

# Barriers and facilitators of ART adherence in Hawassa town, Southern Ethiopia: A grounded theory approach

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## Abstract

**Background:** Antiretroviral therapy (ART) has the potential to significantly reduce the risk of HIV transmission and the spread of tuberculosis and improve quality of life. Patient's adherence is crucial to get the best out of ART. As ART is scaled up in Ethiopia, there is a need for better understanding of the factors that influence patients' adherence to ART and improve the service. This study aims to explore patients' and health care professionals' views about factors that facilitate and hinder adherence to ART among adult HIV patients.

**Methods:** A qualitative grounded theory study using non-participant observation; and in-depth interview with 23 ART users and 5 health professionals were carried out at two health facilities that serve a large number of HIV-positive individuals in Hawassa town, Southern Ethiopia. The study was conducted from February to April 2014. Simultaneous data collection and analysis was conducted and taped Notes were transcribed into Amharic then translated into English. The grounded theory approach was used for analyzing the data. The analysis began by using the constant comparison approach. The coding process was preceded by open coding, axial and selective coding. To manage the overall coding process, **Atlas.ti (v.7)** software was used.

**Results:** The commonest barriers to adherence-included poverty, substance misuse, forgetfulness and being busy, fear of stigma and discrimination, pill burden and medication side effects. The most frequently emerged facilitators to adherence included disclosure of HIV status, using an adherence aid, prospects of living longer, social support, experiencing better health and trusting health workers.

**Conclusion:** The study revealed a range of barriers to adherence including individual, medical, environmental and economic related factors. The findings from our study can be used to inform the development of effective interventions that address the barriers and facilitators of ART adherence in Ethiopia. Priority should be given to improving adherence by alleviating financial constraints to ART adherence, better access to treatment services, education and counseling to tackle culture related obstacles, stigma and discrimination. [*Ethiop. J. Health Dev.* 2016;30(2):66-77]

**Keywords:** Grounded theory, ART, HIV/AIDS, qualitative research

## Background

The emergence of the human immunodeficiency virus (HIV) epidemic is one of the biggest public health challenges the world has ever seen in recent history (1, 2). In 2012, an estimated 35.3million people globally were living with HIV (3). The 2012 UNAIDS Global report stated that the number of people dying from AIDS-related causes began to decline in the mid-2000s because of scaled-up antiretroviral therapy and the steady decline in HIV incidence since the peak in 1997 (3, 4). The report also indicated that 9.7 million people in low- and middle-income countries were receiving antiretroviral therapy in 2012, an increase of 1.6 million over 2011(3). Declines in the annual number of AIDS-related deaths illustrate the powerful health benefits of scaled-up antiretroviral therapy (ART). ART not only prevents AIDS-related illness and death, it also has the potential significantly reduce the risk of HIV transmission and the spread of an opportunistic infection – tuberculosis (5).

Adherence is defined by WHO as “the extent to which a person's behavior- taking medication, following a diet, and or executing lifestyle changes, corresponds

with agreed recommendations from a health care provider” (6). Studies have indicated that at least 95% adherence to ART drug regimen is optimal, but adherence to treatment differs from compliance, which only refers to a client's behavior that conforms to medical orders (7, 8). Non-adherence to ART refers to failing to take the medication correctly, taking it inconsistently or in missing doses, factors which lead to increases in the frequency of opportunistic infections, faster progression of the disease and a substantial decline in health for HIV positive individuals (9). Non-adherence also reduces viral suppression, causing an increase in the risk of the viral strain quickly becoming drug resistant. Studies have found a strong statistical relationship between the failure to obtain scheduled pharmacy refills and a more rapid progression to AIDS (10, 11).In this case, treatment options become fewer as resistance to one drug will sometimes lead to resistance to other similar drugs in the same group leading to cross-resistance (9).

A qualitative study in Addis Ababa hospitals on pediatric patients reported several challenges to adhere for ART such as pill burden, stigma and discrimination

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and awareness, access and economic problems (12). Similarly, a systematic review showed that behavioral interventions, directly observed therapy and adherence reminders were found to be important interventions to improve adherence for ART (13).

According to the UNAIDS report, adult (15-49) HIV prevalence in Ethiopia is estimated 1.3% in 2012. Evidence shows that recent infection has decreased in the country and prevalence among young people has shown a remarkable decline over the last six years. Currently, an estimated number of 760,000 people live with HIV. Moreover, the estimated number of people needing ART stands at 400,000 for adults and approximately 14% of adults that are eligible for ART are not receiving ART (3, 14).

Since 2003, the Government of Ethiopia has launched and implemented an ART program through the federal health sector with the goal of improving the quality of life of HIV positive individuals (2). However, recent studies conducted in Ethiopia suggest that adherence is not optimal, with a rate of 88.1% (15), suggesting that the emergence of drug resistant strains of HIV is a real threat (16).

To date, there have been numerous studies in Ethiopia investigating and describing adherence rate. However, there is a lack of understanding regarding the barriers and facilitators to optimal ART adherence, and qualitative research may be best suited to explore these factors. Qualitative research is able to generate information from the respondent's perspective in order to develop culturally appropriate and effective interventions, which are, in turn, more likely to lead to successful and sustainable programs (17). The scope of this study was to examine and conceptualize barriers and facilitators to adherence among people undergoing ART through key informant interviews in Hawassa town, Ethiopia. We interviewed both patients and health professionals with the intent of using the findings to improve treatment programs of clients with HIV/AIDS. To the best of our knowledge, no reports of previous qualitative adult ART adherence studies in Hawassa have been published.

## Methods

**Approach:** In this study, a grounded theory study design was used. This approach is well suited to study human experiences by considering cultural diversity of the participant under study. It is relevant to generate concepts, model or a substantive theory, which is complete, coherent and sheds light on the area under study rather than testing hypotheses based on existing theory. Despite the fact that events are processed and interpreted through the eyes of both participant and researcher, the grounding of theory in data tend to make the data more reflective of practical situations than speculatively derived theory (18).

**Setting:** We conducted the study in health facilities providing ART services at one public hospital (Adare

Hospital) and one health center (Hawassa Millennium Health center) in Hawassa town. It is located about 275 kilometers south of the nation's capital and lies on the main road joining Ethiopia to Kenya. These two health facilities were chosen because they had already been providing ART for at least one year and had observed an increase in the number of ART users, relative to other health facilities in the region. The hospital launched its ART programme in 2006, while the health center started the programme in early 2012. At the time of the study, Adare Hospital had a total of 982 registered ART users and Hawassa Millennium Health center had a total of 91 registered ART users. The study was carried out from February to April 2014.

**Study participants:** We recruited a total of 28 informants from the two institutions; adult ART-prescribed patients and key informants, such as health professionals, who are involved in the process of ART counseling and care-giving. ART-prescribed patient's participants were eligible for the study if they were at least 18 years old, had been receiving ART in the study clinic for at least a month, and who provided study consent, and health professionals were eligible if they provided study consent. We chose to interview individuals from both groups for a number of reasons. ART-prescribed patients were chosen to better understand barriers and facilitators from the patient perspective.

Health professionals were chosen because of their involvement in counseling and treating people living with HIV and to provide a health care provider perspective. Purposive sampling and theoretical sampling strategies were used to recruit the participants. Purposive sampling was made to seek participants with a variety of ages, gender, duration of ART use and educational status as the study progressed in an attempt to obtain diverse perspectives. Intensity and criterion based purposive sampling was used to identify common themes that transcend a focused sample. Theoretical sampling was also used to provide further insights on the evolving understanding obtained during data analysis. Health professionals were identified with the assistance of the health facilities manager or senior health worker at the clinic. Initially, we interviewed health care providers to have an in-depth understanding of various concepts related to the study objectives.

Health professionals aware of patients' treatment histories, supplemented by checking of patients' medical records, helped to identify and recruit relevant adherent and non-adherent participants into the study. The selection process was simultaneous which is characterized by analyzing the data after the first data was gathered and then emerging concepts/categories were included which in turn leads to more data collection to understand the concepts/categories generated deeply. This process of data collection continued until it reached to the point of saturation (19). In this study, data saturation was obtained after 19

interviews; the final four interviews did not present any new information, rather they strengthened the core category of the theory.

**Data collection and analysis:** The data were collected using non-participant observation and semi structured in-depth interviews by the lead author. After giving consent, all interviews were conducted in Amharic language with each informant in a private room at the clinic. Each session lasted between 45 and 90 minutes.

The lead author concurrently gathered, managed and interpreted the data, and a grounded theory methodology was used. Data were analyzed as interviews were completed to identify emerging concepts and categories, and we sought to more deeply understand initial concept and categories in subsequent interviews. This process of data collection continued until it reached to the point of saturation (19). Accurate transcribing of audiotaped interviews were done and digital audio recordings of the interviews were transcribed verbatim in English by the lead author. The data was entered and analyzed using Atlas.ti (v.7) software, which helped to structure and manage the overall coding and analysis process.

The data analysis process was undertaken in three stages: open/initial, selective, and theoretical coding. In the open/initial coding process, the transcripts were inductively analyzed line by line, and several codes were developed to assess the data. Subsequently, the open codes were clustered into categories.

The lead author led the analysis for each transcript, until the core category emerged. Once the core category was generated, the sampling became selective, and sub-categories and their properties were developed using further data collection and a constant comparison of the data as a whole. In the theoretical phase of the analysis, the relationships between the core category and its sub-categories were determined and described. The processes were continued until no new properties emerged and theoretical saturation was reached. In accordance with the grounded theory method, memos were also written during the entire analytical process to record ideas about emerging categories and assumptions about their relationships (18).

**Rigor and Trustworthiness of the study:** Data were collected from different participants' perspective (subjected to triangulation). We also invited some participants once the data was analyzed to review the findings and ideas, which they think the investigator had presented a true picture from their perspective. In addition, the investigators developed an early familiarity with the culture of the selected health facilities in order to gain an adequate understanding of the organization and to establish a relationship of trust.

An audit trail was created throughout the data collection. Moreover, debriefing sessions with public health postgraduate students from different backgrounds were used to check the consistency between the analyzed data and the theory developed.

Rigor is attained through strict attention to detail, adhering to procedures and through consistency and accuracy throughout the research process (20), each of which the investigators was considered at all times. In this research, we did an explorative study and explained the core phenomena well. Moreover, at the end we left open the stage on the proposed theoretical explanation for further modification of the model.

**Ethical issues:** Ethical approval for the study was obtained from Ethical Review Committee of the College of Health Sciences, Jimma University. Permission was obtained from the facilities and verbal consent was obtained from all informants. The informed consent and interview procedures were conducted completely in a private setting or room. The informants were ensured that all data would be kept confidential by using codes to identify participants instead of names, medical record numbers, or any other personal identifiers. Informants were also clearly informed about their right to refuse to participate in the study or withdraw at any time during the interview session. Completed written and recorded information were kept in a secured place.

## **Results**

**Characteristics of the participants:** A total of 23 patients on ART and 5 health providers participated in the study. Majority of the patients were female, at primary level of education, less than three years since they knew their HIV status and took ART less than a year (Table 1 and 2).

Table 1: Characteristics of ART- prescribed patients involved in in-depth interview from health setup in Hawassa, February - April 2014 (N=23)

Characteristics of participants	Frequency
<b>Gender</b>	
Male	10
Female	13
<b>Age in years</b>	
35 years and below	15
Above 35 years old	8
<b>Educational level</b>	
Illiterate	3
Primary education (1-8 grade)	13
Secondary education (9-12)	6
Tertiary and above (college and above)	1
<b>Duration since knowing HIV test result</b>	
Less than 3 years	14
Above 3 years	9
<b>Length of time on ART treatment</b>	
Taking ART <12 months	12
Taking ART > 12 months	11

Table 2: Health professionals involved in in-depth interview from health setup in Hawassa, February - April 2014 (N=5)

Profession	Age in years	Level of education	Position	Experience with ART (year)
Health officer	38	Bsc	ART clinic focal person	3
Health officer	46	Bsc	ART clinic focal person	4
Clinical nurse	25	Diploma	ART nurse	3
Laboratory technician	29	Diploma	Adherence supporter	3
-	33	Certificates	Case manager	6

**Thematic areas:** The study identified several perceived barriers and facilitators to patient adherence to ART. The categories that emerged were classified into four themes: (I) individual patients' beliefs and behaviors related themes; (II) socioeconomic and cultural related themes; (III) healthcare provision and system related themes; (IV) drug related themes on barriers and facilitators of ART adherence.

#### Individual patients' beliefs and behaviors related themes

##### Barriers

Feeling better (drug holiday), substance-misuse (alcohol use), perception about ART, simply forgetting and being busy and having responsibilities of family work were reported as barriers to adherence.

##### Feeling better (drug holiday)

Patients and health professionals both mentioned that some patients would skip their dose when they were feeling better or their CD4 test result improved.

*"There is this patient in my neighborhood. She has stopped taking her medication after feeling well. She said that the drugs are too many to be taken every day in the morning and evening as if it is a rayer."* (Female patient, 34 years)

A 25 year-old female clinical nurse also agreed that lack of self-motivation to take the drug due to feeling better continuously results in low adherence. She said:

*"Some patients, after taking the ART drug for 6 to 12 months, their CD4 count improve and their health status get better and have no symptoms, they (ART users) assume as if they are cured and then they stop taking ART"*

##### Substance-misuse

Both health professionals and patients as why some patients were not adhering to their ART medications mentioned misuse of substance, especially alcohol use.

*"I used to drink alcohol until 9 to 10 pm, this condition seriously affected the schedule of my pills; hence forth, I was taking the pills irregularly. However currently I stopped taking alcohol and become very strict in taking my pills on time every day."* (Male, patient, 35 years)

##### Simply forgetting and being busy

Both patients and health professionals reported that most patients forgot their medication due to daily routine activities, being busy and away from home, and having responsibilities of family work and social events like wedding and mourning events.

*"Unless I forgot my medication at home due to certain occasions, there is nothing that can prevent me from taking my medication. Yes, let me tell you what I faced once. I remembered, there was my friend's wedding and I was with my friends, that day I forget taking my medication with me and that was the only moment I have never taken medication in my life".* (Male, patient, 30 years)

### Having responsibilities of family work

A 30 years old female ART user also is closed of simply forgetting due to having responsibilities of the family.

*"...I remember I interrupted to take my pills for 3 days, it is because of my daughter having developed severe pain so at that time I should do everything to save my daughters' life even that day I did not worry about my life..."*

### Facilitators

Adherence aids, responsibilities related to family, experiencing better health, and prospects of living longer, and disclosure of HIV status were perceived as facilitators to ART adherence. Both patients and health professionals most frequently mentioned setting alarms on watches and mobile phones as a way to cope with their medication in different situations. In addition, ART patients also used TV or radio programs to remind them to take their pills. A mobile phone alarm is the most common adherence aid that many ART users often use to take their medications.

*"I always set an alarm on my mobile phone to take my pills on time and it helps me to remember the time of my medication even when I am busy ...."* (Male, patient, 29 years)

Both health professionals and several ART users that caring for family and having responsibility for looking after children was one of the most frequently mentioned facilitators of adherence also mentioned it.

*"...for example, when I see my daughter I weep internally all the time because I always dream the best future life for her and I am responsible. By taking my drugs regularly and on time I don't hesitate looking her until my death..."* (Male, patient, 57 years)

### Socio-economic and cultural related themes

HIV is still a sensitive social, economical and cultural issue in Ethiopia, and the findings of this study supported this by identifying the barriers and facilitators below.

### Barriers

Economic constraints, stigma and discrimination, barriers relating to religion and rituals, lack of emotional/psychological support and social events were reported as barriers to adherence.

### Economic constraints

Participants in this study reported that economic worries related to unemployment, food insecurity, charges for diagnosis and treatment and cost of transport problems were some of the economic-related difficulties they experienced in trying to adhere to the treatment regimen.

Individuals who were unemployed had difficulties in meeting their food needs and in facing challenges of getting to and from health care facilities which are often not in the immediate vicinity. The following quote from 68 year old unemployed male patient highlight the challenges he faced due to unemployment and not having money:

*"...because I am in a serious economic problem and nobody supports me, I am not getting my daily breakfast, lunch and dinner properly. If I had money, I would buy vegetables, fruits any other important food item, which increases my immunity against the disease and my body weight too. So being under poor economic condition is my major problem...."*

Similarly, 36 years old ART clinic health professional also spoke of the link between money and adherence:

*"..... sometimes they do not have food at all at home, so they do not take their drugs (ART) because they get hungry"*

### Stigma and discrimination

Despite the positive benefits of ART, throughout the interviews, both ART-prescribed patients and health professionals mentioned that most ART users were more likely to disclose their HIV status to people they live with, and were less likely to tell others, even their very close relatives such as parents, brothers, and sisters. Many of them reported that stigma and discrimination related to being HIV positive were still present in their communities and have a strong influence on how patients adherence, leading to patients hiding pills, occasional skipping of medications and failing to keep clinic appointments for drug refills or examinations.

A 35-year-old female described her fear of self and discrimination of her family by community members:

*"Other than my children, no one knows whether I am taking this medication or not and also I don't want others to know. I would like to go out confidential; without anyone staring and talking at me and my children's because our place is a talkative place which prevents our free movement in and out from home..."*

### Barriers relating to religion and rituals

People are pressured to be abided by their community's local and traditional religious and cultural rituals, which can influence adherence to ART. Religious rituals like fasting and holy water were found to influence medication adherence.

*"I don't take my drugs when I visit church for holy water and the like because I do not want to be seen by anyone because it is not allowed not only to take drug but also to drink water in the church. Due to this reason, sometimes I postpone the time of taking my pills".* (Male, patient, 29 years)

**Facilitators**

Disclosure of HIV status, programs for income generation, and looking someone improved with ART were reported as facilitators of adherence. Despite being regarded by many as an important barrier to adherence, some informants identified self-disclosure of HIV status as a critical facilitator of ART adherence, usually linked to the support by ART users received from partners, children, parents, peers, and self-help groups. Most of the ART users reported that their children play critical and active role in reminding and encouraging taking their pills.

*“The drug schedule does not take my time because I take the drugs at night time. I take the drug exactly at 9 pm. If I forget to take the drug at 9 pm, my children remind me. I take bacterium tablets after lunch at 2pm. At all times my children help me through remembering the time to take the drug. They woke me up from bed so that I should not miss the right time. Hence, I am taking the drug seriously as it is for my survival and also so that my children don’t miss a parent since their father has died.” (Female, patient, 28 years)*

**Healthcare provision and system related themes**

Informants pointed to healthcare provision and issues related to the health system as factors that affected adherence.

**Barriers**

Poor clinic infrastructure and perceived stigma, fatigue of healthcare providers, long waiting times, and charges for diagnosis were all reported as barriers to adherence.

**Poor clinic infrastructure and perceive stigma**

Poor hospital ART clinic location and setup, such as clinics being located in front of the cafeteria, the unsatisfactory conditions of the ART room for counseling, and keeping patient confidentiality during clinical visits were perceived as major barriers to adherence. For example, examining patients, data clerk activity, counseling and consultations often took place in the same and open rooms in the presence of other patients and different health professionals. Many therefore found it difficult to speak openly, as they were worried that peers would judge or expose their current condition.

**Long waiting time at facility (card room)**

The time that the patients spends at the health care facility often leads to frustration and places an additional burden on those who have not disclosed their status to others.

**Charges for diagnosis**

All patients and health professionals involved in this study reported that all of the patients enrolled in the ART clinic receive their ARTs and some laboratory diagnoses (CD4 & CBC) free of charge, and were considered facilitators of ART adherence. However,

the additional ART related cost that a patient had to pay was described as a constraint to adherence and a major reason why some individuals do not come to the health facilities to fill their prescription, even when the treatment itself is free of charge, especially for many ART users who were poor, and unemployed.

*“... The other problem that occurs at this area is that patients need to bear the treatment for most of opportunistic infection treatments and diagnostic (laboratory) costs except for CBC and CD4 even if most of the patients have the problem of money.” (Female, ART clinic focal person, 46 years)*

**Facilitators**

Nutritional support, counseling and education, trusting health workers, and government policy of free ART treatment were mentioned as important for improving adherence. Both patients and health professionals mentioned the Food by Prescription (FBP) nutritional support as another key facilitator.

Most patients said that education and counseling they received about ART in the ART clinics, from an adherent supporter and case manager, motivated them to take the medication. From the observational finding and interview of patients reports suggest that adherence supporter, case managers and health care professional provided education, which focused on the importance of adherence, strategies to improve adherence, consequences of non-adherence, possible side effects of the medications, and the duration of treatment required in a comfortable manner for a patients.

*“Since our government provides us the drug for free, we have no more cost other than some transport cost. This encourages us to take the drug consistently. We should not need to have an appointment or some other advice to take the drugs.” (Male, patient, 35 years)*

**Drug related theme**

Pill burden and side effects of the drug were the major reasons for patients to be non-adherent; while the consistent and contrasting themes experiencing self-improvement of health-facilitated adherence

**Barriers**

Pill burden (duration of the treatment, frequency of dosing), size of the drugs and side effects of the drugs were reported as barriers to adherence.

Most ART-prescribed patients mentioned pill burden as a major challenge of adhering to treatment and in addition to ART drugs, some patients were also taking tuberculosis drugs and co-trimoxazole for PCP prophylaxis as well as other drugs for other illnesses. Side effects were experienced by almost all of the participants, primarily when initiating ART treatment or upon initiation of concomitant treatment. Among side effects, patients mentioned were blurred vision, itching of the skin, generalized body weakness, body shape disturbance, poor appetite, nausea, burning of

the stomach, headache, bad dreams, rash and vomiting. The following response from 57-year-old married man indicated the overall difficulties that ART users face including pill burden, side effects of the drugs, and the size of the drugs:

*“..... for me as you see “it creates depressions over the face”, for others too “it changes the shape of the users that is fat body above and thin body below the loin forming two different shapes within an individual..”.....moreover, related to the size of the drug, you see this drug which I took it now is too large which fills mouth &even difficult to pass through esophagus unless you take it with adequate water. This is one of the reasons why we can’t able to go anywhere by having it much drug at a time”.*

### **Facilitators**

Experience of direct observation of improved health among ART users, experiencing self- improvement of health on ART and having a simple regimen were frequently reported as important for improving adherence. Most ART users were very optimistic about ART efficacy, fear of negative consequences of non-adherence, experiencing improved health while on ART, and observation of improved health among other ART patients as motivators for adherence. Both patients and health professionals reported ART increased body-weight and appetite, reduced opportunistic infections, and improved quality of life.

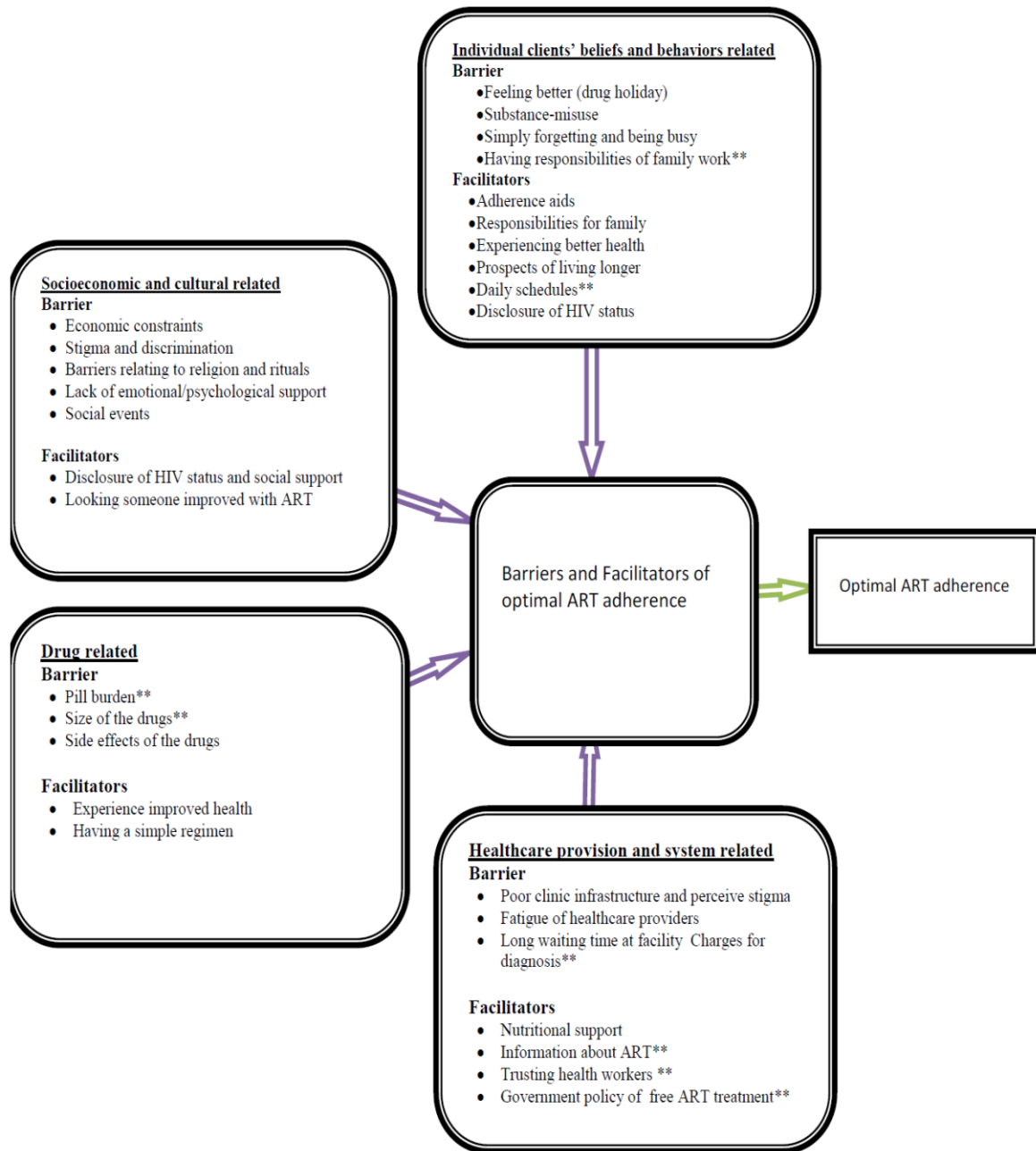
*“..... taking the medications have helped us a lot even it increase our CD4, for example I can see for myself: when I started the treatment my CD4 was 246 but after I took the treatment for 3 month my CD4 increased around 400 and not only that but also I am not exposed for any disease still now, so this one is also best evidence about the effectiveness of the drugs. I believe that the treatment helps because in some way I am seeing the results.” (Male, patient, 35 years)*

A 25 years old female clinical nurse also said:

*“..... yes for example most of our patient were coming after they develop opportunistic infections(OIs) because most of the patient check their HIV status after they observe and develop some sign and symptoms of the disease there are only some patients who are coming to check their results voluntarily. After they take the drugs, they see improvement of health after treatment of OIs and progressive increments of CD4 counts which makes them to develop trust on the drugs and adhere well”.*

Furthermore, both patients and health professionals explained that the fear of returning to a poor physical state or, even worse, death, strongly motivated them to adherence.

Finally, a framework was developed based on the analysis procedures of the study as presented in the following figure (Figure 1).



N.B. Those asterisk (\*) under the barrier and facilitators categories indicates the categories are only mentioned by clients and the rest all indicates the report of both clients and health care provider.

Figure 1. Theoretical framework of Barriers and Facilitators to ART adherence developed from the study

**Discussion**

The study identified barriers and facilitators, which were diverse in nature, with a wide spectrum of factors related to individual patients' beliefs and behaviors attributed to socioeconomic and cultural, the health services and treatment related issues. We identified that using an adherence aid, prospects of living longer, disclosure of HIV status, social support, experiencing better health and trusting health workers were the most frequently cited facilitators. In addition, economic constraints, substance misuse, simply forgetting and being busy, fear of stigma and discrimination, pill burden and medication side effects were the most frequent cited barriers. The study results are similar to

other qualitative studies in developing countries (21) and findings reported in other regions of Ethiopia (22-24) and elsewhere in resource-limited settings (25-27).

The major individual patients' beliefs and behaviors constraints that negatively affected adherence were substance misuse, especially alcohol use. Both patients and health professionals mentioned a direct link between alcohol abuse and non-adherence because alcohol drinkers often "ignore" or "forget" their medications. Some patients also believed that drinking alcohol and taking ART together was harmful, and decided to "skip the pills". Results of this study revealed that alcohol use increased non-adherence, and



similar findings have been reported elsewhere (26, 28, 29), while one study showed that not using substances increased adherence (30).

Socio-economic constraints, such as unemployment and food insecurity, were major limitations that negatively affected medication adherence and remaining in care. Although ART is free in a number of countries in the region, treatment-related expenses still hinder patients' access to treatment (31, 32). The findings of this study are in concordance with those from other studies, which have found that lack of food due to economic constraints is a common obstacle to patients taking their treatment (33-35). Lack of food was mentioned by both patients and health professionals as a cause of non-adherence, and has been identified in other studies as a factor responsible for treatment default (36, 37).

Socio-cultural factors, such as stigma and discrimination and religious rituals, also had undesirable effects on medication adherence and remaining in care. Informants articulated that stigma and discrimination was still widespread, from families of patients as well as communities. Some participants did not take medicine in front of people they knew due to fear of being identified as HIV-positive, similar to other studies (38), while other studies conclude that patients seek treatment at health facilities far away from home to hide their HIV status (39). Interventions targeting communities to improve social awareness in the public including information provision, skill building, counseling and facilitating interaction between people with HIV/AIDS and the community, have the potential to reduce stigma and improve ART adherence (40, 41).

Other barriers to adherence included local cultural factors, especially religious activities; patients miss or delay medications to fulfill religious obligations. One study conducted in Ethiopia also found that seeking traditional treatment to be the most important reason for patients being lost to follow-up care (42). The findings of this study reinforce the importance of considering religious and spiritual beliefs of HIV positive individuals as part of medical care.

This study revealed that poor clinical infrastructure with insufficient facilities for conducting confidential consultations prevented patients from communicating openly with health care providers. Insufficient counseling could facilitate misunderstandings about taking ART, leading to lower adherence. Confidentiality at treatment centers, particularly at card rooms, was another issue that emerged from the study. Studies from Botswana and Senegal have suggested that HIV patients tended to reduce clinical visits because of the risk of being seen by others and potentially having their HIV status exposed (43, 44). This illustrates the importance of bearing in mind confidentiality and issues of stigma and creating infrastructure that is more agreeable to patient

confidentiality, which is an imperative consideration when the provision of ART is being scaled up.

Medication side effect symptoms are frequent in people treated with ART and are of the most important biological elements associated with non-adherence (45, 46). Almost all of the informants reported that side effects contributed in a significant way as to how they managed their regimen. ART medication is associated with adverse side effects ranging from mild to severe, and it is crucial for medical practitioners to manage these symptoms (46, 47). However, as it has been seen in the discussion on the complexity of treatment, taking extra medication to counter the side effects may add to the pill burden for the HIV positive individuals. This is supported by research where it was found that those who were put on mono-therapy instead of dual or triple therapy showed better adherence outcomes (47).

In Hawassa, HIV positive individuals may be in particular need of ART adherence interventions that address strategies to improve adherence through the patient-provider relationship and improved strategies to incorporate ART pill taking regimens into a busy urban lifestyle where individuals may feel stigmatized by their HIV positive status. One effective strategy that may address these factors in an environment such as Hawassa, Ethiopia may involve the use of electronic devices, like mobile phones and alarms. Mobile phones have been successfully used to support patient medication adherence in developed countries (48) and in resource-constrained settings such as Uganda (49), Kenya (50, 51) and South Africa (52). Mobile phones might be an ideal tool to improve ART adherences for HIV patients in Hawassa because they can be private, interactive, efficient, affordable, convenient, and useful as a reminder tool.

A remarkable finding in this study was that patients' feeling of improved health and disclosure of HIV status could be a barrier as well as a facilitator to adherence. Patients and health professionals mentioned that patients were motivated to continue taking their medications when they began to feel better after initiating ART. On the other hand, some patients discontinued taking their medication when they felt better. Improvement of subjective health has to be understood in the context of patients' beliefs about the treatment, as some patients believed they were healed and therefore did not understand why they should continue taking their medication. Earlier studies also reported that feeling better could act as a barrier or as a facilitator to adherence (53). Adherence counseling is commonly offered to patients at the start of ART; however, these findings indicated that the stage of treatment when patients are starting to feel better could be a critical turning point with regard to adherence. Thus, counseling activities that specifically target patients during this treatment phase may be worth considering.

The finding of this study is based on interviews with 28 informants, and is limited to one geographical area. The results of this study reflect diversity in views and experiences; we also triangulated data sources and subject in order to strengthen the validity of our results, although we are unable to determine to what extent different factors are important barriers or facilitators in other contexts. Another limitation of this study is that the research did not include patients who did not seek help at the clinics. Despite these limitations, these findings offer an understanding of the complexity and dynamics of the different factors that may influence ART adherence.

### Conclusions:

The study revealed a range of barriers to adherence: economic constraints, substance misuse, simply forgetting and being busy, fear of stigma and discrimination, pill burden and medication side effects. Experiencing better health, adherence aid, prospects of living longer, disclosure of HIV status, social support, and trusting health workers were the most common reported facilitators. The findings of this study can be used to inform the development of effective interventions that address the barriers and facilitators of ART adherence in Ethiopia. Priority should be given to improving adherence by alleviating financial constraints to ART adherence, better access to treatment services, education and counseling to manage religious and ritual obstacles, stigma and discrimination. In addition, health professionals should explain side effects of drugs and how to manage them. Reshuffling the rooms to make the ART room more private, devise mechanisms by the service providers and develop mechanisms to shorten long waiting hours. The role of Health Extension Workers related to ART adherence and quality of health service on adherence can be further area of investigation.

### Competing interests

We the authors declare that we have no competing interests.

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