FACTORS INFLUENCING ACCESS TO ANTIRETROVIRAL TREATMENT IN BENUE STATE, NIGERIA

OMENKA, CHARITY OCHUOLE
STUDENT NUMBER 2831556

NOVEMBER 2010

UNIVERSITY *of the*
WESTERN CAPE

SUPERVISOR: PROF CHRISTINA ZAROWSKY

A MINI -THESIS SUBMITTED IN PARTIAL FULFILMENT OF A MASTERS DEGREE IN PUBLIC HEALTH (MPH), FACULTY OF COMMUNITY AND HEALTH SCIENCES, UNIVERSITY OF THE WESTERN CAPE, SOUTH AFRICA.

KEYWORDS

HIV/AIDS

Access

Antiretroviral therapy

Benue State

Barriers

Nigeria

Qualitative Research

PLWHA

Sub-Saharan Africa

Coverage

ABBREVIATIONS AND ACRONYMS

AIDS _ Acquired Immune Deficiency Syndrome

ART - Antiretroviral Therapy

ARVs - Antiretrovirals

BENSACA – Benue State Agency for the Control of AIDS

FGDs - Focus Group Discussions

HCT - HIV Counselling and Testing

HIV – Human Immunodeficiency Virus

LGA – Local Government Area

MTCT - Mother-To-Child-Transmission

NACA – National AIDS Control Agency

NASCP – National AIDS/STI Control Programme

OI – Opportunistic Infection

PMTCT – Prevention of Mother-To-Child Transmission

PLWHA - People Living With HIV/AIDS

ABSTRACT

At the end of 2008, Nigeria had the third largest number of people living with HIV/AIDS (PLWHA) in the world, with an estimated 2.95 million people and an average prevalence rate of 4.6%. According to the 2008 prevalence survey, prevalence rates in Nigeria's 36 states and capital ranges between 1.0% in Ekiti State, to 10.6% in Benue.

In Benue State, as at December 2008, only 12% of those requiring treatment were enrolled in an ART programme and only about half of the 23 Local Government Areas (LGAs) had a health centre providing ART services. There are several possible causes for poor coverage of ART services. This study explores some of the barriers preventing PLWHAs from accessing treatment in Benue State.

The study utilized a qualitative case study design to explore the problem of poor access to ART in Benue State. PLWHAs, policy makers, program managers and health workers were involved in an effort to describe the factors influencing access to ART in the State. Semi structured interviews, exit interviews and focus group discussions were used.

To analyse the findings, categorization was done into facilitators and barriers to access, in addition to the ways respondents believe these barriers can be overcome. Other sub-themes were also identified and sorted. Themes were linked to direct quotes from the respondents. Additional literature review was done to review available information on the themes identified.

Facilitators of access included free cost and increased number of sites; beneficial effects of ART; disclosure, membership in a support group and having a treatment partner. Barriers included stigma and discrimination; hunger, poverty, transportation and opportunity costs; hospital factors; non-disclosure; inaccurate knowledge and perceptions about HIV and ART; certain religious beliefs and advice; coverage, capping of services and fear of non-availability of ART. In addition to stigma, patients bypass closer ART access points to further away hospitals because of business opportunities; financial assistance; perceived better standard of care and hope that a cure, when found, will be more accessible to patients in bigger hospitals.

In conclusion, improving health worker attitudes through training; reselection of non-ARV drugs used in HIV management to ensure an uninterrupted supply; highlighting the importance of membership in a support group through patient enlightenment; working with religious leaders to reduce stigma and improve access; income-generating programs for patients; decentralization of ART services and upgrading of primary healthcare centres are important strategies to improve ART access in the state.

DECLARATION

I hereby declare that *Access to Antiretroviral therapy in Benue State, Nigeria* is my own work, and it has not been submitted for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged by complete references.

Full Name: Charity Ochuole Omenka

Signed

Date: November 2010

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

CHAPTER 1 GENERAL INTRODUCTION

1.1 Introduction

HIV/AIDS is the biggest public health concern worldwide. In 2007, an estimated 33.2 million people were living with HIV (67% of them in sub-Saharan Africa), 2.7 million became newly infected and 2 million lost their lives because of AIDS (UNAIDS, 2008). The epidemic causes tremendous human suffering, and has vast adverse effects on the economic growth, social and political stability and health systems of many countries as the infection so far has targeted mostly adults in the most economically productive age groups of 15-39 years (Idigbe, 2006). Although antiretroviral therapy (ART) is not a cure and it presents challenges related to adherence and toxicity, it has greatly decreased transmission and changed perceptions of HIV/AIDS as a plague to a manageable chronic illness (Palella, Deloria-Knoll, Chmiel, Moorman, Wood, Greenberg, et al., 2003, cited in WHO, 2003).

At the end of 2008 it was estimated that 2.95 million people in Nigeria were living with HIV/AIDS (Coker, 2009), making Nigeria the country with the largest number of people living with HIV/AIDS (PLWHA) in West Africa and the third-largest number of PLWHA in the world (UNAIDS, 2008). The first case of HIV was diagnosed in 1986. By 1999, HIV was diagnosed and reported in all 774 Local Government Areas (LGAs) of the country (PEPFAR, 2008). Anti-retroviral therapy (ART) programs began to be implemented by the Government of Nigeria providing ART at a subsidized rate from 20 sites in 2002. As at March 2009, as a result of expanded access initiatives, the number of sites had increased to 393 ART, 670 PMTCT and 1050 HCT (UNGASS, 2010).

1.2 Problem statement

ART coverage in Nigeria has improved from 11% in 2003 and 26% in December 2007 to about 34.7% in 2008 (WHO/UNAIDS/UNICEF, 2008; Coker, 2009). However, access remains dismally low in Benue State, the state with the highest prevalence rate in the country. In Benue State, as at December 2008, only 12% of the estimated 192,400 PLWHAs requiring treatment were enrolled in an ART programme and of the 23 Local Government Areas (LGAs) only 11 had a health centre providing ART services (Personal communication, Policy maker, Benue State AIDS Control Agency, March 2009).

Adherence and access were, and still are, the two major problems related to antiretroviral therapy in developing countries (Kebede et al., 2008 as cited by Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru, & Chukwuogo, 2009). Health professionals working within ART programs tend to concentrate on adherence issues since this is directly related to their own role. However, access and its determinants should also be an important concern because these same professionals are also often the champions of expanded ART (Monjok, Smesny, Okokon, Mgbere, & Essien, 2010).

I had heard a lot about adherence to antiretroviral drugs during my 3 years of work as a Pharmacist in one of Nigeria's biggest ART programs, but I had not realized that access was as huge a problem as it is. An internet search during a 2008 UWC Winter School course on "Promoting Rational Drug Use in the Community" revealed that only 30% of those in need in Africa at the time were actually getting anti-retroviral drugs. Another internet search revealed several studies on adherence but very few on access. The search only identified three studies that had been done on access to ART in Nigeria: Adeneye et al., (2006) on acceptability; Sangowana et al., (2005) on barriers to access; and a third study studied the impact of ART (Lum & Isichei, 2007). Clearly, adherence in the 30% of PLWHA who were accessing ARVs was a critical issue, as 95% adherence is essential in order to maintain optimal viral suppression and avoid the development of large-scale drug resistance (Tuller, Bangsberg, Senkungu, Ware, Emenyonu, & Weiser, 2009). Yet lack of access by 70% of those in need was also a critical problem.

My colleague - at the Institute of Human Virology- Nigeria (IHVN)- and I decided that he would examine adherence and I would begin to explore access issues. This would also provide an opportunity to explore the reasons why some patients enrolled in the IHVN program appeared to prefer to travel long distances to other towns to access care even though ART is available in their home towns. In this way, the Institute and other ARV programs in Nigeria would be able to consider the two major antiretroviral drug problems in their planning, implementation, and program improvement efforts. A consultation with professional colleagues resulted in the decision to explore access issues in Benue, the state with the highest HIV prevalence in Nigeria.

Benue is a mainly agrarian state in North-central Nigeria with a population of about 4.2 million in 2007

This exploratory qualitative study, a small discrete study for a minithesis, was intended to support quality improvement within my organization, and to contribute to understanding the problem of access so that future research could further inform practice. I decided to interview patients, health care workers & program managers in Benue because they may reveal other challenges not previously documented. I also wanted a document my supervisors could refer to in order to improve reach and quality of the services already being offered by the Institute.

In brief, this study sought to explore barriers to ART access, perceived drug use problems and quality of care from the perspectives of patients, care-providers and program managers who have been able to access services provided by IHVN.

1.3 Study purpose

The rationale for this study was to explore some of the barriers encountered by PLWHAs in accessing treatment in Benue State. This information would inform policy makers in designing interventions to reduce these barriers. Identifying the reasons why some patients would rather travel additional hours to neighboring states to access care and other barriers may help program managers design interventions to address those reasons.

1.4 Conceptual framework

The conceptual framework which guided the design and analysis of this study is shown in Figure 1. It combines elements of another problem analysis diagram addressing coverage, problems in medicines use, and illness causation which is described below.

Figure 1: A conceptual framework on access to ARVs in Nigeria
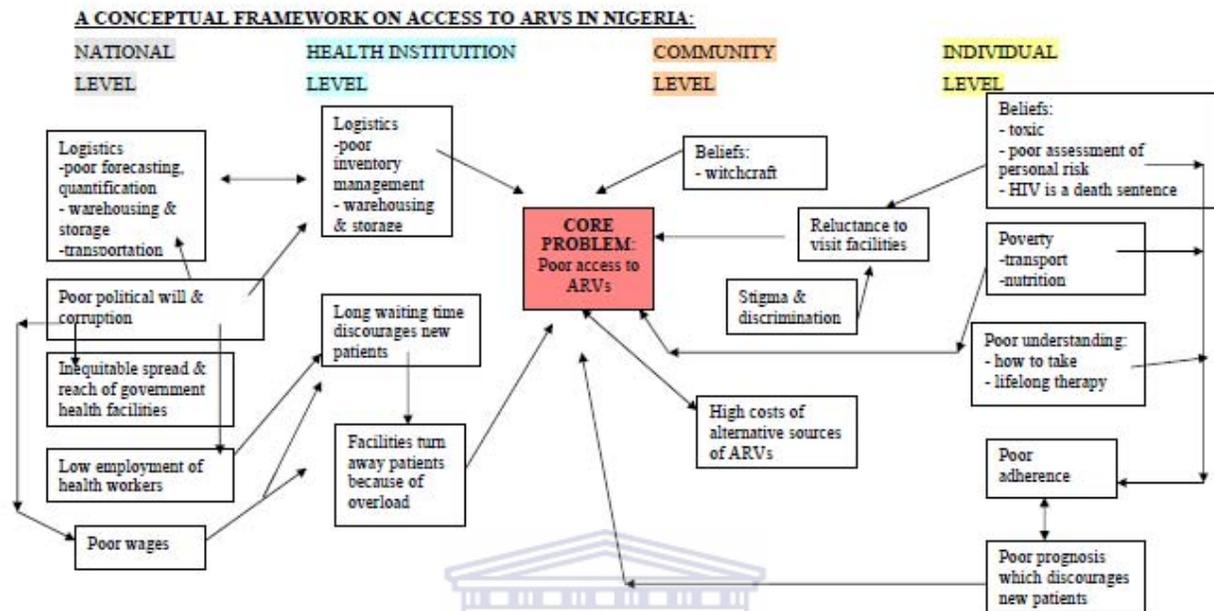
The development of this framework was based on applying the researcher's experience and available literature on the problem of access to ARVs to the problem analysis diagram for focusing and analyzing core problems of medicine use described by Hardon, Hodgkin & Fresle, (2004) (Appendix 1). The diagram described by the authors relates individual drug use behaviour to the multifaceted environment shaping it. This includes the household, community, health service institution, national and international levels. This analysis can also assist in developing interventions aimed at changing behaviours and the environment in which medicines use problems occur, in order to bring about more appropriate use. It helps to identify why medicines use problems happen, so that appropriate, efficient and practicable strategies can be selected to deal with the problems (Hardon et al., 2004).

The framework proposed that barriers at the national level included drug logistics, poor political will, inequitable spread of public health facilities and low numbers and motivation of healthcare workers. At the facility level, poor inventory management, long patient waiting times and patients being turned away because of overload or capping of ART services were the key

barriers. At the community level, erroneous beliefs and stigma were the major barriers while at the individual level, beliefs and understanding that are not consistent with medical models or practitioners' intent, poverty, and adherence were among major barriers to access.

The 2008 World Health report defines universal coverage as *access for all* to quality health services with social health protection where necessary. Universal coverage with social health protection will result in three dimensions of coverage necessary for success: the breadth (increasing proportions of people enjoying services), depth (increasing the range of services covered) and height (reducing cost to patient at service delivery points) dimensions. The report also explained that universal coverage must go beyond numbers (people, services, and costs), to changing what makes people vulnerable (WHO, 2008). Five crucial components of healthcare access are availability, affordability, acceptability of quality services, coverage and impact (WHO, UNAIDS & UNICEF, 2008).

There were several possible causes for poor coverage of ART services. They included: weak health systems (insufficient availability of drugs, inadequate spread and reach of healthcare facilities and insufficient number of properly trained personnel); lack of finances for transport, user fees, and other costs related to accessing healthcare; low public awareness of HIV care; poor adherence, which in turn, fuels wrong perceptions of HIV prognosis, deterring people that might otherwise have accessed care; patient workloads in clinics leading facilities to turn away patients and having less time to properly counsel them (compounding poor adherence); stigma, discrimination, personal beliefs (Peterson & Obileye, 2002).

There was a need to explore whether and how such factors contributed to the poor access to ART identified in Benue State, and an initial exploration into possible interventions that could mitigate them.

Beaglehole, Bonita, Kjellstrom (1993) described four factors that contribute to disease causation: Predisposing factors like age, sex, genes or co-morbidities could make a person more prone to diseases; Disabling factors like poverty, malnutrition, bad housing and poor medical care also increased susceptibility to disease while enabling factors promoted good health; Precipitating

factors like exposure to a particular disease agent was sometimes related to disease onset; finally, reinforcing factors like repeated exposure, environmental conditions and stress from hard labor could worsen an existing disease.

This study focuses on some aspects of the problem of access as proposed in the framework. Some facilitators and impeders existing at health institution, community and individual levels were investigated. Interpretation of the study findings included comparing the respondents' experiences with the model proposed by researcher.

UNIVERSITY *of the*
WESTERN CAPE

CHAPTER 2   **LITERATURE REVIEW**

2.1   Introduction

Five key components of healthcare access are availability, affordability, acceptability of quality services, coverage and impact (WHO, UNAIDS & UNICEF, 2008). This is important in understanding and improving access to ART. As discussed in relation to the conceptual framework, these components can interact with each other and with cultural and other factors in complex ways.

In this chapter, I reviewed studies done mostly in developing countries on access to ART and factors that facilitate or impede access. The chapter begins with a historical and global overview, as the components of access are relevant at all levels, from global efforts to individual poverty and stigma.

2.2   Early efforts at global access to ART

During the first fifteen years of the HIV/AIDS epidemic, AIDS onset and eventual death followed the same pattern in developed and developing countries, even though people in developed countries had access to palliative care and some treatment for opportunistic infections. This changed dramatically in 1996 with the advent of drug cocktails with protease inhibitors (Chirac, 2002) which led to more than 70% drop in AIDS-related mortality in Europe and the USA (Pallela, Delaney & Moorman, 1999, cited by Chirac, 2002). ART was declared cost-effective in the developed world and HIV became an out-patient managed chronic ailment (Chirac, 2002).

In developing countries, however, access to ART remains inadequate: only 31% of people in need of treatment, are receiving treatment (WHO, UNAIDS, UNICEF 2008). Despite the 2003 World Health Organization (WHO) target of providing access to ART for 3 million people by 2005, only an estimated 1.3 million people in low and middle income countries had access to treatment by December 2005 (about 20% of those estimated to be in need) (WHO, UNAIDS & UNICEF, 2008). Many factors slowed large scale ART access, especially in developing countries, including access to and quality of diagnosis, appropriate prescribing and proper selection, distribution, dispensing and cost of medicines as well as limitations of health care

infrastructure, stigma and discrimination, shortage of skilled healthcare providers and misinformation (Chirac, 2002; WHO, UNAIDS & UNICEF, 2008). The high cost of anti-retroviral drugs was the most obvious barrier both globally and in Nigeria. For example, a study of 125 HIV positive persons accessing ART at the Nigerian Institute of Medical Research (NIMR) clinic, Lagos, gave respondents' average monthly income as N11,253 or US$90 at a time when patients were spending a minimum of N15,000 (US$120) monthly on ARVs alone.

In July 2005, the G8 group of industrialized countries also committed to achieving universal access to treatment for all those who need it by 2010. These commitments complement the health-related United Nations Millennium Development Goals (MDGs). However, even the availability of financial resources has not improved access to ART to the desired levels (UNAIDS, 2008). Thus, the cost of drugs is not the only barrier to access to ART, as most of the drugs are now provided free of cost to eligible patients through combined efforts of countries and international partners (WHO, UNAIDS & UNICEF, 2008). The public institutions in these countries are still not able to provide access to all those in need, showing that there are other factors within the health system which hold back the scale-up of ART.

2.3   Recent progress and current challenges in access to ART

Two studies, Lawn, Harries, Anglaret, Myer, & Wood, (2008), and ART-LINC Collaboration & ART-CC Groups, (2006), found very high patient mortality rates in first year of ART in developing countries compared with those in developed countries due to opportunistic infections arising from late ART initiation. The authors conclude that improving access, early ART initiation and abolishing ART costs will reduce these mortalities.

However, WHO, UNAIDS and UNICEF (2008) reported that progress in the scale up to ART in the developing world in the last few years has been unparalleled. This progress has been attributed to increasing political commitments in countries, resource mobilization from international communities and from National Governments, decentralization of the delivery of HIV services, community support, abolishment of user fees in some countries, and decrease in drug prices. Regional and country differences in ART scale-up progress can be traced to differences in these factors.

The Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the US President's Emergency Plan for AIDS Relief (PEPFAR) are the two most significant supporters of HIV/AIDS programs in developing countries. Collectively, they have enabled tremendous gains in scaling up HIV/AIDS treatment in these countries. GFATM, started in 2001, is estimated to have saved about 3.5 million lives in 140 countries with USD15 billion worth of grants; while PEPFAR, started in 2003, has helped African Governments to place over 2 million people on treatment (with plans to scale up to 3 million by 2013), supplied 2 billion condoms and provided PMTCT for 16 million pregnancies between 2004 and 2008 with a fund of USD30 billion (MSF, 2009; Blattner, Dakum, Osotimehin, Nasidi & Abimiku, 2008).

However, recent funding cuts from GFATM and PEPFAR threaten to reverse this significant progress (MSF 2009). Medecins Sans Frontieres (2009) assert that the increasing demands for diverting funds away from HIV/AIDS to other health priorities is dangerous as it could cause avoidable deaths in those still in need of access. The authors call for an increased commitment to other global health priorities like maternal and child health, *in addition* to, not instead of, HIV/AIDS funding as HIV/AIDS increases the risk of death from these other priorities. They argue that despite scale-up gains, at least six million people in need of ART do not have access to it. This number increases dramatically to 18-22 million with the earlier initiation of ART recommended by WHO evidence-based revision of standards. Schneider, Zwahlen & Egger (2004, as cited in MSF, 2009) showed that most PLWHA in need of treatment will die within 3 years if they do not get it.

Because of funding gaps from donor countries, the GFATM imposed 10% cut in already approved grants, cuts that are withdrawn, by receiving countries, from funds earmarked for ARVs. GFATM Round 9 HIV grant was 35% lower than that of Round 8 (which was 2.5 times higher than any previous round) and there was a proposal for no round in 2010. There was no increase in PEPFAR's funding in 2009, after steady yearly increases over the last five years. The proportion of PEPFAR's budget dedicated to treatment decreased in a move from "emergency" to "sustainability". The authors again argue that some African National Governments have slashed HIV/AIDS budgets because of the global financial crisis, even though majority of them

under-spend on health and only 8 allocate 15% of their budgets to health. This is contrary to the Abuja Declaration of 2001, when African leaders agreed to commit 15% of National budgets to health. Individual patients also now have a decreased ability to pay for healthcare costs like transportation, user fees, labs and drugs for opportunistic infections (MSH, 2009; UNGASS, 2010; Avert, 2010).

MSF concludes by recommending that HIV/AIDS funding, from the International donor community and National Governments, should be sustained and even increased. ART should be in line with scientific evidence: earlier initiation of therapy (at CD4 threshold of 350); tenofovir-based first line regimens (which has fewer side effects); viral load testing to support adherence, early detection of treatment failure and prevent resistance; and increasing the use of generic drug regimens, generic production of patented products and support for the patent pool being designed by UNITAID to make patents available to others for generic production (MSF, 2009).

2.4   Impact of decentralization of care on access to ART

WHO, UNAIDS and UNICEF 2008 cited 2 studies in rural South Africa showing evidence that decentralizing the delivery of HIV services improves ART access. One study by Fredlund & Nash (2007) resulted in meeting the needs of more than 60% of people in need of ART after only 24 months of programme initiation in a rural population. Another study by Bedelu, Ford, Hilderbrand, and Reuter, (2007) in Lusikisiki delivered ART through primary health care sites, resulting in faster enrolment and better retention of individuals on treatment as well as 95% treatment coverage of persons in need of therapy.

2.5   A systematic review of studies done on barriers to ART access

Posse, Meheus, Van Asten, Van der Ven and Baltussen (2008) defined access barriers as factors that occur at the population level or health system level which restricts patients' initiation of and continuation in ART. They analyzed ART access barriers based on another conceptual framework introduced and adapted by Andersen (1974, cited in Posse et al., 2008b). The authors searched medical journals and databases for all qualitative and quantitative studies on access to ARVs between 1996 and 2007.They proposed that population level barriers are linked to predisposing (demographic, beliefs about treatment and disease), enabling (finances, information

10

about treatment, familial responsibility, insurance, social support system) and need (evaluation of illness level perceived by individual or healthcare provider) factors which describe health-seeking behaviors of individuals. Health system level barriers can be resource factors (personnel, infrastructure equipment and materials used in treatment provision) and organization (of resources during treatment provision).

Posse et al., (2008) assessed 19 studies in 13 countries and concluded that at the population level, the most frequently mentioned barriers were disabling factors such as the lack of awareness about ART (11/19), stigma (10/19), perceived high costs for ARVs and or related services (7/19) and lack of financial means (5/19). Pre-disposing factors like fear of side effects (2/19) and husband's permission to start ART (1/19) were not as frequent. However, at the health system level, the most often mentioned barriers were resource factors such as length of the travel time and or the long distance from home to the health facility (4/19), organizational factors such as lack of co-ordination across services (2/19), and inadequate community participation in the program planning process (2/19).

2.6   The Nigerian HIV/AIDS response

The HIV prevalence rate among adults ages 15-49 in Nigeria, Africa's most populous nation, is currently estimated to be 4.6% contributing 7% of the global HIV burden. In 2008 alone, there were about 220,000 deaths, 370,000 new infections and 2.23 million orphans. According to the 2008 prevalence survey, prevalence rates in Nigeria's 36 states and capital ranges between 1.0% to 10.6% (United Nations Programme on AIDS, 2008; Coker, 2009).

Since the first AIDS case was reported in Nigeria in 1986, the prevalence of HIV has been on a steady increase (Coker, 2009; UNAIDS, 2008). The first national response to the HIV epidemic was the establishment of National AIDS/STDs Control Program, NASCP, 1987. The National Action Committee in 2000. and the HIV/AIDS Emergency Action Plan developed in 2001 (revised in 2004), serves as the national action framework.

Combating the HIV/AIDS epidemic in Nigeria has been hindered by political instability and biases; lack of involvement by past administrations; lack of a coordinated multi-sectoral

approach against the epidemic; over-centralized intervention programs; managerial/technical problems; drug logistics issues; inadequate and mismanagement of available funds; competing priorities with other development needs; stigma & discrimination and poor resource allocation to HIV/AIDS interventions. Weak health systems and, in particular a critical shortage of health-care personnel, and a lack of long-term sustained funding threaten efforts to achieve universal access to HIV prevention, treatment and care (Peterson & Obileye, 2002; Idigbe, et al., 2006; WHO, UNAIDS & UNICEF, 2007; FMOH, 2005; UNAIDS, 2008).

In 2003, Nigeria became the first country in West Africa to implement a large ART scale up in an ambitious program targeting 10,000 adults and 5,000 children through 25 centres. Although the program enrolled over 8,000 adults, it suffered from drug stock-outs and fees that excluded the poor, insufficient infrastructure, staff, equipment, and supplies for ART services. With the advent of scale-up efforts, the Nigerian ART program enjoyed a sharp increase in points of service and a huge improvement in quality of services, brought about by technical assistance provided by the Institute of Human Virology-Nigeria's AIDS Care and Treatment in Nigeria (ACTION), other PEPFAR, GFATM and World Bank programs. For example, the ACTION program, where the researcher works, has provided training for hundreds of laboratory personnel and implemented a model quality assurance and control program. The Institute of Human Virology, Nigeria (IHVN)'s ART program supported over 23% of the 300,000 patients on ART in 2009 through 49 treatment sites in 27 out of 36 states in Nigeria.

GFATM and PEPFAR also assisted the Nigerian ART program in providing program monitoring and evaluation, capacity building, resistance monitoring and upgrading of tuberculosis diagnostic services in Nigeria, because the country has the largest number of TB cases in Africa, and the fourth largest in the world. TB remains the leading opportunistic infection in West Africa, with 40-60% HIV co-infection rates (Blattner et al., 2008). Of the 120,220 patients initiating ART between October 2005 and March 2007, 73,900 were through the PEPFAR program and 46,320 through Government of Nigeria programs largely funded by the Global Fund, and a portion directly from the government (Blattner et al., 2008). The Global fund directly funds the Government of Nigeria to implement ART programs in several government-owned secondary and primary health facilities. PEPFAR programs are implemented through grants to a number of

Non Governmental organizations, which support government-owned tertiary and secondary facilities, as well as mission hospitals and military facilities.

Since 2006, ART and laboratory fees were abolished by the Government of Nigeria. Additionally, a wider range of first-, second-line and salvage regimens are now available (Idigbe, Odutolu, Okonkwo, Folayan, Uwakwe, Audu, et al., 2006). By December 2008, 269 centres provided ART and about 290 000 out of the estimated 833,000 adults & children requiring ART were enrolled for treatment (Coker, 2009).

The national ART access program was aimed at providing HIV counselling and testing, universal ARV treatment for infected adults, children, exposed health workers and prevention of mother-to-child transmissions in 80% of population groups at risk by 2010 (WHO, UNAIDS & UNICEF 2007) using national protocols and guidelines. It also aimed at scaling up yearly by doubling the number accessing ARV treatment. The focus has been for equity and spread of ART services to all geopolitical zones. However, there are areas with poor access, especially in rural settings (Idigbe, 2006; WHO, UNAIDS & UNICEF, 2008).
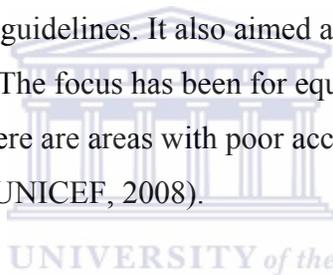
In West Africa, Nigeria has received the most funding for HIV/AIDS services. Between 2001 and 2007, World Bank awarded USD 190.3 million (in interest free loans), GFATM USD 74.4 million and PEPFAR USD 344.8 million. The Nigerian Government had also spent the highest number of dollars of any other West African Government on HIV/AIDS services (Blattner et al., 2008).

Even with the generous funding from three major international donors – World Bank, GFATM and PEPFAR which collectively spent over USD 1.3 billion in West Africa since 2001- huge funding gaps remain. This funding translates to about USD 70 per year per HIV-infected person infected with HIV in West Africa whereas the costs of HIV drugs, patient management costs for physicians and laboratory services total approximately USD 340 per year for infected persons (Huff, 2007 & Kombe et al., 2004, as cited by Blattner et al., 2008).

Figure 2- HIV prevalence by Nigerian States, 2008

HIV Prevalence by state (Nigeria 2008)
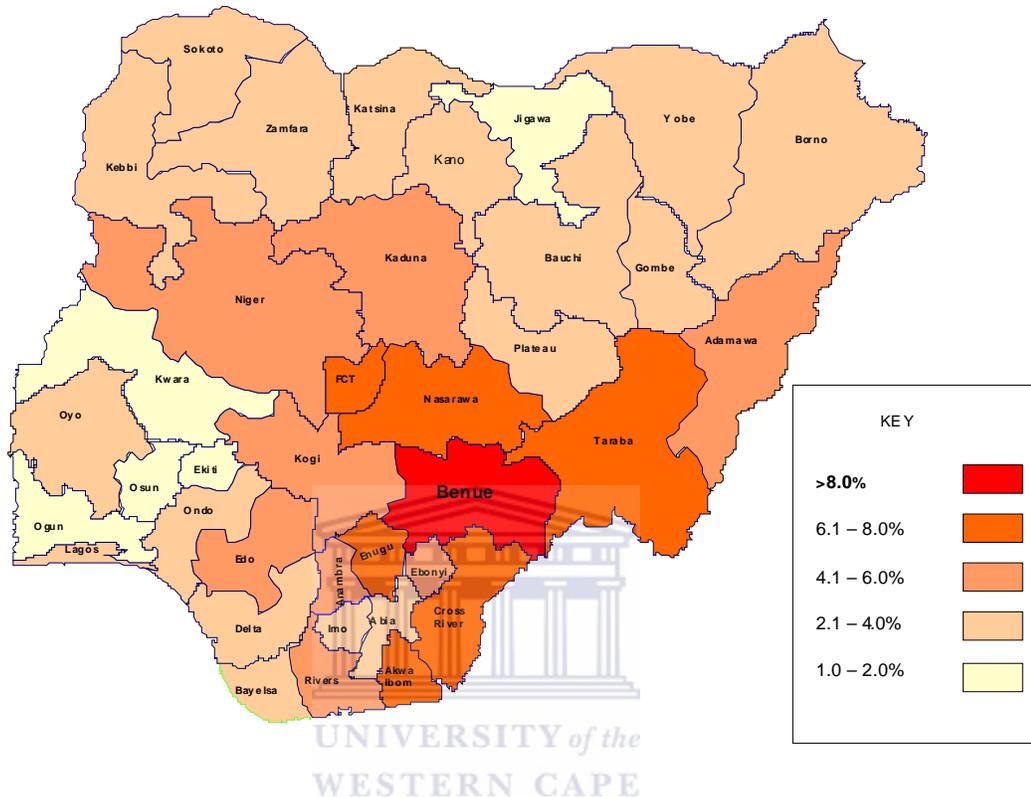
Source: Coker, 2009

2.7   Association between access to ART and adherence

Mills et al., (2006a, 2006b) identified financial constraints (as it relates to transportation and user fees) and interruption in the supply of ART as most important barriers limiting adherence to ART Although free access to care was not associated with higher ART adherence in the 16 studies in Africa they reviewed, the authors concluded that addressing concerns about access to treatment may also be beneficial to adherence and vice versa (Mills et al., 2006a, 2006b).

Mukherjee, Ivers, Leandre, Farmer and Behforouz (2006) put forward convincing evidence that discontinuing user fees, integrating HIV testing with primary health care and providing transport fees and other material assistance to patients, increased dramatically the overall uptake of HIV testing and the use of health care services. The authors concluded that many structural barriers

(cost of medical care, drugs, lack of integration of HIV testing with primary health care, tuberculosis, STI and women's health services, and difficulty on making follow-up appointments during long distances, family responsibilities, and cost of transportation) prevent access to health care and regular supply of antiretroviral drugs for the patients, and adversely affect adherence levels. They also concluded that scale-up of HIV testing and treatment cannot be done without improving access to primary health care and integrating HIV services into primary health care and that adherence programs in resource-poor settings must work to improve access to health care.

A cross- sectional study done in Northern Nigeria to determine pediatric adherence levels and factors affecting non-adherence by Mukhtar-Yola, Adeleke, Gwarzo & Ladan, (2006) identified cost of ART, and non-availability and inaccessibility to medications as the major barriers to adherence. The researchers concluded that improving access should improve adherence in developing countries.

One major barrier mentioned by several researchers is the cost of ART. However, there are other barriers to access and adherence to treatment identified since 2006 when the Government of Nigeria abolished ART treatment fees.

Early studies in developing countries showed cost of ART as the biggest barrier to adherence and access. However, with the abolishment of ART fees in many countries, major barriers to access and adherence are still financial. A study by Tuller, Bangsberg, Senkungu, Ware, Emenyonu, & Weiser, (2009), in Uganda found that, despite considerable commitment to ART adherence, most patients have financial difficulty in paying for transportation to the clinic. Transport costs, which take a significant portion from a family's income, compete with other aspects of welfare like food, housing and school fees and result in non-adherence and lost to follow-up. Transport costs (transportation fares, costs of spending hours, or days at, and traveling to and from the facility) compromise adherence and access. When patients try to cope by rotating who goes to the facilities among partners, the absent partner loses counseling and clinic services for that month.

Lack of access must be differentiated from poor adherence and each targeted for intervention. The authors cite several studies which recommend increased information, motivational and

behavioural skills as a strategy targeting non-adherence, or factors within the patient's control. However, poor access should be targeted using transport subsidies, home-based care, using the neighbouring dispensaries and hospitals as ART pick-ups and mobile clinics (Behforouz et al., 2004; Koenig et al., 2004; Weidle et al., 2006, as cited by Tuller et al., 2009).

Ware et al., (2009) also found that borrowing, begging, difficult choices, going without basic needs were major access barriers, even though ART is now free at the clinics. They assert from their study of patients in Nigeria, Tanzania and Uganda, that adherence obstacles in SSA were mostly linked to scarcity of resources. Patients have to prioritize adherence to ART as a way to surmount financial difficulties because getting well make them fit to earn money for their families. Money for transportation to clinic appointments were often raised through borrowing, begging, selling of their possessions, or doing whatever they can to earn the money, often leading to chronic indebtedness which adds to their emotional distress. Patients also sometimes make distressing choices like HIV care or food/school fees/treatment for sick child. When ART is taken without food, the patients they interviewed reported 'hunger-induced exacerbation' of ARV adverse events like nausea, stomach-ache, vomiting, dizziness and weakness. They also found stigma and fear of disclosure; conflicting messages from healthcare and religious practitioners; and behavioural obstacles like forgetfulness, fear of side effects and traveling without medication as other significant barriers to ART adherence.

2.8   Stigma, access and impact of ART in Nigeria

Adeokun, Okonkwo, & Ladipo, (2006) describe stigma as the reason why individual patients, because of the fear of rejection, discrimination, violence or unemployment, avoid ART clinics or do not adhere to their medication, even when they know the benefits of treatment. Such patients often prefer discrete visits from home-based care volunteers or traditional healers that can be visited a t night. The authors also argue that health workers stigmatize patients in fear of acquiring HIV and in trying to curb the spread. Health workers, when faced with a risk of infection to patients' relatives, lovers or other health workers who are unaware of patients' status may sacrifice confidentiality and informed consent.

The authors, Posse et al., (2008), in their systematic review, found only two published studies on barriers to ART access done in Nigeria: one quantitative study by Adeneye et al., (2006) on acceptability and barriers to access, and a qualitative/quantitative study which looked at barriers (Sangowana et al., 2005). Adeneye et al., (2006) found that, although 88% believed ART would prolong their lives, stigma and cost emerged as the major barriers to access. Sangowana et al., (2006) asserted that the major barriers to access in Nigeria were financial, information and need factors.

Lum, Isichei, Isichei-Wakili, & Redfield, (2007) had some interesting conclusions on the impact of improved access to ART from a 2005 review of their program's expansion of testing and treatment in Jos, Nigeria. Their program, a Faith-based Organization, was ahead of the Government's ART program in providing treatment at no cost to patients. The researchers found better immunologic response among their patients compared with those accessing the Government's subsidized program. They asserted that free treatment in developing countries is associated with decreased mortality and supported this conclusion with analysis from other free ART programs in developing countries showing a "significantly increased probability of virologic suppression" compared to programs where patients pay part or all of the cost of treatment (Lum et al, 2007:99). Stigma, pride, and fear of being sacked or ostracized from family were identified as major reasons why men were unwilling to be tested for HIV. Besides free ART, the researchers propose that treatment for opportunistic infections, other clinic visits costs, emergency care and provision of basic care packages should be made freely available to HIV patients.

A study on the impact of HIV/AIDS on Nigerian households by Canning, Mahal, Odumosu & Okonkwo (2006), conclude that HIV-affected households in Nigeria face both economic and psychological challenges, including the likelihood of substantial income loss within households and an increased burden of caregiving and out-of-pocket health care spending similar to what obtains in other sub-Saharan African countries. The authors propose several interventions to mitigate the financial and psychological impact of HIV on individuals and their families. These strategies include closer proximity to healthcare facility (with better coverage of facilities); increased collaboration with traditional healers through a form of medical training and formal

recognition by the government and remunerations for referrals to healthcare facilities (to offset any 'business' loss to them); increasing access to income-generating schemes for PLWHAs; protection of existing assets and protecting the property rights of AIDS survivors, especially women and children; increasing access to lawyers for those in need, and encouraging HIV-infected people to write their wills.

Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru, & Chukwuogo, (2009) in a study in Southeast Nigeria found that ART adherence is also affected by known barriers to access like drug stock-outs, inaccessibility of ART clinics, transport costs and stigma. Two major adherence problems faced by ART programs in developing countries are inconsistent medication intake and defaulting from treatment (Kebede et al., 2008, as cited by Uzochukwu et al., 2009), both of which are also driven by the problem of poor access. Financial difficulty in paying for treatment or transporting to clinics is a barrier relevant to developing countries, affecting both access and adherence to ART.

Yu et al., (2007), outline the reasons for loss to follow-up in a developing country as death, 50%; transferred to another clinic, 8%; alive & stopped therapy, 15%; and untraced, 27% due to incorrect addresses. Interestingly, the major reason for stopping therapy was transport to clinic costs. A meta-analysis of lost to follow-up in developing countries by Brinkhof, Pujades-Rodriguez, & Egger, (2009), found that about 46% of patients have died, and of those alive, many have transferred to another clinic or have stopped treatment due to financial problems (like transport), stigma, side effects and religious beliefs. Deaths were higher in programs charging user fees than in those offering free ART.

Two other Nigerian studies (Agbonyitor, 2009; Iregbu & Elegba, 2009) found the three major challenges that PLWHA complain of are related to access (stigma, financial constraints affecting food and transport to facilities, and a desire for closer access to ART); and that improving access to ART will reduce incidence of opportunistic infections like Kaposi sarcoma in PLWHAs.

This review looked at global and local issues surrounding availability, affordability, acceptability of quality services, coverage and impact of ART access. It also highlights the need for further study on access in Nigeria, the country that has the world's second largest burden of HIV.

CHAPTER 3   STUDY DESIGN AND METHODOLOGY

3.1   Introduction

This chapter briefly describes the aims and objectives, the advantages and limitations of the study design and methods, sampling and sample size, and research setting, the study population as well as rigour considerations.

3.2   Aims and objectives

The aim of the study was to explore access and factors that influence access to antiretroviral treatment programmes/services in Benue, the state with the highest prevalence of HIV in Nigeria. This exploratory study focused on people who have succeeded in accessing care.

The objectives of the study were

- To map out the distribution of health care facilities within the state offering ART and the services rendered.
- Identify factors that facilitate or impede ART access in Benue State
- To formulate recommendations for improving ART access in Benue State.

3.3.   Study design and methods

A qualitative method was chosen because it puts a human face on an identified problem. Mack, Woodsong, Macqueen, Guest, & Namey, (2005:4) define qualitative research as, a "more flexible" type of scientific research which sets out to understand a problem from the (human angle) perspective of the population it affects using open-ended questions, resulting in culturally specific data on values, attitudes, beliefs of these populations. A qualitative method was chosen for this research to provide in-depth information about some barriers and facilitators of access to antiretroviral drugs, to gain new perspectives and to discover how these factors affect individuals.

Soon after the Institute of Human Virology, Nigeria (IHVN), where the researcher is a staff, started supporting a public hospital in Gwagwalada, Abuja, it was noticed that patients were travelling in busloads from Otukpo, a peri-urban town 5 hours away in Benue State. Most of

these patients still preferred to travel to Gwagwalada even after IHVN started supporting the public hospital in Otukpo to provide ART. Because staffs at the hospital in Abuja were getting overwhelmed with patient-load, IHVN tried various strategies to encourage these patients to use services closer to home. Many of these patients resisted the move and the reason given was mostly stigma-related, yet they were congregating in one place in a small town to charter the buses that would take them away to access care. Qualitative research was needed to explore and understand this apparent paradox.

This explorative study utilized a qualitative case study design to explore the problem of poor access to ART in Benue State. By using the qualitative method, the researcher sought to develop an in-depth understanding of the opinions, perceptions and experiences of HIV Program Managers and support group members on factors they believed were inhibiting or promoting access to antiretroviral therapy in Benue State.

Keen and Packwood (1995) argue for the use of case studies by stating that case studies are helpful where broad, multifaceted questions have to be addressed in complex circumstances because they employ use multiple methods. They further argue that though case studies may be qualitative and quantitative, qualitative case studies are most valuable in answering research questions where the focus is on why and how an intervention in real life is succeeding or failing. This is because the number of relevant variables will be more than can be controlled for, so that experimental approaches are simply not appropriate. In addition, the authors argue convincingly that some circumstances regarding the nature of an intervention being investigated increase the value of the case study approach. Firstly, if the intervention is not well defined from the onset or has a multifaceted blend of changes over different timescales; or the intervention requires the involvement of differing stakeholders; or even that the intervention may not be fully implemented by the end o the study period. The case study offers a different way of thinking about complex situations by taking conditions into account and is still robust enough to give informed conclusions about success or failure. This kind of approach is relevant to the issue of access in Benue state, because interventions based on evidence of what was needed in the first phases of ART – such as making ARVs available in clinics closer to where people lived – did not

seem to be having the desired effect of encouraging people to access treatment close to home, and we wanted to understand why.

Beginning with a qualitative exploration of local perceptions and problems related to access was necessary in order to ensure that a possible subsequent population-based survey seeking to measure and describe access more broadly would ask the right questions. Hardon, Hodgkin & Fresle (2004) recommend that focus group discussions (qualitative) should be used when investigating community drug problems involving drug use practices, perceived effects of medicines, perceived drug use problems, perceived quality of care in health institutions, sources of medicines, and perceived advantages and disadvantages of each and source of information on medicines.

Exit interviews with clinic attendees, focus group discussions (FGDs) with members of identified support groups, and key informant semi-structured interviews were used. In addition to specific interviews about physical availability of treatment sites, existing maps, data bases and NGO and government documents were sought and reviewed to provide data about the distribution of ARV sites.

Two policy makers in Benue - the Heads of the State's AIDS Control Agency and the Health Management Board – and a Senior Manager at the National AIDS/STDs Control Program were interviewed using semi-structured questionnaires. These key informants are in charge of coordinating all government and non-governmental organisational programmes providing ART in the state and the administration all State-owned hospitals respectively. The number of ART programmes, percentage coverage and the State efforts in improving access were discussed. Available documents from governmental and non-governmental sources for information on existing treatment programs were also provided by these key informants.

A total of three focus group discussion with support group members and patients attending clinic, four exit interviews with clinic attendees and three semi-structured interviews each with individual patients and care providers, were conducted in March and April 2010 in and outside Benue State to explore barriers and facilitators of access within the State. Two of these FGDs, 4

exit interviews and 3 care provider interviews were conducted in General Hospital, Otukpo, Benue State. The third FGD and 3 semi-structured interviews were done in Asokoro General Hospital, Abuja. The individual interviews were 30 minutes each while the focus group discussions lasted approximately 1 hour each.

3.4   Research setting and study population

Benue is an agrarian state situated in North-central Nigeria with a population of about 4.2 million in 2007. There are 5 ethnic groups living in the state, with the predominant ones being Tiv, Idoma and Igede. The main crops grown in the state include yams , cassava, potatoes, soya beans, guinea corn, flax and beniseed. It is a mostly rural population and the two major religions are Christianity and African Traditional Religion.

The primary study population was HIV patients accessing in selected facilities within and outside Benue state. In addition, key informants included HIV care providers, program manager and policy makers. PLWHAs, Benue State AIDS Program coordinator and program managers were involved in the effort to describe the factors influencing access to ART in State.

The study setting is further described under 'Findings' as it relates to the distribution of HIV facilities.

3.5   Sampling

The qualitative research method aims to describe processes involved in a phenomenon, rather than their distribution. Therefore, sampling in qualitative research aims to select information-rich cases for studying in depth (Rice and Ezzy 1999). This is achieved through purposive sampling which identifies and studies cases that typify the research problem in view. Types of purposive sampling used in the study included maximum variation, convenience and deviant/negative cases.

The three focus group discussions and semi-structured interviews used purposive sampling while the exit interviews were convenience sampling (the first three clinic attendees willing to be

interviewed after accessing care). Purposive sampling was done to identify patients travelling 5-6 hours from Benue to access treatment.

Three FGDs were conducted in all: two in Benue State, and one outside the state. The two done within the state had men in one group and women in the other. The FGD done outside the state had both sexes in the same group.

3.5.1   *Sampling strategy*

A number of sampling strategies were used to enhance the credibility of this study. One criterion is the selection of cases that typify the problem of access and those that could shed light on the research assumption (that there are factors constraining access to ART in Benue state), "Negative" cases were also recruited (those who have no problem accessing care from facilities within Benue State). Purposive sampling, with maximum variation, to ensure that different socio-economic groups, ages and sexes are represented was used for patients visiting the facilities to access ART to explore differences in barriers to access among groups. Key informants are those with knowledge about the problem and include healthcare workers, program managers and policy makers (Keen and Packwood, 1995).The key informants selected were care providers, managers and policy makers with several years' experience in ART. Potential key informants were identified from a listing of all stakeholders involved in improving, or affected by, access to ART. Key informants were selected after further discussion with professional colleagues in IHVN, especially the Regional Manager in charge of Benue State.

3.5.2   *Sample size*

Sample size in qualitative analysis can not be predetermined accurately but it is reached when it can support the desired analyses and no new information is generated. The total sample size was 34 respondents: 20 from three FGDs, 4 exit interviews, 3 from semi-structured interviews, 3 care provider interviews, 3 policy makers and 1 program manager.

As an exploratory study, the approximate sample size was to some extent determined by the available time and resources; a sample of 35 individuals using different data sources was thought

to be sufficient to reach saturation of information around major themes related to access. However, if tremendous diversity was found in this study it would indicate that the issue was quite complex and further exploratory work would be needed.

3.6   Data collection and analysis

All the FGDs were conducted by the researcher and assisted by a notetaker. The FGDs and key informant interviews were recorded and later transcribed by a paid transcriber and transcripts compared with notes taken during the interviews. The FGDs in Benue State were held in the conference hall of a local hotel and respondents were provided with lunch and $3.3 each for transport. The FGD held outside of Benue State was held in an office within the hospital because respondents were in a hurry to travel back and so unwilling to be transported outside the hospital for an interview.

The researcher read through the participant information sheet with all respondents and informed consent was sought and received in written and verbal form in all cases. The leaders of the support groups were approached, the research objectives explained and they took the lead in the purposive participant recruitment. Appointments were made in advance to interview the policy makers. A semi- structured questionnaire was used to guide the interviews, a questionnaire for the exit interviews and a facilitators guide for the focus groups were used, including probing questions to elicit response on perceptions about ART access.

While the data was being collected, transcription of the discussions from the tapes and notes also started. Proof-reading and confirming that the transcriptions tally with the tapes and notes were done next. After this, the general themes of the transcribed discussions were identified and coded. Non-hierarchical coding (Gifford, Undated) generated units of meaning which were then labelled and categorised. Transcripts were categorized into facilitators and barriers to access, in addition to the ways respondents believe these barriers can be overcome. Other sub-themes were also identified and sorted. Themes were linked to direct quotes from the respondents. Additional literature review was done to review available information on the themes identified.

3.7 Rigour, credibility and trustworthiness

Several steps were taken to ensure rigour, credibility and trustworthiness of the findings. The major step was triangulation of the data sources and methods. Method triangulation by contrasting data from interviews with information from FGDs was done. Data-source triangulation (using purposive sampling) entailed drawing samples of respondents from different sexes, age-groups and socioeconomic groups. In addition, my minithesis supervisor reviewed the analysis conducted by the researcher.

Patton (2002), as cited by Voce (2005) mentioned triangulation and credibility of the researcher as 2 out of 4 of the most important criteria for judging credibility and trustworthiness of qualitative research.

Triangulation is ensured through methods triangulation (combining interviews, document reviews and observation), triangulation of sources (comparing the perspectives from different points of view eg patients and care providers), analyst triangulation (using multiple analysts to analyze findings) and theory or perspective triangulation (using more than one perspective to interpret findings) (Voce, 2005). In this study, the researcher combined interviews with document reviews; interviewed patients, care providers, policy makers and program managers; analyzed the findings together with her UWC supervisor; and interpreted the study on the basis of findings from all perspectives sought.

The researcher received training on conducting FGDs during the above mentioned PRMUC course at the University of the Western Cape (UWC), in 2008. A group of 4-5 participants of the course were sent to different hospitals and conducted FGDs, exit interviews with clinic attendees and semi-structured interviews with health care providers. This process was documented and assessed by course facilitators. Facilitators included esteemed faculty from UWC, WHO in Geneva, Royal Tropical Institute, Amsterdam and the University of Amsterdam.

3.8 Limitations

The major limitation of this study is that interviews were conducted with people who DO have access to HIV treatment. The interviews probed both barriers and facilitating factors for these

patients, as well as their views about people who are not accessing care, but the study did not directly capture the perspectives of people who are not accessing care.

Future research and implementation will need to take into account that the determinants of access are complex and cannot be fully examined in this one study.

3.9   Ethical considerations

Approval was sought and received from the University of the Western Cape, IHVN Institutional Review Board, BENSACA, Benue State Ministry of Health and Head of Asokoro General Hospital.

In the course of conducting the research, voluntary participation for all patients and key informants was ensured. Relevant information about the research topic, objectives, purpose and possible risks was provided on a sheet to all respondents. Informed written consent was then received from all respondents with opt out (at any time within the period of the research) options.

Confidentiality was also ensured through the use of numbers and fictitious names for identification. Additionally, field notes and transcripts did not contain personal identifiers. All raw and processed data are kept locked and all information identifying study participants by name are password protected.

The researcher was prepared to contact local counsellors at each of the study sites to aid respondents who would have needed that as a result of the FGDs.

CHAPTER 4   FINDINGS

4.1   Introduction

This chapter presents the mapping of ART services in Benue State and the main findings of the study, drawn from the literature reviewed, key informant, semi-structured and exit interviews as well as from the focus group discussions held as highlighted in the preceding chapters (two and three) of the thesis.

4.2   Where HIV patients living in Benue go to access ART and services available

4.2.1   Mapping the distribution of health care facilities offering ART and the services rendered in Benue State.

ART sites provide HAART to adults and paediatric patients as well as HIV counselling and testing; PMTCT sites provide HCT and ART to only pregnant women while HCT sites only provide HIV counselling and testing.

As at April 2010, there were 24 ART sites in 12 out of 24 LGAs in Benue State. However, other HIV services included 53 PMTCT sites in 20 LGAs and 181 HCT sites spread across all LGAs.

Findings

1. Location of ART services by Local Government Areas (LGAs) in Benue

Table 1: Breakdown of ART services by LGA and population

S/n	Name of Local Government (Sero-prevalence survey 2008)	Population 2007	Population x10,000	No of ART Sites	No of PMTCT Sites	No of HCT Sites
1	GBOKO	358936	35.89	3	4	9
2	MAKURDI (8.4%)	297398	29.74	5	7	19
3	OTUKPO (7.8%)	261666	26.17	1	4	14
4	KWANDE	248697	24.87	2	2	5
5	VANDEKIYA (16.2%)	230120	23.01	3	3	5
6	KONSHISHA	225672	22.57	0	1	10
7	KATSINA ALA	224718	22.47	1	2	11
8	UKUM	216930	21.69	3	3	9
9	BURUKU	203721	20.37	0	1	5
10	GUMA	191599	19.16	0	0	6
11	USHONGO	188341	18.83	0	2	8

12	ADO	178882	17.89	0	0	3
13	OKPOKWU (5.3%)	176647	17.66	2	1	10
14	OJU	170236	17.02	1	4	9
15	LOGO	169063	16.91	1	0	6
16	GWER	163647	16.36	1	2	7
17	OGBADIBO	128707	12.87	0	1	6
18	GWER WEST	122145	12.21	0	1	5
19	AGATU	115523	11.55	0	3	8
20	OBI	98855	9.89	0	2	7
21	APA	96765	9.68	0	5	5
22	TARKA (15.4%)	79494	7.95	1	4	8
23	OHIMINI	71482	7.15	0	1	6
	TOTAL	**4219244**		**24**	**53**	**181**

Figure 3: Map of ART sites in Benue State
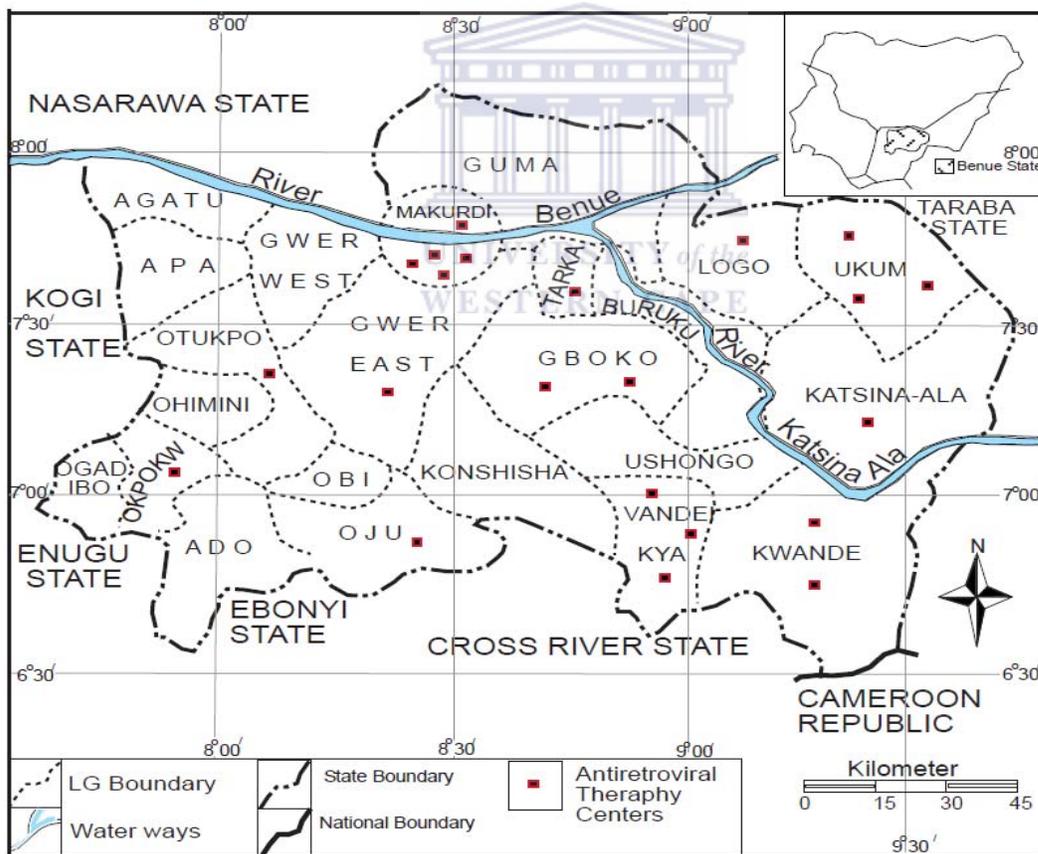
Source: Map created by State Ministry of Lands and Survey, based on data provided by C. Omenka, 2010)

Figure 4: Line Graph of ART services in Benue State with Population
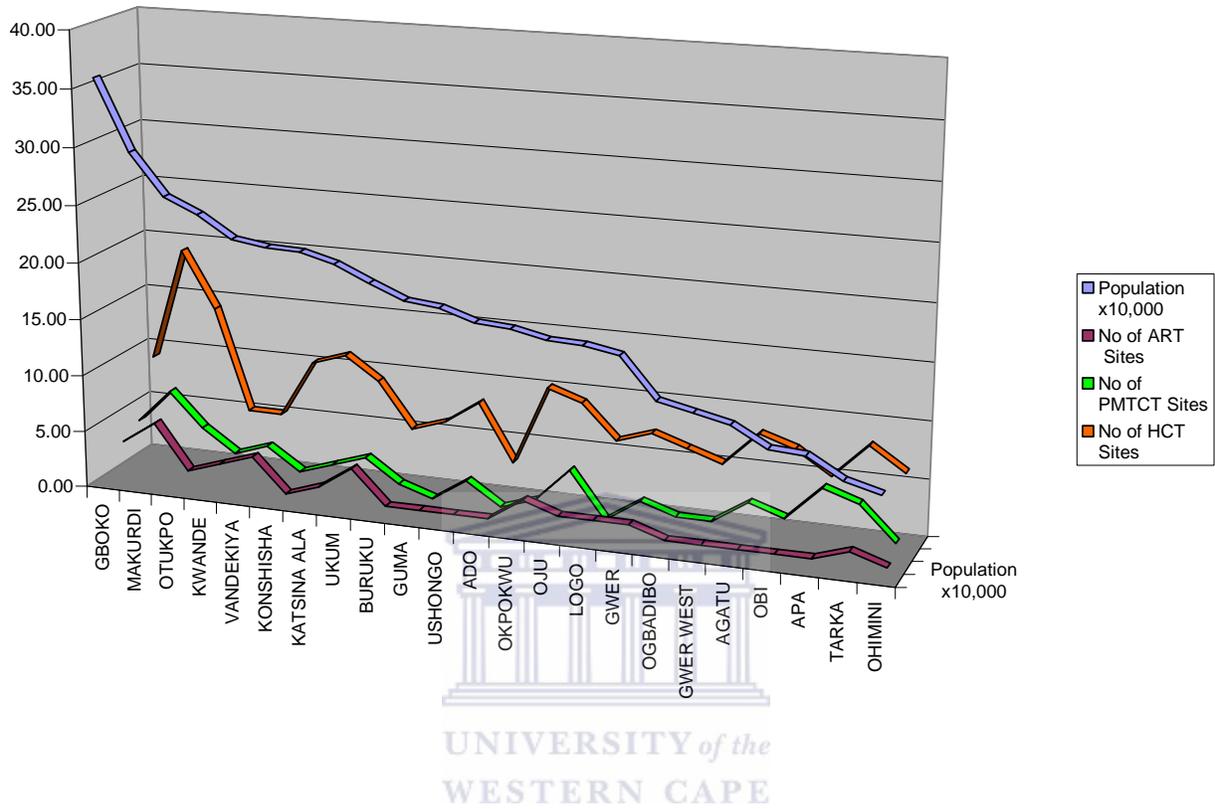
4.2.2 IHVN ART Sites

The Institute of Human Virology, Nigeria (IHVN) ART program currently has over 100,000 patients on HAART in 86 ART sites. IHVN has also provided ART to about 490,660 pregnant women in 139 PMTCT sites across 27 Nigerian states. The Institute has trained about 3,000 health workers in these sites (IHVN, 2010a).

IHVN's ART program accounted for over 23% of the 300,000 patients on treatment in Nigeria in 2009 and has 5 facilities providing ART and an additional 2 sites providing PMTCT in Benue state. A search of IHVN's database was carried out to trace the distribution of Benue State patients accessing care in three sites within 400 kilometres of the State. One limitation was that some of the sites had only manual patient information systems and some of the computerized systems didn't input patient home address in the database. A case study of one of the sites, Asokoro District hospital in Abuja which is 4 hours travel time by road (approximately 310km)

showed that 205 patients out of a total of 5762 were coming from Benue to access ART at the site.

Figure 5: A map of Nigeria showing location of all IHVN sites (IHVN, 2010b)
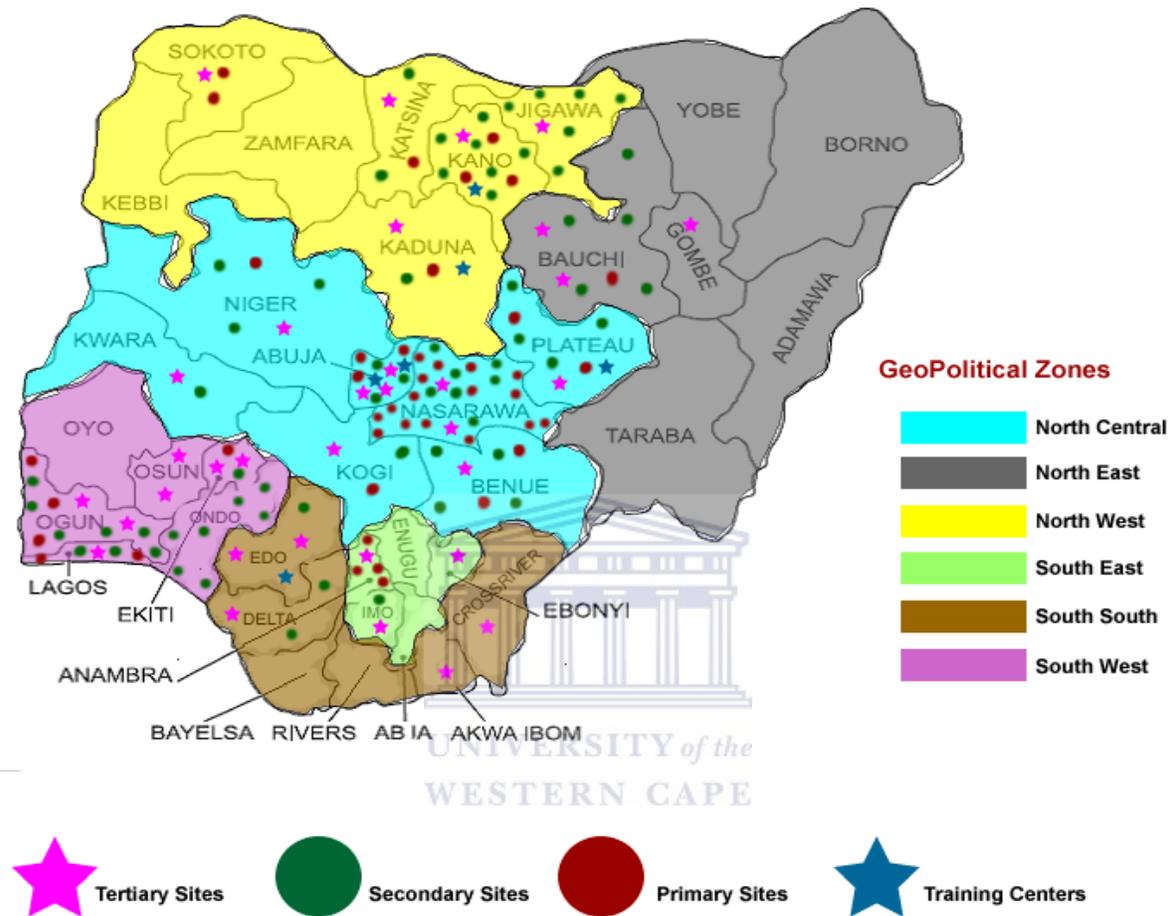
Note on the map: Tertiary and secondary sites provide ART to adult and paediatric patients while the primary sites are mostly PMTCT sites that could later be upgraded to ART sites.

4.3   Description of study respondents

The 34 respondents included patients accessing care within and outside Benue, health care workers, policy makers and program managers.

Twenty eight patients, 3 policy makers (at the State and Federal Level), 3 care providers and 1 program manager were interviewed for the study. Of the 28 patient respondents, twenty were from three FGDs, four from exit interviews and three from semi-structured interviews. All, except one, had initiated ART with years on therapy ranging from 3 to 8 years.

The patient respondents ranged in age from 22 to 55, with a mean age of 33 for the women and 42 for the men. Nineteen respondents were women and there were 9 men. Half of the respondents were not in paid employment (either as housewives or unemployed), and a majority of the remainder was self-employed with only 4 civil servants.

Discussions within same-sex groups were more open when compared with the last FGD done outside the state, which had men and women in the same group. Because of the distance travelled and the eagerness of the patients to travel back, respondents were recruited as they came to the clinic and couldn't be stratified by sex. Participation in the last FGD was dominated by a few individuals and one of the respondents, newly enrolled in care, only got a word or two in. Her co-patients made excuses for her, saying she was still depressed from her test result. The researcher took care to study the group dynamics, encouraging more participation from the quiet ones and gauging whether an opinion shared was consensus and encouraging divergent views.

The questions were structured in order of increasing sensitivity of topics, beginning with demographic information and questions regarding ART initiation and early symptoms, and then progressing to the more sensitive topics of stigma, perceived barriers in the system, and so forth, so that by that time the respondents would feel more at ease with the interviewing process and with the researcher.

Table 2: Demographics of Patient respondents

Age (years)	Male	Female	Total
21-30	2	9	11
31-40	2	7	9
41-50	2	2	4
51-60	3	1	4
Education	Male	Female	Total
Nil	0	1	1
Primary	1	3	4
Secondary	5	12	17
Diploma	2	2	4

Degree	1	1	2

4.3.1 *Costs*

Transport costs ranged from N2,500 to N5,000 ($16-$33) per visit for those travelling hours to access care; and current cost of care ranged from N100 – N500 ($0.65 - $3.2) mainly as hospital registration costs at a time when the minimum wage in Nigeria was N5,500 ($36.7) per month (Aminu, 2008).

4.4 Factors facilitating and impeding ART access in Benue State

4.4.1 *Introduction*

The factors affecting ART access in Benue State can be broadly categorised into:

- Facilitators, which include the free cost of medications and laboratory tests, disclosure, and the positive effects of ART on symptoms.
- Impeders, which include stigma, costs (transport, initial tests), long waiting time, poverty (jobs, food), hospital factors (attitude of healthcare workers and stock out of drugs for opportunistic infections), non-disclosure , inaccurate knowledge and misconceptions about HIV and ART, certain religious beliefs and instructions, and capping of services.

4.4.2 *Facilitators of access to ART*

1.   Free cost of treatment and increased number of sites

Most of the respondents agreed that the major facilitator to access is the free cost of treatment. *"It was confirmed that I had HIV. They put me on drugs in 2002. We were buying it. The first drug I got, I bought for N20, 000. I sold two of my houses to stay alive then I was among those the State Governor gave drugs for free for two months. Now the drugs are free…"* 40-year old woman.

In 2006, the Federal Government mandated that ART and laboratory investigations be provided free to patients. With support from PEPFAR, Global Fund and the Government of Nigeria, a lot of sites have also been opened.

"In 2006, there was only one treatment site but now, the difference is so much. By the end of 2009, there were 23 sites" Policy maker, Benue State.

2.   Effects of ART

All the patient respondents agreed that ART improves the quality of life and reduces the symptoms of HIV. They all knew people who had bounced back to life, after nearly dying, because of ART.

"I was so weak, I could not walk... My mother used to travel with me to collect drugs for me. After 6 months, I started collecting drugs by myself. Now I'm on my own. I go by myself." 42-year old woman.

"There is a man that, his people said I should leave him, that anybody suffering from this disease does not survive so that they have left him for the time of death to come so that they will bury him. That the money that they will spend on him now is for burial and I pleaded with my dad to give me money to take him to the hospital. The man is accessing his drugs now and he is doing fine. He married last month. There are many people like that..." 34-year old woman.

"Me and this woman would go out. I'll say 'look at me'. I use myself as an example for you. I can even go with my drug and show them. Some of them started believing me. There is a lady. I told her that, I am not down with the sickness again as long as drugs are existent. What you do in the morning is, take your bath, brush, take a little cup of tea and take your drugs, you'll see changes in your body. She followed me and she's okay now. There's no day that she doesn't come to say thank you" 40-year old woman

"If I take rice or even water, my stomach will not settle. I decided to sell all my things and go home because if I die outside, no one will know where I am. So I came home and stayed with my mum... If I take any food, if I don't purge, I will vomit. They now tested me and saw this sickness. But I was ashamed and afraid. They were talking about AIDS and I was afraid. But I started taking the drugs. Now, my only problem is that I don't have a job and my artist shop here is not moving ..." 30-year old man.

3.   Disclosure (and membership of a support group)

Those patients who had either disclosed to a spouse or a close relative were more likely to access care within Benue. Most of those accessing care outside admitted that they had not disclosed to anyone in their family or church. Also, none of the people accessing ART outside Benue State were members of any support group.

"People go out of the state, not minding the cost, the transport …Issues of disclosure, even husbands and wives are not disclosing to each other.…" Policy maker, Benue State.

4. Treatment partner

"I don't miss taking my drugs. I have a daughter who is also positive. She lives in Makurdi (one hour away). *Every month when she collects her salary, she buys GSM recharge card and sends to me… If I am taking my drugs, I'll call her to ask if she has taken her drug. She'll say she has. She too calls me and asks 'mummy have you taken? I'll say 'yes'".* 42 year old woman.

4.4.3 *Inhibitors of access to ART*

1. Stigma and discrimination

All respondents agreed that the major reason people will not come to the hospital or would rather travel far outside their state to access care is because of stigma.

"People go out of the state, not minding the cost, the transport because of stigma. The culture of silence is being broken because people are getting better. People go out because of choice, not because of inavailability of drugs. On the issue of stigma, despite high level of awareness is not translated to the necessary action of behaviour change. .. Stigma still exists." Policy maker, Benue State.

"People are not opening up and coming to the hospital because of stigma. Let my neighbour not know about me... The stigma in that village is too much. Anyone that says that he is HIV positive, no one will relate with you...There is a hospital but no one will patronize it. They prefer to hear about typhoid fever than HIV. So even if you test someone and you discover he is positive, you can't tell the person because they will be very angry." 48-year old man.

*"There is a man that always used to come to my house, asking me to sell my remaining drugs to him because of another woman… if I am opportuned to see the woman, I will go and draw her to the hospital so that doctors will talk to her. He said that she is shy, in case of stigmatization and discrimination, that she is ashamed of coming out. Every blessed day, she is inside.…"*26-year old female.

"Stigma is still a major problem. Patient relatives feel HIV is an abomination or a curse and refuse to help patients." Healthcare provider.

"There are cases like that, of people who were sacked from their offices because of going to the hospital. They don't come up out to say it's because you are positive, they find a little fault and use it to sack you. And everyone has faults. So they will be waiting for you to fall. Then they say you should go. When you complain, they say but you missed work or whatever excuse. But generally, the awareness is increasing." 48-year old man.

"Like some people when they know that you are HIV positive, they'll say, don't go to that house. They are HIV positive in that compound, you shouldn't talk to them. It is still an issue in this town. And that's preventing some people, thats a reason for them not to come out. When they have it, they won't come out to say this is what is disturbing them..." 34-year old woman

*"I travel here to take my drugs because of stigma, in Benue State, everybody knows you".*28-year old female.

However, stigma is compounded by other reasons, because when respondents accessing care outside the state were asked if they would go to a facility closer to their homes but outside their immediate vicinity, many of them said no. The reasons for travelling outside of the state are discussed further below.

2.   On hunger, poverty and other costs of ART

Poverty was implicated in four inter-related areas: jobs, food, transport and user fees. All the patients travelling outside the State to access drugs named the cost of transportation as one of the major reason for missing appointments.

*"Most of us are jobless and the drugs work with food. Without food, the drug will not work very well. So most of us, like in the support group, we used to have very big challenges of jobless ones. They'll tell you transportation, they'll tell you I don't have food in my house. So all these things contribute. They are factors that affect them. Sometimes, they take the drugs for a long time without improving".*33-year old man.

*"There is a challenge we are facing... We have nothing we are doing. No jobs, that's why we are doing small small businesses here and there. That's the major challenge and we need the government to help to give us any job to keep us going. We need something to be doing. Mine, sometimes we don't have food at home and if you take the drugs, you will have problem, you will be shaking with hunger."*28-year old woman.

*"The major problem affecting people taking the drugs is hunger. Even if a baby of six months is eating, you can snatch the food because of how hungry you are (*laughter*). Truly, the hunger is too much. Hunger is our major problem. It's your health so it also increases your poverty level. That also contributes to a major problem.....We don't have any help from any body"* 32-year old man.

"There is a lady, if she collects the drugs, she'll not take it because of hunger. She stopped taking the drugs because she cannot withstand the hunger it causes .It affects those that stay in the rural areas and the low privileged people. If the community can help, most people will come up because many people are having that problem since they are down, they can't go to the farm. If

the strength is not there, you can't farm and there is nobody to help. Their relatives abandon them because of the problem. Like me I don't mind selling some of my things to feed myself... I work but sometime... the wrapper I buy for N1000 or N2000 I sell for N500 just to eat. You can't take the drug on empty stomach. If you do, you'll start feeling dizzy." 42-year old woman

"Yes, getting transportation to come is a hindrance, especially for people in the villages. Even if someone gives you transportation, how about feeding. Most of our problem here is feeding. I'm included. The food you ate before you became positive. If you double it, it will not be enough for you, because of the drugs. If you eat, before 30 minutes, you'll be hungry again. If you are hungry, even if somebody says 'good morning', you'll not answer." 40-year old woman.

3. <u>Hospital factors</u>

Patients complained about the attitude of healthcare workers, stock out of drugs for opportunistic infections and the long waiting time both within and outside the State.

"Any day you want to collect drugs, that whole day is for the drugs, you can't move. Some days, you will stay till 4.00pm. As early as 5am, you will go there, you will still stay till 12pm before they attend to you. And you will wait for drugs. Anywhere you go, you will wait. If you go for drugs, you will wait, if you go for test, you will wait, if you go for consultation, you will wait, if you go for adherence, you will wait. Anywhere you go, you will wait. At times before you reach your house, its about 5pm." 55-year old woman.

"The major problem we have here is our nurses and doctors are so rude, the way they talk to patients, you that have the problem, you will feel so bad. I don't condone it. Me, I challenge them. Like this nurse that just passed, she is very rude, very aggressive, very harsh. She doesn't look at us as human beings. That maybe as we are sick, we are finished, they talk to us anyhow. There is no comfort. I don't find joy when my co-patients are talked to in that manner. People like that, I wish they will be removed and taken to other units. Let people with passion for patients be brought to this clinic instead. Not people that will be insulting patients. Patients need to know HIV is not the end of our lives but some staff, the way they talk to you... Some patients sit outside and cry" 33-year old man.

*"The attitude towards HIV patients is bad. Even the health workers, the way the treat patients is bad. If you go to missionary hospitals where I was diagnosed, they treat you like a human being. But if you come to the government hospitals, the attitude... Infact, sometimes, we feel like not coming here again. (*Agreeing nods and murmurs*) Because the way they treat you, the way they look at you. ... they will be insulting you, tossing you here and there. Sometimes, I feel like – let me just sit at home and die"* 38-year old woman.

"Like there are some other drugs, like if someone has malaria or rashes or maybe pain or whatever, the major problem we are having now is concerning this ... treatment of opportunistic infections. If you are sick and come to the clinic, sometimes, they ask you to go and buy outside

the pharmacy and some of them do not have the money. Like aciclovir for herpes zoster, it is expensive, especially if you have to take it 400mg, like 14 days, because 400mg is about N3000 and you have to take it for 14 days so you see some where some of us contribute money to make sure that they get the drug. Like somebody that has cough, not really TB but general cough. They'll ask you to buy ciprofloxacin or azythromycin. You'll take the gravity of the cost but there will be no money so they'll start carrying prescription. And if you have an opportunistic infection like that, without you treating the opportunistic infection, your ARV will not work because something else is disturbing you so the virus waxes stronger." 33-year old man

"You see these hypertensive drugs, some of us are hypertensive. They will ask us to buy these drugs. They are expensive. Diabetic patients too, when you have this sickness and you are diabetic, they don't give the drugs free. You have to go and buy and they are expensive too." 50-year old man.

Stock-outs of non-ARV drugs used in the management of HIV is an issue many patients grapple with. This is so because many of the programs are not fully funded to provide these other drugs.

4.   Non-disclosure

A noticeable difference between the group accessing care within their immediate vicinities and those travelling far out is the increased number of those who have disclosed and were members of a support group within the former group.

"I sleep in the hospital (General assent) *Yes, I have a relation. But those relations of yours too; You don't want them to know. Everytime you tell them you are coming, coming and then you go to the hospital. So sometimes you prefer to come straight to the hospital and sleep."* 28-year old woman who travels 6 hours by road to access care.

Many of those accessing care in the State have disclosed to spouses or close relatives. One woman even disclosed to her employers.

"Me I love my drugs and I can't stop going to the hospital to pick my drugs. There was a time I lost my job. By the time I got another job, I told them that I have this problem. Any time they don't see me, they'll call me to find out whether I am fine. Sometimes, I'm going for drugs, I'll tell them that I'm going for drugs. They'll not do anything." 42-year old woman

5.   Inaccurate Knowledge and Perceptions about HIV & ART

Respondents identified some wrong perceptions about HIV and ART that delayed initiation of treatment and non-adherence in themselves or in someone they know. Some of these include a perception among rural communities that ART only prolongs the agony of living with the disease since it does not provide a cure, or that the morbidity caused by HIV is really due to witchcraft. Fear of poor quality of service in nearby hospitals also was one reason why patients travelled far away from home to access care.

"Yes, I stopped taking my drugs for a while because people were saying that death is inevitable and taking the drugs is only postponing the agony" 28-year old female.

"There is this boy, when I told him all these things, he refused. He said it's charm, it's this, it's witchcraft. See he has lost his life last year. He refused, I tried forcing him to go to the hospital, he refused and it's the virus that killed his wife. I told him everything but he didn't accept. So some people are there who don't care to hear that I am in sickness or it's the virus. They say its witches." 30-year old man.

"There is a cousin of mine. She said, its her own grandmother that is bewitching her. I tried the best I could, she refused, not until when I got married. I told my husband about her. Both of us now started following her up. Because even when her grandmother died, she fell sick, then I said who is bewitching you. She said I talk too much that already the sickness was there before Mama died and that it's the one that mama left over that is still affecting her. I tried, the first time, I took her to the hospital, she tested positive, they put her on TB drugs. She started accessing the drugs, TB drugs. Meanwhile, she was saying that she does not have cough. I told her that there is TB that is why she has to take the drug. She stopped but when she stopped, I brought my husband there again. Now she is accessing her drugs" 34-year old woman

6.   Certain Religious Beliefs and Advice

Certain religious beliefs and advice were also mentioned as a barrier to access. Respondents knew of others who refused to access drugs because they believed their faith will heal them; they also knew of others who died after a crusade by a popular Evangelist (name withheld).

"I have a friend, his wife is positive, we have tried to get him to take the test and he has refused. He said that his faith is enough for him. I cant force him to take drugs. He is a church leader like me. He is always in the church, prayer meeting all the time. He is not taking the drug because he said he has received his healing. But I think he is deceiving himself ..." 32 year old man.

*"Yes, they are times people stop taking their drugs. Like that time when Evangelist... (*name withheld*) came for Revival. I even stopped taking drugs for about a month, then I told*

somebody, who now counselled me. They are some that stopped completely". 42 year old woman.

"*Remember that woman* (name withheld). *She died now, because she stopped taking her drugs after the revival. I know three other people like her who died*". 40 year old woman.

7.   Coverage, Capping of services and Fear of Non-availability of ART

"*Yes. Many villages around here. Like Idaji, Ogbadigbo, Ogobia, Ugwu, Otobi, Adoka, Okpoga and Okpogw villages. They all come here. The people from these villages come to Otukpo even from other local governments like Agatu, Apa, Oju and Obi*". 42 year old woman.

Many of the big ART centres in the state have closed registration to new patients, so new patients often travel hours to sites in other LGAs.

"*Like me, I have excess [drugs]. You must have extra. So whenever the drugs do not come, you continue with the one you have*" 32 year old man.

"*Maybe one day IHVN will hands off supplying the drugs and everyone will start buying. Then you will be using the drugs you have till you prepare to buy for your self. For that we used to collect [the drugs] and keep [Agreeing murmurs]. The contract [PEPFAR] is for five years. No one knows what will happen after these five years. So if in five years…In five years, one should have a minimum of one year of drugs that you can be taking*" 48 year old man

4.4.4   *Why patients travel far to access care*

The reasons respondents gave for why some patients prefer to travel one to six hours from their home to access ART are summarized below, as numbers out of ten respondents accessing treatment outside Benue:

1.   Stigma – 8/10
2.   Business, job hunting or other financial opportunities – 4/10
3.   Spouse or close family living in the town where patient is accessing treatment – 2/10
4.   Better standard of care – 4/10
5.   Hope that one day cure will be found and will be first available to patients in big hospitals – 3/10
6.   I have already started, why go back – 1/10

Two other reasons worth mentioning are those observed by the researcher, but not mentioned by respondents as reason for not accessing.

7. Not disclosed to family – 7/10
8. Not members of support groups - 9/10

Patients that access drugs near their homes think that other patients travel far for access mainly because of stigma, followed by business and other financial opportunities.

"They are hiding themselves. They don't want the people that know them to see them. Some people have people in these places that can assist them so they prefer to go out for feeding money" 40 year old woman.

4.5 How can access be improved?

Most of the respondents within and outside Benue gave financial support and/or empowerment as the ways to improve access. Many pleaded for food support, transport support and job or loan opportunities.

Although long waiting time was a problem in both sites within and outside the site, most respondents didn't mention it as a major challenge. Their responses included - hiring more healthcare workers to reduce patient waiting time; stocking of OI drugs and support with drugs for other co-morbidities like diabetes and hypertension and public enlightenment campaigns to fight stigma.

Summary of how services can be improved from 26 patient respondents and 3 healthcare workers:

1. Financial assistance/ job creation – 20/29
2. Hiring of more healthcare workers – 5/29
3. Improved stocking of OI drugs – 4/29
4. Public enlightenment campaigns – 4/29
5. Timely service – 4/29

### 4.5.1 *What Benue State Government is doing to improve access to ART*

Two policy makers in Benue State revealed the following as steps the State Government was making to improve access:

1. The major reason why some LGAs do not have an ART site is because they only have Comprehensive Health Centres.(CHCs)or Primary Health Centres (PHCs) which are not equipped with laboratory and often do not have a doctor and or laboratory technologist. To tackle this problem, the State MOH is:

   a. Upgrading seven CHCs to General Hospitals in seven LGAs the State that previously did not have one.

   b. Planning to employ the necessary health care workers for these sites

BENSACA is planning to work with an Implementing Partner to pilot the decentralisation of services to a PHC to use it as a point for drug pickups. From the lessons learnt from this pilot, more PHCs can be used as drug pickup centres.

One gap identified by these policy makers was inconsistent and or delayed reporting from ART programs to the State Control Agency.
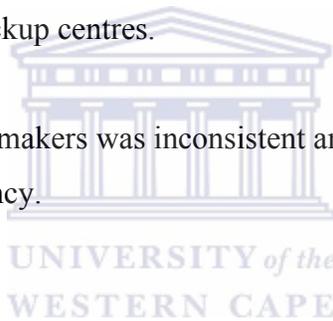
4.6   Limitations of the Study

In addition to the limitations mentioned earlier and recognized at the start of the study – small sample size and exploration of the experiences of people who HAD managed to access ART- the following limitations became apparent during the research:

- The number of FGDs done at the site outside Benue State where patients were accessing ART. Purposively sampling of men into a different group from women was a challenge as these were patients travelling between four to six hours to access care and were impatient to travel back.

- This study could not determine what sites around Benue where patients from living in the State are accessing ART due to huge gaps in providers' databases and lack of access to all the data available. This leaves a gap in the understanding of some of the issues around access to ART.

CHAPTER 5   DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1   Discussion

This study set out to understand the factors facilitating or impeding access to ART in Benue State, which has the highest HIV prevalence of any state in Nigeria. A range of factors related to access were determined using focus group discussions, semi-structured, exit and key informant interview processes.

The first and most obvious factor that is likely to facilitate access is the physical availability and distribution of treatment sites. The map included as Figure 3 above was drawn up by a cartographer in the state ministry of lands and survey, using data provided by the researcher. It is the first such map of this area known to the researcher. The mapping of ART services in Benue showed an uneven distribution of sites, with 11 out of the 23 ART sites in the state concentrated in 3 major towns, with state capital, Makurdi, inclusive. While it is impressive to hear that 22 new treatment centers have been added since 2006 when there was only one treatment centre in Benue, the coverage of this service is still poor.
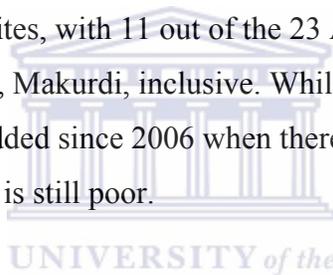
An understanding of the facilitators and barriers, and comparing same to existing literature helped to develop a deeper understanding of the issues and assist in formulating recommendations to strengthen access to ART in Benue State, and Nigeria as a whole.

The major facilitators of access this study found were the free cost of treatment, beneficial effects of ART, disclosure to a loved one and having a treatment partner. Respondents acknowledged the importance of the drugs and some stated their full commitment to taking the drugs, even if that means selling off personal possessions to pay for transport costs.

Several barriers to access were mentioned by the respondents including stigma & discrimination, hunger, transportation costs, poverty, long patient waiting time in the hospitals, unfriendly healthcare workers, costs of other drugs for existing co-morbidities & for the treatment of opportunistic infections, non-disclosure, inaccurate knowledge and perception about HIV &

ART, certain religious beliefs and advice, coverage, capping of services and fear of discontinuation of services.

Interestingly, this study found patients willing to travel long distances at some costs to access treatment even though many studies among people living with HIV/AIDS on antiretroviral therapy in sub-Saharan Africa identified transport costs as a major barrier to access (Ware et al., 2009; Uzochukwu, 2009; Posse et al., 2008; Tuller et al., 2009).

Many of the patients travelling to access care outside Benue State expressed a reluctance to relocate to facilities closer to their homes even though travelling so far was obviously inconvenient for them. Some expressed fear that the ART services provided in facilities close to home were inferior to services obtainable in the bigger facilities further away. One participant expressed that new care developments, like a cure, would be first made available to patients accessing care in bigger facilities than in smaller facilities in the rural areas. Additionally, some travelled to source for business and job opportunities as well as to seek help from relatives living in the cities.
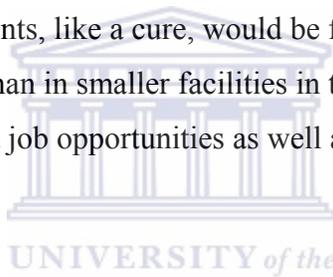
Other intriguing findings from this study not well represented in existing literature are the fear of discontinuation of free HIV services which is leading patients to hoard their drugs and the effect of certain religious beliefs and advices that make patients stop taking their medications. The fear of discontinuation of free HIV services is a very complex issue which could act as either a facilitator or impeder to access. It is a facilitator if it triggers patients already on therapy to report promptly at the facility to shore up more drugs. It is an impeder because it could lead to drug wastages due to expires in patients' homes, leading to fewer drugs available to other patients.

Religious beliefs affect ART access and adherence in conflicting ways. One study (Park & Nachman, 2010) in USA found religious beliefs as a significant facilitator to ART adherence; and another in Tanzania (Zou, Yamanaka, John, Watt, Ostermann & Thielman, 2009) found that although religion added to stigma, it didn't significantly affect patient's willingness to take ARVs. This study differed from the two studies because it suggests that religion as a barrier to access and adherence and agrees with other studies from Uganda, Tanzania and Kenya

(Wanyama et al., 2009; Roura et al., 2010 & Unge, 2010) which found patients discontinuing ART as a result of their religious beliefs.

In comparing the findings of the study with the framework drawn up by the researcher reveals several similarities. Common themes include stigma and discrimination, beliefs that HIV is associated with witchcraft and reluctance to visit facilities at the community level; long patient waiting times and turning away of patients due to overloading and inadequate staff strength at the facility level; HIV as a death sentence, poverty, transport and nutrition at the individual level; and inequitable spread and reach of public health facilities.

However, the framework differed from the study findings on several major themes. Poor inventory management, warehousing and storage, poor political will and corruption, poor wages, poor prognosis which discourages new patients, poor understanding of how to take ARVs and poor assessment of personal risk were factors mentioned by the framework but not identified by the study findings. None of the program managers or policy makers mentioned logistics and drug supply issues as a challenge, probably because the supply of antiretroviral drugs has been fairly stable in the country in recent times. This is not, however, the case with the drugs used for managing opportunistic infections. Certain religious beliefs and fear of discontinuation of services were in the study findings but not in the framework. Also, the framework underestimated the interest individual patients, even the semi-illiterate ones, take in their medications. All patient respondents exhibited a fair knowledge about ART and its benefits.

Of the ten respondents accessing care outside the state, 8 stated stigma as a reason. This may not be as big an issue as the patients allude to. The patients travel several hours, bypassing several other ART centres outside their locality and some ended up in a town where they have relatives. If stigma was the real issue, then any ART centre not close to home, would, also, have sufficed. Factors that may have bigger implication than the study could identify include business opportunities, perceived better standards of care and the hope that a cure would be more accessible to patients in big centres. Further research may be required to investigate this issue

The framework was a useful tool in analyzing the factors affecting access, and determining at what level these factors were seen- health facility, community or individual. Strategies aimed at mitigating identified barriers must be targeted at the relevant level.

Although there were some areas of agreement, patient respondents differed from policy makers and program managers in the angle of the problem that was most obvious to them. The three healthcare workers interviewed identified staff shortages as a critical barrier to access, while patients viewed health worker negative attitudes and non-availability of drugs for their co-morbidities as major challenges facing them. One policy maker felt stigma should no longer be as strong an issue because of all the interventions targeted at it, but most of the patients agreed that stigma was still a major challenge, for some, if not themselves.

5.2   Conclusions

Benue State has the highest prevalence rate in Nigeria but is second to Lagos State in terms of number of HIV positive people. Benue appears to be doing better in terms of number of sites in the State per HIV positive population. This can be attributed to the collaborative efforts between the State Government and Implementing partners.

However, there is still a gap in the services provided and the coverage of these services. Almost half (11 out of 23) of the State LGAs have no ART site. The State MOH is making efforts to upgrade facilities to meet criteria for ART sites but will still in dire need of the requisite staff to run this facilities.

For those LGAs having ART sites, a myriad of factors affect how patients are able to access ART there and they include long waiting time, poor attitude of healthcare workers, stigma and wrong perceptions about HIV within the communities, capping of services, and poverty.

Patients travelling hours to access care state stigma as the major reason but business or job opportunities, perceived better standards of care and being strategically located in case of a cure, may be bigger issues than patients admit.

Religious beliefs can act as a significant barrier to ART access and adherence. Where religious and healthcare instructions conflict, many patients will consider the religious instructions superior to that given by their healthcare providers (Roura et al., 2010). Program managers and policy makers need to be aware of this and work with religious leaders to decrease stigma and improve access to ART.

Many of the patients found the constant stock-outs of non-ARV drugs in the program a source of worry as they do not have the means to buy these drugs themselves. Some pleaded to have the range of products provided widened to include drugs to manage hypertension and diabetes.

The study also suggests a relationship between disclosure or having a treatment partner or membership of a support group on whether a patient will travel far out of his LGA to access ART or not. All of the patient respondents accessing care in their localities had one or more of the above factors. Further research is needed to explore this relationship. Non-attendance of support groups by those accessing care outside could be due to the distance, but could also contribute to the reason for travelling long distance to access care.

5.3   Recommendations for improving ART access in Benue State

Based on the findings of this study, the following recommendations are being proffered:

1. The findings from the study add to the awareness that barriers to access and multifaceted and highlights some patient-level barriers like hunger, poverty and religion. Value can be added by conducting further research on the extent to which these factors affect access.

2. Membership of a support group and disclosure should be incorporated into treatment preparation strategies in programs within and outside the state. This has the potential of encouraging patients accessing care far from home to return to their locality for care. Patients, before initiation of ART, should be encouraged to disclose to a close relative or associate and to have a treatment partner. Support groups can help patients who do not have anyone they trust enough to disclose to.

3. The importance of being in a support group should be highlighted in public enlightenment campaigns and in the talks given by nurses to waiting patients in the hospitals.

4. IHVN should incorporate a module on treating patients with respect and dignity in her training curriculum. Some patients complained about negative attitudes of health workers towards them being a major barrier to access.

5. Supply of non-ARV drugs used in the management of HIV and other co-morbidities should be beefed up. The Management of IHVN could source for additional funding to be able to provide an uninterrupted supply of some of these drugs. The selection of which should be clear to health workers so that they can educate patients better. Cheaper alternatives to these drugs could also help to improve this problem.

6. BENSACA and indeed, IHVN, will need to develop strategies targeting religious leaders in an effort to find common ground on the issue of 'divine cure' vs ART to avoid patients defaulting from therapy as a result of religious instructions.

7. Unemployment, costs of transportation and food were major challenges many patients mentioned. BENSACA should look into empowering support groups to generate income and give loans to members. IHVN and other partners working in Benue State can come to patients' aid in this key area.

8. More efforts need to be made by the State, through BENSACA, to improve coverage to the eleven LGAs that do not have ART centres. One way mentioned by the Head of the Health Management Board is to upgrade primary health centres in these LGAs to support ART. Another strategy mentioned by a Policy maker in Benue State, is the decentralization of ART services to these primary health centres.

REFERENCES

Adeneye A., Adewole T., Musa A., Onwujekwe D., Odunukwe N., Araoyinbo I., Gbajabiamila T., Ezeobi P., Idigbe E, (2006): Limitations to access and use of antiretroviral therapy (ART) among HIV positive persons in Lagos, Nigeria. *Journal of World Health and Populations,* 8: 46–56.

Adeokun l., Okonkwo P., & Ladipo O., (2006): Ch 10 – The Stigmatization of People Living with HIV/AIDS. In O. Adeyi, P.J. Kanki, O. Odutola & J.A. Idoko (eds.). *AIDS in Nigeria: A Nation on the Threshold*. Cambridge: Harvard University Press: 213-233.

Agbonyitor, M. (2009): Home-based care for people living with HIV/AIDS in Plateau State, Nigeria: Findings from qualitative study. *Global Public Health,* 4(3): 303-312.

Aminu A., (2008): *Government Wage Policy and the Dynamics of Public-Private Sector Wage Differential in Nigeria*. University of Ibadan, Nigeria: January 2008. [Online], Available: http://www.iza.org/conference_files/worldb2008/aminu_a4295.pdf [Downloaded: 16/09/10 03:25 PM].
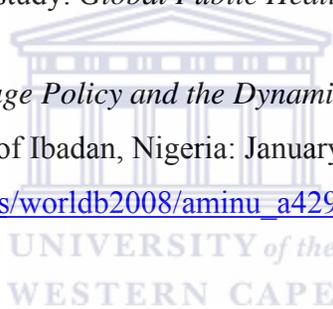
ART-LINC (The Antiretroviral Therapy in Lower Income Countries) Collaboration & ART-CC (ART Cohort Collaboration) Groups, (2006): Mortality of HIV-1-infected patients in the first year of antiretroviral therapy: comparison between low-income and high-income countries. *Lancet* 2006; 367: 817–24.

Avert, (2010): *Funding for the HIV and AIDS epidemic.* [Online], Available: http://www.avert.org/aids-funding.htm [Downloaded 06/09/10 07:10 PM].

Beaglehole, R., Bonita, R. and Kjellstrom, T. (1993): Ch 5- Causation in Epidemiology in *Basic Epidemiology* Geneva: WHO: 29-51.

Bedelu M, Ford, N., Hilderbrand, K., and Reuter, H., (2007). Implementing Antiretroviral Therapy In Rural Communities: The Lusikisiki Model Of Decentralized HIV/AIDS Care. *J

Infect Dis 2007 Dec; 196(Suppl 3):S464-S468. [Online], Available:
http://www.msf.org.za/docs/JID_2007_lusikisiki.pdf [Downloaded: 08/07/07 09:23 AM].

Blattner W., Dakum P., Osotimehin B., Nasidi A., & Abimiku A., (2008): Ch 12 - Public Health
Aspects of HIV/AIDS – Nigeria and West Africa. In D.D. Celentano & C. Beyrer (eds.), *Public
Health Aspects of HIV/AIDS in Low and Middle Income Countries*. Springer Science+Business
Media, LLC 2008: 217-251.

Brinkhof M., Pujades-Rodriguez M., & Egger M., (2009): Mortality of Patients Lost to Follow-
Up in Antiretroviral Treatment Programmes in Resource-Limited Settings: Systematic Review
and Meta-Analysis. *PLoS ONE*, June 2009; 4 (6): 1-9. e5790.

Canning D., Mahal A., Odumosu O., & Okonkwo P., (2006): Ch 9 – The Impact of HIV/AIDS
on Nigerian Households. In O. Adeyi, P.J. Kanki, O. Odutola & J.A. Idoko (eds.). *AIDS in
Nigeria: A Nation on the Threshold*. Cambridge: Harvard University Press: 193-212.

CDC (1999): *Guidelines for Defining Public Health Research and Public Health Non- Research.*
Atlanta: Centers for Disease Control and Prevention. [Online], Available:
http://www.cdc.gov/od/science/regs/hrpp/researchdefinition.htm [Downloaded: 3/10/2010 04:50
PM].

Chirac, P. (2002): Ch 14 Increasing the Access to Antiretroviral Drugs to Moderate The Impact
of AIDS: An Exploration of Alternative Options in *AIDS, Public Policy and Child Well-Being:*
UNICEF 2002. [Online], Available: www.unicef-icdc.org [Downloaded 12/08/08 01:13 PM.

Coker, E. (2009): *Update On Key Health Sector Response to HIV/AIDS at National Level*:
Presentation by the National AIDS Coordinator in (April) Abuja, 2009.

FMOH (Federal Ministry of Health, Nigeria), (2006): *The 2005 National HIV Seroprevalence
Sentinel Survey Among Pregnant Women Attending Antenatal Clinics In Nigeria*: Summary
Position Paper. Abuja (April), Federal Ministry of Health (Nigeria).

Gifford, S. (Undated). Unit 86 - Analysis of Non-numerical Research in C. Kerr, R. Taylor and G. Heard (eds). *Handbook of Public Health Methods.* Sydney: McGraw Hill: 543-554.

Hardon, A., Hodgkin, C. & Fresle, D. (2004): *How to investigate the use of medicines by consumers.* Geneva: WHO.

Hardon, A., Davey, S., Gerrits, T., Hodgkin, C., Irunde, H., Kgatlwane, J., Kinsman, J., Nakiyemba, A. & Laing, R., (2006): *From Access to Adherence: The Challenges of Antiretroviral Treatment Studies from Botswana, Tanzania and Uganda*. WHO 2006.

Idigbe, E., (2006): *ARV Therapy in Nigeria*: Paper Presented By Dr. Oni Idigbe, Director-General, Nigerian Institute of Medical Research, Lagos at the Biennial Conference of Stakeholders. Network on Ethics/Human Rights, Law, HIV/AIDS -Prevention, Support and Care (NELA*)*, Ogun State. 21st November, 2006.

Idigbe, E., Odutolu, O., Okonkwo, P., Folayan, M., Uwakwe, C., Audu, R., Jolayemi, O. & Osagbemi, M. (2006): Evaluation of the Nigerian national antiretroviral (ARV) treatment training programme. *Journal of Social Aspects of HIV/AIDS.* November 2006, 3 (3): 488-502. [Online], Available: http://www.sahara.org.za/dmdocuments/SAHARAJ_3-3_Nov06_pp488-502_OA_%20Nigerian_ARV_treatment_training_programme.pdf [Downloaded 8/4/09 11:13 AM]

IHVN (Institute of Human Virology, Nigeria) (2010a): *ACTION Project at a Glance*. Unpublished paper, IHVN, Abuja.

IHVN (Institute of Human Virology, Nigeria) (2010b): *Adult ART Overview*. Unpublished paper, IHVN, Abuja.

Iregbu K. & Elegba O., (2009): Prevalence of Kaposi's sarcoma among adult HIV-seropositive patients seen in a designated HIV treatment and care center in Abuja, Nigeria. Abstract. In

PubMed. PMID: 16928880. [Online], Available:http://www.ncbi.nlm.nih.gov/pubmed/16928880 [Downloaded: 15/08/10 11:49 AM].

Keen, J. and Packwood, T. (1995). Case Study Evaluation. *British Medical Journal*, 311: 444-446.

Lawn S., Harries A., Anglaret X., Myer L., & Wood R., (2008): Early mortality among adults accessing antiretroviral treatment programmes in sub-Saharan Africa. *AIDS* 2008, 22 (15): 1897–1908.

Lum H., Isichei C., Isichei-Wakili M., & Redfield R., (2007): Expansion of HIV-1 screening and anti-retroviral treatment programs in a resource-poor setting: results from a faith-based organization in Jos, Plateau State, Nigeria. *African Health Sciences*, 7 (2): 93-100. June 2007. [Online], Available: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1925274 [Downloaded 04/03/09 04:32 PM].

Mack N., Woodsong C., Macqueen K.M., Guest G., & Namey E., (2005). *Qualitative Research Methods*: *A Data Collector's Field Guide.* North Carolina: Family Health International.

Map of ART sites in Benue State, 2010. Map created by Benue State Ministry of Lands and Survey, based on data provided by C. Omenka, 2010).

Map of HIV prevalence by Nigerian States, 2008. Source: Coker, 2009*:* Update On Key Health Sector Response to HIV/AIDS at National Level: Presentation by the National AIDS Coordinator in (April) Abuja, 2009.

Mills E, Nachega J, Bangsberg D, Singh S., Rachlis B., Wu P., Wilson K., Buchan I., Gills C., & Cooper C. (2006a): Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Medicine* 3, 2039–2064.

Mills E., Nachega J., Buchan I., Orbinski J., Attaran A., Singh S ., Rachlis B., Wu P., Cooper C., Thabane L., Wilson K., Guyatt G., & Bangsberg D, (2006b): Adherence to antiretroviral therapy

in Sub-Saharan Africa and North America, A meta-analysis. *Journal of the American Medical Association* 296, 679–690. [Online], Available: www.jama.com [Downloaded 20/03/09 01:51 PM].

Monjok, E., Smesny, A., Okokon, I., Mgbere, O., & Essien, J., (2010): Adherence to Antiretroviral Therapy in Nigeria: An Overview Of Research Studies and Implications For Policy And Practice. *Dove Press Journal*: HIV/AIDS - Research and Palliative Care 2010: 2 69-76. 27 March 2010. Open Access Full Text Article. [Online], Available: www.dovepress.com [Downloaded 09/08/10 02:44 PM].

MSF (Medecins Sans Frontieres), (2009): Punishing Success? Early Signs of a Retreat from Commitment to HIV/AIDS Care and Treatment.Campaign for Access to Essential medicines. November 2009.

Mukherjee J., Ivers, L., Leandre, F., Farmer, P., & Behforouz, H., (2006): Antiretroviral Therapy in Resource-Poor Settings Decreasing Barriers to Access and Promoting Adherence. *J Acquir Immune Defic Syndr* 2006; 43:S123–S126. [Online], Available: http://www.jaids.org/pt/re/jaids/abstract.00126334-200612011-00017.htm;jsessionid=J2ZRCNmt2L1gTQkLTMJvv2s3nj3Tbn1QcgLg7ngm6lT1Jd5JTLC7!-1046349743!181195628!8091!-1 [Downloaded 13/03/09 09:31 PM].

Mukhtar-Yola M., Adeleke S., Gwarzo D. & Ladan Z., (2006): Preliminary investigation of adherence to antiretroviral therapy among children in Aminu Kano Teaching Hospital, Nigeria. *African Journal of AIDS Research,* 5, (2): 141 – 144. September 2006. [Online], Available: www.informaworld.com [Downloaded 05/08/10 05:50 PM].

Park J., & Nachman S., (2010): The Link between Religion and HAART Adherence in Pediatric HIV patients. *AIDS Care.* 2010, 1-6, iFirst article.

PEPFAR (President's Emergency Plan for AIDS Relief) (2008): *2008 Country Profile: Nigeria.*

Peterson, K., & Obileye, O., (2002): *Access to Drugs for HIV/AIDS and Related Opportunistic Infections in Nigeria*. POLICY Project, Nigeria, September, 2002.

Posse, M., Meheus, F., Van Asten, H., Van der Ven, A., & Baltussen, R., (2008): Barriers to access to antiretroviral treatment in developing countries: a review. *Tropical Medicine and International Health 13 no 7:904–913 July 2008.* . [Online], Available: www3.interscience.wiley.com [Downloaded 16/03/09 09:50 PM].

Rice, P., & Ezzy, D. (1999): Ch 2 - Rigour, Ethics and Sampling In R. Singh (eds.). *Qualitative Research Methods, A Health Focus*: Oxford University Press: 40-50.

Roura1 M., Nsigaye R., Nhandi B., Wamoyi J., Busza1 J., Urassa M., Todd J., & Zaba B., 2010: "Driving the Devil Away": Qualitative Insights into Miraculous Cures for AIDS in a Rural Tanzanian Ward. *BMC Public Health,* 2010, 10:427.

Sangowana A., Owoaje E., Faseru B., Uchendu O., Ekanem S., & Ebong I., (2005): Factors Influencing Access of People with HIV/AIDS in Ibadan, Nigeria to Antiretroviral Drugs. Abstract. MoPe 11.1C38. Presented at the 3rd IAS Conference on HIV Pathogenesis and Treatment, Rio de Janeiro, Brazil, 26th July, 2005.

Tuller D., Bangsberg D., Senkungu J., Ware N., Emenyonu N., & Weiser S., (2009): Transportation Costs Impede Sustained Adherence and Access to HAART in a Clinic Population in Southwestern Uganda: A Qualitative Study. *AIDS Behav*, March 2009; DOI 10.1007/s10461-009-9533-2. . [Online], Available: www.springerlink.com [Downloaded 20/08/10 12:01 PM].

UNAIDS, (United Nations Programme on AIDS) (2008): *Report on the Global AIDS Epidemic*. July 2008. . [Online], Available: http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp [Downloaded 22/10/08 04:57 PM].

UNGASS, (2010): United Nations General Assembly Special Session Country Progress Report, Nigeria: Reporting Period: January 2008 – December 2009; March 2010.

Unge C., (2010): *Uptake, Adherence and Discontinuation of Antiretroviral Treatment in the Kibera Slum, Nairobi, Kenya*. Sweden: Karolinska Institutet.

Uzochukwu, B., Onwujekwe, O., Onoka, A., Okoli, C., Uguru N., & Chukwuogo O., (2009): Determinants of Non-Adherence to Subsidized Anti-Retroviral Treatment in Southeast Nigeria. *Health Policy and Planning* 24:189–196. Oxford University Press . March 2009. [Online], Available: http://heapol.oxfordjournals.org [Downloaded 06/08/10 08:10 AM].

Voce, A., (2005): *Handout for the Qualitative Research Module*. Department of Public Health Medicine,University of KwaZulu-Nata, February 2005. [Online], Available: *http://ebookbrowse.com/ensuring-credibility-and-trustworthiness-doc-d31143366* [Downloaded 15/02/11 11:39 PM]

Wanyama J., Castelnuovo B., Wandera B., Mwebaze P., Kambugu A., Bangsberg D., & Kamyaa M., 2007: Belief in Divine Healing can be a Barrier to Antiretroviral Therapy Adherence in Uganda. *AIDS,* 21(11): 1486 – 1487.

Ware N., Idoko J., Kaaya S., Biraro I., Wyatt M., Agbaji O., Chalamilla G., Bangsberg D., (2009): Explaining Adherence Success in Sub-Saharan Africa: An Ethnographic Study. *PLoS Medicine*, 6 (1): 39 - 47 January 2009. e1000011.

WHO (2003): *Scaling Up Antiretroviral Therapy in Resource-limited Settings: Guidelines for a Public Health Approach*. 2003 Revision (Draft Version).

WHO, (2005): *Technical Meeting for the Development of a Framework for Universal Access to Prevention, Care, Treatment and Support in the Health Sector*. WHO Executive Board Room, Geneva, 18-20 October 2005. . [Online], Available: http://www.who.int/hiv/universalaccess2010/UA_definitions_detailed.ppt [Downloaded 14/07/09 03:17 AM].

WHO, UNAIDS & UNICEF (2008): *Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector, Progress Report*. WHO, 2008. [Online], Available: http://www.who.int/hiv/mediacentre/2008progressreport/en/index.html# [Downloaded 12/10/09 06:10 PM].

World Health Report, (2008): Primary Health Care: Now More Than Ever. WHO, 2008. . [Online], Available: http://www.who.int/whr/2008/whr08_en.pdf [Downloaded 22/08/10 09:28 PM].

Yu J., Chen S., Wang K., Chang C., Makombe S., Schouten E., & Harries A., (2007): True outcomes for patients on antiretroviral therapy who are "lost to follow-up" in Malawi. Bulletin of the World Health Organization, July 2007:85 (7):550–554. [Online], Available: http://www.scielosp.org/pdf/bwho/v85n7/a13v85n7.pdf [Downloaded 20/08/10 11:45 AM].

Zou J., Yamanaka Y., John M., Watt M., Ostermann J., & Thielman N., (2009): Religion and HIV in Tanzania: Influence of Religious Beliefs on HIV Stigma, Disclosure, and Treatment Attitudes. *BMC Public Health*, 2009, 9:75.

APPENDICES

Appendix 1

Problem analysis diagram

Access barriers to antiretroviral treatment were analyzed based on a theoretical problem analysis diagram for focusing and analyzing core problems of medicine use described by Hardon, Hodgkin & Fresle, (2004). The diagram relates individual drug use behavior to the multifaceted environment shaping it. This includes the household, community, health service institution, national and international levels. The diagram can also assist in developing interventions aimed at changing behavior and the environment in which medicines use problem occurs, in order to bring about more appropriate use. It helps to identify why medicines use problems happen, so that appropriate, efficient and practicable strategies can be selected to deal with the problems (Hardon et al., 2004).

Figure 5. Problem analysis diagram
Example of a problem analysis diagram of the inappropriate use of antibiotics

NATIONAL LEVEL	HEALTH INSTITUTION LEVEL	COMMUNITY LEVEL	INDIVIDUAL LEVEL
Lack of control/ regulation of medicines supply	OTC-availability of ABs in pharmacies and shops	ABs in groceries	
	Inadequate dispensing of ABs	**Core problem: INAPPROPRIATE USE**	Beliefs: • ABs are essential • Parents fear conditions will worsen • Past experience
	Costs		
	Over-subscribing of ABs		
Weak implementation of essential drugs programme	Inadequate information provision on how to use ABs		Lack of knowledge and information

AB = antibiotic

Note the flexible nature of the proposed methodology for focusing and analysing the core problem. It involves learning-as-you-go, whereby newly generated information collected in key informant interviews serves as input into the workshop, where a core problem is selected.

Appendix 2

Focus group discussion guide to be used with patients accessing ART from selected facilities

Name of the interviewer:

Interview number:

Name of health facility where patient contacted:

Date:

NB: Participant's information (with introduction of study and interview), Statement of confidentiality and Informed consent

Socio-demographic information

    a. Sex (M / F)

    b. Age (Years)

    c. Educational level

    d. Marital status

    e. Occupation

    f. Distance from facility (in time or distance)

    g. Cost of care in terms of transport & services

Discussion

- What are the general experiences of people living with HIV in this community in accessing ART care?

- How long did you have to wait before they start ART? Why?

- What are some of the factors that make it easy for you to access care?

- Are there some factors that prevent people from accessing ART services here?

- Are there some beliefs about HIV/AIDS or ART that may prevent PLWHAs from accessing care?

- Why do you think some patients travel very far to access ART?

- How do you think these barriers can be handled: by the facilities, the government, the community and by the individuals?

What has been your experience with access to ART before and after you started?

Appendix   3

Semi-structured interview guide to be used with patients accessing ART from selected facilities (adapted from Hardon, Davey, Gerrits, Hodgkin, Irunde, Kgatlwane et al., 2006)

Name of the interviewer: Interview number:

Name of health facility where patient contacted:

Date:

NB: Participant's information (with introduction of study and interview), Statement of confidentiality and Informed consent.

Socio-demographic information

a) Sex (M / F)

b) Age (Years)

c) Educational level

d) Occupation

e) Distance from facility (in time or distance)

f) Cost of care in terms of transport & services
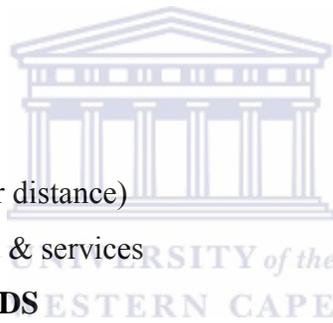
Patient knowledge about HIV/AIDS

Can you tell me what you know about HIV/AIDS? (Allow patient to say whatever, and then probe on the following: cause of HIV infection, cause of AIDS, prevention, life   long infection). Apart from these, is there anything else you have heard from your community that explains AIDS in a different way?

Knowledge about ARVs

Could you tell me what you know about ARVs? (Ask about the following: prolongs life, improves quality of life, life long treatment, knowledge about side effects).

Assessment of access barriers

We are trying to find out what prevents patients from accessing their antiretroviral therapy. It's not always easy coming to the facility to access care. Some patients have problems getting and taking their drugs. Please feel free to be open about the problems you face with these. Everything you say here will remain confidential, and will not be shared with anyone at the clinic.

a) Have you ever missed an appointment at your hospital? (Reasons, and details on type of consultation: review/refill, counselling etc.)

b) Have you ever thought about stopping HIV/AIDS medicines (ARVs)? If yes, give details.

c) How much do you have to pay to cover your travel expenses when you visit the clinic?

d) What is the cost of registering at the clinic (if any)?

e) What is the cost of the drugs that you take or lab tests (if any)?

f) Do you lose any income as a result of your coming to the clinic?

g) Do you incur any other costs as a result of your taking ARVs?

h) What have you and/or your family had to give up in order to be able to take your medicines regularly?

Quality of care

(a) What do you think of the service you receive at this clinic? (General, open ended, and prompt for details as necessary)

- Do you feel listened to? Yes No

- Are you given the chance to state your problems and ask questions?
  Yes No

- Are you treated with respect? Yes No

- Do you feel you can trust the health workers? Yes No

- Do you have privacy during consultation and counselling?
  Yes No

- How do you find the environment of the clinic?

(b) How long did you spend altogether at the clinic today?

(c) How long did you have to wait before being attended to?

(d) How would you rate the services you received here today

(e) If there is another centre offering services closer to your house, would you go there? Reasons for answer

Perceived problems and possible solutions

a) What do you perceive as the biggest problem regarding taking ARV treatment?

b) What do you think could be done to improve this?

c) List the problems you face accessing your ART in order of importance to you.

d) Have you ever had any experience of being treated differently because of your HIV status? (in your family, at work, at the church, community or in this hospital?)

e) What has been your experience with access to ART before and after you started?

Do you have any questions for me?

Thank you.

Appendix 4

Exit interview guide to be used with patients accessing ART from selected facilities

Name of the interviewer: Interview number:

Name of health facility where patient contacted:

Date:

NB: Participant's information (with introduction of study and interview), Statement of confidentiality and Informed consent

Socio-demographic information

a) Sex (M / F)

b) Age (Years)

c) Educational level

d) Occupation

e) Distance from facility (in time or distance)

f) Cost of care in terms of transport & services

Quality of care

(a) What do you think of the service you receive at this clinic? (General, open ended, and prompt for details as necessary)

- •Do you feel listened to? Yes No

- •Are you given the chance to state your problems and ask questions?
   Yes No

- •Are you treated with respect? Yes No

- •Do you feel you can trust the health workers? Yes No

- •Do you have privacy during consultation and counselling?
   Yes No

- •How do you find the environment of the clinic?

(b) How long did you spend altogether at the clinic today?

(c) How long did you have to wait before being attended to?

(d) How would you rate the services you received here today

(e) If there is another centre offering services closer to your house, would you go there? Reasons for answer

Perceived problems and possible solutions

a) What do you perceive as the biggest problem regarding taking ARV treatment?

b) What do you think could be done to improve this?

c) List the problems you face accessing your ART in order of importance to you.

d) Have you ever had any experience of being treated differently because of your HIV status? (in your family, at work, at the church, community or in this hospital?)

e) What has been your experience with access to ART before and after you started?

Do you have any questions for me?

Thank you,

Appendix 5

Key informant interview guide

Name of the interviewer: Interview number:

Name of Program/Instituition where key informant is contacted:

Name of Key Informant:

Position:

Date:

NB: Participant's information (with introduction of study and interview), Statement of
confidentiality and Informed consent

Topics to cover include number of ART programmes and % coverage of those in need of ART

1. What is the total number of ART programmes in the State, broken by LGAs?

2. What is the percentage coverage of those in need and source of data

3. What is the State doing to improve access to ART?

4. Please can you direct me to where I can get and review relevant documentation on existing
programmes in the state.

    5. What has been some of the challenges to improving access to ART in the state?
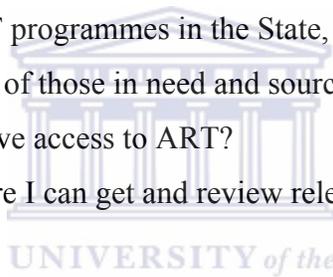
Appendix 6

Participant information sheet

UNIVERSITY OF THE WESTERN CAPE
School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

Participant information sheet

November 2009

Dear Participant,

Thank you for your willingness to hear about this research. I have outlined below my research project for your potential involvement. The study is being conducted in partial fulfilment of my Masters Degree in Public Health at the University of Western Cape, South Africa. Please ask me about anything you do not understand or are unclear about. My contact details and that of my supervisor are included.

Title: Access to Antiretroviral Treatment in Benue State, Nigeria

Purpose:

The rationale for this study is to explore some of the barriers preventing PLWHAs from accessing treatment in Benue State. This information would inform policy makers in designing interventions to reduce these barriers. Identifying the reasons why some patients would rather travel additional hours to neighbouring states to access care and other barriers may help program managers design interventions to address those reasons.

Description of the study and your involvement

The study will include exit interviews, focus group discussions with support group members and individual patients accessing ART. Questions about your experiences prior to, and while accessing antiretroviral care, will be the focus of all discussion/interview that I have with you.

Confidentiality

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose and fill above. I shall keep all personal records on your participation locked away at all times, and destroy them after the data has been collected.

Voluntary participation and withdrawal

The interview may touch on any issues you may have had with access to antiretroviral therapy. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

Your participation in this research is completely voluntary as you do not have to participate. Even if you choose to participate, you may stop at any time.

Informed consent

Your signed consent to participate in this study is required before I proceed to interview you. I have included the consent form with this information sheet. Please review the form and decide whether you would like to participate or not.

Questions

Charity Omenka
Student Number: 2831556
Mobile Number: +234 803 586 6248
Email: **omenkac@gmail.com**; **2831556@uwc.co.za**.

My supervisor at UWC is Prof Christina Zarowsky: telephone- +27 21 959 9394
fax: +27 21 959 2872, email: czarowsky@uwc.ac.za**,** web: www.uwc.ac.za/publichealth.

Appendix 7
Informed consent form

UNIVERSITY OF THE WESTERN CAPE
School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

Informed consent form

Date:	Interviewee's pseudonym:

Interviewer: Charity Omenka
UWC Student no: 2831556
Tel: _+234 803 586 6248__
E-mail: omenkac@gmail.com; 2831556@uwc.ac.za.
Institution: University of the Western Cape, South Africa

Thank you for agreeing to allow me to interview you.

I am a student at the SOPH, University of the Western Cape. I am conducting this study as part of my Masters in Public Health. I am accountable to Prof Christina Zarowsky who is contactable at +27 21 959 9394, email: czarowsky@uwc.ac.za**.**

This study about access to antiretroviral therapy in Benue State, will include exit interviews, focus group discussions with support group members and individual patients accessing ART. Questions about your experiences prior to, and while accessing antiretroviral care, will be the focus of all discussion/interview that I have with

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose. See name above. I shall keep any other records of your participation locked away at all times, and destroy them after the data has been collected.

The interview may touch on any issues you may have had with access to antiretroviral therapy. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

Please indicate that you have given your consent by signing below:

Name: _____

Signature: _____

Date: _____

I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed by interviewer:

Signed by participant:
Date:
Place:

Appendix 8

UNIVERSITY *of the* WESTERN CAPE
DEPARTMENT OF RESEARCH DEVELOPMENT

SR1

UWC RESEARCH PROJECT REGISTRATION AND ETHICS CLEARANCE APPLICATION FORM

This application will be considered by UWC Faculty Board Research and Ethics Committees, then by the UWC Senate Research Committee, which may also consult outsiders on ethics questions, or consult the UWC ethics subcommittees, before registration of the project and clearance of the ethics. No project should proceed before project registration and ethical clearance has been granted.

A. PARTICULARS OF INDIVIDUAL APPLICANT

NAME: **OMENKA, CHARITY OCHUOLE**	TITLE: **MRS**

DEPARTMENT: **School of Public Health**	FACULTY: **Community and Health Sciences**

FIELD OF STUDY: PUBLIC HEALTH

ARE YOU:				
A member of UWC academic staff?	Yes	☐	No	☒
A member of UWC support staff?	Yes	☐	No	☒
A registered UWC student?	Yes	☒	No	☐
From outside UWC, wishing to research at or with UWC?	Yes	☐	No	☒

B. PARTICULARS OF PROJECT

PROJECT NUMBER: TO BE ALLOCATED BY SENATE RESEARCH COMMITTEE:

EXPECTED COMPLETION DATE: **MARCH 2010**

PROJECT TITLE:

THREE KEY WORDS DESCRIBING PROJECT:

ACCESS, ANTIRETROVIRAL, NIGERIA

PURPOSE OF THE PROJECT:

M-DEGREE: D-DEGREE:

POST GRADUATE RESEARCH:

C.   PARTICULARS REGARDING PARTICULAR RESEARCHERS

                                                      FAMILY NAME: INITIALS:
TITLE:

PRINCIPAL RESEARCHER: OMENKA   C.O.
MRS

OTHER RESEARCH PROJECT LEADERS:

OTHER CO-RESEARCHERS:

THESIS: STUDENT RESEARCHER: CHARITY OMENKA

THESIS: SUPERVISOR: PROF. CHRISTINA ZAROWSKY

C. GENERAL INFORMATION

STUDY LEAVE TO BE TAKEN DURING PROECT (days): 2 WEEKS

IS IT INTENDED THAT THE OUTCOME WILL BE SUBMITTED FOR PEER REVIEWED PUBLICATION?

YES ⊠   NO ☐

COMMENTS: DEPARTMENTAL CHAIRPERSON:

SIGNATURE OF THESIS STUDENT RESEARCHER – WHERE APPROPRIATE:

DATE: 29th October 2009

SIGNATURE OF THESIS SUPERVISOR – WHERE APPROPRIATE:

DATE

SIGNATURE OF PRINCIPAL RESEARCHER – WHERE APROPRIATE:

DATE:

SIGNATURE OF DEPARTMENTAL CHAIRPERSON:
DATE:

NOTE: THESE SIGNATURES IMPLY AN UNDERTAKING *BY THE RESEARCHERS*, TO CONDUCT THE RESEARCH ETHICALLY, AND AN UNDERTAKING BY THE THESIS SUPERVISOR (WHERE APPROPRIATE), AND THE DEPARTMENTAL CHAIRPERSON, TO MAINTAIN A RESPONSIBLE OVERSIGHT OVER THE ETHICAL CONDUCT OF THE RESEARCH.

E.   DESCRIPTION OF PROJECT AND RESEARCH ETHICS STATEMENT

Please type below, or attach a typed document, usually between 500 and 5000 words, setting out the purpose and process of the research. Please include a clear research ethics statement. The onus is on the applicant to persuade UWC that the research will be conducted ethically. This will normally require evidence of an up to date research ethics literature search in the particular discipline; evidence of what the world standard ethical practice is, in the particular discipline; an explanation of how the proposed research is to be conducted ethically; a detailed justification of any proposed departure from world standard ethical practice; and a clear undertaking to conduct the research ethically. It may be useful also to agree to conduct the research in line with the published ethical rules of a national or international disciplinary association. UWC reserves the right to stop or suspend any research undertaken by its staff or students, or by outsiders on its property or in association with it, if the research appears to be unethical.

Approval has been sought and received from the Nigeria National Health Research Ethics Committee, whose Chairman gave verbal approval to the researcher, pending approval of the protocol by the UWC Senate Ethics Committee.

In the course of conducting the research, I will ensure that participation in the study is voluntary for all patients and key informants. Relevant information about the research topic, objectives, purpose and possible risks will be provided on a sheet to all respondents. Although the researcher anticipates that the research poses minimal risk to the respondents, a trained counsellor will be part of the research team to help any distressed participant. Informed consent will then be received from respondents with opt out (at any time within the period of the research) options.

Confidentiality will also be ensured through the use of numbers and fictitious names for identification. Additionally, my field notes and transcripts will not contain personal identifiers. I will keep raw and processed data locked and or password protected and share data only with members of the research team who have received research ethics training. I will keep transcripts that have no personal identifiers until the data are analysed and for five years the research has been concluded for reference. Personal information on respondents, which will be destroyed once the data collection and cleaning is complete.

 Research assistants will be given thorough ethics training. To ensure that these standards are kept at all times, regular audits of myself and the research team will be conducted.

Form issued by: Professor Renfrew Christie, UWC Dean of Research, February 2002.

(959 2949; 959 2948 secretary, 959 3170 fax, email: rchristie@uwc.ac.za)