concern among medical personnel, creating psychological and social distance between patients and those who should care for them within health institutions. What does the attitude of the health personnel working in health institutions towards PWAs look like? Are they afraid to take care of PWAs? Is there any demand for the provision of one or the other type of service for PWAs? How important would it be to study the situation of PWAs in Addis Ababa?

Therefore, given the multi-dimensional consequences of the epidemic on the socio-cultural lives of people and community social structures, studying the challenges faced by PWAs, the circumstances under which families are coping with sick members of their family, and the nature and type of social support being rendered by organisations and health institutions is believed to have significance in addressing an issue of public concern.

Previous studies known to the Ministry of Health of the Federal Government of Ethiopia focused on the epidemiology, knowledge, attitude and practices of the different sectors of the society on HIV/AIDS.

My research rather focuses on examining the social dimensions of the epidemic and in particular on looking into the challenges being faced by persons with HIV/AIDS, and how families and societal institutions are responding (positively or negatively) to the consequences of the epidemic. The study will further try to investigate how the epidemic is affecting family and kinship structures and how kinship relations contribute to coping with the problems.

1.2 - Objectives of the Study

General objective

The general objective of this study is to investigate and understand how the HIV/AIDS epidemic is affecting the lives of persons infected by the virus and to assess how they are coping with the consequences of the epidemic.

Specific objectives

The specific objectives of the study are to:

- explore the challenges being faced by persons with HIV/AIDS and to understand the type of relationships they have with family members, relatives, friends and other members of the community,
- understand the different coping mechanisms of PWAs in a continuum of the disease trajectory,
- evaluate the attitude of health personnel and counselors in providing medical, social and psychological support to PWA's within different institutions, i.e. hospitals, counseling services, etc.
- attempt to draw lessons from factors that contribute to the positive or negative responses by families, kinship structures and health institutions as a way to pave the ground for future investigation and research,
- look into the extent to which the AIDS epidemic is affecting the lives of women,
- provide a more sympathetic understanding of PWAs and challenges they face in their lives.

1.3 - Significance of the study

So far, different researchers have made studies with regards to the medical aspects of HIV/AIDS. This study aims at examining the social aspect of the AIDS epidemic. In view of my personal involvement and commitment towards PWAs, I believe that this study may contribute to challenging some of the previous stereotypes about PWAs by presenting experiences and feelings in a more sympathetic fashion. This, I believe is a precondition for developing positive attitudes and policies that take the views and feelings of PWAs into consideration. Hence, the study could make some contributions in informing policy makers and organizations, both government and non-government, in developing appropriate strategies to tackle the challenges that are being faced by PWAs and in mobilizing the community to collaborate in the effort to reduce the stigma attached to PWAs.

1.4 - Methods of the study

The hallmark of anthropological fieldwork has been the intensive participation of the anthropologist in the life of the community. This is usually accomplished when the anthropologist takes up residence in a village. However, this does not apply easily for an anthropologist who undertakes his study in an urban setting.

As this study was intended to be conducted in an urban setting, the nature and methods of the study were somewhat different in certain aspects from the methods followed in carrying out the research in a rural area, among more homogeneous groups guided by conventional ethnographic techniques of anthropology.

The central focus of the study is to assess how persons infected with HIV are coping with the physical, as well as the social aspects of the disease as a way to understand the factors that may contribute to the diverse types of responses on the part of their spouses, families and the community at large.

Depending on the appropriateness of each method of data collection to particular situations in the study, both qualitative and quantitative methods of data collection were employed in carrying out the research. In order to come up with sufficient information about the cases to be studied, a combination of both primary and secondary sources of data collection was applied.

Since the topics of AIDS is extremely sensitive, great care was required in approaching potential informants. Without my prior experience and earlier contacts with PWAs, such a study would probably not have been possible. Given the difficulty of establishing trust with a large size of PWAs, thirty-five PWAs were included in the study. The selection of potential informants for the study was made possible through using institutions which are providing counseling and social services to PWAs and using my previous contact with PWAs while I was working in an AIDS counseling center. Given the prevailing stigma towards persons with HIV/AIDS, it took me quite a while to find persons who were willing to be drawn into the study. I also used PWAs themselves to put me in contact with individuals who are willing to be included in the study. In the beginning of the research, some of the informants were hesitant when asked to become part of this study. However, most of them became convinced as they came to understand that they would not be labeled due to the fact that they are part of this study.

A questionnaire was developed and used to collect data from the respondents. The questionnaire contains questions about the personal background of the respondents such as place of birth, how long they have been in Addis Ababa, marital status, situation and size of family, etc.; questions designed to measure the level of knowledge of the respondents pertaining to issues related to HIV/AIDS; their feelings about knowing their sero status and their reactions to such news and issues related to confidentiality and shared confidentiality. Also, included were questions related to networks, getting care and treatment at times when they are sick.

The actual execution of data collection took place between the months of September and November 1999. However, contacts have continued with those groups of PWAs whose ethnography is presented in this study for a longer time. This is mainly influenced by the need to see the changing patterns of their health status and relations with family members and/or spouses over a period of time. For instance, some informants may stay well for a certain period of time, but fall sick again which may not allow free conversation at the time of their illness. There were even instances where some of my informants get sick and die in a short period of time resulting-in inability to complete their ethnography.

The process of data collection is divided into two stages. In the first stage, an in depth interview was made with the thirty-five PWAs out of whom eight were women. My assistant, who is an HIV+ herself, carried out the interview of women. Following an assessment of the questionnaires, a selection of the cases from the different categories of the respondents was made for further investigation. In this regard, about eleven cases

were selected and a detailed ethnographic account of their experience as a person living with HIV was made.

The selection of these groups of respondents was made based on their significance as illustrative examples in showing the challenges and prospects in their day-to-day lives. Besides, their marital status, i.e. single, married, separated; in terms of occupation, i.e. employed and unemployed were taken into account. Of the eleven cases, 7 were males, 3 were females 6 were married, 1 was single, 4 were unemployed, 2 were separated, and one was a child. In order to keep the confidentiality of the HIV status of some of the informants, their names are changed as it appears in the ethnography.

According to the information gathered during this study, the respondents could be divided into three categories. The first group consists of persons who, due to the stigma attached to persons infected with the virus, are keeping their sero status confidential from spouses, family members and friends. The second group of respondents consist of PWAs who have shared their sero- status to some people within or outside the family circle. The third category are those group of PWAs who have recently come to develop the confidence to go public to speak about their status openly as a way of educating others to protect themselves from infection.

Given the persisting stigma that is attached to PWAs, in this study, an attempt has been made to assess the level at which information related to HIV/AIDS has been dessiminated through the media. Due to time constraints, the assessment did not include such information that has been disseminated through the radio and television. It is limited to making a content analysis of the press, especially the Amharic daily "*Addis Zemen*".

In the effort to obtain data on the attitude health personnel in providing care for PWAs within health institutions and counseling centers, I developed a questionnaire that was to be filled out by physicians, nurses, social workers and counselors working at the Black Lion University Hospital, St. Peter TB sanitarium and the counseling centers for PWAs at the Counseling and Social services Center of the Medical Missionaries of Mary (MMM) and at the Counseling services at St. Mary's Clinic. In order to come up with meaningful results and to contrast the views of health personnel with those of PWAs, another questionnaire was developed in Amharic to be completed by PWAs. Even in this case, it was difficult to find PWAs willing to participate due to fear that negative comments towards health personnel could affect the services they are obtaining currently.

The PWAs were selected in such a way that they have a history in which at one time or another they have been admitted in a hospital or attend medical care at the in and Out Patient Departments (OPD) among different health institutions in Addis Ababa.

A total number of 45 health personnel, counselors and PWAs took part in the assessment. The sample consists of 10 physicians, 15 nurses, and 10 counselors and 10 PWAs. The physicians are residents from the surgical and medical department of the university. In their day-to-day activities, they come in to contact with PWAs in both the in patient and Out-Patient Department (OPD).

Data was collected from these groups for the interrelated questions presented in the questionnaire on the respondent's AIDS related knowledge, attitudes, concerns and experience with AIDS patients. Physicians who completed the questionnaire included 6 males and 4 females; nurses were both females and males (70 percent females) while

among the counselors females constituted 80 percent. The median year of job experience in that hospital and other health institutions was 5 years for physicians, 7 years for nurses and 5 years for counselors.

1.5 - Area of the study

This study was made in Addis Ababa, the capital city of Ethiopia. According to estimates of the Central Statistical Authority, in 1998, the population of Addis Ababa was about 2.4 million, with a population growth rate near 2.9 percent per year. Much of the population growth stems from migration from the countryside and smaller urban areas. Unemployment is high and incomes are low. A recent report indicated that 60 percent of households earn less than Birr 300 per month (HSDP, 1998).

The city is also characterized by low-standard housing conditions, high infant and maternal mortality rates, inadequate health services and poor sanitation. The presence of large numbers of sex workers aggravates the spread of HIV and STDs (AAHB,1999).

As this study is interested in investigating the coping mechanisms of PWAs, it would be difficult to find all of them in one specific area. Therefore, a multi-site study was made based on the willingness of the persons to be studied. Hence, I was going back and forth to the places where my informants were living. For the informants who are living alone, this was not a problem. But for those groups of individuals who are living with spouses or other members of their families, it was not convenient to discuss about their situation openly. This applies especially for individuals who had not yet disclosed

their HIV status. Hence, we often made arrangements to meet at other places where we could sit down and discuss freely without interruption.

1.6 – Organization of the study

As we have seen in Chapter One, efforts were made to set the statement of the problem, determine the objectives of the study and describe the methods that were applied to gather the necessary data to undertake this study.

Chapter Two offers a general description of human health as it is affected by epidemics in the past and basic facts about the epidemiology of AIDS and its impact on the socio- economic lives of societies. In this regard, a brief review of epidemics in Ethiopia will be made for which there is a record. The global epidemiology of AIDS and factors contributing for the spread of the epidemic as well as some of the social and economic impacts of AIDS are reviewed in this section.

Chapter Three examines the situation of AIDS in Ethiopia. Based on the epidemiological studies made by the Ministry of Health, it tries to show the beginnings of the epidemic, common risk factors for the transmission of HIV, the age groups that are affected most by the epidemic, the magnitude of the problem in Addis Ababa. Here, the development of HIV/AIDS prevention programs in the country is considered.

Chapter Four contains the ethnography of PWAs and the issues related to the social dimension of the AIDS epidemic. Here, an attempt has been made to closely examine the factors that contribute for the non-disclosure of one's HIV status and the different faces of stigma as experienced by PWAs and some features of living positively with AIDS. Furthermore, this chapter provide insights for the reader about the

differential responses of families, spouses and care givers in knowing the sero status of their family member and/or partner. Here, we will see how some people are coping better in living positively with AIDS while others are rejected and stigmatized for having HIV in their body.

In Chapter Five, an attempt is made to examine a gender perspective on the AIDS epidemic. In this regard, some of the factors that make women more vulnerable to contracting the HIV will be presented. Examples of some of the challenges that are being faced by women whose spouses were diagnosed to have the HIV could be seen from the ethnographic cases shown in this section. Besides, the chapter touches upon the options that are available for women to protect themselves from infection.

The last Chapter will look into three important elements as part of investigating how PWAs are trying to cope with the challenges of their day-to-day lives. The first section will look at the role of counseling in helping PWAs to live positively with AIDS. Besides, attempts will be made to present the views of the counselors with regards to changes in behavior that might have occurred among PWAs who are covered in this study. The second section will focus on the issue of social network among and between PWAs and efforts that were made to establish an association PWAs. The last section will try to discuss the outcomes of an assessment that was made among health personnel and counselors with regards to services that are rendered to PWAs within health institutions.

Chapter Two

Human Health and The AIDS Epidemic

The aim of this chapter is to briefly touch upon how epidemics in the past have put a strain and still are posing a threat on the lives of people around the world in spite of recent developments in the innovation of vaccines and treatment for most of the infectious diseases known to human beings. Having reviewed the types and nature of epidemics seen among the people of Ethiopia as recorded by foreign travelers and historians, the chapter will then try to discuss issues on the emergence of the AIDS epidemic. In this regard, a definition of HIV and AIDS, its mode of transmission and detection as well as the stages of infection will be presented. Before discussing the epidemiology and the social and economic impact of the epidemic, debates on the issue of the origin of AIDS will be presented.

For many centuries, human populations experienced substantial mortality and morbidity due to infectious diseases. Actually, in many countries today, infectious diseases still are responsible for much morbidity and mortality, especially in children. The chronicle of history provides us a rich and detailed story of human experience with infectious diseases. From the rise of large towns to the development of cities, successive epidemics of infectious disease are recorded in great detail.

According to Gmelch and Zenner, *the plague is a city disease, because in cities, the transmission of P. pestis is greatly facilitated. P. pestis infects the fleas that infest the rats. It is believed that wild animals first harbored the disease, and they transmitted it, through their fleas, to the rats, which shared habitations with humans. There, infected*

fleas could spread the disease to humans either directly or after living on domesticated animals. Once the disease had started in humans, it could spread from person to person by an aerosol route. In a crowded city, the disease would be able to spread quickly. In Europe, in the sixth, the fourteenth and, again, in the seventeenth centuries it killed many people (Schell,L.S.;1995.).

Besides the known epidemics, there are different types of diseases that were and are affecting the health of peoples in different parts of the world to day. Many epidemiologists argue that there is a regular sequence of health problems corresponding to each stage of a nation's change in societal organization from a rural to an urban society and from an agricultural to an industrial producer. For example, the leading cause of death in the United States in 1900 were influenza, pneumonia and tuberculosis. In 1992 these disorders had been replaced by heart disease, cancer, accidents, and cerebrovascular disease or strokes as the major cause of death in an increasingly urban and industrialized society (Schell,L.S.;*et, al*).

Although heart disease, cancer, strokes, accidents, and mental disorders are the leading causes of disability and death in advanced industrial societies, the underdeveloped nations of the world show somewhat different patterns of major health problems. In these societies, the traditional diseases of human history influenced by poor sanitation and malnutrition often prevail. The later are usually characterized by a high birth rate and a high death rate, with a relatively young population.

Improvements in living conditions and medical technology had all but eliminated disorders such as tuberculosis, gastroenterities, and diphtheria as major threats to life by 1992, but smoking, excessive consumption of calories and animal fats, stress reactions,

and inadequate physical activity had helped promote other health problems, such as heart disease and other cerebrovascular diseases. Homicide and AIDS, major health problems in the United States, had made their appearance as top ten killers by 1992 (Schell, L.S.; *et, al*).

These diseases/infections, either kill those they infect or, if the host recovers, leave the host permanently immunized against the disease. Measles is an example of an acute community infection, but flu is not. A natural bout of measles (not the vaccine) leaves permanent, lifelong immunity among the survivors, but people get influenza year after year, there being no permanent immunity to every influenza type. Diseases that leave surviving hosts with permanent immunity need new hosts or the disease-causing organism (pathogen) will perish and no new cases of the disease will occur. If all the adults in a community are survivors from the previous year's infection, the only new hosts are immigrants and new borns.

Like many other countries, Ethiopia has also experienced epidemics that have claimed the lives of many people. These include smallpox, cholera, typhus, dysentery and influenza. In his book *Introduction to the Medical History of Ethiopia*, R. Pankhurst explains that, the precise character of most outbreaks, however, cannot be established, for the records of the time - many of which relate miracles alleged to have occurred in such times of distress - neither mention diseases by name nor provide sufficient detail to allow identification. Nevertheless, many of the unidentified "pestilences" of the past, to judge from the evidence available, were just as serious as later, medically diagnosed outbreaks (Pankhurst, R. 1990).

There were waves of cholera epidemics since the seventeenth century. The first such epidemic occurred after a famine early in the reign of Fasilades (1632-1667). Ethiopia suffered at least five cholera epidemics in the nineteenth and early twentieth centuries. The first occurred when the disease spread in many countries of the East. The medical historian, Hirsch later observed that this attack was "probably the continuation of a pestilential progress from Egypt through Tripoli and Tunis, the wider ramifications of which may be seen in the epidemics that prevailed at the same time in Abyssinia, on the east Coast of Africa from Somaliland to Zanzibar, and in the Sudan (Pankhurst, *et,al.*).

Typhus, though less widespread and devastating than either smallpox or cholera, doubtless accounted for at least some of the major epidemics of early times. It is not, however, until the second half of the nineteenth century that its identification becomes possible.

Although there is no means of assessing how far the influenza epidemic witnessed in other parts of the world impinged on Ethiopia, there are several references to the outbreak of fevers and "pernicious miasmas" which may have been influenza.

Perhaps, the earliest reference to the disease is in Ludolf's Amharic-Latin dictionary of 1698 which lists *gunfan* or "catarrhus" and *gunfanam* or "catarrhis obnoxius". The former probably referred then, as now, to both the common cold and influenza. "... there is, however, evidence of a serious outbreak in 1889-1890 during the Great Famine when the starving population also fell easy prey, as we have seen to other epidemic diseases. This influenza outbreak probably formed part of a world epidemic"(Pankhurst, *et,al.*).

According to Pankhurst, among the non-epidemic sexually transmissible diseases that were prevalent in the nineteenth century is found syphilis. Regarding its origin, there is a popular belief held that the disease was introduced by the Portuguese after the wars of Ahmed Gagn in the sixteenth century and was later diffused by Arab merchants who traveled throughout the land.

2.1 - The AIDS Epidemic

The twentieth century has been characterized by several major infectious disease epidemics: poliomyelitis in the 1940's and 1950's, influenza in 1918, and Acquired Immune Deficiency Syndrome (AIDS) in the 1980's. Currently, AIDS is affecting the lives of millions of people around the world (Schell, L.S.1995).

Signs of the first AIDS cases were seen in 1981, when doctors in the USA began to notice a series of unusual infections in gay men in San Francisco, New York, and other big cities. These infections had previously been extremely rare except amongst people whose immune system had been seriously weakened in some way. A whole range of other severe protozoal, fungal, bacterial and viral infections and tumors had also been detected amongst gay men in these cities. In 1982, the Center for Disease Control (CDC) in the USA acknowledged that there was an epidemic and formally defined the 'Acquired Immune Deficiency Syndrome' (AIDS) The number of people who developed AIDS seemed to be doubling every six months in the USA and AIDS was soon found in every part of the country (Alcorn.K. 1999)

The pandemic of Human Immunodeficiency Virus (HIV) and its multi faceted dimensions resulted in unprecedented global concern. In spite of a worldwide effort to

find cure or vaccine, the epidemic is still on the increase everywhere, but affecting people in the developing world to a greater extent. Countries in Sub-Saharan Africa are severely hit by the epidemic. At present, like many countries around the world, in Ethiopia, the AIDS epidemic has become a concern not only as a health problem, but as a problem having tremendous implications on the lives of children, families, communities and the society at large.

2.2 - What is AIDS?

AIDS was known neither to the scientific community nor to the public at large just two decades ago. Although there is sufficient information about the nature of AIDS, however, it seems appropriate to give a brief account of the basic facts about HIV and AIDS, i.e. what it is, the mode of transmission and its stages of development.

AIDS is an acronym that stands for Acquired Immune Deficiency Syndrome.

This is to mean:

A - Acquired - when a person has obtained something he/she did not have

before; not genetically inherited

I - Immune - against infection or some cancers

D - Deficiency - when a person lacks natural protection

S - Syndrome - a collection of different illnesses

AIDS is a fatal clinical condition resulting from long-term infection with HIV. HIV progressively weakens the body's immune defense system, until it is no longer able to fight off infections, many of which are normally harmless. When the immune system

is severely damaged by HIV, several opportunistic infections are present at once. These are called opportunistic infections because they are caused by organisms which are normally controlled by the immune system but which 'take the opportunity' to cause disease in an individual whose immune system has been damaged. Opportunistic infections refers to the types of infections including tuberculosis, Kaposi's sarcoma (a tumor affecting the skin), *Pneumocystis carinii* (a form of pneumonia), herpes, shingles and infections such as *Cryptosporidiosis* which are associated with severe diarrhea and weight loss (Alcorn, 1999). Death is not caused directly by HIV, but by one or more infections.

Unlike most other diseases, different people with AIDS may experience different clinical problems, depending on which specific opportunistic infections they develop. This is what a syndrome means - a collection of different signs and symptoms that are all part of the same underlying medical condition.

According to the definition given in most scientific literature, AIDS is caused by a virus called HIV, which is another abbreviation for:

- H** - Human - because it lives only in the human body, not in animals or insects, including mosquitoes
- I** - Immune-deficiency - When a person lacks natural protection against infection
- V** - Virus- an organism that causes infectious disease.

The HIV was originally isolated in Paris in May 1983 by Luc Montagnier. It belongs to a group of viruses called retroviruses. Viruses copy their genetic material into

the genetic material of human cells. This means that infected cells stay infected for the rest of their lives (Alcorn, *et.al.*, 1999).

It is widely accepted throughout the scientific community that infection with HIV is the necessary precondition for the development of AIDS. It is of course possible for someone's immune system to be compromised in other ways, and in rare cases this can lead to the same kinds of infections seen in AIDS. Although it is clear that HIV has a central role in the development of AIDS, there remain unanswered questions about some of the specific mechanisms by which it damages the immune system. The human immune system is immensely complex and there are many ways in which it can be affected by a retrovirus such as HIV. Furthermore it is also not clear what role (if any) other factors- known may play in the development of immune damage.

2.3 - Modes of Transmission of HIV

HIV is transmitted through three major ways:

- 1 - Sexually - through any activity which allows blood or sexual (seminal and/or vaginal) fluids from an infected person to get inside an uninfected person either heterosexually - from man to woman and from woman to man,
- 2 - Blood to Blood Contact with an HIV infected person through:
 - receiving blood and blood products intravenously,
 - sharing syringes and needles,
 - using sharp, non- sterilized instruments in cutting or piercing the skin,
 - receiving organ transplants from infected donors.

3 -Vertically - from an infected mother to her child, before, during or after birth (including breast-feeding).

2.4 - Detection of HIV

It is impossible to identify HIV-infected persons just by looking at them. People who carry HIV in their bodies can look perfectly healthy for many years. Even a sturdy - looking person can be infected with HIV or already have AIDS without knowing it, could maintain regular daily activities, and may not show any external signs of the disease to the casual observer.

Usually, HIV infection is detected by an HIV antibody test. The first test to be done, usually on blood, but possibly on saliva, is an ELISA (enzyme linked immunosorbent assay). Since this test can sometimes be positive even when someone is not infected- a 'false positive' a second test called the Western blot is done. This can confirm an ELISA.

2.5 - Stages of HIV infection

A person is diagnosed as having AIDS when he/she 1) tests positive for HIV and 2) has one or more specific recurring opportunistic infections or show other evidence of severe immune dysfunction. In parts of Africa and other areas where testing facilities are not available, a clinical definition of AIDS is often used, relying on symptoms only.

The presence of HIV in a human body is proved through undertaking an antibody test. The test which helps to detect the presence of HIV antibodies in blood and blood products is used for blood transfusions and other forms of therapy or to confirm the

presence of HIV antibodies in persons who have reason to think they may have been infected.

The amount of time between getting HIV infection and developing antibodies varies very widely. The vast majority of people with HIV will produce antibodies by around 45 days after infection. However, in a small proportion, it may take up to six months for antibodies to develop, and in a very few people with HIV infection, it may take even longer (MoH, 1998). This is one reason why a lack of HIV antibodies does not always mean freedom from infection. For most of this period, the person may not have any symptoms and, therefore, may not be aware that s/he is infected. This contributes to the spread of HIV, since the person can transmit the infection to others without realizing it.

2.6 - Debates on the issue of Origin

The origin of HIV is a mystery. No one knows where it came from. However, several hypotheses have been advanced that HIV originated with non-human sources.

The non-human origin of HIV is based on the premise that humans share a number of diseases with other animals. As has been stated in the earlier section, the plague bacillus infects rats and humans alike. According to Cockburn (1977), modern evolutionary theory assumes that all human infections descended from pre-human ancestors, and since humans and animals are descended from a common source, many infectious diseases found in humans through history have also been present in other animals. Over time microbes mutated; some found the human host especially to their

liking and could not survive on or in any other animal. They thus became specific to humans.

In other instances humans are infected with a new disease that is transmitted by a non-human contemporary in what is called a cross-species transfer. Non humans carry many microbes that cannot normally be transmitted to humans, but occasionally one mutates in the non-human host and succeeds or mutates after the cross - species transfer takes place. If the microbe can then "be transmitted from man to man, then the stage would be set for the evolution of a new specifically human pathogen". Cockburn believed that many common infectious diseases originated this way from domesticated animals during the early agricultural period. Some believe that HIV is also a mutated version of a non-human virus.

Western scientists have promoted the hypothesis that the AIDS epidemic began in Africa, arguing that either AIDS had existed for many years in an African "lost tribe" or that a retro virus crossed the species barrier from monkey to man. The scientific evidence in support of this hypothesis has included AIDS-like cases from Africa that predated the epidemic in the West, Seroepidemiological evidence for early African infection, and the isolation from African monkeys of retro viruses considered similar to the Human Immunodeficiency Virus (Bond, G.C. et.al.,1997).

Yet when the scientific literature supporting an African origin is examined it is found to be contradictory, insubstantial or unsound, whilst the possibility that AIDS was introduced to Africa from the West has not been seriously investigated. The belief that the AIDS epidemic originated in Africa has also distorted Western perceptions of the

scale and mode of the spread of the epidemic in Africa, and it would seem that much of the research into AIDS has been influenced by racism and not science.

The Acquired Immune Deficiency Virus (AIDS) was first recognized as a clinical entity in 1981 in the United States and although the majority of cases in the early periods of the epidemic were reported from the United States (WHO 1990b), the Western scientific community has convinced the world that it is primarily an African disease and an African problem. To explain how a disease originating in one continent was yet disseminated to the rest of the world, the scientists have argued that there was a remote central African "lost tribe" in whom the virus had been present for centuries (De Cock 1984), or alternatively who acquired the infection from monkeys 30 or so years ago (Hirsch, Olmstead and Murphy - Corb *et.al.*1989). Haitians (but no one else) working in central Africa then became infected (presumably heterosexually) and, on returning home, spread the disease to homosexual American tourists (Gallo: 1987). By this circuitous route the virus reached the United States and from there spread to the rest of the world. The racist preconceptions of the researchers led them to conclusions that had no scientific foundation.

As this hypothesis became increasingly challenged, attention was diverted to the possibility of a monkey origin of the virus. Such ideas cohabit easily with the racist notions that Africans are evolutionarily closer to sub-human primates. This was further challenged in terms of how the virus crossed the species barrier. Some speculate that the HIV precursor was transmitted to humans by monkey bites or by people eating uncooked parts of monkeys (Rushing 1995). However, since no one is known to have been infected by saliva, and HIV is not enterically transmitted, these ideas are speculative.

Given that HIV can be transmitted many years before the appearance of AIDS, it is exceptionally difficult to try to find a source point for the beginning of the epidemic. So there is simply no clear evidence to suggest any one place where HIV may have come from. And we will probably never know. The epidemiology is very complex and there are technical problems with testing blood samples which have been frozen for many years. Scientific investigation of origins may help us to understand how to combat HIV most effectively. However, it is extremely important to distinguish this from irresponsible speculation about 'where it comes from'.

2.7 - Epidemiology of the Epidemic

HIV/ AIDS knows neither physical nor social boundaries. By the end of 1998, according to estimates from the Joint United Nations Programs on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), the number of people living with HIV will have grown to 33.4 million, 10 percent more than just one year earlier. The epidemic has not been overcome anywhere. Virtually every country in the world has seen new infections in 1998 and the epidemic is frankly out of control in many places.

More than 95 percent of all HIV - infected people now live in the developing world, which has likewise experienced 95 percent of all deaths to date from AIDS, largely among young adults who would normally be in their productive and reproductive years (UNAIDS/WHO, 1998.). The multiple repercussions of these deaths are reaching crises level in some parts of the world.

While no country in Africa has escaped the virus, some are far more severely affected than others. The bulk of new infections continued to be concentrated in East and

especially Southern Africa. The southern part of the African continent holds the majority of the world's hard-hit countries. The following table shows the global statistics on the epidemiology, groups of people that are highly affected and its major mode of transmission.

Table 1. Regional HIV/AIDS statistics and features, December 1998

Region	Epidemic started	Adults & Children living with HIV/AIDS	Adults & children newly infected with HIV	Adult Prevalence rate (*)	Percent of HIV Positive adults who are women	Main mode(s) of transmission(#) for adults living with HIV/AIDS
Sub-Saharan Africa	Late '70s-early '80s	22.5 million	4.0 million	8.0%	50%	Hetero
North Africa & Middle East	Late '80s	210,000	19,000	0.13%	20%	IDU, Hetero
South and South-East Asia	Late '80s	6.7 million	1.2 million	0.69%	25%	Hetero
East Asia and Pacific	Late '80s	560,000	200,000	0.068%	15%	IDU, Hetero MSM
Latin America	Late '70s early '80s	1.4 million	160,000	0.57%	20%	MSM, IDU, Hetero
Caribbean	Late '70s early '80s	330,000	45,000	1.96%	35%	Hetero, MSM
Eastern Europe and Central Asia	Early 90s	270,000	80,000	0.14%	20%	IDU, MSM
Western Europe	Late '70s early '80s	500,000	30,000	0.25%	20%	MSM, IDU
North America	Late '70s early '80s	890,000	44,000	0.56%	20%	MSM, IDU, Hetero
Australia and New Zealand	Late '70s early '80s	12,000	600	0.1%	5%	MSM, IDU
TOTAL		33.4 million	5.8 million	1.1%	43%	

* The proportion of adults (15 to 49 years of age) living with HIV/AIDS in 1998, using 1997 population numbers.

MSM (sexual transmission among men who have sex with men), IDU (transmission through injecting drug use), Hetero (heterosexual transmission).

Source: UNAIDS/WHO: 1998. AIDS epidemic update.

This chapter has tried to look at epidemics that had a significant place in the history of humankind. It has also tried to review some of the major epidemics that prevailed in Ethiopia in the past. More emphasis was made on the AIDS epidemic, an epidemic of our time, which is resulting-in multi-faceted consequences on the lives and futures of societies.

The discussion on the nature of the virus, its mode of transmission and the different levels of HIV infection shows how challenging it is to protect oneself from infections as most people who have HIV look healthy for quite a long period of time while they are still infectious. As could be seen from the section that reviewed the debate on the issue of origin, despite the fact that the first AIDS cases were reported in the U.S. and other countries in the West, there has been an attempt to relate the origin of AIDS to the African continent. However, this has been proved to have no scientific ground.

On the other hand, the epidimiology of the AIDS epidemic shows that there is no country in the world today which has not been affected by AIDS. Countries in sub-Saharan Africa are the ones that are hard hit by the epidemic. In most of these countries, the youth and adults in the productive and reproductive age bracket are the ones that are highly affected by AIDS. There are different factors combining to aggravate the spread of HIV. These include going away from families in search of jobs, armed conflict, rejection and discrimination attached to AIDS. AIDS will have a far-reaching impact on the social and economic lives of people and nations. As more and more skilled and productive people became infected, in both urban and rural settings, there will be a fall in production, both for domestic consumption and export, leading to a decline in badly needed foreign exchange.

Chapter Three

AIDS in Ethiopia

Ethiopia is one of the most populous nations in Africa. It has a population of nearly sixty million in 1999 with an annual growth rate of 2.21%. According to the reports of UNICEF, birth and infant mortality is quite high- 44.7/1000 and 125.7/1000 respectively (UNICEF, 1999). The same source estimates the literacy rate to be 28% and the enrollment rate in primary schools to be 26%. The large majority of the people (85%) live in the rural area. Agriculture is the major economic sector out of which the country's foreign exchange income is earned. Although women have a subordinate position in society, this has been changing economic and household relations. In the last three decades the country has witnessed recurrent drought, famine, internal conflict, manmade and natural calamities which have left many people displaced and children without guardians. Added to the existing problems is the AIDS epidemic.

In this chapter, a discussion will be made about how the AIDS epidemic started in Ethiopia. Based on the findings of studies made by the MoH among different categories of people, the Chapter analyzes the major risk factors that might have contributed to the spread of HIV. In this regard, the outcome of surveys that shows the level of prevalence of HIV in both rural and urban setting, and the age and sex composition of groups of people who are being affected by the epidemic will be presented. As this study is interested to assess the situation of the AIDS epidemic and its impact on the lives of PWAs, it will look into the epidemiology of HIV/AIDS in Addis Ababa. The last section of the chapter will deal with the development of AIDS prevention and intervention programs in Ethiopia. Here, a discussion will be made about

the development of HIV/AIDS policy and the role of NGOs in the prevention and control of AIDS.

3.1 - Beginnings of the epidemic

HIV probably started to spread in Ethiopia in the early 1980's. When compared with other countries in the Great Lakes region of Africa, the epidemic moved into Ethiopia some time later. In the former, HIV existed from around 1980. Once started, the HIV/AIDS epidemic spread quickly along the main trading roads connecting the cities of Ethiopia. Initial sero surveys were carried out between 1982 and 1984 did not reveal infection either in rural or in urban general populations (Zewdie, *et.al.* 1988). The first two sero - positive persons were detected in the 1984 collection of sera in Addis Ababa among 167 hospital patients. Dr. Debrework Zewdie, in her report at the first International Conference on AIDS in Ethiopia, which was held at the UN conference hall in Addis Ababa in November 1999, discussed the two cases as follows:

"There was a student who was deported from Russia along with a Tanzanian both during the final year of their study. As it was the first experience, after a frantic call from the Ministry of Health we were told that a plane has just landed and has a student infected with HIV; The student arrived at my office after a few minutes accompanied by a quarantine officer from the airport who kept as far away from the student as possible. I was pregnant with my second child and when the student entered my office I extended my hand to greet him, and he hesitated. We shook hands, he sat down and told me his story. He had gone to a doctor for a common cold and the doctor had taken a blood sample without explanation. When the results of his blood test came back he was put in an empty room and his food was pushed towards him using a large stick. He never came in direct contact with a human being until the day he was put on the plane. He had attempted to kill himself on the plane using the knife that was provided with the food. When he got to my office I was the first human being who had offered my hand and touched him. What remains with me until today is what he said to me. " I do not know how I got this disease and I do not care, what upset me and the reason I wanted to kill myself was that I have brought disgrace to my country". Of course, he thought he was the first one in Ethiopia and probably in the world. He did not want to shake hands with me because of the way he was treated, he thought I did not know his sero status, and was afraid to infect me.

When I told him I knew, he was more amazed, he said: "You are not afraid for yourself and your child". I felt so sad and said to him: "You know the virus does not jump from one to another". We took a blood sample and sent him home after counseling him. Although his ELISA test was positive, his western not was negative. I later on learnt the same thing had happened to the Tanzanian student whose sero status could not be confirmed by the Tanzanians or when sent abroad. These are the human faces and the history of the epidemic and the lives that have been distorted".*

The other one was a woman, *"Her name is Shewaye and she was weighing only 24 kilograms. She had lost so much weight. Her younger sister carried her like a baby when she came to see the doctor. She was the first patient. Although Shewaye presented all the classical signs and symptoms, her blood was tested at the AHRI laboratory and turned out to be positive. Furthermore, it was sent to Sweden to reconfirm. Sure enough it was positive".*

The presence of HIV/AIDS in different parts of the country was confirmed through a sentinel surveillance carried out in selected sites around the country between 1984 and 1987. The surveys were conducted among a variety of population groups, including blood donors, pregnant women, STD patients, commercial sex workers and truck drivers.

All data obtained between 1984 and 1987 were from Addis Ababa except one study made on 5,265 military recruits in 1986, which covered most geographic areas. The study revealed a very low prevalence rate (0.075%) (Kefene, *et.al.* 1988). This was presumed to be indicative of the national situation since these recruits came from all administrative regions of the country.

Another study was made in March 1991 among 5,512 male military recruits coming from all regions and was analyzed for the presence of HIV-1 antibodies by ELISA and conformed by the Western Blot. The result was compared to the prevalence rate obtained on a similar population five years earlier.

* negative test result implies he has no HIV.

During this study, sera were collected from a stratified sample of 5,512 consecutively seen male military recruits, aged 15-50 (mean 23.2), stationed at *Maslo* (*Bale*) and *Bilaten* (the former *Gamo Gofa*, now *North Omo*) training centers.

Table 2 - *Prevalence of HIV among military recruits by geographical Region of residence, crude and age adjusted (1991)*

Region	Number	HIV	
		Crude	Adjusted
Addis Ababa	153	6.5	6.2
Assab	57	13.8	14
Bale	185	2.2	1.5
Gamo Gofa	371	2.1	2.6
Gojjam	837	3.4	3.5
Gondar	183	4.9	5.3
Hararghe	108	4.6	4.6
Illubabor	408	1.5	1.5
Kaffa	316	.9	1.1
Shoa	1537	2.8	2.5
Sidamo	191	1.6	2.3
Wollega	944	.5	.5
Arsi	16	0.0	0.0
Tigray	9	0.0	0.0
Eritera	8	0.0	0.0
Wollo	31	10.4	13.4

Source: MoH, 1998

The findings of the study revealed that the overall HIV prevalence rate was 2.6%, which is 34 folds higher than the rates observed five years earlier (075%). Even though the infection is seen throughout the country, there is marked variability between the regions. The prevalence rate is higher among urban than the rural people; in those exposed to skin piercing traditional practices than those not exposed; and in those with more than 10 sexual partners compared to those with less number of contacts. There is a remarkable variability in seroprevalence between administrative regions, the highest being Assab (13.8%) and lowest Wollega (0.5%). The infection seems to be higher in regions crossed by the Addis Ababa-Assab road. This distribution conforms with AIDS

cases that were being reported by the regions to the MoH. The highway being the main gateway to the sea and the outside world may be incriminated as a possible port of entry for the virus into the country and further dissemination (MoH, 1998).

In 1988 an HIV surveillance was carried out on sex workers in 23 urban centers of the country among 6,234 female sex workers practicing Multi Partner Sexual Contact (MPSC) [Meheret *et,al.*] The surveillance also included long distance truck drivers who are frequent travelers along the major surface routes of the country. Testing of individuals was voluntary, confidential with pre and post-test counseling. These two studies have given an opportunity to determine the geographic spread and the magnitude of HIV infection among female sex workers and long distance truck drivers in the urban settings. Baseline information on the social status, sexual practices and on various health-related subjects was also obtained from the study. The survey showed HIV prevalence to be 13 percent among truck drivers and 17 percent among prostitutes. Blood samples from pregnant women in Addis Ababa showed HIV prevalence already at 6 percent by 1989 (Meheret, et,al.,1990).

The surveys among pregnant women are believed to be the most representative of the general urban population. In late 1992 surveys were conducted in four major urban areas: Addis Ababa, Baher Dar, Dire Dawa and Metu. The results show that, in urban areas 11-13 percent of pregnant women were infected with HIV (MoH, 1998).

According to the reports of the Ministry of Health, there were 57,000 reported cases of AIDS since the beginning of the epidemic through April 1998 (MoH, 1998). AIDS has spread throughout the country and it has been reported from every region. These reported AIDS cases represent the visible part of the epidemic. This is what the

statistics show. However, there is much more to the epidemic than the number of reported cases. The true number of AIDS cases is not known. However, the MoH estimates that there were about 400,000 persons who had developed AIDS by the end of 1997. The number of people infected with the virus that causes AIDS is expected to be much higher than the reported cases. According to the same report, in 1997, the number of people who are infected with the virus were estimated to reach about 2.5 million (MoH,1998).

3.2 - Age and Sex Composition of reported AIDS Cases

-When we consider the age distribution of reported AIDS cases, about 90 percent occur in adults between the ages of 20 and 49 (MoH,1998). Since this is the most economically productive part of the population, these deaths constitute an important economic burden. This is also the age when investments in education are just beginning to pay off. These deaths also have important consequences for children since most people in this age group are raising young children. There is roughly an equal number of male and female cases. This is because most infections are acquired through sexual contact. According to the reports issued by the MoH in 1998, the peak ages for AIDS cases are 20-29 for females and 20-30 for males. Since AIDS cases result from HIV infection acquired about 8 years earlier, this means that the peak ages for new HIV infection are 15-24 for females and 15-34 for males (MoH,1998).

The number of females infected in the 15-19 age group is much higher than for males in the same age group. This is due to earlier sexual activity by young females and the fact that they often have older partners.

3.3 - HIV/AIDS in Addis Ababa

The HIV/AIDS epidemic exploded quickly in Addis Ababa and adult prevalence increased rapidly in a relatively brief period of time following the diagnosis of the first AIDS cases in 1986. According to the reports issued by the Health Bureau of the Addis Ababa City Administration, by the end of 1997, an estimated 300,000 persons were infected with HIV in Addis Ababa, including about 12,000 children. However, only about 5 percent of infected persons had actually progressed from HIV to AIDS (AAHB,1999). The presence of better health services and institutions in Addis Ababa has played a significant role in carrying out research programs to understand the magnitude of HIV prevalence in the city. The data that has been used for estimating the extent of HIV infection in Addis Ababa was carried out at four sentinel sites. Two of these, *Kazanchis* and *Teke-Haimanot*, are in the inner city, while the other two, *Gullele* and *Higher 23*, are in outer city health centers. At these selected sites, health workers take blood samples from pregnant women visiting for the first time for care for the current pregnancy.

The result showed an HIV infection rate of about 17.5 percent among pregnant women for 1997. The rates were about the same in the inner city and outer city health centers, 17 percent and 18 percent respectively. Hence, HIV prevalence among pregnant women in Addis Ababa has risen from about 6 percent in 1989 to 17-18 percent in 1997 (AAHB, 1999). The sentinel system thus confirms the existence of high rates of HIV infection in Addis Ababa and a rapidly expanding epidemic.

Table 3, based on the US Census Bureau database, shows that urban HIV adult prevalence is even higher in many other African countries. Higher prevalence in other

countries may be due to an earlier start of the epidemic in those countries or to different behavior patterns, or both.

Table 3: *Prevalence of HIV among Pregnant women in selected capital cities (1996-1997)*

Cities	Percent with HIV infection
Addis Ababa	17
Bujumbura	23.5
Dar es Salam	14
Harare	32
Kampala	15.5
Kigali	32.5
Lilongwe	34
Lusaka	27
Nairobi	24.5
Pretoria	20

Source: MoH [1998]

3.3.1 - Age-Sex Distribution of HIV Infections in Addis Ababa

In 1997, the Ethiopia-Netherlands AIDS Research Project analyzed blood samples taken for other purposes in 1994 for HIV infection. This study was used to obtain an idea of the age and sex distribution of HIV infection in Addis Ababa. The following table illustrates the age and sex distribution of HIV infections among the people covered by the study.

Table 4: *Age and sex distributions HIV infections in Addis Ababa (1994)*

Age group (years)	Prevalence (%)
0 – 4	2.6
5 – 9	1.8
10 – 14	0.9
15 – 19	6.1
20 – 24	12.2
25 – 29	25.4
30 – 34	16.7
35 – 39	16.7
40 – 44	8.8
45 – 49	8.8

Source: Arnauld Fontanet "Age and Specific HIV-1 Prevalence in the Urban Community Setting of Addis Ababa, Ethiopia." AIDS (1998), pp.318-319.

3.4 - Development of AIDS Prevention and Intervention Programs in Ethiopia

3.4.1 - Establishment of an AIDS task force

In 1987 The Ministry of Health formed the AIDS control program at a department level (MoH, 1998). The department was responsible for directing and coordinating the implementation of the AIDS Control Program (ACP). The objectives of the National AIDS Control Program are to prevent HIV transmission and to reduce the morbidity and mortality associated with HIV infection. The sections formed under the Department of AIDS Control (DAC) include Epidemiology and Surveillance, Laboratory Diagnosis and Blood Transfusion, Clinical Diagnosis and Management, Information, Education and Communication (IEC). Briefly, the focus strategies of the divisions are presented as follows:

- IEC:- transmit messages to the general population and high risk groups, establish links between the National AIDS control program and community leaders, NGO's, intergovernmental agencies and government offices, educate school children, develop optimal channels and content for communication;
- Surveillance and research:- conduct sero surveys in appropriate geographic areas and asses the status of the epidemic, define priorities for research and enhance collaboration and coordination of research;
- Clinical aspects of AIDS:- conduct case finding and establish an accurate case reporting system, adopt WHO diagnostic criteria and strengthen clinical diagnostic skills of health workers, improve individual clinical management and optimal quality of life;

- Laboratory and blood transfusion:- Strengthen laboratory and diagnostic facilities, asses blood transfusion activities and restrict the overall number of transfusions, provide effective HIV screening of blood and ensure safe, sterile, injection and/or other skin piercing practices;

3.4.2 - Development of an HIV/AIDS Policy

The Ethiopian HIV/AIDS policy was issued in August 1998 with the aim to direct the various efforts at mitigating the impact of AIDS in Ethiopia. As has been stipulated in the document, the general objective of the policy is to provide an enabling environment for the prevention and control of HIV/AIDS in the country. It particularly seeks to:

1. Reinforce the implementation of effective measures to prevent and control the spread of AIDS,
2. Make the necessary provision of care and support to people living with HIV/AIDS and their affected family members,
3. Strengthen the collaborative efforts with regional and international organizations for the prevention and control of HIV/AIDS,
4. Ensure the protection of the human rights of People Living With HIV/AIDS,
5. Provide health care to People Living With HIV/AIDS on a scheme of payment according to ability with special assistance for those who cannot afford to pay,
6. Promote researches and studies on HIV/AIDS and make use of the outcomes of for preventive, curative and rehabilitative purposes.

7. Develop the capacity to detect the HIV infection and its spread in the community through testing and disease surveillance system,
8. Promote integrated coordination of government, NGOs and private sectors for the prevention and control of HIV/AIDS.

3.5 - HIV/AIDS Prevention Programs and Services : The Role of NGOs

One of the strategies designed to reduce the impact of AIDS was to promote intersectoral collaboration between the Non-Governmental Organizations (NGOs) and churches to complement the efforts being made by the Ministry of Health (MoH). In this regard, various NGOs started to include an HIV/AIDS program component in their existing programs. Furthermore, new NGOs which are fully interested to execute activities related to the provision of care and support for persons and families infected and affected emerged especially in Addis Ababa. These include the Organization for Social Services for AIDS (OSSA), the Counselling and Social Services Center of the Medical Missionaries of Mary (MMM) - under the auspices of the Ethiopian Catholic Church, the Counselling Centers of the Ethiopian Orthodox Church and Yehiwot Tesfa Counselling and Social Services Center - under the auspices of the Ethiopian Evangelical Church Mekane Yesus. The Missionaries of Charity (Mother Theresa Home) provides hospice care for the destitute and for the dying. It has also a center to look after HIV positive children.

Activities that were supported by the Christian Relief and Development Association (CRDA), for which there are records include Financial Support to AIDS/STD Projects, Capacity Building of CRDA Member Organizations in HIV/AIDS

programs, AIDS information/Documentation Resources and Advocacy and policy Support.

3.6 - The Issue of HIV/AIDS on the Press

It is evident that the media could play a significant role in the dissemination of information on the issue of HIV/AIDS as a way of giving information for the public about the magnitude of the problem on one hand and in giving some facts about the epidemic that would help people protect themselves from infections.

Given the stigma that is persisting among the people of Ethiopia towards persons who are infected by HIV, and the ever-increasing number of persons getting infected with HIV, I have made an effort to assess the types of information and issues that were covered in relation to HIV/AIDS during the past years on one of the most widely distributed official daily Amharic daily newspapers "*Addis Zemen*". The major readers of this newspaper are people living in the urban centers, mainly government employees. This is because most, if not all, government offices and institutions subscribe to the newspaper.

In this study, a content analysis of the '*Addis Zemen*' was made on the issues that were published beginning from the time when the Ethiopian government made an official statement about the emergence of a new epidemic called AIDS in 1985. Hence a period of 14 years is covered in this review. In the effort in accomplishing this task I have first tried to select all articles, news and issues that say something about/and in relation to HIV/AIDS. There were about 900 such articles that were covered during the period, which this assessment covered. As the articles cover a wide range of issues

pertaining to HIV/AIDS, I have tried to categorize them into three groups based on their content and the messages they were trying to convey.

- International and national news,
- Basic facts about HIV and AIDS.
- Different myths and misconceptions about AIDS.

In the following paragraphs I will try to summarize the issues which have been categorized into the sections listed above. The assessment is made in the hope that it will give the reader an insight about the nature of the issues that were covered during the past years and to see whether or not much has been done with regards to the AIDS epidemic in disseminating information to the public to enable people to get sufficient knowledge on the subject.

A. International/National news

The international news presented in the newspaper made a wide coverage on the global epidemiology of the disease and its impact on the economic, social, demographic and cultural lives of people around the world. Among other things, it included news on: the number of people infected in different parts of the world, the categories of people who are highly affected by the epidemic, i.e. gays, IDU, people who have sex with multiple partners. Also, projections of global and regional HIV prevalence, efforts and challenges that are being made to invent vaccines to prevent HIV, etc. were covered. Besides, stories of some famous men, especially sportsmen, who have been infected by the HIV are mentioned.

The first announcement on HIV was made by the MoH in August 1987. It was reported that AIDS is resulting-in the illness and death of many people especially in developed nations such as the United States and Europe. It was also stated that it is currently spreading into other parts of the world. According to this statement every effort is going to be made by the government to strictly control prevent the disease from entering into the country through the sea, land and air- ports of the country. It was also emphasized that people should take all the necessary care to protect themselves from HIV infections.

The celebration of the World AIDS Day has been given a wide range of coverage on the press. In Addis Ababa, the World AIDS day is celebrated through organizing special events and with different themes. These include press release by the officials of the MoH, organizing parade in which students, teachers, health professionals and other members of the community took part. Alongside with these programs it was reported that symposiums, exhibitions and seminars were held on the issue of AIDS in different regions, government offices, factories and different institutions. Special programs include an event in which the famous Ethiopian athlete Derartu Tulu ran with government officials at the Addis Ababa stadium and another program in which, for the first time, a woman gave a testimonial in public that she is infected with the HIV.

There has also been a lot of information on the current and future trends of the epidemiology of the epidemic in different parts of the country. The news about the epidemiology of the disease is based on the reports that were being received by the MoH from hospitals and health institutions in different parts of the country. In this regard, it has covered the number of people who were diagnosed to have the HV virus in their

body among those groups of people who have come to the hospital for examination and treatment of different health problems. Such reports revealed the fact that HIV infection is expanding to the rural areas of the country.

There were a lot of workshops and awareness raising seminars and conferences reported to have been held in many towns and institutions for students, teachers, government employees, health professionals, youth and women's groups, leaders of religious institutions and leaders of community voluntary associations at the grassroots at different times. The educational programs that were given during these programs include information on the epidemiology of the HIV/AIDS in the country, the age and sex distribution of those already infected, the use of condoms, the need to bring about changes in behavior, care and support for PWAs, the myth and facts about AIDS, etc.

B. Basic facts about AIDS

This refers to the types of information that was covered through the newspaper with regards to the scientific explanation about the transmission and prevention of HIV, the inability of the scientific community to produce a vaccine or treatment to prevent or cure AIDS, the need for behavior change, precautions in the use and sharing of skin piercing instruments, the difficulty involved in identifying the carriers of the virus from the healthy people.

There were also queries from readers forwarding questions about the signs and symptoms of AIDS. Among these are found questions whether or not the losing of weight does mean that one has HIV. Also, questions were asked about the widespread misconception about whether or not the manifestation of an allergy like skin problem,

most commonly known as "Almaze" , is a sign of AIDS. This is a type of skin problem scientifically known as "Herpes Zooster", which is dominantly manifested among AIDS patients. The manifestation of such type of skin problem is mainly attributed to "Almaze" - an insect that causes a similar skin problem like that of Herpes Zooster. In reply to these queries, details of the signs and symptoms of AIDS were given.

C. Myth and misconceptions about AIDS and its treatment

As a new epidemic, it is evident that it would take some time for many people to clearly understand and accept the modes of the transmission and prevention of HIV and to bring about changes in their behavior. Despite the efforts that were being made by the MoH and other NGOs to disseminate information on the basic facts about HIV/AIDS, there are myths and misconceptions that are widespread within the community which could affect the level of acceptance of the scientific explanation about AIDS. Some of these myths extend to a level which some people are questioning the whether or not AIDS exists.

For example, in the early periods of the epidemic where many people were not able to foresee the effects of the epidemic on the lives and futures of people, and when little was heard about persons dying of AIDS, it was considered by some people that the dying of a person of AIDS was as fashionable as driving the Toyota DX (This was a time when driving a Toyota DX was fashionable). On the issue published on December 2, 1988 E.C it was reported that some people say:

"ከነዳ፣ ለይቀር ዳ፣ ሌክሰን፣ ከሞቱ ለይቀር በሌይሰን"

This is to mean, "*If one is going to drive a good car, it should be a Toyota DX; If one is to die, s/he should die of AIDS*".

There were also claims made by some people of having discovered a cure for AIDS. The following two cases demonstrate the bias that was created among many people in both urban and rural settings. The first one is a case of a retired Colonel who put a notice in different parts of the city advertising that he has found a cure for HIV/AIDS. The full statement of this notice was quoted on '*Addis Zemen*' published in June 1993. The content of the notice is that this Colonel has good news for PWAs. The treatment is prepared and given in the form of a tea. One can enjoy drinking it and will feel no pain and will soon be cured. He has also put his address on it.

This has aroused a lot of debate among the officials of the MoH on the one hand and on the part of the public on the other. The concern on the part of the MoH was that this type of advertisement would create distortion about the fact that AIDS is not a curable disease. Besides, many people could spend their time and money in search of a cure for AIDS, while on the other hand they may be convinced that there is a cure for AIDS even if they are infected with the HIV virus.

Having learnt about the advertisement, the Department of AIDS Control called a meeting was held in the MoH, in which the Colonel who claimed to have the cure for AIDS, other health professionals and journalists participated. During this discussion, the Colonel said he has cured three people to date. Following a thorough discussion over the consequences of bringing such news to the public before the fulfillment of the requirements of the international standards set by the WHO, the colonel finally admitted that he should not post such an advertisement without consulting the MoH. The Colonel had been registered as a traditional healer with the MoH prior to this incidence.

Another interesting case presented in the newspaper in June 1994 was a case of two peasants who came from *Debre Zeit* area to sell eggs of birds for people who were interested to get cured from AIDS. These peasants heard that some one is coming to the area where they are living in search eggs of birds and pays two hundred Birr for one egg. It was a widespread news that the eggs would be sold to individuals in Addis Ababa at a rate of one thousand birr each for individuals who would like to get cured from AIDS. hence, these peasants contacted their relative in Addis Ababa working at the MoH in order to make arrangements for them to find people who may be looking for such eggs. According to the report in the newspaper, their relative took them to an expert working in the Department of AIDS control at the MoH. It was reported that they returned to *Debre Zeit* following an explanation by the expert about the basic facts of the transmission and prevention of HIV/AIDS.

From what has been reported in *Addis Zemen*, one can see that a wide range of issues in relation to HIV/AIDS are covered during the past years. Given the fact that only a limited proportion of the community have access to the newspaper and the low level of the development of the culture of reading newspapers, the messages that were intended to be conveyed through the newspaper cannot be said to be sufficient to bring about changes in behavior pertaining to the issue of AIDS.

As in other countries of sub-Saharan Africa, in Ethiopia, the AIDS epidemic is causing multi-faceted problems for the lives and future of its people. Given the current estimates of the prevalence of HIV/AIDS and the age groups it is primarily affecting, it is expected that it will have a negative demographic, economic and social impact in the

coming years. The situation in Addis Ababa is especially acute in that the prevalence rate is already high.

Although steps were taken to institute AIDS prevention and control programs in the early periods of the epidemic, it was observed that this lacked continuity in bringing about changes to curb the spread of HIV in different parts of the country. This could be seen from the long time required to develop an HIV/AIDS policy for the country. This policy came out in 1998, at a time when HIV infections had already reached an epidemic level. Furthermore, details of the implementation of this policy are being developed and issued by the MoH. Recently, an HIV/AIDS counsel has been set, chaired by the President of the Federal government, in order to coordinate the activities of AIDS prevention and care activities in the country. Had this step was taken earlier, it would have made a great deal of contribution in carrying out a wide range of programs throughout the country.

As there is no cure or vaccine to prevent AIDS, it is evident that disseminating information about the modes of transmission and prevention of HIV is indispensable. Although they lack coordination, the programs that were designed and implemented by the NGO sector have contributed in the sphere of the development of HIV/AIDS prevention programs, counseling and social services.

Chapter Four

Coping Strategies of PWAs: The social dimension of the AIDS epidemic

The time has now passed for AIDS to be seen as a purely medical or health problem. The social consequences of AIDS have now started to be noticed as it has begun to impact on the welfare and stability of families, as it leaves children orphaned and as it causes stigma and discrimination against people infected with HIV. As AIDS is essentially a sexually transmitted disease, it could arouse conflict among spouses as to how infection occurred involving the issue of extra-marital relations. Furthermore, lack of sufficient information about the modes of transmission of the virus could force family members and caregivers to refrain from giving the necessary support to PWAs.

This chapter is intended to investigate the factors that influence and/or contribute to the differential responses by spouses, family members, friends, the extended family and other members of the community at large. In this regard, efforts are made to describe some of the theoretical bases for social meanings of diseases, as distinct from its medical meaning.

A detailed ethnographic account of the subjects of the study is presented in this chapter. This section of the study is expected to furnish the reader with a sense of the variety of PWAs' experiences. Hence, we will be looking into the issue of stigma, the implications of disclosure and/or non-disclosure of one's HIV status, the differential reactions by spouses and family members towards PWAs and the situation of PWAs who are living positively with AIDS. The last section will be looking into efforts being made by PWAs and children who have been orphaned by AIDS to come together and get organized in a group to share their feelings and experiences. The discussion will begin

by reviewing the different social meanings of the disease as opposed to its medical and/or scientific meaning.

4.1. The Social Dimension of AIDS

"... one of the most significant aspects of any disease is its social meaning as distinct from its medical meaning and how the former affects the way some people react to those who have the disease. The social meaning of and societal reactions to HIV/AIDS have been usually negative and extreme" (Rushing, 1992:xi).

Medicine defines disease in terms of pathological neurological processes that have natural (including emotional, mental and epidemiological) causes. Many societies, however, do not define diseases by their biological properties at all. Some sociologists conclude, therefore, that physical pathology exists only if a condition is culturally defined as a disease and that disease has no meaning apart from cultural context. Such extreme relativism views the scientific medical conception as just another framework for defining disease (Mishler, 1981).

Regardless of how the physical state is defined, AIDS consists of a syndrome of physical pathologies deriving from an immune system that has been impaired by HIV. But the point that people respond to their definition of a disease rather than just to (and sometimes instead of) the physical aspects of the disease is irrefutable. And that sick people have to cope with the social definitions as well as its physical aspects is also obvious.

In explaining the social dimensions of an infectious disease, Rushing argues that most social definitions of diseases fall into three categories: archaic, metaphorical, or medical scientific.

The archaic conceptions are based on the premises that diseases are caused by spirits, witches, sorcery and other magic religious forces. This archaic conception is dominant in many non-literate societies in the world today such as in Africa (Murdock, *et.al.* 1978,1980). Since in many instances archaic conceptions define disease as punishment for bad conduct and the breaking of cultural taboos (Hallowell,1994; Murdock, 1980), disease is frequently viewed in moral terms. The sick person is considered responsible for being sick, and "blaming the victim" is typical. Action by witches, spirits, or searchers is the immediate cause, but the person who is ill is the ultimate cause.

The metaphorical conceptions, on the other hand, argues that sick people have frequently been (and continue to be) viewed as normally polluted. Their social worth may be questioned, and they are treated as deviants or despised outcasts, as lepers have been for many countries. Metaphorical interpretations of disease may reflect other aspects of society besides conceptions of morality. For example, hated marginal or outcast groups may be scapegoated and accused of causing a disease; in which case the disease is a metaphor for divisions in the social structure. But the general point is that as a social metaphor a disease is interpreted in terms of a condition of a society rather than of a biological organism.

The third category, the medical science conception, defines disease as a biological phenomenon with natural internal and external causes over which the individual has little, if any control. Since science aims for universal generalizations that do not vary by culture (e.g. the laws of thermodynamics are the same in all societies), definitions of disease vary less between societies where medical science provides the

dominant conception of disease than in societies where archaic-metaphorical interpretations are concern, reflecting biology rather than culture (Ackerknecht, 1971).

In general, the dominant societal conceptions of diseases influence the way people react to it and those who suffer from it. However, reactions based on archaic metaphorical conceptions have frequently accompanied infectious epidemics. Such reactions were not simply responses to a disease. They were also shaped by social conditions. Reactions based on archaic metaphorical conceptions also appeared in the AIDS epidemic and were shaped by social conditions in much the same way (Rushing, 1995). As with any disease, societal reactions to HIV/AIDS are not just a function of the medical definition and physical aspects of the disease. They are also a function of social conditions.

Because many infectious diseases may be transmitted by person-to-person contact, they have a social dimension that non-infections diseases do not have: the sick may be feared, leading people to avoid contact with them. Non-infectious diseases are frequently feared, but no one fears getting them from another person. People with HIV/AIDS are more likely to be avoided than persons with cancer and heart disease because, among other reasons, HIV/AIDS is contagious, whereas cancer and heart disease are not.

No less than the etiology of HIV/AIDS, the societal reactions to the AIDS epidemic pose important social problems that are as vexing as are the medical aspects of the disease. The immediate cause of any infectious disease is a microorganism. However, social factors influence person-to-person transmission and may explain why the prevalence of a disease varies between populations. Thus, HIV is the (apparent)

biological cause of AIDS, but social factors determine the behavior that is crucial in most transmissions of HIV and explain why some groups and populations have higher rates than other groups and populations.

The principle that behavioral differences are related to social conditions is the central principle in the analysis of the social etiology of a disease. It applies to HIV/AIDS no less than to other diseases.

"Societal reactions to HIV/AIDS especially during the 1980's, are as significant as the social etiology of the disease. Persons with HIV/AIDS, particularly gays, have been deserted, denied proper medical care, and physically brutalized. Children with HIV/AIDS have been prohibited from attending school and church, and children with hemophilia who have contracted HIV have been stigmatized and treated as outcasts. To many people, persons with HIV/AIDS are morally impaired" (Rushing, 1995:5).

History records similar reactions to past epidemics. As in the past, people respond to the social meaning of a disease, not to its biological features and medical definition. Hence, the social meaning of a disease is determined by the social conditions under which that disease occurs.

4.2 - Facing the challenges of AIDS: Ethnography of PWAs

In the following section of this chapter, I will present the ethnographic accounts of the outcomes of my research. Of the overall cases which were covered by this study during the field research, I have selected cases of some of my informants, which, I believe, would give the reader a picture about the challenges being faced by PWAs and persons who are caring for them. They are selected in such a way that they would represent the different categories of PWAs and their sexual partners and/or spouses

including those who have disclosed and/or not disclosed their sero-status to their partners.

Before getting into the ethnographic cases selected to be discussed in detail, a summary of the demographic data and the responses from the thirty-five cases is presented as follows.

Of the thirty-five respondents, 27 were males and 8 were females. With regards to their marital status, 8 are married, 7 are single, 8 are unmarried, 5 are widowed and 3 separated. Most of them lived in Addis Ababa for over ten years. There were only 9 respondents who lived here for less than ten years. The later, came to Addis Ababa in search of better opportunities get jobs and education. Their educational status ranges from illiterate to those who have reached college level. When we look into the details, those who are illiterate are 5, 12 have a primary level education, 17 have secondary level education and one person has obtained a college diploma.

The respondents were asked if they have heard of AIDS before they found out they had AIDS. Most of them (24) said they had heard of AIDS but did not think it was their problem. When asked about their feelings in learning about their sero-status, 23 of them said they were shocked while 5 respondents said they thought of committing suicide. Only three respondents said they tried to accept their sero status and adjusted to the situation. All of them agreed that the provision of counseling services has helped them to overcome the stress and to better cope with their problem.

Most of the respondents do not know how and when they contracted HIV. Only 6 of the respondents said they contracted the virus from their partner while 25 of them said they do not know how they were infected. However, almost all of the respondents who

said they do not know how they were infected have been practicing multi-partner sexual contact. Only one person said she might have been infected in a health institution through unsterilized needles. The majority of the respondents (17) did not tell their HIV status to members of their families, spouses and/or children. The rest have shared it with at least one member of the family, i.e. mother, sister or brother. Even though they did not tell to a member of their own family, all who said so have told their friends.

4.2.1 - Stigma and PWAs

As we are going to discuss the situation of persons who have been stigmatized because they have AIDS, at this stage, it is worth to examine the concept of stigma in general and its relation to the AIDS epidemic in particular. Stigma is a broad and multidimensional concept whose essence centers on the issue of deviance. Birenbaum and Sagarin saw stigmatized people as “the entire field of people who are regarded negatively, for having violated rules, others for being the sort of people they are or having traits that are not highly valued (Birenbaum and Sagarin 1976:33).

In general, there is consensus in the stigma literature that stigma represents a construction of deviation from the ideal or expected form of behavior. Stigma, from Goffman’s perspective, is a powerful discrediting and tainting social label that radically changes the way individuals view themselves and are viewed as persons. When individuals fail to meet normative expectations because of attributes that are different and/or undesirable, they are reduced from accepted people to discounted ones. Thus, the discrepancy between what is desired and what is actual “spoils” the social identity, isolating the individual from self, as well as, societal acceptance (Goffman, 1963).

When we bring together the various dimensions of stigma as delineated by different scholars, the following issues seem to emerge to the fore:

Stigma is:

- associated with deviant behavior, both as a product and as a producer of deviant behavior;
- viewed as the responsibility of the individual;
- tainted by a religious belief as to its immorality and/or thought to be contracted via a morally sanctionable behavior and therefore thought to represent a character blemish;
- perceived as contagious and threatening to the community;
- associated with unaesthetic form of death; and
- not well understood by the lay community and viewed negatively by health care providers.

Ultimately, stigma creates outsiders and social boundaries between normals and the stigmatized. Thus, the essential meaning of stigma which guides this analysis, drawn from the previous discussion, is that the stigmatized are a category of people who are pejoratively regarded by the broader society and who are devalued, shunned or otherwise lessened in their life chances and in access to the humanizing benefit of free and unfettered social intercourse.

The following is the story a person, who have been diagnosed to have the HIV virus in his body, but rejected by his care providers when they came to realize his illness was caused by HIV. This is one of the cases that have been selected to demonstrate the experience of some PWAs who are faced with the challenges of stigma. It particularly

shows the difficulties that may be involved when one is left without any one to support him/her at such a time.

Case one: Tesfaye

His name is Tesfaye. He owns a small mobile shop located along the main road in one of the less overcrowded areas of Addis Ababa. As usual, when I approach the place where he often tends to sit, he begins to walk towards me holding his crutch in his right hand. I pay a visit to Tesfaye not only as part of this research, but whenever I have time while I am passing by.

I have known Tesfaye for the last six years. He was referred to an AIDS counseling center where I was working. Our relationship was limited to exchanges of greetings until the time I volunteered to take him to the Black Lion Hospital for physiotherapy. At that time, he was unable to walk due to a nerve problem.

Tesfaye was born in Addis Ababa. His parents were separated when he was ten years old. When they shared the household tools and equipment, Tesfaye went to his father's place while his mother decided to take his younger sister with her. Tesfaye began to live with his father. However, he could not cope with the situation in which he was found in. He said,

"My father was used to drink alcohol too much. He often comes home late in the evenings. Besides the discomfort I had at home, I missed my friends, I missed the setting where I was playing and everything that I was doing with my friends. I could not stand the situation any more, I then decided to go back to my previous place of residence". He continued *"I stopped going to school. A family living in the neighborhood was willing to provide me with food and to give me a place where I can sleep. During the day I go to the nearest marketplace and carry goods for people to get some money for my food. Like any members of the household, I was also contributing my share to the family where I was living. I continued to live like this until the time I was recruited to join the army in 1981. I was sent to the Hurso military training center where I*

attended training for six months. I served in different places in the then Bale and Hararghe administrative regions. Then I was assigned, along with my colleagues to the northern part of the country. We soon found ourselves in a war front. I was injured in the war, wounded in three places" ... he showed me the scars on his left and right legs. He added "although it was possible to take out two bullets from his legs in the hospital, the doctors decided not to operate me to take out the third bullet, as it was not endangering my life. The bullet is still present in my body and is displayed on the X-ray films taken at times when I am sick.

He continued "... after being hospitalized for about three months, I returned to my military division. This time, I was not sent to the war front, but I was assigned to the logistics department. There, I worked for three years. By the end of the third year I went back to the war front. I stayed at the war front until May 1991 when the war ended due to the overthrow of the previous government. My colleagues and I traveled for one month and thirteen days by foot to reach the Sudanese border. We sought refuge and stayed there for eight months. We came back to Ethiopia through arrangements that were made by the UNHCR and the Ethiopian Government.

"The next chapter of my life started after this time. I came back to the family where I had been living before the time I left Addis. They welcomed me. Six months after my return, I became sick. I lost weight, I was not able to control my urine and waste, ... My former friend, who is now a physician, visited me and made an arrangement for me to be admitted to Zewditu Hospital. I was discharged from the hospital when I began to feel better. Upon returning home, the family refused to let me back in their place. I was abandoned on the streets. There was no one on whom I can rely at this particular time, except a few people and friends who made efforts to build me a shelter along the street. The owner of one of the garages in the area was kind enough to let me use an old truck that is laid along the fence of the garage. My friends used materials made out discarded timber and pieces of wood on the rest to construct the shelter. The site where the shelter was fixed was located just by the edge of the main road, which has allowed them to make a hole over the existing sewerage system to be used as a toilet. I lived there for three years.

"Having realized my situation and through continued effort, the Kebele administration gave me a small house. After settling into my new house, the MMM Counseling and social services center made an arrangement for me to make medicine bags as a way of assisting me to earn some income to cover some of my expenses myself. I was assisted by the center to get the materials needed for the work and got some guidance as to how to make them. The preparation of these medicine bags had two advantages. First, it enabled me to get an income from the sales, which in turn helped me to cover my expenses related to my daily life, mainly food. I often took a dozen medicine bags to the center. The counselors working at the center made arrangements with different mission clinics to collect the medicine bags and leave the money with the counselors. The second advantage was, it keeps me busy to so that I sometimes do not think of my sero-status at all. I think of living, not of dying. I developed a sense of hope in the future.

"As the market for the medicine bags began to decrease, I began to think of starting another activity which may keep me busy. Using the money I got from the sales of the medicine bags, I started this small mobile shop", pointing to a small cupboard like box with wheels. "I sell different types of cigarettes, gum, matches, etc. When I go for lunch or to some other places, I move it into this shop" showing me a shop where lubricants and motor oil is being sold.

He took me to the place where he lives. It is a small, but clean one-room house. He has a very good brand cassette-recorder, kerosene stove and some other household utensils that he uses for cooking food.

According to Tesfaye, he takes the necessary precautions in his da-to-day life in order to keep himself healthy. He refrains from practicing bad habits that may affect his health conditions such as drinking alcohol, smoking cigarettes, having sex and the like.

I asked him if other people in the area know about his sero status. He said:

"Only one person-my friend knows about my current condition". I asked him why? He said, "If other people knew about my situation, they might ostracize me; let alone give me support, they may even refrain from greeting me". I continued asking him about what other people say about AIDS. He said, "they think it is like a snake, a 'Cobra' ", he laughed.

Tesfaye likes to watch football matches. He told me that he does not miss the football matches that take place at the Addis Ababa Stadium on Sundays. In order to obtain the view of his former care providers, I was interested to talk to some members of the family. However, Tesfaye did not feel comfortable with this idea. He said,

"As I have already cut off any relationship with the family, they might not be pleased with such an interaction. They may think that I am still accusing them for their maltreatment and the money, which they denied giving me. I raised the issue about their current attitude towards him. He said, "... During the time they abandoned me, they thought that I would be dying soon. However, when they see that I am still surviving, I think they feel a sense of guilt".

In response to my question about the reasons why they were not willing to continue to give him support during the time of his illness, he said, "I assume that they were convinced that my illness was related to AIDS and they thought it would contaminate other members of the family".

The physical manifestations of AIDS may also arouse heightened fear because they are constant reminders of one's contagious and tainted status. Despite the fact that the individual is less capable of infecting others, s/he may still be regarded by others as an extreme threat.

When we try to analyze the circumstances through which Tesfaye has gone, one can see that there are certain factors that have contributed for his abandonment. First, the level of knowledge and information disseminated among the general public with regards to HIV/AIDS and the small number of people who are known to have HIV during the time when Tesfaye was sick were limited. Hence, the families where he was living might have the fear that the disease could contaminate other members of the family. Hence, they tend to make sure that there is no contact between him and the rest of the family.

The second point that could be made in relation to this case could be the level of responsibility and relationship that the family had to provide care and support for Tesfaye. Their relationship is the type that exists between a person and his/her foster parents. Given the loose level of their relations in the past the risks involved in contaminating the virus and the stigma toward PWAs. The family may not show a strong level of commitment in taking good care of him. Had he been one of their sons, they might not have abandoned him.

4.2.2 - AIDS in the family

AIDS has a great impact at the household level. The economic, social, sexual and other forms of relationships and the solidarity of the family can be affected. Questions can be raised as to how HIV entered into the family. Hence relations between couples may be negatively affected. The case may be more complicated with serodiscordant couples (where one individual is HIV+ and the other HIV-). They face challenges above and beyond those, which face anyone in a relationship. There is often a great deal of anxiety on the part of the HIV+ partner that he/she will infect his/her partner. Another concern for serodiscordant as well as couples who are both HIV+ is whether or not they should have children. Lack of support from family, relatives and friends can compound the problem. Moreover, it is difficult to obtain adequate social services that address the needs of both partners. As some of the PWAs live healthier and with improved longevity, they tend to have children. Hence, they face the vexing choice of whether to try to have children and risk to pass the virus to the baby. In the following section, an attempt is made to present ethnographic accounts of some of my key informants who had HIV, who did not disclose their HIV status to their spouses, but who, later on faced problems when their HIV status was learnt by their spouses.

In what follows I present the cases of three families. The cases were selected from the informants who were drawn into the present study. A close understanding of the cases of Aba-Biya and Desta is expected to give an insight about the nature type of problems that may arise among serodiscordant couples. In the first two cases, we will see the most common reactions of spouses upon learning the sero status of their partners. The third case (the case of Kidane) shows a situation in which the husband knows about

his HIV status but did not let his wife to know about his sero status. Concealing his sero status is compounded by a risk of having children who might have contacted the virus from their mother.

Case two: Aba-Biya

I met Aba-Biya for the first time at a counseling center where he is getting on-going counseling services. He briefly told me about his background. He left his schooling to join the army. Following his training and military service for two years, he again left his job as soldier. He went to *Dire-Dawa* and was hired as a shop-keeper. With the money he saved from his salary, he learnt to drive and obtained his second and third grade driving licenses.

He said, " Then I got into driving buses in the public transport sector. In 1984, I loved a lady working in a bar. I decided to marry her. We got two children".

"I travel a lot to different parts of the country, especially to Gojam, Bahir Dar and Mekelle and other towns along the main road. I smoke, chew chat and have sex with different women. In 1991 I had a problem on my neck. I went to Kolfe TB Center and I was diagnosed to have TB. I underwent the treatment that is prescribed for TB patients. Although I felt better after the completion of the treatment, after some time I fell sick again. I was not able to return to my job. I stopped working for a period of eight months. I was admitted to Mother Theresa Home, a place for the destitute. After some treatment and care I was sent to Black Lion Hospital. I was given pre-test Counseling for HIV test. When I came back to the hospital for the result I was told that my blood test turned out to be HIV positive. I was advised by the counselor and the social worker of the hospital to take care of others and myself."

"Upon my return to the Mother Theresa Center the Catholic sisters who were responsible to take care of the patients there asked me about the results of the test. I didn't tell them the truth. I told them that I am free from HIV". I asked him why he lied. He answered, "If I told them that the result of the blood test is positive, others may also know about it and they may begin to point their fingers at me. I don't like others to know about my HIV status. During this time my wife was staying with her parents at Debre-Zeit (some 52 kilometers south of Addis Ababa). I decided to go to holy water at 'Gergedu'. On my way back to Addis Ababa I brought my wife and the children from Debre Zeit. I phoned my mum in Jimma. She came and stayed with us for some time".

I asked Aba-Biya if his wife knows about his HIV status. He said, "... of course, she knows". I asked him about her reactions upon hearing about his situation. He said,

" it is because she was curious about me going to the hospital that I was forced to admit about my situation. She asked me the reason why I am going to the Black Lion Hospital on Wednesdays. She knows of other people in the neighborhood who go to the same hospital and who are HIV+. She had already begun to suspect that my illness may have something to do with HIV. When she heard about it she was very angry. She blamed me for bringing the virus into the family. She walked out of the house, and that night she didn't sleep with me. In the morning, she took a poison Malatine. She was about to die had our neighbors not been able to call an ambulance to take her to hospital. I tried to tell her that she might not have the virus in her body unless it is proved through blood test. She refused to be screened for HIV. She ran away to her parents in Debre Zeit. I brought the children to the hospital for check-ups. Their blood results showed negative. I was happy that they are not infected. The kids are now 8 and 6 years old. I tried again to get her back to our family. I told her that I would like to take her to my mother's place. She agreed. Just two weeks ago I took my wife and the children to Jimma. They are now with my mother".

I asked Aba-Biya if he has shared his knowledge of his HIV status with the members of the family in *Jimma*. He told me that his mother, brothers and his sister know about his situation. With regards to their reactions, he said,

"I called my mom, my two brothers and my sister privately and told them that whether they believe me or not, I am diagnosed to have the HIV virus in my body. They were shocked, they wept, and they felt sad for me and for having one member of the family dying of AIDS. I asked them to promise to me to take care of my wife and the children rather than bothering about me. They told me they would do all they can for me as well as the children. They encouraged me to live with them, but I told them that I do not want others to know about my current situation. I decided should go to Addis Ababa where I can get close to the health institutions. I don't want the people whom I know saying he has come back having the new disease with him."

Unlike many other informants, he said that PWA's should be assisted within health institutions rather than in a family setting. This is because even family members may get tired of caring for an AIDS patient. I asked him about his feelings in being

separated from his wife. He said "She might not feel comfortable to live with me, as we no longer want each other for sex".

Case three: Desta and his wife

Desta and Alemitu are a married couple with two children. They earn their living from the income from the sales of cultural/national cloth. Desta is engaged in doing the garments with the looms fixed in their house, while Alemitu assists him in carrying out his work alongside with her other household activities. They live in a place near Desta's house and often visit each other.

There had not been any serious problem that could affect the welfare of the family until the time he became sick and hospitalized. He was having a gastrointestinal problem, which needed close investigation. The doctors decided that he should undergo an operation. However, having an HIV test before undertaking the operation was a must. Following a pre-test counseling, his blood was drawn for an HIV test. He was discharged from the hospital on the grounds that his blood test was HIV+. He said,

"I was called to the doctor's office. They asked me a couple of questions related to the issue of AIDS. Slowly, they informed me that my blood test turned out to be positive. I was not able to control myself and lost my balance and fell down from the chair where I was sitting. When I gained consciousness, I was brought back to my room assisted by a nurse. I felt a feeling that my life is empty. I could not see the point why I was living. I lost all my hopes. My heart was filled with tension. The following day, I was discharged from the hospital".

But, he did not have the courage to share his knowledge either with his wife or his parents due to fear of the stigma. He was advised to go to an AIDS Counseling Center for ongoing counseling. As he was not able to work as he was doing before, he began to rely on the support he obtains from the counseling center in the form of foodstuff, and some financial support.

"My HIV status came to the attention of my wife in relation to this support that I was getting from the center. She asked me from where I am getting the food. I told her that I am getting it from an agency that gives support for the unemployment. it is ... "She finally knew the place. She traced by following him using another taxi. She found the place to be a center where counseling service is given for PWAs. She just left the house and went to the place where her mother lives. She took both the children with her. Attempts made by him and his relatives as well as friends to bring her back were not successful.

We will be seeing the case of desta's wife, Alemitu, in the chapter that discusses the issue of gender in relation to HIV/AIDS.

Case four: Kidane

I have known Kidane since 1994. He was referred to the counseling center where I was working. We have close contact, as he was one of the members of the skills training program at the Center. This program was designed to organize and train PWAs and young boys and girls in different skills so that they will be able to earn some income and assist their families. The training program includes sewing, leatherwork, spinning, weaving and wood work. Kidane was in the sewing program. Having completed the training, he was able to sew clothes by renting a sewing machine. Since I left the counseling center we occasionally meet at the same center when he comes to attend the regular counseling program and to collect his monthly material support. I was interested to include him in this study due to the fact that he was married and currently has two children. Given the scientific explanation that the HIV virus could be transmitted from an infected person to the child, I was interested to closely investigate as to how he decided to get married and have children. I was also concerned to find out what the current health status of his children.

His friend first informed him that I wanted to see him. One Sunday afternoon I went to his place with the person who arranged the appointment. As we approached his house his son appeared before us. While we were asking the boy if his father is round, Kidane came out of the house and greeted us. In order to have a quiet place to chat, we left the place and went to a nearby restaurant. I briefly told him the reason why I came to his place. He expressed his willingness to give me all the information I needed. After fixing the next appointment, we left the place.

During our second meeting, we discussed about his life in the past including his family background, where he was born and brought up, his past carrier and the successes and challenges he faced up to now. He is one of the demobilized soldiers of the *Derge* regime. He was in Eritrea during the change of the government. He managed to reach Addis Ababa and began to live with a prostitute in *Arat Kilo* area.

"In the beginning" he said, "I use to give her money each time I slept with her. When I utilized all the money I had, I was forced to pass the night elsewhere, including the streets. Sometimes, when she does not have a customer, she allowed me to stay the night with her. Finally I decided to live with a friend who allowed me to stay with him".

Kidane learnt about his HIV status during the time when he was sick and admitted to a hospital. He was told that he has the HIV virus and was also diagnosed to have TB. He was treated for the TB and was referred to the Counseling Center of the MMM for further counseling. I asked him how he decided to marry while he knows his HIV status. He answered:

"I was having an affair with my current wife just before I was sick and learnt my HIV status. She was working in one of the bars near the place where I was living. Nevertheless, we began to live together after I knew my sero status. I was not able to discontinue our relationship for two reasons. First, we love each other. We were planning to live together. I have no idea as to how I am

going tell her. The second reason is related to my need to have some one who can assist me when I am sick".

One of the important issues, which I discussed with Kidane, was about his decision to have children and to understand whether his wife knows about his sero status or not. He said:

"even though I know I am HIV+, it was not easy to change my past sexual experience with my wife. If I decided to use condoms, I was afraid it would cause questions why I should use them. I believed, my wife would begin to question the reason as to why we should use condoms. Naturally, the reasons would be directed to two factors. Either I do not trust her, or I have some problem that forced me to use the condom. Therefore, I decided to keep quiet. I realized the fact that if she gives birth to a child, there is a chance that he/she would be born with the virus. But what could I do"? I asked him, " What do you think would be her reaction if she knew that it was infected with the HIV virus"? He responded, " I think she would be very angry and blame me -for all what has happened and she could even leave me. As I understand from what she says about AIDS, I think she is afraid of AIDS. She sometimes says, "had I not quit working in the bar, I would have died of AIDS".

Regarding the health status of the children, he said,

"The children are well. The first child was coughing until he reached the age of three. He was diagnosed to have Pneumonia. His health situation has improved in due course of time. But, my wife was having complications during the delivery of her second child".

In the face of the possibilities of passing the virus on to the child, and given the obligations and long term responsibilities of parents not only to fulfill the basic needs of the children, such as food, clothing, shelter and education, but also to provide them with love and affection, a decision to have children is not an easy one. Especially in the case of Kidane, where the wife is not aware of the sero-status of her husband, it may cause serious problems for the solidarity of the family as well as the welfare of the children.

As could be seen from these cases, knowing that a partner is infected with HIV results in strong reactions on the part of the other partner. They take it for granted that

they are also infected with HIV. They blame their husbands for bringing the virus and for keeping their sero status secret. This has also caused the breakdown of the existing relations between the husband and the wife.

Furthermore, in families where there are children, the consequences go beyond the husband and the wife. They affect the lives of the children too, since they will be forced to miss the family atmosphere where they should get love and affection. In families where they accept their situation and live positively with AIDS, relations between members of the family could stay healthy and be maintained even after the death of one of the partner.

4.2.3 - Living positively with AIDS

What does living positively with HIV/AIDS imply? TASO (The AIDS Support Organization), one of the pioneering organization in the provision of counseling services in Uganda, sees positive living with AIDS in daily life consisting among other things of maintaining a positive attitude toward oneself and others, not blaming others, not feeling guilty or ashamed, following medical advice, continuing to work, if possible, occupying oneself with non stressful activities, socializing with friends and family, using condoms during sex and avoiding pregnancy (Hampton,1990).

There are different reactions by individuals upon learning about their HIV status. Some may feel angry, while most people manifest a sense of shock. However, they will slowly improve and gain the courage to accept their situation if they are assisted by health and home care providers, counselors and the community at large. It is at this stage that people will be considered to have begun living positively with AIDS.

The following two cases show how PWAs could live positively with AIDS within the family setting. Unlike the cases we have looked so far, one can see that some families are trying to cope with the day-to-day challenges of life by accepting the situation in which they are found.

Case five: Ali and Merima

Ali and Merima are married couples with two children. They were leading a quite decent life and with a happy family. When Ali decided to marry Merima, his families did not support his decision. The same holds true for her. Her parents, too were not pleased about the marriage arrangements she was making with Ali. They were having an affair while she was a high school student. Right she completed her high school, they began to live together without holding any official wedding ceremony.

I went to visit Ali using the directions I was given from the clinic where he is getting medical support since the time he became sick. A nurse who accompanied me to introduce me to Ali. We asked the boys standing by the side of the road to show us the place where Ali is living, by telling them to name of a buildings we used as a benchmark to identify his house. We walked just a few meters away from the place we were looking for. While we were asking an old man who was standing by the gate of a compound whether Ali is living in there, an old lady came out from the next house. As a matter of chance she was Ali's mother, and led us to Ali's house.

Merima met us when we approached the house. One could see a smile on her face. She invited us to enter into the bedroom where her husband was lying. We greeted Ali and introduced ourselves. We started a conversation by asking him how he is feeling

these days. He told us that he is feeling better this week as compared to the past two weeks.

I asked him how he began to feel the illness and how he learnt that he has HIV in his body. He told us,

"Until 1997, I was having no problem with my health. I worked in the armed forces garage as a mechanic. I also worked in a private garage for two years. However, I began to feel sick from time to time. One of the major health problems I was facing is diarrhea. I went to the clinic to get assistance. They gave me some medications for relieving the diarrhea. However, I began to lose weight. My wife began to suspect that these are the signs of having the HIV virus. Hence she encouraged me to get the HIV test. I was then tested at Ras Desta hospital and my blood was found to have the HIV virus. Upon hearing the results of the test I was shocked. However I soon began to adjust myself to accept my situation. I was referred to an HIV Counseling center. While I was going for counseling I met other people who had similar problem like myself. They are members of an association of persons with AIDS (PWAs). As I continued to meet these people, my tension reduced and I became more stable".

The movement of a child who slept by his side interrupted his talk. Until then I had not noticed that there was a child sleeping on his bed. This is his second child who is about ten months old.

I asked him about his current relationship with his wife especially with regards to blame and/or accusation for bringing the disease to the family. And, also, if he knew how and from whom he contracted the virus. He paused for a while and continued to talk.

"... I have no idea as to how I contracted the virus. It is now about ten years since I got married. I have no extra marital relations with women other than my wife. I am also confident that she too has had no affair with others. But I suspect I have contracted the virus through getting treatment by health practitioners in my neighborhood. I used to be given injections by such persons around the place where I am living. This is not special for me but many people are used to have such practices. Therefore, they might have used needles used for other people".

He appreciates his wife for giving him the necessary support and for encouraging him to live positively with AIDS.

He says, "She always tell me that I am lucky because she is by my side to assist me, she tells me that she will be by my side up to the end of my life, who else do you think will give me such type of assistance if I am sick. ... this is because she suspects that she could have the virus in her body too. Since no one knows about my HIV status apart from us, it could be kept secret. Her fear lies in the fact that if I die of this disease, she will be left alone. Her parents and relatives may not want to give her support if she is sick. She fears the stigma that other people may how towards her as a wife of a person who has died of AIDS. I asked him if anyone from his family knows about his HIV status. He said, "no one knows about it. But some of the relatives of my wife suspect that it is HIV".

I heard from the counselors of Ali that he seem to be improving. However, his health began to deteriorate subsequently. Before I went back to visit him again, he was dead. As I was out of town during the time he died, I went to see his wife as soon as heard the new of his death. I found her sitting with his mother in the same room Ali uses to during the time of his illness. His portrait is placed net to his father's photo. There is a close resemblance between them. One can read from her face that she has deeply felt the death of her husband. I asked her if she is getting well since the time of the death of her husband. She said, " I am well, what can I do other than making efforts to get the strength in order to bring up the children"? It seems to me that she will need a long time to recover from her grief.

Regarding her relations with the parents of her husband, I learnt from the counselors that his family are not on good terms with her. One of the reasons is the fact that they did not support their marriage in the beginning. They were thinking of making arrangements for Ali to get married with someone from the neighborhood. According to the information I obtained from the counselor, they are blaming her for making Ali sick. This problem was aggravated during the time when he reached a terminal stage of his

illness. The counselor said, *"It is after she disclosed the fact that he has AIDS that members of his family began to stop blaming her. However, when he was dead his brothers continued to blame her"*.

Case six: Talegeta

Talegeta is among the first group of people in Ethiopia, who came out open in public to give his personal testimonial that he had the HIV virus. Like many others whom I interviewed, he has also been in the army for a period of about ten years. He was injured in both legs due to the effects of a bomb in the war front. Despite the fact that he had been attending medical treatment, the wound is still oozing from time to time. He says *"This is my major health problem and I am forced to ask people and sometimes organizations to give me financial assistance for treatment"*.

I asked him when and how he knew about his HIV status. He answered,

"I was asked by the physician at Minilik II hospital who was following my case to be tested for HIV. I agreed and my blood was drawn after which I was told to come for the results. I did not come back to the hospital to hear the results of the test since I left Addis soon after I gave the blood. I came back to the doctor after a period of one year. After being counseled, I was told that my blood test turned out to be HIV+. I was in a state of shock for a while. I thought that I was going to die soon. I went back to Debre Birhan (some 124 kilometers north of Addis Ababa) and sold all my goods and household utensils. I was not able to settle down for a period of two years following my diagnosis.

"I came back to Addis and an arrangement was made for me to follow an on going counseling at the MMM counseling and Social Services Center. Slowly, with the efforts made by the counselors, I came to a stage where I can accept the situation in which I am found and decided to go to my place of birth to teach. In collaboration with the Health Department of the North Shewa Administrative Zone, I began to appear in public places to share my own feelings as a Person Living With AIDS (PLWAs). The staffs of the Health Bureau were very much worried about the stigma that I may face following it. However, I began to stand before a public gathering to give my personal testimonial.

"I stood in a hall before many people who were gathered together to attend an educational program on AIDS. Following the inputs given by the medical staff of the Health department, it was my turn to come up to the podium to deliver a

message to the gathering about my feeling about having the virus. As it was my first experience to appear before so many people I was in a state of confusion. I was having mixed feelings. Should I change my mind and not speak about my HIV status? What would be the consequence of coming out in public?"

"I began to discuss about how I learnt that I am HIV+, and about how I felt upon hearing the results of the test. The audience began to murmur and wonder about my situation. The hall became full of noises. Some people were shouting while others were crying. I was not able to continue my talk. I felt the sweat coming through my back. I found myself to have fallen down on the floor. My front teeth were knocked out. I took me a while to come to a normal situation. The meeting was adjourned subsequently. This was my first experience."

"I slowly began to get acquainted with sharing my feelings in other forums too. Then I came back to Addis Ababa and gave my personal testimonials in different places organized by many other organizations including schools, the army, women's groups, NGOs, etc. In my teachings, I put emphasis on the fact that the audience could learn from my experience and to take care of themselves not to contract the HIV virus. I regularly work for 'Society of Women Against AIDS in Ethiopia – SWAAE'. My fear that I would die soon began to diminish. I began to build the confidence that I can live for more time to come".

I asked him if his family have encountered any form of stigma due to the fact that he went public.

"My son quarreled with a schoolmate when he tried to scold him by saying, 'you are a son of a person who has AIDS'. My son hit him throwing a stone at his forehead. The other kid was injured. I tried to convince my son by telling him that there is no assurance whether his father is HIV+ or not so long as he has not been tested. One of my sons appreciates what I am doing. He encourages me to continue to teach people in different parts of the country. At present my sister is taking care of my three kids".

Did you face any stigma yourself? He answered:

"There are instances where some people do not show you a positive attitude. There are individuals who hesitate to even shake your hands. Having learnt that I am HIV+, the lady who rented me the house I was living in packed all my goods and put them outside of her house in my absence. When I returned home, I found them outside of the house. She told me to leave the house immediately. Since I did not have money in my hands, I was forced to spend the night in one of the Churchyards in Addis Ababa. After a period of a year or so, I heard that her husband and her sister died of AIDS. One day I met this lady in a meeting where I was invited to give my personal testimonial. She came to me and apologized for treating me that way. She said, 'the problem has come to my own house'."

As could be seen from the ethnographic descriptions of the foregoing discussions, there are powerful forces working in favor of non-disclosure. Primarily, there are psychological consequences, especially the risk of rejection. Second, there are practical and social ramifications. These may include missing of desired sexual encounters, and the provision of care and support at times when the person falls sick.

Besides, a stress response characterized by disbelief, numbness and denial, acute turmoil, disruptive anxiety and depressive symptoms is seen after diagnosis. The attention of the individual is drawn to matters pertaining to changes in identity and self-esteem, concealment, discovery and disclosure of their HIV positivity. The individual must struggle with issues concerning the meaning and consequences of their HIV status in terms of managing its potential disclosure to companions, family, friends and others.

But concealing may not be an entirely adequate strategy to avoid the discomfort that accompanies illness-related stigmas. Having crossed the boundary of feeling different from the rest, the individual begins to experience isolation, alienation, denial and the building of identity as a stigmatized person despite the existence of opportunities for normalizing the situation in which they find themselves.

By concealing one's HIV status, PWAs attempt to protect their self-esteem. But there may be other negative consequences in so doing. The stress of living a double life is a heavily felt burden. By keeping their diagnosis secret, the PWAs may be deprived of social support from his or her social network that presumably would normally be available to him/her. By failing to disclose, they also risk engendering the hostility of others when they finally learn that the individual is HIV+ and they were not informed previously. Besides, they may not be motivated to refrain from activities that signal

diagnosis, such as delays in seeking appropriate health care or participation in HIV support groups. Thus, some may jeopardize their health status to appear normal. Lastly, they may be highly motivated to sustain participation in social and occupational activities so as not to let others know or be suspicious of his or her HIV status. They may engage in activities that dismiss and deny the diagnosis, such as unprotected sex with unknowing partners or sharing needles. In so doing, the individual essentially disavows his/her HIV positivity but this will necessarily come at the cost of placing others at risk.

The devastation of revelation for the heterosexual spouse of a person who is HIV+ may be profound because of the implied double life one's partner has led and the now terminal prognosis. This could be seen from the stories of Desta and Aba Biya. Their wives were angry upon knowing the HIV status of their husbands. On the other hand, there is still a danger posed in the relationship of Kidane and his wife. If his wife learns about his sero-status at one point in time, it may arouse a serious problem in maintaining their existing relationship.

However, this does not necessarily imply that the reaction of partners is always negative. As opposed to the cases of individuals who concealed their HIV status there are PWAs who revealed their status to their spouses, friends and relatives, the case of Ali demonstrates that his wife was supportive in knowing his HIV status. She rather tried to help him to accept his situation and expressed her commitment that she will always be by his side and care for him.

When we examine the level at which the ethnographic cases presented in the foregoing section correspond to the theoretical arguments that have been proposed in

explaining the social meanings of diseases, none of them accept the medical and/or scientific explanation for being exposed to AIDS. The reactions of some of the spouses that have been experienced by some of individuals was that of blame and the PWAs were viewed as deviants. According to the cases, to be diagnosed to have the HIV automatically implies that they are practicing multi-partner sexual contact. This have been demonstrated in the cases of Desta and Aba-Biya. The case of Tesfaye is much closer to the fear of contagion and that of the metaphorical conception in which they might have considered him as the one who have been responsible for bringing the disease on himself. In general, This chapter has tried to present to the reader some of the cases, which represent all the three categories of PWAs that have been stated in the methods section of the introduction of this thesis.

4.2.4 - Coping strategies: Social support and networking among PWAs

The discussion of social network and social support in this part of the chapter is an effort to consider how the creation of a social support activity among PWAs helped them to develop a sense of solidarity between and among themselves. This has ultimately reached a stage where some of the members developed the courage to go public and develop a mechanism to support other members of the group at times when they need their support.

The discussion will start by first analyzing the concept of social relation help people to better cope with their health problems. It will then proceed to present the example of a group of PWAs who were obtaining counseling services at the MMM

Counseling and Social Services Center, but who slowly began to establish relationships among themselves to eventually form an association of PWAs.

It is evident that the family environment is the best for the provision of care and support for PWAs. However, due to the strong stigma associated with HIV and AIDS, families experience problems in their efforts to respond positively for members of the family infected by HIV. Predicting what the reactions of the family members would be, PWAs are more likely to continue to try to conceal their diagnosis as a means of avoiding stigma. In the beginning, they are less likely to associate with others or become involved in institutions (e.g. support groups) where their HIV status may be identified or must be acknowledged. However, slowly, some may turn their face to other people who may share their worries and concerns, and who may share the stigma as well. This could create a forum for these individuals to adjust themselves over the course of the stigma trajectory.

This could eventually lead to the creation of social networks among like-minded people. As the contributions of Noble and Mitchell indicates,

"Network analysis is thus first of all an attempt to reintroduce the concept of man as an interacting social being capable of manipulating others as well as being manipulated by them. The network analogy indicates that people are dependent on others, not on an abstract society (Mitchell, 1973:viii).

Research in social relations has attracted much attention in the area of public health and social medicine. There is now documentation that people with strong social relations have a lower morbidity and mortality rate (Berkman and Syme, 1979; Orth-Gomer and Johnson, 1987; Kawachi, 1996). Several intervention studies show that social

relations may increase the recovery or survival of patients (Prince and Frasure Smith, 1984; Spiegel, 1989) Despite the enormous interest in this area of research the conceptualization still lacks a strong consensus. The main concepts that are used are “social support” and “social network”. However, the literature includes numerous related concepts, e.g. “social relations”, “social integration”, “social participation” and “social anchorage”.

According to House and Kahan (1985), social support is the functional aspect of social relationships. O’Reilly (1988) introduced the use of social network as the main concept, defined as: “ *An analytic concept, used to describe the structure of linkages between individuals and groups of individuals*”. Such networks have a variety of functions of which the provision of social support is but one.

The establishment of the first association of PWAs and AIDS orphans in Addis Ababa is closely linked to the effort that has been made by Mengistu, who is one of the first clients of the MMM Counseling Center. The continued support made to the group by the Center has helped them to get organized and share feelings and experiences among themselves and build the courage to go public. With a view that the role played by Mengistu has been a significant move in getting PWAs organized in a group, I have presented it as one of the cases discussed in this thesis.

Case seven: Mengistu

The initiative to bring a group of PWAs together was taken by one staff member of the MMM Counseling Center, who himself is HIV+. He started his discussion by

telling me about his background and as to how he came to the Counseling Center for the first time. He said,

"I was among the first group of persons who were referred to the MMM Counseling Center for counseling. At that time I was sick and depressed. Thanks to the medical support and the counseling programs I attended at the center, I was able to slowly recover from my illness and became psychologically stable when compared to my previous situation. I was also strong in my spiritual life. Through reading brochures, leaflets and other materials on the situation of AIDS and the experience of PWAs in other African countries such as Uganda and Kenya, I began to realize the advantages of sharing one's feelings and experiences with other people who had similar problems. Also, I got an opportunity to be trained as a counselor. The training has helped me a lot in understanding the issues involved in counseling and the advantages of sharing feelings and concerns with others. I then decided to approach other like-minded clients of the Center. We created a group of four PWAs (two men and two women) who showed interest to discuss and share their feelings and experiences as a person living with HIV.

According to Ato Mengistu, in the beginning, the objective of the formation of the group was to get together for a prayer and to share their feelings, concerns and problems as a way of finding a means to tackle it. However, as they get to know and understand each other, and as a result of acquiring better knowledge about AIDS itself, they decided to share their experiences with other groups of people in conjunction with the HIV/AIDS education team of the Counseling Center of the MMM. In his words, he said,

"We give personal testimonials at different places organized by different NGOs and community groups. We did this because we felt it is important to educate the people to protect themselves from infections, as there was a misconception among the general public to the extent of not accepting the fact that AIDS exists.

"Slowly, other PWAs began to join the association and the number of its members increased". "At this stage", he said, "We decided to create an association that meets at least once a month. Most members of the association suggested that we should form a type of spiritual association "Mahiber" in the name of one of the saints. We formed the association and named it "Yegebriel Mahiber" (St. Gabriel's Association). The "Mahiber" meets once a month on

St. Gabriel's day at the house of one of the members of the association where "Kollo" (roasted grain) and "Dabbo" (bread) is served. The administrator of the MMM counseling Center and a Catholic priest (who serves at the Center as Spiritual Counselor) and other staff members of the Counseling Center often come to express their solidarity with the members of the association. Members of the association were also able to introduce each other to their family members.

Mengistu believes strongly that the establishment of the "Mahiber" has been instrumental in building courage, moral and spiritual strength among PWAs and has helped some of them to go public and speak about their feelings and emotions as persons living with the HIV. Besides, it has opened an opportunity for some members of the association to attend skills training programs organized by the Counseling Center that were designed to help PWAs whose physical strength allows them to work.

I asked Ato Mengistu, who is the current President of "Mekdim" (an association of PWAs and AIDS Orphans) whether or not this *Mahiber* evolved into the present day "Mekdim". He said,

"the establishment of "Mekdim" is a result of a long process of ups and downs". Having recalled what he said earlier with regard to the courage being developed among members of the association from time to time, he noted that there were also problems among certain members of the association. This is linked to failure to observe the initial aims and objectives of the association. These people were not able to give-up behavior that may endanger their own health status as well as others. i.e., smoking cigarettes, having unprotected sex, etc. This has resulted-in the cancellation of their membership and the counseling center was not willing to continue to provide support if members are not bringing about changes in their behavior. This decision was prompted by an event that took place out of Addis Ababa. One member of the support group who volunteered to give his personal testimonial in one of the project sites of an NGO was accused of having unprotected sex with a prostitute. Having learnt that he was HIV+, the woman accused the man to the organizers of the program about the incidence. This case aroused a serious debate among the members of the group and the counselors and the administration of the Counseling Center.

According to Mengistu, the establishment of "Mekdim" was related to an effort made by the Counseling Center to organize children and youth orphaned by AIDS in order to give them counseling and social support as a way of helping them to cope with the challenges of day-to-day life. He said,

"I was assigned to lead the activities of the group. The theatre and drama club organized under the group was active in preparing and staging educational programs pertaining to the issue of HIV/AIDS and the situation of children orphaned by AIDS. The educational show that was performed at the conference hall of the Holy Savior Church of the Ethiopian Catholic Church where representatives of NGOs, government institutions such as the MoH (Ministry of Health) aroused interest for strengthening such initiatives as it could ultimately make contributions in fighting the epidemic. Members of the group were convinced about the need to be organized, which was followed by the development of a constitution and the election of an executive body. Regarding membership, it was agreed to embrace PWAs as members of the association. Having obtained a registration certificate from the Addis Ababa City Administration, Mekdim is currently operating in Addis Ababa, with outreach programs in other parts of the country. The programs out of Addis Ababa are limited to the sharing of testimonials of its members in forums organized by other agencies".

The President of the association, Mengistu, believes that becoming a member of the association has helped most of the PWAs to get psychological support and to create a sense of helping one another at times of problems.

"Of course, this is the most important element of getting organized". He said, "Currently, we have developed a home care program especially for those groups of PWAs who have no family support. Members with HIV/AIDS are being assigned to take care of a sick member of the association. They conduct home visits, and help the patient to bathe, wash clothes of the patient, prepare food, clean the house, etc. When PWAs are critically sick, the association makes arrangements with health institutions to help them get admitted to the hospitals. Also, it makes funeral arrangements if they pass away."

In addition to this, according to Mengistu, the association is making efforts to devise ways in which orphaned children could get sustainable support until they reach a level where they are able to help themselves.

The creation of such an association is believed to help PWAs reduce their stress and build a sense of confidence about themselves as important citizens. Furthermore, it serves as forum whereby PWAs build the courage to go public in teaching about HIV/AIDS and to take care in not transmitting the virus to others. Learning from the experiences of PWAs in other African countries has helped Mengistu to build a courage to organize PWAs and create a forum for sharing feelings among PWAs themselves on one hand and go public to teach about the consequences of AIDS.

When we examine the experience of PWAs and the lessons learnt in other countries, we can see that getting organized and going public can bring about tremendous impact on the effort to prevent the further spread of HIV and makes contributions in breaking the stigma towards PWAs. The Philly Lutaaya initiative/ People with HIV/AIDS which was started in Uganda in 1991 was a departure from the previous approaches in educating others about protecting themselves from HIV infections and to provide care and support for the already infected. It has been reported that this approach:

"offers the opportunity to see, hear, talk to and discuss with the wearers of the shoe and has proved to contribute in no small measure in giving AIDS a 'human face'. It provokes emotional responses and triggers off the commitment to adopt behavior change"(UNICEF:1995).

Furthermore, it has generated experience in conducting training for HIV+ persons to prepare them to go public.

Chapter Five

Women and AIDS

The aim of this chapter is to illustrate some of the features of the cultural and economic determinants that are involved in gender relations with respect to the transmission of HIV and to depict the interlocking nature of internalized (learned) values, beliefs, opportunities and constraints that contribute to the increased risk of women being exposed to HIV infections.

In doing so, efforts will be made to review the question of gender as it relates to the issue of health in general and to HIV/AIDS in particular. The Chapter will try to examine how the low economic status of women forces them to be engaged in activities such as prostitution which, in turn, may put them at high risk of contracting the HIV. The discussion will further proceed to consider other factors which are responsible for aggravating the level of risk of acquiring HIV among women. These include, but are not limited to, norms concerning sexuality, violence against women and physiological vulnerability. It is evident that the bearing of children is central in the lives of women. Hence, there are risks of women already infected bearing an infected child. Some discussions are thus made with regards to mother to child transmission of HIV. In relation to this, efforts have been made to make a link between the cases that were reviewed in the ethnographic descriptions of the earlier chapter. The Chapter will be concluded by touching upon some options for preventing HIV infection among women.

In most societies, women's primary role in life is assumed to be to bear and nurture children. Men's main duty is seen to be earning a living and dealing with the broader society on behalf of the family. Until recently, almost universally, women have

been expected to undertake most household tasks, go through pregnancy, childbirth, lactation and rear children. The expectation that women must care for the children is generally extended to all household members needing support, such as the elderly, those who are ill, for instance with HIV/AIDS, and/or orphaned children. Men are not usually expected to undertake care roles. The growing orientation towards home care, may in fact, worsen women's situation, particularly as men are often the first to become sick. The wife may have to nurse her husband while her own health deteriorates, but the main expenditures are for his care. There may be no appropriate caregivers to nurse her through her illness. AIDS-related stigmatization and the extra care burdens brought on by the disease worsen existing gender inequalities, increasing women's vulnerability and exploitation. Girls may be withdrawn from school to look after their sick families, thus increasing their economic and social vulnerability when they grow up.

This supposed division does not correspond entirely to reality, however. Almost universally, women have always have undertaken productive as well as reproductive work. It has simply been unpaid, unrewarded materially and unrecognized. *"In many African countries, for example, well over half of the agricultural work is undertaken by women [68% in Central African Republic and the Congo, 70% in Gambia]* (WHO, 1995). Yet women do not gain equal access to educational opportunities or the paid labor market, both of which may contribute to the social and economic independence and more self-assurance. Gender has historically been invoked by the medical and public health fields as a way to normalize biological differences, thereby overlooking the intricate connections between gender, socioeconomic status and social factors that may put women at risk of HIV.

"Gender refers to widely shared ideas and expectations (norms) about women and men: Ideas about "typically" feminine and masculine characteristics and abilities and expectations about how women and men should behave in various situations. These ideas and expectations are learned from families, friends, opinion leaders, religious and cultural institutions, schools, the workplace and the media. They reflect and influence the different roles, social status, economic and political power of women and men in society" (WHO, 1995:7).

According to reports of the American foundation for AIDS research, Women now account for 46 percent of all adult HIV/AIDS cases worldwide, and in Sub-Saharan Africa, 55 percent of HIV + adults are women. In the U.S., the proportion of AIDS cases reported among women increased from 7 percent in 1985 to 23 percent in 1998, and women now account for nearly one-third of all new HIV infections. Worldwide, 85 percent of all instances of HIV transmission involve heterosexual intercourse (amfAR AIDS Research; 2000).

More women are being widowed at a very young age due to the death of their husbands to AIDS, and will themselves face an early death. Safeguarding their children's future is a desperate worry for these women, yet they may lack the means to provide for them without extended family support. It is difficult for women who have no husbands and no other source of support or income to survive without multiple sexual partnerships and the added risk it entails. Research in both Uganda and Rwanda, for example, has shown that women who are separated, widowed or divorced have significantly higher levels of HIV infection than do married or cohabitating women (Allen, 1991).

In general, a host of economic, cultural and biological factors conspire to heighten women's vulnerability to AIDS in comparison to men. Some of the major factors are presented as follows.

5.1 - Low economic status, HIV and prostitution

In many societies, men are expected to control women in all aspects of relationships. Tradition and the social norms support this type of male power. For example in some cultures, male relatives must assume authority over widows.

Status and power affect the individual's risk of infection and the ability to cope with the epidemic. The low status and power of women lead to their subordination and restrict their possibilities of taking control of their lives in relation to HIV and STDs.

Besides the economic production activities in which the majority of women are engaged, large numbers of women are household heads but lack sufficient authority, money and material resources, family and formal support to provide adequately for their children and for themselves.

Gender stratification is so oppressive that Barnett and Balkie (1992) argued that sexual favors and reproductive potential are about the only way that women can gain access to land, cash, and other economic goods. Material favors gained from sex also lift some of the heavy work burden that women traditionally carry.

Women's economic dependence makes them vulnerable and if selling sex enables them to survive today, long-term concerns remain out of focus. A Ghanaian woman engaged in sex work in Abidjan, Cote de Ivoire, commented, "*I need to feed and clothe my children now. How can I worry about something that may not affect me for many years?*" (WHO, 1995:P.12)".

As gender, sex, and (more recently) AIDS researchers have emphasized, sex is a resource with both symbolic and material value. As a source of sensual and emotional pleasure, as a necessary part of the production of valued offspring, and/or as a means of

acquiring social capital (including prestige, debt, etc.), sex plays multiple roles in personal relationships and in broader social alliances (e.g., through marriage).

Studies have explained very diverse instances of sexual-economic exchange as results of asymmetry in gender power, women's differential denial of access to economic opportunities (especially education and employment) and women's consequent dependence on men (or on sex with men) for their own and their children's social and economic welfare or survival (Wilson: 1990: Wyatt, 1991). A ready market for sexual services exists almost worldwide and is a significant factor exacerbating the HIV epidemic. Unlike cities in the West and elsewhere where urbanization is occurring, in Africa, urbanization is occurring without industrialization. Most cities have little manufacturing or heavy industry, so wage sector jobs are scarce. Jobs for women are especially limited. For example, Zaire's cities have about as many women as men, but women constitute only four percent of formally employed workers (Schoepf, 1992)

Hence, prostitution is widespread in African cities. A study made by Dirrassie (1991), on a sample households made in Addis Ababa as far back as 1973 claimed that eight percent of female heads of households were prostitutes. When prostitutes who were not household heads (e.g. streetwalkers) were included, it was even estimated that 25 percent of adult women were prostitutes. Overall prostitution was "by far the largest occupational category for women" in the "informal" labor sector of Addis Ababa (Dirrassie, 1991).

According to White (1984), prostitution is one of the four main roles to have emerged for women in urban Africa (the other three are housewives, sellers of cooked food, and brewers of local liquors). Since prostitution is combined with other roles, most

frequently with brewing, the number of prostitutes is very high indeed. The rapid growth of urbanization and the concentration of prostitutes in towns and cities in Africa were associated with high STD rates in the 1970's prior to the AIDS epidemic in Africa (Meheus 1974; D'Costa, 1985). For example, of the sixty prostitutes interviewed at length in the 1973 household survey in Addis Ababa, 95 percent said they had contracted gonorrhoea at least twice, and 63 percent had contracted syphilis at least once (Dirassie, 1991).

The customers of African prostitutes seem also to be at high risk of contracting HIV. In a sample of men recruited from an STD clinic in Nairobi, 89 per cent of those who were infected reported having had frequent contact with prostitutes (Simonsen, 1988).

The alarming feature of prostitution in Africa is that it is interwoven with social forces. Poverty is one of the major factors. One author claimed that "financial factors" account for 85 percent of African prostitutes (Williams, 1992), though this would not account for the social acceptance of prostitution.

In societies where postpartum sex taboos exist, often lasting up to two years, husbands may seek sexual pleasure from other women. This may be seen in some urban centers, although it may not account for much of the extra-marital relations.

The tendency for young girls to be partnered with older men increases the likelihood that they will be exposed to HIV. This age gap is likely to increase as older men seek out younger and younger partners in the hopes of avoiding AIDS. Older men have had more sexual partners and, therefore, have a greater chance of being infected with HIV or other STDs. Women clerical workers, school girls and female traders are

examples of the larger population of urban women who occasionally barter sex for the resources and upward mobility that older men provide (Ulin,1992).

5.2 - Norms concerning sexuality

Marriage may be viewed as a social and economic commitment between individuals and families. Within marriage, women may have difficulty negotiating safer sex, such as condom use, as this implies lack of trust and infidelity. Due to their lower social status and economic dependence, married women may be unable to challenge their husbands' extra-marital affairs even when they know they are at risk. But it is essential that they should be able to do so, as most HIV- infected women have been infected by their husband or regular partner.

In a summary of a multi-center study on "Commercial Sex and HIV Transmission", it is stated that "*in Ethiopia female prostitution is usually frowned upon, while male promiscuity is regarded as a positive manifestation of masculinity*" (Bishaw, 1990). Admittedly, the degree of mutuality in the sexual act depends on the preexisting relationships between the male and the female involved. However, social views on female sexual activities in Ethiopia are discriminatory (Kidanemariam, 1991).

Women's subordinate socio-economic status makes it difficult for them to control their sexual lives. The case of Desta and Alemitu, which have been shown in the ethnographic section of Chapter four, could be seen as a good example of such an experience. I was able to meet Alemitu in order to obtain her views regarding her relations with her husband Desta before she stopped to live with him. I have presented the case as follows:

Case eight: Alemitu

I was able to meet Alemitu, Desta's wife through an arrangement that was facilitated by the counseling center. During our discussion I asked her to tell me her feelings about what happened in their family. She said,

"He is the one who is responsible for bringing the virus into the family. He used to go around and even stay the night outside of his house. I have made efforts to convince him to change his behavior. But he was not able to understand what I was telling him. Now he has seen the consequences".

Regarding as to how she came to know his HIV status, she said,

"I become suspicious when he brought different types of foodstuff on a regular basis. It seemed to me that he is getting this support from an aid agency. I wanted to find out from where he is getting it. I knew the day when he was collecting the stuff. After he left the house I followed him. He reached Sidist Kilo and took the street that takes to the Minilik hospital. By the time he entered the HIV counseling center, I was just behind him. I waited until he left the compound. After some time, he came out carrying the usual stuff. After he left the area, I entered the center. The guard asked me where I am going and if I had an appointment with any of the counselors. I told him that I wanted to talk with the counselors. He allowed me to enter and showed me the room where I can find the counselors. I reached to the counselor in charge of my husband. I introduced myself and asked her about the reasons why Desta was here. She thought that I might know about his sero-status. She gave me some advice as to how people can live positively with AIDS. Hence, she did not mind to tell me that he is HIV+. I tried to control my temper and I did not hear properly what she said afterwards. I was heavily depressed when I left the compound. I decided not to live with him. I left the house and moved to my mother's place. I was responsible to take care of the children, I went to the counseling center on another day to ask them if they could help me in getting some support which was allocated to him. They gave me an appointment to come again on the date when he will be coming his regular supplies. They did this because they wanted to bring both of us together to discuss over the matter". (The outcomes of the discussion made with her husband are shown in chapter six where the role of counseling is presented).

This case shows how women are exposed to the risk of acquiring HIV and STDs due to their husband's infidelity. Even if she is not tested for the presence of the HIV in

her body, she thinks that she might have been infected before the time she learnt about his sero status.

Commonly, though not universally, male sexual needs are acknowledged to a greater extent than female needs. Many cultures use words to describe female sexuality in a more negative and judgmental way. Many women and men define sex largely according to what they believe gives men pleasure. For example heavy peer pressure may make it difficult for boys to resist experimenting with multiple pre-marital partners, while girls are expected to remain virgins until marriage or at least to remain faithful to one partner. Women may be reluctant to buy and carry condoms because they will be accused of wanting to "entice" men into having sex.

Many women have an inadequate understanding of their own bodies, mechanisms of HIV transmission and their level of risk in unprotected sex. Low levels of education and literacy contribute to their limited access to printed information on HIV/AIDS and STDs, so that they have little or incomplete information. A female merchant in Senegal commented:

"I do not need condoms because I am not a prostitute. I have a husband and children. It is rare that during my travels I fall to the advances of a man. When I do, it is with someone I trust, I only choose to have sexual relations with men who are clean and visibly healthy, polite, and capable of respecting me. These men know me, trust me and know that they don't need to use condoms with me" (Niang, 1994).

In explaining sexual behavior, the broader social and economic determinants and the cultural context within which sexual behavior takes place should be taken into account. Recent findings from the Women and AIDS program, a research effort undertaken by the International Center for Research on Women (ICRW) provided

insights into the realities of women's lives, their sexual behavior and experiences and the ways in which socio-cultural and economic factors affect their vulnerability to HIV. Of the most immediate barriers that women face in adopting risk reduction behaviors, lack of knowledge and/or skills, and the specific social norms and beliefs that constrain women's ability to protect themselves from HIV are the most significant ones. The study focused on issues related to the knowledge and practice of condom use, partner reduction and/or mutual monogamy as well as assessing appropriate STD treatment. The following table summarizes some of the barriers that affect women's adoption of risk reduction behaviors.

Table 5. Barriers to Women's Adoption of Risk Reduction Behaviors

Condom Use	Partner Reduction/Mutual Monogamy	Accessing Appropriate STD Treatment
<i>Lack of Knowledge and Skills</i>		
<ul style="list-style-type: none"> Do not know that condoms provide protection from infection. 	<ul style="list-style-type: none"> Do not relate their own sexual behavior nor the behavior of their partners to risk of HIV and STDs. 	<ul style="list-style-type: none"> Cannot identify abnormal gynecological signs as symptoms of STDs.
<ul style="list-style-type: none"> Believe that condoms will get stuck inside or travel to the throat. Do not know how to use condoms correctly. Do not know how to negotiate condom use. 	<ul style="list-style-type: none"> Do not know how to communicate with partner about fidelity. 	<ul style="list-style-type: none"> Inappropriately self-medicated with antibiotics as treatment for STD symptoms.
<i>Social Beliefs, Norms, and Realities</i>		
<ul style="list-style-type: none"> Condoms signify lack of trust and intimacy. 	<ul style="list-style-type: none"> Socially acceptable for men to have multiple partners. 	<ul style="list-style-type: none"> Belief that vaginal discharge and abdominal pain are a woman's lot.
<ul style="list-style-type: none"> Condoms are associated with illicit relationships. 	<ul style="list-style-type: none"> Women cannot question men about their sexual behavior. 	<ul style="list-style-type: none"> Acknowledging STD symptoms and their association with illicit sexual behavior is shameful for women.
<ul style="list-style-type: none"> Condoms reduce sexual pleasure. Talking about sex, including condom use is taboo and can result in violence. 	<ul style="list-style-type: none"> Physical violence and abandonment are consequences for women who question male fidelity. 	

Source: Parker and Gagnon; *Conceiving Sexuality*. 1995.

In an assessment that was carried out by Children Aid-Ethiopia (CHAD-ET) on HIV/AIDS related knowledge and practices among 54 children involved in prostitution, the majority (68%) believed that AIDS is their problem too. However, most of them believed that it is not a serious problem than other killer diseases. Almost half of the interviewed children (48%) said they do not use condoms during sexual relations. Reasons given for not using condom include partner's interest and lack of access to condoms. Their responses are summarized on the following table.

Table 6. *Summary of responses for questions related to knowledge about HIV/AIDS and practices of children involved in prostitution (1998)*

Description	Number	Percentage
Number of children who listed only one of the modes of transmission of HIV	26	48
Number of children who listed only one of the means of prevention of HIV	27	50
AIDS is my problem	37	68.5
AIDS is not a serious problem than other killer diseases	34	62.9
Prostitutes are the main transmitters of HIV/AIDS	32	59.2
Children who said they use condoms during sexual contact	28	51.8
Children who said they do not use condoms	26	48.2
Reasons for not using condom		
- Partner's interest	29	53.7
- Lack of access	10	18.5
- No clear reason	15	27.8

Source: CHAD-ET, *The cause and effect of child prostitution*, 1998

5.3 - Violence against women

Violence against women, especially rape, is a risk factor that is inadequately recognized or addressed. It is traumatic and difficult for women to report rape and secure conviction. Women may be reluctant to report abuse because this will affect their position in society: if it becomes known that a young girl has been sexually abused (the result of a trial), in some countries she will have difficulty marrying because both women and men see her as "spoiled".

In the worst situations, physical and sexual violence against women are commonplace. Wars and armed conflicts, generally accompanied by widespread rape, have added the risk of spreading HIV and STD's. The physical trauma of violent sex,

often multiple rape, makes transmission particularly likely. Indeed any coerced sex increases the likelihood of micro-lesions in the vaginal mucosae, which may then be entry points for HIV.

Like many other countries, cases of rape and physical abuse of women happen in Ethiopia too. According to a study report compiled by the Ethiopian Women’s Lawyers Association (EWLA), there are many cases of violence that have been reported to the police. The following table shows statistics collected from the federal criminal courts show the number of abduction of young girls and rape whose victim were virgins during the period of *Meskerem-Tir* (September – May) 1989 E.C.

Table 7. *Statistics of cases of violence against women brought to the federal first instance criminal courts*

	Pending cases	Newly instituted cases	Decided	Withdrawn
Arada	17	13	1	-
Kerra	26	3	2	1
Ledeta	40	18	5	-
Yeka	60	12	-	-
TOTAL	143	46	8	1

Source: Rakeb Messele, 1997. *Violence Against Women and The Role of The Law Enforcing Institutions.*

5.4 - Physiological vulnerability

Researchers estimate that women’s risk of HIV infection from unprotected sex is at least four times higher than that of men (UNAIDS:1999). Semen, which has a high concentration of the virus remains in the vaginal canal for a relatively long time. Women are exposed through the extensive surface of mucous membrane in the vagina and in the cervix through which the virus may pass. In men, the equivalent area is smaller, mainly in the entrance of the urethra.

Certain cultural practices may exacerbate women's physiological risk of HIV infection, especially when HIV is widespread in the population. Many women actively support these practices because they enhance their social status and security with their partners. For example, in some parts of the world, women use herbal and other agents in the vagina to cause dryness, heat and tightness (WHO; 1995). This practice is carried out because women believe men prefer "dry sex" and because they think that female secretions are unclean. However, the substances used can cause inflammation and erosion of the vaginal mucosa, making it easier for HIV to enter.

Female genital mutilation (circumcision) is practiced in various countries. Infubilation leads to extensive tearing and bleeding when sexual intercourse is attempted. The procedure itself could be risky if unsterilized instruments are used for several persons in succession.

Women may have STD's without noticing realizing it. Some 50-80 percent of STDs in women are asymptomatic or go unnoticed because they are internal (WHO,1995). Women are less likely than men to seek timely treatment for STDs for this reason. Stigma attached to STDs, especially for women, inaccessibility of clinics, lack of money and too many responsibilities further prevents them from getting treatment.

Men in some societies may boast about STDs because it shows they are "real men" who have sexual relations. But for a woman the story is different. She is more likely to be looked down on as unclean. In much of Southern Africa, for example, STDs are derogatorily termed "women's disease" and men blame women for their infections. Despite the realities of infection patterns, gender stereotypes allow women to be blamed

for spreading HIV/STDs. Men are often reported to be infected by sex workers or casual girlfriends, who may be castigated by men and women alike, while less blame tends to fall on men than women who have multiple partners.

5.5 - Meeting AIDS with compassion

As we have seen in the ethnographic cases presented in Chapter four, the reactions of spouses (especially those of the wives) is not always similar in that it causes dispute between the husband and the wife leading to the breakdown of the marriage. There are cases in which they try to adjust themselves with the problem and cope with the problem of caring for their sick husband, try to overcome the financial problems they are faced with and be in charge of supporting the family in general. The following case illustrates the case of a Merima, Ali's wife, who is living with her HIV+ husband.

Case eight: Merima

An arrangement was made for me by the counseling center to meet Merima to discuss issues pertaining to ways of coping with task of caring for her husband who was sick at the time of this study. I was sitting with the counselors in one of the rooms before the time she arrived there. After an exchange of greetings, they introduced me to her. They briefed her that I was interested to discuss about the situation of her husband and about how she is coping in taking care of him. Following this I started my conversation with issues more of general in nature such as which area she is living, when and how she was married to Ali, where her parents live and the number of children she had. She told me that she was married to Ali right after she completed her high school education. She

also informed me about the fact that her parents were not pleased about her to get married at the age of 18; (because they think she is too young to become a wife).

She said:

" even if I realize it is too early to get married, I decided to do it. We started to live together. He earns some income to support the family before the time he became sick. I was also as a cleaner in one private hospital. Since the time he became sick, we are not getting a regular income. This happened due to two reasons. First, I should look after him, as he needs care. Secondly, my employers assigned me to work during the night shift and were not willing to give me sufficient maternity leave after I gave birth to my second child. Hence I was forced to leave the job. We are currently rely on the support we obtain from the counseling center and some help from our relatives".

I asked her about how she knew about the sero status of her husband, what she thinks of how he contracted the virus and about her reaction in knowing that he is infected with the virus. She said;

"Since I was working in a hospital, I knew some of the signs and symptoms which PWAs show. I began to suspect that he has AIDS. I encouraged him to get tested and as I have guessed, his blood test turned out to be HIV+. However, I cannot become sure as to how the virus entered into our family. I trust him. I sometimes think if I have caught it while working in the hospital. God knows. I convinced myself that I should not blame him. I was committed to give him all the necessary support as far as my capacity allows".

Unlike the case of Desta and Alemitu, the case of Ali and Merima demonstrates that there are differences in the reactions of spouses upon learning the HIV status of their husbands. Although there is no clear-cut reasons for such differential reactions, it seems to me that it all depends on how the individuals perceive the issue of having HIV. For some people it is like hearing a death sentence of oneself, they take it fore-granted that they are already infected with the HIV, such that they lose all their hope to live. Given the current stigma towards PWAs, spouses are also concerned about the stigma that may occur to them in relation to having their husbands having AIDS. They fear that they may

be labeled to have the HIV virus in their body too. Above everything they will be concerned about the future of their children. All these will put them in a dilemma of deciding to continue and/or discontinue their relations with their husbands. At this particular time, it seems important to make arrangements for them for obtaining counseling services.

5.6 - Mother to Child Transmission of HIV

Given the reproductive role of women in society, and the risk of HIV transmission from mother to child, the issue of having children raises questions. As has been discussed in the earlier sections, it is not possible to determine when and how this form of transmission occurs. It is thought that most infection happens during pregnancy, possibly via HIV in the placenta or if HIV in the mother's blood crosses the placenta. Also infection may happen during childbirth, possibly during the mixing of maternal and infant blood through the umbilical cord, or through ingestion by the infant of maternal vaginal mucus and or blood during delivery. Besides, cases of infants who become infected with HIV through breastfeeding have been reported (Berer; 1993: 74,80).

The rights of women living with HIV to bear children or seek an abortion are hotly debated. Childless women may be considered as 'deviant'. Their social status is often low. Some could try to become pregnant repeatedly with a variety of partners so that they have unprotected sex, thereby increasing their risk of contracting HIV/STDs.

As the rate of hetero-sexual transmission of HIV rises, pregnancy- related infection is expected to comprise a larger and larger proportion of cases of new HIV

infections in infants. In Africa, because there are many women with HIV, the number of children infected through mother to child transmission is the highest (Berer,1993:72).

What are the options available to reduce mother-to-child transmission of HIV? First and foremost, knowledge of HIV status and openness between partners makes prevention and risk reduction much easier to achieve. There are cases in which one partner knows about his/her sero-status but is afraid to disclose it. As has been shown in the ethnography of PWAs of this report, there are cases in which the spouses are not informed about their sero status of their partners. For example, Kidane's wife gave birth to two children after the time he was diagnosed to have the HIV virus. This has been caused due to the lack of courage, on his part, to either disclose his status to his wife or to change his sexual behavior (for example the use of condoms) because he was afraid that it would cause a problem in the stability of the family. One of my informants said that he is using condoms to protect his wife from infection. The justification he used to convince his wife in starting to use condoms was that they should use condoms to prevent pregnancy as opposed to pills, which may not be convenient for her health.

During the collection of data among *PWAs*, I have come across a few cases in which the husband and wife are HIV+ but are leading a peaceful family life. They take all the necessary precautions not to infect and re-infect each other and other members of the family. According to their opinion, this is an outcome of attending a series of counseling programs, which in turn helped them to bring about behavior change and live positively with HIV. In a large study in Zaire, more than 97 percent of pregnant women were unwilling to inform their partners because of fear of divorce, physical harm or public scorn (Robert W., 1991).

The ideal option for HIV+ women is to avoid becoming pregnant. Terminating the pregnancy is an option taken by some women when they learn they have the HIV. But, according to the outcomes of a study, knowledge of positive HIV status did not influence the rate of abortion. In this study made in Scotland, of the forty four women who knew they were positive before they become pregnant, twenty one had a termination (Frank D. 1990) In New York City, four out of eighteen women who learned they had HIV during pregnancy, decided for abortion, on the grounds of risk to themselves and to the infant of HIV infection. Among 11 sero positive women, who had learned their HIV status during the previous pregnancy and had become pregnant again one or more times, one woman decided for abortion (Sunderland, A: 1988). Nonetheless, abortion does not seem advisable with the current state of knowledge. It would even seem that abortion carries an increased risk of precipitating the start of disease. It is the doctor's responsibility to provide sufficient information about the implications of becoming pregnant for HIV+ women. In the end, it is the doctors who must decide, taking into account not only the woman's history but also legal considerations.

5.7 - Children and HIV/AIDS

Children are the ones who are paying the costs of AIDS. This is not bodily when they themselves are contaminated by the virus, but also emotionally when AIDS deprives them of a father, a mother or often the two at once. When their parents are critically sick, children will be forced to care for them. Here, one should note the risks

of contracting the virus in the process of caring due to lack of taking the necessary precautions.

The problems of children affected by HIV/AIDS begins long before their parents die and extend beyond their individual households to affect relatives, neighbors and whole communities. When their parents die, the older children look after the young ones, or they go to live with their grand parents (where they are alive) or as it happens fairly often, find their ways to the streets in the urban centers. According to the reports of UNAIDS, "Child headed homestead" are now common in countries hardly hit by the epidemic (UNAIDS: 1999).

The structure of family life will be radically altered as parents die, households crumble and extended families may find themselves unable to cope. The death of the mother, however, has even greater consequences for the children, as children who lose their parents can become a burden for aging grandparents.

The number of children who are born with the virus is reported to be high, especially in Africa. 90 percent of all children having the HIV virus in their body are in Africa. In Ethiopia, it is estimated that about 150,000 children under the age of 5 are infected with HIV in 1996 (MoH, 1998).

Once they are born from a mother infected with HIV, the children had a chance of either becoming HIV+ or becoming free from the virus. In most of the literature, there is a chance of 30-40 percent of becoming infected (MoH, 1998). Having the virus in their body would mean they are going to suffer of the bouts of the illness of AIDS, and if others know it, they may face discrimination in their day-to-day lives.

The following is the case of a child who is HIV+. She has lost both of her parents due to AIDS. She is currently being cared by her aunt, W/ro Abebech. I contacted W/ro through the counseling center to ask her about the situation of Helen.

Case ten: Helen

Helen is one of such children living with HIV. She is six years old and lives with her aunt, W/ro Abebech. Both her father and mother have died of AIDS before she reached the age of three. Her father had five children from his first wife. His first wife fell ill three years after he married Helen's mother – his second wife. As there was no one to assist her during the time of her illness, he asked the permission of his second wife to let him bring his ex-wife to their place in order to give her a better type of support. She agreed with his proposal and his first wife was brought to their place of residence. As she has already been seriously sick, she died after a period of one week. A year later Helen's father fell ill. According to W/ro Abebech, Helen's aunt, she was among his close relatives, who knew about his HIV status first. In explaining as to how she learnt about the situation, she said,

"He first asked me if I will not be angry by what he is going to tell me. I said, "why should I angry by what he is going to tell me. I said to him: "why should I get angry?" wondering about what he is going to say next. As I was waiting to hear what he was going to tell me, many things began to stir in my mind. Before I could make up my mind, in a low tone, he said. "a crises has come to me and your sister, to refer to his wife, and my daughter to refer to Helen." ... He continued, "I have been caught by the new disease (that is to mean AIDS)". She said, "He paused for a while and asked me to promise him to keep our conversation secret and to try to cope with the consequences of the problem. His major concern was the future of his wife and his daughter, Helen. I did not take much time to tell him that I will do all the best I can to assist them so long as my capacity allows. I showed my commitment by being present on their side. I stayed in my house during the day and I spend the night with them. I continued to do this for a period of one year. He died after six months. His wife began to feel unhealthy before his death. However, she followed him right after six months".

I asked her what she did during her stay with them. W/ro Abebech answered *"I prepared food, washed their clothes, cleaned the house, and assisted them to eat and bathe"*. In response to my question whether or not she was taking the necessary precaution to protect herself from infection, she said, *"He warned me not to get in contact with blood and other body fluids and to take all the necessary care especially if there is a wound on my body"*.

"After his death, his relatives and family members continued to complete the process of the court, to be entitled to inherit his property. He was having a house and little household furniture. I brought Helen with me. Upon the hearing of the witnesses, his family told to the court that they would not accept Helen as one of his daughters. We tried to convince the court that she is his daughter. We were required to present other supporting documents, which could prove that Helen's mother was his wife and Helen, his daughter. At this stage, I decided not to argue any more so long as they are not willing to accept their own blood. The court case came to an end that way".

- With regards to Helen's health status, W/ro Abebech told me that she was having recurrent diarrhea, which led to her HIV test. Her test turned out to be HIV+. Whenever she is sick she takes her to the clinic for treatment. She attends school. She showed me the results of her recent test. She has scored good marks.

According to W/ro Abebech, no other member of her family knows about Helen's sero status. The reason for this confidentiality lies in her view that others may refrain from treating her like any other child in the family and their neighborhood. She said she is determined to do whatever is required of her to keep the child happy.

The case of Helen shows us that so long as there is someone to look after them and provide the necessary treatment and care at times when they are sick, children could lead a peaceful life in terms of fulfilling their basic needs and protected from discrimination. On the other hand, as could be seen from the case of Helen, the issue of property right and inheritance is a challenge for children who are losing their parents due to AIDS.

5.8 - Options for preventing HIV infection among women

Due to reasons outlined earlier, the proportion of women becoming infected with HIV is increasing in every region of the world. Hence efforts have continued to be made by the scientific community to develop and test different types of contraceptive technologies. Male condoms were already in use in family planning programs as a choice in contraceptive and for the prevention of the transmission of STDs. On the other hand, as opposed to the male condom, a female condom (worn within the vagina rather than on the penis) has been manufactured and was being used for less than a decade. The introduction of the female condom was believed to give women more control over their bodies and couples more options for protecting themselves and their sex partners.

In the past years, the use of condoms has been widely promoted as a way of preventing HIV infections among both men and women. In many parts of the world, however, the use of condoms have been restricted due to high cost, limited availability and inability to disseminate knowledge about the advantages of condom use, especially among the rural population where the majority of the people live. However, the condom is a technology that women may influence, but ultimately do not control. This means that women's safety is often predicated on their ability to 'negotiate' condom use with an often-unwilling partner. For women living with abusive or alcoholic partners, the task of consistent condom use is even more problematic.

In the face of the existing high risk of HIV infections among women, there has been a growing demand to create a technology that may help to prevent infection. The development of microbicides emerged out of the need to develop a safe and effective chemical barrier to prevent sexually transmitted diseases and HIV infection. These

products will inactivate infectious agents in ejaculate, as well as cervical vaginal secretions, thereby providing bi-directional protection against infection. Microbicide is prepared in a form of a gel, cream, suppository, or film that can kill or neutralize viruses and bacteria (Microbicides: 2000).

Unlike other barrier methods, a microbicide could be used without the cooperation or even the knowledge of the male sexual partner. Scientists agree that such a product could save many millions of lives. Issues at question with regards to the wide use of microbicides are related but not limited to:

- staging clinical trials to determine how safe they are and how well they work;
- the large companies worry about liability in case a microbicide turns out to be harmful or unable to protect against HIV infection;
- the affordability of its price by the general public.

Many scientists believe that, as the AIDS epidemic is already out of control, microbicides should be considered as part of a wider safer sex strategy.

This chapter has tried to look into the salient features of HIV/AIDS as it affects the lives of women. There are a variety of cultural and economic determinants that are involved in gender relations with respect to the transmission of HIV. We have seen that there are connections between gender and socio-economic status that may put women at risk of acquiring HIV.

In order to overcome their economic problems, many women are engaged in selling sex for survival. Besides becoming infected with HIV, women who are involved in prostitution could transmit the virus to their customers. The existing norms concerning sexuality will put women in an inferior position such that it would be difficult to

challenge the infidelity of their husbands. Hence, they do not have the courage and the power to negotiate safe sex.

Physical and sexual violence against women has been found to pose an additional risk on the health status of women in many countries around the world. In this regard, rape is becoming a serious problem, which seems to be high among women found in situations of armed conflict. In addition to this, we have looked into the physiological vulnerability of women in contracting the HIV.

Given the value placed on having a child for a woman in childbearing age, HIV has become an obstacle to this desire. For women who know about their HIV status, it is difficult to risk bearing an infected child. We have seen some of the consequences of HIV on children as in the case of Helen. However, the option to have or not to have children depends on the wishes of the individual. The options suggested that for women to prevent infections are potentially good. However, the efficiency, availability and acceptability needs time to ensure its proper application.

In general, women need both a new commitment to addressing the underlying inequities that heighten their risk, and new technologies that provide them with a means of HIV protection within their personal control. Within this framework, empowering women and reducing gender inequalities are critical. Promoting personal attitude and behavior change must challenge the structural basis of gender inequality. Women must gain access to education, training and employment, they need to achieve decision-making power over sexual relations on equal terms and to control their risk of HIV/STDs. Cultural expectations that exonerate men from taking responsibility for health and welfare concerns must be transformed.

Chapter six

Counseling and Health Services for PWAs

This chapter is divided into two sections. The issues to be discussed in the first section will focus on the provision of counseling services for PWAs. In this regard, we will see the place of counseling in helping PWAs to live positively with AIDS. Moreover, the challenges and experiences of counselors in relation to some of the ethnographic cases of PWAs discussed in chapter four will be presented. The second section of this chapter is devoted to examining the situation of health and medical services that are being rendered to PWAs within health institutions. The aim of this discussion is to examine if the services available to PWAs are sufficient to meet their needs and to assess the attitude, worries and concerns of health personnel in providing care and support for persons infected with HIV.

6.1- Counseling and HIV/AIDS

As has been discussed in the foregoing sections regarding the stigma associated with HIV and AIDS on the part of society, communities and families, PWAs tend to keep their HIV status confidential. So long as they keep their status confidential, they will find themselves in a stressful situation. Clinicians who treat patients with HIV have long accepted the notion that stress affects immune functions. Until recently, the immune system was thought to be a completely autonomous body system, one responsive to invading body pathogens. The common belief was that the immune system regulates itself, that it is not influenced by other physiological systems, and that immunity is not influenced by psychological factors. Recent research findings revealed that profound

psychological stress could suppress immune function and thereby accelerate disease progression in HIV+ individuals (Leiphart, 1998).

The belief that one's safety, security or survival is threatened can trigger strong emotions of anxiety, fear and anger. If the stress situation is sustained for a long duration of time, it could pose difficulty to the normal functioning of the body. These may include, among other things diminished appetite and disrupted digestion, which in turn could cause malnutrition and weight losses; disturbance of sleep patterns leading to suppressed immune function.

Clinicians who treat PWAs have long accepted the crucial role which counseling could play in reducing stress. Counseling should not be taken to mean solving all the problems of PWAs by the counselors, but helping them to think of the situation in which they find themselves in order to devise ways of overcoming it. Counseling plays a significant role in:

- reinforcing PWAs coping mechanism to live positively with the infection,
- Improving the capacity of PWAs in decision-making to share knowledge of their sero- status to their spouses, family members or care providers, and,
- help in reducing deliberate transmission of HIV to others.

What can be done to alleviate this situation? With a view of examining the role of counseling in helping PWAs to live positively with AIDS and, as a way of assessing the level of impact it has brought about on the lives of PWAs through a period of time, I have tried to obtain the opinion of some counselors who are conducting an on-going counseling services for some of my informants covered in this study

In the face of the large number of PWAs residing in the city of Addis Ababa, the number of counselors in government health institutions as well as other counseling centers being operated by NGOs and religious institutions is minimal. According to the outcomes of a study that was carried out to assess the situation of counseling services in Addis Ababa, it was reported that the total number of counselors trained in Addis Ababa is about 100. Out of these, only 40 of them are providing counseling services in Addis Ababa. (MMM, 1998). Another important point that was revealed by this study was that PWAs do not tend to seek counseling services unless there is another form of material and financial support such as food stuffs or money to cover other household expenses like house rent, school fees for their children, etc.

6.2. – Lessons learnt in the provision counseling services:

The experience of the counselors at the MMM

As most of the respondents drawn into this study get an on-going counseling services at the Counseling and Social Services Center of the Medical Missionaries of Mary (MMM) the consultation of counselors has mainly focused on the experience of the counselors at the MMM Counseling Center. Therefore, in the following sections, I will try to discuss the nature of the counseling service that is being rendered by the Center and the opinions of the counselors regarding some of their clients who are covered in my studies. This could give the reader an insight about the role of counseling services in bringing about changes in behavior over time and in looking at the challenges encountered by the counselors in the process of conducting counseling.

The MMM Counseling and Social Services Center was established in 1992 by the Ethiopian Catholic Church in response to the call made by the Ministry of Health for

NGOs and religious institutions to participate in the national effort to fight the AIDS epidemic. They were particularly encouraged to provide an on-going counseling and social services for persons and families infected and affected by HIV/AIDS. The Center was the first of its kind to be established at that time. The center is open from Monday through Friday and the counselors are available to see clients. There is a referral system between the hospitals and the center whereby PWAs who need ongoing counseling and social support are sent to the center. A file is kept on every client along with a letter of reference from the hospital, which states the HIV status of the client. Since its establishment, a total of 1,623 people were referred to the Counseling Center.

I selected the cases of four of my informants whose ethnography is presented in the study, to discuss with the counselors. These are Desta and his wife Alemitu; Kidane and Tesfaye. Having explained that I have made an in-depth interview with the three of them. I made discussions with the counselors with regards to their past experience in giving counseling to PWAs in general and the selected cases in particular. Three of the counselors who have worked at the center since the time of its establishment took part in this discussion.

First, we discussed over the case of Desta and his wife Alemitu. Having recalled the time as to how Desta started to come to the center, the counselors said,

"Desta came to the center to obtain counseling and social support. He used to come with his two children (boys) on the date of his appointment. Following the regular counseling sessions, we give him supplies such as food stuff, some clothes and exercise books for his kids. We always make every effort to support him and his family. We often encourage him to share the knowledge about his sero-status with his wife. But he was telling us that he is afraid to tell her about his sero status. He tell us that he is using condoms to protect her from getting infected by the HIV virus. He was not willing to show us his house. This may be due to his fear that his wife may come to know about his situation".

According to the counselors, his wife left him not because she knew about his HIV status, but it is because she learnt that he was having an affair with another woman. They said, *"His wife knew the woman with whom he had an affair long before she decided not to live with him. It was her husband who introduced her to the woman"*. A question came to my mind as to how a person introduces a woman to his wife with whom he has an affair.

The counselors continued,

"...He introduced her to his wife by telling her a lie. He told her that she is his 'cousin'. He even convinced his wife to assist and support her during the time she gave birth. Eventually his wife learnt that he was lying. She was very upset and left him. As she was the one who was taking care of the children, she was not able to support her family on her own. She was aware that he used to come to this center to collect his monthly ration. She came and asked for the support that was allocated to Desta. We gave her an appointment to come again on the date he is supposed to come."

"As usual, Desta came to the Center to collect his regular supplies. As has been planned, his wife, Alemitu was already there before by the time he arrived at the Center. He was shocked when he saw her sitting on the bench along the veranda. We arranged a room where both of them could sit down and discuss about what has happened in the family. During the discussion, he admitted all his mistakes and apologized for what has happened. He agreed to the idea that the support should be given to her as she was taking care of the children".

The counselors also informed me that they have learnt that he is currently living with the woman (the woman with whom he had an affair). They said, *"We suspect that this one also does not know about his sero-status yet"*.

Regarding Kidane, the counselors agreed that he seems to have adjusted and has accepted his situation. He has a fair understanding about the disease. They had a feeling that the counseling has helped him to cope with the problem. However, after he started to attend the counseling program, he got married and had two children. In explaining the reason how he ended up having children, he told to the counselors that he was using condoms for a long period of time since the time he was married. They said,

"He was facing challenges from his wife, as she wanted to have children. She often asks him why they are using condoms as long as they are husband and wife. To date, she does not know that he has the HIV virus. We had a feeling that this has put him in a difficult situation as to whether or not he should disclose his sero-status or not. He finally decided not to tell her as it could cause trouble in their relationship. Then he stopped to use condoms".

The counselors are aware of the fact that, at this stage, the virus might have passed to his wife. They believe that, even if the children seem healthy at present, they might have already contracted the HIV virus through vertical transmission (mother-to-child). As compared to some of their clients, Kidane seems to be hard working and makes efforts to support his family. He does not claim his regular supplies as long as he gets sufficient income for his family.

- Regarding Tesfaye, the counselors said,

".....Tefsaye is one of our clients who showed a tremendous change in his life. He has gone through illness and rejection. He always makes all kinds of efforts to cope with his problems. Despite his physical disability, he has demonstrated that he can work and earn some income for himself. He still runs a small business. He could be exemplary person living positively with AIDS". He has been part of the spiritual counseling that was being held at the counseling center. We believe it has helped him to better cope with his psychological problems. It has enabled him to have hope for the future".

6.3 - The experience of PWAs in giving counseling

It is often felt among people and organizations delivering counseling services that PWAs may feel comfortable if they have an opportunity to share their feelings and experiences with other people facing similar problems. As a way of figuring out if this argument holds true, I tried to trace a PWA who has experience of giving counseling to fellow PWAs. Hence, I managed to contact two PWAs (one male and one female) and held discussions with regards to their experiences in the process of giving counseling for PWAs. Through the process of our discussions, besides telling me about some of their

encounters they shared with me their own life histories and the way in which they learnt about their sero status. I will present the experience of the female counselor as I found it more impressive.

Case ten: Emebet

Emebet is one of the members of Mekdim who has been given training in counseling by OSSA. Although she believes that the duration of the training program in which she took part was too short to fully get acquainted with the subject, it has enabled her to acquire some of the basic skills in giving counseling to PWAs. I started my discussion by raising a question as to how PWAs who need counseling services are identified. Emebet said,

" My experience in giving counseling is limited to some PWAs who are members of our association (Mekdim). There are different ways in which persons who need counseling are identified. First, individuals who are not showing changes in their behavior that may endanger their health as well as posing a risk of infecting others may be identified by members of the executive body of the association or any other members of the association. Secondly, individuals who seek counseling come to us for getting counseling. Also, some members are advised to see the counselor when they are showing signs of distress. Besides, the association has asked the hospitals in Addis Ababa to send PWAs who need counseling services".

My next question to Emebet was to know whether or not there are many counseling cases of women and if yes, what are the major problems manifested in the process of counseling? She answered,

" There are not too many cases related to bad habits or behavior that may harm their health status, such as smoking or chewing 'chat'. Some of them have gynecological problems and suffer from lack of personal hygiene. Most common problems are linked to problems that may have to do with lack of sufficient income to support themselves and their family and issues related to their current and future relationships with their spouses which may put them in a stressful condition. Let me tell you about two cases that were brought to my

attention during the processes of counseling. These are cases of an HIV+ prostitute who has been facing a problem with her clients and a case of a woman who is HIV+ and who is facing the difficulty of telling her husband about her sero status to her husband".

Regarding the case of the prostitute, Emebet told me that women who are involved in prostitution face a lot of problems in their interaction with clients. The most common problem is negotiating the use of condoms. While explaining the case of her client, she said;

"I have been informed by my client that even if there are some men who bring condoms with them, most of the men who visit her are not willing to use condoms during sexual relations. Convincing them to use condoms is a difficult task. Some of them would offer more money for letting them have sex without condoms. Even if she is aware that she has HIV, and given the dangers of transmitting the virus to the customer, she has to sleep with them because she needs the money for her survival. She sometimes falls sick and is not able to get income. As she became weak from time to time, I encouraged her to quit prostitution. She finally decided to stop it and with the support she got from an NGO, she rented a small place to live and earns some income from spinning".

The second case was a case of a woman who is HIV+. She is facing the difficulty of letting her husband know about her sero-status. According to Emebet, this lady knew about the outcome of her blood test some years back while seeking treatment in one of the hospitals in Addis Ababa. However, she was afraid of the consequences of revealing the results to her husband. I asked Emebet if this woman suspected her husband of infecting her first. She said,

"She is not sure of this. The reason for not fully suspecting him emanated from the fact that she was having an affair with someone in the past. Rather, her husband suspected this situation and has quarreled with her sometime ago. Hence, if she tells him about her sero status, she is afraid that it will lead to the breakdown of the family. She would be the one who would be blamed for the crises. However, she feels guilty for not letting him know about the situation. She still wants to reveal the situation to him. But she would like someone to do it for her (preferably his doctor). The husband is currently sick".

Emebet is one of the members of Mekdim who went public to teach about HIV/AIDS. She has shared her own feelings and experiences at different forums with over 30,000 people. Regarding the reactions of the people to whom she shared her experience, she said,

" It all depends upon the level of acceptance of the audience. Most of them feel sympathy deep into their heart about what happened in my life. However, you can find some people who still do not believe what we say. They even think that we are paid to say we have the virus in our body, only for the purpose of convincing others to accept that there is AIDS. I sometimes challenge them by asking them if they can do something like that for money".

When we examine the opinion of the counselors, it is apparent that they often come across a variety of cases, which sometimes are difficult for some of their clients to overcome. The cases of Desta and Alemitu as well as Kidane are examples of such difficult circumstances. Another important fact that was revealed during my discussion with the counselors was the disparity between the statements and information given to me by some of my key informants and what the counselors know about them. What Desta and his wife Alemitu told me about the reason why they were separated is different from what they told me. This shows that there still exists lack of openness on the part of PWAs about sharing everything with others, be it counselors, friends or relatives.

In general, counseling is believed to contribute in giving PWAs psycho-social support to solve their problems by their own. The counselors cannot resolve all their problems. Although they are aware of the danger posed to the spouse of PWAs, they cannot disclose the HIV status of the person without his/her consent. This puts counselors in a difficult position. For example, in the case of Desta and Alemitu, they made arrangements for them to come together to discuss the situation in which they

found themselves. This is believed to have caused a psychological stress on Desta. This case shows that such steps may have positive as well as negative implications on the lives of individuals.

Although it is felt that PWAs will feel comfortable if they obtain counseling from a counselor who is HIV+, the practice has not developed much. The cases that were discussed with Emebet were, however, impressive.

6.4 – Attitude, concern and worries of health personnel in relations with PWAs

The AIDS epidemic has already had major ramifications for health care workers, especially those employed in hospitals. Although the actual risk of infection through contact with infected patients is low, (Kuhls, *et al.*, 1987), health care workers experience fear and anxiety about becoming infected as no cure is available for the illness. Douglas, *et al.*, (1985) found that concerns about AIDS had activated underlying homophobia among doctors and nurses. Inpatient psychiatric staff studied by Amchin and Polan (1986) felt extremely vulnerable to death and disease in reaction to their first patient with AIDS and had to confront their anxieties and prejudices toward identified risk groups.

It is evident that the intrusion of AIDS into the health care workplace recasts the existing emotional scripts and places added pressures on those who deliver patient care and on the patients themselves. Thus increased worry and decreased comfort about AIDS on the job is likely to affect the ways in which health professionals care for patients and feel about their work.

In order to assess the feelings and attitudes of health care personnel who are in contact with PWAs, I have prepared a self administered questionnaire and distributed it among physicians and nurses working in two hospitals and counselors working in two counseling centers in Addis Ababa. One of the hospitals is the Black Lion Hospital, the largest referral hospital in the country and a teaching hospital of the Addis Ababa University and St. Peter Hospital, the only TB sanatorium in Addis Ababa. The two counseling centers are the MMM and St. Mary's Counseling Centers.

Worry and comfort are chosen as two different indicators of concern. Worry represents generalized anxiety and may be present even in the absence of a specific threat. Comfort is a feeling of ease or well being in relation to actual contact with persons who have the illness. I have tried to compare these three professional groups, i.e. physicians, nurses, counselors, according to their members' emotional reactions in dealing with AIDS patients.

There were 45 people involved in the assessment. The sample consists of 10 physicians, 15 nurses, 10 counselors and 10 PWAs. Table 9 shows the demographic distribution and educational levels of physicians, nurses and counselors who participated in the study.

Table 8. *Demographic distribution and educational levels of physicians, nurses, counselors and PWAs*

	Physicians	Nurses	Counselors	PWAs
Age				
20-29	2	4	3	3
30-39	8	7	5	4
40	-	4	2	3
Sex				
Male	7	11	4	6
Female	3	4	6	4
Educational level				
MD	10	-	-	-
BA	-	-	2	-
Diploma	-	15	7	-
High school	-	-	1	10

6.4.1 - Findings of the study

Attitudes: 80 percent of the professionals believed that AIDS patients should be treated in a special unit. Physicians had the highest percentage that believed this (70%) followed by nurses (65 %) and then and none of the counselors. With respect to willingness to work on an AIDS unit, all of the counselors agreed to work on an AIDS unit while few physicians and nurses (1 physician and three nurses) disagreed. Almost all of the respondents thought that they have an obligation to care for all patients assigned to them except three nurses and one physician.

Worry: For each question about health or worries about AIDS, more nurses were worried than physicians or counselors. Counselors are not engaged in any of the most invasive categories of contact (lab testing, starting an IV or drawing blood). Both physicians and nurses were clearly more uncomfortable with these procedures than the less invasive contacts discussed above. A substantial percentage of the nurses and physicians worried about getting infections or about their health. Half of the nurses and

less than half of the physicians were worried about treating patients with AIDS. While 60 percent of the nurses and 40 percent of the physicians were worried about spreading HIV infection to their families, 50 percent of the physicians and a large majority of the nurses (87%) expressed that their family is worried about them in working with PWAs. The findings with regards to attitudes and worries are summarized on table 9.

Table 9. Attitudes and worries of physicians, nurses and counselors towards treating PWAs

<i>Attitudes</i>	Physicians	Nurses % Favoring	Counselors
AIDS patients should be treated in a special unit.	70	65	-
Willing to work in on AIDS unit.	90	87	100
Have an obligation to care for all Patients	84	90	100
<i>Worries</i>	<i>% Worried</i>		
My health	80	70	20
Getting infections	70	87	10
Infecting my family	40	60	-
Treating PWAs	30	80	-
My family is worried about me working with PWAs	50	87	30

Comfort: All of the physicians and almost all of the nurses and the majority of the counselors had contact with patients with AIDS. These include: talking with patients; touching objects used by the patient such as clinic cards, food trays, linen, or waste material; touching the patient and providing care such as nursing care, assisting into a wheel chair, X-ray or other service; performing tests on blood or body secretions of AIDS patients, such as laboratory tests, starting an IV or drawing blood from a patient.

The majority of all the three professions were comfortable in talking with patients except for the fact that more nurses are usually uncomfortable in touching objects that belong to patients than physicians and counselors. Only a few physicians and nurses expressed the new that they are not comfortable in performing tests and drawing blood from PWAs.

For the group as a whole, worry about treating patients with AIDS was positively associated with worry about getting infections, about health and about spreading infections to family. Table 10 shows comfort level of physicians, nurses and counselors.

Table 10. *Percentage of comfort level of physicians, nurses and counselors*

<i>Contact</i>	<i>Physicians</i>	<i>Nurses</i>	<i>Counselors</i>
<i>Talking to Patients</i>			
Always comfortable	10	40	70
Usually comfortable	40	40	20
Usually uncomfortable	20	20	10
Always uncomfortable	30	-	-
<i>Touching patients and objects of patients</i>			
Always comfortable	-	20	50
Usually comfortable	60	20	50
Usually uncomfortable	20	40	-
Always uncomfortable	20	20	-
<i>Drawing blood or inserting IV</i>			
Always comfortable	-	20	-
Usually comfortable	60	40	-
Usually uncomfortable	20	30	10
Always uncomfortable	20	10	-

6.4.2 - Views of PWAs towards services in health Institutions

In this study efforts were made to obtain the views of PWAs with regards to the attitude, worry and level of comfort experienced by physicians, nurses and counselors, PWAs who had experienced admissions to hospitals and those group of PWAs who are getting medical support in health institutions. This was made in order to contrast the responses obtained from health personnel with that of PWAs if there is any similarity and/or differences between the health care providers and PWAs. Hence, PWAs were asked to complete a questionnaire designed for this purpose.

In order to measure the level of comfort that health personnel had towards PWAs, respondents were asked how health personnel feel in talking to them, touching objects which they are using, their feelings in performing tests and drawing their blood. The majority of the respondents (80 percent) said health personnel feel uncomfortable when they examining them and while performing tests and drawing their blood. Nine out of ten respondents agreed that health personnel worry about their health and getting infections from their patients. The majority of the respondents share the same feeling that health personnel, especially nurses and physicians worry about spreading AIDS to their family, worry a lot about treating AIDS patients and their family may be worried about them working with PWAs.

PWAs were asked about the in feelings and how the physician who was in charge of investigating their case or the nurse or counselor tried to convince them to make the HIV test and to let them know about the results of their sero-status. Almost all PWAs agreed that the health personnel gave them proper support and advice from the beginning till the disclosure of the test result. They have further explained that they have helped

them to let them accept the situation they are found in and to live positively with AIDS in the future.

Regarding the willingness of the health personnel to work with AIDS patients (in an AIDS unit), 70 percent of PWAs responded that health personnel are not willing to work with AIDS patients as opposed to the results obtained from health personnel regarding willingness to work in an AIDS unit. All PWAs expressed that they are strongly against the opinion that PWAs should be treated on a special unit as opposed to the majority of the physicians (70 percent) and the nurses (80 percent). Besides, all of them agreed that health professionals had an obligation to treat and care for all patients assigned to them.

6.4.3 - Barriers in the delivery of health and counseling services

In the process of gathering this data, respondents were asked to give comments and list barriers that may be affecting the process of delivering proper care and support for PWAs. In their responses, the physicians, nurses and counselors gave comments on some of the barriers that affect the process of service delivery. They have also indicated about the reactions of PWAs upon hearing about their HIV status for the first time, lack and shortage of in the hospitals, difficulties in disclosure and/or non-disclosure of one's HIV status to spouses and care providers, the problems that are faced by PWAs in getting sufficient care and treatment by health personnel and within health institutions. The responses are summarized on table 11.

Table 11. Barriers listed by physicians, nurses, counselors and PWAs in the provision of care and support for PWAs within health institutions

Physicians and Nurses	Counselors	PWAs
<p><i>Interaction with patients</i></p> <ul style="list-style-type: none"> - Lack of readiness to hear about AIDS - Showing a sense of shock and frustration - Violent reaction by some PWAs - Not feeling comfortable to tell unpleasant news to others - Some PWAs think they would die shortly/immediately - The existing stigma poses influence not to cope better - Despite the risk involved in treating PWAs, we have an obligation to treat them <p><i>Precaution</i></p> <ul style="list-style-type: none"> - Lack and shortage of protective materials such as gloves, syringes and needles, etc. - Lack of testing facilities - Lack and scarcity of proper sterilizing materials - Shortage/lack of drugs/facilities for treating AIDS patients - Absence of well organized counseling services for paw's within health institutions - Prophylaxis for opportunities infectious 	<ul style="list-style-type: none"> - Addressing the social problems of PWAs is a difficult task - It is difficult to break the news of their HIV status, it is like telling a death sentence - The stigma towards PWAs results in non-disclosure of one's HIV status to families, partner and other care givers-constraint for bringing about behavior change - Non disclosure of one's HIV status has a risk for care providers to contract the virus due to lack of taking the necessary precaution 	<ul style="list-style-type: none"> - Lack of proper attention, treatment for PWAs within health institutions - Health personnel are reluctant to give proper care for PWAs despite their knowledge about the modes of transmission of the virus - Lack of medicine - Once health personnel are aware of the fact that a patient has HIV, they tend not to give care and support - Most physicians do not show a sense of compassion towards PWAs

- No guarantee for health personnel if they acquire infection on duty (universal precaution for protecting oneself from infection is not practiced)
- No screening during admission—health personnel have fear
- No information/update is given to health personnel about HIV
- The manifestation of opportunistic infections such as Herpes zooster, TB, etc. makes health personnel uncomfortable as they are easily transmissible
- The provision of care and counseling for PWAs is perceived by some health personnel as an extra work resulting in less attention to PWAs

The foregoing discussions reflect health care workers' struggles to cope with the stress of dealing both with the actual threat of illness and perceived vulnerability. Cognitive explanations are insufficient for understanding the complex emotional reactions to AIDS which are based on not only perceived health threats, but also on underlying feelings about professional responsibility, fear of the unknown, death and dying, and moral judgments related to the transmission of HIV infection. Therefore, socio-emotional factors must be seriously considered along with beliefs in order to explain professional behavior in relation to AIDS both on the applied and theoretical levels.

According to the outcomes of other studies that were carried out in the U.S.A. to assess nursing staff attitudes about AIDS, it was argued that higher educational level was associated with more accurate information and more positive attitudes towards dealing with HIV infection (Morgan: 1989). Valenti and Anarella (1986) also found that knowledge about AIDS is positively associated with level of medical education. Other researchers likewise found that AIDS education reduced stress and perceived risk, increased comfort around patients and reduced the inclination to avoid caring for persons with AIDS.

However, according to the findings of this study, despite the level of education and their professional obligation to provide care and support for any patient, the attitude, level of comfort and worry has been influenced by underlying feelings about PWAs, knowledge about HIV/AIDS and due to lack of sufficient protective materials for health care workers in hospitals. As could be seen from the responses of the nurses and to a limited extent, the physicians, there seems to be a need to undertake educational

programs about AIDS, which in turn could contribute for improvements in the level of fear and worry in working with PWAs.

The views of PWAs, on the other hand, shows the level of dissatisfaction about the services being provided to PWAs in health institutions. The level of concern and support that should be given to PWAs as reported by the health personnel does not correspond to the views of PWAs. This shows that there exists a difference between what the health personnel say should be done and what exists on the ground.

Summary and Conclusions

AIDS, like many other epidemics in the past, has become the cause for the death of millions of people around the world. What is special about AIDS as compared to epidemics in the past? In the beginnings of the epidemic, AIDS was understood by most people (including the scientific community) to be a disease of marginalized groups of the society, i.e. gay, IDU, prostitutes, truck drivers and the like, who are categorized as high-risk groups. However, it was soon found to have spread among the rest of the population.

This thesis has tried to examine the similarities and differences of past epidemics with that of AIDS and its impact on the economic, political, social, demographic and cultural lives of societies. Having discussed about the scientific explanation on the modes of transmission and prevention of HIV, the thesis has tried to review the debates that were going on with regards to the origins of AIDS. In this regard, it has been shown that Western scientists have erroneously labeled the African continent to be the place of origin of AIDS. As could be seen from the global epidemiology of the pandemic, there is no country in the world today that is not affected by AIDS. The discussion has also tried to investigate at some of the factors that are responsible for the fast spread of AIDS. Migration in search of employment, armed conflict, rejection, discrimination of PWAs and the silence that has reigned in some countries like Ethiopia were identified to be some of the factors to have fueled the spread of the epidemic. It was also emphasized that AIDS will have a long lasting impact on the social and economic development of nations.

The chapter that looked into the situation of AIDS in Ethiopia has shown the fact that even though the epidemic started late as compared to other countries in sub-Saharan

Africa, the surveillance that was carried out by the MoH revealed that it has spread to most of the urban centers of the country and even to the rural areas in a relatively short period of time. According to the outcomes of these studies, the most important risk factors involved in the spread of HIV infection in Ethiopia were unprotected sexual contact with different partners and the presence of STDs in either of the partners practicing sex.

Although it is difficult to diagnose AIDS in children, it was estimated by the MoH that there were about 150,000 children under the age of five who were infected by HIV in 1996 (MoH, 1998). According to the reports of the Health Bureau of Addis Ababa, more and more young people are becoming infected with HIV. The high percentage of the prevalence of HIV among pregnant women in Addis Ababa shows that there is a high prevalence of HIV among the general population.

In order to prevent and control the danger posed by AIDS, there were efforts made by the government through establishing an AIDS task force under the MoH. The task force was given the responsibility of transmitting messages to the general population and high-risk groups, undertaking surveillance and strengthening laboratory and diagnostic facilities. However, Ethiopia was late in developing an HIV AIDS policy. The policy was issued in 1998. Alongside the efforts made by the MoH, NGOs have made some contributions in the sphere of disseminating information about AIDS and in providing counseling and other social services for PWAs and families affected by the epidemic. Although it was not possible to make an assessment of other forms of the media, i.e. the radio and television, the newspaper content analysis has tried to assess the nature and type of information that was covered by one of the newspapers that is widely

distributed throughout the country. The analysis has shown that a wide range of issues pertaining to basic facts about the HIV/AIDS, the epidemiology of AIDS both at the global and national levels and myths and misconceptions about AIDS and its treatment.

Quite a large section of this thesis is dedicated to investigating the social dimension of the AIDS epidemic. Although medicine defines disease in terms pathological processes, there are social meanings of diseases as perceived by different groups of societies. Hence, the introductory section of this chapter starts its discussion by looking at the social meanings of diseases. This was followed by the ethnography of the PWAs to show the reader about some of the challenges and problems encountered by PWAs in their day-to-day lives.

The ethnographic cases presented in this chapter are selected in such a way that they would show different faces of AIDS. We have seen the problem of stigma in the case of Tesfaye where he was abandoned onto the streets by his care providers due to the stigma attached to AIDS. The knowledge of the HIV status of one's spouse could result in instability in the family and lead to the breakdown of the family. As could be seen from the cases of Ababiya and Desta, there is often fear among spouses and family members that they may contract HIV and be exposed to discrimination and stigma by the members of the extended family, neighborhood and the community at large.

Given the limited level of knowledge among the general public about the modes of transmission of HIV and the stigma towards PWAs alongside with the myths and misconceptions about AIDS, differential responses were observed in the ethnography of the cases presented in this study. Unlike the cases of Desta and Aba-Biya, it was observed that others accepted and understood the situation in which their partner is

found. This has been seen in the case of Ali, whose wife showed commitment to care for him until the time of his death. Where PWAs are getting more positive responses from care providers, families and the society at large, they will be encouraged to live positively with AIDS and go public to teach to protect themselves from HIV infections. There are now signs of support, at least on the part of the government, to encourage PWAs to go public and the society to provide care and support for persons infected with the virus and families affected by AIDS. The section on the development of social networks discussed how PWAs slowly started to create a group which gradually developed into an association that tries to share feelings and experiences as well as supporting each other at times of illness and served as a forum to encourage PWAs to go public. Besides, it is making a great deal of contributions in educating the public through demonstrating the challenges and feelings that are being faced by PWAs.

Fear of rejection has forced most PWAs to keep their HIV status secret, which in turn could pose an additional risk to their partner. Many studies indicate that, generally, people have fears about the AIDS disease. The personal fears are rooted in the fact that the disease is new, has no cure and is fatal. The experience of The AIDS Support Organization (TASO) in Uganda showed that fears of PWAs are centered on stigma and rejection, dying and leaving one's children, going through a long painful period of multiple illnesses, being disfigured, psychologically incapacitated and being impoverished. Since people with AIDS die prematurely, ambitions in life are shattered causing frustration and disappointment (Hampton, J:1990).

Although AIDS is affecting all segments of society, it is heightening gender inequities. Women, especially in the developing world are bearing the burden of the

burden of the epidemic. The chapter on the gender perspective of AIDS tried to identify some of the major factors that makes women more vulnerable to be infected by HIV. The factors discussed in this chapter include, but not limited to, their low socio-economic status, physiological vulnerability and norms concerning sexuality. Besides, it has been indicated that violence against women and lack of knowledge and information about HIV/AIDS are aggravating the transmission of HIV among women. If infected, women may pass the virus to their babies. As the main caregivers for the sick in their households, if they fall sick, the whole family structure will be threatened. Educating women to protect themselves against infection would mean making a great contribution to the welfare of families and the socio economic development of nations as they are the pillars of the family and central to the informal economy of many developing countries.

In the last chapter, an attempt has been made to assess how PWAs are coping with their problems and to examine the contributions of counseling in helping PWAs to live positively with AIDS. Counseling is believed to make contributions in reinforcing coping mechanisms of PWAs to live positively with AIDS, improving the capacity of PWAs in decision making to share knowledge of their sero status with their spouses, family members and/or care providers and help in reducing deliberate transmission of HIV to others. The outcomes of the discussions made with the counselors has revealed that despite the contribution of counseling in helping giving psycho-social support to PWAs, the level at which they put the knowledge of the counseling cannot be influenced by the counselors. The issue of confidentiality forces them to keep their knowledge of the HIV status of the person they counsel secret even if they are aware of the dangers posed to their spouses and care providers.

In the last section of Chapter Six, we looked at the attitudes, worries and concerns of health care workers in providing care and support for PWAs. According to the outcomes of the assessment made among physicians and nurses, their attitude, level of comfort and worry has been influenced by underlying feelings about PWAs, limited knowledge about HIV/AIDS and due to lack of sufficient protective materials in the health institutions. Although health personnel believed that they have an obligation to care for every patient, views of PWAs showed their dissatisfaction about the services that are being provided to them.

Of all the factors that contribute for the transmission of the HIV among the people in countries like Ethiopia is the strong stigma attached to AIDS and PWAs. This hinders people from protecting themselves and others from infection, or from seeking out care and support. The Ethiopian context is still where silence has reigned and even when people with HIV are ill and dying, patients and their care providers choose to view the illness as something that is related to other diseases such as tuberculosis or pneumonia.

The main problem that many PWAs are confronted with is the fear about the attitudes of other people towards PWAs. Major issues include fear of rejection, marginalization, discrimination, rejection, isolation and ostracism. The major task of agencies working in the sphere of HIV/AIDS prevention and care, community organizations, leaders of religious institutions and PWAs as well is to breakdown the labeling of PWAs as people different from each one of us and create a more sympathetic view towards PWAs.

Many studies that were carried out to date show that there are many, and not one, approaches to the AIDS phenomenon: AIDS as scientific, biological, and medical problem; AIDS as a problem in morality, deviance, individual pathology or personal aberration; AIDS as a behavioral and social phenomenon.

It had been observed in the ethnography of the cases presented here that there were differential responses towards knowing about the HIV status of one's spouse, family member or friends. There is no ready made answer for such type of response. This itself demonstrates that the issue of AIDS is a complex subject. Hence, it would be difficult to reach a general conclusion about the categories of people that are being affected by AIDS, and the differential responses by care providers, spouses and the community at large. I hope my thesis can contribute to developing a more sympathetic understanding of the challenges faced by PWAs and may motivate others to further investigate the subject and develop strategies to tackle the problems of PWAs.

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Appendices

ጠንቅቆች ለዘመን

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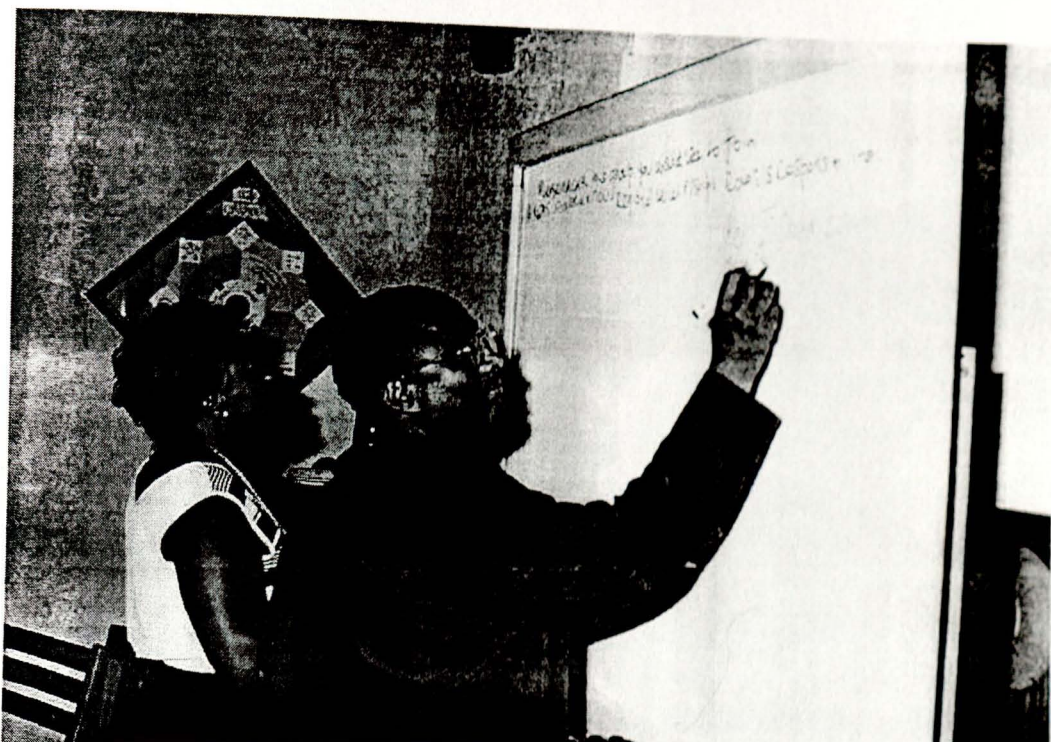
የደንበኞች ስም የገንዘብ መጠን የገንዘብ አይነት የገንዘብ ቀን የገንዘብ ቦታ የገንዘብ ስም

A notice posted at different places regarding the discovery of cultural medicine for AIDS.

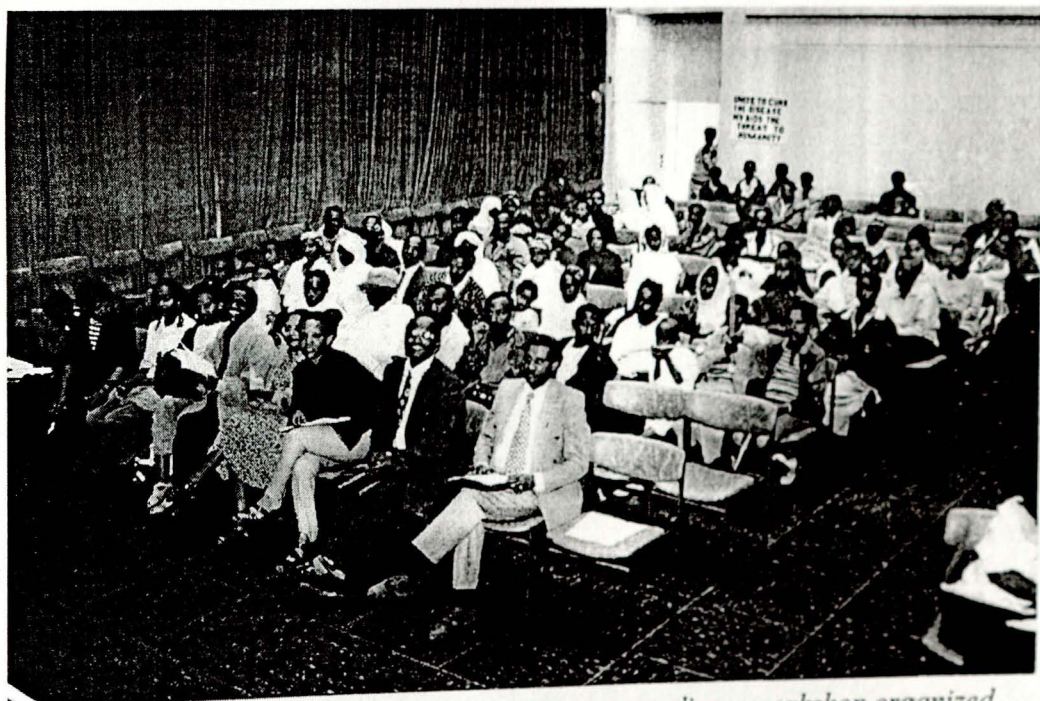
Good News for AIDS Patients and Carriers

Cultural medicine has just been found for the disease. It shall be drunk just like tea and has no side effects. You will be delighted by the outcome.

Address: Gofa area Woreda 20, Kebele 4,
House No. 293 near Gofa Restaurant.
Tel. 11-77-30 Kolonel Eshete Negatu



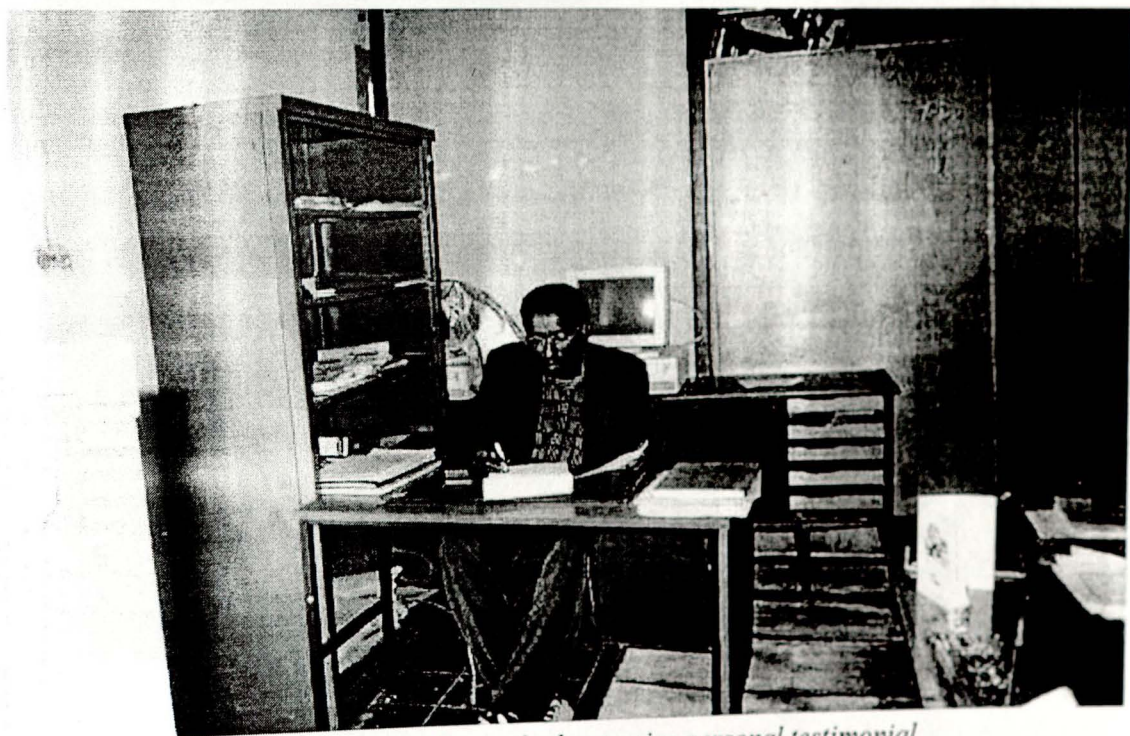
Mengistu, giving briefings in a regional workshop, Senegal, Dakar, 1999



Representatives of the MoH and invited guests attending a workshop organized by "Mekdim"



Mengistu giving his personal testimonial in one of the experience sharing forums



Talegeta working on his work plan to give personal testimonial



Talegeta addressing a gathering of students in Nazareth



Students attending personal testimonial of Talegeta



Mengistu participating regional HIV/AIDS network meeting, Nairobi, Kenya



Members and supporters of Mekdim celebrating its 3rd anniversary in a candle light

DECLARATION

I, the undersigned, declare that this thesis is my work and that all sources of materials used for the thesis have been duly acknowledged.

Name

AWANNIA ADMASSU

Signature



Place

Addis Ababa

Date of Submission

This thesis has been submitted for examination with my approval as a University advisor.

Name

ALVA PANKHURST

Signature



Date

19-06-2000