

Barriers to and Factors Facilitating Adherence to Antiretroviral Therapy from the Perspectives of Patients in Mäqälä City, Təgray Region, Ethiopia

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The decentralization and free provision of life-saving antiretroviral therapy (ART) to health centers in Ethiopia began in 2006. In the Təgray Region, the number of people who began ART increased almost tenfold between 2006 and 2010, yet treatment retention among these patients has been challenging. This qualitative analysis explores the experiences of patients who either continued or interrupted adherence to ART. Conducted at three health facilities in Mäqälä City from August to October 2009, the aim of this study was to document the facilitating factors and barriers to ART adherence from patients' perspectives.

For both continued and interrupted adherence, the most common facilitating factors are a belief in the efficacy of the medication, trust in the health-care providers, low level of side effects, positive treatment results, and having an HIV-positive friend. Each restarter had distinctive reasons for interrupting the ART. Major contributing factors to ART interruption were the side effects and fear of stigma or discrimination.

In urban neighborhoods with a high volume of rural migration, where people lived far from their extended families, ART patients were more dependent on health workers for adherence support.

Key words: HIV, antiretroviral therapy, adherence, lost to follow up, Tigray, Ethiopia

1. INTRODUCTION

1.1. HIV/AIDS in Ethiopia

According to the Demographic and Health Survey (Central Statistical Agency [Ethiopia] & ICF International 2012), the prevalence of HIV among people aged 15 to 49 years in Ethiopia was 1.5%. However, HIV prevalence varied depending on age, sex, geographical location, and wealth quintile. For example, HIV prevalence in men aged 15–49 years was 1.0%, while the prevalence for women in the same age group was 1.9%. Moreover, HIV prevalence in urban areas was 4.2%, compared to 0.6% in rural areas. Among 11 regional and administrative states in Ethiopia, HIV prevalence was highest in Gambela (6.5%) followed by Addis Ababa (5.4%), and lowest in the Southern Nations Nationalities and People Region (0.9%).

In the Təgray Region, where this study was conducted, the adult HIV prevalence rate is currently

1.8%, which is a decline of almost 1 percentage point from 2.7% at the time of this study. In Mäqälä, the region's capital, 8.0% of people tested positive, compared to 3.3% of people in the entire Təgray Region, during the data collection period (Tigray Health Bureau 2010).

1.2. The pathology of human immunodeficiency virus (HIV) infection

The virus attacks and destroys the CD4 cells of the immune system of infected persons, weakening the defense system and resulting in immunodeficiency. Immune function is usually assessed by a CD4 cell count. An immunodeficient person is thus easily susceptible to a wide range of infections and diseases that healthy people can easily ward off. People living with HIV (PLWH) receive anti-retroviral therapy (ART) consisting of three or more antiretroviral (ARV) drugs taken twice a day. The ART suppresses HIV and controls viral replication within the body, thus strengthening the immune system; however, ART does not cure the HIV infection itself. After initiation of ART, an adherence rate of over 95% must be maintained for the treatment to be effective. This rate is required to suppress viral replication, improve immunological and clinical outcomes, decrease the risk of developing ARV drug resistance, and reduce the risk of transmitting HIV to others.

1.3. The launch of free ART services

The free provision of ART since 2005, and the nationwide decentralization of ART services to health centers since 2006, has facilitated ART access to eligible patients. By mid-2013, the number of people in Ethiopia who had started ART increased from less than 9,000 to more than 439,000 (Federal HIV/AIDS Prevention and Control Office, FHAPCO 2013).

In the Təgray Region, ART services are provided at 106 government health facilities, as of September 2015 (personal communication), up from 56 facilities in February 2010 (Tigray Health Bureau 2010), and 10 facilities in 2006 (FHAPCO 2009). An almost tenfold increase in the number of persons receiving ART was observed in Təgray from 2006 to 2010 (FHAPCO 2015). However, accessing ART is still difficult for vulnerable patients. According to an estimate from 2013, about 40% of PLWH in Ethiopia were receiving treatment (317,443/793,700) and 50% of HIV-infected adults (298,512/593,400) were on ART (FHAPCO 2014).

Patients on ART have a monthly appointment at the health center where they are registered. During this monthly visit, patients receive follow-up diagnoses as well as adherence counseling, and collect their monthly supply of ARV medication with a bottle of water purification solution. Patients who do not attend their scheduled appointment will either be traced directly by an ART service provider or, if they are unreachable, will be visited and counseled at home by a community-based outreach worker or case manager.

Patients who miss their follow-up appointments and fail to pick up their medication for one to three months are categorized as “lost” or “lost-to-follow-up”; a patient who is “lost” for more than three months will then be considered a “dropped” patient (Federal Ministry of Health of Ethiopia, no date). According to a large national cohort study conducted by FHAPCO, the percentage of patients categorized as “lost-to-follow-up” in the Təgray Region was 18.3%, compared with the national average of 16.9% (FHAPCO 2009).

1.4. Health Extension Programme (HEP)

Ethiopia's flagship “Health Extension Programme” (HEP) trained and deployed over 34,000 Health Extension Workers (HEWs) throughout the nation between its inception in 2003 and 2010.

For many people in the community, HEWs represent their primary contact with the healthcare system. HEWs reach out to people at the household level, with a special focus on maternal and child health, delivering integrated preventive, promotive, and curative health services (including prevention and control of HIV/AIDS). HEWs are female, 18 years old and over, educated to at least tenth grade level, and speak the local language. Building on the principles of comprehensive primary healthcare, two HEWs are assigned to a health post, which is the lowest level health facility, and serve approximately 1,000 households, or around 5,000 people. HEWs are salaried staff of the government, unlike

community health volunteers in other resource-limited settings (Accorsi et al. 2010, Bilal et al. 2011).

1.5. Literature review of barriers and facilitators to ART

Meta analyses as well as systematic reviews of studies on ART adherence have acknowledged several barriers and facilitators to therapy. The most common barriers include stigma and fear of disclosure (Brinkhof, Pujades-Rodriguez & Egger 2009, Govindasamy, Ford & Kranzer 2012, Langebeek et al. 2014), financial constraints (Brinkhof, Pujades-Rodriguez & Egger 2009, Geng et al. 2010, Langebeek et al. 2014), distance to clinics and transportation costs (Brinkhof, Pujades-Rodriguez & Egger 2009, Geng et al. 2010, Govindasamy, Ford & Kranzer 2012), and perceived good health (Brinkhof, Pujades-Rodriguez & Egger 2009, Geng et al. 2010, Govindasamy, Ford & Kranzer 2012).

Common facilitators for ART adherence identified from meta-analyses and systematic reviews of studies conducted in low- and middle-income countries include patients' self-efficacy (Mills et al. 2006, Langebeek et al. 2014), trust/satisfaction with the HIV care provider (Mills et al. 2006, Langebeek et al. 2014), belief in efficacy of ART (Mills et al. 2006, Langebeek et al. 2014) and the availability of social support (Geng et al. 2010, Langebeek et al. 2014). Although ART patients in Ethiopia share many of the same facilitators and barriers identified elsewhere, there are other factors that are specific to this country. Other such barriers include the use of holy water ⁽¹⁾ and/or religious treatment ⁽²⁾ (FHAPCO 2009, I-TECH 2011, Mamo et al. 2013, Asgary et al. 2014, Hussen et al. 2014, Woldesellassie et al. 2014), fasting ⁽³⁾ (Woldesellassie et al. 2014), or having either an HIV-negative partner or a partner with unknown HIV status (Kebede et al. 2008). Facilitators to ART adherence include disclosure of HIV status as a coping mechanism to gain support from family members and others (Taye, Jeppsson & Bekele 2011, Woldesellassie et al. 2014), and decentralization of ART (Taye, Jeppsson & Bekele 2011, Yibeltal et al. 2014). These have been specifically reported by studies conducted in Ethiopia.

1.6. Study objective

This study was conducted in Mäqälä by the first author of this article and a Təgrəña-speaking research assistant (RA), from August to October, 2009. The objective of this study was to describe facilitating factors and barriers to ART adherence from the perspectives of patients who sought care at three health centers in Mäqälä.

The University of Washington Institutional Review Board and the Ethical Committee of the Təgray Health Bureau approved the research protocol.⁽⁴⁾

1.7. Background of Mäqälä

In the Təgray Region, 95.6% of all residents are Ethiopian Orthodox Christians, 4% are Muslim, 0.4% are Catholic, and 0.1% are Protestant (Population Census Commission 2008). Mäqälä City is the capital of the Təgray National Regional State, and is located 783 km north of Ethiopia's capital, Addis Ababa. The total population of Mäqälä City is 260,250.

The city is divided into seven sub-cities, which are further divided into 33 *qäbäle* (the smallest administrative unit in Ethiopia). It is estimated that 32.3% of Mäqälä residents were living below the poverty line in 2000 (Tesfaye & Whelan 2008). According to Gessesew et al., among the 22% of people who are unemployed in Mäqälä City, 60% are female (Gessesew et al. 2015). The same study suggested that an increasing number of women were engaging in commercial sex work, due to the upsurge in tertiary industries (Gessesew et al. 2015).

The city has a total of 56 health facilities, including 11 public facilities (one referral hospital, one general hospital, and nine health centers). There are also 42 for-profit private facilities (four general hospitals and 38 clinics), two private not-for-profit facilities run by the Family Guidance Association of Ethiopia (FGAE), and one STI clinic operated by Mäqälä University (Rishan et al. 2015). At the time of this study, with the exclusion of hospitals, only three public health centers provided ART services.

1.8. Facility descriptions (as of data collection period in 2009)

The three study sites are located within Mäqälä City. The Mäqälä Health Center (MHC) is located in the heart of downtown Mäqälä. The Kasäç Asfaw Health Center (KHC) is situated on the outskirts of Mäqälä, serving the population of Mäqälä and the surrounding *qäbäle* (villages). The Sämen Health Center (SHC) is located in the vicinity of °Aydär Referral Hospital and primarily serves residents of the catchment districts (*wäräda*). Clinic hours are from 8:00 am to 5:30 pm, with a lunch break from noon until 2:00 pm, Monday to Friday. Mäqälä Health Center is open 24 hours a day, 7 days a week, with limited staff on weekends.

At the time of the field work for this study, the ART clinics at all three sites were staffed by one ART nurse (who counseled and diagnosed patients, and prescribed medication to them), one data clerk (who filled out various forms for each patient on each visit), and one case manager (who worked with patients who were at risk of low adherence to ART); all staff members were female.

The physical arrangement of the ART clinics in these three health centers varied significantly. For example, in one health center, the ART nurse, a case manager, and a data clerk all worked in the same room, meaning that patient consultation, counseling, and data entry were all performed in that same space. At another health center, each staff member had a separate room and completed relevant job tasks in that designated space.

Following the nationwide decentralization of ART services in July 2006, all three of the study sites began providing ART services in February 2007.

2. METHODS

2.1. Selection of key informants

Key informants were selected from a stratified sample of ART patients. Using the ART register at each ART clinic, patients aged 15 to 49 years at the initiation of ART were classified into two groups: the 'good adherers', those who had been on ART for at least six months at the most recent visit, and the 'restarters', those who had resumed treatment after being lost or dropped. From the lists of each group, identified by unique IDs, 10 patients were selected by matching their ID numbers with those from a table of random numbers. ART clinic staff contacted the 10 patients until they had at least five patients who consented to be interviewed from both the good adherer and the restarter treatment groups. Ultimately, a total of 23 informants consented to be interviewed.

2.2. Interview procedure

The principal investigator (PI) and the first author developed both structured and semi-structured interview guides. The PI and the RA piloted these study instruments at K°iḥa hospital, located about 15 km from downtown Mäqälä. Each study interview lasted 45 to 60 minutes and was audio-recorded. Three of the 23 patients refused to be audio-recorded. The PI interviewed the participants in English; the RA then translated the questions into Təgrəña. Immediately after each individual interview, the PI and the RA wrote up their notes. The audio-recordings of each interview were transcribed into Təgrəña, and then translated verbatim into English by a Təgrəña speaking HIV/AIDS professional. The transcriber/translator also added contextual annotations to the translation about the cultural/religious issues mentioned by the patients.

Prior to the fieldwork, the PI had developed a codebook based on previously articulated factors of adherence and non-adherence. The PI used these pre-developed codes, which were later modified and expanded as the analysis progressed. Coding for the themes was performed by using ATLAS.ti software.

3. RESULTS

3.1. Characteristics of the key informants

The interviews were conducted with 23 patients from three health centers: nine from KHC, seven from MHC, and seven from SHC. The 13 female and 10 male patients ranged in age 20 to 58 years. Four patients were transferred from hospitals to the health center when ART became available, as the health center was closer to their homes. Thirteen patients were classified as good adherers and 10 were classified as restarting ART patients.

The mean interruption was 3.2 months after the inception of therapy (range of 0 to 11 months), for the 10 ART restarters. The mean duration of interruption was 4.4 months (range 1 to 9 months). Upon restarting ART, four out of ten patients changed to a regimen different from their original prescription. Two patients interrupted ART twice during their treatment history and one dropped out seven months after the interview.

3.2. Factors that facilitated adherence to ART

The themes presented below were derived from analyses of individual patient interviews. Themes consistent with previous studies are presented first, such as trust in the effectiveness of ART (Mills et al. 2006, Gusdal et al. 2009, Taye, Jeppsson & Bekele 2011), trust in health-care providers (Mills et al. 2006, Gusdal et al. 2009, Langebeek et al. 2014), having social support (Mills et al. 2006, Alemayehu et al. 2008, Ayele et al. 2010, Woldesellassie et al. 2014), and decentralization of the provision of ART (Taye, Jeppsson & Bekele 2011, Yibeltal et al. 2014). Secondly, other themes that emerged from this study are discussed, including fear of losing health gains from ART adherence and obtaining employment.

3.2.1. Trust in ART with improved health after undergoing treatment

Our key informants shared the positive changes they experienced since the initiation of their ART. Regaining health and strength, and being able to perform their daily routine, gave them hope and encouraged them to keep taking the medication. The positive outcomes of the ART bolstered their belief in the efficacy of the medication.

Now I am OK. My CD4 [count] before was only 140, but now it is more than 300. My weight is increasing; now I am 65 kg. I am better. I do not get tired when I work as a day laborer. I have been in very good condition, especially for the last six months. Previously, I suffered from boils, now the boils have vanished. If they come, they don't spread as they did before. They heal quickly...now I eat my breakfast and my appetite is very good. I eat whatever I get. I am regaining my strength... [In response to a probe about what motivates people to continue treatment besides hope, which the patient mentioned earlier] For me the most important motivator is the medicine itself. (Male, age 36, good adherer, 10 months on ART)

3.2.2. Trust in health-care providers

Through the counseling that nurses provided, patients regained their hope to live and continued treatment. They appreciated the friendliness of the ART clinic staff, and felt that they were regarded there as family. The patients' trust in the ART service providers was sustained from the initial counseling sessions throughout the follow-up visits at the health center.

[Name of the Case Manager] and [name of the ART nurse] follow my condition attentively. They always encourage me. I have no one to look after me like they do. (Male, age 29, re-starter, interrupted for 2 months)

3.2.3. Social support as facilitator to ART

Based on responses from the study participants, social support can be grouped into three categories: support from family, relatives, and an HIV-positive partner; support from individuals who are HIV-negative or of unknown HIV status; and support from HIV-positive friends.

Support from family, relatives, and a positive partner

During the interviews, none of the participants voluntarily mentioned support from their partner as a facilitator. However, when probed, those who had a positive partner responded that they reminded and encouraged each other to take the medication and to continue treatment.

One female patient disclosed her status to her relatives because she thought she was dying. As her health improved, she regretted the disclosure. However, she was happy that they knew her status because of their warm and compassionate treatment of her.

... although they [relatives] did not support me materially, they encouraged me. They told me to take it easy. When I visited them in a rural area, their treatment and care were very good. They even gave me their bed. Hence, it was I who was anxious. I was careful and I took my own bottle of drinking water. They told me drinking water or sharing cups could not transmit it. They accepted me warmly. (Female, age 31, good adherer, 20 months on ART)

Support from individuals who are HIV-negative or of unknown HIV status

One patient came to Mäqälä from another town in the region because she could not get along with her stepmother. In Mäqälä, her first job was as a maid, but she then found another job as a waitress at a local cafe. She started ART but discontinued it because she was not allowed to leave work to go to the health center for follow-up counseling and medication. Several months later, she was hospitalized, as her physical condition had deteriorated due to opportunistic infections. She disclosed her HIV status to her neighbor, who provided the necessary care during her hospitalization. The informant said, "She [the neighbor] helps me more than my mother."

Previously nobody knew about my status; I did not tell anyone. However, now I have a trustworthy friend and neighbor. I told her [about my status] and she monitors my condition. If I could not come here [health center] ...she would bring the medications to me... She supports me with food. She cooks for me. The landlords are also good to me. I do not know whether they know about my status or not. When I was in the hospital they helped me with food. I was jobless for six months and they helped me for those months. (Female, age 20, restarter, interrupted for 7 months)

Support from HIV-positive friends

Two informants described their experiences of being supported by their HIV-positive friends. Stigma and discrimination toward HIV-positive people was still prevalent in Mäqälä at the time of the study. With fellow HIV-positive friends, they could reinforce the advice from the health providers to take the medication properly.

I have a friend like me [who is HIV positive]. He used to advise me. When I felt discomfort from the [ART] drugs he encouraged me... It has been a year since he knew of his status but he did not disclose it [to me]. He told me about his status when he saw how worried I was when I learned about my own. He encouraged me by telling me that from his experience, I could live with it. He advised me and encouraged me. We knew each other when we were fighters. He was a TPLF [Tigrayan People's Liberation Front] ⁽⁵⁾ fighter like me. We were comrades. (Male, age 34, good adherer, 12 months on ART)

A female informant who was a member of a local PLWH association mentioned that meeting fellow HIV-positive people changed how she looked at herself and HIV.

Joining the association was helpful. We see one another as brothers and sisters. I thought that I was the only one with the illness but when I saw others like me, [HIV positive], and got advice from them it was helpful. (Female, age 31, good adherer, 20 months on ART)

HIV-positive people are often isolated. Few people disclose their status, beyond telling their spouse, due to the fear of stigma. Joining the association gives them the opportunity to meet other HIV-positive people and learn from their experiences, including the use of ART.

3.2.4. Decentralization of ART: Having ART centers closer to home

Decentralization of ART services began in Ethiopia in 2006, with the provision of ART at the health-center level, to bring the centers closer to patients' homes. This was done because a major cause of ART interruption among the 'lost-to-follow-up' patients, and in other resource-limited settings, was the distance and the cost of transportation from their residences to the ART clinics (Mills et al. 2006, Alemayehu et al. 2008, Kebede et al. 2008, Posse et al. 2008, Brinkhof, Pujades-Rodriguez & Egger 2009, FHAPCO 2009, Geng et al. 2010, Govindasamy, Ford & Kranzer 2012).

All three health centers in this study instituted ART services in February 2007. Among our informants, the mean distance to the health center from their home was 5.1 km (ranging from 0.2 to 15 km). Similarly, the mean travel time was 36.7 minutes (ranging from 2 to 120 minutes). Five out of 23 patients either took the minibus, or a *bajaj* (autorikshaw), paying between 6 and 20 Ethiopian birr, (US equivalent of 46 cents to 1.5 dollars during the data collection period), to reach the health center.

This study was conducted more than two years after ART services became available at the health centers. As the findings from other studies on ART adherence in Ethiopia have shown, our interviewees also suggest that having an ART center close to their residence could be a facilitating factor (Taye, Jeppsson & Bekele 2011, Yibeltal et al. 2014). A good adherer who moved from another part of the city to an area very close to the health center responded that the proximity was beneficial to her, especially when she was ill.

The proximity benefited me. When I was sick I could easily get medicines here. People prefer places far away where they cannot be recognized. Here I am not recognized. I come here and take the medication without being recognized. (Female, age 32, restarter, interrupted for 1 month).

The quotation implies that the patient prefers the closest health center, as long as people who come to the health center do not recognize her.

Although proximity to the ART center may be convenient, it is more likely that patients could meet acquaintances who may inquire about their visit to the health center or may even see them going into the ART center. Two informants intentionally chose a more remote health center, even though there were health facilities much closer to their residences. Their choice demonstrates that to avoid stigma and discrimination, patients select their ART center by prioritizing not only distance to the health facility but also the possibility of being recognized over proximity alone. The following quotation is from a patient who was afraid of being recognized:

The hospital is closer to me, but no one knows me here, so even if it is far I prefer it here. (Female, age 29, good adherer, 8 months on ART)

Although it took her 30 minutes, she chose to walk to the health center to avoid being recognized by people she might know at the hospital.

Urban patients had several ART centers to choose from at the time of data collection, including six public facilities within Mäqälä⁽⁶⁾. Rural patients however, did not have such options and walked for

hours to reach the health center every month. Notably, 16 out of the 23 study participants who chose to go to the health center closest to their homes indicated that fear of being recognized by their acquaintances, and fear of possible stigma and discrimination, were still major concerns for them.

3.2.5. Fear of losing health once regained through ART adherence

Patients may discontinue ART once they regain their strength, primarily because they feel much better in general and see no need to continue treatment (Mills et al. 2006, Tenaw 2008). Conversely, among the patients interviewed, good-adherers and those whose health had improved considerably on ART reported that fear of relapse motivated them to continue with the medication.

ART brought a 100% change to everything...I will not stop ART because it is my health to me. (Female, age 40, good adherer, 24 months on ART)

I will not stop [the ART]...I know my health will deteriorate if I stop taking the drugs. When I interrupted the drug treatment, all the symptoms reappeared. I will not stop taking the drugs so I will not become sick again. (Male, age 46, restarter, interrupted for 4 months)

3.2.6. Obtaining employment

A report from FHAPCO (2009:51) listed unemployment as a predictor of ART discontinuation. In this study, key informants reported that having a job helped them both financially and psychologically to cope with life as a PLWH. One patient who worked as a day laborer and as a guard at night cited work as a facilitating factor in ART adherence:

...It would be better if there were some support; besides, since there is an economic problem work is very important. Work also helps me not to worry. I am always working. Because I was a farmer, I do any kind of available work. This helps me continue treatment. (Male, age 36, good-adherer, 10 months on ART).

3.3. Barriers to adherence to ART

The Federal HIV/AIDS Prevention and Control Office (FHAPCO 2009) described different reasons for 'loss-to-follow-up' status among lost patients who were traced for an interview. A total of 838 patients reported the following reasons for discontinuing ART: Economic problems accounted for 47.6% of all answers, further manifesting as lack of support (17.7%), nutritional challenges (16.3%), and transportation difficulties (13.6%); use of holy water or other religious treatment (21.8%); and fear of side effects from the drugs (11.6%).

The following section describes recurrent themes from interviews with ART restarters in our study, as they relate to the results of the aforementioned FHAPCO study (2009), i.e., lack of food, side effects, and transportation problems/distance to the clinic. Our interviews identified other barriers experienced by restarters, including having no intention of stopping the ART, and desperation. For each case presented, how and what motivated the patient's return to ART care are also described.

3.3.1. Economic problems: nutritional challenges/lack of food

Among our key informants, four out of eleven restarted patients mentioned lack of food as the main reason for their treatment cessation, making it a major cause for ART interruption among this group.

The Ethiopian Demographic and Health Survey reported that 27% of women and 37% of men aged 15 to 49 years were either thin or undernourished (Central Statistical Agency [Ethiopia] & ICF International 2012). According to USAID Ethiopia (2008), 25% to 35% of those enrolled in HIV/AIDS services suffered from moderate to severe malnutrition. Furthermore, up to 75% of pregnant HIV-positive women enrolled in prevention of mother to child transmission programs were eligible for supplemental feeding programs (USAID Ethiopia 2008).

In our study, when asked if they received any kind of support, none of the informants mentioned that they received material support from family members. This may have been due to the living conditions of many of the participants. At least 10 out of 23 patients were originally from outside of Mäqälä and lived far from family and friends. Regardless of their families' knowledge of their HIV-positive status, being away from family and relatives made it difficult for them to receive material support from home.

Ethiopia experienced an unprecedented increase in food prices in July 2008. At the peak, food prices were 92% higher, on average, than 12 months previously. There was then a gradual reduction to a stable level, which was 15% lower than the peak in 2008 (Alem & Söderbom 2012:146). However, the prices of some cereals remained over 50% higher than the 2005 and 2009 averages (jm, kr & ha 2008; USAID Ethiopia 2008; kr & cb 2010). This surge in food prices directly affected the already vulnerable ART patients. The quotation below is from an ART restarter who begged for alms at a local church.

I was very ill. I was very anxious. Even if I was not getting food, the medicine was very helpful. I stopped the medicine because of a lack of food; I have no reason other than lack of food. I interrupted treatment for a month or two weeks. Then Sister [name of a case manager], when she learned that I had stopped taking it, came and advised me to continue. Still, I am weak, and if I do not have food I can hardly tolerate the drugs. When I got food the drugs worked, so I also became good [took the medicine], but if I did not get food the drugs would not stay long in my stomach and would just come back up. (Male, age 29, restarter, interrupted for 2 months)

While he was "lost", a case manager from the health center visited him and counseled him to resume therapy. The patient restarted, relying on food donations from a church where he solicited daily. When asked about interrupting the ART again, he said he would not stop this time because "[T]he [ART] drugs are life" (ibid).

Several local PLWH organizations provided nutritional support to PLWH (usually for six months, or 18 months for nursing mothers). Such nutritional support was critical for the retention of ART patients, especially those who lived in the most vulnerable conditions.

3.3.2. Side effects

Our study shows that three out of the ten restarted patients stopped ART due to side effects, making it the primary cause for treatment interruption. The nation-wide cohort study (FHAPCO 2009:43) reported that 44% of patients classified as 'lost-to-follow-up', became so within three to six months after starting ART. The same study also found that 17% of the 'lost-to-follow-up' patients interviewed discontinued therapy for fear of possible side effects (FHAPCO 2009:56). Below are the words from a male restarter:

When I first started taking the drugs I was very sick. The drugs weakened me very much. As a result, I became anxious, so after taking the drugs for some months I stopped. (Male, age 48, restarter, interrupted for 4 months)

This informant had a wife who was also categorized as 'lost-to-follow-up'. When he discontinued the ART, she encouraged him to resume the therapy. They lived outside the catchment area of the health center they attended, so no outreach worker came to trace them. The patient coincidentally met his ART nurse in Mäqälä where he worked. She counseled him to return to the health center. He soon restarted with a different regimen of ARV drugs.

3.3.3. Distance to the ART clinic

Among the 10 patients who were restarted, three were from K^wiḥa, located about 15 km from the health center. Patients could access care at K^wiḥa hospital, but chose to attend Mäqälä Health Center.

Among the three patients restarted from K^wiḥa, two were male and one was female, and of these, one of the males and the female were a married couple. Only the woman reported the distance and poor road conditions during the rainy season as the cause of her ART interruption.

...the distance is very long. During the dry season I could come but it was difficult during the rainy season... The medication did not cause any problems. I was bedridden; it [the ART] helped me to be healthy. The problem was the distance, especially when I started [to take ARVs] I felt weaker as I was walking for such a long time. (Female, age 40, restarter, interrupted for 8 months)

If a patient did not attend a scheduled appointment, a health worker either contacted them by telephone or sent a volunteer, a *qābāle* (kebele) oriented outreach worker (KOOOW), to the patient's house. According to three restarters from K^wiḥa, no one contacted them when they missed their appointments, since KOOOWs were deployed only in the catchment area of health centers.

3.3.4. No intention of stopping the ART

As previously described, informants enjoyed improved health status soon after initiating ART. A good indicator of their improved health was that they were able to obtain employment. Two patients inadvertently failed to adhere to the ART, as they chose temporary jobs that required them to be physically out of Māqālā. One patient did not know where she was assigned to work, and had been told that it would be near Māqālā. Initially she assumed she could return to get refills once she ran out of the ARVs; however, she later realized that a round-trip to Māqālā would cost her the equivalent of a month's salary.

I got a job somewhere else. I thought the place was near Māqālā like K^wiḥa. Actually it was ḂAlamaṭa, which is far away [about 178 kilometers] from Māqālā. I went to ḂAlamaṭa with drugs for two months. I worked for three months, and the drugs, which I took from here, ran out. I asked them if I could go to collect my medicine, but they did not give me permission. Then I decided to quit and come back here. (Female, age 30, restarter, interrupted for 4 months)

This case can be compared to another female patient who also interrupted her ART because she was not granted permission to leave work to obtain refills. In choosing between the ART and the job, the previous patient quit her job to return to Māqālā and resumed the ART (she knew the ART nurse personally and felt comfortable there). In contrast, this other patient obeyed the orders of the employer and stopped ART, causing her health to deteriorate until she was hospitalized.

3.3.5. Family problems and desperation

One female patient had a supportive HIV-negative husband. Her parents, unaware of her HIV-positive status, disapproved of the marriage and continuously interfered. Consequently, her husband left her and their two children, causing her to interrupt the ART.

I took the medicine secretly. I did not want to disclose my status. However, when I separated from my husband I found myself in a very difficult situation. I could not manage alone so I stopped treatment. I stopped it to work as a laundress in order to raise my children. My husband knew my status; he was supportive and caring. However, my parents were interfering in our lives and we separated. They did not like him and they wanted to split us up and so he left me. I have been in a very difficult situation for the last six months since he left. Thus, I stopped the treatment. (Female, age 23, restarter, interrupted for 2 months)

An outreach worker sent by the ART nurse convinced her to resume the ART.

Sister [name of the ART nurse] used to send someone to me [when the patient did not show up at

the appointment]. *She was the only one who supported me. She told me "If you want to raise your children and you want to be healthy, you have to restart treatment". Because of her I came back. Otherwise there was no one to help me. (Ibid.)*

During a follow-up visit seven months after this interview, the informant above was working at the health center where we interviewed her. She was employed as a facilitator of a mother support group, which raises awareness about HIV among pregnant women and supports pregnant HIV-positive mothers through discussions during a traditional Ethiopian coffee ceremony.

Among the 11 informants with a history of interruption and restarting ART, four informants resumed after being contacted and counseled by a health worker, three decided to restart ART by themselves, another three were advised by their families and relatives, and one restarted while hospitalized. The first author revisited all three study sites in April 2010, seven months after the interviews were conducted. A review of the patients' charts showed that all but one patient were adhering to ART.

4. LIMITATIONS

Two major limitations are present in this study. First, the PI's lack of language skills in Təgrəña may have contributed to the loss of subtle nuances and/or context. However, such loss was minimized by continually working with excellent translators and transcribers. Second, it was not possible to recruit and interview dropout patients because the patients left no contact details with the health center, they relocated without leaving any information, and/or they may have been deceased. Thus, we could not provide a comprehensive description of all the reasons for dropout.

5. CONCLUSION

This study explored barriers and facilitators to ART adherence from the perspective of patients in Mäqälä City, Təgray Regional State in Ethiopia. Our findings concur with previously articulated barriers and factors facilitating ART adherence from earlier studies, conducted in resource-limited settings, including Ethiopia. We also discovered new themes that contributed to identifying additional barriers and facilitators to ART adherence for patients in Mäqälä.

Decentralization of ART services from hospital-based and physician-led activity to health-center-based, and nurse-led services significantly improved access to care and the quality of life among ART patients. In urban settings, health-care providers were often the only ones who offered both clinical and emotional support to patients.

This study took place in urban/semi-urban settings; none of the study sites was a rural facility. Urban patients, if they could afford the extra time and cost of transportation, chose to go to a health center farther away to avoid being identified by their acquaintances. Relocation was also common in urban areas, where more people lived in rented houses. Research in rural areas could reveal the treatment-seeking behavior of ART patients in rural facilities, and enable detailed comparisons of aspects of ART treatment and care between urban and rural areas.

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NOTES

- (1) Holy water is water sanctified by Orthodox Christian priests, found on the premises of Ethiopian Orthodox Churches, and places associated with different saints. Holy water (*may cālot* in Təgrəña, or *ṣābāl* in Amarəña) is believed to ward off evil spirits.
- (2) Traditionally, it is believed that supernatural power can be a cause, as well as a treatment of disease. Therefore, the use of prayer as a treatment for the supernatural power has been commonly practiced in Ethiopia for centuries. For example, Ethiopian Orthodox clergies, called *dābtāra*, use holy water to treat persons thought to be possessed by evil spirits.
- (3) According to Ethiopian Orthodox Christianity, Wednesday and Friday are fasting days, so devotees do not eat until mass ends at midday. Therefore, some ART patients are hesitant to take the morning dose of ARVs while fasting. On fasting days, they also abstain from meat and milk. Ethiopian Orthodox Christians may fast up to 180 days a year, including several fasting seasons prior to religious events.
- (4) The data collected in this study were used to complete the requirements for the first author to obtain a Master of Public Health degree from the University of Washington, Seattle, USA. The study was funded by a University of Washington Global Partnerships Travel Grant.
- (5) TPLF was formed in 1975 to wage guerrilla warfare against the military dictatorship in Ethiopia. The TPLF defeated the military regime and took over Ethiopia in 1991. At the height of the warfare in 1989, the TPLF had an estimated 80,000 full-time fighters, mostly peasants and farmers of the Təgray Region (personal communication). In this study, three patients identified themselves as ex-TPLF fighters.
- (6) One referral hospital, two general hospitals, and three health centers.

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