

HIV Case Management in Ethiopia: A Pragmatic Approach to Maximizing Adherence to Long-Term Treatment and Retention in Chronic Illness Care



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Dedication

This document is dedicated to every health care provider serving in the different levels of the Ethiopian health care system—particularly to those professionals who care for clients with HIV/AIDS and other chronic illnesses requiring lifelong treatment.

In addition, this document is dedicated to every person living with HIV who dares to share their HIV-related experiences, and has shared useful information to help in the prevention, care, and treatment ○

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Preface

As a result of the rapid expansion of antiretroviral therapy (ART) programs in Ethiopia, the number of people living with HIV (PLHIV) enrolled in ART programs has increased dramatically, with overall ART coverage approaching 80%. Yet, poor adherence—characterized by attrition from HIV care, or becoming lost to follow-up—remains a significant challenge to the success of the national ART program. Poor adherence is known to negatively influence the success of HIV treatment, increasing the likelihood that more drug-resistant strains of HIV will emerge.

To mitigate this challenge, the University of Washington's I-TECH Ethiopia launched its **HIV Case Management Program** in 2007. The primary goal of this program is to improve the success of ART by reinforcing efforts to improve treatment adherence and retention. The program aims to achieve this goal through identification of at-risk clients, one-on-one education, and counseling and tracking of lost-to-follow-up clients.

Following critical review of the pilot phases, the program was expanded to cover sixty facilities in northern Ethiopia. In 2009, it was converted to a national comprehensive adherence support program. The program employs a task-sharing approach, in which non-clinician lay workers and HIV-positive individuals are recruited to support the expansion of programs in other resource-limited settings where skilled health workers are in short supply.

Evaluation of the program demonstrated that it has been instrumental in preventing attrition among clients enrolled in HIV services, educating and empowering clients, and referring clients to community support services. Moreover, through the program, the emerging palliative care needs of people living with HIV have been identified, and the services—among them psychological and mental health support—made available to the beneficiaries.

This monograph presents some of the major successes of the case management program, and discusses its application in improving adherence to treatment of chronic illnesses beyond HIV. The authors realize that the issues covered in this document may not be exhaustive; rather, they are meant only to stimulate further dialogue about feasible strategies for improving chronic illness management, and to explore models that best suit such illness.

—The Authors

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Acronyms and Abbreviations

ACM	Adherence Case Management
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CDC	Centers for Disease Control and Prevention
COP	Country Operational Plan
EDHS	Ethiopia Demographic and Health Survey
FBO	Faith-Based Organization
GIPA	Greater Involvement of People Living With HIV/AIDS
FHAPCO	Federal HIV/AIDS Prevention and Control Office
HIV	Human Immunodeficiency Virus
I-TECH	International Training and Education Center for Health
LTFU	Lost to Follow-Up
MDT	Multidisciplinary Team
FMOH	Ministry of Health
NEP+	Network of Networks of HIV Positives in Ethiopia
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
SOP	Standard Operating Procedure
UCSF	University of California San Francisco
UW	University of Washington

Executive Summary

Background: As a result of the rapid expansion of antiretroviral therapy (ART) programs in Ethiopia, close to 400,000 people living with HIV (PLHIV) have accessed ART, for overall coverage of nearly 80%. Nevertheless, poor adherence—characterized by attrition from HIV care, or becoming lost to follow-up (LTFU)—has challenged the success of the national program. A nationwide study showed high LTFU rates—18.4% 12 months after initiation of treatment, and 23.1% at 24 months.

Intervention: High LTFU rates reduce treatment success, which in turn negatively impacts survival rates, and leads to the emergence of drug-resistant strains of HIV. Given the risks posed by high LTFU rates and missed clinic visits, the lack of a structured adherence support program was an obvious gap needing to be filled. Accordingly, it was deemed time to introduce a comprehensive adherence and retention support package.

In response, the University of Washington's I-TECH Ethiopia organization introduced its **HIV Case Management Program**, designed to address the challenges of adherence and retention in the course of ART and chronic illness management, in 2007. Between 2007 and 2009, in collaboration with regional health bureaus (RHBs), the program was implemented in Tigray, Amhara, and Afar, three regions in northern Ethiopia that have been heavily impacted by the HIV pandemic.

The program employs a task-sharing approach, in which non-clinician volunteers and HIV-positive individuals are recruited and trained in the core competencies required of case managers. They are given four weeks of intensive training (both lecture-based and hands-on) in the subjects of HIV transmission, medication adherence, barriers to adherence, palliative care, referrals and service linkages, counseling skills, and maintenance of confidentiality, among others. This training is reinforced through on-site visits and periodic mentoring by HIV-trained nurses.

Similar approaches are practiced to augment the expansion of programs in other resource-limited settings where skilled health workers are in short supply.

Achievement: I-TECH Ethiopia has promoted a task-sharing approach and chronic illness management model, in the form of a pragmatic, culturally competent HIV case management program. To ensure the adoption and sustainability of the program, it has not only been pilot tested, and adapted to the needs of the Ethiopian health care system, but also integrated into existing national HIV prevention, treatment, and palliative care services.

At the national level, technical and financial assistance from the highest levels of government helped to strengthen the national task force on adherence and retention. This led to the development of an adherence strategy and framework; the latter was instrumental in revising and standardizing adherence support activities, HIV case management guidelines, training curricula, job aids, and monitoring tools.

Over a two-year period, case managers were able to identify a total of 5,156 HIV-positive clients at risk for non-adherence, and enroll them in the program. Of this number, 4,338 clients were connected with HIV care and support organizations in their communities; 74% (3,219) made use of these resources and successfully completed the program.

One strategy used to maximize retention is a program for tracing LTFU clients. This strategy was crucial for reaching LTFU clients and understanding the reasons for their status. Dropping out was by far the biggest reason identified. Although dropouts

account for 33% of pre-ART LTFU clients, and 28% of ART LTFU clients, they are typically overlooked by standard HIV program monitoring systems. This observation became a basis for expanding the case management program to serve those clients who are enrolled in chronic HIV care, but are not yet eligible to start ART. Palliative care services provided by health facilities and community organizations in the three regions of northern Ethiopia were mapped, and a service directory compiled and distributed to stakeholders.

Conclusion: The HIV Case Management Program embodies proven strategies to strengthen treatment adherence and maximize retention of clients in chronic HIV follow-up care. Such strategies as health education, active screening for at-risk clients, and one-on-one counseling sessions are critical in empowering clients and their families and preventing dropout. Case managers act as liaisons in referring clients to, and connecting health facilities with, community organizations. Overall, the program has been instrumental in advocating for a comprehensive approach towards adherence. Policymakers and program managers are encouraged to use this program and other chronic care models to maximize adherence and retention, and realize desired outcomes for HIV care and treatment.

Keywords: Chronic illness, adherence, case management, task sharing.

Introduction

According to the World Health Organization (WHO), the global health workforce deficit now exceeds four million. In many of the countries of sub-Saharan Africa, shortages have disabled some health functions at a time when public demand for improved quality of health care is on the rise.¹

Resource-limited countries struggle to mitigate the impact of plagues of both communicable and non-communicable diseases. To meet national and global commitments, such as Ethiopia's Health Sector Development Program (HSDP) and the Millennium Development Goals (MDG), in order to reduce maternal and neonatal mortality, and combat HIV, tuberculosis, malaria, and malnutrition, demands a strong health care system capable of delivering a wide range of services on a much greater scale than at present.

HIV Epidemic in Ethiopia: A 2011 demographic and health survey conducted in Ethiopia showed adult HIV prevalence at 1.5% overall (1% among males, 1.9% among females). Urban and rural HIV prevalence were estimated at 4.2% and 0.6%, respectively. The total number of people living with HIV (PLHIV) was estimated at 790,000, of which 380,900 were eligible for antiretroviral therapy (ART). HIV-positive pregnant women numbered 38,404, with HIV-positive births numbering 7,806. That same year, there were a total of 41,451 AIDS-related deaths, resulting in an estimated 900,000 AIDS orphans.^{2, 3}

Adherence and Retention: Chronic illnesses, both non-communicable and communicable, require long-term treatment and follow up by clinicians in institutional settings. In the case of HIV, most PLHIV end up requiring lifelong ART in order to successfully reduce viral replication, thereby reducing AIDS-related morbidity and mortality.

Nonetheless, ensuring maximum adherence and retention is a major hurdle to overcome in the management of HIV and other chronic illnesses. Today, clinicians, HIV-positive clients, and affected families continuously struggle to maximize adherence to lifelong treatment.

1 World Health Organization. Task shifting: rational redistribution of tasks among health workforce teams : global recommendations and guidelines. 2008. Geneva, World Health Organization.

2 Federal Democratic Republic of Ethiopia. 2011 Ethiopian Demographic and Health Survey (EDHS). Addis Ababa: Central Statistical Agency; 2012.

3 Federal Ministry of Health of Ethiopia. Annual Performance Report of Health Sector Development Program IV (HSDP IV), Report number: EFY 2004 (2011-12). Addis Ababa; 2012.

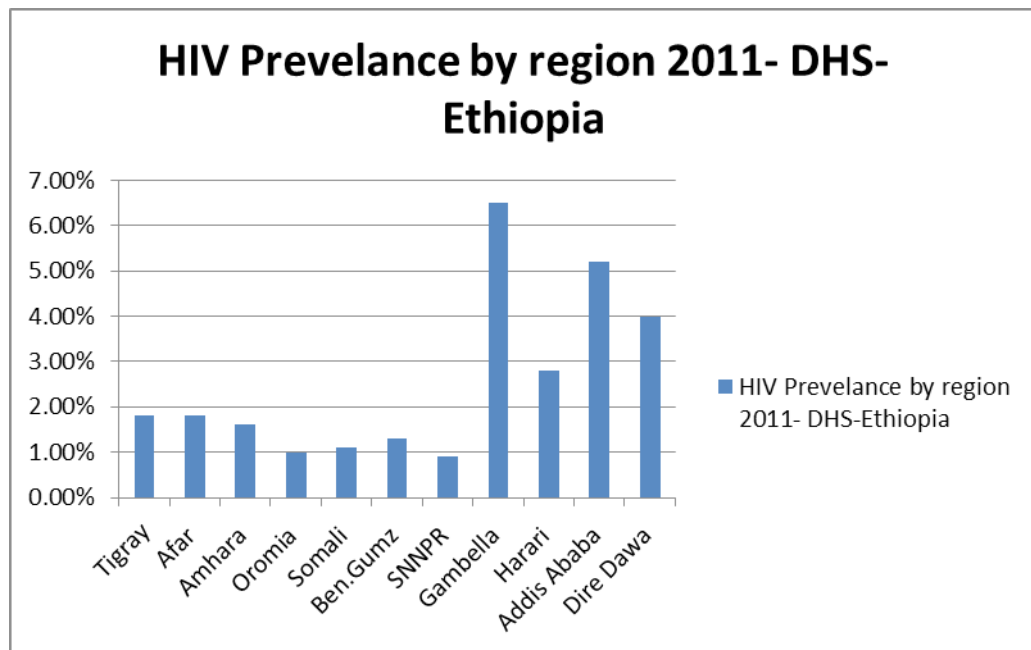


Figure 1. Prevalence of HIV in Ethiopia by Region

WHO defines *adherence* as the extent to which a client's behavior corresponds with agreed recommendations from a health provider. In a broader sense, *adherence* refers to the willingness and extent to which a client modifies behavior to follow health-related advice or recommendations, to take medication as prescribed, to attend scheduled appointments, and to complete recommended investigations. Adherence represents the complex relationships among patients, providers, and medication, and reflects the fact that following a medication regimen is not necessarily a simple task. Hence, the term *adherence* is preferred to *compliance*.⁴

What Is the Desired Level of Adherence for Lifelong ART? The average rates of adherence in clinical trials are generally higher than in clinical practice settings, because study participants receive extra attention, and because participation in trials is voluntary. Yet, even clinical trials report poor adherence rates—from 43% to 78%—among patients receiving treatment for chronic conditions.⁵

Evidence indicates that high levels of adherence (95% or more) to prescribed doses of antiretroviral drugs are required to achieve sustained viral suppression.^{6,7} Studies assessing adherence using unannounced pill counts and electronic monitoring indicated that viral suppression is achieved with a mean ART adherence level of 54%–100%.⁸

On the other hand, studies showed that clients following boosted protease inhibitor-based regimens were less than half as likely to develop HIV drug resistance as those on non-boosted protease inhibitor or non-nucleoside reverse-transcriptase

4 World Health Organization (WHO). Adherence to long-term therapies: evidence for action. Geneva: World Health Organization; 2003. Available from: <http://www.who.int/chp/knowledge/publications/adherence-report/en/index.html>.

5 Osterberg L, Blaschke T. Adherence to medication. N Engl J Med. 2005 Aug 4;353(5):487–97.

6 Conway B. The role of adherence to antiretroviral therapy in the management of HIV infection. J Acquir Immune Defic Syndr. 2007 Jun 1;45 Suppl 1:S14–8.

7 Lima VD, Harrigan R, Bangsberg DR, Hogg RS, Gross R, Yip B, et al. The Combined Effect of Modern Highly Active Antiretroviral Therapy Regimens and Adherence on Mortality Over Time: JAIDS Journal of Acquired Immune Deficiency Syndromes. 2009 Apr;50(5):529–36.

8 Bangsberg DR. Less than 95% adherence to nonnucleoside reverse-transcriptase inhibitor therapy can lead to viral suppression. Clin Infect Dis. 2006 Oct 1;43(7):939–41.

inhibitor combination ART at comparable adherence levels. Although it is possible to achieve viral suppression with highly potent antiretroviral drugs with less than 95% adherence, high levels of treatment adherence must remain a goal of ART programs—especially in resource-limited settings where drug options are limited.⁹

Similar in concept to medication adherence is retention in chronic HIV care. According to studies from sub-Saharan Africa and Ethiopia, the annual retention rate among clients receiving treatment for chronic illness is low, 60% and 73%, respectively.¹⁰

Clinical and Epidemiologic Significance of Adherence: The clinical significance of poor adherence is well documented: adherence to prescribed medication, scheduled follow-up appointments, and pharmacy drug refills is critical in ensuring treatment success. Adherence rates below 80% are associated with unsuppressed viral replication.¹¹ Moreover, the consequences of poor adherence are not limited to individual clinical outcomes; they can include the emergence of drug-resistant viral strains, with possible transmission of resistant viruses to intimate sex partners, and, in the case of mother-to-child transmission, offspring—posing a major public health risk.

Transmitted drug resistance has become an emerging challenge in sub-Saharan Africa; a multicenter observational study from Uganda indicated that transmitted drug resistance among antiretroviral-naïve individuals has a prevalence of 11.6%.¹² Subsequent treatment failure as a result of accumulated drug resistance leads to an unnecessary switch to second-line or salvage therapy, which is often expensive, toxic, or, in the long run, limits future antiretroviral drug options.^{13, 14}

Even beyond clinical and public health significance, poor adherence and high attrition rates have economic implications. For example, when HIV-specific health outcomes are achieved, resulting in declines in death or hospitalization from AIDS-related opportunistic diseases, the direct and indirect costs incurred by clients and/or health care institutions due to unnecessary ambulatory clinic visits, hospitalizations, diagnoses, and treatment fall significantly.¹⁵

Assessment and Monitoring of Adherence: Adherence preparation and assessment should begin at the time of enrollment in chronic HIV care (pre-ART care), or well in advance of the initiation of ART.¹⁶ In general, an objective and ongoing adherence assessment needs to be made part of every scheduled clinic visit. When assessing readiness for long-term treatment, it is crucial to educate clients, and obtain explicit agreement on subsequent treatment plans and clinic follow-up schedules, because

9 Ibid.

10 Fox MP, Rosen S. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007-2009: Systematic review: Patient retention in antiretroviral therapy programs. *Tropical Medicine & International Health*. 2010 Jun;15:1–15.

11 El-Khatib Z, Katzenstein D, Marrone G, Laher F, Mohapi L, Petzold M, et al. Adherence to Drug-Refill Is a Useful Early Warning Indicator of Virologic and Immunologic Failure Among HIV Patients on First-Line ART in South Africa. Maartens G, editor. *PLoS ONE*. 2011 Mar 9;6(3):e17518.

12 Hamers RL, Wallis CL, et al *Lancet Infect Dis* 2011;11:750-9.

13 World Health Organization. HIV Drug Resistance Early Warning Indicators: Indicators to monitor HIV drug resistance prevention at antiretroviral treatment sites. April 2010. Available from: <http://www.who.int/hiv/drugresistance>.

14 Sethi AK, Celentano DD, Gange SJ, Moore RD, Gallant JE. Association between adherence to antiretroviral therapy and human immunodeficiency virus drug resistance. *Clin Infect Dis*. 2003 Oct 15;37(8):1112–8.

15 Munakata J, Benner JS, Becker S, Dezii CM, Hazard EH, Tierce JC. Clinical and economic outcomes of nonadherence to highly active antiretroviral therapy in patients with human immunodeficiency virus. *Med Care*. 2006 Oct;44(10):893–9.

16 Federal Ministry of Health. Guidelines for Management of Opportunistic Infections and Anti Retroviral Treatment In Adolescents And Adults In Ethiopia. Federal HIV/AIDS Prevention and Control Office, Addis Ababa; July 2007.

some of the factors that determine adherence may not be detected by single assessments or quantitative methods. To facilitate ongoing assessment, clinicians and adherence peer supporters need to establish good rapport and build trust with clients, in order to explore social, cultural, religious, behavioral, and sexual factors that may influence client adherence.¹⁷

There are a number of methods for measuring adherence, some quantitative (objectively quantifying adherence), others qualitative. These methods include self-reporting, clinic appointments, pharmacy records (to check refills), and pill counts. Biological assays of drugs active in the blood and electronic drug monitoring are often used in research. Still, despite the many methods being used, accurately assessing adherence is difficult. This is partly because adherence is a dynamic phenomenon, requiring ongoing evaluation.^{18, 19}

Self-Reporting: The self-reporting method relies on client memory recall, and takes into account the numbers of doses clients report missing. The numbers are then compared to agreed-upon thresholds (e.g., 95% of doses taken).

The positive association between self-reporting and HIV viral loads has been demonstrated by several studies. Peterson K, et al. (2013)²⁰, Simoni JM, et al. (2006), and Nieuwkerk PT, et al. (2005) have documented that adherence to ART assessed by the self-reporting method shows positive correlation with HIV viral suppression.

Simoni JM, et al. (2006) conducted a review of 77 papers, published between 1996 and 2004, that used self-reporting to measure ART adherence. The review found that self-reported ART adherence was significantly correlated with viral load in 84% of comparisons.²¹ Nieuwkerk, et al. pooled data from 65 studies and 15,351 patients, finding that the pooled odds ratio of having a detectable viral load was 2.31 (95% CI = 1.99–2.68) for non-adherent patients, compared with adherent patients.²²

Given that the self-reporting method is widely used to assess adherence in both resource-rich and resource-limited settings, its use in routine chronic illness care needs to be maximized. In addition, self-reporting is a viable alternative to other objective measures of adherence, such as biological drug assays, electronic monitoring, or pill counts, for assessing and monitoring adherence.²³ Self-reporting is also less expensive, making it easily applicable to HIV care settings in most resource-limited countries.²⁴

Barriers to Adherence and Retention: Adherence to treatment is inherently difficult, even in the best of circumstances. Both providers and clients must recognize that

17 Berg KM, Arnsten JH. Practical and Conceptual Challenges in Measuring Antiretroviral Adherence: *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2006 Dec;43(Supplement 1):S79–87.

18 Müller AD, Jaspan HB, Myer L, Hunter AL, Harling G, Bekker L-G, et al. Standard measures are inadequate to monitor pediatric adherence in a resource-limited setting. *AIDS Behav*. 2011 Feb;15(2):422–31.

19 Chesney MA. The elusive gold standard. Future perspectives for HIV adherence assessment and intervention. *J Acquir Immune Defic Syndr*. 2006 Dec 1;43 Suppl 1:S149–55.

20 Peterson K, Menten J, Peterson I, Togun T, Okomo U, Oko F, et al. Use of Self-Reported Adherence and Keeping Clinic Appointments as Predictors of Viremia in Routine HIV Care in the Gambia. *J Int Assoc Provid AIDS Care* 2013.

21 Simoni JM, Kurth AE, Pearson CR, Pantalone DW, Merrill JO, Frick PA. Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. *AIDS Behav* 2006; May;10(3):227–45.

22 Nieuwkerk PT, Oort FJ. Self-Reported Adherence to Antiretroviral Therapy for HIV-1 Infection and Virologic Treatment Response A Meta-Analysis. *J Acquir Immune Defic Syndr* 2005; Apr 38 (4):445–448

23 Simoni JM, Kurth AE, Pearson CR, Pantalone DW, Merrill JO, Frick PA. Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. *AIDS Behav* 2006; May;10(3):227–45.

24 Simoni JM, Kurth AE, Pearson CR, Pantalone DW, Merrill JO, Frick PA. Self-report measures of antiretroviral therapy adherence: A review with recommendations for HIV research and clinical management. *AIDS Behav*. 2006 May;10(3):227–45.

adherence is difficult, and requires a lot of effort. However, studies have identified determining factors that are relatively easy to change: client, treatment, health care provider, health system and miscellaneous factors.

1. Client factors: Individual client factors that may help or hinder adherence include sociodemographic factors (e.g., age, gender, income, education, and literacy), behavioral and psychosocial factors (e.g., mental health, substance use), knowledge about HIV, attitudes towards lifelong treatment, and levels of family or social support.²⁵

Adherence status correlates positively with the age of the client; elderly and adolescents in particular face difficulty in maintaining long-term adherence, due to reliance on adult caregivers, and the inability to fully comprehend the need to take drugs daily when not feeling sick. Such drug-related factors as palatability of drugs, orphan child status, and inconsistent caretaker performance also greatly influence adherence. In Africa, only 55% to 60% children were adherent to ART.^{26, 27}

2. Treatment factors: Treatment factors affecting adherence include the number of drugs being taken, complexity of drug regimens (dosing frequency and food instructions), the specific types of antiretroviral drugs being taken, drug toxicity, and interactions with drugs being used to treat concurrent illnesses. Evidences demonstrated that poor adherence to ART is a strong predictor of progression of disease to advanced AIDS stages.²⁸

3. Health care provider factors: The client-provider relationship is another determinant of adherence. This comprises clients' overall satisfaction with the care provided, trust in the competence of providers, the willingness of providers to engage clients in the process of making decisions about their own care, and the concordance of sociocultural values between clients and providers (adequacy of referrals, for example).^{29, 30, 31}

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- 25 Dahab M, Charalambous S, Hamilton R, Fielding K, Kielmann K, Churchyard GJ, et al. "That is why I stopped the ART": Patients' & providers' perspectives on barriers to and enablers of HIV treatment adherence in a South African workplace programme. *BMC Public Health*. 2008;8(1):63.
 - 26 Vreeman RC, Wiehe SE, Pearce EC, Nyandiko WM. A Systematic Review of Pediatric Adherence to Antiretroviral Therapy in Low- and Middle-Income Countries: The Pediatric Infectious Disease Journal. 2008 Aug;27(8):686–91
 - 27 Haberer JE, Kiwanuka J, Nansera D, Ragland K, Mellins C, Bangsberg DR. Multiple Measures Reveal Antiretroviral Adherence Successes and Challenges in HIV-Infected Ugandan Children. Vermund SH, editor. *PLoS ONE*. 2012 May 9;7(5):e36737.
 - 28 Gifford AL, Bormann JE, Shively MJ, Wright BC, Richman DD, Bozzette SA. Predictors of self-reported adherence and plasma HIV concentrations in patients on multidrug antiretroviral regimens. *J Acquir Immune Defic Syndr*. 2000 Apr 15;23(5):386–95.
 - 29 Flickinger TE, Saha S, Moore RD, Beach MC. Higher quality communication and relationships are associated with improved patient engagement in HIV care. *J Acquir Immune Defic Syndr*. 2013 Jul 1;63(3):362–6.
 - 30 Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *J Gen Intern Med*. 2006 Jun;21(6):661–5.
 - 31 Schneider J, Kaplan SH, Greenfield S, Li W, Wilson IB. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. *J Gen Intern Med*. 2004 Nov;19(11):1096–103.

4. Health system factors: Aspects of health care that may affect adherence and retention include accessibility and friendliness of service at health facilities, availability of adherence support programs, distance of facilities from the home, availability of transportation, convenience of scheduled appointments, perceived confidentiality of private information, and overall satisfaction with previous experiences at the same facilities.³²

It is worth noting that lack of continuity of health care, whether due to insufficient laboratory supplies or depleted stocks of antiretroviral drugs, can also contribute to dissatisfaction among clients seeking HIV care.

5. Miscellaneous factors: Where stigma related to HIV and mental illness is prevalent, adherence suffers. Fear of disclosure of one's HIV status to an intimate sex partner becomes difficult.³³ Psychosocial and psychiatric conditions, such as depression, alcohol abuse, stressful life events stemming from loss of loved ones or employment opportunities, and lack of peer or family support, are also strong predictors of poor adherence.³⁴

32 Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW, Gross R, et al. Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel. *Annals of Internal Medicine*. 2012 Jun 5;156(11):817.

33 Ware NC, Idoko J, Kaaya S, Biraro IA, Wyatt MA, Agbaji O, et al. Explaining Adherence Success in Sub-Saharan Africa: An Ethnographic Study. *Beyrer C, editor. PLoS Medicine*. 2009;6(1):e11.

34 Tesfay K, Girma E, Negash A, Tesfaye M, Dehning S. Medication Non-Adherence Among Adult Psychiatric Out Patients in Jimma University Specialized Hospital, Southwest Ethiopia. *Ethiopian Journal of Health Sciences* 2013;23(3):227-236.

Statement of the Problem

Resource-limited countries have been heavily impacted by the critical shortage of health care workers, which is further exacerbated by the HIV pandemic. Nearly 95% of people living with HIV reside in these countries, the vast majority (two-thirds) in Africa. Chronic communicable and non-communicable illnesses (including mental illnesses) currently represent 54% of the global disease burden—and may exceed 65% by 2020.³⁵ However, sub-Saharan Africa hosts only 3% of the world's health care workforce, and commands less than 1% of world health expenditures.^{36, 37}

Therefore, addressing this deficiency in the health care workforce is a priority. One strategy that may help alleviate personnel shortages is the *task-sharing approach*, or redistribution of tasks among health teams. Task sharing, sometimes referred to as task shifting, is a process whereby specific tasks are reassigned, where appropriate, to health workers with less-intensive training and fewer qualifications. Task shifting can help to make more efficient use of existing human resources, and ease bottlenecks in service delivery.

Several countries have implemented the task-shifting approach. In Ethiopia, for example, a government-led community health program recruited and trained over 30,000 volunteer women, now known as health extension workers (HEW). Following the training, these cadres are deployed to the community from where they were recruited to promote maternal, neonatal and child health (MNCH) and link individuals who need further care to health facilities in their vicinity thereby strengthening linkage between community and health facilities. I-TECH piloted and implemented the HIV/AIDS Nurse Specialist program in Ethiopia, a major task-sharing initiative that increased access to care and treatment for most PLHIV. Similarly, emergency obstetric and surgery officers share duties with surgeons and obstetricians, and are deployed in remote health facilities to improve access to life-saving surgical interventions.

When it comes to HIV care, health education and adherence counseling are not given enough emphasis. Ethiopia faced serious challenges to adherence and retention, particularly during the expansion phase of the ART program (2005–2007). Non-adherence and attrition are not uncommon: globally, the rate of non-adherence ranges from 20–50%. Of the 402,599 people who have been started on ART in Ethiopia, only 76%—approximately 308,000—have remained in treatment.³⁸

35 The World Health Report 2002: Reducing Risks, Promoting Healthy Life. Geneva: World Health Organization; 2002.

36 Samb B, Celletti F, Holloway J, Van Damme W, Lawson L, De Cock K, Dybul M. Task shifting: An emergency response to the health workforce crisis in the era of HIV. Lessons from the past, current practice and thinking. *N Engl Med*, 357;24, 2007.

37 Laurant M, Reeves D, Hermens R, Braspenning J, Grol R, Sibbald B. Substitution of doctors by nurses in primary care. CD001271[2]. 2005. Cochrane Database of Systematic Reviews 6. Hongoro C, McPake B. How to bridge the gap in human resources for health. *The Lancet* 2004; 364(9443):1451-456.

38 Assefa Y, Jerene D, Lulseged S, Ooms G, Van Damme W. Rapid Scale-Up of Antiretroviral Treatment in Ethiopia: Successes and System-Wide Effects. *PLoS Medicine*. 2009 Apr 28;6(4):e1000056.

Thus, by 2007, it was imperative that Ethiopia's Ministry of Health (MOH) introduce a targeted, well-structured adherence program to help mitigate the challenges facing the ART program. At that time, adherence programs barely existed; nor were there any guidelines for standardizing adherence and retention actions taken by individual health facilities, local community organizations, or international partners.

Drawing upon lessons learned from follow-up of chronic illness and chronic care models tested in other countries, I-TECH Ethiopia stepped forward to promote the HIV case management model. I-TECH Ethiopia secured funding to provide technical and financial assistance during planning and implementation of the program, which incorporates strategies for adaptation, nationalization, and transition to local PLHIV associations, such as the NEP+. ^{39, 40, 41}

39 Nachega JB, Mills EJ, Schechter M. Antiretroviral therapy adherence and retention in care in middle-income and low-income countries: current status of knowledge and research priorities: Current Opinion in HIV and AIDS. 2010 Jan;5(1):70–7.

40 Fox MP, Rosen S. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: systematic review: Patient retention in antiretroviral therapy programs. Tropical Medicine & International Health. 2010 Jun;15:1–15.

41 Mannheimer S, Friedland G, Matts J, Child C, Chesney M. The consistency of adherence to antiretroviral therapy predicts biologic outcomes for human immunodeficiency virus–infected persons in clinical trials. Clin Infect Dis 2002; 34:1115–21.

The Case Management Model and Program

History of Case Management Once recognized as a cost-effective means of helping vulnerable populations in the United States to navigate the social service system and obtain the care that they need, the Ryan White Care Act of 1990 mandated the case management model to ensure coordination and continuity of services. Such federally mandated acts specified the need for community-based case management programs. To this end, New York, one of the states most affected by the HIV/AIDS epidemic in the US, developed a set of case management standards. The guidelines state that, “the AIDS center is required to ensure that each eligible patient receive case management services, including at a minimum a comprehensive assessment of medical, social and psychological needs, and plan for appropriate follow up services by a designated case manager.”⁴²

Case Management is defined as “a range of client-centered services that link clients with health services to ensure timely, coordinated access to medically appropriate levels of health and support services, continuity of care, ongoing assessment of the client's and other family members' needs and personal support systems.”⁴³

Case management is a client-centered, goal-oriented process for actively assessing and meeting the needs of HIV clients, in order to maximize adherence to ART, long-term care, and overall quality of life. Case management requires engagement of clients through coordinated efforts of multidisciplinary teams (MDTs), and coordination of services both within and outside the health facility. It also enables prudent use of scarce human resources by shifting some vital tasks from overburdened health care workers to trained volunteers.

Broadly speaking, case management involves responding to complex health and human service needs by making use of the resources that allow clients to function independently in the communities of their choice for as long as is practical.

When applied to HIV services, case management refers to coordination of the services recommended to HIV-positive individuals and their partners who are considered at risk of non-adherence to treatment or follow-up care at hospitals, health centers, and community clinics.⁴⁴

Models of Case Management: Several models of case management have been described in the literature over the past several years. Such models are typically classified according to several factors, including target population, setting, the role of the case manager, and scope of services provided. The most prevalent models that have emerged in the field of HIV case management are the broker, rehabilitation, full support, and strengths models.

42 HIV Clinical Resource. New York State Department of Health, AIDS Institute.

43 Fleisher, P, Henrickson, M. Towards a Typology of Case Management. Health Services and Resources Administration (US), HIV/AIDS Bureau; 2002 July.

44 Kenya S, Chida N, Cardenas G, Pereyra M, Del Rio C, Rodriguez A, et al. Case Management: Steadfast Resource for Addressing Linkage to Care and Prevention with Hospitalized HIV-Infected Crack Users. J HIV AIDS Soc Serv. 2014;13(4):325–6.

1. The broker model focuses on connecting clients with needed resources, usually outside the agency. In this model, the relationship between case managers and clients is limited. The main role of the case manager is to identify client needs, and then connect clients to the appropriate providers through referrals. Case ratios are usually higher under this model, with case managers typically responsible for both conducting client assessments and carrying out treatment plans.

2. The rehabilitation model uses the client-case manager relationship as a mechanism for obtaining services for the client. By identifying client strengths and weaknesses, the case manager works to remove a wide spectrum of barriers that prevent clients from functioning independently in their communities. When the barriers that hinder client self-sufficiency have been fully addressed, the relationship between case manager and client is either significantly reduced, or terminated.

3. The full support model builds upon the fundamental principles of the rehabilitation model by employing an integrated, multidisciplinary team of treatment providers, such as case managers, client advocates, and medical professionals. This model differs from the others in that it often relies on in-house treatment teams, rather than on referrals to outside agencies. Most services are provided to clients at the same location. The case manager's role in this model is to not only coordinate care, but also provide a certain level of clinical support and training in life skills. Research has demonstrated that this model reduces the need for patient hospitalization, and is most effective in working with clients who have long-term service needs. However, under this model, it is difficult to evaluate clients and determine when care should be terminated.

4. The strengths model, a newer form of case management, has emerged in the literature in recent years. Rather than assessing client needs based on deficits or problems, this model builds a service plan based on client strengths. The role of the case manager under this model is to assist clients in developing and attaining client-specific goals. The success of this model depends on the levels of outreach and follow-up conducted to ensure that clients are obtaining the needed services and care identified in their service plans.

In Ethiopia, HIV case management in a clinical setting exists on two levels:

The process or system level At this level, the case management model ensures clear connections between health facilities and community resources to address the holistic needs of clients who are unlikely to adhere to treatment and care. It also provides continuity of care, in order to maximize adherence to treatment and care, and minimize the risk of clients being lost to follow-up.

The specialist role level At this level, a case manager within the ART multidisciplinary team is dedicated to managing and finding solutions to the problems of HIV clients who are considered at risk of dropping out of treatment.

In general, the case management model serves to establish better connections between health facilities and community resources, and assists the facilities in preventing, tracking, and reducing the number of LTFU clients.^{45,46}

Multidisciplinary Team Approach: At hospitals and health centers, the health care staff work in MDTs to provide ART services to clients. Each MDT consists of a

45 Katz MH, Cunningham WE, Fleishman JA, et al. Effect of case management on unmet needs and utilization of medical care and medications among HIV-infected persons. *Ann Intern Med* 2001; 135:557–65.

46 Gardner LI, Metsch LR, Anderson-Mahoney P, Loughlin AM, del Rio C, Strathdee S, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*. 2005 Mar 4;19(4):423–31.

physician, nurse, pharmacist, laboratory staff, counselors, and, thanks to this initiative, an adherence case manager. The case manager participates in MDT meetings, updating the other members on the current status of cases under management. The leading coordinator of services for the MDT is the nurse, who guides, coaches, and supervises the adherence case manager. The case manager provides similar oversight of adherence supporters, who facilitate connections between health facilities and community resources.

At the local (facility) level, adherence supporters assist clients from the time they opt to be tested for HIV, and guide them through enrollment in chronic HIV care and other health system entry points—prevention of mother-to-child transmission services, TB clinics, outpatient or inpatient departments, or treatment for sexually transmitted infections. When necessary, adherence supporters escort clients to these different departments. The case manager and adherence supporters are seen as lowering the workloads of the multidisciplinary staff, thus freeing clinical staff to attend to clinical issues.

Care Plan Development: HIV/AIDS case management standards are formulated to reflect the core functions and guidelines necessary to develop HIV/AIDS case management care plans. HIV/AIDS case management comprises six core functions that assess client needs, and assist clients in accessing needed services. These core functions (and key activities) are as follows:

Intake: Screening and evaluating client eligibility, and admitting clients to HIV/AIDS case management services.

1. **Needs assessment:** Evaluating and prioritizing client needs.
2. **Personalized care planning:** Facilitating client access to services, and enhancing the quality of those services.
3. **Care plan monitoring and evaluation (M&E):** Collecting and monitoring data to ensure that services provided are consistent with the care plan. This also includes monitoring and evaluation of client adherence to treatment and care.
4. **Reassessment:** Reevaluating client needs/strengths and the care plan on a quarterly basis, or whenever changes occur in a client's life.
5. **Discharge/Transfer:** Formal notification that a client can no longer obtain HIV/AIDS case management services from the current service provider.

The HIV case management program is intended to overcome barriers to treatment adherence. The goals of the program are broadly categorized as follows:

A. Educate and empower clients

- Improve access to recommended HIV care and treatment services, in order to ensure the client's ability to maintain day-to-day functionality and productivity.
- Identify the specific needs of the client, and/or the client's family, through one-on-one consultation. Individual needs may include health education, adherence counseling, skills for coping with an HIV diagnosis, skills for adhering to treatment and care plans, connection with community resources, and enabling clients to generate more income.
- Ensure regular monitoring of treatment adherence, and tracking LTFU clients and returning them to care.

B. Strengthen the health care delivery system

- To ensure continuity of care for clients enrolled in chronic care programs.
- To ensure strong connections between the health facilities that provide ART treatment and the community resources that provide additional services and support for HIV-positive clients.

Case management seeks to coordinate medical care for individuals with complex medical problems. For HIV-infected patients, it is used to manage complex medication regimens, coordinate primary medical care, and assist with referrals to housing, mental health, and substance abuse services.

If client goals are to be met, the case management program needs to be integrated into other HIV services; adherence case managers will need to work harmoniously with other health cadres.

Accordingly, the goal of case management extends to encompass the following:

- Coordination of services among different points of HIV care.
- Strengthening existing local health education programs.
- Fostering consultation among MDTs.
- Advocating improvements in the care of PLHIV and their families.
- Support for institutional adherence support programs in order to maximize HIV treatment and care outcomes.

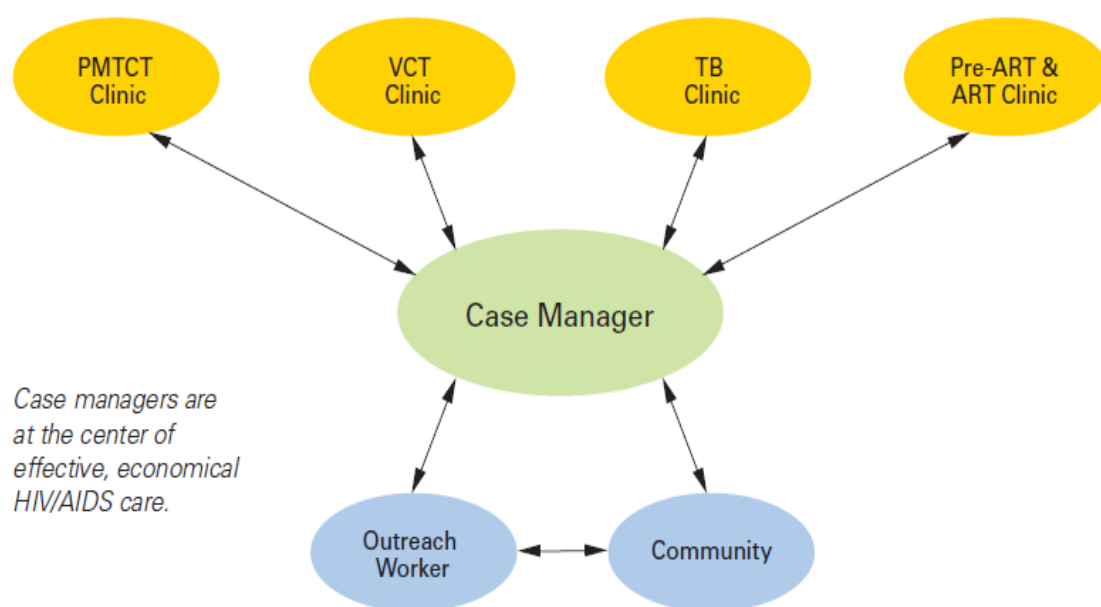


Figure 2: Referral Linkages in the HIV Case Management Program

Inception and Development of the Case Management Model in Ethiopia

In developed countries, case managers are professionals, mostly nurses or social workers. It is difficult or impossible to adopt such a model in resource-limited settings like Ethiopia, where there is a critical shortage of trained health care workers. It is with this in mind that I-TECH developed its case management initiative using task-sharing/shifting principles. This model of using lay workers and volunteers had to be tested and validated before it could be implemented.

Since 2006, I-TECH has played a leading role in the promotion and implementation of the HIV case management model in Ethiopia. The development of the program progressed in phases, starting with conceptualization of the case management model for purposes of improving treatment adherence and retention within chronic HIV care programs.

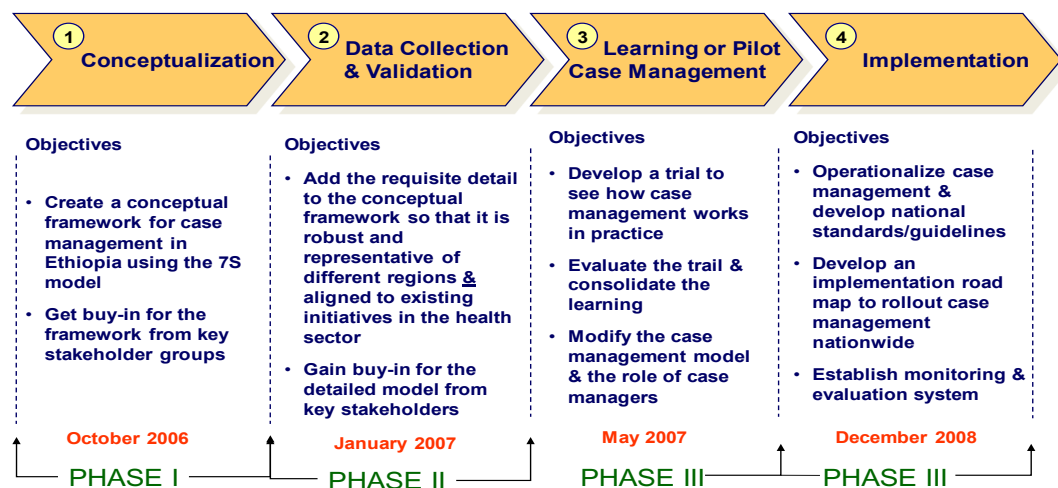


Figure 3: The developmental phases of the case management model and program in Ethiopia.

The key components of these phases are discussed below.

Phase I—Conceptualization (2006): A consultative meeting was held among the key stakeholders involved in providing HIV services and assisting the national HIV program in Ethiopia. The All Africa Leprosy, Tuberculosis, Rehabilitation and Training (ALERT) Centre Hospital community network model in Addis Ababa was reviewed to gain a deeper understanding of the potential benefits of a similar adherence support program. Reports and data were analyzed, and a conceptual model for case management developed.

In summary, the case management program is designed to ensure continuity of HIV care through execution of the following activities:

- Identification of at-risk clients, and prevention of attrition and/or erratic drug refill patterns.
- Identification of barriers to adherence, and reasons for discontinuation of clinical follow-up.
- Proper documentation of client addresses and health information.
- Education of clients on the benefits of adherence to treatment and care.
- Customization of tracking methods to fit individual client preferences.
- Enrollment of clients in the case management program, and completion of individual care plans.
- Early detection and active tracking of missed clinic appointments.
- Documentation of the outcomes of tracking efforts, and ongoing evaluation of 'restarters' to prevent further interruptions to clinic follow-up.

Phase II—Validation of Model (2007): During this phase, a consultative forum was called to discuss the proposed model, this time in the presence of policymakers and health care providers, whose feedback was used in validating the model.

A patient flow (triage) plan was developed to illustrate how HIV-positive clients move among different HIV service outlets, as well as how care providers in different clinics collaborate and interact to ensure continuity of care. This process mapping was a critical element in validating the case management model. The process also provided the basis for developing an operational definition of case management, and preparing job descriptions and job aids for program personnel.

Phase III—Pilot Phase (2007): During this phase, I-TECH Ethiopia pilot tested the program at six HIV clinics in Amhara, Tigray, and Afar.

In collaboration with the respective RHBs and host facilities, I-TECH recruited case managers and adherence support staff. The recruitment criteria outlined in the program implementation guidelines were used—i.e., a case manager candidate should be a secondary-school graduate (having completed at least eighth grade), and, preferably, should be HIV-positive, and be receiving recommended HIV services at the host institution.

In collaboration with the RHBs and PLHIV associations, I-TECH trained adherence case managers for three weeks (two weeks in the classroom, one week on-site), and adherence supporters for two weeks (one each in the classroom and on-site). To further bolster their knowledge and skill, candidates were mentored by field-based nurse mentors, and participated in review forums, where they were given feedback on their performance.

In 2007, after six months in this phase, the program was evaluated at three and six months post-implementation. Informed by the evaluation findings, the pilot phase was declared successful in reducing the number of LTFU clients, increasing client awareness of the importance of medication adherence, and improving connections among HIV service outlets at pilot facilities. Subsequently, I-TECH Ethiopia expanded the program, in phases, to additional facilities from 2008 through 2010.

Phase IV—Implementation (2008): The goal during this phase was primarily to develop guidelines for implementing the case management program, and to complete adaptation of the program to the Ethiopian context.

Following the Ethiopian government's guidance on alignment and integration of national programs, I-TECH Ethiopia played a leading role, and acted as catalyst in

the development and adaptation of the HIV case management implementation guidelines and training curricula. A consultation with key partners was held in June 2009; consequently, the Federal HIV/AIDS Prevention and Control Office (HAPCO) acknowledged the case management program as a pragmatic, culturally competent chronic illness follow-up model.⁴⁷ The program has since become a national program endorsed by the MOH.

Nationalization of the program enabled rollout of the case management program across the nation.

⁴⁷ Federal Ministry of Health. Guidelines for Management of Opportunistic Infections and Anti Retroviral Treatment In Adolescents and Adults in Ethiopia. Federal HIV/AIDS Prevention and Control Office, Addis Ababa; July 2007.

Objectives and Expected Outcomes

In the pilot and expansion phases, the following objectives were identified. These were either tested during the pilot phase in Ethiopia, or adapted from similar work in other resource-limited settings.

These objectives were primarily introduced to maximize medication adherence and retention within chronic HIV care, in order to ensure access of PLHIV to HIV treatment, prevention, and palliative care services, and to quickly address barriers to adherence before clients are lost to follow-up or hospitalized with complications of AIDS or AIDS-related opportunistic diseases.

Objective 1. Introduce a case management model (the case management program) to support management of care and follow up with clients enrolled in chronic HIV care and ART programs.

Expected Outcomes:

- A chronic illness case management model, the case management program, is introduced and implemented at health facilities in Tigray, Amhara, and Afar.
- A task-sharing approach is promoted at all levels; the case management program is rolled out at health facilities in Tigray, Amhara, and Afar.
- The case management program is rolled out at additional health facilities nationwide.

Task shifting (or sharing) is the name given to the process whereby specific tasks are reassigned, where appropriate, to health workers with less-intensive training and fewer qualifications. Task shifting can help to make more efficient use of existing human resources, and ease bottlenecks in service delivery. There are many examples of this type of approach for delivering a range of health services, including for HIV. For example, Ethiopia has implemented a plan to hire community health workers in order to expand the workforce providing HIV services.

Under this approach, such tasks such as adherence education and counseling are delegated to health workers without as much specialized training, or to community volunteers or lay providers. To maintain quality of service in these areas, and ensure the effectiveness of the task-sharing program, the following key activities need to be implemented:

- Define which components of a task to delegate, and set clear objectives for the task-sharing program.
- Define the roles and responsibilities of the health workers to whom tasks are delegated, and the existing health workers whose tasks are being delegated.
- Secure leadership commitment and management support.
- Build the capabilities of the health workers to whom tasks are delegated.
- Establish a robust M&E system to effectively track task-sharing activities, and evaluate the program the task-sharing approach aims to support—in this case, the HIV Case Management Program.

Objective 2. Standardize ART adherence and retention services

Expected Outcomes:

- Technical and financial support is provided to the MOH and HAPCO to develop a national adherence and retention strategy.
- Case management guidelines, training curricula, job aids, and monitoring tools are developed.
- PLHIV are engaged in the promotion and implementation of HIV care and support services; stakeholders are engaged in ensuring standardization of processes used to implement the HIV Case Management Program.

One approach to standardizing health care services, and ensuring uniformity of their delivery to intended beneficiaries, is to develop implementation guidelines, and standardize training curricula, job aids, and monitoring tools. Accordingly, case management guidelines, national training curricula, job aids, and tools for monitoring, client referral, and feedback will be developed.

During development of the guidelines, a consultative workshop will be organized to engage PLHIV associations and other stakeholders engaged in the implementation of palliative care programs. Subsequently, respective program managers will be trained using the standardized curriculum. Partner organizations that provide technical assistance to Ministry's HIV program are given orientation on HIV Case Management concept and its implementation guidelines. Emphasis was given to stakeholders engaged in roll out of antiretroviral therapy program, adherence and retention of PLHIV enrolled to ART program and HIV palliative care and support program.

Objective 3. Strengthen assessment and monitoring of medication adherence among clients enrolled in ART programs.

Expected Outcomes:

- Improved assessment and monitoring of ART using the self-reporting method.
- Monitoring of client adherence and retention; documentation of retention and LTFU rates.
- Regular identification of clients at risk of dropping out of treatment, and barriers to adherence and retention.

Adherence Assessment and Monitoring: Close monitoring of adherence under the case management program is essential to achieving intended outcomes and quickly addressing specific and individual challenges to adherence.^{48, 49} Among the approaches employed to strengthen adherence monitoring are use of self-reports of adherence, on-site mentoring by multidisciplinary mentoring team, and periodic supportive supervision.⁵⁰ The guidelines recommend use of self-reporting to assess a client's medication adherence.

Self-Reporting: The self-reporting method takes into account numbers of missed doses reported by clients, and categorizes their adherence as *good*, *fair*, or *poor* (Table 1). This is then used to determine the need for adherence counseling. Ethiopia's national ART program utilizes the self-reporting method to assess and monitor medication adherence.⁵¹

48 Konkle-Parker DJ, Erlen JA, Dubbert PM. Lessons learned from an HIV adherence pilot study in the Deep South. *Patient Education and Counseling*. 2010 Jan;78(1):91–6.

49 Bangsberg DR, Haberer JE. Lifetime HIV Antiretroviral Therapy Adherence Intervention: Timing Is Everything: Comment on “Managed Problem Solving for Antiretroviral Therapy Adherence.” *JAMA Internal Medicine*. 2013 Feb 25;173(4):306.

50 Berg KM, Arnsten JH. Practical and Conceptual Challenges in Measuring Antiretroviral Adherence: *JAIDS Journal of Acquired Immune Deficiency Syndromes*. 2006 Dec;43(Supplement 1):S79–87.

51 Federal Ministry of Health. Guidelines for Management of Opportunistic Infections And Anti Retroviral Treatment In Adolescents And Adults In Ethiopia. Federal HIV/AIDS Prevention and Control Office, Addis Ababa; July 2007.

Table 1. Self-reporting of medication adherence

Adherence Level	Doses Taken (% of total)	Missed Doses (out of 30)	Missed Doses (out of 60)
Good	> 95	≤ 2 doses	≤ 3 doses
Fair	85–94	3-5 doses	3-9 doses
Poor	< 85	≥ 6 doses	> 9 doses

However, there is limited evidence in Ethiopia of the accuracy of this method as used in the national ART program, or of its level of agreement with other quantitative methods of measuring adherence, especially HIV viral loads. One chart review from I-TECH-supported sites suggested that client adherence exceeded 99%! Based on reported findings in the literature, this is likely too good to be true, raising questions about how effectively the self-reporting tool is used.

In general, it is advisable to be familiar with the characteristics of poor adherence, because it helps to quickly identify factors affecting adherence, and prevent attrition from care. These characteristics may include one or more of the following:

- Missing one or more doses of a given drug.
- Missing entire days of treatment.
- Not taking medications on time.
- Not following dietary instructions.

The review forums are attended by key stakeholders: HIV care providers, health program managers from the RHBs and facilities in lower tiers of the health care system, adherence case managers and supporters, and mentors. The review meetings help to critically look at the progress of activities and intervention outcomes, and to consider targeted solutions to such emerging barriers to adherence as resorting to the use of holy water in place of drugs, or dropping out of treatment altogether.

Understanding Barriers to Adherence: Monitoring adherence on an ongoing basis allows programs to identify clients at risk of dropping out of HIV care. Through one-to-one meetings between adherence case managers and clients, it is possible to identify client-specific barriers to adherence. This allows case managers to design of adherence support sessions targeted specifically to the needs of at-risk clients. Targeted education is among the most effective of behavioral interventions for helping clients improve both their attitudes toward medication adherence and their levels of adherence.

Since sociocultural factors and personal beliefs also influence adherence, case managers should be mindful of their clients' sense of self-worth, perceptions of the beneficial health effects of ART, and acceptance of their HIV-positive status.

Objective 4. Strengthen referrals and linkages within and among health facilities and community organizations.

Expected Outcomes:

- Decline in rates of LTFU clients in ART programs.
- Improved referrals among HIV clinics.

- Mapping of community care and support services; development of a health services directory.

Tracking: The case management program employs client tracking when measures intended to prevent clients from dropping out of HIV care fail. The usual prerequisite for tracking is enrollment in the case management program, at which time the case manager educates the client about the benefits of adherence, and develops an individualized care plan for the client. During the enrollment process, the client voluntarily agrees to provide and update contact information (address and telephone number), and consents to being contacted by program staff when drug refills or clinic appointments are missed.

Client tracking is a process that requires complete patient cooperation and confidentiality. Different methods of tracking are built into the program: telephone contact, home visits, and contact through home care providers or community organizations in their vicinity. The objectives of tracking are to identify client reasons for discontinuing follow-up, update client information, encourage adherence to treatment and care, and take appropriate measures to prevent LTFU recurrence.

The following are the major steps followed in the program to track down LTFU clients:

- Obtain a list of LTFU clients from the data clerk or case manager.
- Try to reach LTFU clients by using the following methods; go to the next method if the previous one does not work (these steps may vary from place to place).
 - Call the client's telephone number.
 - Call an emergency contact person's telephone number.
 - Conduct a home visit.
 - Contact the kebele health desk or health extension workers.
 - Contact the PLHIV association(s) in the catchment area.
 - Contact hospitals or health centers in the catchment area.
- Document what you learn from the client on the client tracking form.
- Provide feedback to the case manager and data clerk about the outcome of client tracking efforts.

To conduct these steps, the client must provide consent at the time of enrollment.

Referrals: Referrals are the process by which client needs for additional services are evaluated, and needed services accessed. The case management program offers assistance in advocating the needs of clients, setting up appointments with attending clinicians, escorting clients to receiving clinics, and providing information on antiretroviral medications.

Roles of Adherence Support Coordinator in the MDT

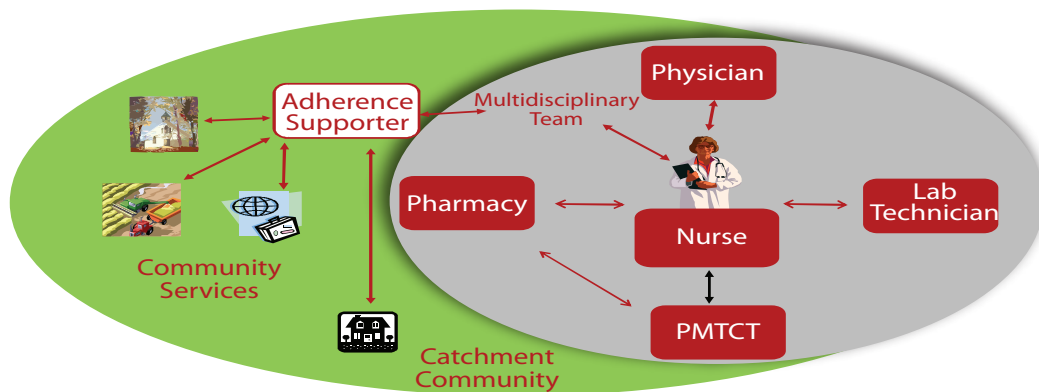


Figure 4: The Roles of Adherence Support Coordinators (Case Managers) and the Relationship Between Coordinators and the MDT.

Service Directory: Identifying and mapping community resources is critical to improving access to and use of existing community resources. Mapping community resources and developing a directory of those resources helps health care workers to connect at-risk clients to relevant community organizations. Each entry in the directory should include the organization's name and address, hours of operation, types of services offered, and a contact person.

Objective 5. Educate and empower HIV-positive clients and their families.

Expected Outcomes:

Strengthening of HIV health education and adherence counseling services at local facilities.

- Promotion of client-centered adherence counseling and support services.
- Engagement of PLHIV associations and peer support groups in adherence support programs.

Client-Centered Approach: The client-centered approach is instrumental in empowering clients and involving them in their own health care. This approach entails advocacy for client needs, improved quality of services, and respect for the client autonomy, self-determination, and participation in making decisions.⁵²

Education and Counseling: Health education and adherence counseling services performed by non-clinicians have several advantages: clients have better rapport with non-clinician care providers, and more time to openly discuss barriers to adherence, whereas busy clinicians may not be able to address the psychosocial, family, and economic challenges faced by clients.

⁵² Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW, Gross R, et al. Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons With HIV: Evidence-Based Recommendations From an International Association of Physicians in AIDS Care Panel. *Annals of Internal Medicine*. 2012 Jun 5;156(11):817.

These educational activities are designed to complement existing local health education services provided primarily by clinicians. To ensure the effectiveness of this type of intervention, required competencies and educational methods will be drawn from standardized case management program training guidelines, which will be well structured, with well-defined goals. The correlation with subsequent interventions—counseling, for example—is also emphasized. Modalities used in adherence education and counseling include peer support group involvement, and collaboration with PLHIV associations.⁵³ Ongoing, targeted counselling is necessary to sustain adherence to ART and other forms of lifelong treatment, and avoid “pill fatigue.”

The 5 A's of Adherence Counseling: Counseling will be most effective when sessions are well structured, and planned in collaboration with clients. To ensure consistency, case managers involved in adherence counseling are encouraged to follow the five stages of counseling sometimes referred to as the “5A's.”⁵⁴

The 5A's approach was initially developed to guide smoking cessation counseling; it was later adapted to suit other health interventions.⁵⁵ This approach is also used in the context of HIV care and treatment adherence. Adherence case managers begin discussions when clients are enrolled in chronic HIV care (when the decision to start ART is made), but before actual treatment begins. Discussion should continue throughout the course of HIV treatment.

Assess: Ask questions to assess client knowledge, attitudes, and concerns about ART and adherence.

Advise: Address client concerns by providing information, counseling and advice on HIV treatment; review important aspects of care.

- Review ART regimens.
- Emphasize the importance of adherence.
- Review dietary recommendations.
- Explain limits on alcohol and drug use.
- Explain possible drug side effects.
- Provide information on smoking cessation and safer sex practices.
- Make it a point to summarize, repeat, and reinforce key information.

Agree: Make sure the client agrees to the regimen, and is committed to fitting it in to daily routines.

Assist: Help the client develop the resources, support, and/or arrangements needed to ensure adherence:

- The ability to come in for required and scheduled follow-up appointments.

53 Horvath KJ, Smolenski D, Amico KR. An empirical test of the information-motivation-behavioral skills model of ART adherence in a sample of HIV-positive persons primarily in out-of-HIV-care settings. *AIDS Care*. 2014 Feb;26(2):142–51.

54 Goldstein MG, Whitlock EP, DePue J, Planning Committee of the Addressing Multiple Behavioral Risk Factors in Primary Care Project. Multiple behavioral risk factor interventions in primary care. Summary of research evidence. *Am J Prev Med*. 2004 Aug;27(2 Suppl):61–79.

55 Whitlock EP, Orleans CT, Pender N, Allan J. Evaluating primary care behavioral counseling interventions: an evidence-based approach. *Am J Prev Med*. 2002 May;22(4):267–84.

- A home and work situation that permits taking medication as directed.
- The support of family and friends.
- Disclosure of HIV status to family members and significant others.
- Adherence support groups (e.g., PLHIV groups or other local or community associations, if available).

Arrange: Arrange for follow-up appointments, support, and/or referrals, as needed. All of these are needed to maintain adherence.

Partner or Peer Support Groups: Studies show that peer support groups have proven to be one of the most effective ways of shaping behaviors and attitudes regarding modern treatment, stigma, and adherence. In these support groups, intimate partners and peers share their experiences coping with HIV diagnosis, treatment, side effects of antiretroviral drugs, reproductive health issues, stigma and discrimination, disclosure of HIV diagnosis to partners, and positive living.

Conversations among peers create a favorable climate for mutual learning and exploration of uncertainties, and misconceptions, as well as opportunities to address the challenges of managing HIV. Also, peer support groups enable their participants to discuss all of this information and share their experiences in their local languages.

Greater Involvement of People Living with HIV (GIPA): The participation and contribution of PLHIV is one of the best examples of client engagement in their own health care. In Ethiopia, PLHIV associations have helped to fight the HIV epidemic and mitigate its impact, especially in reducing the stigma associated with HIV, and the discrimination faced by PLHIV. The GIPA principle is an essential component of programs that aim to curb the HIV epidemic, improve treatment literacy, increase medication adherence, and improve access to palliative care services.^{56, 57}

Objective 6. Build the capacity of HIV program managers and care providers at all levels of the health care system; ensure the successful implementation of the HIV Case Management Program.

Expected Outcomes:

- Technical assistance provided to program managers at all levels; gaps in the knowledge and skills of MOH and RHB program managers addressed.
- Pool of HIV Case Management Program trainers created for all regions in Ethiopia.
- Health care providers, including adherence case managers and adherence supporters, trained in HIV case management

Training: Training is an essential component of any new program that uses new cadres of health workers, especially programs like the case management program. In addition to training, opportunities to provide ongoing technical assistance need to be created at all levels of the system. For example, it is vital to provide assistance to the national technical working groups established by MOH, HAPCO, RHBs, and partner organizations in order to train workers in the competencies required to lead

⁵⁶ UNAIDS. Report on progress towards implementation of the UN Declaration of Commitment on HIV/AIDS, Federal Democratic Republic of Ethiopia, Federal HIV/AIDS Prevention and Control Office. 2010; Oct 23(10): Available from: <http://www.unaids.org/en/dataanalysis/monitoringcountryprogress/2010>.

⁵⁷ HAPCO. Guidelines for Greater Involvement of People living with HIV (GIPA) in Ethiopia. 2009.

an HIV care and support (palliative care) program.

To help achieve this goal, the program needs to conduct orientation workshops and training seminars on medication adherence, HIV transmission, HIV drug resistance, positive living, the case management model, and the expected duties of health care workers. More importantly, adherence support services need to be coordinated so they function together smoothly.

A standardized training curriculum that comprises didactic (classroom) and practicum (on-site) learning methods will be used to train adherence case managers and adherence supporters. The design of the curriculum will be informed by the needs assessment conducted during the conceptualization phase of the program. Refresher training and program review forums will be used to reinforce skills and competencies learned previously, and incorporate new skills determined to be necessary during the implementation phase.

Integration of Mental Health Services with the Case Management Program

Prevention with Positives (PWP): As part of its HIV prevention strategy, PWP activities (i.e., preventive counseling, and the distribution of PWP packages) have been made available to clients through the Case Management Program. Thus, integration of the PWP guidelines into the program may help to screen PLHIV suffering from common mental health conditions, and refer them for appropriate counseling.⁵⁸

Mental Health Integration: Around the world, mental health problems are generally more than twice as common among PLHIV than in the general population. PLHIV have disproportionately high rates of psychosis, mood and anxiety disorders, and substance abuse. Targeted interventions to identify and treat mental health conditions may improve individual well-being, treatment adherence, and use of effective coping skills following HIV diagnosis. In this way, integration of mental health services into the HIV Case Management Program may help with mental health screening and referrals.^{59, 60}

Mother Mentors: Mother support groups are widely used in Ethiopia to provide peer support for HIV-positive pregnant and postpartum women in HIV/AIDS programs. I-TECH has incorporated the mother mentor program into the case management program, recognizing that what mother mentors do is effectively case management. Mother mentors are subject to the same requirements as case managers.

58 Federal Ministry of Health. Federal HIV and AIDS Prevention and Control Office (HAPCO). 2008. Prevention with Positives (PWP), Five HIV Prevention Steps for People Living with HIV/AIDS. A Tool for Health Care Providers in HIV Care and Treatment Setting.

59 Sikkema KJ, Watt MH, Drabkin AS, Meade CS, Hansen NB, Pence BW. Mental Health Treatment to Reduce HIV Transmission Risk Behavior: A Positive Prevention Model. *AIDS and Behavior*. 2010 Apr;14(2):252–62

60 Abera M, Tesfaye M, Belachew T, Hanlon C. Perceived challenges and opportunities arising from integration of mental health into primary care: a cross-sectional survey of primary health care workers in south-west Ethiopia. *BMC Health Services Research*. 2014;14(1):113.

Results

Objective 1. Introduce a case management model (the case management program) to support management and follow up with clients who are enrolled in chronic HIV care and ART programs.

Expected Outcomes:

- A chronic illness case management model, the case management program, is introduced and implemented at health facilities in Tigray, Amhara, and Afar.
- A task-sharing approach is promoted at all levels.

I-TECH Ethiopia has provided leadership and support for the MOH and RHBs in rolling out the HIV Case Management Program in Amhara, Tigray, and Afar. The program was implemented in the regions in phases, starting in August 2007, with the selection of six hospitals as pilot sites. Following the success of the pilot phase, I-TECH conducted post-implementation assessment to evaluate the program's contributions toward improving adherence and retention.

Based on favorable results from the evaluation, the program was expanded to and additional 40 health facilities. This expansion was conducted in three phases, starting in April 2008, November 2009 and October 2010, respectively. To improve the program at these 46 facilities, a total of 59 case managers and 132 adherence supporters were recruited.

Objective 2. Standardize ART adherence and retention services.

Expected Outcomes:

- Development of a national adherence and retention strategy and framework.
- Standardization of adherence support programs; development of case management guidelines, training curricula, job aids, and monitoring tools.

I-TECH Ethiopia spearheaded a national task force on adherence and retention, led by the Federal HAPCO. The task force helped to promote the adherence agenda, and tapped into the expertise needed to develop the materials to be used in standardizing disparate adherence support activities. Review of research conducted in resource-limited settings informed development of these materials. International experts were invited to share their experiences and present international perspectives on case management in the context of the chronic care model.^{61, 62} The result of these efforts was the development of a national adherence strategic framework.⁶³ National case management implementation guidelines, training curricula, and supplemental job aids and monitoring tools were developed and launched in 2009.^{64, 65}

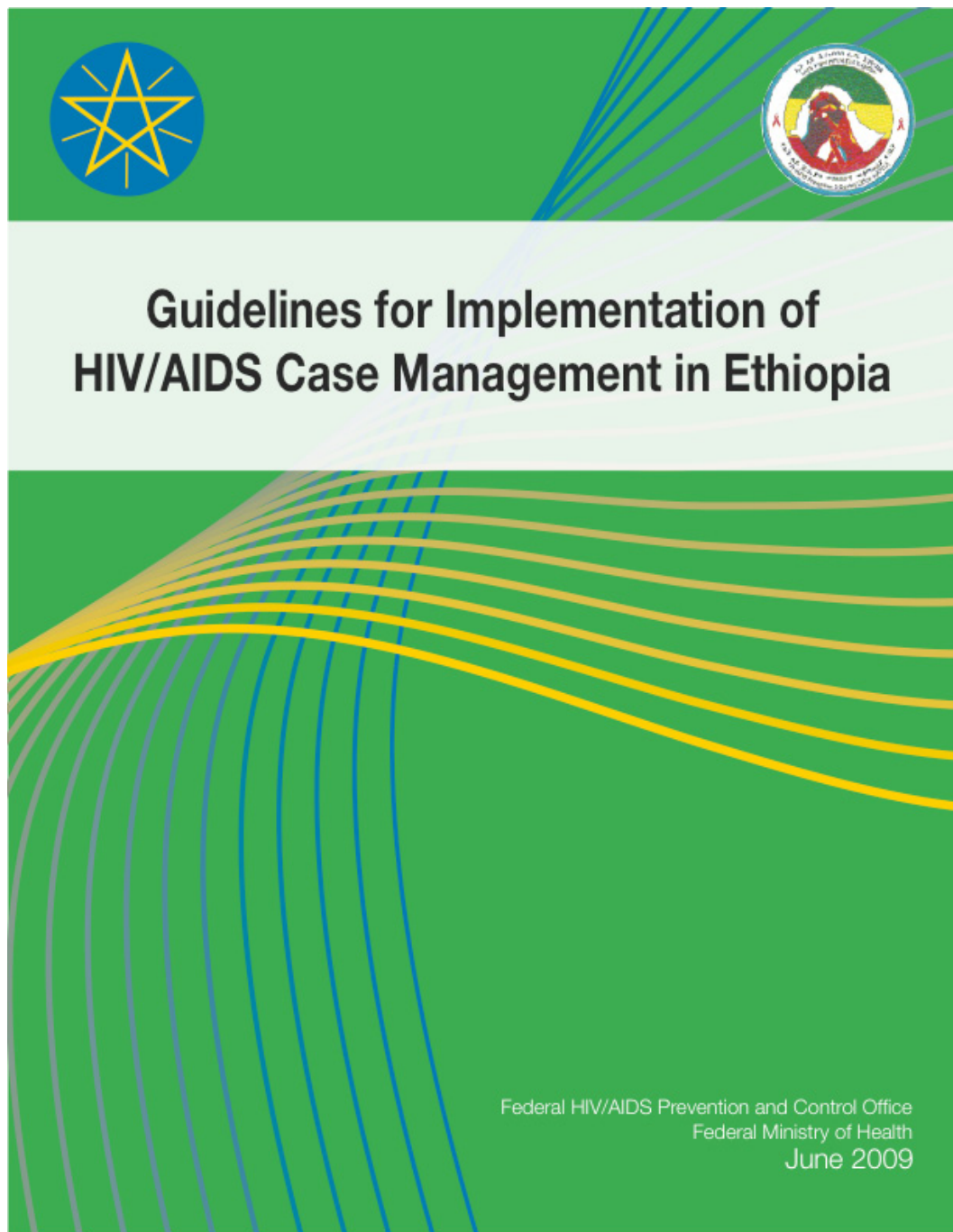
61 Family Health International (FHI). Adherence Support Worker Training: Participant's Guide. Prepared by FHI for USAID through the implementing AIDS Prevention and Care (IMPACT) Project. 2007.

62 International Center for AIDS Care and Treatment Programs (ICAP). Antiretroviral Therapy Adherence Baseline. Adherence Review. New York. New York, USA: International Center for AIDS Programs at the Columbia University Mailman School of Public Health. 2007.pp.1-6.

63 Federal Ministry of Health, 2013. Strategic framework to improve adherence to ART and retention to care in Ethiopia

64 Federal HIV Prevention and Control Office, Ministry of Health. Guidelines for Implementation of HIV Case Management in Ethiopia. June 2009.

65 HAPCO. Guidelines for Greater Involvement of People Living with HIV (GIPA) in Ethiopia. 2009.

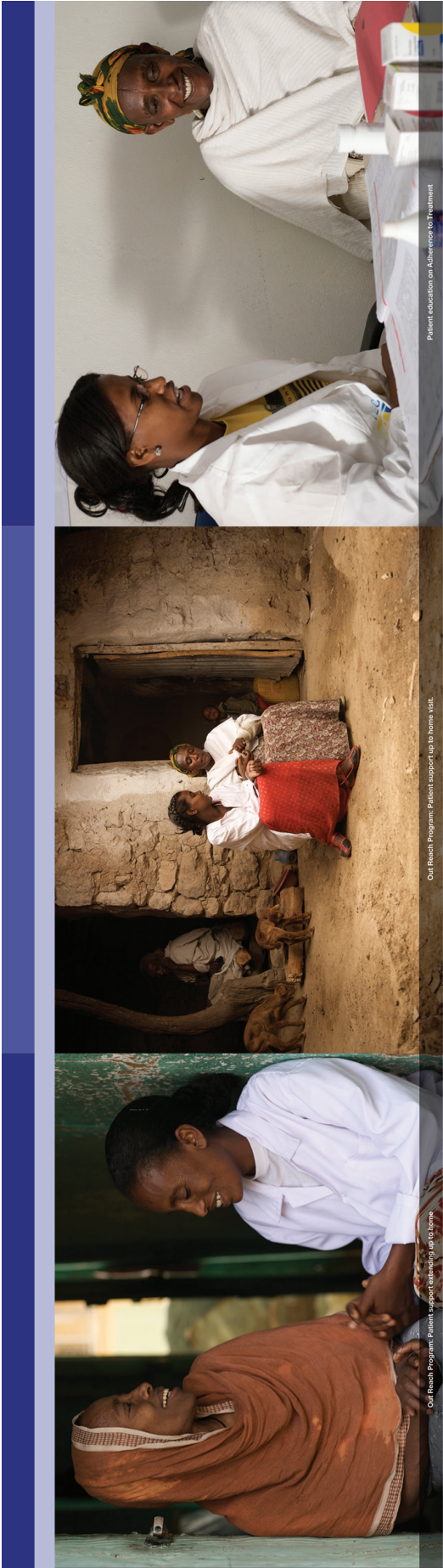


Adherence counseling pocket guide: In order to standardize and structure counseling sessions, a pocket guide to adherence counseling was developed for case managers and adherence supporters, and translated into Amharic.⁶⁶

As more PLHIV and peer support groups began to participate in the program, the need to ensure consistency in the practices of these groups, as well as the larger adherence support groups, also grew. Accordingly, standard operating procedures (SOP) and adherence support group guidelines were developed, and distributed to I-TECH-supported regions in August 2010. The HIV case management SOP document lays out the flow of patients within the health care facility, as well as to community resources for case management services (Annexes).⁶⁷

⁶⁶ I-TECH Ethiopia, 2010. Antiretroviral Therapy Adherence Counseling Pocket Guide.

⁶⁷ I-TECH Ethiopia, 2010. Guidelines for Establishing and Operating Adherence Support Group for People Living with HIV.



ART

Antiretroviral Therapy Adherence Counseling

Pocket guide

I – TECH Ethiopia

- FOR A HEALFUL QUESTION LIST OPEN HERE





I-TECH Ethiopia

Guidelines for Establishing and Operating Adherence Support Groups for PLHIV

August 2010

Objective 3. Strengthen assessment and monitoring of medication adherence among clients enrolled in ART programs.

Expected Outcomes:

- Improve assessment and monitoring of adherence by RHGs and health facilities, using the self-reporting method.
- Monitoring of client adherence and retention; documentation of retention and LTFU rates at regional and local (facility) levels.
- Identification of clients at risk of dropping out of treatment; enrollment in the case management program.

All newly enrolled ART clients were assigned to case managers for adherence preparation, and screening for the case management program. As a result, a total of 5,156 new clients deemed at risk for non-adherence were enrolled in the program.

Of 4,338 at-risk clients referred to community resources, 3,219 (74%) were successfully provided with services.

A total of 4,729 clients completed the case management program. Of this number, 3,778 (80%) completed the program with obstacles to adherence addressed, and were successfully adhering to treatment regimens.

A total of 13,673 clients who either had missed appointments or were LTFU were tracked by adherence supporters. Of these,

- 5,338 were LTFU ART clients.
- 3,597 were ART clients who had missed appointments within the last month.
- 4,259 were pre-ART clients who had missed appointments.
- 365 were infants exposed to HIV who had missed appointments.⁶⁸
- 114 were clients who had dropped out of TB treatment.

As shown in Figure 7 below, the most common reasons for ART becoming LTFU were dropping out ("self-transferred out") (28%), and death (26%).⁶⁹ Death certificates were reviewed; clients who were on ART accounted for 14% of LTFU clients, with clients who had discontinued ART accounting for 12%.

Of the 890 clients who could have resumed ART (i.e., who were alive, and not in care), 631 (71%) chose to restart care and treatment.

ART LTFU Trends: Since the implementation of the case management program, the percentages of LTFU clients at some of the health care facilities have either remained steady or significantly decreased (see the time series chart below). The likely reason for this achievement is that the program actively identified potential LTFU clients by examining socio-medical indicators, and provided the support needed to retain those clients and prevent them from becoming LTFU. As part of LTFU prevention efforts, all clients who have either been newly diagnosed with HIV, or recently started on ART, have been assigned to the case management program to prepare them for adherence to treatment regimens, and assess their risk of non-adherence. In addition, the program reached out to those clients who were already LTFU, and provided them with the support they needed to resume care and treatment.

68 Tessema WT, Ellington S, Sibhatu MK, Mekonnen A, Bedri A. Early infant diagnosis and linkage to care and treatment services at health facilities in Northern Ethiopia. *Reviews in Antiviral Therapy & Infectious Disease*. 2014; Available from: http://regist2.virology-education.com/abstractbook/2014_6.pdf

69 Sibhatu MK, Tafesse B, Elias, Temesgen C, Ahmed I, Feleke G. Self Transfer out of Clients initiated on Antiretroviral Therapy Has Challenged Decentralization of Antiretroviral Therapy Program in Northwest Ethiopia. *International Conference on AIDS and Sexually Transmitted Infections in Africa (ICASA)*. 2010.

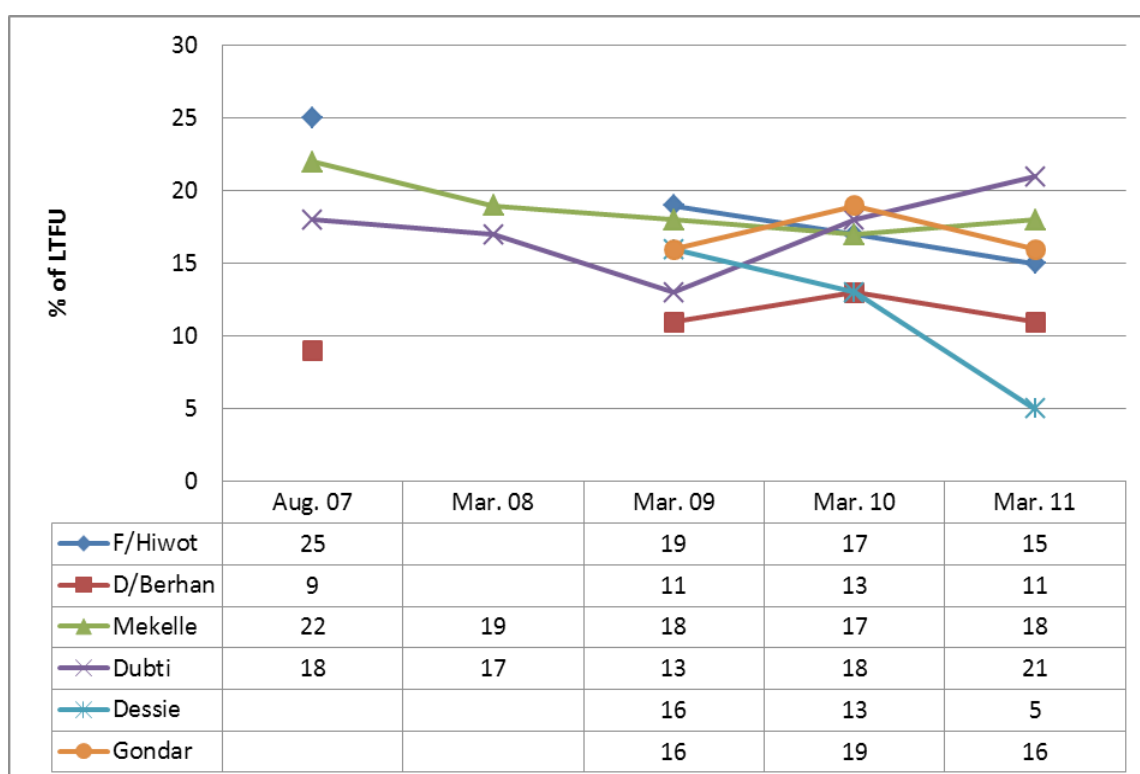


Figure 5. Percentage of ART LTFU Clients at Pilot Sites Starting Case Management in August 2007.
(Note: The case management program began in August 2007; numbers following months indicate years)

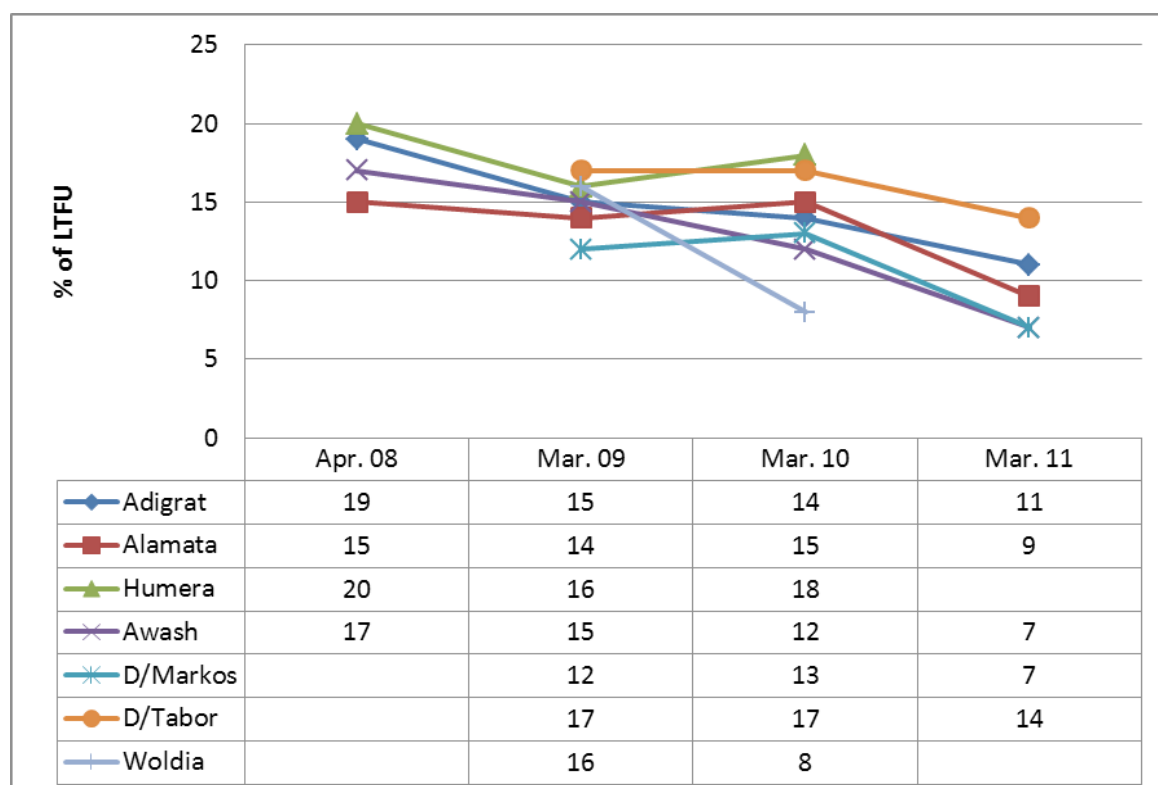
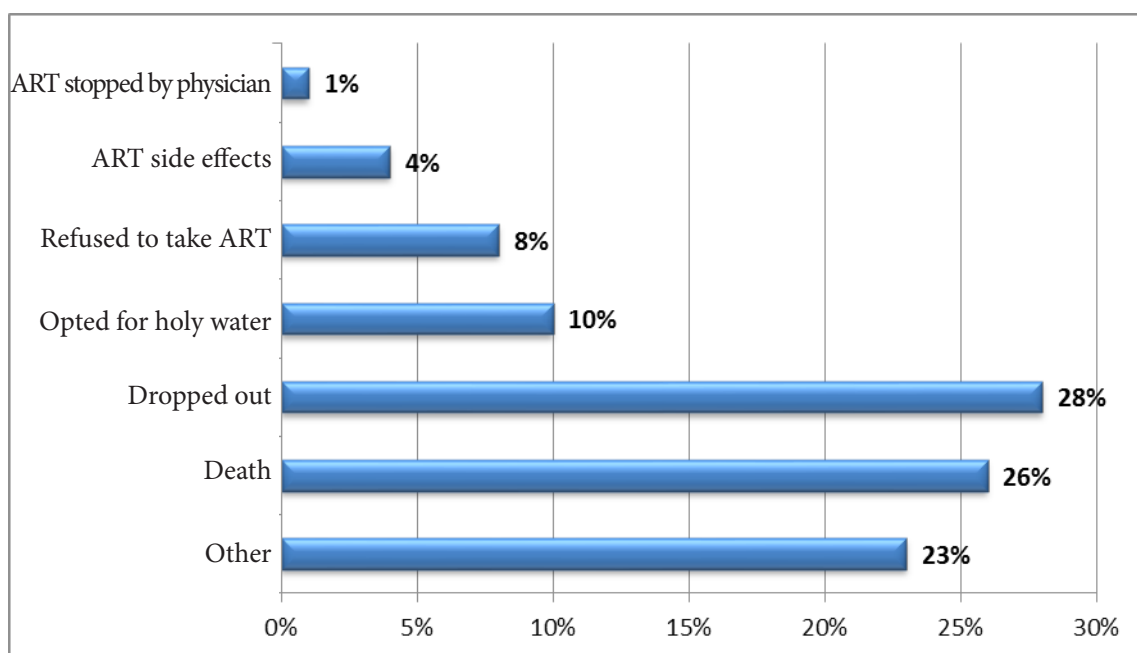


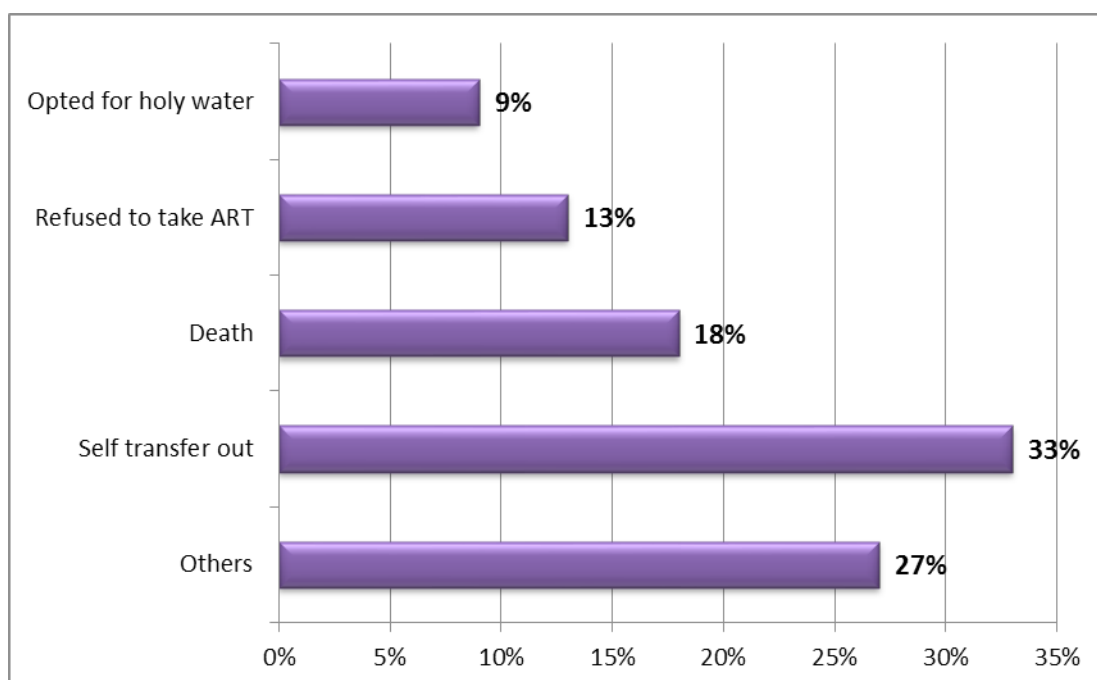
Figure 6. Percentage of ART LTFU Clients at Selected Sites Starting Case Management In April 2008.
(Note: The case management program first expanded to other facilities in April 2008; numbers following months indicate years.)



(*Other: Forgot appointment, change of address, duplicate medical records.)

Figure 7. Reasons Given for ART Clients Becoming LTFU During Routine Tracking, April 2011–March 2012.

As depicted below, the reason given most frequently by pre-treatment enrollees for becoming LTFU was dropping out ("self-transferred out"). This was also one of the most frequently reported reasons among those LTFU cases reached during active tracking campaigns.⁷⁰



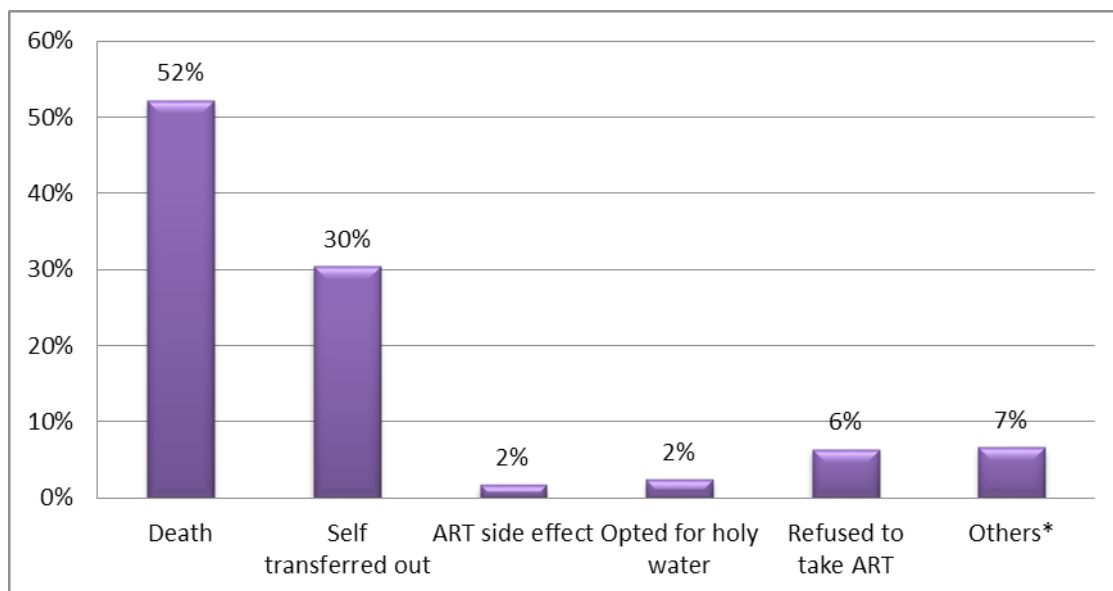
(*Other: Forgot appointment, change of address, duplicate medical records.)

Figure 8: Reasons Given for Pre-ART Clients Becoming LTFU During Routine Tracking, April 2011–March 2012.

⁷⁰ Sibhatu MK, Tafesse B, Elias, Temesgen C, Ahmed I, Feleke G. Self Transfer out of Clients initiated on Antiretroviral Therapy Has Challenged Decentralization of Antiretroviral Therapy Program in Northwest Ethiopia. International Conference on AIDS and Sexually Transmitted Infections in Africa (ICASA). 2010.

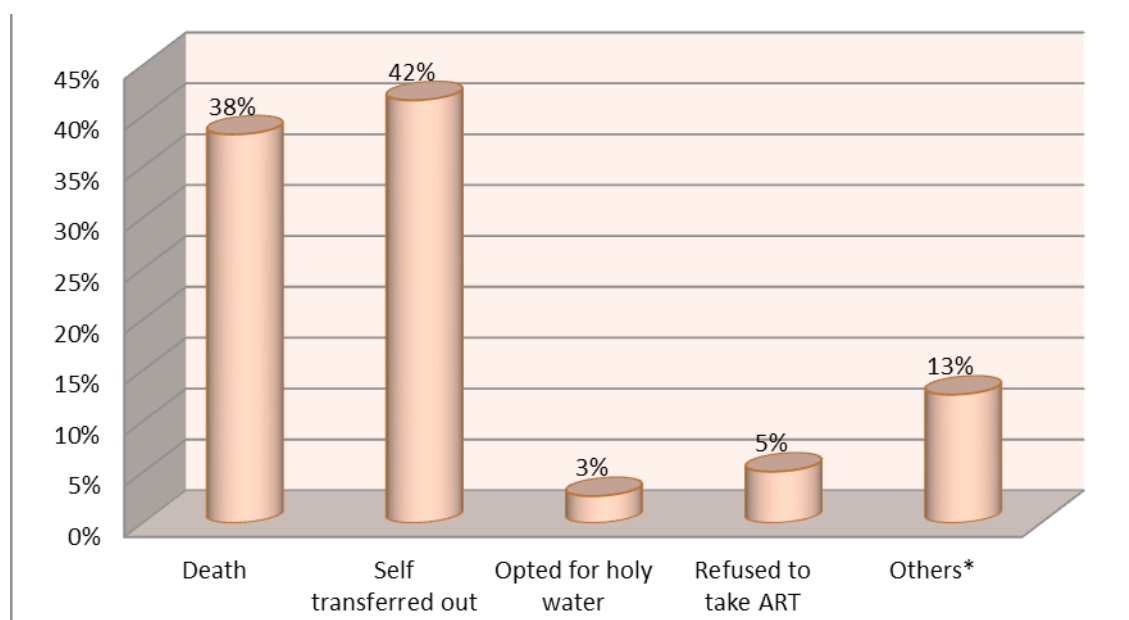
Active LTFU Tracking Campaigns: Three active tracking campaigns were conducted in the catchment areas of the Gondar, Mekelle and Axum referral hospitals. The campaign aimed to reach out to LTFU clients residing outside the service areas of hospitals where they were enrolled in ART, or who lived in towns 200 kilometers or more from the nearest hospital.

As depicted in the following graphs, the major reasons reported for ART clients becoming LTFU were death and dropping out ("self-transferred out"); the reverse was true for pre-ART clients.



(*Other: Had extra pills, forgot appointment, change of address, duplicate medical records.)

Figure 9: Reasons given for ART clients becoming LTFU during tracking campaign.



(*Other: Forgot appointment, change of address, duplicate medical records.)

Figure10: Reasons Given by Pre-ART Clients for Missed Appointments During Tracking Campaign.

Review of the death certificates for ART LTFU clients revealed that 52% died while they were on ART; the rest (48%) died after discontinuing treatment.

During the tracking campaign, adherence workers provided education and adherence counseling services to clients. As a result, 52% of clients reached through the campaign decided to restart treatment; 61% of PLHIV decided to resume chronic HIV and pre-ART care. It is important to note that, as initially conceived, the adherence case management program was intended to target clients who were either already on ART, or about to start. However, because the results of the survey discussed above showed significant rates of pre-ART LTFU, I-TECH changed the criteria for enrollment in case management services. All patients are now enrolled in case management at the time they begin chronic care.

Objective 4. Strengthen referrals and linkages within and among health facilities and community organizations.

Expected outcomes:

- Decline in rates of LTFU clients in ART programs.
- Improved referrals among HIV clinics.
- Mapping of community care and support services; development of health services directory.

Through successive dialogue and close collaboration with faith-based organizations and the Ethiopian Orthodox Church, a consensus was reached to allow concurrent use of ART and holy water in the Amhara region.

Service mapping and directory: In order to facilitate referrals and assignment to services among health facilities and community organizations, a survey of community resources and support services was conducted, and a directory of services compiled. For each organization listed, the directory includes contact information, the organization's mission, target beneficiaries, and eligibility requirements for accessing services.



Objective 5. Educate and empower HIV-positive clients and their families.

Expected outcomes:

- Increased number of health education sessions.
- Increased number of adherence counseling sessions.
- Increased number of adherence support group and peer group sessions.

A total of 12,977 health education sessions were conducted at health facilities, and in community settings.

A total of 48,819 adherence counselling sessions were conducted with clients enrolled in case management, and with all newly enrolled HIV (pre-ART) clients and their family members.⁷¹

A total of 1,296 adherence support group sessions were held.

Accordingly, I-TECH Ethiopia has supported the GIPA principles, and, in collaboration

⁷¹ Whitelock, EP, Orleans, CT, Pender, N, and Allan, J. Evaluating Primary Care Behavioral Counseling Interventions: An Evidence-Based Approach. In AmJ Prev Med. 2002. Volume 22:267-284.

with the RHBs and regional PLHIV networks, has supported the government of Ethiopia in its efforts to put them into practice. Among the partner organizations are members of the NEP+: Mekdim Ethiopia National Association (Amhara), Save the Generation Association Tigray (Tigray), and the Afar Region PLHIV Association (Afar).

During COP 11, I-TECH Ethiopia deployed a total of 253 task-sharing workers to the HIV case management and mother support group programs. PLHIV with prominent roles in providing peer support for patients enrolled in HIV care and prevention of mother-to-child transmission programs comprised 82% of these workers.

In general, I-TECH Ethiopia:

- Provides technical and financial support to improve the capabilities of PLHIV associations/networks and their members to support HIV clients in meaningful ways.
- Establishes partnerships with PLHIV associations for HIV program intervention.
- Advocates and supports the meaningful involvement of PLHIV and affected communities in HIV prevention, care, and support,
- Prioritizes initiatives and maintains funding to build and sustain the capacity of organizations and networks to help them perform their stated functions.

The program has been particularly effective in promoting protection of the dignity and human rights of PLHIV, especially women, young children, and other vulnerable populations. This is demonstrated by the fact that over 955 of the program's case managers and adherence supporters are women, most of whom are themselves HIV-positive.

Objective 6. Build the capacity of HIV program managers and care providers at all levels of the health care system; ensure successful implementation of the HIV Case Management Program.

Expected outcomes:

- Increase in the number of health care workers trained, including case managers, mother mentors, and adherence supporters.
- Creation of a pool of program trainers to assist in expansion of the case management program throughout Ethiopia.

At the request of HAPCO, I-TECH Ethiopia dispatched a technical expert to HAPCO for three months (December 2008–March 2009) to assist in coordinating implementation of the HIV Case Management Program throughout the country, and in developing national program guidelines.

I-TECH Ethiopia has provided technical support to HAPCO and the MOH from conception of the case management model to national implementation of the program. I-TECH has also provided technical support to the various local and international partners during rollout of the program at the regional level.

I-TECH's efforts extended to helping the PLHIV associations build up their capabilities, by subcontracting palliative care services, and awarding grants through a competitive application and assessment process.

I-TECH also helped the MOH to create a national pool of 30 program trainers (often referred to as "trainers of trainers," or TOTs).

Program Monitoring and Evaluation

Monitoring and evaluation of the case management program, or of similar adherence and retention programs, involves periodic evaluation of the implementation process, and tracking of planned activities. The evidence gathered helps program managers to determine the success of the program.

Accordingly, at the same time it worked to improve HIV services (particularly adherence to treatment and retention of clients in chronic care), the program established a robust monitoring system, designed to ensure that proposed interventions bring about intended results.

The program's monitoring and evaluation mechanisms include:

- Standard adherence and retention measuring indicators and targets to monitor levels of ART adherence and retention in care.
- Activity monitoring and reporting tools included in the standardized case management program implementation guidelines. Health care providers are encouraged to enter, compile, and analyze data/information, then report and provide feedback in a timely manner.
- Periodic on-site mentoring, supportive supervision, and program review meetings. These are used to identify successes, and find solutions to challenges.
- Promoting the use of program data and improving processes within the facility. Data are also used for monitoring the effectiveness of the task-sharing approach, and the performance of program personnel.

Through these mechanisms, the case management program is monitored through all of its phases, from inception to development, then during its transition to local government oversight. The program has its own reporting and monitoring tools, plus it is subjected to baseline assessments and post-implementation evaluation at three and six months into the pilot phase. The key findings of the case management program evaluations are described below.

Baseline Assessment: Baseline assessments of client adherence to care and treatment were conducted at the six pilot sites in Amhara, Tigray, and Afar from May 2007 to July 2007. The key findings were:

- There were no mechanisms in place to actively identify and support clients at risk for non-adherence and LTFU clients.
- Clinicians were overloaded—i.e., they lacked the time needed to provide client-focused support.
- It took a month or longer to determine that a patient did not show up for treatment.
- Health education was not provided on a regular basis, nor were there patient education materials available in ART clinics.
- Hospitals had no directories listing care and support organizations, and services available in their catchment areas.

Pilot Phase—Three-Month Evaluation: Three months into the case management pilot

phase, the first evaluation was conducted to measure the impact of the program, and obtain information from the results that could be used to improve the model. Interview and observation methods were used to collect data from clinicians, data analysts, and clients. The major findings of the study included the following:

Improvements had been made in management systems, and referrals of 'at-risk' patients.

- Adherence case managers and adherence supporters played significant roles in obtaining updated information that reflected the true status of LTFU clients.
- Some case management duties were assigned to adherence case managers, easing clinician workloads.
- Routine health education was now being provided at all hospitals, as well as at various levels of the community: e.g., prisons, PLHIV associations, religious institutions, rehab centers.
- Retention had improved; clinicians worked closely with adherence case managers to manage the cases of 'at-risk' patients.
- Clients reported improvement in use of resource materials, which were being provided to clients more often.

Pilot Phase—Six-Month Evaluation: The six-month evaluation focused on the program's impact on the quality of services provided by health care facilities, by comparing service quality and client responses to treatment at selected intervention and control sites (a matched case control). The study, which was conducted from February to May 2008, collected secondary data from client charts, care plans, and log books. In addition, data analysts, clinicians, and selected patients were surveyed. Some of the major findings of the study:

Intervention sites showed greater improvement in the proportion of clients with adherence status marked as 'good' by clinicians, compared to the control sites.

- The biggest problems faced by at-risk clients at intervention sites were poor adherence to medication (69%), lack of access to food and nutrition (34%), and lack of economic support (23%). More than half of at-risk clients had these problems fully addressed.
- Clinicians used the systematic information gathered by adherence case managers to meet the psychosocial needs of their at-risk patients, something they had not been able to do before implementation of the case management program.
- The qualitative data collected demonstrated that client satisfaction and reliability of services were higher at intervention sites than at the control sites.

Review of the Costs of the Case Management Program: This review applied standard micro-costing methods to identify the incremental costs of the case management program.⁷² The review analyzed the costs, outputs, unit costs, and correlates of unit cost variation for case management services at 14 ART sites in Ethiopia from October 2008 through September 2009. The study revealed that:

72 Marseille EA, Kevany S, Ahmed I, Feleke G, Graham B, Heller T, et al. Case management to improve adherence for HIV-infected patients receiving antiretroviral therapy in Ethiopia: a micro-costing study. *Cost Effectiveness and Resource Allocation*. 2011;9(1):18.

Costs attributed to the case management program were: \$36 per client-quarter, \$33 per client served, and \$84 per client successfully completing the program.

- Unit costs varied inversely with scale (r , -0.70 for cost per client-quarter versus client-quarters of service), and with the service-volume-to-staff ratio (r , -0.68 for cost per client-quarter versus staff per client-quarter).
 - High client volume was found to be a major determinant of program efficiency.
 - The observed variations in unit costs also indicated that there may be opportunities to identify staffing patterns that increase overall efficiency.
-

Sustainability, Ownership and Transition

Sustainability strategies introduced with the case management program comprised activities designed to ensure technical and program management sustainability. These activities included ongoing individual and institutional training activities carried out to ensure continuity of adherence support and other palliative care services when administration of the program is transferred to local stakeholders.

Between 2008 and 2010, program management was subcontracted to three PLHIV associations and three RHBs through a competitive grant award process. This strategy greatly helped to build local capacity, increase use of HIV care and support services, and promote the adherence support program itself. Below are two testimonials from leaders of key stakeholders:

The health facilities should integrate case management program activities into their existing health care plans, and also conduct periodic performance appraisals of the new cadre of health workers, as they would for other employees of the facility. According to the program guidelines, case managers are expected to regularly submit activity reports to the supervisor assigned by the respective health facility to oversee the activities of the case managers. —Head of the Tigray RHB.

We will facilitate the issuance of sick leave, provide health care access, and offer all staff benefits to adherence case managers, just like all other facility staff receive. —Joint statement issued by the health leadership in Amhara, delegates from the Amhara RHB, and hospital CEOs.

Until 2012, I-TECH continued to provide technical and financial support; subgrantees managed the program and executed planned activities. As directed by CDC Ethiopia, all components of the program were transitioned to the NEP+, a local organization.

The transition process was outlined step-by-step, and encompassed the transitioning of program management tools, human resources, and lines of accountability. The transition of adherence workers has been a challenging process, since the NEP+ required all adherence workers to be HIV-positive, and some of I-TECH's adherence workers were HIV-negative. To facilitate the transition, a task force was established, which outlined roles in its terms of reference. Finally, an agreement was signed by the RHBs, the NEP+, and I-TECH Ethiopia.

Challenges and Lessons Learned

Challenge: In the early phase of ART expansion, the lack of standardized adherence support programs made it difficult to ensure best practices on the same scale. Lack of expertise and systems of accountability at national and regional levels created roadblocks to uniform implementation of the case management program on a national scale.

Lessons Learned: The establishment of a national task force, and the subsequent mobilization of adherence and retention experts, led to the drafting of program framework and implementation guideline documents. These helped greatly in the standardization of adherence and retention services, enabling regular evaluation and comparison of adherence programs.

Challenge: Unlike clients enrolled in ART programs, clients enrolled in chronic HIV care (a.k.a., pre-ART), did not receive applicable education and adherence counseling services; as a result, their LTFU rates were higher than for those clients receiving ART. Additionally, pre-ART programs lacked standard definitions for LTFU, and follow-up recommendations.

Lessons Learned: The case management program was expanded to include chronic HIV care, offering clients appropriate education and adherence counseling services. This change helped to identify many pre-ART clients at risk for non-adherence, and offer them targeted support. The program advocated standardization of LTFU definitions, and recommendations for follow-up clinical visits.

Challenge: Based on charted data, more than 99% of clients were recorded as having good records of adherence. This was significantly higher than most adherence rates reported in the literature, suggesting flaws in the self-reporting method for measuring adherence.

Lessons Learned: Case managers and health care providers should be trained in the proper use of the self-reporting method. Documented adherence rates should be tracked at MDT meetings.

Challenge: Contrary to the reports that came from routine HIV monitoring systems, active tracking campaigns showed that dropping out of treatment ("self-transferred out") was the most common reason for both pre-ART and ART clients becoming LTFU. Although this accounted for 33% of pre-ART clients becoming LTFU, and 28% of ART clients, it was usually missed under the standard HIV monitoring program.

Lessons Learned: Dropping out ("self-transferred out") stood out as the biggest reason for clients becoming LTFU. Subsequently, this observation became a basis for expanding the case management program to serve clients who were enrolled in chronic HIV care, but not yet eligible to start ART. One explanation for the high LTFU rates is that HIV services are decentralized, meaning that clients obtain care at their nearby health centers (rather than at large hospitals or clinics). Because the stigma of HIV is decreasing, clients sometimes opt out of treatment at one clinic, choosing to continue their follow-up visits at another facility. However, hospitals fail to transfer such clients in an orderly fashion, so when clients do decide to enroll in treatment at another clinic, they often do so on their own. These clients then end up being counted twice—reported as LTFU at one clinic, and newly enrolled in care at another.

Challenge: However limited, HIV care and support services in the community are often inaccessible to clients who need them, because of a lack of effective linkage with health facilities, and lack of awareness of community services on the part of health care providers.

Lessons Learned: Networking community organizations and improving their programs helped to expand client access to care and support services. In order to establish effective networks with community organizations, maintaining a directory of resources is essential. Involving family members, community support groups, and religious organizations in the care and treatment of HIV-positive clients helps to reduce the stigma associated with HIV, which in turn helps clients to accept their HIV-positive status and take their medication on a regular basis.

Successful referrals require reasonable follow-up on the part of service providers, and regular feedback from clients. Accordingly, we recommend the following to improve referral services:

- Establish a system to monitor the effectiveness of referrals—e.g., registries, reporting, regular review meetings.
- Prepare SOPs for internal and external referrals.
- Build positive attitudes toward referrals among health service providers, and improve their ability to make referrals when needed.
- Develop service directories to aid providers in making appropriate referrals.
- Organize regular joint review meetings that make referrals the main agenda; regularly document the decisions made at these meetings, and communicate them to agencies at the next higher level.

Challenge: During the expansion phase of the case management program, progress was slowed by the lack of effective leadership needed to promote the adherence and retention agenda, and oversee implementation of adherence and support programs.

Lessons Learned: Effective leadership and program management is crucial when new programs are to be introduced or implemented on a large scale. This is especially true when concrete actions have to be taken in cases where medical records are incomplete, when allocating resources to improve relevant programs, and when integrating new cadres of health workers with existing staff.

Challenge: The socioeconomic and cultural factors affecting the ability of HIV-positive women to access HIV services and adhere to recommended treatment regimens were not well understood. For example, clinics often failed to adequately address their fears of disclosing their HIV status to their male partners, and of such consequences of disclosure as violence or divorce.

Lessons Learned: Gender inequality is now recognized as a barrier to effective HIV prevention, treatment, and care efforts. Health care providers need to be sensitive to the sociocultural and economic barriers related to gender, so that they can take a client-centered approach to service delivery.

Conclusion and Recommendations

Conclusion

The case management model, as it is implemented in Ethiopia, using lay workers and volunteers, is effective in improving the quality of HIV/AIDS care and treatment, and is worth adopting for treatment of other chronic diseases.

Recommendations

- 1) Dropping out of treatment ("self-transferred out") as a reason for clients becoming LTFU was an unforeseen challenge, requiring further study by researchers and program managers. Dropping out can lead to double counting of clients, as they are reported as LTFU at one facility, and as newly enrolled in care at another. Therefore, the connections between hospitals and health centers should be improved, and clients educated about the importance of formal transfers. Introducing mentorship programs between high-level facilities and primary health care units is critical to ensuring continuity of care, and improving the quality of health care services.⁷³
- 2) Management of adherence among infants and adolescents exposed to HIV is particularly difficult because of the emotional and psychosocial issues that are unique to their stages of development.⁷⁴ A family-centered health care model could be useful when HIV clinics are working to identify families of HIV index cases.
- 3) Integration of HIV case management with mental health services helps to both expand mental health care, and improve retention of HIV clients who are also suffering from mental illness.⁷⁵
- 4) Such empowerment aids as medication and appointment reminders, should be made available to clients to encourage adherence. Studies have showed that, when combined with education and/or counseling, calendars, pillboxes, pill organizers, dose planners, and alarm devices are effective in supporting adherence.
- 5) Mobile or cellular technology can be used to improve connections between health facilities and clients, particularly by improving communication with clients, who can easily be contacted when they miss appointments, or can be reminded of their appointments through text messaging.^{76, 77}

Obtaining local evidence on factors affecting adherence and retention is required for designing interventions that are both relevant and feasible at the local level. It is possible to extrapolate from the HIV/AIDS case management experience that the program can be beneficial in the management of other chronic diseases.

73 International Training and Education Center on HIV. "Social Worker Assessment Tools" in Clinical Mentoring Toolkit: A Resource for Clinical mentoring in Resource-constrained Settings: Seattle, Washington, USA: University of Washington-Seattle. 2008.

74 Tadesse AW, Berhane Tsehay Y, Girma Belaineh B, Alemu YB. Behavioral and emotional problems among children aged 6–14 years on highly active antiretroviral therapy in Addis Ababa: A cross-sectional study. *AIDS Care*. 2012 Nov;24(11):1359–67.

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Testimonial—A Client's Story

One client had lost all hope when he was presented with an HIV-positive test result. His wife also tested positive. He could not find a job, became depressed, started to avoid others, and stopped treatment. Due to untreated medical complications, the client became blind, and lost hearing in one ear. He said, "I lost all of my strength, and was counting the days until I died."

A year and a half after receiving his diagnosis, the client was introduced to a case manager at Mekelle Hospital. "My hope was rekindled," he says. The case manager provided him psychosocial support and ongoing counseling, and discussed with him the importance of adhering to the recommended treatment; he now takes his medication regularly.

Now, rather than hiding from people who might recognize him, this client is publicly educating others about HIV/AIDS. The client further stated:

I am a full member of the adherence support group organized by my case manager. I regularly attend the meetings, and have assumed the task of counseling fellow clients who are about to quit taking the medications. My wife also is involved in counseling fellow clients.

He added:

Even though I am visually impaired, I have found that I can [still] work and learn. My case manager referred me to different care and support organizations. I received four months of training in rope weaving at the association for disabled people. I received my certificate, and some money as startup capital. Now I am making preparations to start working at home to sell the items. I had quit my education after passing the eighth grade, but now my case manager is helping me [continue] my education at a school for the blind.

Glossary

Below is a glossary of the terms used in this monograph.

Adherence: The terms *adherence* and *compliance* are often used interchangeably. *Compliance* is the extent to which a client follows the health care provider's instructions and recommendations for taking medication. *Compliance* connotes a paternalistic relationship between the physician and client, and suggests that the non-compliant client is being uncooperative. In other words, *compliance* implies an obligation on the part of the client to follow the practitioner's instructions, while *adherence* implies a therapeutic partnership with the practitioner.

Adherence support group: A group of ART clients who support each other by meeting to share their experiences about treatment and care in order to promote adherence.

Acquired Immune Deficiency Syndrome (AIDS): Stage of immune deficiency due to HIV infection when client manifests with opportunistic diseases.

Antiretroviral therapy (or treatment) (ART): The name given to treatment regimens recommended by leading HIV experts to aggressively suppress viral replication, and the progression of HIV.

Caregivers: The friends, family, and/or neighbors who do most of the day-to-day, home-care tasks for sick clients.

Care plan: A client- and family-centered action plan that is developed by a case manager in collaboration with a client at risk for non-adherence (or the client's caretaker), after a comprehensive needs assessment, in order to promote the client's adherence to treatment and care.

Client: An HIV/AIDS patient receiving HIV/AIDS case management services.

Client at risk for non-adherence: A client who may likely not follow the treatment regimen and care plan, and could become lost to follow-up care.

Client empowerment: Giving clients the knowledge, skills, and support necessary to enable them to follow medication regimens and recommendations made by health care providers.

Community: A group of people who have something in common, and will act together in their common interest.

Community health worker: A health worker who has received training that is outside the nursing and midwifery medical curricula, but is nevertheless regulated and nationally endorsed. This category can include health workers with a range of different roles and competencies, as well as those who provide essential services at a health facility, or in the community as part of, in connection with, a health team at a facility.

Community mobilization: Obtaining and/or ensuring a supportive environment for HIV-positive clients and/or people affected by HIV in order to promote adherence and reduce the likelihood of becoming lost to follow-up care.

Expert client: A person living with a long-term health condition who is able to take more control over his or her health by understanding and managing his or her condition, leading to improved quality of life. Becoming an expert client is

empowering for people with chronic conditions. Expert clients can also use the skills and knowledge they have acquired to support their peers.

Health (care) facilities: Public, private, or non-profit non-governmental or institutional hospitals and health centers that provide ART services.

HIV services: A package of HIV prevention, care, treatment and support services. This includes adherence preparation prior to initiation of antiretroviral therapy (ART).

Human Immunodeficiency Virus (HIV): The virus that weakens the immune system, ultimately leading to AIDS.

Human resources for health: All people engaged in actions whose primary intent is to enhance health. Included are those who promote and preserve health, as well as those who diagnose and treat disease. Also included are health management and support workers—i.e., those who help make the health system function, but do not directly provide health care services.

Lost to follow-up (LTFU): Clients who miss clinic appointments over a period of one month or longer.

Mental health: According to WHO, a state of well-being in which an individual can realize his or her own abilities, interact positively with others, cope with the stressors of life, study, and work productively and fruitfully, and contribute to family and community.

Mental illness: A diagnosable health condition that is characterized by changes in thought, mood, and/or behavior, and associated with distress and/or impaired functioning.

Monitoring: The regular observation and recording of activities. *Monitoring* is the process of routinely gathering information, whereas *evaluation* involves using monitoring and other information to make judgments, changes, and improvements.

Non-adherence: Not taking ART medications as prescribed.

Non-physician clinician: A professional health worker who is not trained as a physician, but who is capable of many of the diagnostic and clinical functions of a medical doctor, and has more clinical skills than a nurse. Non-physician clinicians include health officers, clinical officers, physician assistants, nurse practitioners, and nurse clinicians, and are found in the health care systems of both high- and low-income countries.

Pill fatigue: Sometimes known as *treatment fatigue*, this occurs when clients with incurable or chronic diseases that require lifelong treatment (e.g., ART for HIV-positive clients) become bored with or tired of taking daily medications or following other medical instructions.

Referral: Referral is the process by which client needs for additional services are evaluated, and needed services accessed.

Resource: A tangible thing that is supplied to, or can be accessed by, the client to help achieve goals.

Task-sharing (task-shifting) approach: Task sharing involves the rational redistribution of tasks among workforce teams. Specific tasks are transferred, where appropriate, from highly qualified health workers to health workers with less-intensive training and fewer qualifications, in order to make more efficient use of available human

resources. There are four basic types of task shifting practices, as follows:⁷⁸

I: Expanding the scope of practice of non-physician clinician, in order to enable them to assume some tasks previously handled by medical doctors.

II: Expanding the scope of practice of nurses and midwives, in order to enable them to assume some tasks previously handled by non-physician clinicians and medical doctors.

III: Expanding the scope of practice of community health workers, including people living with HIV/AIDS, in order to enable them to assume some tasks previously handled by nurses, midwives, non-physician clinicians, and medical doctors.

IV: People living with HIV trained in self-management may assume some tasks related to their own care that would previously have been handled by health workers. Task shifting can also be extended to other cadres that do not traditionally perform clinical functions—e.g., health educators, pharmacy technicians, laboratory technicians, administrators, and records managers.

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