

**“If I have nothing to eat, I get angry and push the pills bottle away from me”: a qualitative study of patient determinants of adherence to antiretroviral therapy in the Democratic Republic of Congo.**

Journal: AIDS Care

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## Abstract

The global response to the HIV/AIDS epidemic has improved access to antiretroviral therapy (ART) and has contributed to decreased HIV/AIDS morbidity and mortality in Sub-Saharan Africa. Patient adherence to ART is crucial to the success of HIV/AIDS treatment. However, little is known about the determinants of adherence to ART among people living with HIV/AIDS (PLWHA) in the Democratic Republic of Congo (DRC). This qualitative study used in-depth semi-structured patient interviews, a purposive sampling strategy and thematic analysis scheme to identify barriers and facilitators of adherence to ART in the DRC. We recruited three categories of participants from the Centre Hospitalier Monkole and the NGO ACS Amo Congo including participants on antiretroviral (ARV) treatment (n=19), on ARV re-treatment (n=13) and lost to follow up (n=6). Among 38 participants interviewed, 24 were female and the median age was 41 years. Food insecurity as a barrier to adherence emerged as a dominant theme across the three categories of participants. Other barriers included financial constraints, forgetfulness and fear of disclosure/stigma. Religious beliefs were both a barrier and facilitator to ART adherence. We found that food insecurity was a common and important barrier to ART adherence among patients in the DRC. Our findings suggest that food insecurity should be appropriately addressed and incorporated into antiretroviral treatment programs to ensure patient adherence and ultimately the long-term success of HIV treatment in the region.

**Keywords:** ART; adherence; food insecurity, AIDS, Democratic Republic of Congo

## **Introduction**

Access to antiretroviral therapy (ART) in Sub-Saharan Africa has improved considerably over the past several years and has contributed to decreased HIV/AIDS morbidity and mortality in the region (Brinkhof et al., 2009; Mills et al., 2011; UNAIDS 2012). However, in addition to treatment access, high and sustained patient adherence to ART is sine qua non for maximizing both its therapeutic and preventive benefits (Kalichman et al., 2010; Paterson et al., 2000).

Prior studies have documented a number of determinants of adherence to ART, ranging from economic and structural to socio-cultural factors, as well as factors such as the complexity of the regimen, side effects; forgetfulness and inadequate knowledge (Badahdah & Pedersen, 2011; Balcha et al., 2010; Curioso et al., 2010; Hardon et al., 2007; Mills et al., 2006; Mshana et al., 2006; Tsai & Bangsberg, 2011; Tuller et al., 2010; Wanyama et al., 2007). However, there are still important research gaps which need to be addressed.

Previous studies have not examined adherence to ART among patients with different treatment profiles; this approach might allow new insights into factors that constrain and facilitate ART adherence. In addition, there is a very limited literature on ART adherence in Democratic Republic of Congo (DRC) which remarkably restricts our understanding of factors associated with ART adherence, and renders studies on ART adherence in the DRC a research priority.

This qualitative study expands on the current available knowledge and address the above cited research gaps by exploring barriers and facilitators of adherence to ART in three different groups of participants including those on ART with no history of treatment interruption, on ART with history of treatment interruption and those lost to follow-up in the DRC's socio-cultural context.

## **Methods**

### ***Participants***

The study was conducted in Kinshasa, the DRC in March 2011. Participants were recruited from two health facilities, the Centre Hospitalier Monkole (CHM) and the NGO Actions Communautaires Sida/Avenir Meilleur pour les Orphelins (ACS/Amo-Congo) through a maximum variation, purposive sampling strategy (Bowers, House, & Owen, 2011). Our participants consisted of 1) participants who successfully completed at least 6 months of treatment since antiretroviral (ARV) treatment initiation, herein referred as participants **on ARV treatment**, 2) participants who were on ARV re-treatment after at least one month of ART interruption, referred to as participants **on ARV re-treatment**, and 3) participants who were **lost to follow-up**. We considered as lost to follow-up, participants who were unable to show up for antiretroviral refills for three consecutive months (90 days) after the date of the last medical appointment. To be eligible for inclusion in the study, participants had to be at least 18 years old, HIV positive, and belong to one of the aforementioned categories. Subjects were recruited when they attended the health centers for routine medical examination or when refilling their monthly ART prescription. Participants from the lost to follow-up group were recruited through phone calls made to mobile numbers that were available on their medical files. The research team conducted additional outreach to patients lost to follow-up who could not be reached through phone calls, using addresses from medical

files. Upon explaining the purpose of the study and assuring strict confidentiality, all participants provided written informed consent and completed a questionnaire on socio-demographic characteristics prior to conducting interviews. Participants were compensated for their time and transportation with an amount of 10 US dollars. This study was granted ethical approval from the Committee for Research on Human Subjects at Kyoto University and the Kinshasa School of Public Health Ethics Review Committee in the DRC.

### ***Data collection and analysis***

A literature review of ART adherence informed the development of a semi-structured interview guide. The interview guide was designed to explore topics related to participants' experiences, beliefs, behaviors, opinions, and knowledge about HIV/AIDS and ART. Probes were used to gain detailed insights and facilitate emergence of new themes. Specific questions explored reasons for medication interruption, cues to restart ART among participants on ARV re-treatment and reasons for dropping out and barriers to restarting ART among patients lost to follow-up. A preliminary insight of data were obtained through debriefing sessions conducted at the end of each interview to note the main emerging themes and to plan how to address those themes more effectively in subsequent interviews. Interviews lasted from 25 minutes to 1 hour and were conducted in French and Lingala, the most commonly used languages in Kinshasa.

Interviews were digitally recorded, then transcribed verbatim and translated into English. All the transcripts were reviewed for accuracy by comparing with the recordings. Field notes and data set transcripts constituted the final material for analysis. Data were manually analyzed using a thematic analysis approach. This approach involves getting familiarized with the data through an iterative process of reading the data set transcripts, generating initial codes, arranging codes into larger categories, drawing connections between codes and categories until generation of a saturated thematic map of the analysis (Braun & Clarke, 2006). The analytical process included a separate data analysis of participants on ARV treatment, re-treatment and lost to follow-up, allowing new insights into determinants of ART adherence across the three categories of participants. Initially, two investigators (PMM & TT) independently coded the transcripts and identified emerging themes relevant to the research question. Discrepancies in coding were discussed and resolved by consensus and codes were organized into larger categories. In the second phase, codes, and categories were revised and refined through regular meetings with an expert panel (MDF, MOK & MK). Quotes from the participants are provided in support of the themes we identified and are lightly edited for ease of reading. Efforts were made to not substantially alter the contents of the quotes.

## **Results**

### ***Description of study participants***

38 participants were interviewed, considering the sample size of 5 to 25 participants potentially needed to achieve thematic saturation from previous studies (Creswell, 2007). 19 participants (50%) were currently on ARV treatment, 13 (34%) on ARV re-treatment and 6 (16%) were lost to follow-up. The median age of participants was 41

years; most had completed primary education but were without standard employment and had a monthly income of less than 20 US dollars. Almost half reported having irregular meals (Table 1).

### ***Barriers to Adherence***

We found an overall similarity in the pattern of themes that emerged across the three categories of participants (Table 2).

#### *Food insecurity*

Food insecurity was the most common theme that emerged both as a day to day barrier to ART adherence among participants from ARV treatment and re-treatment group and as one of the principal reasons for ART interruption among participants from the ARV re-treatment and lost to follow-up group. Participants described two pathways through which food insecurity constrained adherence to ART: 1) experiencing increased ART side effects and 2) the belief that ART does not work or is harmful when taken without food. Several participants reported experiencing uncomfortable side effects when they took medication on an empty stomach. One participant said:

“It’s very tough to take the pills when there is nothing to eat. I made two weeks I was not taking the pills. When I took them without food I had stomach aches.”  
(41 year-old female on ARV treatment)

The belief that the medicines are not effective or harmful when taken on an empty stomach also affected adherence to ART:

“The only problem is just about eating. You need to eat for this treatment to work. If I have no food I don’t take pills. Like today I didn’t take my pills because I couldn’t eat.” (35 year-old female on ARV re-treatment)

“The medication can be good but can also be bad for the body if you take them without foods. Taking pills without eating can actually cause much damage in your body.” (63 year-old male lost to follow-up)

Food insecurity was a daily concern and a source of frustration for participants and their family members. As one participant stated:

“I really have financial problems; I don’t know what to do. Sometimes I am just fed up, mainly if I have nothing to eat, I get angry and push the pills bottle away from me.” (45 year-old female on treatment)

#### *Financial insecurity*

Another important theme that impacted adherence was financial insecurity. Participants expressed difficulty securing money for transportation to attend clinical visits or other medical related expenses such as medical tests or clinical examination fees. This resulted in some of them missing their medication refill appointments or temporarily interrupting their medication. Moreover, we noted that other medical related expenses constituted a barrier to restarting ART among patients lost to follow-up. Although both health facilities offered ART free of charge, participants still had to pay for other ancillary costs. For example, a 48 year-old male participant who interrupted ART after relocating in the hinterland of Congo explained his difficulties in restarting the

treatment when he came back to the city of Kinshasa:

“I was discouraged when I learned from somebody that there (meaning the health facility) they ask 25\$ for the CD4 test. I was really trying to figure out how to take contact with the health facility for restarting my treatment until when you contacted me.”(48 year-old male lost to follow-up)

Participants sometimes had to balance between allocating their very limited budget on either their medical expenses or on household needs such as paying for children's education or securing food for the household. One participant said:

“At a certain time I stopped taking my medication because I had many financial problems, I had to take care of children's education and moreover you need to eat when you take those pills.” (48 year-old male on ARV re-treatment)

### *Forgetfulness*

Forgetfulness was a common reason for skipping doses among participants from all the categories. In a few instances, forgetfulness resulted in taking more than the prescribed dose. One participant said:

“Sometimes, it happens that I forget that I have already taken my evening pills; in that case I will take another one just to be sure I don't miss. I notice that when I run out of pills before the next appointment for treatment refill and then I just remember that I took more than two doses the other day.” (44 year-old male on ARV treatment)

### *Fear of disclosure/stigma*

Participants often did not disclose their HIV status out of fear of rejection and gossip. Some participants pointed to stigma as a potential barrier to ART adherence; however, this did not affect adherence inasmuch as most of them used coping strategies such as taking pills secretly or faking the name of pills when asked. In contrast, a number of participants admitted to interrupting their medication out of fear of inadvertently disclosing their HIV status. One participant said:

“I was not here (meaning that she was not at home). I went to live at my grandparents' place; over there they were not aware of my disease, so I didn't want them to know” (28 year-old female on ARV re-treatment)

### *Religious and traditional beliefs*

Religious beliefs were both a barrier and a facilitator of ART adherence. The belief that one's disease was caused by witchcraft led a few participants from the ARV re-treatment and lost to follow-up groups to interrupt their medication and to use prayers and/or traditional medicines in search for potential cure. On the other hand, many participants sustained the belief that it is God who provided the knowledge to make ARVs; this mindset motivated them to keep adhering to the treatment.

“I am a Christian and a believer, I know that God exists but those medicines also were inspired by God. God is the one who gave inspiration to doctors to make those medicines for us.” (59 year-old male on ARV treatment)

“Those medicines just give you strength but God is the one who cures. Because it is God who gave you intelligence to find out medicines, so through medicines I can get cured; before putting the pills in your mouth you must have faith.” (37 year-old female on ARV re-treatment)

#### *Other barriers*

Other reported barriers included travel or migration, feeling hopeless, side effects, and the use of traditional medicines. Other participants reported delaying or skipping ART doses after alcohol consumption.

### **Discussion**

This is the first qualitative study to examine ART adherence correlates among HIV-positive people with different treatment experiences, and the first to examine adherence among HIV-infected adults in Kinshasa, DRC. We found that food insecurity was the most frequently reported barrier to ART adherence among our participants. Previous studies on ART adherence have identified food insecurity as a contributing factor of nonadherence to ART, but none of these prior studies examined barriers to ART adherence among participants with different treatment experiences (Hardon et al., 2007; Nagata et al., 2012; Sanjoko et al., 2008; Weiser et al., 2010). Our study purposively selected participants with different treatment profiles, namely participants who were on ARV treatment, re-treatment and lost to follow-up. Examining adherence barriers exclusively with participants on ARV may reveal only a partial picture of barriers to ART adherence; since this group represents participants who have so far managed to adhere to treatment so, barriers identified essentially reflect those that interfere with day-to-day ART adherence. Thus, knowledge on these two last patients groups is vital as poor adherence and ART interruption foster emergence of HIV drug resistance, which, besides affecting long-term effectiveness of ART at the individual level, raises serious public health implications with potential transmission of drug-resistant strains of HIV (Danel et al., 2009; Gupta et al., 2012; Lima et al., 2010; Luebbert et al., 2012).

Participants reported skipping ART doses in the absence of food; this held true for participants in the ARV treatment and re-treatment groups. In addition, participants in the ARV re-treatment and lost to follow-up groups identified food insecurity among the main reasons for their treatment interruption.

Food insecurity is associated with a number of adverse health behaviors. For instance, a previous study found increased risky sexual behaviors among food insecure women in Botswana and Swaziland (Weiser et al., 2007). Moreover, food insecurity was shown to be associated with unsuppressed viral load which may lead to treatment failure (Wang et al., 2011). These findings suggest that effective strategies to promote food access to patients on ART should be implemented in order to curtail the negative effects of food insecurity on ART adherence in the DRC. For example, nutritional support to food insecure patients was shown to improve both ART adherence and patient retention in care in Sub-Saharan Africa (Cantrell et al., 2008).

Additionally, addressing financial constraints is also critically important in improving adherence to ART. These results are in line with a recent study in Mozambique which showed that adherence to ART and patient retention in care

improved when patients were organized in small groups, and collected pills for all the members on a rotating basis to reduce the cost of transportation (Decroo et al., 2010).

We also found that stigma and fear of disclosure were barriers to ART adherence. Most participants kept their HIV status secret and revealed it only in a very restricted social network such as the immediate family. Although patients listed stigma and fear of disclosure as a barrier to ART adherence, this did not seem to decrease their actual adherence since many of them used strategies such as disguising or taking their medication secretly to avoid disclosure. However, such strategies were more difficult to sustain over long periods of time in an environment which they considered hostile for disclosure; for example when patients relocated to a relative's home, then resolved to interrupt medication to avoid unintentional disclosure.

We found that religious beliefs were both a barrier and facilitator of ART adherence. Previous studies have identified beliefs in spiritual healing and/or beliefs around the causes of HIV to impact negatively on ART adherence (Mshana et al., 2006; Roura et al., 2009; Wanyama et al., 2007). Participants who believed their disease was caused by witchcraft interrupted their medication to seek healing through prayers and/or traditional medicine. Conversely, some patients thought of ART as an expression of God's knowledge transmitted to care providers, and this was sufficient incentive for them to stick with medication. These findings fit with the social context of the DRC where religious and spiritual beliefs are essential components of people's lives (Maman et al., 2009). Addressing religious barriers in interventions designed to promote adherence to ART in such settings might help to improve patient retention in ART programs. Faith-based organizations can positively impact on ART adherence by promoting ARVs as a divine tool to fight HIV/AIDS.

Our study has some limitations. First, there might be a selection bias with participants lost to follow-up. A significant number of lost to follow-up were reported dead suggesting that those we recruited might represent a specific group of survivors with different views and experiences. Second, participants were all selected from private health facilities that supplied ARVs free of charge. It is possible that participants from the public health sector may offer another picture of barriers of adherence to ART, especially in settings where ARVs are not free. Lastly, although we believe that our results may be extended to similar settings; it is unclear to what extent they can be applied in different contexts in Sub-Saharan Africa.

However, this study is unique in that it captures diverse perspectives of determinants of adherence to ART from participants with different treatment profiles. In addition, we found that in response to the same adherence barrier, participants adopted different medication-taking behavioral trajectories namely the interruption or just skipping a daily dose of their medication. Furthermore, it would not have been possible to unveil the negative impact of religious beliefs, travel/migration, feeling hopeless, and traditional medicines on ART adherence if we examined adherence only with participants in the ARV treatment group.

## **Conclusion**

We found that food insecurity emerged as a common and an important barrier to ART adherence among patients in the DRC. HIV treatment and care programs should comprehensively address food insecurity in the context of other socio-cultural related



factors to ensure patient adherence to ART and ultimately long-term success of HIV treatment in the region.

### Acknowledgements

This study was sponsored by the Department of Global Health and Socio-epidemiology of the Kyoto University School of Public Health. We especially acknowledge and thank the participants of this study as well as the health personnel at the CH Monkole, Codec and ACS/Amo Congo for making this study possible. We extend our great appreciation to Dr Barthélemy Kamba, Dr Henri Mukumbi, Dr Léon Tshilolo, Dr Adolphe Ndarabu, Dr Baron Ngasia, Dr Aimé Mboyo, Dr Kayembe Patrick, Dr François Lepira, Dr Modeste Kiumbu, Dr Saman Zamani and Samy Mbikayi.

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**Table 1. Sample characteristics**

<b>Variable</b>	<b>N=38</b>	<b>%</b>
<b>Age in years (Median)</b>	41	
<b>Gender</b>		
Male	14	36.8
Female	24	63.2
<b>Marital status</b>		
Single, Separated	13	34.2
Married, Cohabiting	21	55.3
Widow/Widower	4	10.5
<b>Treatment category</b>		
On ARV treatment	19	50.0
On ARV re-treatment	13	35.2
Lost to follow-up	6	15.8
<b>Education level</b>		
None	2	5.3
Primary	8	21.1
Secondary	20	52.6
University	8	21.1
<b>Profession</b>		
with employment	13	34.2
without employment	25	65.8
<b>Monthly income</b>		
<20\$	17	44.7
20\$-100\$	17	44.7
>100\$	4	10.5
<b>Meal/day</b>		
Regular ( $\geq 2$ meals)	22	57.9
Irregular ( $\leq 1$ meal)	16	42.1

**Table 2. Summary of themes by treatment category**

Themes	Treatment category		
	On ARV treatment	On ARV re-treatment	Lost to follow-up
Food insecurity	√-	√-	√-
Financial insecurity	√-	√-	√-
Forgetfulness	√-	√-	√-
Fear of disclosure/stigma	√-	√-	√-
Religious beliefs	√+	√- /+	√-
Others:			
Travel/migration		√-	√-
Feeling hopeless		√-	√-
Side effects	√-	√-	√-
Alcohol	√-		√-
Traditional medicines		√-	√-

√ indicates in rank order the themes that emerged and affected ART adherence

- indicates a barrier of adherence to ART

+ indicates a facilitator of adherence to ART