

**THE PSYCHOSOCIAL CHALLENGES OF  
PEOPLE LIVING WITH HIV/AIDS: A CASE OF  
AWASSA AND DILLA TOWNS**

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**A Thesis presented to the school of Graduate studies**

**In partial fulfillment of the requirements for the Degree of Master  
of Arts in Counseling Psychology**

**Addis Ababa University  
School of Graduate Studies**

**April, 2007  
Addis Ababa**



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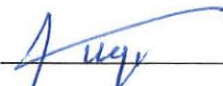
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## **ACKNOWLEDGMENT**

I would like to express my appreciation and heart felt gratitude to Dr. Sintayehu Tadesse, my thesis advisor, for his emphatic understanding and invaluable professional advice by giving me intellectual guidance, unreserved suggestions and constructive comments without his great dedication and assistance, the completion of this study would have been impossible.

I would like to express my deepest gratitude to my colleagues Kebede Ararssa and Getu Girma , whose all rounded support has contributed to successful accomplishment of the study.

My sincere thanks goes to the entire sample PLWHA, representatives and social workers who helped me by facilitating and providing me an appropriate data with out their sensational support this finding would have been totally impossible.

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## **ACRONYMS**

AIDS - Acquired Immunodeficiency Syndrome

ANC - Antenatal Care

FSW - Female Sex Workers

HAPCO - HIV/AIDS Prevention & Control Office

HIV - Human Immunodeficiency Virus

NGO - Non-Governmental Organization

NSS - National Sentinel Surveillance

PLWHA - People Living with HIV/AIDS

SNNPR - Southern Nations and Nationalities Peoples Region

VCT - Voluntary Counselling and Testing

CT - Counselling and Testing

## ABSTRACT

*This study examined the psychosocial challenges particularly that of depression, anxiety, stress, fear, stigma and discrimination of people living with HIV/AIDS, N=200 (100male, 100female), and the coping strategies they employed. Data were collected by means of structured interview schedule. Case study and focus group discussion were used to gather in-depth individual data. Depression, anxiety and stress were assessed by using Center for Epidemiologic Studies Depression Scale (CES-D), Beck Anxiety Inventory (BAI) and Perceived Stress Scale-10 (PSS-10) respectively and others by a set of items developed by the researcher. Results revealed that 56 % of the participants experienced clinically significant symptoms of depression with mean score of 2.60 and 40 % of the respondents showed clinically significant anxiety symptoms with mean score of 32.31. The mean score of perceived stress was 24.52 (S.D=5.64) where 50.50 % of the respondents scored above the mean. The mean score of stigma and discrimination using Likert type scale was 32.94 (S.D=11.34) where 58.4 % of the respondents scored above the mean. The participants of the case study also showed episodes of depression, anxiety, stress, fear, stigma and discrimination.*

*Statistically significant differences were found between males' and females' scores of depression and stigma and discrimination at 0.05 level with 95% confidence interval and 191 and 194 degrees of freedom respectively. Females participants were found to experience more depression and stigma and discrimination than male participants. No statistically significant differences were found between males' and females' scores of anxiety and stress.*

*The most often utilized coping strategies identified by the participants were: listening to music, Praying to God, try on their own to deal with the problem, day dreaming and talk to a friend. The participants also reported low utilization of certain maladaptive coping strategies such as alcohol and chewing 'chat'.*

# CHAPTER ONE

## 1 Introduction

### 1.1 Background

HIV/AIDS has been a scientific, psychosocial and health development challenge for the last two decades. Presently, it has become the leading cause of death and psychosocial complexities in Sub-Saharan region. According to UNAIDS report at the end of 2003 an estimated forty million people were living with HIV/AIDS globally, of these 70% were from Sub-Saharan Africa (UNAIDS, 2003).

Available evidences uncover that the people living with HIV/AIDS (PLWHA) and their associates face severe psychosocial challenges which further intensifies the problem. In addition to the other burdens of disease, PLWHA are subject to stigmatization and fear. They often are avoided and rejected by others, which lead them to loneliness, withdrawal and helplessness (Chikwampu et al, 2001). Some individuals remain silent about their serostatus to avoid the risk of being recognized by the community as being PLWHA. This in turn, further complicates the Problem. Thus, the available literature suggests that PLWHA highly demand social acceptance and empathy to help them deal with the traumatic nature of their situation and to curb the dread consequence of the spread of HIV/AIDS.

Appalling as the current HIV/AIDS related data are, they are unlikely to present the full scale of devastation and misery that will result from HIV/AIDS epidemic in Ethiopia. What has already been known is that Ethiopia is one of the countries hosting the largest number of PLWHA globally. 9% of the PLWHA are estimated to be found in the country. Thus, Ethiopia has the largest number of PLWHA next to South Africa and India (World Bank 2001). Yet, to the Knowledge of the researcher,

there is no empirical evidence if the prevalence of the infection rate is declining and little is known about psychosocial challenges in which these people are facing.

These alarming figures of the PLWHA with little knowledge about their psychosocial complexities, in poor countries like Ethiopia (UNAIDS Report,2003), prompt to the inevitable need for a better understanding of their situations so as to assist them in coping with the disease and to stop its spread.

To the knowledge the researcher, there has been no study to date on the psychosocial challenges facing PLWHA in Ethiopia. Even though there have been numerous studies from the West, the distinct features of the psychosocial aspects in Ethiopia makes it difficult to draw conclusions in our context based on these studies. Besides, to the knowledge of the researcher, there is only little information available about the psychosocial problems of the PLWHA in Southern National Nationalities People Regions, particularly in its main towns, Awassa and Dilla (MOH,2003). Hence, this research attempts to study the psychosocial situations of the PLWHA in Awassa and Dilla towns where the majority of PLWHA are believed to dwell in these towns are economic, commercial and administrative centers of the Region (Ibid).

## ***1.2 Statement of the Problem***

Research indicates that HIV/AIDS is bringing a large social, psychological and economic impact on individuals in particular and to the society in general. The psychosocial impact of being HIV positive on the individual include indistinctiveness, isolation, depression, instability, hatred, anger, fear and shame. This impact also entails the cost paid such as divorce, job termination, and school dropout and several others due to the consequences of HIV infection (Johnson, 2000).

Thus, the presence of these psychosocial challenges in addition to their own illnesses may adversely affect the PLWHA by decreasing their ability to obtain and adhere to proper medication and positive living. Hence, the need for paying due attention to the psychosocial aspect of the PLWHA.

Although significant number of research have not seem to be done in Ethiopia, experience seem to indicate that the contributions of the medical professionals and the significant others seem to be of paramount important to bring about a progress in the life of the PLWHA (World Bank 2002). Yet this leaves too much to be desired with out properly addressing the psychosocial aspects of the PLWHA.

HIV policy of Ethiopia also underscores the indispensable importance of psychosocial intervention to curb the challenge of the PLWHA. However, adequate research does not seem to be conducted on the psychosocial consequences of HIV infection in the Ethiopian scenario. This indeed implies that more than ever before there is a need to make concerned effort on the socio-emotional problems of the PLWHA by conducting specialized studies on their psychosocial challenges.

Therefore, having considered the reality and assumptions, this study would focus on investigating the psychosocial challenges of the PLWHA. More specifically, the study tried to address the following research questions:

- Do the PLWHA experience anxiety as a result of their HIV positive serostatus?
- Do the PLWHA experience depression as a result of their HIV positive serostatus?
- Do the PLWHA experience stress as a result of their HIV positive serostatus?
- Do the PLWHA experience fear as a result of their HIV positive serostatus?

- Do the PLWHA face stigma and discrimination?
- Do PLWHA face all or any of the divorce; job termination, and school drop out as a result of HIV infection?
- What are the coping strategies adopted by the PLWHA to deal with the situation?
- Is there any sex difference in experiencing any of the aforementioned challenges?
- What intervention strategies should the concerned bodies use to reduce the psychosocial challenge?

### **1.3 Objectives of the Study**

#### **1.3.1 General Objective**

The general objective of this study, therefore, was to identify and describe the main psychosocial problems of the people living with HIV/AIDS face in Awassa and Dilla towns of the Southern National Nationalities People Region (SNNPR).

#### **1.3.2 Specific Objectives**

This research had the following specific objectives:

- To find out if the PLWHA experience anxiety as a result of their HIV positive serostatus.
- To identify if the PLWHA depression as a result of their HIV positive serostatus.
- To detect if PLWHA experience fear as a result of their HIV positive serostatus.
- To identify if the PLWHA face stigma and discrimination.
- To find out if the PLWHA face all or any of the divorce; job termination, and school droop out as a result of their HIV positive serostatus.

- To assess the strategies and coping mechanisms PLWHA employ to reduce their psychosocial consequences of their HIV positive serostatus.
- To forward possible prevention mechanisms and intervention strategies to help the PLWHA cope up with the psychosocial consequences of their HIV serostatus.

#### ***1.4 Significance of the Study***

This study would have the following significances:

- It motivates the concerned bodies to give due attention to the problems and play an active role in reducing such challenges.
- It gives insight to governmental and non-government organizations on the importance of policy implications and designing possible intervention program for the PLWHA.
- As to the knowledge of the researcher, there has not been any research undertaken on the deep psychosocial challenges of PLWHA in Ethiopian context and particularly in the Southern Region. Thus, this study might bridge the gap and could possibly serve as a stepping stone for further research.
- Suggest viable intervention strategies to curb the problems.

#### ***1.5 Delimitation of the Study***

The study is delimited to members of two PLWHA associations: Down of Hope Association of People Living with HIV/AIDS in Awassa and Dilla, and Tilla Association of People Living with HIV/AIDS in Awassa.

## **1.6 Operational Definitions**

**Psychosocial Challenges** – One's psychological( such as depression, anxiety, stress, fear, ) patterns of unacceptable behaviors and social( such as social isolation, stigma, discrimination, rejection, and the cost paid such as job termination, divorce etc, ) experienced by PLWHA as a result of their serostatus.

**PLWHA-** People who reported to have been screened for HIV seropositive result, who have not been consistently bedridden, their physical strength may vary but are healthy enough to do some work and carry on a somewhat daily life in between their bouts of illnesses.

**Asymptomatic** - A symptom-free period in the life of people who are infected with HIV virus.

**Symptomatic** – The stage in the person who lives with HIV virus in which infection associated with the presence of the virus in blood could be manifested.

**Seronegative** A clinical HIV blood test result which indicates the absence of HIV virus in the blood of the individual.

**Seropositive** A clinical HIV blood test result which indicates the presence of HIV virus in the blood of the individual.

**Coping Strategies** Behavioral tool which may be used by an individual to offset or overcome psychosocial challenges.

## CHAPTER TWO

### Review of the Related Literature

#### 2 Psychosocial Challenges of People Living with HIV/AIDS

All persons with HIV are at risk not only of developing AIDS but also of experiencing social and psychosocial hazards associated with AIDS. This situation is what Brandt (1987) has called "the double jeopardy of lethal disease and social oppression." According to him, PLWHA experience a wide range of psychosocial problems. These include: anxiety, anger, depression, poor self-esteem, isolation, loneliness, guilt, shame, depression, suicidal thoughts and attempts, stigma and social rejection.

According to Muller (1997), people affected by HIV infection face greater emotional strain than most people ever do. Furthermore, many face it at an unconscionably young age. Those affected by the disease are shocked or angry or depressed or afraid or guilty or confused or have any number of these emotions at once. They worry about revealing the diagnosis, about being dependent, about expressing sexuality, about relations with the people they love. They worry about dying. The rest of the society not directly affected by the disease reacts with fear and prejudice, making those affected by the disease also feels like outcasts, isolated and lonely.

Psychosocial challenges associated with living with HIV infection identified through a research by World Health Organization are isolation, blame and punishment issues, lack of family support, poor long-term survival, fear of disclosure and/or discrimination, uncertainty about course of illness Distancing of friends and/or lover, poor financial resources, concerns about sexual activity, substance abuse, and concerns about transmission of HIV and fear of contagion (World Health Organization, 1987)

Common psychosocial issues faced by PLWHA, according to Barry (1996) include: living with stigmatization and others' fear of contagion, adjusting multiple losses and uncertainty in maintaining quality of life with increasing debilitation, coping with body image changes, confronting end-of-life decision, in terminal stages of the illness; maximizing functioning in spite of cognitive impairment.

To Fleishman & Vogel (1994), the psychosocial challenges associated with HIV Infection are: anxiety and depression, social stress, isolation, blame and punishment issues, lack of family support, poor long-term survival, fear of disclosure and/or discrimination, uncertainty about course of illness, distancing of friends and/or lover, poor financial resources, concerns about sexual activity, substance abuse, and Concerns and fear about contagion of HIV virus to significant others.

A study by Evans et al. (1998) also postulated that fears of the unknown, coupled with worry about pain and suffering during the progression of the disease, and feelings of isolation and rejection may cause higher levels of stress on the PLWHA.

The onset of HIV-related symptoms such as fatigue, weight loss, and diarrhea, on the other hand, can trigger feelings of discouragement and despair. The awareness of symptoms often generates feelings of decreased self-control. Demoralization can occur as self-esteem declines. During this self-devaluing process, PLWHA may develop homophobic feelings of guilt (Navia et al., 1986). Anger and blame focused at lovers for provoking sexual behavior is typical of such homophobic reaction.

In an American study by Sarna & van Servellen et al. (1999), it was found out that eight psychosocial aspects challenge the PLWHA. These psychosocial challenges include: withdrawal of family support, loss of occupation, long-term dependency, loss of friends, lovers (often from

AIDS), overwhelming, perpetual grief, disfigurement, delirium and dementia, past emotional or psychiatric problems (depression, anxiety, stress disorders).

A research conducted by Gelder, Mayou and Geddes (1999) found out that PLWHA were at risk for complicated and prolonged bereavement. They have often experienced the loss of numerous friends from the same disease. Grief reaction, thus, is triggered by the physical impairment of symptomatic HIV/AIDS which creates severe challenge on the lives of PLWHA.

The aforementioned literature, therefore, clearly depicts the depth of psychosocial challenges PLWHA face. In this study, however, depression, anxiety, stress, fear, stigma and discrimination, coping strategies and the role of social support were tried to be focused through the following subsections.

## **2.1 Depression**

Depression, according to (Gelder, Mayou and geddes,1999) is a mental illness in which a person experiences deep, unshakable sadness and diminished interest in nearly all activities. It is a serious psychological condition that affects thoughts, feelings, and the ability to function in everyday life. People also use the term depression to describe the temporary sadness, loneliness, or blues that everyone feels from time to time. Unlike normal sadness, severe depression, also called major depression, can dramatically impair a person's ability to function in social situations and at work. People with major depression often have feelings of despair, hopelessness, and worthlessness, as well as thoughts of committing suicide.

### 2.1.1 Symptoms of Depression

According to (Gelder, Mayou and Geddes,1999), person who develops severe depression may appear so confused, frightened, and unbalanced that observers speak of a “nervous breakdown.” However it begins, depression causes serious changes in a person’s feelings and outlook. A person with major depression feels sad nearly every day and may cry often. People, work, and activities that used to bring them pleasure no longer do. (Gelder, Mayou and Geddes, 1999). Exhaustively discussing the entire symptoms of depression is beyond the scope of this paper. However, the main symptoms which could inevitably be essential for this piece of work have tried to be summarized as follows.

Depression usually alters a person’s appetite, sometimes increasing it, but usually reducing it. Sleep habits often change as well. People with depression may oversleep or, most of the time, sleep for fewer hours. (Gelder, Mayou and Geddes,1999).

Depression also changes one’s energy level. Some depressed people may be restless and agitated, engaging in fidgety movements and pacing. Others may feel sluggish and inactive, experiencing great fatigue, lack of energy, and a feeling of being worn out or carrying a heavy burden. Depressed people may also have difficulty thinking, poor concentration, and problems with memory ( Champion and Power,2000).

People with depression often experience feelings of worthlessness, helplessness, guilt, and self-blame. They may interpret a minor failing on their part as a sign of incompetence or interpret minor criticism as condemnation. Some depressed people complain of being spiritually or morally dead. The mirror seems to reflect someone ugly and repulsive. Even a competent and decent person may feel deficient, cruel, stupid,

phony, or guilty of having deceived others. People with major depression may experience such extreme emotional pain that they consider or attempt suicide. Many psychologists and mental health professionals agree that one of the very means in which depression revealed is suicidal ideation. The case of suicidal ideation in PLWHA has been discussed in a separate subsection (Gelder, Mayou and Geddes,1999 ).

### **2.1.2 Depression and HIV**

Several community-based studies of the natural history of HIV illness and associated psychological adjustment were initiated in the mid- to late-1980s. Investigators conducted formal clinical diagnostic evaluations of depression. Most of these "cohort" studies consisted predominantly or exclusively of gay men and most were asymptomatic or mildly symptomatic at study entry. Since then, at least one longitudinal study of intravenous drug users has been conducted (Strong et al., 2001) and there is an ongoing longitudinal study at Cornell following a group of men with symptomatic HIV illness or AIDS. All of these studies included HIV-negative comparison groups from the same communities as the HIV-positive groups. In the studies of gay men and non-intravenous-drug using women, the findings cumulatively show that rates of current (past month) major depression are in the range of 5 - 10% in both the HIV-positive and HIV-negative groups.

Cross-sectional studies of patients at different stages of illness have yielded mixed findings regarding rates of depression in patients with symptomatic HIV/AIDS, compared to those who are asymptomatic. In the few longitudinal studies following the same people as they get sicker, no increases in rates of depressive disorders over time have been observed (Barry, 1996; Burack, 1993; Ironson,1995).

Recent literature, however, found out the fact that depression is the most serious problem for many PLWHA. A study by (Margoese, 2003) shows

that almost 60 percent of PLWHA display clinical signs of depression and up to 75 percent display at least some depressive symptoms. HIV+ women are 20 percent more likely to be depressed than HIV+ men.

Key findings of a national physician and patient survey conducted by the International Association of Physicians in AIDS Care (IAPAC) also demonstrate a strong link between HIV infection and the mental health of patients diagnosed with HIV seropositive. According to physician respondents, more than 80% of their HIV-positive patients suffer from symptoms of depression or anxiety. Although psychiatric symptoms in patients with HIV infection have a variety of causes, including the direct CNS [central nervous system] effects of HIV, CNS opportunistic infections, and street drugs, the majority of surveyed physicians also believe that HIV medications (antiretroviral drugs) are a leading cause of their patients' most common mental health symptoms (83.6%). The results of the survey, which queried more than 130 HIV-treating physicians and 235 HIV-positive men and women, were presented today in Chicago, in conjunction with the 40th Annual Meeting of the Infectious Disease Society of America (IDSA). Horwath | ([www.thebody.com](http://www.thebody.com)) who analyzed the survey results, has authored a supplement to IAPAC's quarterly scientific peer-reviewed journal, JIAPAC, which focuses on HIV and mental health issues, incorporating data from the survey. In the survey, more than eighty percent (84.3%) of physicians said that their HIV-positive patients frequently or very frequently suffered from symptoms of depression.

Studies have shown that PLWHA with depression are twice as likely to die as those with few or no depressive symptoms (Margolese, 2003).

Therefore, as with other serious illnesses such as cancer, heart disease or stroke, HIV often can be accompanied by depression (Champion and Power, 2000).

### 2.1.3 Suicide in People with HIV Infection

Suicide, attempted suicide, and suicidal ideation are complex clinical issues associated with life-threatening conditions such as human immunodeficiency virus (HIV) infection. It has been considered that suicidal impulses were common in people who were aware of their positive serostatus (Holland & Torss, 1985; Faulstich, 1987). Evidence accruing in the late 1980s, has demonstrated that there is a definite risk of suicide in patients with active HIV disease. Marzuk et al. (1988), in what has become a widely quoted study, reviewed all cases of suicide in New York City during 1985 in an attempt to determine how many were AIDS related. Rates of suicide for people with AIDS were 66 times higher than in the general population of the City and men with AIDS aged 20 to 59 years were 36 times more likely to commit suicide than their counterparts without such a diagnosis. Half of the people in the sample had expressed suicidal intent and one-quarter killed them by jumping from windows of medical units in general hospitals. Statistics based on death certifications may underestimate the rate of deaths due either to suicide or AIDS (king, 1989) and thus these figures are likely to be a lowest estimate of the true rate. There were, none the less, several other problems with this data. The methods by which rates were estimate have been criticized (Beltangady, 1988). There is other evidence that suicide rates among homosexual men, who made up the majority of the AIDS deaths in Marzuk et al.'s study, are by far higher than among the general public, possibly confounding the findings (Hull et al., 1988). Finally, no attempt was made to estimate the psychological status of people prior to their suicide.

Evidence from other research findings also indicates that the suicide rate in people with HIV infection is increasing. A systematic investigation of medico-legal autopsy cases with regard to HIV infection was carried out in Stockholm for the period July 1, 1985 to June 30, 1990 (Rajs &

Funglestad, 1991). These concerned sudden deaths outside hospital as a result of violence or other cause where previous disease was unknown or where there were suspicious circumstances. The data covered 96 percent of all suicides in a closely demarcated area of Sweden but were somewhat complicated in that samples for HIV antibody testing were taken consistently only in the final 33 months of the study. During the five years of the study, 21 people with HIV infection committed suicide, 12 of whom were homosexual and bisexual men, eight drug users and one who had acquired HIV via a blood transfusion.

Two other studies are divided on the risks of suicide in people with HIV infection. Mckegeeny & O'Dowd (1992) reported that suicide was less likely in patients with AIDS than in those with earlier stages of HIV infection, and that the risk for AIDS patients was even lower than in those who were HIV negative or whose HIV status was unknown. Conversely, Gala et al. (1992), in a study of 213 asymptomatic men with HIV infection, 123 of whom were IV drug users, reported that vulnerable periods for acts of deliberate self-harm were within six months of HIV testing and with the development of AIDS, Risk of deliberate self-harm was elevated by a factor of 7.7 for men with a history of psychiatric disorder and by a factor of 5 for those who had deliberately harmed themselves in the past. Although this was a careful prospective study of up to 42 month's duration, 53 (25 percent) men dropped out, most of whom were drug users. It is always difficult to know whether dropouts from studies such as this one are more or less psychologically robust. In this case, the authors assumed the latter.

As evidenced by the findings discussed above, there remains considerable evidence that so-called rational suicide may mask a depressed mood, inappropriate guilt about being a burden to others, or an erroneous perception of the development of the illness and methods available to alleviate suffering (Glass, 1988).

## **2.2 Anxiety**

Anxiety is an emotional state in which people feel uneasy, apprehensive, or fearful. People usually experience anxiety about events they cannot control or predict, or about events that seem threatening or dangerous. People often use the words fear and anxiety to describe the same thing. Fear also describes a reaction to immediate danger characterized by a strong desire to escape the situation.

### **2.2.1 Symptoms of Anxiety**

Anxiety is not always bad (Collins, 1988). When there is no anxiety, can be boring and inefficient. A moderate amount of anxiety motivates people and adds zest to one's life. When anxiety is intense, prolonged, or uncontrolled, however, people begin to experience crippling physical, psychological, and defensive reactions.

As far as physical reactions are concerned, anxiety can produce ulcers, headaches, skin rashes, shortness of breath, inability to sleep, increased fatigue, loss of appetite, feel numb, increased muscle tension slowing of digestion, and a variety of other physical symptoms.

On psychological functioning, anxiety can reduce productivity, hinder interpersonal relations, dull the personality, and interfere the personality, the ability to think or remember. In extreme case, anxiety so immobilizes an individual that s/he is unable to function independently as an adult (Collins, 1988).

When anxiety builds, most people unconsciously rely on behavior and thinking that dulls the pain of anxiety. These include the feelings of anxiety, denial, blaming someone else for one's problems (Brown, 2001).

### **2.2.2 Anxiety and HIV**

The relationship between anxiety and HIV has been widely documented in several research findings (Perkins et al., 1994; Kantin et al., 1998; Fernandez and Ruiz, 1989; Fernandez and Levy, 1991). In these studies, it was found that up to 43% of the PLWHA were found to experience clinically significant anxiety symptoms. Causes maybe fatalness of HIV its cure is uncertainty of its cure, and the presence of stigma and discrimination attached to it.

## **2.3 Stress**

Stress is an unpleasant state of emotional and physiological arousal that people experience in situations that they perceive as dangerous or threatening to their well-being. The word stress means different things to different people. Some define stress as events or situations that cause them to feel tension, pressure, or negative emotions such as anxiety and anger. Others view stress as the response to these situations. This response includes physiological changes—such as increased heart rate and muscle tension—as well as emotional and behavioral changes. However, most psychologists regard stress as a process involving a person's interpretation and response to a threatening event.

If not managed appropriately, stress can lead to serious problems. Exposure to chronic stress can contribute to both physical illnesses, such as heart disease, and mental illnesses, such as anxiety disorders.

### **2.3.1 Symptoms of Stress**

Stress is most commonly manifested in sleep disorders and lack of ability to concentrate, muscle tension, headaches, migraines, ulcers, short temper, job dissatisfaction, low morale, and sexual dysfunction, among many other symptoms. It is also manifested in feelings of powerlessness, being rejected, and trapped.

### 2.3.2 Stress and HIV

Numerous studies have shown that PLWHA experience excessive stress which in turn can accelerate the progression of HIV. There may be different factors which could account for this association. HIV is often fatal, is accompanied by other related illnesses, its cure is uncertain, has a mysterious origin and has been associated with groups that were already stigmatized in other ways.

Being HIV positive by itself may also cause more stress because it can be passed between sexual partners, among people who inject drugs and from a mother to a child (during pregnancy, childbirth and breastfeeding). Before blood screening programs were in place, some people were also infected through transfusions of blood or blood products. People who are infected often say that they feel "unclean." They have to deal with the challenges of the fear or guilt of infecting others and with the difficult process of changing sexual and other behaviors to protect others and to safeguard their own health. The sometimes real risk and sometimes irrational fear of infection also creates stress for sexual partners, family members, caregivers and friends (Lehrman et al., 2001).

Other aspects which may intensify stress could be worry about financial dependency on their parents or on the welfare system because they depend more and more on the social service and medical systems. Both systems require PLWHA to give up control, one system over their personal resources, the other over their bodies. The requirements, though necessary, are distressing. People who give over control of their resources and their bodies feel they have little left of their own. They feel powerless, ineffective, and incompetent (Davies, Bachanas, & McDaniel, 2002).

## 2.4 Fear

One of the psychosocial issues frequently experienced by PLWHA is fear. Available literature also uncovers a variety of themes of fear. PLWHA are normally in fear because they have to adjust to a new lifestyle (Watstein and Chandler 1998)

A study conducted by UNAIDS came up with common aspects of fear often experienced by PLWHA (UNAIDS, 2000). These are:

- Fear of AIDS stigma (of being identified with deviant morally sinful behavior mainly sexual promiscuity and visiting sex workers).
- Fear of loss of reputation in the family and society.
- Fear of damaging the family's social reputation.
- Fear that HIV serostatus will be revealed and of being identified as sexually deviant.
- Fear of social discrimination and isolation of being aviated or shunned by others.
- Fear of being judged and categorized as member of a "deviant" group such as promiscuous people and gay men.
- Fear of social ridicule.
- Fear of various illnesses and debilitating ill-health, of painful conditions of not receiving medical attention and of being denied admission to hospital.
- Fear of being deserted of loss of significant relationship, and of loss of trust and confidence.
- Fear of losing one's job or source of income
- Fear of passing the infection to others, whether spouses or other family members

Three of the most significant fears PLWHA experience, according to Brown (2001), is: fear of abandonment and isolation, fear of pain, suffering and disfigurement and, fear of dependency and loss of control.

In a study by Gray (1999), of 80 HIV+ women, in which they described the most difficult aspects of living with the HIV infection, fear related to disclosure was more frequently described than fear of dying. HIV+ people might blame themselves for their experiences with stigma, feeling that they deserve mistreatment. In this way fear deprives PLWHA from experiencing the most basic of human rights. It is often stated or implied that if we can break down this fear, we can transform PLWHA's position in society, their opportunities and wellbeing.

## ***2.5 Stigma and Discrimination***

HIV/AIDS challenge respect for human rights in profound ways. The AIDS epidemic has been accompanied by epidemics of fear and discrimination against those with AIDS and infected with HIV. The prevalence and impact of AIDS and HIV infection have been apparently in and on particular groups and populations.

### **2.5.1 Definition of Stigma and Discrimination**

Stigma generally refers to a negatively perceived defining characteristics used to set individuals and groups apart from the normalized social order (Gilmore & Somerville 1992). The AIDS stigma, thus, refers to the prejudice, discounting and discrediting directed at people perceived to have HIV or AIDS, and at the individuals, groups and communities with which they are associated (Herek and Mitnick, 1996). This stigma may be the actual infection or may be based on behavior believed to lead to the infection. According to (Busza 2001; Bunding, 1996 ) HIV can evoke a particularly strong stigma response because it is a sexually

communicable disease, is often fatal, has a mysterious origin and has been associated with groups that were already stigmatized in other ways.

Discrimination, on the other hand, is 'the action or treatment based on stigma and directed towards the Stigmatized' (Bunding, 1996). The stigmatized find themselves ostracized, rejected and shunned (Alonzo & Reynolds, 1995) and may experience sanctions, harassment, and even violence based on their infection or association with HIV/AIDS (Mc Grath, 1992). Stigma and discrimination are closely linked and they are frequently referred to together. Because discrimination often involves action, it can often be more easily identified. Sayce (1998) also suggests that the concept 'stigma' is limited and would prefer the use of the concept discrimination to see the action-oriented effect.

### **2.5.2 Contexts of Discrimination**

Since the onset of the HIV epidemic, discrimination tends to fall into two categories: Legislative forms of discrimination which reflect stigma enacted in law or policy and Community level forms, in which the marginalized experience discrimination in less formal context, often those related to family and other structures of civil society. Thus the context of discrimination could be: in family/immediate community, at workplace, in health sector, religion and the media (Brandt, 1988).

Discrimination in family/immediate community includes: isolation of both infected and affected due to fears of casual contact, restriction on participation in local events, refusal to allow affected children in local schools, lack of support for affected bereaved family members, including orphans.

Discrimination in workplace includes: mandatory testing before hiring/refusal to employ, involuntary periodic testing/dismissal on grounds of HIV status, violations of confidentiality, and refusal to work with infected colleagues for fear of contagion.

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In the health sector, discrimination could be revealed in the form of refusal to treat, violations of confidentiality, provision of care in specific establishments (such as STD clinics that further stigmatize the client, or any advice given or pressure applied for HIV positive person to undergo treatment that would not be emphasized for others (e.g., abortion, sterilization).

Religion could be a sector in which discrimination is apparently seen. This may be through, denial of traditional rituals (e.g., funeral practices, restricted access to marriage, restriction on participation in religious activities.

Discrimination in media includes: deionization by public health campaigns of Specified 'transmitters' such as sex workers reinforcing division between 'guilty ' and 'innocent' people living with HIV/AIDS, depiction of HIV/AIDS as death, perpetuating fear and anxiety rather than normalization, and reinforcement of stereo-typed gender roles that perpetuates women's vulnerability to sexual coercion and HIV infection.

Discrimination in rendering health care to patients with HIV/AIDS is seen in denial of care, especially obstetrics and surgical care to many patients (Bhargava, 1998). Fear of infection is also responsible for actions such as isolation of HIV patients, neglect and discrimination. Poor quality of testing facilities and mandatory testing in woman in case of HIV positive husbands are some of the other discriminating practices followed (Bharat, 1999). The patient's right to confidentiality is often seen to be breached in both public and private hospitals. It is taken casually in all hospitals. Universal practices are never in place- instead the personnel often perform irrational procedures and activities like use of gloves and AIDS kit even in non invasive procedures and activities like giving food or medicines to the patients. These practices are often not only financial burden, but also discriminatory and stigmatizing for the patient and families. About 90% of people with HIV live in developing

countries and have no access to any scientifically proven treatment for the infection. Greater access to the clinics was seen to reduce the risk of hospitalization of people infected with HIV. Greater accessibility to regular and Low cost medical care is significant in reducing the suffering of full blown AIDS patients.

### **2.5.3 Reasons for Stigma and Discrimination**

De Bruyn (1999) has recently identified five reasons as contributing to HIV/AIDS-related stigma and discrimination. These, according to his findings are: the fact that HIV/AIDS is a life-threatening disease; the fact that people are afraid of contracting HIV; the disease's association with behaviors (such as sex between men and injecting drug use) that are already stigmatized in many societies; the fact that people living with HIV/AIDS are often thought of as being responsible for having contracted the disease; religious or moral beliefs that lead some people to conclude that having HIV/AIDS is the result of a moral fault (such as promiscuity or "deviant" sex) that deserves punishment.

Discrimination exists because most hospitals lack adequate knowledge about HIV/ AIDS and consider themselves to be at great risk of contracting the infection. No special training programmes have ever been arranged for support staff in the hospital. These feelings of anxiety and fear result in their meting out derogatory behavior to the patients. There is a sense of insecurity due to inadequate protection by the society, which generates apathy and insensitivity to the cause. (Centers for Disease Control and Prevention [CDC], 2000; Herek, Capitanio & Widaman, 2002).

### **2.5.4 Impact of Stigma and Discrimination**

According to (Herek GM, et al.1998; CDC, 2000) the discrimination and devaluation of identity associated with HIV-related stigma do not occur naturally. Rather, they are created by individuals and communities who,

for the most part, generate the stigma as a response to their own fears. HIV-related stigma manifests itself in to discrimination of various sorts. HIV-positive individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most. They may be forced out of their homes, lose their jobs, or be subjected to violent assault (Alonzo & Reynolds, 1995).

Lower levels of perceived stigma and the ability to cope effectively with HIV/AIDS have been associated with greater overall life satisfaction (Gill et al., 2002; Heckman et al., 1997). Depression, often a detrimental side effect of illness, requires a tremendous amount of coping and stigma management on the part of the HIV-positive individual shown to be integral to re-establishing one's sense of self-identity (Pearson et al., 1999; Stanley, 1999).

Besides, in response to the anticipated fear of severe personal and social consequences arising from this stigma and discrimination, many people avoid knowing their HIV status. This decline in HIV testing undermines public health efforts to combat the spread of HIV infection. A lack of respect for human rights and dignity has been recognized as the root cause of vulnerability to the HIV epidemic (Stansbury & Sierra, 2004).

PLWHA might also decide not to disclose their diagnosis to other people because they anticipate rejection. People with HIV are exposed to the prejudice of others and are confronted with the negative feelings others might have towards their own behavior. Disclosing to others is therefore risky since it might strain family relationships and friendships, and may lead to the restriction of career opportunities and loss of employment.

Internalization of HIV related stigma was a phenomenon discovered in an American study which focused on another group, the HIV affected caregivers. These caregivers based disclosure decisions on their

anticipation of AIDS related stigma and expectations of rejection and, as a result, often did not tell anybody that they were caring for an HIV infected person, adding further to their isolation (Poindexter and Linsk, 1999). Thus, PLWHA lose the chance of getting social support and other related accesses.

Stigma and discrimination experienced within the health sector can prevent people with HIV/ AIDS from seeking care if they feel they will receive unwelcome reception or their confidentiality will not be respected (Malcolm et al, 1998). It also causes psychological distress (Hisung, 2001).

## **2.6 Coping Strategies**

Coping is defined as the things people do to master, tolerate, and minimize life strains or demands. Coping is "a constantly changing process involving cognitive and behavioral efforts deployed to manage specific external and or internal demands that are appraised as stressful" (Lazarus & Folkman, 1991). Coping is also defined as a process by which an individual manages the ever-changing environment (McFarland & McFarland, 1993). Coping may be seen as actions taken by persons directed at confronting demands, solving problems, and/or altering and managing stressors (McCubbin, Thompson, & McCubbin, 1996).

How a person handles the diagnosis psychologically has implication for health outcomes. According to (Antoni et al. 1995), some individuals cope with illness; that is termed "denial coping." Others may be apathetic about their illness and possibly feel hopeless. Both denial coping and helplessness are associated with faster HIV disease progression. Passive coping strategies are predictive of greater immunologic impairment (Ironson et. 1994). Specifically, denial coping is associated with faster progression to AIDS (Leserman et al. 2000), and active confrontational coping is associated with a lower probability of symptomatic disease

progression (Mulder et al. 1995). Furthermore, HIV infected subjects who became symptomatic after one year have more denial and less fighting spirit (Solano et al. 1993). Alternatively, a person may actively try to understand a disease. Such a person, engaging in “active coping, “may look for support networks and resources and try to reinterpret the disease to understand its positive effects on life. Coping with the threat of HIV progression to AIDS by means of active strategies has been associated with less psychological distress, increased life satisfaction, and improved quality of life compared to using passive coping strategies (Carver et al. 1989; Demas et al . 1995; Folkman et al. 1991; Heckman et al. 1997; Swindells et al. 1999).

A study of 736 individuals with AIDS noted that these individuals practiced a variety of coping behaviors categorized as positive coping, social support seeking, and avoidance coping. The coping behaviors were associated with health behaviors, affect, and disease progression in both cross-sectional and longitudinal analyses (Fleishman & Vogel, 1994). Similar findings were reported in a phenomenological pilot study conducted by Russell & Smith (1999) which explored the experiences of five HIV-infected African American women. Audiotaped interviews from these women were examined. Twelve themes emerged from the data: violence, addiction, it couldn't happen to me, shock and denial, education, time, uncertainty, cycles, secretive nature of their lives, someone, survival, and children. It is evident, even from this small pilot study, that these individuals have complex experiences and that the complexities of stress has an effect on coping and psychological well being.

Reeves, Merriam, & Courtenay (1999) utilized in-depth interviews with eighteen HIV--infected individuals who were younger than 45 years of age. Analysis of the qualitative data using the constant comparative method revealed that these individuals used specific coping strategies immediately after diagnosis which differed from coping strategies used

later. The development process uncovered in this study included a period of transition that served as the testing ground for the following adaptive strategies: humor, faith, altruism, seeking the support of others and balance. In a similar study where coping styles and levels of hope were examined in HIV-infected African American women of reproductive age, it was found that a significant relationship existed between hope and avoidance coping (Phillips & Sowell, 2000).

A qualitative study of HIV seropositive and seronegative injecting drug users indicated that the most common styles of coping were seeking social support, substance abuse, and mental disengagement (Demas et al. 1995). Some individuals with HIV have coped by forming positive perceptions of life because of their illness (Carver et al. 1989), turning to religion (Carver et al. 1989; Demas et al. 1995), or utilizing active strategies such as researching new treatment and illness information (Folkman et al. 1991; Heckman et al. 1997).

In terms of seeking care, women have been found to initiate HIV related care later than men (Siegel et al. 1997). Several reasons for such delays have been reported: cognitive distortions of the reality and significance of HIV; paralyzing fear and anxiety about having HIV (i.e., physical symptoms, stigma of HIV/aids, and fear of dying from HIV/AIDS); turning to substance abuse to blunt the emotional impact; actively abusing substances; being incarcerated; suffering financial constraints; possessing limited HIV related knowledge; and experiencing problems with medical personnel (Siegel et al. 1997).

### 2.6.1 The Role of Social Support

The role of social support in alleviating the psychosocial challenges of PLWHA is well documented in current literature.

Strong support networks among persons with chronic diseases can result in positive health outcomes (Stanton and Snider 1993). In addition to providing a greater array of resources to draw from, social support appears to buffer people from potentially pathogenic effects of stressful events (Cohen, Wills 1985; Sorensen et al. 1998). Support systems are associated with behavioral changes such as adherence to medical regimens, successful smoking cessation, and diet changes (Sallies et al. 1987; Stanton, Snider 1993).

Social support positively affects self-efficacy, which is correlated with fewer HIV-related, high-risk behaviors (Montoya 1998) and greater use of health services. Additionally, support of friends and family early in the course of HIV has been found to be associated with good coping skills (Brook et al. 1997). The combination of an available social support network and lack of conflict within these networks has been found to be related to healthier psychological status (O'Brien et al. 1993) and higher quality of life (Friedland et al. 1996; Heckman et al. 1997; Pakenham et al. 1994), while poor social networks lead to combined physical and psychiatric illness (Andrews et al. 1978).

A study (American Journal of Psychiatry, 1993) also found out that support groups were superior to standard psychotherapy among PLWHA with depressed moods. 86% of the support group participants showed significant improvements in "distress severity". These groups helped people with HIV maintain so far sexual practices and guide individuals in making positive behavioral changes.

## 2.6.2 The Role of Spirituality

The role of spirituality in coping with psychologically stressful situations particularly with the psychosocial challenges PLWHA face is well documented in literature.

In a study of ten men and women with symptomatic HIV disease in the USA, they identified themselves as having had spiritual or religious experiences that helped them to cope with their disease and they showed a spiritual understanding of life that developed as their illness progressed. Initially an HIV+ diagnosis results in the PLWHA a learning to cope with the rejecting social context and the knowledge that one has limited time to live. These circumstances caused this group of HIV+ people to become separated from the larger society and, as a result, a meaning emerged that was largely free from the values of established belief systems. PLWHA attributed their new spirituality to the opportunities that HIV provided to their lives (e.g. to make a difference in the fight for acceptance).

Obstacles, constrained informed meaning, and initial depression often marked by self destructive behavior, were overcome by some encouraging event. The PLWHA gained confidence in recovery took control and selected treatments that were right for them. The fear they experienced when they realized their time was limited was ameliorated by awareness that there was still a lot of life before death and that all people eventually die. They became more hopeful, accepted health information and actively sought social support. As the disease progressed they showed the development of a spiritual understanding of life. People cleared their lives of stressful and meaningless aspects (e.g. hated jobs) and embraced those that strengthened their faith and defined personal meaning (Corbett, 1999).

Hope in a longer future ,thus, have been enhanced by religious beliefs, which help PLWHA find peace in their future death because they now believe that their God is not punishing them with HIV, as they once believed, and pray daily (Kaldjian et al. 1998).

This spiritual well-being is also correlated with psychological well-being and health (Coleman, Holzemer 1999).

## CHAPTER THREE

### 3 Methods of the Study

#### 3.1 *The Population*

The total population of the study was people living with HIV/AIDS who were found in Awassa and Dilla towns and were members of the Down of Hope Association of People Living with HIV/AIDS and members of Tilla Association of Women Living with HIV/AIDS in Awassa.

#### 3.2 *Sampling*

A total of 403 (286 female and 117 male) PLWHA were identified from the selected sources – (71 female and 62 male) and (57 female and 53 male) from Down of Hope Association of People Living with HIV/AIDS in Awassa and Dilla respectively and 170 (all females) from Tilla Association of Women Living with HIV/AIDS in Awassa. From this population, using a purposive sampling method, a total of two hundred, i.e., 66 (9 female and 57 male) and 57 (7 female and 50 male) samples were selected from Awassa and Dilla Down of Hope Association of People Living with HIV/AIDS, and 84 (all females) from Awassa Tilla Association of Women Living with HIV/AIDS.

#### 3.3 *Instrument*

Respondents were interviewed through a comprehensive interview schedule that assessed their psychological conditions specifically their experience of depression, anxiety, stress, fear, stigma and discrimination, and coping strategies. Each instrument is described below.

##### 3.3.1 **Depression Measure**

Depression was assessed through **Center for Epidemiologic Studies Depression Scale (CES-D)** enclosed in *appendix i* section of this thesis

w. Radloff (1977), Cited in (Clement, 1999), developed this scale to measure depressive symptoms in the general population. This instrument consists of 20 items that are rated for the past week on a 4-point scale ranging from "Rarely or None of the times (Less than 1 day)" to most or all of the Times (5-7days)."

Alpha coefficients have been about 0.85 for the general population and 0.90 for clinical samples. This scale has correlated with several other measures of depression. It has known-groups validity, discriminating between psychiatric inpatients and the general population.

As to the interpretation of the scale, euthymic (i.e., of normal mood), scores of 15 and below; distressed (probable depression), scores from 16 to 21; and depressed (syndromic depression), with scores of 23 and above.

This scale was selected for this study because it is the most widely used depression scale for HIV related research (Sarna, Servellen and Padilla, 1996), for its simplicity to translation from English to Amharic and vice versa, for its sound psychometric properties and for its accessibility.

### 3.3.2 Anxiety Measure

Anxiety was assessed through **Beck Anxiety inventory** (<http://www.cps.nova.edu/cpphelp/BAI.html>) enclosed in *appendix i* section of this thesis. The Beck Anxiety inventory (BAI) was developed to address the need for an instrument that would reliably discriminate anxiety from depression while displaying convergent validity. Such an instrument would offer advantages for research purposes over existing self-report measures, which have not been shown to differentiate anxiety from depression adequately (<http://www.acf.hhs.gov>). The scale consists of 21 items, each describing a common symptom of anxiety. The

respondent is asked to rate how much he or she has been bothered by each symptom over the past week on a 4-point scale ranging from 0 to 3. The items are summed to obtain a total score that can range from 0 to 63.

As to the interpretation of the scale, scores of 8 to 21 indicate "Mild anxiety"; scores of 21 to 36 reflect "Moderate anxiety" and scores of 37 and above indicate severe anxiety ([http://: www.acf.hhs.gov](http://www.acf.hhs.gov)).

As far as its psychometric properties are concerned, the scale obtained high internal consistency and item-total correlations ranging from .30 to .71 (Median = .60). A sub sample of patients (n=83) completed the BAI after 1 week, and the correlation between intake and 1-week BAI scores was .75. The correlations of the BAI with a set of self-report and clinician-rated scales were all significant. The correlation of the BAI with the HARS-R and HRSD-R were 0.51 and 0.25, respectively (Beck and Steer, 1993).

This scale is selected for this study because it is the most widely used scale of its type for research and clinical purposes. ([www.psychocrcpcenter.com/content/bai.htm](http://www.psychocrcpcenter.com/content/bai.htm)).

### 3.3.3 Stress Measure

Stress was measured through **Perceived Stress Scale-10 (PSS-10)** developed by (Cohen and Robert, 1983) enclosed in **appendix i** section of this thesis. The PSS was designed for use with community samples with at least a junior high school education.

The scale consists of 10 items, each describing a common symptom of stress. The respondent is asked to rate how much he or she has been bothered by each symptom over the past month on a 4-Point scale

ranging from 0 to 3. The items are easy to understand and the response alternatives are simple to grasp. Moreover, the items are quite general in nature and hence relatively free of content specific to any sub population group (Cohen and Williamson, 1988). The scale is well validated in community norms to determine, stress levels over 1 month. (American Journal of Psychiatry 2004; 49:385-390).

In light of the generality of scale content and simplicity of language and response alternatives, this scale is selected for this study.

### **3.3.4 Measure of Fear**

To assess whether PLWHA experience fear, the eight aspects of fear PLWHA experience identified by UNAIDS (UNAIDS, 2001) were presented to the respondents in the form of yes/no response items.

### **3.3.5 Measure of Stigma and Discrimination**

A Likert scale (ranging from "strongly disagree" to "strongly agree" was used to measure the PLWHA's experience of stigma and discrimination. The scale consisted of 12 items and was developed by the researcher based on (Goffman, 1963; Gilmore & Somerville 1992; Herek and Mitnick ,1996; Pearson et al., 1999) models of identifying perceived stigma and discrimination reviewed on chapter two of this paper. The range would enable the respondents to express their position. PLWHA were required to rate each item on the Likert type scales (strongly disagree=1, disagree=2, don't know= 3, agree=4, strongly agree=5) following the specific instruction given. The mean was used to classify the PLWHA in to high, medium, and low experience of stigma and discrimination. Those who scored above the mean were classified in high experience of stigma and discrimination while whose score fell below the mean were classified in

low experience of stigma and discrimination. The PLWHA whose score was equal to the mean were classified in the medium experience of stigma and discrimination.

### **3.3.6 Measure of coping Strategies**

A Likert type scale was designed based on (Weilsman, 1974) behavioral and cognitive model of coping strategies. This is designed to identify the behaviors. The scale consists of 18 items. The items are rated on a 5-point Likert scale (1= never, 2 = hardly ever, 3= sometimes, 4= often, 5= most of the time). The higher the score, the greater the use of coping strategies. Example: smoking, praying to God etc.

### **3.3.7 Case Interview**

Case interview was prepared to explore the very psychosocial experiences of individual PLWHA in detail so as to substantiate the findings obtained in other means. The reason case interview is selected is that it provides an opportunity to the investigator to question thoroughly certain areas of inquiry and it permits greater of responses, which is not possible through any other means.

The basic criteria adopted to select these samples were the ability and consent to self-disclosure so as to get in-depth information about them. Interviews were semi-structured (Merriam, 1988). Initial interview questions were prepared based on the literature and observations of the group, but individual interviews varied as themes emerged through the respondent's input.

### **3.3.8 Focus Group Discussion (FGD)**

In order to explore the psychosocial challenges in depth, the focus group discussion method was considered compatible to the nature of the study

and is substantial to the quantitative qualitative methods mentioned above. Therefore, the Focus Group Discussion was used to explore more open and a closer perspective of the subjects, which was impossible to obtain in the other methods. The basic criteria adopted to select these samples were the ability and consent to self-disclosure, availability and relatively longer experience of living with HIV virus.

### ***3.4 Test Try-Out***

Before giving the test to the selected subjects, a pilot test was conducted to check to revise and determine the specificity, relevance, and clarity of the items and to determine the reliability of the tests. Thus, the selected items (translated in to Amharic) were tried on 30 PLWHA who lived in and were members of the Shashemene Down of Hope Association of People Living with HIV/AIDS. This site was selected because of its similarity with the way of life at the sites of the main study.

In this Association there were 137 PLWHA (76 females and 61 females). Of these, 7 were aged under fifteen. As the participants in this research need to be 15 years or older, they were aged under fifteen. As the participants in this research need to be 15 years or older, they were excluded from the test. And from the remaining 130 PLWHA, 30 (15 males and 15 females) were selected by stratified random sampling method. The age range of the respondents was from 18 to 47 years and the mean age was 27.6.

The main purpose of the pilot test was test to improve the quality of the instruments since the instruments either directly adopted or newly prepared. Accordingly, the following changes were made after the pilot test

1. The originally administered questionnaire to be filled out independently by the respondents was changed in to an interview schedule from because the majority of the respondents were found to be unable to clearly conceive words of psychological concepts.
2. Some of the questionnaire items, which had been reversal phrased and require indirect interpretations, were replicated in to a direct form so that the respondents clearly understand them.
3. Some items that ask the background characteristics of the respondents were found to be less relevant and were dropped. Instead, more relevant ones were added.

The psychometric information of the test is presented as follows:

**Table 1 Reliability Coefficient of variables in the Study.**

<b>No</b>	<b>Variable</b>	<b>Reliability indices</b>
1	Depression scale	0.87
2	Anxiety scale	0.83
3	Perceived stress scale	0.79
4	Fear scale	0.68
5	Coping strategy scale	0.81
6	Stigma and discrimination scale	0.714

### **3.5 Data Collection Procedure**

For collecting data, 2 male and 2 female 4<sup>th</sup> year students two from English and one from business management departments of Debu university Awassa Campus; the other from Geography department of the Dilla Campus, were trained to be research assistants. They all had prior training related to HIV/AIDS and are leaders in the HIV club respective campuses. Things like how to establish rapport, before preceding the

interview and how to simplify words related to psychological concepts were discussed between the researcher and the assistances.

The researcher's main task was coordinating the activities of the interview schedule.

There was no time limit to complete the interview schedule. The average time taken to complete it was between 30 to 40 minutes.

The researcher alone made the case interview. Due to the highly sensitive and confidential nature of the subject, it was very important to establish a positive rapport with the respondents in order to build a high level of trust before any interviews were the power to decide when and where the interviews should take place. Retaining control of the interview process seemed especially important to the respondents.

Three respondents were selected and agreed to participate in the in-depth interviews. Each participant chose to be interviewed in isolated places where there was no chance of the conversation being overheard or interrupted. They were instructed that they could refuse to answer any question or end the interview at any point.

The period of interviews was approximately two hours each with longest initial interview taking two hours and fifteen minutes. In these interviews, the purpose of the study was restated, and respondents were again assured anonymity.

After providing basic descriptive information about themselves, the respondents were asked open-ended questions about how they felt their HIV diagnosis and how it affected their experience, both psychologically and socially.

With each respondent's permission, notes were taken in Amharic language during the interviews. The respondents reviewed the interview notes and copies of the report in Amharic to check for accuracy of quotes and perceptions.

Participants for the Focus group Discussion were selected and approached immediately after they finished the interview schedule. Two groups consisting of eight members each was male's group. A female or a male enumerator was present in each respective discussion to assist the researcher by taking notes and recording tape.

### **3.6 Analysis of the Data**

In the quantitative data analysis, each variables was coded, sorted out according to its specific measure and was entered in to the computer for analysis. The statistical analysis was then made using the SPSS software for Windows Version 13 for data analysis in percentage, mean, standard deviation and t-tests. Percentage, mean and standard deviation were used to describe the socio-demographic characteristics, causes and nature of the psychosocial problems and the coping strategies employed by the samples. T-test was used for testing the significant differences between sex.

The data collected through the interview and focus group discussion methods were analyzed using Colaizzi's procedural steps (1978) cited in (Merriam, 1988). All interviews were transcribed verbatim and then read several times individually to gain a feeling for the data. Significant statements, ideas and phrases were then highlighted on the transcript and notes were made. An initial list of key themes was created and codes were given to them. A word processing program was then used to cut and paste the significant statements, ideas and phrases in to themes. The key

themes were then summarized, staying as closely to the participants' words as possible.

### **3.7 Ethical considerations**

Psychological research related to PLWHA has to be highly confidential and ethically sensitive (Sieber, 1993). As the nature of the study demands, the following ethical considerations were strictly taken care of through out the research process:

Communicating respectfully and openly with the respondent's throughout the data collection process, and providing a debriefing about the nature, findings, and value of the research, were essential components for obtaining informed consent.

#### **3.7.1 Right to Decide to participate**

Each participant was free to decide whether he/she wanted to participate in the study not, and not filling out the interview schedule or being absent was the easiest way to decline participation. The PLWHA also had the right to decide to terminate their participation at any stage of completing the interview schedule or not to answer specific question. The PLWHA exercised these rights that resulted in different totals (n) for different questions.

All the four individuals assisting with the data collection process were unknown to the PLWHA and they guaranteed the confidentiality of the information shared, which may or may not have involved personal experiences. The respondents of the interview schedule were not identifiable. This anonymous process was selected to guarantee the PLWH/A's right to privacy.

# CHAPTER FOUR

## 4 Results

### 4.1 Background of Respondents

Some background characteristics of respondents are presented in table 2 below (N=200).

**Table 2 background characteristics of respondents**

Characteristics	Male		female		Total	
	No	%	No	%	No	%
Ethnicity						
Amhara	22	11.0	25	12.5	47	23.5
Oromo	20	10.0	22	11.0	42	21.0
Tigre	8	4.0	7	3.5	15	7.5
Wolayta	12	6.0	15	7.5	27	13.5
gurage	6	3.0	7	3.5	13	6.5
sidama	5	2.5	2	1.0	7	3.5
others	27	13.5	22	11.0	49	24.5
Religion						
Orthodox	44	22.0	41	20.5	85	42.5
Muslim	19	9.5	17	8.5	36	18.0
Protestant	32	16.0	36	18.0	68	34.0
Others	7	3.5	5	2.5	11	5.5
Education						
Illiterate	3	1.5	11	5.5	24	7.0
Can read write	7	3.5	21	10.5	28	14.0
1-4	6	3.0	16	8.0	22	11.0
5-8	14	7.0	7	3.5	21	10.5
9-12	53	26.5	40	20.0	93	46.5
vocational	14	7.0	5	2.5	19	9.5
Highereducation	3	1.5	-	-	3	1.5
Marital states						
Umarried	27	13.5	27	13.5	54	27.0
Married	4	2.0	6	3.0	10	5.0
Divorced	4	2.0	2	1.0	6	3.0
Separated	13	6.5	9	4.5	22	11.0
Widowed	52	26.0	56	28.0	108	54.0
Occupation						
Professional	0	0	0	0	0	0
Vocational	21	10.5	8	4.0	27	13.5
Petty trade	42	21.0	51	25.5	93	46.5
House wife	-		10	5.0	10	5.0
Unemployed	28	14.0	42	21.0	70	35.0

As table 2 above shows, the ethnic composition of the respondents are: Amhara 23.5%, Oromo 21.0%, Tigre 7.5%, Wolayita 13.5%, Gurage 6.5%, Sidama 3.5% and other ethnic group comprised 24.5%.

Concerning the religious affiliation of the respondents, 42.5% of the respondents were found out to be followers of orthodox Christianity followed by Protestants 34%, Muslims 18%, and others 5.5%.

As to the educational background of the respondent, 7% were illiterate, 14% can read and write only, 11% completed first cycle primary education, 10.5% were second cycle primary education complete, 46.5% reached grade 9-12, 9.5% vocationally trained, and 3(1.5%) respondents obtained a college diploma in chemistry, Amharic and the other accounting field of study.

More than half (54%) of the respondents were widowed. Still a majority of them (27%) were single followed by the separated (11%), 3% of them divorced. Only 5% of them have had a marriage life. 21% of the respondents reported to have one or more than one children to take care of.

As far as their occupational status is concerned, about half (46%) of them were engaged in a petty trade followed by unemployed (36%), vocational (13.5%), house wives (5%). No one of them was found to be engaged in a professional work.

As to their economic status, respondents were asked to respond about their monthly income. Table 3 summarizes the result.

**Table 3 Average Monthly Income of Participants**

Average Monthly Income	Frequency	%
Below Birr 100	72	36
Birr101- 300	64	32
Birr 301- 500	38	19
Above Birr 501	26	13

As depicted in table 2, almost one third (36%) of the respondents' average monthly income was below hundred birr. Besides, 68% of the respondents lived on less than 300 birr a month. As the income of the majority of the respondents fluctuate from month to month, however, it became difficult for them to manage to do so. A descriptive statistics computed for this proportion of the cases show that their average income ranges from 125.00 to 1,100.00 birr with the mean and standard deviation of 225.27 and 26.71 respectively.

The age of the respondents ranged from 18 to 60 years. Their mean age was 30.18. Table 4 summarizes the result.

**Table 4 The age wise Distribution of the Respondents( N=200)**

Age range	Frequency	%	Mean	S.D
18- 30	112	66	30.18	6.84
31 - 43	68	34		
44- 56	19	9.5		
age above 56	1	0.5		

As indicated in table 4, more than half of the respondents (66%) were below 30 years of age, which is in the youth category. The rest of them (43.5%) except one (0.5%) were in their middle age category.

The time since the respondents' diagnosis for the HIV test ranged from 1 to 15 years. The mean age in which they came to know to live with the virus is 4.4 years. It is summarized in table 4 below.

**Table 5 The Year which the respondents Lived with HIV Virus (N= 196)**

Year	Min.	Max.	Mean	S.D	%above the mean	%below the mean	t- test
	1	15	4.44	2.45	63.6	36.4	1.07

P>.05

The summary in the table above indicates that the majority of the respondents (63.6%) have come to know their HIV serostatus since 2001. To check if there was any sex difference in the time lived with HIV virus, t- test was calculated. The t- test result (1.07) with 95% confidence interval and 118 degree of freedom indicated there was no significant difference between the two means.

Respondents gave different reasons for the question why they made an HIV diagnosis. Table 5 summarizes their reply.

**Table 6 Respondents Reason for HIV Diagnosis (N=193)**

Reason for HIV Diagnosis	%
To donate blood	3
Getting ill	39
Pregnant and sought parental care	13
Suspecting sexual partner	21
Persuaded by others( friend, health professional)	11
Required for employment or to go abroad	21
Voluntary Counseling Testing (VCT)	22

Of the 193 participants for whom we know why they were tested for HIV, the majority (39%) did not get tested for HIV until they became ill, 22% got tested because they got access for VCT, 21% of them got tested because it was a requirement, 13%( which is 26% of the women sample) were tested only because they were pregnant and sought prenatal care. Only two of the participants had been tested regularly.

27% of the respondents reported to shift their living place after they knew their HIV positive serostatus. 34% of the respondents knew some one with the virus to live with them as a family member. 31% of the respondents had already started taking ART medications.

## 4.2 Prevalence of Psychosocial Challenges of PLWHA

### 4.2.1 Depression

The first research question was “Do PLWHA experience depression as a result of their HIV serostatus?” In order to answer this research question, the score of Center for Epidemiologic Studies Depression Scale (CES-D) was summarized as follows.

**Table 7 Depression Score of the Participants(N=198)**

Depression Score	Frequency	%	Mean	Median	S.D
0-15 (normal mood)	33	16.5	27.6	25.5	11.5
16-21 (probable depression)	55	27.5			
and above (syndromal depression)	111	56			

As can be seen in table 6 above, the mean CES-D depression score for the participants in this sample was 27.6 (median = 25.5; SD = 11.5; range = 0-58). This score falls within the range of significant depression on the CES-D and may be indicative of clinical depression. More than half of the participants (56%) reported significant symptoms of depression, and about one fourth (27.5%) of the respondents had scores in the range indicative of probable depression (16-22). 16.5% of the respondents' depression scores were nonsignificant (15 and below).

To check the prevalence of suicidal ideation which could be a manifestation of severe depression, a question was asked if the participants have ever thought of suicide. 76 % of the respondents (N=198) replied a thought of killing themselves by saying “yes”. From

this, 9 % replied 'always', 41% replied 'sometimes', and 49% replied 'rarely'.

#### 4.2.2 Anxiety

The second research question was "Do PLWHA experience anxiety?" Table 8 below gives a summary of the results based on Beck Anxiety Inventory (BAI).

**Table 8 Anxiety Score of the participants (N=200)**

Anxiety Score	Frequency	Percentage	Mean	Median	S.D
8-21 (Mild anxiety )	27	13.5	32.31	29.4	8.14
22- 36 (Moderate anxiety)	93	46.5			
37 and above ( severe anxiety)	80	40.0			

As depicted in the table above, 13.5 %of the respondents showed mild anxiety experience, 46.5 % showed moderate anxiety experience, and 40% showed clinically significant experience of severe anxiety. The mean BAI score for the participants in this sample was 32.31 (median = 29.4; SD = 8.14; range = 7-59).This reveals that nearly half (40%) of the respondents showed clinically significant anxiety symptoms.

#### 4.2.3 Perceived Stress Symptoms

The third research question was if PLWHA experience stress. To explore this, the result of Perceived Stress Scale-10 score was summarized as follows.

**Table 9 Summary of Perceived Stress Scores of the participants  
(N=190)**

PSS-10	Min.	Max.	Mean	S.D	%above the mean	%below The mean
Stress score	13	40	24.52	5.64	50.5	49.5

As the table above indicates, the mean score of the respondents is 24.52 which is greater than the cutoff point (which is 19 for a research purpose). Half of the respondents' score (50.5%) fall above the mean score. This indicates the presence of stress symptoms by the majority of the respondents.

#### **4.2.4 Fear**

The following table summarizes the fourth research question which inquired, "Do PLWHA experience fear as a result of their seropositive status?"

**Table 10 Summary of Fear experienced by the participants (N= 197)**

Type of fear experienced	Responses			
	yes	%	No	%
Fear of AIDS stigma	184	93.4	13	6.6
Fear of loss of reputation of the family and society	185	93.9	12	6.1
Fear of damaging the family's social reputation	142	72	55	28
Fear of death and of dying early	132	67	65	33
Fear of dying uncared for, and being denied last rites	177	89.8	20	10.2
Fear of being deserted, lose of significant relationships	139	70.6	58	29.4
Fear of losing one's job or lose of income	126	63.9	71	36.1
Fear of passing the infection to others whether spouse, children, or other family member.	118	59.9	79	40.1

As table 6 indicates, the participants expressed fear of all the eight themes with slightly varying degrees but with a high frequency. Accordingly, a type of fear which was experienced by almost all of the participants is fear of loss of reputation of the family and society (93.9%) followed by fear of AIDS stigma (93.4%), fear of damaging the family's social reputation (72 %), fear of death and of dying early (67%), fear of dying uncared for and being denied last rites (89.8%), fear of being deserted and lose of significant relationships (70.6%), fear of losing one's job or lose of income (71%), fear of passing the infection to others whether spouse, children, or other family member (59.9%).

#### 4.2.5 Stigma and Discrimination

The fifth research question was "Do PLWHA experience stigma and discrimination?" In order to answer this research question, the Linker's type scale result was summarized as follows.

**Table 11 Result of Stigma and Discrimination Experienced by Participants**

Scores of Stigma and Discrimination	Min.	Max.	Mean	S.D	%above the mean	%below the mean
	12	58	32.94	11.34	41.6	58.4

As the table above indicates, the mean score of the respondents is 32.94. Less than half of the respondents' score (41.6.%) fall above the mean score and slightly more than half of the respondents score(58.4) fall above the mean score. This indicates the presence of stigma and discrimination in a considerable amount.

#### 4.2.6 Result of Coping Strategies utilized by PLWHA

PLWHA were found out to utilize a wide variety of coping strategies to cope up with their psychosocial challenges. Table 12 on next page summarizes the result.

**Table 12 The coping strategies used by the participants.**

<b>Coping Strategy</b>	<b>N</b>	<b>Mean</b>	<b>SD</b>
Think about Good Things	198	3.04	1.08
Listen to Music	198	4.21	.95
Talk to a close friend	197	3.21	0.92
Talk to a family member	197	2.23	1.20
Try on your own to deal with the problem	197	3.75	1.55
Pray to God	197	4.36	0.97
Talk to Minister/Priest	197	2.71	1.67
Smoke cigarette	197	1.64	1.43
Take drugs (such as hashish)	197	0.00	0.00
Chew 'chat'	195	2.76	1.16
Drink Beer/Wine/Liquor	195	2.13	1.67
Daydream	197	3.76	1.44
Learn more about the problem	197	2.98	1.46
Get Professional Counseling	197	1.14	1.36
Take journal, read/write poetry, literature	197	1.85	1.34
Do physical exercise	197	1.23	1.34
Get medical attention	197	1.96	1.22
Adhere to ART	197	1.04	1.32

As depicted in table 12 above, participants used all ways of coping strategies with varying degrees except taking drugs (such as hashish) which was utilized by none of the participant. Mean scores for the coping strategies used by the participants ranged from 0.00 to 4.36. The most often utilized coping strategy was praying (m=4.36) followed by, listen to music (m=4.21), day dream(m=3.76) , try on your own to deal with the problem(m=3.75), talk to a close friend(m=3.21), think about good

things(m=3.04) learn more about the problem(m=2.98), Chew 'chat'(m=2.76), talk to minister/priest(m=2.71), talk to a family member(m=2.23), ,drink beer/Wine/Liquor(m=2.13), take journal, read/write poetry or literature(m=1.85),smoke cigarette(m=1.64), do physical exercises(m=1.34), get medical attention(m=1.23), get professional counseling(m=1.14). The least often utilized coping strategy was adhering to ART (m=1.04).

#### 4.2.7 Gender Differences in the Manifestations of Psychosocial Challenges.

In order to answer the research question, "Is there any sex difference in experiencing the psychosocial challenges?" analysis was made using t-test and come up with the following results. The summary of the results was put in table 13 below.

**Table 13 Summary of Independent t-test Results**

	Degree of freedom	Mean D/ce	t	Sig.(2-tailed)	P-value
Depression	191	3.11	2.496	0.013	<0.05
Anxiety	193	8.14	0.073	0.942	>0.05
Stress	188	- 0.38	-0.462	0.644	>0.05
Stigma and Discrimination	194	6.53	4.201	0.000	<0.05

The t- test result of the CES-D depression score of the respondents, with 95% confidence interval and 191 degree of freedom revealed that there is a statistically significant difference between males and females at 0.05 level. And the mean of the female respondents is higher than the male respondents by 3.11. This shows that females experience depression in a higher degree than their male counter parts.

As could be seen in the table, the t- test result of the BAI anxiety score of the respondents indicated that there is no statistically difference between male and female respondents score on anxiety at 0.05 level(  $t=.073$ ,  $df=193$ ,  $p>0.05$ ).

The t- test result of the PSS- 10 stress score of the respondents indicated that there is no statistically difference between male and female respondents score on stress at 0.05 level(  $t= -.462$ ,  $df= 188$ ,  $p>0.05$ ).

The t- test result of the stigma and discrimination score of the respondents, with 95% confidence interval and 194 degree of freedom revealed that there is a statistically significant difference between males and females at both 0.05 and 0.01 levels. And the mean of the female respondents is higher than the male respondents by 6.53. This shows that females experience stigma and discrimination in a higher degree than their male counter parts.

### ***4.3 Case Presentation***

One of the qualitative methods employed to study the psychosocial challenges of PLWHA was the case study method. The results of the three cases were summarized in the following subsections. In all the cases pseudo names were used to keep confidentiality.

#### **4.3.1 The Case of Aster - a Widowed PLWHA**

Aster has been living with HIV/AIDS for the last 8 years. She is 36 years old. She was married for fifteen years and had two sons- one is 17 and the younger is 14 now. Her husband was a finance police officer in Moyale, a border between Ethiopia and Kenya. He visited the family usually once in two months. He had good relationship with her and

excessively lived his sons. He died six years ago. She remembered the case:

*I was at home when I got a call from my fiancé's sister, telling me that Alemu (my fiancé) had collapsed and was rushed to the hospital. He spent one week there. The day after he was admitted - Monday - Alemu became delirious with high fever and chills. On Wednesday, he started having uncontrollable diarrhea and had to be put in diapers. By Friday he was comatose. He died the following Monday. I was there every day except the day that he died.*

Six months after, she got desperately sick was hospitalized where she was advised to take an HIV test which came out positive. She learned her HIV positive status was one of anger - the wave of fear came later. Her initial reaction was:

*I went home dazed. It took three days crying, without eating, until I felt that I was weak and could not do anything. I felt numb, lost, terrified and abhorrently ill. The emptiness inside was shattering. I suffered from bouts of irritable bowel syndrome, headaches, nervous stomach, and lost appetite. I also experienced these strange periods of "unreality." It's hard to describe these eerie, dreamlike periods. But I would feel strangely detached from my surroundings and myself. Besides, I started to worry blindly. I worried constantly - about every thing! I worried about being named HIV positive. I worried that something bad was going to happen to my family as a result. I worried about my health - fearing I had this disease or that illness. What ate me, above all, was I knew no one sexually except my husband.*

She spent two weeks with such emotion and short after that, "I quit my job (took accumulated annual leave), sold or gave away most of my

possessions and literally waited to die. My children were puzzled as I did not disclose my HIV positive result."

After one month, she realized that nothing was happening to her except that she was running out of money. Thus, she returned to work. In the mean time, *"I decided that instead of waiting to die, I would find out more about HIV/AIDS."*

Before she diagnosed for HIV in April 1998, she believed all sorts of things about people with HIV: that you had to stay away from "those" people... that they were bad ... that you couldn't get near them because they were extremely contagious.

What made things worse was that Aster had little support. She did not let any one know her HIV status. Aster also had to contend with a stressful, full-time job as secretary cahier for a government institution. Despite, she cried almost everyday and it was taking a toll on her health.

She admits that she was completely ignorant about HIV. "I didn't get a lot of background information at the time. The doctor just said I was positive and, at the beginning, I didn't ask any questions."

*"I kept the plates I ate on and my cup separate for a year and a half,"* she says, thinking she was protection her children from HIV. *"My older son kept asking me why I was doing this. He kept pestering me."* Finally, she learned that sharing plates did not put her kids at risk and she stopped. She laughs now at how ignorant she was.

For four long years, Aster lived with her HIV in silence. In that time, Aster grew more depressed:

*I felt always sad about being HIV positive for the reason I didn't know. I did not remember any time I felt happy. I feel headaches, dizziness, didn't like to talk, and took no pleasure in things. My head and eyes felt swollen as if I were drunk. My hair is falling out. My thinking slowed down. Symptoms worse when I was with others, better when I was alone. Whenever I did anything I had no confidence. I think because of the disease I lost my youth and much time and everything. I grieve for my lost health. I had to work a lot every like the others, but I had no hope in what lies ahead always thought there was nothing I could do.*

Two years latter, she stopped seeing her friends and attending in social life activities like 'Idir' and burials. She kept herself isolated, just staying home with her children. Though physically she was fine, she had no one to talk to, no one to share her worries with. She made unsuccessful suicide attempts three times. Those four years, she says, were the worst years of her life; her previously active social life was at a standstill.

### **The Turning Point**

In September 2003, for reasons she can't explain, it suddenly hit her that she had HIV. She closed the curtains, stayed in bed and for four days couldn't bring herself to go to work. Aster had worked at the same office for 16 years. She had good friends at work. But now she wouldn't take their calls. When one of her coworkers stopped by to visit, Aster pretended nobody was home; she hushed her children and wouldn't answer the door.

But when her coworker Emebet (not her real name) came to check up on her, it wasn't as easy for Aster to ignore her. In the mean time she was trying to commit suicide, which later failed. (Aster showed the researcher the final letter she wrote (to whom it may concern) which reads:

*I am responsible for my death. I want to say good-bye to you and just try to understand that this is my condition, this is why I really want to end my life, I just don't want to go on living... Is it just the depression, or is it my whole life and the fact that I am no longer satisfied with it, to go on living and to go on suffering this illness and to go through the rejections and the stuff connected with HIV and AIDS. I just don't want to do it... I just hope I will be able to do it, I hope I will not fail this time around... I know I've been very innocent and faithful. But looking back, I do have many regrets throughout my life. Forgive me my children.*

Emebet banged and banged at the door. She kept shouting, "I know you're in there!" Finally, Aster reluctantly opened the door.

A normally outgoing person, she was silent. Her house was dark. Still in her robe and nightgown, she just looked numbly at her friend. "What's wrong?" Emebet cried over and over. "What's wrong? You haven't even showered! What's wrong?!"

Finally, Aster could stand it no longer. She broke down and sobbed out the story right in the doorway. Together they then walked to her room, sat on the bed and cried. As Aster tells it, Emebet, noticing how listless Aster was, pulled her into the shower-- and pushed her in, clothes and all.

Aster recalls yelling, "What are you trying to do?" "You going to shake out of it!" Emebet responded, "It's not like you're going to die tomorrow! What are you going to do with these boys? You've got to think about your boys! You have to do it for them!"

"That's what made me snap," Aster says: trying to figure out who would take care of her boys if she died. Her parents? Her sister? Maybe-- but

she knew that no one could take better care of her kids than she could. "Life is too precious to let it go just like that," she says. "I started out slowly," she admits. "But eventually I got my self doing what I had to do."

What Aster says truly changed her life was the special support group for HIV-positive women run by Tilla Association of Women Living with HIV/AIDS. "Talking to these women helped me a lot emotionally," she says. "They showed me ways to deal with the disease. Just by going to the groups and being inspired by the older people and younger people. I kept saying, if they can do it, why can't I?"

Two years after joining, Aster still goes to the group at least once every few weeks.

Soon after she started reaching out for help, Aster finally decided to tell her children she had HIV. One Sunday evening, she gathered her boys into the living room and told them she had a chronic disease called HIV. Although they asked her questions, she says it took time for it to sink in. Her sons had the most difficult time coping with her diagnosis, but they're now completely supportive.

She also told her parents. Though it was heart wrenching, she has no regrets about telling her family. "You carry something so heavy for so long," she says. "It was such a relief to stop carrying this secret around with me."

### **A New Life**

In that year of momentous changes, Aster also decided to quit her job, accept a reduced pension and live on renting some rooms in her house. It was time for her to take care of herself. Her HIV infection had begun to progress and she had stopped feeling healthy.

Before she left work, though, Aster decided to tell eight close work friends that she was HIV positive. They reacted so much better than she imagined, she says. *“I got all kinds of prayers and compassion from them. I could've kicked myself for not speaking up sooner. There are people out there who care, and I didn't give them the chance to show it!”*

During this time, she began HIV treatment; it consisted of two medications. Although she suffered through various side effects including a skin rash and headaches and high emotional disturbance, her health was quite well at the time of this interview.

#### **4.3.2 Case 2: The Case of Daniel**

During this interview, Daniel was thirty one years old. He was tall, sturdy and handsome with an attractive posture. It has been six years since he knew his positive HIV serostatus. He is a member of the executive committee of Down of Hope Association of People Living with HIV/AIDS, Awassa branch. He started narrating his psychosocial experience of living with HIV virus saying, *“Now that I am alive and quite healthy, no infections, no illness, no worry, pretty much a “normal” life. But it's a normalcy that comes with a price, and that price presents itself in many forms.”*

Daniel was an accounting graduate of the Commercial College in Addis Ababa with a diploma and had been working in one of the international NGO's here in the capital. Though he was a member of a well-to-do family, since his father was an engineer and his mother a businessperson with one of the boutiques in the city, he lived on his own for personal reasons. He was acclaimed by his family and neighbors for his decent and stable behavior. Well paid as he was, he had a decently furnished three-room house in the center of Addis. He also had a

beautiful and well-educated girl friend who visited his home at least once a week.

In the course of his employment, Daniel had an opportunity to go abroad for a scholarship, which was a turning point in his life. He resigned from his job as soon as possible in order to having enough time for personal arrangements in addition to completing the processes necessary to leave the country.

To have enough money for airfare and other payments, he sold his automobile including most of his household articles. He also asked his fiancé to marry him immediately. She refused his request without giving a reason and betrayed him by disappearing from that day onward. He did not know her whereabouts till the date of this interview.

Since Daniel was very eager to go abroad, he started the process for his immigration visa as soon as possible. At this time, having completed many of the requirements successful, he was sent to a laboratory for HIV test which came up positive.

This was totally unexpected news, especially for a 25-year-old young man who was reserved, quiet, and softhearted like Daniel. He fainted and fell on the ground on hearing his test result. He remembered how he felt:

*One could say that I started liquidated while I was still in the compound of the testing laboratory. At first I was in a state of shock and felt numb and confused. I felt detached—as if I were watching a movie or having a bad dream that did not end. I immediately started projecting my own death – a horrible, ugly, lonely fate that could start at any moment.*

Since he was unable to stand and walk on his own, he had to be carried to a nearby taxi terminal and escorted to his house by some people who

had also been at the laboratory to have HIV tests. The next morning, still unable to eat, drink, talk, or walk, some relatives and friends took him to one of the biggest hospitals in Addis Ababa. Not long before at the same hospital, he had been told that he was very healthy, having had a number of examinations and laboratory tests. Although he was labeled healthy, he knew he was not feeling good for several months after his diagnosis. He expressed his experience as:

*After three months, the initial shock had subsided, but another emotion began to take place. At the time I didn't know there was a specific medical name for what I was feeling. I thought I was just nervous, very nervous. The feeling descended on me when I thought what was happening to me. I started sweating, my heart began to race, and I couldn't seem to breathe.*

*I felt overpowered by sorrow and intense grief. I was suffering from tremendous confusion, pain, and some guilt in anticipation of my death, sooner. I often cried uncontrollably for a long time. I felt a deep sense of shame and regret, because I had made a decision (to have unsafe sex with his fiancé) that turned out to be a mistake. But everyone does that -- everyone makes that kind of mistake. I felt it wasn't fair that I had HIV, so I just pretended that I didn't for as long as I could. As when I could no longer pretend, I felt like "I might just as well be dead." I can't tell you what it is to like to live with the feeling of "death" looming over your shoulder daily.*

After carefully checking Daniel's situation which could not respond to medical treatment, the doctor referred him to one of the counseling and social services giving organization for psychosocial support. There, he was given counseling services which made him feel better. This time his health partly recovered. He would learn how to develop positive attitudes towards life and was repeatedly advised not to feel bitter towards past events. He was told in general, what to do and what not to do about HIV/AIDS. He was also advised to pursue his job or find another. Yet, his

response was, *“No need to take a new job because I would never last long to see it through.”*

However, he did not stop his worries. He was worried about his future, because of fear of death and fear of stigma. He totally isolated himself from friends and acquaintances. Actually it seemed, he had slowly been developing a moderate major depressive episode, with symptoms of early morning wakening, depressed mood for most of the day, diminished interest for almost all daily activities, strong feelings of guilt and worthlessness, and suicidal ideation. He stopped attending what he termed *inefficient* the psychosocial service he was receiving for about three months. He spent most of his time drinking in his closed room. His words run:

*However, within four months, the depression began to rear its ugly head again and by this time, I thought I was condemned to spending the rest of my life hopelessly, depressed and despondent. I couldn't remember a time when I did not feel sad and I began to question why I was still alive. Every social commitment became a burden. I even avoided my family even during the holidays. I found that the only time I was not unhappy was when I was asleep and having those vivid dreams. I spent most of the time drinking and crying.*

*My being drunk made the feeling away, but eventually, I was running out of money. I felt so scared and alone that I wanted to die. Then a certain recurring idea came to me: instead of dealing with money, family and this ugly virus, I would just kill myself.*

*Soon I turned to anger. I was angry that I was going to die, angry at my fiancé, angry at all the people around me that were going to keep on living normal lives while I was dying of AIDS, angry at my foolishness to bring HIV on me.*

In the mean time, with the idea of maintaining his peace of mind and building up self- determination to cope with his condition, two social workers from the PLWHA social service support group tried to help Daniel. He was also encouraged to create close contacts and relationships with some members of a support group for people living with HIV.

However he persisted on his inner idea of committing suicide. He went to Awassa and attempted suicide by consuming a rat poison, though he did not die. He preferred Awassa thinking that he was far away from home and nobody would support him. After that he had some experiences from his family members, though highly subtle, which made him realize that he was no more the same person he was. Knowing his HIV serostatus, his relatives did not do much to help him. One of his relative said, *"Why are you in a hurry? You are already destined to death."* Again, he went to Debre Zeit, collected sleeping pills, took a room in a lodge and consumed the tablets. This time also he did not die, but was admitted in hospital with toxic effects of the drugs. Again, the relatives were informed. Though they took him back to home, he had become sensitive to the subtle experience of avoidance.

Somewhat a year later, once again he left home and cut the vein in the wrist in a hotel room after consuming alcohol. The reason for this detachment, depression, hopelessness and loss of affection was created not only by the impending death, but also by the attitude and behavior of close relatives.

### **The Turning Point**

After a while, he joined a support group formed by people living with HIV. This time his life started to be changed rapidly:

*It still amazes me whenever I think of it. Suddenly, I was surrounded by people who wanted to help me. People who are like me. People who know how it feels to be HIV positive. I felt I was not alone. ... people who were willing to go the extra mile to ensure my survival. And it all happened simply because I changed my mind about living. I just changed my mind. In an instant, it seems, I no longer thought of myself as someone who was dying. I thought of myself as a survivor*

*I began to have an appetite. I started feeling new energy. I wanted to joke and laugh and dance. And I did! I began living again. And, greatest of all, I met a wonderful man, a friend and a colleague now -- a man who wanted nothing more than to help me live. A man who showed me I could not only live, but do something valuable ... both more and better than ever.*

### **A New Life**

After two years of psychosocial suffering, Daniel started a new life with an indispensable role of helping others with the same experience. Being a part of the support group, he could find meaning in life by doing social work. He underscored the importance of HIV support group in changing one's life. Being religious has also helped him profoundly:

*I am a very spiritual person, and God has been so good to me and has brought me through so much. That's for sure. I am truly grateful that God allowed me to see a better day. I don't take things for granted anymore. When God allows me to wake up and see another day, I take full advantage of it. I work in this field because it helps me to see, to stay grounded and to not forget where I come from. It's also about me giving back to someone else.*

### 4.3.3 Case 3- The Case of Almaz

The researcher found Almaz at Dilla branch of Down of Hope Association of People Living with HIV/AIDS. At the time of this interview, Almaz was separated and had a four-year-old daughter. It had been two years since she diagnosed for HIV.

Almaz was born in Robe town in 1984, Bale Zone, Robe town. Since her mother died when Almaz was six, her father who lived with his three sons and another wife brought her to Shashemene town. At the age of twelve she was forced to marry one of the Noble in her area. She refused and left for her relatives who lived in Jimma. Again the environment was not conducive for her so that she left to the near by urban center and joined the sex industry as a bargirl.

As she recalled after few days of stay, she lost her virginity in the bar. Five months later she noticed that she had been pregnant and no more needed by the bar owner. She went back to her father but thrown out. Then she went to work as a housemaid. She was full of tears when she recalled that her first child had died of malaria because she had no enough time to look after him.

At 15 she again joined the bar in Nazareth. Some five years back she met a man at the bar who said to be a merchant and who offered her two hundred birr for a night.

Happy with her money, Almaz dated him time and again. She finally accepted his offer for marriage and moved with him to Della town which is about 350 k.m south of Addis where she gave him a birth of a baby son. They lived for two years in good marriage life.

For her unfortunate life, something strange has happened after two years in her health for which she was dangerously ill and forced to visit Dilla

hospital. The symptoms of her illness were dry cough, night sweat and low-grade fever. She was diagnosed as having pulmonary tuberculosis for which she was treated but to no avail. She was advised to get a VCT which turned HIV positive serostatus.

Expressing her reactions, she said to be felt lonely, sad, angry, and desperate about her ill health and about her fate, abandoned music, and people. Sometimes she feels guilty and blames herself for her situation; at other times she blames her problems for causing her feelings of isolation, joylessness, and occasionally hopelessness. When her husband knew her HIV status, he fled to Moyalle Kenya selling all his property secretly and leaving her together with the baby alone.

Despite some financial support she received from the Dilla branch of Down of Hope Association of People Living with HIV/AIDS, her psychological tortures recurred for about six months. Her words run:

*I always felt deserted, being abused to death, and extremely sad about my fate. His (her husband's) family made me liable for his losses and stigmatized and discriminated me subtly. I feel headaches, dizziness, don't like to talk, take no pleasure in things. My head and eyes feel swollen. My hair is falling out. My thinking has slowed down. Symptoms are worse when I am with others, better when I am alone. Whenever I do anything I have no confidence. I think because of the disease I have lost my youth and much time and everything. I grieve for my lost health. I grieve for this unlucky child. For the first time in my life I seriously thought about killing myself. Obviously I didn't try, mainly because I was afraid I wouldn't succeed, and what will be the fortune of my baby whose father abandoned.*

## **The Turning Point**

After a while, Almaz joined a support group formed by people living with HIV. This time her life started to be changed rapidly. Thanks to her Christian friends and the counselor she lessens her negative thinking and started to live positively. In addition, she has been given the chance to receive trainings and to teach others particularly the commercial sex workers about HIV/AIDS. She got married to one of the individuals who lives with the virus and is a member of Down of Hope Association of People Living with HIV/AIDS. He accepts her and her child who is HIV negative unconditionally.

## **A New Life**

During this time, she began HIV treatment which has rapidly changed her health. Although she suffered through various side effects including a skin rash and headaches and high emotional disturbance, her health was quite well at the time of this interview. After years of psychosocial suffering, Almaz started a new life by disclosing her HIV positive serostatus and identifying herself with others living with the virus. She teaches from her life experience which gives her a psychological relief and peace of mind. She underscored the fact that many commercial sex workers particularly face psychological problems like her a special attention should be given to their psychological and economic need.

#### **4.4. Results of the Focus Group Discussion**

The first issue raised in the focus group discussion, as a point of departure, was if they suspected a positive result and how they reacted about their HIV positive result.

When participants were asked whether they suspected that they were HIV positive before receiving the test result, nine said that it had not occurred to them that they might be HIV positive. Five male and five female participants identified being diagnosed HIV positive as a traumatic event in their life. What is perhaps striking is that about half of the participants did not identify their HIV diagnosis as a major event.

Three participants reported that they were notified of their HIV status in an unsympathetic manner. Two participants reported simply being left alone after being told, while others were given inadequate information about the virus and its effects. Most participants knew very little about HIV: they believed only that they would soon die, leave their children to grow up alone and never be close to anyone again. They feared rejection (the stigma) and did not want to share the HIV diagnosis with their family or friends for a certain period of time. Some participants were indeed viewed as a "disgrace" to their family once they told their family about being HIV positive.

#### **Experience of Depression**

All participants of the focus group discussion said depressive feeling was one of the most painful feelings a person could have. The participants of the focus group discussion reported that they often felt depressed or guilty or they disliked themselves whenever they thought of their HIV positive status. One of the participants said that she felt hopeless and

stopped seeing her friends for three months. She said, *"I wonder what I'm going to do when I get sicker. I get confused. I get drastic thoughts. I sit in my chair and cry. I get real depressed."*

Most of them said they felt alone and helpless in an indifferent world. They said there were moments in which they lost interest in things, had no energy, and felt generally tired. They were also moments in which they felt empty and uninterested in things they are normally interested in. All reported they felt lonely and alienated from their friends, relatives, neighbors, co-workers sometimes in their life after their HIV diagnosis. They doubt themselves or blame themselves or felt they have failed. One female participant called it *"drastic thoughts"*: she frequently thought about dying, sometimes about killing herself. She said she often felt, *"I wonder why I need to visit a doctor. I think, may be they'll come up with something that will help, but I don't think so. You start to wonder why you're going to the doctor, why take the medication, why fight for another month, another year, just to be sick longer."* Another male participant also said, *" I don't remember a time I ever felt totally happy the day after I learned my HIV serostatus."* Another female participant blurted out, *"I thought about killing myself this week,"*

Some participants reported they could not think as clearly or quickly as they used to. One participant reported eating too much. He said he ate too much thinking he had to finish all his money before he died; he gained eight kilos in two months time.

Some could not sleep too often. One participant expressed her inability to sleep in the morning saying, *"I wake up some early mornings and for no reason just and be really down"*. Some said they were mostly sad and lonely, and they often cried a lot: *"For a while, I cried all the time. I didn't want to cry in front of my family. I cried when I was alone in a toilet, or while walking."*

### **Experience of Anxiety**

Participants reported to feel anxious and not to experience a proportional degree of worry because their families and significant others do not want them to worry and encourage them to be positive. In other words, they did not have permission within the family to feel appropriately worried or upset. So they fear to express their feelings. Many Participants reported that they felt they are letting others down when they acknowledge or show negative feelings. They tried to protect their family and significant others by adopting a positive demeanor and seldom showing their true feelings. They know how worried and upset the family and significant others are, and do not want to contribute to that by expressing his or her own worries. This is another challenge they bear in addition to the illness.

Participants said that they felt anxious and guilty about the impact of their illness on their families and significant others. They dare not show how worried or upset they are because the resulting distresses within the family and significant others would create a burden on them to make family members and significant others feel better. Still others said not to show their emotions because they fear that others will not respond with appropriate support; thus, they would end up feeling rejected and hurt in addition to feeling upset over their illness.

### **Experience of Stress**

Participants discussed some of the stressful situations in their day to day life. Thoughts of death were frequently brought up during the discussion. Several participants seemed consumed by the belief that they could pass away at any moment. The participants knew many people who died from AIDS including friends and their association members. Visiting sick friends and taking care of them always reminded them of their death. One female participant said, *"I was always preoccupied with the thought*

*of how awful my death would be when I visit sick friends of mine.*" Watching friends sicken and die from AIDS has had the effect on many of the participants of forcing them to begin to face the reality of their own mortality of HIV or AIDS. This often was a dreadful experience according to them.

They reported that either they experienced or they knew members in their association several families in which two or more than two family members died from AIDS in less than a year. Many participants experienced multiple AIDS-related deaths, leaving the surviving family members anxious.

According to the participants, the impact of being so surrounded by people who are in the final phase of their lives, or who have died, can understandably result in the surviving individuals feeling very shaken, sad, depressed angry and vulnerable. This sense of fragility and vulnerability would be heightened if the surviving people are themselves at risk of succumbing to the same condition that killed the people they loved. Living in the midst of this can impact upon a person in several ways. They reported to be overwhelmed with despair and hopelessness that they became withdrawn and give up on any hope for a meaningful quality of life. Some became so depressed as a result that they were incapable of accomplishing the things they have decided were important.

### **Experience of Fear**

Participants in the focus group discussion expressed fear of different sort. They reported to fear and worry about symptoms that may or may not be serious. They feared being a patient in a hospital, or undergoing painful medical tests and procedures. They feared dependency: *"I have a tremendous fear of being bedridden and others caring for me,"* said one participant. Most of them feared rejection. Another participant was afraid that people would treat him as though he had leprosy. Still another said she was fearful of telling her sisters who lived abroad about her

serostatus though she is an HIV activist. Some participants reported being afraid of giving someone else the virus (contagion) especially for a care taker.

One of the focus group discussion participants said she was very disturbed that she could not speak to her children who lived in a rural area with their grandparents about her HIV status. She thought that she would be rejected even by her offspring. Some reported worrying about dying and being forgotten. They felt pain about not having a legacy to leave behind for the children, not even memories.

Participants reported to fear what the infection might do to them: they fear becoming blind, or losing their 'cognitive abilities' (my relative translation). Some said they feared dying. They said they feared not death, but the way death comes. *"I could handle dying,"* said one female participant, *"if I knew how I might die. My biggest fear is what the end will be like."*

### **Experience of Stigma and Discrimination**

All participants reported that there have been declines in the prevalence of stigma and discrimination they have been facing. According to their information, although the severity has been considerably declining, they recounted some experiences of stigma and discrimination. The researcher summarized their experiences as follows.

Criticism of the ineptness, uncaring behavior, and negative attitudes of physicians appeared frequently in discussions. Physicians and occasionally other health care personnel, such as x-ray technicians, became concrete and localized sources of stigma. A male participant recounted his experience of stigma and discrimination in a hospital as: *"The staffs in the hospital were looking after me very well, but after they*

*tested my blood for HIV their behavior changed and they became reluctant to take care of me."*

A female participant discussed that she had earlier been rejected by the relatives and the community, but after she went public and declared her serostatus, those who had deserted her now come for assistance and guidance on how to cope with AIDS. She said, *"They avoided me. They made my reputation sullied. They called me names, laugh at me, jeer at me, and I had no other option than changing my home town."*

A widow explained her experience of stigma and discrimination by her husband's family although she knew he brought the virus to her through an extra marriage relationship: *"My in-laws blamed me for their son's death. They have severed all relationships with me. They never discriminated with their son but to me. After his death, they took most of our possessions with different pretexts."*

Male participants in the discussion reported that there is a general lack of understanding and compassion towards the HIV positive. One participant said *"There's still a stigma; we're treated like lepers. I don't look at it any different than cancer, really, and people with other illnesses are treated with respect and compassion. But we're still fighting for that compassion."*

### **Experience of Utilizing Coping Strategies**

There were varieties of coping strategies discussed by the participants utilized to lessen their psychosocial challenges. One participant said he reads novels, biographies, science, philosophy or poetry. One female participant shared her coping experience saying, *"I usually notice depression when I hit the house after work. Then I find things to do, to keep my mind relaxed. I dig in the dirt. I walk anything physical."*

*Sometimes I go to church and listen to the Word of God. Read the Bible, help someone else."*

Some of the participants said they try to deny the event and think as if there is nothing happened to them. One male participant summarized his experience saying, *"As far as I can, I don't want to give myself a chance to think about the problem and my HIV serostatus decided to forget all about it. I make myself busy by working at home and making a walk at the Lake's beach (Lake Awassa).I try my best not to be alone so as to avoid any bad memories."*

When most participants spoke about occasions when they felt supported, accepted, and safe, it was most often when a friend, family member, or health care provider took the time to listen to their story, validate their experience, advocate for their needs, and respect their autonomy.

Two male participants emphasized the role of drinking as a coping mechanism. One of them mentioned the Bible's saying, *"Give strong drink to him who is perishing, and wine to those who are bitter of heart. Let him drink and forget his poverty, and remember his misery no more,"* (NIV Version,1973) discussed how important drinking alcohol was in minimizing his depressed mood.

Participants emphasized the benefit of the social support they got from their umbrella associations. Participants explicitly expressed their desperate need for social contact or activities to help cope with the extreme isolation of many individuals. In part this isolation was self-imposed due to shame from HIV stigma or from depression accompanying ill health and fear of death. In part the isolation stemmed from rejection by family and friends. But the social support

they got from the members in their umbrella association gave them a paramount importance.

The need for social support in coping meant different things in the various groups. Some identified the need for emotional support in coping with the disease, the need for more support groups, and the need for support for people caring for those with AIDS. Other participants referred primarily to the need for professional support for coping.

Some participants said to be supported by their religious beliefs. These beliefs helped them find peace and forgiveness. A male participant said: *"You do not expect much help from people. You do not even think of negative ideas. All you need is God to talk to you. You should never get away from Him. He really is the entire friend you need if you use it right."*

One female participant used to think negatively about life, but she now believed that having God in her life helped her to *"have a lot more positive to look forward to .He's given me a lot more love in my heart. Forgiveness for things that I may have never forgiven people for."* Still another female participant said, *"Whenever I feel down inside, I start to pray and feel that God has already forgiven me. I tell myself that I have a place in heaven. Thus, I feel good and soon forget my impediments."*

### **Other Related Psychosocial Issues Raised on the Way**

Although the participants were not prompted, they raise some important psychosocial concerns on the discussion which the researcher briefed in the paragraphs below.

For the participants, finding adequate housing and something to eat outweighed their concern for the disease. They mentioned unemployment and being idle as one of their challenges. Most of them did not have something to spend their time on. They were unemployed or did not go to school. Other challenges reported included finding physicians with

expertise in HIV, access to clinics, nutrition, and treatment for depression and related psychological problems, information about HIV, relationships with health care professionals, and dental care.

Some participants of the focus group discussion pointed out that adherence to antiretroviral medication and medical regimen was often a significant challenge. Some of the reasons include: the complicated and confusing regimen of the medication, forgetting to take the medication, change in ordinary schedule such as working late or arriving home late from an appointment, its negative side effect on their mood, and lack of money for transportation to go to the hospital which is about fifty K.ms away.

One negative effect of living with HIV according to the participants was its effect on one's ability to work or volunteer because of episodes of illness and general lack of energy. All the participants wanted to teach others. For several participants, however, the sheer lack of energy to do any activity for more than a few hours was the most frustrating symptom of living with HIV. This lack of energy made working difficult. Inability to work or be active in the community left them lonely and diminished their self-worth.

Despite this, however, most participants said they found meaning in having HIV because they were now in the position to educate others, especially the young, to avoid risk factors. Focus group participants actively sought ways to break or disrupt the stigmatizing impact of HIV. Public education was one of the most prominent strategies.

Significantly, participants relied on education not only to reduce the condemnation of others through increased empathy and compassion, but also to enhance their ability to cope with the stigma through improved understanding.

## CHAPTER FIVE

### 5 Discussion

The major purpose of this study was to investigate the psychosocial challenges of people living with HIV/AIDS. It has also attempted to explore different strategies that they adopted to manage their challenges. Of the various psychosocial challenges PLWHA proved to experience, a focus was given to investigate the prevalence of depression, anxiety, stress, fear, stigma and discrimination, and coping strategies

In this section, the findings of the study are discussed in light of previous findings.

To start with some background information of the respondents that has some interesting implications for the findings of the psychosocial challenges of PLWHA, most of the participants were from a very low socioeconomic status (62%) of the respondents lived on less than 300 birr a month which might have intensified the psychosocial challenges PLWHA face. About one third of them (35%) were unemployed. Above all, most of the respondents were found to be young with a mean age of (30.8) and 66% of them below 30 years old. Thus, consistent with previous findings, the participants were predominantly young, (Kelly, et al, 1998) with very low and precarious financial situations (Kelly, et al, 1998; Ammassari, et al, 2002; Wagner, 2002).

Becoming infected with HIV at a relatively young age will radically change people's expectations for their future, at a time in life when they would normally be establishing their independence, relationships, careers and lives separate from their families. According to Erickson's individual life cycle (1963) cited in(Champion and Power,2000), these are the adolescent and young adult years when people first struggle to establish a sense of identity, and then leave home and begin to establish intimate

ties with other people through marriage, collaboration or other important intimate relationships. It is not a stage of life when people expect to deal with a life-threatening illness, and they may not have the emotional, social or financial resources to do so. This finding, thus, implies how vulnerable the respondents' age is for psychosocial challenges.

This finding suggests for a due attention to be given for PLWHA. Social and economic concerns are particularly important to PLWHA because low income, lack of private insurance, unemployment, and low education level are predictors of poorer health and poorer psychosocial effects particularly, depression, anxiety and stress (HIV/AIDS Bureau, 2004).

### **Depression**

In this study, it was found that more than half of the participants (56%) reported significant symptoms of depression, and about one fourth (27.5%) of the respondents had scores in the range indicative of probable depression. This indicates elevated depression prevalence among the participants. This finding is consistent with more recent findings. For example, (Morrison et al., 2002; Heckman et al., 2004) found out even higher depression prevalence among PLWHA. 54% of HIV positive subjects were found to have symptoms of depression (Morrison et al., 2002), and Heckman and colleagues (2004) reported that 60% of their HIV positive sample had significantly elevated depressive symptoms.

Although a comparison was not made with HIV negative subjects in this study, other findings indicate that major depression in HIV-positive population is elevated about two fold above those in healthy community sample (Chandra, Ravi and Desai, 1998). According to the study made by Morrison et al. (2002), HIV positive subjects were found to have a four-fold increased risk for depressive disorders than noninfected persons.

The study conducted at the specialty HIV clinic at a tertiary care centre of south India (Chandra , Ravi and Desai, 1998) reported that 40 per cent of the seropositive individuals studied suffered from syndromal depression. Majority (90%) of the PLWHA who had depressive symptoms also had prominent anxiety symptoms and fulfilled the ICD-10 criteria for generalized anxiety disorder.

These findings suggest that depression is extremely common in people with HIV virus – it is probably the most common psychological effect after HIV diagnosis.

Other findings such as that of (Fernandez and Ruiz, 1989; Fernandez and Levy, 1991; Burack et al.1993) indicated that the reason behind the high prevalence of depression in PLWHA is that diagnosing depression in PLWHA is complicated by several factors. First, the AIDS dementia symptoms of apathy, social withdrawal and decreased cognitive efficiency may be mistaken for signs of depression. In addition, both depression and AIDS dementia complex may be present. Another factor that complicates diagnosis is side effects of some antiretroviral therapy, which may include lethargy, insomnia and dysphoric mood. Physicians may and psychologists also erroneously view depressive symptoms as a "natural" reaction to being diagnosed with the virus and not aggressively pursue treatment of the depression. While depression may not appear to directly affect immune status as measured by CD4 counts, it is likely to contribute to a poorer quality of life and a decreased likelihood of the PLWHA's seeking appropriate medical and psychological treatment. This finding suggests that depression in PLWHA has to be treated using a psychological means separated from HIV treatment.

In this study, a significant difference was also found between depression result of males and females ( $t=2.496$ ) with a higher depression result in

females than in males. This is consistent with the findings by (Franke GH, Jaeger H, Thomann B, Beyer B1992.; Kennedy CA, Skurnick JH, Foley M, Louria DB. 1995). The difference in depression levels could be attributed to disparities in contextual and sociocultural issues, such as poverty, childcare responsibilities, responsibilities for giving care to others infected with HIV, and the differential stigma and social isolation that women living with HIV experience. Recent data from the HIV Epidemiological Research Study in USA, a prospective investigation of the natural course of HIV in women, also documented depression in up to 62% of HIV-positive women participating in the study at baseline. Depression scores over time in this 4.5-year study were significantly related to CD4 (t-lymphocyte cell) count and viral load and to HIV-related symptoms (Summers et al., 1995). Results such as these indicate that women diagnosed with HIV experience more elevated psychological concerns than men with HIV and emphasize their need for psychological treatment and support.

The findings through the qualitative data of this study also indicated the presence of episodes of depression on the participants particularly on the individuals in the case study. This finding is consistent with the study of Sarna & van Servellen et al. (1999). In this study, depression was mainly noted in the psychosocial domain and included financial problems, worry about the family, distress about losing others from HIV, and worry about disease progression. The most pressing physical disruptions included reduction in energy, difficulty with daily activities and frequent pain. When first diagnosed, most people feel depressed and might engage in self-destructive behavior.

Among the participants in this study, 76.0 percent expressed thoughts of death, 9 percent reported persistent suicidal ideations, and 41 percent reported unfrequent thoughts of suicide whereas all the participants of the case interview had made persistent attempts to commit suicide. Notably all those, who had attempted suicide showed

symptoms of depression. All the suicide attempts were made during the first two years after revelation of the seropositive status. This presence of suicidal ideation may indicate the presence of psychosocial factors hampering the positive living PLWHA. Suicide is a complex biopsychosocial outcome of depression, hopelessness, isolation and lack of support (Morrison et al., 2002; Kelly et al., 1998). HIV infection with all its negative connotations and discrimination can be a harbinger of future suicidal ideation or completed suicide. Several factors have been associated with suicidal ideation among PLWHA. Promiscuous life style, partner's HIV status, loss of an infected partner, past history of deliberate self-harm and presence of physical symptoms have been reported as risk factors (Demi et al., 1998; Kalichman et al., 2000). Some of the psychiatric variables predicting suicidal ideation include concurrent substance abuse, past history of depression and presence of hopelessness (Santosh, 2004). These results, thus, underscore the importance of assessing the PLWHA suicidal situations to ascertain their overall psychosocial well-being.

### **Anxiety**

In this study, it was found that (40%) of the respondents experienced clinically significant anxiety symptoms with a mean BAI score of 32.31 (median = 29.4; SD = 8.14; range = 7-59). This result is more elevated than the findings in the western countries like U.S.A which ranged from 29% - 38% (Perkins et al., 1994; Kantin et al., 1998; Fernandez and Ruiz, 1989; Fernandez and Levy, 1991) and somewhat consistent with findings in India which was 36 - 40% (Chandrasekhar et al., 2000). Consistent with other findings (Perkins et al.; Kantin et al., 1998), the proportion of women with anxiety was not significantly different from that of males ( $t=0.462$ ). In a study by (Kapalan, Marks, and Mertens, 1997), however, it was found out that 43% of the women in the sample screened positive for clinically significant anxiety symptomatology which is a bit elevated.

In comparison with the western studies, the number of individuals diagnosed as having anxiety disorders in this study was higher. It is notable that the sample in this study differed from that in the western studies in terms of recruiting a very small number of PLWHA. Economic factor could account for the higher rate of anxiety disorders. In addition, cultural factors like stigma, relative lack of appropriate treatment facilities, and poor access to the health care and low educational level could have significantly contributed. Since the individuals were assessed for anxiety relatively soon after revelation of HIV status (mean time lived with the virus= 4.44), it could also account for the higher incidence of anxiety disorders in this study.

The findings of the qualitative data of this study also indicated the presence of episodes of anxiety on the participants particularly on the individuals in the case study. All the three individuals in the case study considered received their HIV positive test result with great shock and confusion. This finding is consistent with other earlier findings. "Initially, these necessary behavioral changes seem so daunting that some HIV clients consider them equivalent to a death sentence (Adams, Sears 1996)".

The findings in this study suggest that anxiety has become very prominent among PLWHA (Fernandez and Ruiz, 1989; Fernandez and Levy 1991). Anxiety may manifest throughout the course of HIV infection. Many of the medications used in treatment of HIV/AIDS have been reported to cause anxiety as a possible side effect. Psychoactive substances, both prescribed and recreational, should also be considered *in evaluation of anxiety*.

### **Stress**

This study found out that half of the respondents (50.5%) experienced stress scoring above the mean. The mean score of the respondents was 24.52 which is greater than the cutoff point (which is 19 for a research

purpose). There was no statistically significant difference found between male and female participants.

There may be different factors which step up this elevated stress. HIV is often fatal, is accompanied by other related illnesses, its cure is uncertain, has a mysterious origin and has been associated with groups that were already stigmatized in other ways.

Being HIV positive by itself may also cause more stress because it can be passed between sexual partners, among people who inject drugs and from a mother to a child (during pregnancy, childbirth and breastfeeding). Before blood screening programs were in place, some people were also infected through transfusions of blood or blood products. People who are infected often say that they feel "unclean." They have to deal with the challenges of the fear or guilt of infecting others and with the difficult process of changing sexual and other behaviors to protect others and to safeguard their own health. The sometimes real risk and sometimes irrational fear of infection also creates stress for sexual partners, family members, caregivers and friends (Lehrman et al., 2001).

Other aspects which may intensify stress could be worry about financial dependency on their parents or on the welfare system because they depend more and more on the social service and medical systems. Both systems require PLWHA to give up control, one system over their personal resources, the other over their bodies. The requirements, though necessary, are distressing. People who give over control of their resources and their bodies feel they have little left of their own. They feel powerless, ineffective, and incompetent (Davies, Bachanas, & McDaniel, 2002).

### ***Fear***

Consistent with the finding by (USAID, 2000), this study found different aspects of fear experienced by PLWHA. Fear of loss of reputation of the

family and society and fear of AIDS stigma were found out to be experienced by almost all (93.9 and 93.4 %) of the respondents. All sorts of fears namely fear of death and of dying early, fear of dying uncared for and being denied last rites, fear of being deserted and lose of significant relationships, fear of losing one's job or lose of income, fear of passing the infection to others whether spouse, children, or other family member were found to be experienced by the PLWHA in this study which is consistent with the earlier finding.

The finding from the focus group discussion confirmed that PLWH fear what the infection might do to them: they fear becoming blind, or losing their 'cognitive abilities' (my relative translation). Some said they feared dying. They feared not death, but the way death comes. Because of the stigma associated with the disease, participants specially women with HIV usually feared that they would be rejected or discriminated against. They feared being judged for their sexual behavior or being considered "promiscuous," and they feared being isolated with the illness. Women often feared that they would become the topic for gossip, and that friends they tell may not keep the information in confidence. Many women, particularly those with children, avoid support groups or other women with HIV; because they feared the impact their HIV may have their families.

Fear of passing the virus to children was specially recurred theme by participants who had children to take care of during the focus group discussion and in the case of Aster (cases no 1). In many ways, telling their children about HIV infection is different from telling most other relatives. This may be because they may feel responsible for their children; they want to protect them against fear and worry and life's hard fact. They think of themselves as their children's safe haven, and they want to avoid bringing uncertainty into their lives. As a result, many PLWHA decide to put off telling their children until they have to. This

finding indicates that a parent's worst fear and worry is whether he or she has unknowingly infected a child. Fathers worry that they have infected their children through casual contact; mothers worry that they have infected their children during the birth process. In addition, parents with older children fear being a burden on the children. People can often accept that a friend or relative worries about them. But they are unhappy to think that their children worry about them. The reversal of the normal role of parents and children makes parents uncomfortable; they feel intensely responsible for their children and hate the idea of being told, and do than their parents are. This finding was consistent with other findings on parent- child relationship (De Bruyn, 1992).

This fear further implies that parents specially mothers and a single head of a household, may become too weak to be able to actively take care of their children. The enormity of the loss of being able to care for their children is overwhelming. This naturally contributes to a growing sense of powerlessness, helplessness and worthlessness, since many women derive an important sense of value and accomplishment from their role in life as a mother (Ibid).

### **Stigma and Discrimination**

While capacity-building and non-discrimination have been highlighted as central features of Ethiopia's response to the spread of HIV/AIDS(Policy on HIV/AIDS of Federal Democratic Republic of Ethiopia, 1998), there was clear evidence from data collected through both quantitative and qualitative methods that the rejection, stigmatization, and discrimination of PLWHA by health service providers, family and the community continued. The result of this study indicated that PLWHA experienced stigma and discrimination with an elevated mean score of (32.94) where 41.6% of the respondents scored above the mean. A finding in the focus group discussion also indicated approximately the same number of PLWHA reported having been

rejected by their families and the community as reported having been accepted.

An experience with stigma was found to vary dramatically based on gender ( $t= 6.53$ ). This indicates that females experience stigma and discrimination in a higher degree than their male counterparts. A number of possible explanations could be given for this exaggerated difference between males and females experience of stigma and discrimination some are discussed in the following paragraphs.

In many developing countries, women are already economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. Being outside the structures of power and decision-making, they may be denied the opportunity to participate equally within the community and may be subject to punitive laws, norms and practices exercising control over their bodies and sexual relations. In a number of societies, women are erroneously perceived as the main transmitters of sexually transmitted infections (STIs), which may be referred to as “women’s diseases” (de Bruyn, 1992). Together with traditional beliefs about sex, blood and other kinds of disease transmission, these perceptions provide a fertile basis for the further stigmatization of women within the context of HIV/AIDS (Ingstad, 1990; Peterson, 1990; Mushingeh, Chana & Mulikelela, 1991; Thant, 1993).

There were findings in which stigma was found to be associated with depressive symptomatology; although the associations were not strong, they are theoretically and clinically important. HIV positive subjects were found to have a four-fold increased risk for depressive disorders than noninfected persons (Morrison et al., 2002), and Heckman and colleagues (2004) reported that 60% of their HIV positive sample had significantly elevated depressive symptoms. Therefore, elevated scores in both depression, and stigma and discrimination found in this study might strengthen the consistency this of finding with the aforementioned studies.

In this study, it was also found out that PLWHA experience other psychosocial challenges. Poor housing, lack of transportation and childcare, non- HIV-related illnesses, and the lack of a social support system as common challenges faced by PLWHA. Access to care also appears to be an additional factor facing those affected by HIV. Non adherence to ART medication was also another challenge. Identified barriers for nonadherence included such things as forgetting or an unwillingness to take the medications while in social situations, which were consistent with previously identified barriers (Holzmer, 1999; Proctor, Tesfa & Tompkins, 1999; Paterson, 2000).

### **Coping Strategies**

In this study, it was found that participants utilized a variety of coping strategies to lessen their psychosocial challenges. The most predominantly used coping strategy was prayer to God (mean=4.36), listening to music( mean=4.20) and day dream( mean=3.76).

A considerable number of respondents were found to use substance as their coping mechanism (Chew 'chat' m=2.76; smoke cigarette m=1.64; and drinking=2.13).This particular coping strategies, however, negatively affect the health of the individuals and could be accountable for the alarming progression of HIV related illnesses (Lazarus & Folkman, 1991)

Seeking help from professionals was found to be one of the least frequently used means of coping strategy only next to adhere to ART. This may be because there was no sufficient professional counseling available or participants' knowledge of the role professional counseling service was less. This fact entails the need for a research on this particular aspect.

Findings from the case study and the focus group discussion also confirmed that believing in a higher power and prayer was important for several participants, particularly when they felt there were no people available to support them. The sense of calm gained from these religious or spiritual beliefs was sustaining and sometimes motivating.

Findings of the case study indicated that participants who felt suicidal also benefited from peer support. This implies that the reassurance from someone who has been through the same thing and survived. Friends and other people with HIV can be a strong source of support, because they can relate to the experience of having HIV and help people with HIV see others who are living and coping with the illness.

Findings of this study also suggest that support from friends, family members, and others who care for PLWHA goes a long way in helping them to get by in times of trouble. Social support systems provide PLWHA with emotional sustenance, tangible resources and aid, and information when they are in need. People with social support feel cared about and valued by others and feel a sense of belonging to a larger social network.

A large body of research has linked social support to good health and a superior ability to cope with stress. For example, one long-term study by California University on thousands of residents, cited in (Encarta Encyclopedia Standard, 2004) found that people with extensive social ties lived longer than those with few close social contacts. Another study found that heart-attack victims who lived alone were nearly twice as likely to have another heart attack as those who lived with someone. Even the perception of social support can help them cope with stress. Studies have found that people's appraisal of the availability of social support is more closely related to how well they deal with stressors than the actual amount of support they receive or the size of their social network.

## CHAPTER SIX

### 6 Summary, Conclusions and Recommendations

#### 6.1 Summary

The major purpose of this study was to investigate the psychosocial challenges of people living with HIV/AIDS. It has also attempted to explore different strategies that they adopted to manage their challenges. Of the various psychosocial challenges PLWHA proved to experience, a focus was given to investigate the prevalence of depression, anxiety, stress, fear, stigma and discrimination, and coping strategies.

This research had the following specific objectives:

- To find if the PLWHA experience depression.
- To identify if the PLWHA experience anxiety.
- To point out if PLWHA experience stress.
- To investigate if PLWHA experience fear as a result of their HIV positive serostatus.
- To find out if the PLWHA face stigma and discrimination.
- To find out if the PLWHA face all or any of the divorce; job termination, and school drop out as a result of their HIV positive serostatus.
- To assess the strategies and coping mechanisms PLWHA employ to reduce their psychosocial consequences of their HIV positive serostatus.
- To forward possible prevention mechanisms and intervention strategies to help the PLWHA cope up with the psychosocial consequences of their HIV serostatus.

To achieve the above objectives, the following research questions were formulated.

- Do the PLWHA experience depression as a result of their HIV positive serostatus?
- Do the PLWHA experience anxiety as a result of their HIV positive serostatus?
- Do PLWHA experience stress as a result of their HIV positive serostatus?
- Do PLWHA experience fear as a result of their HIV positive serostatus?
- Do PLWHA face stigma and discrimination?
- Do PLWHA face all or any of the divorce; job termination, and school drop out as a result of HIV infection?
- What are the coping strategies adopted by the PLWHA to deal with the situation?
- Is there any gender difference in experiencing in any of the aforementioned challenges?
- What intervention strategies should the concerned bodies use to reduce the psychosocial challenges the PLWHA face?

In order to find out answers for the above research questions, people living with HIV/AIDS who were members of down of Hope Association of people living with HIV/AIDS and Tilla association of women living with HIV/AIDS were selected as subjects of the study. Data were collected from 200 samples selected using stratified and purposive sampling.

To gather the required information for the study, both quantitative and qualitative methods were used, the literature was reviewed. Four assistants who had experience in coordinating HIV/AIDS related advocacy were recruited. Moreover, training was given to the assistants on the objective, content and ethical issues of the study.

To analyze the data, descriptive statistics and t-test were applied for the quantitative data using SPSS and case studies were analyzed using Colaizzi's procedural steps (1978).

With the help of the interview schedule, the case study and the focus group discussions, the psychosocial challenges and coping strategies were assessed, differences in sex were examined.

Findings were analyzed and discussions were reported on the basis of existing literature.

## **6.2 Conclusion**

In this study, an attempt was made to investigate the psychosocial challenges of people living with HIV/AIDS particularly the case of depression, anxiety, stress, fear, stigma and discrimination, the coping strategies utilized by the participants. Therefore, based on the findings, the study has come up with the following conclusion.

- PLWHA experience depression. In this study, it was found that more than half of the participants (56.0 %) reported significant symptoms of depression, and about one fourth of the respondents had scores in the range indicative of probable depression. The findings through the qualitative data of this study also indicated the presence of episodes of depression on the participants particularly on the individuals in the case study.
- It was also found out that the majority (40%) of the PLWHA experienced clinically significant anxiety symptoms.
- This study found out that half (50.5%) of the respondents experienced stress scoring above the mean where the mean score is more elevated than the mean score of the norm

- This study found out different aspects of fear experienced by PLWHA. Fear of loss of reputation of the family and society and fear of AIDS stigma were found out to be experienced by almost all of the participants. Different sorts of fear namely fear of death and of dying early, fear of dying uncared for and being denied last rites, fear of being deserted and lose of significant relationships, fear of losing one's job or lose of income, fear of passing the infection to others whether spouse, children, or other family member were found to be experienced by the PLWHA.
- PLWHA also experienced other psychosocial challenges such as poor housing, lack of transportation and childcare, non- HIV-related illnesses, and the lack of an appropriate social support system.
- PLWHA used a variety of coping strategies. The most often utilized coping strategies identified by the participants were: praying (m=4.36) followed by, listen to music (m=4.21), day dream(m=3.76) , try on your own to deal with the problem(m=3.75), talk to a close friend(m=3.21), think about good things(m=3.04) learn more about the problem(m=2.98). The participants also reported low utilization of certain maladaptive coping strategies such as alcohol and chewing 'chat'. Getting professional counseling was one of the least utilized means of coping.

### **6.3 Recommendations**

Based on the findings of this study, the following prevention and intervention strategies have been recommended:

- People should not be forced or persuaded to undergo mandatory HIV screening test for job recruitment or to go abroad especially in

situations where the pretest and ongoing counseling services are inadequate or substandard. This might complicate the psychosocial challenges they encounter if found to be seropositive.

- Psychosocial counseling and psychosocial support should be incorporated by the concerned governmental and non-governmental bodies as part of the main HIV/AIDS prevention and intervention programs giving a special heed to the areas raised below.
- PLWHA should get subsequent trainings as to the causes, the effects and how to cope with psychosocial challenges they may encounter before they arise. If they are to cope successfully, they need to involve themselves in voluntary activities, hobbies and interests that are personally satisfying. Involvement in religious activities, spending time with friends, finding meaningful work which goes in line with their unique HIV related drawbacks, pursuing educational and other goals, and engaging in physical exercise can be therapeutic for PLWHA. Research on stress, coping, and health behavior suggests that interventions tailored to individual appraisals and coping behaviors are likely to be most effective in terms of enhancing coping, reducing stress, and improving health behavior and physical well being.
- Mutual Aid Groups among the PLWHA should be strengthened. Working with professional counselors or health professionals, these group members can give mutual support, tangible assistance, pertinent information, opportunities to help others, social interaction, encouragement, protection, acceptance, and special help in times of crisis.
- Mobilizing the community for the support of PLWHA should be emphasized. Although the community sometimes creates problems on PLWHA by stigmatizing and discriminating them, it can also be

a source of psychosocial support. The community agents such as, community elders, lawyers, policemen, idir (funeral) leaders, youth workers, clergy, and others in the community who may have little or no training in counseling but often are the first to see PLWHA in times of psychosocial crisis. Thus, they could help curb the problem if given an awareness briefs.

- Most PLWHA probably discuss about problems with friends or family members long before they disclose their serostatus to the concerned bodies and seek help from professionals. Friends or family members, thus, often could be the major source of encouragement, behavior modification, confrontation and guidance. Family members and friends, thus, should be given awareness briefs or trainings so that they can play a significant role in curbing the psychosocial challenges PLWHA face.
- Media should play a significant role in sensitizing the public about the very psychosocial challenges PLWHA face. These media can provide information, give guidance and show PLWHA where to get help.
- Efforts should be made by the concerned governmental and non-governmental bodies to strengthen supportive and income generating opportunities for PLWHA according to their peculiar situation and need.
- The organizational, infrastructure and capacity of PLWHA associations should be strengthened so as to develop their full capacity to provide quality care and psychosocial support programs that are appropriately designed, implemented and evaluated.

The following are just a few actions that should be taken to specifically address stigma and discrimination:

- Creating awareness: people need accurate and continuous

information in order to know more about stigma and discrimination, their manifestations and what to do about them.

- Encouraging and supporting greater and more meaningful participation of PLWHA: by giving the epidemic a human face and voice, by actively participating in the response at all levels and by shattering some of the myths and misconceptions roaming around about HIV, PLWHA play a key role in reducing stigma if they are adequately empowered.
- Creating a legal and policy environment that makes it possible to challenge discrimination in justice court and monitoring human rights violations.
- Tackling some of the other inequalities that fuel HIV such as gender, age etc.

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**Appendix I**  
**Addis Ababa University**  
**School of Graduate Studies, Department of**  
**Psychology**  
**Questionnaire prepared for PLWHA**

Code No -----  
Date -----  
Place -----

Dear Respondent,

The principal purpose of this questionnaire is to obtain data for a study intended to investigate **the psychosocial challenges of people living with HIV/AIDS**. The study will be useful for control and prevention of **HIV/AIDS**, care and support of the people living with the virus and for various professionals working for the welfare of the PLWHA. You are selected for this project because you could give enough information on the issue. Therefore, your unreserved cooperation in providing the most genuine information will have a greater significance to the solution of the problem.

I understand the question might be very sensitive. However, from the practical importance of your ideas and views for the project, I truly need to ask you such questions. PLEASE NOTE THAT:

- Any information that you give is confidential
- You are not required to write your name anywhere in the questionnaire.
- The information you give will be used for this research purpose only.

Thank you in Advance.

Getahun Hailemariam

## Part One: Socioeconomic Background

1. Sex \_\_\_\_\_
2. Age \_\_\_\_\_
3. Place of Birth \_\_\_\_\_
4. Place of Living \_\_\_\_\_
  - 4.1. Before knowing your HIV serostatus \_\_\_\_\_
  - 4.2. After knowing your HIV serostatus \_\_\_\_\_
5. When have you come to know your HIV serostatus? \_\_\_\_\_
6. How long have you lived with HIV virus? \_\_\_\_\_
7. How have you come to know your HIV serostatus?
  - 7.1. Through voluntary counseling testing (VCT) \_\_\_\_\_
  - 7.2. Through a referral by a medical professional \_\_\_\_\_
  - 7.3. Pregnant and sought parental care \_\_\_\_\_
  - 7.4. Suspecting sexual partner \_\_\_\_\_
  - 7.5. Required for employment \_\_\_\_\_
  - 7.5. Required to go abroad \_\_\_\_\_
  - 7.6. Others (specify) \_\_\_\_\_
8. Have you ever taken ART? Yes  No 
  - 8.1. If your answer for item no 8 is yes, how long? \_\_\_\_\_
  - 8.2. Have you ever quitted taking the ART? Yes  No
  - 8.3. If quitted, how long? \_\_\_\_\_
9. Educational Background( put "X" sign)
  - 9.1. Illiterate \_\_\_\_\_
  - 9.2. Able to read and write \_\_\_\_\_
  - 9.3. First cycle elementary education complete \_\_\_\_\_
  - 9.4. Second cycle elementary education complete \_\_\_\_\_
  - 9.5. Secondary education complete \_\_\_\_\_
  - 9.6. Technical or vocational education complete \_\_\_\_\_
  - 9.7. College diploma \_\_\_\_\_
  - 9.8. Degree \_\_\_\_\_
  - 9.9. others( Specify) \_\_\_\_\_

10. Marital Status

- 10.1. Single \_\_\_\_\_
- 10.2. Married \_\_\_\_\_
- 10.3. Divorced \_\_\_\_\_
- 10.4. Widowed \_\_\_\_\_
- 10.5. Separated \_\_\_\_\_

11. Ethnic Background( Amhara, Oromo, Tigre, Gurage, Sidama etc,

\_\_\_\_\_

12. Occupation

- 12.1. Employee of Governmental or NGO \_\_\_\_\_
- 12.2. Daily Laborer \_\_\_\_\_
- 12.3. Vocational \_\_\_\_\_
- 12.4. Petty trade \_\_\_\_\_
- 12.5. Business person \_\_\_\_\_
- 12.6. house wife \_\_\_\_\_
- 12.7. unemployed \_\_\_\_\_
- 12.8. Others, Please Specify \_\_\_\_\_

13. Religion

- 13.1. Orthodox \_\_\_\_\_
- 13.2. Muslim \_\_\_\_\_
- 13.3. Protestant \_\_\_\_\_
- 13.4. Catholic \_\_\_\_\_
- 13.5. Others, Please Specify \_\_\_\_\_

14. How much is your average monthly salary?

\_\_\_\_\_

15. Do you know any one in your family living with the virus?

- 15.1. Yes       15.2. No

16. If your answer for item No 15 is "yes", how many? \_\_\_\_\_

Your relationship? \_\_\_\_\_

## Part Two: Psychosocial Situations

### I. Depression (Center for Epidemiologic Studies Depression Scale(CES-D))

*Below is a list of common symptoms of depression. Please carefully read each item in the list. Circle the number which indicates how much you have been bothered by that symptom during the past week.*

No	Item	Not often	1-2days	3-4days	5-7days
1	I worry with unnecessary thoughts	0	1	2	3
2	I lost appetite	0	1	2	3
3	the help of friends could not stop my depressed feelings	0	1	2	3
4	I feel I am as good as others	0	1	2	3
5	I have difficulty to concentrate	0	1	2	3
6	I feel depressed	0	1	2	3
7	I feel all my work is useless	0	1	2	3
8	I feel like to have bright future	0	1	2	3
9	I feel all my life is full of failure	0	1	2	3
10	I fear a lot	0	1	2	3
11	I have experienced distorted sleep	0	1	2	3
12	I am happy	0	1	2	3
13	I do not talk with others as I did before	0	1	2	3
14	I feel lonely	0	1	2	3
15	People become uncooperative to me	0	1	2	3
16	I am quite satisfied in life	0	1	2	3
17	I eyes have crying spots	0	1	2	3
18	I feel sad	0	1	2	3
19	I feel people hate me	0	1	2	3
20	I am unmotivated	0	1	2	3

## II. Anxiety (Beck Anxiety inventory)

*Below is a list of common symptoms of anxiety. Please carefully read each item in the list. Indicate how much you have been bothered by that symptom during the past month, including today, by circling the number in the corresponding space in the column next to each symptom.*

No		Not At All	Mildly but it didn't bother me much.	Moderately - it wasn't pleasant at times	Severely - it bothered me a lot
1	Numbness or tingling	0	1	2	3
2	Feeling hot	0	1	2	3
3	Wobbliness in legs	0	1	2	3
4	Unable to relax	0	1	2	3
5	Fear of worst happening	0	1	2	3
6	Dizzy or lightheaded	0	1	2	3
7	Heart pounding/racing	0	1	2	3
8	Unsteady	0	1	2	3
9	Terrified or afraid	0	1	2	3
10	Nervous	0	1	2	3
11	Feeling of choking	0	1	2	3
12	Hands trembling	0	1	2	3
13	Shaky / unsteady	0	1	2	3
14	Fear of losing control	0	1	2	3
15	Difficulty in breathing	0	1	2	3
16	Fear of dying	0	1	2	3
17	Scared	0	1	2	3
18	Indigestion	0	1	2	3
19	Faint/lightheaded	0	1	2	3
20	Face flushed	0	1	2	3
21	Hot/cold sweats	0	1	2	3

### III. Perceived Stress Scale-10 (PSS-10)

*The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling how often you felt or thought a certain way.*

No	Item	Never	Almost Never	Sometim es	Often	Very Often
1	I have been upset because of something that happened unexpectedly	0	1	2	3	4
2	I have been unable to control the important things in your life	0	1	2	3	4
3	I have felt nervous and "stressed"	0	1	2	3	4
4	I have not felt confident about my ability to handle personal problems	0	1	2	3	4
5	I felt that things were going my way	0	1	2	3	4
6	I found that I could not cope with all the things that I had to do	0	1	2	3	4
7	I have been able to control irritations in my life	0	1	2	3	4
8	I have felt that I was on top of things	0	1	2	3	4
9	I have been angered because of things that were outside of your control	0	1	2	3	4
10	I have felt difficulties were piling up so high that I could not overcome them	0	1	2	3	4

**IV. Experience of Fear**

Have you experienced fear as a result of your HIV positive serostatus?

Yes \_\_\_\_\_ No \_\_\_\_\_

If your answer of the question above is "yes", which of the following types of fear have you experienced?

<b>Type of fear experienced</b>	<b>Yes</b>	<b>No</b>
Fear of AIDS stigma		
Fear of loss of reputation of the family and society		
Fear of damaging the family's social reputation		
Fear of death and of dying early		
Fear of dying uncared for, and being denied last rites		
Fear of being deserted, lose of significant relationships		
Fear of losing one's job or lose of income		
Fear of passing the infection to others whether spouse, children, or other family member.		

Others, please specify

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## V. Coping Mechanism

Which of the coping mechanisms do you use to cope up with the psychosocial problems you face?

Coping Strategy	Yes	No
Think about Good Things		
Listen to Music		
Talk to a close friend		
Talk to a family member		
Try on your own to deal with the problem		
Pray		
Talk to Minister/Priest		
Smoke cigarette		
Take drugs (such as hashish)		
Chew 'chat'		
Drink Beer/Wine/Liquor		
Daydream		
Learn more about the problem		
Get Professional Counseling		
Take journal, read/write poetry, literature		
Do physical exercise		
Get medical attention		
Adhere to ART		

Others, please specify

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### Part Three: Experience of stigma and discrimination

*The following questions are about your experiences, feelings and opinions as to how PLWHA feel for the society's reaction towards the disease and how they are treated. Please answer all questions.*

No	Items	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	I was forced to displace my home town/zone/ woreda due to the stigma of HIV					
2	I am fired from a job without any clear reasons for being dismissed					
3	I got divorced because I have HIV					
4	I was forced to depart any family as a result of my HIV serostatus					
5	I lost my friends after they learned that have had HIV.					
6	I have no power of decision making either in my home or in my local community for I have HIV					
7	I am not welcomed in social gatherings because I have HIV					
8	I was forced to dropout education due to stigma and discrimination					
9	I was terminated from my job due to the stigma and discrimination of my colleagues					
10	I worked hard to keep my HIV serostatus secret from my friends, neighbors, etc for maintaining of our relationship					

Please state if you have experienced any form of stigma or discrimination as a result of your HIV serostatus.

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9.9 ህጋዊ ህግ

9.8 ገጽ 8

9.7 የህግ ጽሑፍ

ቀጠለ

9.6 የግብርና ስራ ስርዓት (10+2=10+2=10+2) ወይም የግብርና ስራ ስርዓት

9.5 የግብርና ስራ ስርዓት

9.4 የግብርና ስራ ስርዓት (5-8 ክፍል) የግብርና ስራ ስርዓት

9.3 የግብርና ስራ ስርዓት (5-8 ክፍል) የግብርና ስራ ስርዓት

9.2 የግብርና ስራ ስርዓት

9.1 የግብርና ስራ ስርዓት

9. የግብርና ስራ ስርዓት ( « X » ስራ ስርዓት )

8.3 የግብርና ስራ ስርዓት ስራ ስርዓት

8.2 የግብርና ስራ ስርዓት ስራ ስርዓት

8.1 የግብርና ስራ ስርዓት ስራ ስርዓት

8. የግብርና ስራ ስርዓት ስራ ስርዓት

7.6 የግብርና ስራ ስርዓት

7.5 የግብርና ስራ ስርዓት

7.4 የግብርና ስራ ስርዓት

7.3 የግብርና ስራ ስርዓት

7.2 የግብርና ስራ ስርዓት

7.1 የግብርና ስራ ስርዓት

7. የግብርና ስራ ስርዓት

6. የግብርና ስራ ስርዓት

5. የግብርና ስራ ስርዓት

4.2 የግብርና ስራ ስርዓት

4.1 የግብርና ስራ ስርዓት

4. የግብርና ስራ ስርዓት

3. የግብርና ስራ ስርዓት

2. የግብርና ስራ ስርዓት

1. የግብርና ስራ ስርዓት

10. የጋብቻ ሁኔታ

- 10.1 ያላገባ \_\_\_\_\_
- 10.2 ያገባ \_\_\_\_\_
- 10.3 በፍቺ ምክንያት የተለያየ \_\_\_\_\_
- 10.4 የትዳር ጓደኛን በሞት ምክንያት ያጣ \_\_\_\_\_
- 10.5 ከትዳር ጓደኛ ጋር በተለያየ ምክንያት የተለያየ \_\_\_\_\_

11. ዘር (አማራ፣ ትግሬ፣ አሮሞ፣ ወላይታ፣ ሲዳማ፣ ከንባታ ወዘተ...) \_\_\_\_\_

12. የስራዎ ዘርፍ

- 12.1 የመንግስት ወይም መንግስታዊ ያልሆነ መስሪያ ቤት ተቀጣሪ \_\_\_\_\_
- 12.2 የቀን ስራተኛ \_\_\_\_\_
- 12.3 የእጅ ባለሞያ \_\_\_\_\_
- 12.4 የግል ንግድ \_\_\_\_\_
- 12.5 የቤት ስራተኛ \_\_\_\_\_
- 12.6 የቤት እመቤት \_\_\_\_\_
- 12.7 ሥራ የለኝም \_\_\_\_\_
- 12.8 ሌላ ይጠቀስ \_\_\_\_\_

13. ሐይማኖት

- 13.1 የኦርቶዶክስ ተዋህዶዎ ክርስቲያን \_\_\_\_\_
- 13.2 የእስልምና ሐይማኖት ተከታይ \_\_\_\_\_
- 13.3 የወንጌላዊያን አማኝ \_\_\_\_\_
- 13.4 ካቶሊክ \_\_\_\_\_
- 13.5 ሌላ፣ ይጠቀስ \_\_\_\_\_

14. የወር ገቢዎ በአማካይ ምን ያህል ነው? (በገንዘብ መጠን ይገለጹ)

15. በቤተሰብዎ ውስጥ ከHIV ጋር እንደሚኖር የሚያወቁት ሌላ ሰው አለ?

- 15.1 አዎ
- 15.2 የለም

16. በጥያቄ ቁጥር 15 መልስዎ አዎ ከሆነ

- ስንት ናቸው? \_\_\_\_\_
- የዝምድና ሁኔታ \_\_\_\_\_

ቁ.ተ.	መጠቀ	አምብዳሞ	ቀን	ቀን	ቀን
1	0	1	2	3	1-11 የወይን ጉዳይ ጥያቄ
2	0	1	2	3	መመዘኛ ለሥራ ጥያቄ
3	0	1	2	3	ሁለተኛ የጥያቄ ጥያቄ ለመጠቀም
4	0	1	2	3	አንድ ሌላ ሰው ለሥራ መልካም ለውጥ ለማድረግ ጥያቄ
5	0	1	2	3	ሰው ለሥራ ላይ የሥራ ጥያቄ ጥያቄ
6	0	1	2	3	የሥራ ሰው ጥያቄ
7	0	1	2	3	የሥራ ሰው ላይ ሥራ ጥያቄ ጥያቄ
8	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ
9	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ ለመጠቀም
10	0	1	2	3	አራት ሰው ጥያቄ
11	0	1	2	3	አንድ ሰው ለሥራ ላይ ጥያቄ ጥያቄ
12	0	1	2	3	የሥራ ሰው ጥያቄ
13	0	1	2	3	የሥራ ሰው ላይ ጥያቄ ጥያቄ ለመጠቀም
14	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ
15	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ ለመጠቀም
16	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ
17	0	1	2	3	አንድ ሰው ለሥራ ላይ ጥያቄ ጥያቄ
18	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ ለመጠቀም
19	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ
20	0	1	2	3	ሰው ለሥራ ላይ ጥያቄ ጥያቄ ለመጠቀም

1. የአዕምሮ ጭንቀት (Depression) በተመለከተ ክፍል ሁለት፡ ስለአዕምሮ ማህበራዊ ጥግግር በተመለከተ

መመሪያ፡- የሚከተሉት መጠቀሚያዎች በአምስት ዝዕ ውስጥ እየተሰጡበት ለሰው ጭንቀት (Depression) ስሜቶች መረጃ የሚያስገኙ ናቸው፡- ስለሰው ጭንቀት ስሜት ስሜት ከተሰጡት አማራጭ አንዱን በማክበብ ማለብ፡፡

## II ሥጋትን (Anxiety) በተመለከተ

መመሪያ:- በወር ጊዜ ውስጥ ከሚከተሉት የሥጋት(Anxiety) ምልክቶች ውስጥ የትኞቹ ተለምተውሃል/ሻል?(አክብብ/ቢ)::

ተ. ቁ.	መጠይቅ	በጭራሽ	በመጠኑ (ምንም ያህል አላሳለበኝም)	በልኩ (አሳለበኛል)	በከፋ ሁኔታ (አሳለበኛል)
		0	1	2	3
21	የመጽደቅ ወይም መጠነኛ የመወጋጋት ስሜት::	0	1	2	3
22	የቆይታ ስሜት ::	0	1	2	3
23	የአጭቶች መሸመድ መድ ወይም የመራድ ስሜት::	0	1	2	3
24	በጥንጥን አለመቻል::	0	1	2	3
25	በአይወድ የባለ ገዢ ይመጣል ብዬ መፍራት::	0	1	2	3
26	የላይኛው ወይም የመጨመን ስሜት::	0	1	2	3
27	ልዩ ተግባር ይመቻቅል::	0	1	2	3
28	የሰውነት ስሜት::	0	1	2	3
29	መሬት የመሸጋገል/የመታወክ/ስሜት::	0	1	2	3
30	የግልጽ ስሜት::	0	1	2	3
31	የግልጽ ወይም ብዙ የማለት ስሜት ::	0	1	2	3
32	አጭቶ ጭጭ ይርዳብኛል::	0	1	2	3
33	ግልጽ የማለት ስሜት ወይም ያለመረጋጋት ስሜት::	0	1	2	3
34	አጭቶ ልሰብ የሆነ ብሎ መፍራት::	0	1	2	3
35	የግልጽ ግንኙነት ማጋጠም ፣ በቀላሉ መተንፈስ አለመቻል::	0	1	2	3
36	አጭቶ ይሆን ብሎ መፍራት::	0	1	2	3
37	የግልጽ ስሜት::	0	1	2	3
38	የግልጽ ምንጭ ሳይፈጸም በሆድ ውስጥ መቆየት::	0	1	2	3
39	የግልጽ ስሜት የማልተለው ቁጣ ፊት መነበብ::	0	1	2	3
40	የግልጽ ስሜት ያልበኛል::	0	1	2	3







## Appendix III

### Guidelines for Focus Group Discussions

1. How does a person living with HIV virus view himself in relation with others who do not live with the virus?
2. What negative feelings have you ever experienced as a result of your living with HIV virus? In what specific situations?

*Prompt:*

- fear of the unknown, fear of death
- self-hatred, losing hope in life, feeling of worthlessness
- Feeling angry, being easily provoked etc.,

What do you do in such feelings?

3. What psychosocial challenges have you ever come across as a result of your HIV serostatus? If yes, where, when, in what situations?

*Prompt:* Death of family member or close friend

- Lose of finance, status, marriage life, employment, conflict in the family or the community
- Denied of religious duties, rights
- Feeling angry, being easily provoked etc.,

What do you do in such feelings?

4. What psychosocial services have you ever received?

*Prompt:* Counseling services

- Financial and material aid,
- Training on positive living, life skills training etc.,

5. What psychosocial services do you expect to get in a bid to relieve your challenges if any and encourage positive living? From where?
6. Have you ever experienced stigma and discrimination as a result of your HIV positive serostatus?
7. Have you used ART? Is there any problem you come across in relation to ART?

