

Barriers to HIV Treatment Adherence: Findings from a Treatment Center in South-South, Nigeria

ABSTRACT

Aims: Non-adherence to treatment represents a significant challenge to anti-retroviral treatment goals. This study aimed to identify and explore perceived barriers to adherence in non-adherent HIV patients attending the University of Port Harcourt Teaching Hospital.

Study design: This was a descriptive, cross-sectional study of HAART experienced patients who had less than 95% adherence to their HAART medication

Place and Duration of Study: The study was carried out between May and June 2011 at the Antiretroviral treatment center of the University of Port Harcourt Teaching Hospital in the Southern part of Nigeria

Methodology: Data collection was via quantitative and qualitative methods. A structured interviewer administered questionnaire adapted from the Adult Antiretroviral Clinical Trials Group (AACTG) study was used to identify barriers to adherence. In addition, four focus group discussions (FGDs) were held with 27 purposively selected participants. Quantitative data was analyzed with SPSS version 18, while the FGDs were analyzed using thematic content analysis.

Results: Ninety-six (96) patients, 39 (40.6%) males and 57 (59.4%) females with median age of 35.5 years participated in the study. Identified barriers to adherence included; being away from home during medication times 41 (42.7%), being busy with other things 35 (36.5%), forgetfulness 33 (34.4%), running out of pills 25 (26%), difficulty taking pills at specified times 25 (26.0%), the need to avoid side effects 16 (16.7%), and lack of a social support system 15 (15.6%). Barriers identified by the FGDs were fear of taking HIV drugs in front of others, sharing drugs with infected spouse, alcohol use, financial challenges, poor understanding about the effects of the drugs, forgetfulness, long clinic hours and poor attitude of health workers.

Conclusion: Adherence counselling, use of reminder systems and treatment supporters are useful Public Health interventions for improving adherence and should be integrated into service delivery at this and other centers. In addition, better organization of the clinic, increasing staff strength and training will go a long way to address these barriers. Decentralization of HIV treatment centers to secondary and primary health facilities needs consideration.

Keywords: [adherence, barriers, HAART, HIV]

1. INTRODUCTION

The success story of Highly Active Anti-retroviral Therapy (HAART) in HIV and AIDS management has led to the categorization of the condition as a chronic illness.(APHA, 2004) The aim of HAART is to achieve reduction in the viral load of patients to undetectable levels in order to allow for immune reconstitution and lead to clinical improvement.(APHA, 2004; Fong, 2006; WHO, 2004)

Where access to HAART exists, the issue often of concern to clinicians and programme managers alike is that of adherence to treatment. This is crucial to achieving treatment goals, increasing CD4+ cell counts and improving the clinical condition of people living with HIV-AIDS (PLHIV).(Mills et al., 2006) Although there is currently no standard clinical definition of adherence, several definitions are in use (APHA, 2004). Stedman's Medical Dictionary defines adherence as the extent to which the patient continues the agreed upon mode of treatment under limited supervision.(Stedman, 1982) Adherence in the context of HIV Medicine can be defined as the whole process from choosing, starting, managing to

maintaining a given therapeutic medication regimen to control HIV viral replication and improve function of the immune system.(Fong, 2006)

Non-adherence is thus defined as the discontinuity or cessation of part or all of the treatment such as dose missing, under dosing, overdosing or drug holidays.(Fong, 2006) Medication adherence can also be defined mathematically as the percentage of prescribed doses taken.(Ickovics, J.R, 1997) The Nigerian National Guidelines for HIV and AIDS Treatment and Care in Adolescents and Adults also defines adherence using a 95% cut-off, asserting that for a patient to be tagged as adherent he/she must not miss more than one dose in ten days if on a twice daily regimen.(Federal Ministry of Health, 2007) Some experts also agree with this stating that for best results treatment adherence to HAART therapy should be as high as 95%. (Paterson et al., 1999; Reiter et al., 2000) Several factors have been postulated to influence adherence behaviour to medication in general and HAART in particular. These factors have been classified into patient based factors, provider based factors and treatment based factors.(APHA, 2004) Patient based factors that have been shown to impact on HAART adherence include patient socio-demographics, patient treatment readiness including the patient's understanding of, motivation and commitment to a treatment plan, culture and the patient's health beliefs, presence and management of side effects/symptoms, presence or absence of a social support system, presence of co-morbidities such as substance abuse and mental health and stage of patient's disease.(APHA, 2004) With regard to provider based factors, the following have been found to be relevant; level of patient satisfaction with medical care, patient's perception of provider's attitude to them, long waiting time and procedural delays, and consistent access to health care and medicines.(APHA, 2004) Treatment related factors to be considered are the characteristics of treatment regimen, and side effects of regimen. (APHA, 2004)

Several studies on factors influencing adherence both in Nigeria and other developing countries have reported many of these issues listed above as barriers to adherence among their study populations.(Adedayo, Modupeola, & Timothy, 2005; Agu, Ochei, Oparah, & Onoh, 2010; Asekomeh, Ebong, & Onwuchekwa, 2010; Daniel et al., 2004; Idigbe et al., 2005; Iliyasu, Kabir, Abubakar, Babashani, & Zubair, 2005; Mills et al., 2006; Nwauche, Erhabor, Ejele, & Akani, 2006)

There is no doubt that adherence to HAART constitutes a challenge for many people living with HIV in Nigeria. Two previous studies carried out in the study site in 2006 and 2010, reported adherence levels of 49.2% and 72.2% respectively(Asekomeh et al., 2010; Nwauche et al., 2006). These sub-optimal levels were similar to what was observed in other parts of Nigeria' (Adedayo et al., 2005; Agu et al., 2010; Daniel et al., 2004; Idigbe et al., 2005; Iliyasu et al., 2005) It is a signal that much needs to be done to achieve and sustain optimal levels of adherence in the country. In 2008, the National Agency for the Control of AIDS (NACA) reported that close to 170, 000 people were benefitting from HAART in Nigeria. By simple extrapolation, using a recent adherence rate,(Asekomeh et al., 2010) it can be inferred that as many as 47,000 patients had suboptimal adherence and were at risk of treatment failure.

Several studies have been carried out on factors influencing adherence to antiretroviral treatment. However, only a few of them specifically targeted non-adherents or employed mixed methods in an attempt to gain deeper insight on the barriers to adherence. It is against this backdrop that this study was conceived in order to identify and explore perceived barriers to drug adherence among non-adherent patients receiving HAART, at the treatment center of the University of Port Harcourt Teaching Hospital.

2. MATERIAL AND METHODS

The study was carried out in the Antiretroviral Treatment (ART) Center of the University of Port Harcourt Teaching Hospital, south-south Nigeria. The hospital is a referral center to many health facilities both within and outside the state. The ART center runs daily and has an annual average of 5000 registered patients.

2.1 Study Design and Population

This was of a descriptive, cross-sectional design, targeting non-adherent patients on HAART at the treatment center. It was carried out between May and June 2011, using a combination of quantitative and qualitative methods.

2.2 Inclusion Criteria

People living with HIV (PLHIV) on HAART for at least three months prior to the study and patients whose self-reported adherence to HAART was below 95% in the month preceding the study were included.(Federal Ministry of Health, 2007)

2.3 Exclusion Criteria

Patients on HAART with other chronic co-morbidities such as tuberculosis, hypertension or diabetes requiring daily medications were excluded in order to eliminate increased pill burden from co-morbidities as a possible confounder in the study.

2.4 Sample Size

A minimum sample size of 96 non-adherent patients was determined for the study using the formula for sample size determination for a single proportion,(Kirkwood, 2003) based on a prevalence of 27.8% non-adherence from a previous study at the same ART center in 2010,(Asekomeh et al., 2010) with margin of error set at 10%.

2.5 Sampling and Data Collection

The quantitative study was carried out through convenience sampling of non-adherent patients who presented at the clinic and were recruited over a six week period until the minimum sample size was attained. Participants were recruited via a short screening questionnaire for adherence based on a one month recall of actual doses taken of all doses prescribed. At every clinic day, all patients determined to be non-adherents through the screening procedure, were included in the study if they consented to participate.

The qualitative research was through focus group discussions with the non-adherent patients at the conclusion of the quantitative research. Participants were recruited purposively to reflect the heterogeneous characteristics inherent in the study population such as age, education, socioeconomic status etc. Four FGDs were held. All sessions were held at the Department of Community Medicine of the hospital located reasonably away from the ARV clinics in order to encourage participants to express their opinions freely.

2.6 Study Instruments

Quantitative tool: It consisted of a validated, structured interviewer administered questionnaire adapted from the Adult AIDS Clinical Trials Group (AACTG) (Chesney et al., 2000). The questionnaire contains a section on socio-demographic information, and three sections related to patient, provider and treatment barriers to adherence.

Qualitative Tool: This was a topic guide developed by the researchers for the focus group discussions (FGDs). It contained a list of topics relating to patients perceptions of factors affecting adherence. These topics explored patient, treatment and provider related barriers in order to provide insight into the findings of the quantitative study.

All interviews and discussions were conducted by the researchers in simple English for literate participants and *pidgin* English for non-literate participants.

2.7 Data Analysis

All data generated from the quantitative study were analysed in SPSS version 18.0 and presented in frequency tables, with level of significance set at $p=0.05$. The focus group interviews were recorded and transcribed. All descriptions that were relevant to themes of patient related, treatment related or provider related barriers to adherence were identified, coded and described in line with the procedure for thematic content analysis.

3. RESULTS AND DISCUSSION

3.1 RESULTS

Ninety six patients participated in the quantitative component of the study. They consisted of 39 (40.6%) males and 57 (59.4%) females with a median age of 35.5 years. About half 47 (49.0%) were married, and had at least secondary school education 50 (52.1%). Majority, 58 (60.4%) were employed on a full time basis as in Table 1 below.

Table 1: Socio-demographic profile of study participants

VARIABLE	FREQUENCIES	PERCENTAGE
Gender		
Male	39	40.6
Female	57	59.4
Age		
20-29	29	30.2
30-39	35	36.5
40-49	20	20.8
50-59	9	9.4
60-69	3	3.1
Marital Status		
Single	38	39.6
Married	47	49.0
Divorced/Separated	7	7.3
Widowed	4	4.2
Highest Education		
None	4	4.2
Primary	10	10.4

Secondary	50	52.1
Post-secondary	18	18.8
Tertiary	12	12.5
No Response	2	2.1
Employment Status		
Working full time	58	60.4
Working part time	7	7.3
Unemployed	17	17.7
Looking for work	9	9.4
Full time housewife	1	1.0
Retired	1	1.0
Student	3	3.1

Of these, 27 (14 females and 13 males) participated in four FGDs. The female participants were aged between 24 and 54; half of them were married, while others were single. They all had at least secondary education. The male participants were aged between 34 and 56 years. Three of them were married, while others were single. Nine males had secondary education, while the rest had post-secondary education. Three major themes emerged after content analysis; barriers relating to patient behaviour and relationships, barriers associated with the treatment and barriers associated with the service providers.

3.1 Patient Related Barriers

Most respondents 82 (85.4%) claimed they understood the HIV treatment regimen and were willing to take medications as prescribed. In addition, 93 (96.9%) felt that the treatment was useful. However, only 15 (15.6%) of respondents were active members of a treatment support group Table 2 below provides more detail.

Table 2: Other Patient Related Barriers to Adherence

Factors Implicated in Adherence	Yes	No	No Response
Treatment Readiness			
Understands HIV treatment	82 (85.4)	14 (14.6)	
Is willing to take treatment	82 (85.4)	14 (14.6)	
Perceives Treatment as helpful	93 (96.9)	3 (3.1)	
Social Support			
Had disclosed HIV status to family member or friend	77 (80.2)	19 (19.8)	
Is a member of a Support group	15 (15.6)	81 (84.4)	
Substance Abuse (previous 6 months)			
Takes Alcohol	35(36.5)	54(56.3)	7(7.3)
Takes Cocaine	1(1.0)	82(85.4)	13(13.5)
Takes Heroin	3 (3.1)	80(83.3)	13(13.5)
Takes Marijuana	9(9.4)	75(78.1)	12(12.5)
Takes Amphetamine	4(4.2)	77(80.2)	15(15.6)

Many discussants described the various challenges with taking drugs that were associated with individual behaviours and relationships. They included the fear of stigmatization when taking the drugs in front of family and friends as a result of non-disclosure of their HIV status. In the words of a participant,

"...if my friends and room-mates are in the room, it makes me not to take my drugs because seeing me take drugs every day will make them start asking questions which I might find difficult to explain" (PLHIV, 26 years, female, university student) .

Another discussant, a described his predicament with non-disclosure with this statement;

"I didn't tell my wife for six years now...because if she hears it, it will scatter my marriage." (PLHIV, 40 years, male, married man)

Some female discussants admitted that their husbands did not collect their drugs as often as they should, so they were compelled to share their drugs with their husbands. As a result, the drugs get exhausted before the next appointment date. One participant's statement best describes this challenge, *"I used to give my husband my drugs when his own finishes. He will not have chance to come to clinic because of work, so I have to help him. But when my own finishes before the appointment date, I will not have drugs again..."* (PLHIV, 36 years, Female, Married)

About a third of the participants 35(36.5%) confessed to alcohol consumption. A few others confessed to the use of other substances like marijuana, 9.4%, amphetamines, 4.2% heroin 3.1%. This was recognised as a challenge to adherence by male focus group discussants. They agreed that their indulgence in alcohol was partly responsible for their poor adherence to drugs. One participant put it this way:

"I often said to myself, let me drink and forget my problems". (PLHIV, 47 years, male, single)

During the FGDs, some participants complained about high costs of transportation to and fro the clinic, challenges with getting money to eat well and even money to conduct the routine investigations. One discussant described the situation in the following statement,

"I didn't used to have transport sometimes so I will not come..." (PLHIV, 28 years, female, single) Another discussant had this to say, *"they like sending somebody for test especially this CD4 of a thing. Somebody does not have money to eat...where will the N1,000 come from..."* (PLHIV, 48 years, female, married)

3.3 Treatment Related Barriers

The most common reasons for missing medications included being away from home at medication times 41 (42.7%), being busy with other things 35 (36.5%) and forgetfulness 33 (34.4%). Other pertinent reasons included running out of drugs 25 (26%), problems with taking pills at specified times 25 (26.0%), the need to avoid side effects 16 (16.7%) and the feeling of being overwhelmed by too many pills 16 (16.7%). See Table 3 below.

Table 3: Treatment Related Barriers to Adherence

Reasons for Missing Medications	Yes	No	No Response
Was away from home	41(42.7)	49(51.0)	6(6.3)
Was busy with other things	35(36.5)	54(56.3)	7(7.3)
Simply forgot	33(34.4)	57(59.4)	6(6.3)
Had too many pills to take	7(7.3)	82(85.4)	7(7.3)
Wanted to avoid side effects	16(16.7)	70(72.9)	10(10.4)
Did not want others to notice me taking drugs	15(15.6)	73(76.0)	8(8.3)
Had a change in daily routine	14(14.6)	72(75.0)	6(6.3)
Felt like the drug was toxic/harmful	6(6.3)	86(89.6)	7(7.3)
Felt sick or ill	12(12.5)	77(80.2)	7(7.3)
Slept away through dose time	16(16.7)	74(77.1)	6(6.3)
Felt depressed/ overwhelmed	16(16.7)	73(76.0)	7(7.3)
Ran out of pills	25(26.0)	62(64.6)	9(9.4)
Had problems taking pills at specified times (e.g. with meals, on empty stomach etc.)	25(26.0)	64(66.7)	7(7.3)
Felt good (didn't need to take drugs)	6(6.3)	85(88.5)	5(5.2)
Needed a break from too many drugs	3(3.1)	87(90.6)	6(6.3)

A discussant said she was deliberately taking her drugs once daily in disregard of the prescription of twice daily, because she felt that the drugs would make her gain weight. Another felt that she was not going to be able to get pregnant if she kept taking the drugs, so she would take drug holidays from time to time. In her words,

"I am not missing my menstruation since these drugs. I want to be pregnant, so I have to stop it. (PLHIV, 33 years, female, married).

Many said they often forgot to take along their drugs when travelling or even when going to work. Others said they occasionally slept through dose time or procrastinated taking their drugs until they felt it was too late for that dose. One male discussant exclaimed;
"Doctor, I used to forget to take my drugs every time oh ..." (PLHIV, 45 years, male, single)
 Most of the patients expressed fears about the repeat of the side effects they had experienced when they commenced medication such as severe vomiting, generalized rashes and severe weakness. One female said,
"Doctor, when I started taking this medicine newly, I thought I was going to die. All my body just scattered. It was terrible." (PLHIV, 32, female, married)

3.4 Provider Related Barriers

Participants were asked about their satisfaction with the services provided. Most were satisfied with the availability of services, 80 (83.3%) and promptness in delivery, 75 (78.1%), while 58 (60.4%) were satisfied with the waiting times at the clinic. Overall, 76 (79.2%) were satisfied with services at the clinic. See Table 4 below

Table 4: Provider Related Barriers to Adherence

Service Delivery/Satisfaction Issues	Satisfied	Dissatisfied	No Response
Satisfaction with Services over the Preceding 2 Months			
Promptness of Services	75(78.1)	17(17.7)	4(4.2)
Availability of Doctors for consultation	80(83.3)	12(12.5)	
Waiting time	58(60.4)	33(34.4)	
Post Initiation Adherence Counselling	73(76.0)	18(18.8)	5(5.2)
Satisfaction with Pre-ART initiation Adherence Counselling			
Was counselling done?	81(84.4)	11(11.5)	4(4.2)
Counsellor's communication skills	81(84.4)	9(9.4)	6(6.3)
Counselling was easy to understand	85(88.5)	7(7.3)	4(4.2)
Side effects of drugs was adequately discussed	69(71.9)	21(21.9)	6(6.3)
Counselling sessions were helpful	82(85.4)	8(8.3)	6(6.3)
Counsellor was professional	78(81.3)	7(7.3)	11(11.5)
Questions asked concerning treatment was satisfactorily answered	87(90.6)	3(3.1)	6(6.3)
Overall Satisfaction Rating			
Courtesy and Respect	83(86.5)	9(9.4)	4(4.2)
Overall Satisfaction with Services	76(79.2)	16(16.7)	4(4.2)
Overall Expectations met?	82(85.4)	10(10.4)	4(4.2)

However, some pertinent issues were raised at the FGD sessions that concerned the attitude of some health workers, the time spent at the clinic and the overall organization of the clinic. Some discussants felt poorly treated by the health care workers. They complained of sometimes being yelled at or ignored. One discussant commented,
"At least we are human beings too, even if we are sick... The way they will talk to you as if you are not somebody". (PLHIV, 48 years, female, married)
 Another said...
"Some of the nurses are too harsh, they should be careful because we are all human beings". (PLHIV, 54 years, male, married)
 Some discussants were not happy with the amount of time they spend in the hospital waiting to collect drugs or see the doctor. A visibly upset discussant said...
"When I remember what I will pass through here, the problem I will get to come for my drugs, I'll rather stay and manage the little ones that I have..." (PLHIV, 54 years, male, married)
 Many discussants also stressed that the clinics were usually crowded, rowdy and poorly organised.

3.2 DISCUSSION

This study identified some important patient, treatment and provider-related barriers to treatment adherence among a sample of HIV patients attending the ARV clinic of the University of Port Harcourt Teaching hospital. Most of the study

participants lacked the relevant social support structure, provided by belonging to a support group, necessary for treatment adherence. The absence of such support might have been caused by the reluctance of some respondents to disclose their HIV status to close family members or friends. A study by Taiwo et al highlighted the benefit of having active treatment supporters for patients on HAART.(Taiwo et al., 2010) Nearly a third of the study participants confessed to alcohol or other addictive substance use. Patient indulgence with alcohol or other abusive substances while under medication could impair their sense of responsibility and judgement and lead to missed doses as demonstrated by some studies.(Adedayo et al., 2005; Golin et al., 2002) It is therefore pertinent for counsellors to identify patients with such challenges and offer timely management of substance addiction, while referring difficult cases for psychotherapy. A few of the respondents were involved in drug sharing with their spouses. This unwholesome practice is a recipe for missed drug doses that impacts negatively on the patient's ability to adhere to HAART. This challenge can best be handled via individual and couple counselling.

The most prominent treatment related barriers identified in this study were those of being away from home at the time of medication, being busy with other issues and forgetfulness. These were in conformity with the results of the study by Asekomeh et al (Asekomeh et al., 2010) that also identified forgetfulness, no pills at dosing time, feeling uncomfortable after taking medication, trying to save money and having too many medications as the commonest reasons for non-adherence to HAART. A systematic review of 84 studies on HIV drug adherence carried out in 72 developed and 12 developing countries also revealed that forgetfulness, a lack of understanding of treatment benefits, complicated regimens, and being away from their medications were major barriers to adherence.(Mills et al., 2006) One important effect of these barriers is the risk of HIV drug resistance with severe implications for patient management and survival and the ARV treatment programme in general. This situation therefore calls for interventions such as training patients to use reminder systems to help them remember to take their medications when due. Treatment facilities could also employ the use of text message reminders to reinforce adherence behaviour. This call is necessary as evidence from studies (Dieckhaus & Odesina, 2007; Maduka & Tobin-West, 2013; Reiter et al., 2000) documents the relevance of interventions in improving and sustaining drug adherence.

Although most respondents expressed satisfaction with the services provided at the treatment center from the questionnaire survey, some were disappointed with the attitude of some health workers during the focus group sessions. They claimed that they were sometimes yelled at or simply ignored. Such maltreatment of patients serves as an obvious disincentive for future clinic attendance and a potential reason that could compromise drug adherence. Similar findings have been reported by patients attending ARV clinics.(Adebajo, Bangbala, & Oyediran, 2003; Reis et al., 2005) It is an indictment on the facility and calls for concerted efforts to improve quality of care. These findings also validate the use of multiple approaches for data collection and the importance of triangulating the findings of these approaches.

The strengths of this study lie on its focus on non-adherent patients and the employment of a combined approach to data collection, such that deeper insights and perceptions concerning barriers to adherence were adequately explored. While quantitative tools identify barriers to adherence, qualitative tools explore underlying reasons for non-adherence (Vervoort, Borleffs, Hoepelman, & Grypdonck, 2007) On the other hand the small sample size and the use of self-reported adherence to ascertain eligibility for the study were limitations of the study. Although some may argue that more objective methods of assessing adherence exist, these methods are also fraught with challenges as there is no gold standard for measuring adherence. Studies have shown that reports of poor adherence are more reliable than those of good adherence (Flexner, 1997; Gill, Hamer, Simon, Thea, & Sabin, 2005; Miller & Hays, 2000)

This study highlights some perceived barriers to adherence in non-adherent patients, It did not assess facilitators of adherence neither did it focus on adherent patients. These are possible areas for future research.

4. CONCLUSION

A high level of adherence of 95% and above to HAART is essential for achieving treatment goals. The many barriers to adherence identified in this study are surmountable. Interventions are needed at provider, patient and treatment levels to achieve and sustain adherence. Patients on HAART should benefit from adherence counselling sessions and training to use reminder systems such as alarms for dosing time and clinic appointments, to always carry their drugs with them and to take clinic appointments seriously in order not to run out of supply. A system for text message reminders can be used by the treatment center to remind patients of clinic appointments and to reinforce adherence messages. Establishing and sustaining vibrant support groups as well as actively engaging treatment supporters for each patient enrolled in the clinic is also recommended. Increasing the ARV clinic staff strength and training and re-training the health workers, will go also a long way in addressing barriers to adherence.

ETHICAL APPROVAL

Ethical clearance for the study was received from the Ethics Committee of the University of Port Harcourt Teaching Hospital. Written informed consent was also obtained from all participants after full explanation of the purpose of the

267 study. All prospective participants were assured that their participation was voluntary and non- participation would not
268 attract any sanctions.

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