Effect of Perceived Social Support, Depression Symptoms, and Stigma on Adherence and Treatment Outcome of Highly Active Antiretroviral Therapy at Zewditu Memorial Hospital, Addis Ababa, Ethiopia

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Dissertation for the Degree of Doctor of Philosophy (Ph.D.)

School Of Public Health,
College of Health Sciences,
Addis Ababa University,
Ethiopia

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A Dissertation Submitted to the School Of Graduate Studies of Addis Ababa University in Partial Fulfillment of the Requirement for the Degree of Doctor of Philosophy (Ph.D.) in Public Health

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Internal Examiner

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Internal Examiner

Dedication

This dissertation book has been dedicated to my mother, W/ro Abundeje Belay Tiruneh and my father, Ato Alemu Tilahun Feleke for their exceptional parenting of me, two of my brothers and three of my sisters.

Original Papers

Number	Title of the original paper	Journal	Status
1	Correlates of highly active antiretroviral therapy adherence among urban Ethiopian clients	African Journal of AIDS Research	Published (AJAR. 2011; 10(3): 263–270).
2	Effect of depressive symptoms and social support on weight and CD4 count increase at HIV clinic in Ethiopia	AIDS Care	Published (AIDS Care. 2012 Jan 24. PMID: 22273149).
3	Effect of perceived stigma on adherence to a dose of Highly Active Antiretroviral Therapy and self-confidence to take medication properly in Addis Ababa, Ethiopia	Journal of HIV/AIDS & Social Services	Accepted for publication (Manuscript ID: WHIV-2011-0033)

List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARD	Antiretroviral Drugs
ARV	Antiretroviral
ART	Antiretroviral Therapy
ANC	Antenatal Care
CDC	Center for Disease Control
CES-D	Center for Epidemiologic Studies Depression Scale
CI	Confidence Interval
DHS	Demographic Health Survey
HAART	Highly Active Antiretroviral Therapy
HAPCO	HIV/AIDS Prevention and Control Office
HBC	Home Based Care
HRQOL	Health Related Quality Of Life
HIV	Human Immunodeficiency Virus
HSDP	Health Sector Development Program
MEMS	Medical Event Monitoring System
MSF	Medicine San Frontiers
MTCT	Mother to Child Transmission
MDG	Millennium Development Goals
NGO	Nongovernmental Organization
NNRTI	Non Nucleoside Reverse Transcriptase Inhibitors
NRTI	Nucleoside Reverse Transcriptase Inhibitors
NSSQ	Norbeck Social Support Questionnaire
OD	Odds Ratio
PHC	Primary Health Care
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission

PEPFAR	President's Emergency Plan for AIDS Response
QOL	Quality Of Life
SD	Standard Deviation
STI	Sexually Transmitted Infections
TB	Tuberculosis
WHO	World Health Organization
VCT	Voluntary Counseling and Testing
UNAIDS	UNAIDS United Nations Joint Program on HIV/AIDS

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Abstract

Background

In 2009, globally 1.2 million people received HIV antiretroviral therapy for the first time—an increase in the number of people receiving treatment of 30% in a single year. Overall, the number of people receiving therapy has grown 13-fold since 2004, with more than five million people in low- and middle-income countries including Ethiopia currently receiving ART.

Despite the increase in the scale-up and expanded coverage of HAART, yet, many challenges are confronting the program. Among these are; adherence to treatment regimen and attrition from HAART. Adherence to HAART regimens has been found to be the most important determinant of the success of HAART at the individual patient level. On the other hand attrition from treatment, a prerequisite for achieving any adherence at all, is also crucial for the success of HAART programs. Different studies had demonstrated the effect of social support, psychosocial factors, and stigma on adherence to HAART, weight and CD4 cell progression, attrition from HAART, and perceived quality of life. Evidences consistently show perceived social support to facilitate; adherence to HAART, weight and CD4 cell progression, survival, and perceived quality of life. On the other had psychosocial factors, particularly depression symptoms, was associated with; non-adherence to HAART and poor weight and CD4 cell progression. Stigma has been also associated with non-adherence to HAART.

The purpose of this study was to assess the effect of perceived social support, psychosocial factors and stigma on adherence to HAART, weight and CD4 progression, attrition from therapy and perceived quality of life among persons infected with HIV and who were receiving HAART at Zewditu Memorial Hospital, Addis Ababa, Ethiopia.

Methodology

This study took place at Zewditu Memorial Hospital HAART clinic in Addis Ababa City administration. The study population were adult age persons (age $\geq$ 18 years) who were receiving HAART from Zewditu Memorial Hospital at the time of the study. This study utilized both cross-sectional and cohort study designs. The main sources of data for the study were:

interviews with study participants using pre-tested standard questionnaire, review of medical records, and key informant interviews. Based on four different scenarios the maximum sample size needed to undertake the study was identified to be 1,815. By using computer generated random table numbers, 1,815 eligible samples were selected for the study based on their unique HAART identification number. The quantitative data were collected by nurses. The data collectors received three days training on the data collection tools, methodology, probing, maintaining quality, and other issues.

The four-item self-reported *Morisky*'s scale was used to assess self-reported HAART adherence. Weight and CD4 count were taken from patients while they visit the clinic for routine check-up and to collect their ARV drugs. To assess perceived health related quality of life the core "Healthy Days measures" which were developed by CDC were utilized. To assess depressive symptoms related to major or clinical depression, the shorter ten item version of the Center for Epidemiological Studies Depression Scale (CES-D) questionnaire was used .To assess social support, six questions from the Norbeck Social Support Questionnaire (NSSQ) were used. Berger's stigma scale was used to measure the level of perceived stigma. A total of nine key-interviews were conducted by social work expert with patients who were on HAART

The dependent variables for the study were: adherence to HAART, self-confidence to take HAART properly, attrition from HAART, CD4 cell progression, weight progression, perceived quality of life. The independent variables were; perceived social support, psychosocial factors/depressive symptoms, negative self-image, concern about public attitude, concern about disclosure, personalized stigma, age, sex, marital status, religion, duration of stay on HAART, alcohol drinking, *kalt* chewing/smoking, education level, income level, and disclosure of HIV status.

Ethical clearance was obtained from the School of Public Health, Addis Ababa University College of Health Sciences. To assure participation based on willingness, informed consent was obtained from each study participant. Privacy, confidentiality and benefits were maintained. All responsible authorities were informed about the study and its process to get their support and commitment to the study.

Result

Of the 1,815 Patients selected for the study, 1722 agreed to participate – a response rate of 94.9%. The majority of the respondents were females (61%) and more than 75% were age 31 years or older. Fifty eight percent of the respondents were extremely sure about their ability to take most or all of their HAART medication as prescribed. About 62% of the respondents said they had never missed their HAART medication.

The odd of self-confidence was 1.44-times higher among males than females (AOR: 1.44; 95% CI: 1.15–1.79). The odds of self-confidence was 0.35-times and 0.41-times lower among those who were within the spending categories of Birr 501–999 (AOR: 0.35; 95% CI: 0.24–0.49) and Birr 1000–1999 (AOR: 0.41; 95% CI: 0.29–0.60), respectively. Regarding regular alcohol drinking, the odd of self-confidence was 2.86-times higher among those who did not drink alcohol regularly.

The odds of ever missing HAART medication was 0.76-times lower among males than females (AOR: 0.76; 95% CI: 0.61–0.95). A one-year increase in age was also associated with 0.98-times lower odds of ever missing HAART medication (AOR: 0.98; 95% CI: 0.97–0.99). The odds of ever missing HAART medication was 1.36-times higher among those who had stayed 25–48 months on HAART (AOR: 1.36; 95% CI: 1.04–1.78). With regard to drinking alcohol, the odds of having ever missed HAART medication was 0.48-times lower among those who did not drink alcohol regularly (AOR: 0.48; 95% CI: 0.35–0.64).

Perceived social support was significantly associated with both adherence to HAART and self-confidence on the ability to take medication properly. A one unit increase in perceived social support was associated with 1.32 (OR: 1.14 – 1.54) times more likelihood of never missing HAART and 1.20 (OR: 1.06 – 1.35) times more likelihood of being confident to take HAART properly.

Pertaining to stigma, the three measures of stigma (negative self-image, concern about public attitude, and concern about disclosure) and psychosocial problems were negatively associated

with self-reported adherence to HAART medication and with self-confidence to take medication correctly.

A one unit increase in depressive symptoms was associated with a decrease in weight on average by about 10kgs between baseline and recent levels (p=0.023), while a one unit increase in perceived social support was associated with an average of 10kg increase in weight between baseline and recent levels (p=0.033). A one unit increase in depressive symptoms was associated with reduced CD4 cell progression on average by 10.72 CD4 cells between baseline and recent CD4 cell count levels (p=0.013) while a one unit increase in perceived social support was associated with an increase in CD4 cell count levels on average by 9.43 CD4 cells between baseline and recent levels (p=0.043).

According to the present study, out of the total cohort of 1.722 study subjects 86.6% had been retained at the time of the 12 month follow-up. The 4.1% had been formally transferred to other health facilities and they were considered "active". The remaining 9.3% had discontinued treatment either because of confirmed death (2.0%), or because of being dropped from treatment (5.4%) or being lost from follow-up because of unknown reasons (1.9%). Other studies in Africa had reported relatively lower levels of retentions compared to the findings of this study.

Controlling for possible confounding variables in the Cox proportional hazard model, those who reported higher levels of adherence to HAART had 48% (Hazard Ratio = 0.52, CI: 0.34 – 0.81) lower risk or hazard of failure. On the other hand those who reported better perceived social support had 23% (Hazard Ratio = 0.77, CI: 0.64 – 0.93) less hazard or risk of failure.

The regression model on the effect of social support on perceived quality of life demonstrated significant association being adjusted for possible confounding variables. A one unit increase in perceived social support is associated with 0.84 less likelihood of unhealthy days due to some sort of physical or mental health problem and 0.75 times less likelihood of unhealthy days because of some sort of pain, depression, anxiety, and sleeplessness.

Conclusion and recommendations

Perceived social support was significantly associated with adherence to HAART while depression symptom and stigma were associated with non-adherence. Furthermore, perceived social support facilitated while depression symptom hampered CD4 and weight progression. Social support was positively associated with survival / retention and perceived quality of life. Designing and implementing programs which will help to facilitate social support, and address problems of depression and stigma will be crucial to improve outcomes of the treatment.

1. Introduction and Background

According to the 2010 Joint United Nations Programme on HIV/AIDS (UNAIDS) report on the global AIDS epidemic, 33.3 million people are living with Human Immunodeficiency Virus (HIV) worldwide with 2.6 million new infections and 1.8 million deaths in 2009 alone [1].

The overall growth of the global AIDS epidemic appears to have stabilized. The annual number of new HIV infections has been steadily declining since the late 1990s and there are fewer AIDS-related deaths due to the significant scale up of antiretroviral therapy over the past few years. Although the number of new infections has been falling, levels of new infections overall are still high, and even with significant reductions in mortality the number of people living with HIV (PLHIV) worldwide has increased [1].

In 2009, there were an estimated 2.6 million people who became newly infected with HIV. This is nearly one fifth (19%) fewer than the 3.1 million people newly infected in 1999, and more than one fifth (21%) fewer than the estimated 3.2 million in 1997, the year in which annual new infections peaked [1].

In 33 countries, the HIV incidence has fallen by more than 25% between 2001 and 2009; 22 of these countries are in sub-Saharan Africa where the majority of new HIV infections continue to occur. An estimated 1.8 million people in sub Saharan Africa became infected in 2009; considerably lower than the estimated 2.2 million people newly infected with HIV in 2001 [1].

In Ethiopia, the 2005 Demographic and Health Survey (DHS) estimated national adult HIV prevalence to be 1.4% [2]. The Antenatal Care (ANC) and DHS results were calibrated into a single-point prevalence estimate. For the year 2010, the estimated prevalence is 2.4%. According to this estimate, for the same year the estimated number of people living with HIV is 1,216,908 (717,669 female and 499,239 male) [3].

The development of life saving antiretroviral (ARV) drugs has brought new hope to the world. This has been one of the dramatic advances in the history of medicine [4, 5]. In high income countries, combination antiretroviral therapy has extended and improved life for large numbers of people living with HIV/AIDS and transformed perceptions of HIV/AIDS from a fatal disease

to a manageable, chronic illness. In the poorer parts of the world, precisely the regions where HIV/AIDS has spread most rapidly, this transformation is just happening [6].

Zidovudine was first tested on humans in 1985, and introduced as a treatment in March 1987 with great expectations. Initially, at least, it did not seem to be very effective. The same was true for the nucleosides; zalcitabine, didanosine and stavudine, introduced between 1991 and 1994. In June 1996, new and promising advance was made through the introduction of combination therapy called "Highly Active Antiretroviral Therapy (HAART) [5].

Between 2004 and 2005, the number of people receiving HAART globally increased by about 300,000 every six months [7]. By June 2005, only 1 million people were actually receiving HAART [6]. During the same period in East, South and Southeast Asia, the number almost tripled, and in Eastern Europe and Central Asia most countries had provided universal access by the end of 2005 [4].

In 2009, 1.2 million people received HIV antiretroviral therapy for the first time—an increase in the number of people receiving treatment of 30% in a single year. Overall, the number of people receiving therapy has grown 13-fold since 2004, with more than five million people in low- and middle-income countries currently receiving ART [1].

Despite the increase in the scale-up and expanded coverage of HAART, yet, many challenges are confronting the program. Among these are; adherence to treatment regimen and attrition from HAART. This study will be paramount in assessing these issues by using a hospital based study in the Addis Ababa City Administration. The recommendations to be drawn from this study will have significant impact in improving adherence to HAART and address problems of attrition in Ethiopia and other Sub-Saharan African counties.

1.1. Literature Review

1.1.1. The Launch of "3 by 5" Initiative and Coverage of HAART

Given the proven feasibility of treating people living with HIV/AIDS in industrialized and developing countries, a global target of treating 3 million people with antiretroviral therapy by

the end of 2005 was launched in December 2003. This was said to be a necessary and feasible target to reach the ultimate goal of universal access to antiretroviral for everyone who requires such therapy. The goal of the "3 by 5" strategic framework was to prolong survival and restore the quality of life of individuals with HIV/AIDS by providing universal access to antiretroviral therapy to those who need it, as a human right and within the context of a comprehensive response to HIV/AIDS [8].

Since the launch of "3 by 5", encouraging global trends in the scale-up of antiretroviral treatment have been observed. In December 2003, when World Health Organization (WHO) and UNAIDS launched the "3 by 5" strategy, around 400,000 people were receiving antiretroviral therapy in low and middle-income countries. Since then, increased efforts by states, supported by multilateral and bilateral partners, have resulted in a significant boost in the number of people receiving antiretroviral therapy [9, 10].

The number of people on Antiretroviral Therapy (ART) in sub-Saharan Africa had more than tripled between July 2004 and June 2005. As of December 2006, it is estimated that more than 1.3 million people in sub-Saharan Africa were receiving antiretroviral treatment, with coverage of 28% (24%–33%), whereas in 2003, only 100,000 people living with HIV/AIDS were on treatment and coverage was only 2%. Of the people now receiving antiretroviral treatment in low and middle income countries, 67% live in sub-Saharan Africa, whereas the corresponding figure in late 2003 was only 25%. This region also accounts for two-thirds of the total treatment needed in such countries [10].

Expanding access to treatment has contributed to a 19% decline in deaths among people living with HIV between 2004 and 2009. This is just the beginning however, as 10 million people living with HIV who are eligible for treatment under the new WHO guidelines are still in need. Efforts are now underway for "Treatment 2.0", a new approach to simplify the way HIV treatment is currently provided and to scale up access to life-saving medicines. Using a combination of efforts, this new approach could bring down treatment costs, make treatment regimens simpler and smarter, reduce the burden on health systems, and improve the quality of

life for people living with HIV and their families. Modeling suggests that, compared with current treatment approaches, "Treatment 2.0" could avert an additional 10 million deaths by 2025 [1].

1.1.2. Access to HIV/AIDS treatment in Ethiopia

Ethiopia has reacted aggressively as a response to the HIV pandemic. This is demonstrated by the development and ratification of the National HIV/AIDS Policy in 1998. In 2001, the National HIV/AIDS Prevention and Control Council declared HIV as a national emergency; this was followed by various interventions focusing on prevention, risk reduction, and behavior change. As a follow-up to this, in 2003, the Government of Ethiopia introduced the ART program with the goal of reducing HIV-related morbidity and mortality, improving the quality of life of people infected by HIV and mitigating some of the impact of the epidemic [11].

In line with this, the President and Prime Minister of the Federal Government of Ethiopia have shown the Ethiopian Government's commitment towards ensuring universal access to HIV/AIDS treatment by launching a free ART program in January 2005 (Federal Ministry of Health, 2005). In Ethiopia, ART was first offered in July 2003 through 12 government hospitals on a co-payment basis. Now the number of ART sites has remarkably increased to more than 329 within three years. This has contributed significantly to making the service accessible to those people in need of it [12, 4].

By the end of 2004, a total of 8,278 patients were getting antiretroviral treatment in Ethiopia, out of which only 900 used to get free of charge. By the end of June 2010, the cumulative number of patients who started treatment totaled 268,934; and at present 207,733 people are taking the treatment, consisting of 61.8% coverage of the estimated total number of HIV positive patients that require the treatment. The target set being 100% coverage at the end of 2010, the achievement in terms of the number of patients who ever started treatment becomes 80%. All patients, since the end of 2004, are getting the treatment free of charge [13].

1.1.3. Adherence to HAART and its determinants

There is no universally accepted definition of medication adherence. With respect to HIV/AIDS care specifically, "medication adherence" has been defined as "the ability of the person living with HIV/AIDS to be involved in choosing, starting, managing, and maintaining a given therapeutic combination medication regimen to control viral replication and improve immune function [14].

Scaling-up therapy by its own is not enough. Adherence to treatment is crucial and yet many factors affect it. In order to achieve an undetectable viral load and prevent the development of drug resistance, a person on HAART needs to take at least 95% of the prescribed doses on time [6, 15, 16, 17, 18].

Some people forget to take the drugs or stop taking them because of bad side effects. Others find it difficult to take the drugs at the right time. Some people share the drugs with family members or friends, which means that no one takes the correct dose. Many people want to take their drugs with food, which becomes a problem in places where there are food shortages. Failure to follow the regimen at least 90% of the time can lead to drug resistance where the drug no longer suppresses the virus and the immune system is weakened again. Adherence is as important as access, because survival depends on how much people are adherent to treatment [4, 10, 15 - 18].

Adherence to HAART regimens has been found to be the most important determinant of the success of HAART at the individual patient level [10, 15 - 18]. One way to improve the success of a large-scale treatment program, while at the same time limiting access, could therefore be to restrict therapy to persons who are judged to have the ability and willingness to adhere or who demonstrate high adherence after initiating therapy [19].

Measuring adherence is problematic as there is no single method to assess adherence accurately. Studies use different techniques to assess adherence to HAART. The most commonly used methods are; self-reports, pill counts, pharmacy records, biological markers, electronic devices and measuring drug levels in the blood [14].

Different studies had reported Africans to be good at adhering to their medication. Two new systematic reviews prove speculations that Africans will not adhere to treatment regimen were mistaken. These studies correct the misconception of earlier, non-systematic reviews that concluded that Africans' adherence to medicines is "often poor". A systematic review identified 31 studies from North America and 27 from sub-Saharan Africa examining adherence to ART. In this review 82% of Africans succeeded in taking ART correctly in 95% or more cases compared with only 55% of North Americans [20].

There are different explanations for higher levels of adherence in Africa. According to the Ethnographic study done in HIV treatment sites in Jos, Nigeria; Dar Es Salaam, Tanzania; and Mbarara, Uganda; sub-Saharan Africans adhere to ART because they want to be healthy. Findings indicate that individuals taking ART routinely overcome economic obstacles to ART adherence through a number of deliberate strategies aimed at prioritizing adherence: borrowing and ''begging'' transport funds and making ''impossible choices'' to allocate resources in favor of treatment. Prioritization of adherence is accomplished through resources and help made available by treatment partners, other family members and friends, and health care providers. Helpers expect adherence and make their expectations known, creating a responsibility on the part of patients to adhere. Patients adhere to promote good will on the part of helpers, thereby ensuring help will be available when future needs arise. According to this study adherence success in sub-Saharan Africa can be explained as a means of fulfilling social responsibilities and thus preserving social capital in essential relationships [21].

Different factors affect adherence to HAART. Ickovics categorized these factors into four groups: patient characteristics; aspects of the provider and the patient-provider relationship; variables related to the treatment regimen or illness; and contextual or environmental factors [22].

A study reported lower CD4 cell count at enrolment, lower level of education, and illicit substance use to be associated with non-adherence to treatment. Meta-Analysis done on the effect of alcohol use on nonadherence reported a significant and reliable association of alcohol use and medication nonadherence. There are also evidences that adherence is fostered when the

act of taking medication is a priority, when patients believe in the efficacy of their medications, and when there is a strong patient and provider relationship [23, 233].

A prospective 24 week study of adherence was conducted in a group of 64 subjects using the Medication Event Monitoring System (MEMS). In this study factors which were independently associated with lower adherence rates were current smoking, lower CD4+ lymphocyte count at enrolment, and lower educational attainment. Current cigarette smoking was an important and significant marker of nonadherence to antiretroviral medication [24].

According to a study done at a Hospital in Matola, Mozambique of the 154 patients, 127 (82.5%) kept more than 90% of their appointments. Three fundamental elements which contributed to the high rate of adherence to treatment were the fact that treatment was completely free, availability in a single pill, nutritional aid and availability of computerized methods to check adherence and intervene when necessary [25].

In Ethiopia, different studies have reported high level of self-reported treatment adherence among adults. A study by Tadios and his colleagues reported a level of at least 95% self-reported adherence to HAART medication in the previous seven days among 81.2% of the adult respondents [26]. Another study reported 95% of adults as being adherent to HAART based on self-reports of the preceding seven days adherence practices [27]. Family support was found to be the most important predictor of adherence in that study. In another study done in Jimma Hospital, Western Ethiopia, out of the 1,270 patients who started treatment in the hospital, 28% had missed two or more clinical appointments. Most commonly cited reasons for missing their appointments were loss of hope in medication, lack of food, mental illness, wanting to use traditional medicine, and lack of money for transportation [28]. According to a study done in Southern Ethiopia at Yirgalem Hospital 1.4% had missed at least their medication in the previous day while 2.1% and 11.7% had missed at least one dose in the previous three days and in the previous seven days respectively [29].

In general, factors which are consistently associated with nonadherence to HAART are current alcohol and drug use, smoking, stigma, poor physician and patient relationship, poor self-esteem, low level of belief in medication, younger age, longer time on HAART, not experiencing

positive effects of taking the medications, social aspects, lack of family or social support, and active psychiatric illness [30, 31].

1.1.4. Attrition from HIV/AIDS treatment and its determinants

For this study ‘‘retention’’ refers to patients known to be alive and receiving highly active ART at the end of a follow-up period. ‘‘Attrition’’ is defined as discontinuation of ART for any reason, including death, and stopping medication. Transfer to another ART facility, where reported, is not regarded as attrition—patients who transfer are assumed to be retained [32].

In the past half decade, since the first large-scale HAART programs were launched in sub-Saharan Africa, including Ethiopia, much attention has focused on patients' day-to-day adherence to HAART. Long-term retention of patients in treatment programs, a prerequisite for achieving any adherence at all, has received far less attention [33]. Perhaps because most large scale treatment providers have few resources available to track missing patients, most studies treat patient attrition as a side issue and focus solely on describing those patients who were retained.

Treatment discontinuation raises some of the same concerns about drug resistance that incomplete adherence does and, even worse, negates much of the benefits sought by those implementing treatment programs. Patients with clinical AIDS who discontinue HAART will likely die within a relatively short period. High rates of attrition from treatment programs thus pose a serious challenge to program implementers and constitute an inefficient use of scarce treatment resources [34].

While adherence to HAART has been well studied, less is known about treatment discontinuation. Findings from literature review among studies done in sub-Saharan Africa indicated that HAART programs are, on average, retaining roughly 80% of their patients after 6 months of their being on HAART; and between one-fourth and three-fourths of their patients by the end of 2 years. Prior to the availability of HAART in Africa, the median interval from HIV infection to AIDS-related death was under 10 years; once a patient was diagnosed with AIDS, median survival was less than 1 year [35]. Since most patients in Africa initiate HAART

only following an AIDS diagnosis, most HAART patients would have died within a year had ART not been available. Each patient who is retained in care and on ART can thus be regarded as a life saved and a source of tremendous benefit to patients' families and communities [36].

A systematic review of literatures on retention in Africa was carried out by reviewing 32 publications reporting on 33 patient cohorts (74,192 patients, 13 countries). For all studies, the weighted average follow-up period reported was 9.9 months, after which 77.5% of patients were retained. Loss to follow-up and death accounted for 56% and 40% of attrition, respectively. Weighted mean retention rates as reported were 79.1%, 75.0% and 61.6 % at 6, 12, and 24 months, respectively. Of those reporting 24 months of follow-up, the best program retained 85% of patients and the worst retained 46%. Attrition was higher in studies with shorter reporting periods, leading to monthly weighted mean attrition rates of 3.3% per each month, 1.9% per each month, and 1.6% per each month for studies reporting to 6, 12, and 24 months, respectively. In sensitivity analyses, estimated retention rates ranged from 24% in the worse case to 77% in the best case at the end of 2 years. According to this review since the inception of large-scale ART access, ART programs in Africa have retained about 60% of their patients on care at the end of 2 years of follow-up. As it has been explained above loss to follow-up was the major cause of attrition, followed by death [32].

In a retrospective study conducted in Johannesburg, South Africa, persons discontinuing follow-up for at least 6 weeks were identified and further studied, and causes for treatment default were thus recognized. In this study, 16.4% discontinued follow-up within 15 months, and death accounted for 48% of those lost from follow-up. Characteristics associated with death were older age at HAART initiation, lower baseline CD4 cell count, higher initial HIV RNA load, and loss of weight while on ART. Common non-mortality losses included relocation or clinic transfer and hospitalization or illness not resulting in death. Few cited financial difficulty or medication toxicity as reasons for discontinuing follow-up. According to this study, nearly 1 in 6 patients receiving ART in a resource-constrained setting had discontinued follow-up over a 15-month period. Early mortality was high, especially in those with profound immune-suppression [37].

Information on those who are lost to follow-up is very limited. The problem of attrition cannot be addressed effectively without better means to track patients. Only then can we address the pressing question of why patients drop out and what conditions, assistance, or incentives will be needed to retain them. Higher levels of attrition were reported during the first few months of HAART initiation. There are several plausible explanations for this. One possibility is that limited availability of resources to a given program could affect both its ability to retain patients and to conduct long-term surveillance of its outcomes. Another, less pessimistic explanation is that shorter durations of reporting reflect newer programs that are still in the process of developing optimal strategies for patient retention: had they reported at a later point in their implementation, retention rates might have been higher [38]. Findings of the Antiretroviral Therapy in Lower Income Countries (ART-LINC) Collaboration and ART Cohort Collaboration (ART-CC) group follow-up study show that, mortality rates of HIV-infected people from low-income settings in Africa, South America, and Asia fell substantially within the first few months of HAART, and approached those seen in Western Europe and North America after 4 to 6 months. This is because people in low-income settings started treatment with considerably more advanced immunodeficiency than those from industrialized countries, but virological and immunological response to HAART were similar in both settings [39]. In addition to this, insufficient community and patient preparation, erratic and unsustainable drug supplies, and inadequate training and support of health care providers are also reasons for the low levels of patient retention in Africa [40].

Regardless of this, higher level of patient retention rates had also been reported from other studies done in Africa and other parts of the world. For example according to a study in Cambodia, after a median follow-up of 23.8 months, 84.1% of patients were still on HAART, l2.7% had died, 1.4% was transferred, and 1.7% was lost to follow-up. Estimates of survival were 85.5% at 24 months [41]. A study done in South Africa followed two-hundred and eighty-seven adults naive to prior ART for a median duration of 13.9 months. The cumulative probability of remaining alive was 86.3% at 24 months on treatment for all patients. This study evidenced that ART can be provided in resource-limited settings with good patient retention and clinical outcomes [42]. According to a follow-up study in Senegal survival probability at 3 years was 0.81wih similar clinical and biologic results with those seen in Western countries [43].

In Ethiopia attrition from treatment is unacceptably high. A cohort study found that nearly 30% of patients who initiated ART either died, stopped treatment or are lost to follow-up within three years after initiation of treatment [6]. A very high mortality rate was also reported from a cohort study especially during the first month of treatment. The prognosis was particularly worse in patients with advanced disease [44].

A study at Jimma Hospital, Western Ethiopia followed 1,270 patients who initiated HAART for 24 months. From the total who were on follow-up 13.6% defaulted, 8.0% were transferred out, 5.9% died. Reasons for defaulting were unclear in most cases. Reasons given were loss of hope in medication, lack of food, mental illness, preferring traditional medicine and lack of money for transport. Taking hard drugs (cocaine and cannabis), excessive alcohol consumption, being bedridden, and having an HIV negative or unknown HIV status partner were associated with defaulting from ART [45].

In general, there are measurable and worthwhile social and economic benefits from ART, as people living with HIV are able to resume their lives as productive members of society. The evidence from pilot and scaled-up projects in Botswana, Senegal, South Africa, Ethiopia and Uganda indicate that treatment works in Africa [44, 46].

1.1.5. Perceived Quality Of Life (QOL)

According to the World Health Organization, the concept of QOL is defined as: "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [47]. It refers to a patient's perceived physical and mental well-being over time. It is dependent on disease symptoms, treatment efficacy in relieving symptoms, and treatment-related side effects [48, 49]. Quality of Life is determined by the extent that ambitions and expectations correspond to personal experience; by personal perception about one's position in life, considering the cultural context and value systems in which people live; and in relation to personal goals, expectations, standards and beliefs through the evaluation of the current state in relation to the ideal, as well as to what people consider as important factors in their lives not only health, as represented by

physical and functional attributes, is important for understanding the quality of life for a person facing a disease, but other social and emotional aspects carry equal value [50, 51].

Human Immunodeficiency Virus is a chronic disease. For a person living with HIV, this means having to cope with a range of HIV-related symptoms for extended periods. Symptoms may be related to the infection itself, comorbid illnesses, or iatrogenic effects from HIV-related medications [52, 53]. Many of the HIV patients struggle with numerous social problems such as stigma, poverty, depression, substance abuse, and cultural beliefs which can affect their QOL not only from the physical health aspect, but also from mental and social health point of view and cause numerous problems in useful activities and interests of the patients [55].

Assessing health-related quality of life (HRQOL) is useful for documenting the patients' perceived burden of chronic disease, tracking changes in health over time, assessing the effects of treatment and quantifying the return on health care investment [56]. Once an increase in survival has been achieved, the measurement of health-related quality of life (HRQoL) in HIV-infected patients as an outcome measure of drug therapy becomes increasingly important as it may provide evidence that can be helpful in decision-making regarding treatment options (57 – 59]. Quality of life has also been identified as a key component of overall health among people living with HIV [59 – 65].

Different studies had been carried out to assess QOL among people living with HIV. In a study done using the Medical Outcomes Study HIV (MOS-HIV) health survey and the EQ-5D self-report, individuals with HIV achieved significantly lower HR-QOL scores than individuals in a general population database using both the EQ-5D utility and EQ-5D visual analogue scales [66].

A quantitative study at the University of Washington Center for AIDS Research assessed the effect of HAART on quality of life from the year 1996 to 1997. In this study therapy-naive individuals were 2.2 times more likely to rank their health status as poor rather than fair and 2.3 times more likely than patients receiving treatment to rank their health status as poor versus any other rating option [67].

Another study compared clinical end points and QOL between patients treated in 1994 (pre highly active antiretroviral therapy) and those treated in 1998. The mortality rate at the 6-month follow-up was significantly higher in the precombination ART cohort than in the 1998 cohort (33.8% versus 3.9%), and the 1994 cohort had higher hospitalization rates with a longer length of stay (28.1 days versus 12.6 days). The improved clinical outcomes of the post-HAART group were paralleled by improved QOL and psychosocial function: after 6 months of treatment, the emotional and energy domains scores were higher for the 1998 cohort than for the 1994 cohort and fewer patients in the 1998 cohort were totally dependent on outside care (1.4% versus 6.8%) [68].

HAART has been associated with positive QOL outcomes in several studies. For example, in a cohort of 138 patients starting therapy with two nucleoside reverse transcriptase inhibitors (NRTIs) and indinavir (IDV), both clinical variables and HR-QOL domain scores improved beyond 3 months [69].

From a study of 1053 patients significant improvements were reported in physical role functioning, vitality, general health perception, social functioning, emotional functioning, general mental health, mental composite score, and general HR-QOL [70].

Studies more specifically designed to assess the effect of therapy on QOL in patients stratified by disease stage indicate that the positive effects of ART on QOL apply in particular to symptomatic patients. In a study of 56 adults, stratified as asymptomatic, symptomatic, or AIDS (defined as occurrence of an AIDS-defining opportunistic infection or CD4_ T cells less than 200 cells/mm3), data showed a significant difference in QOL scores between strata at baseline; however, combination ART eliminated this difference at follow-up [71]. Clinical evidence generally supports a direct link between the introduction of effective ART in 1996 and improved HR-QOL. One study examined QOL over 12 months among a prospective cohort of HIV-1-infected adults who were on HAART. In this study, physical and mental health summary scores at enrollment were 39.2 and 40, respectively. By 12 months of HAART, scores increased by 11.2 points and 7.4 points, respectively. Financial dependence on others was the main predictor of QOL [72].

Another study assessed changes in QOL over 12 months among HIV-infected individuals receiving HAART and evaluated how this relates to HAART adherence. In this study significant improvements in mean QOL scores were seen after 1 to 4 months on HAART, and persisted for 12 months. Participants reporting 100% HAART adherence achieved significantly higher QOL scores at 12 months compared to those with poorer adherence. In this analysis, HAART adherence was associated with improved QOL, particularly if adherence was sustained [39].

1.1.6. Monitoring progress of HAART based on weight and CD4 cell progression

There are different mechanisms to measure how much treatment is succeeding. Some of these measures depend on laboratory tests like viral load and CD4 cell count. Although measuring viral load is the gold standard, it is not affordable in most developing countries, such as Ethiopia. Because of this, treatment outcome, in most instances, is measured through following the CD4 cell count level, which is immunological measure of success. CD4 cell count informs how much a person is likely to develop AIDS diseases. Other physical measures like monitoring weight are also important [5].

There is no strict guideline on measuring CD4 cell count regularly, but it is advisable to measure CD4 cell count every 6 months as long as the person has a CD4 cell count level within the optimal range. Once CD4 cell count is good, it requires less frequent monitoring. A CD4 cell count level of 200 CD4 cell/ µl or less is an alert for the occurrence of AIDS related disease. In most cases AIDS-related disease occur when CD4 cell count level is below 100 CD4 cell/ µl [5].

Different studies have demonstrated the positive effect of HAART on CD4 cell count levels. A study done in Senegal by Laurent and his colleagues found median baseline CD4 cell count of 108.5 CD4 cell/ µl at baseline but after HAART CD4 cell count increased by 82 cell/µl at 6 months and by 179.5 cell/µl at 18^{th} months [73].

In some proportion of people, CD4 cell fails to recover after HAART. A Swiss cohort study documented that CD4 cell count failed to recover in 16% of individuals after HAART for 4 years. In this study, about 50% of the study population did not reach CD4 cell counts of 500 cell/µl or greater. The finding showed that after 2 to 3 years of treatment, CD4 cell count

appeared to reach a plateau level. The main predictor for recovery of CD4 was being younger in age and female [74].

Even without suppression of viraemia, HAART may have a prolonged effect on CD4-cell counts with potential clinical benefits [75, 74]. However, when baseline CD4 cell count is lower there is high probability of risk for virological failure [76]. In most instances, within the first 4 to 6 months of HAART therapy, there is significant recovery in CD4 cell count [77].

The association of HIV related weight loss and virological and immunologic faller had been well demonstrated. Increase in virus load is associated with decrease in body weight and decrease in CD4 cell count is associated with decrease in body weight [78].

A study reported weight loss as the strongest independent predictor of mortality. Weight loss of 10% from baseline or previous visits was significantly associated with a four to six fold increase in mortality compared with maintenance or gaining of weight. Even one episode of weight loss of 3% from baseline, or 5% from the previous visit, was predictive of mortality in this study [79]. Another study indicated that weight gain after HAART initiation was associated with improved survival and decreased risk for clinical failure [80].

1.1.7. Effect of perceived social support on adherence to HAART, attrition from HAART, CD4 and weight progression, and perceived quality of life

Perceived social support relies on interpersonal networks and the extent to which an individual believes his or her needs for support, information, and feedback are fulfilled through interpersonal processes [81 – 83]. Perceived social support refers to a person's perception of readily available support from friends, family, and others. It also shows the complex nature of social support including both the history of the relationship with the individual who provides the supportive behavior and the environmental context [84]. It consists of transactions with others that provide the recipient with emotional support, affirmation of self, appraisal of the situation, instrumental support, and information [85 – 86]. More contemporary studies have defined social support as a person’s generalized cognitive appraisal of being supported by important members

of social networks such as family, friends, and significant others rather than actual enacted behaviors [87 – 90].

There is evidence that family social support is related to numerous factors including loneliness [91], social isolation and disintegration [92], stress and a buffer to stress [93, 94], self-esteem [95, 96], adjustment [97], positive affect, adult attachment styles and coping strategies, general physical health, and recovery from illness. In general, research suggests that it is not the amount of social support that is protective, but the positive interpretation of the interactions of the individual [98].

Social support provides the most important and significant environmental resources. It a mutual network of caring that enables one to cope with stress better. Social support from friends and family plays an important role in almost every aspect of stress and coping. In addition, social support refers to: having a group of family and friends who provide strong social attachments; being able to exchange helpful resources among family and friends; and the feeling of having supportive relationship and behaviors [84]. Furthermore, advice and encouragement from sources of support may also increase the likelihood that an individual will rely on active problem solving and information seeking. These techniques may assist students in dealing with various stressors in the environment and facilitate a positive adjustment process [99]. To measure social support, individuals' perceptions are commonly studied.

Studies had demonstrated the effect of social support on adherence to HAART. A study reported that having a high perception of self-efficacy, a positive attitude towards taking medication, not living alone, and being male have also been associated with better rates of treatment adherence [23, 100].

A hospital based study in Rio de Janeiro City demonstrated that non-adherence was associated with personal factors (i.e. sexual orientation, self-efficacy), physical factors (i.e. loss of appetite) and interpersonal factors (i.e. doctor-patient relationship). Promoting patient self-efficacy and behavioral skills for adherence, increasing social network support and having healthcare providers directly address patients' medication beliefs, attitudes and experience with side effects were found to be essential [100].

Similarly, another longitudinal study examined determinants of adherence to HAART over a period of 12 months. Predictors of adherence were: high perception of self-efficacy, positive attitude towards taking medication, not living alone and being male. Subsequent analysis showed that a positive attitude towards taking medication was associated with a high level of satisfaction with their physician, high perceived social support, being optimistic, living with HIV for five years or less and experiencing no side effects. Also, a strong sense of self-efficacy was associated with positive perception of social support, high level of patient satisfaction with their physician and not living alone [100].

According to a prospective observational study of 614 consecutive patients attending an HIV/AIDS outpatient clinic in Coˆte d'Ivoire lack of social support emerged as the most important predictor of poor adherence to HAART in addition to other factors like age less than 35 years and lack of optimism [101].

A follow-up study at Jimma Hospital in Western Ethiopia reported presence of social support to be an important facilitator of adherence to HAART [102]. According to a qualitative study in South Africa the key facilitators which facilitated adherence were social support, belief in the value of treatment, belief in the importance of one's own life to the survival of one's family, and the ability to fit ART into daily life schedules [103]. A qualitative study at Zambian Copper belt indicated that looking and feeling better, support from the patients' family, physical reminders and supports in the form of watches or clocks, to take drugs were important facilitators of adherence [104].

Several studies have demonstrated the effect of social support on weight gain and CD4 cell progression. According to a study done in Canada, HIV-positive adults consistently taking HAART appeared to experience better clinical outcomes if they perceived interpersonal, informational and emotional support to be available [105]. Another study done among hemophiliac patients reported lesser social support as being related to faster deterioration in CD4 cells [106]. A study also showed HIV infected subjects as becoming symptomatic after 6 months if they had less social support [107]. In another study faster progression of AIDS was associated with lower cumulative average satisfaction with social support [73, 108 – 109].

A study that explored the relationship between social support and clinical outcomes for HIV positive person suggested causal directionality in which cross-sectional social support and/or improvements in social support over time predicted virological outcome, with better social support associated with greater likelihood of viral load suppression to 'undetectable' level, an outcome achieved for 68% of the sample. In contrast, cross-sectional virological status reflected immunological outcomes but did not predict subsequent ratings of social support or changes in social support ratings. HIV-positive adults consistently taking HAART appeared to experience better clinical benefit if they perceived interpersonal, informational and emotional support to be available, a finding that underscores the importance of social support in relation to treatment outcome [105].

Another study used Cox regression models with time-dependent covariates, adjusting for age, education, race, baseline $CD4^+$ count, tobacco use, and number of antiretroviral medications. In this study faster progression to AIDS was associated with more cumulative stressful life events, more cumulative depressive symptoms, and less cumulative social support. At 5.5 years, the probability of getting AIDS was about two to three times as high among those above the median on stress or below the median on social support compared with those below the median on stress or above the median on support, respectively. These data demonstrate that more stress and less social support may accelerate the course of HIV disease progression [108].

A study that examined the effect of positive psychosocial factors on HIV disease progression found positive psychological resources to be negatively related to mortality and immune system decline during a 5-year follow-up period. Only 6% of those with psychological resources died versus 17% of without [73].

In addition to the studies presented above, other studies have also reported social support to be a predictor of better health [110]. For example a study showed that larger network sizes to be predictor of longer survival during 5 years follow-up period among those with AIDS [163]. A longer follow-up study by Leserman also reported the positive effect of social support on clinical AIDS condition and mortality [111].

A study found that higher cumulative social support to be predictor of rapid progression to AIDS or to an AIDS clinical condition. At 7.5 years, 24% of those above the median on social support progressed to AIDS compared with 49% below the median [107]. Another study also found less social support at baseline to be associated with more HIV/AIDS related symptoms after 1 year of follow-up [112]. A study by Theorell also found that higher social support predicted less increase in HIV symptoms over 12 months in a mixed group of 65 men and women studied in the HAART era [106]. Two other studies reported that higher social support to be associated with slower disease progression [113, 114].

Although some studies reported positive association between social support and slower HIV/AIDS disease progression, a few other studies reported social support not to be significantly associated with HIV health outcome [115 – 118].

The effect of perceived social support on quality of life with respect to people living with HIV/AIDS can be explained by the fact that social support is an important determinant of health outcomes. Perceived support has been found to be associated with adjustment and coping in relation to HIV diagnosis and its potentially chronic, disabling course [108, 119 - 124].

In the context of highly active antiretroviral therapy treatment regimens, the focus has shifted somewhat from an emphasis on the psycho-neuro-immunological effects of stress to the potential buffering aspects of social support. More recently, research has investigated social support as a potential mediator in terms of the degree to which such things as treatment adherence and resource accessibility influence clinical outcome [125 – 128].

Although social support and quality of life appear to figure as salient factors affecting overall health and wellness status for PLHIV, there is a dearth of research examining their interrelations. A recent review article cited social support as an important factor affecting quality of life among PLHIV, yet identified that there was scant research in which the relationship between social support and quality of life had been addressed for this population [129 – 135].

Although the degree of social support stability over time or potential influence of perceived social support on quality of life outcomes for PLHIV has not been thoroughly examined,

recommendations to explore causal relationships between social support and quality of life have been highlighted in previous HIV-related research [136]. Causal directionality of relations between social support and overall health for PLHIV is unclear. Another issue is whether social support promotes psychological well-being or, alternatively, whether good health attracts positive social support and poor health leads to requirements for psychological adaptation that render social support more challenging to maintain [137, 138]. Exploring causality is complicated by the possibility of shifts over time in the direction of the relationship between support and health [139]. Similar questions can be applied to consideration of the causal relationships between social support and health-related quality of life among PLHIV. Exploring the causal directionality between social support and health, including its quality of life component, requires a comprehensive and systematic evaluation of the temporality, strength, consistency, gradient and plausibility of associations between the two variables of interest [140].

1.1.8. Effect of depressive symptom on adherence to HAART, attrition from HAART, CD4 and weight progression, and perceived quality of life

Psychological factors are those thoughts, feelings, emotions that affect the mental state and well-being of the infected and affected persons. It is particularly important to understand psychological effects of HIV/AIDS, such as: fear, loss, grief, guilt, denial, anger, anxiety, low self-esteem, depression, suicidal behavior and thinking, and socio-economic issues. The psychological or internal challenges a person with HIV/AIDS faces vary from individual to individual. Not everyone will experience all of the emotional responses or stages of the emotional responses described [141].

As HIV has become a long-term condition, which not only affects physical health, but also causes psychological and social problems because of stigma and discrimination. These challenges present many decisions and dilemmas for PLHIV which involves complex emotional and psychological issues. A literature review of 46 articles on psychosocial effect of HIV summarized three key decisions that HIV infected persons face; these are (i) whether or not to disclose their diagnosis to others; (ii) decisions about adherence to treatment; and (iii) decision about sexual activity and desire about parenthood. Problems associated with these decisions

often result in isolation and mental illness such as depression and anxiety, lack of social support, and refusal to seek treatment [142].

While some PLHIV are able to effectively manage their care and lead fulfilling lives, a significant proportion report difficulties coping with stress [143]. Elevated psychosocial stressors, coupled with poor stress management skills, can exacerbate existing psychiatric illnesses or heighten an individual's risk for a new disorder including major depression, alcohol or drug dependence, and anxiety disorders [144, 145]. Indeed, research suggests elevated rates of psychiatric illness among PLHIV relative to non-infected samples [146]. For instance, a recent investigation found a 19% prevalence rate for major depressive disorder among PLHIV, compared to only 5% in a non-infected comparison sample. Elevated psychological distress may contribute to poor disease management and negative health outcomes among PLHIV. Prior investigations demonstrate that heightened psychological distress is associated with accelerated disease progression, as indicated by CD4 decline, increased viral load, and fewer natural killer cells [108, 147 – 149, 171].

Lower engagement in protective health behaviors may mediate the association between psychological functioning and disease outcomes. Mental health difficulties may also be associated with suboptimal medication adherence and less engagement in preventative health practices, including missed medical appointments and sexual risk taking. Thus, there is increasing evidence that psychological distress is associated with poor health outcomes and less engagement in protective health behaviors among PLHIV [150 – 155].

Due to multiples of complex issues related to their HIV infection, HIV-positive individuals are more likely to be diagnosed with major depressive disorder than HIV-negative individuals. Depression can precede diagnosis and be associated with risk factors for infection. The experience of illness can also exacerbate depressive episodes and depression can be a side effect to treatment. A systematic review of 90 studies on depression among HIV positive individuals reported prevalence of depression to range from 0 to 80%; measures were diverse and rarely adopted the same cut-off points. In this review psychological interventions were particularly effective and in particular interventions that incorporated a cognitive-behavioral component.

Psychotropic and HIV-specific health psychology interventions were generally effective. Evidence is not clear-cut regarding the effectiveness of physical therapies and psychosocial interventions were generally ineffective. Interventions that investigated the effects of treatments for HIV and HIV-associated conditions on depression generally found that these treatments did not increase but often decreased depression [156].

As a result of these changes in both working and personal relationships, the behavior of those infected may change. They may become withdrawn, aggressive, and rude to colleagues and friends. This may be because the infected person may feel (or imagine) being victimized. Infected, and in some cases, affected, people can experience a decrease in self-esteem as they are no longer confident in themselves or what they can achieve. This is likely caused by the stigma within society against infected and affected people [141].

Studies have reported the negative effect of depression on adherence to HAART. A study examined the association of substance abuse with adherence to HAART among HIV-infected people with a history of alcohol problems using a prospective cohort study. The study subjects were followed every six months for up to seven occasions. More depressive symptoms and use of drugs or alcohol in the previous 30 days were associated with worse 30-day adherence [157]. According to a study at Mulago Hospital in Kampala, Uganda, all patients reported 95% adherence, but pill counts showed that only 60% of the clients had 95% adherence. In this study depression was found to be the most important predictor of adherence [158]. A study at Jimma Hospital in Western Ethiopia reported depression to be an important barrier to adherence to HAART [102]. A study explored factors associated with non-adherence over a 10 year follow-up in Europe. Reasons for non-adherence depended on both psychosocial conditions and treatment-related characteristics [159].

The effect of depressive symptom on attrition has also been documented. A study examined predictors of discontinuation of HAART among HIV-infected people with alcohol problems. Findings indicated substantial depressive symptoms as being significantly associated with HAART discontinuation. Among HIV-infected adults with alcohol problems, depressive symptoms, but not substance use, predicted subsequent ART discontinuation. Recognition and

treatment of depressive symptoms may result in better maintenance of ART and its associated clinical benefits [160].

In-terms of the effect of depression on weight and CD4 progression, studies carried out in the years 1992, 1993, and 1996 reported lack of significant association between depressive symptom and progression of HIV infection and CD4 cell count [161 – 163]. On the other hand other studies done in the same era reported significant association between worse baseline depressive symptom and decreased CD4 cell progression [164, 165]. Similarly, multiple studies done from the year 1999 to 2006 reported significant association between worse depressive symptom and decreased CD4 cell progression [73, 108, 109, 166 – 176].

Neuropsychiatric aspects of HIV are also strongly associated with overall QOL. Depression is the most common neuropsychiatric aspect of HIV and studies have consistently reported robust relationships between depression and QOL among persons infected with HIV [177 – 185].

Apathy has been identified as a potentially important neuropsychiatric symptom associated with HIV. Apathy refers to a reduction in goal-directed behavior that is manifested by decreased behavioral, cognitive, or psychological activity. Apathy is more common among patients with HIV compared to healthy control subjects, although the impact of apathy on QOL has not been investigated [177 – 185].

Although there were conflicting ideas about the effect of depression on HIV/AIDS disease progression in the years from 1991 – 1999 [186 – 197], currently there is evidence that that depression alters the function of killer lymphocytes in HIV infected individuals suggesting that it decreases natural killer cell activity and leading to an increase in activated CD8 T lymphocytes and viral load [198].

The role of depression in HIV-1 disease progression has been examined in several longitudinal studies. A 9-year study of seropositive men showed that baseline depression was associated with faster progression to AIDS [199] and that elevated depression at every visit increased the risk of mortality [200]. Data from the Multicenter AIDS Cohort Study showed no relationship between

baseline depression and AIDS progression [201]; however, self-reported depressive symptoms increased 1.5 years before AIDS diagnosis [202]. Mixed findings might be explained by the reliance on a baseline measure of depression and by the need to consider other moderating factors (e.g., coping, social support).

Studies have also reported a link between passive coping strategies (e.g., denial) and HIV-1 disease progression. Coping by means of denial was found to correlate with lower CD4+/CD8+ ratios 1 year after serostatus notification and with a greater probability of disease progression 2 years later [203]. Less denial and more active coping strategies (e.g., fighting spirit) were associated with a lower probability of developing HIV-related symptoms after 1 year [204].

In a study done by Ickovics and colleagues faster progression to AIDS was associated with higher cumulative average stressful life events, coping by means of denial, and higher serum cortisol as well as with lower cumulative average satisfaction with social support. Other background (e.g., age, education) and health habit variables (e.g., tobacco use, risky sexual behavior) did not significantly predict disease progression. The risk of AIDS was approximately doubled for every 1.5-unit decrease in cumulative average support satisfaction and for every cumulative average increase of one severe stressor, one unit of denial, and 5 μg/dl of cortisol. In multivariate analyses controlling for clinical, treatment, and other factors, women with chronic depressive symptoms were 2 times more likely to die than women with limited or no depressive symptoms [166].

Another study by Ickovics and colleagues examined the health effects of chronic depression in HIV-infected women during a 7-year period when HAART began to be available. Women with chronic depressive symptoms were about two times more likely to die from AIDS than those who never experienced depression; the effects of depression were particularly pronounced among women who began the study with low CD4 cell counts. Depression was also associated with greater decline in CD4 count. These analyses controlled for baseline CD4, HIV viral load, HIV-related symptoms, antiretroviral therapy, and HAART use. In another reanalysis of the data, Ickovics and colleagues found that women with more positive psychological resources (e.g.,

positive affect, finding meaning, and positive HIV expectancy) had greater decreases in AIDS-related mortality [205].

The Women's Interagency HIV Study (WIHS), with 7.5-year investigation of 1716 women showed that those with chronic depressive symptoms were more likely to die from HIV (13%) than those with few or no depressive symptoms (6%) [168]. In addition, women who received mental health services were significantly less likely to experience AIDS-related mortality. Depression (time-varying) was associated with poorer virologic response, and greater risk of immunological failure, AIDS-defining illness, and all-cause death among [169].

In studying 490 HIV-infected men and women, Leserman and colleagues found that each standard deviation increase in depressive symptoms was related to a 49% increased risk of AIDS mortality, controlling for demographic variables, CD4, viral load, and antiretroviral therapy [194, 108]. No effect of depressive symptoms on all-cause mortality was found.

Ironson and colleagues also found that cumulative depression and hopelessness were associated with decreases in CD4 count and increases in viral load in a 2-year study of 177 HIV infected patients, controlling for HAART and medication adherence [116].

Several studies have examined depression at the time of HAART initiation in persons previously naive to the medication. Depression at initial HAART use was associated with: over five times the risk of clinical progression to AIDS [170], slower virologic suppression [206], and shorter survival. In addition, cumulative depression (with and without somatic symptoms) was associated with progression to AIDS during 6.5 years, adjusting for demographic variables, nonadherence, CD4 cell count, and virological response [170].

1.1.9. Effect of stigma on adherence to HAART and attrition from HAART

Any measure of arbitrary differentiation among persons due to their confirmed or suspected HIV serostatus or state of health is referred to as HIV related stigma. Discrimination is the negative act that results from stigma; it is the end result of the process of stigma [207, 208]. Stigma can

cause social marginalization which lead to loneliness. Stigma can also contribute to fear of disclosure of HIV status. All of these will affect adherence to Highly Active Antiretroviral Therapy (HAART) [209].

Fear of social abandonment and losing intimate partners prevents many people infected with HIV from sharing their diagnosis with loved ones and sexual partners. Lapses in adherence to treatment often occur when there is concern that an acquaintance may witness pill-taking or find pill bottles, leading to unwanted questions about a person's health and, potentially, an unexpected "outing" as being HIV-positive [210, 211].

The association between stigma and adherence difficulties is usually mediated by accompanying changes in depressed mood and lack of social support [127, 212]. Stigma and discrimination can lead to depression and lack of self-esteem. Negative attitudes about HIV also create a climate in which people become more afraid of the stigma and discrimination associated with the disease than of the disease itself [213, 214].

Devastating the social, economic and family lives of individuals, HIV/AIDS stigma is cited as a major barrier to accessing prevention, care and treatment services of HIV [215 – 217]. HIV/AIDS stigma is documented as a barrier to the uptake of HIV testing and treatment services in numerous settings, particularly in resource-limited countries [218 – 221]. Specifically, stigma impedes access to and retention in HIV care and adherence to antiretroviral medications. Non-disclosure of HIV status for fear of stigma may result in missing doses of medications in order to maintain secrecy about one's illness [222 – 224, 227]. Studies demonstrating the adverse effects of stigma on retention in care and adherence are also emerging in Africa [228 – 230].

In a study which was carried out in Botswana, 94% of study subjects kept their HIV status secret from their community, while 69% withheld this information even from their family, and 27% feared loss of employment as a result of their HIV status. The study showed that 40% reported delaying HIV testing and of these, 51% cited fear of a positive test result as the primary reason for the delay in seeking treatment, which was often due to HIV-related stigma [231].

A study carried out among youth reported that about 50% skipped doses of medication because they did not want families or friends to discover their status. These results suggest that HIV stigma impacts treatment for youth by influencing medication adherence negatively [224]. In another study, 1 in 5 study subjects reported high concern for stigma related to their HIV status. In this study, a high degree of concern about stigma was found to be a predictor of non-adherence to medication regimen [232].

Financial constraints, stigma, travel difficulties, side-effects, and poor physician and patient relationships have also been documented as barriers to adherence [33, 210].

An assessment aimed at identifying barriers to HAART adherence was also conducted in Botswana. Principal barriers to adherence included financial constraints (44%), stigma (15%), travel and migration (10%), and side effects (9%) [210]. Another study indicated that multiple physician-patient relationships were associated with medication adherence in persons with HIV infection, suggesting that the quality of physician-patient relationships is a potentially important point of intervention to improving patients' medication adherence [33].

In general multiples of studies had been carried out in Africa to assess adherence to HAART and long-term retention of patients on HAART care. The findings had been diverse with some studies reporting higher rates of self-reported adherence to HAART and good levels of retention rates. Yet, a few studies had reported alarmingly high levels of attrition from HAART care and low levels of adherence to HAART. The effect of perceived social support, depression symptoms, and stigma on adherence to HAART, weight and CD4 progression, attrition from treatment and perceived quality of life has also been evidenced. With the existence of scanty information on the effect of perceived social support, depression symptoms and stigma on HAART outcome in Ethiopia, the current study will have paramount significance.

2. Rationale of the Study

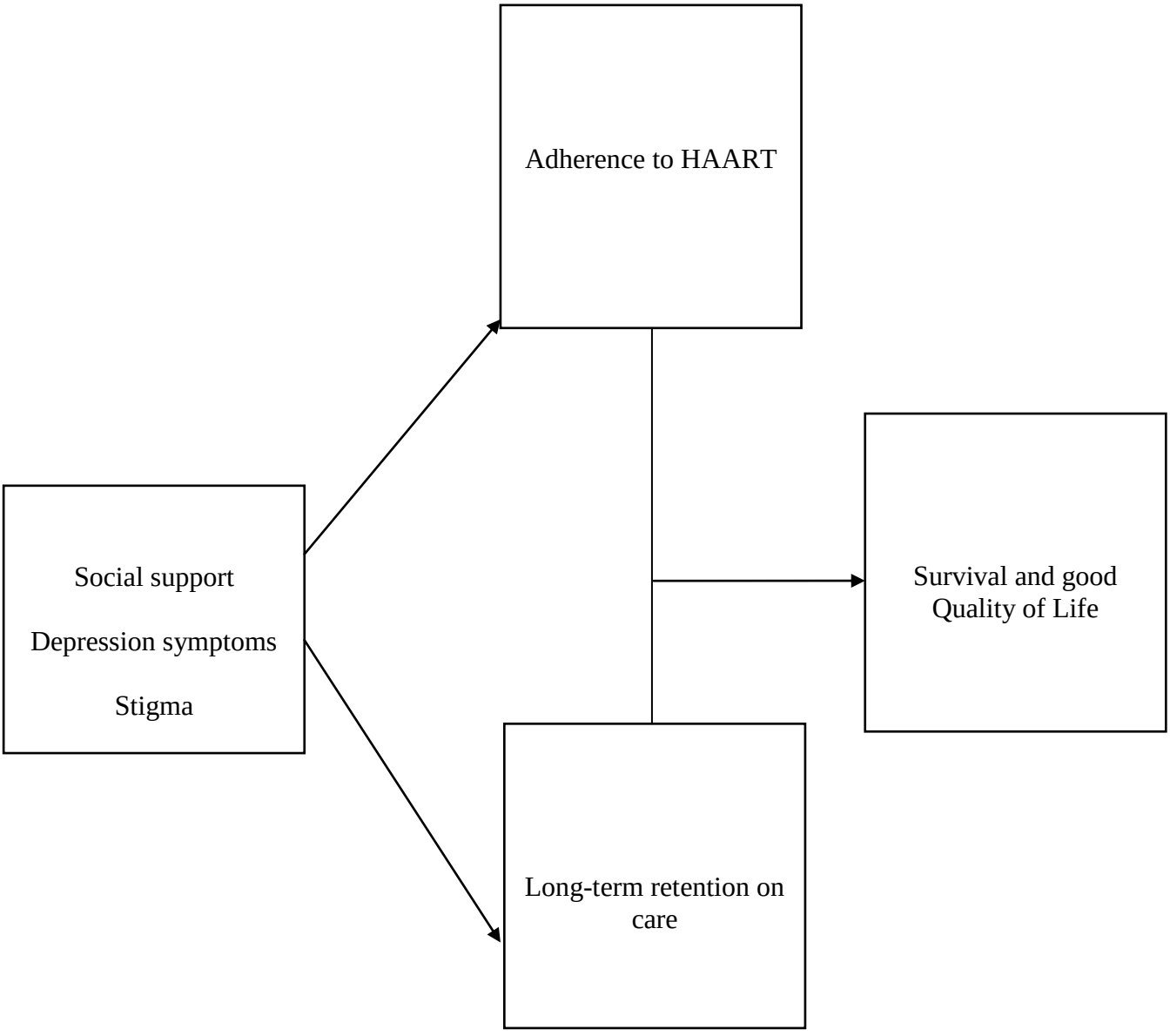
It is widely known that long-term follow-up and day to day dedication to therapy is essential for HAART to be successful. At the same time, it is known that committing for lifelong treatment is difficult unless people who are taking HAART are supported socially, psychologically, and emotionally.

Taking into consideration that adherence and long-term dedication to HIV/AIDS treatment is sub-optimal in Ethiopia, as in other African countries, this study aims to explore relationships between social support, depression symptoms, and stigma with engagement and dedication to HAART. In addition to this, improvements in quality of life were also explored.

2.1. General framework of the proposed study

As presented in figure 2.1 the overall study outcome is survival of the person who is infected with HIV and receiving HAART, improved perceived quality of life, and good CD4 count and weight progression. For the person to live long and have better clinical outcomes he or she need to take the medication on time for their life. Staying on care and treatment for life is critical. It is hypothesized that survival, quality of life, CD4 count and weight progression, adherence to HAART are influenced by perceived social support positively and by depression symptoms, and stigma negatively.

Figure 2.1: Conceptual framework of relationship between social support, depression symptoms, and stigma with adherence to HAART and retention on care influencing survival and quality of life.



3. Objectives of the Study

3.1. General Objective

Explore the effect of social support, depression symptoms and stigma on adherence to HAART, self-confidence to take HAART properly, attrition from HAART, weight and CD4 progression, and perceived quality of life.

3.2. Specific Objectives

- Explore socio-demographic and behavioral correlates of adherence to HAART and self-confidence to take HAART properly.
- Assess the effects of social support and depression symptoms on adherence to HAART and self-confidence to take medication properly.
- Assess the effect of negative self-image, concern about public attitude, concern about disclosure, and personalized stigma on adherence to HAART and self-confidence to take HAART properly.
- Assess the effects of social support and depression symptoms on CD4 and weight progression.
- Assess the effect of social support on attrition from HAART and perceived quality of life of people infected with HIV.

4. Hypothesis

The general hypothesis of the study is that attachment (adherence to HAART) and dedication (long-term retention on HIV/AIDS care) to HAART is influenced by social support, depression symptoms, and stigma.

Under this general hypothesis this study tested six specific hypotheses.

4.1. Hypothesis I

Adherence to HAART and self-confidence to take HAART properly is influenced by gender, age, religion, income, educational status, duration of stay on HAART, regular alcohol drinking, and *khat* chewing/smoking practices. The model to be tested under this hypothesis will be:

> **Adherence to HAART and Self-confidence to take HAART properly** = β0+ β1*sex+ β2*age+ β3* religion + β4* income+ β5*educational status+ β6*duration of stay on HAART + β7*regular alcohol drinking + β8**Khat* chewing/smoking.

4.2. Hypothesis II

Adherence to HAART and self-confidence to take HAART properly is influenced by social support and depression symptom controlling for the possible confounding effects of disclosure of HIV status, age, sex, regular alcohol drinking, educational status, income, marital status, and duration of stay on HAART. The model to be tested under this hypothesis will be:

> **Adherence to HAART and Self-confidence to take HAART properly** = β0+ β1*social support + β2*depression symptoms+ [β3* disclosure of HIV status + β4* age+ β5*sex+ β6*regular alcohol drinking + β7*educational status + β8*income + β9*marital status + β10*duration of stay on HAART].

4.3. Hypothesis III

Adherence to HAART and self-confidence to take HAART properly is influenced by negative self-image, concern about public attitude, concern about disclosure, and personalized stigma controlling for the possible confounding effects of gender, age, income, educational status, religion, marital status, and duration of stay on HAART. The model to be tested under this hypothesis will be:

> **Adherence to HAART and Self-confidence to take HAART properly** = β0+ β1*negative self-image + β2*concern about public attitude+ β3* concern about disclosure of HIV status + β4* personalized stigma+ [β5*gender+ β6*age + β7*income + β8*educational status + β9*religion + β10*marital status + β11*duration of stay on HAART].

4.4. Hypothesis IV

Weight and CD4 progression is influenced by social support and depression symptom controlling for the possible confounding effects of disclosure of HIV status, age, sex, regular alcohol drinking, educational status, income, marital status, and duration of stay on HAART. The model to be tested under this hypothesis will be:

> **Weight and CD4 progression** = round + baseline depression symptom + baseline depression symptom X visit + social support + social support X visit + [sex + age + income + education + marital status + adherence to treatment].

4.5. Hypothesis V

The hazard /risk/ of failure from HAART at 12 months of follow-up is influenced by baseline perceived social support controlling for the possible confounding effects of disclosure of HIV status, age, sex, regular alcohol drinking, educational status, income, marital status, and duration of stay on HAART. The model to be tested under this hypothesis will be:

Hazard /risk/ of failure at time‘t’ (12 months) = h(t) exp (β1*social support + [β2* age+ β3*sex+ β4*regular alcohol drinking + β5*educational status + β6*income + β7*marital status + β8*duration of stay on HAART].

4.6. Hypothesis VI

Perceived quality of life is influenced by social support controlling for the possible confounding effects of age, sex, regular alcohol drinking, educational status, income, marital status, and duration of stay on HAART. The model to be tested under this hypothesis will be:

Perceived quality of life = β0+ β1*social support [β2*sex + β3*age+ + β4*regular alcohol drinking + β5*income + β6*educational status + β7*marital status + β8*adherence to HAART].

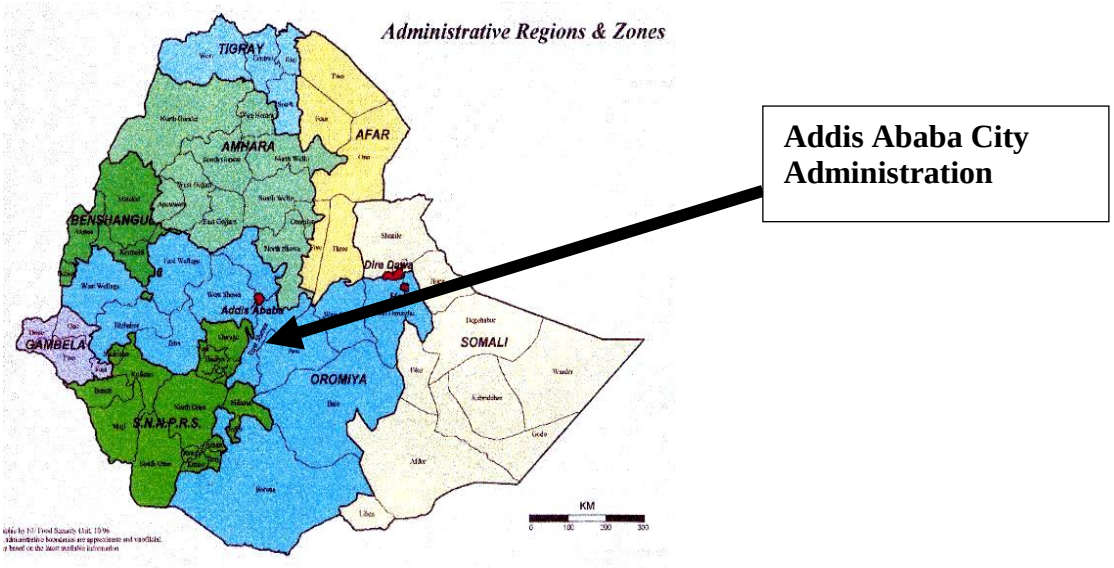
5. Methodology

5.1. Study area

This study was conducted in the capital city of Ethiopia, Addis Ababa. Ethiopia is located in the Eastern part of Africa. The land area is estimated to be about 1.1 million square kilometers. The country is among the three most populous countries in Africa with a total population of 79,221,000 persons, of whom 65,996,000 are rural and 39,691,000 are males [235].

Ethiopia is a Federal Democratic Republic country composed of nine National Regional states: namely Tigray, Afar, Amhara, Oromia, Somali, Benishangul-Gumuz, Southern Nations Nationalities and People Region (SNNPR), Gambella and Harari and two administrative states (Addis Ababa City administration and Dire Dawa city council) [236].

Figure 5.1: Map showing administrative regions of Ethiopia and location of the study area.



Ethiopia experiences a heavy burden of disease with a growing prevalence of communicable infections. Many Ethiopians face high disease morbidity and mortality largely attributable to potentially preventable infectious diseases and nutritional deficiencies [236].

Addis Ababa being the capital city of Ethiopia has a total population of 3,147,000 [235]. This study took place specifically at Zewditu Memorial Hospital HAART clinic in Addis Ababa City administration.

There are three reasons why this research was focused at Zewditu Memorial Hospital:

1. It is the oldest HAART clinic in the country.
2. It had the highest number of people enrolled for HAART among all other sites in the country.
3. The HAART site has a computerized data management system which facilitates the research process.

As of June 2008, in Addis Ababa City administration, a total of 34 public and 13 private health facilities (hospitals and health centers) were delivering HAART services. Four additional HAART sites serve the army and police forces. According to the recent report, 30,609 people (26,982 in public and 3,627 in private ART sites) were receiving HAART in the city. The total number of people who had ever started HAART amounts to 42,787 [13, 237].

5.2. Source population

People living with HIV/AIDS formed the main source population for the study.

5.3. Study period

The first round of quantitative data was collected from February 1 – March 19, 2010. The qualitative data and follow-up quantitative data were collected in June, 2011.

5.4. Study population

The study population were adult age persons (age $\geq$ 18 years) who were receiving HAART from Zewditu Memorial Hospital at the time of the study.

5.5. Operational definitions

Acquired Immune Deficiency Syndrome (AIDS): It refers to the advanced stage of HIV illness, when the CD4 count falls under 200 [5].

Antiretroviral (ARV) drugs: Refers to drugs used against retroviruses, commonly anti-HIV drugs [5].

CD4: A receptor on the surface of cells that HIV attaches to. The cells involved in cell-mediated immunity known as T-lymphocytes have the CD4 marker. Other cells, including some in the brain have the same marker and are the targets of HIV [5].

CD4 count: Represents the count of the cells with CD4 receptor in circulation [5].

CD4 cell progression: Gradual increase in the number of CD4 cells once the person initiated HAART [5].

Combination therapy: Certain illnesses and infections require more than one medication taken at the same time to improve their effect. Three drugs are needed to suppress HIV replication. Combination therapy refers to such an intervention [5].

Discrimination: The negative act that results from stigma; it is the end result of the process of stigma [207, 208].

Depression: A lowering of mood from normal. Symptoms of depression can vary greatly and include: crying, loss of interest or pleasure in previously enjoyable activities, loss of appetite, change in appetite, and change in sleep patterns [238].

HAART (Highly Active Antiretroviral Therapy): A treatment with a combination of at least three different ARVs [5].

Human Immunodeficiency Virus (HIV): The virus that causes AIDS. There are two different types HIV-1 and HIV-2. Worldwide HIV-1 is the most common type [5].

HIV related stigma: Any measure of arbitrary differentiation among persons due to their confirmed or suspected HIV serostatus or state of health [207, 208].

Health Related Quality of Life (RQOL): "an individual's or group's perceived physical and mental health over time" [246].

Immune system: The body's natural defense mechanism against foreign substances [5].

Immunosuppression: A state of the body in which the immune system is suppressed or damaged so that it can no longer defend the body against infections and disease [5].

Medication Adherence: The extent to which persons take medications as prescribed by the health care providers [14].

Non Nucleoside Reverse Transcriptase Inhibitors (NNRTI): Classes of antiretroviral drugs which work by blocking the action of the HIV enzyme reverse transcriptase [5].

Nucleoside Reverse Transcriptase Inhibitors (NRTI): Classes of antiretroviral drugs which work by blocking the action of the HIV enzyme reverse transcriptase. These drugs are sometimes known as Nucleoside Analogues [5].

Nucleotide Analogues: Antiretroviral drugs that work in a very similar way to the Nucleoside Analogues [5].

Opportunistic Infection (OI): Infections that normally do not infect or manifest in patients with intact immunity. These infections cause disease in people with damaged immune systems [5].

Perceived social support: the extent to which an individual believes that his/her needs for support, information, and feedback are fulfilled". It is an individual's subjective view of how other people, in particular families or peers, are available to meet and/or assist with meeting the individual's needs for comfort and support [83].

Regimen: Medicine or medicines formulated for a specific illness or disease [5].

Replication: The process of viral reproduction/multiplication [5].

Resistance: The ability of organisms to grow/multiply in the presence of chemicals/drugs that would normally kill them or suppress them [5].

Self-confidence to take HAART: Being confident to be able to take all or most of the HAART properly [14].

Social support: Help for people in a difficult life situation, it is the individual belief that one is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligation [81 , 82].

Psychological factors: those thoughts, feelings, emotions that affect the mental state and well-being of person [141].

Viral load: The amount of viruses in the blood circulation. The viral load in HIV infection directly correlates with the degree of immune suppression [5].

Weight progression: gradual increase in weight once the person initiated HAART [5].

5.6. Study design

Epidemiologic research encompasses several types of study designs, including experimental studies and observational studies, such as cohort and case–control studies. Each type of epidemiologic study design simply represents a different way of harvesting information. The selection of one design over another depends on the particular research question, concern about validity and efficiency, and practical and ethical considerations. As experimental studies are often infeasible because of difficulties enrolling participants, high costs, and thorny ethical issues, most epidemiologic research is conducted using observational studies [239, 240].

Observational studies are considered “natural” experiments because the investigator lets nature take its course. Observational studies take advantage of the fact that people are exposed to noxious and/or healthy substances through their personal habits, occupation, place of residence, and so on. The studies provide information on exposures that occur in natural settings, and they

are not limited to preventions and treatments. Furthermore, they do not suffer from the ethical and feasibility issues of experimental studies [239, 240].

The two principal types of observational studies are cohort and case–control studies. A classic cohort study examines one or more health effects of exposure to a single agent. Subjects are defined according to their exposure status and followed over time to determine the incidence of health outcomes. In contrast, a classic case–control study examines a single disease in relation to exposure to one or more agents. Cases, who have the disease of interest, and controls, who are a sample from the population that produced the cases, are defined and enrolled in the study. The purpose of the control group is to provide information on the exposure distribution in the population that gave rise to the cases. Investigators obtain and compare exposure histories of cases as well as controls.

Additional observational study designs include cross-sectional studies and ecologic studies. A cross-sectional study examines the relationship between a disease and an exposure among individuals in a defined population at one point in time. Thus, it takes a snapshot of a population and measures the exposure prevalence in relation to the disease prevalence. An ecologic study evaluates an association using the population rather than the individual as the unit of analysis. The rates of disease are examined in relation to factors described on the population level. Both the cross-sectional and ecologic designs have important limitations that make them less scientifically rigorous than cohort and case-control studies [240 – 242].

The goal of all of these studies is to determine the relationship between an exposure and a disease with validity and precision using minimal resources. Validity is defined as the lack of bias and confounding. Bias is an error committed by the investigator in the design or conduct of a study that leads to a false association between the exposure and disease. Confounding, on the other hand, is not the fault of the investigator. It reflects the fact that epidemiologic research is conducted among free-living humans with unevenly distributed characteristics. As a result, epidemiological studies that try to determine the relationship between an exposure and disease are susceptible to the disturbing influences of extraneous factors known as confounders. Precision is the lack of random error, which leads to a false association between the exposure

and disease just by "chance," an uncontrollable force that seems to have no assignable cause [240 – 242].

Several factors help epidemiologists determine the most appropriate study design for evaluating a particular association. These factors include the hypothesis being tested, state of knowledge, the frequency of the exposure and the disease, and the expected strength of the association between the two [240 – 242]

The study designs for this specific research were both cross-sectional and cohort study designs. A cohort is defined as a group of people with a common characteristic or experience. In a cohort study, healthy subjects are defined according to their exposure status and followed over time to determine the incidence of symptoms, disease, or death. The common characteristic for grouping subjects is their exposure level. Usually two groups are compared, an "exposed" and "unexposed" group. The unexposed group is called the referent group or comparison group [240].

Cohort study is the term that is typically used to describe an epidemiologic investigation that follows groups with common characteristics. Other similar expressions include 'follow-up', 'incidence', and 'longitudinal study'. There are several additional terms for describing cohort studies that depend on the characteristics of the population from which the cohort is derived, whether the exposure changes over time, and whether there are losses to follow-up. The term fixed cohort is used when the cohort is formed on the basis of an irrevocable event. Thus, an individual's exposure in a fixed cohort does not change over time. The term 'closed cohort' is used to describe a fixed cohort with no losses to follow up. In contrast, a cohort study conducted in an open population is defined by exposures that can change over time [240].

In this study, baseline characteristics of study subjects in terms of social support, depression symptoms, and stigma were assessed and study participants were followed for 12 months being on HAART. At the end of the 12 month, study subjects were either still on therapy, or they may have stopped treatment. The outcome of interest for the study was attrition from treatment either because of death or discontinuation of treatment while alive.

Three terms are used to describe the timing of events in a cohort study: prospective, retrospective, and ambidirectional. In a prospective cohort study, participants are grouped on the basis of past or current exposure and are followed into the future in order to observe the outcomes of interest. When the study commences, the outcomes have not yet developed and the investigator must wait for them to occur. In a retrospective cohort study, both the exposures and outcomes have already occurred when the study begins. Thus, this type of investigation studies only prior outcomes and not future ones. An ambidirectional cohort study has both prospective and retrospective components. The decision to conduct a retrospective, prospective, or ambidirectional study depends on the research question, practical constraints such as time and money, and the availability of suitable study populations and records. Taking this into consideration, this study used an ambidirectional cohort study [240].

The choice of the exposed group in a cohort study depends on the hypothesis being tested, the exposure frequency, and feasibility considerations, such as the availability of records and ease of follow-up. There are three sources for the comparison group in a cohort study: an internal comparison group, the general population, and a comparison cohort. An internal comparison group consists of unexposed members of the same cohort. An internal comparison group should be used whenever possible, because its characteristics will be most similar to the exposed group. In single cohort studies, those people who do not develop the outcome of interest are used as internal controls. Where two cohorts are used, one group has been exposed to or treated with the agent of interest and the other has not, thereby acting as an external control. The general population is used for comparison when it is not possible to find a comparable internal comparison group. The general population comparison is based on preexisting population data on disease incidence and mortality. A comparison cohort consists of members of another cohort. It is the least desirable option because the comparison cohort, while not exposed to the exposure under study, is often exposed to other potentially harmful substances, and so the results can be difficult to interpret. In this study, the control groups were those who did not develop the outcome of interest [240].

Cohort study investigators typically rely on many sources for information on exposures, outcomes, and other key variables. These include medical and employment records, interviews,

direct physical examinations, laboratory tests, biological specimens, and environmental monitoring. Some of these sources are preexisting, and others are designed specifically for the study. Because each type of source has advantages and disadvantages, investigators often use several sources to piece together all of the necessary information [240].

The general strengths and weakness of the study designs utilized in this study has been presented in Table 5.1.

Table 5.1: Analysis of the characteristics, strength and weakness of the selected study designs.

Analysis of the selected study design: Cohort Study [240].		
Characteristics	**Strengths**	**Weakness**
• Describe incidence or natural history. • Analyze predictors (risk factors) thereby enabling calculation of relative risk. • Measure events in temporal sequence thereby distinguishing causes from effects. • Retrospective cohorts, where available, are cheaper and quicker. • Confounding variables are the major problem in analyzing cohort studies. • Subject selection and loss to follow up cause of bias.	• The best way to study incidence of the outcome. • Ideal for studying rare exposures (or initial conditions). • Can examine multiple effects from a single exposure. • If prospective, minimizes bias in the measurement of exposure. • Sometimes the best or only ethical way to do the study.	• Inefficient for study of rare outcomes: unless the attributable-risk is high for the exposure. • If prospective, resources are expensive. • If retrospective, is dependent upon the adequacy of records. • Because these are "follow-up" studies, validity of results is highly sensitive to losses to follow-up.

Analysis of the selected study design: Cross-sectional Study [240].

Characteristics	Strengths	Weakness
• Make observations concerning the prevalence and characteristics of a disease in a well-defined population over a defined period of time (period prevalence). • Estimate prevalence. • Examine characteristics associated with condition or disease by comparing cases to noncases.	• Relatively quick and easy to conduct (no long periods of follow-up). • Data on all variables is only collected once. • Able to measure prevalence for all factors under investigation. • Multiple outcomes and exposures can be studied. • The prevalence of disease or other health related characteristics are important in public health for assessing the burden of disease in a specified population and in planning and allocating health resources. • Good for descriptive analyses and for generating hypotheses.	• Difficult to determine whether the outcome followed exposure in time or exposure resulted from the outcome. • Not suitable for studying rare diseases or diseases with a short duration. • As cross-sectional studies measure prevalent rather than incident cases, the data will always reflect determinants of survival as well as etiology. • Unable to measure incidence. • Associations identified may be difficult to interpret. • Susceptible to bias due to low response and misclassification due to recall bias.

Health care records are used to describe a participant's exposure history in studies of possible adverse health effects stemming from medical procedures. The advantages of these records include low expense and a high level of accuracy and detail regarding a disease and its treatment. Their main disadvantage is that information on many other key characteristics, apart from basic demographic characteristics, is often missing. In this study, the following data were collected from records:

1. General background information
2. HAART adherence
3. CD4 count
4. Weight
5. Duration on HAART
6. WHO stage
7. Status of patients (active on treatment, lost from follow-up, dropped, died).

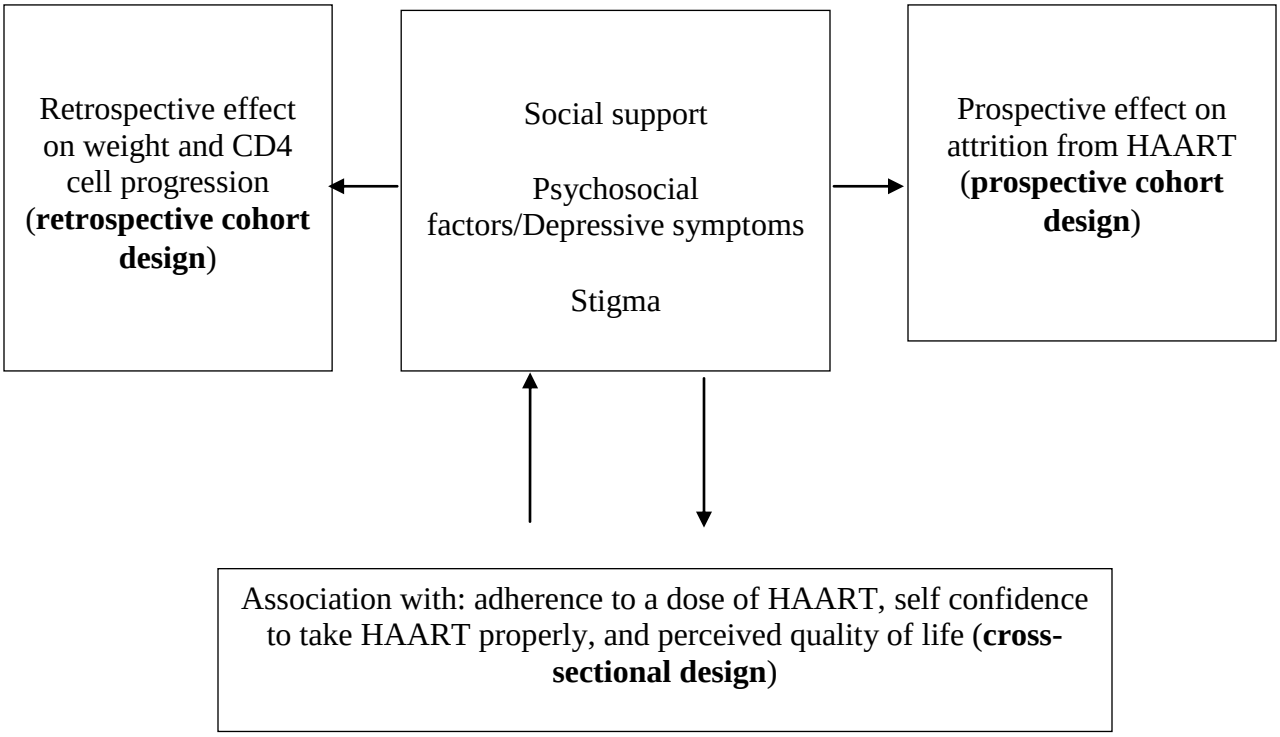
Because existing health care records have limitations, many studies are based on data collected specifically for the investigation. These include interviews, physical examinations, and laboratory tests. Interviews and self-administered questionnaires are particularly useful for obtaining information on lifestyle characteristics (such as use of cigarettes or alcohol), which are not consistently found in records.

Whatever the source of information, it is important to use comparable procedures for obtaining information on the exposed and unexposed groups. Biased results may occur if different sources and procedures are used. Thus, all resources used for one group must be used for the other. In addition, it is also good to mask investigators to the exposure status of a subject so that they make unbiased decisions when assessing the outcomes. Standard outcome definitions were used to guarantee both accuracy and comparability.

The general framework of the proposed study and the application of the different study designs have been presented in Figure 5.2. The general purpose of the study was to explore the effect of social support and depressive symptoms on weight and CD4 progression using retrospective cohort study design and to determine the effect of perceived social support and depressive

symptoms on attrition from therapy using prospective cohort study design and to assess the effect of socio-demographic variables, social support, depressive symptoms, and stigma on adherence to HAART and self-confidence to take HAART properly and perceived quality of life using cross-sectional study design.

Figure 5.2: Flowchart showing the overall outline of the study.



5.7. Data Source

The main sources of data for the study were; interviews with study participants using pre-tested standard questionnaire, review of medical records, and key informant interviews.

5.8. Sample size determination

From March 2005 to June 2008, Zewditu Memorial Hospital HAART Clinic had enrolled 14,001 people infected with HIV for care, support, and treatment services. As of June 8, 2008, 5,142 people were regularly following treatment [237]. Different assumptions were used to estimate

the total number of study subjects who needed to be included in the study. This is presented in Table 5.2.

Table 5.2: Sample size estimation based on the different assumptions.

Scenario	Sample Size
Scenario I: A sample-size calculation formula for two population proportions was used to enable comparisons on adherence to HAART according to differences in socio-demographic variables and other individual characteristics of the respondents. Proportion of people who adhere to their treatment (never forget taking the medication) among those who did not drink alcohol (52%), Proportion of people who adhere to treatment (never forget taking the medication) among people who drink alcohol regularly (43%) [233], an alpha level of 0.02 and power of 0.90, the proportion of people among exposed and non-exposed=1, and a non-response rate of 10%	**1,808**
Scenario II: A sample size calculation formula for two population proportions was used so that differences in treatment progression by depression symptoms and social support status could be detected. Studies had reported a 10% difference in treatment progression between those who had better support versus poor support [243]. This study was designed to detect a difference of 7%, 80% power and 5% alpha level of error and 5% non-response rate was used.	**1,815**
Scenario III: A study carried out by K. R. Waite et al [244] reported that, among those with high levels of social stigma, 46.4% to be non-adherent while among those with low levels of social stigma concern, 22.5% were non-adherent. Although this study reported a difference of 24%, this study was designed in a way to detect a difference as low as 8%. A power of 90%, 5% alpha level of error and 5% non-response rate were utilized.	**1,733**
Scenario IV: Although studies had reported more than 10% attrition rates by 12 months of follow-up [32] this study was designed to detect attrition rate as low as 7%, a power of 80%, 5% alpha level of error and 5% non-response rate were utilized.	**1,733**

Based on the three different scenarios the maximum sample size needed to undertake the study was identified to be 1,815.

5.9. Sampling technique

During the data collection period, there were 5,142 active adult clients who were receiving HAART from Zewditu Memorial Hospital [237]. All clients who fulfilled the inclusion criteria were included in the sampling frame. By using computer generated random table numbers, 1,815 eligible samples were selected for the study based on their unique HAART identification number.

5.10. Inclusion and Exclusion criteria

People eligible for inclusion were HIV-positive adults, age 18 or over, who were infected with HIV and were on HAART follow-up at Zewditu Memorial Hospital. Children were excluded from the study.

5.11. Method of data collection

Trained data collectors stayed at the HAART clinic from February 1 – March 19, 2010 to interview study subjects while patients came to the clinic for follow-up. A standardized questionnaire, which addressed all study variables, was developed to collect quantitative data. The questionnaire was pre-tested in a similar population of those who were excluded from the final study. The quantitative data was collected by nurses. The data was checked for completeness every day by a supervisor and the Principal Investigator. To complement the quantitative data, qualitative data was collected utilizing key informant interviews.

The data collectors received three days training on the data collection tools, methodology, probing, maintaining quality, and other issues. The training was facilitated by the Principal Investigator and Field Supervisor. It was supported with practices in the classroom and at a Hospital.

5.12. Measurements

5.12.1. Measurement of adherence and self-confidence to take medication correctly

To assess the respondents' self-confidence in taking medication correctly and belief in their medication, three questions were used: 'How sure are you that you will be able to take all or most of the medication as directed?'; 'How sure are you that the medication will have a positive effect on your health?'; and, 'How sure are you that if you do not take this medication exactly as instructed, the HIV in your body will become resistant to HIV medications?' The three questions were rated on a scale of '0-4' from: 'Not at all sure' (indicating low self-confidence, level 0) to 'Extremely sure' (indicating a high level of self-confidence, level 3). For the three items the Cronbach's alpha estimate was found to be 0.72, which reflects fairly good reliability.

The four-item self-reported *Morisky's* scale was used to assess self-reported HAART adherence, with a scale measurement ranging from '0' indicating a low level of self-reported adherence to '4' indicating a high level of self-reported adherence. The four questions asked were: 'Many people forget to take medications on time. Do you ever forget to take your medicines?'; 'Are you careless at times about taking your medicines?'; 'When you feel better, do you sometimes stop taking your medicine?; and 'Sometimes, if you feel worse when you take your medicine, do you stop taking it?'. *Morisky's* scale [245] was preferred because it helps to assess treatment adherence in a positive, nonjudgmental atmosphere, delivered in a trusting relationship in order to understand what is actually happening with the respondent's adherence practices rather than what the respondent thinks the interviewer wants to know. The predictive validity of these scales was tested in different settings.

The mean self-reported adherence level for the four items was calculated using an alpha coefficient, with a self-reported adherence level of '4' indicating prefect self-reported adherence, and <4 indicating a low level of self-reported adherence. The reliability coefficient alpha for the four items was low (0.37).

5.12.2. Measuring weight and CD4 cell progression

Weight and CD4 count were taken from patients while they visit the clinic for routine check-up and to collect their ARV drugs. Weight was supposed to be measured at least in quarterly basis while CD4 count was supposed to be collected every six months but due to unknown reasons complete information on weight and CD4 count were not found from patient records. For the purpose of this study at least three retrospective weight and CD4 measures were identified to explore progression in the preceding 24 months from baseline data collection time.

5.12.3. Measuring Health Related Quality of Life (HRQL)

To assess perceived health related quality of life the core "Healthy Days measures" which were developed by CDC were utilized. The four major question were; 1) self-rated health ("Would you say that in general your health is excellent, very good, good, fair or poor?"), 2) number of recent days when physical health was not good ("Now thinking about your physical health, which includes physical illness and injury, how many days during the past 30 days was your physical health not good?") 3) number of recent days when mental health was not good ("Now thinking about your mental health, which includes stress, depression, and problems with emotions, how many days during the past 30 days was your mental health not good?"), and 4) number of recent activity limitation days because of poor physical or mental health ("During the past 30 days, approximately how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?") [246].

In addition to the above core question ten additional questions about health-related quality of life were also assessed. These questions ask about recent pain, depression, anxiety, sleeplessness, vitality, and the cause, duration, and severity of a current activity limitation an individual may have in his or her life.

5.12.4. Measuring depression symptom

To assess depressive symptoms related to major or clinical depression, the shorter ten item version of the Center for Epidemiological Studies Depression Scale (CES-D) questionnaire was

used [247 , 248]. Responses were based on the frequency of occurrence during the past week. The questionnaire used a 4-point ordinal scale: rarely or none of the time (less than 1 day); some or little of the time (1-2 days); occasionally or a moderate amount of the time (3-4 days); most or all of the time (5-7 days).

For the 10 questions, the reliability coefficient alpha was 0.85 and the average inter-item covariance was 0.40. As the reliability of the scale was good, factor analysis was applied and it was found that factor1 explained about 78% of the variance with Eigen-value of 3.7. Following this, one summary variable that could explain the nature of depression symptoms among study subjects was predicted.

5.12.5. Measuring perceived social support

To assess social support, six questions from the Norbeck Social Support Questionnaire (NSSQ) were used [249, 250]. A 5-point rating scale was used to describe the amount of support available from families, friends, and close relatives. The six questions measured functional properties of social support like emotional and tangible support.

Alpha was calculated to explore the reliability of the measurement and was found to be 0.96, which was high. The average inter-item covariance was 1.47. The reliability test factor analysis was then applied and the Eigen-value for factor1 was found to be 4.85. About 99.4% of variance was explained by factor1. Following this, one social support variable that could explain the pattern of the different perceived social support questions among study subjects was predicted.

5.12.6. Measuring stigma

Berger's stigma scale was used to measure the level of perceived stigma. The scale has four subscales: personalized stigma (11 questions), disclosure concerns (10 questions), negative self-image (8 questions), and concern with public attitudes toward people with HIV (10 questions). Each item or question is rated on a 4-point scale from "Strongly Disagree'' (1 point) "Disagree" (2 points) "Agree" (3 points) and "Strongly Agree" (4 points). This instrument has been tested

for internal consistency and reliability (coefficient alphas=0.96). The scale was recommended as reliable and valid with a large and diverse sample of people [251].

As presenting the details about all questions under each of the four subscales were found to be cumbersome the details about selected questions which explained more than 90% of the variability in the sub-scale has been presented. These questions were determined based on factor analysis.

The total stigma score values were calculated for each study participant. Higher total score values indicate serious levels of social stigma. Minimum and maximum scores, mean and median values, and proportions of study subjects who fall into the four different quartiles were calculated.

5.13. Qualitative data

A total of nine in-depth interviews were conducted with patients who were on HAART. Out of the nine, four were male and five were female.

The qualitative data was collected to generate more ideas about the effect of social support, depression symptoms and stigma on adherence to HAART and attrition from HAART.

Each interview lasted for a maximum of 40 minutes. Interviews were conducted in an area that was comfortable in terms of its privacy, location, and nonthreatening environment. The interviews were carried out by a female expert who has tremendous experience on qualitative studies and social studies and holds a Master of Arts degree from Addis Ababa University. In addition to the moderator, an additional female expert was assigned to co-facilitate the interview and take notes.

The interview was guided by a discussion guide that had been prepared by the Principal Investigator. The guide was tested by the Principal Investigator before the final use. The guide was prepared in Amharic.

All in-depth interview participants were informed of the aim of the study and they were asked consent to participate. Privacy, confidentiality and benefits were maintained.

The notes were read and themes that emerged regarding the topic area were identified. Different positions or dimensions that emerged were then summarized and analyzed in the final write up.

5.14. Data quality

To assure the quality of data, data collectors were selected based on their ability, skill, and past experience. Those who had experience in similar past studies were used for data collection. Intensive and problem oriented training was provided to data collectors about the objective of the study and ways of data collection. Questionnaires were prepared in English and then translated to the local language (Amharic) and then translated back to English in order to maintain consistency. Pilot testing of the questionnaire was also done in a homogenous population and these populations were excluded from the study. In addition to this, the Principal Investigator stayed at the Hospital throughout the data collection time and spot-checked the quality of data by checking completeness. Data was entered using EPI-INFO software by experienced data entry clerks. Of the total data, 5% was double entered and level of error was found to be very minimal. Data was cleaned before analysis.

5.15. Data Analysis

Before fitting the statistical model and conducting detailed analysis, exploratory analysis was done. Data was explored using lines plots (spaghetti plot), average and distribution plots (box plot, quintiles), empirical covariance, residual "pairs" plots, and variograms [240].

Following the exploratory analysis, appropriate models were fitted to the data. Rarely is there only one statistical model that adequately fits a set of data. Rather, researchers find themselves choosing a few models that summarize the information fairly. The choice between models that adequately fit the data is based on various criteria, one of which is the research question. Relative risks are computed for studies that focus on measuring an association(s) between an exposure(s)/risk factor(s) and an outcome. Unlike predictive models, regression models for

studies of association often keep several factors that may not explain large amounts of the variance in the outcome. However, these variables confound the association between exposure(s) and outcome sufficiently to warrant adjusting for them in the analysis. Other criteria considered in model selection include the existence of influential individuals, extreme outliers, and other factors related to model fit [240].

As this research is an epidemiologic study grounded on the assessment of socio-cultural, psychosocial and stigma related factors that affect adherence to HAART and long-term retention on HAART care, most outcome variables of interest are dichotomous. A tool popular in assessing the risk or benefit of a treatment is a logistic regression model. For this type of data, logistic regression model is very appropriate [240].

To estimate the relative risk directly, binomial regression and Poisson regression are usually recommended. Poisson regression is generally reserved for studies of rare diseases where patients may be followed for different lengths of time, such as cohort studies of rare outcomes conducted over many years, with some patients lost to follow-up. In contrast, unconditional logistic regression is typically utilized when every patient is followed for the same length of time or for a defined period with equal follow-up for subjects. For cohort studies where all patients have equal follow-up times, Poisson regression can be used in a similar manner as logistic regression, with a time-at-risk value specified as "one" for each subject. If the model adequately fits the data, this approach provides a correct estimate of the adjusted relative risk(s). For studies of common outcomes, Poisson regression is likely to compute a confidence interval(s) that is conservative; suggesting less precision than is true. Poisson regression produces wider confidence intervals compared with a log-binomial model and stratified analysis because the Poisson errors are overestimates of binomial errors when the outcome is common (Poisson errors approximately equal binomial errors when the outcome (disease) is rare [252, 240].

5.16. Regression Model

The goal of regression model is estimation, testing and prediction of outcome based on predictor variables. When we say estimation, it means estimating the effect of one variable (exposure), called the predictor of interest, after adjusting, or controlling for other measured variables. It

gives an opportunity to control confounding variables and avoid bias. In addition to this, a regression model allows testing whether variables are associated with the response and gives a chance to make prediction of a response variable given a collection of covariates [253, 240].

There were six different outcome variables in this study. These were; "adherence to HAART", "self-confidence to take HAART properly", "attrition from treatment", "perceived quality of life", "CD4 count", and "weight". The first four outcome variables were categorical and the remaining two were continuous variables. For the categorical outcome variables binary logistic, ordered logistic, and Cox proportional hazard regression models were applied. For the continuous outcome variables linear difference-in-difference regression model has been fitted [239, 254 – 256].

The formula for the regression model was: $y = \beta 0 + \beta 1\, x1 + \beta 2\, x2 + \ldots\ldots$

Where "y" is the probability of occurrence of the outcome variable, "β" is the coefficients, and "xi" is the explanatory variables.

For the outcome on survival during the 12 months prospective follow-up period, integrated hazard and survival functions were estimated using Kaplan-Meier product-limit and life table methods. Cox Regression Model, or the proportional hazards model, was used to analyze the effect of covariates on hazard or risk of death [240].

For this model the covariates act in a multiplicative fashion on the hazard rate.

$$\lambda(t|\mathbf{Z}(t)) = \lambda_0(t)\exp\{\boldsymbol{\beta}\mathbf{Z}(t)\},$$

The relative risk for a subject with a covariate vector Z1 as compared to a subject with covariate vector Z2 is a constant given by;

$$\frac{\lambda_0(t)\exp\{\boldsymbol{\beta}\mathbf{Z}_1\}}{\lambda_0(t)\exp\{\boldsymbol{\beta}\mathbf{Z}_2\}} = \exp\{\boldsymbol{\beta}[\mathbf{Z}_1 - \mathbf{Z}_2]\}.$$

Once a logistic regression model has been fitted to the data set, the adequacy of the model was examined by overall goodness-of-fit tests, which is the area under the receiver operating characteristic curve, and the examination of influential observations. The purpose of any overall goodness-of-fit test is to determine whether the fitted model adequately describes the observed outcome experienced in the data. Goodness-of-fit tests are usually general tests that assess the fitted model's overall departure from the observed data [240]. Summary of the different types of regression models used in the study has been presented in Table 5.3.

To measure association among exposure variables and outcome variables, different statistical techniques were applied. These include: Chi square, Relative Risk / Odds Ratio, 95% confidence interval, p-value and log rank test [240].

Additionally, factor analysis was utilized to calculate Eigen-values, scale reliability coefficient, and average inter-item covariance. An unpaired t-test was also used to verify the significance of difference in mean weight and CD4 cell measures between two different periods [240].

Table 5.3: Summary of the regression models used in the study.

Aim / purpose	Type of outcome variable	Type of regression model used
Relationship between socio-demographic characteristics of study participants with self-confidence in the ability to take HAART properly	Ability to take all or most of the medication (0: Not at all sure, 1:Somewhat sure, 2:Very sure, and 3: Extremely sure)	Ordered logistic regression model (Table: 6.9)
Relationship between socio-demographic characteristics of study participants with adherence to HAART	Ever forgets taking medication (0: Never 1: Rarely 2: Sometimes 3: Often 4: Always)	Ordered logistic regression model (Table: 6.9)
Effect of perceived social support and depression symptoms on adherence to HAART	Good adherence practices in the preceding month (1: Did not miss HAART in past month and 0: Missed at least a dose of medication)	Logistic regression model (Table 6.12)
Effect of perceived social support and depression symptoms on self-confidence to take HAART properly	Confident in ability to take medication properly (1: Good confidence 0: poor confidence)	Logistic regression model (Table 6.12)
Effect of "negative self-image", "concern about public attitude", "concern about disclosure", and "personalized stigma" on adherence to HAART	Good adherence practices in the preceding month (1: Did not miss HAART in past month and 0: Missed at least medication)	Logistic regression model (Table 6.17)
Effect of "negative self-image", "concern about public attitude", "concern about disclosure", and "personalized stigma" on confidence in the ability to take HAART properly	Confident in ability to take medication properly (1: Good confidence 0: poor confidence)	Logistic regression model (Table 6.17)

Effect of depression symptoms and social support on weight progression	Retrospective weight measures from baseline data collection period to 18 months	Difference-in-difference regression model (Table 6.22)
Effect of depression symptoms and social support on CD4 cell progression	Retrospective CD4 count measures from baseline data collection period to 18 months	Difference-in-difference regression model) (Table 6.23)
Effect of sex, age, self-reported adherence to HAART, baseline weight and CD4 count on hazard or risk of failure	Hazard /risk/ of "failure" by 12 months of follow-up period (death or dropped)	Cox proportional hazard ratio model (Table 6.25)
Effect of baseline perceived social support on hazard or risk of "failure"	Probability of "failure" by 12 months of follow-up period (death or dropped)	Cox proportional hazard ratio model (Table 6.26)
Effect of perceived social support on perceived quality of life related to physical or mental health condition	Number of unhealthy days because of some sort of physical or mental health problems (0: no unhealthy days 1: One or more unhealthy days in the past month)	Logistic regression model (Table 6.29)
Effect of perceived social support on perceived quality of life related to pain, depression, anxiety, or sleeplessness	Number of unhealthy days because of some sort of pain or feeling depressed, anxious, or worried, or sleeplessness (0: no unhealthy days 1: One or more unhealthy days in the past month)	Logistic regression model (Table 6.29)

5.17. Missing data analysis

A common approach to dealing with missing data is to restrict analyses to individuals with complete data on all variables required for a particular analysis. Although such 'complete-case' analyses are unbiased in many circumstances, they can be biased and are always inefficient. Bias arises if individuals with missing data were not typical of the whole sample. Inefficiency arises because of the reduced sample size for analysis. Imputation, in which each missing value is replaced with an assumed or estimated value, may lead to attenuation or exaggeration of the association of interest, and without the use of sophisticated methods described below may produce standard errors that are too small. Data are described as missing completely at random (MCAR) if the probability that a particular observation is missing does not depend on the value of any observable variable(s). Data are missing at random (MAR) if, given the observed data, the probability that observations are missing is independent of the actual values of the missing data. Data are missing not at random (MNAR) if the probability of missing still depends on the missing value even after taking the available data into account. When data are MNAR, valid inferences require explicit assumptions about the mechanisms that led to missing data. Methods to deal with data MAR fall into three broad classes: likelihood-based approaches, weighted estimation and multiple imputation. Of these three approaches, multiple imputations are the most commonly used and flexible, particularly when multiple variables have missing values. In this study, multiple imputations were applied in the case of missing data [240].

The main statistical software utilized for analysis was STATA Version 10 and SPSS Version 15.

5.18. Dependent and Independent variables

The dependent variables for the study were:

- Adherence to HAART
- Self-confidence to take HAART properly
- Attrition from HAART
- CD4 cell progression
- Weight progression

- Perceived quality of life

The independent variables were:

- Perceived social support
- Depression symptoms
- Negative self-image
- Concern about public attitude
- Concern about disclosure
- Personalized stigma
- Age
- Sex
- Marital status
- Religion
- Duration of stay on HAART
- Alcohol drinking
- *kalt* chewing/smoking
- Education level
- Income level
- Disclosure of HIV status

5.19. Communication of results

The results of this research work had been shared phase by phase to responsible bodies and organizations. A series of seminar presentation were done both locally and abroad, at the School of Public Health, Addis Ababa University, and Bloomberg School of Public Health, John Hopkins University. Globally, findings of this study were presented at the Global Health Council annual meeting and at the International Urban Health Conference.

The first outputs of this study have been published in the African Journal of AIDS Research, the second manuscript has been accepted for publication on AIDS Care Journal, and the third manuscript is also being reviewed by the Journal of AIDS and Social Services. The reports were

also shared with Zewditu Memorial Hospital and the Ethiopian National HIV/AIDS Prevention and Control Office so that they can take the findings into account while developing and implementing programs to improve adherence to HAART and attrition from HAART.

5.20. Ethical Considerations

Ethical clearance was obtained from the School of Public Health, Addis Ababa University College of Health Science. To assure participation based on willingness, informed consent was obtained from each study participant. Privacy, confidentiality and benefits were maintained. All responsible authorities were informed about the study and its process to get their support and commitment to the study.

Participation in the study was completely voluntary. All participants provided oral informed consent. Study recruitment was conducted by trained interviewers not affiliated with the HAART clinic, only after the HAART services have been provided. Interviewers were instructed to assure clients that participation was entirely voluntary. When oral informed consent was obtained from clients, the interviewer signed the consent form, which acknowledged that study subjects had orally consented to participate.

Consent was asked in a private room, after the interviewers shared the disclosure information with the client and provider, respectively, and before any survey questions were administered. Disclosure and consent forms were read in Amharic.

Potential risks associated with enrollment in the study were related to psychological risks associated with completing the interview. Psychological risks could include anxiety or other emotional reactions provoked by questions in the study instrument. The number of potentially sensitive questions, however, was limited given the study topic and research aims.

Confidentiality was ensured by the use of study identifications, rather than participant names or other identifying information, on study instruments. There was no link between participants' names and study subjects' identification. All study questionnaires were stored in a locked cabinet. The trained interviewers brought completed questionnaires for storage at the end of each

day of field work. All study subjects were assured that all data will be confidential and that their names were not linked to the data in any way.

The data was electronically entered into EPI-INFO using a password protected filing system. The interviewers and study participants were advised to report adverse events related to this research to the Principal Investigator. As part of the disclosure process, they were told that the questions can be skipped or the interview can be stopped if they feel uncomfortable at any point. Additionally, all interviewers explained that this information will be used to improve HAART services in the country.

Potential benefits from participation in this study include the opportunity to increase awareness on HAART, and producing information to improve future HAART service delivery. Also, participants had the opportunity to talk openly and confidentially with trained interviewers, as they were asked if they had any questions or if they want to find out more information about HAART. Those who were non-adherent or defaulting from treatment were also referred for special support and counseling.

The research burden to individuals included: time spent completing the interviews (about 45 minutes for client interviews) and psychological effects of answering questions related to disclosure, psychosocial issues, and adherence to treatment or related to service provision. These burdens were mitigated by letting study subjects know the impact of their contribution.

6. Results

The results of this study have been presented in seven sections. These are:

- Socio-demographic and HIV/AIDS related background characteristics,
- Self-confidence to take HAART properly, adherence to HAART and its socio-demographic correlates and the effect of social support, depression symptoms, stigma on self-confidence to take HAART properly and adherence to HAART,
- Disclosure of HIV status, perceived benefits, and consequences,
- Survival estimates by 12 months of follow-up and the effect of social support on attrition from HAART,
- Perceived Quality Of Life (QOL) of study subjects and the effect of perceived social support on perceived QOL,
- Qualitative findings from the key-informant interview.

6.1. Socio-demographic and HIV/AIDS related background characteristics

6.1.1. Socio-demographic characteristics

Of the 1,815 Patients selected for the study, 1722 agreed to participate – a response rate of 94.9%. The majority of the respondents were female (61%) and more than 75% were age 31 or older (mean age 37.9 years, standard deviation [SD] 9.0). The median age was 37 years. About 54% were married or in a union with a sexual partner. A large majority (81%) were Orthodox Christian. The respondents were asked how much they spent every month on different expenses (‘expenditures income’) and about one-third (35%) reported spending less than Birr 500 (~US$31), and a similar proportion reported spending more than Birr 1,000 (~US$61). About 90% had received some level of formal education. Drinking alcohol was found to be more prevalent than chewing *khat* (a locally grown stimulant); about 11% said they drank alcohol regularly, while only 3% reported chewing *khat*. The demographic information for the sample study population has been presented in Table 6.1.

Table 6.1: Sociodemographic characteristics of the respondents (n = 1722 HAART Patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**N**	**%**
Sex:		
Males	667	38.7
Females	1056	61.3
Age (years):		
<30	414	24.1
31–39	641	37.2
≥40	667	38.7
Mean age 37.9 (SD: ±9.0); median age: 37		
Partner status:		
Currently in union	932	54.1
Currently not in union	791	45.9
Religion:		
Orthodox Christian	1393	80.8
Muslim	79	4.6
Protestant	220	12.8
Catholic	24	1.4
Other	7	0.4
Monthly spending (in Ethiopian Birr*):		
<500	600	34.8
500–999	541	31.4
1000–1999	368	21.4
2000+	214	12.4
Education:		
Cannot read or write	166	9.6
Has some level of formal education	1168	67.9
Has a college diploma or higher	388	23.5
Drinks alcohol regularly:		
'Yes'	192	11.2
'No'	1530	88.8
Chew *khat* regularly		
'Yes'	52	3.0%
'No'	1670	97.0%

At the time of the study US$1 = Birr 16.4

6.1.2. HIV-related background characteristics

As shown in Table 6.2, about 60% of the respondents reported that they became infected with HIV because of unsafe sexual intercourse, and a significant proportion (25%) reported that they did not know exactly how they became infected. More than 41% said they were not aware of the presence of antiretroviral drugs (ARVs) to treat HIV infection before they knew about their HIV-positive status. Interestingly, two-thirds (67%) of the respondents reported not having information about the benefits of anti-HIV drugs before initiating treatment.

Table 6.2: HIV/AIDS-related background characteristics of the respondents (n = 1722 HAART Patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**N**	**%**
Most likely way you became infected with HIV:		
Unsafe sexual intercourse	1030	59.8
Blood contamination(sharing sharp instruments with an HIV-infected person)	177	10.3
Blood transfusion	12	0.7
Outcome of rape	22	1.3
Do not know how	423	24.5
Do not want to respond	58	3.4
Knew the existence of anti-HIV drugs:		
After knowing HIV status	716	41.6
Before knowing HIV status	1006	58.4
Knew the benefits of HAART before starting treatment:		
'Yes'	577	33.5
'No'	1145	66.5

About 65% did not know the importance of strict adherence to HAART at the time they initiated treatment. The two main sources of HAART information reported were health workers (58.7%) and the mass media (39.0%). It was also investigated whether patients were actively engaged in monitoring their treatment progress by following their CD4 cell count and found that 37% did

not know their most recent CD4 level. More than 70% of the respondents had been on HAART for longer than one year, and among those about 25% had been on treatment for more than 48 months (4 years) (Table 6.3).

Table 6.3: Information on adherence and HAART, CD4 count and duration of stay on HAART (n = 1722 HAART Patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**N**	**%**
Knew the importance of adherence when started treatment:		
'Yes'	598	34.7
'No'	1124	65.3
Sources of information about HAART:		
Health worker	1010	58.7
Mass media	671	39.0
Family	16	0.9
Friend	14	0.8
Co-worker	4	0.2
Other	7	0.4
Know most recent CD4 cell count:		
'Yes'	1085	63
'No'	637	37
Duration on HAART (months):		
<12	477	27.7
12–24	262	15.2
25–48	560	32.5
>48	425	24.6

6.2. Self-confidence to take HAART properly, adherence to HAART and its socio-demographic correlates and the effect of social support, depression symptoms, stigma on self-confidence to take HAART properly and adherence to HAART

6.2.1. Self-confidence to take HAART properly and belief in medication

Fifty eight percent of the respondents were extremely sure about their ability to take most or all of their HAART medication as prescribed. A similar proportion (57%) said they were extremely sure that the medication would have a positive effect on their health. Furthermore, about 53% said they were extremely sure that their HIV infection would become resistant to the drugs if they did not strictly adhere to the medication schedule. The mean level of self-confidence was calculated out of 3, with a mean value of '3' indicating a very high level of self-confidence. Thus, the mean level was found to be 2.4 (SD = 0.18), indicating a moderately low level of self-confidence (Table 6.4).

Table 6.4: Measure of the respondents' self-confidence to take HAART properly (n =1722 HAART Patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**'Not at all sure' N (%)**	**'Somewhat sure' N (%)**	**'Very sure' N (%)**	**'Extremely sure' N (%)**
'Are you confident that you will be able to take most or all of your medication?'	17 (1.0)	114 (6.6)	589 (34.2)	1002 (58.2)
'How sure are you that the medication will have a positive effect on your health?'	14 (0.8)	81 (4.7)	643 (37.3)	983 (57.1)
'How sure are you that if you don't take the medication exactly as instructed, your body will become resistant to the HIV medication?'	169 (9.8)	241 (14.0)	390 (22.6)	917 (53.3)
Self-confidence scale reliability coefficient = 0.72				
Score of mean level of self-confidence in taking medication = 2.4 (±0.18)				

The minimum and maximum sum of score values for the self-confidence scale questions were 0 and 9 respectively. The mean of sum of self-confidence scores was 7.2. It was higher among males (7.32) and lower among females (7.09). This difference was statistically significant ($p < 0.01$). About 43% of study subjects (40.6% among females and 46.9% among males) scored 9 out of 9, indicating a high level of confidence in ability to correctly take HAART medication. Nearly 48% of study participants (44.8% among females and 45.1% among males) scored below the median value (Table 6.5).

Table 6.5: Sum of scores for self-confidence and belief in medication scores of respondents'', Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**Female (N=1056)**	**Male (N=666)**	**Total (N=1722)**
Self-confidence in taking medication			
Sum of scores for self-confidence in taking medication (three questions with four scales*)			
Minimum and Maximum scores	0 , 9	0 , 9	0 , 9
Mean (SD) of the score	7.09 (+1.92)	7.37 (+1.82)	7.20 (+1.89)
Proportion with sum score of 9 out of 9	427 (40.6%)	312 (46.9%)	739 (43.1%)
Proportion with score of below the median	471 (44.8%)	300 (45.1%)	771 (45.1%)
Proportion with sum of scores 6 and below	471 (44.6%)	250 (37.5%)	721 (41.9%)
Proportion with sum of scores 7 and above	585 (55.4%)	416 (62.5%)	1001 (58.1%)
One way anova	**R-Squared:=0.0052 , F=0.0027**		
*sum of three questions with four scales			

6.2.2. Self-reported adherence to HAART

About 62% of the respondents said they had never missed their HAART medication. Additionally, large proportions said they were never careless about taking their medication (95%), that they never stop taking their medication at times when they feel better (98%), and that they never stop taking their medication at times when they feel worse (98%). In general, the self-reported adherence score for the sample was also found to be high, with an overall mean of 3.8 (SD = 0.2) (4 being the maximum mean score) (Table 6.6).

Table 6.6: The Respondents' self-reported adherence to HAART (n =1722 HAART patients), Zewditu Memorial Hospital, March, 2010.

Adherence practices (*Morisky* scale)	**'Never'**	**'Rarely'**	**'Sometimes'**	**'Often'**	**'Always'**
	N (%)	**N (%)**	**N (%)**	**N (%)**	**N (%)**
'Do you ever forget to take your medication?'	1072 (62)	433 (25)	201 (12)	14 (1)	2 (0.1)
'Are you careless at times about taking your medicines?'	1638 (95)	47 (3)	32 (2)	5 (0.3)	0
'Do you sometimes stop taking your medicines when you feel better?'	1693 (98)	15 (1)	11 (0.7)	3 (0.3)	0
'Do you sometimes stop taking your medicines when you feel worse?'	1695 (98)	18 (1)	6 (0.4)	2 (0.1)	1 (0.1)
Self-reported adherence scale reliability coefficient = 0.37					
Mean self-reported adherence score = 3.8 (±0.2)					

More than 94% reported that they had taken their medication at all the designated times in the past four days. But the most commonly cited reasons for ever missing a dose were: being busy (57.5%), being away from home (42.2%), simply forgetting (37.8%), and not wanting to be noticed taking medication (17.8%) (Table 6.7).

Table 6.7: The Respondents' past four-days-adherence practices and commonly cited reasons for missing HAART (n = 1722 HAART Patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**N**	**%**
'How closely did you take your medication in the past four days?'		
'All the time'	1625	94.4
'Not all the time'	97	5.6
Commonly cited reasons for ever missing a dose (multiple responses possible):		
Being busy	374	57.5
Away from home	274	42.2
Simply forgot to take	246	37.8
Don't want people to notice	116	17.8

As presented in Table 6.8, the minimum and maximum sum of scores for the *Morisky's* scale (four questions with four scales from 0 to 3) questions were 0 (0 among both male and female study participants) and 12 (12 among female and 9 among male study participants) respectively. The mean sum of scores value was 0.64. The mean value was higher among females (0.69) and lower among males (0.55). This difference was statistically significant ($p < 0.01$).

The proportion of study subjects with perfect adherence (sum of scores value equal to zero which means those who had never missed single dose of HAART medication since the start of treatment) was 60.1%. This proportion was higher among males (63.5%) and lower among females (57.9%). The proportion with better adherence (sum of scores for the four questions equals 1) was 24.4% (24.1% among females and 24.9% among males) and the proportion with poor adherence (sum of score for the four questions equals 2 or above) was 15.6% (18.1% among females and 11.6% among males).

Table 6.8: Respondents' sum of scores for adherence to HAART scores (N = 1722 HAART patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**Female (N=1056)**	**Male (N=666)**	**Total (N=1722)**
Adherence characteristics			
Sum of scores for adherence to HAART (*Morisky* scale*)			
Minimum and Maximum scores	0 , 12	0 , 9	0 , 12
Mean score (SD)	0.69 (+1.06)	0.55 (+0.97)	0.64 (+1.03)
Proportion with perfect adherence (sum of the three scales=0)	611 (57.9%)	423 (63.5%)	1034 (60.1%)
Proportion with better adherence (sum of the three scales=1)	254 (24.1%)	166 (24.9%)	420 (24.4%)
Proportion with low adherence (sum of the three scales=2 and above)	191 (18.1%)	77 (11.6%)	268 (15.6%)
One way anova	**R-Squared=0.0041 , F=0.0078**		

6.2.3. Self-reported treatment adherence in relation to alcohol drinking

Among those who drank alcohol regularly, 44.3% said they had never forgotten to take their HAART medication; among those who did not drink alcohol regularly, the proportion who said they had never forgotten to take their medication was 64.5%. This difference was statistically significant ($p < 0.0001$).

6.2.4. Correlates of self-reported adherence to HAART and self-confidence in ability to take medication properly

As presented in Table 6.9, in the first model from the eight explanatory variables gender, income and regular alcohol-drinking were significantly associated with the odds of self-confidence in

taking the medication properly. The odd of self-confidence was 1.44-times higher among males than females (AOR: 1.44; 95% CI: 1.15–1.79). The odds of self-confidence was 0.35-times and 0.41-times lower among those who were within the spending categories of Birr 501–999 (AOR: 0.35; 95% CI: 0.24–0.49) and Birr 1000–1999 (AOR: 0.41; 95% CI: 0.29–0.60), respectively. Regarding regular alcohol drinking, the odd of self-confidence was 2.86-times higher among those who did not drink alcohol regularly.

In the second model, sex, age, duration of stay on HAART in months, and drinking alcohol regularly were significantly associated with the odds of ever missing HAART medication. The odds of ever missing HAART medication was 0.76-times lower among males than females (AOR: 0.76; 95% CI: 0.61–0.95). A one-year increase in age was also associated with 0.98-times lower odds of ever missing HAART medication (AOR: 0.98; 95% CI: 0.97–0.99). The odds of ever missing HAART medication was 1.36-times higher among those who had stayed 25–48 months on HAART (AOR: 1.36; 95% CI: 1.04–1.78). With regard to drinking alcohol, the odds of having ever missed HAART medication was 0.48-times lower among those who did not drink alcohol regularly (AOR: 0.48; 95% CI: 0.35–0.64). Details of the two regression models have been presented in Table 6.9.

Table 6.9: Ordered logistic regression model for the relationship between sociodemographic characteristics of study participants with self-confidence in the ability to take HAART properly and adherence to HAART (n=1715 patients), Zewditu Memorial Hospital, March, 2010.

	Confidence in taking medication correctly	**Ever forgets taking medication**
Respondents' characteristics	**AOR (95% CI)**	**AOR (95% CI)**
Sex:		
Females	1.0	1.0
Males	**1.44 (1.15–1.79)**	**0.76 (0.61–0.95)**
Age (years)	1.00 (0.99–1.01)	**0.98 (0.97–0.99)**
Religion:		
Muslim	1.0	1.0
Orthodox Christian	1.05 (0.65–1.68)	1.06 (0.66–1.71)
Other Christian	0.97 (0.57–1.64)	1.09 (0.64–1.86)
Income (Ethiopia Birr):		
2 000+	1.0	1.0
≤500	0.72 (0.50–1.04)	0.96 (0.68–1.35)
501–999	**0.35 (0.24–0.49)**	1.31 (0.94–1.82)
1 000–1 999	**0.41 (0.29–0.60)**	1.28 (0.90–1.81)
Education:		
College diploma or higher	1.0	1.0
Less than a college diploma	1.07 (0.81–1.42)	0.78 (0.60–1.02)
Duration on HAART:		
1–12 months	1.0	1.0
13–24 months	0.95 (0.70–1.29)	1.09 (0.80–1.49)
25–48 months	0.82 (0.63–1.07)	**1.36 (1.04–1.78)**
49+ months	0.90 (0.67–1.19)	1.26 (0.94–1.67)
Alcohol:		
Drinks regularly	1.0	1.0
Does not drink	**2.86 (2.11–3.89)**	**0.48 (0.35–0.64)**
Khat chewing and smoking:		
Chews *khat*	1.0	1.0
Do not chew *khat*	1.32 (0.71–2.44)	1.38 (0.72–2.65)

6.2.5. The effect of perceived social support and depression symptoms on adherence to HAART and self-confidence to take HAART properly

6.2.5.1. Respondents' perceived social support characteristics

As shown in Table 6.10, 34% of study participants did not have someone from whom to borrow small amounts of money (6 USD) for immediate help. An almost equal proportion (32.5%) did not have anyone who could provide them with support if they were confined to bed for several weeks. Approximately one quarter reported that they had no one to make them feel liked or loved (23.5%) and to make them feel respected or admired (24.8%).

Table 6.10: Respondents' reported perceived emotional and tangible social support using modified Norbeck Social Support Questionnaire (NSSQ) by sex (N = 1722 HAART patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**Female: N=1056 Freq (%)**	**Male: N=666 Freq (%)**	**Total: N=1722 Freq (%)**	**P level**
Proportion of Patients who reported they have no or have very little support to provide any of the following;				
Make you feel liked or loved	256 (24.2)	149 (22.4)	405 (23.5)	0.120
Make you feel respected or admired	271 (25.7)	156 (23.4)	427 (24.8)	0.201
Have someone to confide in	307 (29.1)	166 (24.9)	473 (27.5)	0.098
Have someone who agree with your actions	302 (28.6)	158 (23.7)	460 (26.7)	**0.047**
Have someone to borrow 100 Birr	369 (34.9)	225 (33.8)	594 (34.5)	0.133
Have someone to support if confined to bed	358 (33.9)	202 (30.3)	560 (32.5)	0.230
Scale reliability coefficient for the 6 questions	0.96			
Eigen-value for factor 1	4.85			
Average inter-item covariance	1.47			

6.2.5.2. Respondents' depression symptoms related characteristics

A significant proportion of females had been bothered by things that usually did not bother other people (12.6%), had been depressed (13.1%), and their sleep had been restless (18.3%) for about 5 - 7 days in the previous week. Among males, 8.4% had been bothered by things, 8.7% had been depressed, and 13.2% had experienced restless sleep for 5-7 days in the previous week.

On the other hand, 51% of females and 60% of males felt hopeful about the future and only 38% of females and 47% of males felt happy for 5 - 7 days in the previous week. The detailed depression symptoms related characteristics of study subjects have been presented in Table 6.11.

As presented in the logistic regression model in Table 6.12, perceived social support and psychosocial factors were significantly associated with never missing HAART and confidence to take HAART properly after controlling for the possible confounding effect of age, sex, alcohol drinking, education, income, marital status, and duration of stay on HAART. A one unit increase in perceived social support was associated with 1.32 times higher likelihood of never missing HAART and 1.20 times higher likelihood of being self-confident in ability to take HAART properly.

On the other hand, a one unit increase in depression symptoms was associated with 0.58 times less likelihood of never missing HAART and 0.81 times less likelihood of being self-confident to take HAART properly.

Table 6.11: Respondents' reported depression symptoms related characteristics using Center for Epidemiological Studies Depression Scale (CES-D 10) by sex (N = 1721 HAART patients), Zewditu Memorial Hospital, March, 2010.

Respondents'' characteristics	**Female: N=1055 Freq (%)**	**Male: N=666 Freq (%)**	**Total: N=1721 Freq (%)**	**P level**
Proportion who have encountered psychosocial problems most or all of the time in the past week				
Bothered by things that usually did not bother me	133 (12.6)	56 (8.4)	189 (11.0)	**0.000**
Had trouble keeping my mind on things I was doing	108 (10.2)	41 (6.2)	149 (8.7)	**0.000**
Felt depressed	138 (13.1)	58 (8.7)	196 (11.4)	**0.000**
Felt that everything I did was an effort	89 (8.4)	46 (6.9)	135 (7.7)	**0.000**
Felt hopeful about the future	542 (51.3)	397 (59.6)	939 (54.5)	**0.007**
Felt fearful	105 (9.9)	51 (7.7)	156 (9.1)	**0.000**
Sleep was restless	193 (18.3)	88 (13.2)	281 (16.3)	**0.007**
Was happy	402 (38.1)	315 (47.3)	717 (41.6)	**0.001**
Felt lonely	162 (15.3)	91 (13.7)	253 (14.7)	0.066
Could not "get going"	113 (10.7)	59 (8.9)	172 (10.0)	**0.004**
Scale reliability coefficient for the 10 questions	0.85			
Eigen-value for factor 1	3.70			
Average inter-item covariance	0.40			

Table 6.12: Logistic regression model on the effect of perceived social support and depression symptom on adherence to HAART controlling for age, sex, alcohol drinking, educational status, income, marital status, and duration of stay on HAART (N = 1722 HAART patients) , Zewditu Memorial Hospital, March, 2010.

	Never missing HAART		**Confident to take HAART**	
Respondents' characteristics	**Odds Ratio**	**95% Conf. Interval**	**Odds Ratio**	**95% Conf. Interval**
Perceived social support	**1.32**	**1.14 – 1.54**	**1.20**	**1.06 – 1.35**
Depression symptom	**0.58**	**0.50 – 0.68**	**0.81**	**0.73 – 0.91**
Disclosed HIV status to families, friends, or sexual partner				
'Yes'	1.00	1.00	1.00	1.00
'No'	1.04	0.76 – 1.43	1.00	0.78 – 1.28
Age	1.00	0.99 - 1.02	1.01	1.00 - 1.03
Sex				
Female	1.00	1.00	1.00	1.00
Male	1.11	0.82 – 1.49	1.35	1.07 – 1.70
Alcohol drinking				
Yes	1.00	1.00	1.00	1.00
No	1.83	1.26 - 2.66	2.39	1.74 – 3.30
Education in completed grades	1.02	0.99 - 1.05	1.02	1.00 - 1.04
Expenditure income (Birr)				
2000 and above	1.00	1.00	1.00	1.00
500 and less	0.82	0.50 - 1.33	1.20	0.84 - 1.73
501 – 999	0.80	0.50 – 1.28	0.50	0.35 – 0.71
1000 – 1999	1.07	0.64 - 1.78	0.43	0.30 - 0.63
Marital Status				
'Yes'	1.00	1.00	1.00	1.00
'No'	1.28	0.94 – 1.74	0.58	0.46 – 0.74
Duration of stay on HAART in months	1.00	1.00 - 1.01	1.00	0.99 - 1.00

6.2.6. Effect of stigma (negative self-image, concern about public attitude, concern about disclosure, and personalized stigma) on self-confidence to take HAART properly and adherence to HAART

In the negative self-image stigma sub-scale category, 25.7% of the respondents feel as not a good person as others because they have HIV, 36.5% think that having HIV makes them feel unclean, 34.6% feel as if they are set apart and isolated from the rest of the world since learning that they have HIV, and 28.4% feel as if they are bad persons because of having HIV.

The minimum and maximum total score values for the "negative self-image" sub-scale were 8 and 31 respectively. The mean value (SD) of the total score was 18.66 (4.61). There was no significant difference by sex (18.79 among females and 18.44 among males). When categorized by quartiles based on their total scores, 26.9% and 22.2% of study participants were in the first and second quartiles respectively while equal proportions (25.4%) were in the third and fourth quartiles (Table 6.13).

In the "concern about public attitude category" 47.3% of the respondents think that most people act as if it was because of their fault that they had HIV, 48.4% feel that people tend to ignore their good points sine knowing that they have HIV, 49.0% feel that people are afraid of them once they learn that they had HIV, 46.6% think that when people know that they have HIV they look for flaws in their character.

The minimum and maximum total score values for the "concern about public attitude towards HIV infected persons" sub-scale were 10 and 40 respectively. The mean value (SD) of the total score was 26.71 (6.63). There was no significant difference by sex (26.88 among females and 26.45 among males). When categorized by quartiles based on their total scores, 25.2% of study participants were in the first quartile while the remaining 18.9% were in the second quartile, 27.9% in the third quartile and 28.0% in the fourth quartile (Table 6.14).

Table 6.13: Proportion of respondents who reported that they will agree or strongly agree with the list of four questions under the "negative self-image" sub-scale category , sum of score for the sub-scale including minimum, maximum, mean and median values, and proportions under the four quartiles (N= 1722 patients), Zewditu Memorial Hospital, March, 2010.

	Female	**Male**		
	N=1056	**N=666**	**Total N=1722**	**P**
I feel I am not as good a person as others because I have HIV	304 (28.8)	138 (20.7)	442 (25.7)	**0.001**
Having HIV makes me feel unclean	406 (38.5)	222 (33.3)	628 (36.5)	0.152
Since learning I have HIV, I feel set apart and isolated from the rest of the world	376 (34.8)	230 (34.5)	597 (34.6)	0.974
Having HIV makes me feel that I'm a bad person	306 (28.9)	183 (27.5)	489 (28.4)	0.833
Minimum sum score	8	8	8	
Maximum sum score	31	31	31	
Median(IQR) score for the sum	19 (16-22)	18 (16-21)	19 (16-22)	
Mean (SD)	18.79 (4.69)	18.44 (4.47)	18.66 (4.61)	0.120
Proportion 1st Quartile	282 (26.7)	181 (27.2)	463 (26.9)	
Proportion 2nd Quartile	229 (21.7)	154 (23.1)	383 (22.2)	
Proportion 3rd Quartile	266 (25.2)	172 (25.8)	438 (25.4)	
Proportion 4th Quartile	279 (26.4)	159 (23.9)	438 (25.4)	0.678
Reliability (alpha) for the 8 questions	0.82	0.78	0.81	
Eigen value for factor1	3.09	2.76	2.96	
Average inter-item covariance	0.29	0.34	0.32	

In the "concern about disclosure of HIV status" category, 80.6% reported that in many areas of their life no one knows that they have HIV, 75.5% think that telling someone that they have HIV is risky, 73.0% reported that they work hard to keep their HIV secret, and 81% were careful on whom to tell that they have HIV

The minimum and maximum total score values for the "concern about disclosure of HIV status" sub-scale were 10 and 40 respectively. The mean value (SD) of the total score was 29.69 (5.59). There was no significant difference by sex (29.90 among females and 29.34 among males). When categorized by quartiles based on their total scores, 27.1% of study participants were in

the first quartile while the remaining 23.2%, 20.8%, and 28.9% of study participants were in the second, third, and fourth quartiles respectively (Table 6.15).

Table 6.14: Proportion of respondents who reported that they will agree or strongly agree with the list of four questions under the "concern about public attitude" sub-scale category , sum of score for the sub-scale including minimum, maximum, mean and median values, and proportions under the four quartiles (N= 1722 patients), Zewditu Memorial Hospital, March, 2010.

	Female N=1056	**Male** N=666	**Total** N=1722	**P**
Some people act as though it's my fault I have HIV	469 (44.4)	345 (51.8)	814 (47.3)	**0.020**
People who know I have HIV tend to ignore my good points	533 (50.5)	300 (45.1)	833 (48.4)	0.079
People seem afraid of me once they learn I have HIV	535 (50.7)	309 (46.4)	844 (49)	0.315
When people learn you have HIV, they look for flaws in your character	517 (49.8)	285 (42.8)	802 (46.6)	**0.013**
Minimum	10	10	10	
Maximum	40	40	40	
Median(IQR)	27 (23-30)	26 (22-30)	26 (22-30)	
Mean (SD)	26.88 (6.55)	26.45 (6.75)	26.71 (6.63)	0.192
Proportion 1st Quartile	259 (24.5)	174 (26.1)	433 (25.2)	
Proportion 2nd Quartile	200 (18.9)	125 (18.8)	325 (18.9)	
Proportion 3rd Quartile	288 (27.3)	192 (28.8)	480 (27.9)	
Proportion 4th Quartile	309 (29.3)	175 (26.3)	484 (28)	0.558
Reliability (alpha) for the 10 questions	0.86	0.87	0.85	
Number of items in the scale	10	10	10	
Eigen value for factor1	4.1	4.3	4.2	
Average inter-item covariance	0.38	39	0.38	

Table 6.15: Proportion of respondents who reported that they will agree or strongly agree with the list of four questions under the "concern about disclosure of HIV status" sub-scale category , sum of score for the sub-scale including minimum, maximum, mean and median values, and proportions under the four quartiles (N= 1722 patients), Zewditu Memorial Hospital, March, 2010.

	Female N=1056	**Male N=666**	**Total N=1722**	**P**
In many areas of my life, no one knows that I have HIV	855 (81)	532 (79.9)	1387 (80.6)	0.770
Telling someone I have HIV is risky	812 (76.9)	488 (73.3)	1300 (75.5)	0.146
I work hard to keep my HIV a secret	788 (75)	475 (71.3)	1263 (73)	0.136
I am very careful who I tell that I have HIV	849 (80.4)	546 (81.9)	1395 (81)	0.106
Minimum sum score	10	10	10	
Maximum sum score	40	40	40	
Median(IQR)	30 (26-34)	29 (26-34)	29 (26-34)	
Mean (SD)	29.90 (5.78)	29.34 (6.08)	29.69 (5.90)	0.054
Proportion 1st Quartile	268 (25.4)	199 (29.9)	467 (27.1)	
Proportion 2nd Quartile	249 (23.6)	150 (22.5)	399 (23.2)	
Proportion 3rd Quartile	221 (20.9)	137 (20.6)	358 (20.8)	
Proportion 4th Quartile	318 (30.1)	180 (27.0)	498 (28.92)	0.201
Reliability (alpha) for the 10 questions	0.81	0.83	0.82	
Eigen value for factor1	3.3	3.6	3.4	
Average inter item covariance	0.27	0.31	0.29	

In the "personalized stigma" category, 50.7% of the respondents feel that people whom they care about stopped calling them after learning that they have HIV, 53.3% feel that people do not want them to be around their children once they knew that they have HIV, 50.3% feel that people backed away from them when they learn that they have HIV, and 45.9% had lost friends by telling them that they have HIV.

The minimum and maximum total score values for the "personalized stigma" sub-scale were 11 and 44 respectively. The mean value (SD) of the total score was 28.98 (8.24). There was no significant difference by sex (29.09 among females and 28.80 among males). When categorized by quartiles based on their total scores, 28.5% of study participants were in the first quartile. The

remaining 18.9%, 23.8% and 28.8% were in the second, third, and fourth quartiles respectively (Table 6.16).

Table 6.16: Proportion of respondents who reported that they will agree or strongly agree with the list of four questions under the "personalized stigma" sub-scale category , sum of score for the sub-scale including minimum, maximum, mean and median values, and proportions under the four quartiles (N= 1722 patients), Zewditu Memorial Hospital, March, 2010.

	Female	**Male**		
	N=1056	**N=666**	**Total N=1722**	**P**
People I care about stopped calling after learning I have HIV	542 (51.3)	330 (49.6)	872 (50.7)	0.883
People don't want me around their children once they know I have HIV	569 (53.9)	349 (52.4)	918 (53.3)	0.863
People have physically backed away from me when they learn I have HIV	529 (50.1)	336 (50.4)	865 (50.3)	0.874
I have lost friends by telling them I have HIV	498 (47.2)	294 (44.1)	792 (45.9)	0.301
Minimum sum score	11	11	11	
Maximum sum score	44	44	44	
Median(IQR) score	29 (24-33)	29 (23-33)	29 (24-33)	
Mean (SD) score	29.09 (8.15)	28.80 (8.24)	28.98 (8.24)	0.478
Proportion 1st Quartile	292 (27.7)	199 (29.9)	491 (28.5)	
Proportion 2nd Quartile	203 (19.2)	123 (18.5)	326 (18.9)	
Proportion 3rd Quartile	249 (23.6)	161 (24.2)	410 (23.8)	
Proportion 4th Quartile	312 (29.6)	183 (27.5)	497 (28.8)	
Reliability (alpha) for the 10 questions	0.92	0.92	0.92	
Eigen value for factor1	6	5.8	5.9	
Average inter item covariance	0.5	0.52	0.51	

As presented in Table 6.17, "negative self-image" was significantly associated with both self-reported adherence to HAART medication and self-confidence in ability to take medication correctly. Persons who had higher levels of negative self-image (those who were in the second, third and fourth quartile category) were less likely to take all of their medication properly (second quartile: OR= 0.51, CI= 0.37 – 0.69, third quartile: OR= 0.40, CI= 0.28 - 0.58, and fourth quartile: OR= 0.42, CI= 0.30 – 0.59). Similarly, persons who had higher levels of negative self-image (those who were in the second and fourth quartile category) were less

confident in ability to take their medication correctly (second quartile: OR=0.65, CI= 0.48 - 0.88 and fourth quartile: OR= 0.60, CI= 0.43 - 0.84).

Likewise, "concern about disclosure of HIV status" significantly determined self-reported adherence to HAART medication and self-confidence to take medication correctly. Persons who were more concerned about disclosure of HIV status (those who are in the third quartile category) were less likely (third quartile: OR= 0.68, CI = 0.49 – 0.94) to take all of their medication (never miss medication since the start of HAART). Similarly, those who were more concerned about disclosure of HIV status (those who were in the third and fourth quartile category) were less likely to be confident to take medication correctly (third quartile: OR= 0.63, CI = 0.46 – 0.88 and fourth quartile: OR = 0.49, CI = 0.35 – 0.70).

Similarly, "concern about public attitude towards HIV infected people" was significantly associated with both self-reported adherence to HAART medication and self-confidence to take medication correctly. Persons who were more concerned about the public's attitude towards HIV infected people (those who were in the second and third quartile category) were less likely to ever take all of their medication correctly (second quartile: OR= 0.66 , CI= 0.46 – 0.94 and third quartile: OR= 0.58 , CI= 0.38 – 0.87). Likewise, persons who were more concerned about public attitude towards HIV infected people (those who were in the fourth quartile category) were less confident to take their medication correctly (fourth quartile: OR= 0.60, CI= 0.37 – 0.98).

The associations between "personalized stigma" and self-reported adherence to HAART and self-confidence in taking HAART medication correctly were not statistically significant. The full regression model has been annexed (Annex Table 14.1).

Table 6.17: Logistic regression model on the effect of "negative self-image", "concern about public attitude", "concern about disclosure", and "personalized stigma" on confidence to take HAART properly and never or rarely missing HAART controlled for gender, age, income, education, religion, marital status, duration of stay on treatment and disclosure of HIV status to families, friends, and sexual partner (N=1706 HAART patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	**Never miss taking HAART**			**Self-confident to take HAART**		
Negative self-image						
1st Quartile	1.00			1.00		
2nd Quartile	**0.51**	**0.37**	**0.69**	**0.65**	**0.48**	**0.88**
3rd Quartile	**0.40**	**0.28**	**0.58**	0.75	0.53	1.08
4th Quartile	**0.42**	**0.30**	**0.59**	**0.60**	**0.43**	**0.84**
Concern about public attitudes						
1st Quartile	1.00			1.00		
2nd Quartile	**0.66**	**0.46**	**0.94**	0.88	0.61	1.27
3rd Quartile	**0.58**	**0.38**	**0.87**	0.73	0.48	1.12
4th Quartile	1.01	0.62	1.63	**0.60**	**0.37**	**0.98**
Concern about disclosure						
1st Quartile	1.00			1.00		
2nd Quartile	0.97	0.72	1.32	1.16	0.84	1.59
3rd Quartile	**0.68**	**0.49**	**0.94**	**0.63**	**0.46**	**0.88**
4th Quartile	1.10	0.77	1.56	**0.49**	**0.35**	**0.70**
Personalized stigma						
1st Quartile	1.00			1.00		
2nd Quartile	0.84	0.60	1.18	1.06	0.75	1.50
3rd Quartile	0.81	0.55	1.20	1.07	0.72	1.60
4th Quartile	1.29	0.85	1.95	1.26	0.82	1.92

6.3. Disclosure of HIV status, its benefits, and consequences

Out of the total 1722 study subjects, about half (50.5%) had disclosed to parents and 27.1% disclosed to friends. while a lesser proportion disclosed to neighbors (12.5%), networks of people living with HIV (9.3%) and religious organizations (18.4%). About 61.2% had disclosed their HIV status to sexual partners, parents, friends, neighbors, network of people living with

HIV or religious fathers or parents. Among the total 931 study subjects who had disclosed to sexual partners, the majority (80.1%) had disclosed their HIV status to their sexual partners. The proportion was significantly higher among males (65.0%) compared to females (58.7%) (Table 6.18).

The majority of study subjects (61.7%) who disclosed their HIV status to their sexual partners did it one day after the date of diagnosis. About an equal proportion disclosed on the date of diagnosis (11.8%) and one week to 12 months after diagnosis (12.6%). About 14 percent (13.9%) disclosed the test result to their sexual partner after one year (Table 6.18).

Table 6.18: Respondents' disclosure of HIV status to sexual partners, parents, friends, neighbors, associations, religious organizations, and duration from knowing HIV status to disclosing to sexual partners (N = 1722 HAART patients), Zewditu Memorial Hospital, March, 2010.

Respondents' characteristics	Female N=1053 Freq (%)	Male N=669 Freq (%)	Total N=1722 Freq (%)	P value
Disclosed HIV status to;				
Spouse or sexual partner	395 (75.4)	351 (86.2)	746 (80.1)	
Parents	373 (54.3)	297 (44.6)	870 (50.5)	
Friends	279 (26.4)	188 (28.2)	467 (27.1)	
Neighbor	141 (13.5)	73 (10.9)	214 (12.5)	
Association or networks of people living with HIV	98 (9.3)	62 (9.3)	160 (9.3)	
Religious father or priest	220 (20.9)	95 (14.3)	315 (18.4)	
Disclosed either to parents, sexual partner, friends	620 (58.7)	433 (65.0)	1053 (61.2)	**0.009**
Duration from knowing HIV infection to disclosing to sexual partner in days				
On the date of diagnosis	55 (13.9)	33 (9.4)	88 (11.8)	
One day after diagnosis	249 (63.0)	211 (60.1)	460 (61.7)	
One week to 12 months after diagnosis	44 (11.1)	50 (14.3)	94 (12.6)	
More than one year after diagnosis	47 (11.9)	57 (16.2)	104 (13.9)	
Median time of disclosure in days	1	1		

Out of the total 1053 study subjects who disclosed their HIV status, 92.4% reported that their medication adherence improved because of disclosing their status. A significant proportion (50.5%) received psychosocial support because of their disclosure. A relatively smaller proportion received economic support (15.8%), nutrition support (12.0%), and social support (9.0%).

Only a small proportion of study subjects who disclosed their HIV status encountered physical assault (2.2%), separated from partners (5.0%), and lost economic support (2.5%). Relatively larger proportions (14.2%) were emotionally or orally abused as a result of their disclosure (Table 6.19).

Table 6.19: Benefits and consequences from disclosing HIV status as reported by respondents' (N = 1053 HAART patients), Zewditu Memorial Hospital, March, 2010.

	Female	**Male**	**Total**
	N= 620	**N=433**	**N=1053**
Respondents' characteristics	**Freq (%)**	**Freq (%)**	**Freq (%)**
Benefits from disclosing HIV status			
Adherence improved	599 (96.6)	374 (86.4)	973 (92.4)
Economic support	110 (17.7)	56 (12.9)	166 (15.8)
Nutrition support	75 (12.1)	51 (11.8)	126 (12.0)
Psychosocial support	321 (51.8)	211 (48.7)	532 (50.5)
Social support	63 (10.2)	32 (7.4)	95 (9.0)
What did you encounter from disclosing your HIV status			
Physically assaulted	17 (2.7)	6 (1.4)	23 (2.2)
Separated from partner	42 (6.8)	11 (2.5)	53 (5.0)
Lost economic support	19 (3.1)	7 (1.6)	26 (2.5)
Emotionally / orally abused	107 (17.3)	43 (9.9)	150 (14.2)

6.4. The effect of social support on weight and CD4 cell progression

6.4.1. Median baseline and recent weight

As presented in Table 6.20, the median baseline weight for the entire study population was 54kg and median recent weight was 59kg. There were significant differences by gender, with males having higher median weight at baseline (58kg) and recent weight (63kg) compared to females with baseline median weight of 51kg and recent median weight of 56kg.

Table 6.20. Respondents' median weight at baseline* and recent** period by duration of stay on HAART and sex of study participants, Zewditu Memorial Hospital, March, 2010.

Duration of stay on HAART	**Less than 12 months**		**12 - 48 months**		**Above 48 months**		**Total**		
Sex	F	M	F	M	F	M	F	M	Both sex
Baseline weight (Kg)									
N	75	49	526	272	423	331	1024	652	1676
Median	54	62	51	58	50	58	51	58	54
Recent weight (Kg)									
N	72	49	539	273	416	327	1044	660	1704
Median	55	62	56	63	56	65	56	63	59
Difference in weight (Kg)									
Recent less baseline	1	0	5	5	6	7	5	5	5

*All baseline measurements recorded at the start of treatment

**All recent measurements were based on last visit's record

6.4.2. Median baseline and recent CD4 cell count

Median baseline and recent CD4 cell count for the entire study population were 119 CD4 cell/µl and 284 CD4 cell/ µl respectively. Twenty eight percent of the study population had a recent CD4 cell count less than 200 CD4 cell/µl. Females had better median CD4 cell count levels both at baseline (131 CD4 cell/µl) and recent measures (296 CD4 cell/µl) compared to males with median baseline CD4 cell count of 103 CD4 cell/µl and recent CD4 cell count of 261 CD4 cell/µl (Table 6.19).

Table 6.21: Respondents' median CD4 levels at baseline* and recent** period by duration of stay on HAART and sex of study participants, Zewditu Memorial Hospital, March, 2010.

Duration of stay on HAART	**Less than 12 months**		**12 - 48 months**		**Above 48 months**		**Total**		
Baseline CD4 cell count (cell/µl)	F	M	F	M	F	M	F	M	Total
N	74	51	536	276	435	334	1045	661	1706
Median	150	131	131	103	112	92	131	103	119
F value***	0.555		0.060		**0.020****		**0.000****		
Recent CD4 cell count (cell/µl)	Less than 12 months		12 - 48 months		Above 48 months		Total		
N	57	40	531	266	430	334	1018	640	1658
Median	254	253	296	261	325	285	296	261	284
F value***	0.181		**0.002****		**0.001****		**0.000****		
Difference in CD4 (cell/µl)									
Recent less baseline	104	122	165	158	213	193	165	158	165

*All baseline measurements recorded at the start of treatment

**All recent measurements were based on last visit's record

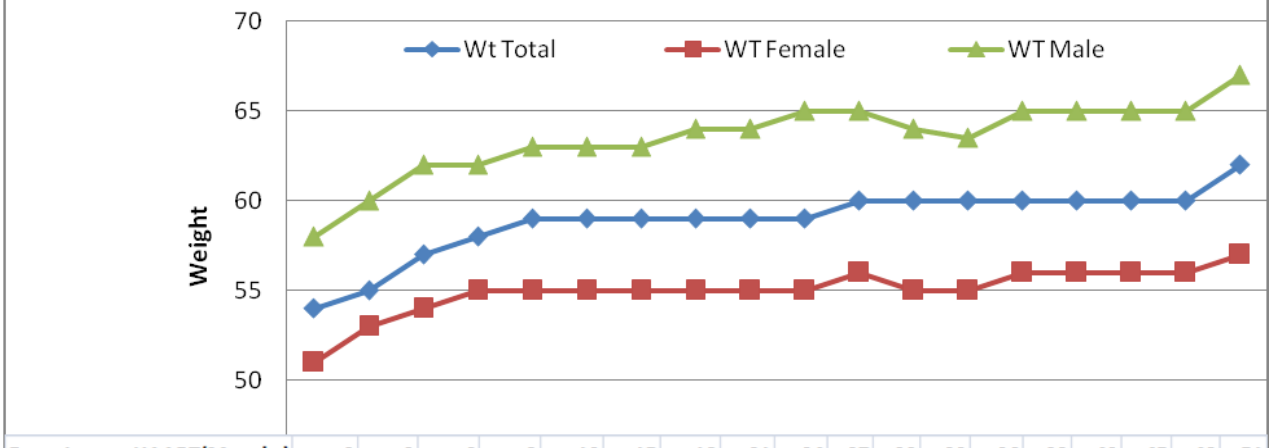
***One way analysis of variance (ANOVA) for mean difference in CD4 cell count by sex

****P<0.05

6.4.3. Trend in weight from baseline to 51 months of follow-up

Although study participants stayed on treatment for varying period of time, the general weight measure taken every three months was utilized to get the median weight for the specific periods (Figure 6.1). In the first 15 months of treatment there was a sharp increase in median weight, but from the 18th to 49th month period there was not much variability.

Figure 6.1: Change in median weight by sex from baseline to 51 months based on measurements taken every three months after the start of HAART, Zewditu Memorial Hospital, March, 2010.



Duration on HAART(Months)	0	3	6	9	12	15	18	21	24	27	30	33	36	39	42	45	48	51
N: Female	1024	874	855	804	765	702	674	644	595	550	308	283	246	218	185	158	133	107
N: Male	652	537	526	472	474	424	415	414	396	360	232	212	188	177	146	125	109	92
N: Total	1676	1411	1381	1276	1239	1126	1089	1058	991	910	540	495	434	395	331	283	242	199

0 – 6 months p=0.000	9 – 21 months: p=0.193	24 – 36 months: p=0.905	39 – 51 months: p=0.143

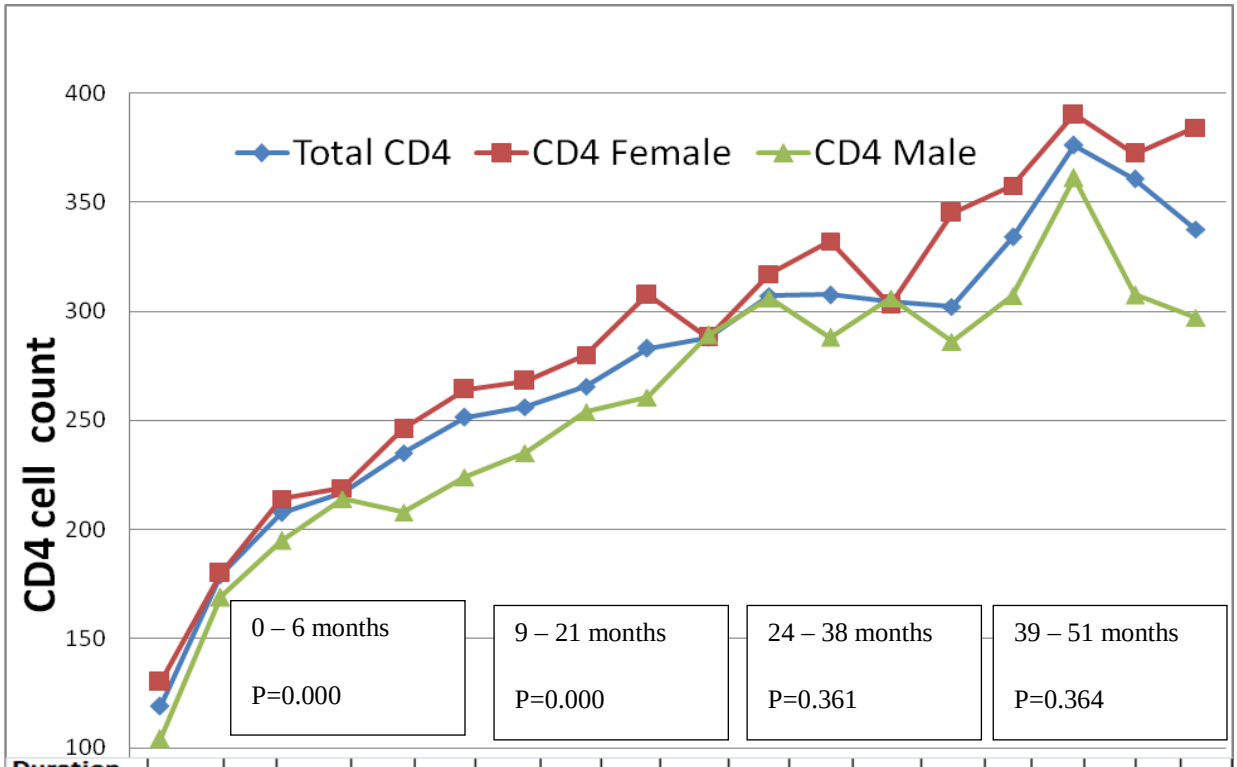
Additionally, the differences in mean weight between baseline and 6th month measure were significant. On the other hand, mean weight between 9th and 21st, 24th and 36th, and 39th and 51st months were not significantly different.

6.4.4. Trend in CD4 cell count from baseline to 51 months of follow-up

The median trend of CD4 cell count progression is presented in Figure 6.2. Varying number of observations contributed to the estimation of median CD4 cell count at different periods.

The mean CD4 cell count level was significantly different between baseline and 6th, 9th and 21st month measures. On the other hand, the mean CD4 cell count level between 24th, 36th, 39th and 51st month measures were not significantly different.

Figure 6.2: Change in median CD4 cell count by sex from baseline to 51 months based on measurements taken every three months after the start of HAART, Zewditu Memorial Hospital, March, 2010.



Duration (months)	0	3	6	9	12	15	18	21	24	27	30	33	36	39	42	45	48	51
N: Female	1045	40	382	306	235	185	190	203	166	170	76	77	75	52	50	41	32	34
N: Male	661	37	284	163	166	126	123	107	138	97	70	53	41	45	27	38	20	26
N: Total	1706	77	666	469	401	311	313	310	304	267	146	130	116	97	77	79	52	60

6.4.5. Effect of depression symptoms and perceived social support on weight and CD4 progression

In the regression model both depressive symptoms and perceived social support had significant effect on weight gain after adjusting for duration between baseline and recent measures, sex, age, income, education, marital status, and adherence to treatment (Table 6.22). A one unit increase in depressive symptoms was associated with a decrease in weight on average by about 10kgs between baseline and recent levels (p=0.023), while a one unit increase in perceived social support was associated with an average of 10kg increase in weight between baseline and recent levels (p=0.033).

Similarly the effect of depressive symptoms and perceived social support on CD4 cell progression was explored, adjusting for duration between baseline and recent measures, sex, age, income, education, marital status and adherence to treatment. As shown in Table 6.23, depressive symptoms had a negative effect on CD4 cell progression while perceived social support had a positive effect.

A one unit increase in depressive symptoms was associated with reduced CD4 cell progression on average by 10.72 CD4 cells between baseline and recent CD4 cell count levels ($p=0.013$) while a one unit increase in perceived social support was associated with an increase in CD4 cell count levels on average by 9.43 CD4 cells between baseline and recent levels ($p=0.043$).

Table 6.22: Regression model of effect of depression symptoms and social support on weight progression controlled for duration on HAART, sex, age, income, education, marital status and adherence to treatment among study participants on HAART for six months or more (N=1427), Zewditu Memorial Hospital, March 2010.

Weight	**Coef.**	**95% CI**		**P-level**
Duration	180.80	172.81	188.80	0.000
Depression symptoms unadjusted for duration	5.88	-1.25	13.02	0.106
Perceived social support unadjusted for duration	-1.31	-8.91	6.29	0.735
Depression symptoms adjusted for duration	**-9.84**	**-18.33**	**-1.34**	**0.023**
Perceived social support adjusted for duration	**10.00**	**0.79**	**19.21**	**0.033**
Sex				
Female	1.00			
Male	-19.88	-31.54	-8.23	0.001
Age	-0.12	-0.74	0.49	0.692
Income (Birr)				
2000 and above	1.00			
500 and less	-5.09	-23.46	13.26	0.586
501 – 999	-8.16	-26.21	9.88	0.375
1000 – 1999	-6.61	-25.52	12.29	0.493
Education				
College diploma and higher	1.00			
Below diploma level of education	0.15	-14.81	15.11	0.984
Marital status				
Married	1			
Not married	6.66	-17.24	3.92	0.218
Ever forget taking medication				
Yes	1.00			
No	-1.84	-12.74	9.05	0.739
Constant	147.79	117.58	178.00	0.000

Table 6.23: Regression model of influence of depression symptoms and social support on CD4 cell progression controlled for duration on HAART, sex, age, income, education, marital status and adherence to treatment among study participants on HAART for six months or more (N=1451), Zewditu Memorial Hospital, March 2010.

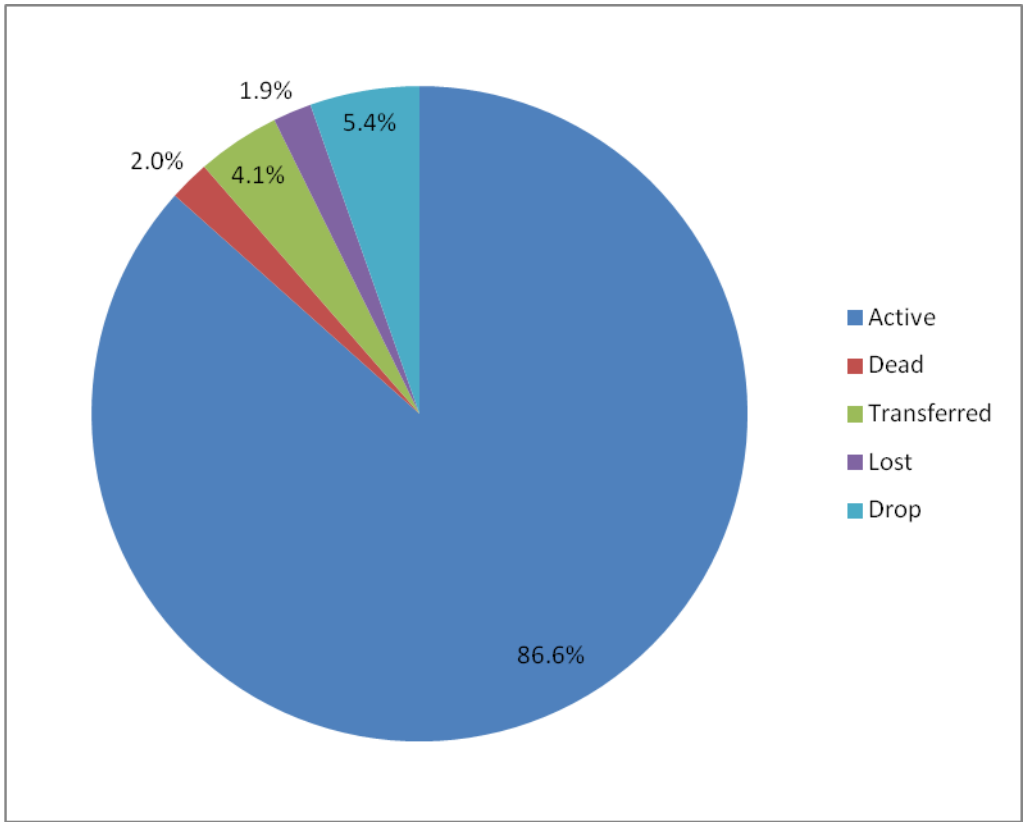
CD4	**Coef.**	**95% CI**		**P value**
Duration	178.41	170.48	186.34	0.000
Depression symptom unadjusted for duration	5.71	-1.38	12.80	0.115
Perceived social support unadjusted for duration	-0.66	-8.19	6.87	0.864
Depression symptoms adjusted for duration	**-10.72**	**-19.16**	**-2.27**	**0.013**
Perceived social support adjusted for duration	**9.43**	**0.30**	**18.56**	**0.043**
Sex				
Female	1.00			
Male	-19.88	-31.54	-8.23	0.000
Age	-0.12	-0.74	0.49	0.759
Income (Birr)				
2000 and above	1.00			
500 and less	-5.09	-23.46	13.26	0.617
501 – 999	-8.16	-26.21	9.88	0.405
1000 – 1999	-6.61	-25.52	12.29	0.493
Education				
College diploma and higher	1.00			
Below diploma level of education	0.15	-14.81	15.11	0.970
Marital status				
Married	1			
Not married	6.66	-17.24	3.92	0.222
Ever forget taking medication				
Yes	1.00			
No	-1.84	-12.74	9.05	0.609
Constant	153.78	115.64	191.93	0.000

6.5. Survival estimates by 12 months of follow-up and the effect of social support on attrition from HAART

6.5.1. Survival estimates

By 12 months after baseline data collection, 86.6% of study participants were still actively taking their treatment and were in good physical health. About four percent had been transferred out to other HAART clinics. The remaining 2.0% had died, 1.9% had been lost to follow-up and 5.4% had discontinued taking treatment.

Figure 6.3: Status of study subjects who were on HAART by 12 months of follow-up, Zewditu Memorial Hospital, March 2010 and June, 2011.



As presented in Figure 6.3, a total of 127 study subjects (7.4%) had either died or discontinued taking their treatment. Most of those who discontinued treatment were expected to have died but not reported. Because of this, all of the 127 study subjects were considered as those with

"failure". Although some of those who were lost from follow-up could have died they were not counted as "failure" to avoid over estimation.

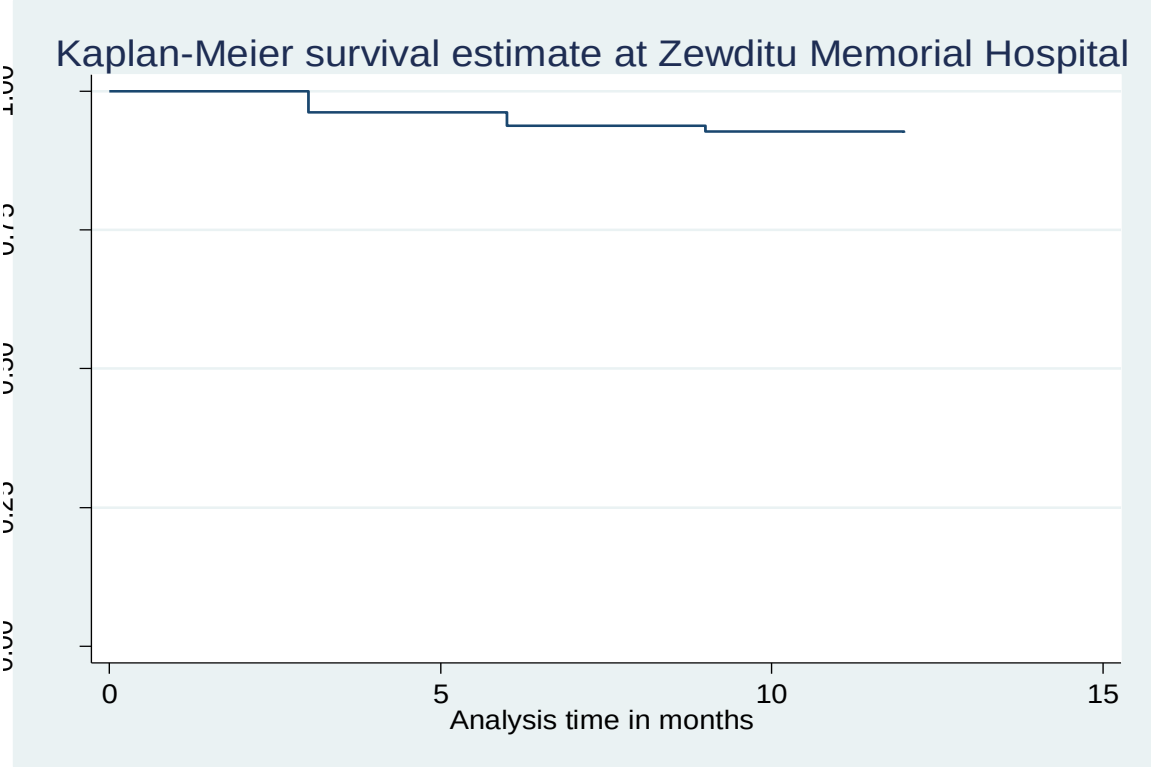
As presented in Table 6.24, 94.4% of the study subjects survived through 3rd to 4th months of follow-up while only 91.7% and 88.0% survived through 6th to 7th months and 9th to 10th months of follow-up respectively.

Table 6.24: Survival estimates within the 12 Months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.

Interval in months	**Total**	**Survival**	**Std Error**	**[95% Conf. Int.]**
3 - 4	1722	0.944	0.006	0.932 - 0.954
6 - 7	1625	0.917	0.007	0.903 - 0.929
9 - 10	1579	0.880	0.008	0.864 - 0.894
12 - 23	1515	0	.	. .

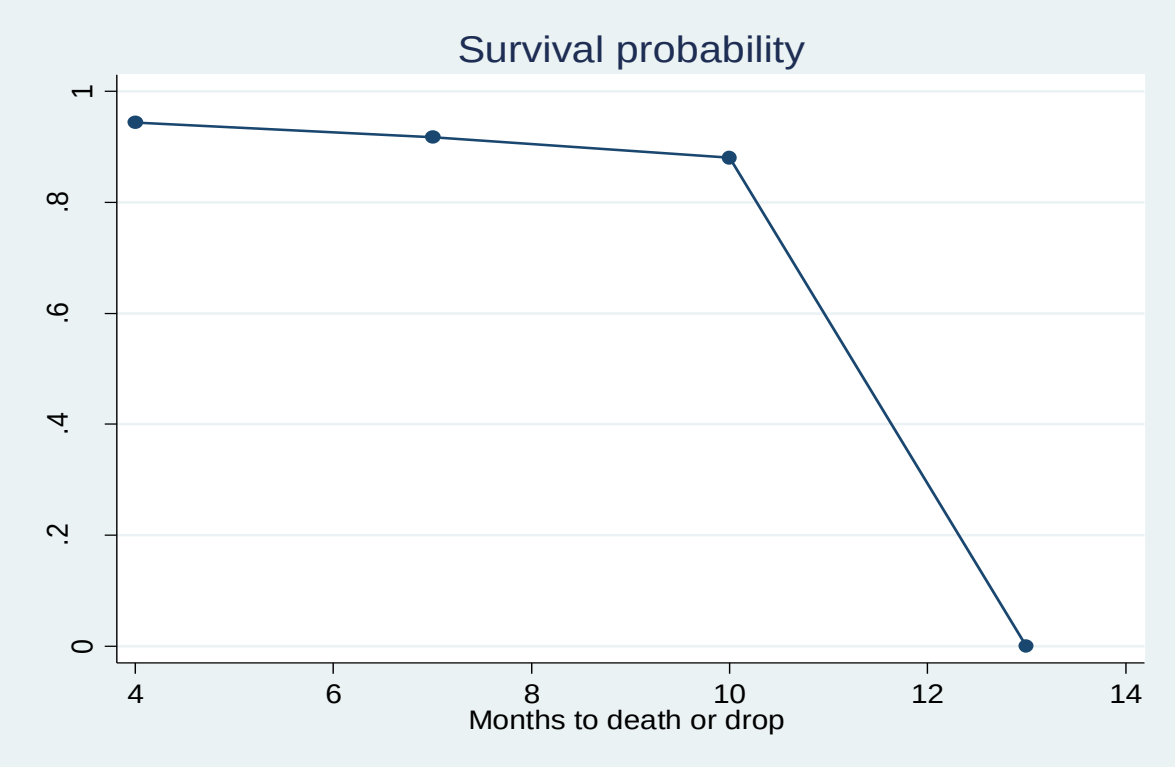
The Kaplan-Meier survival estimate presented in Figure 6.4 presents a relatively sharp drop in survival between 0 and 3rd months of follow-up and better survival between 3rd and 6th months of follow-up and then higher drop in survival between the 6th and 9th months of follow-up period.

Figure 6.4: Respondents' Kaplan-Meier survival estimate for the 12 months follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.



As presented in Figure 6.5 the probability of survival at the 3rd – 4th, 6th – 7th, and 9th – 10th months of follow-up was 94.4%, 91.7%, and 88.0% respectively. According to the estimate the probability of "failure" by 12 months of follow-up for the general HAART population in the urban context could be estimated as high as 12%.

Figure 6.5: Respondents' Probability of survival by 12 months of follow-up, Zewditu Memorial Hospital, March 2010 and June, 2011.



The probability of survival has been found to differ by different socio-demographic, social and clinical characteristics.

As presented in Figures 6.6 and 6.7, females had longer survival rates compared to males. Similarly, those who were within the age group of 36 – 45 years survived longer than those who were within the age groups of 15 – 35 years and 46 years or above. Those who were within the age group of 46 years or above had the lowest survival rate. The log-rank test demonstrated a significant difference in survival by differences in sex ($p<0.0000$) and age groups ($p <0.0000$).

Figure 6.6: Respondents' survival probability estimates by sex by 12 months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.

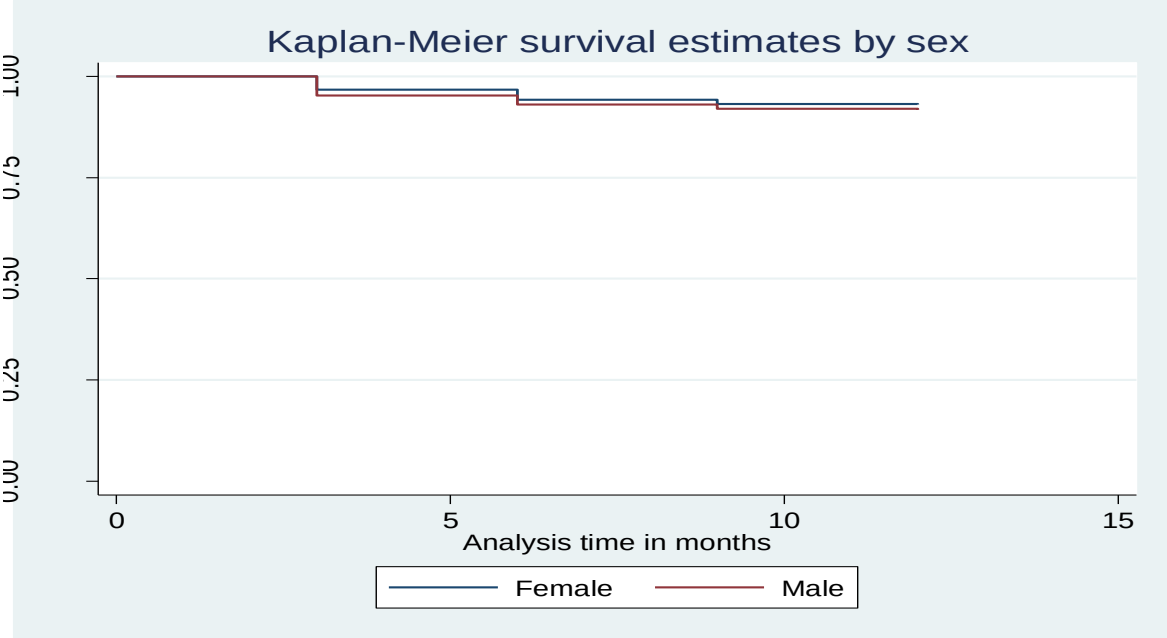
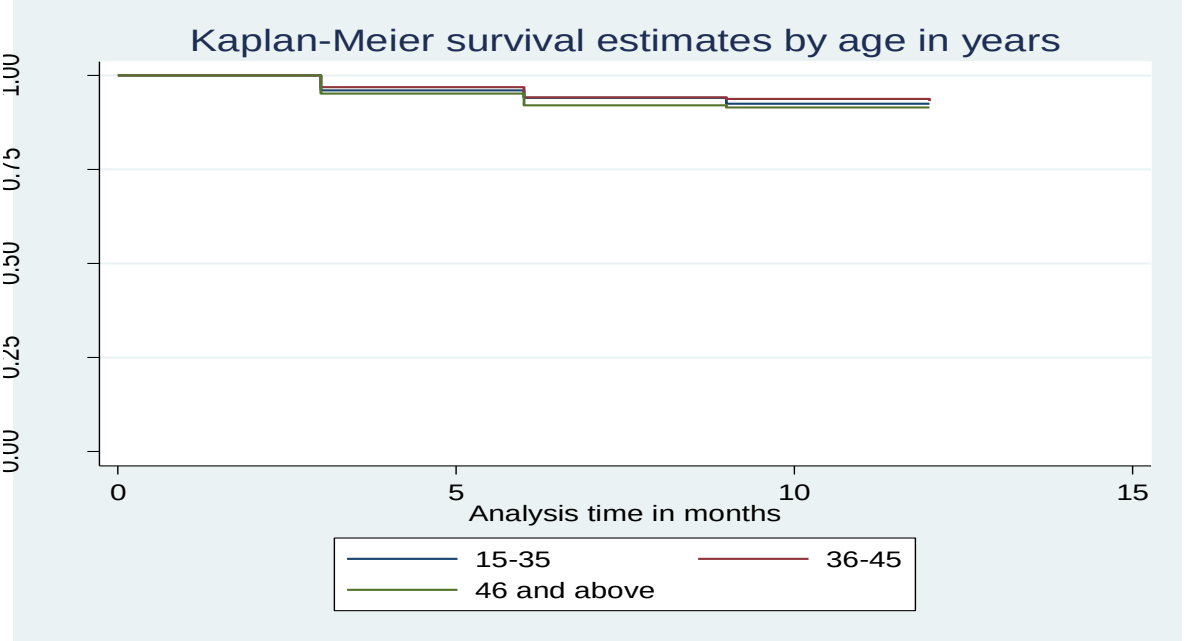


Figure 6.7: Survival probability estimates by age groups within 12 months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.



As shown in Figure 6.8 and 6.9, those with a baseline weight of 52kg or above and a baseline CD4 cell count of 200 or above survived longer than those with a baseline weight less than 52kg and a baseline CD4 cell count less than 200. The differences in survival by weight ($p < 0.000$) and CD4 count ($p < 0.0000$) were significant.

As presented in Figure 6.10, probability of survival was found to differ significantly ($p < 0.0000$) by the level of self-reported adherence to HAART. Those who reported better adherence to HAART survived longer than those who reported poor adherence to HAART.

Figure 6.8: Survival probability estimates by baseline weight within 12 months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.

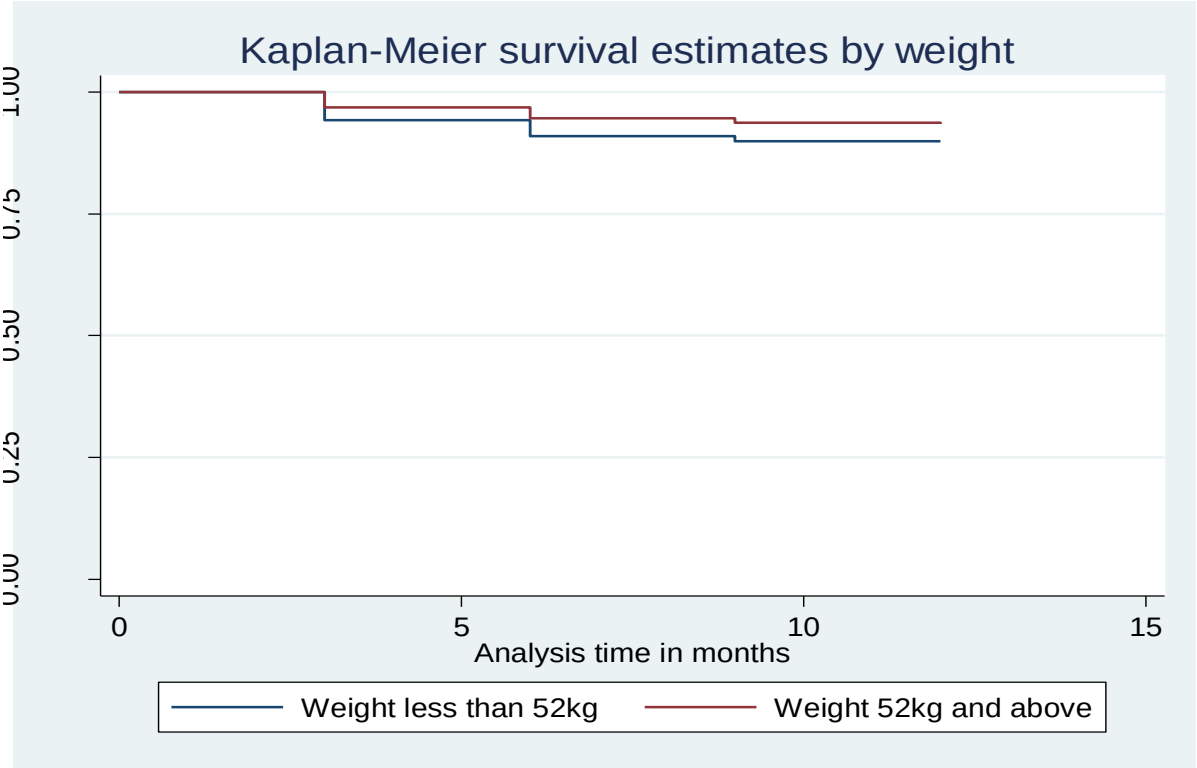


Figure 6.9: Respondents' survival probability estimates by baseline CD4 count within 12 months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.

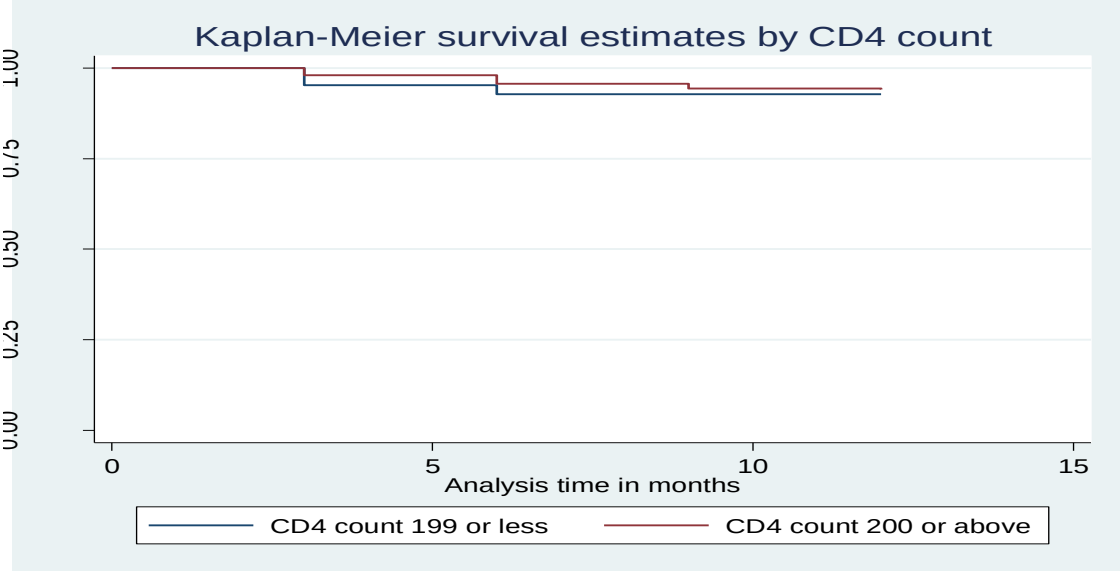
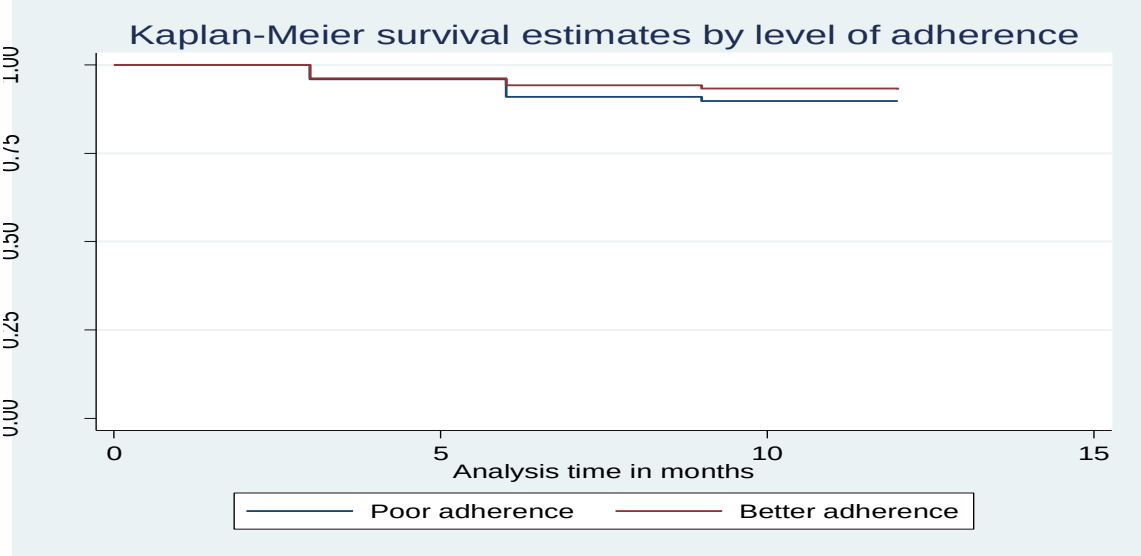
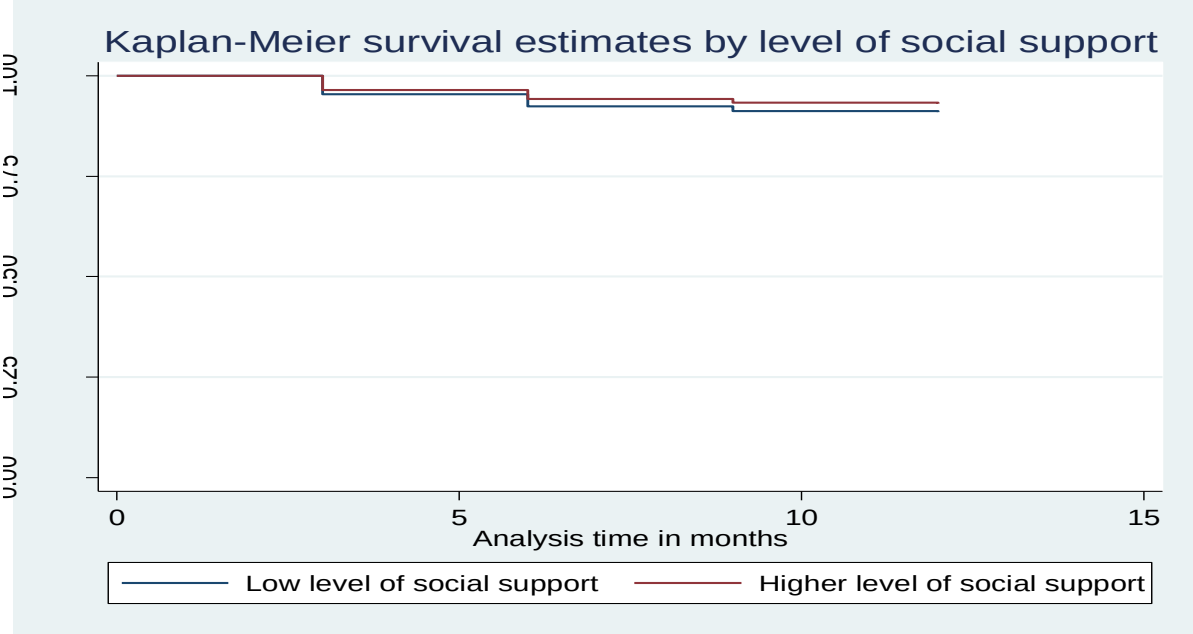


Figure 6.10: Respondents' survival probability estimates by self-reported adherence to HAART within 12 months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.



As presented in figure 6.11 probability of survival was found to differ significantly ($p < 0.0000$) by the level of baseline social support. Those who reported better perceived social support from families, friends, and communities survived longer than those who reported a low level of perceived social support.

Figure 6.11: Respondents' survival probability estimates by perceived social support within 12 months of follow-up periods, Zewditu Memorial Hospital, March 2010 and June, 2011.



6.5.2. *The effect of socio-demographic characteristics (sex and age), clinical characteristics (baseline weight and CD4 count), and self-reported adherence to HAART on survival*

In the Cox proportional hazard model presented in Table 6.25, sex, age, adherence to HAART, baseline weight and CD4 count were applied together, controlling for level of education and income. In the model sex, age, baseline weight and CD4 count were not significantly associated with the hazard or risk of "failure". Self-reported adherence to HAART was significantly associated with the hazard or risk of "failure". Those with good self-reported adherence had 48% lower hazard or risk of "failure" than those with poor adherence.

Table 6.25: Cox proportional hazard ratio model on the effect of sex, age, self-reported adherence to HAART, weight and CD4 count on hazard or risk of failure at Zewditu Memorial Hospital, March 2010 and June, 2011.

Respondents' characteristics	**Haz. Ratio**	**95% Conf. Interval**
Sex		
Female	1.00	1.00
Male	1.42	0.89 - 2.24
Age	0.99	0.97 - 1.02
Adherence		
Poor adherence	1.00	1.00
Good adherence	**.52**	**0.34 – 0.81**
Weight		
< 52kg	1.00	1.00
≥ 52kg	0.69	0.43 – 1.09
CD4 cell count		
199 and less	1.00	
200 and above	0.82	0.55 – 1.24
Education in completed grades	0.97	0.93 - 1.00
Income (Birr)		
2000 and above	1.00	1.00
500 and less	0.71	0.39 - 1.29
501 – 999	0.81	0.45 - 1.47
1000 – 1999	0.76	0.40 - 1.45

6.5.3. The effect of perceived social support on survival

In the Cox regression model presented in Table 6.26, the effect of perceived social support on hazard or risk of "failure" was explored, controlling for possible confounding variables; disclosure of HIV status, age, sex, regular alcohol drinking, education, income, marital status,

and duration of stay on HAART. Perceived social support was negatively associated with the hazard or risk of "failure". Those who reported a good level of perceived social support had 23% less hazard or risk of "failure" compared to those who reported low level of perceived social support.

Table 6.26: Cox proportional hazard ratio model on the effect of baseline perceived social support on hazard or risk of "failure" controlling for age, sex, alcohol drinking behavior, educational status, monthly expenditure income, marital status, and duration of stay on HAART at Zewditu Memorial Hospital, March 2010 and June, 2011.

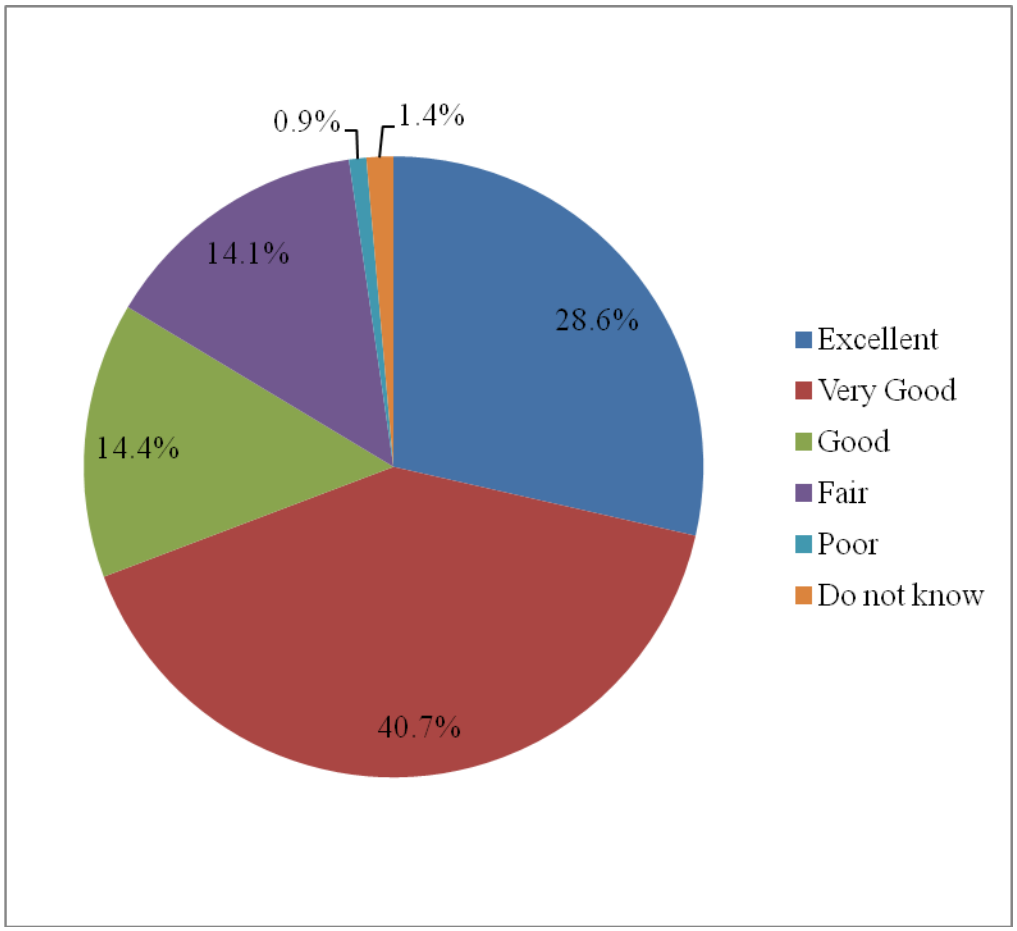
Respondents' characteristics	**Haz. Ratio**	**95% Conf. Interval**
Perceived social support	**0.77**	**0.64 - 0.93**
Disclosure of HIV status		
Did not disclose	1.00	1.00
Had disclosed partners	1.09	0.71 - 1.67
Age	0.99	0.98 - 1.02
Sex		
Female	1.00	1.00
Male	1.27	0.87 - 1.86
Alcohol drinking		
Yes	1.00	1.00
No	1.02	0.59 - 1.77
Education in completed grades	0.98	0.94 - 1.01
Income (Birr)		
2000 and above	1.00	1.00
500 and less	0.66	0.38 - 1.14
501 – 999	0.76	0.44 - 1.32
1000 – 1999	0.74	0.41 - 1.35
Marital Status		
Yes	1.00	1.00
No	1.39	0.91 – 2.13
Duration of stay on HAART in months	0.99	0.98 - 1.00

6.6. Perceived Quality of Life (QOL) of study subjects and the effect of perceived social support on perceived quality of life

6.6.1. Respondents' perceived quality of life

As presented in Figure 6.11, the majority (41%) of the study subjects graded their physical and mental health condition as "very good", while about 29% graded their health condition as "excellent". About an equal proportion of study subjects graded their health condition as "good" (14.40%) and "fair" (14.05%). A very small proportion, about 1%, graded their health condition as "poor". The remaining 1.39% were unable to grade their general health condition.

Figure 6.12: Respondents' perceived quality of life (N= 1722 HAART patients), Zewditu Memorial Hospital, March 2010.



As presented in Table 6.27, study subjects reported the number of days in the past 30 days at which their physical or mental health condition was “not good”. The mean number of days at which physical health was “not good” was found to be 2.28 days. The mean number of days at which physical health was “not good” was higher among females (2.55 days) compared to males (1.86 days). Similarly, the mean number of days at which mental health was not good was found to be 2.77 days. Similarly the mean number of days at which mental health was “not good” was higher among females (3.14 days) compared to males (2.19 days). The total mean number of days at which either physical health or mental health was “not good” was 4.76 days, with the number being higher among females (5.35 days) compared to males (3.84 days).

About 19% of study subjects reported that they were limited from activities because of some kind of health problem. The main health problems reported as limiting their activities were lack of energy (12.5%), lung problems (5.2%), depression or anxiety (5.1%), and weight loss (4.4%).

Table 6.27: Respondents' general health condition, mean number of days in the past 30 days with physical or mental health problems, total number of unhealthy days, and activity limitation because of health problem, Zewditu Memorial Hospital, March 2010.

Respondents' Characteristics	**Female (%) N=1056**	**Male (%) N=666**	**Total (%) N=1722**	**P value**
General health condition				
'Excellent'	300 (28.4)	192 (28.8)	492 (28.6)	0.925
'Very good'	438 (41.5)	263 (39.5)	701 (40.7)	
'Good'	150 (14.2)	98 (14.7)	248 (14.4)	
'Fair'	145 (13.7)	97 (14.6)	242 (14.0)	
'Poor'	10 (0.9)	5 (0.8)	15 (0.9)	
'Do not know'	13 (1.2)	11 (1.7)	24 (1.4)	
Mean number of days physical health was "not good"	2.55 $\pm$ 5.6	1.86 $\pm$ 5.35	2.28 $\pm$ 5.74	0.0154
Mean number of days mental health was "not good"	3.14 $\pm$ 6.48	2.19 $\pm$ 5.49	2.77 $\pm$ 6.13	**0.0019**
Mean number of days poor physical and mental health keep from activities	1.46 $\pm$ 4.79	1.19 $\pm$ 4.71	1.35 $\pm$ 4.76	0.2649
Mean number of total unhealthy days due to either physical or mental problems	5.35 $\pm$ 9.14	3.84 $\pm$ 7.95	4.76 $\pm$ 8.73	**0.0005**
Are you limited in any from activities				
'Yes'	215 (20.4)	112 (16.82)	327 (18.9)	0.155
'No'	725 (68.7)	471 (70.7)	1196 (69.5)	
Not sure	116 (10.9)	83 (12.5)	199 (11.6)	
Major health problem limiting activity				
Depression/Anxiety	55 (5.2)	33 (4.9)	88 (5.1)	0.816
Lung problem	53 (5.0)	36 (5.4)	89 (5.2)	0.728
Lack of energy	138 (13.1)	77 (11.6)	215 (12.5)	0.357
Weight loss	47 (4.5)	28 (4.2)	75 (4.4)	0.807

As presented in Table 6.28, in addition to the general physical and mental health condition, study subjects reported number of days in the past 30 days at which they experienced specific health problems. The mean number of days at which study subjects experienced pain was 1.70 days. There was no significant difference between females (1.75 days) and males (1.62 days).

The mean number of days with sadness, feeling blue, or depression in the past 30 days was 3.04 days, with the number of days being higher among females (3.69 days) compared to males (2.31 days). The mean number of days at which study subjects felt worried, tense or anxious was 3.35 days. The number of days was higher among females (3.69 days) compared to males (2.80 days). The mean number of days at which study subjects felt that they did not get enough rest or sleep was 3.35 days. This was also higher among females (2.82 days) compared to males (2.09 days).

The mean number of days in the past 30 days at which study subjects felt either pain or any sort of sadness, feeling blue, depression, anxious, or those who felt worried, felt they did not have enough rest or sleep, was found to be 7.77 days. The mean number of days was significantly higher for females (8.54 days) compared to males (6.56 days).

The total mean number of days at which study subjects felt healthy and full of energy was 25 days, the mean number of days being significantly higher among males (26.66 days) compared to females (25.40 days).

Of total study subjects, 8.5% reported that they needed the support of others to carryout different kinds of activities like personal care and household chores.

Table 6.28: Mean number of days with pain, sadness, blue, or depression, anxiety, sleeplessness, and mean number of days felt very healthy and full of energy in the past 30 days at Zewditu Memorial Hospital, March 2010.

Respondents' Characteristics	**Female N=1056**	**Male N=666**	**Total 1722**	**P value**
Mean number of days with pain in the past 30 days (SD)	1.75 ± 5.12	1.62 ± 5.51	1.70 ± 5.27	0.598
Mean number of days with sadness, blue, or depression in the past 30 days (SD)	3.50 ± 6.76	2.31 ± 5.52	3.04 ± 6.34	**0.000**
Mean number of days felt worried, tense, or anxious (SD)	3.69 ± 6.89	2.80 ± 6.35	3.35 ± 6.70	**0.007**
Mean number of days felt did not get enough rest or sleep (SD)	2.82 + 6.20	2.09 + 5.26	2.54 ± 5.86	**0.0011**
Mean number of days felt very healthy and full of energy (SD)	25.40 ± 7.40	26.66 ± 6.87	25 ± 7.22	**0.000**
Mean number of days either pain or sadness, blue, depression, felt worried, tense, or anxious, felt did not get enough rest or sleep (SD)	8.54 ± 10.90	6.56 ± 9.94	7.77 ± 10.58	**0.000**
Need help of other persons for personal care				
'Yes'	97(9.3)	49(7.4)	146(8.5)	0.174
'No'	950(90.7)	615(92.6)	1565(91.5)	

6.6.2. Relationship between perceived social support and perceived quality of life

As presented in Table 6.29 perceived social support was significantly associated with both 'number of unhealthy days because of some sort of physical or mental health problems' and 'number of unhealthy days because of some sort of pain or feeling depressed, anxious, or worried, or sleeplessness' in the previous 30 days. A one unit increase in perceived social

support was associated with 0.84 times less likelihood of unhealthy days due to some sort of physical or mental health problems. Similarly, a one unit increase in perceived social support was associated with 0.75 times less likelihood of unhealthy days due to some sort of pain or feeling depressed, anxious, or worried, or sleeplessness controlling for possible confounding effect of age, sex, regular alcohol drinking, education, expenditure income, marital status, and duration of stay on HAART.

Table 6.29: Logistic regression model on the effect of perceived social support on the number of days spent with pain, depression, anxiety, and sleeplessness controlling for the possible confounding effect of age, sex, alcohol drinking, education, income, marital status, and duration of stay on HAART (N=1722 HAART patients), Zewditu Memorial Hospital, March 2010.

Respondents' characteristics	**Number of unhealthy days because of some sort of physical or mental health problems**		**Number of unhealthy days because of some sort of pain or feeling depressed, anxious, or worried, or sleeplessness**	
	OR	**95% CI**	**OR**	**95% CI**
Perceived social support	**0.84**	**0.75 – 0.94**	**0.75**	**0.67 – 0.85**
Disclosed HIV status	1.12	0.88 – 1.42	1.04	0.81 – 1.33
Age	1.00	0.99 - 1.01	0.99	0.98 - 1.00
Sex				
Female	1.00	1.00	1.00	1.00
Male	0.63	0.51 – 0.79	0.66	0.53 – 0.84
Alcohol drinking				
Yes	1.00	1.00	1.00	1.00
No	0.67	0.49 – 0.92	0.64	0.46 – 0.88
Education in grades	0.99	0.97 - 1.01	0.98	0.96 - 1.01
Income (Birr)				
2000 and above	1.00	1.00	1.00	1.00
500 and less	1.27	0.90 - 1.78	1.36	0.92 – 2.00
501 – 999	1.96	1.39 – 2.75	2.78	1.90 – 4.07
1000 – 1999	1.64	1.15 – 2.34	2.74	1.84 – 4.08
Marital Status				
Yes	1.00	1.00	1.00	1.00
No	1.11	0.88 – 1.40	1.15	0.90 – 1.47
Duration of stay on HAART	1.00	0.99 – 1.01	1.00	0.99 – 1.01

6.7. Qualitative findings from key-informant interviews

Adherence had been reported to be good but not perfect, with patients missing doses due to various reasons. But in general they were committed to taking their medication on time.

All of the respondents who started their medication in the last 3 years confirmed that they had received enough counseling before starting HAART and they knew about the importance of the medicine, including the side effects. Hence, they started when they were ready.

However, those who started HAART before 5 years indicated that they started the medication to stay alive without knowing the side effects and what may happen if they stopped taking the medication. This group also indicated that as HAART was new, the knowledge about the medication was very low at that time. Moreover, they started HAART at a critical stage, thus they were just hoping to stay alive. One of the respondents said that she would not have started the medication if she had known the side effects before.

Most of the respondents gave themselves 7 out of 10 when gauging their adherence. Explaining their reason, they indicated that they know the importance of the medication to their health and livelihood as well as the consequences of not perfectly adhering to it. All of them believed that it is the medications that keep them alive, next to God.

None of the respondents had discontinued taking their medication, and they never had a plan to stop taking their medication as long as there is supply of the medicine. All of them travel with their medication. All respondents confirmed that their medication and treatment brought a significant difference to their lives and the lives of others. Their CD4 count and physical wellbeing improved due to the treatment.

All respondents revealed that at least one of their close family members (their children, husband, wife, sister, mother, brother) and their best friends knew their HIV status. They also confirmed that disclosing themselves to their family helped them to take their medicine on time and to follow up on their treatment properly. Moreover, their family took care of them - they urged

them to eat on time, helped them in household chores, comforted them, and advised them to refrain from drinking and other harmful habits.

For one respondent, the disclosure helped her and her family to talk about HIV/AIDS freely in the house so that her children could take care of themselves. Moreover, she said that she lived freely in the community, as most people know her status. She had no fear of other people knowing her status or gossiping about it, as she knew she could live like everyone else. She also got a house from the government because she disclosed her HIV status.

However, some of them indicated that disclosure occasionally hurt since there was still discrimination from the community. Some were prevented from being members in local community associations. Some still did not want to take their medication in the presence of others.

Four of the respondents indicated that they never felt any stress or depression because they were living with the virus or because they were on HAART. They said they used to be depressed when they discovered their HIV status nine or ten years ago because there was no treatment for the virus. Currently, they all consider HAART to be a blessing and look for further developments in the area like a vaccine that could create a better future for the coming generation, especially their children born with HIV.

The rest, five of the respondents, confirmed that taking HAART for life has psychological impacts. They always ask God "why me?" and "for how long would I be able to take it?" and sometimes taking the medication makes them weary. One respondent even said that taking her medication always makes her think that she is sick and she always feels that she could have accomplished more financially if she was not HIV positive. The other two confirmed that they were at times depressed because there are things they cannot do like work in other countries, due to their HIV status. The stress and the medication itself also affected their health due to the side effects and in turn this impacted their diet because they had to eat selectively (low fat, well cooked), even if it is not their preference.

Nevertheless, these feelings did not lead any of them to stop their medication because they have sources of inspiration. For one it is her sister, for some their children, and for others it is their love for life. Yet, all respondents know other people who quit their medication due to despair resulted from the stress of being HIV positive and taking medication for life.

All respondents confirmed that stigma and discrimination is currently decreasing but not abolished. Still there is indirect discrimination like people telling them they can do it better as it requires strength and alike. Yet, all agreed that it never impacted their adherence to their medication, as they are aware of its implication on their health and livelihood. Most of them also stressed that they have their own life.

Explaining their past experience, two respondents said that they have been stigmatized and discriminated. In the past their landlords did not allow them to use their toilet and their clothes drying ropes. But currently there are no such problems.

Only two respondents said that they have never been stigmatized or discriminated until now, as nobody knows their status except their family who were very supportive.

However, they know several individuals who quit their medication due to discrimination, especially from their closest ones like family and best friends. If their family blame them for their HIV status or stigmatize them, people tend to leave their house without their medication, change their address and start to live in a different community. One respondent indicated that she knew a 17 year old girl who quit her medication due to stigma from her sister; other said she knew several individuals who threw out their medication in a river; and others said some people stop medication because of loneliness resulted from fear of criticism from people who were very close to them, especially if they knew their parents badmouth HIV positive persons.

One respondent also said that her HIV positive friends do not want to be seen with her anymore because she was part of a documentary film on HIV that was aired in the media.

The major reasons identified by the participants of key-informant interviews as barriers to adherence were poverty, which is mainly related to lack of food to enable them tolerate their

medication, discrimination from their family, loneliness and helplessness, side effects, inadequate adherence counseling, preference of traditional medicine, and fear of other people's attitude towards people taking HAART.

Respondents recommended the following to increase individuals' adherence to their medication;

- continuous education in hospitals, health centers, worship places, and at every community structures,
- adequate adherence counseling before initiating HAART,
- linking HAART patients with organizations that provide food and nutritional support,
- integrating HAART services with other services of the hospital so that Patients will not be identified, and
- initiate peer to peer support.

7. Discussion

The discussion has been presented in four sections. These are:

- Adherence to HAART, self-confidence on ability to take HAART properly and its socio-demographic correlates,
- Effect of social support and depression symptoms on adherence to HAART,
- Effect of stigma on adherence to HAART,
- The effect of social support and depression symptoms on weight and CD4 cell progression,
- Survival estimates by 12 month of follow-up and its determinants,
- Perceived quality of life of persons infected with HIV and its association with social support.

7.1. Adherence to HAART, self-confidence on ability to take HAART properly and its socio-demographic correlates

The respondents' initial knowledge about the benefits of anti-HIV drugs (67%) and the importance of strict adherence (65%) at the time of treatment initiation was found to be poor. This suggests that most of these clients, particularly those who initiated treatment earlier, had initiated their treatment without adequate counselling and education regarding the benefits of HAART and the importance of adherence. This is indicative of concern regarding quality of service delivery especially on providing adequate counselling to persons who are eligible for treatment before initiating HAART. The focus should not be only on treating the virus but both the patient and virus together. Along with providing the drug to treat the virus there needs to be enough counselling to the patient to enable them know the benefits of strict adherence to HAART.

A significant portion of the respondents did not know their most recent CD4 cell count. This might indicate that HAART clients at the hospital clinic were not actively engaged in monitoring

their treatment progress. This entails engaging and empowering clients to monitor their own progress and to make healthy decisions that will improve their treatment outcomes. The focus of HAART service delivery need to be provision of client-centered services which means patients need to be empowered with enough information about the effect of treatment on their own health. When patients understand the positive effect of their treatment they will be motivated to adhere properly. Similarly if the progress is not good they will take appropriate action on time to improve treatment outcome.

Another important finding was the relatively low level of self-confidence in correctly taking HAART medication (mean value of 2.4 out of 3). This might be because HIV is still considered by some to be a 'deadly disease'. Thus, even though a person may take the medication, they might not believe that it will prolong their life for a long time. HAART clients need to be supported, encouraged, and counselled so that they will be hopeful and believe in the effect of the medication. Specifically higher proportion of patients were "not all sure" (9.8%) or "some what sure" (14%) about how sure they were that if they did not take the medication exactly as instructed their body will become resistant to the HIV medication. This can go with the inadequate counselling provided by service providers. Patients need to be educated about drug resistance; what it means, reasons or causes, and its adverse effect utilizing easy to understand behaviour change communication materials.

The mean adherence score for *Morisky's* scale was 0.64 and higher for females (0.69) than males (0.55). Sixty-two percent of study participants had never missed HAART. This implies that 38% had missed their medication at some point — a situation that requires targeted intervention. The proportion that had never missed medication was higher among males (63.5%) than females (57.9%). This implies that males adhere to their medication better than females. Mean self-confidence level was also higher for males (7.32) and less among females (7.09). This suggests that males are more self-confident than females in taking their medication correctly. Overall, the proportion of study subjects with sub-optimal adherence to HAART was 15.6%. This result is lower than the 23% sub-optimal adherence level reported from a meta-analysis of adherence studies carried out in Africa [258]. The reasons why self-reported adherence to HAART was higher in this study could be explained in different ways. One of the reasons could be under

reporting of missed doses by respondents. Although the study utilized different techniques to reduce the level of under reporting, it is unrealistic to say it was nonexistent. Due to the different social reasons some of the study subjects might not have reported the reality. This was evidenced by other studies [259, 262]. For example in a study done in Mulago Hospital in Kampala, all respondents reported 95% adherence, but pill counts showed that only 60% of the clients had 95% adherence [259].

Although some level of under reporting of missed doses might exist, yet adherence to HAART is never perfect but generally good in the African context and in Ethiopia too. A meta-analysis of studies done in North America and Africa reported that Africans adhered to treatment better than North Americans. According to this study, the fact that treatment adherence appeared to be better among clients in Africa may have come about due to generally limited access to treatment – those who eventually get the therapy are more likely to be adherent. In time, once more people are able to initiate treatment, the people on treatment might resemble the general population of people with HIV infection, and so the adherence rate might decrease [258].

According to an ethnographic study done at HIV treatment sites in Nigeria, Tanzania, and Uganda, the primary reason most Sub-Saharan Africans adhere to HAART is because they want to be healthy. But the desire for health alone does not adequately explain adherence success. The role of social capital in relationships is also highlighted as important for overcoming economic obstacles to care [21]. This difference may also be attributed to differences in the methodology of the studies and social desirability bias.

Even if self-reported adherence to HAART was generally good in the present study, yet, 38% of respondents had reported ever missing their medication. This is indicative of the need for adherence support interventions to help them improve their adherence practices.

Pertaining to respondents recent adherence practices, higher proportion (94.4%) reported that they had never missed their HAART medication in the previous four days, and this finding is comparable to other studies carried out in Ethiopia [260], South Africa [261], and Zambia [262]. However the Zambian study found that self-reporting had greatly overestimated adherence based on comparative data from the pharmacy. In this study, most respondents reported missing their

medication because they were busy, away from home, simply forgot to take it, or because they did not want other people to notice them taking medication. Similarly higher levels of recent self-reported adherence practices were reported from studies done in Uganda [259], Kenya [263], Zambia [104] and Ethiopia [102].

In the ordered regression analysis; being male, having higher expenditure income, and not drinking alcohol regularly were associated with higher odds of self-confidence in taking the medication. The higher level of self-confidence among males may be explained by the generally higher status that males have within communities. A higher income can be associated with better living conditions, including better nutrition, which could boost a person's self-confidence.

Age was significantly associated with better self-reported adherence. It might be important to explore why the odds of ever missing medication were found to be lower as the age of the respondent increased. This may simply be due to better life experience, decision making ability, and confidence which might come with age.

Drinking alcohol regularly is expected to decrease people's self-esteem and this was indeed demonstrated in this study. The proportion of persons who had never forgotten to take their medication was higher (by 20%) among those who did not drink alcohol regularly as compared to those who drank regularly. Similarly, in the regression model, those who did not drink alcohol regularly had higher odds of self-confidence and lower odds of ever forgetting their medication. Persons with HIV infection are advised to not drink alcohol because of its negative effects, including the likely consequences on treatment adherence. Similarly, in a South African HIV/AIDS workplace programme, drinking alcohol was reported as a barrier to HAART adherence [103]. A meta-analysis of studies carried out to assess the effect of alcohol-drinking on HAART adherence also reported poor adherence among those who drank regularly [233].

Another socio-demographic variable significantly associated with self-reported adherence was sex. Males had lower odds of having ever missed HAART medication. This may need further study to understand why females may possibly not adhere as well to treatment. Furthermore, exploratory qualitative studies might increase the understanding of gender dynamics in patterns of adherence to HAART.

7.2. Effect of social support and depression symptom on adherence to HAART

Regarding social support, a significant proportion did not have someone to borrow 100 Birr (6 USD) from if they needed it in an emergency (34%). A similar proportion did not have someone to provide care if they were confined to bed (33%). This implies that HIV infected individuals were struggling on their own to cope with their HIV infection and the lifelong treatment that they need. On top of this almost a quarter of the respondents had no one; to make them feel respected or admired, to make them feel liked or loved, to confide on and who agree with their actions. This indicates the low level of emotional and tangible social support that people with HIV were receiving from friends, families, and the community.

In the logistic regression model perceived social support was significantly associated with both adherence to HAART and self-confidence on the ability to take medication properly. A one unit increase in perceived social support was associated with 1.32 (OR: 1.14 – 1.54) times more likelihood of never missing HAART and 1.20 (OR: 1.06 – 1.35) times more likelihood of being confident to take HAART properly.

The effect of social support on adherence to HAART has been demonstrated by different studies both in Africa and Ethiopian context [16, 23, 100, 264]. A study done by Daves and his colleagues reported that not living alone to be an important predictor of better rates of treatment adherence [23, 100]. In this study high level of perception of self-efficacy, which was associated with high perceived social support, was found to be an important predictor of adherence to HAART.

Similarly, other studies done in; Cote d'Ivoire [101], Ethiopia [102], South Africa [103] and Zambia [104] reported social support to be an important predictor of adherence to HAART.

In line with this the findings of the current study are suggestive of the importance of social support in improving adherence. Social support's effect in facilitating adherence could be explained in-terms of support in reminding patients to take medication on time, providing nutrition support, or support in the form of encouragement so that patients will be hopeful in their life and be motivated to adhere to their medication. Supportive friends and families play

significant role in facilitating adherence. Treatment buddies and peer counsellors play significant role in improving adherence [16, 264].

With regards to depression symptoms, a significant proportion of the study population suffered from depressive symptoms including; restless sleep (16.3%), feeling lonely (14.7%), felt depressed (11.4%), and bothered by things that usually did not bother them before (11.0%). Significantly more females experienced these symptoms as compared to males ($p<.000$). These symptoms could arise because of lack of social support, inadequate psychosocial counseling, and due to the prevailing stigma and discrimination within the community. HAART service delivery sites need to integrate psychosocial counseling services within their programs on top of dispensing drugs to address the prevailing psychosocial problems.

The effect of psychosocial factors and specifically of depressive symptoms on adherence to HAART has been demonstrated in different studies both in Africa and Ethiopian context. The current study also indicated psychosocial factors to be negatively associated with adherence to HAART and self-confidence in the ability to take medication properly. In the logistic regression model a one unit increase in psychosocial factors was associated with 0.58 (OR: 0.50 – 0.68] times less likelihood of never missing medication and 0.81 (OR: 0.73 – 0.91) times less likelihood of being confident on ability to take HAART properly. This result is in line with the findings from other studies. According to a prospective cohort study depressive symptom was associated with worse 30-days adherence [157]. Similarly, studies done in; Uganda [259], Ethiopia [102], and Europe [159] reported depressive symptoms to be associated with non-adherence to HAART.

The effect of psychosocial problems on non-adherence to HAART could be explained with its negative effect on motivation to take medication, hopelessness and lack of meaning in life.

7.3. Effect of stigma and associated depression symptoms on adherence to HAART

Pertaining to stigma, the three measures of stigma (negative self-image, concern about public attitude, and concern about disclosure) and psychosocial problems were negatively associated with self-reported adherence to HAART medication and with self-confidence to take medication

correctly. Other studies have also demonstrated the negative effect of stigma and depression symptoms on adherence to HAART. In a study by Talam and colleagues, 29% of study subjects missed HAART due to stigma [263].

Studies have also documented a relationship between increased stigma and decreased life satisfaction and depression. Perceived HIV stigma has a significant negative impact on life satisfaction and quality of life [265]. Dissatisfied persons often lack motivation to take medications properly. The more negative self-image one has, the more likely they are to be depressed and desperate about life. This can lead to decreased interest in life and thus poor adherence to medication and a low level of self-confidence. Hopelessness and negative feelings are expected to reduce motivation to take medication properly. According to study by Byakika-Tusiime et al, people with depression were found to be less likely to properly adhere to medication [259]. Studies and literature reviews about predictors of adherence indicated depression and stress to be the most significant predictors of non adherence [16, 102, 266, 267].

Disclosure of HIV status is also expected to have implications on adherence to HAART. If persons do not disclose their HIV status, they can be forced to hide their medication from people. In this particular study, higher level of concern about disclosure of HIV status was associated with being less likely to never miss medication and to be self-confident to take medication properly. Similar findings were reported from other studies in Africa. A study done in Tanzania at Kilimanjaro Christian Medical Centre reported not disclosing HIV status as one of the reasons for non adherence to HAART [268]. Likewise, in a study carried out by Birbeck et al, disclosing medication taking to a sexual partner was associated with good adherence [262].

Stigma is not only associated with psychological problems and adherence difficulties, it is also experienced more commonly among people who disclose their HIV status to a broad range of social contacts [269]. When people disclose their HIV status, they are often put in a difficult situation within their community because of the prevailing stigma. Due to this fear of stigma, HIV infected persons often do not want to disclose their HIV status. Yet not disclosing their status can prevent them from receiving the desired social support from communities and make it difficult to properly adhere to treatment.

Findings of the quantitative data were reinforced by the qualitative data. Key-informant participants stressed stigma and discrimination from close family members, loneliness and lack of social support to be the most important determinants of adherence to HAART.

7.4. The effect of social support and depression symptoms on weight and CD4 cell progression

Progression of weight was affected by depressive symptoms negatively and by perceived social support positively. Presence of depressive symptoms is expected to lead to poor appetite and lack of interest which result in low progression of weight. On the other hand, better social support is closely associated with a person's capacity to purchase food or get support from others, which can contribute to weight gain positively. This calls for strengthened and sustainable interventions to help those who are critically in need of support. Weight loss is closely correlated with poor survival among HIV infected people. This means those who were suffering with depressive symptoms and who were receiving low social support were at a disadvantage for survival unless they received support [79, 270].

Depressive symptoms were also negatively correlated with CD4 cell progression, and social support had a positive effect on CD4 count. Several studies have been carried out to explore the potential effect of social support and psychosocial issues on the well being of HIV infected individuals. Some studies have demonstrated correlations, and a few did not come up with the expected associations.

A study carried out by Lyketsos and colleagues reported that depressive symptoms did not predict an accelerated mortality or worse medical course for people who were infected with HIV. None of the outcomes that they assessed, AIDS, death, and CD4 decline, were related to depression symptoms [162]. Similarly Kessler and Rabkin reported no relationship between stressor and CD4 decline or developing AIDS related diseases [271, 272]. However, other studies carried out by Burack, Patterson and Rabkin and their colleagues reported significant a relationship between depression and subsequent decline in CD4 cell [272 – 274].

In addition, recent studies indicated a significant association between depressive symptoms and decreased CD4 cell progression [166 – 176, 275, 276]. This highlights the existence of evidence about the association between depressive symptoms and CD4 progression, especially among studies carried in late 1990s and 2000 and beyond. Possible reasons for the lack of significant association among studies carried out in early 1990s are differences between studies in research design, data collection, number and quality of control variables, and measurement of depression.

Pertaining to social support, a study by Leserman and colleagues found that higher cumulative social support predicted less rapid progression to AIDS or to an AIDS related clinical condition [276]. Theorell and his colleagues found stronger social support to be associated with a slower drop in CD4 cell count [277]. Another study by Patterson and colleagues indicated large social network size to be predictive of longevity among those with AIDS [278]. According to a study carried out by Solano, social support was related to the development of AIDS related symptoms among those with low CD4 count [279].

In general, findings of this study were indicative of the negative role of depressive symptoms on both weight gain and CD4 cell count progression and the positive effect of social support on both outcomes. This is in line with the expected direction of association based on a review of the literature, and it is supported by results published in the late 1990s and 2000 and beyond.

Based on the findings, the provision of psychosocial and social support services to HIV positive persons is recommended in order to avoid the negative consequences of depressive symptoms and low levels of social support on weight and CD4 cell progression. Social support and psychosocial issues are highly interconnected. A strong social support environment could help lessen the effects of depression. An intervention that addresses social support and depression symptoms at the same time should be designed and implemented.

7.5. Survival estimates by 12 months of follow-up and its determinants

According to the present study, out of the total cohort of 1.722 study subjects 86.6% had been retained at the time of the 12 month follow-up. The 4.1% had been formally transferred to other health facilities and they were considered “active”. The remaining 9.3% had discontinued

treatment either because of confirmed death (2.0%), or because of being dropped from treatment (5.4%) or being lost from follow-up because of unknown reasons (1.9%). Other studies in Africa had reported relatively lower levels of retentions compared to the findings of this study.

In a study carried out in South Africa, 72% of adults remained in care after 4 years on ART. The remaining 28% were either lost from treatment or had died [280]. In the same line the 1.9% proportion who were lost from follow-up is comparable with the finding of a study on the incidence of lost to follow-up among a sample of 12,304 persons which reported 3.72 lost from follow-up per 100 person-years of follow-up [281].

In another study from South Africa, 16.4% of participants discontinued treatment within 15 months. Of those that discontinued treatment, 64.8% were successfully traced. Death accounted for 48% of those traced. Characteristics associated with death were older age at ART initiation, lower baseline CD4 cell count, higher initial HIV RNA load, and loss of weight on ART. According to this study nearly 1 in 6 patients receiving ART in a resource constrained setting had discontinued follow-up over a 15-month period. Early mortality was high, especially in those with profound immune suppression [282].

A study with comparable findings about the proportion who had died was the one carried out in low-income countries. In this study 16.0% were lost to follow-up and 2.6% were known to have died in the first 6 months. Early patient losses were associated with a fee for service and advanced immunodeficiency at baseline [283].

Similarly, a study in rural South Africa reported a retention rate of 83.6%. Out of those who discontinued treatment, 9.2% had died, 4.7% had transferred out, and 2.6% were lost to follow-up. Death was the major reason for cohort exit [284].

In the present study 2.0% of study participants were confirmed to have died. This is a very small percentage compared to the finding from other studies in the African context. The main reason for this could be because most deaths were not reported and they had been recorded as “dropped” [284]. Efforts made to trace those who had been dropped were not successful, as most patients gave an incorrect address. Due to this if we add the two together the proportion that had died

might be as high as 7.4%. This is very close to the 6.4% mortality estimate for low income countries [285].

The mortality proportions reported from different studies in Africa vary from as high as 26% [287] to as low as 8% after 12 months of follow-up [286]. Studies from Africa have reported mortality rates between 19% and 12% after 12 months of follow-up on HAART [42]. Few studies reported mortality rates higher than 20% [287 – 289] and lower than 10 % [286, 290]. Most of the deaths in the African context happen during the first year of antiretroviral treatment, with the majority occurring in the first few months. Patients typically access antiretroviral treatment with advanced symptomatic disease, and mortality is strongly associated with baseline CD4 cell count less than 50 cells/ml and WHO stage 4 disease (AIDS) [291].

A study reviewed 32 publications reporting on 33 patient cohorts with 74,192 patients from 13 countries. For all studies, the weighted average follow-up period reported was 9.9 months, after which 77.5% of patients were retained. Loss to follow-up and death accounted for 56% and 40% of attrition, respectively. Weighted mean retention rates as reported were 79.1%, 75.0% and 61.6 % at 6, 12, and 24 months respectively. Of those reporting 24 months of follow-up, the best program retained 85% of patients and the worst retained 46%. In sensitivity analyses, estimated retention rates ranged from 24% in the worse case to 77% in the best case at the end of 2 years, with a plausible midpoint scenario of 50%. According to this study, African ART programs retained about 60% of their patients in the first two years. At one end of the spectrum represented by the reviewed studies, two-year retention was nearly 90%; at the other end, attrition reached 50% [32].

In the Ethiopian context a study carried out among 162 individuals with 144.1 person-years of observation reported an overall mortality rate of 16.7 per 100 person years. The highest death rate occurred in the first month of treatment. Compared to the first month, mortality declined by 9-fold after the 18^{th} week of follow-up [44].

Although survival rates were significantly different by sex, age, baseline weight and CD4 count, in the Kaplan-Meier survival estimate, only self-reported adherence to HAART and perceived

social support were significantly associated with the hazard or risk of death in the Cox proportional hazard model.

Controlling for possible confounding variables in the Cox proportional hazard model, those who reported higher levels of adherence to HAART had 48% (Hazard Ratio = 0.52, CI: 0.34 – 0.81) lower risk or hazard of failure. On the other hand those who reported better perceived social support had 23% (Hazard Ratio = 0.77, CI: 0.64 – 0.93) less hazard or risk of failure.

Persons who had better social support in terms of emotional, information and material support could have better treatment outcomes, as better social support could create an opportunity to be motivated to be committed to their treatment. This may lead to better satisfaction in life. Better social support could mean better nutrition support or better health advice for better health. Similarly, adherence to treatment protocol has been demonstrated to be one of the key factors in successful treatment outcomes.

Different factors were reported by different studies as contributing to death or to being lost from treatment. A study carried out among a sample of 1,052 patients reported compromised immunologic status to be the main risk for being lost to follow-up [292].

A study reported substantial depressive symptoms to be significantly associated with HAART discontinuation. One of the reasons for depression could be a lack of social support [293].

From a cohort study, 2% of participants discontinued treatment within 12 months time. According to this study the proportions who were still receiving care showed a slow linear decrease, to 92% after 3 years. The independent predictors of patient retention were higher baseline body mass index, missing scheduled clinical visits and scheduled drug pickup appointments, and HAART initiation earlier in the calendar year [294].

Similarly, a study done on the relationship between depression symptoms and morbidity and mortality due to AIDS reported depressive symptoms and poor adherence to be the most likely reasons for death. Those with depression and adherence levels below 95% were 5.90 times more likely to die than adherent patients with no depressive symptoms. The estimated median model-

based survival probabilities stratified by adherence and depressive symptoms levels ranged from 81% (inter-quartile range, 72-89%) for depressive symptoms and adherence < 95% to 97% (inter-quartile range, 94-98%) for no depressive symptoms and adherence ≥ 95%. Both depressive symptoms and adherence were associated with shorter survival among individuals with HIV patients accessing HAART [295].

Another follow-up study reported that after 5.5 years of follow-up, the probability of getting AIDS was about two to three times as high among those above the median on stress or below the median on social support compared with those below the median on stress or above the median on support, respectively. This study demonstrated that more stress and less social support accelerated the course of HIV disease progression [275].

Another prospective follow-up study explored the effects of stressful events, depressive symptoms, social support, and coping methods on the progression of HIV-1 infection. According to this study faster progression to AIDS was associated with higher cumulative average stressful life events, and coping by means of denial as well as with lower cumulative average satisfaction with social support. The risk of AIDS was approximately doubled for every 1.5-unit decrease in cumulative average support satisfaction and for every cumulative average increase of one severe stressor, and one unit of denial [276].

Although the effect of adherence on risk of hazard of failure is straightforward, the effect of perceived social support on the risk or hazard of failure could be explained with its effect in the form of information, nutrition, financial, and emotional support which are instrumental in keeping patient in care.

7.6. Perceived quality of life of persons infected with HIV and its association with social support.

In the present study a higher proportion of study subjects evaluated their physical and mental health condition as “excellent” (28.6%) and “very good” (40.7%). When we add the two, about 69% of the study subjects were experiencing very good quality of life. This may be attributed to the effect of HAART added up with other socio-demographic and social factors.

On the other hand, significant proportions (15%) were not experiencing a good quality of life. This may be attributed to the lack of social support linked with depression symptoms and other clinical reasons.

The regression model on the effect of social support on perceived quality of life demonstrated the significant presented statistically significant association being adjusted for possible confounding variables. A one unit increase in perceived social support is associated with 0.84 less likelihood of unhealthy days due to some sort of physical or mental health problem and 0.75 times less likelihood of unhealthy days because of some sort of pain, depression, anxiety, and sleeplessness.

Several factors have been reported by other studies to be associated with better QOL among HIV-infected persons. Socio-demographic characteristics such as male gender [80], younger age [86], higher socioeconomic status [296] and employment [296] have been associated with improvement in QOL. Other variables such as lower HIV viral load [297], higher CD4+ cell count [80, 296, 297], fewer or less bothersome HIV symptoms [298] and higher levels of hemoglobin [299] have been shown to be important clinical/immunological indicators of better QOL. In addition, patients with no difficulty in taking medications [297], those using regimens with a lower number of pills [297], and those with better adherence to antiretroviral therapy [80, 296, , 297] tend to have improved QOL following the start of treatment.

Similar to the findings of this study the impact of social, psychological, and spiritual factors on QOL in HIV infection is well recognized [300 , 301].

Stressful events and social support were related to HIV-1 disease progression to AIDS [302]. Research on the psychosocial aspects of HIV-positive status has shown that living with HIV is associated with higher levels of stress and depression [303].

Social support for patients with HIV/AIDS has shown a strong potential to influence QOL. The three major components of social support are emotional, tangible, and informational support [304]. Distinction among the different types of social support is relevant, since their functions may not necessarily be interchangeable. The emotionally sustaining function of social support,

which serves to fulfill and gratify one's need for nurturance, belonging, and alliance, is well recognized to buffer stress in non-HIV settings. At least two studies have reported that emotionally sustaining support was considered more desirable and was more often used than other forms of [305].

A case study from Nepal reported overall satisfaction from social support and hope to be significantly correlated with QOL [306]. Similarly, a study by Jia et al reported the effect of coping and social support on health related quality of life. According to this study the effect of both social support and coping were mainly through the intermediate variable, which was depression [307]. In line with lack of social support, the impact of psychiatric comorbidities, specifically depression, on the QOL of patients with HIV disease has been well documented [308 – 311]. The presence of a major psychiatric disorder (independent of HIV-related disease progression) was associated with a negative impact on QOL dimensions of mental health, social functioning, and general health perceptions but not on physical health, role functioning, or pain [312]. A larger study showed that patients with comorbid mood disorders had significantly worse functioning and well-being than those without mood disorders [312].

Treatment of depression in patients with HIV disease may not prolong life but can improve QOL, both directly and through increased adherence to complex medical regimens [313]. Overall self-perception of QOL has been shown to be a useful screening item for assessing global QOL. QOL relates both to adequacy of the material circumstances and to personal feelings about these circumstances. As health is generally cited as one of the most important determinants of overall QOL, it has been suggested that QOL may be uniquely affected by specific disease processes, such as AIDS. There is lack of clarity in defining QOL and concomitant operational difficulties in it, but there is still urgency in evaluating QOL in HIV-infected individuals.

Although the present study and other studies indicated relationships among various psychosocial and spiritual factors, symptomatology, and physical health, much more research is needed to document their potential influences on immune function, as well as health status, disease progression, and QOL among persons with HIV disease.

8. Bias, Confounding and Generalizability

Bias is a systematic deviation of a study's result from a true value. Typically, it is introduced during the design or implementation of a study and cannot be remedied later. Bias and confounding are not synonymous. Bias arises from flawed information or subject selection so that a wrong association is found. Confounding produces relations that are factually right, but that cannot be interpreted causally because an underlying, unaccounted for factor is associated with both exposure and outcome. Also, bias needs to be distinguished from random error, a deviation from a true value caused by statistical fluctuations (in either direction) in the measured data [240].

In this study, efforts were made to control information bias and selection bias. Information bias occurs when systematic differences in the completeness or the accuracy of data lead to differential misclassification of individuals regarding exposures or outcomes. As people on HAART will have regular follow-up visits, there is a probability of having 'detection bias' or 'medical surveillance bias'. To control this, the intensity of medical surveillance was measured in the different study groups, and this was adjusted in the statistical analyses. To reduce 'Interviewer bias,' interviewers were blinded from the study hypothesis. This prevented them from selectively gathering data subconsciously or consciously [240, 257].

Confounding literally means confusion of effects. A study might seem to show either an association or no association between an exposure and the risk. In reality, the seeming association or lack of association is due to another factor that determines the occurrence of the event that is also associated with the exposure. The other factor is called the confounding factor or confounder. Confounding thus gives a wrong assessment of the potential 'causal' association of an exposure. In the analysis phase, multivariable analysis was employed to reduce the effect of confounders [240, 257].

In additions, the findings might not be generalizable for the whole country, as data were collected from one HAART clinic. However, the findings can be generalized to the urban context with caution and may contain important information that can be applied to rural areas.

9. Strengthens and Limitations

This study has lots of strengths. Some of these are;

- It is the first of its kind in Ethiopia in-terms of exploring the effect of perceived social support and depression symptoms on CD4 and weight progression, attrition from HAART, and perceived quality of life,
- The study utilized different outcome variables to identify the net effect of the predictor variables. For example "self-confidence" was used with "self-reported adherence", CD4 and Weight progression" were used with "risk of failure", and "perceived quality of life" was used with "risk of failure" and "weight and CD4" progression,
- Different kinds of tools were applied to measure the different predictor variables. This will pave the way for other researcher to use these tools for other similar studies,
- The study used both prospective and retrospective follow-up data,
- Different types of regression models were used for analysis and to control for possible confounding variables,
- Important confounding variables were identified and controlled in the regression model,
- Quality of data maintained at high level, and
- Preliminary result were presented; as series of seminars at the School of Public Health, Addis Ababa University and Gates Institute at Bloomberg School of Public Health, at the Global Health Council meeting (Washington DC), at the International Conference on Urban Health (Brazil), and at the annual meeting of the society of social workers (Ethiopia). Analysis was refined based on comments received during the presentations.

Although this study has a number of strengthens, it also has limitations that need to be considered carefully. First, follow-up data was utilized as an outcome variable, yet the explanatory variables were collected once. This may not be an ideal design to determine factors influencing weight gain and CD4 progression. It also relied on secondary data collected from study participants' medical records. The study is therefore subject to the limitations of using secondary data from records.

The outcome of interest for the survival estimates considered those dropped from treatment as "failure" and at the same time it did not consider those lost from follow-up as "failure". While the first might overestimate "failure" the second one might have under estimated the probability of "failure".

Although the measurements utilized to assess social support, depression symptoms, and quality of life had been tested and approved for use in developing countries context, these tools were not tested and validated for the Ethiopian context. Because of this the measurements might have their own limitations.

The reliance on clients' self-reports for assessing adherence to HAART presented the possibility that missed doses were underreported, as some level of social desirability bias can be expected. The reliability of the scales was also low.

10. Conclusion and recommendations

10.1. Conclusion

Although significant proportion of respondents' initiated HAART without adequate counseling on the benefit of HAART and importance of strict adherence, generally the level of self-reported adherence to HAART (especially recent past four days adherence practices) and confidence on ability to take medication properly were not perfect but generally good. This finding is supported by evidences from other studies in Africa and Ethiopia.

Among the socio-demographic correlates of adherence; being female, those who drink alcoholic drinks regularly, young age persons, and those who stayed on treatment for longer period of time were more likely to ever miss their medication. Similarly being female and drinking alcoholic drinks regularly were associated with lower confidence on ability to take medication properly.

In this study, lack of adequate social support, prevalence of depression symptoms, and stigma were recognized among persons who were infected with HIV and who were receiving HAART.

Perceived social support was significantly associated with better self-reported adherence to HAART and self-confidence on ability to take medication properly while depression symptoms were significantly associated with non-adherence to HAART and lower self-confidence on ability to take HAART properly. This underscores the importance of social support and depression symptoms in determining adherence practices.

The three forms of stigma; "negative self-image", "concern about disclosure", and "concern about public attitude" were significantly associated with non-adherence to HAART. On top of this, all of the three measures of stigma were negatively associated with self-confidence on ability to take medication properly. From the key informant interview, HIV related stigma by peers and family emerged as important factor driving non-adherence. The effect of stigma on adherence is also evidenced by previous researches.

Significant proportions of study subjects did not disclose their HIV status to sexual partner / spouse, families, friends, or other people in the community. This is indicative of their concern of

stigma and discrimination within the community. Most who disclosed their HIV status reported more benefits from disclosing than negative consequences like physical assault, separation from partners, and loosing economic support.

Significant proportion of study participants had good progression in weight and CD4 cell count in the first few months of HAART. Weight and CD4 cell count progression did not last longer especially after six months of HAART. In general, findings of this study were indicative of the negative role of depressive symptoms on both weight gain and CD4 cell count progression and the positive effect of social support on both outcomes. This is in line with the expected direction of association based on a review of the literature and it is supported by results published in the years late 1990s and 2000 and beyond.

The level of attrition from HAART by 12 months of follow-up was relatively low which is below 10%. Yet, very small number of deaths were identified and recorded at the clinic while large majority of those who discontinued treatment were recorded as "dropped" or "lost" from follow-up and treatment. Majority of those who were reported as "dropped" or "lost" might have died but were not identified by the clinic. This will miss inform service providers by under estimating the proportion that had died.

Adherence to HAART and perceived social support were identified to be important predictors of attrition from HAART. Good level of self-reported adherence to HAART and better perceived social support were significantly associated with lower risk or hazard of failure.

Perceived quality of life among the study population was generally good with significant proportions of respondents' rating their general physical or mental health condition as "Excellent" or "Very good". Yet, significant numbers of unhealthy days were reported due to some sort of physical or mental health problem or because of pain, anxiety, or depression. Perceived social support was significantly associated with better perceived quality of life.

10.2. Recommendations

As access to HAART increases dramatically in Ethiopia and throughout Sub Saharan Africa, key issues like adherence to HAART and attrition from treatment and care need to be addressed in order to ensure the highest possible from HAART.

Health education and counseling on anti-HIV drugs, their benefit, and on the importance of strict adherence need to be prioritized as focal areas. In addition, interventions that specifically aims to improve adherence need to be designed and implemented. Focused interventions targeted at patients known to be at risk will have better results than do untargeted interventions. Evidence is emerging that mobile-phone text messages and other reminder devices, treatment supporters, directly observed therapy, education and counseling, and food supplements can be effective approaches to increase adherence. In this study context; females, younger age persons and those who drink alcohol need to get notable attention.

Facilitating support from family members, friends, neighbors, community health workers, or HIV-infected community members will be critically important to improve adherence further. Treatment supporters could have different tasks including provision of psychosocial support and education about adherence to HAART.

Furthermore, it is important to understand that adherence is a dynamic behavior that changes over time. It is determined by a matrix of interrelated factors, which vary in impact throughout a person's treatment. Therefore, adherence interventions require an integrated, multidisciplinary approach by physicians, nurses, counselors and pharmacists. On top of this, in order to improve adherence, programs that aim to address stigma in communities and depression among persons infected with HIV need to be designed and implemented.

Stigma, lack of social support, and depression are very much interrelated in their effect on adherence. Because of the prevailing stigma within the community persons infected with HIV will not disclose their HIV status. This will put them at a disadvantage to get social support. Thus, the association of stigma to adherence difficulties may be mediated by accompanying changes in depressed mood and social support. Decreased social support and depressed mood

which will have significant effect on adherence to HAART. Due to this, to improve adherence practices it is essential to design and implement comprehensive interventions which help to address stigma, facilitate disclosure, and establish emotionally supportive and cohesive network which will facilitate social support and address depression. Social support will help to improve adherence through improved cognitive functioning, self-efficacy, intrinsic motivation, personal control, and confidence. Due to this promoting social support needs to be the centerpiece of adherence interventions.

Social support can improve health through enhancing access to resources, activating immune response, and by improving health-related behaviors. Supportive networks could improve mental and physical health by reducing levels of stress or by buffering individuals from stressors that diminish health and well-being. Depression could suppress cellular immunity which would be expected to have a negative impact on HIV progression. On another note, a considerable body of evidence suggests that psychosocial factors play an important role in progression of HIV infection, leading to morbidity and mortality. Provision of psychosocial and social support services to HIV positive persons is recommended in order to avoid the negative consequences of depressive symptoms and low levels of social support on weight and CD4 cell progression, attrition from treatment, and on perceived quality of life. Social support and psychosocial issues are very much interconnected. A strong social support environment could help lessen the effects of depression. An intervention that addresses both at the same time should be designed and implemented.

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13. Appendices

13.1. Annex 1: Result Tables

Annex Table 14.1. Logistic regression model on the effect of "negative self-image", "concern about public attitude", "concern about disclosure", and "personalized stigma" on confidence to take HAART properly and never or rarely missing HAART controlled for gender, age, income, education, religion, marital status, duration of stay on treatment and disclosure of HIV status to families, friends, and sexual partner (N=1706 HAART patients), Zewditu Memorial Hospital, March, 2010

Respondents' characteristics	Never miss taking HAART			Self-confident to take HAART		
Negative self-image						
1st Quartile	1.00			1.00		
2nd Quartile	0.51	0.37	0.69	0.65	0.48	0.88
3rd Quartile	0.40	0.28	0.58	0.75	0.53	1.08
4th Quartile	0.42	0.30	0.59	0.60	0.43	0.84
Concern about public attitudes						
1st Quartile	1.00			1.00		
2nd Quartile	0.66	0.46	0.94	0.88	0.61	1.27
3rd Quartile	0.58	0.38	0.87	0.73	0.48	1.12
4th Quartile	1.01	0.62	1.63	0.60	0.37	0.98
Concern about disclosure						
1st Quartile	1.00			1.00		
2nd Quartile	0.97	0.72	1.32	1.16	0.84	1.59
3rd Quartile	0.68	0.49	0.94	0.63	0.46	0.88
4th Quartile	1.10	0.77	1.56	0.49	0.35	0.70
Personalized stigma						
1st Quartile	1.00			1.00		
2nd Quartile	0.84	0.60	1.18	1.06	0.75	1.50
3rd Quartile	0.81	0.55	1.20	1.07	0.72	1.60
4th Quartile	1.29	0.85	1.95	1.26	0.82	1.92

Annex Table 14.1 continued……..

Sex						
Female	1.00			1.00		
Male	1.34	1.06	1.68	1.34	1.06	1.68
Age(Years)	1.01	1.00	1.02	1.01	0.99	1.02
Income (Birr)						
2000	1.00			1.00		
<500	1.64	1.14	2.36	1.10	0.76	1.60
500 – 999	1.16	0.81	1.66	0.51	0.35	0.74
1000 – 2000	1.09	0.75	1.58	0.49	0.34	0.72
Education						
College diploma and higher	1.00			1.00		
Lower than college diploma	1.53	1.14	2.05	1.05	0.78	1.41
Religion						
Moslem	1.00			1.00		
Orthodox Christian	1.01	0.62	1.65	1.18	0.73	1.92
Other Christian	0.90	0.52	1.56	1.41	0.82	2.44
Marital status						
Married	1.00			1.00		
Not married	0.85	0.66	1.09	0.59	0.46	0.76
Duration of stay on HAART(months)						
1 - 12 months	1.00			1.00		
12 - 24 months	0.92	0.66	1.28	1.00	0.72	1.39
25 - 48 months	0.77	0.59	1.00	0.88	0.68	1.15
Above 48 months	0.79	0.59	1.05	1.01	0.76	1.36
Disclosure						
Did not disclose to either sexual partner or families	1.00			1.00		
Disclosed	0.77	0.60	1.00	0.94	0.73	1.22

13.2. Annex 2: English version of the consent form and questionnaire

Welcome to this interview,

My name is _____. I am working for HIV/AIDS Prevention and Control Office. We are conducting an assessment about the health of people who are taking ART at Zewditu Memorial Hospital. We would very much appreciate your participation in this survey. I would like to ask you about your health and associated matters. This information will help the Regional Health Bureau to plan better health services. The questionnaire usually takes about 1 hour. Whatever information you provide will be kept strictly confidential and will not be shown to other persons. Participation in this interview is entirely on voluntary basis and you can chose not to answer any individual questions or all of the questions. However, we hope that you will participate fully in this assessment since your views are important.

Again, I want to assure you that all of your responses will be confidential and it is meant only for research purpose. As it is known, people in the world have difficulties to take medications always properly and on time. Through this is the fact, even your Physician will not have access to your responses to the questions?

Are you willing to participate in the interview, if YES, continue the interview and if NO, thank and stop the interview?

Person who took the consent:

_____ _____ _____

Name Signature Date

Code Number of the Questionnaire: _____

Interview Date: _____

Name of Hospital: _____

Name and Signature of Supervisor: _____

Section I: Background Information			
	QES NO [__|__|__|__]	HAART Code No [__|__][__|__|__][__|__|__|__|__]	Phone No _____
101		Sub-city_____ Kebele_____ Hose No _____	
102	Gender of respondent	1. Male 2. Female	
103	Personnel	a) Interviewer_____ code_____ b) Field Supervisor_____ code_____ c) Data Entry Clerk _____Data entry code_____	
104	Date of interview	[_____|_____| _____| dd | mm | yyyy	
T1	Time at beginning of interview	____:____	
Section 2: Background and Household Characteristics			
201	How old were you on your last birthday?	Age in years…….. [___|___]	
202	How long have you been living continuously in (NAME OF CURRENT PLACE OF RESIDENCE)? IF LESS THAN ONE YEAR, RECORD '00' YEARS.	Years . . . . . [ ] 94. Always 95. Visitor	
203	Are you able to read or write a simple sentence?	1. Yes 2. No	If no, skip to 207
204	Did you ever attend formal school?	1. Yes 2. No	If no skip to 207

205	What is the highest grade you completed?	Grade [___|___] 1. Technical/vocational certificate 2. University/college diploma 3. University/college degree or Higher	
206	What is your religion?	1. Orthodox 2. Catholic 3. Protestant 4. Moslem 5. Traditional 6. Other(Specify)_____	
207	Are you currently married or living together with a man / woman as if married?	1. Yes, currently married 2. Yes, living with a man 3. No, not in union	If the answer Is 1 or 2 pass to 210
208	With whom are you living now?	1. Live alone 2. Live with family / parents 3. Unstable	
209	Is your husband/partner / wife living with you now or is he / she staying elsewhere?	1. Living together 2. Staying elsewhere	
210	How old were you when you first married?	Age [ ]	IF Male, skip to 218
211	<u>Questions 212 – 217 only for Females</u> How many times pregnant were you? (including those that did not end with a live births), record "00" if none	Number [|]	If "00" skip to 218
212	How many times have you given birth? *[I mean, to a child who ever breathed or cried or showed other signs of life – even if he or she lived only a few minutes or hours], record "00" if none*	Number [___|___]	If none skip to 218
213	How old were you when you first gave a live birth?	Age [|]	
214	Have you ever given to a live birth last years? (I mean, to a child who ever breathed or cried or showed other signs of life – even if he or she lived only a few minutes or hours)	1. Yes 2. No	If no skip to 217
215	Is the child born last year alive?	1. Yes 2. No	If no skip to 217
216	FOR THE CHILD BORN LAST YEAR:	If died before a month, age at death	

	If dead, how many days, months after birth did he/she die?	in days [ ] If died at the age of 1 month or later, age at death in months [ ]	
217	Total number of Children ever born?	Boys _____ Girls ____Total_____	
218	On average how much do you spend per month (house rent, transportation, food, school fee, etc in ETB)	1. < 500 2. 501 - 999 3. 1000 – 1999 4. 2000 - 5000 5. >5000	
219	Working situation	1. Work active 2. Unemployed (Jobless) 3. Pensioner 4. Student	
Section III: Alcohol and drug use			
301	Do you drink Alcohol	1. Yes 2. No	If no skip to 305
302	How often have you had a drink containing alcohol – a glass of beer, wine, a mixed drink, or any kind of alcoholic beverage – in the last 30 days? Check one.	1. Daily 2. Nearly every day 3. 3 or 5 times a week 4. Once or twice a week 5. 2 or 3 times a month 6. Once a month 7. Never	
303	On days when you drank any alcoholic beverages in the last 30 days, how many drinks did you usually have altogether? By a drink we mean a can or glass of beer, a 4-ounce glass of wine, a 1-1/2 ounce shot of liquor, or a mixed drink with 1-1/2 ounces of liquor? Check one.	1. 1 or 2 drinks per day 2. 3 or 4 drinks per day 3. 5 or 6 drinks per day 4. 7 or 8 drinks per day 5. 9 to 11 drinks per day 6. 12 or more drinks per day	
304	During the past 30 days, how often have you had 5 or more drinks of alcohol in a row, that is, within a couple of hours (e.g. 2-4 hours)? Check one.	1. Daily 2. Nearly every day 3. 3 or 5 times a week 4. Once or twice a week 5. 2 or 3 times a month 6. Once a month 7. Never	
305	Do you use drugs or other substances like Khat	1. Yes 2. No	If no skip to section IV

306	What substance do you use	1. khat 2. cigarette 3. Cocaine 4. Marijuana 5. Other specify_____	
307	How often have you had the drug / substance in the last 30 days? Check one.	1. Daily 2. Nearly every day 3. 3 or 5 times a week 4. Once or twice a week 5. 2 or 3 times a month 6. Once a month 7. Never	
Section IV: Psychosocial Variables			
401	Do you have a sense of care, safety, security of support from your family, co-workers, fewer do or other people in your common	1. Yes 2. No	If No, skip to 404
402	what kind of support or care you obtain from the above people,	1. Material / practical 2. Information / advice 3. Other specify: _____ _____	
403	Are you satisfied with their help	1. Yes 2. No	
404	Are you esteemed or valued for you skills or abilities by other	1. Yes 2. No	
405	Are you satisfied with the way people hold you in esteem or value for your skills or abilities	1. Yes 2. No	
406	Are you fully convinced that you are infected with HIV and needs ARV	1. Yes 2. No	
407	Do you have any doubts about ARV	1. None 2. Some 3. Many	
408	Do you think this treatment benefits you	1. Yes 2. No	

409	Do you feel confident about your ability to take the medication accordingly to the regimen of restrictions or do you have some duet or difficulties	1. Yes 2. No	
410	The following questions ask about how often the questions has happened in the past week and past month: ***(Please circle one response for each question)***		

IN THE PAST WEEK HOW OFTEN DID YOU:	0	1	2	3	*0: Rarely or none of the time (less than 1 day)* *1: Some or a little of the time (1-2 days)* *2: Occasionally or a moderate amount of the time (3-4 days)* *3: Most or all of the time (5-7 days)*
410.1 was bothered by things that usually don't bother me?	0	1	2	3	
410.2 I had trouble keeping my mind on what I was doing	0	1	2	3	
410.3 I felt depressed	0	1	2	3	
410.4 I felt that everything I did was an effort	0	1	2	3	
410.5 I felt hopeful about the future	0	1	2	3	
410.6 I felt fearful	0	1	2	3	
410.7 My sleep was restless	0	1	2	3	
410.8 I was happy	0	1	2	3	
410.9 I felt lonely	0	1	2	3	
410.10 I could not get "going"	0	1	2	3	
410.11 I had crying spells	0	1	2	3	
410.12 I felt sad	0	1	2	3	

IN THE PAST MONTH HOW OFTEN DID YOU: *0: Never 1: Almost Never 2: Sometimes 3: Fairly often 4: Very often*	0	1	2	3	4	
410.13 Been upset because of something that happened unexpectedly?	0	1	2	3	4	
410.14 Felt unable to control the important things in your life?	0	1	2	3	4	
410.15 Felt nervous and "stressed"?	0	1	2	3	4	
410. 16 Felt confident in your ability to handle your personal problems?	0	1	2	3	4	
410.17 Felt that things were going your way?	0	1	2	3	4	

410. 18 Found that you could not cope with all the things that you had to do?	0	1	2	3	4	
410.19 Been able to control irritations in your life?	0	1	2	3	4	
410.20 Felt that you were on top of things?	0	1	2	3	4	
410.21 Been angered because of things that happened that were outside of your control?	0	1	2	3	4	
410.22 Felt problems were piling up so high that you could not overcome them?	0	1	2	3	4	

Section V: Social Support							
501	Do you feel satisfied with the overall support that you get from friends and families	1. 1.Yes 2. 2.No 3. 3.Not sure					
502	To what extent do your friends or family members help you remember to take your medication?	1. Not At All 2. A Little 3. Somewhat 4. A Lot 5. Not Applicable					
503	In general, how satisfied are you with the overall support you get from your friends and family members?	1. Very Dissatisfied 2. Somewhat Dissatisfied 3. Somewhat Satisfied 4. Very Satisfied					
504	Are you member of any network or social support group of PLWA	1. Yes 2. No 3. Not sure					
505	Do you feel as valued member of the society you are living with	1. Yes 2. No 3. Not sure					
506	Consider the support from families, friends, partners;	1	2	3	4	5	*0 = not at all* *1 = a little* *2 = moderatel*
	506.1 How much does they make you feel liked or loved?						
	506.2 How much does they make you feel respected or admired?						
	506.3 How much can you confide in them?						
	506.4 How much do they agree with or support your actions or						

	thoughts?						*y*
	506.5 If you needed to borrow 100 Birr, a ride to the doctor, or some other immediate help, how much could these persons usually help?						*3 = quite a bit*
	506.6 If you were confined to bed for several weeks, how much could these persons help you?						*4 = a great deal*
507	Now we will discuss about the support you are getting from friends, families, etc. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is in your mind)?	___ ____					
	507.1 Do you have someone;	1	2	3	4	5	*1. None*
	507.1 To help you if you are confined to bed						*2.A little*
	507.2 You can count on to listen to you when you need to talk						*3.Some*
	507.3 To give you good advice about a crises						*4. Most*
	507.4 To take you to the doctor if you need it						*5. All / of the time*
	507.5 Who show you love and affection						
	507.6 To have a good time with						
	507.7 To give you information to help you understand a situation						
	507.8 To confined in or talk to about yourself or your problem						
	507.9 Who hugs you						
	507.10 To get together for relaxation						
	507.11 To prepare your meals if you are unable to do it yourself						
	507.12 Whose advise you really want						
	507.13 To do things with your to get your mind off things						
	507.14 To help you with daily chores if you were sick						

	507.15 To share your most private worries and fears with						
	507.16 To turn to for suggestions about how to deal with personal problems						
	507.17 To do something enjoyable with						
	507.18 Who understands your problem						
	507.19 To love and make you feel wanted						
508	During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?	1. Yes 2. No, If No skip to section VI					
509	Overall, how much of your support was provided by these people who are no longer available to you?	0. None at all 1. A little 2. A moderate amount 3. Quite a bit 4. A great deal					

VI: Assessment of stigma

	1. Strongly Disagree 2. Disagree 3. Agree 4. Strongly Agree	1	2	3	4
601	In many areas of my life, no one knows that I have HIV				
602	I feel guilty because I have HIV				
603	People's attitudes about HIV make me feel worse about myself				
604	Telling someone I have HIV is risky				
605	People with HIV lose their jobs when their employers find out				
606	I work hard to keep my HIV a secret				
607	I feel I am not as good a person as others because I have HIV				
608	I never feel ashamed of having HIV				
609	People with HIV are treated like outcasts				
610	Most people believe that a person who has HIV is dirty				
611	It is easier to avoid new friendships than worry about telling someone that I have HIV				
612	Having HIV makes me feel unclean				

613	Since learning I have HIV, I feel set apart and isolated from the rest of the world				
614	Most people think that a person with HIV is disgusting				
615	Having HIV makes me feel that I'm a bad person				
616	Most people with HIV are rejected when others find out				
617	I am very careful who I tell that I have HIV				
618	Some people who know I have HIV have grown more distant				
619	Since learning I have HIV, I worry about people discriminating against me				
620	Most people are uncomfortable around someone with HIV				
621	I never feel the need to hide the fact that I have HIV				
622	I worry that people may judge me when they learn I have HIV				
623	Having HIV in my body is disgusting to me				
Many of the items in this next section assume that you have told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation. Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.					
	1. Strongly Disagree 2. Disagree 3. Agree 4. Strongly Agree	1	2	3	4
624	I have been hurt by how people reacted to learning I have HIV				
625	I worry that people who know I have HIV will tell others				
626	I regret having told some people that I have HIV				
627	As a rule, telling others that I have HIV has been a mistake				
628	Some people avoid touching me once they know I have HIV				
629	People I care about stopped calling after learning I have HIV				
630	People have told me that getting HIV is what I deserve for how I lived my life				
631	Some people close to me are afraid others will reject them if it becomes known that I have HIV				
632	People don't want me around their children once they know I have HIV				

633	People have physically backed away from me when they learn I have HIV				
634	Some people act as though it's my fault I have HIV				
635	I have lost friends by telling them I have HIV				
636	I have told people close to me to keep the fact that I have HIV a secret				
637	People who know I have HIV tend to ignore my good points				
638	People seem afraid of me once they learn I have HIV				
639	When people learn you have HIV, they look for flaws in your character				

Section VII : Health status and health care delivery			
701	Were you aware of HIV/AIDS when you first meet your doctor	1. Yes 2. No	
702	When did you hear about ARV	1. Before my illness 2. After my illness 3. During my illness 4. Recently	
703	From where did you get the information about ARV	1. Healthcare Professionals 2. Mass Media 3. Families 4. Friends 5. Co-workers 6. Others_____	
704	were you aware of the benefit of ARV	1. Yes 2. No	
705	Do you know the importance of adherence before you start ART	1. Yes 2. No	
706	How long you have been on HAART	_____	In days / months
707	what was your CD4 count	Initial_____ Recent_____ 88. Don't Know / Can't remember	

708	Do you feel the health care providers treating you are capable	1. Yes 2. No 3. Not sure	
709	Do you have open communication with HCP treating you	1. Yes 2. No 3. Not sure	
710	How frequent do you visit the clinic	1. every month 2. every 2 month 3. every 3 month 4. Variable	
711	Do you get health education or assistance you need during your visits	1. Yes 2. No 3. Not sure	
712	Are you satisfied by the changes/ improvements you obtain for your treatment	1. Yes 2. No 3. Not sure	
713	At present do you have a biological child under your care	1. Yes 2. No	If no skip to 716
714	Are all your children tested for HIV?	1. Yes, positive 2. Yes, negative 3. Not all tested	
715	Are you satisfied in the scheduling appointments and confidentiality of the treatment unit	1. Yes 2. No 3. Not sure	

Section VIII: Adherence to treatment						
	*0: Never 1: Rarely 2: Sometimes 3: Often 4: Always	0*	1*	2*	3*	4*
801	Many people forget to take medications on time. Do you ever forget to take your medicines?					
802	Are you careless at times about taking your medicines?					
803	When you feel better, do you sometimes stop taking your medicine?					
804	Sometimes, if you feel worse when you take your medicine, do you stop taking it?					
805	Many people forget to take tablets, How frequent do you miss a dose?	1. Once a day 2. More than once a week, but less than once a day 3. Once a week 4. Once a month 5. Rarely 6. Never				
806	Did you take your medication on time yesterday?	1. Yes 2. No				

807 When was the last time you missed taking any of your medications? Check one.	1. Today 2. Yesterday 3. In the past three days 4. In the past seven days 5. 1-2 weeks ago 6. 2-4 weeks ago 7. 1-3 months ago 8. More than 3 months ago 9. Never skip medications or not applicable ***If never skip medication, skip to question no 809***

808. Ask questions about number of doses skipped	1. Today, number of doses skipped _____ 2. Yesterday, number of doses skipped _____ 3. In the past three days, number of doses kipped _____ 4. In the past seven days, number of doses skipped _____ 5. Past month, number of doses skipped _____ 6. Past three months, number of doses skipped_____
809. During the past 4 days, on how many days have you missed taking all your doses?	1. None 2. One day 3. Two days 4. Three days 5. Four days
810. For people who brought their pills, count the pills remaining in the pill bottle and calculate the difference between actual and expected number of pills remaining.	1. Number of pills remaining _____ 2. Number of pills dispensed last time _____ 3. Expected number of pills remaining _____
811. Most anti-HIV medications need to be taken on a schedule, at specified time. How closely did you follow your specific schedule over the last four days?	1. Never 2. Some Of The Time 3. About Half Of The Time 4. Most Of Time 5. All Of Time
812. Some people find that they forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend— last Saturday or Sunday?	1. Yes 2. No

813. **How sure are you that:** ***(Please circle one response for each question)***	Not at all sure	Somew hat sure	Very sure	Extreme ly sure
813.1. You will be able to take all or most of the medication as directed?	0	1	2	3
813.2. The medication will have a positive effect on your health?	0	1	2	3
813.2. If you do not take this medication exactly as instructed, the HIV in your body will become resistant to HIV medications?	0	1	2	3

814. IN THE PAST MONTH HOW OFTEN DID YOU SKIP MEDICATION BECAUSE YOU:	Never	Rarely	Sometimes	Often
814. 1. Were away from home?	0	1	2	3
814. 2. Were busy with other things?	0	1	2	3
814. 3. Simply forgot?	0	1	2	3
814. 4. Had too many pills to take?	0	1	2	3
814. 5. Wanted to avoid side effects?	0	1	2	3
814. 6. Did not want others to notice you taking medication?	0	1	2	3
814. 7. Had a change in daily routine?	0	1	2	3
814. 8. Felt like the drug was toxic/harmful?	0	1	2	3
814. 9. Fell asleep/slept through dose time?	0	1	2	3
814. 10. Felt sick or ill?	0	1	2	3
814. 11. Felt depressed/overwhelmed?	0	1	2	3
814. 12. Had problem taking pills at specified times (with meals, on empty stomach, etc.)?	0	1	2	3
814. 13. Ran out of pills?	0	1	2	3
814. 14. Don't feel good?	0	1	2	3

815	What were your reasons for non adherence ?	1. I was too busy with other things or simply forgot. 2. I was away from home. 3. There was a change in my daily routine. 4. I felt asleep. 5. I felt depressed or overwhelmed. 6. I had problem taking medication at specific times. 7. I felt sick or ill at that time 8. I ran out of medication. 9. I had too many pills to take. 10. I felt the drug is too toxic/ harmful and want to avoid side effects. 11. I did not want other to notice me I am taking medicine. 12. Taking the drugs is a reminder of my HIV. 13. I was confused about the dosage directions at that time. 14. I did not think the drug is doing anything to improve my health. 15. People told me the medicine is no good. 16. Other reasons;_____-	

		_____	
Section IX : Sexual and Reproductive Health			
901	What is your current sexual relationship?	1. Married and living with spouse 2. Divorced and living with other 3. sexual partner 4. Divorced and not living with spouse or any other sexual partner 5. Not married living with sexual partner 6. Not married not living with sexual partner 7. Spouse died and living alone 8. Have and practice same sex sexual practice 99-No response	
902	If married Do you ever had extramarital sexual intercourse in the past 12 months?	1- Yes 2- No 88- Don't know 99- No response	
903	Did you ever had sexual intercourse in the last 12 months?	1- Yes 2- No 99- No response	If No, Skip to 1006
904	If yes; with who did you have the sexual intercourse	1. Wife / husband 2. Regular sexual partner 3. Commercial sex partner 4. Non-regular sexual partner 5. Same sex sexual partner	
905	During your last sexual intercourse, did you use condom	1. Yes 2. No	If no skip to 907
906	How frequently do you use condom?	1. Not at all 2. Sometimes 3. Always 4. Often	

907	What is (are) the most likely way(s) that you became infected with HIV? (check "Yes" or "No" for each question.) 1. Sex with a man who was HIV+ 1) YES 2) NO 2. Sex with a woman who was HIV+ 1) YES 2) NO 3. Shared needles with a person who was HIV+ 1) YES 2) NO 4. Blood transfusion or other medical procedure 1) YES 2) NO 5. Don't know 1) YES 2) NO 6. Other (needle stick at work, etc.) 1) YES 2) NO Please specify: _____		
908	Do you or your partner use birth control methods	1. Yes 2. No	
909	What kind of methods do you / your partner use?	1. Pills 2. Condom 3. Injectable 4. Implant 5. IUD 6. Other: _____	
910	From where do you get your contraceptives?	1. Government health facilities 2. Private health facilities 3. Shop 4. FGAE 5. NGO 6. Other _____	If no skip to section X
911	Do you prefer to get contraceptive services at the ART clinic with the medications	1. Yes 2. Not that much 3. No	
Section X : Quality of Life Assessment			

1001	Would you say that in general your health is:	<u>Please Read</u> 1. Excellent 2. Very good 3. Good 4. Fair 5. Poor <u>Don't Read</u> 6. Don't Know / Not sure 77 7. Refused 99	
1002	Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?	1. Number of Days ____ ____ 2. None 8 8 3. Don't Know / Not sure 77 4. Refused 99	
1003	Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?	1. Number of Days ____ ____ 2. None 88 3. Don't Know / Not sure 77 4. Refused 99	
1004	During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?	1. Number of Days ____ ____ 2. None 88 3. Don't Know / Not sure 77 4. Refused 99	
1005	Are you LIMITED in any way in any activities because of any impairment or health problem?	1. Yes 2. No 3. Don't Know / Not sure 77 4. Refused 99	

1006	What is the MAJOR impairment or health problem that limits your activities?	1. Arthritis/rheumatism 2. Back or neck problem 3. Fractures, bone/joint injury 4. Walking problem 5. Lung/breathing problem 6. Hearing problem 7. Eye/vision problem 8. Heart problem 9. Stroke problem 10. Hypertension/high blood pressure 11. Diabetes 12. Cancer 13. Depression/anxiety/emotional problem 14. Lack of energy 15. Weight loss 16. Other impairment/problem 17. Don't Know / Not sure 77 18. Refused 99	
1007	For HOW LONG have your activities been limited because of your major impairment or health problem?	Do Not Read. Code using respondent's unit of time. 1. Days _____ 2. Weeks_____ 3. Months_____ 4. Years_____ 5. Don't Know / Not sure 77 6. Refused 99	
1008	Because of any impairment or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house?	1. Yes 2. No 3. Don't Know / Not sure 77 4. Refused 99	
1009	Because of any impairment or health problem, do you need the help of other persons in handling your ROUTINE needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?	1. Yes 2. No 3. Don't Know / Not sure 77 4. Refused 99	
1010	During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work,	1. Number of Days _____ 2. None 88 3. Don't Know / Not sure 77	

	or recreation?	4. Refused 99	
1011	During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?	1. Number of Days _____ 2. None 88 3. Don't Know / Not sure 77 4. Refused 99	
1012	During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?	1. Number of Days _____ 2. None 88 3. Don't Know / Not sure 77 4. Refused 99	
1013	During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?	1. Number of Days _____ 2. None 88 3. Don't Know / Not sure 77 4. Refused 99	
1014	During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?	1. Number of Days _____ 2. None 88 3. Don't Know / Not sure 77 4. Refused 99	
1015	How much do you feel that the treatment is benefiting you?	1. Not at all 2. Some 3. Very much	

XI: Disclosure of HIV status			
1101	When was the time that you came to know your HIV status	[___|___] Years ago [___|___] Months ago	
1102	Are you married / in long-term relationship with a partner	1. Yes 2. No	If no skip to, 1106
1103	How long have you been in relationship with your current partner	_____ In month / years	
1104	Did you disclose your HIV status to your sexual partner	1. Yes	

		2. No	
1105	How long ago did you disclose to your sexual partner (time from diagnosis to disclosure)	[___|___] Days [___|___] Months [___|___] Weeks [___|___] Years	
1106	Of the following whom do you feel very close to; 1. Parent 2. Child 3. Other family members 4. Sexual partner or significant other 5. Friends 6. Co-workers	 1. 1. Yes 2. No 3. Doesn't apply 2. 1. Yes 2. No 3. Doesn't apply 3. 1. Yes 2. No 3. Doesn't apply 4. 1. Yes 2. No 3. Doesn't apply 5. 1. Yes 2. No 3. Doesn't apply 6. 1. Yes 2. No 3. Doesn't apply	
1107	Of all that you feel close to, whom have you told your being infected with HIV?	1. All 2. Some 3. None	
1108	How long ago did you disclose to friends, families, and others (time from diagnosis to disclosure)	***Freinds*** [___|___] Days [___|___] Months [___|___] Weeks [___|___] Years ***Families*** [___|___] Days [___|___] Months [___|___] Weeks [___|___] Years	

		Sexual Partner [___|___] Days [___|___] Months [___|___] Weeks [___|___] Years	
1109	At this time do you feel that there is anyone you would like to tell about your being infected with HIV	1.Yes 2. No 3. Not sure	
1110	If yes, what are the reasons that you didn't disclose? (Mark all that apply)	1. I don't know enough about HIV 2. The person might leave me 3. The person may be afraid of catching HIV from me 4. The person might be angry with me 5. The person might think I am a bad person 6. The person is too young too handle it 7. The person might tell others 8. The person has too many problems to deal with about right now 9. There is no need to tell until I am sick 10. I don't want to worry them 11. I might loose my job 12. The person might hurt me physically 13. The person might kill me 14. The person might think I am a drug abuser 15. The person might think I am gay other_____ _____ ___	

1111	Other than the above, did you disclose your HIV status to the following people	1. Yes, 2. No , 3. NA	
		Grand Father 1. Yes, 2. No, 3. NA	
		Grandmother 1. Yes, 2. No, 3. NA	
		Neighbour 1. Yes, 2. No, 3. NA	
		Network/association 1. Yes, 2. No, 3. NA of people infected with HIV	
		Religious Father 1. Yes, 2. No, 3. NA	
		Students 1. Yes, 2. No, 3. NA	
1112	What did you benefit from disclosing being infected with HIV	1. Improved adherence to treatment 2. Economic support 3. Nutrition support 4. Psychosocial support 5. Social support Other:_____ _____	
1113	What did you encounter from disclosing your HIV status	Physically assaulted 1. Yes 2. No	
		Separated from partner 1. Yes 2. No	
		Lost economic support 1.Yes 2. No	
		Emotionally / orally abused 1.Yes 2. No	
		Other: _____ _____ __	

As soon as you finish the interview, refer the client's medical history from the registration book and complete the following information

	Weight	CD4	Functional status	Adherence	Lost to follow-up	Died	Transferred out
					If the client is not in follow-up		
At baseline							
3 months							
6 months							
9 months							
12 months							
15 months							
18 months							
21 months							
24 months							
27 months							
30 months							
33 months							
36 months							
39 months							
42 months							
45 months							
48 months							
51 months							
57 months							
60 months							
63 months							
66 months							
69 months							

13.3. Annex 3: Amharic version of the consent form and questionnaire

ይህንን ቃለ መጠይቅ ለማድረግ እንኳን በደህና መጡ!

ስም _____የምሰራው ለኤች.ኤይ.ቪ መከላከያና መቆጣጠሪያ ቢሮ ነው፡፡ በዘውዲቱ መታሰቢያ ሆስፒታል የፀረ ኤች.አይ.ቪ. መድኃኒት ተጠቃሚ በሆኑ ሰዎች ጤና ላይ ጥናት እያካሄድን እንገኛለን፡፡ በዚህ ጥናት ላይ በመሳተፎ እናመሰግናለን፡፡ ስለጤናዎ እና ከጤናዎ ጋር ተያያዥ የሆኑ ጉዳዮች ላይ ጥያቄዎች እጠይቆታለሁ፡፡ ይህ ከእርሶ የማገኘው መረጃ የክልል ጤና ቢሮው የተሻሻለ የጤና አገልግሎትን እንዲያቅድ ይረዳል፡፡ ይህ ቃለ መጠይቅ ፣ ሰዓት ይፈጃል፡፡ ይህን ቃለመጠይቅ በሚያከናውኑበት ወቅት የሚሰጡት ማንኛውም መረጃ ለሌላ ለሦስተኛ ሰው የማይተላለፍና በሚስጢር የሚጠበቅ ይሆናል፡፡ በዚህ ቃለ መጠይቅ መሳተፍ፤ በግለሰቡ ሙሉ ፍቃደኝነት ላይ የተመሰረተ በመሆኑ የተወሰኑ ጥያቄዎችን ወይም በሙሉ ጥያቄዎቹን ያለመመለስ/የመመለስ መብት የተጠያቂው ነው፡፡ ነገር ግን ለጥያቄዎቹ የሚሰጡት መልሶች ለጥናቱ በጣም ጠቃሚ በመሆናቸው ተጠያቂዎች፣ ጥያቄዎቹን ሙሉ በሙሉ መመለሳቸው ለጥናቱ መሳካት ከፍተኛ አስተዋፅኦ ይኖረዋል፡፡

ለጥያቄዎቹ የሚሰጡት መልሶች ሙሉ በሙሉ በሚስጢር የሚያዙና ለጥናቱ ብቻ የምንጠቀምባቸው ይሆናሉ፡፡ እንደሚታወቀው ሰዎች የታዘዘላቸውን መድኃኒቶች በጊዜው እና በትክክል ለመጠቀም የተለያዩ እንቅፋቶች ያጋጥማቸዋል፤ በዚህ ምክንያት ሀኪሞች መልሶቹን እንዲያዩ አይፈቀድላቸውም፡፡

በዚህ ቃለ መጠይቅ ላይ ለመሳተፍ ፈቃደኛ ነዎት? ምላሹ አዎ ከሆነ ቃለመጠይቁን ይቀጥሉ፡፡ ምላሹ አይደለሁም ከሆነ ተጠያቂውን በማመስገን ቃለ መጠይቁን ያቋርጡ፡፡

በቃለመጠይቁ ለመሳተፍ ተስማምቻለሁ፡-

ስም _____

ፊርማ _____

ቀን _____

የቃለመጠይቁ መለያ ቁጥር _____

ቃለመጠይቁ የተካሄደበት ቀን _____

የሆስፒታሉ ስም _____

የሱፐርቫይዘር ስም እና ፊርማ _____

Section I: Background Information			
	QES NO [__|__|__|__]	HAART Code No [__|__][__|__|__][__|__|__|__|__]	Phone No _____
101	አድራሻ	ክፍለ ከተማ_____ ቀበሌ_____ የቤት ቁጥር _____	
102	የተጠያቂው ፃታ	1. ሴት 2. ወንድ	
103	የጥናቱ ሠራተኞች	□መረጃ ሰብሳቢ ስም_____□መረጃ ሰብሳቢው፡ መለ□_____ □ተቆ□□ሪው፡ ስም_____□ተቆ□□ሪው፡ መለ□_____ ወደ ኮምፒውተር ያስገባ/ች/ው ስም _____መለ□_____	
104	መ□□ቁ የተደረገበት ቀን	[_____|_____|2002| ቀን | ወር | □ም	
T1	መጠይቁ የተጀመረበት ሠዓት	____:____	

Section 2: Background and Household Characteristics			
201	ዕድሜዎ ስንት ዓመት ነው?	ዕድሜ በሙሉ ዓመት ..... [___|___]	
202	አሁን በሚኖሩበት ቀበሌ ያለማቋረጥ ለምን ያህል ጊዜ ነው የኖሩት? ከአንድ ዓመት በታች ከሆነ 00 ዓመት ብለው □ሙሉ።	ዓመት .....[ ] ከተወለዱ ጀምሮ .....95 እን□ዳ 96	
203	ማንበብ ወይም መጻፍ ይችላሉ?	1. አዎ 2. □ለም	If no, skip to 206
204	መ□በኛ ትምህርት ተከታትለዉ □ውቃሉ?	1. አዎ 2. □ለም	If no skip to 206

205	ያጠናቀቁት ከፍተኛ ክፍል ስንት ነው?	□□ል [___|___] 1. ቴክኒክና ሙያ ሰርተፊኬት 2. ዩኒቨርሲቲ/ኮሌጅ ዲኘሎማ 3. ዩኒቨርሲቲ/ኮሌጅ ዲግሪ ወይም ከዚያ በላይ	
206	ሐይማኖትዎ ምንድነው?	1. ኦርቶዶክስ 2. ካቶሊክ 3. ኘሮቴስታንት 4. ሙስሊም 5. ባህላዊ ዕምነት 6. ሌላ(□□ለ□)_____	
207	አሁን በጋብቻ ላይ ነዎት ወይም ከፍቅር ጓደኛዎ ፉር እንደባልና ሚስት እየኖሩ ነው?	1. አዎ ባለትዳር ነኝ 2. አልተጋባንም ግን ከፍቅር ጓደኛ ፉር □እኖራለሁ 3. የለም አላገባሁም፤ ከፍቅር ጓደኛ ጋርም አልኖርም	If the answer Is 1 or 2 pass to 209
208	አሁን ከማን ጋር ነው የሚኖሩት?	4. ብቻየን 5. ከቤተሰብ ጋር 6. ያልተረጋጋ አኗኗር	For all answers pass to 211
209	አሁን የትዳር አጋርዎ /የፍቅር ጓ□ኛዎ/ አብርዎት ይኖራሉ?	1. አዎ 2. □ለም	
210	በስንት ዓመትዎ ነው የመጀመሪያ ጋብቻዎን የፈጸሙት?	ዕድሜ በሙሉ ዓመት [ ]	If Male, skip to 217
211	Questions 212 – 217 only for Females እስከ አሁን ስንት ጊዜ ነፈሰጡር ሆነው ያውቃሉ (በሕይወት ያልተወለዱትንም ይጨምራል) ከዚህ በፊት ነፍሰጡር ካልሆኑ "00" ብለው□□□	□እርግዝና ብዛት [|]	If "00" skip to 218
212	ስንት ልጅ ወልደው ያውቃሉ? *[ማለቱ ሲወለድ ያለቀሰ ወይም በሕይወት ተወልዶ ነገር ግን ከጥቂት ደቂቃ ወይም ሠዓት በኋላ የሞተ ልጅን ያጠቃልላል], ከሌለ "00" ብለው □□*	የወሊድ ብዛት [___|___]	If none skip to 218
213	በስንት ዓመትዎ ነው የመጀመሪያ ልጅዎን የወለዱት?	ዓመት [|]	
214	ባለፈው ዓመት ልጅ ወልደዋል? (ማለቱ ሲወለድ ያለቀሰ ወይም በሕይወት ተወልዶ ነገር ግን ከጥቂት ደቂቃ ወይም ሠዓት በኋላ የሞተ ልጅን ያጠቃልላል)	1. አዎ 2. □ለም	If no skip to 217
215	ባለፈው ዓመት የተወለደው/ችው ሕጻን አሁን በሕይወት ይገኛ ል/ትገኛለች?	1. አዎ 2. □ለም	If no skip to 217
216	ባለፈው ዓመት የተወለደው/ችው ሕጻን: ሞታ/ሞቶ ከሆነ ስንት ቀናት፤ ወር፤ ቆይታ/ቶ ሞተች/ሞተ?	የሞተው/ችው ከአንድ ወር በፊት ከሆነ, የሞተችበት/በት ዕድሜ በቀናት [ ] የሞተው/ችው ከአንድ ወር በኋላ ከሆነ, የሞተችበት/በት ዕድሜ በወራት [ ]	
217	እስከ ዛሬ ድረስ በጠቅላላ ስንት ልጆች ወልደዋል?	ወንድ ልጅ ____ ሴት ልጅ____□ምር____	

218	**በአማካኝ በወር ዉስጥ በአጠቃላይ ለተለያዩ ጉዳዮች (ለቤት ኪራይ፣ትራንስፖርት፣ ምግብ፣ ትምህርት፣ወዘተ) ምንያህል ብር ያወጣሉ?**	1. < 500 2. 501 - 999 3. 1000 – 1999 4. 2000 - 5000 5. >5000	
219	**የሥራ ሁኔታዎ?**	1. ሥራ ይሠራሉ 2. ሥራ የላቸዉም 3. ጥሮተኛ 4. ተማሪ 5. ህመምተኛ ናቸው	

Section III: Alcohol and drug use			
301	አልኮልነት ያለው መጠጥ ጠጥተዉ ያውቃሉ?	I. አዎ 2. የለም	**If no skip to 305**
302	ባለፉት 30 ቀናት አልኮልነት ያለው መጠጥ ለምሳሌ ቢራ፣ወይን፣የተቀላቀለ መጠጥ፣ማንኛውም አልኮል መጠጥ በየምንያህል ጊዜ ይወስዳሉ?	1. በየቀኑ 2. በአብኛው ቀናት 3. በሣምንት ከ3-5 ጊዜ 4. በሣምንት 1 ወይም 2 ጊዜ 5. በወር 2 ወይም 3 ጊዜ 6. በወር አንድ ጊዜ 7. ጠጥቼ አላውቅም	
303	ባለፉት 30 ቀናት በጠጡበት ቀን በአማካኝ ምን ያህል መጠጥ በቀን ይወስዱ ነበር? (መጠጥ ስንል አንድ ብርጭቆ ቢራ፣ አንድ ብርጭቆ ወይን እንዲሁም የተደባለቀ መጠጥን ያጠቃልላል) በአንዱ ሣጥን ውስጥ ምልክት ያድርጉ፡፡	1. በቀን 1-2 መጠጥ 2. በቀን 3 - 4 መጠጥ 3. በቀን 5 - 6 መጠጥ 4. በቀን 7 - 8 መጠጥ 5. በቀን 9 - 11 መጠጥ 6. በቀን 12 እና ከዛ በላይ	
304	ባለፉት 30 ቀናት ውስጥ ለምን ያህል ቀናት 5 እና ከዚያ በላይ መጠጥ በተከታታይ ሰዓታት ጠጥተዋል? (ለምሳሌ ከ2-4 ሰዓት) ***አንድ መልስ ብቻ ያክብቡ***	1. በየቀኑ 2. በአብኛው ቀናት 3. በሣምንት 1 ወይም 2 ጊዜ 4. በሣምንት ከ3 -5 ጊዜ 5. በወር 2 ወይም 3 ጊዜ 6. በወር አንድ ጊዜ 7. ጠጥቼ አላውቅም	
305	ሰውነትን የሚያነቃቁ ነገሮችን ይወስዳሉ (ለምሳሌ፣ጫት፣ ሲጋራ፣ ወዘተ)?	1. አዎ 2. የለም	**If no skip to section IV**
306	ምን አይነት ማነቃቂያዎች ይጠቀማሉ?	1. ጫት 2. ሲጋራ 3. ኮኬን	

		4. ማሪዋና 5. ሌላ _____	
307	ባለፉት 30 ቀናት ውስጥ ምን ያህል ጊዜ ማነቃቂያዎች ወሰዱ? ***አንድ መልስ ብቻ ያክብቡ***	1. በየቀኑ 2. በአብኛው ቀናት 3. በሣምንት ከ3-5 ጊዜ 4. በሣምንት 1 ወይም 2 ጊዜ 5. በወር 2 ወይም 3 ጊዜ 6. በወር አንድ ጊዜ 7. ወስጇ አላውቅም	

Section IV: Psychosocial Variables			
401	**ከቤተሰብዎ እንዲሁም ከስራ ባልደረቦችዎ እንክብካቤና ድጋፍ አገኛለሁ ብለው ያስባሉ?**	1. **አዎ** 2. **የለም**	**If No, skip to 404**
402	**ከቤተሰብዎ እንዲሁም ከስራ ባልደረቦችዎ የሚያገኙት እንክብካቤና እርዳታ ምን አይነት ነው?**	1. የቁሳቁስ ድጋፍ 2. የምክር 3. መረጃ 4. ገንዘብ 5. ምግብ 6. ሌላ _____ _____	
403	**ከእነሱ በሚያገኙት እርዳታ ረክተዋል / ደስተኛ ነዎት?**	1. **አዎ** 2. **የለም**	
404	**ችሎታዎ እና ሥራዎ በሌሎች ጥሩ ግምት / ምላሽ ይሰጠዋል / ይታወቃል?**	1. **አዎ** 2. **የለም**	
405	**በችሎታዎ እና በስራዎ ከሌሎች በሚያገኙት ምላሽ ረክተዋል?**	1. **አዎ** 2. **የለም**	
406	**ኤች አይ ቪ በደምዎ እንዳለና የፀረ ኤች አይ ቪ መድሐኒቱን መውሰድ እንዳለብዎ አምነውበታል?**	1. **አዎ** 2. **የለም**	
407	**በእድሜ ማራዘሚያ መድሐኒቱ ላይ ጥር□ሪ አለዎት?**	1. የለኝም 2. የተወሰነ ጥርጣሬ አለኝ 3. በጣም ብዙ ጥርጣሬ አለኝ	
408	**የፀረ ኤች አይ ቪ መድሐኒቱ ጥቅም አለዉ ብለው ያምናሉ?**	1. **አዎ** 2. **የለም**	

409	የ ኤች አይ ቪ መድሐኒቱን ሰአቱን □ብቀዉ እንዲሁም አስፈላጊዉን ጥንቃቄ አድርገው እንደሚወስዱ በራስዎ ይተማመናሉ?	1. አዎ 2. የለም	
410	የሚከተሉት ጥያቄዎች ባለፈው ሳምንት እንዲሁም አንድ ወር ጊዜ ውስጥ ምንያህል ጊዜ ተከስተብዎት እንደነበረ ይነግሩኛል። *(Please circle one response for each question)*		

0. ምንም ወይንም በጣም ትንሽ ጊዜ (ከ1 ቀን ያነሰ) 1. የተወሰነ ጊዜ (2 ቀን) 2. በርከት ላለ ጊዜ (3 - 4 ቀን) 3. በጣም ብዙ ጊዜ / ሙልጊዜ (5 — 7 ቀን)

ባለፈው ሳምንት ምንያህል ጊዜ

410.1 አብዛኛውን ጊዜ በማይረብሽዎ ነገር ተረብሽው ነበር?	0	1	2	3	
410.2 በሚሰሩት ሥራ ላይ አይምሮዎን ሰብስበዉ የመቆየት ችግር?	0	1	2	3	
410.3 የስሜቴ መጎዳት / መከፋት?	0	1	2	3	
410.4 የሰሩት ሥራ ሁሉ ከሙከራ ያልዘለለ እና ዉጤት የሌለው እንደሆነ ተሰምቶወት ነበረ?	0	1	2	3	
410.5 ስለወደፊቱ ጥሩ ነገር ተስፋ አደርገው ነበረ?	0	1	2	3	
410.6 ፍርሃት ተሰማዎት?	0	1	2	3	
410.7 እረፍት ያጣ እንቅልፍ ነበረዎት?	0	1	2	3	
410.8 ደስተኛ ነበሩ?	0	1	2	3	
410.9 ብቸኝነት ተሰማዎት?	0	1	2	3	
410.10 በኑሮ ተስፋ ቆርጠው ነበር?	0	1	2	3	
410.11 አልቅስ አልቅስ ብሎዎት ነበር?	0	1	2	3	
410.12 ሐዘን ተሰምቶዎት ነበር?	0	1	2	3	

0. ምንም 1. በጣም ትንሽ ጊዜ (1 — 2 ቀን) 2. የተወሰነ ጊዜ (3 - 7 ቀን) 3. ብዙ ጊዜ (8 - 14 ቀን) 4. በጣም ብዙ ጊዜ (15 — 30 ቀን)

ባለፈው ወር ለምን ያህል ጊዜ

410.13 በድንገት በተፈ□ረ ነገር የተነሳ ተበሳጭተዉ ነበረ?	0	1	2	3	4	
410.14 በሕይወትዎ አስፈላጊ የሆኑ ነገሮችን ለመቆጣጠር ያልቻሉ መስሎ ተሰማዎ?	0	1	2	3	4	
410.15 ግራ መጋባትና ጭንቀት ተሰማዎ?	0	1	2	3	4	
410. 16 የግል ችግርዎን ለመፍታት የራስ መተማመን ተሰማዎ?	0	1	2	3	4	

410.17 ነገሮች በእርስዎ መንገድ እንደሚሄዱ ተሰማዎ?	0	1	2	3	4	
410. 18 መስራት የሚ□በቅብዎትን ስራ መስራት ተሳነዎት?	0	1	2	3	4	
410.19 ብስጭቶችን የመቆጣ□ር ችሎታ እንዳለዎ ተሰማዎ?	0	1	2	3	4	
410.20 ነገሮችን የተቆጣጠሩ መስሎ ተሰማዎት?	0	1	2	3	4	
410.21 ከቁጥጥርዎ ውጪ ሆነው በተከሰቱ ነገሮች ተበሳጩ?	0	1	2	3	4	
410.22 ችግሮች ከአቅምዎ በላይ እንደሆኑ ተሰማዎ?	0	1	2	3	4	

Section V: Social Support							
501	በጃደኞችዎ፣ በቤተሰብዎ፣ እንዲሁም በሌሎች የህብረተሰብ ክፍሎች በሚደረገልዎት ድጋፍ እና እርዳታ ደስተኛ ነዎት?	1. አዎ 2. የለም 3. እርግ□ኛ አይደለሁም					
502	ቤተሰቦችዎ ወይም ጃደኞችዎ መድሐኒትዎን አስታውሰው እንዲወስዱ ምንያህል ያግዙዎታል?	1. ምንም 2. ትንሽ 3. እማካኝ የሆነ 4. ብዙ					
503	በአ□ቃላይ ከጃደኞችዎ እና ከቤተሰብዎ በሚያገኙት እርዳታ ምን ያህል ደስተኛነዎት?	1. በጣም አዝኛለሁ 2. አልተደሰትኩም 3. በመ□ኑ ተደስቻለሁ 4. በጣም ረክቻለሁ					
504	ኤች አይ ቪ በደማቸዉ ያለባቸው አባላትን የሚያሳትፉ ወይም በሌላ ማህበራት ውስጥ በአባልነት ይሳተፋሉ?	1. አዎ 2. የለም 3. እርግ□ኛ አይደለሁም					
505	በሚኖሩበት ማህበረሰብ ውስጥ ጥሩ እይታ እና ተቀባይነት አለኝ ብለው ያስባሉ?	1. አዎ 2. የለም 3. እርግ□ኛ አይደለሁም					
506	ከቤተሰብዎ ከጃደኞችዎ እና ከፍቅር ጃደኛዎ እያገኙ ያለዉን ድጋፍ ያስቡና ለሚከተሉት ጥያቄዎች ***ምንም ፣ በጣም ትንሽ፣ የተወሰነ፣ ብዙ፣ በጣም ብዙ*** በማለት ይመልሱልኛል ***1.ምንም 2. በጣም ትንሽ 3. የተወሰነ 4. ብዙ 5. በጣም ብዙ***						
506.1	ቤተሰብዎ እና ጃደኞችዎ ምን ያህል የመወደድ እና የመፈቀር ስሜት እንዲሰማዎት ያደርጉዎታል?	1	2	3	4	5	
	ቤተሰብዎ እና ጃደኞችዎ ምን ያህል የክብር እና የመደነቅ ስሜት እንዲሰማዎት ያደርጉዎታል?	1	2	3	4	5	
	ምን ያህል ይተማመኑባቸዋል?	1	2	3	4	5	

506.2	የእርስዎን እንቅስቃሴዎችና ሐሳብዎን ምን ያህል ይደግፋሉ?	1	2	3	4	5	
506.3	ሐኪም ቤት ለመሄድ ወይንም ለሌላ አስቸኳይ ጉዳይ መቶ ብር መበደር ቢፈልጉ ብዙውን ጊዜ ምን ያህል ይረዱዎታል?	1	2	3	4	5	
506.4	ለሳምንታት ያህል የአልጋ ቁራኛ ቢሆኑ ምን ያህል ይረዱዎታል?	1	2	3	4	5	
506.5							
506.6							
507	አሁን ከጓደኞችዎ እና ከቤተሰብዎ ስለሚያገኙት እርዳታ እንነጋገራለን። በ□ም የሚቀርቧቸው ስንት ጓደኞች / ዘመድ አለዎት?	___ ___					
	የሚከተሉት ቢያጋጥምዎት ሊረዳዎ የሚችል ሰው አለዎት? *1. ምንም 2. በጣም ትንሽ 3. የተወሰነ 4. ብዙውን ጊዜ 5. በማንኛውም ጊዜ*						
	507.1 የአልጋ ቁራኛ ቢሆኑ ሊረዳዎ የሚችል?	1	2	3	4	5	
	507.2 ሐሳብዎን ለማወያየት ቢፈልጉ የሚያዳምጥ ብለው የሚመኩበት?	1	2	3	4	5	
	507.3 በከባድ ጊዜዎች ሁለ ጥሩ ምክር የሚለግስ?	1	2	3	4	5	
	507.4 ወደ ሐኪም መሄድ ሲፈልጉ የሚወስድዎ?	1	2	3	4	5	
	507.5 ፍቅርና መተሳሰብ የሚለግስዎ?	1	2	3	4	5	
	507.6 አብረውት ጥሩ ጊዜ ሊያሳልፉ የሚችሉ?	1	2	3	4	5	
	507.7 ሁኔታዎችን እንዲረዱ የሚያግዙ □ቃሚ መረጃዎችን የሚሰጥዎ?	1	2	3	4	5	
	507.8 ስለራስዎና ስለችግርዎ የሚያወሩለትና ያዳምጠኛል ብለው የሚተማመኑበት?	1	2	3	4	5	
	507.9 በተለያዩ ጊዚያት ከጎንዎ የሚሆን?	1	2	3	4	5	
	507.10 ራስዎን ማዝናናት ሲፈልጉ አብሮዎት የሚሆን?	1	2	3	4	5	
	507.11 ምግብዎን ማብሰል ባልቻሉ ጊዜ የሚያበስልልዎት?	1	2	3	4	5	
	507.12 ምክር የሚለግስዎ (**ምክሩ በጣም የሚያስፈልግዎ**)?	1	2	3	4	5	
	507.13 ስራዎችን አብሮዎት በመስራት በአይምሮዎ ከሚያሰላስሉት ሃሳብዎ የሚያላርፍዎ?	1	2	3	4	5	
	507.14 በሚታመሙበት ወቅት የቀን ከቀን ስራዎን የሚረዳዎ?	1	2	3	4	5	

	507.15 ስጋትዎን እና ፍርሃትዎን የሚያካፍሉት?	1	2	3	4	5	
	507.16 ችግር ሲገጥምዎ እንዴት መወጣት እንደሚችሉ ሐሳብ የሚሰጥዎ?	1	2	3	4	5	
	507.17 የሚያስደስትዎትን ነገር አብሮ የሚያሳልፍ?	1	2	3	4	5	
	507.18 ችግርዎን የሚረዳዎ?	1	2	3	4	5	
	507.19 ፍቅር የሚሰጥዎ እና ተፈላጊነት እንዲሰማዎ የሚያደርግ?	1	2	3	4	5	
508	ባለፉት አመታት ውስጥ (የመኖርያ ቦታ በመቀየር፣ ሥራ በመቀየር፣ በፍቺ ወይም መለያየት በሞት ወይንም በሌላ ምክንያት) ድጋፍ ያደርግልዎት የነበረን ሰዉ አጥተዋል?	1. አዎ 2. የለም *የለም ከሆነ ወደ VI ይለፉ*					
509	በአ□ቃላይ ከዚህ ሰው ምን ያህል እርዳታ እና ድጋፍ ያገኙ ነበር	*1*. ምንም *2*. ትንሽ *3*. እማካኝ የሆነ *4*. ብዙ					

VI: Assessment of stigma					
	ከዚህ ቀጥሎ ለማኅበልዎት ጥያቄዎች መስማማት እና አለመስማማትዎን ይነግሩኛል፤ **1. በጣም አልስማማም 2. አልስማማም 3. እስማማለሁ 4. በጣም እስማማለሁ**				
601	በእለት ተእለት ኑሮዬ ማንም ሰው ኤች አይ ቪ እንዳለብኝ እንዲያውቅ አልፈልግም	1	2	3	4
602	ኤች አይ ቪ ስላለብኝ ጥፋተኝነት ይሰማኛል	1	2	3	4
603	ሰዎች ስለ ኤች አይ ቪ ያላቸው አመለካከት ሕይወቴን እንድ□ላ ያደርገኛል	1	2	3	4
604	ኤች አይ ቪ እንዳለብህ/ሽ ለሰው መንገር ለችግር ያጋልጣል	1	2	3	4
605	በኤች አይ ቪ የተያዙ ሰዎች የስራ ቀጣሪዎቻቸው ኤች አይ ቪ እንዳለባቸው ካወቁ ከስራ ያሰናብቱዋቸዋል	1	2	3	4
606	በተቻለኝ ሁሉ ሰዎች ኤች አይ ቪ እንዳለብኝ እንዳያውቁብኝ ጥረት አደርጋለሁ	1	2	3	4
607	ኤች አይ ቪ ስላለብኝ ከሌሎች ሰዎች ያነስኩ ነኝ ብዬ አስባለሁ	1	2	3	4
608	ኤች አይ ቪ ስላለብኝ የማፈር/መሳቀቅ ስሜት ተሰምቶኝ አያውቅም	1	2	3	4
609	ኤች አይ ቪ ያለባቸው ሰዎች ይገለላሉ	1	2	3	4
610	ብዙ ሰዎች ኤች አይ ቪ ያለባቸው ሰዎችን ዝቅ አድርገው ይመለከታቸዋል	1	2	3	4
611	ኤች አይ ቪ እንዳለብኝ ከመናገር አዲስ ጓደኝነት አለመመስረት ይቀለኛል	1	2	3	4
612	ኤች አይ ቪ ስላለብኝ ንፁህ ያልሆንኩ ያህል ይሰማኛል	1	2	3	4
613	ኤች አይ ቪ እንዳለብኝ ከአወቅሁ ጀምሮ ከሌላው አለም የተነ□ልኩ ያህል ይሰማኛል	1	2	3	4

614	ብዙ ሰዎች ኤች አይቪ ያለበት ሰው አስፀያፊ ነው ብለው ያስባሉ	1	2	3	4
615	ኤች አይ ቪ ስላለብኝ እራሴን መጥፎ ሰው አድርጌ እቆጥረዋለሁ	1	2	3	4
616	ብዙ ኤች አይ ቪ ያለባቸው ሰዎች ኤች አይ ቪ እንዳለባቸው ሲታወቅ በሕብረተሰቡ ይገለላሉ	1	2	3	4
617	ኤች አይ ቪ እንዳለብኝ ለሰዎች ከመንገሬ በፊት አስፈላጊውን ሁሉ ጥንቃቄ አደርጋለሁ	1	2	3	4
618	የተወሰኑ ኤች አይ ቪ እንዳለብኝ የሚያውቁ ሰዎች አሁን ርቀውኛል	1	2	3	4
619	ኤች አይ ቪ እንዳለብኝ ካወቅሁ ጀምሮ የሰዎች መድልዎ ያስጨንቀኛል	1	2	3	4
620	ብዙ ሰዎች ኤች አይ ቪ ካለበት ሰው ጋር ሲሆኑ ደስተኝነት አይሰማቸውም	1	2	3	4
621	ኤች አይ ቪ እንዳለብኝ መደበቅ አስፈላጊ ነው ብዬ በፍፁም አላምንም	1	2	3	4
622	ሰዎች ኤች አይ ቪ እንዳለብኝ ካወቁ ዝቅ አድርገው ይመለከቱኛል ብዬ እጨነቃለሁ	1	2	3	4
623	በሰውነቴ ውስጥ ኤች አይ ቪ መኖሩ የሚያበሳጭ እና የሚያስጨንቅ ነገር ነው	1	2	3	4

ከዚህ ቀጥየ የምጠይቅዎት ጥያቄዎች እርስዎ ለሌሎች ሰዎች ኤች አይ ቪ እንዳለብዎ ነግረዋል ብየ ታሳቢ አድርጌ ሲሆን ለሰዎች ባይነግሩ እንኳ እንደተናገሩ አስበው ለጥያቄዎቼ በጣም አልስማማም፤ አልስማማም፤ አስማማለሁ፤ በጣም አስማማለሁ በማለት ይመልሱልኛል

	1.በጣም አልስማማም 2. አልስማማም 3.አስማማለሁ 4.በጣም አስማማለሁ				
624	ሰዎች ኤች አይ ቪ እንዳለብኝ ሲያውቁ በሚያደርጉት ድርጊት እጎዳለሁ	1	2	3	4
625	እኔ ኤች አይ ቪ እንዳለብኝ የሚያውቁ ሰዎች ለሌሎች ይነግሩብኛል ብዬ እጨነቃለሁ	1	2	3	4
626	ለተወሰኑ ሰዎች ኤች አይ ቪ እንዳለብኝ በመናገሬ እፀፀታለሁ	1	2	3	4
627	እንደ መመሪያ ለሰዎች ኤች አይ ቪ እንዳለብኝ መናገሬ ስህተት ነው ብዬ አስባለሁ	1	2	3	4
628	አንዳንድ ሰዎች ኤች አይ ቪ እንዳለብኝ ካወቁ በኋላ እኔን ላለመንካት ይጥራሉ	1	2	3	4
629	እኔ እንከባከባቸው የነበሩ ሰዎች ኤች አይ ቪ እንዳለብኝ ካወቁ በኋላ እኔን ማግኘት አቁመዋል	1	2	3	4
630	ሰዎች እኔ ካሳለፍኩት ሕይወት አንፃር በኤች አይ ቪ መያዜ ትክክል ነው ይላሉ	1	2	3	4
631	ለእኔ ቅርብ ለሆኑ ሰዎች እኔ ኤች አይ ቪ እንዳለብኝ ሰዎች ካወቁ እነሱንም ያገሉናል ብለው ይፈራሉ	1	2	3	4
632	ሰዎች እኔ ኤች አይ ቪ እንዳለብኝ ካወቁ በኋላ ከልጆቻቸው ጋር አብሬ እንድሆን አይፈልጉም	1	2	3	4
633	ሰዎች ኤች አይ ቪ እንዳለብኝ ካወቁ በኋላ ከእኔ ርቀዋል	1	2	3	4
634	የተወሰኑ ሰዎች በራሴ ጥፋት ኤች አይ ቪ እንደተያዝኩ ያምናሉ	1	2	3	4
635	ኤች አይ ቪ እንዳለብኝ በመናገሬ ብዙ ጃደኞቼን አጥቻለሁ	1	2	3	4
636	በጣም የሚቀርቡኝን ሰዎች የእኔን በኤች አይ ቪ መያዝ በሚስጥር እንዲይዙት ነግሬያቸዋለሁ	1	2	3	4
637	ኤች አይ ቪ እንዳለብኝ የሚያውቁ ሰዎች ያሉኝን ጥሩ ጉኖች በሙሉ ቦታ አይሰጧቸዉም	1	2	3	4
638	ሰዎች ኤች አይ ቪ እንዳለብኝ ካወቁ በኋላ ይፈሩኛል	1	2	3	4
639	ሰዎች ኤች አይ ቪ እንዳለብኝ ካወቁ በኋላ ጥፋት ይፈልጉብኛል	1	2	3	4

Section VII : Health status and health care delivery			
701	ስመጀመሪያ ጊዜ ከሐኪምዎ ጋር ሲገናኙ ስለ ኤች አይ ቪ ኤድስ ያውቁ ነበር?	1. አዎ 2. አላውቅም	
702	ስለ ፀረ ኤች አይ ቪ መድሐኒቶች የሰሙት መቼ ነበር?	1. ኤች አይ ቪ እንዳለብኝ ከማወቁ በፊት 2. ኤች አይ ቪ እንዳለብኝ ካወቅሁ በኋላ 3. በሕመም ላይ እያለሁ 4. በቅርቡ	
703	ስለመድሐኒቶቹ የሰሙት ከየት ነው?	1. ከጤና ባለሞያዎች 2. ከመገናኛ ብዙሐን 3. ከቤተሰብ 4. ጓደኛ 5. የሥራባልደረባ 6. ሌላ _____ _____	
704	መድሐኒቶቹን ከመጀመርዎ በፊት ስለጠቀሜታቸው ያውቁ ነበር?	1. አዎ 2. አላውቅም	
705	መድሐኒቶቹን ከመጀመርዎ በፊት መድሐኒቶቹን ሳያቋርጡ በሰዓቱና በታዘዘው መሠረት መውሰድ በጣም አስፈላጊ መሆኑን ያውቁ ነበር?	1. አዎ 2. አላውቅም	
706	የእድሜ ማራዘሚያ መድሐኒቶቹን መጠቀም ከጀመሩ ምን ያህል ጊዜ ሆነዎት?	[___|___] Days [___|___] Months [___|___] Weeks [___|___] Years	In days / months
707	ሲዲ ፎር ቁጥር መ□ንዎ ስንት ነዉ?	የመጀመሪያ _____ በቅርቡ የተሰራ _____ 88. Don't Know 99. Can't remember	

708	የሚያከሞትን የጤና ባለሞያዎች ብቁ ናቸው ብለው ያምናሉ (በእነሱስ ላይ አመኔታ አለዎት)?	1. አዎ ብቁ ናቸው 2. አይ ብቁ አይደሉም 3. አላውቅም	
709	ከሚያከሙዎት የጤና ባለሞያዎች ጋር ግልጽ የሆነ ውይይት ወይም መግባባት አለዎት?	1. አለኝ 2. የለኝም 3. አላወቅም	
710	የሐኪም ቤት ቀጠሮዎ በየስንት ጊዜው ነው?	1. በየወሩ 2. በየ2 ወሩ 3. በየ3 ወሩ 4. ይለያያል	
711	በቀጠሮዎ ቀን ትምህርት እንዲሁም የሚፈልጉትንና የሚጠይቁትን ድጋፍ ያገኛሉ?	1. አዎ 2. የለም 3. አላወቅም	
712	በሕክምናዎና በኤድሜ ማራዘሚያ መድሐኒቶቹ ባገኙት ለውጥ ረክተዋል?	1. አዎ ረክቻለሁ 2. አልረካሁም 3. እረግጠኛ አይደለሁም	
713	በአሁኑ ሰዓት በእርስዎ እንክብካቤ ሥር ያለ ሕፃን ልጅ አለዎት?	1. አዎ አለኝ 2. የለኝም	**If no skip to 715**
714	ልጅዎ/ልጆችዎ ተመርምረዋል?	1. አዎ ሁሉም ተመርምረዋል 2. አዎ የተወሰኑት ተመርምረዋል 3. ሁሉም አልተመረመሩም	
715	በክትትልና ሕክምና ክፍሉ ቀጠሮ አያያዝና ምስጢራዊነት ረክተዋል?	1. ረክቻለሁ 2. አልረካሁም 3. መልስ የለም/አላወኩም	

Section VIII: Adherence to treatment							
	0 በፍፁም አልረሳም *1* አልፎ አልፎ *2* አንዳንዴ *3* ብዙ ጊዜ *4* ሁልጊዜ						
801	ብዙ ሰዎች መድሃኒት በሰዓቱ መውሰድ ይረሳሉ፡፡ እርስዎ መድሐኒትዎን በሰዓቱ መውሰድ ረስተው ያውቃሉ?	0	1	2	3	4	
802	መድሐኒትዎን መውሰድ ችላ ብለው ያውቃሉ?	0	1	2	3	4	
803	አንዳንዴ ጤንነት ሲሰማዎት መድሐኒትዎን መውሰድ አቁመ□ ያውቃሉ?	0	1	2	3	4	
804	አንዳንዴ መድሐኒቱን መውሰድ ቢሰለችዎ መድሐኒቱን መውሰድ ያቆማሉ?	0	1	2	3	4	
805	ብዙ ሰዎች መድሐኒታቸውን መውሰድ ይዘነጋሉ ምን ያህል ጊዜ መድሐኒትዎን መውሰድ ይዘነጋሉ?	1. በቀን አንድ ጊዜ 2. በሣምንት ከአንድ ጊዜ በላይ 3. በሣምንት አንዴ 4. በወር አንዴ 5. አልፎ አልፎ 6. በፍፁም አልረሳም					
806	ትናንትና መድሐኒትዎን በሰአቱ ወስደዋል?	5. አዎ 6. አይደለም					
807 መድሐኒትዎን መውሰድ ለመጨረሻ ጊዜ የረሱት መቼ ነው? አንድ መልስ ላይ ምልክት ያድርጉ፡፡	1. ዛሬ 2. ትናንት 3. ባለፉት 3 ቀናት 4. ባለፉት 7 ቀናት 5. 1-2 ሣምንት በፊት 6. 2-4 ሣምንት በፊት 7. 1-3 ወር በፊት 8. ከ3 ወር በፊት 9. መድሐኒት መውሰድ ረስቼ አላውቅም						
808. የሚከተሉት ጥያቄዎች ሳይወሰዱ ስለተዘለሉ መድሐኒቶች ላይ የሚያተኩሩ ይሆናሉ፡፡	1. ዛሬ ምን ይህል እንክብሎች ሳይወሰዱ ተረስተዋል _____ 2. ትናንት ምን ይህል እንክብሎች ሳይወሰዱ ተረስተዋል _____ 3. ላለፉት 3 ቀናት ምን ይህል እንክብሎች ሳይወሰዱ ተረስተዋል_____ 4. ላለፉት 7 ቀናት ምን ይህል እንክብሎች ሳይወሰዱ ተረስተዋል _____ 5. ላለፉት 30 ቀናት ምን ይህል እንክብሎች ሳይወሰዱ ተረስተዋል _____ 6. ላለፉት 90 ቀናት ምን ይህል እንክብሎች ሳይወሰዱ ተረስተዋል _____						

809. ባለፉት 4 ቀናት ውስጥ ምንያህል ቀን መድሐኒትዎን መውሰድ ረሱ	1. ምንም ቀን 2. 1 ቀን 3. 2 ቀናት 4. 3 ቀናት 5. 4 ቀናት
810. መጀመሪያ መድሐኒቱ ሲሰጣቸው ከነበረው ብዛት ላይ አሁን የቀረውን ማስላት	1. የቀረው የመድሐኒት ፍሬ ብዛት _____ 2. ለመጨረሻ ጊዜ እንዲወስዱ የተሰጣቸው የመድሐኒት ፍሬ ብዛት _____ 3. ለመጨረሻ ጊዜ እንዲወስዱ የተሰጣቸው የመድሐኒት ፍሬ ብዛት ላይ የቀረው የመድሐኒት ፍሬ ብዛት ሲቀነስ _____
811. ባለፉት 4 ቀናት ምንያህል የፀረ ኤች አይ ቪ መድሐኒቶችን በሰአቱ ያለማቋረጥ ወሰዱ	1. ምንም አልወሰድኩም 2. የተወሰነ 3. ግማሽ ያህሉን 4. አብዛህኛዉን ጊዜ 5. ሙሉ ለ ሙሉ
812. በባዕል ቀናት ብዙ ሰዎች መድሐኒታቸውን መውሰድ ይዘነጋሉ:: እርስዎ ያለፈው ቅዳሜ ወይም እሁድ መድሐኒትዎን መውሰድ ዘንግተዉ ነበር?	1. አዎ 2. የለም

813. ምን ያህል እርግጠኛ ነዎት? (እባክዎ አንድ መልስ ላይ ያክብቡ)	ፍፁም እርግጠኛ አይደለሁም	በተወሰነ ደረጃ እርግጠኛ ነኝ	በጣም እርግጠኛ ነኝ	እጅግ በጣም እርግጠኛ ነኝ
813.1. ሁሉንም ወይም አብዛኛውን ጊዜ መድሐኒቱን በትእዛዙ መሰረት ይወስዳሉ?	0	1	2	3
813.2. መድሐኒቱ በጤናዎ ላይ ጥሩ ለውጥ አለው?	0	1	2	3
813.2. በታዘዙት መሠረት በትክክል መድሐኒቱን የማይወስዱ ከሆነ በሰውነትዎ ውስጥ የሚገኘው የኤች አይ ቪ ቫይረስ የትኛውንም ዓይነት መድሐኒት የመቋቋም ባሕርይ ያመጣል?	0	1	2	3

814. ባለፈው ወር ምን ያህል ጊዜ በሚከተሉት ምክንቶች የተነሳ መድሐኒት መውሰድ ረስተዉ ያውቃሉ?	በፍፁም	በተወሰነ ደረጃ	አልፎ አልፎ	ሁልጊዜ
814. 1. ከቤትዎ እርቀው ሄደው ስለነበረ?	0	1	2	3
814. 2. በሌላ ስራዎች ተጠምደው ስለነበረ?	0	1	2	3
814. 3. ባጋጣሚ ስለረሱ?	0	1	2	3
814. 4. ብዙ የሚወስዱ መድሐኒቶች ስለነበርዎት?	0	1	2	3
814. 5. የጎንዮሽ ችግሮች ለማስወገድ?	0	1	2	3
814. 6. መድሐኒትዎን ሲወስዱ ሌሎች ሰዎች እንዳያይዎት ስለፈለጉ?	0	1	2	3
814. 7. በተለመደው የቀን አዋዋልዎ ላይ ለውጥ ስለፈጠሩ?	0	1	2	3
813. 8. መድሐኒቱ መጥፎ /ጎጅ እንደሆነ ስለተሰማዎት?	0	1	2	3
814. 9. መድሐኒት በመውሰጃዎ ሰዓት እንቅልፍ ስለወሰድዎ?	0	1	2	3

814. 10. ሕመም ስለተሰማዎ?			0	1	2	3
814. 11. መከፋት/ሐዘን ስለተሰማዎት?			0	1	2	3
814. 12. መድሐኒት በሰዓቱ የመውሰድ ችግር ስለገጠመዎት? (ከምግብ ጋር፣ በባዶ ሆድ ወዘተ)			0	1	2	3
814. 13. መድሐኒት ስለአለቀብዎ?			0	1	2	3
814. 14. ጥሩ ስሜት ስላልተሰማዎ?			0	1	2	3
815	መድሐኒት በወቅቱ ያልወሰዱበት ምክንት ምንድን ነበረ (ከአንድ በላይ መልስ መስጠት ይቻላል)	1. በሌላ ነገሮች ተጠምጀ ስለነበር ረሳሁት 2. ከቤቴ ሩቅ ቦታ ነበርኩ 3. ከእለት ተእለት ተግባሬ የተለየ ነገር ገጥሞኝ ነበር 4. እንቅልፍ ወስዶኝ ነበር 5. ከፍቶኝ ነበር 6. መድሐኒቶችን በሰዓታቸው የመውሰድ ችግር አለብኝ 7. ጤንነት አይሰማኝም ነበር / አሞኝ ነበር 8. መድሐኒት አልቆብኝ ነበር 9. በጣም ብዙ የምወስደው መድሐኒት ነበረኝ 10. መድሐኒቱ መርዛማ ይሆናል ብዬ አስብኩኝ እና የሚመጡትን ችግሮች ለማስወገድ ብዬ ተውኩት 11. ሌሎች ሰዎች መድሐኒቱን ስወስድ እንዳያዩኝ ብዬ ተውኩት 12. መድሐኒቱን ስወስድ ኤች አይ ቪ / ኤድስ እንዳለብኝ ያስታውሰኛል 13. ምን ያህል ፍሬ መውሰድ እንዳለብኝ በደንብ አልተረዳሁም ነበር 14. መድሐኒቱ በጤናዬ ላይ ምንም ለውጥ ያመጣል ብዬ አልገመትኩም ነበር 15. ሰዎች መድሐኒቱ ጥሩ እንዳልሆነ ነግረውኝ ነበር 16. ሌሎች ምክንያቶች _____		

Section IX : Sexual and Reproductive Health			
901	የወቅቱ የትዳር /የፍቅር/ ግንኙነትዎ ምን ይመስላል?	1. አግብቸ ከባለቤቱ ጋር እየኖርኩ ነው 2. ፈትቸ ከሌላ ሰው ጋር እየኖርኩ ነው 3. ከፍቅር ጓደኛ ጋር እየኖርኩ ነው 4. ፈትቻለሁ ከሌላ ሰው ጋርም እየኖርኩ አይደለም 5. አላገባሁም ነገርግን ከፍቅር ጓደኛ ጋር እየኖርኩ ነው 6. አላገባሁም ከፍቅር ጓደኛ ጋር እየኖርኩም አይደለም 7. ባለቤቴ ሞቶ/ሞታ ብቻየን እኖራለሁ 8. ተመሳሳይ ፃታ ካለዉ ሰው የፍቅር ጓደኛ ጋራ እየኖርኩ ነው 99. መልስ የለም	If not married pass to Qes 903
902	ያገቡ ከሆነ፡ ባለፉት 12 ወራት ከትዳር ውጭ ወሲብ ፈጽመዋል?	1. አዎ 2. አልፈፀምኩም 88. አላዉቅም 99. መልስ የለም	
903	ባለፉ 12 ወራት ወሲብ ፈጽመዋል?	1. አዎ 2. አልፈፀምኩም 3. መልስ የለም	If No, Skip to 907
904	ከፈፀሙ ከማን ጋር ነበረ?	1. ከባለቤቱ 2. ቋሚ የፍቅር ጓደኛ 3. ገንዘብ ከፍዬ ካገኘሁት ሰው 4. ቋሚ ካልሆነ ሰው 5. ከተመሳሳይ ጾታ ጓደኛ ጋራ	
905	በመጨረሻዉ የወሲብ ግንኙነት ወቅት ኮንዶም ተጠቅመው ነበር?	1. አዎ 2. አልተጠቀምኩም	If no skip to 907

906	ምን ያህል ጊዜ ኮንዶምን ይጠቀማሉ	1. በጭራሽ አልጠቀምም 2. አንዳንዴ 3. ብዙ ጊዜ 4. ሁልጊዜ	
907	በዋናነት በምን መንገድ በ ኤች አይ ቪ የተያዙ ይመስልዎታል (1ን ወይንም 2ን አክብብ) 1. ጥንቃቄ በጎደለው የግብረሥጋ ግንኙነት 1) YES 2) NO 2. በስለታም ነገር ወይንም ከህክምና ጋር በተያያዘ 1) YES 2) NO 3. ደም በመውሰድ 1) YES 2) NO 4. በመደፈር 1) YES 2) NO 5. ሌላ 1) YES 2) NO _____6. አላውቅም		
908	እርስዎ ወይም አጋርዎ የወሊድ መከላከያ ይጠቀማሉ?	1. አዎ 2. አልጠቀምም	If no skip to 911
909	የትኛውን የወሊድ መከላከያ መንገድ ይጠቀማሉ	1. ፒልስ 2. ኮንዶም 3. መርፌ 4. ኢምፕላኖን 5. ዐ ዩ ዲ (IUD) 6. ሌላ _____	
910	የወሊድ መከላከያ መድሐኒቶቹን ከየት ያገኛሉ?	1. ከመንግሥት ጤና ተቋማት 2. ከግል ጤና ተቋማት 3. ከሱቅ 4. ቤተሰብ መምሪያ 5. NGO 6. ሌላ _____	
911	የእድሜ ማራዘሚያ መድሐኒቱን ከሚያገኙበት ክሊኒክ የወሊድ መከላከያውን ቢያገኙ ይመርጣሉ?	1. አዎ በጣም ጥሩ ነው 2. ያን ያህል አይደለም 3. አይ አልመርጥም	

Section X : Quality of Life Assessment			
1001	በአጠቃላይ ጤንነትዎን እንዴት ይመዝኑታል?	<u>ያንብቡ</u> 1. እጅግ በጣም ጥሩ ነው 2. በጣም ጥሩ ነው 3. ጥሩ ነው 4. ደህና ነው 5. መጥፎ ነው <u>አያንብቡ</u> 77. አላውቅም/አኒንጃ 99. ፈቃደኛ አይደሉም	
1002	ካለፉት 30 ቀናት ውስጥ ጤናዎ ለስንት ቀናት ያህል ተቃውሶ ነበር? ይህ አደጋንም የጠቃልላል።	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/አኒንጃ 77 ፈቃደኛ አይደሉም 99	
1003	ካለፉት 30 ቀናት ውስጥ የአእምሮ ጤናዎ ለስንት ቀናት ያህል ተቃውሶ ነበር? ይህ ጭንቀት፣መከፋትን ያጠቃልላል።	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/አኒንጃ 77 ፈቃደኛ አይደሉም 99	
1004	ካለፉት 30 ቀናት ውስጥ ለምን ያህል ቀናት በአእምሮ እና በአካላዊ ጤና ችግር የእለት ተእለት ተግባርዎ ተስተጓጉሏል?	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/አኒንጃ 77 ፈቃደኛ አይደሉም 99	
1005	በማንኛውም የጤና ችግርም ሆነ አደጋ ምክንያት ሥራዎን በሙሉአቅምዎ ከመስራት ተወስነዋል?	3. አዎ 4. አይደለም አላውቅም 77 ፈቃደኛ አይደሉም 99	

1006	ሥራዎን በሙሉ አቅምዎ ከመስራት የወሰነዎ ሕመም ምንድን ነው? ***ከአንድ በላይ መልስ መስጠት ይቻላል***	1. የአጥንት ወይም የመገጣጠሚያ ሕመም 2. የጀርባ ወይንም የአንገት ሕመም 3. ስብራት 4. የመራመድ ችግር 5. የሣንባ የመተንፈስ ችግር 6. የመስማት ችግር 7. የአይን ወይም የእይታ ችግር 8. የልብ ሕመም 9. ስትሮክ 10. የደም ግፊት ሕመም 11. የስኳር ሕመም 12. የካንሰር ሕመም 13. የመከፋት ወይም የመስጋት ችግር 14. የአቅም ማነስ 15. የክብደት ማነስ ሌላ የሚረብሽ ሕመም ወይም አደጋ _____ አላውቅም 77 ፈቃደኛ አይደሉም 99	
1007	ባለፈው 12 ወራት በጤና ችግር ምክንያት ሥራዎ ለምን ያህል ጊዜ ተስተጓጉሎ?	ቀናት ---- ---- ሣምንታት --- ---- ወራት --- --- ዓመታት --- --- አላውቅም 77	
1008	በጤናዎ ችግር ምክንያት ለተለያዩ እንቅስቃሴዎ የሰዎች እርዳታ ያስፈልግዎታል? ለምሳሌ ለመመገብ፣ለመታጠብ፣ለመልበስ፣በቤት ውስጥ ለመንቀሳቀስ	1. አዎ 2. አይደለም አላውቅም 77 ፈቃደኛ አይደሉም 99	
1009	በጤናዎ ችግር ምክንያት ለተለያዩ የግል የቀን ተቀን እንቅስቃሴዎ የሰዎች እርዳታ ያስፈልግዎታል? ለምሳሌ ለቤት ውስጥ ሥራዎች፣ገበያ ለመውጣት፣ለተለያዩ ጉዳዮች ለመንቀሳቀስ	1. አዎ 2. አይደለም አላውቅም 77 ፈቃደኛ አይደሉም 99	
1010	ባለፉት 30 ቀናት ውስጥ በሕመም ስሜት ምክንያት የእለት ተእለት ተግባርዎትን ያልፈፀሙት ለምን ያህል ቀናት ነው?	ቀናት ---- ---- አላውቅም 77 ፈቃደኛ አይደሉም 99	

1011	ካለፉት 30 ቀናት ውስጥ ለምን ያህል ቀናት ሐዘን እና መከፋት ተሰማዎት?	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/እኔንጃ 77 ፈቃደኛ አይደሉም 99	
1012	ካለፉት 30 ቀናት ውስጥ ለምን ያህል ቀናት የመስጋት እና የመጨነቅ ስሜት ተሰማዎት?	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/እኔንጃ 77 ፈቃደኛ አይደሉም 99	
1013	ካለፉት 30 ቀናት ውስጥ በቂ እረፍት እና እንቅልፍ ያላገኙት ለምን ያህል ቀናት ነው ብለው ያስባሉ?	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/እኔንጃ 77 ፈቃደኛ አይደሉም 99	
1014	ካለፉት 30 ቀናት ውስጥ መሉ ሐይል እና መሉ ጤንነት የተሰማዎት ለምን ያህል ቀናት ነው?	የቀኖች ብዛት____ ____ ምንም 8 8 አላውቅም/እኔንጃ 77 ፈቃደኛ አይደሉም 99	
1015	መድኃኒቱ ጤንነቱን አሻሽሎልኛል ብለዉ ያስባሉ?	4. አዎ 5. አይደለም	

XI: Disclosure of HIV status			
1101	ኤች አይ ቪ እንዳለብዎ ያወቁት መቼ ነበር?	[___|___] አመት በፊት [___|___] ወራት በፊት	
1102	ባለትዳር ነዎት ወይም የፍቅር ጓደኛ አለዎት?	1.አዎ 2. የለም	**If no skip to, 1106**
1103	ከአሁኑ ባለቤትዎ ወይም ቋሚ የፍቅር ጓደኛዎጋር ለምን ያህል ጊዜ አብረው ቆይተዋል?	[___|___] ቀናት [___|___] ወራት [___|___] ሳምንታት [___|___] አመት	

1104	ለባለቤትዎ ወይም ለፍቅር ጓደኛዎ ኤች አይ ቪ እንዳለብዎ ተናግረዋል?	1.አዎ 2. የለም	
1105	ለባለቤትዎ ወይም ለፍቅር ጓደኛዎ ኤች አይ ቪ እንዳለብዎ ያሳወቁት መቼ ነው (ተመርምረው ካወቁበት ግልጽ እስካወ□ብት ያለው ጊዜ)?	[___|___] ቀናት [___|___] ወራት [___|___] ሳምንታት [___|___] አመት	
1106	ከሚከተሉት የቤተሰብ አባላት መካከል እርስዎ በ□ም የሚቀርቡት ማንን ነዉ? 1 ወላጅ 2 ልጅ 3 ሌላ የቤተሰብ አባል 4 የፍቅር ጓደኛ 5 ጓደኛ 6 የስራ ባልደረቦች	1. 1. Yes 2. No 3. Doesn't apply 2. 1. Yes 2. No 3. Doesn't apply 3. 1. Yes 2. No 3. Doesn't apply 4. 1. Yes 2. No 3. Doesn't apply 5. 1. Yes 2. No 3. Doesn't apply 6. 1. Yes 2. No 3. Doesn't apply	
1107	እርስዎ በ□ም ከሚቀርቦችዉ የቤተሰብ አባላት መካከል ለምን ያህሉ ኤች አይ ቪ እንዳለብዎ ተናግረዋል?	4. ለሁሉም 5. ለተወሰኑት 6. ለማንም አልተናገርኩም	
1108	ኤች አይ ቪ እንዳለብዎት ያሳወቁት መቼ ነበር? *(ተመርምረው ካወቁበት ጊዜ ግልጽ እስካወ□ብት ያለው ጊዜ)* *ካላሳወቁ **00** የሚል ሁሉም ክፍት ቦታዎች ላይ ሙላ*	ጓደኛ [___|___] ቀናት [___|___] ወራት [___|___] ሳምንታት [___|___] አመት ቤተሰብ [___|___] ቀናት [___|___] ወራት	

		[___|___] ሳምንታት [___|___] አመት የግብረ ሥጋ ንደኛ [___|___] ቀናት [___|___] ወራት [___|___] ሳምንታት [___|___] አመት	
1109	በአሁኑ ወቅት በኤች አይ ቪ እንደተያዙ ሊገልፁለት የሚፈልጉት ሰው አለ?	1.አዎ 2. የለም 3. እርግጠኛ አይደለሁም	If no skip to 1111
1110	መልስዎ አዎ ከሆነ እስካሁን ያልተናገሩበት ምክንያት ምንድን ነበረ? *(ከአንድ በላይ መልስ ይቻላል)*	1.ስለ ኤች አይ ቪ በቂ እዎቀት ስለሌለኝ 2. እንዳይሸሸኝ 3. ኤች አይ ቪ ከእኔ ይይዘኛል ብሎ እንዳይፈራ 4. እንዳይቆጣኝ 5. መጥፎ ሰው ነው ብሎ እንዳይቆጥረኝ 6. ልጅ / ወጣት ስለሆነ 7. ለሌሎች ሰዎች እንዳይነግርብኝ 8. ሰውየው የራሱ ችግሮች ስላሉት 9. ስላልታመምኩ መንገር አላስፈለገኝም 10. ላስጨንቀው ስላልፈለግሁ 11. ሥራየን ላጣ ስለምችል 12. ሊደበድበኝ ስለሚችል 13. ሊገድለኝ ስለሚችል 14. የእፅ ተጠቃሚ ነው እንዳልባል 15. ግብረሰዶም ነው እንዳልባል 16. ሌላ other_____	

1111	ከላይ ከተዘረዘሩት በተጨማሪ ኤች አይ ቪ እንዳለብዎት ለሚከተሉት ሰዎች ነግረዋል?	1.ወንድ አያት 1. Yes, 2. No, 3. NA 2.ሴት አያት 1. Yes, 2. No, 3. NA 3.ጐረቤት 1. Yes, 2. No, 3. NA 4.ለኤች አይ ቪ ማህበራት 1. Yes, 2. No, 3. NA 5.ለሐይማኖት አባት 1. Yes, 2. No, 3. NA 6. ተማሪዎች 1. Yes, 2. No, 3. NA	
1112	ኤች አይ ቪ እንዳለብዎ በማሳወቅዎ ምን ጥቅም አገኙ?	1 መድሀኒት አወሳሰዴ ተሻሻለ 2 የኢኮኖሚ እርዳታ 3 ምግብ እርዳታ 4 የስነልቦና ድጋፍ 5 ማሕበረሰባዊ እርዳታ ሌላ_____	
1113	አይ ኤች ቪ እንዳለብዎ በማሳወቅዎ ምን ግ□መዎ?	1.ድብደባ ተፈፀመብኝ 1. Yes 2. No 2.ከባለቤቱ /ፍቅረኛየ ጋር ተለያየሁ 1. Yes 2. No 3.የገንዘብ ድጋፍ ተቋረጠብኝ 1.Yes 2. No 4.አእምሮን የሚጎዱ ቃላቶች ተሰነዘረብኝ 1.Yes 2. No 5.ሌላ: _____	

As soon as you finish the interview, refer the client's medical history from the registration book and complete the following information

	Weight	CD4	Functional status	Adherence	WHO stage
At baseline					
3 months					
6 months					
9 months					
12 months					
15 months					
18 months					
21 months					
24 months					
27 months					
30 months					
33 months					
36 months					
39 months					
42 months					
45 months					
48 months					
51 months					
54 months					
57 months					
60 months					
63 months					
66 month					
69 months					

13.4. Annex 4: English version of the key informant interview guide

- Readiness at the start of therapy
    - Did you get adherence counselling before starting therapy?
    - Was it adequate?
    - Did you start the therapy because you were ready for it?
    - Do you know the potential adverse effects if you are not well adherent to the therapy?
- Capacity to Follow the Medication Regimen
    - How much accurately did you take / give the medications in the past; 1 day, three days, a week?
    - On a scale of 1 to 10, (1: don't take right at all and 10: take perfectly) where do you put yourself?
        - What is the reason for that?
    - When are you most likely to miss doses?
    - What are some of the reasons that people infected with HIV become non-adherent to their therapy?
    - What mechanisms do you use to remember the medication time?

- Did you disclose your HIV status to spouse, sexual partners, families, friends, other community members?
    - Are you comfortable taking medication in front of others?
    - What are the benefits and risks of disclosure on adherence to treatment and long-term retention on care?
- Are you in fear of stigma? How do you cope with it?
    - Can you explain the effect of stigma on adherence and long-term retention on care?
- What kind of support do you get from families, friends, community?
    - How do you explain the extent of support? It that adequate?
    - Can you explain the effect of social support on improving adherence to HAART and ensuring long-term retention on care?
- Have you ever felt depressed, anxious, restless, sleeplessness, and other mood changes?
    - How frequently do you feel these symptoms?
    - What is their effect on adherence and long-term retention on care?
- How do you explain the effect of HAART on your general health?
    - What are some of its health benefits?
        - How about side effects?

Thank you for your participation in the key interview!

13.5. Annex 5: Amharic version of the key informant interview guide

እንክብካቤ ሲጀመር ያለ ዝግጁነት

- መድኃኒቱን ከመጀመርዎ በፊት የምክር አገልግሎት አግኝተዋል?
- በቂ ነበር ብለው ያስባሉ?
- መድኃኒቱን የጀመሩት ዝግጁ ሆነው ነበር?
- መድኃኒቱ ሊያስከትል የሚችለውን ችግር ያውቃሉ?

መድኃኒቱን በአግባቡ መከታተል

- ከ1 እስከ 10 ባለው (1፣ በአግባቡ እየተጠቀምኩ አይደለም እና 10፣ በአግባቡና በትክክል እየተጠቀምኩ ነው) እርስዎ፣ እራስዎን ስንት ቁጥር ላይ ያስቀምጣሉ?
    - ምክንያቱን ይግለፁ?
- መድኃኒቱን ሳይወስዱ የሚቀሩት በምን በምን ዓይነት አጋጣሚ ነው?
- በቫይረሱ የተጠቁ ሰዎች እንክብካቤውን ለመከታተል የሚያመነቱት ለምንድን ነው?
- መድኃኒት የሚወስዱበትን ሰዓት ለማስታወስ የሚጠቀሙበት ዘዴ ምንድነው?

በቫይረሱ ተጠቂ መሆኖን ለባለቤትዎ፣ ለፍቅር ጓደኛዎ፣ ለቤተሰብዎ፣ ለጓደኞች እና በአከባቢዎ ለሚገኙ የህብረተሰቡ አባላት ገልፀዋል?

- መድኃኒቶን በሌሎች ፊት መውሰድ ይፈራሉ?
- እራስን ግልፅ ማድረግ መድኃኒቱን በአግባቡ ለመውሰድ እና ለዘለቄታው ለመከታተል የሚኖረው ተጽዕኖ እና ጥቅም ያብራሩ?

በማህበረሰቡ መገለል ያስፈራዎታል? የሚደርስቦትን መገለል እንዴት ይቋቋሙታል?

- በማህበረሰቡ መገለል መድኃኒቱን በአግባቡ ለመውሰድ እና ለዘለቄታውየሚኖረው ተጽዕኖ ያብራሩ?

ከማህበረሰቡ፣ ከቤተሰብ እና ጓደኞች ምን ዓይነት ድጋፍ ያገኛሉ?

- የሚያገኙት ድጋፍ እስከ ምን ድረስ ነው? ድጋፉ በቂ ነው?
- መድኃኒቱን በአግባቡ ለመውሰድ እና ለዘለቄታው ለመከታተል የሌሎች ሰዎች ድጋፍ የሚኖረውን አስተዋጽኦ ያብራሩ፡፡

ከባድ ጭንቀት፣ ሀዘን፣ የእእምሮ እረፍት ማጣት፣ እንቅልፍ መተኛት አለመቻል እና ምክንያታዊ ያልሆኑ የፀባይ መቀያየር ያጋጥሞታል?

- በየምን ያህል ጊዜው እንደ እነዚህ ዓይነት ስሜቶች ይሰማዎታል?
- እነዚህ ስሜቶች መድኃኒቱን በአግባቡ ለመውሰድ እና ለዘለቄታው ለመከታተል ተጽዕኖ ያሳድራሉ?

እንክብካቤውን መከታተሉ በአጠቃላይ ጤናዎ ላይ ያመጣው ለውጥ አለ?

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Correlates of highly active antiretroviral therapy adherence among urban Ethiopian clients

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There has been a massive expansion of highly active antiretroviral therapy (HAART) services in Ethiopia since 2005. To assess clients' self-reported adherence to HAART medication, a descriptive, comparative cross-sectional study was carried out among adults receiving HAART medication at the Zewditu Memorial Hospital ART clinic in Addis Ababa. Of 1 808 clients eligible for the study, 1 722 agreed to participate. The data were collected over six weeks in February and March 2010. Ordered and binary logistic regression models were applied to analyse the data. The majority of participants were over age 30 years, most were females, and 90% had some formal education. More than half reported being 'extremely sure' about their ability to take most or all of their medication. Self-reported adherence to the medication was generally good, as 62% said they had never missed a dose. The most commonly cited reason for missing medication was being busy (57.5%). The odds of ever missing a dose of HAART were lower for males (adjusted odds ratio [AOR]: 1.44; 95% confidence interval [CI]: 1.15–1.79), older persons (AOR: 0.98; 95% CI: 0.97–0.99), and those who did not drink alcohol regularly. Similarly, the odds of being self-confident about taking the medication properly were higher for males and for those who did not drink alcohol regularly (AOR: 0.48; 95% CI: 0.35–0.64). The odds of self-confidence in taking the medication were lower among those in lower income group. Those who reported an expenditure income of Birr 501–999 (AOR: 0.35; 95% CI: 0.24–0.49) or Birr 1 000–1 999 (AOR: 0.41; 95% CI: 0.29–0.60) had less self-confidence in taking their medication properly as compared to those who had an expenditure income of Birr 2 000 or more. There is a need to design and implement targeted adherence interventions that could lead to better treatment outcomes.

Keywords: Africa, compliance, HAART, health knowledge, HIV/AIDS, quantitative research, self-efficacy, self-reporting

Background

As of 2010, estimated HIV prevalence in Ethiopia was 2.4%, with more than 1.2 million people in the country living with HIV (Ministry of Health, 2007). Similar to the expansion of highly active antiretroviral therapy (HAART) in most developing countries, the number of HIV-infected people receiving HAART has dramatically increased — from 3 880 in 2004, to 179 183 as of February 2010 (World Health Organization [WHO] & UNAIDS, 2003; Panos Southern Africa, 2006; HIV/AIDS Prevention Control Office [HAPCO], 2007; Ministry of Health, 2008).

Scaling up therapy, however, is not enough for ensuring survival of people infected with HIV. Adherence to treatment is crucial and it is affected by many factors. In order to achieve an undetectable viral load and prevent the development of drug resistance, a person on HAART needs to take at least 95% of the prescribed doses on time (WHO & UNAIDS, 2003; Panos Southern Africa, 2006). Thus, treatment adherence is as important for survival as is access to treatment. Surveys in Haiti have shown survival rates of 87% for adults and 98% for children with 96% adherence among those who had been on treatment for one year or more (Panos Southern Africa, 2006). Some reports have expressed concern over poor rates of adherence to HIV/AIDS treatment in the African region. However, two recent systematic reviews do not support speculations that treatment adherence is generally low in Africa. Despite poverty, Africans do overcome barriers and are oftentimes better than North Americans at adhering to HAART (Mills, Nachega, Buchan, Orbinski, Attaran, Singh *et al.*, 2006; Attaran, 2007).

Numerous studies have been carried out to explore the factors influencing adherence to HAART. In one study, depressive symptoms and the patient's use of drugs or alcohol were associated with poor 30-day adherence (Palepu, Horton & Tibbetts, 2004).

In another study, a lower CD4 cell count at enrolment, a lower level of education, and illicit substance use were associated with non-adherence to treatment (Hendershot, Stoner, Pantalone & Simoni, 2009). Financial constraints, stigma, travel difficulties, side-effects, and poor physician/patient relationships have also been documented as barriers to adherence (Weiser, Wolfe, Bangsberg, Thior, Gilbert,

Makhema *et al.*, 2003; Schneider, Kaplan, Greenfield, Li & Wilson, 2004). Lewis, Colbert, Erlen & Meyers (2006) presented evidence that adherence is fostered when medication-taking is a priority, when patients believe in the efficacy of their medications, and when there is a strong patient/provider relationship. Having a high perception of self-efficacy, a positive attitude towards taking medication, not living alone, and being male have also been associated with better rates of treatment adherence (Davies, Koenig, Stratford, Palmore, Bush, Golde *et al.*, 2006; Lewis *et al.*, 2006).

In developing countries, adherence to medications for chronic diseases generally averages only 50% (Sabaté, 2003). Treatment-completion rates for tuberculosis, which requires a temporary rather than permanent commitment to adherence, average 74% in the African region, with an overall range of 22% to 94% among different countries (World Health Organization [WHO], 2007). Taken in this context, the records of different African HAART programmes lie within the bounds of experience for other treatment efforts.

In Ethiopia, different studies have reported high self-reported treatment adherence among children and adults. A study by Tadios & Davey (2006) reported a level of at least 95% self-reported adherence to HAART medication in the previous seven days among 81.2% of the adult respondents. A qualitative study among caregivers of children who were taking HAART reported that heavy pill burden, fear of stigma, transportation access and costs, lack of understanding about the benefits of medication, economic hardships, and lack of nutrition support were barriers to adherence to HAART (Biadgilign, Deribew, Amberbir & Deribe, 2009). Another study reported 95% of adults to be adherent to HAART based on self-reports of the preceding seven-days' adherence practices (Tiyou, Belachew, Alemseged & Biadgilign, 2010). Family support was found to be the most important predictor of adherence in that study.

The objective of this study was to assess the level and correlates of self-confidence in taking HAART medication, self-reported adherence to HAART, and knowledge of recent CD4 cell count among clients at one of the longest-running ART clinics in Ethiopia.

Methods

Ethiopia is the second most-populous country in Africa, with 79.2 million persons, of whom nearly 66 million live in rural areas and 39 million are males (Central Statistical Authority, 2010). This study was carried out in the capital city, Addis Ababa, at the Zewditu Memorial Hospital ART clinic.

Study design

The study uses a descriptive cross-sectional design with a sample population of HIV-infected adults (age 18 years or above) who were receiving HAART medication at the Zewditu Memorial Hospital ART clinic in 2010.

Sample size and sampling method

A sample-size calculation formula for two population proportions was used to enable comparisons according to differences in sociodemographic variables and other individual characteristics of the respondents. In this regard, the following assumptions were considered (cf. Hendershot *et al.*, 2009): proportion of people who adhere to their treatment (never forget taking the medication) among those who did not drink alcohol (52%), proportion of people who adhere to treatment (never forget taking the medication) among people who drink alcohol regularly (43%), an alpha level of 0.02 and power of 0.90, and the proportion of people among exposed and non-exposed = 1 (i.e. equal proportions of participants were sampled from the two groups), and a non-response rate of 10%. This required 1 808 study subjects.

During the period of data collection there were 5 142 adult, active clients receiving HAART from the hospital's clinic. All clients aged 18 years or above and those who were actively receiving HAART were included in the sampling frame. By using computer-generated random table numbers, 1 808 eligible samples were selected for the study based on their unique HAART identification number. Trained data collectors stayed at the HAART clinic, during a six-week period in February to March 2010, to interview study subjects while clients' attended the clinic for follow-up.

Data collection

Data were collected utilising a standardised questionnaire that addressed all the study variables. The questionnaire was translated into the local language (Amharic) for easy administration and then back-translated to English to check for consistency. The data were collected by nurses who were trained for three days. The questionnaire was pre-tested in a similar population (who were excluded from the final study). The collected data were checked for completeness every day, by a supervisor and the principal investigator.

Measurement

To assess the respondents' self-confidence in taking medication correctly and belief in their medication, we used three questions: 'How sure are you that you will be able to take all or most of the medication as directed?'; 'How sure are you that the medication will have a positive effect on your health?'; and, 'How sure are you that if you do not take this medication exactly as instructed, the HIV in your body will become resistant to HIV medications?' The three questions were rated on a scale of '4,' from: 'Not at all sure' (indicating low self-confidence) to 'Extremely sure' (indicating a high level of self-confidence). For the three items the Cronbach's alpha estimate was found to be 0.72, which reflects fairly good reliability.

The four-item self-report Morisky scale was used to assess self-reported HAART adherence, with a scale measurement ranging from '0' indicating a low level of self-reported adherence to '4' indicating a high level of self-reported adherence. The four questions were: 'Many people forget to take medications on time. Do you ever forget to take your medicines?'; 'Are you careless at times about taking your medicines?'; 'When you feel better, do you sometimes stop taking your medicine?'; and, 'Sometimes, if you feel worse when you take your medicine, do you stop taking it?' Morisky's scale (see Morisky, Green & Levine,

1986) was preferred because it helps to assess treatment adherence in a positive, nonjudgmental atmosphere, delivered in a trusting relationship in order to understand what is actually happening with the respondent's adherence practices rather than what the respondent thinks the interviewer wants to know. The predictive validity of these scales was tested in different settings.

The mean self-reported adherence level for the four items was calculated using an alpha coefficient, with a self-reported adherence level of '4' indicating prefect self-reported adherence, and <4 indicating a low level of self-reported adherence. The reliability coefficient alpha for the four items was low (0.37).

Variables

For developing the regression models, because of the low level of scale reliability and as more than 98% of the viabilities within the three questions were explained by the first question. To explore self-confidence in taking medication we used the question: 'How sure are you that you will be able to take all or most of the medication as directed?' And to explore self-reported adherence from the Morisky-scale questions, we used the question: 'Many people forget to take medication on time. Do you ever forget to take your medicines?' Pertaining to CD4 cell count, the categorisation was between those who knew their recent CD4 cell count versus those who did not know it.

Predictor variables

The predictor variables in this study were the respondents' key sociodemographic and risk characteristics: sex, age in years, religion, income for monthly expenditures, educational attainment, duration of stay on HAART in months, drinking alcohol regularly and khat-chewing behaviour.

Data analysis

An ordered logistic regression model was used to explore associations between the two outcome variables (i.e. self-confidence in taking medication and self-reported adherence to treatment). A binary logistic regression model was utilised to explore relationships between knowing one's CD4 cell count and the predictor variables. Adjusted odds ratios (AOR) and 95% confidence intervals (CI) were calculated to determine the significance of the relationships. All the predictor variables were included in each of the three models and the models were checked for fit to the data.

Ethical clearance

This study was reviewed and approved by the institutional review board of the College of Health Sciences at Addis Ababa University. To assure voluntary participation, informed verbal consent was obtained from each participant. Privacy, confidentiality and benefit were maintained. All responsible hospital authorities were informed about the study and its procedures to ensure their support and commitment.

Results

Of the 1 808 clients selected for the study, 1 722 consented to participate, giving a response rate of 95.2%. The majority of the respondents were females (61%) and more than 75% were age 31 or older (mean age 37.9 years, standard deviation [SD] 9.0). The median age was 37 years. About 54% were married or in a union with a sexual partner. A large majority (81%) were Orthodox Christian. The respondents were asked how much they spent every month for different expenses ('expenditure income') and about one-third (35%) reported spending less than Birr 500 (~US$31) and a similar proportion reported spending more than Birr 1 000 (~US$61). About 90% had received some formal education. Drinking alcohol was found to be more prevalent than chewing khat (a locally grown stimulant); about 11% said they drank alcohol regularly, while only 3% reported chewing khat. The demographic information for the sample is presented in Table 1.

HIV-related background characteristics

As shown in Table 2, about 60% of the respondents reported that they became infected with HIV because of unsafe sexual intercourse, and a significant proportion (25%) reported that they did not know exactly how they became infected. More than 41% said they were not aware of the presence of antiretroviral drugs (ARVs) to treat

Table 1: Sociodemographic characteristics of the respondents (*n* = 1 722 HAART clients), Zewditu Memorial Hospital ART Clinic, Ethiopia, 2010

Respondents' characteristics	*n*	%
Sex:		
Males	667	38.7
Females	1 056	61.3
Age (years):		
<30	414	24.1
31–39	641	37.2
≥40	667	38.7
Mean age 37.9 (±9.0); median age 37		
Partner status:		
Currently in union	932	54.1
Currently not in union	791	45.9
Religion:		
Orthodox Christian	1 393	80.8
Muslim	79	4.6
Protestant	220	12.8
Catholic	24	1.4
Other	7	0.4
Monthly spending (in Ethiopian Birr*):		
<500	600	34.8
500–999	541	31.4
1 000–1 999	368	21.4
2 000+	214	12.4
Education:		
Cannot read or write	166	9.6
Has some formal education	1 168	67.9
Has a college diploma or higher	388	23.5
Chews khat:		
'Yes'	45	2.6
'No'	1 677	97.4
Drinks alcohol regularly:		
'Yes'	192	11.2
'No'	1 530	88.8

*At the time of the study US$1 = Birr 16.4

Table 2: HIV/AIDS-related background characteristics of the respondents (n = 1 722 HAART clients), Zewditu Memorial Hospital ART Clinic, Ethiopia, 2010

	n	%
Most likely way you became infected with HIV:		
Unsafe sexual intercourse	1 030	59.8
Blood contamination via sharing sharp instruments with an HIV-infected person	177	10.3
Blood transfusion	12	0.7
Outcome of rape	22	1.3
Do not know how	423	24.5
Do not want to respond	58	3.4
Knew the existence of anti-HIV drugs:		
After knowing HIV status	716	41.6
Before knowing HIV status	1 006	58.4
Duration on HAART (months):		
<12	477	27.7
12–24	262	15.2
25–48	560	32.5
>48	425	24.6
Knew the benefits of HAART before starting treatment:		
'Yes'	577	33.5
'No'	1 145	66.5
Knew the importance of adherence when started treatment:		
'Yes'	598	34.7
'No'	1 124	65.3
Sources of information about HAART:		
Health worker	1 010	58.7
Mass media	671	39
Family	16	0.9
Friend	14	0.8
Co-worker	4	0.2
Other	7	0.4
Know most recent CD4 cell count:		
'Yes'	1 085	63
'No'	637	37

HIV infection before they knew about their HIV-positive status. Interestingly, two-thirds (67%) of the respondents reported not having information about the benefits of anti-HIV drugs before initiating treatment. About 65% did not know the importance of strict adherence to HAART at the time they initiated treatment. The two main sources of HAART information reported were health workers (58.7%) and the mass media (39%). We also investigated whether clients were actively engaged in monitoring their treatment progress by following their CD4 cell count and found that 37% did not know their most recent CD4 level. More than 70% of the respondents had been on HAART for longer than one year, and among those about 25% had been on treatment for more than 48 months (4 years).

Self-esteem and belief in medication

Fifty eight percent of the respondents were extremely sure about their ability to take most or all of their HAART medication as prescribed. A similar proportion (57%) said they were extremely sure that the medication would have a positive effect on their health. Furthermore, about 53% said they were extremely sure that their HIV infection would become resistant to the drugs if they did not strictly adhere to the medication schedule. The mean level of self-esteem and belief in medication was calculated out of3, with a mean value of '3' indicating a very high level of self-esteem and belief in medication. Thus, the mean level was found to be 2.4 (SD = 0.18), indicating a moderately low level of self-esteem and belief in medication (see Table 3).

Self-reported treatment adherence practices

About 62% of the respondents said they had never missed a dose of their HAART medication. Additionally, large proportions said they were never careless about taking their medication (95%), that they never stop taking their medication at times when they feel better (98%), and that they never stop taking their medication at times when they feel worse (98%). In general, the self-reported adherence score for the sample was also found to be high, with an overall mean of 3.8 (SD = 0.2) (Table 4). More than 94% reported that they had taken their medication, all the designated times, in the past four days. But the most commonly cited reasons for ever missing a dose were: being busy (57.5%), being away from home (42.2%), simply forgetting (37.8%), and not wanting to be noticed taking medication (17.8%) (Table 5).

Self-reported treatment adherence in relation to alcohol drinking

Among those who drank alcohol regularly, 44.3% said they had never forgotten to take their HAART medication; among those who did not drink alcohol regularly, the proportion who said they had never forgotten to take their medication was 64.5%. This difference was statistically significant (p < 0.0001).

Correlates of self-confidence in taking the medication properly, self-reported adherence, and knowing one's recent CD4 cell count

As presented in Table 6, in the first model from the eight explanatory variables, gender, income and regular alcohol-drinking were significantly associated with the odds of self-confidence in taking the medication properly. The odds of self-confidence were 1.44-times higher among males than females (AOR: 1.44; 95% CI: 1.15–1.79). The odds of self-confidence were 0.35-times and 0.41-times lower among those who were within the spending categories of Birr 501–999 (AOR: 0.35; 95% CI: 0.24–0.49) and Birr 1 000–1 999 (AOR: 0.41; 95% CI: 0.29–0.60), respectively. Regarding regular alcohol drinking, the odds of self-confidence were 2.86-times higher among those who did not drink alcohol regularly.

In the second model, sex, age, duration of stay on HAART in months, and drinking alcohol regularly were significantly associated with the odds of ever missing HAART medication. The odds of ever missing a dose of HAART medication was 0.76-times lower among males than females (AOR: 0.76; 95% CI: 0.61–0.95). A one-year increase in age was also associated with 0.98-times lower odds of ever missing HAART medication (AOR: 0.98; 95% CI: 0.97–0.99). The odds of ever missing HAART medication was 1.36-times

Table 3: Measure of the respondents' self-esteem and belief in medication (*n* =1 722 HAART clients)

	'Not at all sure' *n* (%)	'Somewhat sure' *n* (%)	'Very sure' *n* (%)	'Extremely sure' *n* (%)
'Are you confident that you will be able to take most or all of your medication?'	17 (1)	114 (7)	589 (34)	1 002 (58)
'How sure are you that the medication will have a positive effect on your health?'	14 (1)	81 (5)	643 (37)	983 (57)
'How sure are you that if you don't take the medication exactly as instructed, your body will become resistant to the HIV medication?'	169 (10)	241 (14)	390 (23)	917 (53)
Self-esteem scale reliability coefficient = 0.72				
Score of mean level of self-esteem and belief in medication = 2.4 (±0.18)				

Table 4: The respondents' self-reported HAART-adherence practices (*n* =1 722 HAART clients)

Adherence practices (Morisky scale)	'Never' *n* (%)	'Rarely' *n* (%)	'Sometimes' *n* (%)	'Often' *n* (%)	'Always' *n* (%)
'Do you ever forget to take your medication?'	1 072 (62)	433 (25)	201 (12)	14 (1)	2 (0.1)
'Are you careless at times about taking your medicines?'	1 638 (95)	47 (3)	32 (2)	5 (0.3)	0
'Do you sometimes stop taking your medicines when you feel better?'	1 693 (98)	15 (1)	11 (0.7)	3 (0.3)	0
'Do you sometimes stop taking your medicines when you feel worse?'	1 695 (98)	18 (1)	6 (0.4)	2 (0.1)	1 (0.1)
Self-reported-adherence scale reliability coefficient = 0.37					
Mean self-reported-adherence score = 3.8 (±0.2)					

Table 5: The respondents' past four-days-adherence practices and commonly cited reasons for missing a dose of HAART (*n* = 1 722 HAART clients)

Variables	*n* (%)
'How closely did you take your medication in the past four days?'	
'All the time'	1 625 (94.4)
'Not all the time'	97 (5.6)
Commonly cited reasons for ever missing a dose (multiple responses possible):	
Being busy	374 (57.5)
Away from home	274 (42.2)
Simply forgot to take	246 (37.8)
Don't want people to notice	116 (17.8)

higher among those who had stayed 25–48 months on HAART (AOR: 1.36; 95% CI: 1.04–1.78). With regard to drinking alcohol, the odds of having ever missed a dose of HAART medication was 0.48-times lower among those who did not drink alcohol regularly (AOR: 0.48; 95% CI: 0.35–0.64).

The third regression model focused on the respondents' knowledge about their most recent CD4 cell count. In this model, age, education level, and duration of stay on HAART all presented significant associations. A one-year increase in age was associated with 1.02-times higher likelihood of not knowing one's recent CD4 cell count (AOR: 1.02; 95% CI: 1.01–1.03). Those with an education level below college diploma had 1.48-times more likelihood of not knowing their most recent CD4 cell count (AOR: 1.48; 95% CI: 1.09–2.01). A longer duration of staying on HAART was associated with a low likelihood of not knowing one's recent CD4 cell count. Details of the three regression models are given in Table 6.

Discussion

This study used a reasonably large sample size to assess self-reported HAART-adherence practices. This allowed comparisons to be made among different categories of respondent characteristics and behaviours. In addition, three different outcome variables were used to assess the respondents' self-esteem and confidence in taking all of their HAART medication, their self-reported adherence practices, and knowledge of their most recent CD4 cell count. These outcome variables were used as indicators for the HAART clients' commitment to taking their medication.

The respondents' knowledge about the benefits of anti-HIV drugs and the importance of strict adherence at the time of treatment initiation was found to be poor. This suggests that most of these clients had initiated their treatment without adequate counselling and education regarding the benefits of HAART and the importance of adherence.

A significant portion of the respondents did not know their most recent CD4 cell count. This might indicate that HAART clients at the hospital clinic were not actively engaged in monitoring their treatment progress. This entails engaging and empowering clients to monitor their own progress and to make healthy decisions that will improve their treatment outcomes.

Another important finding is the low levels of self-esteem, belief in medication, and self-confidence in correctly taking HAART medication. This might be because HIV is still considered by some as a 'deadly disease.' Thus, even though a person may take the medication, they might not believe that it will prolong their life for a long time. HAART clients need to be supported, encouraged, and counselled so that they will be hopeful and believe in the effect of the medication.

Self-reported adherence to treatment was found to be good in this study (substantiating the findings of other

Table 6: The relationship between the respondents' background characteristics with self-confidence in taking their medication correctly, medication adherence, and knowledge of their most recent CD4 cell count, using an ordinal logistic regression model (n = 1 715 HAART clients) (bold type indicates an adjusted odds ratio [AOR] and 95% confidence interval [CI] significant at $p \leq 0.05$ or better)

	Confidence in taking medication correctly AOR (95% CI)	Ever forgets taking medication AOR (95% CI)	Not knowing most recent CD4 count AOR (95% CI)
Sex:			
Females	1.0	1.0	1.0
Males	**1.44 (1.15–1.79)**	**0.76 (0.61–0.95)**	0.87 (0.69–1.09)
Age (years)	1.00 (0.99–1.01)	**0.98 (0.97–0.99)**	**1.02 (1.01–1.03)**
Religion:			
Muslim	1.0	1.0	1.0
Orthodox Christian	1.05 (0.65–1.68)	1.06 (0.66–1.71)	1.45 (0.88–2.41)
Other Christian	0.97 (0.57–1.64)	1.09 (0.64–1.86)	0.95 (0.54–1.68)
Income (Ethiopia Birr):			
2 000+	1.0	1.0	1.0
≤500	0.72 (0.50–1.04)	0.96 (0.68–1.35)	1.10 (0.78–1.55)
501–999	**0.35 (0.24–0.49)**	1.31 (0.94–1.82)	0.98 (0.69–1.38)
1 000–1 999	**0.41 (0.29–0.60)**	1.28 (0.90–1.81)	0.83 (0.57–1.19)
Education:			
College diploma or higher	1.0	1.0	1.0
Less than a college diploma	1.07 (0.81–1.42)	0.78 (0.60–1.02)	**1.48 (1.09–2.01)**
Duration on HAART:			
1–12 months	1.0	1.0	1.0
13–24 months	0.95 (0.70–1.29)	1.09 (0.80–1.49)	**0.70 (0.51–0.95)**
25–48 months	0.82 (0.63–1.07)	**1.36 (1.04–1.78)**	0.63 (0.48–0.82)
49+ months	0.90 (0.67–1.19)	1.26 (0.94–1.67)	**0.43 (0.32–0.58)**
Alcohol:			
Drinks regularly	1.0	1.0	1.0
Does not drink	**2.86 (2.11–3.89)**	**0.48 (0.35–0.64)**	1.08 (0.77–1.51)
Khat chewing and smoking:			
Chews *khat*	1.0	1.0	1.0
Does not chew *khat*	1.32 (0.71–2.44)	1.38 (0.72–2.65)	0.96 (0.49–1.86)

studies in Africa). Sixty-two percent of the respondents reported that they had never missed a dose of HAART medication. This implies that 38% *had* missed a dose of their medication at some point — a situation that requires targeted intervention. However, there could have been some underreporting of missed doses of HAART. For example, in a study done in Mulago Hospital in Kampala, all respondents reported 95% adherence, but pill counts showed that only 60% of the clients had 95% adherence. Yet, a meta-analysis of studies done in North America and Africa reported that Africans adhered to treatment better than North Americans. The fact that treatment adherence appeared to be better among clients in Africa may have come about due to generally limited access to treatment — whereas those who eventually get the therapy are more likely to be adherent. In time, once more people are able to initiate treatment, the people on treatment might resemble the general population of people with HIV infection, and so the adherence rate might decrease (Mills *et al.*, 2006).

The 94.4% of respondents who reported that they had never missed a dose of their HAART medication in the previous four days is comparable with the findings of other studies done in Ethiopia (Markos, Worku & Davey, 2008), South Africa (Malangu, 2008), and Zambia (Birbeck, Chomba, Kvalsund, Bradbury, Mang'ombe, Malama *et al.*, 2009).However, the Zambian study found that self-reporting had greatly overestimated adherence based on comparative data from the pharmacy. In this study, most respondents reported missing their medication because they were busy, away from home, simply forgot to take it, or because they did not want other people to notice them taking medication. This finding is similar to those of other studies done in Uganda (Byakika-Tusiime, Crane, Oyugi, Ragland, Kawuma, Musoke & Bangsberg, 2009), Kenya (Talam, Gatongi, Rotich & Kimaiyo, 2008), Zambia (Grant, Logie, Masura, Gorman & Murray, 2008) and Ethiopia (Amberbir, Woldemichael, Getachew, Girma & Deribe, 2008).

Being male, having higher expenditure income, and not drinking alcohol regularly were associated with higher odds of self-confidence in taking the medication. The higher level of self-confidence for males may be explained by the generally higher status that males have within communities. A higher income can be associated with better living conditions, including better nutrition, which could boost a person's self-confidence.

Age was significantly associated with better self-reported adherence. It might be important to explore why the odds of ever missing a dose of medication were found to be lower as the age of the respondent increased. This may simply be due to better life experience with age. Similarly, older persons tended to know their most recent CD4 cell count.

Drinking alcohol regularly is expected to decrease people's self-esteem and this was indeed demonstrated in this study. The proportion of persons who had never

forgotten to take a dose of their medication was higher (by 20%) among those who did not drink alcohol regularly as compared to those who drank regularly. Similarly, in the regression model, those who did not drink alcohol regularly had higher odds of self-confidence and lower odds of ever forgetting their medication. Persons with HIV infection are advised to not drink alcohol because of its negative effects, including the likely consequences on treatment adherence. Similarly, in a South African HIV/AIDS workplace programme, drinking alcohol was reported as a barrier to HAART adherence (Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard & Grant, 2008). Meta-analysis of studies carried out to assess the effect of alcohol-drinking on HAART adherence also reported poor adherence among those who drank regularly (Hendershot *et al.*, 2009).

Another sociodemographic variable significantly associated with self-reported adherence was gender. Males had lower odds of having ever missed a dose of HAART medication. This may need further study to understand why females may possibly not adhere as well to treatment. Furthermore, exploratory qualitative studies might help us understand the gender dynamics in patterns of adherence to HAART. Pertaining to knowledge of one's CD4 cell count, the respondents who had been on treatment for a shorter period were less likely to know their CD4 count, while better-educated individuals were more likely to know their CD4 cell count. Although knowledge of one's most recent CD4 cell count might indicate a person's engagement and dedication to treatment, it might also be influenced by the quality of HAART services. Health providers need to regularly follow clients' CD4 cell counts by testing at least once every six months.

Limitations of the study

The reliance on clients' self-reports for assessing adherence to HAART presents a possibility that missed doses were underreported, as some level of social desirability bias can be expected. The reliability of the scales was also low. Moreover, the study was carried out in one hospital and so the findings may not be generalised to all HAART clinics in the country.

Conclusions and recommendations

As access to HAART increases dramatically in Ethiopia and throughout sub-Saharan Africa, key issues must be addressed in order to ensure the highest possible quality of HAART services. Health education and counselling that includes the topics of anti-HIV drugs and their benefits, as well as the importance of strict adherence to treatment, need to be prioritised. In addition, interventions with the specified aim of improving clients' treatment adherence still need to be designed and implemented. Those found to be predisposed to poor self-confidence in taking medication and with low self-reported adherence (in this case, females and those who drank alcohol regularly) need to be targeted for such interventions.

Finally, it is vital to understand that HIV-treatment adherence is a dynamic behaviour that changes over time. Adherence to medication is determined by a matrix of interrelated factors which vary in impact throughout a person's course of treatment. Therefore, adherence interventions require an integrated, multidisciplinary approach by physicians, nurses, counsellors and pharmacists.

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13.7. Annex 7: Manuscript II (AIDS Care)

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Effect of depressive symptoms and social support on weight and CD4 count increase at HIV clinic in Ethiopia

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Studies have reported an inverse relationship between depressive symptoms and weight and CD4 gain and a positive association between social support and weight and CD4 gain. The main objective of this study was to explore the effect of depressive symptoms and perceived social support on weight change and CD4 cell progression in an HIV clinic in Ethiopia. The study design was descriptive cross-sectional, with a sample of 1815 HIV-infected adults age 18 years or above. Depressive symptoms and perceived social support were the independent variables, while weight and CD4 cell count were the dependent variables. Regression modeling was the main statistical approach used for the analysis. A significant proportion of females reported depressive symptoms: being bothered by things that do not bother other people, they had been depressed, and their sleep had been restless for 5–7 days a week. A lesser proportion of males reported these problems. A significant proportion of study participants did not have someone to borrow a small amount of money (6 USD) from for immediate help and did not have somebody to support them if they were confined to bed for several weeks. Worse depressive symptoms had a negative effect on weight gain and CD4 cell progression, while better perceived social support had a positive effect on both weight gain and CD4 cell progression. Interventions that address both of these background factors need to be designed and implemented as part of the HAART program to improve weight gain and CD4 cell progression.

Keywords: weight; CD4 cell; HAART; depressive symptom; perceived social support

Background

The ultimate goal of HIV treatment is to prolong life and improve quality of life of people infected with HIV, both in the developed and developing world. Research carried out in resource limited settings have shown that people infected with HIV can be successfully treated, achieving clinical outcomes similar to those seen in the developed world (WHO, 2003). Yet, several factors influence outcome of HIV treatment.

There are mixed findings about the effect of depressive symptoms and perceived social support on weight gain and CD4 cell progression. Studies carried out in the years 1992, 1993, and 1996 reported lack of significant association between depressive symptom and progression of HIV infection and CD4 cell count (Lyketsos, Hoover, & Guccione, 1993; Patterson et al., 1996; Perry, Fishman, Jacobsberg, & Frances, 1992). On the other hand other studies done in the same era reported significant association between worse baseline depressive symptom and decreased CD4 cell progression (Burack et al., 1993; Page-Shafer, Delorenze, Satariano, & Winkelstein, 1996). Similarly multiple studies done from the year 1999 to 2006 reported significant association between worse depressive symptom and decreased CD4 cell progression (Anastos et al., 2005; Antelman et al., 2007; Bouhnik et al., 2005; Cook et al., 2002, 2004, 2006; Ickovics et al., 2001; Ironson et al., 2005; Leserman et al., 1999, 2000, 2007; Lima et al., 2007; Pence, Miller, Whetten, Eron, & Gaynes, 2006).

Similarly several studies have demonstrated the effect of social support on weight gain and CD4 cell progression. According to study done in Canada HIV-positive adults consistently taking HAART appeared to experience better clinical outcomes if they perceived interpersonal, informational, and emotional support to be available (Burgoyne, 2005). Another study done among hemophiliac patients reported less social support to be related to faster deterioration in CD4 cells (Theorell et al., 1995). A study also showed HIV-infected subjects to become symptomatic after 6 months if they had less social support (Solano et al., 1993). In another study faster progression of AIDS was associated with lower cumulative average satisfaction with social support (Jane et al., 1999, 2000).

Taking the existing evidence in to consideration the main aim of this study was to explore the

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association between depressive symptoms and perceived social support, and weight gain and CD4 cell progression in an HIV clinic in Addis Ababa, Ethiopia.

Methods

Study population

This study was carried out in the capital city of Ethiopia, Addis Ababa, at Zewditu Memorial Hospital's HAART clinic. It is the largest HIV clinic in Ethiopia with more than 14,000 clients in its care.

The study design was descriptive cross-sectional with a sample population of HIV-infected adults age 18 years or above who received HAART medication at the clinic. Retrospective follow-up data was also utilized.

A sample size calculation formula for two population proportions was used so that differences by depression symptoms and social support status could be detected. Studies had reported a 10% difference in treatment progression between those who had better support versus poor support (Ironson & Hayward, AQ2 2008). This study was designed to detect a difference of 7%. We used 80% power, 5% alpha level of error to come-up with a total of 1650 samples. By adding 5% nonresponse rate the total study sample was 1815.

By using a computer generated random table number 1815 eligible samples were selected for the study based on the unique HAART identification number. Trained data collectors stayed at the HAART clinic from 1 February 19 March 2010 to interview study subjects when they came to the clinic for follow-up.

Data collection

Data were collected using standard questionnaires, which were prepared in English and translated into the local language (Amharic) for easy administration. Consistency of the questions was checked by back-translation. The questionnaire was pretested in a similar population which was excluded from the final study.

Four different types of information were collected from medical records utilizing a data abstraction questionnaire: weight and CD4 cell count at baseline and recent period, duration of stay on HAART, and current status (active on treatment, death, drop, transfer out, or lost to follow-up).

Study variables

The outcome variables for this study were the difference between baseline and recent weight and CD4 cell count measures. The model was adjusted for duration between baseline and recent measures, sex, age, income, education, marital status, religion, and adherence to treatment.

The two main predictor variables were depressive symptoms and perceived social support. To assess depressive symptoms related to major or clinical depression the shorter 10 item version of the Center for Epidemiological Studies Depression Scale (CES-D) questionnaire was used (Radloff, 1977, 1991). Responses were based on the frequency of occurrence during the past week. The questionnaire used a 4-point ordinal scale: rarely or none of the time (less than 1 day); some or little of the time (1 2 days); occasionally or a moderate amount of the time (3 4 days); most or all of the time (5 7 days).

For the 10 questions, the reliability coefficient alpha was 0.85 and the average inter-item covariance was 0.40. As the reliability of the scale was good, we applied factor analysis and we found factor1 explaining about 78% of the variance with Eigen-value of 3.7. Following this, one summary variable that could explain the nature of depression symptoms among study subjects was predicted.

To assess social support six questions from Norbeck Social Support Questionnaire (NSSQ) were used (Norbeck, Lindsey, & Carrieri, 1981, 1983). A 5-point rating scale was used to describe the amount of support available from families, friends, and close relatives. The six questions measured functional properties of social support like emotional and tangible support.

Alpha was calculated to explore the reliability of the measurement and was found to be 0.96, which was high. The average inter-item covariance was 1.47. Following the reliability test factor analysis was applied and found the Eigen-value for factor1 to be 4.85. About 99.4% of variance was explained by factor1. Following this one social support variable that could explain the pattern of the different perceived social support questions among study subjects was predicted.

Data analysis

The main statistical analysis techniques used in this study were frequencies, percentages, median, inter-quartile range, standard deviation, *p* value, and 95% confidence intervals. On top of these factor analysis was utilized to calculate Eigen-values, scale reliability coefficient, and average inter-item covariance. An unpaired *t*-test was also used to verify the significance of difference in mean weight and CD4 cell measures between two different periods. A regression model was used to explore the effect of depressive symptoms

and perceived social support on weight gain and CD4 cell progression. Quality of the study was maintained from design to actual data collection, and data were consciously analyzed to control for bias and possible effect modifications.

This study was reviewed and approved by the Institutional Review Board of the College of Health Sciences, Addis Ababa University. To assure voluntary participation, informed verbal consent was obtained from each study participant. Study participants' consent was obtained before reviewing their medical record. Privacy, confidentiality, and benefit were maintained.

Results

The response rate was high (94.9%), but it varied across variables as a few respondents did not want to respond to some of the questions. In few instances respondents' medical records were also incomplete but this did not affect the power of the study as it used large sample size.

Basic socio-demographic characteristics

As presented in Table 1, a significant proportion of the study participants (61.3%) were female. This is in line with the general sex proportion of persons who are receiving HAART in the country at which larger proportion are females (HAPCO, 2008). The mean age for the entire study population was 37.93, with standard deviation of 8.97. Females (mean 35.54 ± 8.16) were much younger than males (mean 41.71 ± 8.83).

The proportions of study participants who were in union with their sexual partner were 54.1%. More males (61.1%) than females (49.6%) were in union with sexual partner. A large proportion of study participants (80.8%) were Orthodox Christians by religion followed by Protestant (12.8%) and Moslem (4.6%).

A majority of females (40.2%) spent less than 500 Birr (31 USD) per month on all expense, while among males only 26.4% fell into the same category. More than 65% of the study population were in the low income (less than 1000 Birr which was about 61 USD per month) category.

More than 70% of study participants had stayed on HAART for more than 12 months during the time of data collection. The median duration of stay on HAART was 46 months with inter-quartile range between 27 and 62 months.

Of the entire study population, 24% did not know their baseline and recent CD4 cell count level.

Depressive symptoms

A significant proportion of females had been bothered by things that usually did not bother other people (12.6%), had been depressed (13.1%), and their sleep had been restless (18.3%) for about 5 7 days in the previous week. The proportions of males who had been bothered by things, that had been depressed and those whose sleep had been restless were 8.4%, 8.7%, and 13.2%, respectively.

On the other hand, 51% of females and 60% of males felt hopeful about the future and only 38% of females and 47% of males felt happy for 5 7 days in the previous week. The detail psychosocial characteristic of study subjects is presented in Table 2.

Perceived social support

As shown in Table 3, 34% of study participants did not have someone to borrow small amount of money (6 USD) from for immediate help. Almost equal proportion (32.5%) did not have anyone who could provide them with support if they were confined to bed for several weeks. Approximately one quarter reported that they had no one to make them feel liked or loved (23.5%), and to make them feel respected or admired (24.8).

Median weight

As presented in Table 4, the median baseline weight for the entire study population was 54 kg and median recent weight was 59 kg. There were significant differences by gender, with males having higher median weight at baseline (58 kg) and recent weight (63 kg) compared to females with baseline median weight of 51 kg and recent median weight of 56 kg.

CD4 cell count

Median baseline and recent CD4 cell count for the entire study population were 119 CD4 cell/μl and 284 CD4 cell/ μl, respectively. Twenty-eight percent of the study population had a recent CD4 cell count less than 200 CD4 cell/μl. Females had better median CD4 cell count levels both at baseline (131 CD4 cell/μl) and recent measures (296 CD4 cell/μl) compared to males with median baseline CD4 cell count of 103 CD4 cell/ μl and recent CD4 cell count of 261 CD4 cell/μl.

Trend in weight

Although study participants stayed on treatment for varying period of time, the general weight measure taken every 3 months was utilized to get the median

Table 1. Basic socio-demographic characteristics of study participants, $N = 1722$.

Characteristics	Female (%)	Male (%)	Number (%)	p level
Gender	1056 (61.3)	667 (38.7)	1722 (100.0)	0.000
Age (complete years)				
≤30	354 (33.5)	60 (9.0)	414 (24.1)	0.000
31–39	423 (40.1)	218 (32.7)	641 (37.2)	
≥40	279 (26.4)	641 (58.3)	667 (38.7)	
Mean ± SD	35.54 ± 8.16	41.71 ± 8.83	37.93 ± 8.97	
Marital status				
Currently in union	524 (49.6)	407 (61.1)	932 (54.1)	0.000
Currently not in union	532 (50.4)	259 (38.8)	791 (45.9)	
Religion				
Orthodox Christian	855 (80.9)	537 (80.6)	1393 (80.8)	0.027
Moslem	39 (3.7)	40 (6.0)	79 (4.6)	
Protestant	139 (13.2)	81 (12.2)	220 (12.8)	
Catholic	20 (1.9)	4 (0.6)	24 (1.4)	
Other	3 (0.3)	4 (0.6)	7 (0.4)	
Monthly expense (Birr[a])				
<500	424 (40.2)	176 (26.4)	600 (34.8)	0.000
500–999	336 (31.8)	204 (30.6)	541 (31.4)	
1000–1999	179 (16.9)	189 (28.4)	368 (21.4)	
2000 and above	117 (11.1)	97 (14.6)	214 (12.4)	
Duration on HAART				
Less than 12 months	244 (23.1)	141 (21.2)	477 (27.7)	0.001
12–24 months	190 (17.9)	113 (16.9)	262 (15.2)	
25–48 months	229 (21.7)	105 (15.8)	560 (32.5)	
More than 48 months	393 (37.2)	307 (46.1)	425 (24.6)	
Median duration (inter-quartile range)	44 (26–58)	49 (29–67)	46 (27–62)	
Know baseline and recent CD4 cell count level				
Yes	261 (24.7)	146 (21.9)	1315 (76.3)	0.184
No	795 (75.3)	520 (78.1)	407 (23.6)	
Proportion who ever forget taking a dose of HAART				
Yes	416 (39.4%)	234 (35.1)	650 (37.8)	0.076
No	640 (60.6%)	432 (64.9)	1072 (62.2)	

Note: Percentages rounded to one decimal point.
[a]1 USD is equivalent to 16.38 Birr at the time of study.

weight for the specific periods (see Figure 1). In the first 15-month period of treatment there was a sharp increase in median weight, but from the 18th to 49th month period there was no much variability.

Additionally, the differences in mean weight between baseline and 6th month measure were significant (see Table 5). On the other hand, mean weight between 9th and 21st, 24th and 36th, and 39th and 51st month were not significantly different.

Trend in CD4 cell count

The median trend of CD4 cell count progression is presented in Figure 2. Varying number of observations contributed to the estimation of median CD4 cell count at different periods. The mean CD4 cell count level was significantly different between baseline and 6th and 9th and 21st month measures. On the other hand, the mean CD4 cell count level between 24th and 36th and 39th and 51st month were not significantly different.

Status of study participants 6 months after baseline data collection

By 6 months after baseline data collection, 94% of patients were still actively taking their treatment and were in good physical health. Two percent had been transferred out to other HAART clinic. The remaining 4% had either died, stopped taking treatment, or had been lost to follow-up.

Effect of depression symptoms and perceived social support on weight and CD4 cell progression

As shown in Table 6, in the first model effect of depressive symptoms and perceived social support on

Table 2. Reported depression symptoms using CES-D 10[a] by gender.

	Female: $N=1055$, Frequency (%)	Male: $N=666$, Frequency (%)	Total: $N=1721$, Frequency (%)	p level[b]
Proportion of study participants who reported that they have encountered the following psychosocial problems most or all of the time in the past week				
Bothered by things that usually did not bother me	133 (12.6)	56 (8.4)	189 (11.0)	0.000
Had trouble keeping my mind on things I was doing	108 (10.2)	41 (6.2)	149 (8.7)	0.000
Felt depressed	138 (13.1)	58 (8.7)	196 (11.4)	0.000
Felt that everything I did was an effort	89 (8.4)	46 (6.9)	135 (7.7)	0.000
Felt hopeful about the future	542 (51.3)	397 (59.6)	939 (54.5)	0.007
Felt fearful	105 (9.9)	51 (7.7)	156 (9.1)	0.000
Sleep was restless	193 (18.3)	88 (13.2)	281 (16.3)	0.007
Was happy	402 (38.1)	315 (47.3)	717 (41.6)	0.001
Felt lonely	162 (15.3)	91 (13.7)	253 (14.7)	0.066
Could not "get going"	113 (10.7)	59 (8.9)	172 (10.0)	0.004
Scale reliability coefficient for the 10 questions	0.85			
Eigen-value for factor 1	3.70			
Average inter-item covariance	0.40			

Note: Percentage rounded to one decimal point.
[a]Center for Epidemiologic Studies Short Depression Scale CES-D 10 [30].
[b]Significance level based on χ^2.

weight gain and CD4 cell progression was explored among the entire study population. In this model both depressive symptoms and perceived social support had significant effect on weight gain after adjusting for duration between baseline and recent measures, sex, age, income, education, marital status, religion, and adherence to treatment.

One unit increase in depressive symptoms was associated with a decrease in weight on average by about 10 kg between baseline and recent levels ($p=0.023$), while one unit increase in perceived social support was associated with an average of 10 kg increase in weight between baseline and recent levels ($p=0.033$).

Table 3. Reported perceived emotional and tangible social support using modified NSSQ[a] by gender.

	Female: $N=1056$, Frequency (%)	Male: $N=666$, Frequency (%)	Total: $N=1722$, Frequency (%)	p level[b]
Proportion of clients who reported they have no or have very little support to provide any of the following:				
Make you feel liked or loved	256 (24.2)	149 (22.4)	405 (23.5)	0.120
Make you feel respected or admired	271 (25.7)	156 (23.4)	427 (24.8)	0.201
Have someone to confide on	307 (29.1)	166 (24.9)	473 (27.5)	0.098
Have someone who agree with your actions	302 (28.6)	158 (23.7)	460 (26.7)	0.047
Have someone to borrow 100 Birr	369 (34.9)	225 (33.8)	594 (34.5)	0.133
Have someone to support if confined to bed	358 (33.9)	202 (30.3)	560 (32.5)	0.230
Scale reliability coefficient for the six questions	0.96			
Eigen-value for factor 1	4.85			
Average inter-item covariance	1.47			

Note: Percentage rounded to one decimal point.
[a]Norbeck Social Support Questionnaire(NSSQ) [31 and 32].
[b]Significance level based on χ^2.

Table 4. Median weight and CD4 levels at baseline[a] and recent[b] period by duration of stay on HAART and gender of study participants.

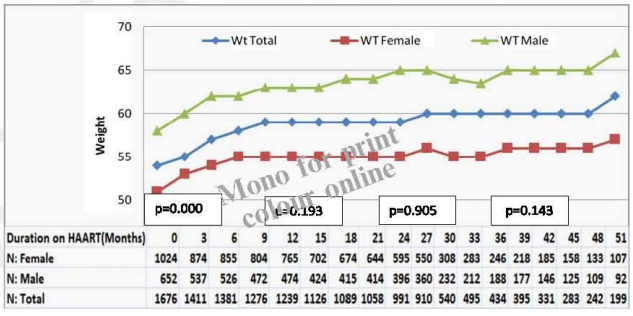
Duration of stay on HAART	Less than 12 months		12–48 months		Above 48 months		Total		
Sex	Female	Male	Female	Male	Female	Male	Female	Male	Both sex
Baseline weight (kg)									
N	75	49	526	272	423	331	1024	652	1676
Median	54	62	51	58	50	58	51	58	54
Recent weight (kg)									
N	72	49	539	273	416	327	1044	660	1704
Median	55	62	56	63	56	65	56	63	59
Difference in weight (kg)									
Recent less baseline	1	0	5	5	6	7	5	5	5
Baseline CD4 cell count (cell/μl)									
N	74	51	536	276	435	334	1045	661	1706
Median	150	131	131	103	112	92	131	103	119
F value[c]	0.555		0.060		0.020*		0.000*		
Recent CD4 cell count (cell/μl)									
N	57	40	531	266	430	334	1018	640	1658
Median	254	253	296	261	325	285	296	261	284
F value[c]	0.181		0.002*		0.001*		0.000*		
Difference in CD4 (cell/μl)									
Recent less baseline	104	122	165	158	213	193	165	158	165

*$p < 0.05$.
[a]All baseline measurements recorded at the start of treatment.
[b]All recent measurements are based on last visit's record.
[c]One way analysis of variance (ANOVA) for mean difference in CD4 cell count by gender.

In the second model, only female study populations were used. In this model, depressive symptoms did not have a significant effect on weight gain, and there was weak evidence to say perceived social support had a positive effect on weight gain ($p = 0.097$) and this may be because of reduced sample size.

In the third model, only the male study populations were used. In this model, severe depressive symptoms had a significant negative effect on weight gain ($p = 0.002$). One unit increase in depressive symptoms was associated with a decrease in weight on average by 9.84 kg. Perceived social support did not affect weight progression significantly.

Similarly the effect of depressive symptoms and perceived social support on CD4 cell progression was explored, adjusting for duration between baseline and recent measures, sex, age, income, education, marital



Duration on HAART(Months)	0	3	6	9	12	15	18	21	24	27	30	33	36	39	42	45	48	51
N: Female	1024	874	855	804	765	702	674	644	595	550	308	283	246	218	185	158	133	107
N: Male	652	537	526	472	474	424	415	414	396	360	232	212	188	177	146	125	109	92
N: Total	1676	1411	1381	1276	1239	1126	1089	1058	991	910	540	495	434	395	331	283	242	199

Figure 1. Change in median weight by gender from baseline to 51 months based on measurements taken every 3 months after the start of HAART.

Table 5. Student *t*-test for mean difference in weight and CD4 cell count between specific intervals by gender.

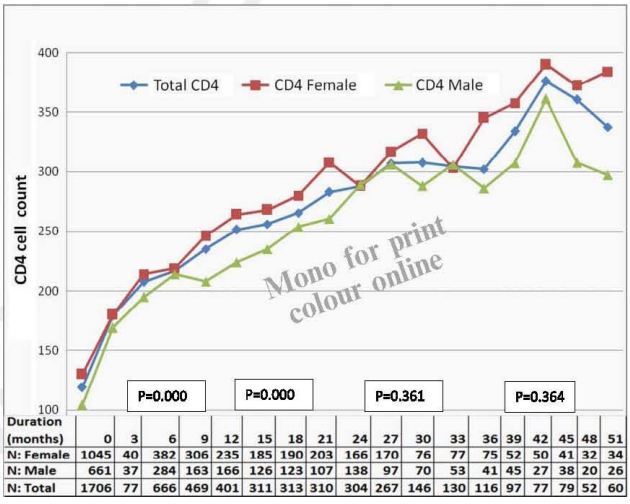
	Weight (kg)			CD4 cell count (cell/μl)		
Interval	Female	Male	Total	Female	Male	Total
Mean difference between baseline and 6th month						
Baseline	1024	652	1676	1045	661	1706
6 months	855	526	1381	382	84	666
t-test significance	0.000*	0.000*	0.000*	0.000*	0.000*	0.000*
Mean difference between 9th and 21st month						
9th month	804	472	1276	306	163	469
21st month	644	414	1058	203	107	310
t-test significance	0.802	0.106	0.193	0.000*	0.031*	0.000*
Mean difference between 24th and 36th month						
24th month	597	396	991	166	138	304
36th month	246	188	434	75	41	116
t-test significance	0.811	0.922	0.905	0.626	0.084**	0.361
Mean difference between 39th and 51st month						
39th month	218	177	395	52	45	97
51st month	107	92	199	34	26	60
t-test significance	0.894	0.429	0.143	0.100	0.840	0.264

*$p < 0.05$;**$p < 0.1$.

status, religion, and adherence to treatment. As it is shown in Table 7, the first model used the entire study population. In this model, depressive symptoms had a negative effect on CD4 cell progression while perceived social support had a positive effect.

A one unit increase in depressive symptoms was associated with reduced CD4 cell progression on average by 10.72 CD4 cells between baseline and recent CD4 cell count levels ($p = 0.013$) while a one unit increase in perceived social support was associated with an increase in CD4 cell count levels on average by 9.43 CD4 cells between baseline and recent levels ($p = 0.043$).

In the second model, the female study populations were used. In this model, there was weak evidence to say better perceived social support had significant positive effect on CD4 cell progression ($p = 0.08$). Similarly depressive symptoms did not show a



Duration (months)	0	3	6	9	12	15	18	21	24	27	30	33	36	39	42	45	48	51
N: Female	1045	40	382	306	235	185	190	203	166	170	76	77	75	52	50	41	32	34
N: Male	661	37	284	163	166	126	123	107	138	97	70	53	41	45	27	38	20	26
N: Total	1706	77	666	469	401	311	313	310	304	267	146	130	116	97	77	79	52	60

Figure 2. Change in median CD4 cell count by gender from baseline to 51 months based on measurements taken every 3 months after the start of HAART.

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Table 6. Regression model of influence of depression symptoms and social support on weight progression controlled for duration on HAART, sex, age, income, education, marital status, religion, and adherence to treatment among study participants on HAART for 6 months or more by gender.

	All, $N=1427$				Female, $N=872$				Male, $N=555$			
Weight	Coefficient	95% CI		p-level	Coefficient	95% CI		p-level	Coefficient	95% CI		p-level
AQ7 Duration	180.80	172.81	188.80	**0.000***	184.77	174.35	195.19	**0.000***	170.97	158.09	183.85	**0.000***
Depression symptoms unadjusted for duration	5.88	−1.25	13.02	0.106	0.47	−8.41	9.34	0.918	17.19	4.91	29.48	**0.006***
Perceived social support unadjusted for duration	−1.31	−8.91	6.29	0.735	−3.55	−13.66	6.56	0.491	2.25	−9.31	13.81	0.703
Depression symptoms adjusted for duration	−9.84	−18.33	−1.34	**0.023***	−4.68	−15.44	6.07	0.394	−22.97	−37.41	−8.54	**0.002***
Perceived social support adjusted for duration	10.00	0.79	19.21	**0.033***	10.46	−1.91	22.82	0.097	9.08	−4.65	22.80	0.195

*$p<0.05$.

Table 7. Regression model of influence of depression symptoms and social support on CD4 cell progression controlled for duration on HAART, sex, age, income, education, marital status, religion, and adherence to treatment among study participants on HAART for 6 months or more by gender.

	All, $N=1451$				Female, $N=882$				Male, $N=569$			
CD4	Coefficient	95% CI		p-value	Coefficient	95% CI		p-value	Coefficient	95% CI		p-value
AQ7 Duration	178.41	170.48	186.34	**0.000***	182.41	172.05	192.78	**0.000***	168.23	155.52	180.93	**0.000***
Depression symptom unadjusted for duration	5.71	−1.38	12.80	0.115	0.14	−8.73	9.00	0.976	19.70	7.64	31.76	**0.001***
Perceived social support unadjusted for duration	−0.66	−8.19	6.87	0.864	−2.86	−12.95	7.22	0.578	3.37	−7.89	14.64	0.557
Depression symptoms adjusted for duration	−10.72	−19.16	−2.27	**0.013***	−4.74	−15.47	6.00	0.387	−25.11	−39.36	−10.85	**0.001***
Perceived social support adjusted for duration	9.43	0.30	18.56	**0.043***	11.01	−1.31	23.33	0.080	7.17	−6.35	20.70	0.299

*$p<0.05$.

significant effect on CD4 cell progression among female study populations. The lack of association among female study population may be because of the sample size.

In the third model, the male study populations were used. In this model, worse depressive symptoms had a negative effect on CD4 cell progression ($p = 0.001$). One unit increase in depressive symptoms was associated on average with decrease in 25.11 CD4 cells between baseline and recent levels. In this model, perceived social support did not affect CD4 cell progression significantly.

Discussion

A significant proportion of the study population suffered from depressive symptoms including being upset, feeling unable to control important things in life, nervousness, and related issues. Significantly more females experienced these symptoms as compared to males ($p < 0.000$).

Regarding social support, a significant proportion did not have someone to borrow 100 Birr (6 USD) from if they needed it in an emergency (34%). A similar proportion did not have someone to provide care if they were confined to bed (33%). This implies that HIV-infected individuals were struggling on their own to cope with their HIV infection and the lifelong treatment that they need.

Progression of weight was affected by depressive symptoms negatively and by perceived social support positively. Presence of depressive symptoms is expected to lead to poor appetite and lack of interest which result in low progression of weight. On the other hand, better social support is closely attached with person's capacity to purchase food or get support from others which at the end can contribute to weight gain positively. This calls for strengthened and sustainable interventions to help those who are critically in need of support. Weight loss is closely correlated with poor survival among HIV-infected people. This means those who were suffering with depressive symptoms and who were receiving low social support were at a disadvantage for survival unless they got support (Koethe et al., 2010; Tang et al., 2002).

Depressive symptoms were also negatively correlated with CD4 cell progression and social support had a positive effect on CD4 count. Several studies have been carried out to explore the potential effect of social support and psychosocial issues on the well-being of HIV-infected individuals. Some studies have demonstrated correlations, and a few did not come with the expected associations.

A study carried out by Lyketsos and colleagues reported that depressive symptoms did not predict an accelerated mortality or worse medical course for people who were infected with HIV. None of the outcomes that they assessed, AIDS, death, and CD4 decline, were related to depression symptoms (Lyketsos et al., 1993). Similarly Kessler and Rabkin reported no relationship between stressor and CD4 decline or developing AIDS-related diseases (Kessler et al., 1991; Rabkin et al., 1991). However, other studies carried out by Burack, Patterson and Rabkin, and their colleagues had reported significant relationships between depression and subsequent decline in CD4 cell (Burack et al., 1993; Mayne et al., 1996; Rabkin et al., 1991).

In addition multiples of recent studies indicate significant association between depressive symptom and decreased CD4 cell progression (Anastos et al., 2005; Antelman et al., 2007; Bouhnik et al., 2005; Cook et al., 2002, 2004, 2006; Ickovics et al., 2001; Ironson et al., 2005; Leserman et al., 1999, 2000; Leserman et al., 2007; Lima et al., 2007; Pence et al., 2006). This highlights the existence of evidence about association between depressive symptoms and CD4 progression especially among studies carried in late 1990s and 2000 and beyond. Possible reasons for the lack of significant association among studies carried out in early 1990s are differences between studies in research design, data collection, number and quality of control variables, and measurement of depression.

Pertaining to social support, a study by Leserman and colleagues found that higher cumulative social support predicted less rapid progression to AIDS or to an AIDS-related clinical condition (Leserman et al., 2000). Theorell and his colleagues found stronger social support to be associated with a slower drop in CD4 cell count (Theorell et al., 1995). Another study by Patterson and colleagues indicated large social network size to be predictive of longevity among those with AIDS (Patterson et al., 1996). According to study carried out by Solano social support was related to the development of AIDS-related symptoms among those with low CD4 count (Solano et al., 1993).

In general, findings of this study were indicative of the negative role of depressive symptoms on both weight gain and CD4 cell count progression and the positive effect of social support on both outcomes. This is in line with the expected direction of association based on a review of the literature and it is supported by results published in the years late 1990s and 2000 and beyond.

Based on the findings the provision of psychosocial and social support services to HIV positive persons is recommended in order to avoid the

negative consequences of depressive symptoms and low levels of social support on weight and CD4 cell progression. Social support and psychosocial issues are very much interconnected. A strong social support environment could help lessen the effects of depression. An intervention that addresses both at the same time should be designed and implemented.

Limitations

This study had a number of noteworthy limitations. First, follow-up data was utilized as an outcome variable, yet the explanatory variables were collected once. This may not be an ideal design to determine factors influencing weight gain and CD4 progression. It was also relied on secondary data collected from study participants' medical records. The study is therefore subject to the limitations of using secondary data from records.

In addition, the findings might not be generalizable for the whole country, as data were collected from one HAART clinic. However, the findings can be generalized to the urban context and may contain important information that can be applied to rural areas.

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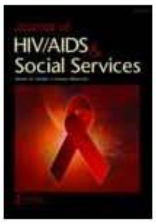
13.8. Annex 9: Manuscript III (Journal of HIV/Aids & Social Services)

Journal of HIV/AIDS & Social Services



Effect of perceived stigma on adherence to a dose of Highly Active Antiretroviral Therapy and self-confidence to take medication properly in Addis Ababa, Ethiopia

Journal:	*Journal of HIV/AIDS & Social Services*
Manuscript ID:	Draft
Manuscript Type:	Research and Practice Article
Keywords:	HIV, stigma, adherence

Abstract

Stigma has been major barrier to accessing HIV prevention, care and treatment services. This study seeks to assess the effect of stigma on self-reported adherence to Highly Active Antiretroviral Therapy (HAART) and self confidence to take medication correctly among HIV infected adults in Addis Ababa, Ethiopia. A descriptive cross-sectional study utilizing both quantitative and qualitative data was carried out at Zewditu Memorial Hospital's HAART clinic. Self-reported *Morisky* scale was used to assess adherence to HAART and *Berger's* stigma scale was used to measure the level of perceived stigma. The three measures of stigma (negative self image, concern about public attitude, and concern about disclosure) were negatively associated with self reported adherence to HAART and with self confidence to take medication correctly. In order to improve adherence, programs that address stigma need to be designed and implemented.

Key words: Stigma, adherence, HIV/AIDS, HAART, Self confidence

Introduction and background

Any measure of arbitrary differentiation among persons due to their confirmed or suspected HIV serostatus or state of health is referred to as HIV-related stigma. Discrimination is the negative act that results from stigma; it is the end result of the process of stigma (Goffman, 1963 & Carael, 2000). Stigma can cause social marginalization leading to loneliness, and can also contribute to fear of disclosure of HIV status. All of these will affect adherence to Highly Active Antiretroviral Therapy (HAART) (Ware et al., 2006).

Fear of social abandonment and losing intimate partners prevents many people infected with HIV from sharing their diagnosis with loved ones and sexual partners. Lapses in adherence to treatment often occur when there is concern that an acquaintance may witness pill-taking or find pill bottles, leading to unwanted questions about a person's health and, potentially, an unexpected "outing" as being HIV-positive (Weiser et al., 2003 & Chesney et al., 1999).

The association between stigma and adherence difficulties is usually accompanied by changes in mood and lack of social support (Catz et al., 2000; Gonzales et al., 1999). Stigma and discrimination can lead to depression and lack of self-esteem. Negative attitudes about HIV also create a climate in which people become more afraid of the stigma and discrimination associated with the disease than of the disease itself. When fear and discrimination prevail, people may choose to ignore the possibility that they may already be, or could become HIV positive even if they know they have taken risks (UNAIDS, 2003 & Ogden et al., 2005).

Through effects on the social, economic and family lives of individuals, HIV/AIDS stigma is cited as a major barrier to accessing HIV prevention, care and treatment services (Bond et al.,

2002; Chesney & Smith, 1999; Kalichman & Simbayi, 2003). HIV/AIDS stigma is documented as a barrier to the uptake of HIV testing and treatment services in numerous settings, particularly in resource-limited countries (Herek et al., 2003; Obermeyer et al., 2007; Herek et al., 2003; Ford et al., 2004; Pool et al., 2001). Specifically, stigma impedes access to and retention in HIV care, and adherence to antiretroviral medications. Non-disclosure of HIV status for fear of stigma may result in missing doses of medications in order to maintain secrecy about one's illness (Kinsler et al., 2007; Reif et al., 2005; Rao et al., 2007; Sayles et al., 2006). Studies demonstrating the adverse effects of stigma on retention in care and adherence are also emerging in Africa (Weiser et al., 2003; Nachega et al., 2006) and Asia (Kumarasamy et al., 2005).

In a study carried out in Botswana, 94% of study subjects kept their HIV status secret from their community, while 69% withheld this information even from their family. Twenty-seven percent feared loss of employment as a result of their HIV status. Forty percent reported delaying HIV testing and of these, 51% cited fear of a positive test result as the primary reason for the delay in seeking treatment, which was often due to HIV-related stigma (Wolfe et al., 2006).

A study carried out among youth reported that about 50% skipped doses of medication because they did not want families or friends to discover their status, demonstrating that HIV stigma impacts treatment for youth by influencing medication adherence negatively (Rao et al., 2007). In another study, 1 in 5 study subjects reported high levels of concern over stigma related to their HIV status, and level of concern about stigma was a predictor of non-adherence to medication (Rintamaki et al., 2006).

Taking the global evidence into consideration and because of lack of evidence within Ethiopia, this study seeks to assess the effect of stigma on self-reported adherence to HAART and on self confidence to take medication correctly.

Methods

This study was carried out in Addis Ababa, the capital city of Ethiopia, at Zewditu Memorial Hospital's HAART clinic. It is the largest HIV clinic in Ethiopia with more than 14,000 clients in its care.

The study design was descriptive cross-sectional with a sample population of HIV infected adults age 18 years or above who received their medication at the HAART clinic. A sample size calculation formula for two population proportions was used so that it would be possible to detect differences by the different types of stigma. A study carried out by K. R. Waite et al (Waite et al., 2008) reported that among those with high levels of social stigma concern, 46.4% were non-adherent while among those with low levels of social stigma concern, 22.5% were non-adherent. Although this study reported a difference of 24%, this study was designed in a way to detect a difference as low as 8%. Considering a power of 90% and 5% alpha level of error, the total sample size needed was calculated to be 1,733.

During the data collection period, 5,142 active adult clients were receiving HAART from Zewditu Memorial Hospital. All clients who fulfilled the inclusion criteria were included in the sampling frame. By using computer generated random table numbers, 1,733 eligible individuals were selected for the study based on their unique HAART identification number. Trained data collectors stayed at the HAART clinic from February 1 – March 19, 2010 to interview study subjects while clients came to the clinic for follow-up.

Quantitative data were collected utilizing a standard questionnaire which was prepared in English and translated into the local language (Amharic) for easy administration. Consistency of

the questions was checked by back-translation. The questionnaire was pre-tested in a similar population who were excluded from the final study.

To complement the quantitative data, qualitative data were collected through in-depth interviews with 9 clients. Three of the nine respondents were males. The interviews were conducted with each of the respondents, for a maximum of 30 minutes, using a discussion guide prepared to address issues which needed further exploration. The saturation level was reached with the nine interviews.

The two outcome variables for this study were self-reported adherence to HAART and self-confidence in taking medication properly. Both were measured by self report using questions which have standard scales of responses.

The four-item self-report *Morisky* scale was used in this research to assess adherence to HAART with scale measurement ranging from "0" indicating a low level of adherence to "4" indicating a high level of adherence. The four questions were: "*Many people forget to take medications on time. Do you ever forget to take your medicines?"*; *"Are you careless at times about taking your medicines?"*; *"When you feel better, do you sometimes stop taking your medicine?"; and "Sometimes, if you feel worse when you take your medicine, do you stop taking it?"*(Morisky et al., 1986).

To assess self-confidence in taking medication correctly and respondents' beliefs in their medication, three four-point questions were used. These questions were: "*How sure are you that you will be able to take all or most of the medication as directed*?"; "*How sure are you that the medication will have a positive effect on your health*?"; and "*How sure are you that if you do not*

take this medication exactly as instructed, the HIV in your body will become resistant to HIV medications?" The three questions were rated from; "not at all sure" indicating low self-confidence to "extremely sure" indicating high levels of self-confidence.

For both scales of measurements, the total score was calculated and study subjects were categorized into two groups. *Morisky* scale scores were categorized into those with sum of scores of 0 (never missed medication) and those with sum of scores of 1 and above (have ever missed medication). The sum of self confidence scores was also categorized into two; one with sum of self confidence score values of 6 and below and the other with sum of scores of 7 and above.

Berger's stigma scale was used to measure the level of perceived stigma. The scale has four subscales: personalized stigma (11 questions), disclosure concerns (10 questions), negative self-image (8 questions), and concern with public attitudes toward people with HIV (10 questions). Each item or question is rated on a 4-point scale from "Strongly Disagree'' (1 point), through "Disagree" (2 points), "Agree" (3 points) to "Strongly Agree" (4 points). This instrument has been tested for internal consistency and reliability (coefficient alphas=0.96). The scale was recommended as reliable and valid with a large and diverse sample of people (Berger et al., 2001).

Total stigma score values were calculated for each study participant. Higher total score values indicate serious levels of social stigma. Minimum and maximum scores, mean and median values, and proportions of study subjects who fell into the four different quartiles were calculated.

A binary logistic regression model was used to explore associations between the two outcome variables (self-reported adherence to treatment and self-confidence in taking medication) and the different forms of stigma (concern about disclosure, concern with public attitudes toward people with HIV, negative self-image, and personalized stigma) by controlling for gender, age, income, education, religion, marital status, duration of time on treatment and disclosure of HIV status.

This study was reviewed and approved by the institutional review board of the College of Health Sciences, Addis Ababa University. To assure voluntary participation, verbal informed consent was obtained from each study participant. Privacy, confidentiality and benefit were maintained.

Results

Socio-demographic characteristics of study participants

As presented in Table 1, the majority of study participants were female (61.3%) and older than 30 years of age (75.9%). Among the females, a significant proportion (33.5%) were 30 years old or younger, but among male study participants only 9% were in this age category.

More than half of the respondents were in a union with a sexual partner (54.1%). Most participants were Orthodox Christians by religion (80.8%), followed by Protestant Christian (12.8%), Moslems (4.6%), and Catholics (1.4%).

About 35% of study participants (40.2% of females and 26.4% of males) reported spending less than 500 Birr (30 USD) per month for all living expenses. More than 31% (31.8% of females and 30.6% of males) spent from 500 to 999 Birr (30 – 59 USD) per month, and 21.4% (16.9% of females and 28.4% of males) spent from 1000 to 1999 Birr (60 – 119 USD) per month. Only 12.4% (11.1% of females and 14.6% of males) spent 2000 Birr (120 USD) or more per month.

The median duration of time on HAART for the entire study population was 46 months (44 months for females and 49 for males) with Inter Quartile Range (IQR) from 27 to 62 months. About 22% (23.1% of females and 21.2% of males) of study participants had been on HAART for less than 12 months, 17.6% (17.9% of females and 16.9% of males) for 12 to 24 months, 19.4% (21.7 of females and 15.8% of males) for 25 to 48 months, and the remainder (40.6%, 37.2% of females and 46.1% of males) had been on HAART for 48 months or more(.

A significant proportion of study participants (61.2%, 58.7% of females and 65.0% of males) had disclosed their HIV status to families, friends, or sexual partners.

Adherence to HAART and self-confidence to take medication correctly

As presented in Table 2, the minimum and maximum sum of scores for the *Morisky's scale* questions were 0 (0 among both male and female study participants) and 12 (12 among female and 9 among male study participants), respectively. The mean sum of scores value was 0.64. The mean value was higher among female (0.69) and lower among male study subjects (0.55). This difference was statistically significant ($p < 0.01$).

The proportion of study subjects with perfect adherence (sum of scores value equal to zero which meant those who had never missed a single dose of HAART since the start of treatment) was 60.1%. This proportion was higher among males (63.5%) and lower among females (57.9%). The proportion with fair adherence (sum of scores for the four questions equals 1) was 24.4% (24.1% among females and 24.9% among males) and the proportion with poor adherence (sum of score for the four questions equals 2 or above) was 15.6% (18.1% among females and 11.6% among males).

The minimum and maximum sum of scores values for the self-confidence scale questions were 0 and 9 respectively. The mean sum of self-confidence score was 7.2. It was higher among males (7.32) than females (7.09), and this difference was statistically significant ($p < 0.01$). About 43% of study subjects (40.6% of females and 46.9% of males) scored 9 out of 9, indicating a high level of confidence to correctly take HAART. Nearly 48% of study participants (44.8% of females and 45.1% of males) scored below the median value.

Prevalence of the different forms of stigma (concern about disclosure, concern about public attitude, negative self image, and personalized stigma)

Concern about disclosure of HIV status

The minimum and maximum total score values for the "concern about disclosure of HIV status" sub-scale were 10 and 40 respectively. The mean total score was 29.69. There was no significant difference by gender (29.90 among females and 29.34 among males). When categorized by quartiles based on their total scores, 27.1% of study participants lay in the first quartile while the remaining 23.2%, 20.8%, and 28.9% of study participants lay in the second, third, and fourth quartiles respectively.

Concern about public attitude towards HIV infected persons

The minimum and maximum total score values for the "concern about public attitude towards HIV infected persons" sub-scale were 10 and 40 respectively. The mean value of the total score was 26.71. There was no significant difference by gender (26.88 among females and 26.45 among males). When categorized by quartiles based on their total scores, 25.2% of study participants lay in the first quartile while the remaining 18.9% lay in the second quartile, 27.9% in the third quartile and 28.0% in the fourth quartile.

Negative self image

The minimum and maximum total score values for the "negative self image" sub-scale were 8 and 31 respectively. The mean value of the total score was 18.66. There was no significant difference by gender (18.79 among females and 18.44 among males). When categorized by

quartiles based on their total scores, 26.9% and 22.2% of study participants lay in the first and second quartiles respectively while equal proportions (25.4%) lay in the third and fourth quartiles.

Personalized stigma

The minimum and maximum total score values for the "personalized stigma" sub-scale were 11 and 44 respectively. The mean value of the total score was 28.98. There was no significant difference by gender (29.09 among females and 28.80 among males). When categorized by quartiles based on their total scores, 28.5% of study participants lay in the first quartile. The remaining 18.9%, 23.8% and 28.8% lay in the second, third, and fourth quartiles respectively.

Effect of concern about disclosure of HIV status, concern about public attitude towards HIV infected people, negative self image and personalized stigma on self-reported adherence to HAART and self-confidence to take medication correctly

As presented in Table 4, "negative self image" was significantly associated with both self-reported adherence to HAART and self-confidence to take medication correctly. Persons who had higher levels of negative self image (those who lay in the second, third and fourth quartiles) were less likely to take all of their medication correctly (second quartile: OR= 0.51, CI= 0.37 to 0.69, third quartile: OR= 0.40, CI= 0.28 to 0.58, and fourth quartile: OR= 0.42, CI= 0.30 to 0.59, all compared with first quartile). Similarly, persons who had higher levels of negative self image (those who lay in the second and fourth quartiles were less confident to take their medication correctly (second quartile: OR=0.65, CI= 0.48 to 0.88 and fourth quartile: OR= 0.60, CI= 0.43 to 0.84, compared with first quartile).

Likewise, "concern about disclosure of HIV status" significantly determined self-reported adherence to HAART and self-confidence to take medication correctly. Persons who were more concerned about disclosure of HIV status (those who lay in the third quartile) were less likely than those in the first quartile to have taken their medication (third quartile: OR= 0.68, CI = 0.49 to 0.) . Similarly, those who were more concerned about disclosure of HIV status (those who lie in the third and fourth quartiles) were less likely to be confident to take medication correctly (third quartile: OR= 0.63, CI = 0.46 to 0.88 and fourth quartile: OR = 0.49, CI = 0.35 to 0.70, compared to first quartile).

Similarly, "concern about public attitude towards HIV infected people" was significantly associated with both self-reported adherence to HAART and self-confidence to take medication correctly. People who were more concerned about the public's attitude towards HIV infected people (those who lay in the second and third quartiles) were less likely to take all of their medication correctly than those in the first quartile (second quartile: OR= 0.66, CI= 0.46 to 0.94 and third quartile: OR= 0.58, CI= 0.38 to 0.87). Likewise, people who were more concerned about public attitude towards HIV infected people (those who lie in the fourth quartile category) were less confident to take their medication correctly (fourth quartile: OR= 0.60, CI= 0.37 to 0.98, compared to first quartile).

Neither the associations between "personalized stigma" and self-reported adherence to HAART, nor that between personalized stigma and self-confidence in taking HAART correctly were statistically significant.

Findings from qualitative data

In-depth interview respondents confirmed that their medication and treatment had brought significant positive effects in improving their physical health and wellbeing. Because of this improved wellbeing, many were attending higher levels of education, were employed or were able to earn an income, and women had given birth to HIV-negative children, bringing them hope for the future. They had never stopped taking their medication, nor did they plan to do so. Respondents were asked to rate their adherence to daily dose of HAART out of 10: one rated it as 7, five as 8, one as 9 and two as rated 10 out of 10.

Respondents confirmed that the prevalence of stigma and discrimination had been decreasing over time, but that it still existed. They reported knowing several individuals who stopped taking their medication due to serious stigma and discrimination from close families and friends. One female respondent indicated that she knew a 17 year old woman who discontinued her medication due to mistreatment from her sister. Others also confirmed knowing lots of people who had difficulties taking medication correctly, and those who had stopped their medication because they were highly stigmatized, especially by close families and relatives.

One of the female in-depth interview participants said *"... I know a woman who was hiding her medication under her bed because she did not want her husband to know. She usually missed her medication, or took it very late as she could not take it in front of her husband or other people. After some time, she quit taking her medication and died after serious suffering."*

Another female in-depth interview participant said *"...until now I have never been stigmatized or discriminated since nobody knew my status. However, I knew lots of people who gave up taking*

their drugs due to discrimination, especially from those closest to them, like their mother, husband/fiancé, and best friends."

The major reasons for poor adherence reported by in-depth interview participants were: poverty, especially not having enough food to eat; discrimination from close family members; loneliness and lack of social support; wanting to die due to hopelessness because of stigma and discrimination; fatigue of taking so much medication daily; side effects; inadequate adherence counseling and support; and shifting from drug to spiritual therapies.

Discussion

The mean adherence score for *Morisky's* scale was 0.64, higher for females (0.69) than males (0.55). More than 60% of study participants stated they had never missed medication. The proportion that had never missed medication was higher among males (63.5%) than females (57.9%). This implies that males adhere to their medication better than females. This may be due the higher status of men both economically and socially in most developing countries including Ethiopia. Studies had also reported higher HIV-related depression, stress, and stigmatization among women compared to men that predispose them to lower adherence levels (Applebaum AJ, 2009; Kacanek D., 2010; Lima VD, 2007; Peretti-Watel P., 2006; Turner BJ., 2003). Mean self-confidence level was also higher for males (7.32) and less among females (7.09). This suggests that males are more self confident than females in terms of taking their medication correctly. Overall, the proportion of study subjects with sub-optimal adherence to a dose of HAART was 15.6%. This result is lower than the 23% sub-optimal adherence level reported in a meta-analysis of adherence studies carried out in Africa (Edward et al., 2006). Other studies in Africa have also shown high adherence levels. There are various explanations for this. According to an ethnographic study done at HIV treatment sites in Nigeria, Tanzania, and Uganda, the primary reason most Sub-Saharan Africans adhere to HAART is because they want to be healthy. But the desire for health alone does not adequately explain adherence success. The role of social capital in relationships is also highlighted as important for overcoming economic obstacles to care (Ware et al., 2009). This difference may also be attributed to differences in the methodology of the studies and social desirability bias.

Concerning the extent of perceived stigma; 28.9% (those who lay in the fourth quartile) of the study participants were highly concerned about disclosure of HIV status, and a similar proportion were suffering from personalized stigma (28.8% lay in the fourth quartile). Twenty eight percent of the study participants were highly concerned about public attitudes towards HIV infected persons (in the fourth quartile) and 25% were highly concerned about negative self image (also in the fourth quartile).

The three measures of stigma (negative self image, concern about public attitude, and concern about disclosure) were negatively associated with self reported adherence to HAART and with self-confidence to take medication correctly. Other studies have also demonstrated the negative effect of stigma on adherence to HAART. In a study by Talam and colleagues, 29% of study subjects missed a dose of HAART due to stigma (N.C Talam et al., 2008).

Studies have also documented relationships between increased stigma and decreased life satisfaction and depression. Perceived HIV stigma has a significant negative impact on life satisfaction and quality of life (Minrie et al., 2010). Dissatisfied individuals often lack the motivation to take medications correctly. The more negative the self image one has, the more likely one is to be depressed. This can lead to decreased interest in life and thus poor adherence to medication and low levels of self-confidence. Hopelessness and negative feelings are expected to reduce motivation to take medication correctly. According to a study by Byakika-Tusiime et al., people with depression were less likely to properly adhere to medication (Byakika-Tusiime et al., 2009). Studies and literature reviews about predictors of adherence indicate that depression and stress are the most significant predictors of non-adherence (Paterson et al., 2000; Chesney et al., 2000; Amberbir et al., 2008 & Rintamaki et al., 2006)

Disclosure of HIV status is also expected to have implications on adherence to HAART. If people do not disclose their HIV status, they may be forced to hide their medication from others. In this particular study, higher level of concern about disclosure of HIV status was associated with being less likely to never miss medication and to be self confident to take medication correctly. Similar findings have been reported from other studies in Africa. A study done in Tanzania at Kilimanjaro Christian Medical Centre reported not disclosing HIV status to be one of the reasons for non adherence to HAART (Habib O. et al., 2007). Likewise, in a study carried out by Birbeck et al., disclosing medication-taking to a sexual partner was associated with good adherence (Birbeck et al., 2009).

Stigma is not only associated with psychological problems and adherence difficulties, it is also experienced more commonly among people who disclose their HIV status to a broad range of social contacts (Vanable et al., 2006). When people disclose their HIV status, they are often put in a difficult situation within their community because of the prevailing stigma. However, not disclosing HIV status may prevent patients from receiving the desired social support from communities and make it difficult to correctly adhere to treatment.

Findings of the quantitative data were reinforced by the qualitative data. In-depth participants stressed stigma and discrimination from close family members, loneliness and lack of social support to be the most important determinants of adherence to HAART. Thus, lack of social support is expected to result in poor adherence to medication (Deribe et al., 2008). However, the presence of social support systems addressing psychosocial problems is positively related to adherence with HAART. Supportive friends and families also play a role in

facilitating HAART adherence. Treatment buddies and peer counseling are of additional help (Paterson et al., 2000 & Morse et al., 1991).

In summary stigma makes disclosure of HIV infection difficult. If people do not disclose their HIV status and medication taking to others they will have difficulties of adhering to their treatment. On the other side, although people might disclose their HIV status they might be forced to shoulder the stigma from the community which might lead to hopelessness and patients may become careless at taking their medication properly.

Strengths and limitations

This study focused on an important research agenda which has negative implication on HIV/AIDS treatment and care services. It also used relatively large sample size and standardized and pre-tested questionnaire to assess the effect of stigma on adherence to HAART. Furthermore, the study used both quantitative and qualitative data and quality of data was maintained at all levels from collection to analysis.

One of the noteworthy limitations of the study is the fact that it used self-report to assess adherence to HAART which might entertain some level of underreporting due to social desirability. In additions, the findings might not be generalizable for the whole country, as data were collected from one HAART clinic. However, the findings can be generalized to the urban context and contains important information that can be applied to Ethiopia and other Sub-Saharan African countries

Conclusion and recommendation

The findings from this study and previous evidence suggest that stigma is associated with non adherence to HAART. HIV-related stigma from peers and family emerged as an important factor driving non-adherence. In order to improve adherence, programs that aim to address stigma in communities and facilitate social support need to be designed and implemented.

Implications of the study

Although further research in the area has been recommended the effect of stigma on adherence to HAART has been evidenced in the current study using quantitative and qualitative data. Policy makers and implementers need to design targeted interventions to address stigma in the county to counterpart its negative effect on adherence.

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Table 1. Basic socio-demographic characteristics of study participants, N=1722

Characteristics	Female (%*)	Male (%*)	Number (%*)	P level
Gender	1056 (61.3)	667(38.7)	1722(100)	0.000
Age (complete years)				
≤30	354(33.5)	60(9)	414(24.1)	0.000
31-39	423(40.1)	218(32.7)	641(37.2)	
≥40	279(26.4)	641(58.3)	667(38.7)	
Mean	35.54± 8.16	41.71+ 8.83	37.93± 8.97	
Marital status				
Currently in union	524(49.6)	407(61.1)	932(54.1)	0.000
Currently not in union	532(50.4)	259 (38.8)	791(45.9)	
Religion				
Orthodox Christian	855(80.9)	537(80.6)	1393(80.8)	
Moslem	39(3.7)	40(6.01)	79(4.6)	
Protestant	139(13.2)	81(12.2)	220(12.8)	0.027
Catholic	20(1.89)	4(0.6)	24(1.4)	
Other	3(0.28)	4(0.6)	7(0.4)	
Monthly expense (Birr**)				
<500	424(40.2)	176(26.4)	600(34.8)	
500 – 999	336(31.8)	204(30.6)	541(31.4)	
1000 – 1999	179(16.9)	189(28.4)	368(21.4)	0.000
2000 and above	117(11.1)	97(14.56)	214(12.4)	
Duration on HAART				
Less than 12 months	244(23.1)	141(21.2)	385(22.4)	
12 – 24 months	190(17.9)	113(16.9)	303(17.6)	
25 – 48 months	229(21.7)	105(15.8)	334(19.4)	0.001
More than 48 months	393(37.2)	307(46.1)	700(40.6)	
Median duration (Inter-quartile range)	44(26 – 58)	49(29-67)	46(27-62)	
Disclosed HIV status to either sexual partner or families or friends				
Yes	620(58.71)	433(65.02)	1053(61.15)	
No	436(41.29)	233(34.98)	669(38.85)	0.009

* *Percentage rounded to once decimal point*

** *1 USD is equivalent to 16.38 Birr at the time of study*

Table 2. Adherence to HAART using Morisky scale and self confidence in taking medication accurately, by gender

	Female (N=1056)	Male (N=666)	Total (N=1722)
Adherence characteristics			
Sum of scores for adherence to HAART (Morisky scale*)			
Minimum and Maximum scores	0 & 12	0 & 9	0 & 12
Mean score (SD)	0.69 (±1.06)	0.55 (±0.97)	0.64 (±1.03)
Proportion with perfect adherence (sum of the three scales=0)	611(57.9%)	423(63.5%)	1034(60.1%)
Proportion with fair adherence (sum of the three scales=1)	254(24.1%)	166(24.9%)	420(24.4%)
Proportion with poor adherence (sum of the three scales=2 and above)	191 (18.1%)	77(11.6%)	268(15.6%)
One way ANOVA	R-Squared=0.0041 & F=0.0078		
Self confidence in taking medication			
Sum of scores for self confidence in taking medication (three questions with four scales**)			
Minimum and Maximum scores	0 & 9	0 & 9	0 & 9
Mean (SD) of the score	7.09(±1.92)	7.37(±1.82)	7.2(±1.89)
Proportion with sum score of 9 out of 9	427(40.6%)	312(46.9%)	739(43.1%)
Proportion with score of below the median	471(44.8%)	300(45.1%)	771(45.1%)
Proportion with sum of scores 6 and below	471(44.6%)	250(37.5%)	721(41.9%)
Proportion with sum of scores 7 and above	585(55.4%)	416(62.5%)	1001(58.1%)
One way ANOVA	R-Squared:=0.0052 & F=0.0027		

*sum of four questions with five scales **sum of three questions with four scales

Table 3. Concern about disclosing HIV status, concern about public attitude, concern about negative self image, and personalized stigma scores classified by quartiles and by gender

	Female N=1056	Male N=666	Total N=1722	P
Concerns about disclosing HIV status (sum score)				
Minimum and maximum sum score	10 & 40	10 & 40	10 & 40	
Mean score (SD)	29.90(±5.78)	29.34 (±6.08)	29.69(±5.90)	0.054
Proportion 1st Quartile	268(25.4)	199(29.9)	467(27.1)	
Proportion 2nd Quartile	249(23.6)	150(22.5)	399(23.2)	
Proportion 3rd Quartile	221(20.9)	137(20.6)	358(20.8)	
Proportion 4th Quartile	318(30.1)	180(27.0)	498(28.9)	0.201
Concern about public attitude (sum score)				
Minimum and maximum score	10 & 40	10 & 40	10 & 40	
Mean score (SD)	26.88(6.55)	26.45 (6.75)	26.71(6.63)	0.192
Proportion 1st Quartile	259(24.5)	174(26.1)	433(25.2)	
Proportion 2nd Quartile	200(18.9)	125(18.8)	325(18.9)	
Proportion 3rd Quartile	288(27.3)	192(28.8)	480(27.9)	
Proportion 4th Quartile	309(29.3)	175(26.3)	484(28.0)	0.558
Concern about negative self image (sum score)				
Minimum and maximum score	8 & 31	8 & 31	8 & 31	
Mean score (SD)	18.79(4.69)	18.44(4.47)	18.66(4.61)	0.120
Proportion 1st Quartile	282(26.7)	181(27.2)	463(26.9)	
Proportion 2nd Quartile	229(21.7)	154(23.1)	383(22.2)	
Proportion 3rd Quartile	266(25.2)	172(25.8)	438(25.4)	
Proportion 4th Quartile	279(26.4)	159(23.9)	438(25.4)	0.678
Personalized stigma (sum score)				
Minimum and maximum score	11 & 44	11 & 44	11 & 44	
Mean score (SD)	29.09(8.15)	28.80 (8.24)	28.98(8.24)	0.478
Proportion 1st Quartile	292(27.7)	199(29.9)	491(28.5)	
Proportion 2nd Quartile	203(19.2)	123(18.5)	326(18.9)	
Proportion 3rd Quartile	249(23.6)	161(24.2)	410(23.8)	0.356
Proportion 4th Quartile	312(29.6)	183(27.5)	497(28.8)	

Table 4. Logistic regression model for correlation between never missing medication since the start of treatment and being self confident in taking medication with disclosure status, negative self image, concern about public attitude, concern about disclosure, and personalized stigma controlled for gender, age, income, education, religion, marital status, duration of stay on treatment and disclosure of HIV status to families, friends, and sexual partner, N=1706

Characteristics	**Never miss medication**				**Have better self confidence in taking medication**			
	OR	[95% Conf.]		P>z	OR	[95% Conf.]		P>z
Negative self-image								
1st Quartile	1				1			
2nd Quartile	0.51	0.37	0.69	0.000	0.65	0.48	0.88	0.006
3rd Quartile	0.40	0.28	0.58	0.000	0.75	0.53	1.08	0.125
4th Quartile	0.42	0.30	0.59	0.000	0.60	0.43	0.84	0.003
Concern about public attitudes								
1st Quartile	1				1			
2nd Quartile	0.66	0.46	0.94	0.021	0.88	0.61	1.27	0.485
3rd Quartile	0.58	0.38	0.87	0.009	0.73	0.48	1.12	0.147
4th Quartile	1.01	0.62	1.63	0.979	0.60	0.37	0.98	0.040
Concern about disclosure								
1st Quartile	1				1			
2nd Quartile	0.97	0.72	1.32	0.859	1.16	0.84	1.59	0.374
3rd Quartile	0.68	0.49	0.94	0.018	0.63	0.46	0.88	0.006
4th Quartile	1.10	0.77	1.56	0.610	0.49	0.35	0.70	0.000
Personalized stigma								
1st Quartile	1				1			
2nd Quartile	0.84	0.60	1.18	0.308	1.06	0.75	1.50	0.757
3rd Quartile	0.81	0.55	1.20	0.295	1.07	0.72	1.60	0.740
4th Quartile	1.29	0.85	1.95	0.226	1.26	0.82	1.92	0.287

Declaration

LETTER FOR DECLARATION (Dissertation Work)

I, the under signed, declared that this is my original work, has never been presented in this or any other University, and that all the resources and materials used for the thesis, have been fully acknowledged.

Name: _____

Signature: _____

Date: _____

Place: _____

Date of Submission: _____

This thesis has been submitted for examination with my approval as University Supervisor

Name: _____

Signature: _____

Date: _____