

**Factors Affecting Antiretroviral Treatment Adherence amongst Young Adults Living with HIV/AIDS in, Yaba, Lagos, Nigeria:  
A qualitative study**



**By**

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# CHAPTER1: INTRODUCTION

## 1.1 Background

The emergence of HIV/AIDS in sub-Saharan Africa over two and half decades ago presented a devastating health crisis to millions of people in the continent. Over 24.5 million people were estimated to be living with the disease at the end of 2005 (UNAIDS, 2006), which represents about 65% of the global figure. Also an estimated 2.7 million people were newly infected and 2.5 million adults and child deaths occurred from AIDS in the region during 2005 (UNAIDS, 2006). The prevalence rates of the epidemic among nations in sub-Saharan Africa ranges from above 25% in Zimbabwe, South Africa and Botswana to as high as 35% in Swaziland. West and Central Africa maintained a constant rate of 4% with Senegal having the lowest rate of 1%. There is a steady decline in the prevalence rates recorded in East African countries such as Kenya and Uganda (UNAIDS, 2006).

Statistical data reveals that 2.6 million people were infected in 2007. The national seroprevalence rate has risen from 1.8% in 1991 to 4.4% in 2005 (FMH, 2006) while as at 2009, an estimated 2.98 million people are living with HIV and AIDS (UNAIDS, 2010). However, HIV prevalence is said to be high in young adults with age ranges from 15-24 and of this group, the number of young women living with HIV and AIDS was almost twice that of men (KFF, 2005). This reveals the importance of attention on young adults due to their vulnerability to HIV infection. Other studies have been carried out to measure the impact of prevalence on mortality. UNAIDS (2008) reveal that an estimated 300,000 deaths occurred from AIDS in 2004.

Transmission of HIV is predominantly heterosexual but mother to child spread is also significant with an estimated 2 million AIDS orphans in Nigeria. Many factors increase the high rate of prevalence including poverty, ignorance about the infection, unprotected sex and cultural practices. With no available cure for HIV/AIDS, Antiretroviral therapy (ART) provides the only viable remedy to manage and reduce the health crises posed by the infection in sub-Saharan Africa. ART is a combination of antiretroviral medication that suppresses the viral load in the body to minimal levels, boost the patient immune system by increasing the number of CD-4 cells and enhance the quality of life of people living with HIV/AIDS (Lewis, Colbert, Erlen, & Meyers, 2006; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). The virus, however, is not totally eliminated from the body, hence patients have to take the medication life-long.

Nigeria commenced their ART programme in 2002 in response to the high prevalence situation among the populace. From an initial 15,000 people on ART treatment, with 25 ART

centres located within the six geopolitical zones in the country, more people now have increasing access to antiretroviral treatment with over 250,000 people receiving treatment in 2006. Antiretroviral treatment centres increased further from 74 to 251 between 2006 and 2008 (FMH, 2006). As at 2009, the estimated number of people receiving antiretroviral treatment rose to 302,973 out of an estimated 1.4 million people who are actually in need of antiretroviral treatment in Nigeria (KFF, 2010).

Adherence to treatment is important for long-term treatment effectiveness (WHO, 2003). Adherence is defined as the extent to which a person's behaviour in terms of taking medications, following a diet, and executing life style changes follows agreed recommendations from a health care provider (WHO, 2003). Many reports have linked non-adherence to antiretroviral treatment as a major challenge to successful management of patients with HIV/AIDS. Non-adherence to antiretroviral treatment has been a critical issue in addressing the menace of HIV/AIDS globally. It is estimated that adherence rates of 90% or more generally need to be obtained to achieve virologic success (e.g., (Paterson et al., 2000). Additionally, non-adherence to antiretroviral therapy has been associated with transmission of drug resistance viral strains (Monjok, Smesny, Okokon, Mgbere, & Essien, 2010). Non-adherence to ART in the adult population has been shown to range from 33% to 88% depending on how adherence is defined and evaluated (Mills et al., 2006). Despite increasing access to treatment, non-adherence and drop-out of care (and thus stopping treatment) has been described as the major obstacle in the fight against HIV/AIDS (Mills, et al., 2006). Hence, after availability of HIV medication, a key-challenge is to promote adherence and retention in care in order to obtain optimal treatment outcomes for the patient. This also substantially reduces the risk of infecting sexual partners (Cohen et al., 2011).

## **1.2 Problem Statement**

In the case of ART, adherence to treatment implies taking the drugs in their right quantities, at the right time, life-long. It has been established by several studies that adherence to ART is a problem in Nigeria. Erah & Arute (2008) in their review on young adults aged (15-18) living with HIV/AIDS in Nigeria reported that there is poor knowledge of HIV/AIDS among young adults living with HIV/AIDS and this affects adherence. A study conducted by Weiser et.al, (2003) in three private clinics in Botswana found self-reported and provider assessment adherence rates of 54% and 56%, respectively. In another study done in Dakar, Senegal (Laurenta et al., 2002), the authors found that 78% of the patients were adherent while the optimal level of adherence was set at 80% (which is a low cut-off, since typically 95%

adherence is recommended). A relatively lower adherence level of 66% was reported in a study conducted in Uganda (Byakika *et. al.*, 2005). A meta-analysis of adherence studies done in Sub-Saharan Africa and North America established an estimated 77% in Africa (Mills, et al., 2006). A similar adherence level was reported by a study conducted by Mukhtar, Adeleke, Gwarzo, & Ladan (2006) in Aminu Kano Teaching Hospital, Nigeria. This study found that 80% of study patients achieved the optimal adherence. Hence, these studies reveal that non-adherence seems to be a major challenge and threatens the long-term success of available ART's in sub-Saharan Africa.

Although there has been promising research among adults, showing that adherence need not be a much larger challenge in Sub-Saharan Africa compared to resource-rich settings, it is clear from the existing literature that the rate of adherence to ART in Nigeria among the Young adults living with HIV/AIDS is still too low. In order to develop programs to support adherence, it is important to understand the causes. Whereas plenty of research on causes of non-adherence has been conducted among adults (Olowookere, S. A., Fatiregun, A. A., Akinyemi, J. O., Bamgboye, A. E., & Osagbemi, G. K. (2008). There are almost no studies that have focus on young adults specifically. However, this group is very vulnerable to the infection and constitutes about 50% of the infected population. It is estimated that 5000-6000 young people becoming infected everyday (Bruce *et.al.*, 2006).

Despite the high prevalence of HIV among the young adults in Nigeria, and the apparent problems with adherence and retention in care, it is not yet clear how they are dealing with their treatment and which challenges they are facing with ART adherence. A study carried out in Nigeria by Erah & Arute (2008) revealed that there is stigma and discrimination among young adults living with HIV/AIDS Nigeria and that this affects adherence. Although young adults in Nigeria are heavily affected by HIV/AIDS and many of them use antiretroviral therapy, beyond the study by Erah & Arute (2008) there is limited information on the challenges youngsters face with retaining in care and adherence to antiretroviral treatment. Against this background, this study aims to identify more comprehensively the factors affecting antiretroviral treatment adherence among young adults living with HIV/AIDS in Nigeria.

### **1.3 General Research Question**

Based on the rationale of this study, the general research question of this study is: What factors affect antiretroviral treatment adherence among young adults living with HIV/AIDS in Nigeria?

## **CHAPTER TWO: THEORETICAL FRAMEWORK**

The aim of this chapter is to have a better understanding on the factors which affect antiretroviral treatment. The first section reviews literature on previous research work done. In the second section an adherence behaviour theory will be discussed, and in the third section this theory will be integrated with the literature review in one conceptual theoretical framework. This framework will guide this research. The final section of this chapter presents the objectives of the study.

### **2.1 Literature Review on Factors Affecting Adherence**

Reviews on factors affecting antiretroviral treatment adherence are structured in the categories Individual factors, Regimen factors, Socio-cultural factors and Health care provider and patient-doctor relationship factors. Therefore the literature review in this study will be arranged according to these categories.

#### **2.1.1 Individual Factors**

Patient beliefs and behaviours play an important role in adherence. Studies have shown that patient beliefs about illness and the efficacy of the treatment regime affect adherence (Mills, et al., 2006). Many people living with HIV/AIDS have developed faith in the effectiveness of antiretroviral treatment. Patient knowledge and information contribute to adherence; available studies suggest that a good understanding of HIV/AIDS and awareness of the consequences of non-adherence are associated with good adherence. (Fisher, Amico, & Harman,(2006). Consequently, misinformation and misconception about treatment can compromise individuals' ability to adhere. Cases of lacking accurate information abounds, leading to some HIV/AIDS patients sharing medications as well as not taking their dose correctly.

Patient forgetfulness to take their oral dose contributes significantly to non-adherence and makes it an issue of considerable debates. The patient-centred perspective on adherence points an accusing finger to the patient habit of forgetfulness. Findings on this issue are mixed. Hardon et al, (2006) ,on one hand, cases of patients with HIV/AIDS failing to take their medication as required on account of forgetfulness has been documented by some studies (Mukhtar-Yola, et al., 2006; Olowookere, Fatiregun, Akinyemi, Bamgboye, & Osagbemi, 2008; Skhosana, Struthers, Gray, & McIntyre, 2006; Uzochukwu et al., 2009). On the contrary, HIV/AIDS patients on treatment observed that forgetting to take their

medication is out of question. There are findings which suggest that Alcohol and substance use affects adherence in sub-Saharan Africa. Some of the patients who take alcohol end up forgetting to take their tablet or omitting treatment (Hardon, et al., 2006)

Studies on antiretroviral treatment adherence suggest that depression or and mental health is associated with non-adherence (Malcolm, Ng, Rosen, & Stone, 2003; Murphy, Johnston Roberts, Hoffman, Molina, & Lu, 2003; Proctor, Tesfa, & Tompkins, 1999; Wood, Tobias, & McCree, 2004). Findings reveal that many HIV positive people portrayed a sense of depression and hopelessness, of lacking the will to live with this chronic disease. Emerging evidence has shown that social support is vital in fostering adherence for PLHAS on treatment. A blaming community discourages people from adherence to medication recommendation. The reactions of family, friends affect the decision to seek and adhere to treatment which is manifested through poor self-management. Financial constraint/lack of money contributes to non-adherence. Although, ART are available now for free to HIV positive patients in sub-Sahara Africa, the cost of transportation to obtain the drug remain a reason for non-adherence. This finding has also been report in another study (Yu et al., 2007)

### **2.1.2 Regimen Factors**

Regimen factors affecting non-adherence can further be sub-divided into pill burden and drug complexity. In addition to the number of pills, antiretroviral treatment users are expected to take their doses at the same regular intervals for life and follow dietary requirements. People living with HIV/AIDS on antiretroviral treatment have problem in adhering to their treatment schedule. This applies to patients in Nigeria as reported by Uzochukwu, et al., (2009). Side-effects from antiretroviral medication were mentioned by patients as a factor contributing to their non-adherence to treatment. Antiretroviral treatment is known to cause some side effects to some patients. Some of these reported side effects include vomiting, nausea, anaemia, hepatitis, skin rashes, dizziness and hallucination (Laurenta, et al., 2002; Rao, et al., 2007). A Botswana study by Weiser, et al., (2003) established that about half (51%) of the survey respondents reported experiencing one sort of side effects or another. The people who reported side effects were 82% less likely to adhere to their treatment than those who had no side effects. Some of these side effects affect adherence in different ways as illustrated by some patients in Skhosana, et al., (2006).

### **2.1.3 Socio-cultural factors**

A major socio-cultural factor which affect non-adherence of antiretroviral treatment is disclosure of ones status as HIV positive and stigma. Patients and health care professionals

mentioned that stigma and discrimination related to being HIV infected were still present in their communities and families, despite the positive advantage of antiretroviral treatment (Mukhtar-Yola, et al., 2006; Olowookere, et al., 2008; Skhosana, et al., 2006; Uzochukwu, et al., 2009). This also is a common and major factor for non-adherence among young adults aged 15-18 in Nigeria as revealed in the study by Erah & Arute (2008). Disclosure of one's status as HIV infected and taking antiretroviral treatment was linked with stigma for many patients and most of them said they did not disclose their status for fear of being victimized, rejected or accused of infidelity. Because of the traumatic nature of such experiences, some patients had ended up hiding their doses and not adhering to their medication (Mukhtar-Yola, et al., 2006; Olowookere, et al., 2008; Skhosana, et al., 2006; Uzochukwu, et al., 2009). Many patients have opted out of antiretroviral treatment for an alternative treatment such as traditional medicine and lack of food were reported by some patients as barriers to their adherence to antiretroviral treatment (Mukhtar-Yola, et al., 2006; Olowookere, et al., 2008; Skhosana, et al., 2006; Uzochukwu, et al., 2009). Some patients have also complained of lack of emotional/ psychological support from friends and family members which have resulted in abandonment.

#### **2.1.4 Health Care Provider Related Factors**

In relation to the health services related factors affecting non-adherence, there is a growing concern with health services and facilities in sub-Saharan Africa because it poses serious hindrance to adherence. To start with, there is lack of adequate health facilities or services in sub-Saharan Africa and when they are available they are not well equipped and lack good infrastructures. Some of these health facilities are located far away from the patients and sometimes, some of the patients do not have the fare to travel long distances to the clinic to receive their antiretroviral treatment, hence end up missing their doses which affects their adherence, (Uzochukwu, et al., 2009). Secondly, there is inadequate room in health facilities that would allow for confidentiality. An example of this was a situation in which three doctors were sharing one consultation room and consulting with three different patients at the same time. This practice can stop some patients from attending consultations or from communicating openly, and so affects their adherence (Hardon, et al., 2006). Lack of information and communication about antiretroviral treatment between health care professionals and patients can also affect adherence to antiretroviral treatment. The long hours spent by patients at the clinic waiting for health care personnel and during consultations, hours constitute time constraint to the patients and has also been mentioned as

one of the factors affecting adherence.(Torpey et al., 2008) Patient follow up to treatment were also reported as barriers to adherence. Shortage and inadequate supply of antiretroviral medication is a problem that health facilities in developing countries are contending with and this factor is forcing people living with HIV/AIDS to miss taking their required antiretroviral doses. For example, the study carried out by Hardon, et al., (2006) reveal that antiretroviral drugs were out of stock for a whole month in Arumeru Hospital, causing an interruption in antiretroviral treatment. Similarly, in Nigeria between 2004 and 2006, the antiretroviral treatment programme had problems with drug supply, during this period several patients did not receive medication (Monjok, et al., 2010; Uzochukwu, et al., 2009). Furthermore, language has been also mentioned as a barrier to adherence by some patients in remote villages and towns (Nwauche, Erhabor, Ejele, & Akani, 2006).

There is evidence that a great deal of adherence hinges on the positive interaction between the patients and the health care providers (Marelich, Roberts, Murphy, & Callari, 2002). The complexities of antiretroviral treatment require that patients are involved in their treatment decisions which entail a frank and open discussion between the patient and health care provider. The specific needs and peculiar circumstances of people living with HIV/AIDS need to be given due consideration (WHO, 2003). There are, nonetheless cases where patient-provider interaction is not cordial. The increase in the number of cases of patients on ART treatment in sub-Saharan Africa has occurred without a commensurate increase in the number of medical personnel, there by aggravating the already poor provider – patient ration. This has translated into a number of problems. Firstly, the medical personnel are over whelmed by the influx of patients coming in everyday for antiretroviral treatment. The increase in the number of patients coming for antiretroviral treatment everyday which outnumbered health providers increase the workload of the providers, this leads to a situation, where by the provider will spend less time with the patient and will not have enough time to give the patient proper counselling. Shortage of medical personnel, Inadequate training of medical personnel and poor counselling skills of the health provider has also been reported as a barrier to adherence (Tawfik and Kinoti, 2003).

## **2.2 Information Motivation and Behavioural Skills Model**

In this study, several literature reviews on medication adherence cited made limited use of theoretical models and framework which is vital in understanding adherence behaviour of patients. The Information motivation, behaviour skills models will be reviewed to discuss adherence to antiretroviral treatment. According to Fisher, et al., (2006) Information-Motivation–Behavioural Skills-Model of adherence assumes that adherence related

information, motivation and behavioural skills are critical determinants of adherence to antiretroviral treatment.

The model states that adherence-related information, motivation work through adherence-related behavioural skills to affect adherence to antiretroviral treatment. The implication of this model translate therefore to the extent that HIV patients are well informed,

Motivated to take action and possess the required behavioural skills to act effectively. substantial health benefit of the treatment. Conversely, poor or non-adherence will occur and health benefit lost when HIV positive patients are poorly informed, motivated to take action and lack the required behavioural skills to act effectively, they will be more likely to adhere to medication regimens over time and in turn derive/experience.

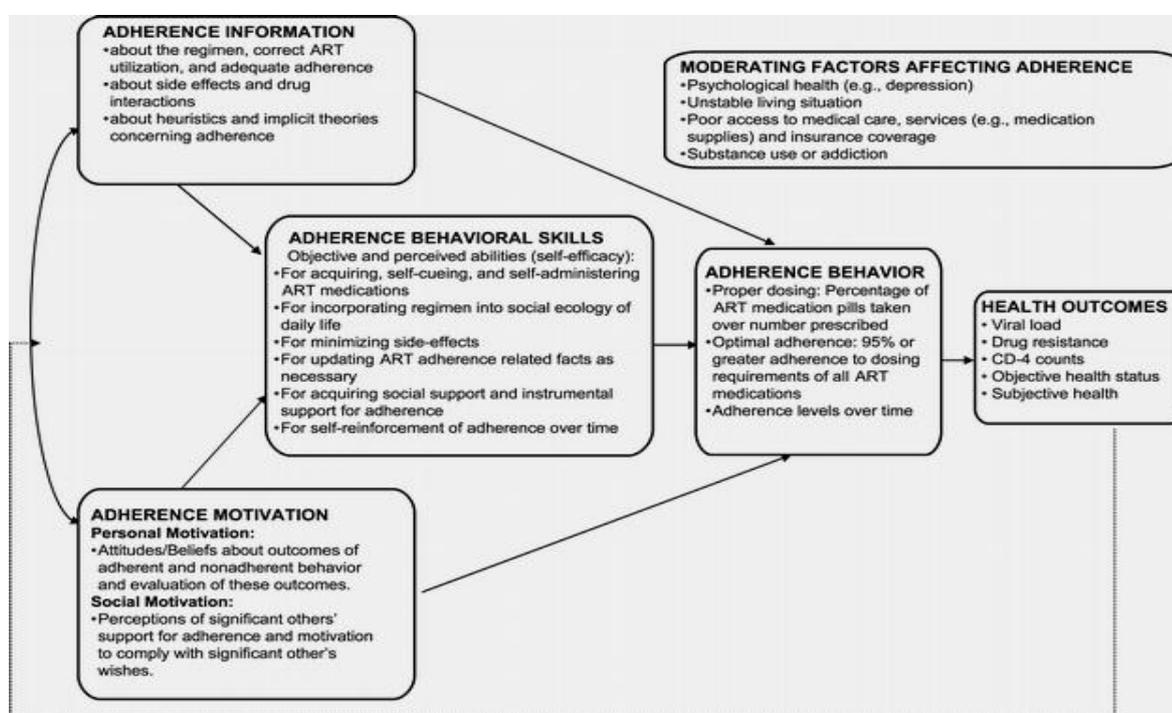


Figure 1: Information Motivation – Behavioural Skills Model of Adherence to antiretroviral treatment. Source: (Fisher, et al., 2006).

This model is of very significant value as a wide range of health related behaviours is linked to the profound influence of three key elements of information, motivation and behavioural skills Fisher, et al., (2006).

### 2.2.1 Adherence Information

Comprehensive and accurate information relevant to adherence to medication (ART) is a catalyst of consistent and appropriate use of therapy by the individual. For example adherence is facilitated when a patient is thoroughly informed about his medication, regimen,

when and how to, what to take, about what constitutes adequate antiretroviral adherence, as well as potential side effects. In turn, information may be inaccurate and may impede adherence in an individual who is misinformed or lacks information about the medication usage and side effects. In summary, application of appropriate information about HIV/AIDS infection, medication and medication adherence is vital to overcoming non-adherence to antiretroviral treatment by young adults living with HIV/AIDS in sub Saharan Africa in general and Nigeria in particular. Lack of information about what to do concerning missed doses and health effects of missed doses leads to poor adherence of HAART (Albert et al., 1999; Chesney et al., 2000).

### **2.2.2 Adherence Motivation**

An individual motivation to adhere to his or her treatment regimen is critical to antiretroviral treatment adherence and this is based on the personal and social motivation to adhere to the therapy. Personal motivation to adhere to his regimen involves positive attitude towards adhering to his regimen based on his beliefs about the outcomes of ART adherence (or non-adherence) and the evaluations of these outcomes (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). Favourable belief about effects of antiretroviral treatment adherence for example the belief that antiretroviral treatment adherence will improve my health and positive evaluations of these outcomes (for example, an improvement in my health would be good are assumed to be linked with adherence to therapy. The social motivation to adhere rests on the individuals' perceptions of social support from important people in the patient's life (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). Murphy, Wilson, Durako, Muenz, & Belzer (2001) reported that social support from family and friend can influence one's initiation of and continuation on Antiretroviral treatment Additionally, there is also a growing body of evidence for an association between the perception of positive client – clinician relationship, and the perception of physician-based social support for adherence and antiretroviral treatment adherence (Altice, Mostashari, & Friedland, 2001; Gerbert B, Love C, Caspers N, Linkins K, & Burack J H, 1999; Murphy, Marelich, Hoffman, & Steers, 2004).

### **2.2.3 Adherence Behavioural Skills**

The behavioural skills component of IMB model of adherence to antiretroviral treatment comprises of the individual ability in addition to his perceived self-efficacy concerning the performance of the complex sequence of behaviours that is involved in adherence to antiretroviral therapy. To self-administer combination of antiretroviral medication, acquire, keep accessible, cope with side effects, stick to prescription schedule, obtain and update

information on antiretroviral treatment, communicate effectively with health care provider, ability to be able to mobilize social support for antiretroviral adherence and to reinforce oneself for maintaining adherence to ART over time and challenges to adherence form the behavioural skill and is influenced by both the adherence information and motivation. Available evidence from study by Smith, Rublein, Marcus, Brock, & Chesney (2003) reported that self-management skills such as setting goals, using daily events to cue medication dosing is found to be associated with adherence. A study by Holzemer, Bakken Henry, Portillo, Miramontes (2000) confirm a relation between skills for seeking out relevant information, skills for seeking out support for HAART adherence and HAART adherence behaviour in that, a poorly adherent individuals report problems seeking out such resources when needed.

### **2.3 Proposed Conceptual Theoretical Framework**

Adherence to antiretroviral treatment is affected by a number of factors described in the literature review section, namely individual patient factors, regimen and health care provider factors, and socio-cultural factors. The Information Motivation and Behavioural skills model gives an overview of the most important factors at the individual level (information, motivation and behavioural skills). This Information Motivation and Behavioural skills model will be used as the basis for this study, but it is also important to realize how the regimen, health care provider and socio-cultural factors are related to these individual patient factors. For example, if people experience a lot of side effects (regimen) or stigma (socio-cultural), this may negatively affect their motivation and confidence to comply with the treatment. If, on the other hand, patients receive social support and have a good relationship with their health care provider, this may give them sufficient knowledge, motivate them, and provide them with important skills for adherence. Hence, it is important to explore the individual level factors that cause non-adherence within the treatment, socio-cultural, health care context.

### **2.4 Research Objectives**

The general objective of this study is to identify factors that determine adherence or non-adherence of young adults to ART treatment in Nigeria. Following the literature review, the specific research objectives for this study are:

- To identify the individual and socio cultural factors which affect young adults' adherence to antiretroviral treatment.

- To identify how health care and treatment factors affect antiretroviral treatment adherence among young adults living with HIV/AIDS.
- To identify the knowledge, motivation and skills available for young adults non-adherence to antiretroviral treatment.
- To explore how these individual level and socio-cultural, treatment and health care factors are related.

## **CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY**

This chapter presents the various research methods of data collection and research analysis approaches employed to answer the research questions. The first section of this chapter presents the study area and setting of this study, followed by the methods of data collection, elaboration of the methods of data analysis of the generated information. The final section is a description of the various problems encountered and the ethical issues that manifested during this study.

### **3.1 Study Area**

The study was conducted in Yaba council area of Lagos in Nigeria. Nigeria is divided into six geopolitical zones of which Lagos is situated in the south-south geopolitical zone. Lagos geographically is located at 6° 27' 11 N and 3° 23' 45 E, and it is bordered by Benin Republic in the west, Atlantic Ocean in the south and Nigerian states in the North and East. Lagos is the smallest state in Nigeria and covers area of 356,861 hectares of which 21% is wetlands, and it is the most populated state and the centre of Nigerian economy with a population of 17 million people. Lagos is one of the fastest growing cities in the world and the most populated city in Africa after Cairo in Egypt (UN-HABITAT, 2008). Lagos is divided into 20 local government areas (LGA), which are further grouped into five administrative divisions (Badagry, Epe, Ikeja, Ikorodu and Lagos). The study area of this research, Yaba, is situated in Surulere LGA in Lagos Division. Yaba is one of the local development council areas in Surulere LGA Lagos State, and has number of higher institutions located in it for example the University of Lagos, Queens College, Nigerian Institute of Medical Research, Yaba College of Technology etc. In Lagos, Yaba has one of the busiest markets- Tejuosho Market. The specific study area is the APIN clinic/Nigerian Institute of Medical Research (NIMR) located in Yaba. Nigerian Institute of Medical Research is a government agency of the Federal Ministry of Health Nigeria and has five research divisions (Biochemistry, Clinical Sciences, Microbiology, Molecular biology/genetics, and Public Health). NIMR has two specialised units which specifically deal with patients living with HIV. The units are Antiretroviral Clinic (supported by Harvard School of Public Health funded by APIN/PEPFAR programme) and Human Virology Laboratory (managing people living with HIV/AIDS). The decision to choose this institute is based on the fact that it is, the best funded outpatient HIV clinic and accommodates the highest number

of HIV patients undergoing treatment in Lagos State ([www.nimr.gov.ng](http://www.nimr.gov.ng)). A map showing the study area and setting of this research is visualized in figure 1 below:



Figure 2: Showing the location of Yaba in Surulere LGA of Lagos State.

(Source: <http://aderemiadeboyejo.wordpress.com/2011/01/24/map-of-lagos-state/lagos-map2/>)

### 3.2 The health care setting and adherence support

Information on the organization of care was obtained through a stakeholder analysis, document analysis and observations at the treatment side. APIN Clinic/NIMR is an outpatient clinic funded by US President's Emergency Plan for AIDS Relief (PEPFAR). Patients attend the clinic because it serves as a referral clinic. It is a research institute with the state of art blood screening equipment for HIV confirmatory test. The staff in APIN Clinic/NIMR sign confidentiality forms and therefore do not stigmatise patients compared to general hospitals. 1,600 patients access treatment at NIMR. The hospital is equipped with infrastructure for haematology, immunology, CD4, viral load and serology tests. The clinic has 10 nurses, 16 doctors, 7 counsellors and 10 laboratory technicians.

In this study stakeholders were identified to fully understand how care is organized and provision of care to the patient during treatment start and follow up in APIN Clinic/NIMR Yaba, Lagos. Stakeholder is a person, organisation or group of persons who have interest in a concernment (for example project activities, health programme) or particular resources (de Groot, Stuip, Finlayson, & Davidson, 2006). In this study a stakeholder is an individual who controls and executes health programme or individual who is affected directly or indirectly by a programme. Four stakeholders were identified with relevance to organizing care, care giving and managing the system.

First, young adults are the target population of the study and are directly involved in the issues of adherence and use of the anti-retroviral drugs. They receive care for antiretroviral treatment and are equipped with relevant information through counselling from the counsellors and nurses. The next category of stakeholders include doctors, nurses, counsellors and clinicians. Responsibilities of these health workers in care giving for the young adults involve co-ordination and administration of antiretroviral treatment in APIN Clinic/NIMR. They possess adequate knowledge about antiretroviral treatment which is disseminated to young adults living with HIV/AIDS. They also have the task of providing treatment advice for young adults living with HIV/AIDS, counsel and educate patients on antiretroviral treatment adherence. This care is delivered by providing 3 weeks anti-retroviral treatment adherence counselling for young adults before they start receiving treatment. A document analysis revealed that the pre-antiretroviral treatment counselling classes are carried out with five manuals such as “HIV Basics” and “What AIDS is”. These documents are used by the counsellors to educate young adults what HIV/AIDS is, how HIV is transmitted from one person to another, the role of CD4 T Cells and viral load, and so forth. Young adults on treatment undergo information update counselling on treatment with nurses and doctors when they come for their regular appointments. In APIN Clinic/NIMR each patient is assigned to a counsellor. Hence, informing the patient and supporting adherence seems to be well-organized in this setting.

In relation to managing the system at the APIN Clinic/NIMR, other stakeholders are two tiers of government involved in HIV/AIDS campaigns in Nigeria (the state and federal government). There is the national body called NACA which provides interventional strategies for control of HIV/AIDS in Nigeria. With respect to this study, the state government (Lagos State) is involved in initiatives on HIV/AIDS are less directly involved in the clinic’s activities except for overall clinical obligations to the society. The state government provides funding for the support groups that deal with young adults living with HIV/AIDS.

Non-governmental organizations and support groups are stakeholders armed with knowledge about the needs and challenges of young adults living with HIV/AIDS. Some young adults are members of support groups and non-governmental organisations. They provide social support for young adults living with HIV/AIDS. This includes raising awareness about HIV/AIDS, empowerment through skills acquisition and psychological help to overcome stigmatization.

### **3.3 Methods of Data Collection**

Due to the nature of the research, qualitative interviews with young adults were used to generate data. The rationale behind this is to gain insight on the different factors affecting antiretroviral treatment adherence among young adults living with HIV/AIDS. A purposive sampling method was used to select the sample population from among the eligible patients. This was done by selecting the first 28 young adults from the clinic register who were approached by counsellors for study participation.

#### **3.3.1 Inclusion and Exclusion Criteria**

The inclusion criteria involved recruiting young adults living with HIV/AIDS between the ages of 18-21 years who have been on antiretroviral therapy for a period of 1 year and are receiving treatment at APIN Clinic/NIMR. Eligible patients with informed consent were recruited and their anonymity was not revealed.

#### **3.3.2 Interviews**

Interviews were conducted to have in-depth knowledge on the aim of this study. This method was used to generate primary data on topic of this research and also to assess the views of young adults living with HIV/AIDS. A semi-structured interview was conducted with young adults living with HIV/AIDS to examine their perception, experience and views with adherence to antiretroviral treatment and challenges facing they face with adherence. A semi-structured interview was conducted to create a room for flexibility but the primary aim of the interview was retained.

In total 28 young adults living with HIV/AIDS were interviewed in order to assess their view. The interviews were recorded and transcribed ad verbatim. The data generated were coded according to the following themes and analysed with the theoretical framework.

The coding strategy involved grouping the data according to the theoretical framework described in the introduction (i.e., individual, regimen, socio-cultural and health care related factors) The interview schedule is described in Appendix (1).

Besides factors affecting adherence, young adults were also asked to report their medication intake. In this study, adherence was defined as taking antiretroviral medication at the right time according to the doctors' recommendation (WHO, 2003). According to Kwara, Flanigan, & Carter (2005) non-adherence means incorrect use of a drug, missing the dose of a given drug and missing the time intervals. Adherence in this study was measured using the patients self-report. This method requires patients to report their adherence by answering questions on their adherence to treatment by recall of four days, one week and one month

(Horizon/Population Council, International Centre for Reproductive Health, & Coast Province General Hospital, 2004). In this study, the recall method of one month was used by asking respondents this question “In the last one month did you miss your antiretroviral medication?”

### **3.3.3 Interview setting and procedure**

Young adults living with HIV/AIDS receiving treatment at NIMR/APIN Clinic are the respondents of this study. Qualitative research design was used to find out the different factors affecting antiretroviral treatment adherence among this target group. The interview schedule was constructed with established information from the theoretical framework and literature review on the different factors affecting antiretroviral treatment adherence. The interviews were conducted in NIMR/APIN Clinic counselling room. The interaction was strictly between the interviewer and interviewee. 28 young adults were interviewed, face to face interviews were conducted. Semi structured interviews gave the respondents flexibility to express themselves using slogans and non-verbal expressions. At the beginning of the interview, the interviewer made respondents feel comfortable answering questions by informing them that their identity will not be revealed in the study. The respondents were asked several questions on individual, socio-cultural, health related and behavioural skills related factors which affects their adherence to antiretroviral treatment. The interviews lasted for 45 minutes to 1 hr and they were conducted in English. Though a female respondent who complained about depression and feeling of death talked for 2 hours during the interview.

### **3.4 Ethical approval**

Ethical approval for the study was sought from the management of APIN/NIMR Clinic. At the time of enrolment an informed consent from young adults living with HIV/AIDS who participated in this study was obtained. The objective of the research will be explained to the respondents and their consent will be obtained. The purpose of the study was explained to the respondents. Respondents were given the informed consent form to sign. The information they provided was confidential and their identity protected. In the final document, their names and identity were grouped as Participant A, B, C. The tape recorder containing information is stored in a safe place after the interview for 9 months, after which it will be destroyed. Their response was collected with a tape recorder and analysed using code numbers created by the researcher. The information is not in any way identified with the respondents: it will remain confidential and will not be disclosed. No physical, social or

economic risks were posed to participants of this study. The participants were informed before the study started that they were free to withdraw from the study without any prejudice

### **3.5 Limitations of the Study**

Initially when I went to NIMR/APIN clinic, the hospital staffs were not friendly. There was high level of resistance and uncooperative behaviour. They were not ready to give me information on how to approach young adults for the study. When I finally identified my target group, the respondents thought I want to use the data for personal reasons such as getting funding from abroad. It took me a lot of talking and explanation before the respondents shared their experiences on living with HIV/AIDS and issues related to antiretroviral treatment adherence.

## CHAPTER FOUR: RESULTS

### 4.1 Demographic characteristics of respondents and adherence among the respondents

In line with focus of the study on young adults, age of the 28 respondents interviewed was between 18-21 years, with the higher percentage being 21 years old (12 respondents 21 years; 4 respondents 20 years and 12 respondents 18 years old). Both males and females were interviewed, but 18 of the respondents were females and 10 respondents were males. Marital status of the respondents shows that, only one of the youth is married, while the rest are single patients. Relatively, occupational distribution of respondents shows 12 of them to be self-employed in petty trading, apprenticeship to middle income businesses. Six respondent are skilled labourers and employed with the exception of 10 un-employed. Information provided on the economic status of the families of the respondent indicates that all of them come from middle class families, with only three from wealthy families. Most of the patients interviewed live with their parents and access treatment from there, with the rest living alone or with friends. Literacy level of the patients is average, as 9 of them have tertiary education and 19 of them do not have more than secondary education. Beliefs of the patients were also documented and 18 of them are Christians and the rest ten are Muslims. Family types of respondents show 2 from polygamous families, while the rest 26 are from nuclear families. Through interviews with 28 young adults treated for HIV in APIN Clinic/NIMR, the results revealed that 23 out of 28 young adults reported non-adherence.

### 4.2 Information on adherence

With respect to information on the functioning of the antiretroviral treatment, most of the respondents gave their opinions. All the patients in these interviews claim to possess knowledge of how the medication works. They attributed this knowledge to the three weeks antiretroviral treatment adherence counselling they received before initiating treatment, which is indicated by statements such as

*“I learned a lot from the adherence counselling class” (Female, 20 adherent)*

*“It makes me to be knowledgeable about antiretroviral treatment” (Female, 20 adherent)* To verify whether they indeed possessed the accurate knowledge, a follow up question was asked if they know the consequences of not taking their antiretroviral medication regularly. All of the patients were very clear in their understanding of the consequences.

*“It is better not to start at all than to start and stop (Female 21, adherent)*

*“The consequences are grave, every sickness that passes by will catch you when you don’t take your drugs” (Female 20, adherent)*

*“You will have drug resistance and they will change drugs for you, it is a costly mistake because if you miss on first and second line regimen third line regimen is very expensive” (Male 18, adherent)*

A follow up question was asked whether they have missed their drugs in the last 1 month. Five of them are adherent to their medication and always mindful of it. Some of the responses given are presented.

*“I don’t miss my drugs” (Male 18, adherent)*

*I can’t be lazy for taking my drugs” (Female, 20 adherent)*

*I take my drugs 6.00 in the morning and 6.00 at night” (Female 20, adherent)*

*I make sure I take my drugs every day” (Male 18, adherent)*

*I can’t miss my drugs, it is like playing with fire” (Female 21, adherent)*

The consequences of missing the regimen plan and non-adherence thus seems to be well understood by the patients undergoing ART treatment, and the intensive 3-week educational course seems to be very useful in this respect.

#### **4.3 Motivation for Adherence**

The respondents were asked to explain the reasons that motivate them in taking their drugs and adhering to the medication on daily basis. Factors such as the provision of free treatment, information received from counselling, friends and family support, cordial relationship with doctors at the clinic were identified by patients as important factors that motivate patients to continue taking the antiretroviral treatment. Other reasons given by the respondents include the fear of death and also going back to the former sickly state before they began using the drugs. These factors are captured in the responses of the patients.

*“The feeling of fear and death motivate me to take my drugs regularly” (Female 21, non-adherent)*

*Whenever I remember how my health changed from the time I was very ill to the period I started medication I always get encouraged to continue with treatment” (Female 20, non-adherent)*

*“The doctor told me not to fail my drugs, I always remember his advice, I used to be very sick when I tested positive, I don’t want to go back to that stage again” (Male 18, non-adherent)*

Young adults claimed that Family and friend support motivates them to adhere to antiretroviral treatment, this reflects in their responses below.

*“My mother’s encouragement is my motivation to continue with my drugs” (Female 18, non-adherent)*

*The support I receive from my family motivates me to take my drugs” (Female 21, non-adherent)*

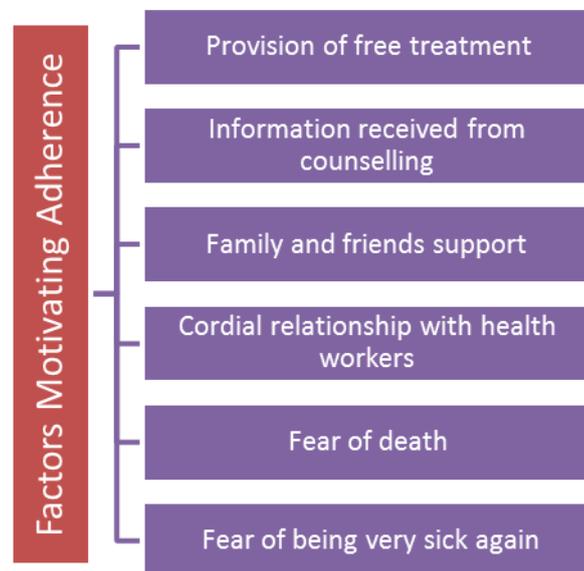


Figure 8: Factors Motivating Adherence in Young adults

As mentioned above during the interviews, when patients have adequate knowledge, good advice and relationships with the health workers, and support from family members, friends and acquaintances is available, sticking to the drugs is possible. This is an important factor that helps address non-adherence.

#### **4.4 Factors Demotivating Adherence**

Patients who live far away from the clinic complained that the far distance to the clinic hinders their adherence to treatment while some cannot even afford the high transport cost to go to the clinic. Most respondents reported stigmatization as a barrier to adhering to their ART because of the fear that society might turn against them. Some respondents reported

forgetfulness as a factor responsible for non-adherence. They claimed that they are willing to adhere but they often forget to take their drugs along while they are going away from home. Most respondents reported the usual long waiting hours as at the clinic as demotivating, tiring and time consuming which sometimes discourages them from coming to the clinic for the drugs. Some of the respondents reported lack of food as demotivating factor because they sometimes feel very hungry after taking the drugs and for that reason, they avoid taking their drugs if there is no food available at that time.

Side effects of the medication are a major demotivating factor for non-adherence to antiretroviral treatment. These factors are captured in the quotes below.

*“The side effects of the drug discourages me” (Female, 20 non-adherent )*

*“The waiting time in the hospital is long”(Female 20, non-adherent)*

*It takes me 9 hours to get to the clinic (Male 21, non-adherent)*

*“Anyday, I don’t have food, I cannot take my drugs”(Female 21, non -adherent)*

#### **4. 5 Adherence Behavioural skills**

Findings from the interviews revealed that young adults living with HIV/AIDS between the ages of 18 -21 years can administer the antiretroviral drugs by themselves and according to the doctor’s prescription. Possible challenging situations that could hinder collection of the drugs, carrying them along or taking them on time were also looked into. Most of them did not see any challenge in this, as it is not written on the drugs that they are for HIV/AIDS patients. The following issues were considered with respect to their behavioural skills; the ease of collection of drugs, ability to carry it around and the knowledge to minimize side-effects.

Some patients believe people use and carry drugs around as well for other ailments and diseases. Therefore, carrying the drugs around was not perceived by everybody to be a major barrier, which is illustrated by the following quote.

*“No challenge with my drugs, I am happy” (Female 20, adherent)*

*“No challenge, I can carry my drugs around If you go to my house you will see it” (Male 21, adherent)*

*“I am confident and I carry it around” (Female 21, adherent)*

Apparently, from the responses above, the respondents that influences their behavioural abilities in terms of being able to get the drugs and carry the drugs around, which in turn may affect their adherence to the ART treatment.

Possession of adequate behavioural skills is critical if young adults must be adherent to antiretroviral treatment.

A lot of respondents opt out of the treatment when they cannot cope with the side effects. However, all the respondents said they have knowledge on how to minimise side effects due to the counselling they received before initiating treatment.

*“The counsellors taught us on side effects of drugs such as tingling in hands and feet, skin rash and diarrhoea” (Male 18, non-adherent)*

*“For my own case I have skin rash so I use calamine lotion for it” (Female 21, non-adherent)*

*“The drugs make me to have blurry vision so I stopped taking drinks with caffeine” (Male 21, non-adherent)*

#### **4.6 Individual Factors affecting adherence**

Respondents reported on their beliefs and benefits in the efficacy of antiretroviral treatment. Majority of them believe it is very effective if it is taken as prescribed, as they could see marked differences between when they were not accessing the treatment and when they started. Excerpts of some of the responses of the patients are presented below.

*“Antiretroviral treatment gives me a life span, it helps me to fight other diseases working” (Female, 21 adherent)*

*“The change in the way I look shows that the drug is working like magic” (Female, 21 adherent)*

*“Ever since I started this medication, I have never been hospitalized I have not had malaria or typhoid” (Female, 21 adherent)*

*“Before I was like a skeleton but when I started my drugs then I have great change, now you can see my cheeks, I am fat” (Male, 20, non-adherent)*

Two of the respondents said that they initially thought ART was ineffective and for that reason tried traditional medicine. They went back to ART because their condition was getting worse; the belief was that traditional medicines will remove every trace of HIV virus from their blood. Another group believed that ART cannot permanently solve their problem and that their faith in God can completely heal them of the HIV infection. Therefore they abandoned their treatment and relied on “divine healing” through prayers.

*“I stopped taking my drugs because I had so much diarrhoea, I went to church and I believe in God and I think he will do a miracle” (Male 18, non-adherent)*

*“I switched to traditional medicine, I later came back to the hospital in a wheel chair” (Female 18, non-adherent)*

This group also claimed that their condition was getting worse and that is the reason why they went back to ART.

Some respondents reported forgetfulness as a factor responsible for non-adherence. They claimed that they are willing to adhere but they often forget to take their drugs along while they are going away from home.

*“Sometimes you can forget and you may travel without planning ahead” (Male 18, non-adherent)*

*“Let’s assume that you planned well and take your pills for a week and stay longer than that, these things happen” (Male 18 non-adherent)*

*“There was a point in time, I left my drugs at home, I was at work and I didn’t take it that morning but in the night I took it” (Male 18, Non-adherent)*

A female respondent expressed her disappointment with ART because it makes her feel sad and depressed.

*“Since I started taking my drugs, I have feeling of sadness all the time” (Female 21, non-adherent)*

#### **4.7 Socio-Cultural Factors affecting adherence**

Patients living with HIV infection may fear to disclose their status to family members or friends due to fear of negative reactions from them. Questions on what their experiences were like and how it affects them emotionally were asked.

*“The fears are real because when you tell people if they are not educated about HIV they will maltreat you” (Male 18, non-adherent)*

*“The fears are real, I am afraid because of stigma” (Female 21, non-adherent)*

*“I feel bad sometimes and I will be crying for hours” (Female 21, non-adherent)*

Social support to young adults undergoing treatment plays an important role in their adherence. Three respondents reported that their family members remind to take their drugs on time.

*“My brother reminds me to take my drugs” ‘He calls me on phone by 9am in the morning and 9 pm at night because I take my drugs twice daily”(Female 21, non- adherent)*

*I come for my appointments with my elder sister (Male 20, non- adherent)*

*My mother encourages me not to give up and supports me financially (Female 21, non-adherent)*

From the information gathered from the respondents, stigma, however, also seemed to have a potential detrimental impact on adherence. Young adults reported that they had problems taking their drugs because of the presence of their peers, others risk losing their jobs and being castigated by the society. These the patients believe influences the way they take the drugs, where they take and why they miss taking it sometimes. For example, two male respondents said,

*“They may fire me in the office if they find out so I delay taking my drugs for several hours till my break time. I hide in the toilet to take my drugs because of stigma” (Male, 18, non - adherent)*

*“I face stigma because people noticed that I take drugs at a particular time of the day. I face stigma but I don’t allow that to bother me, I am a normal human being” (Male, 18, non-adherent)*

Stigmatization within the immediate family also poses some form of psychological problems to the patients, as they do not use same utensils such as spoons, plates and forks with other members of the family.

*“It took me a year to be free from stigma in my own home my parents separated my plates and spoon from other peoples own I am stigmatised by my family members, they instructed my younger siblings to stay away from me.”(Female 21, adherent)*

*“I am sharing apartment with my friend, due to this, I hide my drugs all the time, if she discovers that I am living with HIV she will ask me to leave the besides she pays bigger part of the rent”(Female 21,non- adherent)*

On issues relating to social barriers, respondents admitted that they face social barriers and also devised means of dealing with them.

*“When I see that I am in the midst of people. Then I have to wait till the time I close from school. On my way going home, I will put in my mouth and swallow it” (Female, 20 Adherent)*

All the respondents were asked if they have family support or any other social support in their adherence to antiretroviral treatment. Often times, they have support from different groups and some do not.

*“I told some of my relatives and they have supported me” (Male 18, adherent)*

*My mother is very supportive” (Female 20, adherent)*

*“My friend supports me” (Female 21, adherent)*

*“The support group is the only family I have” (Female 21, adherent)*

Three other respondents reported that their family members remind to take their drugs on time. For example, a respondent said this,

*“My brother reminds me to take my drugs. He calls me on phone by 9am in the morning and 9 pm at night because I take my drugs twice daily” (Female 21, adherent)*

Social support to young adults undergoing treatment plays an important role in their adherence. Three respondents reported that their family members remind to take their drugs on time. In addition, all the participants want to live, and despite high levels of perceived stigma fear does not seem to affect them going to the clinic. Stigma remains a major challenge to adherence, however, and some respondents device effective means of coping with it. The majority of the respondents reported to have family support and this was a motivating factor for adherence to antiretroviral treatment.

#### **4. 8 Regimen Factors**

The respondents reported that they have difficulties adhering to antiretroviral treatment due to side effects and other reasons such as pill burden. A substantial number of young adults also had Tuberculosis treatment, and they complained about the pill burden. They have to take Tuberculosis drugs early in the morning without food before taking the antiretroviral medication. A considerable number of side effects were also identified to be experienced by the respondents based on the use of the drugs. Some of the highlighted comments are given below.

*“The side effects are not easy, I have headache every day because of my drugs but I have to continue” (Male 18, adherent)*

*“I missed my drugs for two months I stopped taking my drugs in May, 2011 because of rashes all over my body” (Male 21, non-adherent)*

*“I missed my drugs because the pain in my stomach was too much. (Male 21, non-adherent)*

*“I stopped taking my drugs because I had so much diarrhoea, (Female 20, non-adherent)*

*“The tablet causes me so much itching that was why I stopped taking my drugs I put my drugs in the drawer and I never opened it” (Male 21, non-adherent)*

Some reported that they can cope with these side effects while others said that they stopped treatment due to side effects and try to get back to treatment.

Possession of adequate behavioural skills is critical if young adults must be adherent to antiretroviral treatment. A lot of them opt out of the treatment when they cannot cope with the side effects. However, majority of the respondents said they have knowledge on how to minimise side effects due to the counselling they received before initiating treatment.

*“I pass out gas through my vagina, a foul smell, it discourages me sometimes” (Female 21, non-adherent)*

*“Recently my breasts started growing big and it is painful. I am a young man, this is very embarrassing, the doctor said it is the side effects from the drugs” (Male 19, non-adherent)*

*“Take a look at rashes all over my body, I scratch till blood starts coming out of my body” (Female 20, non-adherent)*

Despite these side effects experienced by the patients, they were of the opinion that they have to keep using the drugs to stay alive.

#### **4. 9 Health care provider related factors**

Services offered by the health workers were identified to play certain roles in adherence of respondents to their medication. Some people were really satisfied with the health care provided, others have complained about a shortage of care and lack of good and adequate services and communication with patients. The waiting times at the hospital for treatment and accessing drugs was identified as one of the issues due to shortage of health workers with respect to the number of patients to be attended to. Responses of the patients on this differed,

*“It has improved now, it is faster, the doctors always ask me about my body and how I feel” (Female 20, adherent)*

*“Collecting my drugs depends on when they will call you. Sometimes doctors are not many, Sometimes nurses are not many. The waiting time is long” (Female 20, non- adherent)*

*“Sometimes only 2 doctors report for duty, this makes it difficult for the patients because I to wait for hours before it get to my turn”(Male 18, non- adherent)*

Availability and proximity of the treatment to where the patients live were also put into consideration. On question of the location of the treatment centre to where they reside, some of the respondents have the following to say.

*“It takes me 3 hours to get to the clinic” (Female 20, adherent)*

*“The distance from my house to the hospital is very far”(Male 18, adherent)*

*“I wake up around 4 am to come to the hospital, early you come, early you go” (Female 20, adherent)*

Availability of drugs for treatment and access by the respondents was recorded to be no issue, as all the respondents agreed to the fact that, drugs are always available in abundant quantities.

*“There is no time I come here and they say there are no drugs” (Female 20, non- adherent)*

*“NIMR has drugs all the time, enough drugs” (Male 18, non- adherent)*

From the above responses, far distance to the clinic demotivates most patients from adhering to their drugs as it is inconvenient to leave home as early as 4 am in order to arrive the clinic on time.

The relationship with the health care providers can be very important to patients. In situations where patients receive good and adequate attention, it goes a long way in boosting their morale towards visiting the clinic and using their drugs. Patients reported that the cordial relationship they have with the doctor motivated them to take antiretroviral treatment regularly. Most of the respondents maintain that they feel very open and have some trust in the health workers. The communication style between the patients and health workers is usually informal, which makes them calm and free to express themselves. But, some respondents still stated that the Nurses are rude and shout at patients sometimes. Excerpts of the views of the respondents are recorded below.

*“I feel free with them, we play and crack jokes, here is one of the best hospitals, heaven is next to their gate, they are very friendly here, and some of my friends who go to general hospitals are stigmatized” (Female 21, adherent)*

*“The Doctor informs us that we have a right to ask questions, so whenever I go to the hospital I am free to ask my doctor questions even if I forget, on my way home, I can call him on phone and he will tell me what to do” (Male 18, adherent)*

*“I can remember when I was having running stomach I called the doctor around 2 am and he told me what to do” (Female 21, adherent)*

Another health care provider factor which affects young adults adherence to antiretroviral treatment is rudeness from the nurses. The nurses are rude especially when there are many patients and few nurses on duty so they have a lot of work to do. Young adults reported that sometimes they shout at them or are rude to them when they ask questions on their card or clarification on treatment.

*“Sometimes the nurses are very rude; maybe it is because of overwork” (Female 21, non-adherent)*

*“The nurse shouted at me last time I came for drugs” (Female 21, non-adherent)*

Hence, it seems that the health care setting is well-organized and that the personnel is well trained, by that a high workload can affect the communication and therefore the relationship between the patients and the health care providers.

## CHAPTER FIVE: DISCUSSION

The survival of people living with HIV/AIDS is predicted by antiretroviral treatment adherence and the major obstacle in the fight against HIV/AIDS is poor adherence (Mills *et al.*, 2006). Erah *et al.*, (2008) in their review on young adults living with HIV/AIDS in Nigeria reported that there is poor knowledge of HIV/AIDS among young adults living with HIV/AIDS and this largely affects adherence. This group is vulnerable to the infection and constitutes about 50% of the infected population. Against this background, the aim of the study was to identify the factors affecting antiretroviral treatment adherence among young adults living with HIV/AIDS in Nigeria.

Therefore the following objectives were identified as the focus of the study:

- To identify the individual and socio-cultural factors that affect young adults adherence to antiretroviral treatment
- To identify how health care related and treatment factors affect antiretroviral treatment adherence among young adults living with HIV/AIDS.
- To identify knowledge, motivation and skills available for young adults adherence to antiretroviral treatment adherence.
- To explore relationships between individual and treatment, health care and sociocultural factors.

The interviews revealed that the major causes for non-adherence were at individual factors, socio cultural factors, the medication regimen, and health services and patient-doctor relationship. These factors are discussed in more detail in this chapter, followed by a critical reflection on the research performed, and end with conclusions as well as recommendations for future research and clinical practice. The discussion is organized in factors that promote adherence and barriers to adherence.

### 5.2 Factors affecting Adherence

#### 5.2.1 Individual Factors

Patient's knowledge and belief motivates their adherence to ART. From the results of this present study, young adults have strong beliefs that the antiretroviral treatment they take has a positive outcome. The young adults reported benefits of antiretroviral treatment which manifests through the improvement in health, increase in weight and reduction of opportunistic infections, which motivates them to adhere to treatment. According to the Information Motivation and Behavioural Skills Model, patients beliefs about the efficacy of the treatment they are taking motivate them to adhere to the treatment (Mills, et al.,

2006). These findings are in agreement with Fisher et.al, (2006), where a relation was observed between perceived benefits of antiretroviral treatment and treatment adherence.

Besides knowledge and motivation, adherence to ART treatment requires a number of behavioural skills. These are skills for administering antiretroviral treatment, incorporating regimen into daily life, minimizing side effects and acquiring social support. Young adults interviewed confirmed that they can administer the antiretroviral drugs by themselves. From the observation carried out in this study, young adults were seen taking their medication. They reported that they have the ability to take the drugs according to doctors' prescription. Only 2 respondents are not able to follow the regimen and incorporate it into their daily lives as prescribed because most of them are dependent on family members, friends and relatives financially. Therefore, this study confirms that young adults are able to self-administer drugs and possess the necessary skills on how to deal with side effects.

However, other individual factors demotivating adherence are also identified in this study. Some patients reported lack of food as factor against adherence because they feel hungry after taking their drugs and therefore would not take the drug if they cannot afford to buy food at that time. As reflected in the literature review in this study from previous studies carried out on adult population. Malcolm, Ng, Rosen, & Stone (2003) stated that depression is a major factor affecting adherence but in this present study, only a female respondent reported depression as a factor demotivating her from adhering to ART which implies that depression could be a factor but cannot be regarded as a major factor affecting adherence to ART among young adults in Yaba. Another major factor as revealed by the respondents is forgetfulness. They usually forget to take their drugs along with them mostly when they are on a long trip away from home. Patient's beliefs could also demotivate adherence because some patients believed that alternative means of treating HIV/AIDS could be more effective than ART and for that reason; one abandoned her ART for traditional medicine while another believed that prayers can miraculously heal him of the virus completely but their health conditions got worse and went back to ART.

### **5.2.2 Socio-cultural Factors**

It has been reported that other motivating factors include expression of love from family members, support group and friends (Murphy, Wilson, Durako, Muenz, & Belzer,(2001). In the present study, the majority of the respondents did not belong to any support group, they rely only on support from family and friends. In another study, it was revealed that some patients have complained about lack of emotional/ psychological support from friends and

family members which resulted in abandonment (Mukhtar-Yola, et al., 2006; Olowookere, et al., 2008; Skhosana, et al., 2006; Uzochukwu, et al.). This study disagrees with this finding, as no respondent indicated abandonment as a factor affecting adherence to their antiretroviral treatment. In fact, they reported a high level of family support. This support was not only emotional, but also practical. For example, family and friend provided money to pay for hospital transport costs, gave phone calls as reminder for treatment, and accompanied young adults to hospital appointments. Patients described these forms of social support as very motivating for adherence.

In relation to socio-cultural factors demotivating patient's adherence, stigmatization is widely reported by the respondent as having severe psychological effects on them because it jeopardizes their chances of being economically empowered. This study showed that disclosure is a major socio cultural factor as majority of respondents would prefer not to disclose their status to others apart from their family and friends. For instance, most respondents reported that they will prefer not to tell their colleagues about their status at work because of the fear of being sacked. It was revealed by some of the young adults that the risk of losing their jobs, being alienated by friends and neighbours often affects the routine intake of their drugs in the public. This makes them take their drugs only when they are away from these people, which is a barrier to adherence. Some respondents opined that they stand no chance of getting a job if the employer is aware that they are HIV positive and for that reason will prefer to keep their status secret.

### **5.2.3 Health care and treatment related Factors**

From this study, it is revealed that the doctors are friendly, there is open communication. A three weeks treatment adherence training is organised in order to improve patients' knowledge of ART and to enhance adherence. Respondents confirmed that the training is helpful to them. On the other hand, the number of nurses to attend to the patients is limited, this puts a lot of pressure on both the nurses and the patients as patients waits for hours before they are attended to while the nurses could not attend to the patients as friendly as they desired. Most respondents reported that the nurses are rude and impolite to them which they find demotivating. A health care barrier in this study was the far proximity and high transport cost to get to the clinic which is another major factor leading to non-adherence. Majority of the respondents reported that they could not afford the transportation cost while some who can afford the cost often come late due to reported difficulties in making it to the clinic because of the travel distance.

Regimen factor is widely reported by the respondents that they experience side effects from ART. Some claimed that they are able to cope with the side effects while others reported their inability to cope. These side effects include stomach pain, rashes, itching, head ache and hunger. Some patients reported that they normally stop taking the drugs when the side effects are severe and start again when the effect reduces. From the results, it is revealed that a combination of ART with other treatment such as treatment for tuberculosis leads to pill burden which respondents have identified as demotivating them from adhering to ART.

#### **5.2.4 Relationship between the Factors**

There is inter-relationship between identified factors affecting adherence. Patient's belief is identified as a socio cultural factor because naturally, society influences the individual's belief. However, belief in the context of this study is also identified as individual factor because belief could be influenced by the individual's perception. Similarly, claims by respondents that they feel hungry after taking their drugs and therefore prevents them sometimes from taking their drugs when there is no food available is seen as a regimen factor because hunger is a side effect while this could also be individual factor because inability to afford food at a given point in time is a problem at individual level.

#### **5.2.5 Conclusion**

This study identified factors which affect antiretroviral treatment adherence among young adults living with HIV/AIDS in Nigeria. Factors affecting young adults' adherence to antiretroviral treatment were divided into individual, sociocultural, health related factors and skills. This study discovered that young adults were on average knowledgeable about adherence and treatment, they had skills to comply with treatment, they could administer the treatment by themselves, and they had positive beliefs on the positive outcome of antiretroviral treatment. It is further revealed that patients enjoy support from friends and family on adherence to their drugs. However, some young adults were not adhering to their drugs due to health care related and treatment factors such as side effects of the drugs, far distance to the clinic and long waiting hours at the clinic. Other identified factors demotivating adherence include religious beliefs, disclosure and stigma.

#### **5.2.6 Limitations of the Research**

The research work was conducted to identify factors that affect adherence and non-adherence to ART treatment amongst young adults in Yaba, Nigeria. The sample space of the research work was not big enough to explore all the possible factors limiting adherence as some might not have been captured. A bigger sample space and time is important to explore all the

possible factors and experiences of young adults undergoing ART treatment in Nigeria. Also the setting, being in the city is quite different from the setting in rural places. Stakeholders considered in the study excluded the civil society and the government agencies that have stakes in addressing HIV/AIDS in Nigeria.

### **5.2.7 Recommendations**

This research work has been able to identify factors affecting adherence to antiretroviral treatments in young adults. Addressing these factors is possible and a number of recommendations have been made with respect to possible solutions.

- ☞ More personnel such as doctors and most especially nurses should be employed to attend to HIV/AIDS patients in order to reduce pressure due to work overload on the staffs. This will forestall unfriendly treatment by the nurses as reported in this study by the respondents.
- ☞ Stigma and discrimination are major stumbling blocks in antiretroviral treatment adherence, this can be reduced through family and community education.
- ☞ Economic empowerment through skills acquisition programmes provided to young adults and provision of jobs to earn a living. This is because youth unemployment is a serious problem in Nigeria and PLWHA even find it harder to secure jobs.
- ☞ Patients should also be monitored for treatment failure due to non-adherence and drug resistance and the second line treatment alternative should be adopted.
- ☞ Patients travel long distances and are exhausted by the time they get to the clinic. Government should provide clinic annex in strategic locations across the city as a means of bringing treatment closer to patients. In this case they will not need to travel far distance before accessing treatment.

Giving consideration to these factors and adopting pragmatic approaches towards addressing these factors may help to guide future research in adherence support programs, and possibly improve the adherence of young adults living with HIV/AIDS in Nigeria.

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# **APPENDICES**

## **APPENDIX I**

### **INTERVIEW SCHEDULE**

#### **1. INDIVIDUAL FACTORS**

- Do you know how this medication works?
- Do you believe that antiretroviral treatment you are taking is working for you?
- In the last one month, did you miss your doses?
- Which reason is responsible for this?
- Can you explain the reasons which motivate you to take your medication regularly?
- Do you know the consequences of not taking of not taking your antiretroviral medication regularly?
- Do you think that you can administer your drugs the medicines on time according to the doctor's prescription
- Do you experience side effects due to the intake of your medication
- How do you cope with these side effects?
- Can you explain the reasons that motivate you or demotivate you to take your medication every day?
- What are the challenging situations for you always collecting the medicines, carrying them along or taking them on time?
- What practical /social barriers do you face?
- How do you combine or manage your daily routine with your antiretroviral treatment?

#### **2. SOCIO-CULTURAL FACTORS**

- Do you think that the fears expressed by some of the patients are real?
- What is your own experience like?
- How does that affect you emotionally?

- How does that affect your behaviour, like going to the clinic, collecting your pills, carrying your pills around or taking them every day?
- Do you have your family support or any other social support in your adherence to ART?

### **3. HEALTH SERVICES RELATED FACTORS**

- What are your experiences about the health care provided to you?
- How are the waiting times at the hospital?
- Do you receive information and education about HIV and how to handle the treatment?
- What is the location of the treatment center to your house?
- Does your clinic always have medication available for you?

### **4. REGIMEN FACTORS**

- Do you experience any difficulty after taking your medication?
- How do you combine or manage your daily routine with your antiretroviral treatment?

### **5. PATIENT - DOCTOR RELATIONSHIP**

- How would you describe your relationship with your health care providers?
- What are the barriers and difficulties you face with treatment?
- Which give you strength and confidence to deal with the disease and adhere to the medication?
- What is your view about antiretroviral treatment?

- For how long have you been on antiretroviral treatment?

## **GENERAL QUESTIONS**

- Can you please share your experience with us briefly as a youth living with HIV?
- How did you get infected?
- How long you have been living with the infection?
- How did you start antiretroviral treatment?
- How you have been coping with your positive status?

## **DEMOGRAPHIC QUESTIONS**

- How old are you?
- What is your level of education (Junior school, High school, Tertiary Institution)
- What is your religion?
- What is your occupation? (Student, employed, self-employed, unemployed)
- Do you live in a rural area or in the urban area?
- What type of housing condition do you live in?
  - (i) Do you live alone?
  - (ii) Are you sharing an apartment with family members?
  - (iii) Are you living with your friends?
- Are your parents/guardian gainfully employed/self-employed?
- What type of family do you come from? (Nuclear or extended)

## APPENDIX 2

### Experience of PLWHA on Infection, Initiation of Antiretroviral Treatment and Coping with Positive Status

Transmission of HIV/AIDS virus occurs through different processes, this include heterosexual and homosexual sex, mother to child transmission, use of unsterilized equipment. All the respondents in this study reported different experiences of infection with HIV/AIDS, 12 respondents admitted that they were infected through heterosexual sex; other respondents claimed they cannot trace the source of their infection. They were explicit in saying that, they only got to know about their infection after experiencing some form of unusual health problems for which they had to be tested for HIV/AIDS. Health related problems that prompted their going for HIV/AIDS tested as claimed by the respondents range from malaria, loss of weight, general body weakness, problems with the eye, lumps on the neck to general body rashes. They also described that they how they have been coping with their positive status by having that feeling that antiretroviral therapy is a lifelong treatment. Some of the experiences of the respondents as captured during the interview are highlighted below.

*“In 2006, I developed lumps on my neck; they treated me with herbal leaves until part of my skin around the neck area started to fall off. The wound and scars on my neck almost disfigured me. When the herbal treatment was not working, my uncle took me to his office hospital, they ran tests on me. Thereafter the doctor referred me to Federal Medical Center in Owerri. The drugs they were giving me in the hospital did not work for me so they gave me a referral letter from to APIN clinic/NIMR. After I started treatment in APIN clinic/NIMR, I joined a support and since then I became stronger”*

*“I was tested in 2006, ever since I matured I have never had sickness. Suddenly, I became sick. The sickness was not going and my family started panicking My family friend took me to a private hospital and they said I was positive I took the test 2 to three times just to make sure. After that someone directed me to APIN clinic/NIMR, since then I have been taking treatment there and life as a positive person has been not been easy but constant taking of antiretroviral treatment and eating food and fruits helps me to live a normal life”*

On the occasion of testing positive to HIV/AIDS, experience of the respondents on initiation to treatment differs. It was quite not difficult for some to admit their status and start looking on the bright side of things to initiate treatment. Some were in a state of shock and could not

easily admit their status, as they claimed they could not recall any experience of being disposed to the infection. Others claimed that, after testing positive, they were ignorant of ways of accessing the treatment and proximity to treatment centres. Practice of, Knowledge and information on routine medical check-up is lacking in Nigeria and this not unconnected with inability of the citizens to pay for the service. It shows here that young adults only often get to know they are HIV positive when they get sick more often than normal.

Some respondents shared their experience on when they tested positive and started initiating treatment. This is linked to their ability to admit their status and begin to seek for treatment.

*“I was tested in 2006, my family friend took me to a private hospital and they said I was positive I took the test 2 to three times just to make sure, I stayed for a year before commencing treatment, I later started treatment in APIN clinic/NIMR in 2007”*

*“I tested positive to HIV through a voluntary test and I have taken it as one of those troubles of life, my doctor referred me to NIMR and I have been taking treatment there”*

*“When I tested positive to HIV, someone directed me to NIMR, I was placed on Septrin for 6 months before I started antiretroviral treatment, partaking in the counseling increased my confidence to live a normal life. HIV is not on my face, it is only a virus in my blood”*

After testing positive, young adults who admitted their status started accessing treatment, while those who struggled to admit their status delayed in accessing treatment. Thus, it is not because of non-availability of treatment centres or lack of information that prevented them from accessing treatment, but personal objection.

Living with HIV/AIDS as stated by the patients is about the worst thing that can happen to anybody. Their experiences on stigmatization have greatly affected them psychologically. They claim they suffer being stigmatized both by the society and their immediate family members. A lot of them recount their experiences after testing positive and how they were stigmatized.

*“I tested positive to HIV 3 years ago when I felt ill, I noticed that my family’s attitude changed, even my mother became very unfriendly and hostile. My parents separated my things from other members of the house, they kept my spoon, fork and plates separate far away from other peoples own. The hospital where I was going to for treatment referred me to NIMR Yaba and I have been on treatment since that time”*

*“I tested positive to HIV 2 years ago, I disclosed my status 6 months after I tested positive. My family was very angry with me, it was a difficult period in my life. Someone directed us to NIMR and since then I come here to collect my drugs”*

Stigmatization of PLWHA is often as a result of ignorance and societal belief about HIV/AIDS. Often times, people lack information on the mode of transmission and they tend to stay away completely from people infected. Meanwhile, others feel uncomfortable associating with a positive patients and not because they lack the knowledge of mode of transmission of the virus.

Nevertheless, some of the respondents had positive stories to tell about how their family members were supportive of them after being infected and testing positive.

*“I was falling sick every day and the hospital decided to run a test on me. It has not been easy, when I disclosed my status to my parents, my mum was of great help and she encouraged me. I know about NIMR before so I had to come and start treatment here”*

The statement above confirms that personal affection and family ties could also surpass the lack of information and societal belief in providing help for PLWHA.

## **APPENDIX 3**

### **Factors Affecting Antiretroviral Treatment Adherence among Young adults Living with HIV/AIDS in the NIMR/APIN Clinic, Yaba, Lagos.**

#### **INFORMED CONSENT FORM**

##### **Nigerian Institute of Medical Research/APIN Clinic- Lagos, Nigeria**

You are being invited to participate in a study that will be conducted at the Nigerian Institute of Medical research/ APIN clinic, Yaba Lagos.

##### **Purpose of study**

The purpose of the study is to identify more the factors affecting antiretroviral treatment adherence among young adults living with HIV/AIDS in Nigeria.

Participation in this study will not affect your treatment program in this clinic.

##### **Possible Risks**

There are no physical risks for participating in this study but time taken in answering some of the questions being asked.

##### **Benefits from participating in the study**

Participation in this study will not cost anything. There may be no direct benefits to your participation in this study. You will not receive any payment for participation. Participation in this study may provide benefits for the young adults. Exploring the factors affecting antiretroviral treatment adherence among young adults and adopting pragmatic approaches towards addressing these factors will help to improve the adherence of young adults living with HIV/AIDS in Nigeria.

##### **Confidentiality**

Your information will be handled in a way that will protect your identity and confidentiality. You will be assigned a study serial number that will not be linked to your identity. Only authorized persons involved in this study will have access to the study documents.

##### **Rights**

Participation in the study is voluntary and if you choose not to participate or to stop before completing the study, it will not affect access to your routine care and treatment in the clinic.

##### **Contact Information**

If you have more questions about this study, or any problem caused by participating in this study, you should contact the principal Investigator:

Mrs. Chinyere Okonkwoh

Phone no: 08037163579

##### **Questions about your right in this study may be directed to**

Name: Mrs Yetunde Oyelakin

Job title: IRB Secretary

**CONSENT STATEMENT**

Name of Participant: .....

I have read (or have been read to) and understand the informed consent for this research study (including the possible risks). I have been given a chance to ask questions about this study. I understand that I can withdraw my consent at any time for any reason.

Signature of participant: .....

Date: .....

Name of Researcher: .....

Signature of Researcher: .....

Date: .....

Name of Witness.....

Chinyere Okonkwoh  
Lagos Nigeria  
August 1, 2011

The Director General  
Nigerian Institute of Medical Research  
Yaba  
Nigeria

Dear Sir

**Request to carry out Master Thesis Research in your Institute.**

I hereby request for permission to carry out a research with Nigerian Institute of Medical Research on factors affecting Young adults adherence to Antiretroviral treatment.

I am enrolled as a Master student in Wageningen University, Netherlands.

Thank you for your approval.

Yours faithfully,

Chinyere Okonkwoh

**Letter of reference of Chinyere Okonkwoh**

To:

The Institutional Review Board  
Nigerian Institute of Medical Research (NIMR)  
Yaba, Nigeria

August 15, 2011

Dear Sir, Madam,

This letter serves to confirm that Chinyere Okonkwoh is an Msc Public Health and Society student of Wageningen University, Netherlands.

She is presently about to conduct her Master Thesis research on the topic "Factors affecting antiretroviral treatment adherence among youths living with HIV at APIN clinic/NIMR". We know from much research that for an effective treatment of HIV, adequate medication use and continuation of treatment is important. However, many patients struggle in retaining in care and taking the antiretroviral regimen as prescribed. In order to develop behavioral interventions to promote adherence and treatment continuation, it is necessary to have detailed insights in the barriers and facilitating factors of these behaviors. Little of such research has been done in Nigeria, especially among youngsters who may struggle most with their HIV status and treatment. I therefore think this research could be a value for the improvement of care.

I write this letter as her research supervisor on her request, to ask your good office to give her your support and assistance to conduct this research.

Thank you for your co-operation.

With kind regards,

Dr. Marijn de Bruin  
Assistant professor Intervention design & Behavior change  
Field expertise: Health behavior, adherence, HIV treatment  
Wageningen University, the Netherlands

