



USAID | HEALTH POLICY
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EQUITY AND ACCESS TO ART IN ETHIOPIA

JUNE 2010

This publication was produced for review by the U.S. Agency for International Development (USAID). It was prepared by Yared Mekonnen, consultant, and Rachel Sanders, Senait Tibebe, and Priya Emmart of the Health Policy Initiative, Task Order I.

Suggested citation: Mekonnen, Yared, Rachel Sanders, Senait Tibebe, and Priya Emmart. 2010. *Equity and Access to ART in Ethiopia*. Washington, DC: Futures Group, Health Policy Initiative, Task Order I.

The USAID | Health Policy Initiative, Task Order I, is funded by the U.S. Agency for International Development under Contract No. GPO-I-01-05-00040-00, beginning September 30, 2005. HIV-related activities of the initiative are supported by the President's Emergency Plan for AIDS Relief (PEPFAR). Task Order I is implemented by Futures Group International, in collaboration with the Centre for Development and Population Activities (CEDPA), White Ribbon Alliance for Safe Motherhood (WRA), and Futures Institute.

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The views expressed in this publication do not necessarily reflect the views of the U.S. Agency for International Development or the U.S. Government.

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ACKNOWLEDGMENTS

The authors thank Ethiopia's HIV/AIDS Prevention and Control Office (HAPCO) for its support in coordinating the study and facilitating access to the study sites, conducting the methodological review, and holding consultative meetings. Gratitude also goes to the facilities that hosted the study and the data collectors and supervisors who carried out the study (coordinated by Mela Research, PLC). Special thanks go to USAID/Washington and USAID/Ethiopia, particularly Dawit Abraham; and to all the study participants without whom this would not have been possible.

EXECUTIVE SUMMARY

The advent of antiretroviral treatment (ART) in Ethiopia has improved the quality of life for HIV-positive people and increased their rate of survival. Since Ethiopia's ART program began in 2003, 210,637 people have started on treatment in 481 facilities throughout the country. ART service expansion has been recent and fast from only four facilities in 2003 to 481 in 2009.

Thus far, the Ethiopian government has approached ART provision within the context of universal access for all. Thus, equity is certainly among the most important aspects of Ethiopia's policy agenda on ART scale-up. However, although there is a policy mandating free-of-charge ART for all, many people living with HIV (PLHIV) are not accessing ART through the system or are lost to follow-up.¹ To help address this issue, the USAID | Health Policy Initiative, Task Order 1, explored the barriers to accessing ART in Ethiopia to gain a better understanding of those people both currently undergoing ART, as well as those who need ART but are prevented from accessing it..

The study focused on nine health facilities and the surrounding communities in the Addis Ababa, Amhara, and Oromia regions. The findings are predominately based on qualitative methods, involving focus group discussion (FGDs), in-depth key informant and health worker interviews, and a document review. Individual-level ART data were also extracted from health facilities. The study's key findings and recommendations are presented below.

Progress Toward Equity in ART Access

Overall, equity is explicitly or implicitly a part of most of Ethiopia's policies, programs, and guidelines regarding ART. However, equity monitoring is insufficient, decreasing accountability and hindering improvement to equitable access for all.

More women than men are using ART. Both the national ART data and data extracted from sample facilities show that 55–60 percent of ART users are female. This increase in the number of women accessing ART is encouraging; however, an increase in the percentage of women versus men does not translate to equity, as the proportion of HIV-positive women remains 50 percent higher than the proportion of HIV-positive men.

ART access for the poor and vulnerable groups is improving. Patient-level ART data extracted from health facilities sampled for this study provide information on sex, age, work status, and education and marital status of ART users. Although the data represent only a small fraction of the ART users in Ethiopia, some important patterns are apparent when viewed through the equity lens. The majority of ART users in the facilities were female (59.2%), non-working (42%), illiterates or with elementary education (54%), and widow/divorced (32%), showing that those who often lack access to services are being reached. Improved access to ART for these population groups is likely a result of the recent provision of ART in health centers, bringing services closer to the community.

More effort is needed to expand access to the rural population—ART services are urban-biased. While the number of PLHIV accessing treatment has increased, evidence suggests that the majority of ART users are from urban areas. While HIV prevalence in the rural areas is only 0.7 percent, nearly nine times lower than urban prevalence, 40 percent of the population needing ART resides in rural areas (MOH, no date). Expanding ART to rural areas is challenging due to the dispersion of the population over vast geographic areas, but expansion of both testing and care and treatment services to

¹ ART patients' outcomes encompass the following broader categories: patients who (1) are alive and still on treatment, (2) stopped treatment, (3) transferred to another facility, and (4) were lost to follow-up. A patient who misses appointments for one to three months is considered lost to follow-up.

the community-level through satellite facilities and outreach programs is necessary to ensure equitable access for all.

Barriers to ART Use

The key barriers identified at the individual, community, and health system levels are described below. Focus groups found that although all the barriers were important, the individual- and community-level barriers had the most significant impact on ART use.

Individual-level barriers. Many PLHIV have perceived constraints to beginning ART based on a reluctance to commit to treatment adherence for life or a fear of side effects. In addition, the personal belief that their fate is in God's hands or that they can be cured or slow the disease's progression if they eat well and lead a serene life keeps many from turning to medical treatment.

Social/Community-level barriers. Stigma, whether perceived or real, is a barrier to treatment for many. PLHIV often do not disclose their status to others due to stigma and put their adherence at risk when they take steps such as traveling long distances for anonymous treatment or hiding or skipping pills to ensure that others, especially employers, do not find out their status.

Pressure from community members to shun ART for traditional treatments or religious options, such as the use of Holy water, keeps many PLHIV from accessing ART. Although the Ethiopian Orthodox Church endorsed concurrent use of Holy water and ART, PLHIV still receive mixed messages and pressure to abandon ART for Holy water.

Health system-related barriers. Facility-related indirect costs noted as barriers to ART included transportation costs and laboratory and drug-related costs associated with opportunistic infections and other health issues. These additional costs are unbearable for many already financially vulnerable PLHIV.

Long queues and waiting times, often due to understaffing, was reported as a barrier in larger hospitals. Facilities suffer from high staff turnover—in many cases due to lack of incentives and overworked providers who cannot keep up with the demand for services. This constant turnover leads to healthcare providers who are stretched beyond their limits and patients who are frustrated by a lack of consistency between visits.

Issues with equipment and supplies, especially related to the crucial CD4 machines, posed problems for many patients and healthcare staff. Absence and malfunctioning of machines, power supply issues, and frequent shortages of necessary kits and laboratory supplies cause delays in processing of samples and spoilage of blood samples.

Lack of integration with other services can increase stigma for PLHIV accessing ART when they are sent to obviously marked, separate wards and areas for treatment. Lastly, operational barriers such as required ID cards and proof of permanent residence hinder those people without ID and those who are transient or renting housing from accessing services.

Discontinuation Factors

Men, youth, and non-working PLHIV are more likely to discontinue ART, and those accessing treatment at health centers are 80 percent more likely to discontinue ART. Common reasons for discontinuation included lack of resources, such as food and money for transport and medical costs; and situational factors including stigma, addiction, incarceration, and stopping treatment during fasting seasons. Also, PLHIV often make discontinuation decisions based on self-assessment. For example, an individual may

stop treatment when (1) it does not seem to be working or improves the individual's health so much that he/she believes he/she is cured and does not need treatment; (2) the individual cannot handle side effects; or (3) he/she experiences treatment fatigue and lack of commitment to continue treatment for life.

Recommendations

Actions at the policy, community, and facility levels are recommended to lessen the barriers identified in this study.

Policy level

- Clearly define potentially underserved populations for ART-related services and develop equity monitoring indicators at the national level to evaluate progress toward equity in access to treatment for these groups.
- Because food support programs were shown to be crucial to recruiting and maintaining ART users, map food support programs available for PLHIV on ART and evaluate program efficiency, sustainability, impact, and pitfalls.

Community level

- Work to educate communities about HIV and ART to facilitate an enabling environment in which PLHIV will be more comfortable disclosing their status and accessing the services they need. Increasing access is closely linked to reducing stigma at the community level.
- Work with churches, PLHIV associations, and communities to address the prevailing confusion between simultaneous use of ART and Holy water, and vigorously promote ART as the single most effective treatment option for HIV. Partnerships with Islamic faith groups can also benefit PLHIV by helping patients adhere to ART during fasting seasons.

Facility and health systems level

- Meet treatment demand by strengthening facilities' physical assets (equipment, supplies, integrated service delivery areas), as well as improving conditions for healthcare workers to reduce turnover and maintain an experienced cadre of ART providers.
- Solicit viable options to reduce or eliminate the costs for PLHIV associated with diagnosis, treatment, and drugs for opportunistic infections and other health problems.
- Expand access to ART service for the rural population through initiatives that bring services closer to the community, such as the Accelerated Plan for the Expansion of Primary Health Care Coverage in Ethiopia (2005–2009), which envisages availing one health post per rural Kebele with five health posts serving as satellite sites to one health center. These health centers can thus be used as entry points to expand access to ART services to the rural population.

Because this study had limited geographic coverage and a small facility sample, further research is recommended. Studying the barriers to accessing ART in emerging regions and private facilities may provide additional dimensions and improve our understanding of contextual and institutional barriers.

ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
CI	confidence interval
DHS	Demographic and Health Survey
EQUINET	Network on Equity in Health in Southern Africa
FGD	focus group discussion
HAPCO	HIV/AIDS Prevention and Control Office
HCT	HIV counseling and testing
HEW	health extension worker
HIV	human immunodeficiency virus
M&E	monitoring and evaluation
MOH	Ministry of Health
NGO	nongovernmental organization
OR	odds ratio
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
UN	United Nations
USAID	United States Agency for International Development

BACKGROUND AND OBJECTIVE

In Ethiopia, the HIV epidemic has remained a major public health problem, mainly affecting people of prime productive and reproductive age. At the end of 2005, an estimated 1.3 million people were living with HIV (MOH, 2006). HIV prevalence in the general population is estimated at 2.1 percent.² The epidemic is well established in the urban areas with prevalence as high as 5.5 percent in 2005. In the same year, 0.7 percent of the rural population was estimated to be HIV positive (CSA and ORC Macro, 2006).

The expansion of antiretroviral treatment (ART) services has been recent and fast—from only four facilities in 2003 to 481 in 2008. The number of people who have accessed ART has increased substantially from 900 in 2003 to 210,637 in 2009. The impact of the program on patient survival and quality of life has also been demonstrated (MOH/HAPCO, 2008). A recent population-based study revealed significant decline in adult AIDS mortality as a result of ART scale-up in Addis Ababa (Reniers et al., 2009).

Ethiopia's policy and guidelines on the provision of ART show a strong commitment to equitable access to ART. The documents touch on roles for all levels of the health service provision program, as well as communities and the private sector—with the intent that different segments of the population will be served by different sectors—all with the end goal of providing an equitable ART program. The country also envisages achieving universal access to ART by the end of 2010 (Road Map II). Thus, equity is certainly among the most important aspects of Ethiopia's policy agenda on ART scale-up.

Despite the recent gains, universal access to ART is still far from being achieved. The number of patients ever started on ART represents a commendable 73 percent of the population needing ART, but 27 percent of those ever started have been lost to follow-up³ or died—many of whom are from the most vulnerable populations (HAPCO, unpublished). Although ART is being provided free of charge, with a rapid expansion of facilities providing treatment, the population's access to ART cannot be assumed equitable and universal due to a number of deterrents that operate at individual, community, and facility levels.

This research aims to inform policy on and improve equitable access to ART by identifying barriers to treatment and how these barriers impact groups differently. With this information, the government and other actors can design policy solutions that will help diminish barriers, bring more people into facilities for ART, and ensure adherence once treatment is initiated.

This report provides an overview of the policies and programs relevant to ART provision in Ethiopia; examines the full continuum of care related to ART—from HIV counseling and testing (HCT) to treatment adherence—and presents findings on equitable access to ART by selected socio-demographic divisions. The report also examines factors influencing ART access at the individual, community, and health center levels, as well as reasons for discontinuation of treatment. Lastly, the report concludes with recommendations for improved equity.

² Agreement on a point prevalence of 2.1 percent was reached in April 2007.

³ ART patients' outcomes encompass the following broader categories: patients who (1) are alive and still on treatment, (2) stopped treatment, (3) transferred to another facility, and (4) were lost to follow-up. A patient who misses appointments for one to three months is considered lost to follow-up.

METHODOLOGY

The study was done in two parts: (1) preliminary research, which included document review and analyses of national data and individual-level ART data; and (2) a study based on qualitative methods, involving focus group discussions (FGDs) and in-depth key informant and health worker interviews. A brief description of the research methods is included below. For the full protocol, including questionnaires and data collection tools, study limitations, and ethical considerations, please see *Equity and Access to ART in Ethiopia: Study Protocol*. For an overview of the activity and implementation process, please see *Equity and Access to ART in Ethiopia: Activity Report*.⁴

Document Review and Analysis of National Data

Using an equity lens, the team reviewed and analyzed available policy and strategy documents relevant to Ethiopian HIV/AIDS and ART service provision. National data on HIV prevalence, HCT, and ART uptake and their trends over time were also examined.

Secondary Data: Individual-level ART Data

Researchers extracted baseline data from health facility records, including patients' sex, age, education, occupation, religion, marital status, CD4 counts, World Health Organization staging, and functional status for a total of 9,703 patients who started ART between January 2007 and August 2009.

Qualitative Information

To understand the factors underpinning ART use at individual, community, programmatic, and structural levels, researchers analyzed the qualitative information generated through the FGDs and in-depth interviews through using a social-ecological framework adapted to the Ethiopian context (Roura et al., 2009). The framework builds on existing theories to illustrate possible interactions between contextual and individual determinants and the pathways through which these affect health-seeking behavior.

Focus group discussions

Researchers conducted a total of 22 FGDs. Orientation on the study's purpose and the participant selection procedure was given to health workers, PLHIV associations, home-based care workers, and representatives of Kebele administration, who then recruited ART users, PLHIV not using ART, individuals who discontinued ART, those on pre-ART follow-up, and male and female community members. The FGD Guide developed for this research is included in the aforementioned study protocol.

In-depth interviews with health service providers

Researchers interviewed 27 health workers providing ART and related services from the nine facilities. The participants included facility medical directors, ART focal persons, counselors, nurses, and clinical officers. The interviews focused on barriers to ART service delivery, including treatment continuation and adherence. The In-depth Interview Guide developed for this research is also found in the study protocol.

Community key informant interviews

Researchers interviewed 63 representatives of key community groups—including associations of PLHIV, religious groups, Idirs (burial associations), women's groups, local nongovernmental organizations (NGOs) providing care and support services, and home-based care workers—to collect information on factors influencing ART use and barriers operating at the community level.

⁴ The study protocol and activity report are available at www.healthpolicyinitiative.com.

Although as many perspectives were covered as possible, it was recognized that some gaps exist, such as those persons who test positive but do not get their results

Study Sites and Facilities

Study sites were selected from varying geographic locations to include major urban areas, urban slums, and semi-urban and rural (proximate) areas and were not intended to be representative of all ART sites in the country. The study focused on five public hospitals and four health centers and their surrounding communities. The sites were distributed across three regions known for a high concentration of ART users, namely Addis Ababa, Amhara, and Oromia.

POLICIES/PROGRAMS RELATING TO ART PROVISION: AN EQUITY ANALYSIS

This section reviews existing national policies, strategies, guidelines, and programs relevant to providing equitable HIV/AIDS and ART service provision.

The **national HIV/AIDS policy (1998)** makes direct references to gender and economic equity, noting the contribution of gender inequity to the further spread of HIV. The policy recognizes the need to empower women, provide women and youth with HIV/AIDS services and information, and provide special assistance for those who cannot pay. In 1998, the most promising and highly active antiretroviral treatments were not widely available and were largely limited to Western countries; ART was therefore not mentioned in the policy. Subsequently, more specific HIV/AIDS policies have generally reflected the commitment to equity laid out in the overarching HIV/AIDS policy.

The **Ethiopian Strategic Plan for Intensifying Multi-Sectoral HIV/AIDS Response (2004–2008)** states that “the gender inequality that has prevailed in rural and urban communities for years has fueled the vulnerability of and contributed to the spread of the virus among women.” It goes on to give the Women’s Health Bureau responsibility for “addressing gender inequality and advocating for mainstreaming gender in all sectors of development and services” (Government of Ethiopia, 2004, p.49).

With increasing access to ART and in recognition of its positive impact in improving the lives of PLHIV, the Ministry of Health (MOH) endorsed a **policy on the supply and provision of antiretroviral drugs (2002)**. The policy demonstrated the Ethiopian government’s political commitment to making ART easy to access for its population. Although this policy did not specifically mention equity in ART, some of the policy statements are relevant regarding improving equitable access. The policy emphasized the government’s commitment in several areas: mobilizing all stakeholders, allowing the importation of antiretroviral (ARV) drugs free from tax, lowering the price of ARV drugs through negotiation, encouraging international initiatives on ART in the country, and promoting research on ART.

The **free-of-charge ART program (2005) and the 1st Road Map (2005–2006)** by far represent the most important steps taken by the government toward promoting equitable access to ART. The free-of-charge ART initiative was launched on January 24, 2005, demonstrating the governments’ commitment toward the Global “3-by-5” initiative that aimed to have 3 million people in developing and middle-income countries on treatment by the end of 2005. As part of accelerating access to ART, the MOH issued a Road Map for 2005–2006, which provided a clear target for ART rollout and also allowed all actors to extract their individual targets to ensure timely delivery of their specific responsibilities.

The **Guideline for Cotrimoxazole Prophylaxis in HIV/AIDS Care and Treatment (2006)** does not specifically reference equity but does emphasize that this prophylaxis should be prescribed to *all* persons testing HIV positive, as well as the parents/guardians of babies born to HIV-positive women. In addition, it states that Cotrimoxazole should be prescribed at all health facility levels, allowing people who may not be able to access the more centralized ART delivery sites to receive it closer to home.

The **Guidelines for Implementation of ART in Ethiopia (2007)** were intended to guide the implementation of the national ART program, stating that one guiding principle of the program is strong promotion of universal access through a safe, effective, and equitable national ART program. Although universal access is the goal, resource constraints mean that the program must have eligibility criteria in place to ration the drugs. At the national level, the ART scale-up effort follows regional HIV prevalence patterns and population density. Furthermore, access priority at the national level focuses on vulnerable groups including infected pregnant women and their infants, health workers infected in the line of duty, and rape victims. At the facility level, biological and clinical criteria are the bases for decisions on ART

initiation (HAPCO and MOH, 2007). These criteria formalize the commitment to gender equity and to the protection of vulnerable groups.

The **Accelerated Access to HIV/AIDS Prevention, Care and Treatment in Ethiopia and Road Map: 2007–2008/10** aims to ensure quality of impact and equity of coverage/access by basing infrastructure expansion on a carefully targeted prioritization system that creates new ART service delivery sites in communities with higher prevalence rates, based on available strategic information.

The objective of the **Guidelines for Counseling and Testing in Ethiopia (2007)** is to “promote and provide standard HCT services to individuals, couples, and community groups of all ages regardless of gender, and especially to vulnerable and high-risk groups” (MOH, 2007a, p.3). This policy also promotes the availability of high-quality HIV counseling and testing for people with physical disabilities and mental impairment, children, and women. Be it voluntary, provider-initiated, or mandatory, counseling and testing is the entry point for most people who discover they are HIV positive.

The **Guidelines for Prevention of Mother to Child Transmission of HIV in Ethiopia (2007)** have a clear emphasis on equity. The first guiding principle is equity, stating that “access to services must be equitable without any discrimination” (MOH, 2007b, p.2) Although priority is given to women with advanced stages of the disease, there is a clear focus throughout the document on ensuring equitable access to ART and antiretroviral prophylaxis for prevention of mother-to-child transmission (PMTCT).

The **Guidelines for Pediatric HIV/AIDS Care and Treatment in Ethiopia (2008)** state that the goal for pediatric HIV/AIDS care and treatment is to maximize resources while ensuring equitable care. It aims to reduce barriers within the healthcare system, improve the health of HIV-affected families, reduce the risk of perinatal transmission, support adherence to treatment, and highlight the role of families in HIV prevention.

Literature indicates that ensuring a diet with sufficient quantities of nutrient-rich foods is crucial for all people, and nutrition is an integral component of care and support of PLHIV (Tony et al., 2004). ART can reduce viral loads and contribute to improved nutritional status but can also create additional nutritional needs and dietary constraints. The Ethiopia ART program recognizes the nutritional needs of PLHIV on ART. The overarching **Policy on HIV/AIDS and Nutrition** states that “PLHIV taking ART and receiving associated treatments require special nutrition care and support because HIV-related medications can reduce the overall quality of health.” Government ministries, donor agencies, NGOs, and international organizations have implemented programs to address the food and nutrition needs of PLHIV in Ethiopia (MOH, 2008b). The World Food Program, funded in part by the President’s Emergency Plan for AIDS Relief, is the leading provider of food and nutrition support to PLHIV on ART. At the grassroots level, the food support program is directly implemented by Kebele administrations, PLHIV associations, local NGOs, religious organizations, and community-based organizations. The most recent national monitoring and evaluation (M&E) report by HAPCO (2008/2009) indicates that 70,928 PLHIV received food and shelter support and 18,733 received start-up financial support (HAPCO, unpublished). This Health Policy Initiative study found that the food support program linked to the ART service encourages PLHIV from the lower socio-economic class to access ART and, thereby, contributes to equitable access to ART.

In summary, equity is explicitly or implicitly a part of many policies governing the delivery of ART. These policies recognize roles for all levels of the health service provision program, as well as communities and the private sector—with the intent that different segments of the population will be served by different sectors—all with the end goal of providing an equitable ART program. Nevertheless, equity monitoring appears to have received marginal attention in these policies. Neither the Guidelines for Implementation of the ART Program nor the National ART Strategic Framework incorporates equity in

their monitoring and evaluation plans. The gap is most notable in the strategic framework, which lays out a detailed M&E plan, including an extensive list of examples of specific indicators—none of which pertain to equity (AIDS Resource Center, 2005, p.5). This is despite the inclusion of “equitable access to ART” as one of the “Guiding Principles” of the framework (AIDS Resource Center, 2005, p.10). The commitment to equitable access to ART in Ethiopia could be strengthened by clearly defining the groups for protection and by adding indicators that measure equity of access. In addition, this identification will enable the identification of M&E indicators that can evaluate progress toward equity.

ACCESSING ART: AN EQUITY ANALYSIS

Analyzing equity in ART services requires considering the full continuum of care, including HCT, uptake of ART, adherence, and treatment outcome. Most important from the equity perspective is to determine where and how these services are provided and who is accessing them. This section presents analyses of national data on HCT and ART, as well as the socio-demographics of ART users extracted from the health facilities sampled for this study.

HCT Service Expansion and Uptake

Equitable access to ART must include access to HCT, the main gateway to treatment. HCT should be accessible to all population groups, including the rural, poor, and most vulnerable. There are numerous entry points. At the facility level, a client may opt to test for HIV and enroll in chronic HIV care through PMTCT, tuberculosis clinics, out- or in-patient departments, and services for sexually transmitted infections. Other HCT access points include voluntary counseling and testing in workplaces, stand-alone, youth-friendly services, and mobile counseling and testing that is linked to health facilities and ART programs through a referral system (Mekonnen, 2009).

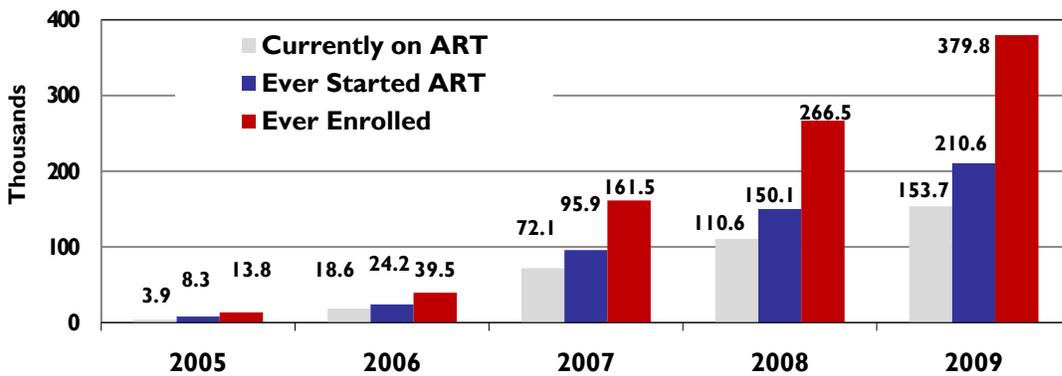
There has been a rapid scale-up of HCT services in Ethiopia—from a low of 23 sites (Panos Global AIDS Program, 2006) in 2003 to 658 in 2005, 775 in 2006, 1,005 in 2007, 1,336 in 2008, and 1,596 in 2009 (HAPCO, unpublished). The population undergoing HCT also increased dramatically, starting at 10,000 tested in 2003 to 5.8 million in 2009. HCT uptake for 2009 revealed a slightly higher proportion of males (53%) tested than their female counterparts (47%). Data from the 2005 Demographic and Health Survey (DHS) revealed a considerably large urban-rural disparity in use of HCT, with only 1.1 percent and 2.9 percent of the rural women and rural men, respectively, having been tested for HIV during or before 2005, compared with 17.2 percent and 19.1 percent, respectively, for urban women and men. Furthermore, those people in the wealthiest quintile⁵ and those with a higher education were reported to be more likely than others to test for HIV.

ART Services Expansion and Uptake: National Picture

The expansion of ART services has been rapid in Ethiopia. The launch of free-of-charge ART in 2005, followed by the expansion of ART to health centers in 2007 significantly improved access to treatment (see Figure 1). By 2009, 210,637 individuals had ever started ART and were accessing treatment at 481 facilities. In addition, the pre-ART program has thus far captured 379,800 PLHIV in chronic care follow-up.

⁵ The wealthiest quintile includes the top 20 percent of the income distribution, calculated using the asset methodology used by DHS.

Figure 1. Adults and children receiving ART and on chronic HIV care: 2005–2009

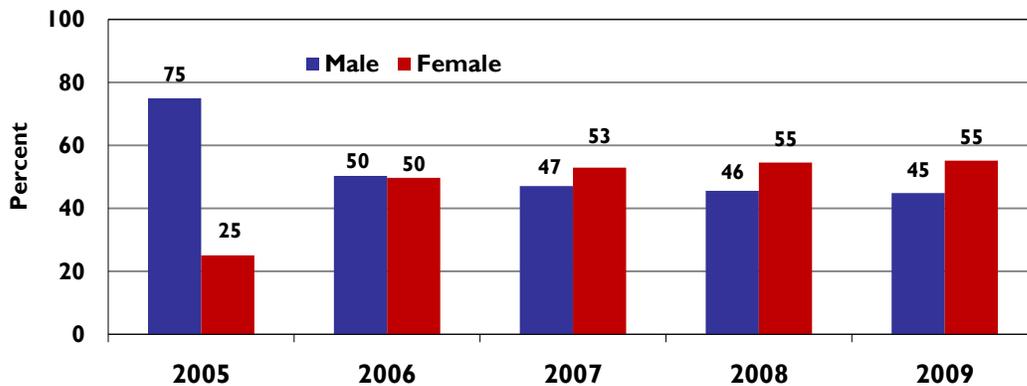


Source: HAPCO, unpublished.

Among the challenges of the ART program is the substantial number of ART patients lost to follow-up or death. Of those so far enrolled on ART, 56,900 (27%) are reported lost to follow-up or dead, while 73 percent are currently on treatment (73%=153,700/210,637. Chapter 6 of this present report deals with this in greater detail.

The number of people accessing ART by sex provides crucial information on gender equity in access to ART. The most recent national HIV M&E report (2009, Unpublished) revealed an important trend showing that more women than men were now accessing ART (see Figure 2). However, this does not imply true equity, as the total proportion of females infected is higher than the proportion of males (sex ratio of HIV prevalence female to male = 2.1:1) (CSA and ORC Macro, 2005). The female-to-male HIV infection ratio could go as high as 3.2:1, as documented by DHS 2005 for urban Ethiopia.

Figure 2. Trend in proportion of males and females ever started on ART: 2005–2009



Source: HAPCO, unpublished.

The Urban/Rural Divide in Access to ART

The urban-rural divide in Ethiopia is complex. Although the rural prevalence is 8.6 times less than urban prevalence, the rural population needing ART represents about 40 percent of the total (see Table 1) (MOH and HAPCO, 2007). This is due to the high concentration of the country's population in the rural area (85%).

Table 1. HIV prevalence, number of PLHIV, and population needing ART among urban and rural national populations

	Urban	Rural	National
HIV Prevalence	7.7%	0.9%	2.3%
Number of PLHIV⁶	695,414	420,802	1,116,216
Population Needing ART	204,049*	132,111*	336,160

* Authors calculated the urban and rural figures based on the MOH national estimate for population needing ART.

Although it is recognized that the rural population should have equal access to ART, to date, the national ART scale-up effort has been urban-focused. The national accelerated access to HIV/AIDS prevention, care, and treatment road map (2007–2008/10) (MOH, no date) stated that (p16):

“Although the projected scale up calls for **equity of access** for the population, there are activities that can be intensified using the guiding principle of high impact and high yield. For example, the single point estimate report that 60.7% of ART-eligible people reside in urban areas, where only 15.5% of the population lives. Partly because of this concentration of ART eligible individuals, urban centers have been more successful in meeting their targets over the last two years. Without limiting the rural population's access to all HIV/AIDS services, an intensified focus should be placed on activities that are easier to implement in urban areas...”

Urban-rural disaggregated figures on the number of people on ART are hitherto absent. Anecdotal evidence suggests that the vast majority of ART users are from urban areas, but it is unknown whether this is due in part to a lack of awareness among rural residents about ART services (Panos Global AIDS Program, 2006). The vast geographic scope and scattered nature of the rural population, coupled with limited resources available to expand services, points to hard choices regarding whether ART should focus on urban populations to achieve high impact and high yield within the reach of available resources, or expand to rural areas for the sake of equity. One potential improvement is the Accelerated Plan for the Expansion of Primary Health Care Coverage in Ethiopia (2005–2009), which envisages availing one health post per rural Kebele, with five health posts serving as satellite sites to one health center. This translates to 13,635 health posts—each staffed by two female health extension workers (HEWs)—and 3,153 health centers. These health centers can thus be used as entry points to expand access to ART services to the rural population.

ART Uptake by Selected Socio-demographics

There is in general a dearth of national ART data disaggregated by socio-demographics. This information is necessary for monitoring equity. The study team extracted available individual patient enrollment characteristics, including sex, age, educational status, occupation, and marital status for a total of 9,703

⁶ MOH and HAPCO, 2007.

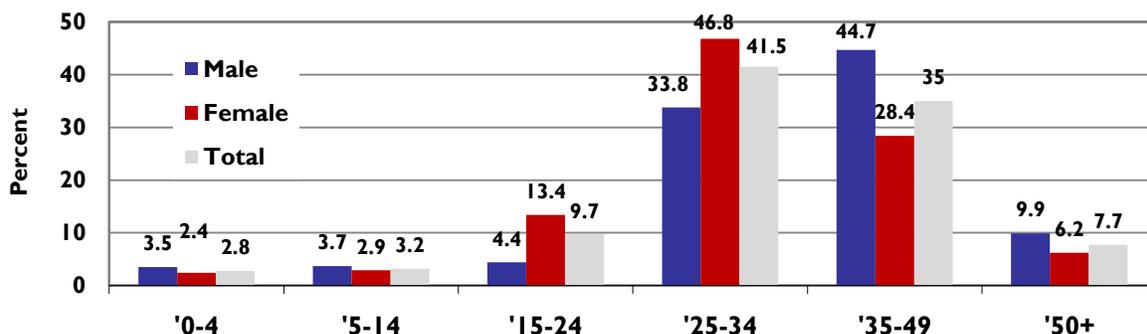
individuals from the nine study facilities who ever started on ART during January 2007–August 2009. This sample covers a significant portion of patients but obviously excludes those who receive services at other facilities or who have not yet entered care.

Age-sex differential of ART uptake

The overall mean age at start of ART was 33 years (35 for males and 31 for females). It appeared that females tended to start on ART four years earlier than their male counterparts, which corresponds to the earlier age at HIV infection among females.

Figure 3 illustrates that the majority (41.5%) of individuals on ART are in the age group 25–34, followed by the age group 35–49 (35%). As expected, the highest rate of female users was found in the age group 25–34 (46.8%), while the highest rate of male users was in the age group 35–49 (44.7%). The noted age-sex pattern of ART users in these facilities is similar to the age-sex pattern of HIV infection in the general population, suggesting that ART access and use follows the epidemiological pattern of HIV infection.

Figure 3. Proportion of males and females ever started on ART by age (January 2007–August 2009), Nine Health Facilities (N=9703)



Overall, available epidemiological data appear consistent in that females are disproportionately infected with HIV—although the excess risk varies across studies (Berhane et al., 2008). The noted disproportionately higher ART use by females is encouraging and signals the recent improved gender equity in access to ART.

Socio-demographic and economic differentials in ART use

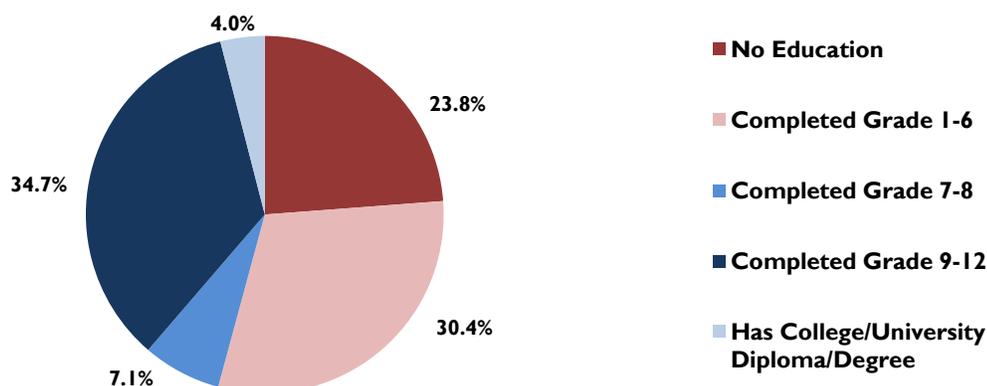
This section presents distribution of ART users by education, marital status, and occupation. This analysis is restricted to seven health facilities,⁷ with more than 95 percent complete information on education, occupation, and marital status of adult ART users ages 15 or higher (n=5773).

Education

ART users span all levels of education (see Figure 4), suggesting that access to ART is not limited by educational status. However, the relationship between education and HIV is complicated by conflicting data. Some research indicates an increased HIV prevalence with educational status (CSA and ORC Macro, 2005), while some reveals an inverse relationship between educational status and HIV prevalence (Mekonnen, 2009). Although the findings on the relationship are not consistent, the fact that individuals with various education levels are accessing ART is positive.

⁷ Two of the facilities (1 hospital and 1 health center) were excluded because more than 35 percent of the records were missing data on education, marital status, and occupation due to misplacement and failure to store the intake forms properly.

Figure 4. ART users in 7 facilities by education level



Employment

In terms of equitable access to ART, what is most remarkable is the finding that both the working and non-working population is benefiting from the program. Of the ART users in these facilities, 42.2 percent were unemployed, suggesting that the free ART program is successfully reaching this population. The vulnerability of the unemployed can be seen in 2007/2008 research noting that of 6,738 unemployed individuals tested for HIV in 40 major towns, 9.6 percent tested HIV positive (Mekonnen, 2009).

Marital status

Research suggests that ART services are most utilized by married individuals (44.8%), followed by those never married (23.2%), divorced (24.1%), and widowed (7.9%). The number of ART users in each marital status category is influenced by myriad factors—the HIV prevalence in each group, size of each group, and access to services, among others. Thus, the recorded highest number of married ART users does not necessarily imply a higher HIV infection rate among those married than the other groups. In this study, 40 percent of all female ART users from the seven facilities comprised widowed and divorced women—many of whom are poor. This is another indication of improved equity in access to ART among the poor and most vulnerable groups of society.

Religion

Of the number of ART users in the study, 78.2 percent were Orthodox Christians, 13.8 percent were Muslims, and 8 percent were followers of other religions. Previous epidemiological studies showed the highest HIV prevalence among Orthodox Christians (Abebe et al., 2003; and Mekonnen et al., 2005), which is partly a reflection of high ART use in the group but also can be attributed to the overall high number of Orthodox Christians in Ethiopia (43.5%) (CSA, 2008). Of the entire population, 33.9 percent is Muslim and the remaining 22.8 percent are from other religions.

ART Service in health centers: Advancing equity in access to ART

This study collected available socio-demographic data on ART users from three hospitals (n=3006) and four health centers (n=2767), allowing comparison of patients' characteristics between the two types of facilities. As shown in Table 2, compared with hospitals, health centers serve more women, those uneducated and unemployed, and widowers. These findings, taken together, suggest that the recent scale up of ART services to rural health centers not only improves physical access to treatment for the general HIV-positive population but also considerably attracts women, the poor, and the most vulnerable section of the population who otherwise do not have easy access to treatment.

Table 2. Proportion of patients (ages 15+) ever started on ART (January 2007–August 2009), according to selected characteristics of patients, 7 health facilities (N=5773)

	Hospital N=3006	Health center N=2767	P-value
Sex			
Male	41.1	38.1	P=0.019
Female	58.9	61.9	
Age			
15–24	9.4	10.3	P=0.588
25–34	44.5	43.2	
35–49	37.8	37.9	
50+	8.3	8.6	
Education			
No education	17.3	31.2	P=0.000
Grade 1–6	35.1	25.1	
Grade 7–8	2.2	12.5	
Grade 9–12+	45.3	31.2	
Work status			
Working	64.7	46.9	P=0.000
Not working	33.4	51.7	
Student	1.9	1.4	
Marital status			
Currently married	47.1	42.1	P=0.000
Divorced	27.7	20.1	
Widow	4.1	12.3	
Never married	21.1	25.6	

FACTORS INFLUENCING ART USE

This section presents findings on the factors that facilitate or hinder ART uptake at individual, community, and health system levels. The analyses emerge from the qualitative information gathered through the FGDs and in-depth interviews with community key informants and health service providers.

Individual Factors

Perceived benefits

For most individuals, ART was perceived to be useful, enabling HIV-positive people to regain health, go back to work, and fulfill family and other social responsibilities and obligation including nurturing children. This perception was reported to be the main motivator for individuals to uptake treatment.

Most participants perceived ART as a miracle treatment after witnessing other terminally ill patients recover quickly and return to productive life.

I was almost dead when I started ART. The physician told me that my CD4 count was only 50 and I should start treatment. I recovered rapidly with the drug... and I am now capable of working like any healthy person. —ART user, FGD participant

ART users are becoming even healthier than HIV negative people.—Community FGD participant

The provision of food and other material support in concert with ART service was repeatedly reported to have attracted patients, especially those from the lower socio-economic class. Having access to adequate food is essential to treatment success, making nutritional support especially important to patients who are already vulnerable to food insecurity due to low socio-economic status and unemployment. Of note, the finding that 42 percent of ART users from the nine facilities were unemployed further corroborates this supposition.

I can't take this drug [ART] with [an] empty stomach. I receive some wheat and oil every month; it is not enough but better than nothing. Without this support, I will not continue with this drug [ART]. It can burn my stomach and can cause more damage than cure. —ART user, FGD participant

Perceived and actual constraints

In contrast, there are numerous individual-level factors hindering ART use. These revolve around reluctance to take treatment for life, the conviction that ART only prolongs life but it does not cure AIDS, the conviction that a person's fate is in God's hand, fear of side effects, and fear of stigma.

Taking medicine for the whole of my life frustrates and scares me. I prefer dying than taking this drug [ART] for life. — Non-ART user, FGD participant

I have witnessed ART improving health. On the other hand I also saw some terrible side effects of the drug, which scares me a lot. I haven't started the drug and will not be using one in the future; the side effects are so scary. —Non-ART user, FGD participant

There is a lady whose husband is on ART. She refused to take ART, because she wants to leave everything to God. —Home-based care worker, Key Informant

Another limiting factor for individuals not to take ART is the belief that HIV disease progression can be prevented or slowed by having nutritious food and general serenity and happiness in life.

I believe that if you have peace and happiness in your life and get proper nutrition, you do not need the medicine [ART] which has serious side effects even if it improves your health. —Non-ART user, FGD participant

Addictions to Khat, cigarettes, and alcohol emerged as individual-level barriers to using ART. Starting ART entails quitting these habits, which some individuals are not willing to do, especially men and urban dwellers.

...despite my relentless effort to convince him to start ART, an HIV-positive man whom I know in this village remains a refusal. He always tells me that he couldn't withdraw from Khat and Alcohol, which he believes antagonizes with the drug. —Home-based care worker, Key informant

Community Factors

While some community-level factors positively influence ART use, others serve as impediments. This section presents the social/community factors that facilitate or hinder people from accessing and benefiting from ART.

Community awareness of and attitude toward ART

Participants across the study sites were generally aware that free ART was available at public facilities and of the treatment's ability to improve the health of PLHIV. This high level of awareness and positive attitude toward ART among community members positively influenced individuals' ART use.

Participants noted easy access to ART through community health centers and increasing numbers of PLHIV on ART.

The number of users is on the rise day by day because everybody has seen the miracles of the treatment. —PLHIV association representative, Key informant

Most FGD participants attributed the decline in mortality among young people and adults to the high number of patients accessing ART in public facilities.

In our Idir [Burial Association], we have witnessed dramatic turn down in the number of people dying recently. As a result, our Idir has begun to recover from serious financial trouble. This is because of the drug [ART]. —Idir Representative, Key informant

Home-based care workers, peer and community support

Participants across the study sites unanimously commended home-based care workers for their unreserved and relentless effort to reach out to PLHIV with health information and counseling, which persuaded many to initiate treatment.

HIV-positive, home-based care workers are particularly successful in influencing fellow PLHIV to start ART and adhere to treatment. When patients are lost to follow-up from ART, case managers and outreach workers work in close collaboration with home-based care workers to locate patients and persuade them to resume treatment.

I was bed-ridden and at the verge of death. One day a home-to-home worker visited me with other people and asked me a lot of questions about my symptoms. He told me about his situation that he was HIV positive and that he was using the drug [ART]. I told him, I did not have HIV but he insisted I had to test for HIV. He came back the next day and, finally, I agreed and...sadly, my test result was bad—I have HIV. I started the drug and soon became well. He has convinced many others in our Kebele to start ART. —ART user, FGD participant

I am serving as a home-based worker and counselor to people who have HIV. I am not paid. I have many stories to tell about my work. I persuaded patients to start treatment and to also restart after discontinuing treatment. Recently, I was able to convince a man who discontinued treatment to resume treatment [ART] in the health center. —ART user, FGD participant

Some self-motivated PLHIV encourage others in their community to test for HIV and use ART. Such individuals often use their own stories and experiences to motivate others. Indeed, this has helped to lessen internal stigma that prevents PLHIV from seeking care.

It has become four years since I started ART. Since then, I have been able to bring a number of patients to join our association [PLHIV association] and also seek care in health facilities. I use my story and experiences to convince others and most listened to me and trusted me a lot. —ART user, FGD participant

Several community actors—including faith and community based organizations (e.g. Idirs), youth clubs, and women’s groups—are participating in the provision of care, support, stigma reduction, and the promotion of ART use in the communities. Some communities embrace PLHIV, providing them with financial and material support ranging from help with meal preparation and supplies to paying rent or building a house. Nonetheless, participants underlined that the limited community resources are not enough to meet the needs of an ever-growing number of PLHIV.

Stigma toward PLHIV and ART use

Participants noted that stigma toward PLHIV in general and toward people using ART in particular is less severe than in the past, but discrimination still prevails in the study sites.

On the positive side, participants of varying backgrounds including PLHIV, community members, and health workers noted that communities have begun to understand HIV/AIDS and embrace PLHIV as productive and useful members of society. The most frequently cited reason for the noted decline in stigma was the general understanding by the community that AIDS has become a manageable chronic disease as the result of the wider availability of ART. The burden-related stigma that PLHIV endured due to their inability to conduct routine activities, as well as stigma related to the community’s fear of death and disease (Kidanu, et al., 2003), have been eased as more PLHIV begin ART and return to their roles as healthy, productive community members. Community members noted that HIV-related morbidity and deaths are declining and their behavior toward PLHIV is improving.

Stigma and discrimination that was common toward AIDS patients has improved a lot in recent years. This is because people have realized that the death threat of HIV/AIDS has decreased due to the drug [ART]. — Idir representative, Key informant

Stigma was terrible before. Due to the intensive health education and access to ART, it has changed now. The community has started to accept them [PLHIV] as useful community members. —Community member, FGD participant

There are also reports of “normalization” of the disease among people on ART as they begin to recover from severe health problems, become more productive, and are more comfortable with their HIV status.

I am a mother of six and was bed-ridden for almost four years. My CD4 dropped as low as 9; my legs and hands were almost paralyzed. I wished my death and kept on blaming myself and felt ashamed. The treatment [ART] changed my life and am a healthy and happy person now - ART user, FGD participant

PLHIV also suffer from internal stigma, which is associated with feelings of shame and fear of being discriminated against. Both internal and external stigma can keep PLHIV from accessing and adhering to ART. Among ART users, stigma tended to be more serious among those living in small towns and rural communities.

... two of my patients who are on treatment [ART] always wear Hijab when they come to take ART to disguise themselves. These women are both Christians and sex workers. —Health worker, Key informant

For some PLHIV, fear of stigma was implicated as a major barrier to accessing ART from nearby facilities. Such patients use ART from those facilities furthest away from their usual residence—often at hospitals in big towns. This was reported to be common among men, employed and better-educated patients. The poor and most vulnerable tended to access treatment within their vicinity when available.

There is a general consensus among participants across the sites that disclosure should be done carefully and selectively, as its consequences could be encouraging or damaging. ART users who did disclose their status and ART use, often did so only to close relatives, their spouses, offspring, parents, and priests—while few wanted to disclose to close friends and neighbors.

I openly told my mother and sister that I was taking the AIDS drug. While my mother accepted and supported me, my sister tried to poison me. —ART user, FGD participant

I told [that I was taking ART] to my uncle and aunt. While my aunt was passionate, my uncle evicted me from the house. —ART user, FGD participant

Those who disclosed their taking of ART to families or friends reported to have benefited, as they could now take the treatment without fear and achieve a high adherence level. In some cases, adherence is improved when PLHIV can count on a family member or close friend as a “treatment buddy” who will remind them to take the pills and stay on schedule.

My close friend always reminds me the time that I should take the tablets [ART]. Even when she is away she calls me from her cell phone. —ART user, FGD participant

Disclosure of ART use to employers and workplace colleagues was singled out to be the most challenging thing to do. Losing jobs and being discriminated against in workplaces was repeatedly noted as a possible consequence of disclosure. Housemaids, sex workers, and those working in food and beverage establishments most frequently reported to have lost their jobs as a result of being seen using ART.

Last year, a women reported to our institution that a bar owner in this town sacked her from the job as she was accidentally seen by the bar owner taking ART. —Local NGO representative, Key informant

While I was working as a maid in one family, the owner saw me taking the drug [ART]. When she asked me what it was, I told her the truth and tried to convince her. She threw me away even without paying my wage. —ART user, FGD participant

Holy water and other traditional treatment options

Holy water emerged by far the most utilized and preferred traditional treatment option for HIV among followers of the Orthodox Church.⁸ Inconsistent messages around the use of both Holy water and ART have negatively impacted the success of the treatment program. There appears a general consensus among

⁸ The ART data extracted from the facilities indicated that 78 percent of the ART users are Orthodox Christians.

participants from the religion, across all the study sites, and irrespective of their education and economic background, that Holy water has the power to cure HIV/AIDS and other diseases.

There are a number AIDS patients who have gone to Tsadikane Mariam [a famous Holy water site around Debre brihan] and have been cured. —Community member, FGD participant

While most Orthodox followers, including those on ART, do not dispute the efficacy of Holy water, they also believe that lack of strong conviction from patients makes the Holy water less potent. A remark by a FGD participant who discontinued ART provides a good insight into this attitude.

I started Tsebel [Holy water] after quitting the drug [ART]. But the Tsebel did not cure me. By the way, I do not question the healing power of Tsebel rather the strength of my faith. — Discontinued ART user, FGD participant

The Archbishop of the Ethiopian Orthodox Church, *Abune Paulos*, noted that "*Both are gifts of God, they neither contradict nor resist each other. You can swallow your drugs with the holy water.*"⁹ While the Ethiopian Orthodox Church promotes the idea of simultaneous use of Holy water and ART, messages received by PLHIV from leaders in the Church remain mixed, leading to confusion among PLHIV and discontinuation of ART for some.

Last year, I sought Tsebel at Gishen Mariam [a church and Holy water site near Dessie town]. I told to a priest that I was using the AIDS drug and brought some tablets with me. The priest said to me that I could use the drug with Tsebel based on the directive that came from the Synod. — ART user, FGD participant

I carried the tablets [ART] adequate for a month and went to Tsadikane Mariam [A church and holy water site] because people were talking a lot about the miracles of the holy water there... I was told to throw the tablets [ART] before I started Tsebel and I did so. I stayed there for four months but my condition worsens. I became so desperate and returned to Jimma hospital to resume the drug. —ART user, FGD participant

I had the belief that Tsebel could cure HIV and used it for a long time before starting the AIDS drug. However, I could not recover, and the priest once advised me to use ART along with Tsebel. The drug helps me a lot, and I am now healthier than ever. —ART user, FGD participant

The ART-Holy water combination raises some concerns, as reported by participants and health workers. Patients are unclear whether the ART or Holy water is responsible for the improvement in their health, and in some cases, combination users can become lenient about treatment adherence or stop ART altogether. Even those who are aware that it is the drugs that helped them are sometimes unwilling to denounce Holy water as a treatment for HIV/AIDS because they want to protect their religion and fear this would bring curse to them. Few participants denounced Holy water as a treatment for HIV/AIDS, but the following are among the negative remarks opponents made about Holy water.

Tsebel does not cure HIV/AIDS and it has cured no one. We use Holy water because we think it is a religious duty and therefore gives us psychological strength. —ART user, FGD participant

I am disappointed when I hear that Tsebel cures HIV/AIDS. In the contrary, I think that it can cause pneumonia to AIDS patients. I know people who died using Tsebel. —Community member, FGD participant

⁹ UN Integrated Regional Information Networks, May 25, 2007.

Patients resort to prayers, repentance, and even living in the churches and monasteries in pursuit of recovery and a cure. The use of traditional medicine/herbs by PLHIV was also mentioned among the treatment options in all the study sites. Hoofs of cattle and a mix of garlic, onions, roots, leaves, and other unknown plants were among the ingredients of the traditional medicine believed to treat AIDS. Most patients reported using some form of traditional medicine before they resorted to ART. Participants across the study sites unanimously agreed that the use of traditional medicine by PLHIV has become less common recently, as most patients have access to ART. Its efficacy as a treatment for HIV is also dubious, as suggested by most participants.

Though limited to two of the study sites, a spiritual-based ritual, known as *Wodaja*¹⁰ or *Du'a*, was repeatedly implicated as traditional treatment for PLHIV. In this type of ritual, close relatives and friends gather and pray for the patient, which often involves the use of Khat. Participants also reported that most PLHIV in their community have undergone *Wodaja*, and it is only when they lose hope with this ritual that they seek care in health institutions.

We gather around a patient who is usually naked, pray and spit at him, wishing a fast recovery.
—ART user, FGD participant

I am sure my husband has HIV because I have the disease. But he denies and refuses to have an HIV test. I took him for Wodaja since his relatives in the rural area insisted. Despite that, there was no improvement in his health. —On pre-ART, FGD participant

Finally, seeking witch doctors' advice and wisdom was also noted as a tactic to improve health.

Health System Factors

Pre-ART/chronic care

Those who do not meet the clinical or biological criteria to start on ART are enrolled into the chronic HIV/AIDS care (pre-ART program), continually monitored, and treated for other opportunistic infections. Such patients are put on ART when they meet any of the criteria for initiating ART. Patients see health providers regularly for evaluation. As part of chronic HIV care/ART, care providers have responsibility to support adherence, provide psychosocial support, and ensure the integration of HIV prevention into routine clinical services.

The strength and efficiency of the pre-ART program is necessary to successfully enrolling patients into ART. This study attempted to assess the pre-ART program from the perspective of patients and the health workers in order to identify factors for program success and barriers.

In general, FGD participants who were on pre-ART follow-up saw their follow-up care and monitoring as satisfactory. They indicated that the regular follow-ups take place every three or six months. During each follow-up visit, healthcare workers provide thorough medical examinations, CD4 counts, and weight measurements. Based on these observations, counseling is provided and the decision to initiate or not to initiate ART is made. Participants across the study sites held positive attitudes toward the counseling received in the health facilities during the pre-ART visits and the maintenance of confidentiality, including health workers responsiveness to patients needs.

The reception and counseling by the health workers is excellent. They comfort us and encourage us to feel good. —on pre-ART, FGD participant

¹⁰ *Wodaja* is a traditional practice where close friends/families gather together for pray and appeal to their God. *Wodaja* is held in time of sickness, birth, assumed danger, or any other social problem faced by the individuals and their family members.

Though not universal, patients on pre-ART appeared to have a good understanding of the preconditions and criteria to start ART. Most were also cognizant of and trusted health workers advice and decision on the initiation of ART. Most mentioned a CD4 count less than 200 cells/ml as a threshold to initiate treatment; although, participants exhibited limited understanding of the other clinical criteria for the initiation of ART.

On the negative side, long queues and long waiting times during their regular follow-up visits were among the common problems mentioned. The high turnover of health workers in the health facilities frustrated patients on pre-ART follow-up who do not appreciate being examined and queried by new health workers every time they visit facilities for regular and unscheduled follow-ups.

I am always seen by a new health worker who is new to my conditions and asking me a lot of questions. The hospital should do something to retain health workers. —On pre-ART, FGD participant

Most patients on pre-ART expressed a strong desire to begin treatment and some suggested starting ART even before their CD4 drop to below 200. This intention appears to be universal across the study sites. In fact, patients on pre-ART follow-up argued that they should start on ART before the virus causes further destruction on their health.

I do not think it is good to wait until we are debilitated by the AIDS virus. I think it is good to start ART as soon as we are tested positive for HIV and when are still strong. I know a patient on pre-ART who died before his CD4 count fall below 200. —On pre-ART, FGD participant

Indirect costs to accessing ART

The recent scale-up of the ART service to health centers improved physical access to ART services dramatically, yet transportation costs still emerged as the most important barrier to accessing ART across the study sites. Transportation problems appear most pressing for patients from rural areas. Even when services are closer to the community, some patients prefer to take treatment in areas far from their residence due to fear of stigma. Even for participants in Addis Ababa, where physical access to ART service is nearly universal, transportation fees emerged among their major concerns.

ART users as well as health workers recounted circumstances whereby patients appointments have to be rescheduled due to absence of health workers; long waiting times; malfunctioning of equipment, including CD4 machines; and misplacement and clotting of patients blood samples, among others. These factors may delay accessing services, testing, and obtaining results, as a result of which patients have to shoulder additional transportation cost.

ART users are sometimes obliged to come more frequently to health facilities because of the failure of CD4 machines. —PLHIV association representative, Key Informant

I was once told that my blood sample was lost when I came to collect my CD4 result. They took another blood and told me to come some other time. I did not know whether that was due to a technical problem, as they told me, or due to negligence. —On pre-ART, FGD participant

In most of the sites, patients on ART and pre-ART are required to cover medical, laboratory, and drug costs associated with opportunistic infections and other health problems, including medical costs for children. For many participants, this is an unbearable cost in the face of the other financial burdens placed on them because of HIV.

We face difficulty to pay for diagnostic and treatments that are not available in the health centers including for x-rays, ultra-sound, and some important drugs. These and other services should be made available free for us [PLHIV] in the health centers. —ART user, FGD participant

Health workers' concerns

The health workers providing ART services have repeatedly reported concerns and discontent with their work. Heavy workload due to the ever-increasing number of patients taking ART created fatigue and impatience with their work. Most reported that the workers employed are not adequate to serve the increasing number of patients. High staff turnover and a lack of incentives for health workers such as risk allowance add to workers' discontentment. Incentives are provided in some facilities in the form of overtime or duty exemption fees, but these were reported to be intermittent or recently terminated.

Some facilities are addressing the gaps in human resources and compensating for staff turnover by training existing staff from other departments on ART service provision and providing training opportunities for those providing ART services. One facility reported providing allowances and special benefits, including accommodations and free provision of basic services such as water and electric power.

Although a few participants expressed their resentment, ART users in general held positive attitudes toward service providers across the study sites. The psychological and moral support, as well as the medical care given by the healthcare providers, was highly commended by PLHIV on ART and pre-ART follow-up.

The attention, love, and care we receive from health workers is like the care one gets from parents. They [health workers] embraced and comforted my child as their own child and they counseled as their relatives. —ART user, FGD participant

Laboratory facilities and supplies

All of the study facilities reported problems with CD4 machines either being absent from facilities or overburdened by the workload. Frequent malfunctioning of the machines and delay in repairing them emerged among the major problems.

There is only one CD4 machine that is adequate in the first place. Moreover, it is out of service most often due to the frequent failures of the machine and associated delays in repairs. —Health worker, Key informant

Power interruptions and supply shortages hamper the processing of blood samples, leading to spoilage, requiring patients to provide blood samples repeatedly. This was found to have created patient dissatisfaction with the ART services.

ART wards/rooms in the health facilities

ART services are often provided in wards or sites in the health facilities that clearly identify patients' HIV status to others, impeding their right to privacy. This lack of anonymity prevents some PLHIV from using nearby ART facilities.

I know a guy living in this neighborhood who often come to the hospital and patrol around the room where the treatment is given [ART room] to spy on who is taking ART. This frustrated me and my friends taking treatment. —ART user, FGD participant

Once I accidentally ran into three women from our neighborhood queuing in front of the room where the AIDS drug is offered. They shouted at me and warned me not to tell to anyone. I tried to explain that this is a right thing to do and must not be afraid of. —Community member, FGD participant

In recognition of this dilemma, the MOH recently began integrating ART services with general outpatient departments of hospitals. In 2009, ground was broken on a new Integrated Outpatient Department Annex within the compound of Zewditu Memorial Hospital in the hopes of reducing stigma toward ART users and ensuring that all patients receive the same level of care. Integrating ART services with other routine care may reduce stigma, but it is yet to be seen whether it increases waiting time. Further investigation into the pros and cons of merging services is recommended.

Lack of permanent addresses and ART access

A permanent residence and an identification card that signifies permanent address is a prerequisite to register in pre-ART care and receive ART. This emerged as a barrier to using ART in big cities, especially in Addis Ababa, where many individuals rent rather than own homes. It is also a barrier for the homeless and others who do not hold Kebele ID cards. Healthcare workers do what they can to facilitate access.

.... I helped one man who lived on the street to register and use the drug [ART] in the health center through my house address. —Home-based care worker, Key informant

DISCONTINUING ART

This section presents the level of treatment discontinuation, factors influencing and the reasons for discontinuation, and treatment options pursued during discontinuation. Both quantitative data and qualitative information form the analyses in this section. The quantitative data were extracted from the health facilities. The qualitative data presented is based on FGDs and key informants interviews with PLHIV who have discontinued treatment, those who restart treatment after discontinuation, selected community representatives, home-based care workers, and health workers.

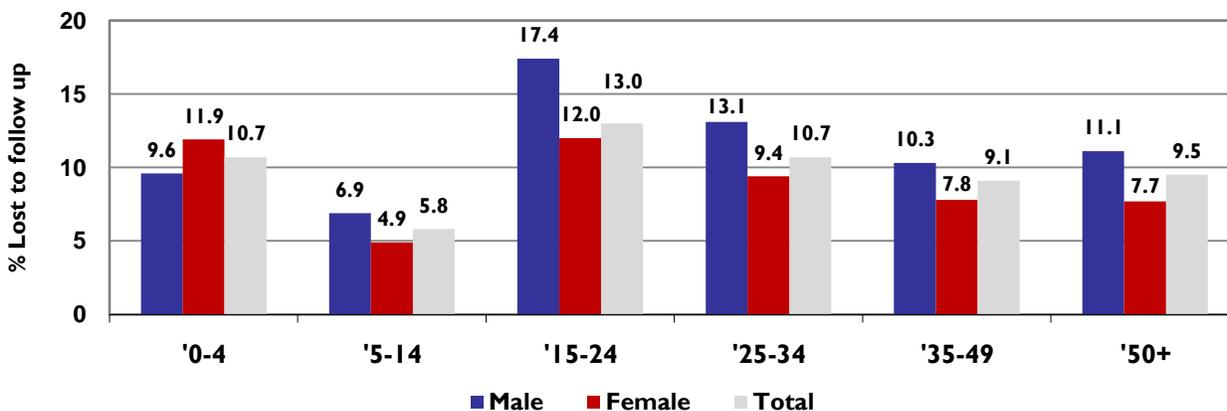
ART patients' outcomes encompass the following broader categories: patients who (1) are alive and still on treatment, (2) stopped treatment, (3) transferred to another facility, and (4) were lost to follow-up. A patient who misses appointments for one to three months is considered lost to follow-up. The category also includes those considered dropped (if discontinued follow-up for 3 or more months) and patients who have died.

Level of Treatment Discontinuation: Lost or Dropped

In the nine facilities, 9,703 patients were started on ART during January 2007–August 2009. Of these, 72.7 percent are still in follow-up, 10.6 percent transferred out to other facilities, 4.2 percent were lost to follow-up for less than 3 months (considered lost), 5.8 percent dropped (discontinued for more than 3 months), and 6.7 percent were dead. Few (6 patients, 0.1%) reported stopped treatment. When combined, the proportion of lost to follow-up and presumably alive (dropped or lost) from these facilities during January 2007–August 2009 are estimated at 10 percent. The lost to follow-up rate documented by this study is lower than previously reported because previous studies failed to capture the transfer-out rate, which represents about one-tenth. While the proportion still in follow-up is similar to the 73 percent reported at the national level (HAPCO, unpublished), it is unknown if the documented lost to follow-up, transfer-out, and mortality patterns from these sample facilities reflect the national picture.

The age-sex differential of patients lost to follow-up is detailed in Figure 5. In general, males appeared more likely than their female counterparts to be lost to follow-up across all age brackets, except in the age group 0–4. The peak lost to follow-up proportion was documented among youth (ages 15–24) of both sexes, followed by the age group 25–34. Children under five years old also exhibited a considerably high lost to follow-up rate.

Figure 5. Proportion of patients who ever started on ART (January 2007–August 2009) lost to follow-up by age and sex, 9 health facilities (N=9703)



Factors Influencing Lost to Follow-up

In the seven facilities with complete information on patients' socio-demographics, the proportion that were lost to follow-up was 12.6 percent, transfer out was 7.8 percent, dead was 7 percent, and still in follow-up was 72.5 percent.

Multivariate Logistic Regression analysis revealed that patients' sex, age, type of health facility, and duration in treatment appeared to be independently and significantly associated with the risk of discontinuing ART (see Annex 1). Compared to the females, males were 60 percent more likely to discontinue ART. Young patients ages 15–24 were found to be at increased risk of discontinuing treatment. The odds of discontinuing treatment were 2.1 times higher among young patients ages 15–24 years compared with their older (50+) counterparts.

The noted relationship between education and the risk of discontinuing treatment is unclear. There appears to be a 60 percent increased likelihood of discontinuing treatment among those with no education compared with those having 9–12 or more years of schooling. ART users of 7th and 8th graders also exhibited a significantly higher risk of discontinuing ART. In contrast, the education category, grades 1–6, did not carry significantly higher excess risk than the highest education category. This finding is difficult to interpret, which is likely confused by some uncontrolled confounders.

ART users in health centers were 1.8 times more likely than those from the hospital to discontinue treatment after controlling for age, sex, and selected socio-demographics.

Reasons for Discontinuation of ART

The reasons given by participants for discontinuing ART mirror the barriers to ART described in Section V. Reasons for discontinuation ranged from issues related to lack of resources, to situational factors, and to decisions made based on self-assessments of health.

Lack of resources

Lack of Food

Most ART users are poor, and their access to resources, including food, is further limited by their HIV status. Many discontinue treatment because they do not have adequate food with which to take the drugs. One woman who discontinued ART made the following remark.

This drug [ART] is like a poison without adequate food. —Discontinued ART user, FGD participant

While the food support programs linked to ART services entice many PLHIV to start ART and adhere to treatment, the interruption or cessation of these nutritional programs also leads to discontinuation by patients.

I stopped using ART for over 6 months last year when they stopped the free food rationing. The wheat and oil support are too little but are important for someone like me who has nothing to eat... when they resume providing the food support recently, I restarted using treatment. —ART users (restarted after discontinuing), FGD participant

In some cases, nutritional gains by patients can lead to the end of food support, as seen in programs that use a body mass index cut-off point at which they initiate and discontinue support. For older patients, even when food is available, they may lack the support they need to continue ART.

I know an elderly woman who discontinued because she did not have food and when the food is available; there is no one to prepare the food and care for her. —On pre-ART, FGD participant

Indirect Costs

Indirect costs for transportation to services, laboratory diagnosis, and drugs for opportunistic infections prove too great for many, forcing them to discontinue treatment.

Situational

Perceived and Actual Stigma

Due to perceived and actual stigma, some PLHIV choose not to disclose to family and friends, forcing patients to adhere to ART secretly, adding additional challenges.

Lack of openness is the main cause for treatment discontinuation. Most often, patients take the drug [ART] secretly, as a result of which they face several problems, such as skipping tablets, missing appointments, etc., which ultimately lead to discontinuation. —Health worker, Key Informant

Treatment discontinuation due to fear of stigma and disclosure of ART use reported to be most common among sex workers, housemaids, those working in food and beverage establishments, barber shops, and beauty salons across the study sites. Due to the nature of their work, such patients were reported to be very secretive in their use, as disclosure of ART use may lose them their jobs. Health workers across the study sites also reported that treatment adherence and continuous use of ART appeared most challenging among such groups.

A sex worker discontinued and disappeared from the town. I tried to locate her but in vain. There is also another sex worker who regularly collects her tablets [ART] but does not use them everyday because of fear of being seen by a client while taking the drug. —ART users, FGD participant

Addiction with Alcohol and Khat

Some patients, especially men, are unwilling or unable to quit addictions, such as alcohol and Khat—a step that is recommended by health workers as necessary to maintain treatment.

Discontinuation during Fasting Season

Some Orthodox and Islam followers discontinue ART during fasting seasons due to a desire to fulfill their religious obligation, as well as fear of stigma.

I stopped the drug in the Ramadan month because I was afraid what would people say if I was eating and taking the medicine [ART] during Ramadan. —Discontinued ART user, FGD participant

Incarceration

Access to ART in prisons is limited, making adherence difficult.

I know someone who discontinued ART because he was arrested and convicted. —Health worker, Key informant

Self-assessment

Discontinuation Based on Self-assessment of Treatment Outcome

Some patients make decisions to discontinue ART on their own based on self-assessment of treatment outcome. Patients who did not see their health conditions improving after taking ART for a number of months or years lost hope and opted to stop treatment.

My aunt's daughter who was using the drug [ART] stopped treatment when the drug did not improve her health. We took her to Arsema [Holy water site]. Suddenly she became so well....and after few months her health deteriorated again and died after seven months. —Community member, FGD participant

In contrast, some patients regain health, return to normal life, and see themselves as cured with no need for further treatment.

Side-effects

Patients frequently mentioned severe side effects, such as vomiting, skin rash, skin yellowing, nausea, headache, vomiting, skin sores, burning sensation, and blurring of the sight as reasons to discontinue treatment. Although many side effects fade with time, some patients on ART could not bear the symptoms and chose to discontinue treatment. Participants felt that having noticeable side effects could lead to stigmatization by community members who associate them with ART use.

I discontinued because I could not bear the pain of repeated and consistent vomiting whenever I took the tablets. —Discontinued ART user, FGD participant

The skin rash, etching and vomiting when I started treatment were difficult to continue treatment and decided to leave the treatment and started Tsebel [Holy water]. —Discontinued ART user, FGD participant

Treatment Fatigue and Inconvenience

The need to incorporate ART and the strict treatment schedule as part of one's daily life leads to treatment fatigue for some ART users.

Taking the drug everyday is awful. I forgot and skipped tablets in several occasions and finally decided to abandon it altogether. —Discontinued ART user, FGD participant

Treatment Options Pursued During Discontinuation

During discontinuation, most patients resorted to Holy water and traditional medicine. Participants noted that ART-Holy water users are often lost to follow-up as they move to using only Holy water.

I have been using Tsebel since I stopped the drug. Previously, I was using Tsebel with the drug [ART]. —Discontinued ART user, FGD participant

I have been using traditional medicine that I myself prepared but did not see any improvement so far. —Discontinued ART user, FGD participant

In general, PLHIV who discontinued ART and participated in this study expressed a willingness to restart treatment but wanted to see improvements in those conditions that forced them to stop treatment. The few participants who resumed ART after discontinuing for several months did so because of further deterioration in health conditions, resumption of the food support, counseling, and persuasion by family, friends, and home-based workers.

I re-started because the care and support workers arranged the free food aid for me. —ART users (restarted after discontinuing), FGD participant

During the time I discontinued the drug [ART], a traditional healer gave me a mix of garlic, onions, and other herbs. He told me I should take it without interruption for a month, but I couldn't resist it even for a week. I then came back to the health center and resumed the drug since it was the only option I had. —ART users (restarted after discontinuing), FGD participant

CONCLUSION AND RECOMMENDATIONS

The paucity of existing data limits our analyses of equity in access to ART. Yet, available data suggest that the country has made considerable progress toward equity in access to ART. The expansion of ART services has been rapid, bringing services closer to those people in need. More than 73 percent of the population needing ART has started on ART. Females and the urban poor have recently begun benefiting from the free ART service available through the public hospitals and health centers.

Although there is recognition that the rural population should have equal access to ART, to date, services remain urban-biased. Understandably, the vast geographic scope and the scattered nature of the rural population, coupled with the limited resources available to expand services, means there are hard choices to be made in future investments. The aim is to reach as many people as possible in the most equitable yet cost effective manner. Expanding service to the rural population through satellite facilities and outreach programs may be one solution to increasing equity.

This study identified barriers operating at individual, community, and health system levels, noting that individual/community-related barriers remain the biggest deterrents to ART use. This does not, however, mean that the other barriers operating at health facility or policy levels are less relevant. In fact, addressing barriers at all levels and throughout the treatment continuum is central to improving equitable access to ART. Barriers at the health facility level may prove to be the easiest to address, but they require significant resources and political will. Community-level barriers such as stigma and the prevailing widespread faith on Holy water as a treatment option for ART may be most challenging for programmers.

Taken together, the study findings point to several recommendations for programming, policy, and research aimed at reducing the many barriers to ART uptake and retention in treatment. However, this study did have limited geographic coverage and a small facility sample size. Studying the barriers to accessing ART in emerging regions and private facilities may provide additional dimensions and improve our understanding of contextual and institutional barriers. It will also be important to study different ART provision options and entry points for the underserved population, including the rural population, homeless, and inmates, as well as to undertake more research to better understand the higher discontinuation rate in health centers. The following are some identified recommendations:

Policy Level

- Identify and clearly define vulnerable, marginalized, or other potentially underserved populations for ART, HCT, and other related services at the national level.
- Identify indicators for monitoring equity at the national level to evaluate progress toward equity in access to ART.

Community Level

- ART rollout requires interventions to ensure community acceptability of ART. The community should be sensitized to deal with HIV stigma and create an enabling environment for HIV disclosure, ART use, and treatment continuation.
- Enhance community knowledge and understanding of ART and its benefits. Such efforts should embrace the rural population, sex workers, women working in informal sectors, domestic workers, homeless, etc.
- Promote ART use disclosure to families and spouses.

- Address the prevailing confusion between simultaneous use of ART and Holy water, and vigorously promote ART as the single most effective treatment option for HIV. Involve the Ethiopian Orthodox Church, PLHIV associations, and communities in this endeavor.
- Actively involve home-based care workers and PLHIV associations and encourage peer support for ART use and treatment continuation and adherence.
- Work with religious groups, especially the Islamic affairs and Mosques, to help patients adhere to ART during fasting seasons

Facility and Health System Level

- Strengthen laboratory logistics systems for ART, emphasizing uninterrupted availability of CD4 services and other laboratory supplies. Put in place an efficient laboratory equipment maintenance system, especially for CD4 machines.
- Solicit viable options to cover the cost for diagnosis, treatment, and drugs for opportunistic infections and other health problems of poor and bedridden patients on ART, including health insurance and social security.
- Create education and training opportunities, incentive schemes, and a functioning performance appraisal system as part of human resource management. Programs should solicit ways to motivate and retain health workers providing ART services.
- Devise ways to integrate ART services with the outpatient department within health facilities so that ART users access treatment without fear of stigma. As part of this effort, evaluate the pros and cons of the impact of service integration on efficiency in ART service delivery.
- Extend ART access to accommodate inmates and the homeless.
- Expand access to ART service to the rural population. The Accelerated Plan for the Expansion of Primary Health Care Coverage in Ethiopia (2005–2009) envisages availing one health post per rural Kebele, with five health posts serving as satellite sites to one health center. These health centers can thus be used as entry points to expand access to ART services to the rural population.
- Address lost to follow-up from ART by strengthening counseling and peer support. Counsel patients to develop self-efficacy and commitment in ART use. Men, youth, and non-working ART users should be given due emphasis in adherence counseling.
- Provide sufficient information about the side effects associated with ART use and the transitory nature of the side effects.
- Counsel and support patients with addictions such as alcohol, cigarettes, and Khat to quit these habits and continue using ART.

Food Support Programs

This study has confirmed the importance of some form of food support as a motivating factor for ART initiation and adherence, especially to the severely ill, poor, and vulnerable patients who are on ART. Interruption of food support emerged among the major reasons for discontinuing ART. It is therefore imperative to map out the food support programs available for PLHIV on ART and evaluate program efficiency, impact, and pitfalls. Assessing the sustainability of the program should also be among the priority activities.

ANNEX I: REGRESSION ANALYSIS

Table A.1. Adjusted odds ratio and 95 percent CI according to selected characteristics of patients (ages 15+) during January 2007–August 2009, 7 health facilities, Ethiopia (N=5773)

	Adjusted OR [95% CI]
Age	
15–24	2.1[1.4-3.1]
25–34	1.4 [1.0-2.0]
35–49	0.8[0.8-1.5]
50+ (Ref)	1.0
Sex	
Male	1.6[1.3-1.9]
Female(Ref)	1.0
Education	
No education	1.6[1.2-2.0]
Grade 1–6	0.1[0.9-1.4]
Grade 7–8	1.6[1.2-2.1]
Grade 9–12+ (Ref)	1.0
Work status	
Working (Ref)	1.0
Non-working	1.0[0.8-1.2]
Student	0.7[0.4-1.5]
Marital status	
Currently married (Ref)	1.0
Divorced	1.1[0.9-1.4]
Widow	1.0[0.8-1.2]
Never married	1.0[0.7-1.4]
Religion	
Orthodox (ref)	1.0
Muslim	1.1[0.9-1.5]
Others	1.2[0.9-1.7]
Type of facility	
Hospital	1.0
Health Center (Ref)	1.8[1.5-2.2]
Year start of ART (Eth. Cal.)	
1999 (ref)	0.8[0.6-1.0]
2001	0.4[0.3-0.5]
2002	1.0

Ref: Reference category; OR=Odds Ratio

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