THE EFFECT OF GENDER ON ACCESSING ANTIRETROVIRAL THERAPY AND ITS LINK TO NEUROCOGNITIVE FUNCTIONING

by

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Declaration

I **Joyce Tholiwe Sibanda-Kunda** do hereby declare that this dissertation is a product of my individual effort. All scholarly content has been acknowledged. This dissertation has not been submitted previously at this university or indeed any other university elsewhere for a degree qualification.

Signature……..Date……..

Certificate of Approval

This dissertation by **Joyce Tholiwe Sibanda- Kunda** has been approved as partial fulfilment of the requirement for the award of the degree of Master of Science in Clinical Neuropsychology by The University of Zambia.

Examiners

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Abstract

Objective: To determine the effect of gender on accessing antiretroviral therapy and its link to neurocognitive impairment.

Methods: The study was in two parts. Part 1 used the qualitative approach and 38 participants comprising 34 HIV infected adults, equal numbers of men and women and 4 health providers were recruited. The 34 HIV infected adults were a subset of the full sample tested in part 2. Part 2 used the quantitative approach and 263 participants from the bigger study were recruited. All participants were recruited from 6 clinics run by the Lusaka Urban District Health Management Team (LUDHMT).These were Chilenje, Chipata, Matero main,Matero referral, Kabwata and Kalingalinga. For the qualitative approach all the participants (N= 38) went through interviews using semi structured interview guides-one for the HIV infected adults and the other for the health providers. The interviews were audio-recorded and transcribed, and the scripts were analysed qualitatively. In the quantitative approach the participants(N =263) were evaluated with the neuropsychological test battery to assess executive function, verbal fluency, working memory, learning memory, recall, motor skills and speed of information processing. The test scores were subjected to analysis of variance as a function of gender, age and level of education.

Results: In the first part of the study, the qualitative part two sets of themes emerged from the interviews. The first set was that of barriers to ART access that affected both males and females. In this set of themes 7 barriers were identified and these were: i) beliefs and misconceptions; ii) stigma; iii) medical environment; iv) side effects; v) disclosure; vi) feeling better; and vii) socio-economic status. In the second set of themes the following 3 gender barriers were identified: a) Male dominance; b) men less proactive in health matters; and c) unequal distribution of HIV and AIDS programmes across gender groups. Based on the significant barriers faced by women it was hypothesised that the performance of the female participants on the neuropsychological test would be lower than that of the male participants of the same age and educational level. However, the results revealed that there were no significant differences except in one test the stroop word where the performance of the female participants was higher than that of the male participants.

Conclusions: The results from this study revealed that despite the gender barriers that exist in the access to ART there were no gender differences in performance in the neuropsychological testing. Failure to find any significant differences in the test scores was due to biased sampling of women who were accessing and adhering to ART.

To the two mothers: Naka Joyce and Bana Kunda

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Table of Contents

List of tables

Acronyms

ADC- AIDS Dementia Complex

AIDS- Acquired Immunodeficiency Syndrome

ANC-Anti Natal Care

ART-Antiretroviral Therapy

ARV-Anti-Retroviral drugs

AZT-Zidovudin

CART-Combination Antiretroviral Therapy

CNS-Central Nervous System

FAO-Food and Agriculture Organisation

GP- General Practitioner

GRZ-Government of the Republic of Zambia

HAART-Highly Active Antiretroviral Therapy

HAD-HIV Associated Dementia

HAND-HIV Associated Neurocognitive Disorder

HIV-Human Immunodeficiency Virus

ILO-International Labour Office

IPPF-International Planned Parenthood Federation

LIWA-ANS- The Living With Antiretroviral

LUDHMT-Lusaka Urban District Health Management Team

MCMD-Minor Cognitive/ Motor Disorder

MDG-Millennium Development Goals

NAC-National AIDS Council

NHSP-National Health Strategic Plan

PLWHA-Persons Living With HIV and AIDS

PMTCT-Prevention of Mother to Child Transmission

PNS-Peripheral Nervous System

SAFAIDS-Southern Africa HIV & AIDS information Service

STD-Sexually Transmitted Disease

STI- Sexually transmitted Infection

TB-Tuberculosis

UNAIDS-United Nations AIDS

UNICEF-United Nations International Children's Emergence Fund

UN-United nations

UNZABREC- University of Zambia Bio-Medical Research Ethics Committee

USA-United States of America

WHO-Word Health Organisation

ZAT-Zambia Achievement Test

ZDHS-Zambia Demographic Health Survey

List of Appendices

Chapter 1

INTRODUCTION

1.0 Background

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) pandemic has devastated the world since the early 1980s when the first recognised cases occurred in the United States of America. Globally an estimated 35.3 million people were living with HIV in 2012.There were 2.3 million new infections showing a 33% decline in the number of new infections from 3.4 million in 2001. The number for AIDS related deaths is declining with 1.6 million deaths in 2012 from 2.3 million in 2005. The decline in deaths has been due to antiretroviral therapy (ART). Antiretroviral therapy can help to prevent people living with HIV from dying from AIDS and from developing tuberculosis (TB), becoming ill and transmitting TB and HIV. The drugs are not curative but they are used to inhibit the reproduction of retroviruses thus slowing disease progression. Their continued use particularly in multi-drug regimens significantly slows disease progression which indicates that people should start treatment early. In 2012, 9.7 million people in low and middle income countries received ART representing 61% of all who were eligible under the 2010 World Health Organisation (WHO) treatment guidelines. However, under the 2010 WHO guidelines the HIV treatment coverage in low and middle income countries represented only 34% of the 28.6 million people eligible in 2013 that year (UNAIDS, 2013, WHO, 2013).

Zambia, like the rest of Southern Africa has a high adult HIV prevalence. It is estimated that 950,000 adults are infected with AIDS and 490,000 of these are women accounting for 51% of the infected adults (WHO, 2010).Throughout the 1990s, as observed by Stephen Lewis, then United Nation's special envoy for HIV and AIDS in Africa, the government was 'disavowing the reality of AIDS' and doing nothing about the problem

but the new millennium signalled a marked political change because there was an entirely new level of determination to confront the epidemic. This was seen in 2002 when the National HIV/AIDS/STD/TB council (NAC) through an Act of Parliament, became operational as a legal body able to apply for funds. The government also got involved in a challenging ART treatment programme when the late President Mwanawasa declared HIV and AIDS a national emergency in 2005. This came with a commitment to provide free antiretroviral drugs to 10,000 people by the end of that year. Since then, progress on the reduction of HIV prevalence has been encouraging, reducing from 16.1%to 14.3%. Efforts to scale up access to ART have led to an increase in the number of HIV positive eligible clients accessing Antiretroviral Therapy (ARVS). In 2012, of the estimated 610,000 people eligible for ART according to 2010 guidelines 480,925 were reported to be receiving the treatment. Consequently, the number of deaths reduced from 77,000 in 2001 to 30,000 in 2012. This number could have been reduced even further if all who were eligible to ART had access. This, therefore, means that greater efforts in prevention and treatment are paramount if Zambia is to increase prevention in coming years.

New infections have also reduced from 97,000 in 2006 to 56,000 in 2012 making Zambia one of the 26 countries where the adult HIV incidence has declined more than 50% between 2001 and 2012. This has been due to the programmes that have been put in place to curb the epidemic. (WHO 2010, Partnership between GRZ and USA, 2011, WHO 2012, UNAIDS2013, National health Strategic Plan 2011-2015).

While barriers of testing and adherence commonly feature in the assessment of ART, far less is known about barriers faced in the middle of the continuum to accessing treatment. When looking at access we consider factors that aid or motivate initiating and maintaining of ART to individuals who are HIV infected. These are things that will encourage them and not hinder them when they are put on treatment (Mshana et al, 2006).

Many studies have cited different barriers to accessing HIV treatment such as stigma, feeling better, beliefs and misconceptions about the treatment, health service,

forgetfulness, socio-economic status, side effects. Among these, stigma has been cited as a major barrier in accessing medication, seconded by socio-economic status. In reviewing some studies Mahajan et al, (2008), indicated that in addition to devastating the family, social and economic lives of individuals, HIV and AIDS stigma is cited as a major barrier to accessing prevention, care and treatment services in numerous settings, particularly in resource limited countries. Erving Goffman (1963, p1), one of the most influential sociologists of the 20th century defined stigma as, 'the phenomenon whereby an individual with an attribute which is deeply discredited by his or her society is rejected as a result of the attribute.' Stigma is a process by which the reaction of the others spoils normal identity. Many people who have been stigmatised feel devalued by others. Their behaviour is affected. Stigma does not only change their behaviour but it also shapes their emotions and beliefs. Their social identity is put in a threatening situation like low self-esteem which influences their ability to disclose their HIV status and seek treatment.

Social and economic effects of the HIV pandemic have been experienced in many households. The HIV and AIDS epidemic affects the labour available in the household. While the income is reduced due to inability to work and the eventual death of the bread winner, it also increases expenditure through incurred medical bills. In some studies it has been reported that households with an AIDS patient spend on average 20 times more on health care than the households without an AIDS patient (Isaksen et al, 2002). This situation forces the household to embark on strategies to cope with the difficulties of substantially reduced income. The household is caught in a double binding of needing more resources at a time when the production capacity of the household is reduced.

The government of Zambia has made concerted efforts to provide the ARVS but gender differences in ART access have continued to prevail. Monitoring ART distribution is critical to identify emerging problems and adapt programmes accordingly. Persisting questions regarding equality of access need to be addressed to ensure programmes lead to successful treatment outcomes.

One of the challenges of the HIV epidemic is that there are insurmountable medical complications along with neurocognitive disorders. Over the years and with the introduction of (ARV) it has become clearer that HIV infection leads to progressive impairment in the brain function. Although the scaling up of ARV continues in developing countries, in Zambia the effect of the ARV treatment on neurocognitive function remains to be determined. Even though Highly Active Antiretroviral Therapy (HAART) has reduced the incidence of HIV dementia, HIV associated cognitive impairment continues to be a major clinical problem among individuals with advanced infection. Research has indicated that in the last 20 years or so there are studies that addressed HIV associated neurocognitive impairment in Sub-Saharan Africa with a wide range of HIV Associated Neurocognitive Disorders (HAND) prevalence rates of 3.2% to 56 %. This can be partly attributed to the methodological approaches of earlier studies that were based mostly on clinical assessment to determine HIV neurocognitive impairment. In Zambia the neurological and psychological effects of HIV are not defined. This has been attributed to lack of Neuropsychological tools. Not until recently, there was a lack of trained personnel to administer the neuropsychological tests to the patients. Even then, despite having some trained personnel, structures have not been established for them to carry out the assessments in the clinical settings (Holguin et al, 2011& Sacktor, 2002).

Research has shown that there are gender differences in the performance in neuropsychological tests. In most studies the performance of women has been poor, an indication that they are more prone to suffer from HIV associated Neurocognitive deficits as compared to their male counterparts. The few studies that have been done in Zambia have confirmed these findings (Holugin et al, 2011 & Hestad et al, 2012). Some studies have found that HIV positive women as compared to their male counterparts more often present a history of substance use, a greater number of psychiatric problems, show a faster development of the disease as well as mortality rates and tend to have attained lower levels of formal education. All these aspects could theoretically explain the differences found in the neuropsychological performance of

HIV positive men and women. As the incidence of HIV infection continues to grow among women neuropsychological research should include both men and women in its samples and furthermore analyse the data by gender (Garrido et al 2013).

1.1 Statement of the problem

Access to health care varies across countries, groups and individuals and is largely influenced by social and economic conditions as well as the health policies in place. Many National HIV and AIDS programmes have not attended to gender equality issues. The few studies that have been documented have suggested that there are significant gender issues in access to ART. Gebo et al (2005), observed that data from mid 1990s demonstrated that many eligible patients did not receive ART and that gender disparities existed in ART access. Men may be less likely to take up treatment, while women are more likely to take up treatment but they are constrained by the socio-economic factors. It has been a general finding in public health research that men are less likely to take up positive health initiatives than women. This may be the same with HIV testing and access to treatment (Parslow et al, 2004, Owen, 2008 & Smith, Mayer, Wittert, 2006). In 2008, 52% of the countries who reported to the United Nations (UN) General Assembly included specific budgeted support for women focused on HIV and AIDS programmes such as the Prevention of Mother to Child Transmission (PMTCT). For some time there appeared to be no specific programme directed at men until recently when Voluntary Medical Male Circumcision (VMMC) was introduced as one of the interventions in HIV prevention in countries with a high prevalence of HIV but with a low prevalence of Male Circumcision. (WHO, 2010 & WHO, 2013).

Research has shown that lack of access to HIV treatment is associated with neurocognitive impairment (Ettenhofer et al, 2009). HIV positive patients who face barriers in accessing treatment are more likely to suffer from neurocognitive deficits than those who are on treatment. Very few studies have examined the neuropsychological performance of HIV infected women and even fewer studies have attempted a comparison of cognitive functioning by gender.

1.2 Study justification

In the field of health, access is defined as the degree to which individuals are inhibited or facilitated to receive care and services from the health care system. While ART is a service that most individuals infected with HIV have the right to access at some point, securing that right may be more difficult for some than others. Research has shown that not every individual has access to ART due to factors such as geographical location, financial considerations, stigma, traditional beliefs, and family support among others.

Gender is defined as the relations between men and women both perceptual and material and is not determined biologically as a result of sexual characteristics of either women or men, but is constructed socially. These distinct roles and behaviours may give rise to inequalities between men and women in both health status and access to health (FAO, 2007& WHO, 2011).

Nobel Prize winner, Amartya Sen asserts that gender inequality restricts women's freedom in different ways and does not only make women's lives gloomy but also shortens their lives. (Nussbaum, 2000 in Bah, 2005).

The researcher was motivated to carry out the study to explore if there was inequality in accessing ART and if so what could be the causes for this.

The study was therefore, aiding in documenting any possible gender differences in ART access, if so what they were and how much was their impact. The study would also come up with findings on impact of ART access on neurocognitive measures across gender groups. These results would in turn assist in coming up with recommendations that would aid health workers and policy makers to come up with ART programmes that would include everyone infected despite their gender as well as address the neurocognitive impairment.

1.3 General Objective

To document the effect of gender on access to antiretroviral therapy among HIV positive adults in Zambia and its link to neurocognitive functioning.

1.4 Specific Objectives

I. To determine whether inequality in ART access exists between men and women in Zambia.
II. To identify barriers that may lead to unequal access to ART between men and women in Zambia.
III. To explore the link that may exist between gender access to ART and Neurocognitive function among HIV positive individuals

1.5 General Research Question

To what extent are there gender differences in the access of antiretroviral therapy among HIV positive adults in Zambia?

1.6 Specific Research Questions

I. Does ART access vary between gender groups in Zambia?
II. What are the barriers to ART access and how do these work across gender groups in Zambia?
III. What is the link that may exist between gender differences in access to ART and gender differences in neurocognitive function among HIV positive individuals in Zambia?

Chapter 2

REVIEW OF LITERATURE

2.0 Introduction

The number of people dying from AIDS related illnesses has declined partly due to the life prolonging effects of Anti-retroviral therapy (ART). Since the introduction of the first drug for HIV infection zidovudin (AZT) in 1987, significant advances have been made in ART. With the introduction of HAART, HIV-1 infection is now manageable as a chronic disease. Individuals who are in their most productive years (15-49) are the most infected and as such the disease has a wide socio-economic impact that threatens development progress in many poor countries especially Sub-Saharan Africa (Rathbian, 2009 & Chigwedere et al, 2008).

Over the past years the health sector in Zambia has recorded significant progress in most of the key areas of health service delivery and health support systems leading to major improvements in most of the key health performance indicators. According to the 2007 Zambia Demographic Health Survey (ZDHS), HIV prevalence in adults aged 15 to 49 had reduced from 16.1% to 14.3%. This reduction came about as a result of the free antiretroviral drugs provided at most of the government health facilities (NHSP, 2011).

Provision of treatment is essential to alleviate suffering and to mitigate the devastating impact of the epidemic. It also presents unprecedented opportunity for a more effective response by involving people living with HIV and AIDS, their families and the communities in providing care and strengthening of HIV prevention through increased awareness. Increased awareness will create a demand for counselling and testing and reducing stigma and discrimination. This is why despite the economic difficulties; Zambia has continued to invest in the health sector (Kandala et al,2008 & SAFAIDS, 2007).In the partnership framework between Zambia and The United States of America on health, (2011), one of the objectives is, ‘to accelerate the provision of universal access to comprehensive and quality treatment, care and support for people living with

HIV and AIDS (PLWHA), their caregivers and their families including services for tuberculosis (TB), Sexually Transmitted Infections (STI) and other opportunistic infections.'

All people living with HIV have the right to health with access to essential HIV prevention and care services to know their HIV status, improve their quality of life, delay progression of the disease and prevent transmission to others. In recent years considerable energy and money have been spent trying to achieve universal access to treatment for HIV and AIDS. This was part of a wider objective to provide universal access to treatment, care and prevention by 2010. Most countries aspiring to expand treatment access set a goal of providing ART to about 80% of those who were in need. Despite this target not having been met, the goal of universal access to HIV treatment still remains an important one for low and middle income countries around the world. At the beginning of the 21st century very few people in the developing countries had access to treatment due to high costs .(WHO 2007; WHO,UNAIDS, UNICEF,2009). Now the treatment has been provided free of charge and Zambia is one of those countries that has taken up the initiative of providing these drugs for free.

2.1 Barriers in ART Access

The availability of Antiretroviral drugs has not led automatically to their uptake and this has been due to the barriers that have continued to exist (NHSP, 2011).In a qualitative study carried out in Kisesa, Tanzania ,the researchers explored perceptions and experiences of barriers to accessing the national ART programme among self-identified HIV positive persons. The results were that although participants welcomed ART, they feared that transportation and supplementary food costs, the referral hospital reputation for being unfriendly and confusing and difficulties in sustaining long term treatment would limit accessibility. Fear for stigma framed all concerns, posing challenges for contacting referrals who did not want their status disclosed (NHSP, 2011 & Mshana et al, 2006).

Tuller et al, (2009) revealed that the cost of transportation for monthly clinic visits had been identified as a potential barrier to both ARV adherence and access to care. Some

people struggled with competing demands between transport costs and other necessities such as food, housing and school fees.

Posse et al, (2008), presented a review of literature of barriers impeding people living with HIV/AIDSin developing countries from accessing treatment. (In conformity with current practice in the literature, the present author will use the expression "HIV and AIDS," in preference to the widely used expression "HIV/AIDS", except when citing other research reports verbatim) In a total of 19 studies which constituted 7 articles and 12 abstracts the barriers were cited at two levels, the population level and health system level. At population level the barriers frequently cited were; lack of information about ART, perceived high costs and stigma. At the health system level the barriers cited were; long distances from home to the health facility, lack of coordination across services and limited involvement of the community in the programme planning process.

Nakigozi et al, (2013) also carried out a study to explore barriers to entry into care from HIV positive clients who had never enrolled for care and HIV care providers. The barriers identified were fear of stigma and HIV disclosure, women's lack of support from male partners, demanding work schedules and high transport costs. Programmatic barriers included fear of drug side effects, long waiting and travel times, and lack of respect for patients by staff, denial of HIV status, belief in spiritual healing and absence of AIDS symptoms.

Of the studies reviewed, the major barriers noted were stigma and financial costs. Research has reported stigma to be a major barrier to accessing ART. Stigma has been a component of the HIV and AIDS scenario since the onset of the pandemic and a large body of research exists concerning diverse aspects of the phenomenon. Stigma takes many different forms sometimes overt and public and sometimes more subtle and implied. Many people do not disclose their HIV status for fear of stigma and some do not access health care because of previous experiences with health workers. Socio-economic status, age and gender all influence the experience of stigma. The poor are blamed less for their infection than the rich, yet they face greater stigma because they

have fewer resources to hide their HIV status (Bond et al, 2003, Jurgensen et al, 2012 & Nyblade et al 2003).

AIDS has the potential to create severe economic impacts in many African countries. It is different from other diseases because it strikes people in their prime productive and reproductive age groups and all sectors of the Zambian society have been affected. Zambia like many other developing countries is faced with a number of challenges. The two major economic effects are a reduction in the labour supply and increased costs. The economic effects of HIV and AIDS are first felt by the individual, and then ripple outwards to firms and business and the macro-economy. (Lwamba, C n.d, Bollinger & Stover, 1999).

Disclosure is another barrier to ART that has commonly been cited in research. Disclosure may reduce the transmission of HIV by raising awareness and decreasing risky behaviour. Thus status disclosure is an issue to be addressed for HIV prevention and treatment. As universal moves onto the HIV agenda, there is a need for more understanding of the relatively low uptake of HIV testing and the dynamism of disclosure in Sub-Saharan Africa. Despite the expanding provision of ART in Zambia since 2004 disclosure of HIV status beyond a closed network remains limited (Amoran, 2012 & Bond 2010).

Kangwende and colleagues, (2009) carried out a study to examine the prevalence, patterns and reasons for disclosure of HIV status among people living with HIV and AIDS in Zimbabwe. The results indicated that there was 79% disclosure to the family, 72% to the health workers and 72% to the sexual partners. While public disclosure was 23%, more people wanted to disclose but did not get an opportunity. The main reasons for disclosure depended on whom the participants were disclosing to and they were cited as follows: to the family, it was to get psychosocial and material support; to the public it was to give HIV a face and to the sexual partner it was to have safer sex. Those in abusive relationships were less likely to disclose to sexual partners. Non-disclosure of one's HIV status can lead to gender inequalities in getting tested and later on accessing treatment. Deribe et al, (2009,p1), state that, 'There exists a strong

relationship between gender and HIV with gender inequalities contributing to HIV transmission in turn worsening gender inequalities in Sub-Saharan Africa. Only a few studies have examined gender differences in HIV status disclosure." This, therefore, calls for disclosure counselling needs to be prioritised in the programmes of ART delivery.

2.2 Gender differences in ART access

Gender is the only characteristic among many that people use to distinguish themselves to unite with others. Skin, colour, sexual orientation, social class, occupation, lineage, national identity, geographical location, political ideology, and physical status are just a few other dimensions that may have a particular relevance in different women's lives and experience with HIV and AIDS. Equality between men and women entails that all human beings, both men and women are free to develop their personal abilities and make choices without the limitations set by stereotypes, rigid gender roles and prejudices. Gender equality means that different behaviour aspirations and needs of women and men are considered, valued and favoured equally. It does not mean that women and men have to become the same but that their rights, responsibilities and opportunities will not depend on whether they are born male or female. (M & E PLAN 2011-2012).

The importance of gender equality is highlighted by its inclusion as one of the eight Millennium Development Goals (MDGs) that serve as a framework for halving poverty and improving lives. Men and women are physically different but it is the social, economic, political and legal interpretation of these differences that lead to inequality between them. Throughout the developing World the impact of HIV on women has been significant and rising. Women are more vulnerable than men both epidemiologically and biologically. Women are frequently less educated than men. This disparity is critical because literacy rates for women are strong predicators of infant mortality and fertility decisions. Apart from that education plays a role in one getting employment as well as the type of job that they will get. Women suffer from gender differences in the quality of employment as in comparison to men. Women with higher

education might have the opportunity to work in occupations or sectors where gender equality in terms of career opportunity is better. While gender segregation affects both men and women, the consequences are often more serious for women. They often have less access to facilities and resources than men. For example nearly 70% of the world's poor are female and the number of women living in vulnerable conditions when it comes to issues related to HIV and AIDS are in the majority. The life cycle of women is also impacted by sexual and domestic violence (Women and HIV/AIDS concerns n.d, Global Education, n. d, IPPF, n.d & ILO, 2012).

The findings of published material related to gender and utilisation of health services are contrasting in result (Prosser 2007).Research from developed countries on gender differences in health and patterns of health service use suggests that women's rate of utilisation of almost all health services is higher than that of men. But women are more likely to defer the primary health care because of cost. In developing countries, research has shown that women not only have lower access to resources to pay out of pocket costs for medication and other health care services, but they also have lower access to health care than men due to greater demands placed on their time, especially for those who combine employment with domestic responsibilities. Women are also more likely to face non-financial barriers to care such as inconvenient location, non-availability of female General Practitioner (GP), family/ child care responsibilities, transportation problems or long distance or lack of other resources to seek care (Jatrana & Crampton, 2012). The issue of costs comes to the fore due to the fact that globally most women are not in employment. From 2002 to 2007 the gender gap in unemployment was constant at around 0.5 percentage points with the female unemployment rate higher at 5.8% compared to male unemployment at 5.3%. The crises raised this gap to 0.7% points for 2012 with projections showing no significant reduction in unemployment rates expected by 2017. Regional trends show that between 2002 to 2007 women had higher unemployment rates than men in Africa, South and South East Asia and Latin America. Women also suffer from a difference in the quality of employment in comparison to men (ILO, 2012).

The adult HIV infection rate in Zambia is higher for women at 16% compared to men at 12%. The gender inequalities perpetuated by male dominance are deeply enshrined in Zambian culture through the socialisation processes which begin in early age. The government of the Republic of Zambia acknowledges that gender inequalities and imbalances have a negative impact on the economic growth, development and human well being of both men and women. The vision of the government on gender as contained in the vision 2030, Zambia's first ever written long term vision, is to achieve Gender equity and equality in the socio-economic development by 2030. In its effort to achieve this vision the government has developed the gender policy (M & E Plan 2011-2015, Partnership framework, 2011). This policy is to serve as a guide to ensure that there is equality in the distribution of the national resources in all sectors and at all levels.

At the beginning of the epidemic, men outnumbered women among persons infected with HIV and AIDS and the virus was at one point not even considered a threat to women. The situation, however, drastically changed such that in most regions an increasing number of people living with HIV are women and girls and this proportion is continuing to grow. New infections for women are occurring at a fast rate. This then signifies that the fight against HIV and AIDS cannot only concern health but also gender equality. (Bah, 2005). On the other hand, research(WHO, UNAIDS, UNICEF, Report 2009) has shown that in low and middle-income countries overall, adult women are slightly advantaged compared with adult men in accessing ART and this is due to the programme of Prevention of Mother To Child Transmission(PMTCT). In 35 countries 64% of the adults receiving ART were women while men accounted for 60% of those in need.

Similarly in Thailand gender differences in access to treatment have been reported. In 2007 The Living with Antiretroviral (LIWA-ANS 12141) study investigated the gender distribution of all adult patients receiving Antiretroviral in four community hospitals in Northern Thailand and factors influencing the disparities observed. The results revealed that 53% of women were on ART. This was an unexpected result for a country with a higher proportion of infections among men who were more likely to initiate treatment

within one year of diagnosis and were at a more advanced stage compared to women (Le Coeur, Collins & Lelievre, 2009).

Another study was also carried out in Tanzania but in Tanga by Theilgaard and colleagues (2011), 'Addressing the fear and consequences of stigmatisation-a necessary step towards making HAART accessible to women in Tanzania.' The qualitative approach using interviews and focus group discussions was used to understand issues as perceived and interpreted by HIV infected women. The findings were that the main deterrent to presenting for treatment appears to be fear of stigmatisation including ostracism from the community, divorce and financial distress.

To compare the gender distribution of HIV infected adults receiving Highly Active Antiretroviral Therapy (HAART) in resource constrained settings, Braitstein and colleagues (2008) carried out a study at 29 centres in 13 countries which included Zambia. The majority of the participants were receiving ARVS in centres that provided free treatment while 3,453 (10%) were receiving treatment from 3 private clinics in Botswana, India and Zambia. Of the 33,163 participants 19,989 (60.3%) were women. Of the 22 centres in Sub-Saharan region 16 were over represented by women. Nine of these were antenatal clinics that mainly saw pregnant women, 6 were general public clinics and 1 was a research cohort.

WHO (2010) reviews that strong health systems are essential for equitable and sustainable HIV- related programmes. Health systems need to be accessible and responsive to the specific needs of excluded groups. Against a background of wider inequalities in health care, the expansion of HIV and AIDS treatment and care should tap any opportunities to strengthen equality in the provision of good quality services. The report further reveals that ART coverage is higher in women (53%) than men (40%). In sub-Saharan Africa this result could be influenced by the fact that sentinel surveillance among pregnant women attending Ante Natal Clinic (ANC) has been the main source of information on HIV trends (Garcia et al, 2006). According to Mitchell et al, (2010, p5), 'Several studies from Africa have found that women are more likely to get tested than men. Some of the explanation for the highest testing rate among women

could be their more frequent interaction with health services, including ante natal care and PMTCT programmes.'

Men have been encouraged to attend antenatal clinics with their spouses but several studies have shown that male participation has been low in the antenatal care of their spouses together with couple counselling and testing for HIV. This increases use of intervention for HIV prevention. In a study by Byamugisha and colleagues (2010), the barriers to male involvement in this programme were related to health system factors, socio-economic factors and cultural factors. The researchers recommended that there was need for community sensitisation about the benefit of antenatal care and prevention of mother to child transmission. There was need to also prioritise the improvement in order to improve low male participation and mitigate the effect of socio-economic and cultural factors.

In another study using qualitative methods to describe midwives perspectives on male participation in PMTCT of HIV and the methods that could be used to improve male participation in Lusaka, Auvinen et al (2014) identified several barriers. These were linked to the individual male partner, to health-care services and to the society. The methods that were recommended to improve the situation were: first influencing individuals in the community, employers and health personnel; second intervening in risky behaviour and third providing disease intervention services.

Although PMTCT is presumably a good entry point for male involvement in prevention of sexual and perinatal HIV transmission, the traditional clinic based approach only reaches a few men. This suggests that a different approach for promoting male participation in VCT is urgently required. Within the PMTCT, counselling program should emphasise the advantage of male participation to encourage women to inform and convince male partners to attend VCT. Promotion of couple counselling outside antenatal settings in male friendly and accessible settings should be given priority (Msuva et al, 2008).

The men have not been side lined in terms of programs. The male circumcision programme which is relatively new in the country is targeting men. Through this

programme men are accorded a chance to test for HIV and if found positive they can access the treatment that is provided at the health centres for free. Studies in Uganda, South Africa and Kenya have shown that medical male circumcision reduces the risk of transmission of HIV in men up to 60% or even 70%.The Zambian government has taken up that health initiative by coming up with a strategic plan. The first objective of this plan is to achieve the goal of 50% coverage of Male circumcision by 2020 (MOH/WHO, 2010).

Gender inequalities have been observed in most studies that have been reviewed. Women have been reported to be more in number when it comes to accessing ART than their male counterparts. The over-representation of women has been motivated by the programme of PMTCT which most men shun as maternal health issues are perceived to be woman's business in most African societies.

2.3 HIV and neurocognitive functioning

Since the beginning of the HIV and AIDS epidemic HIV associated neurocognitive disorders (HAND) have been commonly observed in infected populations. In developed countries there is now a better appreciation for the effects of HIV on cognitive function. These conditions ranging from subtle neuropsychological impairments to profoundly disabling HIV associated dementia are frequently seen in advanced stages of HIV disease (AIDS) but can occur even in individuals having medically asymptomic HIV infection(Holguin 2011 & Heaton et al, 2010). From the early stages of the HIV epidemic in the United States, it has been recognised that central and peripheral nervous systems (CNS &PNS) are affected by HIV. Prior to ART 40% of those infected with HIV developed neurological disease called HIV associated Dementia (HAD) or AIDS Dementia Complex (ADC) while 30% of these had multiple lesions. Other patients have evidence of less severe nervous system dysfunction which has been termed HIV associated minor cognitive/ motor disorder (MCMD), (Hall, 2004 & Robertson et al 2005).

Kanmogne et al (2010, p1) state that, 'The burden of HIV and AIDS is highest in sub-Saharan Africa but there are few studies on the associated neurocognitive disorders in

this region.' This was in their study to determine whether western neuropsychological methods were appropriate for use in Cameroon and to evaluate cognitive function in a sample of HIV infected adults.' The sample consisted of 44 HIV positive adults and 44 demographically matched HIV controls. The findings were that there was worse overall cognition in the HIV positive individuals and significantly lower performance was seen on tests of executive function, speed of information processing, working memory and psychomotor speed. The HIV positive participants with AIDS performed worse than those with less advanced AIDS. Their findings were similar to those in the western cohorts which suggested that HIV infection, particularly in advanced stages is associated with worse performance on standardised, western neurocognitive tests.

2.4 ART and neurocognitive functioning

Since the introduction of combination Antiretroviral Therapy (CART), the manifestation of HIV-associated central nervous system involvement have generally become less severe and more manageable. Patients initiating on ART have demonstrated improvement in cognitive functioning. Recent studies demonstrate that CART regimens with higher central nervous system penetration effectiveness ranks may improve neurocognitive functioning. Considering these factors, earlier treatment initiation may be considered to protect the central nervous system (Kevin et al, 2008 & Liner et al, 2010).

Having observed that HAART could improve cognitive performance in some patients with HIV associated cognitive impairment in the United States of America, Sacktor and colleagues (2006) carried out a study to evaluate neuropsychological tests and performance in HIV positive individuals after 3 and 6 months of HAART in Uganda. In the study 23 HIV positive individuals received HAART and in addition they also received detailed clinic history, neuropsychological testing and functional assessment. The follow up evaluations were performed in the third and sixth month after starting treatment. The results indicated that there was improvement in the following: CD4 cell count, memory, psychomotor speed and executive functioning. Their conclusion was

that HAART can be associated with improvement in neurocognitive and functional performance in HIV positive individuals in Sub-Saharan Africa.

In another study to determine whether HAART is associated with better neurocognitive outcome over time among HIV-infected women with severely impaired immune functioning, Cohen and colleagues (2001) carried out a semi annual neurocognitive examination. Four tasks were administered: colour trail making, controlled oral word association, grooved peg board and four word learning. HAART was not available to any participant at the time of the enrolment. Those treated with HAART had improved neurocognitive performance as compared to those that were not treated. The participants that were taking HAART showed the strongest neurocognitive performance with improved verbal fluency, psychomotor and executive function. These functions worsened among those participants who were not taking HAART. Substance abuse status, severity of depressive symptoms, age and educational level did not influence the HAART treatment effects on neurocognitive performance.

The results suggest that HAART appears to produce beneficial effects on neurocognitive functioning in HIV infected adults. If available in areas with limited resources in Sub-Saharan Africa it should be provided for patients with HIV- associated cognitive impairment.

2.5 Gender differences in neurocognitive functioning

From a scientific standpoint women have long been under-represented in biomedical and psychological research. This has been the case in studies done on the neurological consequences of HIV in which the majority of research has been carried out with all male samples. Although this tendency has begun to change in recent years, there is still only a limited number of studies which examine neuropsychological aspects of HIV positive women or which compare the cognitive functioning of the infected groups by gender. Maki et al, (2009, p3) postulate that, 'There have been some indications that women might be more vulnerable to the development of neurocognitive impairment.'

Martin (2011), carried out a study to determine if HIV positive men and women show different performance patterns on procedural learning tasks. In this study they administered measures of motor skill and probabilistic learning-tasks with a procedural learning component that is dependent on integrity of prefrontal striatal systems, to well matched groups of 148 men and 65 women with a history of substance dependence. Of this group 45 men and 30 women were HIV positive. The results revealed that HIV positive women performed significantly more poorly on both tasks than those who were HIV negative. For the men who were HIV positive the performance on both tasks did not differ significantly compared to those who were HIV negative.

In a retrospective review of 6,548 AIDS cases, the AIDS in Europe study group found the risk of HIV associated dementia in Europe from 1979 to 1989 to be twice as high in women than in men (Chiesi et al, 1996). These results show that features of HIV Associated Neurocognitive Disorders (HAND) cannot always be generalised from men to women. There is a possibility that women could be more vulnerable to the effects of HIV on neurocognitive functioning.

2.6 Clinical neuropsychological assessment

Clinical Neuropsychology specialises in the diagnostic assessment and treatment of patients with brain injury or neurocognitive deficits. The Neuropsychologists use models of brain behaviour relationships to determine whether expected neurobehavioral function is different from normal or has changed to a degree that is consistent with impairment. Such relationships are demonstrated through the interpretation of performance that is derived from a variety of specialised assessment procedures. Thus, the domain of neuropsychologists is expressed brain function such as reasoning, recall processes selection, attention, and concentration. A series of neuropsychological examination may be used to monitor deteriorating neurobehavioral performance or to monitor improving neurobehavioral function. HIV disease may exhibit a wide range of neurocognitive difficulties. Therefore, neuropsychological assessment is important in order to reflect current strengths and weaknesses and provides a baseline for comparison in future evaluation.

Resource limited regions of the World represent the areas most affected by the global HIV epidemic. Currently there are insufficient data on the neurocognitive effects of HIV in these areas and neuropsychological studies that have been carried out thus far are marked by inconsistent methods, test batteries and rating systems for levels of cognitive impairment. Sub-Saharan Africa and other developing continents are the areas most devasted by HIV epidemic. These areas offer considerable potential for research and stand to gain the most from effective therapy (Laudry & Smith, 2011&Robertson et al, 2009).

Literature has revealed that neuropsychological assessments are the most important tools in diagnosing and categorising HIV effects on the central Nervous system. As such resource limited countries such as Zambia where neuro imaging technology is often unavailable, the use of these tools is crucial to successfully diagnose and treat neuro dysfunctions.

The objective of this study was to determine the effect of gender on accessing Antiretroviral therapy and its effect on neurocognitive functioning. This chapter gave an in-depth understanding of what has been done and how it has been as well as bringing out the key issues in the area of study. Most of the literature reviewed covered some aspects of the topic but there was none that covered all the aspects of the current study an indication that nothing much has been done in the area of gender access to antiretroviral therapy and its effect on neurocognitive functioning. In reviewing previous studies the researcher came up with 6 sub topics which determined the direction of the study. These are: i) Barriers in ART access; ii) Gender differences in ART access; iii) HIV and neurocognitive functioning; iv) ART and neurocognitive functioning; v) gender differences in neurocognitive functioning; and vi) clinical neuropsychological assessment.

Chapter 3

METHODOLOGY

3.0 Introduction

This chapter will focus on the methods that were used to evaluate the effect of gender in the access of Antiretroviral Therapy and its link to neurocognitive impairment. The study was part of a bigger project looking at neurobehavioral effects of HIV in Zambian adults and the aim was to study the impact of HIV on Neurobehavioral functioning.

3.1 Research design

The study was in two parts, part 1 used the qualitative research approach and part 2 used the quantitative research approach.

3.1.1 Qualitative Research design

This method reveals the nature of the situation as well as the relationships (description).It also enables the researcher to discover the problems that exist within a phenomenon (interpretation). In this case the participants spoke about the issues according to their experience.

A phenomenological study design was used. This design attempts to understand people's perceptions, perspectives, and understanding of a particular situation and makes generalisations by looking at multiple perspectives on the study (Leedy and Ormrod, 2010).

3.1.2 Quantitative Research design

A cross sectional study design was used to determine the effect of gender access to ART on performance in the neuropsychological tests.

3.1.2.1 Hypothesis

Female participants would score lower on the neuropsychological tests than the male participants of the same age and educational level. In a multivariate ANOVA the main effects of Education, age and Gender would all be significant.

3.1.2.2 Rationale

Experiences in gender inequalities can create differences in accessing ART. Research has shown that HIV treatment has been associated with improvement in neurocognitive performance in HIV infected populations (Sacktor et al, 2002). If gender barriers in ART access continue to exist it is likely that the gender that is usually disadvantaged in this case the females will suffer more from neurocognitive deficits as compared to their male counterparts. Therefore this study set out to explore the effect of gender on ART access and its link to neurocognitive performance in HIV positive men and women.

3.2 Study population

The study population was adults aged 20 to 65 who were HIV positive from selected clinics in Lusaka urban. This age range matches the one that was used for the normative data. The normative study was carried out by the first cohort of the clinical Neuropsychology class. They used the same Neuropsychology test battery on participants who were HIV negative. Their study population was from both the rural setting as well as the urban setting whereas the present study was only of those from the urban setting. A total of 34 HIV positive adults and 4 Health providers were recruited for the present study. The HIV positive adults were part of the larger sample of 263 tested by all the members of the research team.

3.3 Study sample

The study comprised two samples, the sample for the qualitative part of the study and that of the quantitative part of the study.

3.3.1 Qualitative study sample

A total of 38 participants was recruited in the qualitative research part of the study comprising, 34 HIV infected adults who were on ART, equal numbers of men and women and 4 health providers. The 34 HIV infected adults were a subset of the full sample of 263 tested in the quantitative part of the research. The health providers

included three nurses two who were sisters in charge of the ART clinics and one peer supervisor.

3.3.2 Quantitative study sample

The quantitative study sample was the full sample tested in the bigger study (N= 263) shared by the 10 students of the second cohort of Clinical neuropsychology.

3.4 Study areas

Six clinics run by The Lusaka urban District Health Management Team (LUDHMT), namely, Chipata, Chilenje, Kabwata, Kalingalinga, Matero Main and Matero referral were selected for the bigger study. These clinics provide ART services which include voluntary counselling and testing as well as the required care for those infected with the HIV virus.

3.5 Recruitment

The nurses helped in the recruitment of the 263 participants for the quantitative part of the research. The purposive sampling was used to select participants for the neuropsychology assessment. This is a sampling technique where a researcher consciously selects particular subjects for inclusion in the study so as to make sure the elements will have certain characteristics pertinent to the study.

The nurses helped by selecting those participants who met the criteria specified in section 3.6 below. It was observed that a good number of the participants worked as volunteers at the clinics and as such were well informed about issues of HIV and AIDS as well as ART. Regarding the informed consent, the researcher provided the participants with the information sheet which they read and asked questions where they were not clear. This was followed by signing the consent form. The health providers were selected by virtue of working at the ART clinic.

3.5.1 Recruitment for Qualitative study sample

The initial plan was to have a sample of those with poor adherence. This includes those who had missed appointments for picking up the drugs and clinical check-ups. However, these were difficult to locate due to two major reasons:

- It would have meant going through the files to trace them but due to the poor filing system it was not possible, and
- If they were to be traced it would have meant calling them to the clinic which would have been an additional cost on the part of the researcher as the participants would have to be compensated more than the rest for their transport unlike a situation where they had come to the clinic on their own.

Due to these unforeseen challenges the researcher used convenience sampling for the qualitative part of the research. This is a sampling technique where a researcher uses any subjects available to participate in the research study. In this case the researcher recruited those participants who had been assigned to her for the Neuropsychological assessment sessions. All the participants gave consent to be interviewed after administering the Neuropsychological test battery.

3.6 Inclusion Criteria

Individuals with the following characteristics were included in the study:

- Adults aged 20 to 65 years
- HIV positive
- those who were accessing Antiretroviral therapy
- those with education 5 years and above
- ability to speak and understand English
- Willing to provide informed consent.

For the health providers, the inclusion criterion was:

- Health providers working at a targeted ART clinic.

3.7 Exclusion Criteria:

Individuals with the following characteristics were excluded from the study:

- Physically handicapped because the time needed to administer the test battery was about two to three hours and an additional twenty minutes or more was required for the interview and this was likely to cause distress on the participant and in turn affect the study;
- those who were not physically well as determined clinically by the health providers;
- those with Psychiatric conditions and Substance users as it would be difficult to differentiate effects caused by these conditions with a neuropsychological disorder; and
- those who were willing but lacked capacity to provide informed consent despite having attained 5 years of education as determined by the ZAT scores.

3.8 Procedure

After approval from the Ethics committee, permission was sought from The Lusaka Urban District Health Management Team. Six clinics (see section 3.4) were selected for the study. On 17th October the researcher started collecting data from the clinics.

In order to get the required sample, the participants went through two stages of screening. The first was done by the health providers, sisters in charge of the ART clinics to be specific. These were able to identify the participants who were on antiretroviral therapy and those who were physically fit. Those who passed the first assessment were referred to the researcher.

The researcher gave the participants an information sheet that gave the details of the study. Participants were free to ask questions when they did not understand something and an explanation was given. Those who understood the study and were willing to participate were given the consent form after which the screening tools were administered.

The Zambia Achievement Test (ZAT) was the first to be administered. The next screening tool was the Neurobehavioral Medical Screen and those who qualified proceeded to the next level of being tested using the neurocognitive battery.

Concerning the administering of the test battery, the researcher first administered the questionnaires which were followed by the tests. The participants were allowed to take breaks in between whenever they felt like doing so.

For both the patients and the health providers the researcher used an interview guide and responses were recorded using a voice recorder.

Both the neuropsychological tests and the interviews were carried out in a room that was provided by the clinic staff. Since the interview guide was not piloted the researcher treated the other interviews as a pilot study. This gave an opportunity to the researcher to make amendments were required.

3.9 Ethical Issues

High standards of research ethics were maintained by observing the following:

I. Protections from harm - Participants were not exposed to any physical or psychological harm.
II. Informed consent-Participation in the study was strictly on voluntary basis. Participants were free to withdraw from the study without any penalty or withholding of incentives from them. Each participant was presented with an informed consent form that contained the regulations pertaining to their participation in the study.
III. Right to privacy-the participants' right to privacy was respected by using unique code numbers instead of names; research report both oral and written would not be presented in a way that would reveal the identity of the participant and the recordings were kept under lock and key and were destroyed after analysing the data.

IV. Honesty with professional colleagues-the researcher presented the findings in an honest manner without fabricating the findings and appropriate credit was been given where it was due by acknowledging other people's works.

V. The study was only undertaken after approval from The University of Zambia Biomedical Research Committee (UNZAREC) and The Lusaka Urban District Health Management Team (LUDHMT).

3.10 Study Limitations

Financial resources and time were not adequate for the researcher to have worked on a larger sample that would represent the general population of Zambia.

3.11 Delimitations of the study

The study only included male and female adults who were HIV positive from the selected clinics in Lusaka urban.

3.12 Instruments used

3.12.1 Neuropsychological test battery

The neuropsychological test battery was used to assess the neurocognitive functioning of the participants. One test from each of the seven domains was used to collect data for neurocognitive functioning in the respondents. This battery assessed seven domains. Listed below are the domains and the type of tests used in each:

A. Executive Functioning

Wisconsin Card sorting test

This test developed by Berg and Grant to assess abstraction ability and the ability to shift cognitive strategies in response to changing environmental contingencies (Berg, 1948; Grant and Berg, 1948) is a measure of executive function that requires planning, use of feedback and shifting cognitive sets. Strauss et al, 2006, states that, 'the purpose of this test is to assess the ability to form abstract concepts, to shift and maintain set and to utilise feedback'.

The subject is required to match the card that appears at the bottom of the computer screen to one of the four stimulus cards that are present on the upper part of the computer screen. These cards have four different designs on them; the first with a red triangle, the second with two green stars, the third with three yellow crosses and the fourth with four blue circles. The cards that the participant is required to match to one of the four stimulus cards vary in colour, geometric form and number.

While it is permissible to clarify the meaning of the stimulus cards the examiner must never give the participant an indication of the sorting principle or the nature of the shift from one category to the other. The participant is required to sort first to colour other responses being called wrong. After 10 consecutive correct responses to colour have been achieved the required sorting principle then shifts to form meaning colour responses are now considered wrong. After ten consecutive responses to form, the principle shifts to numbers and then back to colour. This procedure continues until the participant has completed 128 items or six sorting categories (colour, form number, colour, form, number). There is no time limit for this test.

B. Verbal Fluency

Stroop word

The strop word is a test of how fast one can read the words on the word page with 100 colour words (red, green, blue) printed in black ink. No word is allowed to follow itself within a column. The participant is given instruction to read down the columns starting with the first one until they complete it and then continue without stopping down the remaining columns in order until they are told to stop. The examiner starts timing as the participant reads the first word and after 45 minutes they tell the participant to stop.

C. Working Memory

Spatial Span

This test assesses the participant's ability to hold a visual-spatial sequence of locations in working memory and then reproduce the sequence. In the first part the researcher points to a series of blocks at a rate of approximately one block per second and asks the participant to point to the same blocks. In the second part instead of pointing to the blocks in the exact order the participant has to do it in the reverse order. Two trials for each sequence are done.

D. Learning Memory or verbal episodic domain

Hopkins Verbal (learning and delayed)

This test was devised by Brandt and Benedict (2001) and it was intended for use by moderately demented patients (Strauss et al, 2006). The test includes a list of 12 words which the examiner reads to the participant who repeats as many words as they can remember in any order. The words are; Lion, copper, horse, tent, iron, hotel, cave, lead, tiger, zinc, cow, hut. The process is repeated three times and 20 to 25 minutes later the participant is asked to recall as many words as possible. For the final task a list of 24 words which includes the twelve words that were presented before, is read and the participant is asked after each word whether it was on the list or not. This test provides information on the ability to learn verbal information and immediately recall it. It also assesses the ability to retain, reproduce and recognise this information after a delay.

E. Recall or visual episodic memory

Brief Visual Memory Test (BVMT)

The BVMT measures visual learning and memory using multiple-trial list- learning .This test was designed as an equivalent multiple test form assessment of visual memory. The test comprises six alternate equivalent forms that is form 1 to 6. For this particular study form 1 was used. Each form has six geometric figures printed on a

separate paper of the recall stimulus booklet and 12 Recognition stimulus booklet manual.

F. Motor

Grooved pegboard (Dominant and Non dominant)

This is a test of fine motor coordination and speed. In this test subjects are required to place 25 small metal pegs into holes on a metal board. All the pegs are the same, they have a groove that is a round side and a square side and the holes are the same. What the participant is expected to do is to match the groove of the peg with the groove of the board. The researcher times the participant from the time they touch the first peg. The test can be discontinued if the participant fails to complete the task in 301 seconds or five minutes.

G. Speed of Information Processing

Symbol search

This is a test were psychomotor speed, attention and concentration is required. The participant is asked to scan two groups of symbols visually and determine if either of the two target symbols matches any of five symbols appearing to the right of the target symbols. The participant has to complete as many items as they can within a time limit of 120 seconds.

3.12.2 Screening tools- Two screening tools were used

3.12.2.1 Zambia Achievement Test (ZAT)

This test is made up of twenty sets of words and each set has four words. The participant had to read words from the first five sets correctly. When the participant missed a word they had to read all the words from the remaining sets. A participant who failed to read two words from each of the first two sets was disqualified from the study.

3.12.2.2 The neurobehavioral medical screen

This instrument provides for the collection of information that is useful in determining the possibility of one having neurocognitive impairment. It also has provision for one's age since the study had a specific age range.

The researcher asked the participants questions from the instrument that would aid in determining whether the participant had suffered neurocognitive impairment at some stage in their lives.

3.11.3. Interview Guides

Two in- depth interview guides on accessibility of ART were used, one for the patients and another for the health providers. These interview guides were constructed in a relatively informal way. The researcher designed the guides which were checked by the supervisor and approved as part of the research proposal by the Ethics committee board.

3.13 Variables

Independent-Gender and ART access

Dependent-Neurocognitive functioning and Responses from interview

3.14 Data analysis.

3.14.1 Qualitative data analysis

The qualitative data was analysed using thematic analysis. This is the type of analysis used to analysis classifications and present themes that relate to the data. It is considered the most appropriate for any study that seeks to discover using interpretations.(Alhojailan,2012& Braun & Clarke,2006). The 34 patients and the 4 Health providers were invited for structured interviews. The interviews were recorded and transcribed. Themes were derived using a technique based on an analysis of words(Ryan and Bernard, n.d). The researcher used the informal mode of the technique

by simply reading the transcripts several times to note the words that the respondents used frequently and through that emerging themes were identified. The following were codes used and their meaning:

PT 03-----Participant Number 03

F/M--------Female or Male

HP……Health Provider

3.14.2Quantitative data analysis

The quantitative data was analysed using the Statistical Package of Social Sciences (SPSS version 16). The package was used to generate percentages and frequency distributions of demographics. ANOVA was used to generate the statistics. The raw scores were used in the analysis

To find out if age, education and gender had an effect on the different neuropsychological tests we computed Univariate three-way, factorial Analysis of Variance of scores by the full sample of 263 participants. Education, age and gender were entered as independent variables whereas the scores on the neuropsychological tests were entered as dependent variables. The following were the hypotheses tested

i. It was hypothesised that gender would account for significant amount of variance in scores on neurocognitive impairment arising from HIV infection, with female participants scoring lower on those tests than the males.

ii. It was hypothesised that age would account for a significant amount of variance with older participants scoring lower due to declining neurocognitive functioning on those domains as a function of normal aging.

It was hypothesised that level of education would account for a significant amount of variance in scores on some tests, with less educated participants scoring lower due to

advantages (perceptual and cognitive skills) conferred by schooling for coping with the task demands of these tests.

Chapter 4

PRESENTATION OF RESEARCH FINDINGS

4.0 Introduction

This chapter discusses the research findings. The findings for part 1 are presented according to the themes derived from the research questions. The findings for part 2 are presented according to the research question.

4.1 Participants and gender

A total of 34 participants were recruited in the qualitative study, 17 females and 17 males. Each gender had a 50% representation. A total of 263 participants were recruited for the quantitative study, 156 females and 107 males. The females had 59% representation while the males had 40%.

Table 1: Demographics according to gender

DEMOGRAPHICS	GROUPING	MALES	FEMALES
YEARS OF SCHOOLING	1	13	27
	2	21	57
	3	62	62
	4	11	10
AGE	1	22	17
	2	23	57
	3	34	54
	4	18	23
	5	10	05
MARITAL STATUS	1	17	28
	2	73	66
	3	08	43
	4	09	18
	5	00	01

KEY

Years of Schooling

1=5-7; **2** =8-9; **3**=10-12; **4**=13^{+}

Age

1=20-29; **2**=30-39; **3**=40-49; **4**=50-59; **5**=60-65

Marital Status

1=Single

2=Married

3=Widowed

4=Divorced

5=Living with another person(Cohabiting)

4.2 Qualitative analysis

The data was analysed using thematic analysis. This involved transcribing of the recorded material and going through it several times to get acquainted with the information that was coming from the respondents. Two sets of themes emerged, Barriers to ART access and the Gender barriers in ART access.

4.3 Barriers to ART access

These are barriers that affected both the males and females. Seven sub-themes were identified in the first set and these were:

- Beliefs and misconceptions
- stigma
- medical environment
- side effects
- disclosure
- feeling better, and

- ❖ Socio-economic status

4.3.1Beliefs and Misconceptions

The two groups of respondents pointed out that the beliefs and misconceptions people have about antiretroviral drugs before and after testing for HIV are a potential barrier to accessing ARVs.

> *….there are people out there who are on the same medicine and are vulnerable, who cannot even have food on the table and it's like taking this medicine is shortening their life span hence the belief in the compound that ARVS only shorten your life span.*
>
> (PT 31 M)

The respondent points out that some of the beliefs come about due to some experiences that people undergo. In this case what shortened the lifespan were not the drugs but hunger. People took the drugs on an empty stomach which was not good for one's health.

> *People say ARVs are only for promiscuous people and those who are not promiscuous cannot be on ARVs.*
>
> (PT 23 F)

The respondent talks of misdirected information. While it is true that promiscuity can lead to one being infected with the HIV virus it does not mean that promiscuity is one of the qualifying factors for one to be on ARVS. One may have been infected with the virus by a promiscuous partner or they may have acquired the virus at birth from their infected parents. Such judgemental statements may demotivate someone from accessing ARVS for fear of being labelled promiscuous.

The practice by some churches discouraging their members from taking the ARVS and instead depend on prayer for cure is one barrier that is spreading at a fast rate in the communities.

> *There are some beliefs that when the pastor prays for you then you will be healed and as such one should not take some ARVS. One of our support*

group members died. He was told he should be on forty days fasting. That forty days fasting took him to death. He was attached to one of the churches.

(PT 8 Male)

In this testimony the informant attributed what turned out to be lethally dangerous advice to an ethno theoretical belief by the pastor that fasting would heal the condition of the support group member and would make ARV irrelevant. The belief that fasting would heal the sick person was not grounded in a biological understanding model of disease but instead relied on an alternative model of illness where the symptoms were seen as arising from a spiritual condition(sin) which could be corrected by the act of self-denial, i.e. fasting. This view of how AIDS is caused or healed relies on or invokes a completely different system of causation from the bio-medical system that uses ART to combat HIV. Thus the ethno theoretical belief that informs the advice offered by the pastor runs into direct contradiction with the theoretical model that justifies the ARV prescription.

The barrier to accessing treatment in this case runs deep below the surface and involves sympathy to the patient, a belief that leads him or her not to want the ARVs.

Some people are told that ARVS are chemicals and as such can destroy the body so they refuse or stop to take the medication.

(PT 20, M)

The term 'chemical' is usually associated with something that is very dangerous and deadly. So when people are told that ARVS are chemicals they do not see anything good coming from taking them. They would rather abandon them and seek alternative +means of treatment such as churches or witchdoctors.

I know of my brother's son who started the treatment quite alright but a certain woman told him that she could pray for him to be healed. He was told to stop taking the medication and be on prayers instead. Unfortunately after three months of not taking medication he died.

(PT 12 F)

The informant reports an unfortunate incident that transpired in her family when her brother's son was told to stop taking the ARVs and instead concentrate on prayer for

healing. Instead of getting healed the man died. Many people who are infected with HIV and would have benefitted from the ARVs have died because of heeding to such beliefs.

> *I went for prayers after I was found with TB. I was told to buy a 2.5 litre container of water at Kwacha 1.5 million (*old currency) *which they claimed was from the ocean. Since I was not keen I was given a date for the following year to go back to prove if I would still be alive. That date came and I went to see the pastor who was very ashamed.*
>
> (PT 30 M)

The informant gives a testimony of how he was threatened by one of these pastors who discourage people from taking ARVS and give false prophecies. The prophecy that the informant would die if he did not take the water believed to be from the ocean was not fulfilled meaning it was false prophecy. Many of these pastors discouraging the uptake of ARVS use such emotional provoking statements to woo people into believing that ARVS cannot heal. Out of desperation a number of people have fallen into their trap and discarded the medication.

The Health providers were aware of the belief being advanced by some churches.

> *Okay there are people who believe that if they are prayed for they can get healed and we found out that most of them are stopping the ARVs. You find that most of them go to the famous Emmanuel in Nigeria. When they come back they say they are healed and they stop coming to ART clinic but one finds that after some time they come back very sick and unfortunately most of them die…*
>
> (HP 4)

In the health provider's testimony it was indicated that people even spent large sums of money to travel to other countries to seek for healing, shunning the ARVS that were free of charge. They later discovered that the travel did not benefit them at all because they ended up in a much worse condition which could have been prevented if they had continued taking the ARVS.

> *Okay the myths that are there are mainly traditional myths. We have heard people say one can be cured by going to these traditional healers. They are*

> *given medicine. Other people say, if one just takes aloe Vera it can prevent the spread of HIV … They just believe if one takes the traditional medicine then they will be healed especially the same aloe Vera that is mostly talked about, they say it can prevent one from getting any other infections.*
>
> (HP 3)

The aloe Vera plant has been widely promoted by herbalists that it cures many if not all kinds of ailments. This has led some people who are infected by the HIV virus to go for that instead of the ARVS. Others who start the ART discontinue in due course and instead begin to take the aloe Vera in the hope of getting cured.

The church has a role to play in changing society and this includes people's perceptions and attitude to HIV and AIDS. Respondents observed that the church was not doing much in disseminating information to its congregants about issues of HIV and AIDS. This could also be what is contributing to the upcoming churches preaching against taking of ARVS because the traditional churches are silent on the matter.

> *…. Most people even in church you can't find that they are talking about death but death is real, it is there and everyone is prone to die whether you like it or not it is eminent. So that is the same with HIV, we should talk about these things in the church so that we encourage the people. People are there in churches who are HIV positive but they are failing to come to the clinic to access the VCT and the ARVs which are available and free for all because the church leaders are silent about the matter. Even the president and ministers they also have the power to influence the nation if they too can disclose their status and encourage other people to do the same. Like the way I have seen on these TVs where MPs who are also talking about MCs* (male circumcision) *it's quite encouraging…now if they shun they will kill a lot of people.*
>
> (PT 32 Male)

Beliefs and misconceptions have been a part of the HIV and AIDS story from the time it was discovered. Despite the dissemination of scientific information not everyone has accepted it wholly. There are still some people who cling to what they have come to believe to be true. These beliefs and misconceptions about HIV have continued to be a barrier to access of ART for some individuals.

4.3.2 Stigma

Stigma came out to be a major barrier in accessing ART.

> *The primary barrier would be stigma like I mentioned, it is a very big barrier. If someone has got self-stigma or enacted stigma I think that is a great barrier that deters people from coming to access these facilities.*
>
> *(*HP1)

The health provider alluded to the fact that stigma was a major barrier to accessing ART.

There was stigma that manifested due to dysfunctional consequences.

> *Now what happened to me is that before I came to the clinic for treatment I had taken the HIV tests several times. Wherever I found VCT services being offered I would do the test. I did that because I did not believe that I was HIV positive but each time I took the test I was found to be HIV positive.*
>
> (PT 28, F)

The respondent did not believe she could be HIV positive and as such spent most of the time getting retested to reconfirm if for sure she was infected. She could have used the time to go to the clinic to start accessing treatment. She was still in denial which could lead to stigmatising one self.

People who felt stigmatised sometimes opted to seek medical services in distant places for fear of being known that they were HIV positive. Choosing a distant place to access treatment becomes a barrier when one has no means to take him there, for instance money for transport.

> *…..So you find someone instead of accessing medicine at a nearby clinic or residential area where he lives you end up going to maybe Matero , maybe someone stays in Kabwata, he will end up going to Matero because not so many people know him there, you know. He doesn't want people to know that even him accesses medicine.*
>
> (PT 01, M)

The respondent gave a situation of how some people left the nearest health centre to go to distant places to seek treatment. This practice came about due to stigma because the infected individuals did not want to be seen by those who knew that they were on medication. This became a barrier in that when they failed to raise the money for their transport they would miss their clinical appointments which might lead to non-adherence to the medical protocols.

PT 21: *As for me I stay near the clinic. The people who complain about the distance to the clinic, it is just their problem because our government has put up ART facilities centres in all government health centres. Now you find that someone living in Chelstone will be accessing treatment from here in Chipata compound. There are others who live in Chilenje but go to Chelstone when there are ART services at Chilenje clinic. So why should they complain when it is their problem. For me I live in chaisa, my nearest health facility is chipata clinic, why should I go to kalingalinga when I know that I will have challenges on the way*?

RES: *But what could be causing that? Why should someone go to a faraway clinic when there is a clinic where they live?*

PT 21: *Stigma…*(pauses), *they don't want to be seen by people who live in their community, they want to go to clinics where they are not known.*

Some patients indicated that the people, who actually stigmatised them, especially when they just got tested, were their relatives who normally should have rendered them with the needed social and emotional support.

My mother in law's reaction was different because she started telling almost everyone in the neighbourhood about our status and that we would die within a short time. Even the way she started treating us was bad….

(PT 28 F)

The attitude of the mother- in- law in this case would discourage one from accessing ARVs as it would lead to a self-fulfilling prophecy where one believed they would die soon and as such did not need to go to the clinic to get the ARVS.

> *The other brother encouraged me… but the other one though he was not showing it, I could see that he was thinking that maybe I am dying …though I was talking about going to school he thought, 'how? you are old and you are about to die ...?'…and there is this incidence that happened when we were staying with him, he was not buying food for me so I could move out of the house to go and search for food …. My sister came from Kanyama and when she visited she found that there was no food in the house where we were staying with my brother so my sister confronted my brother; my brother was working….. So she confronted him to say, why are you not buying food?…why should I buy food that man is dying so am reserving money to buy him a coffin and transport to take him to the village….so my sister started crying and said my brother…lets go to my house.*
>
> (PT 32 M)

In this instance, the informant attributed the behaviour of one of his brothers to an attribute which devalued him as a person to such a degree that he was unwilling to provide him with even basic support such as food. Such stigmatisation would clearly reduce the respondent's access to social support for travelling to the clinic to collect ARVS.

> *Anyway I felt it(*stigma*) in the community, people were looking at me when I come out of the house, people were looking at me, the way they were looking at me I felt stigmatised but in the family, no I didn't feel it. I felt they were. What word can I use, balengufwishabwino, balenchita motivate ba family (My family used to make me feel good, they used to motivate me)'.*
>
> (PT 26 F)

Although this particular patient felt stigmatised by the community the social and emotional support that she received from the family made her feel worthy and this motivated her to access the ARVs. This experience reveals the importance of family support in relation to accessing ART.

Stigma was also brought about by misdirected information.

It is a well-known fact in the medical field that promiscuity is one of the predisposing factors for acquiring HIV but this should not be used to judge everyone that they contracted the virus in this manner. When one has tested positive the cause of infection is not the main issue but their treatment is what should be the focus. When a person is

already infected, it is too late to start condemning them: but they should be encouraged to seek treatment. Dwelling on the cause may demean the infected person to an extent where they will not seek treatment.

> *Yes I was somehow stigmatised by my mum because when I disclosed the status to her she said I think the person who might have given you this virus could be that first wife you married because I am told her movement was not all that good you see, when you go for piece work at the industry then she would go out. Maybe that person she is the one who has given you this virus and also after divorcing that first wife you were also…'tawaleumfwa walenwa sana ubwalwa. Mubwalwa emowasangile aka kene akashishi(Even yourself, you were promiscuous, you were also taking too much alcohol and that is how you got that virus).So, that is some of the stigma I faced.*
>
> (PT 18, M)

The patient in this case felt stigmatised by the mother who was talking about his past. He felt judged and condemned for his past mistakes instead of getting the much needed encouragement. Such a situation can lead to one hiding their status and not accessing the treatment.

The researcher observed something that caught her attention. After getting the medication the patients were seen removing the packets that contained the drugs and throwing them in the bins. This is what one patient said:

> *That is stigma; they don't want to be seen, as you know the box of the medicine. That is stigma number 1 and then ignorance because each medicine, each ARV you are getting there is an instruction inside, so you even end up throwing the instruction paper which is there. So it is stigma and it is ignorance, they don't know what they are doing. The major thing is stigma they don't want to be seen by the people, they think it is portable when you remove that cover*.
>
> (PT 21, M)

The respondent explained that packets were thrown away because people did not want to be seen carrying them or to be known that they were on antiretroviral therapy. When people saw the packet of the drugs then they would know they were on medication and they might begin talking about their status or treat them differently. While not everyone would know how a packet of ARVS looked, the patients believed everyone knew.

Interestingly the packets for other drugs were not thrown but for some reason patients believed the packet for ARVS was known by everyone and as such would expose them if found on them.

The intense stigma associated with HIV was manifested in a wide variety of ways in the testimonies cited in this section.

4.3.3 Medical Environment

Four aspects of the medical environment were observed to be contributing to barriers in the access of ART among adults infected with the HIV virus. These were:

- The slow process,
- Isolation of the ART clinic
- Frequent visits and
- Attitude of the medical providers

4.3.3.1 The Slow process

The slow process which was confirmed by the long queues was reported to be a deterrent to accessing ART. The patients felt they wasted a lot of time at the clinic, time which they could use in doing other things especially those that were of an income generating nature.

> *The challenges are there and one of them is the competing needs, for instance there are times when one has to attend to some income generating activity and at the same time have to come for their medication. This becomes a challenge especially that we spend long hours here at the clinic.*
>
> (PT 15, F)

The respondent reported that the long hours spent at the clinic became a hindrance to one accessing ART especially where one had to decide between going to the clinic to access the medication and attending to something that would provide them with an income to use for basic needs. Where one opted to go to the clinic it was very difficult

for them to determine how long they would take there and as such it became a challenge to plan accordingly.

> *..... Many people can be on ARV but it is actually a big problem, it is actually a stress, coming to get your medication. Because even when you are approaching the day, you know that on Monday I am going to get my medication, you won't even sleep because you know the agony that you will go through....you should even look for money maybe if it is lunch or just to be buying things around but if I don't have money I find it very difficult. Yes.*
>
> (PT 01, M)

The respondent brought out two things, the psychological aspect as well as the economical aspect. He alluded to the fact that when the day to visit the clinic was approaching one experienced some stress such that they were even unable to sleep well because of thinking of what they had to go through at the clinic, that is, the slow process. This could lead one to stop taking the ARVS. He also brought out the need for one to have some money as they attended the clinic so that in the event that they were not attended to in good time they could buy something to eat. For those who could not afford it meant that they had to spend the whole day at the clinic on an empty stomach. This became a barrier to accessing medication.

The respondents indicated that some people failed to persevere and left the queue before they were attended to.

> *There are some people who are impatient and cannot wait for a long time. There are people who leave the queue to go and eat nshima in the hope of coming back but never do so.*
>
> (PT 19, F)

> *If you did a survey you check on the people you will find some people will come in the morning, fine, but they will end up going back home and some files they will just be calling this name, 'oh naba…bayenda, bayendakudaala(*even that one has left, they left a long time ago) *You know,they have gone, why? Because they were tired, maybe because of waiting they can't wait anymore because there are a lot of people.*
>
> (PT1, M)

The two respondents above reported how some people got so impatient and left the clinic before being attended to because of the delays. There were some who left because they became hungry and had to go home to eat but in the process they failed to get back to the clinic.

The health providers attributed the slow process to the shortage of staff as the numberof patients kept on increasing.

> *…. manpower, is less. In ART Clinic we are just a few of us. When one goes on leave you remain the two of you. If the other one has a problem then one has to remain alone and looking at the number of people that we see like 200, is a lot.*
>
> (HP 3)

> *The facilities are not adequate, there is a shortage of manpower, we have a shortage of nurses especially here in ART, instead of six nurses we are only three and the CO (*Clinical Officer*) instead of having three there is only one.In the pharmacy instead of having three pharmacists there is only one.*
>
> (HP 1)

The health providers above indicated that their desire to provide the services to the clients within the shortest possible time was hindered by the shortage of staff. This became a barrier because the few staff members that were available were overworked and could not meet the clients' expectations.

The health providers and patients observed that the poor filing system also contributed to slowing down the process of attending to the patients.

> *So with the filing that is here at Chipata clinic it is a bit bad, we do not have cabinets where filing can be properly done, files are in boxes where it is very hard for one to find a file. To pull a file it can take even five minutes per file and if you have 200 people it is a challenge...., provided the filing is done very well then it means even the flow of work is made easier because it starts from there.*
>
> (HP 3)

> *The issue of filing is a problem at this clinic. Files are supposed to be in order according to the series, for example the hundreds or two hundreds are supposed to be in order but the shelters are full and as such files are found on the floor making it difficult to trace them when needed.*
>
> (PT28, F)

One of the obstacles to stream lining the work at the clinic was the location of the patients' files. With the increase in the number of people who were accessing ART keeping files in order had become a challenge due to lack of space. The containers that were placed at the clinics for that purpose had become full and could not store any more files. This had forced the clinic workers to put files in other rooms where they could find space but the problem had been how to put them in order. Some files were found lying on the floor. This made retrieval difficult and patients had to spend long hours waiting for their files to be traced before being attended to. In some cases patients had been seen without a file. Follow up procedures were affected as the medical personnel had no records to refer to and this in the long run discouraged some people from continuing with the clinic appointments.

> *…….the way they keep files, so it takes time for them to get files because they are keeping these files manually. Gone are the days when we used to keep files manually like this, it is better if we can have a computer where we can have this information, so that when you come you just present your number so that they give you the necessary documents to go and be attended to.*
>
> (PT 31 M)

> *If there can be a system whereby the government introduced what we call the smart cards I think the problem of files can be reduced because with a smart card what normally works there is computer. You go there you produce your smart card, from there then you go and get the drugs. There is nothing like pulling the file, no.*
>
> (PT 18, M)

The respondents observed that using the modern methods of filing would help solve the problem that was being experienced. The modern methods involved the use of the computer which made things move faster. Since most institutions were moving to the use of computers to store information, it would be something worth exploring for the clinics as well.

The health providers and the patients revealed that the ever increasing numbers not only led to the process being slow but the quality of the services being offered at the ART clinic was also being compromised as not all required procedures could be followed.

> *One I think it is staffing we have got few nurses, like in the ART clinic per day we see around three hundred, two hundred and there only three nurses and one clinical officer which is a challenge so even if you want to do quality things sometimes it is very difficult.*
>
> (HP 4)

> *For you to work well at least you should have a good man power so that you give attention to the patient, whatever problem they are facing you see them all but like this it is like you just touch here and there to help them, assist them to get whatever they are here for and you will not give them a proper nursing care as required.*
>
> (HP 3)

It has been the cry of most patients at the ART clinic that procedures were not conducted as they were supposed to. In the two testimonies the health providers acknowledged this fact and attributed it to the low health provider-patient ratio. There were more patients than staff could handle if they were to follow all the procedures. In order to attend to everyone who visited the clinic on a particular day, the health providers had resorted to skipping some procedures on some patients depending on one's health condition on that particular day. When patients observed that procedures were not carried out in the way they were supposed to, they got discouraged and stopped accessing treatment.

> *Because of the numbers not everyone can have access to the doctor when they come to the clinic; others just get medication while those who are looking ill are the ones who are seen by the medical practitioner.*
>
> (PT 23 F)

> *…. Because of lack of staff, I may put it as lack of staff; they don't take temperature and BP. You see that when you get a card you go straight to adherence, from adherence to the pharmacy … and sometimes you have to request to see the doctor if you have a complaint… I feel the doctor is supposed*

to be seen by us patients almost every now and then because of the graveness of our disease.

(PT 31, M)

The ideal situation was that every patient who attended the clinic be seen by the doctor or clinical Officer before getting the medication. Due to the ever increasing numbers of patients and shortage of health providers this had not been possible. This became a barrier in that there were patients who would want the doctor to review them on a particular visit but because the health providers screened the patients to determine those who were eligible, it was not possible to accord them that opportunity because it was not everyone who was free to approach them and explain how they were feeling. They (patients) would rather get their drugs and leave. This might discourage one from visiting the clinic. For instance, someone who was experiencing side effects of the drug and did not have access to the doctor or clinical officer might give up taking the medicine.

It is not done correctly because as you know when somebody is tired, a person who is supposed to see maybe a clinician who is supposed to see 20 people maybe he ends up attending to 150 people per day so as a human being he is tired so even the work is compromised because he is tired…..and it is not done according to the way it is supposed to be done.

(PT 21, M)

The respondent reported that because of seeing more people than they were supposed to the health providers got tired and ended up not doing the work efficiently. This could also pose a danger to the patient because they were being handled by someone who was tired, be it physically or mentally. In the event that something went wrong for instance, a wrong drug or wrong procedure was administered a patient might lose confidence in the clinic and discontinue the treatment. A tired body and mind had the potential to make mistakes that could be avoided if someone was alert.

4.3.3.2 Isolation of the ART clinic

The system of isolating the ART clinic received mixed feelings as some felt it was stigmatising.

> *As for me I don't like this system of isolating us because it exposes us even to those who do not know we are HIV positive. I say so because the moment we are seen to be coming here then everyone knows we are coming for ARVs.*
>
> (PT 16, F)

> *That (isolating the ART clinic) is stigmatisation because I know that if a person comes from OPD there and when he has been asked to say what about this.. 'kuseli uku nikwachani?' (*What is this place behind for?*), that person will always know that this place is for those who have got HIV and AIDS where they access ARVs so if there was a situation whereby they are all mixed together then that can be better because isolating ART is one way of stigmatisation.*
>
> (PT 18, M)

In the two testimonies the respondents revealed how they had found the isolation of the ART clinic to be stigmatising. They felt the moment they were seen heading towards that area then those who saw them knew what they were going there for, to get the ARVS because they were HIV positive. Many people who should have been receiving ART had not done so because of not wanting to be seen at the ART clinic.

> *No it's not the best because whoever comes here will just know that ART department and what is ART? Antiretroviral treatment, ooh it means that all people who are there they are HIV positive. Now if we mingle together with those from OPD, from Maternity, people might not notice the difference and might not know who is going in the pharmacy to get ARVs or whatever…*
>
> (PT 33, M)

The respondent advocated for the implementation of the inclusion philosophy where all patients despite their illness would be seen from the same place. In other words there had to be one queue for everyone, for all patients and only the health providers would know what each one of them had gone there for. While this might be perceived as something that might help reduce stigma, it had other challenges like the long queues which respondents complained about.

RES: *I also want you to talk about the issue of isolating the ART clinic from the rest doesn't it create some kind of stigma to some people?*

HP 2: *It does, yes, but when they are here on their own they are more free than being mixed with other people, but from the people who are there it creates stigma because most of the time they will point, ' oh, there it is where the HIV people are found' , but I think it is not bad because at least they are free, everyone who is found here they know that as long as someone is found here they are also HIV positive so there is no need of being ashamed.*

The respondent who happened to be a health provider agreed to the fact that isolating the ART clinic did create a certain level of stigma but considered it a good idea in that it created emotional support among the patients. As they were isolated each one of them had a sense of belonging when they saw that they were not the only ones in that condition.

4.3.3.3 Frequent visits

Most of the frequent visits to the health centre were due to the low supply of drugs. When the drugs were not in adequate supply the health providers found a way of sharing them equally amongst the patients. This would lead to a situation where the patients would get less drugs than required and told to go for the remainder (what was referred to as balance) some other day. For instance those getting a three month supply of the drugs would only get a month's supply and in worse situation they may be given a two or one week supply. This became a barrier especially to those who came from distant places as they could not have the money for transport.

> *Yes maybe you want to go somewhere you can't travel, you say, no, I have to choose for me to go to the hospital to get medication or I go out there to look for money. But again there are two issues here involved because you have to look for money so that you can sustain yourself ,you can eat, but when it comes to money looking of course you say ,okay, fine I will go for money. This one if it's dying, let me just die….,in my own opinion if at all they were giving medication like maybe five months somewhere there so that someone can be given ARVs, you go for a long time and then comes back. That can work out not a situation whereby they give one month.*
>
> (PT 1, M)

The respondent observed that getting drugs every month interfered with some of his daily activities especially those of an income generating nature. When faced with a situation where he had to choose between ARVS and money he would rather go for the money. This was a family man who had to fend for his family and subjecting him to so many visits at the clinic became a barrier to accessing ARVS.

Most of those who are working do complain. They would like to be getting medication at least every three months because at some work places if they get permission every now and then they fear to be fired. So in three months they will only ask for permission once.

(PT 20, M)

In a similar situation truck drivers were noted to miss clinical appointments because some days coincided with the time that they were out of town or out of the country on duty.

RES: *How can these truck drivers be assisted?*

PT 19: *The assistance is that of giving them a two or three month supply of drugs. The wives can come and collect the other supplies for them.*

....there are those truck drivers who go out of the country but as at now we do not have enough. It is rare that we have more drugs in stock so we find ourselves just giving them one month and you find people defaulting because like a truck driver if you have to put him on the safe side you have to supply him at least three months or four months in advance.

(HP 4)

The respondents believed the solution to the truck drivers' problem was providing them with a sufficient supply of the drugs that would last even when they were out of their stations.

That is difficult, at least if I could be given six or three months instead of coming here every month. It is quite stressful as one's mind is always thinking of the next visit.

(PT 15, F)

One of the challenges I see is that there are times when the drug supplies are low and we are given supplies for a week. This is a problem because some people come from far and coming to the clinic frequently is tiring.

(PT 23)

The two respondents above indicated that giving supplies of drugs that would last for a longer period of time would be helpful to many because visiting the clinic more often could be stressful. When people were stressed it affected their health. It was even worse to those who were infected by the HIV virus because their immune system was already compromised. An addition of stress would undoubtedly worsen the situation. Furthermore, when something was tiring and stressful chances of giving it up were quite high.

The health providers indicated that a high supply of the drugs would ease their work as a low supply meant them seeing the same people over and over.

I think it would have been better to give our patients enough drugs so that they go by the time they are coming back we have another supply to give them, not every month's supply. I think if we were to be in their boots it is so tiresome as well because most of them they have recovered and they just come here for refill…

(HP4)

The health provider had interacted with the patients and knew their situation. The saying, 'put yourself in one's shoes,' was appropriate in this regard as she imagined how it would have been if she was the patient. It would definitely be tiresome to be at the clinic frequently. Therefore, it would be helpful if enough supplies of drugs were provided to meet the demand. Another important aspect that came out of this testimony was that most of the clients had recovered meaning they were not ill but were getting ARVS to avoid multiplication of the virus. Going through the hustle of accessing treatment when one was not feeling ill could lead to discontinuity.

Even at the moment we do not have enough nevirapine so we are giving for one month only then they will be coming to collect the balance monthly and that creates a lot of work because we are seeing the same people that we saw last

week, again next week again we will come and see them .It creates a lot of work for us.

(HP, 3)

It is an advantage on our side if we supply them more drugs than to see them coming every one month because there are people staying very far and there are those truck drivers who go out of the country but as at now we do not have enough.

(HP, 4)

The health providers in the two testimonies reported that the frequent visits to the clinic by the patients did not just affect the patients but the health providers as well in that they ended up having more work by seeing the same people within a short period of time.

The health providers revealed that some frequent visits were due to the condition of the patient and as such could not be avoided since they were meant to save one's life.

It depends; when you are starting someone to collect drugs for example today I have started someone on ARV he has to come after two weeks. Then he has to come again after two weeks we have to excarate and again we will give another two weeks. After one month then we will come and give for one month one month for three months. If someone is stable now it is when you can start giving maybe after six months of taking drugs it is when you can be giving three months, every other three months if someone is stable.

(HP2)

The above explanation was about the procedure that was carried out when introducing someone to ARVS. In this instance the frequent visits became inevitable.

4.3.3.4 Attitude of the health providers

While a number of patients found the health providers to be helpful despite the strenuous working environment, some still felt their attitude towards the patients was a deterrent to accessing treatment.

The other thing is that of health workers attitude, sometimes we are harassed as patients, what they need to understand is that we are human as they are too. They should not be shouting at us but just attend to us nicely.

(PT 15)

It appears some of the health providers we receive work on part time basis. I say so because at times there are health providers who shout at us telling us that after all they are working on part time basis and they can stop attending to us at any time.

(PT 11, F)

When the health environment displays signs of hostility in one way or the other patients will fear to go there. There are people who may not access the HIV treatment because they fear to interact with the health providers lest they be humiliated. Being infected with the HIV virus is stressful enough but it is even worse when one is treated inhumanly where they are supposed to find help.

The health providers felt people living with HIV and AIDS were generally difficult to deal with and sought so much attention.

Working with people with HIV and AIDS is a bit of a challenge because, I will say so not every one of them has accepted their status not every one of them has understood the way to take care of their lives….The challenges are there because you find that the way people react to certain, let me say certain situations here is kind of different. They are very sick and all they want is maybe the attention there and then.

(HP 3, F)

These people, most of the time they have short temper so you have to bear with them.

(HP 2, F)

From the health providers testimonies People with HIV had been observed to be difficult. This could be due to the psychological trauma they went through when they discovered their HIV status. They would also feel rejected and over react on most issues thinking some treatment by the staff was attributed to their status. At times they became so expectant that they forgot that the situation at the clinics was the same for everyone, even at OPD there were so many people who had to go through the long processes.

It is not very easy actually to work with people who are living with HIV and AIDS for a beginner but as time actually progresses you get to know these people their needs and how you can actually address them .I think having

worked as a peer educator supervisor has really saved me in understanding the people living with HIV and AIDS Since I am one of them, Actually I am living with this virus…..

(HP 1, M)

The above testimony was from a health provider who was also HIV positive. Like the other health providers, he acknowledged the fact that it was difficult to work with people living with HIV but what had helped him was that he knew what they were going through because he was one of them. As the saying goes, 'Experience is the best teacher.'

A conducive environment would provide the condition that would make it easier for one to function properly. This includes the medical environment. When the medical environment is not operating to the expected standards of the clients who in this case are the patients chances of patients keeping away from accessing the services are quite high. Accessing of ARVS is not an exception. From the discussions one can conclude to say the medical environment does play a role in encouraging or discouraging one from accessing the ARVS.

4.3.4 Side effects

The side effects experienced when one was put on treatment could be a barrier to accessing treatment.

One of the challenges that we go through is that of the side effects, some people give up and stop taking these drugs when they experience the side effects such as vomiting.

(PT 19, F)

My experience was I used to feel dizzy, nausea and would vomit so much in the morning like someone who has just fallen pregnant. I also used to have severe headaches and heart palpitations and had I not been strong I would have stopped taking the medication but I had to persevere for the sake of my children, otherwise it was not easy. By then I was taking that zidovidine which used to be red in colour and it used to be very strong. I went through this experience of side effects for about three months.

(PT 19, F)

When I started taking them yayaya ….when I just started taking ARVS I became so sick such that it was even difficult for me to move, I was just vomiting through and through. Every morning I wake up I had to vomit and when I vomit I become weak. The appetite went so I had those experiences.

(PT 26, F)

When I started I had a bad sweaty smell, but after sometime that stopped…

(PT 20, M)

The different experiences given by the respondents when they started the medication were potential barriers for stopping the medication. Vomiting is something that most people dread because it makes one weak and lose appetite. When one has to go through this on a daily basis for a long time they are likely to stop the ARVS if they know that is what is causing the problem. One has to be strong willed to persevere. Also, many people will avoid being near someone who produces a bad smell. This is what PT 20 had to go through when he started taking the drugs.

The major side effect I experienced was that of vomiting and it took quite some time. I started taking the medication on 25th August 2008 but I only stopped vomiting in April 2009.

(PT 30, M)

Well… at first I used to have nasty dreams I would say…when you take it… I used to take it in the night. I couldn't sleep, sometimes it's like you are drowsy. The dreams were… visions were coming…and going just like that. At one time I almost stopped but I was encouraged when someone said, 'this is a passing phase; this is what you go through.'

(PT 31 M)

Actually the first two, three weeks I started taking my drugs, that is, ARV drugs I experienced some vivid dreams. People who initiated me on these drugs told me some of the side effects of these drugs so when I started having those bad dreams I just said, 'oh no these are the things that the counsellor told me about', but I continued taking the drugs and after some months those dreams stopped.

(PT 18, M)

A side effect is an undesirable or unpleasant effect from a drug. When one takes a drug the desire is for the drug to bring healing. When the drug does not produce the intended results there is a possibility that one will discontinue taking it. This has been the case with ARVS. While people have had hope in finding healing, to some, it has been difficult because the side effects have been severe. This becomes a treatment barrier because one may choose to discontinue taking the medication.

4.3.5 Disclosure

Lack of disclosure of one's HIV status was indicated as another barrier to accessing ARVS.

> *Disclosure is good, even when you are sick, very much sick if you disclose to someone when they take you to the clinic they will know that this person is on ARVs because you have disclosed. If you don't disclose by the time you are sick if they take you to the clinic by that time they may give you the wrong medication since you are on ART, because when you are on ART, you go to OPD, they have to give you the right medication which suits to that one which you take at ART.*
>
> (PT 8, M)

When one is on antiretroviral therapy, treatment should be continued even when one is very sick. In a situation where one has not disclosed their HIV status to the family members or friends this becomes a problem. It can also lead to death in that the medical practitioner will not get the right information about the patient especially when the condition is so critical that they are not able to talk.

In every society there are people who can only take action on a situation after seeing others take the lead. Disclosure of one's status enables others to take that example and also access treatment.

> *It has been a long journey for me because initially when I discovered that I was positive it was a little bit of a challenge for me to open up to other family members. But I discovered a problem that was in the family that a lot of my family members educated as they are, they were dying of the same problem, so I decided to open up so that I could try and save more lives.*
>
> (PT 4, M)

The respondent observed that while education was considered to be the answer to many problems it was not the case with HIV and AIDS. The educated relatives were expected to have information pertaining to HIV and AIDS and that included stigma and ARVS but this was not the case as many had died of AIDS.

Disclosure of one's status was also observed to be important at one's place of work as they were able to get permission for their clinic appointments.

> *Yes it really helps, if you disclose status it becomes easy, even at the place of work if you confide in your supervisor or immediate boss when you get permission to say I am going to get this and that, maybe I am going for medical check up he will understand and then they will give you a day off. But if you have not disclosed they may say no, maybe they may need you. They may not understand you're getting permission to attend a clinic appointment.*
>
> (PT 5, M)

The saying, 'Lead by example' is better than, 'Do as I say'. Respondents expressed their concern at the lack of disclosure of one's HIV status by the leaders. Apart from the former President Doctor Kenneth Kaunda who disclosed that his son had died of AIDS, no other prominent person in the country was known to have disclosed their HIV status even though some could be infected.

> *....those leaders church leaders even the president and ministers also they have got the power to influence the nation if once they disclose about their status and encourage people, like the way I have seen on the radio and TVs like these MPs who are also talking about MC. MC male circumcision, it is very much encouraging. You see a female MP talking about circumcision, go now. A female MP comes there to say, 'go now' you get motivated, you get encouraged but now if they are also shy they will kill a lot of people.*
>
> (PT 33, M)

> *First and foremost I would urge a lot of people to come out in the open that is cardinal, not a common person like myself a school head no but some of the most prominent people of which I am pretty sure that majority of them they are on drugs but they are not coming out in the open, so prominent people should come out in the open so that they should be an example, people should learn from them, right. So from there on people will be able to learn one or two things. What if such a person who is a big person possibly in government or possibly in business has come out in the open and is living positively and a lot of good things that he is doing if he can do those things why can't I, then a lot of*

people will open up and all these myths about the HIV and whatever will be wiped out. People will take it normally like any other disease and people will be able to open up, yes.

(PT 4, M)

The two respondents reported that more people would have been accessing HIV and AIDS services such as testing and receiving treatment if only the leaders in the nation could also come out and disclose their status to the nation. It appeared most people who disclosed their HIV status were of the low socio-economic status and hence their being misunderstood to be doing it for monetary benefit in some cases. The barrier of disclosure is partly caused by those affluent in society who do not want to be known that they are infected with the HIV virus. This also brings the misunderstanding that the virus only affects the poor just like cholera.

Disclosure of one's HIV status was seen to be therapeutic as it helped one cope with the stigma as well as find healing of the mind.

Disclosure is one of the most important things, it helps to heal yourself and it helps the client you are talking to. When you disclose to someone they will not be in the dark city but will also go for testing. Like the way my friend did it. My friend tested and he disclosed to me you see so I also went for testing, even as at now I am doing the same thing because when you disclose to someone they will be open to everyone. You avoid stigma, the most thing you avoid is stigma.

(PT 29, M)

It has helped me to remove the stigma because I am open about my status to everyone.

(PT 17, M)

It(disclosure) *helped me because I had somewhere to breathe, it is like carrying a heavy burden and you have someone to say don't worry nangunachifinawalafika(even if the burden is heavy you will reach your destination). You know you feel encouraged. Even if the distance is long, just those words you feel encouraged and… you know like some of us who have been to villages, they will never tell you if you ask about a village that you are going to that it is far, they know that you will feel discouraged and maybe you won't pursue the route. But in the village they will tell you it is nearby you are almost there. I felt relieved because it was like I was offloading my thoughts to my brother who also encouraged me so I felt encouraged, it was a relief.*

(PT 31, M)

The respondents found disclosure to be helpful in removing stigma and was therapeutic. PT 31 likened it to laying one's burden on someone and this burden was that of discovering that one was infected with HIV.

> *It has helped me so much because as I was saying I used to hide when taking those drugs but since I came out in the open and explained everything to my family I feel relieved. They do encourage me very much, that I have a future ahead of me especially my mother.*
>
> (PT 16, F)

In the testimony the respondent reported how she used to hide the drugs. Hiding of drugs can hinder adherence because the patient may not take the medication when they are in the company of others who do not know about their HIV status.

> *The goodness is that you can get assistance from people, for instance when people know that you are on ARVs they will remind you to take medicine when it is time to do so. Now if you hide you will not be assisted for instance if you have an appointment at the clinic and there are visitors at home you will fail to tell them that you want to go to the clinic because they will ask why you are going to the clinic when you are not sick. A friend may even ask to escort you and you will not accept to be escorted and as such may miss the appointment. When you have not disclosed you may fail to be taking the medicine at the right time and that will affect adherence.*
>
> (PT 30, M)

The respondent indicated that disclosure had helped in being reminded to take the medication in the event that one forgot to do so thus maintaining adherence. It also helped one to keep to the clinic appointments because they would be free to go there regardless of who was with them, they could easily tell the person that they had to go to the clinic and even explain what they were going there for.

RES: *Let me just take you back, to the time you got tested. Since you were with your husband which person apart from him did you disclose your status to?*

PT 19: *It was something very difficult but after sometime I disclosed to my sister. It was not easy for me though.*

RES: *How did your sister take it?*

PT 19: *She accepted it. She encouraged me by saying 'vinabwelela bantu' (This disease came for people).*

RES: *What was it that made it difficult for you to disclose to another person, what was it that was on your mind?*

PT 19: *I thought she was going to laugh at me that I had AIDS and was going to tell so many people about it even relatives. In short I did not trust her.*

People's perception about what will happen is a potential barrier to disclosure. The respondent above was so sure if she disclosed her HIV status to the sister she was going to be laughed at but that was not the case. The sister comforted and encouraged her and this motivated her to continue being on treatment.

From the foregoing the researcher concluded that while disclosure of one's HIV status was difficult it played an important role in one accessing and remaining on treatment because of the support they received from those they disclosed to. What made disclosure difficult was the perceived reactions the patients had about the people they chose to disclose to. These reactions may be real and may have been experienced by someone else making the infected person feel they may go through such experiences as well.

4.3.6 Feeling Better

While getting better is a good thing, to some it becomes a barrier to their treatment. This deception has caused the death of some who would have had more years to live.

> *Some people do not see the need of continuing with the medication when their CD4 is high but what I know is that one is not supposed to stop at all.*
>
> (PT 14, F)

> *It is because they think and feel they are fit enough and can do without the medication but when they stop they get sick.*
>
> (PT 11, F)

> *One challenge is that there are people who are on this medication and when their health starts improving they stop taking the drugs. They even start smoking*

and by the time they are coming back they are in a critical condition maybe on a wheelchair. That is one major challenge I have observed.

(PT 20, M)

The three respondents reported that feeling better to some became a barrier in that they stopped the treatment thinking they had fully recovered and did not have to continue accessing ART. They went back to leading an unhealthy life style such as smoking and drinking.

From the interactions with the patients it was clear that the taking of drugs on a daily basis was quite demanding. The respondents looked forward to a day when they would stop taking the drugs and being found at the clinic more often. This had resulted in some people being deceived when they felt better. They thought they were fine and could do away with the medication only to end up in more serious conditions which in some cases were fatal. Some respondents wished there was a drug that could be taken once in a month or even once a year.

4.3.7 Socio-economic Status

The socio-economic status of most of the participants was low. The majority of the respondents were not in sustainable income generating activities such as employment or business. Many reported challenges in meeting basic needs especially food.

The other thing that is needed is food and it is something that deters a number of people. You find one is on medication but they have no food in their homes. The drugs are not effective if one takes them on a hungry stomach. Someone who is on this medication must also have food.

(PT 20, M)

RES: *Now those challenges of basic needs and you are saying you are not in employment, do you think it is easy for one to maintain this treatment when they have challenges where basic needs are concerned?*

PT 6: *No, those are some of the treatment barriers, it is not easy. Like for me being a volunteer at least sometimes I have one or two meals a day, but for some it's one meal while others go without a meal. Now to take theses antiretroviral drugs on an empty*

stomach it is really a challenge, it becomes a treatment barrier on itself.

As I earlier mentioned I am a widow so there are times when I have difficulties in finding food since I have no one to help me. These are the times I am left with no option but to just take the drugs without eating because there is nothing else I can do.

(PT 19 F)

Being on medication is a difficult thing; I say so because these drugs make one feel so hungry. When one feels so hungry nausea also creeps in and if one has no food in the home it becomes a problem. What we need, especially those of us who do not work is assistance to set up businesses that will help us raise money to buy food. There are some people I have talked to who have stopped taking the drugs and the reason they give is that they used to feel so hungry but had no food. They say the hunger they experience when not on ARVS is better than the one when they were on medication. Now even if they stop because of hunger the problem of HIV will still be there, so the best is to empower them so that they have means to get food.

(PT 28, F)

The respondent described the severity of hunger and how it caused one to discontinue the treatment. Being a volunteer at the clinic her experience was that she knew of people who had discontinued treatment because of hunger. In other words discontinuing the treatment was the best option they could think of. This hunger was mainly due to lack of means to get the needed food.

Food is a vital basic need for everyone. While shelter is a basic need too it is possible for one to sleep outside for a number of days and still survive. It is different for food in that one needs to eat almost on a daily basis. For someone who is on treatment it is not just a matter of eating but eating the right kinds of food in order for the drugs to be effective in the body. When one cannot afford the needed food they are likely to discontinue the treatment.

RES: *Do you find being on medication costly especially in terms of basic needs such as transport and food? Tell us your experience.*

PT 11: *It depends on individuals.*

RES: *What is your experience?*

PT 11: For me I manage I have a sister and a mother who really support me.

The respondent received adequate support from the relatives and this encouraged her to continue being on the medication. Patients who received the necessary support from the families be it financial, emotional, spiritual were more likely to stay on the treatment than those who did not receive any, especially when they were faced with challenges of basic needs.

Some respondents believed that being on ART was not expensive. It was individuals who were making it appear expensive because of the lifestyle that they had adopted of wanting to live way beyond their means, for instance going to distant places to seek treatment when the government had taken the initiative of putting up health facilities in most communities.

There was a time in Zambia when ARVS were considered drugs for the rich because they were so expensive that only those with the money could afford them. Now they are given for free to anybody who is willing to access them but despite this there is still the challenge of meeting the basic needs such as food and transport. The majority of the participants reported to be barely managing to access those needs. This poses a danger in that when the basic needs are not easily accessible then levels of adherence to medication will be so low.Patients are advised to eat a balanced diet which many reported cannot afford because they have no reliable source of income.

4.4 Gender barriers to ART access

It was observed that gender inequalities in the access of ART existed between men and women infected with the HIV virus. Women were found to be more in accessing ART. This was attributed to some gender barriers that existed.

Three sub themes were identified in the second set of themes and these were:

- Men' dominance,
- Men less proactive in health matters

- ❖ Unequal distribution of HIV and AIDS programmes

4.4.1 Men's dominance and Women's Socio-economic empowerment

Research has shown that women are proactive in matters pertaining to health but their lack of economic empowerment has been a barrier to take up these initiatives. Most women will depend on a man for financial support. These men could be their husbands, partners or those who just want to have casual sex in exchange for money. This has contributed to the number of women being infected with HIV and consequently of those accessing ART to be higher than that of men.

> *Most of the women like the ones who come for MCH* (Mother and child health) *would have a problem in taking ARVs in the house because their husbands would tell them that, ' me I don't even want you to bring ARVs in my house so if you want to be taking those ARVs move out of my house.' So that is a challenge I used to see with women taking ARVs. And sometimes they would keep the drugs in someone else's home, different from the one they are living in.* (Grammar edited to add meaning)
>
> (PT 26, F)

In this testimony the participant brought out the point suggesting that women with a low socio-economic status took marriage to be some form of social security and as such would endeavour to live by the husband's dictates. If the husband was against the taking of ARVS the woman would adhere to that. Where the woman chose to be adamant and took the forbidden treatment it had to be done secretly without the husband's knowledge. This has a negative impact on adherence because medication is something that a patient has to keep where they live. In this case a woman who is eligible to taking ARVS is threatened by the husband not to do so lest she lost her marriage. A number of women have chosen to keep the marriage than accessing the ARVS for fear of being divorced and become destitute in turn.

The barrier of disclosure is common in couples. While a man will not disclose his HIV status due to stigma and fear of being blamed, a woman will not disclose her status due to fear of losing her marriage or love relationship which in most cases is what she depends on for her daily sustenance.

The other challenge faced by some women is that when they are tested and are found to be positive they do not disclose to their husbands for fear of being divorced. There are actually a number of women with this problem. In some cases they will even refuse to access the drugs for fear of their husbands discovering they are on ART.

(PT 28, F)

I think maybe just because we are called mothers, with mothers we have no problem, though they are scared to disclose the status at home to their spouses because they are scared they might be chased from their husbands.

(PT, 7 F)

Disclosure as earlier mentioned (in the first set of themes) plays a major role in one's access to ART. The two participants above give scenarios of what women go through when it comes to the issue of disclosure. They have no problem when it comes to testing for HIV and accessing the treatment. The problem is on disclosing the status to the husbands or partners. This becomes a barrier because the woman is disadvantaged in accessing the treatment and risks re-infection.

In my case I have to catch a bus to come to the clinic because I experience some pain on my legs when I walk long distances. I am not in employment and I have no business so I have to depend on my husband. When he does not give me the money then it becomes difficult for me to come to the clinic.

(PT 27, F)

The respondent confessed that she could not afford the means to get to the clinic and depended on the husband. Some information given outside the interview was that the husband was also taking ARVS and would always ensure he had the means to get to the hospital when he had an appointment. When there was only enough money for one he would rather be the one to use it while the wife had to wait or find other alternatives to get to the clinic which could be walking or borrowing.

4.4.2 Men less proactive in health matters

Respondents reported that men shunned health issues. While stigma was experienced by both genders it was found that men were more affected than the women, one of the reasons that led to delay in seeking treatment.

> *The barriers to us men are several but the major one is stigma. We think that once we get tested because of our nature people will think that we have been having woman after woman. Now because of thinking like that we fear that we will be tested for HIV when we go to the clinic. Because of that we would rather not go there and instead go and fend for our families.*
>
> (PT 21, M).

The respondent revealed that the major barrier for men was stigma. In most cases this came about because of perceptions people had about HIV being caused by womanising. Such perceptions are true because it is common belief that a man cannot do with one woman in order to be satisfied sexually meaning even if one is married they will engage in extra marital affairs.

Women were reported to take health issues seriously and were proactive unlike men who waited until it was too late for them to take action.

> *The reason is that men I do not know how I can say this, for a man to come all the way from home to the clinic then it means the condition is bad, which is very different with a lady. For a lady if she just has a headache she has to rush to the clinic but for the men it is different. For the men they have got stigma .I can say they have got a lot of stigma….*
>
> *(*PT 18, M)

The participant indicated that women were so alert and mindful about what was happening in their bodies. The moment they felt that something was not fine they would not wait until it was so serious. They would seek medical attention immediately. This is unlike men who wait partly because traditionally a man must be strong and enduring. This has led to a number of men going for HIV treatment when it is too late.

> *.....But women are the first people even when they are just okay they will try to do it to go for testing, access treatment or be enrolled and access treatment so that's how I find it*.
>
> (PT 29, M)

The respondent reported that women did not wait for the illness or symptoms of the illness to show for them to take an HIV test. Even when they were in their best of health

they would be keen to do the test and where necessary access the treatment. More women were accessing the Voluntary Counselling and testing service than men who waited until they were ill and in most cases critically ill.

> *The other thing I have observed is that men are very difficult. Even when they know they have tested positive they will not access the medication but will wait till it is too late and only to be brought in a wheel burrow. When they come to the centre and find that there are so many women they go back.*
>
> (PT 28, F)

In the testimony, the participant indicated that the problem of men shunning health initiatives was not only in the testing but throughout the whole process. Where a man had tested HIV positive unless they were critically ill they would likely not access treatment. When they were feeling well they would not see the importance of seeking treatment.

> *But for a man it has to take a lot of time to be convinced; as I alluded to, my girlfriend went for VCT which I was not prepared to do. … Women I would say they are mothers…So when they hear of something that will prolong their life they go for it. Even at clinics because it takes two to tangle. Like the ART, they know that if I don't take this, I may leave my children in shambles. So you find that's the more reason there are more women than men. Not that men are not infected.*
>
> (PT 31, M)

In this case the participant indicates that he had to be convinced by a woman to take the HIV test. It is likely that without the woman insisting that he too goes for the test after she tested HIV positive he could not have done so. He goes further to indicate that the motherly traits in women make them not only think of themselves but even their beloved ones and mostly it is their children.

4.4.3 Unequal distribution of HIV and AIDS programmes

The participants indicated that the HIV and AIDS programmes were unequally distributed between men and women. Women were reported to be captured in many areas.

These women are captured in many areas, whether they go to under-five they are captured, they go for anti natal they are captured, they go to TB maybe they are just escorting their relatives or friends they just get interested in testing so they are captured in many areas. So there are many in accessing these ARVs compared to men. Men are very few.

(PT 33, M)

For sure with the coming of PMTCT women in most cases go for testing like the way I have said in the first place in PMTCT. When they do it whether they want it or not they will do it when they are pregnant so they are the ones to force their husbands to go and do the testing.

(PT 29, M)

The participant observed that most women were able to access services that had to do with HIV and AIDS because they were captured in many areas unlike men who mostly had to depend on VCT. Prevention of Mother to Child Transmission was one programme that advantaged most women in that it was almost mandatory for every expectant woman to be tested at the anti-natal clinic. The other place was at under five clinics where it was mostly mothers who took the children and were encouraged to take the test.

When asked which gender accessed more ART this is what one health provider had to say.

HP 4: *I think it is the females, yes?*

RES: *Why could it be so?*

HP 4: *I think maybe like MCH it is all about women, people are coming from MCH and I think females go for VCT more than men, men wait until they are sick that is when they go for VCT.*

The health provider also alluded to the fact that more women were getting tested through MCH and this made the number of women being tested to be more.

While the PMTC programme was perceived to be for women only it was reported that men were also encouraged to accompany their wives but most of them shunned it taking it to be a woman's business.

> *For me I can say we the men are unfair to the women because we are supposed to accompany them for antenatal clinic so that both husband and wife get tested together but in most cases we do not do that. We let them go alone while we stay behind. It is better we accompany them so that we are given information together.*
>
> (PT 17, M)

In the above testimony the respondent acknowledged the fact that most men did not want to accompany their wives to the antenatal clinic so that they could receive the information together on how best they could take care of the pregnancy to prevent the baby getting infected with the HIV virus.

> *From my observation I think there are more programmes for women than for men. For instance when I was pregnant a few months ago I was advised to come with my husband for the first visit at the anti natal clinic but my husband refused saying he could not attend the clinic for females. As such I received the information on how to care for ourselves so that our baby is not infected with the virus without him.*
>
> (PT 15, F)

In this testimony the respondent revealed how the husband refused to go with her to the clinic after being advised by the health providers. This is the common scenario at most clinics. Most men refuse to go with their wives to the antenatal clinic to receive the necessary information. The other thing that discourages them is the fact that for a long time the antenatal clinics and under five now called Mother and child Health (MCH) have been associated with women. Even the current name Mother and Child Health (MCH) does not encourage a man to go there.

> *When it comes to the issue of PMTCT, men are encouraged to accompany their wives so that they get tested together but very few do so. There are instances where out of the 30 women that may visit the anti natal clinic on a particular day only 3 or 4 may come with their husbands. The majority will refuse.*

(PT 28, F)

The respondent who was doing some voluntary work at the clinic gave a picture of the situation concerning men participating in the PMTC programme. In this case, out of every 30 women only 4 men (16%) would accompany their wives to the clinic for anti natal services. This meant that a number of men were not getting the information on the precautions to be taken to have a baby who was not infected with the HIV virus.

In the first set of themes it was reported that the medical environment had an effect on one accessing ART. In this second set of themes men were found to be in the majority of those who avoided the clinic because of the long hours spent there. As for PMTCT it was reported that the environment was made conducive for them so that they did not spend long hours at the clinic.

> *In most cases what men dislike about the clinic is the long hours that they spend, they don't like that. Men want to go fast, so they don't want to be delayed, so what we normally do is for those who accompany their wives we help them to move from point A to B until they finish everything.so the environment allows that men are attended to as quickly as possible and we feel very proud if we see a man coming with a wife. We feel encouraged and we encourage them to keep on supporting one another*. (Volunteer)

(PT 33, M)

> *I would also say the clinic environment favours such men in that they will be attended to quickly together with their wives. As such they do not spend much time in the queues.*

(PT 28, F)

The two participants alluded to the fact that while the medical environment was a barrier in accessing ART when it came to the PMTCT the health personnel did all they could to make the place friendly for men by giving them first priority when they accompanied their wives. Despite all these efforts the turn out for men was reported to be still very low.

> *When it comes to PMTCT it is important that when our pregnant wives go in labour we should have something like smoking rooms where we the men can be as we wait for our wives. Now it is a challenge that we can't even support our wives. You find that the labour begins maybe at 24 hours, I book a cab and take*

my wife to the hospital and the health personnel that side will just say 'leave her'. Suppose I do not have any transport money to go back home, how do I go? So it is quite a challenge, so at least we should be nearby to give support to our wives. So that even if it means giving health education we can be together .Even if the government is trying to encourage us to escort our wives for MCH, it is still a challenge because at a later stage on the last day of birth we are not recognised.

(PT 6, M)

The participant alluded to the fact that while the men were being encouraged to be involved in the PMTCT programme; the medical environment did not allow them to be there at every stage. At some point they were not recognised and this could be frustrating and demotivating.

While the programmes at MCH were seen to be targeting mostly women, participants indicated that men were not completely left out in term of programmes because there was a programme that exclusively catered for them and that was the Voluntary Medical Male Circumcision. It was reported that before being circumcised the men were counselled to take the HIV test. This gave them an opportunity to be in an exclusively, 'men only environment'.

Maybe the Male Circumcision which government has introduced. I am sure that is what will help men get tested and know their HIV status. I know that before they do that male circumcision they do the HIV test, although I have not done it myself.

(PT 1, M)

4.5 Quantitative analysis

Table 2.1. Results of 3-way ANOVA for scores on Brief Visual memory Test

Tests of Between-Subjects Effects

Dependent Variable: BVMT learn raw

Source	Type III Sum of Squares	Df	Mean Square	F	Sig.
Corrected Model	2452.144[a]	35	70.061	1.491	.046
Intercept	16177.186	1	16177.186	344.302	.000
Gender	27.771	1	27.771	.591	.443
Agelev	600.829	4	150.207	3.197	.014
Edulev	542.303	3	180.768	3.847	.010
gender * agelev	77.293	4	19.323	.411	.800
gender * edulev	90.957	3	30.319	.645	.587
agelev * edulev	381.247	11	34.659	.738	.702
gender * agelev * edulev	482.781	9	53.642	1.142	.334
Error	10618.726	226	46.986		
Total	58764.000	262			
Corrected Total	13070.870	261			

a. R Squared = .188 (Adjusted R Squared = .062)

Table 2.2: Education, Age, and Gender on Neuropsychological Tests.

Test	Variable	F	P value
wisconsin card sorting test	Gender	2.618	0.107
	Education Level	3.549	0.015
	Age group	1.966	0.101
Stroop Word	Gender	6.331	0.013
	Education level	7.694	0.000
	Age Group	1.773	0.135
Spatial span	Gender	1.933	0.166
	Education Level	3.440	0.018
	Age Group	1.900	0.111
Hopkins Verbal Learning test	Gender	4.79	4.90
	Education level	4.166	0.007
	Age Group	2.143	0.076
Brief Visual Memory Test	Gender	0.591	0.443
	Education level	3.847	0.010
	Age Group	3.197	0.014
Grooved Pegboard(dominant)	Gender	1.411	0.236
	Education level	3.872	0.010
	Age Group	2.932	0.022
Grooved Pegboard (non dominant)	Gender	0.333	0.564
	Education level	1.710	0.166
	Age Group	2.051	0.088
Symbol Search	Gender	0.047	0.829
	Education Level	2.696	0.047
	Age Group	1.764	0.137

Tables 2.1 and 2.2 show the effect of gender, education level and age level on neurocognitive functioning.

Table 2.1 presents the full output summary table of the 3-way ANOVA with Brief Visual Memory Test scores as the dependent variable. In this analysis, the main effects of education (F=3.847) and age (F=3.197) were both significant at the .01 level, whereas the main effect of gender (F=0.591) was not significant (p=.443). Moreover there were no significant interactions between the effects of age, education and gender.

Table 2.2 presents the F values for the main effects of gender, education and age in comparable ANOVAs conducted for each of the selected neurocognitive tests. The results showed that education level had a significant effect on Wisconsin card sorting test, stroop word, spatial span, HVLT, BVMT, peg (dominant), and symbol search with $p < 0.05$, but no significant effect on peg (non dominant) ($p \geq 0.05$).

Age level had a significant effect on HVLT, BVMT, peg(dominant) and peg (non dominant) ($p < 0.05$) but no significant effect on WCST, stroop word, spatial span and symbol search ($p \geq 0.05$).

Gender had a significant effect on stroop word ($p<0.05$) and had no significant effect on the rest of the selected tests.

Thus, while the effects of education expected were confirmed with participants with higher levels of education scoring higher on 7 of the 8 tests, and the expected effect of age was found on 4 of the tests, gender had no significant effect on 7 of the tests, and in the one remaining test, female participants scored higher than males.

Table 3: Mean scores in the Neuropsychological tests according to gender

TEST	MALES (mean)	FEMALES (mean)
wisconsin card sorting test	33.94	36.16
Stroop Word	69.07	71.08
Spatial span	11.22	10.37
Hopkins Verbal Learning test	19.18	19.22
Brief Visual Memory Test	14.29	12.45
Grooved Pegboard(dominant)	84.52	85.85
Grooved Pegboard (non dominant)	95.84	99.93
Symbol Search	14.88	14.29

Table 3 shows the effect of gender on neurocognitive functioning. The results showed that males had less errors on the WCST and high scores on the spatial span, BVMT, peg (dominant) and symbol search while the females scored high on the stroop word, HVLT, peg (dominant) and peg (non dominant)stroop word. Though there were differences in performance among the two groups they were not significant.

Table 4: Mean scores in the Neuropsychological tests according to education level

Test	Primary	Lower Secondary	Upper Secondary	Tertiary
wisconsin card sorting test	39.29	36.46	34.03	29.80
Stroop Word	62.83	67.19	73.76	76.10
Spatial span	10.44	10.25	10.98	11.50
Hopkins Verbal Learning test	17.05	18.62	20.07	20.55
Brief Visual Memory Test	11.71	11.62	14.63	13.65
Grooved Pegboard(dominant)	87.85	89.47	82.00	84.05
GroovedPegboard (non dominant)	98.20	100.70	96.74	98.25
Symbol Search	11.51	12.99	16.30	15.90

Table 4 shows the effect of years of school on neurocognitive functioning. In the WCST groups showed a trend of reduced errors with higher education. There was an increase in scores with higher education in the stroop word and HVLT. In the spatial span the tertiary group scored the highest. The upper secondary group scored high in the BVMT and symbol search. The lower secondary scored high in both the peg(dom) and the peg (non dom). Of the seven tests the tertiary group scored highest in four of them, an indication that performance in neurocognitive functioning is increased with the number of years in schooling.

Table 5: Mean scores in the Neuropsychological tests according to age level

Test	**21-29**	**30-38**	**39-47**	**48-56**	**57-65**
wisconsin card sorting test	32.64	35.99	34.10	37.52	37.20
Stroop Word	69.82	69.10	73.34	67.20	67.29
Spatial span	10.86	10.56	11.17	10.27	9.86
Hopkins Verbal Learning test	18.89	19.13	20.06	18.00	18.64
Brief Visual Memory Test	15.50	12.85	14.29	11.30	9.43
Grooved Pegboard(dominant)	79.04	78.01	81.71	103.48	105.57
GroovedPegboard (nondominant)	90.61	91.44	95.59	115.91	115.25
Symbol Search	14.82	14.60	15.88	12.18	12.21

Table 5 shows the effect of age level on neurocognitive functioning. The results showed that the 39-47 group was scoring high in most tests while the 48-56 and 57 and 65 were scoring low. These results show that there is a decrease in neuropsychological performance with increase in age. From the three tables; 3, 4 and 5 it is evidenced that while there were significant differences in performance according to age and education there was no significant difference in performance according to gender. This is as cited earlier when the three way ANOVA is presented.

Chapter 5

DISCUSSION OF THE FINDINGS

5.0 Introduction

This chapter will discuss the research findings presented in chapter 4. The discussion begins with a summary and then followed by a detailed account in relation to previous studies that have been carried out in Zambia and other parts of the world, especially in Africa.

5.1 Summary

In chapter four, the results presented identified two sets of themes. In the first set, seven barriers to ART access were identified and three in the second set. In the first set of barriers it was indicated that stigma was not just a major barrier but that it manifested even in the other six barriers. Holding on to some **beliefs and misconceptions** kept some people away from accessing the treatment by not visiting the clinic. They upheld their beliefs to an extent where they missed out on the free treatment available in most government health facilities. There are **side effects** that are prominently associated with the taking of ARVS. Where one experienced such they chose to discard the drugs lest people discovered it was because of the ARVs reaction .While **Disclosure** was viewed to be a good thing it was not easy for one to do so because of the unexpected reaction from those disclosed to. Some reactions were stigmatising as the people who were trusted turned out to be the ones taking the lead of stigmatising the respondents. The **medical environment** which is supposed to be a source of comfort to those who are infected was reported as stigmatising because it exposed the participants when one's HIV status was supposed to be a confidential issue. The isolation of the ART clinic was not appreciated. The attitude of the health providers was also a source of concern as patients felt they were treated inhumanly attributing the ill-treatment to their status. The frequent visits to the clinic, apart from being a burden, were also seen to expose those who had not accepted their HIV status and had not disclosed to anyone such that the moment they **felt better** they stopped taking the medication to save themselves the

embarrassment of being at the clinic and the stigma that was associated with it. While it is true that the government has put up medical facilities in most communities the patient also has the right to privacy and as such they can choose to go to a clinic where they will be free to access the services. The issue of **costs** was a common limitation to the majority. They could not go to a clinic of their choice because they had no means and at the same time they did not want to use the facility near their location for fear of being stigmatised.

In the second set of themes gender differences were observed in accessibility the access of antiretroviral therapy. While women were more at accessing ART they did face socio-economic challenges because they lacked socio-economic empowerment. Their dependence on men made them vulnerable, subsequently leading to failure in accessing treatment. Men were reported to be less proactive when it came to issues that affected their health. They took a casual approach even in serious health matters such as HIV and AIDS. While there was no written demarcation to indicate which programmes were for males and which ones was for females, it was observed that most programmes appeared to target women increasing the number of those being tested and accessing the treatment.

5.2 Barriers in accessing ART.

In a similar study the following barriers to accessing ART were identified: beliefs about ART, side effects, stigma and discrimination, lack of disclosure, feeling better, lack of nutritional support, forgetfulness, lack of follow up and counselling, inadequate time during consultation, lack of confidentiality in treatment rooms and socio-economic status (Nawa et al, 2008).Seven of these barriers were also identified in the current study.

5.2.1 Beliefs and Misconceptions

Research has reported that the use of other alternatives has been perceived as a barrier to HIV treatment. Patients have been reported to have stopped taking ARVs in preference for traditional medicines or spiritual rituals. The beliefs and misconceptions

that people had about ARVS before and after being initiated on ART were reported to be potential barriers in accessing treatment. Some beliefs were due to misdirected information where people believed the HIV infection was only for those who were promiscuous. While it is true that promiscuity can aid in the transmission of HIV, it is not always that one will be infected because of this. There are people who are infected through other means such as at birth from the infected mother, through use of sharp instruments or through an unfaithful partner. When one has tested HIV positive the concern should be on encouraging them to access treatment rather than dwelling on how they got infected. The Phenomenon of believing in prayer and discarding the ARVS was reported to be fast growing and a number of HIV infected people had discontinued the treatment and taken up prayers. Apart from the prayers the churches also offered what is called holy water which they gave to the patients to take and it was believed it contained the power to cure AIDS.

In many African societies there is a belief that where conventional medicine has failed the traditional medicine can do better, so some people believed herbs could cure AIDS. General scepticism toward modern medicine among community members or family members and strong roles of elders and their beliefs could influence decisions to use traditional healers and medicine alongside or in place of ARVS (Annabelle, 2013). The use of herbs was prominently advanced and this stemmed from the belief that herbs were more effective than conventional medicines. Aloe Vera is one plant that was popular due to the belief that it can cure most if not all ailments including HIV and AIDS.

The word chemical is usually associated with something deadly, something dangerous. There was a belief that ARVS were chemicals and as such they were not safe for one's body. People feared that if they took the ARVS something may happen to their bodies, for instance their body structure could change and men believed it could harm their manhood.

ARVS are drugs that require one to eat a well-balanced diet. The people from the communities where the study was carried out were of a low socio-economic status and

as such faced a lot of challenges accessing food. This meant they had to take the drugs on an empty stomach which reduced their life span. This shortening of one's life was translated as being caused by the ARVS hence the belief ARVS shorten life. Since they shorten life people were of the view that it was better not to take them so that one's life is prolonged when actually the opposite was true.

Beliefs and misconceptions have a negative impact on one's treatment. HIV beliefs especially those related to treatment mistrust can contribute to health disparities by discouraging appropriate treatment behaviour (Bogart et al, 2010).

5.2.2 Stigma

Since the early years of the HIV epidemic stigma has been understood to be a major barrier to successful HIV prevention, care and treatment. Early in the history of the epidemic the late Jonathan Mann, former head of WHO global program on AIDS identified stigma as the third epidemic following the accelerating spread of HIV infection and the visible rise of AIDS. It was recognised that stigma, discrimination, blame and denial were potentially the most difficult aspects of HIV and AIDS to address, yet addressing them was key to preventing HIV transmission and mitigating the impacts of the disease on individuals, families and communities. A number of studies carried out in Zambia and other areas within the region have acknowledged the fact that stigma is a major barrier to access of treatment (PulerWitz et al, 2010; Mshana et al, 2006; Theilggard et al, 2012 ; Jurgensen et al, 2012).

In the current study, the other barriers identified also carried an element of stigma. There were various ways in which stigma was manifested. One way was where people sought medication in distant places so that they were not seen by those who knew them. This became a problem when they had no money for transport to enable them visit the clinic in the distant place for their clinical appointment. One common reason given for accessing medication at a place far from their home was that they were attached to the place and had developed friendships with both the staff and other patients. This made it difficult for them to relocate to another clinic.

Removing and throwing away the packets of the medicine was another way stigma was manifested. The patients did not want the people in their communities to know they were taking the ARVS so they would throw away the packets and put the bottles that contained the drugs in bags. Some argued that they did that to lighten the load they had to carry.

Family members that were expected to be a source of support to those that had been infected with the HIV virus were found to be the ones that stigmatised them. In most cases this was through reminding them of their past, especially in cases where the respondents had disclosed their status.

5.2.3 Medical environment

Posse et al, (2008) in their study, 'barriers to access to antiretroviral treatment' conducted a review of studies to assess the common barriers impeding people living with HIV AND AIDS from accessing treatment. Of the 19 studies reviewed 9 identified health system level barriers. In the current study 4 aspects of the medical environment were identified to be barriers to accessing ART.

The medical environment was also reported to be contributing to stigma because it lacked privacy. Participants felt the confidentiality was not guaranteed given that they were isolated from the other patients. Stigma appears to influence testing indirectly through barriers related to confidentiality and privacy concerns (Jurgensen et al, 2008). Persons living with the HIV infection are socially vulnerable and experience stigma and discrimination at all levels and this poses challenges in accessing as well as remaining in care. The effectiveness of the care programme is threatened (Bond et al, 2003, Chipungu 2006 & Mugisha et al, 2009). The participants advocated for an inclusion policy where all patients regardless of what they were suffering from would use the same place as was the case at the out -patient department (OPD). They felt this would create more privacy as no one would know what they had gone to the clinic for except for the health providers who would attend to them.

5.2.3.1 Slow process

The slow process was characterised by long queues where people waited for long hours to be attended to. While people could be at the clinic as early as 05:00 hours in the hope of being attended to quickly, this was not the case as they left the clinic quit late. Even when staff reported on time there were still delays. The patients found this slow process to be tiring and at times they had to leave because they were tired and hungry. A similar situation was observed in a study carried out in Tanzania by Mshana and colleagues (2006, p 4), where they stated that 'The hospital also had a reputation for long waiting times that resulted in exhaustion and hunger for patients, particularly in combination with journey times. 'Patients complained that the long waiting affected other activities especially those of an income generating nature. This led to missing some clinical appointments when it came to choosing between the clinic and an activity that would enable them put food on the table.

The shortage of health providers was indicated as a major factor for the slow process. The health providers acknowledged the fact that they were overwhelmed with the ever increasing number of patients. In trying to do their best to cater for each patient that visited the clinic on a particular day they avoided following some of the procedures when administering care to the patient because more time would be required on individual patients. This meant compromising the quality of service offered. The ideal was for every patient to be seen by a doctor or clinical officer at each visit but this was not possible. Only those whose condition necessitated for that could be attended to otherwise the rest just got their drugs and left. A year could elapse without someone being seen by the clinical officer or doctor but just getting the drugs. Seeing more patients not only compromises the quality of service but it induced burn out in the health providers. They felt very tired and fatigued and this could be the reason they were irritable to patients at times.

Like many developing nations in the region, Zambia is faced with a severe human resource crisis in the health sector. The ratio of physicians to the population is lower than the mandated minimum of 1 doctor per 5,000 population standing at 1:1,000.

Existing staff shortages present Zambia with the added challenge of rapidly increasing the number of staff providing HIV and AIDS services without negatively affecting the provision of other health services (Global HIV initiative, 2008).

The filing system was another factor that contributed to the delay because due to the increasing numbers of patients on the one hand and inadequate storage space on the other it had become difficult to put the files in an orderly manner where they could easily be traced. At each clinic a container had been positioned for storage of the files. Initially there was enough room and the files were neatly packed according to their serial numbers. With time as the number of the patients increased, proper filling has become a serious challenge. As one entered some rooms in the clinics, heaps of files could be seen on the floor. Finding a file for a patient on that heap was a nightmare. In the end the patient who would have been first to arrive would be the last one to leave. Participants observed that it was time modern technology was used in the filling system that is, computerising it. That way it will be easier as the patients' information will be in the system. This will also aid the clinic staff to do their work faster.

5.2.3.2 Isolation of the ART clinic

Just like any other specialised clinic the ART clinics at the health facilities are isolated. While the isolation of the other clinics such as the mother and child clinic were ante natal and under five services are offered have not raised any concerns, the isolation of the ART clinic was cited as stigmatising to the patients. One's HIV status is viewed as something confidential but the isolation of the ART clinic was reported as breaking that confidentiality, in that the moment people were seen heading towards there then their status was revealed to all those who saw them. The participants indicated that an inclusion philosophy must be advocated for, so that everyone who visited the clinic whether infected with HIV virus or not could be grouped together and the rest be the patient-doctor secret.

5.2.3.3 Frequent Visits

While the services that were being offered at the health facilities were appreciated the participants complained of the frequent visits they had to make to the clinic. They did acknowledge that some visits were inevitable and could not be avoided but most of them were not necessary. One factor that led to these frequent visits was the low supply of the ARVS. When the drug supply was low the health providers had to ensure everyone went home with something. In order to achieve this it was difficult to give everyone the required supply but had to share to cater for everyone. For instance, those who received a three month supply would only be given a month's supply and in worse scenarios a two week supply, if not one. This was seen to be a challenge especially to those coming from distant places. They also feared the slow process that they were subjected to each time they went to the clinic and having to go through the same experience over and over again.

The health providers reported that the frequent visits did not only affect the patients but affected them as well because they were seeing the same patients within a short period of time thus increasing their work load. They hoped the drug supplies would improve so that their workload could be made lighter as well.

5.2.3.4 Attitude of Medical Staff

The patients who had been taking the ARVS for a long time reported to have seen the changing attitude of the medical staff from good to bad. The patients attributed this to the ever increasing number of patients. As the numbers have been raising the work load has been rising proportionately and the medical staff has been finding a challenge coping with the increased workload leading to overworking and stress. The gentleness for patients had been replaced by harshness. This discouraged patients from accessing treatment because of the fear for staff. Patients found it easy to talk to the volunteers at the clinic if they had to enquire about something than to the medical staff. The volunteers were found to be more accommodating and understanding than the medical personnel. This may be attributed to the fact that the volunteers were also HIV positive and started as ordinary patients before joining the clinic as volunteers. Other than that it

was also indicated that the medical staff was not giving clear explanations to the patients unlike the volunteers.

The issue of the medical staff's attitude being a barrier to accessing ART was also indicated in the qualitative studies carried out by Mshana and colleagues, 2006 and Grant and colleagues, 2010.

On the other hand the health providers indicated that they were doing the best they could in the given circumstances but the problem was that people infected with HIV were very difficult and threw tantrums when things did not move according to their expectations. In a study of physician-patient relationship it was revealed that when patients were dissatisfied with their care it was often because there was a mismatch between the patient's expectations of care and the physician's consultation style. The results also showed that good quality physician-patient relationship tended to promote adherence while lesser quality relationships impeded it. These findings suggest that strengthening and promoting the bonds between physicians and HIV and AIDS patients should be an absolute priority not only at interpersonal level of physician- patient interactions but also at organisational level (Roberts, 2004).When the communication between patients and medical staff is bad then problems such as adherence to medication will arise and the patient will not see the benefits of the treatment. Kalogianne, (2011, P1) states that, 'The relationship of the doctor- patient is one of the most important health care system related factors impacting on adherence. Poor or lack of communication concerning benefits, instructions for use and side effects can contribute to non-adherence.'

5.2.4 Side effects

ARVS have improved and prolonged the lives of many people infected with the HIV virus. While this has been the case it is interesting to note that there are some who have avoided these lasting treatment benefits because of the significant side effects. These people may have heard rumours about the side effects or had experienced them to an extent that they did not see the benefit in the ARVS but misery. UCSF studies reviewed that side effects accounted for 24 % of the reasons for non-adherence to HIV treatment.

They farther indicated that side effects ranked third out of five in the common reasons for non-adherence (Bamberger et al, 2000).

In the current study, the common side effects reported were diarrhoea, vomiting, nausea, hunger and nasty dreams. These were among the same side effects that were reported in other studies carried out in Zambia (Grant et al, 2010 & kazzoba et al, 2012). Concerning hunger as a side effect patients reported that the hunger they experienced while taking the ARVS was worse than the one they experienced before they started the treatment and since they did not have the food, discontinuing the medication was a better option for them. Vomiting and diarrhoea made them feel very weak and this caused some discomfort in that they could not perform certain activities as they felt very sick. Sometimes the discontinuing of the treatment would come with other alternatives such as prayers or taking traditional herbs. Some would choose to do nothing and allow nature to take its course.

While patients were informed of the likely side effects at the start of the treatment, the frequency was not known and as such some gave up because they did not think the side effects would stop at one time. In one study it was observed that patients did not get all the required information about side effects. To make informed decisions about taking medicinal drugs, people need accurate information about side effects. Such information should be presented in a language or format that is understandable to the patient. In most patient information leaflets side effects are listed with the information but the frequency of such events is rarely provided. A European Union guideline recommended that the frequency of side effects should be described with one of the qualitative descriptions; very rare, rare, uncommon, common, very common (The lancet,2002).

Contrary to what other researchers have written about side effects being a barrier to access of ART, in their study, 'Why are antiretroviral treatment patients lost to follow up?' Candace and colleagues (2010) found side effects to be a less influential barrier in one accessing HIV treatment.

5.2.5 Disclosure

Disclosure of HIV status is identified as an important step in effective access and adherence support because the moment one discloses it means they have accepted their status and are ready to commit themselves to a lifelong therapy. Disclosure can also work as a drive to reduce the transmission of the HIV virus. This can be done by raising awareness and reducing risky behaviour. In this study disclosure was viewed as something good but too difficult to do. The major reason identified for not disclosing one's status was fear of the reaction from those disclosed to, especially if it was a spouse. Some respondents indicated that they disclosed in the hope of getting emotional support but ended up regretting because of the bad treatment received from those they had trusted to render them the emotional support they needed at that time. In one study the respondents indicated fear of disclosing their HIV status to family members who drink least when they got drank they would scorn at them and spread rumours about them (Nachega et al, 2006).There were also respondents who feared to be judged for their past actions being the cause of their infection while others feared to be suspected of what they were not. For instance, due to the belief that HIV was for the promiscuous, one would not want to be suspected to be a prostitute.

It was also reported that it seemed public disclosure of one's HIV status was mostly from those of a low socio economic status which is why at times they were misunderstood to be doing it for financial gain. Prominent people in society were not coming out to disclose their status when a good number of them were taking the ARVS. While these prominent people were seen in the media promoting other health related programmes such as Voluntary Medical Male Circumcision (VMMC) they were not seen to promote disclosure by revealing their HIV status in the same manner they revealed that they had been circumcised. More males were seen to be going for male circumcision because the leaders were in it also but for HIV disclosure the picture being painted was that HIV and AIDS was for those in the low class in society. To support this concern the researcher observed that when prominent people in society visited the clinic for ART services they were not exposed to the public. All the confidentiality was observed so that others could not suspect them to be patients who had gone to the clinic

for ART. For instance, they would be given appointments outside clinical hours such as very early in the morning or after all the patients had been attended to and left. This clearly indicates that they too are still battling with the issue of stigma. When they visited the clinic very early in the morning they were confined to a room where all the procedures would be carried out and drugs brought to them instead of them going to the pharmacy.

Lack of disclosure became a barrier in various ways. One was that if one did not disclose their status at their place of work it was difficult for them to ask for permission to attend the clinic on appointed days. It was either they lied, sent someone to collect the medication for them or totally absconded.

5.2.6 Feeling better

Feeling better after being initiated on the ARVS is good but it was cited as a barrier. This was so because there were people who got deceived by that feeling better and discarded the ARVS thinking they would not need them again as they had been cured only to realise when the condition was bad that they should have not stopped. The major reason given for stopping the treatment when they felt better was that taking of the medication on a daily basis was tiring and they looked forward to a day when they would stop and an opportunity was availed when they felt better. They looked forward to a time when a lasting solution would be found. The medical environment earlier explained led to people stopping medication when they felt better because to them it was a big relief to stop going to the clinic. Similar results were reported in a study by Nawa and colleagues, (2008) on the Copperbelt province were participants reported feeling better and healthier after a period of treatment as the reason for not taking the medication. They went further to indicate that some respondents were overwhelmed by 'pride' as they were looking physically fit and had regained their health so they did not see the need to take the medication.

5.2.7 Socio-economic status

Although HIV and AIDS have a negative impact in all sectors and at all levels of the economy, people engaged in informal work activities are more vulnerable than others. In Zambia HIV and AIDS was most concentrated among the poor in urban areas (McKay & Rommn, nd & Hajizadeh, 2014) and the majority of the participants in the study were coming from those areas. The majority of the respondents reported not being in gainful employment or any income generating activities. Lack of financial resources was a barrier to treatment because respondents faced challenges in meeting basic needs such as food and transport. In his book, 'One day in the life of Ivan Denisovich', Aleksandr, (1962), Quoted from Goodreads, 2014,p1) states that, 'The belly is an ungrateful wretch; it never remembers past favours, it always wants more tomorrow.' No matter how much one eats they will still need more food after some time. Lack of adequate food was viewed as a major challenge to many. It was reported that the hunger one felt when they were on medication was different from the usual one in that it made one feel very weak and have nausea. In other words it was a severe uncomfortable type of hunger. It was revealed that at one time the government with its collaborating partners used to supply food such as maize meal, beans, cooking oil and some food supplements to those who could not afford. With the passing of time this was discontinued making it difficult for those who are under privileged to continue with the drug regime.

While the government had endeavoured to put up health facilities in most of the communities there were still places especially in the outskirts that did not have these facilities and people had to go to distant places to access medication. An example is Matero clinic which catered for people coming from Mungule area. These needed transport money to get to the clinic. With the frequent visits that they made this would be a challenge and some would discontinue the medication. In a qualitative study to explore in depth the relationship between transportation cost in low resource settings Tuller and colleagues, (2009) found that even when participants managed to pay for transportation to the monthly clinic visit, the constant search for money caused them significant psychological and emotional distress. They struggled with competing

demands between transport costs and other necessities such as food, housing and fees. This concern was confirmed by the participants in the current study.

While the medication has been provided free of charge there are still some costs that one has to incur and this becomes a challenge to those who cannot afford. Lack of basic needs can lead to one discontinuing the treatment.

5.2 Gender barriers

Nyirenda et al, (2006,p1)state that, 'Gender issues influence people's access to HIV testing and counselling services as well as their access to Antiretroviral Therapy services. In the current study the following set of themes were identified to be gender barriers in accessing Antiretroviral Therapy:

- Women's lack of Socio economic empowerment and Male dominance
- Men less proactive in health matters
- Unequal distribution of HIV and AIDS programmes

5.3.1 Women's lack of Socio-economic empowerment and male dominance

HIV has an adverse and often debilitating socio-economic impact on individuals and their household. In most developing countries in Africa, Asia and the Pacific, traditional and entrenched gender inequalities exacerbate the disproportionate impact of this socio-economic burden on women living with HIV by restricting their access to social and economic resources, coping mechanisms and care and support services (Johri, 2011).Women's lack of socio-economic empowerment was identified as a barrier to treatment in the current study. The majority of women were not in gainful employment and did not engage in income generating ventures and as such they depended on a man for anything that required money including the basic needs. These men were husbands, partners or those who just wanted casual sex in exchange for money. Most of the women captured did some voluntary work at the clinic in the hope of getting employed if opportunities availed. These opportunities were very rare as some of them had spent a long time at the clinic without getting any job except for workshops or seminars where

they received a bit of money, at the most K20, which is not enough to buy a bag of maize meal.

It was reported that marriage was something that the women guarded jealously at the expense of their health. Women had no problem when it came to the issue of testing and receiving treatment but the problem came when they had to disclose their status to their husbands so that they too could go for testing. If the husband was against the taking of ARVS the woman could abandon the treatment to save the marriage. It was reported that some women would still go ahead with the treatment despite the husband's objection but they had to do this secretly. One way was by not keeping the drugs in the home were the husband could stumble on them but keep them elsewhere, probably at a neighbour's home. This was still not helpful because such men are against the use of condoms. This increased the risk of re-infections. Mataka (n.d,P1), postulates that, 'The socio-economic disparity between men and women has a great impact in fuelling the spread of HIV. Socio-economic problems may limit women's access to counselling and treatment'. Kazzoba et al, (2012) observed that women who were widowed, separated or never married were more likely to be screened for HIV and AIDS than those who were married. Research from developed countries on gender differences in health service use suggests that women's rate of utilisation of almost all health services is higher than that of men but women are more likely to defer health care because of cost (Jatrana & Crampton, 2012).

There were instances where a couple was on treatment but living far from the clinic. In such situations it was the man who got the first priority in terms of money for transport if it was only enough to carter for one person. Despite the treatment being free it has been reported that women usually face challenges related to other costs involved like transport. The cost of transportation for monthly visits has been identified as a potential barrier to treatment (Hestad et al, 2012 &Tuller, 2009).

In an HIV comparison study of Asia and Africa, Nath (2006) observed that in many Asian and pacific societies just as in African societies the promotion of safe sexual practices is made more difficult by cultures of silence that surround sex and sexuality.

Social expectations of ‘good woman’ require that they remain ignorant about their sexuality, are passive and subservient to men and give up autonomous control over their bodies. Lack of economic independence and low social status restricts women‘s ability to discuss fidelity and insist on condom use.

The other challenge that the women faced in relation to their socio-economic status was that despite their status, they still had to find means to take care of their families. The situation was even made worse if one was a widow and had no one to depend on. In a report from Thailand, it was stated that HIV positive women experienced a social death as many people living with HIV, but they often still carried the responsibility to care and provide for their families (Women and HIV concerns, n.d).

5.3.2 Men less proactive in health matters

Women were reported to have a passion for issues of health. Whenever they received information concerning health whether from friends, the clinic or in the community they were keen to implement what was being offered. This also applied to testing for HIV. They did not wait until they were sick but would take the initiative to do so while they were still feeling fine. The story was different for men as they shunned most of the health initiatives. They waited until they were sick and critically so for them to be tested. In the event that men tested positive when they were feeling fine and were put on medication they would not adhere to the treatment until the condition worsened to near death. It was reported that the major reason for shunning these initiatives was that while both genders suffered some level of stigma it was worse for the men. The other reason was that men were too busy with income generating activities such as work and if those coincided with clinic appointments they chose to put bread on the table for their families at the expense of their health. The cultural beliefs of, ‘you are a man so you ought to be strong’ led men to access the treatment late.

The other reason that led men to delay accessing treatment was the fear to be blamed for being responsible for the HIV in the home. Many a time because of the belief that men are never satisfied with one woman so they get involved in extra marital affairs and in the end get infected with the HIV virus which they in turn transmit to the spouse.

5.3.3 Unequal distribution of programmes

Programmes that enabled people to take up the initiative of accessing treatment were reported to be unequally distributed between men and women. Women were found to be captured in many areas. One area where they were mostly captured was in the Mother and Child Health Clinic where antenatal and child health (under five) services were offered. At the antenatal section there was a programme called Prevention of Mother to Child Transmission (PMTCT) where pregnant women were tested for HIV to prevent transmitting it to the unborn child. Many women were captured in this programme because while the health providers indicated that it was not compulsory for the women to be tested the patients said it was almost mandatory for them to be tested as they were not given any option. At the under-five section the mothers who took their children there were also encouraged to get tested so that they could know their HIV status. These services raised the number of women as compared to that of men. In a similar study in Malawi,Muula and Kataika, (2008), reported that the key informants generally indicated that females were more likely to access HIV testing through maternity services and child care services.

The health providers revealed that while the programme of PMTCT was mostly targeting women, the men who were spouses or partners to the expectant mothers were encouraged to accompany their wives so that they could be given information together but unfortunately the men shunned this initiative. The antenatal and child health clinics have for a long time been associated with women and as such very few men will be courageous enough to go and mingle with the female folk. This is supported by Benkele, (2013, P iv) in a study in Chipata, Zambia where he postulates that, 'The PMTCT programme has been integrated in ANC, which traditionally offered care to pregnant women. Therefore men naturally felt left out despite having positive views regarding roles they can play at PMTCT programme.' In a review of 24; (21 from Sub-Saharan Africa, 2 from Asia and 1 from Europe) studies to identify barriers to male PMTCT, barriers were identified mainly at the level of society, the health system and

the individual. The most pertinent was the societal perception of anti natal care and PMTCT as a woman's activity and it was unacceptable for men to be involved. The health system factors included long waiting times, reluctance of men to learn their HIV status, unwillingness of women to get their partners involved due to fear of domestic violence (Morfaw, 2013).In the current study, it was reported that while the medical environment was identified as a barrier in accessing ART, when it came to the issue of PMTCT it was made conducive for the men. This was done by giving first priority to women who went to the anti natal clinic with their spouses. They would be the first to be attended to and left the clinic early enough to attend to other programmes of the day. What was observed was that men did not like waiting for long hours because they were busy people. Despite all these efforts the numbers for men were still very low.

Research has revealed that the focus for PMTCT must be on men because in male dominated societies such as Zambia men do significantly influence attitudes and behaviours related to HIV and AIDS.

Men still felt the medical environment was still not conducive for them to be involved in PMTCT programme because they were not given an opportunity to be there throughout. At some point they were not recognised as partners who should be involved in the programme. This was shown by the way they were treated when it was time for their wives to deliver. They were turned away from the clinic. This was also reported in a study in Eastern Uganda where men indicated that in some instances the health workers did not allow them to enter the antenatal clinics with their wives (Byamugisha et al, 2010) making it pointless for a man to be there .

There is need for community sensitisation on the benefits of PMTCT. The medical environment also has to be made friendly for the men. For instance in private facilities men can be with their wives all the way up to the delivery room. Leaving them out at some point may water down a well-intended programme.

While there was a concern of unequal distribution of programmes it was reported that men were not completely left out because of the introduction of VMMC It is projected that circumcising 80% of uncircumcised adult men in the countries with high HIV

prevalence and low prevalence of male circumcision by 2015 would avert 1 in 5 new infections by 2025 (WHO, 2013). This was a men only domain where they had the opportunity to be tested for HIV as was the requirement. Zambia has adopted male circumcision as one of the comprehensive preventive interventions and has a target of achieving 50% circumcision target by 2020. One of the guiding principles states that, 'male circumcision information and services will be integrated into male reproductive health services such as STI services and family planning as well as counselling and education on sexuality, gender issues etc,' (MOH, 2010).

5.4.1 Gender access to ART and Neurocognitive functioning

Although the qualitative analysis revealed many barriers that are faced by women in accessing ART, the data obtained from testing the participants using the neuropsychological test battery revealed no significant difference in the level of neurocognitive impairment between men and women on ART. This disconfirmed the hypothesis that 'female participants would score lower on the neuropsychological tests than the male participants of the same age and educational level. This result was different from what Hestad et al, (2012) found in a pilot study in Zambia on sex differences in neuropsychological performance as an effect of HIV infection. Their findings were that women were more at risk of developing cognitive deficits possibly because of sex related social, financial and health care disadvantages.

Most studies have revealed that women's performance on neuropsychological test is usually low but in the current study the scores for women were not different from those of men. This could be attributed to the fact that the selection of the sample in the current study only included respondents who according to health needs were consistently on ART. This meant that the women who were admitted to the neuropsychological test battery were for whatever reasons a relatively successful group at overcoming the barriers to access that they described. Despite the gender based obstacles to access of ART the women in the sample actually accessed and used ARVS more consistently than the men. This explanation of the study's findings is consistent with the interview responses to the effect that women are more in evidence at the clinics.

Chapter 6

CONCLUSION

6.0 Conclusion

The objective of this study was to determine the effect of gender on accessingAntiretroviral therapy and its link to neurocognitive functioning. The researcher designed the study in two parts. In part 1 a qualitative research approach was used and the design was the phenomenological study design. In part 2 the quantitative research approach was used and the design was the cross sectional design. Interviews were used to get the information on how gender affects access to ART. For the neurocognitive functioning 7 tests from the neuropsychological test battery were used, each testing a particular domain. The following were the tests used and the domain assessed: Executive functioning-Wisconsin; Verbal fluency- Stroop word; working memory- spatial span; learning memory- Hopkins verbal learning test; recall-brief visual memory test; motor- grooved peg board and speed of information processing-symbol search.

The qualitative results obtained indicated that there were barriers to access that affected both male and female respondents while other barriers were gender specific. The findings of the study were that women faced greater barriers to accessing ARVS due to male dominance and the lack of socio-economic empowerment. This led them to being dependent on men even when it came to making decisions on accessing ARVs. Women were not free to discuss issues of infidelity and condom use for fear of being abandoned by their partners. When it came to sharing of financial resources to enable one access ART in a home where both husband and wife were infected the man was given first priority. Another factor was that women were so burdened with tasks of providing for their families that it became difficult for them to find means and time to access treatment. The barriers for men were that they were not proactive when it came to health matters and most programmes favoured women over men.

While barriers 2 and 3 favoured women over men they were not strong enough to outweigh barrier 1. This was because a woman's life was to a very large extent dependent on a man's decisions. For instance a man would choose not to go for treatment whereas a woman had to get consent from the spouse or partner if she wanted treatment. The woman did not have power to make independent decisions. Her choices were tied to what the man thought was best for her even if this was at the expense of her health. Regarding programmes more of these appeared to target women though not exclusively. For instance the programme PMTCT encouraged men to accompany their wives but they chose not to, mainly due to cultural orientation that considered such programmes as women's.

Research has shown that access of ART for women is impeded by gender biases in that they face a lot of barriers. Populations that do not access ART are at a greater risk for neurocognitive impairment. In the current study women were reported to face serious barriers in accessing ART but contrary to what was hypothesised that women would score low, there were no significant differences in the performance on the neuropsychological tests between the male and female samples tested except on one test, the stroop, where the women actually scored higher. This probably was reflecting the fact that all the females tested were on ART.

6.1 Limitations and strengths of the study

One notable limitation was observed in this study. There was need for a Zambian version of the neuropsychological battery unlike the international version which poses a challenge in determining whether poor performance is attributed to lack of understanding the instructions or the presence of neurocognitive impairment. Despite this limitation the strength of the study is that it may be the first qualitative study to explore the gender effect in access to ART and its link to neurocognitive functioning.

6.2 Recommendations

Given the foregoing, the following recommendations are advanced:

i. There is need for more studies to be carried out on the link between access to ART and neurocognitive functioning among HIV positive individuals in relation to gender in Zambia. So far not much has been done in this area;
ii. New strategies to promote PMTCT programme outside the clinic environment must be considered and implemented so that more men are also captured.
iii. The neuropsychological tests must accommodate the use of local languages; and
iv. There should be objectivity in the selection of the sample which could be done by independent people unlike those who have an interest as was the case with this study where the clinic staff prioritised selection to people volunteering at the clinic who were so knowledgeable about issues of HIV and AIDS. Most of the information given in the interviews was not from personal experiences but from what the respondents observed while doing voluntary work at the clinic.

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APPENDICES

Appendix 1-Approval Letter from Lusaka District Health Management Team

P.O. Box 50827
Lusaka
Tel: +260-211-235554
Fax: +260-211-230420

In reply please quote

No.....

Republic of Zambia

MINISTRY OF HEALTH
LUSAKA DISTRICT HEALTH MANAGEMENT TEAM

Thursday, July 19, 2012

Professor MPS Ngoma
Associates Professor
Paeadiatrics and Child Health
University Teaching Hospital
LUSAKA.

Dear Dr. Ngoma,

RE: PERSMISSION TO CONDUCT RESEARCH AT LUSAKA DISTRICT CLINICS: MASTERS IN CLINICAL NEUROPSYCHOLOGY.

The District Health Office is in receipt of your letter dated 16th July, 2012 on the above subject.

Approval has been granted for the ten named students to conduct research in the Lusaka District Clinics.

However, the research should only commence upon production of a copy of UNZA REC approval.

You will also be required to furnish the DHO with a summary of your research findings at the completion of the study.

Yours sincerely,

DR. M. M. CHIKO
ACTING PRINCIPAL CLINICAL CARE OFFICER
For/ACTING DISTRICT MEDICAL OFFICER.

c.c.: Health Centre in charges.

Appendix 2-Approval letter from Biomedical Research Ethics Committee

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza.zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

25th September, 2012.

Your Ref: 006-05-12.

Ms Joyce Tholiwe Sibanda,
School of Medicine,
Department of Psychiatry,
PO Box 50110,
Lusaka.

Dear Ms. Sibanda,

RE: RE-SUBMITTED RESEARCH PROPOSAL: **"AN EXPLORATION OF THE EFFECT OF GENDER ON ACCESS TO ANTIRETROVIRAL THERAPY AND ANY SUBSEQUENT IMPACT ON NEUROCOGNITIVE FUNCTIONING IN LUSAKA PROVINCE"**

The above mentioned research proposal was re-submitted to the Biomedical Research Ethics Committee with recommended changes on 13th July, 2012. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr. J.C Munthali
CHAIRPERSON

Date of approval: 25 September, 2012 **Date of expiry:** 24 September, 2013

Appendix 3- ZAT – Reading Recognition Test

1

Eat	Four
Good	She

2

Old	His

Fly	Round

3

Five	Green
Sing	Around

4

Warm	Fall
Start	Drink

5

Outside	Fishing
Town	Smile

6

Wagon	Houses
Meaning	Families

7

Question	Change
Joined	Brook

8

Instead	Blaze
Signs	Colt

9

Pleasant	Dangerous

Ledge	Escape

10

Northern	Towel
Kneel	Height

11

Exercise	Observe
Ruin	License

12

Uniforms	Pigeon
Moisture	Artificial

13

Issues	Quench
Hustle	Thigh

14

Guardian	Vein

Civilisation	Anchor

15

Composition	Elegant
Sympathy	Authorities

16

Utensil	Geometry
Condemn	Unparalleled

17

Reign	Adjourned
Limousine	Manoeuvres

18

Heroine	Statistics
Phenomenal	Vicinity

19

Judicial	Medieval
Rheumatism	Silhouette

Appendix 4-Interview guide for Health providers

1. How aware is the community about ART? (Probe: on awareness programmes; view of those on ART by community)
2. Which gender has more access to ART between men and women? Give reasons.
3. What strategies have been put in place to ensure equal access of ART? Explain.
4. Do you think there are barriers to equal access of ART? Explain
5. Which gender between men and women resist ART? Give reasons
6. Which gender is likely to seek voluntary, counselling and testing services? Give the reason to your answer.
7. Which gender is likely to disclose their HIV status to their families and friends? Explain
8. Which gender is more likely to join a support group? Give reasons
9. How does the socio-economic status have an impact on seeking medical services in this area? Explain
10. What are your observations on adherence?(Probe: who is more likely to adhere and why; barriers to adherence)

Appendix 5

Interview guide for patients

1. When did you start taking ART?(probe: on how long it took from time of testing; if testing was voluntary or it was due to another medical problem)
2. Where you aware of ART before you got tested?(Probe: how they came to know about ART)
3. How would you describe the environment at your medical centre?(Probe on: Medical staff treatment; explanations given; adequacy of facilities) .
4. Do you feel stigmatised for taking Art? Explain your answer.
5. What are some of the problems you experience when accessing ART? Explain your answer.
6. Do you think taking of ART makes you need more food?(Probe if they are able to afford the food and how.)
7. Do you think it is easy to sustain treatment? Explain your answer.
8. Do you think support groups are helpful when it comes to accessing ART? Explain your answer.
9. Do you think accessing ART takes much of your time? Explain your answer.
10. Do you think disclosure of one's status makes it easy to access ART? Explain your answer.
11. Do you feel there is equal access of ART between men and women? Explain your answer
12. Do you know some common beliefs that may discourage men and women from taking ART? Explain your answer.
13. Do you think there are adequate HIV/AIDS programmes for both men and women? Explain your answer.

Appendix 6- The neurobehavioural test battery