

UDS International Journal of Development [UDSIJD] Special Issue, Volume 10 No. 1, 2023 https://www.udsiid.org

# PERCEIVED DETERMINANTS OF ADHERENCE TO ANTIRETROVIRAL DRUG THERAPY AMONG PERSONS LIVING WITH HIV IN HEALTH FACILITIES IN THE UPPER EAST REGION: AN EXPLORATORY STUDY

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### Abstract

Several people living with HIV (PLHIV) currently receiving antiretroviral therapy (ART) do not commence early treatment. This has failed viral suppression and led to excess mortality. It is therefore relevant to explore perceived factors of ART adherence among HIV clients in the Upper East Region. Ten in-depth interviews and three focus group discussions were held with thirty HIV clients on ART and seven key informant interviews were held with ART nurses, pharmacist and data managers. Qualitative interviews were recorded, transcribed and analyzed thematically using Nvivo version 11. Most PLHIV adhered to ART treatment and adherence inhibitors were side effects of ART, lack of National Health Insurance, lack of nutritional support, stigma and discrimination against PLHIV, poor attitudes of health staff, non-disclosure of HIV status, inadequate family support, economic problems, lack of confidentiality and queuing up for ART. Promoters of adherence were nutritional support, reminder aids, effective counselling, improved health status and a desire to have children as well as stigma-reduction policies. Policymakers and health promoters should reemphasize the strengths associated with adhering to ART. Policymakers and donors should support PLHIV with food and health staff should be regularly refreshed on HIV case management.

Keywords: Adherence, Antiretroviral, Therapy, HIV, Clinic

## Introduction

Globally, HIV is still a public health challenge despite the introduction of antiretroviral therapy (ART). During the year 2018, about 38 million persons were living with HIV (PLHIV) and 35 million people perished due to AIDS (UNAIDS, 2018a). Evidence suggests that in 2017, about 22 million PLHIV were given ART (WHO, 2017) and 940, 000 people died due to the infection (UNAIDS, 2018a). In Africa, about 26 million people are infected with HIV (Addo et al., 2022; World Health Organization, 2012) and sub-Saharan Africa had the majority of the global cases; about 70% (Kharsany & Karim, 2016; WHO; UNAIDS; UNICEF, 2010). Even though there is considerable progress in expanding ART services, sub-Saharan Africa recorded the most AIDS-related deaths; seventy-four per cent of the 1.5 million deaths are associ-

ated with AIDS (Kharsany & Karim, 2016). HIV and AIDS negatively affect the physical, social and economic lives of people living with it, their families, communities and countries (King & Winchester, 2018; WHO, 2017). Although Ghana is a sub-Saharan African country with a relatively stable HIV epidemic, some evidence suggests that HIV is becoming a public health challenge (Chen et al., 2004). In 2017, about 310,000 Ghanaians were living with HIV (Ghana AIDS Commission, 2016). Ghana has an HIV prevalence of 1.7%, new HIV cases are 20,000 and 14,000 people have died from AIDS (UNAIDS, 2018b). Also, in 2016, the national HIV prevalence among pregnant women was 2.4%, the then Volta region recorded a prevalence of 1.7%, the prevalence for the then Brong Ahafo region was 2.7% and the Upper East Region had an HIV prevalence of 1.7% (Ghana

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AIDS Commission, 2016). Also, each year, 10,000 PLHIV in Ghana die because of AIDS-related complications (Ghana AIDS Commission, 2016; UNAIDS, 2013). Unprotected sex and homosexual intercourse are primary modes of transmission of HIV (Cauldbeck et al., 2009).

Currently, there is no cure for PLHIV and for that matter clients are managed with antiretroviral therapy (Mberi et al., 2015). The introduction of treatment interventions for managing AIDS-related issues to a large extent has reduced AIDS-related illnesses and deaths (Igumbor et al., 2011; UNAIDS, 2018a). Scaling up ART in most developing countries has averted 4.2 million deaths (Ghana Statistical Service (GSS), Ghana Health Service (GHS), 2018). Nonetheless, in developing countries, late initiation of ART among PLHIV has been reported (Bor et al., 2018; Clouse et al., 2013; Fox & Rosen, 2017; Haber et al., 2017). In 2017, only 22 million PLHIV were on ART. ART-related benefits will only be realized if clients comply with treatment (Loutfy et al., 2013; Mayanja et al., 2013).

Adherence refers to how PLHIVs take their medications as recommended by physicians (Osterberg & Blaschke, 2005). In sub-Saharan Africa, poor adherence affects HIV care. Components of poor adherence include missed or late doses, treatment disruption and stoppage, denial of care by caregivers and delayed diagnosis (UNAIDS, 2013; Yi et al., 2018). However, systematic reviews suggest that only two-thirds of eligible PLHIV commenced ART and utilization of ART services is lower among PLHIV(Bor et al., 2017, 2018; Mugglin et al., 2012). Between 95% and 100%, optimal adherence is required for viral suppression, attainment of outstanding antivirological response, and reducing morbidity and mortality among PLHIV (Cauldbeck et al., 2009; WHO, 2010). Nonetheless, this is difficult to attain among PLHIV who are on ART. If clients adhere to treatment, most of them will experience long-term viral load suppression (Loutfy et al., 2013; O'Connor et al., 2017).

In developing countries, several factors affect ART adherence among HIV clients. A systematic review disclosed that determinants of ART non-compliance were demandside factors such as improved health status, low social support and stigma and discrimination and gender norms. However, the supply-side factors were high healthcare costs, lack of confidentiality, poor-quality health services and inaccurate knowledge of treatment benefits (Ahmed et al., 2018). In Kenya, a mixed-method cross-sectional study among adolescents disclosed that the estimated level of adherence was 67% and the motives for missing ART included forgetfulness, long waiting time and stigma (Naomi, 2018). A qualitative study in Cameroon also showed predictors of adherence such as the family, environment, medication, health system and compliance with ART were described as serious punishment (Heestermans et al., 2019). Despite these previous studies conducted, poor adherence to ART is still common. This is therefore vital for up-to-date studies on factors influencing uptake of ART services among PLHIV.

In Ghana, the prevalence of ART adherence range from 34% to 75% (Adjei, 2019; Dako-Gyeke et al., 2016; Obirikorang et al., 2013; Yarney et al., n.d.). In 2014, 1,523 deaths were identified among PLHIV on ART and 143 PLHIV on ART stopped treatment because of the obnoxious effects of the ART. Again, 5,378 PLHIV were lost to follow-ups (Ghana AIDS Commission, 2016). This worrying situation affects the provision of ART services in Ghana including the Upper East Region. Moreover, although some related previous studies have been conducted to unearth predictors of treatment adherence among HIV clients in the Greater Accra Region (Dzansi et al., 2020), Upper West Region and Central Region of Ghana (Obirikorang et al., 2013), these studies were conducted in hospitals and not ART clinics. Again, there are limited qualitative studies on the level of adherence and its predictors.

This study, therefore, goes beyond previous studies to explore the level of adherence and its associated determinants in seven ART clinics in the Upper East Region.

#### Methodology

## Study Design and Settings

The research was a phenomenological qualitative study that involved PLHIV and ART nurses. The phenomenological strategy looked into the experiences of PLHIV on adherence to ART. Key informant, focus group discussion, and in-depth interviews were conducted in seven ART clinics in the Upper East Region of Ghana. The Region is located in the north-eastern corner of Ghana and has about 3% of the total land area of Ghana it has six major hospitals, twenty-six health centres and thirtysix clinics (Awoonor-Williams et al., 2013; Ghana Health Service, 2012).

#### Participants and Procedures

PLHIV who were on ART for more than six months and health professionals (ART pharmacists, nurses and data managers) working in the ART centres were the target group. The participants were purposively selected to participate in the interviews. The sample size for the entire study was identified through data saturation, so recruitment of participants ended when data saturation was attained. Forty-seven respondents participated in the study.

#### Data Collection

In-depth interviews and focus group discussions were

held with PLHIV while key informant interviews were held with pharmacists, data managers and nurses. The data collection tools were developed based on previous literature (Obirikorang et al., 2013; Shumba et al., 2013). The components of the guides were the nature of ART adherence, promoters and inhibitors of ART adherence. To ensure the reliability of the guides, we pre-tested the data collection tools among ten PLHIV. Some questions that were not clear after the pre-test were modified. Two data collectors interviewed study participants in English at places that were convenient to them. Generally, most interviews were done at ART clinics. FGDs and IDIs were done with PLHIV whilst KIIs were done with health workers working with ART clinics. The health staff were interviewed because of their vast experiences in managing PLHIV. Three FGDs were conducted with 30 PLHIV. In-depth interviews and key informant interviews were also done with 10 PLHIV and seven health workers, respectively. Generally, these interviews lasted between 30-45 minutes. Qualitative interviews with study participants were audio-recorded, and field notes were written.

### Ethical Considerations

Ethical principles were extensively applied in the conduct of the study. Before the conduct of the study, approval was obtained from the Ghana AIDS Commission and the Upper East Regional Health Directorate and informed consent was acquired from all respondents before interviewing them. Participants were informed about the usefulness of the study, what the study entails, the risks and benefits and voluntariness. Confidentiality, anonymity and privacy were guaranteed during the interviews and respondents were given some cakes of soap as compensation for their participation in the study.

#### Data Analysis

All the transcripts were critically read and later uploaded into NVivo version 10. The thematic analysis approaches used were 'coding of text 'line-by-line'; the development of 'descriptive themes'; and the generation of 'analytical themes '(Thomas & Harden, 2008). Textual data was then coded into themes and sub-themes (Jugder, 2016). FGDs, KIIs and IDIs were coded separately, but similar findings were integrated. Again, key findings were presented through representative quotes that were amended to enhance readability and understanding.

#### Results

#### **Demographic Characteristics**

In all, forty-seven (47) participants were interviewed. Forty (40) of them were PLHIV whilst seven (7) were health staff working in ART clinics. The majority (35) of PLHIV were females and the majority (31) of them were between the ages of 40-45 years. Again, six of the health workers were males, and the remaining one was female.

### Level of Adherence

Almost all respondents indicated that they complied with ART treatment and adherence was monitored through appointment dates and pill counts, home visits and regular attendance for medication. The majority of health workers affirmed this finding by disclosing that most PLHIV had high levels of adherence to treatment and adherence is monitored through pill counts, the date for a refill, physical assessment (temperature, weight and blood pressure) and assessment of the CD4 count as well as home visits if there is a default. The main quotes below illustrate these points well;

'Yeah, most of them adhere to treatment' (Nurse, Health Centre).

To a large extent, the majority of them adhere to ART treatment but some come two days late and end up dying at the facility (Data Manager, Male, 38 years).

'Most of us adhere to ART treatment. If we do not, we will end up with AIDS-related complications and die' (IDI participant, Female, 35 years).

'We monitor adherence through their appointment dates and the date for refill' (Data manager, ART Clinic).

However, a few health staff revealed that some PLHIV do not adhere to treatment and they do not have strategies to monitor adherence.

'No strategies in place to monitor adherence but in my way, I enquire of the number of tablets left since the last refill and I can deduce whether they are adhering or not' (Nurse, Female, 29 years).

"They don't adhere at all times but most of them are doing well but others have to be always counselled' (Pharmacist, Male, 50 years).

## Facilitators of ART Adherence

The majority of PLHIV mentioned the following as determinants of ART adherence; benefits associated with taking ART, positive attitude of health staff, effective adherence counselling, use of reminder aids, social support, and support from models of hope. Almost all participants mentioned the benefits associated with taking ART as the primary reason why they adhere to ART. Primary benefits include relieving one from opportunistic infections and making one healthier and stronger to be able to undertake hard work. Adherence to ART reduces viral load and makes it possible for PLHIV to get pregnant. Some participants in the study averred as follows; "I am now healthy because of the ARVs. Initially, I was seriously sick but now I am very healthy and able to work diligently" (Female IDI Participant).

Adherence to ART will reduce viral load and prevent one from other opportunistic infections; I feel strong and healthy when I take my drugs regularly (Male, Focus Group Discussion).

Years back, people died from HIV because of a lack of medication but now there is hope with ART (Female, Focus Group Discussion).

The varied views expressed by PLHIV were affirmed by health workers who were interviewed through key informant interviews.

Facilitators of ART adherence were motivated by improvement in health status, motivated by colleagues' improvement in health status (Male, In-depth Interview).

'They adhere because they don't want the condition to manifest on their physical appearance' (Nurse, 29 years, female).

'Clients come in a very bad state, and when they are put on ART, they look very healthy, and this facilitates adherence to treatment' (Health worker, Female, 32 years).

Most of them take the drugs because they yearn to reduce their viral loads and to get pregnant (Health worker, Female, 29 years).

### Effective Counselling by Health Staff

The majority of participants disclosed that they adhered to ART because the health staff do not discriminate against them, and so they are given effective adherence counselling. Some of these views are captured below;

"Counseling and linking clients to Models of Hope enabled me to take my medications with ease" (FGD Female Participant).

Just as some views expressed by participants were collaborated by health staff, the same way the views expressed by health staff collaborated by participants. Some health staff confirmed views expressed by the participants that:

Effective adherence counselling helps them a lot. Once they start taking the drugs and they see improvement in their health, they are motivated to continue taking the drugs' (Female, nurse, 32 years).

Both PLHIV and health workers admitted that most PLHIV used to adhere to ART back then because of the presence of food from non-governmental organizations such as the World Food Programme and World Vision.

Food and counselling made it easier for me to take my drugs' (Female, IDI)

National AIDS Control Programme and Catholic Relief Services are examples of organizations that made it easier for me to adhere' (Male, 42 years, FGD).

Most participants admitted that when they disclosed their status to trustworthy people who support them regularly, they are encouraged to take their drugs regularly, but when these people discriminate against them, they are demotivated. Models of hope have served as primary sources of motivation for PLHIV. Family members who are supportive help greatly to promote adherence to ART. Models of hope and family members often link them to treatment facilities and remind them to take their drugs.

An alarm of phones; one participant disclosed that to enable him to adhere to ART, she usually set the alarms on her phone, and as soon as it is time for her to take the drugs, the alarm will ring to alert her to take her drugs.

"Some of us set reminders/ alarms on our phones to remind us of the time to take our drugs" (Female IDI participant).

## Barriers to ART Adherence

Inhibitors of ART adherence were transportation challenges, stigma, and discrimination, lack of food, forgetfulness, spirituality, and side effects of the ART. Most participants complained that at times t is very cumbersome to obtain means of transport to visit the ART clinic for medication. Most participants living with HIV live in rural areas and have to travel from such areas to visit ART clinics. They complained that because they don't have any source of livelihood, they at times find it difficult to find money to pay for the travel cost to access the drugs.

If I don't get food to eat and means of transport to visit ART clinics, I find it difficult to adhere to treatment' (Male, IDI participant).

All health workers interviewed affirmed that most clients from remote areas find it difficult to access ART services because of transportation challenges.

Means of transport to ART clinics is a challenge' (Data Manager, Male).

Most of them now understand the need to adhere to treatment but sometimes default due to lack of transportation (Data Manager, Female, 39 years).

The majority of participants complained of family stigma and community stigma. They explained that stigma and discrimination from close relatives and community members make it cumbersome for them to take their drugs. When some family members and friends get to know your HIV status, they start shunning you, and you are not given the needed support to adhere to treatment. Other participants also complained that discordant couples do not disclose their HIV status to one another.

What makes it difficult for me are stigmatization and discrimination from some relatives and acquaintances (FGD Participant, Male).

Lack of family support due to stigma and discrimination (Data Manager, Male, Paga).

Lack of food; there were also complaints from both FGD and IDI participants that some clients lack food to take their medication. Without eating an adequately balanced diet, treatment adherence

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becomes a big issue.

"Ever since World Food Program stopped supporting us with food items, some PLHIV have not been able to feed themselves. Some have defaulted because of that" (FGD, Female Participant).

When I did not get food to eat, treatment adherence is challenging' (IDI, Male Participant).

Health staff working in the ART clinics confirmed that some clients are poor and find it difficult to get a balanced diet to adhere to treatment.

Some clients are not able to take their pills daily when they don't eat anything at that time (Data Manager, Female, 35 Years).

They always say they don't get food to eat before taking the drugs. When there is no food, ARVs cannot be taken on an empty stomach' (Pharmacist, Male, 45 Years)

When they don't get food to eat, adherence becomes a problem' (Data manager, Female, 39 years).

Mostly they complain that they don't get food to eat and others remarked that they travelled or went for a social activity like funerals, fell sick or was busy that explains why they didn't come to pick up their drugs' (Nurse, Male, 40 Years).

Some participants mentioned that due to illiteracy, some clients forget to take their drugs.

'Some forget to take their drugs according to the dosage given by the ART nurse' (Nurse, Male, 42 years).

Clients' adherence to treatment is good in the early years of treatment, but when they get well, they resort to other means like herbal treatment and prayer camps (Data manager, Male, ART Clinic).

All participants complained of the side effects of the drug, making it difficult to adhere to treatment. When clients are initially put on ARVs, they experience a lot of negative effects such as nightmares, rashes, and nausea, among others.

"I had nightmares, nausea, rashes, and itches when I started taking the ARVs. I stopped taking the drugs for a while" (IDI, Female Participant).

"The big size of the ART makes it difficult for me to take it regularly" (IDI, Female, 39 years).

'Some clients don't adhere to treatment because of the smell or scent of ARVs, the large size of ARVs, fed-up with constant consumption of ARVs and improved health condition/status'(Nurse, Male, 46 years).

All health workers interviewed affirmed these views expressed by participants.

Due to side effects, some of them are compelled to stop the ART treatment' (Nurse, Female, 32 years).

The side effects of the ART sometimes make them skip some of the days' (Nurse, Female, 29 years).

'Some of them are fed-up with taking drugs due to constant consumption of drugs' (Data manager, Male, Pagga).

#### Discussion

The study discovered that PLHIV had higher levels of adherence. Earlier evidence has affirmed that, generally, PLHIV has higher levels of adherence (Heestermans et al., 2019; Reda & Biadgilign, 2012). Nonetheless, a recent study in Accra revealed that compliance with ART was low (45%) (Addo et al., 2022).

The study showed that promoters of ART adherence include improvement in health status, reminder aids, effective counselling, nutritional support, and a desire to get pregnant and policies on stigma and discrimination. A systematic review that revealed similar information suggested that promoters of adherence counselling interventions, and memory aids (Heestermans et al., 2019), but inhibitors of non-adherence to ART were gender, intake of alcohol and herbal medicine, discontentedness with the health system, discrimination and stigmatization, and inadequate social support (Heestermans et al., 2019; Reda & Biadgilign, 2012). Another study among 397 PLHIV disclosed that clients who developed side effects and received reminders were more likely to adhere to treatment (Addo et al., 2022).

Challenges associated with adherence to the use of ART were side effects of the medication, poor social support and nutritional support, failure to secure a health insurance card, challenges associated with transportation, economic hardships, inadequate confidentiality at ART clinics, negative attitudes toward health staff, long waiting times at health facilities, stigma-related issues and non-disclosure of HIV status. Earlier studies have also identified medication side effects as one of the reasons why clients do not comply with ART (Legesse & Reta, 2019). In Nigeria and Tanzania, stigma and discrimination have also been reported as factors for poor adherence (Afolabi et al., 2009; Lyimo et al., 2012). Also, studies conducted in Botswana and Togo have affirmed that the intake of alcohol negatively affects clients' compliance with treatment (Do et al., 2010; Yaya et al., 2014). Again, similar findings have affirmed that non-disclosure of HIV status has serious implications on clients' compliance with treatment (Legesse & Reta, 2019; Prah et al., 2018; Yaya et al., 2014). It is pertinent for interventions to be put in place to address these challenges because poor adherence is associated with increased hospitalization rates and mortality among PLHIV in developing settings (Yakubu et al., 2019).

## **Conclusions and Recommendations**

The study showed that compliance with ART was high among HIV clients. Facilitators to ART adherence were improved health status, nutritional support, reminder

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aids, stigma-reduction policies and a desire to have a child. Even so, perceived barriers to adherence were poor nutritional support, side effects of the medication, inadequate family support, lack of health insurance, transportation challenges, negative attitudes of health personnel and issues with confidentiality. We, therefore, recommend that effective counselling techniques should be provided to clients at all times, funding agencies such as the World Food Program should support vulnerable HIV clients with food, stigma-reduction policies, and regular training programmes for health staff on HIV cases management will promote compliance with ART drugs. If all these interventions are implemented, Ghana will attain its objective of having zero deaths among PLHIV by 2030.

#### Acknowledgement

The main author was a former Technical Coordinator incharge of the Upper East Region. The authors wish to thank the Director General of the Ghana AIDS Commission, Dr Kyeremeh Atuahene and other officials including Mr Cosmos Owusu-Adjei, Mr Opoku Twumasi Samuel for their technical and financial support. We also wish to acknowledge the Upper East Regional Director of Health Services, the Regional HIV Coordinator, Health Workers and Data Managers as well as PLHIV for their support during data collection.

### **Conflict of Interest**

The authors declare that there are no conflicts of interest.

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