

# Perceived Barriers to Accessing and Adhering to Antiretroviral Therapy by People Living with HIV/AIDS (PLWHAs) in Akwa Ibom State, Nigeria

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## Abstract

There have been various studies on barriers to accessing and adhering to Anti Retroviral Therapy by People with HIV/AIDS. This paper presents empirical data using questionnaire and interview on barriers to accessing ART by PLWHAs. The study was carried out in Akwa Ibom state Nigeria using a cross sectional survey design with questionnaire and in-depth interview. Five hundred and forty (540) respondents were drawn from twenty (20) support groups in the state. They were selected only on the basis of their willingness to participate in the study. Ten respondents who were not administered questionnaire to were interviewed. Findings suggest that side effects of the drugs appear to be a major barrier as 67.2 percent of the respondents attested to that. Also it was found that due to fear of stigmatization, some of the PLWHAs visit ART centres far from their place of residence and so distance and waiting period before one is attended to by health personnel became a barrier for them but not for others. We suggest the need for more enlightenment of the public to reduce stigmatization. Also health personnel should educate the PLWHAs more on how to manage the side effects. There is also need to sustain the progress made so far in reducing some of the barriers to accessing ART and one way of sustaining is by educating and organising on the job training for health personnel periodically.

**Keywords:** Barriers, Access, ART, Side effects, PLWHAs, Nigeria.

## Introduction

Since the first case of Human Immunodeficiency Virus (HIV) in 1986 in Nigeria, and 1989 in Akwa Ibom State, the virus has impacted negatively on the lives of many people irrespective of their sex, ethnicity, and socio-economic status. It has also increased the number of orphans and vulnerable children and thus, become an obstacle to development. Globally, the annual number of people newly infected with HIV continues to decline, although there is stark regional variations. In sub-Saharan Africa, where most of the people newly infected with HIV live, an estimated 1.9 million people became infected in 2010. Akwa Ibom State is rated second in terms of HIV/AIDS pandemic out of the 36 states in Nigeria and the Federal Capital Territory. According to Ante Natal Clinic sentinel surveys of 2003 to 2008, the HIV prevalence rate of Akwa Ibom State was 7.2 percent in 2003, 8.0 percent in 2005, and 9.7percent in 2008 (Federal Ministry of Health [FMOH], 2007). The 2010 National Sero-Sentinel Survey puts the prevalence rate of the pandemic in Akwa Ibom at 10.9 percent (FMOH, 2011). It has been posited by Modo, Modo and Enang (2011) that there may be some socio-cultural reason why HIV prevalence rate is high in Akwa Ibom state.

Efforts have been made by successive government to manage the spread of the virus. To this end government all over the world adopted a comprehensive response using a multi-sectoral approach which includes prevention and management strategies (WHO, 2009). Funds were invested into awareness and sensitization campaign to enlighten the populace in English and local languages about HIV, its prevention, care and treatment. To manage the virus, antiretroviral therapy (ART) was introduced as it has been postulated to be effective in decreasing viral load.

Though antiretroviral therapy is not a cure for HIV/AIDS, it greatly improves the health of people living with HIV (PLWHAs). Scholars have reported that adherence to ART is one of the major determinants of how PLWHAs will fare in future (Erah and Arute, 2008; Bangsberg, Ware and Simoni, 2006; Nwauche, Erhabor, Ejele and Akani, 2006; Wood et al 2000). Weidle et al (2002) in their study found that HIV/AIDS can be managed successfully with antiretroviral therapy if access and adherent to therapy is promoted earlier in the course of the patient's disease and finding solutions to reasons for discontinuing therapy.

Unfortunately, access and adherent to ART is still problematic as has been shown by various studies. Whereas findings by Duff, Kipp, Wild, Rubaale and Okech-Ojony (2010), Tuller et al (2010), Hardon et al. (2007), Mills et al. (2006), Mshana et al (2006), Mukherjee et al. 2006, Orrel (2005), and Weiser et al. (2003), blamed access on transportation difficulties, findings by Giuliano and Vella (2007), Crane et al. (2006), Makombe et al (2006), Mshana et al. (2006), Ivers, Kendrick and Doucette (2005), Kumarasamy et al. (2005) and Weiser et al. (2003) blamed it on economic reasons. Other factors found to be impeding access to ART

include adverse reaction to the ART drugs, attitude of the staff administering the drug, lack of information about ART and fear of stigma (Roura et al 2009; Posse & Baltussen, 2009; Grant et al , 2008; Posse et al 2008; Mshana, et al 2006; Kumarasamy et al, 2005).

Today, many countries around the world including Nigeria now provide antiretrovirals (ARVs) free of charge, eliminating the need to pay for them as a source of concern and anxiety for PLWHAs. However, the provision of free antiretroviral therapy has not resulted in 100% adherence in many countries (Zamberia, 2011; Skovdal, 2011; Kabore et al , 2010; Assefa , Van Damme, Mariam and Kloos, 2010). In Nigeria for example, the levels reported for studies conducted in Kano (Northern Nigeria), Niger Delta and Sagamu (Southern Nigeria) are 49.2% (Mukhtar-Yola et al., 2006), 80% (Nwauche et al., 2006), and >85% (Idigbe et al., 2005), respectively.

Chesney (2000) had earlier stated that in order to implement measures to improve adherence, it is first essential to identify the principal factors that contribute to the inability of patients to take or access their medication. In Nigeria various studies have reported barriers to access of ART. In a study in Benue state, Omenka (2010) found that the first and most significant factor that is likely to facilitate access is the physical availability and even distribution of treatment sites. Adeneye, Adewole, Musa et al. (2006) and Sangowana et al (2005) in their study in Lagos and Ibadan, Nigeria respectively found that finance and stigma where the major reason why PLWHAs do not utilise ARTs.

Based on literature, one can conclude that some of these factors are likely to influence access. They include distance to the ART site, conduciveness of the ART venue, cost of ART, waiting period before obtaining the ART, attitude of staff, adaptability to side effects of ART and availability of ART. Therefore the present study seeks to investigate PLWHA's perceived barriers to accessing ART in Akwa Ibom state Nigeria with a view to finding out which of the above variables are most likely to constitute barriers. In order to do this, the study sought answer to the following question: What are the perceived factors that impede access to ART in Akwa Ibom State?

## Methods

### *Sample and Procedure*

The study was carried out using a cross sectional survey design with questionnaire and in-depth interview. Five hundred and forty (540) respondents were drawn from twenty (20) support groups in the state. They were selected only on the basis of their willingness to participate in the study. Ten respondents who were not administered questionnaire to were interviewed. This was to enable us obtain qualitative data that will support the quantitative. Consent and ethical approval was obtained from the leaders of the support groups in writing before any of their members were approached. Respondents were given the questionnaires on meeting days of the support group. Care was taken to ensure that equal privilege was given to both male and female respondents.

### *Measures*

Seven items were used to measure respondents' perceived barriers to accessing antiretroviral therapy. These items are, Distance to the ART site, Conduciveness of the ART venue, Cost of ART, Waiting period before obtaining the ART, Attitude of staff, Adaptability to side effects of ART and Availability of ART.

## Findings

### Demographic characteristics of the respondents

Table 1. Demographic characteristics of respondents

Variables	Frequency	Percentages (%)
<b>Gender</b>		
Male	218	40.4
Female	322	59.6
<b>Age</b>		
Younger Respondents (<36years)	367	68
Older respondents (>36 years)	173	32
<b>Marital Status</b>		
Single	225	41.7
Married	240	44.4
Ever Married	75	13.9
<b>Level of Education</b>		
6 years or less of schooling	91	16.9
12-15 years of schooling	289	53.5
16 years or more of schooling	160	29.6
<b>Employment Status</b>		
Employed	318	58.9
Unemployed	222	41.1

More than half of the respondents (59.6%) were female. A slight majority (53.1%) of the respondents were urban dwellers. Marital status of the respondents reveal that less than half (44.4%) were married while about the same proportion (41.7%) were single; the rest (13.9%) are widowed, separated or divorced. Slightly more than half of the respondents (53.3%) have between twelve to fifteen years of schooling, while very few (16.9%) had only six years or less of schooling. The Table also revealed that more respondents (58.9%) were employed.

Table 2. Perceived barriers to assessing ART

Possible Barriers	Frequency	Percentage	P value
<b>Distance to ART Centre</b>			
Near	267	49.4	.796
Far	273	50.6	
<b>Conduciveness of ART venue</b>			
Conducive	336	62.2	.001
Not conducive	204	37.8	
<b>Payment for ART</b>			
Free	513	95	.001
Not Free	27	5	
<b>Waiting Period</b>			
Short wait	261	48.3	.439
Long wait	279	51.7	
<b>Attitude of staff at ART venue</b>			
Friendly	426	78.9	.001
Rude	114	21.1	
<b>Side Effect of ART</b>			
Bearable	177	32.8	.001
Unbearable	363	67.2	
<b>Availability of ART at the Centre</b>			
Always available	517	95.7	
Not available	23	4.3	.001

In Table 2 we present respondents views on possible barriers to accessing ART. Result shows that slightly more than half of the respondents (50.6%) travel far for the ART. More than half of the respondents (62.2%) were of the view that ART venues were quite conducive for them though a good number (37.8%) felt that the venues were not conducive. Majority of the respondents (95%) said that they do not pay for the ART. Also the Table shows that more respondents (51.7%) feel that they wait for too long at the ART centres before they are attended to. Pertaining to attitude of staff at the ART centres, more respondents (78.9%) were of the view that the staff attitude is friendly though an appreciable percentage (21.1%) felt the staff attitude can be said

to be rude. The side effects of the ART appear to be a barrier because more than half (67.2%) said that the side effects are quite unbearable. On the availability of ART, majority (95.7%) of the respondents said that the ART are readily available.

#### *Findings from interviews*

Some of the PLWHAs that were interviewed about the possible barriers to receiving ART had similar views as seen in Table 2. One female respondents (53years) when asked about the distance of the ART centre had this to say:

*"This place is far away from my house. My transport is about 400 Naira every time I come here but the medicine is free, we are not paying"*

However another female respondents (40years) noted that:

*"They give ART in the hospital in my town but I cant go there, so that is why I spend money on transport to come here"*

This then means that ART may be readily available at nearby centres but some PLWHAs may not want to go to nearby centres for fear of being recognised and its attendant stigmatization.

On the issue of waiting period before the ART is obtained, some respondents noted that they waiting period is long before one is attended to. A male respondent (47 years) puts it this way:

*"If you want to go home before 12 noon then you must come here by 6 am or even earlier. The crowd is usually much"*

However another male respondent (41years) said:

*"Where I go to, they attend to you in less than 30 minutes. It is those that go to the Teaching Hospital that spend a whole day there"*

However it was discovered that many them prefer the Teaching Hospital because of the anonymity there. This then makes for long waiting period.

The side-effect of the ART drug were also addressed by the PLWHAs. Among those interviewed about 8 of them complained about the side effects. One of the female respondents (52 years) had this to say:

*"The side effect of the drug is too much. For me the one that I don't like most is that it gives me lizard skin. If not that one is looking for life, I will stop taking it. I now wear long sleeve clothes, long skirts and trousers always".*

While a male respondent (48years) said:

*"Because I know I don't have a choice, I am managing the side effect, like dizziness and spitting like a pregnant woman, I now carry handkerchief everywhere".*

In all, it does appear as if the major barrier is the side effects of the ART drugs.

## **Discussion**

Studies on barriers to access and adherent to ART, have found that finance, distance to ART centres, side effect of drugs, attitude of health care personnel are all potential barriers (Duff, Kipp, Wild, Rubaale and Okech-Ojony, 2010; Tuller et al, 2010; Roura et al, 2009; Posse and Baltussen, 2009; Giuliano and Vella, 2007). In the present study, the striking finding that could impede adherent to ART in Akwa Ibom state was the side effects of the ART. More than half (67%) of the respondents described the side effects as unbearable. Some of the respondents interviewed also agreed that the ART had side effects. This findings is in agreement with that of many scholars who have also reported that the side effect of ART can constitute a barrier to adherence (Joglekar et al, 2011; Weiser et al, 2010; Curioso , Kepka , Cabello, Segura and Kurth, 2010; Sanjobo, Frich and Fretheim, 2008; Melchior, Nemes, Alencar and Buchalla, 2007; Malta, Petersen, Clair, Freitas and Bastos, 2005; Remien, Hirky, Johnson, Weinhardt, Whittier and Le, 2003).

In order to help PLWHA to overcome these side effect and maintain adherence it may be necessary according to Malta, Petersen, Clair, Freitas and Bastos (2005) for health care personnel to explain to them the side effects of the treatment and the measures to be taken when these occur before they start having them. This may help PLWHAs to take these side effects in their strides as some of them appear to be doing in the present study where someone reported that she now wears trousers and long sleeves clothes and another respondents said he has developed the habit of moving about with handkerchiefs to help check nausea. Also Weiser et al (2010) found that there appears to be a relationship between food intake and side effect of ART. This is because many participants in Weiser et all (2010) study reported that taking the ARV medication without sufficient food exacerbated medication side effects. Health care personnel, counsellors and social workers can also offer advice to PLWHAs on the need to eat sufficiently before taking ART.

In this study, an appreciable number of the respondents (51% ) reported that distance to the ART centre is a potential barriers to accessing and adhering to the ART regimen. Although one can assume that distance means that cost of transportation will be high, however, findings from the interviews seem to suggest that PLWHA who spend money on transportation are those that do not want to go the centres that are near their place of residence for fear of stigmatization. This is perhaps a reflection of the level of stigmatisation that still exist on the issues of HIV/AIDS in Akwa Ibom state. Therefore there is need for sustained efforts towards

enlightenment and programmes that are aimed at reducing and eradicating the stigma attached to HIV/AIDS.

Related to this is the issue of long waiting period at the ART centres. Half of the respondents (51%) in the study said that they have to wait for a long period before collecting the ART. This findings agrees with that of Joglekar et al (2011), Muchedzi et al (2010), Posse and Baltussen (2009) and Hardon, et al (2007) who found long waiting time to be a barrier to accessing and adhering to ART. However it should be noted that about half (49%) said that the waiting period was short. This may be attributed to the fact that many PLWHAs do not like to visit the ART closer to their homes for fear of stigmatization as reported by one of the respondents who was interviewed. Although this finding is contrary to that of Tuller et al (2010) who found that some PLWHAs wanted ART centres to be closer to their homes so as to save transport cost, however, it does appear that in the present study the issue of stigma and discrimination are making PLWHAs to go to facilities that are farther away from their homes. This being the case, when they all congregate at the ART centres that are in the urban centres (Teaching Hospitals) where anonymity is likely to be achieved, the problem of long waiting period before one can receive the ART arises.

What this points to is that availability of ART has not reduced the stigma as opined by WHO (2009) though findings by Zuch and Lurie (2012) in a study in South Africa seem to suggest that the trend will soon change. In their study, Adeokun, Okonkwo, & Ladipo, (2006) found that stigma was the singular reason why PLWHAs avoid ART clinics closer home but would rather visit facilities further away from their homes.

The present study seem to suggest that availability of ART, attitude of staff, cost of ART and the conducive nature of the ART centres do not constitute barriers to access and adherent to ART. Currently in Nigeria, ART is free and readily available (USAID, 2010). This was also attested to by some of the respondents that were interviewed. Although the study shows that health care personnel were viewed as being friendly and that the environment where ART is administered is conducive, there is need to ensure sustainability of these factors. One way of ensuring that is by way of frequent workshops and seminars for health care personnel and hospital authorities.

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