Barriers to Retention in Care as Perceived by Persons Living with HIV in Rural Ethiopia: Focus Group Results and Recommended Strategies


Abstract
Inability to retain HIV-infected patients in care undermines the benefits of starting millions in low-income countries on antiretroviral therapy (ART). In a hospital HIV clinic in rural southern Ethiopia, we conducted focus groups of HIV-infected men and women to learn more about experiences with and barriers to attending clinic appointments. Respondents reported multiple barriers, including those that were patient related (eg, misunderstandings about ART, mistaken belief in AIDS cures, and drug/alcohol use), clinic related (eg, negative provider interactions, lack of familiarity with patients’ medical situation, and overcrowding), medication related (eg, side effects), social (eg, stigma and discrimination and lack of support), and situational/resource related (eg, distance to clinic, lack of funds, competing domestic/work priorities, and lack of food). Based on the lessons learned from these focus groups, we implemented a community intervention to improve retention, using trained community support workers who provide patient education, counseling, social support, problem-solving assistance, needed referrals, and improved communication/linkage to the patients’ HIV clinic.

Keywords
HIV, rural health, retention, community support workers

Introduction
Despite global success in starting 6.65 million people in low- and middle-income countries on antiretroviral therapy (ART),1 the inability to retain HIV-infected patients in care can undermine medical and public health benefits of this accomplishment. One meta-analysis reported that in sub-Saharan Africa (SSA) only 77% of those started on ART are retained in care for 12 months, with loss to follow-up being the most common cause of attrition.2 Attrition rates are greatest in the first year after initiating treatment.3 The World Health Organization (WHO) lists retention in care as an important indicator of HIV program efficacy.1 Attrition among patients started on ART is associated with reduced survival.3–6 In Cote d’Ivoire, loss to follow-up resulted in an average reduction in life expectancy of over 9 years5; and in Malawi, 54% of ART patients defaulting from care were found to have died.6 The ART interruption (even if later reinitiated) is associated with an increased probability of AIDS-related opportunistic diseases, serious non-AIDS events (such as cardiovascular, renal, or hepatic disease), and death.7,8 Failure to continue ART and to suppress virus load also results in an increased probability of sexual and perinatal HIV transmission.10,11 Suboptimal adherence and retention in care can also lead to viral resistance to first-line ART drug, a particular burden in resource-poor countries for whom second-line drugs are more costly.12

There are an estimated 1.2 million Ethiopian people living with HIV (PLWH), including over 456,000 living in rural areas.13 Ethiopia’s national AIDS plan includes rapid expansion and decentralization of HIV care, with over 500 HIV care sites throughout the country14; however, loss to follow-up remains a major challenge. A study of 89,451 Ethiopians starting ART at 270 facilities during 2003 to 2007 found that after only 6 months,
14.5% were lost to follow-up and 6.5% were known to have died; by 24 months, 23% were lost to follow-up and 12% had died.\(^\text{15}\) Although there are limited data on pre-ART loss to follow-up, an Ethiopian study of 2191 HIV-positive patients at 1 hospital reported that a quarter of patients were lost to follow-up before starting the treatment.\(^\text{16}\)

In a hospital-based HIV clinic in rural southern Ethiopia, where treatment default has been a significant concern, focus groups were conducted to learn more about HIV-positive persons’ experience with and barriers to HIV care, including community-based factors that may affect retention. We describe key themes that emerged from these groups as well as how lessons learned from this qualitative assessment were utilized to develop and implement community-based interventions designed to improve retention in HIV care.

### Methods

#### Setting

Focus groups were conducted at Arba Minch Hospital. Arba Minch is a town of approximately 75,000 people and is located in the Southern Nations and Nationalities Peoples Region of Ethiopia.\(^\text{17}\) Arba Minch Hospital is the referral hospital for the Gamo Gofa Zone, and in 2003 was among the first public hospitals to start ART in Ethiopia. Since HIV care was initiated, 2886 PLWH had enrolled for HIV care with the hospital as of February 2010.\(^\text{14}\) Of 1849 PLWH who ever started ART, 1240 (67%) were currently on ART with this clinic.\(^\text{14}\)

#### Selection and Recruitment of Participants

Inclusion criteria for focus group participants included being a patient at the HIV Clinic at Arba Minch Hospital and age \(\geq 18\) years. Recruitment of focus group participants took place at the Arba Minch Hospital HIV Clinic, with the objective of selecting approximately 10 men and 10 women per group. The recruitment process was finalized after discussion with the hospital manager and HIV clinic staff. Although the HIV clinic has a large number of patients, we appreciated from our discussions that because of stigma, many HIV-infected patients would not feel comfortable publically discussing their HIV-positive status and the challenges it imposes as well as other personal issues, especially in an open group. For focus groups, we wished to select those patients who would be most willing to engage in a group discussion to openly share their experiences and challenges and who would not feel inhibited talking with focus group facilitators and other HIV-positive patients. For ethical reasons, we also wanted to select patients who would most likely respect the confidentiality of the group discussion. Finally, we included patients who were available on the specific time and date the focus group was conducted. With these guidelines in mind, the choice of potential focus group participants as well as the initial invitation to participate in the focus group was made by the HIV clinic physician and nurse who were familiar with all patients at the clinic.

Once potential focus group participants were identified, the initial contact was made by the HIV clinic physician or nurse who briefly explained the purposes of the study; those potentially interested then followed up with the focus group facilitator for additional information. As part of informed consent, potential participants were told that their decision would not affect care they receive from the hospital or HIV clinic, that their participation was voluntary, that they could withdraw at any time or refuse to answer any specific question, and that all results would be kept strictly confidential. At the conclusion of the focus group, participants received a modest compensation for transportation and for a meal before returning home.

#### Focus Groups

Two focus groups (1 male and 1 female) were conducted in Amharic (the Ethiopian national language) by a trained facilitator. A second member of the study team served as data recorder to transcribe participant responses, while a third member served as an observer to record general overall impressions and major issues raised. Because of participant concerns about confidentiality, tape recorders were not used. Each group lasted from 2 to 3 hours.

As part of the focus group, participants were asked the following questions: “Tell us what you like and don’t like about the services you get at the HIV Clinic”; “What makes it difficult for you to follow clinic instructions on managing your HIV when you are at home?” “What do you think are the most important reasons people have trouble taking their HIV medicines every day when they are supposed to, and what could be done to improve this?” and “What do you think are the most important reasons people have trouble going to their clinic appointments and what could be done to improve this?” Additional questions and discussion issues included how participants interacted with their family, friends, and community in terms of their HIV status.

At the beginning of the group, basic data such as age and number of years in HIV care (and on ART if applicable) were recorded. Based upon the transcribed notes as well as the overall impressions from members of the study team, the focus group facilitator prepared a written report of major answers and key issues raised in response to each focus group question; this summary report included illustrative specific replies. Based upon this written report, the study team then categorized perceived barriers to retention in care into 5 major categories, each of which is described below.

This study was reviewed and approved by human subject review boards in Ethiopia and at the University of Minnesota. Verbal informed consent was obtained from all group participants.
Results

Characteristics of Focus Group Participants

Ten female participants had a mean age of 30 years (range, 25-38 years). Six participants had been taking ART for 3 to 5 years (mean, 3.8 years), and 4 had not started ART. Female participants first learned they were HIV positive 1 to 6 years ago (mean, 3.6 years). Eleven male participants had a mean age of 42 years (range, 29-61 years). All 11 participants were taking ART for 3 months to 6 years (mean, 2.7 years). Male participants first learned they were HIV positive from <1 year to 6 years ago (mean, 2.9 years).

Patient-Related Barriers

A number of misconceptions about HIV and ART were identified. Participants reported many individuals who received a positive HIV result felt that this was a death sentence and were unaware that ART and other medical interventions can help patients remain healthy. At the same time, there was a widespread mistaken belief in holy water or other spiritual interventions as “cures” for AIDS, such that ART and other HIV clinic-based care was not needed. Another common belief was that starting ART would result in increased hunger which could only be satisfied by larger quantities of food and/or specific foods such as meat; if these foods are not available, some PLWH are reluctant to begin ART.

Participants reported patients who abused alcohol or drugs were less likely to have good adherence and retention. Alcohol abuse included araki, a locally distilled beverage with very high alcohol content. The most common drug of abuse is khat, an amphetamine-like plant native to Ethiopia, which is legally and widely used for its stimulant effects.

Clinic-Related Barriers

Negative experiences of receiving HIV care which were felt to adversely affect retention were both provider and system based. Negative provider interactions included the perception that doctors or nurses did not have patience or express a welcoming attitude as well as concern about lack of confidentiality by clinic staff, including counselors; clinicians that were polite and welcoming were greatly appreciated. Negative health system factors included frequent change of clinicians, which may result in changed treatment plans; a poor medical records system that might result in patient records being lost or incomplete; overcrowding and shortage of chairs in waiting rooms; and long waiting time for appointments, test results, or other services. For example, because results for laboratory tests such as CD4 count were not immediately available, patients might have to return several days to a week after an initial visit for counseling about their results. The following 2 examples illustrate some of these challenges (1) “Different doctors prescribe different drugs. One time a new doctor gave me new drugs and, as a result, there was swelling of my body. When I went back to the clinic, they changed the drugs to the original ones. This also happened to my colleagues.” (2) “Among the major reasons . . . people discontinue their medications are . . . long waiting times for lab tests results. They say they can’t afford staying in town to wait for the result.”

Positive examples of clinic interactions felt to promote retention included (if offered) patient education and counseling. Patients appreciated receiving information about HIV, ART, and other health promoting measures such as nutrition and water sanitation. Given limitations of clinic staff (both number of personnel and available time), focus group participants recommended that such support also be offered at the community level, including assistance interacting with the HIV clinic concerning registration at the clinic for medical appointments, drug side effects, and other medical concerns.

Medication-Related Barriers

Troubling drug-related side effects reported by focus group participants that were felt to contribute to treatment default by some patients included lipodystrophy, peripheral neuropathy, and gastrointestinal distress, including nausea and diarrhea. Participants appreciated receiving combination drugs with simple dosing schedules.

Social Barriers: Stigma and Discrimination

These were among the most often cited barriers by almost all participants, as the following 3 examples illustrate: (1) “Once my wife was known to have HIV, the neighbors did not allow her to take water from common pipe they were using before. Our child was told not to play with their child”; (2) “The landlord where I was living in a rental house told me not to use their latrine”; (3) “Someone asked my 9 years old boy ‘Does your father have HIV?’ When my child came back to home, he asked me that whether I have HIV or not. He told me the history he faced. This was shocking to me and I cried.”

Although the Ethiopian HIV plan is to decentralize care to local health clinics, because of feared stigma and discrimination, many patients do not want to be seen receiving HIV care at a nearby clinic by neighbors or friends; some instead elect to go far distances to larger and more crowded tertiary hospital clinics where there is less chance of being recognized. However, distance to these clinics can be a major barrier to retention in care, especially for those from rural communities and those with limited funds for transportation. As one respondent reported, “Most people do have fear of stigma. Because of this, they are afraid to come to the clinic.”

Participants said lack of personal or social support from family, friends, and the community was a barrier to remaining in care and adhering to ART, while strong and consistent support made retention easier. Several participants reported that disclosure of HIV status to family or friends, although initially difficult, typically resulted in greater social support. Participants recommended that education and awareness raising programs be strengthened to avoid misconceptions about HIV and to decrease stigma toward PLWH by family and
community members. Participants also reported the beneficial effect of PLWH associations that offer social support, encouragement, and the opportunity for PLWH to share challenges and strategies for coping with HIV.

**Situational/Resource Barriers**

Focus group participants reported that distance to the HIV clinic could be a barrier, with the requirement for transportation, lodging, and other travel-related expenses; this was a particular problem for rural patients who might have to spend the night in town near the clinic before returning to their home village. Competing priorities for work, child care, and other domestic responsibilities were also barriers to clinic attendance. Many families supported themselves by farming or day labor, and many women had child care and other household responsibilities; being in the clinic for an entire day could impose hardships on the entire family.

Food insecurity represented another barrier to retention in HIV care. Lack of food and malnutrition are issues for many Ethiopians including PLWH, especially those who are seriously ill. Taking ART on an empty stomach can exacerbate certain gastrointestinal side effects, and malnutrition can worsen clinical and immune status. Lack of funds not only led to decreased ability to buy food but other challenges affecting health status. For example, focus group participants reported that although ART drugs were provided for free, other medical drugs (e.g., antibiotics and vitamins) were not, an additional financial burden for patients, most of whom are poor. If available, participants reported the important role of PLWH associations and other community organizations which offered assistance such as nutritional and modest income support. Facilitating linkages to such community-based groups was felt to be very important.

**Discussion**

Studies from Ethiopia and elsewhere in SSA indicated that approximately one-quarter of patients are no longer retained in care after 1 year. To better understand some of the challenges that HIV-infected patients have in regularly attending their medical appointments, we conducted focus groups of PLWH who were recruited from a hospital HIV clinic in rural southern Ethiopia. Respondents reported a variety of potential barriers, including those that were patient, clinic, medication, social, and structural/resource related.

Focus group participants felt that patients who had a greater understanding of the benefits of HIV treatment and how to manage their care would be less likely to default. Examples of misunderstandings included mistaken beliefs in HIV/AIDS “cures” such as holy water, which might result in patients stopping prescribed medical treatments or defaulting from clinical care. Focus group participants reported that clinicians who appeared interested and who explained treatment-related issues to their patients promoted retention in care, in contrast to those who were perceived as impatient or unfriendly. This suggests that clinic staff may benefit from training on counseling and education skills, including delivering health messages in ways that are culturally and educationally appropriate to the client’s background. Because the skills, time, and resources that the HIV clinicians need to counsel and educate their patients may be limited, especially in busy and overcrowded clinics, through “task shifting,” lay counselors (including PLWH) can be trained to provide these services.

Focus group participants reported that for some patients, alcohol or drug abuse was a barrier to remaining in care. In Ethiopia, khat (a drug with amphetamine-like properties) is widely used and may be more common among PLWH. Comprehensive health care for PLWH needs to address alcohol and drug abuse, which not only has adverse medical consequences in its own right but may also affect linkage to and retention in HIV care.

Additional clinic-related barriers felt to contribute to patient default included frequent change of doctors, poor medical records, overcrowding, and long waiting times. These issues may be especially acute in large HIV clinics located in regional and referral hospitals, where a great number of patients are seen each day. To help manage the increasing numbers of HIV-infected patients being referred for care, Ethiopia and other countries in SSA have promoted decentralization of HIV treatment to local health clinics. In settings where clinics are smaller and more local, patients are more likely to encounter the same clinicians at each visit, who are more familiar with the clients’ needs and their care plan. To help reduce loss to follow-up, such decentralization can be augmented by measures such as on-site laboratory and other services, such as point-of-care CD4 tests.

Drug side effects were mentioned as one reason for treatment default. In many cases, these side effects can be managed with supportive care and treatments without stopping ART. Patients need to be counseled about expected side effects when starting the treatment, how to manage mild signs and symptoms, and when to return to the clinic for more severe ones. Current WHO guidelines also recommend regimens that do not contain ART drugs such as stavudine (d4T), which have some of the most frequent and troubling side effects.

Some of the most commonly cited barriers to retention in care were related to stigma and discrimination. Our own surveys in Arba Minch (the same area from which focus group members were recruited) confirm such negative attitudes among a number of community members. Addressing stigmatizing attitudes and discriminatory practices in patients’ families and by their communities may provide more support for PLWH and improve retention in care. Community education programs should provide accurate information about HIV infection and disease, including lack of HIV transmission through casual contact contagion, as well as opportunities to ask questions, express concerns, and engage in interactive discussion; the Ethiopian community conversation program is built on such a model. The PLWH themselves can play an important role in helping to develop and implement community-based stigma-reduction efforts.
Respondents also described a number of situational or resource-related barriers to attending HIV clinics, including distance (especially for those who attend clinics far from their homes because of feared recognition and discrimination); financial constraints (e.g., for transportation or additional medical-related costs); competing priorities for work, child care or other domestic responsibilities; and lack of food. Ethiopia is a poor and largely rural country, and similar barriers to retention have been described in other studies from Ethiopia and elsewhere in SSA. Where available, PLWH associations and other nongovernmental organizations (NGOs) have played an important role, offering assistance with microfinance, income generating activities, nutrition, and other support. Focus group participants felt facilitating linkage to such groups was very important.

Based on lessons learned from our focus groups and key informant interviews, we developed and are implementing in Arba Minch a community-based intervention to improve retention in HIV care. Each HIV-infected patient who is newly diagnosed and enrolled in care (a time when the risk of treatment default is greatest) is assigned a community adherence support worker (CASW) from the same village or neighborhood as the patient. The CASWs, many of whom are also PLWH, are trained by the project and meet with the client on a frequent basis to educate about HIV and treatment, including ART; counsel about ways to remain healthy, including proper nutrition; and provide social support to reduce isolation and the sense of despair many newly diagnosed patients feel. The CASWs are aware of and can facilitate linkage to PLWH associations and other NGOs that provide community-based support services. The CASWs also meet on a regular basis with HIV Clinic staff and have cell phones to contact clinic staff to help answer patient questions or concerns and to discuss medical problems that may arise, including ART side effects. Follow-up after the CASW confers with a designated HIV clinic nurse might include additional patient counseling by the CASW or arranging for the client to be seen at the clinic. All these measures help to improve continuity of care, client satisfaction, and clinical outcome.

Other interventions have also utilized varying forms of community-based support for PLWH to help reduce treatment default, and this project will complement a needed knowledge base about how to best reach and support clients in their home settings. Community-based programs can provide a critical and needed linkage between individual clients and their medical care providers, and complement other efforts at the clinic level to reduce treatment default.

Several cautions must be considered in generalizing our results to other PLWH. Because participants were recruited from an HIV clinic, they represent those who by definition were engaged in care rather than defaults. In addition, those who were recruited for this focus group were selected because they were considered most likely to engage in a group discussion to openly share their personal experiences and challenges with focus group facilitators and other HIV-positive patients; therefore, they may not have been typical of all patients receiving care at the HIV Clinic. To help reduce the impact of any selection bias, participants were asked to reflect on not only their own experiences but also those of other PLWH in their communities. Because many focus group members also participated in local PLWH associations, they were able to better appreciate and share this wider perspective. Retention barriers given by our focus group participants are also consistent with those reported in other studies of PLWH, including studies of those who defaulted from care. Finally, respondents in our focus groups were from a primarily rural setting. Because many PLWH are from rural settings, it is important to have a better understanding of the particular challenges they face in accessing and remaining in care.

Because this was a qualitative study, we cannot say how often identified barriers reported by our focus group occur in HIV-infected patients. However, findings from our focus groups will be incorporated into pre- and postintervention surveys for our subsequent CASW program to determine how often specific barriers occur and how they are modified in response to our community interventions. Data from preintervention surveys will help us to determine to what extent barriers to retention mentioned by focus group participants are also reported by a much larger sample of patients recruited from the same HIV clinic from which focus group participants were selected.

Based on our experience and lessons learned in conducting these focus groups, we have a number of suggestions for other researchers. First, before conducting the groups, it was useful to solicit the advice of hospital and HIV clinic officials and to give the HIV clinic enough time to identify and recruit potential participants. A modest reimbursement for transportation and a meal after the group was appreciated by the participants. Second, although we planned for each group to take slightly more than an hour, groups took up to 3 hours to complete. Participants had a great deal to say, but they needed adequate time and space to tell their personal stories and relate their experiences in their own way. The facilitator for the focus groups was skilled in allowing this to happen, greatly increasing the value of the information we received. Participants enjoyed and appreciated the opportunity to share experiences and advice with other PLWH; this served as a positive motivation for participation. Finally, a challenge to focus groups is when some participants are reluctant to express in a group certain opinions that could be considered socially unpopular and identified with the respondent. To minimize this challenge, the group facilitator conducted groups in an open, nonjudgmental fashion; separate groups were conducted for men and women. Participants were asked more general questions such as “What are the most important reasons people have trouble going to their clinic appointments?” and if a respondent did not want to have a barrier identified with their own personal situation, they could share their opinions in more broad-spectrum terms. The importance of keeping all personal details and information discussed as confidential was also repeatedly reinforced.

In summary, the inability to keep PLWH engaged in care has serious consequences for both the individual patient and
public health. The HIV-infected patients in resource-limited settings such as this rural Ethiopian community may face particular challenges and barriers leading to treatment default. We describe commonly reported patient-, clinic-, medication-, social-, and structural/resource-related barriers to clinic attendance from our focus groups as well as strategies to help overcome these barriers. Although no single strategy will meet all challenges, and solutions will need to be individualized to meet specific situations, our findings suggest that a partnership of clinic and community-based approaches (including those we are currently evaluating in our work with community-based adherence support workers) may represent the most effective one to this critical HIV treatment issue.

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References


